

MARK J. BLITON and STUART G. FINDER

## TRAVERSING BOUNDARIES: CLINICAL ETHICS, MORAL EXPERIENCE, AND THE WITHDRAWAL OF LIFE SUPPORTS

**ABSTRACT.** While many have suggested that to withdraw medical interventions is ethically equivalent to withholding them, the moral complexity of actually withdrawing life supportive interventions from a patient cannot be ignored. Utilizing interplay between expository and narrative styles, and drawing upon our experiences with patients, families, nurses, and physicians when life supports have been withdrawn, we explore the changeable character of “boundaries” in end-of-life situations. We consider ways in which boundaries imply differences – for example, between cognition and performance – and how the encounter with boundaries can generate altered meanings important for understanding decisions and actions in these contexts. We conclude that the reliance on mere roles to support the moral weight of withdrawing medical interventions is inadequate. Roles that lead us to such moments are exceeded by the responsibility encountered in such moments. And here, we suggest, is the momentous character of withdrawal: it presents the grave astonishment, the trembling awe, in the “not-being-there” of the other in death.

**KEY WORDS:** boundaries, clinical ethics, expository and narrative styles, moral experience, responsibility, singularity, withdrawal of life support

O dreadful sophistry which expands microscopically and telescopically in volume after volume and yet, qualitatively understood, yields nothing but certainly fools men into giving up a simple and profoundly passionate admiration and wonder of things which is the motive power of ethics.

Søren Kierkegaard *Journals*<sup>1</sup>

### INTRODUCTION

Boundaries. As peripheries mapped out from some pre-established center, they serve as limits or constraints. As lines of demarcation between this and that, they reveal and highlight difference, and thereby imply perspective. When there are many different perspectives and complex lines of constraint present, boundaries take on additional, although not always intentional, possibilities for meaning. In our work as clinical ethics consultants, we recognize that for clinical contexts, within which the meanings of particular choices, decisions, and resultant actions are embedded in complex webs of cultural and social relationships among



*Theoretical Medicine* 23: 233–258, 2002.

© 2002 Kluwer Academic Publishers. Printed in the Netherlands.

the diverse individuals who participate in the specific context [27: 29–44], boundaries are abundant, as are the complex meanings attendant to them.

Identifying and articulating these different meanings requires participation in a continual flow of questions and responses generated within the specific situations in which such meanings arise. This is, in fact, part of what makes clinical ethics “clinical.” Other “clinical” factors such as uncertainty, continual change, necessary and forced trust likewise make each set of circumstances unique, even when other features and themes are shared across situations [2]. Accordingly, even if meanings external to a specific situation should appear to remain somewhat more stable, clinical ethics consultants must be responsive to the flux and shifts among context-*dependent* meanings.

This need for being responsive in clinical ethics is especially evident when considering the withdrawal of medical interventions, the likely aftermath of which is a patient’s death. Not only facing, but participating in, the death of another confronts us with meanings that may be altered because of our participation. Yet, even as they are transformed, these meanings may also persist across other sets of “boundaries:” for example, there are the meanings of life and death, meanings about our own life, and recognition (even if only temporarily) of our own eventual death, about responsibility in life and for death, and likewise accountability for choices made and actions taken. Having been privileged to participate in some of the most intimate and grave discussions that individuals experience – involving decision making about the end of someone’s life – and having been with patients and families, nurses, and physicians, immediately prior to, during, and after the discontinuation of life supportive measures, we are particularly interested in the dynamics of moral experience that occur in these situations. More specifically, we are interested in the “boundary” between the cognitive and the performative as experienced in the acts of withdrawing medical interventions.

Inescapable ambiguity often characterizes the acts associated with end-of-life decisions. For example, in the attempt to distinguish between treating pain and killing, the appeal to the rule of double effect – while an attempt to choose the “right” words, or identify an appropriate rationale – does not transform, nor alleviate the moral ambiguity contained in these situations [9]. Caught in the transition between treating illness and caring for the dying, and confronted with feelings that one might be killing, the anguish of caregivers – in particular, nurses, physicians, and others – can become especially acute in large part because such ambiguity cannot be easily dismissed or avoided.<sup>2</sup> In the performance of ethics consultation

in such contexts, an ethics consultant must therefore attend to actual as well as potential moral disruptions initiated in the ambiguity between the cognitive and the performative. In this paper, then, we explore the dynamics of that shifting boundary as it arises and falls away in the setting of the withdrawal of life supportive interventions.

