

# PHILOSOPHICA

## FILOSOFIA E MEDICINA SOBRE DOR E SOFRIMENTO



LISBOA

UNIVERSIDADE  
DE LISBOA

Departamento de Filosofia  
Faculdade de Letras da Universidade de Lisboa  
Centro de Filosofia da Universidade de Lisboa

# AT THE HEART OF A DECISION IS A NARRATIVE<sup>1</sup>

**R. M. Zaner<sup>2</sup>**

(Vanderbilt University Medical Center, Nashville)

During my early days at Vanderbilt University Medical Center, I was actively in pursuit of how best to regard ethics in clinical encounters; I could hardly otherwise justify what I had found myself being asked to do by nurses and physicians in the units where I had only just begun to participate in clinical rounds and discussions with and about patients. Before long, it occurred to me that the best way to approach the issue might best be found in the naturally occurring conversations during those rounds—conversations which take the form of stories, even though few are ever complete, especially when prompted by the illness, injury, genetic or congenital circumstances.

I was especially impressed with the way stories have such a unique way of helping people, myself included, take care of each other.<sup>3</sup>

- 
- 1 This narrative has a history. A much earlier version appeared in my book, *Conversations on the Edge: Narratives of Ethics and Illness*, Washington, D. C.: Georgetown University Press, 2004, 1-15; an expanded and rewritten version has been published as “Narrative and Decision,” in a special issue of *The Journal of Communication Research*, devoted to Rita Charon’s idea of narrative medicine, and edited by Lynn Harter, Vol. 37, No. 2 (May, 2009), 174-187 (see Rita Charon, *Narrative Medicine: Honoring the Stories of Illness*, New York: Oxford University Press, 2006). Although based on these previous narratives, the present version is substantially new and unpublished.
  - 2 Richard M. Zaner, Ph.D., Ann Geddes Stahlman Professor Emeritus of Medical Ethics & Philosophy of Medicine, Vanderbilt University Medical Center, Nashville, TN 37232. rmorrisz@comcast.net.
  - 3 Poignantly expressed by Barry Lopez, *Crow and Weasel*, San Francisco, CA: North Point Press, 1990, p. 48.

Eventually, it dawned on me that sharing such stories may itself express a kind of moral imperative,<sup>4</sup> for it really does seem to be how we learn about and especially learn to care for each other—*there*, within the unique context of circumstances and relationships where such issues at all occur in the first place. My way of exploring these matters has taken the form of engaging in telling stories myself—an art or craft I am still trying to learn.

The story I want to relate here is simple enough, but has unexpected dimensions that I found deeply disturbing. As I first began to write about what was going on in these encounters, it slowly but surely occurred to me, not unlike an eerie obbligato riding atop an otherwise uncomplicated melody, unable as I was to take myself out of the story, that I also needed help—a great deal of it, as I sought to keep my bearings in the face of the grief and loss that so marked those occasions.

I also saw that I had to try and tell each particular story, how each of the individuals involved took care of each other in their talk with me and with one another. It may be, I thought, that at the heart of these matters are acts of giving and receiving through which each story is displayed. Perhaps, in other words, in giving you my story, I not only help myself get through at times very disturbing issues, but might also help you care for yourselves and others as, growing older together, in Alfred Schutz's idiom, we tell and listen while our common lives unfold, especially in those crucial times.

Infused in all this is something harder to get straight in words: that, while telling you a story, it is not only because I somehow need to tell it—though there is that, I readily confess—but that in the telling of it, I—and you, too, if you go with me—must ineluctably face certain essential questions: Why is it that telling stories enables us to be what we are, each of us in ourselves, and yet together? Why is it, to move to a different plane for a moment, that a dying person needs more than anything else someone to bear witness (often it doesn't matter who), to listen—and, to what?

While I must say that I do not know how far along that path I have come, I do think I am gradually getting much closer to that place where wonder holds sway.

---

4 In the same way that we tell stories to help our children understand the world: without them, understanding would hardly be possible. I am thus convinced that story-telling is a key part of what Edmund Husserl analyzed as his method of “free-phantasy variation,” the core component, for him, of phenomenological method and insight. He emphasized, for instance, that this is “...*the fundamental form of all particular transcendental methods*,” and provides “the legitimate sense of a transcendental phenomenology.” Husserl, *Cartesian Meditations*, The Hague: Martinus Nijhoff, 1960 [1950], p. 72. See Richard M. Zaner, *At Play in the Field of Possibles: An Essay on Free-Phantasy Method and the Foundation of Self*, Zeta Books, Bucharest, 2012.

