



Ethics Talk; Talking Ethics: An Example of Clinical Ethics Consultation¹

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Abstract. This written account of a clinical encounter – depicting fragments of a more extensive array of events – attempts to exemplify many facets and associated complexities of clinical ethics consultation. Within the general telling, I provide more detailed portrayals of several key events. In section 1, I document briefly my initial interactions at the beginning of the consultation, focusing on the information gained – in the context of those interactions – as I read the medical chart of Mrs. Rose. Next in section 2, I briefly describe my initial conversation with Mrs. Rose’s three sons. Section 3 illustrates several questions raised in sections 1 and 2. Then section 4 presents my encounter with Paul, the youngest son, as he was carrying out his vigil at his mother’s bedside in the hospital. Section 5 chronicles my interactions with several care providers involved in Mrs. Rose’s situation, including two different meetings that occurred with Mrs. Rose’s attending physician. I conclude in section 6 by telling about a conversation I had with Mrs. Rose’s middle son, Russell, approximately one month after Mrs. Rose died.

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passes in & out
of more difficult things
and by so passing
apophainesthai

Charles Olson, *The Maximus Poems*

1. What’s Going On?

The beginning of this consultation had two features that were unusual. First, I received a call from one of the executive secretaries in the administrative suite at the hospital – suggesting administrative anxiety, concern, and expectations that were already focused as an urgent need for me to respond immediately. The other significant feature was that the request for ethics consultation came from the patient’s son, Russell Rose, who was associated with and had knowledge about health care facilities. The secretary said that Russell knew hospitals such as this had ethics committees, and he wanted to talk with a representative about his mother’s treatment. I agreed to meet with him as soon as I could and then asked where I could find his mother in the hospital.

Mrs. Rose was on the second floor, a complex that included forty critical care intensive care beds, and seventy-five step-down intensive care beds. Most of my consultations occurred in that area. I walked down the long, carpeted corridor busy with the hustle and bustle of respiratory technicians, dietitians, unit clerks, and nurses shuttling back and forth among the various rooms. While I was familiar to most of these people, my presence usually signaled that a certain kind of problem was occurring. Nurses, residents, and other physicians experience and immediately interpret the mere presence of other providers.

I gathered Mrs. Rose's chart from the station facing out from her room, and my first clue to what was going on came when I asked a nurse who Mrs. Rose's nurse was. After pointing Molly out among the other nurses, she informed me that Molly had had a relative who had treatment withdrawn, thus "telling" me that Molly herself would surely be understanding of Mrs. Rose's situation. I went to Molly; we sat down and I tried to find out why I was called. She said she didn't know who had called, but she did know that the family was concerned that their mother "would not want to be hooked up to the ventilator."

Her words, their tone, and her demeanor – one of careful, descriptive speaking, but not engaged with their concern as a problem – suggested that she was not entirely in agreement with the family. So I asked her.

"She's really sick," Molly said, "but she might get better. Besides, there's a No-code on the chart. It's too early to just let her die, at least that's what I think. You know what else, the residents really feel undermined by the family going down and calling you."

It was revealing that in the time that Russell had gone down to the administrative offices and come back for a visiting hour, the residents and the nursing staff on the unit already knew that I had been called. "Undermined:" already intimated was a theme that, in their concern about the level of medical intervention, this family was thought to be circumventing the efforts and assessments of the residents.

Molly asked, "Do you want me to find them?"

While she went to get the residents I returned to reading the chart. Mrs. Rose, eighty-four-years-old, had a history of atherosclerotic heart disease, coronary insufficiency, cancer of the colon, and breast cancer. The latter had been surgically managed by a modified right radical mastectomy. She had been hospitalized for nine days before her son's request for ethics consultation. She had been admitted to the hospital to undergo a uterine suspension and bladder repair. However, the evening prior to her admission, she developed a temperature of 102.3 and had "shaking chills." On the morning of admission, her temperature remained over 100 and the surgery was postponed. Within two days, a mild pneumonia was diagnosed, which subsequently worsened dramatically.

During my brief scan of the chart, I was able to identify several medical questions. She was probably septic, although the medical team had not been able to identify the source of infection. Her pneumonia had been further complicated by congestive heart failure.

I looked for and located the attending physician's note mentioning that he had discussed with the patient and her daughter whether or not a Do-Not-Resuscitate (DNR) order was appropriate. That discussion occurred four days prior to the request for ethics consultation. The attending also noted that the patient "wishes every effort made including ventilator if needed." Subsequently that same day, Mrs. Rose had experienced acute clinical deterioration of her pulmonary capacity, breathing forty times a minute with her blood pressure unstable. She had been intubated and placed on mechanical ventilatory support. The consulting pulmonologist noted that she was "deteriorating clinically" and that a bronchoscopy was needed for tissue diagnosis.

The acute character of her deteriorating condition was emphasized throughout the recent chart notes. On the morning following her intubation, the attending physician's note indicated that Mrs. Rose's prognosis was "certainly graver," in particular because she required such high levels of oxygen while on the ventilator.