#### CLINICAL ETHICS ACTIVITIES: THE FIRST BOUNDARY

Bioethics is well-endowed with numerous divisions – policy/practice, academic/clinical, humanities/legal/medical, and institutional role/individual activity – that are frequently looked on as boundaries. Given that these contested divisions most often delineate concerns about expertise and authority, no one should be surprised when confronted with the accompanying wide spectrum of positions regarding the conduct and content of ethics consultation [6]. In that light, we are quite cognizant of the various ways in which ethics consultations are conceptualized, and thus are well aware that the considerations that follow may not cohere easily with several other positions [1]. While fully acknowledging the need to understand the placement, function, and constitutive power of institutional and professional roles in the formation of boundaries, we caution that such understanding is neither complete nor adequate to illustrate their *moral* significance. Even with a stable grasp of the role one actually occupies, the ways that an ethics consultant understands his or her activities *while in the midst of consulting* are constrained by incomplete information, the limits of insight, as well as the uncertainties (expected and unexpected) pervasive in medical predictions and clinical situations. Thus, we presuppose the need to pay deliberate and careful attention to textures and nuances that help us in understanding ‘what is at stake’ for those individuals actually involved in clinical circumstances. Just as “ethics consultation” does not refer to any single set of activities, neither does “ethics consultant” refer to a uniform or coherent set of individuals. Likewise, although typically valorized as an univocal term, “ethical view” can refer to a variety of beliefs and perspectives. Consider, for example, the discordant views described in a survey of ethics consultants regarding recommendations for withholding and withdrawing life-prolonging interventions [11].

Although the resultant differences among “ethical views” are often presented as determinate divisions or boundaries, it seems more accurate to consider these as “options” for interpretation [26]. Well aware that a particular way of understanding – and engaging in – ethics consultation is presented in this essay, we by no means intend to dismiss the possible legitimacy of other perspectives. In fact, as part of the understanding of

“boundary” that we develop, we embrace the other in, and through, the presentation of our own view.

There is, thus, something else with which we begin. Since at least 1983, with the bench mark publication of the President’s Commission report [17], there has been ongoing and vigorous argument in the ethics literature [12], as well as in the medical literature [7], claiming that withdrawing medical interventions is morally equivalent to withholding such interventions.<sup>3</sup> Yet, although “prominent ethical commentators have considered resistance to the moral equivalence thesis to be ‘purely psychological’ ” [16: 696], such claims seem motivated by the brute experiential fact that it “feels” different to withdraw interventions than merely not to provide them.<sup>4</sup> Why is that? Although one influential study found that “for many practitioners, it does feel worse to withdraw than it does never to have initiated a course of treatment,” and recommended that efforts should be made to “allow clinicians to reflect on the inevitable burdens and conflicts they experience as they provide care to patients near the end of life” [22: 20], not many have explored this experiential component – perhaps understandably, given that an adequate examination would require a daunting combination of wide-ranging theoretical and empirical studies. In the course of our brief reflection, we cannot and do not presume to satisfy those demands. We will, however, propose what we think is an important clue. As a way to help situate our exploration, imagine the following.

#### ENCOUNTERING “MORAL SENSE”: THE CLINICAL CONTEXT

The call came around lunchtime from Jonah Rustig, one of the well-respected cardiologists in the hospital. Over the years, he’d requested ethics consultations a number of times, always inviting me into complex situations in which various issues – questionable patient decision making capacity, families alienated from patients, uncertain prognoses, complicated medical regimens – blended together. So, when he called, I anticipated a complicated, even convoluted, scenario. All Jonah said, however, was that he wanted to get together and talk about what was going on with Mrs. Mercer, a patient in the intensive care unit. He asked whether I had any time today or tomorrow to come by his office. We set the time, and I told him I’d look things over in the meantime – meaning, as he well knew from our previous interactions, that I’d review the patient’s chart, talk with the nurses and maybe the residents, and one or two of the consulting

physicians, so that I could begin to gain some perspective on what might be going on. He said OK, and we hung up. I gathered up my clipboard and notebook, and headed over to the ICU.