\*\*\*

Years ago, not long after the time I first became a regular if also somewhat odd presence in our NICU, an attending physician relatively new to the service, Dr. Max Sherwell,<sup>5</sup> requested that a nurse, Joanne, ask me to meet with the parents of a tiny baby, a premie who had in fact already been there for some time. I was a bit startled at the request, for it was one of a very few that I had received; it was just before I had set up an ethics consulting service.<sup>6</sup>

Born at about twenty-five weeks gestational age and now about twenty-seven weeks, it seemed rather certain that the baby, a boy, “would not make it,” as Joanne said. The complications evident already at birth, she said, presented serious complications, especially from the hyaline membrane disease,<sup>7</sup> but the parents still hoped he might yet survive. The sad fact was that if against all odds it did in fact survive the boy would—like so many of these extremely premature infants—most likely suffer severely compromising neurological and other problems throughout the rest of its life.<sup>8</sup> However, since survival was thought to be only a remote

---

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

6 In fact, the service was supposed to be set up only for the NICU; the hospital-wide service requested by the Medical Board came about a year or so later.

7 Hyaline membrane disease (HMD), also called respiratory distress syndrome (RDS), is one of the most common problems of premature babies. It can cause babies to need extra oxygen to assist pulmonary function. HMD typically worsens over the next 48 to 72 hours and then improves with treatment. HMD occurs when there is not enough of a substance in the lungs called surfactant, made by the cells in the airways and consists of phospholipids and protein. It begins to be produced in the fetus at about 24 to 28 weeks of pregnancy. Surfactant is found in amniotic fluid between 28 and 32 weeks. By about 35 week’s gestation, most babies have developed adequate amounts of surfactant, which is normally released into the lung tissues to help lower surface tension in the airways. This helps keep the alveoli (air sacs) open. When there is not enough surfactant, the tiny alveoli collapse with each breath; as they collapse, damaged cells collect in the airways and further affect breathing ability. These cells are called hyaline membranes and when there is insufficient surfactant, the condition is HMD: as the baby’s lung function decreases, less oxygen is taken in and more carbon dioxide builds up in the blood. This can lead to increased acid in the blood called acidosis, a condition that can affect other body organs. Without treatment, the baby becomes exhausted trying to breathe and eventually gives up. A mechanical ventilator (breathing machine) must do the work of breathing.

8 One or another degree of cerebral palsy would be among the most likely, although others were clearly at issue as well: blindness from high settings of the ventilator (which, on the other hand, were needed to keep the baby’s lungs appropriately oxygenated), for instance.

possibility, the immediate concern was to ensure comfort measures for the baby and, equally important, for the well-being of the parents—who kept insisting that the NICU staff “please, do everything, don’t give up.” This phrase, I soon learned, was parents’ most frequently way to express hope, but also anguish.

At the moment, I don’t really recall all of the problems this particular baby faced, but I know they were not unusual for such preemies: as noted, hyaline membrane disease (HMD) is common, as well as hypoxia (shortage of oxygen in the blood) and asphyxia (severely deficient supply of oxygen) resulting in abnormal pulmonary function requiring ventilation at unusually high oxygen settings; likelihood of brain insult from ventricular hemorrhage; pneumothoraces (collapsed lungs) with insertion of chest tubes for drainage of accumulating fluids; persistent hypotension (abnormally low blood pressure); and other problems that challenge even the most competent and caring neonatologist.

The baby had been delivered at a local hospital close to the small community to which these parents had recently moved. As the father, Gabriel Diekma, later mentioned, he had just been employed by a manufacturing concern that had only recently moved to the area—helping it become a sort of ‘bedroom’ community for the urban area where our institution was located.

Kayla Diekma, the baby’s mother, was already some way into her pregnancy, which was unplanned but welcomed by them and their families—many of whom were within easy driving distance of each other. During one of her regular visits to her local obstetrician, Dr. Hester, they learned that the fetus was already about 18 weeks gestational age, was male and, from all indications, was doing quite well. Both parents observed the office ultrasound pictures. Kayla was excited when she saw the baby’s fingers moving and Dr. Hester pointed out the baby’s beating heart.

The pregnancy proceeded normally for several more weeks when Kayla, as she later told me, “began to feel strange.” She became nauseous and felt that “things just weren’t right”—the only words she could find to explain the odd feelings she was experiencing. A quick visit to Dr. Hester and she “quickly found myself in an ambulance” being taken to the local hospital. She was able to have her husband called, and by the time she had been wheeled out of the ER to an observation room, he arrived. She was in some pain and, together, they heard a nurse urgently call for the doctor. She was then moved into a delivery room, given a local anesthetic and, before long, their son was born, with her husband in the room watching. The trouble was, he was such a “tiny, tiny thing,” as he later told me, that he feared it just couldn’t be alive. It was rapidly taken out of the room.