The next day, the resident diagnosed her condition as adult respiratory distress syndrome (ARDS). Despite escalating antibiotic coverage, Mrs. Rose's temperature spiked to 102.3. She required transfusion. The treatment team also gathered results from various medical procedures, including the bronchoscopy and lung biopsy, in order to identify whether any malformation or pathological process which might be present in her lungs. Her pulmonary status continued to deteriorate and the pulmonary consultant confirmed "ARDS with an unclear etiology."

Two days prior to the request for clinical ethics consultation, the attending noted that prognosis was "very poor, doubt that patient will survive." His note also indicated that he knew of "no other therapeutic moves to make."

One can appreciate that the diagnosis was acute but uncertain as to the specific cause, and therefore uncertain about what clinical management for treatment might be most effective. Despite that diagnostic uncertainty, the attending's clinical opinion was that she had a "very poor" prognosis—a term that, like "dismal," in this clinical reference, clearly indicated that the patient was not expected to survive. Nevertheless, on the basis of current clinical indications—i.e., acute deterioration and lack of clear diagnosis—therapeutic interventions at that point were maximized.

On the day before the request for ethics consultation, Mrs. Rose's oldest child, her daughter Janice, had requested that a DNR order be written. The nursing notes quote her saying "that is what my mother would want." Here

the chart began to reveal a possible source of concern. The attending noted that “her prognosis remains very poor,” and he concurred with Janice’s request, as he had written in the chart, because he “would not be able to add any further support anyway.”

On the morning that I was eventually called, the same physician noted that he did not “expect her to survive and family aware.” Again he stated that he had “no additional therapeutic moves.” He also told them he would be “out of town” for a few days.

There was neither a mention nor even a hint, in the chart, about whether or not continued ventilatory support would be beneficial, only that there were no further therapeutic options. Even in my brief review of the chart while waiting to speak to the residents, it was clear that two themes had already developed. On the one hand, the typical temporary trust important for understanding among physicians, families, and patients had for some reason been disrupted. On the other hand, that erosion of trust might have been complicated by the family’s concern that their mother not have to undergo this level of medical treatment, if it was not going to restore her health.

Those were plausible interpretations of the family’s request to speak with me. Since medical consultants confer with patients only at the attending physician’s request, however, simply by Russell’s walking down the administrative offices to bring this matter to the attention of the hospital administrators and “ethics committee,” a tension had been demarcated between the attending and the family.

These complications exposed yet another theme. The attending had documented that he did not expect her to survive and that the family was “aware” of this. Yet, the clues from the nurse clearly suggested that the care providers were not prepared to discuss the limitations of therapeutic interventions. The treatments provided had not demonstrated any improvement of her condition. In response, the treatment team remained focused on diagnostic evaluation, therefore, on the degree and extent of diagnostic uncertainty. Since they could not yet say just what was causing her condition, perhaps they were thinking that it was too early even to consider discontinuation of medical interventions. The “very grave” prognosis was, in this way, pervaded by multiple forms of diagnostic and prognostic uncertainty.

I was approached by Max, a resident physician with whom I had worked on several other difficult cases during the past year. He and I were thus able to proceed with some directness to the questions I had. He explained and clarified the trajectory of this woman’s dramatic and acute decline.

“He’s really paying attention to her, and asking us a lot of questions,” Max said, referring to the attending. “He hasn’t really talked to us about the level of treatment though . . . and, we haven’t been there when he’s talked to the family, so I really don’t know what they think. We’ve really worked to keep her stable, to give her a chance, and they’ve (apparently he was referring to the family)

kind of taken the rug out from underneath us . . . like they don't appreciate what we are doing for her, because we still don't know what's causing this. It's just not good medicine," he concluded, "to withdraw treatment at this point."

A tenacious resident, experienced in these wards, I was interested that he had this view, and further by the way he expressed it. What was going on? Although he had not spoken with the family, they were identified as the source of what was unquestionably taken as a lack of regard for the medical team's efforts. Was it the attending's style, or the family's request for ethics consultation, that they felt had cut them out of the "loop?" Was that feeling in part motivated by some preference to avoid that issue on the part of the attending? On the family's part, was their sensing of that avoidance part of their preference to want to get their information straight from the "man in charge?" What was behind the call for ethics?

2. Questions

Amid the hectic activity of the unit, I started back to my office, and phone, knowing that I had to talk to the attending. On my way, I had one of those moments – invariably present in these situations, sometimes striking in the way they form and inform perceptions and future actions. As I was placing the chart back at her station, glancing into her room, I saw two men in their late 40's or early 50's. Sensing that they wanted to talk with me, it was awkward not to stop, yet, as a matter of protocol, I needed to talk to the attending and get his acknowledgment prior to talking with his patient or family. Beyond the protocol, though, I thought that talking with them at this point would likely only add to the confusion, and thus recognizing them now might only make it more awkward to talk with them in the future. So, after putting the chart back, I left the unit without stopping to speak with the two men.