Mrs. Mercer, I learned from a quick scan of the Progress Notes, had been in the intensive care unit since being brought to the hospital nearly nine weeks ago. She was sixty-two years old, had collapsed at home, and her husband had called 911. She arrived at the ED intubated and was found to have suffered a large interior myocardial infarction (MI) with possible anoxia. Her medical history was significant for long-standing hypertension, diabetes, renal insufficiency, peripheral vascular disease, and chronic obstructive pulmonary disease (COPD), and she was morbidly obese.

From the Notes I also learned that she had been unable to be weaned from the vent – she required a tracheostomy during week three – and was now requiring 60% O<sub>2</sub> at a rate of 10 and pressure support of 5 to maintain her sats in the low 90s. Not only was she dependent on dopamine, dobutamine and milrinone, but over the past five days she was requiring higher levels of each. Although she had no history of dialysis, her renal insufficiency had worsened to the point that, when her hemodynamics allowed, dialysis was provided on an “as needed” basis. In terms of her neurological status, she responded to pain but had not demonstrated the ability to follow commands. Unfortunately, despite also being on broad spectrum antibiotic coverage, she had become febrile again in the past several days but no etiology had as yet been determined.

Katie, who had been Mrs. Mercer’s nurse over the weekend, told me that Mrs. Mercer’s family had visited during the weekend, including her son who lived out of state and only had been able to come into town a few times before. Hence, Mrs. Mercer’s husband, two daughters and their husbands, her son, a sister and brother-in-law, a brother and sister-in-law, another brother, and several nieces and nephews had all been around.

I asked Katie what was going on. She’d seen me going through the chart.

“You know, she’s been here a long time,” Katie told me, “and the family’s worn. I think with her temp back up and her pressure’s going south again, and her kidney’s not working, well, I think they’re near their end. And I can’t blame ‘em. Poor thing, she’s sick as stink and it doesn’t look too good.”

Katie gave me a look that suggested, “Don’t tell anyone I said so, but . . .” and then said in a slightly hushed voice, “I think they

should've stopped weeks ago. We're not gonna get her off the vent. We've been unable to get her off pressors. She's never responded to anything but pain. And the family's been talking about not wanting to have her end up in a nursing home, that she'd never want to be that way." Her voice modulated back to its usual tone. "I tell ya, I don't ever want to be like that. I'm really thinking about getting a 'DNR' tattooed right across my chest so that no one touches me if I'm down!" She made a funny expression and laughed.

Since I've heard Katie tell about the tattoo probably six times in the past five years, I laughed along with her. "Have you talked with Jonah about this?" I asked.

"Of course. And I think he's starting to think that maybe it's time, too. You know, he talked with the family on Sunday for about twenty minutes. I was busy helping Sheila in the next room so I didn't hear what they said, but afterwards, the family seemed a bit lighter. And this morning during rounds, Jonah said he was gonna call you. I think maybe he's starting to see the light."

I'd been there forty-five minutes already, and I had a few more patients to check up on before seeing Jonah, so I told Katie I had to go. "Don't work too hard," I said as I began to walk away. "What, me, come on, this is my break from those bratty kids of mine!" she chirped back, "Don't worry." I went out into the main hallway and headed for the stairs.