Concern marking her face, Dr. Hester later told them that their baby would have to be taken to the nearby medical center where they had the experts and the equipment to take care of such tiny babies—“neonates,” was one word that stuck in Mr. Diekma’s mind. Their baby’s problems were evident already at birth: the “Apgar’s,” Dr. Hester explained, were “not encouraging,” and she went on to explain that the “Apgar score” is one of the first checks on any new baby’s condition: respiratory rate, reflexes, color, skin tone, and other indicators. To help them understand, she explained that each area checked right at birth is given a number between zero and ten, with ten the best. So, if, as in their baby’s case, there is difficulty breathing, this is given a lower score, and so on for each area. Normal is usually between 9 and 10; any lower score indicates that there are problems that will need special attention; ever lower scores call for more intense attention. As their baby’s Apgar score was, Dr. Hester thought, between 4 and 5, it faced very serious problems needing the specialized facilities and personnel of the critical care unit known as “neonatal intensive care” or NICU. So, she said, their baby would soon be on its way to our NICU. As soon as Mrs. Diekma felt up to it, she should of course visit there; in the meantime, though, Mr. Diekma needed to go there immediately to help arrange admissions for his baby.

Mr. Diekma decided to wait for a short time when his wife pleaded with him that she wanted, needed, to go with him. Waiting until the next day, they arrived at the hospital, Kayla still shaky, asked for and located the NICU, and went in to find out what they could. It was then that they met Dr. Sherwell—“Max” was what he wanted everyone to call him.

“Just call me ‘Max’,” he said to the Diekma’s when they first met. He had just come out of the unit after he was paged to meet them and still wore the long gown common to the unit’s staff and physicians. They immediately liked him—a large, bearish, and gentle sort of person. “We’ve just begun to evaluate your baby boy,” he said, “but I can already tell you that he’s facing some pretty difficult problems. The fact that he’s only a week or so into the third trimester—we think he’s about 26 weeks gestational age—is of itself a strong indicator that serious problems are ahead. We’ll do all we can, of course, but you should know right off that it will be a long and tough course before he comes out of this.”

The Diekma’s were both still stunned, even though Dr. Hester had done her best to prepare them for what they might hear. But hearing it now, in person, they didn’t know what to say—not unlike most such parents. They were sitting in a small conference room. Four chairs were in it, along with a small table with a few magazines lying on top. Next to one chair was another table, holding a lamp that glowed softly. Dr. Sherwell at first

stood behind one chair across from where the Diekma's sat, his hands on the back of the chair. He then sat down and asked if they had any questions.

They sat there, completely bewildered. Then Mrs. Diekma, sobbing, asked what she and her husband could do. "Not much at this time," they were advised. But they were also told that they could, and should, come into the unit after a day or so after further evaluations were done and as much as possible could be learned about the baby's condition and immediate prospects. "It's important for both you and the baby that you touch as much as you can, and you shouldn't worry about all the tubes and such you'll see. Nurses are there 24/7 and can help you."

"You'll do everything to help, won't you?" Mr. Diekma asked.

"Oh, never worry about that; we're set up to do any- and everything. We just have to do a number of checks and tests so that we can find out just what's going on with your baby—by the way, do you have a name for him? We like that, if you've got one. We'll put it up right on his bed."

"Name?" Mrs. Diekma asked.

"We've talked about it some," Mr. Diekma said, "but haven't really settled on one yet, not really..."

"Well," Dr. Sherwell said, "soon as you do, let us know, okay? Now, I've got to get back, much to do, much going on." He was obviously in a hurry, but continued briefly. "Just stop by that office you came to when you got here, and ask to see the nurse taking care of him. She'll have more information for you by the time you return—and yes, you should go home, get some rest. There's a long haul ahead of us all. We'll know more tomorrow evening, when the test results start coming in. So, at the moment, the best you can do is get on home, get some rest, and read the literature you can pick up at the office—oh, I see, yes, that's the main one, the one on prematurity. That will help you begin to understand what your baby's facing now and in the future, but be sure to get the others there, too."

They were quiet. Dr. Sherwell got up, the Diekma's got up. Dr. Sherwell looked at them, then turned and left. After a moment, the Diekma's went out, over to the office, asked for any other material they could have so help them understand what their baby was going through, were given several colorful information sheets; they sat down. Then got up, looked at each other, hugged, and turned to leave.

"Just let us know when you've had a chance to read the material and if you have any questions, just jot them down and bring them in, okay?" The person at the desk—also a nurse, they later learned—seemed very kind, and smiled gently at them. But the parents couldn't say anything, couldn't think anything. They thanked her, turned uncertainly, then left, walking down the corridor to the elevators.

\*\*\*

The baby had been in the unit, not doing at all well for at least several weeks—in fact its condition seemed quite hopeless—when Joanne was dispatched to see me about this situation. As I listened, it was clear that what concerned Dr. Sherwell, Max, and the baby’s nurses, was that though they had held many conversations with the parents, they had still seemed not to hear what they were being told—that their baby was just not going to make it. Despite this, each time one or the other, or both, of them came into the unit, they voiced their concern that “everything be done” for their baby—who had been given the name, Logan, after the maternal grandfather.