The attending physician was nonplussed by my call, for what seemed to me several reasons. One, with Russell's request for ethics involvement, the balance of control had shifted, even if due only to an appearance of increased scrutiny. Furthermore, the indication of apparently displaced trust could not have been lost on the attending. At best, it would have been awkward for him to restrain me from speaking to them. As he was himself scheduled to undergo minor surgery at another hospital in town within hours, he was abrupt in response to my questions about any difficulties or concerns the family might have expressed. With barely veiled irritation that betrayed a hint of feeling besieged, he told me to go ahead and do whatever I felt I needed to do.

At that point, in the quiet of my office, I reviewed what had transpired and made some notes, all part of gathering myself to talk with Mrs. Rose's family. Then, as I was walking to the unit from my office, I saw the same two men I had glanced earlier; they were now standing in the corridor poised with a

subtle, yet quite obvious, urgency. I went up and asked them, “Are you members of Mrs. Rose’s family? Are you looking for someone from the ethics committee? If so, that’s me and I am looking for you.”

They acknowledged they were and, shaking hands, I directed them back to a quiet room adjacent to the waiting room, so that we could sit and talk. The brothers were composed and exhibited quite evident concern about their mother. Russell was older, probably in his mid 50’s, and had requested the consultation. The younger one, Paul, had just that day flown in from the West coast and was visibly enervated by his equally visible attempts to restrain the potent mixture of apprehension and foreboding about his mother. As it turned out, when I met them in the hall, they had just spoken with the attending physician (which meant he had found them, or they him, very shortly after his abrupt conversation with me) and he had given them some further explanation regarding her current condition.

I explained to them that I was there to talk with them about what was happening with their mother, and to be of whatever assistance I could in conveying their concerns to the physicians. I would also attempt to clarify any confusions that might have developed. Paul told me that they were waiting for their older brother and their sister.

But then Russell said, “Well, no, Janice was with Mom when the doctor asked if she wanted to go on the ventilator. Janice really didn’t think that was what Mom wanted, but Mom told the doctor, ‘Yes, if it will help,’ so now Janice won’t come back here. She says she knows Mom’s not coming off the ventilator and she doesn’t want to wait here and watch her die . . . after she’s told us all that she doesn’t want this. She’s had to care for Dad, at home. He’s not doing well either . . . until she came to the hospital Mom was taking care of him. His memory is gone. He doesn’t remember who’s with him, and he’s gotten worse since Mom’s been here.”

As a means to assess, at least indirectly, the extent of their understanding gathered from talking with the attending, I asked what they had been told about the differences between pneumonia and the adult respiratory distress syndrome (ARDS) which had been diagnosed two days earlier. I also asked about any statements that their mother might have made to indicate what she would want done in these circumstances.

On the first point, I did discuss with them the idea that there was quite a bit of medical uncertainty about the extent of pulmonary compromise, and that this uncertainty was both different from and possibly might have exacerbated their concerns. Two matters bothered them. They wanted to know the best thing to do for their mother at this time. Understandably, they were also concerned to alleviate her suffering.

During our conversation, the dual question of her being intubated and her “being hooked up to that machine” became something of a touchstone, returned

to and reconsidered several times. The urgency of their concern stemmed from the fact that each had talked to their mother during the previous months, and she had indicated to both of them that she knew that her health was not good, and especially that she would not want to be on a ventilator for a prolonged time in the hospital.

“When they told me that she was intubated,” Paul said, “I thought that it had been done against her will. I just don’t know.”

They were clearly anxious to find out if that was correct. On my part, several questions became prominent. Because they had only moments earlier told me that Janice was present when that issue was discussed with the doctor, did she have stronger feelings than they about the intubation? If so, how were her brothers evaluating her report to them? Was there some significant wavering about this matter, even among themselves, regarding what their mother had said, or meant, or would want?

As we were talking, Russell heard the older brother, John, talking at the bank of phones outside the room. He went and told him to come join us. With John’s entrance, the dynamics of the conversation shifted. Russell appeared to be more tolerant of the physician’s position, perhaps due to the fact that he lived in town and was more familiar with the times, places, and discussions that his mother had had with this physician, or, perhaps, he was responding to John’s straightforward insistence that something ought to be done to resolve things.

“Why should we wait, if she’s not going to get any better? She wouldn’t want this.” John seemed very explicit and clear.

“But we don’t know if she’s going to get better,” Paul countered. “We just talked to her doctor. He said she’s very sick, and he doesn’t know whether she can recover.”

“What do you mean?” exclaimed John, “I called him yesterday and he said she’s gotten worse. What he doesn’t know,” John went on, “is just when or how she’ll die. We can’t just let her go on like this.”

Silence punctuated John’s statements. As we all sat there, crowded in the small room, that silence evoked anticipation and anxiety. All three looked at me as though I was to now say something. In response, I tried to clarify what I had learned up to that point: that even if their mother had been diagnosed with only pneumonia, she had been on the ventilator four days at this point and that this was typical for treating the pneumonia. Moreover, that she had ARDS meant something in addition to the kind of infection that one finds with pneumonia. It meant that there was some source of infection, other than the pneumonia, and that sepsis was causing an inflammatory response. The congestive heart failure, which complicated her condition, stemmed from the extent of inflammation in the vascular bed of the lungs. Given that the potent antibiotics being used were having little, if any, effect on the infection, the actual tissues of the lungs were inflamed and possibly damaged.