#### ATTENTIVE LISTENING AS CLINICAL PRAXIS: DISCOVERING BOUNDARIES IN CONTEXT

Our commitment toward an understanding of practice in clinical ethics consultation is one that is robustly clinical in orientation. Clinical ethics consultants seek to identify and discuss moral concerns by persistently helping to elicit *from the primary participants* (patient, family, physicians, nurses, and so on) what *they themselves* find troubling and in need of resolution. On that basis, clinical ethics consultants help the participants imagine aftermaths they can live with in the light of what is most worthwhile to, and for, them [3]. We follow Zaner's recognition that "an ethics consultant's involvement serves as the occasion for highly specific talk – among just *these* individuals with just *their* lives, circumstances, concerns, feelings, aims, and proposals for acting" [28: 147]. He says further, "the circumstances are *theirs*," not the consultants, "as are the issues, options, decisions, and the outcomes." The role for the ethics consultant "is *not* to

try and figure out what is right or what these people should do, nor is it to make guesses about what you would do were you the one on the spot – few if any of us really knows what we might do were we so involved” [28: 147–148].

Thus, we are concerned with the disciplined listening necessary to help those individuals primarily involved in specific situations to discover what matters to them, to identify the shifting of “boundaries” which emerge in the conduct of ethics consultation. The problems are theirs, these other people. Zaner’s point, rightly taken, is that in talking with each person the aim is to help them think about what’s at stake for each of them as carefully and fully as their circumstances allow, and as much as possible within the frameworks of their own respective beliefs.

Therefore, when talking to others one needs to be, as Husserl noted, “continually asking what can actually be ‘seen’ and given faithful expression – accordingly it is to judge by the same method that a cautiously shrewd person follows in practical life wherever it is seriously important for him to ‘find out how matters actually are’ ” [14: 278–279]. This insight, as a guiding orientation for an ethics consultant, reinforces the need to pay close attention to the actual circumstances of various individual’s understanding, how what are perceived as the “issues” have come about, in what ways those individuals view the circumstances, and how they understand the identifiable factors specific to their situation.

As it is not possible to know in advance, beyond common themes, just which moral issues are actually presented by any specific situation, these must be learned at the time of the consult. A core part of that learning is accomplished in clinical situations by attentive *listening* [29] – not merely to those persons who are gravely ill, or injured, and dying, but also to their families as well as to the care providers.

However, in what is perhaps this most obvious sort of example for ethics consultation – *How do we identify and make sense of the experiences undergone when actually involved with the withdrawal of medical life supports?* – we encounter very little, indeed almost no discussion about the moral experience of ethics consultants involved in such situations. Given the presumed prevalence of this sort of involvement, not to mention the moral gravity and prominence accorded the issues of withdrawing medical interventions, the lack of actual documentation and discussion about what participation in the dying of another actually means is particularly troubling. After all, if in fact the ethics consultant does get involved in discussion about, *and the actual withdrawal of* medical interventions, that involvement will likely have inevitable moral ramifications for the consultant akin to ways in which patients’ dying and deaths

“adversely affects the physician’s sense of accomplishment and satisfaction, and foments feelings of guilt, failure and unworthiness” [25: 1449]. Involvement in situations of dying and death are reflexive for all involved, reverberating to and with the moral experience of each participant, in distinctive ways quite as much as each participant’s experience has its own kind of effect on the other clinical participants [29].

#### ENCOUNTERING “MORAL SENSE”: *FACE TO FACE*

At 4:05, I made my way to Jonah’s office. I was a few minutes late, but given how Jonah practices, I expected him to be held up; I was right, and so I sat in his conference room and waited. Around 4:15, Jonah came in, apologizing for being late. “No big deal,” I told him. “What’s up?”

Jonah asked if I’d been by to see Mrs. Mercer, which I had. “So you know the gist then.” He sat back in his chair, stretched out his legs, and folded his hands behind his head; he was looking slightly upwards, towards the ceiling. “You know, I really thought she’d make it through this. She had a big hit, but we were on top of it pretty quickly. She’s taken a few turns for the worse, but we’ve always been able to pull her back . . . I don’t know.” He paused, shifted his eyes from the ceiling to the wall, then a quick glance to me before settling back onto the ceiling. “I had a long talk with the family on Sunday. They’ve been really hanging in there. Her husband just retired two months ago. But I think they’re getting worn out and starting to see that even if she survives, she’s not going to be the same. And they’re right. But given the past few days, I’m not so sure she can survive. And so I told them, if she gets worse, that is, if we need to go up again on the pressors, then we’re done. And they agreed, they understood.”

Another pause, this one longer.