There would then follow a pretty typical conversation, with the couple growing increasingly restive. Mrs. Diekma: ‘you’ve got to do everything possible for Logan, okay?’ Nurse: ‘well, you must know that we’ve been doing just that for the last three weeks, and nothing’s changed.’ Mr. Diekma: ‘but have you really done everything for him?’ Nurse: ‘of course we have, Mr. Diekma, of course we have; that’s what we do in this unit.’ Mrs. Diekma (growing more agitated): ‘well, that’s what you say, but since as you say nothing’s changed, have you really tried everything? I mean, his oxygen stats haven’t changed at all.’ Nurse: Mrs. Diekma, we explained all that several times; we’ve tried to wean his oxygen down, but when we do he starts to fail and we have to move them back up. You know this, we’ve told you before. If we could...’. Mr. Diekma: ‘well, what’s going on, then, huh?’ Nurse: ‘...we would bring them down. As it is, though, we just can’t...’.

And so it would go, every day: the Diekma’s would come in, see Logan all wrinkled and curled up with multiple tubes snaking out away from the bed to three or four instruments, eyes closed... . And they would start in with whichever nurse was on duty at the time, insisting that “everything needs to be done,” and then listening as they grew increasingly distressed, edgy and, with each exchange, more and more exasperated.

Finally, the nurses reported to the attending that month, Dr. Sherwell, that they had had it; something had to be done; nobody seemed able to get through to the parents; they seemed each time as if they had not heard a word before. And, their anger seemed to be getting more evident. So, Max told Joanne “to go get Zaner; let him try to get through to them.” With that, good old Max turned and went back into the unit.

Joanne and I stood for a while in the hall just outside the unit while she told me the story. This was one of the first times I heard what I soon came to realize seemed as much threat as appeal: “please, do everything.”



It was already clear that the phrase rarely meant what the words seemed to say—at least not when it became a sort of mantra. The first few times you heard it, well, okay; that, you’d expect from concerned parents who were just learning to live with the usual disaster (if disaster can ever be usual) of bad news about their just-born premature baby. But after hearing it for the fourth and more times, well, it was a clue that something else was also going on with the parents. Still, each time was, invariably, unique, just as each parent was unlike any other while yet facing much the same sort of issues as others, forever stretched between the common and the singular; life in the NICU.

\*\*\*

I asked Joanne what she thought was going on with them, why they seemed, as she said, so unhearing and adamant. All she could tell me was that it just wasn’t normal, that kind of insistent impatience and anger. Plus, she pointedly mentioned how impatient the nurses were becoming toward the Diekma’s. “We’re heading for a crash,” was the way she expressed it. “And you know,” she went on, “the father seems so determined to get his way, he just doesn’t realize what he’s demanding, what he’s saying. I mean, Dr. Z, it’s not as if we’re trying to kill that little baby, you know?”

I wondered aloud if Mr. Diekma had actually ever said such a thing, and she immediately backed off, but kept insisting that he was “just so angry, so on edge, you know? He’s just so stiff, and I guess traumatized.”

I then asked her what she thought the silences meant: “Well,” she slowly said, “I don’t really know, but it just isn’t normal, not when Max is trying to get them to reach a decision about the first twin,” the one whose death seemed imminent. She repeated that she, Dr. Sherwell, and others on the care team were really worried about this father: why was he so tense, so restrained? That just wasn’t what you’d expect to hear from a parent when it became clear that treatments were only prolonging “the inevitable:” that death is near and must be acknowledged. But most parents just can’t acknowledge that, not right away. Time and talk are needed.

I let it go at that, nodded to Joanne, told her I’d see these parents just as soon as they came back to the unit. She thanked me, turned and went back into the second of three rooms that made up the NICU. I stood for a moment, thinking about what Joanne had said, then went over to the office and asked that I be notified as soon as the Diekma’s came in, and then went back to my own office. Not ten minutes later, I got the call; they were back. I asked to let them know of my pending visit, that I would be over just as soon as I wrapped up several things I had to do.

\*\*\*

When I went into the quiet room—the very one where they had heard the bad news from Max—I was still mulling over what Max and the others really expected of me. What can I say to them? How can I say it where it doesn't offend them? Would they even talk to me? They were sitting in several of the chairs, tense, just like Joanne had said. They still seemed shocked by what was going on, Mrs. Diekma was weeping; Mr. Diekma was palpably on edge; he even sat at the edge of his chair. They both still appeared dazed.