It was that combination of factors that indicated the poor prognosis. At the same time, I urged that, in view of the acute nature of their mother's deterioration, they needed to understand that the uncertainty was not only about what caused her condition; the additional, more immediate question was the extent of the damage and whether the damage could be treated, or was irreparable. One medical problem was to find some way to allow the lungs to heal and at the same time not create damage by that very mode of treatment: the ventilation that was designed to help might also cause problems.

Russell leaned forward, "You mean she needs the machine, but the oxygen is going to hurt her lungs?"

"It can," I said. "She's getting 100% oxygen, and the ventilator tries to transport oxygen across those inflamed tissues. As time goes on, that level of oxygen could possibly cause more damage, but that's difficult to assess right now."

"That assessment is complicated by the sort of immediate medical uncertainty we're talking about here," I continued. "You seem concerned, if I am hearing you right, with the uncertainty about what is the best thing to do for your mother. Let me see if I can put this problem in words so we can talk about it, OK? If you are saying that she probably does not want the things being done to her now, then to get exactly clear on the medical uncertainty might not be "best," if as a result we find that her condition could not be reversed, and in that process continue to do all the things being done now."

All three were fixed attentively on what I was saying. When I noticed this, I paused, not sure just how to continue. "Can you remember what she has told you that might indicate what her preferences might be?"

With that, John recounted his mother's Southern Baptist upbringing: "Mom used to say, as long as your heart was beating and your brain was still alive, then you were alive . . . and only in the past six months, well you know how it is with these conversations happening over the phone. It's when I called Mom up to ask her how she is doing. She told me she had already planned the place where she wanted to be buried, and that she did not want to die hooked up to these machines. So she's changed in her way of thinking over the years, because being a Southern Baptist, I mean you just don't talk about that."

Apparently, from what he said, Mrs. Rose had been considering the ramifications of her health for some time prior to this hospitalization, and from all indications, according to her sons, would not want to be on the ventilator for a prolonged period of time, if at all. But, the question about what was meant by "prolonged" was difficult to resolve, given the impasse created by the medical uncertainty about any recovery, and complicated by the fact that she had agreed to be placed on the ventilator. They pressed me to say why we couldn't do something now to relieve her from the burdens of mechanical ventilation.

“Why can’t that just be stopped, now?” insisted John. Why not? Why not. In view of indications noted by her physician that their mother was dying, and because I had little sense of what the attending had actually told them, I could only point to the uncertainty about the extent of damage and the possibility of treating it. Clearly, they wanted to honor their mother’s requests to them.

I told them that from my experience – emphasizing that I was not a physician – with the diagnosis of ARDS being made only recently, it was going to take several days in order to sort out just what were the consequences of that diagnosis and the actual limits of medical interventions. I suggested that we meet again, because the medical team, as was not unusual, was itself not very clear about what to do, and thus would require some time to address their issues. Moreover, I emphasized, now that I had talked with the three of them, I also needed time to clarify, for myself, several of the issues that they had put to me.

3. The Chart Revisited: What Does “Self-Extubation” Mean?

They appeared to be relieved that their mother had not been intubated against her will, but why did they have that perception? As I thought about that question, several implications regarding the actual practice of clinical decision-making – ones that required further probing – were evident. With respect to the conventions regarding the authority and accountability to make decisions in situations such as this, a cluster of issues had evolved for the attending physician and Mrs. Rose’s family: Why should or shouldn’t they withhold or withdraw certain treatments? Closely tied to that was the correlated question about whether those treatments were providing benefit.

Those questions and their associated implications can be surmised from the statements of her first nurse, from her chart, from Molly, Max, and the three brothers. So far as I understood what I had found up to that point, medical options had apparently become limited to waiting to see what happened – which could take a variety of forms – or, perhaps, withdrawing the intensive medical support. Yet, at the same time a series of responses and strategies had developed that appeared to resist the option of withdrawing medical intervention.

I went back and reviewed the chart more carefully. I found what was perhaps only a small, yet very revealing detail, that clearly suggested why the practice of ethics consultation requires vigilance within a vortex of complicated relationships and meanings – that this practice proceeds not only from fragments, but from gaps, hints and subtle insinuations.

Immediately after the attending physician’s note documenting that the “family does not wish her resuscitated if she arrests,” and his co-signing the DNR written by the resident the day before, were two notes written within

two minutes of each other. The first, from the respiratory therapist, reported that this patient, with pneumonia and ventilator dependent, “extubated herself.” “Masked ventilation with 100%” oxygen was provided. The patient was “awake without sedation” and the endo-tracheal tube was placed “19 cm at teeth.” Frequently, chart notes by respiratory therapists and nurses provide similar accounts from the perspective of their respective roles and responsibilities. So, I read the nursing note immediately after, which said that “in the process of turning the endotracheal tube dislodged and patient extubated.”