“So what’re you thinking about? Why’d you call?” I tried to ask in an inviting manner, needing more time myself to think before responding. Something was bothering Jonah, although I didn’t know what. Always direct and to the point in previous talks, today he seemed a bit tentative. I was choosing to be direct.

“I know it’s the right thing to do. The family’s ready, the prognosis is dismal at best – my residents have been saying for a week that maybe we need to back off. But something’s holding me back. It’s like, we got her this far, and if we stop, then what’s the justification for having put her through all this? We kept her alive, and we caused



her to go through all this. And now, if we stop, we'll still be causing her to go through all this, only this time, it's her death."

"But didn't you say that you thought that if she got any worse, you really don't have much to offer that would likely help?" I was fishing for something to latch onto, so that I could get a better sense of what was nagging him. If I could get a hook, then maybe I could help him. "In which case, you're relieving her of the burdens of the interventions. Sure, you're responsible for starting them, but doing so was the only way to possibly get to a point where you could tell whether you might be able to help her." I'd made that move, about 'relieving the burdens of interventions' enough to know that if that was what was bothering him, not much more would need to be said.

"I know that in the same way I fully understand that we're about maxed out on the pressors. But it still feels like I'm making the decision for her to die, that my recommendation to stop is the death warrant. And in a way, it is 'cause if we just kept on treating, kept pushing the meds, she'd die just the same, but it would be in *spite* of what we've done, not *because* of what we've done."

Again, Jonah's gaze shifted from ceiling to wall to me.

His eyes had a piercing look to them, focused. This time, though, he didn't turn away. For a moment or two, neither did I.

#### THE ETHICS CONSULTANT AS PARTICIPANT

It is difficult to describe the struggle in these situations where all parties are trying "to make sense" at such poignant moments. What is it about the experiences of illness and injury that evokes a feeling of recoil in response to the daily spectacle of pain, illness, dysfunction, and dying at the source of the modern acute health care? Is that feeling brought about by an underlying sense of limit, of uncertainty and finitude? In that resistance is there a dimension of foreboding, which is suppressed? Perhaps: yet there is also a possibly more pervasive, subtle, hidden sense of astonishment that we are alive.

To be concerned about ethics in this sort of context is to recognize the unavoidable necessity of undergoing the disquiet and hardship of self-reflection and deliberation about what one believes is most precious, most hoped for, and most worthwhile in life. To come into such a scenario as an ethics consultant, as Zaner says, "is not only to be a reminder of that need for deliberation about deeply serious issues, but it is also to serve as an affirmation of that need and the significance of those issues

and the profound feelings they evoke” [28: 147]. Invariably, an ethics consultant becomes involved with a conversational exploration of matters that frequently prove “very difficult to get to and discuss, much less to figure out what course of action seems most congruent with their respective beliefs” [28: 148].

There is, thus, on the part of the ethics consultant a “concerted, focused effort to hear and, perhaps, even help” give to those with whom s/he interacts “their needed moral voice and [the] courage to hear themselves in their own telling, as they are encouraged to probe ever more deeply into their own lives and circumstances and, ultimately, to take responsibility for what must be done and lived with” [29: 272 (brackets ours)]. And yet, as actual, if only partial and temporary participants, ethics consultants confront an ever-present possibility of error. Whether in the attempts to understand, and nevertheless not yet understand, the fuller implications of the others’ values and desires, or whether due to some unforeseen result of the consultant’s own deeds, not only might an entire conversation break down – “it can be betrayed, led astray, become aborted, and for many reasons: flat refusal to talk, failed insight, sloppy thinking and talking, dishonesty, impatience” [29: 270] – but as Howe notes, the “emotional responses of the patients and their families to ethics consultants may determine what patients and family members come to believe” [13: 23].