I knew just a little about them; their ages—he was 25, she 23; this was their first pregnancy; both were apparently well-educated, and both worked at what Joanne thought were “some sort of executive-type jobs.” Still, they seemed terribly immature. When I first saw them, they seemed much younger than their actual ages. He sat up and glared, as if daring me to say something. I felt as if I were on a precipice: a single wrong word and all would be lost, the case crumbling down around my ears—and me, unclear whether or how I might be somehow to blame for all that. I even wondered whether I should just say “hi” and leave: I could allege I made a mistake, got into the wrong room, and just take off. But I didn't; I searched instead for words, unsure to the last moment whether I could speak at all.

But, I did. I introduced myself. But, after giving my name, I then said, “I'm in ethics,” wondering the while whether that was what I was “in” or “did” or whatever; what does one do when one ‘does ethics’? Then, I said, “the doctors and nurses here have asked me to try and help you...” Before I could finish the sentence, though, Mr. Diekma got an odd look in his eyes as he turned toward me; Mrs. Diekma stopped weeping and quickly looked up at me, obviously perplexed...and I just knew that I'd blown it.

“In ‘ethics’?” he demanded, not without a certain admirable candor, I might add. “What in the world are *you* doing here?” A reasonable question, I knew, and said so, wondering what, indeed, I *was* doing there. Trying to keep my bearings, I tried to explain what sort of thing I did in the hospital—what *does* someone ‘in ethics’ *do* in such a place?

I should say right off, though, that two things struck me. First, neither of them seemed in the least interested in what I had to say as I talked about the unit, the staff, or their baby's condition. After his outburst, he simply sat back, glaring at me but remaining tensely silent. She continued to weep quietly, looking back down at the floor. Clearly, he was disturbed. Second, as I went on talking, he became increasingly agitated; shortly he interrupted me: “Why,” he bluntly asked, “are you here *now*?” Eyes narrowed with

suspicion, he demanded: “Has someone been doing something *unethical*? I told you, Kayla,” he said looking over at his wife, “I told you things just weren’t right...”

“Now wait a moment,” I spoke up a bit more loudly than I intended, trying to get his attention. “You’ve got things all wrong,” then I grew silent a moment as I thought of what he had said, the way I introduced myself; and what he promptly concluded.

Hearing his questions was a bit unnerving, I admit, and the conversation sagged into a nervous hush. For the first couple of years in this practice, almost every time I introduced myself, someone invariably thought that, since I was “in ethics,” I was obviously on the scene because somebody had been *unethical*. I was the local “ethics cop,” brought on the scene in order to catch ‘em out! Curious, and not a little frustrating; being seen as “the police” gives conversations a whole ‘nother sense, in part because of the ways in which “ethics” has come to have such prominence in our public life: athletes cheating the system (and themselves) with drugs, corporate shenanigans, physician fraud, questionable conduct of congress-folks, etc.

In any event, Mr. Diekma also seemed taken aback—‘being in ethics,’ as I had said to him, seemed as unsettling to him as his abrupt questions had been to me. But, he cooled down, sat back in the chair, and quietly listened as, pushing aside my own worries, I went on to tell them that nobody to my knowledge had done anything wrong, nor was that why I was there. Rather...and I went on to explain how many of the medical and nursing staff had been concerned about him—his edginess and even anger were disturbing; that, I said, was why I had been asked to talk with them. Did he, did she, did they, understand what had been going on, what they’d been told about their baby, Logan? Had they been listening, had they heard? Did they understand specifically what they were being asked to recognize, to accept, agree to, and decide on?

And, again, with rare directness and before I could finish, he emphasized that *of course* he understood, and so did Kayla—she nodded vigorously, tears still glistening in her eyes, her hands fluttering, never quite still. Obviously, Mr. Diekma said, they knew that their son was just not going to make it. But, he went on to emphasize how the “folks back home” kept up asking how Logan was doing, whether he was getting better, when he’d be coming home, all of that. And he just didn’t know how to handle that, especially as most of these people were friends, most members of the same church as he and Kayla. Questions, he went on, invariably came on the heels of the preacher’s usual prayer for them and the baby, expressing

confidence that all would be well, that God would see to it that Logan came home all well and active. Those people, he said, simply did not know, or couldn't know, even though he and Kayla had told them straight out just the prior Sunday, hoping they would then understand that their son was not going to make it, he was going to die—Gabriel said he used the awful word few can use, especially in these situations—despite every effort to treat him. At that, friends and others alike turned away, shaking their heads. And when they came into the unit, saw little Logan, he did seem better somehow, and so they'd go into their routine, asking questions about the most minute things of his treatment (“have his O<sup>2</sup> stats improved?” or, “is the pneumothorax any better?”) then getting anxious and wondering if “everything” was being done. and on and on.