That first account stated that she had extubated herself. Did the family even know about this? If they were told, who told them? Did the family think that Mrs. Rose deliberately extubated herself, and was then re-intubated against her will? Was that the sense of Janice’s report to her brothers, and the reason she requested the DNR – in view of her beliefs about the earlier decision to intubate? Which was it, then, “self-extubation” or dislodgment by “turning?” Given the way such notes are written, it was possible, although not likely, that Mrs. Rose had “self-extubated,” been re-intubated, and then the tube dislodged when “turning,” thus requiring a second intubation. Moreover, even if that were the case, that in itself demonstrated the routine manner of treatment. Did anyone explain this to the family?

Also mentioned in the nurse’s note was that the “patient was reintubated without difficulty,” and wrist restraints were placed on the patient. That was the first mention of wrist restraints in the chart, and I wondered why these were placed on an awake patient, if the extubation was caused by turning? What was the influence of the nurse’s perspective on this situation, particularly in terms of some possible erosion of the family’s trust? Was this what these sons were referring to, after a DNR order was written one day prior? Did they have some sense or clue – and if so, from whom? – that she had been re-intubated against her wishes? Certainly she had been re-intubated. That was within the policy guidelines for the hospital. Typically, inadvertent or accidental extubation results in re-intubation. But, did any of that, and if so, how, account for the family’s interpretation of their mother’s experience – if she had actually pulled out the tube, after telling them over the past year that she would not welcome “being left on a machine?”

I called the consulting pulmonologist. On several occasions in the past we had discussed various intricate details of the management for ventilator-dependent patients, including issues associated with the shift from curative to palliative management and withdrawal of ventilatory life support with provision of narcotics for dying persons. His candor was frequently very helpful in these sorts of situations.

He did not know any of the particulars of the re-intubation, but his impression was that such an action was not unusual. I asked him to clarify the

diagnosis of ARDS. He said that clearly Mrs. Rose had deteriorated very quickly – a very bad sign for her overall prognosis – but he wasn't certain enough at this point to recommend that the ventilator be withdrawn. It was simply too early for him to tell. Later that day, however, he did recommend, in the chart, that the ventilator support and other interventions be withdrawn if she continued to deteriorate.

I went to see Mrs. Rose. She was very pale, withdrawn, and quite ill. She did not have wrist restraints. Although she did not respond when I spoke to her, I could see her start to breathe. Those feeble movements, unmistakably those of a very sick person, would prompt the ventilator to fill her lungs. Whether or not she was aware of me or her situation, everything in the room was oriented to her in both direct and indirect ways. She was the focus that directed all of the equipment. She was hooked up to the various IV lines that were providing the cardiac medications and the antibiotics. From the foot of the bed, I could see a monitor up off on the right that displayed all sorts of information about her heart rate, rhythm, and blood pressure. There was an oximeter to gauge the estimated percentage of oxygen saturation in her blood. Off to her left was the ventilator itself with its almost-neon array of digitalized information. All of this and the activities and procedures of anyone who came in to see her – nurses, doctors and visitors – were all oriented to her. I took this in, as part of my habitual practice, in order to gauge and conduct my own relationship with her in this situation: she seemed to be dying.

4. Talking with Paul: A Moment in the Encounter

The next morning I found Paul sitting in the recliner in his mother's room. With her bed between us, I could see him rise from the chair as I entered. I had stepped into his vigil.

Moving from the chair his greeting was subdued yet open. He seemed willing, if not eager, to talk. I asked how his mother was doing.

"She's not much different. I know it's a matter of waiting . . . like we talked about yesterday . . . So I'm watching for the family."

His oldest brother was preparing to leave the country, Russell had pressing business requiring attention, and Janice not only was at home taking care of their father, but she felt unable to sit and wait, in this room, with her mother fading on the ventilator.

"You know this book has ethical implications," he said as I stepped around the bed to see. It was a recent book by Fritjof Capra, *Belonging to the Universe*,² with one of the brothers from a Camaldolese monastery somewhere north of Big Sur in California.

"I'm not very well versed in this kind of theology," I said, "although I have read some of Capra's stuff . . . you know *The Tao of Physics*. That was a while

ago.” I was searching for some way to balance his openness with my desire to solicit his understanding of the situation. On the book cover was a blurb describing the monk as a contemporary Thomas Merton.

Attempting irony, I remarked, “you know both this monk and Thomas Merton would want to know what that means . . . to be like Thomas Merton.” We chuckled. I was grateful, but my own discomfort alerted me to the compensation made for interrupting the vigil. I attempted to recover. “I mean that in the sense that this book certainly has ethical relevance in the question it poses: What is the best end for human being? . . . that’s something we know very little about.” I was trying to find a way to talk about his mother dying, to discover if, and in what way, we might talk.

So was Paul, and he glanced over the book as if to ask, ‘How is it that you are here, with me, talking like this?’