Moreover, if others may be helped or harmed by the activities of an ethics consultant, then the same holds for the ethics consultant him- or herself. Faced with the intense, specific, and explicit attention to the actual circumstances, to the genuine agony and potential moral disruption encountered by vulnerable patients and their loved ones, and by clinicians, the ethics consultant’s own sensibilities and judgment may undergo a kind of disequilibrium. What, then, is being learned should the consultant’s own sensibilities become dramatically disrupted? After all, one’s own disruptions are not necessarily analogous to those of others. Thus, if a key moral guide is understanding, risked in the consultant’s disruption is that s/he *may fail*, or likely fail, to understand those others and their circumstances in their own terms, frameworks or narratives. On the other hand, to disregard one’s own disruption is to ignore clues possibly relevant to understanding just those matters. On both accounts, by participating, the ethics consultant risks aiding and abetting in the other participants misconstruing what they face and how they live, surely a “grievous moral failure” [29: 272].

Several crucial conditions relevant to our understanding of boundaries in these situations demand emphasis. The first is that the ethics consultant be – and be understood by others as – an actual, if only partial and

temporary, participant in that situation. That is, s/he must reflectively participate in the questions and uncertainties at hand. Second, the ethics consultant needs to encounter and pursue the same sort of issues, for him- or herself, in a kind of imaginative variation [24], while helping those others consider the aspects and ramifications, questions and uncertainties to be faced. Although it is difficult to say for sure, and certainly in advance of asking questions, it nevertheless seems that many situations require just this sort of focused and attentive inquiry, seeking to make explicit certain presumptions and activities, all the while reflectively considering whether or not, and how, interactions in the situation may change should implicit ideas and assumptions be made explicit. Precisely in this way, an ethics consultant confronts a core question of mutual responsibility, both for him- or herself, and the others: Is it more harmful or beneficial to articulate what has remained unspoken, and possibly unacknowledged, prior to the participation of the ethics consultant [3]?

#### ENCOUNTERING “MORAL SENSE”: MOMENT OF REPRIEVE

It's not common that people actually look at one another for more than a glancing moment. We walk past others all the time, take a quick peek toward their faces, their bodies, their appearance, then turn away, back toward the way we're going. Occasionally, however, when turning toward another, we do so at the same time the other is turning toward us, and our eyes meet. But mostly we do not look long; our eyes meet, the recognition of that meeting flashes between us, and we turn away. To hold the glance feels risky: it risks misperceiving both what we see and what we are seen as.

I was sitting in Jonah's conference room, a small room. It was the room where Jonah sat with patients to talk at more length about their illnesses; he on one side of the table, they on the other. It was also where drug reps spread out their wares. It was the room where Jonah taught his residents about the finer points of diagnosis, prognosis, and the work of being a physician. And now, it was the room where Jonah and I sat, his eyes looking my way with that kind of intensity that makes us want to turn away, to not see or be seen.

But I didn't turn away, at least, not right away. Jonah had asked me to come talk with him, and so I did because, not only is that part of my role – to listen to and talk with others – but because I think it is important to do.

What he had to say was simple, if not direct: Mrs. Mercer was going to die, and she was going to die during this hospitalization,

under his care. He, his residents, the nurses, the family, they all seemed to be coming to that same understanding. Now I knew too: Mrs. Mercer was going to die. And Jonah was looking at me, and I at him.

“Do we?” I remembered asking my colleague after we had led our students through a discussion of Plato’s dialogue, *Phaedo*, in response to Socrates’ question, “Do we believe that there is such a thing as death?” To which Simmias replies, “Certainly” (64c).

***Do we?***

Jonah had just told me that Mrs. Mercer was going to die, that he had a role in it, in her death. Do we believe in death? Jonah seemed to be struggling with something: was that it? If I looked him in the eye, maybe I could tell, maybe I could learn, maybe I would know.

And so I looked back towards Jonah. His eyes were focused, but his “look” was not hard. His glance was intense, but not threatening. Jonah was looking towards me, and I to him. What was he looking for? What did he see? What was he thinking? I think I know what I saw: I saw a man, a physician, a cardiologist, who was thinking about his role in his patient’s death; I know what I was thinking: How do I tell him I understand, because, I know I might not?