They were just so anxious about little Logan. “Yes,” he said, now more rapidly, “both of us know full well that our baby isn't well, and if things keep up, well,” he paused, looked over at Kayla, back to me, grew silent and stared down at the floor. “Well,” he tried to continue, still staring at the floor, “we know that though there's a slight chance that Logan can pull out of this pit, poor thing, that he might still live despite all the odds against him, but, well,” he again paused. “But we're not at all sure that it is fair to him, to force him to live the kind of life he'd have to live if he did survive.” He stopped, again looked over at Kayla, then back to the floor. “How can we do that?”

“Why haven't you told the doctor and nurses, then?” I wondered aloud, in my inexperience, still somewhat mystified: why was he so straightforwardly vocal with me, showing no anger at all? It may be, strange to say, that what had broken the dam—that impatient edginess mixed with strained silence—was the oddity of what I had said a moment ago when introducing myself.

Then he came right to the point: “You think we *haven't* told them? Excuse me, Dr. Zaner, but of *course* we have!” But then he stopped, hesitated, as if realizing that his gestures contradicted what he had just said. What had promised to be another torrent of words didn't happen; he withdrew into himself, into that dark place to which he had often retreated even while he was physically on the scene in the unit and said to be so agitated.

When I pointed out how angry, at times even hostile, he so often appeared to be, he crawled up out of that hole, now meditative, and, it seemed to me, profoundly, inescapably sad. What eventually emerged was not expected by me or, when I talked with Max the doc, by him, or the nurses.

He began to talk, slowly and with evident grief, about how much they had welcomed the pregnancy, how eagerly they had looked forward to having a child. When they told friends at church about it, how joyous they all were, and how often they would, in his words, “come at us with questions, questions, questions.” He was, he said, just not able to make it all clear about little Logan; unable to explain just what was going on, especially why, and despite all the hopes invested in them by everyone, their little boy was—prayers, friends, preacher, God, or not—going to die. How live with that?

“I tried to explain,” he said at one point, “so far as we understood these things, just what Logan would be like even if he survived—that he would be ‘neurologically compromised’, as they say here—but the words just wouldn’t come.” Especially, he went on, his efforts were made so difficult by what he heard his preacher say one day when he and Kayla first tried to say what life would be like if survival did indeed happen. The preacher, he said, interrupted right away with words of hope, all about how God and Christ would not let anything like that happen, that Logan would be just fine, if only the doctors would do everything in their power—and there was that powerful “everything”. On and on he went, she related, and then several friends from the church came up and joined in, one of them talking about someone else in the congregation who’d had a “tiny little preemie just like Logan,” and they had prayed and prayed, and soon, well, the person said, that little baby grew and before you knew it was home and all was well. “Just you hold on,” Mrs. Weathersby advised, “just hold on and you’ll see, God will work His wonders to behold. You’ve just got to make sure that those doctors don’t give up. Because they will, you know,” she went on, “sometimes, well, it’s just true, you know? Doctors sometimes seem to count more on money than on God.”

The words stuck in Gabriel’s mind, kept Kayla up at nights. And, when they read about some premature babies getting well after intensive care, well that seemed to seal it: they *had* to insist on “doing everything,” even while they also read about those babies that didn’t make it, or who survived to live such compromised lives. “How do you know,” Gabriel pleaded with me, “that they’re being honest with us, that they really are doing everything possible for Logan?”

Which set the tone for the rest of our conversation. Trust, that was one major issue; inevitable accompaniment of not understanding. Yet, not so much trust in the sense of whether you could trust doctors—after all, Kayla was quick to insist, “Max is such a good man; and the nurses? Well, they are just super.” And he emphasized, “they are decent folks,

Max especially, and we know they are doing all they know how to do, but then I get back to us, Kayla and me, that we have to trust them, that we have to trust that they are doing what they can. I don't know," he paused, thinking over what he had said, "I don't know, but what we've seen here, and what folks back home tell us, well, those are two different things. And everywhere we turn we hear about 'probabilities' and 'odds' and 'chances' and just don't know what all that means. "

I decided to interrupt. "Mr. Diekma," I slowly began, "let me see if I understand what you're getting at. Do you mean that you do not doubt that the doctors are trustworthy?"

"Heaven's no," he blurted out.

"Well, so you're not talking about..."

"Look," he interrupted me, "I know that Max and the others are doing whatever they can; we've seen them in there and what they do for every baby. But Kayla and I, well, all we can do is just stand there and watch, we can't do anything ourselves, everything is in their hands and, and..." he stopped talking.

I asked, "well, Gabriel, Kayla, what is it? Do *you* want to do something? Is that it?"

"Yes," Kayla spoke up this time, "and we just feel so helpless, we can't do anything to help our baby, have never been able to do anything all the time he's been in this hospital, since I gave birth to him. Then, I did everything, don't you see? And now I can do nothing, nothing at all, and there he lies and he's just dying, dying... and, well, our friends and preacher, they just don't see what we see, they, I hate to say this, but they just don't know what they are talking about!" She broke off, tears now streaming down her cheeks. Gabriel moved over to her, put his arms around her and talked softly to her.