Retreating to the professional stance of a helper I said, “I wouldn’t pretend to understand what you are going through, but I know its difficult to wait” – and, taking up the institutional voice – “we are trying to proceed as carefully as possible, to be as attentive and responsive to your mother’s needs as we can. If there is anything I can tell the people taking care of her, just let me know.”

He moved to the bed. “I want to sit and hold her hand . . . but when I touch her arms, stroke them to let her know I’m here” – he sat on the bed, softly cupped her hand with his – “I draw her back into this world . . . here . . .” – and just as gently stroked it, using his head to point to the room, moving it around his shoulders, while keeping his body still, focused in that caress. She moved weakly, turned her head against the ventilator tube without opening her eyes, grimaced slightly, then even that trace withdrew.

“I’m not even sure she knows I’m here, and I just want to hold her, you know . . . but when I do, she moves just enough to let me see how uncomfortable she is.”

We both knew that his mother was sedated, receiving approximately two mg of Ativan every four hours. Even slight movements, these faint stirrings of a weakened and ravaged person, conveyed the gravity of her discomfort. He wasn’t sure that she felt these in any conscious way, nor was I, but that in no way lessened their evocation of her dying. With little to do except acknowledge that, I moved to an issue now confronting him, his family, and me.

“You know,” I said, “she was alert before she got so ill. Probably nothing that has happened has irreversibly compromised her mental capacity.” I suppose I was taking refuge in such language. I tried to get out of it. “If the sedation were decreased, she would probably become more alert. I don’t mean to make this more difficult, but that raises an issue we need to anticipate.”

Worried that I might be treading on perilous ground, I pushed on: “A typical way moral reasoning is constructed in medicine is that it’s her choice – if she wants the ventilator withdrawn. But, the way I see it, well, that doesn’t make

sense here. If she has made it clear that she doesn't want to be in this condition . . . a question we must continue to consider carefully . . . then I see it as a matter of responsibility for the people taking care of her to respond fully to the fact that their attempts to help may have contributed to her current state. What we are really faced with is a decision in a network of relationships . . .” – Man, I thought, I can't take him through that – “what I mean is we need to rely on your family's sense of her life, what would make sense for her, in that history you share with her.”

That question of relationships kept coming up, and I kept on: “What I mean is that to let up on the sedation, and then ask an impossible question like ‘Do you want us to withdraw the ventilator?’ . . . that doesn't make sense.”

Trying to resist naming it, I couldn't, so I continued, “That would border on cruelty. What a terrifying thing, because who but the most courageous could say ‘yes’? If she has told you and your family her wishes as clearly as she is capable – and certainly she is the most vulnerable in any way imaginable in this situation – to ask her to be the most courageous, so that we can resolve this waiting, that's really not the way to do this.”

I was trying to help, immediately vexed by the thought that I had presumed too much with my speech. Compelled by this situation, I had clearly implicated those persons involved in the question of its violence. Was I making a mistake? I would only know as my inquiry pressed through to its own limits.

Paul appeared to be relieved, and I wondered whether it was because my compressed, and possibly presumptuous, speech had ended, or if I had happened onto something that was helpful – and now later, whether he was trying to help me. It would be difficult to say, because we – both of us – were gripped by sorrow.

We moved to the end of the bed and talked about San Francisco. He told me what he did for a living and about his civic involvements. He called himself an “entrepreneur,” although at that time several of his projects were “on hold.” He talked about his concern for the poor in the city and his effort to use his skills and time to raise money for some of the indigent and vulnerable in his community. We talked about that kind of service for a while. He was intrigued that the hospital had provided someone to talk with him about ethics, with a willingness to speak candidly to these issues. In my awkwardness, brought on in my anticipation of this mutual conversation, I ventured another topic.

“You know, in my experience it is people like you and your family, who allow me to participate . . . I try to understand what it's like to face these decisions, it enables me to learn, which gives me the hope that I can help other people in similar ways in completely different situations. I don't have an answer or a theory from which to derive an answer, but I am trying to stand with you as you look ahead to discover what is going to be best for your mother, for you and your family. That's my focus.”

He turned to me, “that’s well said and I appreciate that.”
Our talk was over. When we said good-bye, I thought we would talk again.

5. Clinical Ethics: An Affiliation With Courage

During the weekend, after my talk with Paul, the covering pulmonologist progressively increased the level of ventilatory support. Mrs. Rose had been initiating and sustaining all inspiratory efforts. By Monday she was on full ventilatory support, including sedation to suppress spontaneous breathing. The attending noted that he expected the “patient to continue to deteriorate.” Because oxygen saturation levels were fluctuating to forty percent (40%) with one hundred percent (100%) oxygen, he noted, “expect demise soon.”

That afternoon I found the first pulmonologist as he stood over Mrs. Rose’s chart.

“What do you think?” I asked. He looked at me intently, waiting until he was clear just what the question was. So I described my conversation with Paul.

“She’s gotten worse,” he said. “She was starting to drop her sats during the weekend. Today her blood oxygen is dropping to forty percent (40%) on 100% oxygen on an assist control rate of 33.”