## THE MEANING OF BOUNDARIES

As social persons, we participate in a variety of tricks, devices, disguises, guises, in order to avoid discomfort and disequilibrium. These present as clues for occasions where, as Zaner states, the “potential violations of relationships among people are of the very essence of clinical conversation, its commanding center” [29: 271]. By implication, and by contrast, the clinical ethics consultant “is, or ought to be, at every moment of interaction with patients and their loved ones, as well as with health professionals, the constant reminder of the moral freedom” [29], soliciting genuine interaction and conversation about these momentous concerns. In other words, if encounters with persons rendered vulnerable by illness means to encounter a moral challenge to respond, *with* its attendant risks of violence (whether intentional or not), then just what does transgression, or crossing of boundaries, *mean*?

Our view of “boundaries” in a clinical ethics situation involves transformation. Boundaries are places, as Scott says, where “definitive attitudes face the possibility of definitive change, where basic patterns of thought and feeling find openings to thoughts and feelings that those patterns

cannot hold or conceive, where mutations seem to compose a different species of awareness and affection" [20: 249]. Examples of definitive attitudes would be attitudes toward death, attitudes toward others, and likewise self-understanding. Consider, for instance, a common tendency in our everyday language to reify and make death into an abstraction. One motivation for such abstraction might stem from the sense that whatever death is, "it" is fearful or threatening. That sensibility seems to be commonplace and is associated with the experience of certain emotions, for example, fear of "some thing." In this sort of abstraction, the perceived "thing" (death) is considered to possess a vitality of "its" own – in some sense "active" – and the individual, when confronted with that fearful "thing" (death) seeks to withdraw from "its" influence.

This brief example serves merely to note that in such abstraction, this "thing" (death) is endowed with a threatening, possibly injurious, quality against which the individual feels she or he must resist. At the same time, this abstraction appears to presuppose a primordial relation between subject and "thing" – which for the lack of a better term reveals the uncanny significance of the subject. It's uncanniness is precisely due to the fact that what is revealed is not bounded by what is familiar. Holding back or turning away from such revelation, from the possibility of transformation, is to fall back into repetition of the familiar. This repetition of the familiar involves "finding something like a mirror in the boundaries' thresholds that reflects appearances back to one of where and who one is and that seem to say, very quietly, 'nothing essential changes; all remains the same'" [20]. In contrast, with the uncanny revelation of oneself, "I" am presented with the problematic activity of probing my own being-in-the-world as a salient factor in understanding the other who is dying and the others related to that individual. In reaching an understanding with those others about what is the right thing to do in a situation directly involving the dying and death of that individual, neither those others, nor "I," am in a position to objectify, and make familiar, "it" (death).

What confronts me is this uncanny, although seemingly more direct, connection with the limit of my own existence – for in that individual's death, due to actions that I participate in, the fullness of who/what I am becomes reduced. What, then, does it mean to encourage someone, apparently vulnerable, to inspect that "something like a mirror," to see how it actually works, or more to the point, to note explicitly that considerable effort is being directed to re-create images that were there, but which are actually changing – or to take the metaphor to its limit, to look and see that death does not "mirror" back? Encouraging others to adopt such a perspective requires that we value their experience and endorse the need to

give an account of their experience in decision making – which may well be the core sense of *respect*, a much maligned but crucial moral concept.

### ENCOUNTERING “MORAL SENSE”: APPROACHING BOUNDARIES

Our glance broke as I looked down towards my buzzing pager. The number was one I recognized: it was from another ICU in the hospital. As I looked back up, Jonah was already starting to get up from his chair. “Thanks for coming by,” he offered, “It helps sometimes just to talk.”

As Jonah continued to rise, I felt as though he and I had just gone through something significant, that moment of silence shared between us. But now it had passed and so too was gone the time to acknowledge my sense to him. I stood up as well.

“Do you want me to talk with Mrs. Mercer’s family?” I asked, to which Jonah said he did. Always cordial, Jonah extended his hand to me; he had a firm grasp as we shook and then parted.

Jonah headed back towards a patient examining room while I went to the front desk to use a phone. In the corridor of Jonah’s office, I was once again cloaked in my role. A nurse answered on the other end, and after I identified myself and said that someone had paged me, she told me Dr. Jackson had asked that I be paged, that I’d know why; and I did.