\*\*\*

It was obvious to me, even at that early stage of my own growing into this clinical work that a dam had broken. They were both in tears, had both clearly stated their understanding of their baby's condition and dismal prospects, survive or not. While concerned over the way their friends and preacher were so apparently caught up in their own views that they just didn't understand the dilemma.

What really worried them was not so much all that as their own sense that *they* could do nothing in this most vital of all events, their own son's desperate condition. How explain that you, this mother who held

that baby in her womb for so many months—or you, this father whose actions led to the conception in the first place—how explain that now, at this time, you are completely incapable? For that is how they came to feel after so long a time in the NICU, able to do nothing, help not at all, and all along badgered by friends and others urging you just to focus on your faith. And there, right before your very eyes, your son lies dying. What can you possibly say, when you can do nothing at all? Where is God in all this? How could a good God allow this to happen to their son, who had nothing to deserve this? Questions plagued them endlessly, none of them usual, all of them unfamiliar.

At this point, it was possible to bring things to a kind of closure—he was, after all, calm, even talkative, as was she; and, they made it very clear that they needed to discuss matters with the staff. I asked them if they would like me, or Max and me, to talk with some of their friends, even their preacher. They thought about that, then decided that, no, they'd prefer to talk with those folks on their own; I then urged them to let the others know that they could, if they wished, come to see me. A meeting with the staff was arranged, and the terrible issues in this case came to a kind of closure when life supports were finally withdrawn; Logan died in their arms soon after.

\*\*\*

Issues were thus settled; except for me. I remember going home the night after that final discussion, resolved to say nothing to anyone, neither close students nor friends; I would, though, talk with my wife; I always did, vaguely knowing I needed to do that.

I remember, too, the whisper of something, an icy shard of feeling that suffused through me, about the time when I was at my mother's bedside in an adult intensive care unit—it was merely a year or so before the events I have related here. And that silent sigh of feeling brought to mind as well how I quarreled with the ICU doctor about removing her vent, and eventually 'won the case,' if that's what it was. I recalled, too, being at her side, assisting the nurse as we disconnected the ventilator; then, as my mother was still breathing, how, again together, we removed the tube from her throat, and how after she returned to her tasks I sat and watched her cardiac monitor almost imperceptibly cease to mark the electric up and down traces of her life, as she herself, suspended for but a slight moment, faded, ebbed, dying, and then, somehow she was no more. Awesome and dreadful, I recalled shuddering as I shouldered all that away, and then

drove into my driveway at home and geared up to be with my family, eat supper, chat a while, watch a bit of television, then go to bed and try to sleep. I began to realize at that very point just how much I really did understand Gabriel's words, Kayla's too: how live with that sense of utter helplessness? How try to help when help's no longer possible?

At the time, I couldn't quite figure out what I felt; I probably did not want to anyway, not then; later, I assured myself. But then, I realized that Gabriel and Kayla had, after all, come to a "decision," hadn't they? And didn't they get to that decision to *let their baby die* only after I intruded into their lives and led them down that fateful path to that same dark and brooding place Gabriel had already found and where, surely, he would find his way again? and who was I to dare bring even that about? And then it struck me that, finding myself inarticulate and puzzled, I was in much the same desolate place where Gabriel, and doubtless Kayla, too, had been. It hit me that, while it's true that helpers help those in need of help, and that's just what clinician's do. No matter how inevitable, nor how unwanted, parents must be told, and someone has to tell them; and if it falls to me, so be it—so long as I am, or pretend to be, a clinician in such settings.

But who helps the helpers get through? I needed help, it dawned on me. Not that the help any of us needs in such times is all that big a deal; often, it may not be; just a chance to hear yourself talk about your thoughts and feelings and, ultimately, who you are. There are times when we need someone only to listen quietly, nodding and touching perhaps, while the simple acts of telling and listening do their powerful, magically cleansing work.

What Arthur Frank says, rightly, about what he terms "telling-illness," is also true for those of us who tell stories, not just about ourselves, but about what others suffer. In his words:

The loss of the taken-for-granted world—being wrenched out of the natural attitude and facing the fundamental anxiety of death<sup>9</sup>—induces panic, in the mythic sense of unexpectedly encountering the terrifying god who screams in despair.<sup>10</sup>

---

9 These are references to Alfred Schutz, for instance: "Symbol, Reality and Society, in M. Natanson (Ed.), Alfred Schutz: *Collected Papers I*, The Hague: Martinus Nijhoff, 1971, pp. 287-356.

10 Arthur Frank, "Experiencing Illness Through Storytelling," in S. Kay Toombs (Ed.), *Handbook of Phenomenology and Medicine*, Dordrecht & Boston: Kluwer Academic Publishers, 2001, p. 241.