Now it was my turn. I pressed. “Forty percent; the family’s understanding was that if she didn’t improve after intubation, she would not want continued support.”

“Well, she’s not improving. Looking at her today, I’d say she’s terminal.”

Explaining the different characteristics of uncertainty I had discussed with her sons, and their explicit and repeated concern about her suffering, I asked, “Can you say that clearly, I mean will you chart that at this point?”

“I don’t have any problem with that,” he said, “But, I don’t know what the attending will do – its his patient.”

I said, “Look, I think I understand the attending’s hesitation – would more liberal pain medication be appropriate? This woman was alert, but now she is dying and she’s getting only two milligrams (2 mg) of Ativan. Can you help her?”

He turned back to the chart without answering. When talking to physicians over a chart, that was not unusual. An unwritten rule pertained here. The message was that I should not continue to press, because he had only moments before made explicit his judgment that she was dying, yet he could only recommend a course of action that he might take to the attending. If I pressed further, my questions would appear too clearly to be about his conduct, as well as to challenge the implicated “rule” that was supposed to protect him from the question: *If she’s going to die, and if her family believes that she made it clear that she did not want the ventilator when it was determined that she wasn’t going to improve, what are you going to do?*

On the basis of previous discussions with him, I had to trust his own understanding of his involvement with her medical care, against the background of his history with the attending in this environment. Perhaps he had heard me and wanted to consider it more carefully – which I also understood. Perhaps he had already thought of it, and in view of my concern for the questions being obscured here, I had reminded him. Thus, the conversation broke at a natural point, even though I could not, at the time, tell his sense of it. As I left, he was writing in the chart.

Apparently he agreed. I found the next morning that he had written an order for morphine: two milligrams (2 mg) PRN. Also, his note in the chart suggested “withdrawing all but basic support. Patient is terminal.”

Later that evening the attending met with Mrs. Rose’s children. I could not attend, but a colleague of mine did and later told me what occurred.

The attending had been her primary care physician for many years, and had discussed the issue of life sustaining therapy with her. To give them a sense of his involvement with their mother’s care, he told a story. When she had first developed problems with coronary insufficiency, she decided to move from her second floor apartment, but had to get on a waiting list for first floor apartments. She mentioned her need to him. As he knew the apartment manager he called – without ever mentioning it to Mrs. Rose. It turned out that she was able to move, and he never bothered to tell her about his role.

He also acknowledged that further medical intervention would not alter the fact of her dying and that he had understood her preference not to have such means as the ventilator used. However, given what he interpreted as her decision to be intubated, he believed it had been necessary to be aggressive in her management. He also stated his belief that she would die very soon.

The next morning the attending’s note stated that he agreed with the pulmonologist’s note, and mentioned that the “family is aware of horrible prognosis.” Yet, he ended with the statement: “no change in treatment.”

What was going on here? It had been over four days since the family had first voiced their concerns, quite clearly. Those were very explicit, had been clearly emphasized to the attending in conference, and he publicly acknowledged his own understanding of Mrs. Rose’s preferences gathered from his own discussions with her. Was that one, momentary “decision” to be intubated actually so decisive – even though made while Mrs. Rose was experiencing, as one might imagine, dreadful feelings of air hunger?

That afternoon, my colleague and I discussed the possible meaning of the attending’s position and the need for the family to talk with him. In his conversation with them, my colleague recommended that they speak directly with the attending. As part of that recommendation, my colleague suggested that they go to the physician’s office and talk there, rather than waiting in their

mother's room. All four children went to the attending's office and waited for over two hours to speak with the attending. They later reported that they utilized that time to confirm their own understanding with each other and to clarify just who would be responsible for stating different parts of their overall concern. In that way they prepared for the discussion in order to ensure that the attending would "see" the necessity for withdrawal. Their emphasis was on their understanding of their mother's terminal condition, her expressed preferences, and their commitment to honor her preferences. Later that evening, the attending noted in the chart that "they very strongly want her disconnected from the ventilator. I have asked them to wait until the morning and we will re-evaluate."

The following morning I met with the family early, just after 7 a.m. They had requested this, after talking with the attending the previous afternoon. They said that the attending told them he wanted to wait because of his concerns about the nursing staff.

More than ironic, this was quite revealing, even in its ambiguity. After having queried the pulmonologist about adequate pain relief, over the past several days I had been discussing with the primary nurse the exact issue of the moral ramifications of PRN provision of morphine for Mrs. Rose. The nurse wanted to honor what we had reasonably determined as Mrs. Rose's preferences. She was explicit in her agreement to avoid futile or burdensome treatment. However, she was concerned that her acts of providing morphine, over time, might produce death sooner than "natural" causes. Including the unwieldy conceptual relations brought on by referring to "natural causes" of death in an intensive care unit, she and I had talked about the moral differences that seemed relevant in terms of her actions. Her purpose was to relieve suffering caused by the continuation of non-beneficial treatments for a dying woman, not to hasten her death. Prompted by the increased morphine dosage from two milligrams to four, her point was that entertaining that subtle point was one thing, but injecting the bolus of morphine and watching life fade from the person was something much different. If the attending shared those concerns, to my knowledge he had not discussed these with the nurses. If the primary nurse had raised the issue with the attending, she did not relate to me any of that conversation – even though, like I said, she and I had what I took to be an extensive discussion on just that point.

The four children wanted to review our discussions, and, based on my most recent conversation with the pulmonologist, I did what I could to assure them. In the throes of the overwhelming character of the situation, they were, after all, awaiting the final moments of their mother's life. I was aware that I would probably not see them again, and I wanted to give them some sense of my gratitude, despite the awkwardness of my recognizing the limitations for my understanding what they were going through.

“What is extraordinary,” my clumsy hortatory went, “is what I learn from people like yourselves.” Having come that far, I decided to take the risk of what else was on my mind: “What I’ve seen is your courage in the love for your mother, to struggle with what was best for her. That’s hard enough. Most of all was your willingness, for the sake of that love, to stay in conversation with her doctor, and to understand what he might be going through. Even though he couldn’t or wouldn’t talk about it, you were careful to consider his relationship with your mother, for her sake and for his. Your openness in allowing me to see that, by talking with me, helps me learn about that capacity, in you, myself, possibly him and others. Maybe I can help somebody else. See, even as I’m telling you, I’m showing you how awkward that can be. I must stop.” This they had allowed me to do.

The family beeped me during an Ethics Committee meeting (which happened to coincide with that morning) about 45 minutes after I left them. I called the unit, where Mrs. Rose’s nurse told me that she had been extubated and then died less than 30 minutes later. She also relayed that the family wanted to talk with me. I went to the floor after the committee meeting.

The family thanked me for my efforts, which I accepted. In turn, I reaffirmed my own gratitude for their trust. Then as they turned to go, Paul glanced back. Our gaze met, and the recognition I still cannot express. Then he turned back, and moved through the hall with the others.

6. Limits of Insights and Forecasts: Was It Euthanasia?

It had been over a month since his mother had died when Russell came back to see me at my office. His brothers and sister had returned to their homes, leaving him to manage his mother’s affairs—as he had done previously. Having been involved with his mother’s care prior to her final hospital stay, his experience was more informed by the nuances and details of her encounters with health care professionals. He wanted to talk about the decision to withdraw the ventilator.

His concern was direct, his question clear: Was it euthanasia? He wanted to know. He appeared burdened, even haunted, by that question. I at least was clear and reviewed for him my understanding: her’s was an instance of relieving the burdens of treatment, given that there were no treatments that would provide any benefit. As plainly as I could, I went over our deliberations as I recalled them. I concentrated on the idea that removing the ventilator may have had the appearance of “causing” death, primarily because of the preconception (one certainly encouraged by its portrayal in television shows and other media) that ventilators “save” lives. I reminded him that everyone had been focused on relieving her suffering and honoring her expressed wishes.

He and I had talked about then, and reviewed again, matters like futility, benefit, and courage. We even got into how the details of conversation are influenced by the transience of relationships and the unpredictable timing of events.

The point I was trying to make was that, textured by the limits of insight and forecasts, these situations display multiple and complex orientations. The moments of moral recognition are borne, not just by what seems clear at any moment, but by insight into the limited degree to which the future remains open to expectation and planning, and that such expectation and planning is finite and limited. Moral experience requires a kind of bearing, an endurance in the face of the question of how one's continuity is preserved in the disruption of even those limits. In contrast to what is proposed by some "routine" understanding, such a bearing is manifestly different in its necessity, and its demands for how individuals ought to conduct themselves.

"As I saw it," I said to him, "the real issue was one of choosing among relative harms according to her stable convictions, which you did." He seemed relieved.

Notes

1. During the course of my clinical work, I have been privileged to participate in some of the most intimate, and gravest, passages that individuals experience. The written account provided here is accurate in its core ethical, medical, and human dimensions. To achieve that accuracy, as much as possible I have stayed with the tenor of my notes from the time of consultation. However, out of respect for the privacy and confidentiality of the persons involved I have altered all identifying information so that they cannot be recognized. In this manner, I have traced the moments of this encounter, all the while acknowledging that I can hardly discursively account for the situation *for its own sake*, except in rudimentary ways that, ineluctably, do violence to the textures and nuances crucial to some sustained understanding for the sake of the individuals involved – which is the exact sort of thing that the writing attempts to elicit. In that regard, I trust, we go beyond ourselves in our actions, and in that "going beyond," as Merleau-Ponty suggests, "each of our perceptions is an act of faith in that it affirms more that we strictly know" ([1964] *Sense and Non-Sense*, tran. H.L. Dreyfus and P.A. Dreyfus. Evanston: Northwestern University Press: 179). Thus, without pretending that this account will adequately describe the complexity of its source, it nonetheless exemplifies important facets of clinical ethics consultations.
2. Fritjof Capra and David Steindl-Rast with Thomas Matus, *Belonging to the Universe: Exploration on the Frontiers of Science and Spirituality* (Harper: San Francisco, 1991).