Every ethics consultation is a journey that calls for extraordinary caution, for what illness always bodes is the shattering of the ill persons' world. It is also an appeal to others, the consultant in particular, to help rebuild shattered worlds—if and as they begin that healing work. What Frank means, I think, is that understanding comes, if it comes at all, through listening to those who are sick as they talk their way in and through their enigmas and dilemmas, thus recognizing the need to help. These acts, he says, “create conditions for [stories] to occur.”<sup>11</sup>

As you've doubtless surmised, behind my story is another, one more hidden; the *obligato* is a stealthy project. I cannot forget that still haunting image I earlier alluded to, of my mother moving, ever so slowly, into being no longer: *Where* did she go? What happened to *her*? What now?

All of this, unfortunately, needs another story, one that I am constantly trying to get down, just right, but have as yet to succeed. But I promise this: when and if I do get it down, I will share it with you, as best as I can.

## ABSTRACT

After a brief review of some of the issues facing ethicists becoming involved in actual clinical situations, as I experienced these at the beginning of my career, I present a detailed narrative focused on an encounter I had with parents of a badly damaged neonate, a situation for which I was asked to provide a consultation focused on unstated ethical issues. The narrative continues through these issues and concludes with what parents described as an acceptable resolution. The essay concludes with a brief indication of what are taken as the basic issues in the situation.

**Keywords:** Clinical ethics – narrative – consultation – impact on parents and caregivers – listening.

## RESUMO

### No âmago da decisão há uma narrativa

Após revisitar brevemente algumas das questões com as quais são confrontados os eticistas implicados em casos clínicos concretos, tal como os que experienciei no início da minha carreira, apresento uma narrativa detalhada,

---

11 *Ibid.*, p. 243.

centrada no encontro que tive com os pais de um neonato com imaturidade das funções fisiológicas, situação a propósito da qual me foi pedida uma consulta em torno de questões éticas não declaradas. A narrativa prossegue através destas questões e termina com aquilo que os pais descrevem ser uma resolução aceitável. O artigo conclui com uma indicação sumária das questões consideradas basilares no caso.

**Palavras-chave:** Ética clínica – narrativa – consulta – repercussão em progenitores e cuidadores – escuta.

EDITORIAL

ARTIGOS

*AT THE HEART OF A DECISION IS A NARRATIVE*

R. M. Zaner

*AGONIA E RAZÕES PARA AGIR: UMA CRÍTICA A PARFIT*

Pedro Galvão

*A PROPÓSITO DA NATURALIZAÇÃO DA DOR NA OBRA DE FILIPE MONTALTO*

Manuel Silvério Marques e José Morgado Pereira

*AS MEDITAÇÕES SOBRE AS LÁGRIMAS E O CHORO DE JOHAN FRIEDRICH SCHREIBER*

Palmira Fontes da Costa

*REDESCOBRIR A SAÚDE QUE NUNCA SE PERDEU. DOENÇA, SOFRIMENTO E CURA NO BUDISMO*

Paulo Borges

*COMPREENDER A DOR. A PROPÓSITO DE UM CASO DE ANOREXIA NERVOSA CRÓNICA*

Dulce Bouça

*O PASSO DO ABISMO: O DESVIVER, A AGONIA E A MORTE DIGNA*

Manuel Silvério Marques

*A “BOA MORTE” DE BACON*

António Lourenço Marques

*SEDAÇÃO PALIATIVA, PERSPETIVA DE UM CLÍNICO*

Madalena Feio

ENSAIOS

*LA RESPUESTA AL PROBLEMA DEL NO-SER EN LA METAFÍSICA DE ARISTÓTELES*

Maria Carmen Segura Peraita

*GRAMSCI E I QUADERNI: FILOSOFIA DELLA PRASSI E IMMANENZA TRA MATERIALISMO E IDEALISMO*

Luca Onesti

*PRÉMIO PROF. DOUTOR JOAQUIM CERQUEIRA GONÇALVES PARA ALUNOS*

*DO 1.º CICLO/ CURSOS DE LICENCIATURA (Edição de 2018)*

*KANT NO JARDIM DO NÃO SEI QUÊ. NOTAS AO PARÁGRAFO §49*

*DA CRÍTICA DA FACULDADE DO JUÍZO*

João Maria Carvalho

DISSERTAÇÕES

*LUDO-ESTÉTICA*

Pedro Miguel Celestino Pereira

RECENSÕES

*THOMAS P. KASULIS, ENGAGING JAPANESE PHILOSOPHY:  
A SHORT HISTORY, HONOLULU, UNIVERSITY OF HAWAII PRESS, 2018*

Ricardo Santos Alexandre

*INSTRUÇÕES AOS AUTORES – NORMAS DE PUBLICAÇÃO  
INSTRUCTIONS TO AUTHORS – PUBLICATION PROCEDURES*



Patrocínios