Merle Denton was a 46 year-old man who had suffered an extensive stroke about ten months prior, who had been discharged to a long-term nursing facility in the hopes of recovering enough to undergo rehabilitation, but had subsequently been in and out of the hospital three times due to aspiration pneumonia requiring short-term intubation and aggressive intervention. Mr. Denton’s wife, brothers, and parents had all been involved in his care, and they had remained quite optimistic that, while never fully returning to his former state, he would recover to the point that he could live at home. A little over a week ago, however, he appeared to have suffered another stroke, this time affecting his brainstem, and his prognosis had changed dramatically; he was not expected to make it through this hospitalization.

Despite several family conferences in which the neurologists and the critical care team both stressed the very low chance that Mr. Denton would survive, his family remained optimistic and asserted that “everything be done” not only to keep Mr. Denton alive, but to prepare him for transfer to a rehabilitation facility. Tension had

developed between the medical team and the family, and I had been called in by Tom Jackson, Medical Director of the ICU and attending physician for Mr. Denton, to see if I could help adjudicate the situation.

Tom Jackson is a big man with a dominating presence, a loud voice, and a sharp mind. Many people are intimidated by him because of how he comes across – I was too when I first met him – so it wasn't hard to imagine, when first called about this situation, that there might be some tension between family and medical team. However, having worked with Tom in several previous situations, as well as having served with him on a few hospital committees, I also knew that, if you can overcome his presentation, Tom's really quite a careful and attentive person who is very committed to his patients; their needs always come first for him.

As it had turned out, after several conversations with the family, I discovered that the so-called "tension" had been over-emphasized by the physicians and nurses; this family understood quite fully that Mr. Denton – father, brother, son – was not going to get better, was not going to be discharged to a rehab facility, was not going to survive. In fact, this morning they had decided that the time had come to withdraw the ventilator. All they wanted was to wait until later in the day when family and friends could gather, to say goodbye. This was why I was being paged.

After the decision was made that morning, Tom and I had talked about what actually would be done and how to proceed. Tom involved his residents, and we had a fairly spirited discussion about the various ways to sedate a patient and then withdraw a ventilator. At the end of that discussion, Tom turned to me and said, "So, are you going to be there?"

The question harkened back to a discussion Tom and I had eight or nine months earlier concerning the difference between deciding to withdraw and actually removing the ventilator. Tom told me that unless you had actually "done the deed," so to speak, then you really had no basis to tell others about how to proceed or what was acceptable. He also said that the next time I was involved in a situation in the ICU in which life support was to be withdrawn, I not only should be there when interventions are actually discontinued, but that I could help do so. That manner of assertion was part of what made Tom so intimidating to many, although at that time, I simply told Tom that my participating would not make much sense since I'm not a physician or a nurse or other kind of health care provider per se.

However, I did agree that there was a difference between talking about it and actually participating in it. I reminded him, in that conversation, that I was, in fact, acutely aware of that difference because, after all, *I'm* the one who often gets called in at just that point such that if *I* present withdrawal as an acceptable option, both families and health care providers will use *my* having said it's OK – when they may be unsure or unwilling to say what they think – as the lynchpin for now determining that it *is* permissible. That had satisfied Tom for the moment, but now, months later, he was asking.

"I will," I said. But I wanted to be clear to Tom, and to myself, as to why. "I don't know if I mentioned it to you, but the family asked me to be there if I could. There's no reason why I can't. So I will." That's what I'd said this morning to Tom. Now I was being paged to come to the ICU. I went.

Merle Denton's wife, his 24 year-old son, 22 year-old daughter, and 18 year-old son were standing with Mr. Denton's parents, his brothers and their wives, several of their kids, and a few others when I arrived. In all, there were 18 family members present. I greeted Mrs. Denton and the others that I had met previously; it was an awkward sort of greeting since the circumstances under which we were meeting – instead of merely being discussed as a possibility – were *these* circumstances, the afternoon on which medical supports would be withdrawn from their loved one. One of the nurses went to get Tom, who was at the other end of the ICU talking about another patient. I stood with the family and waited.

As Tom approached, members of Mr. Denton's family moved around, leaving Mrs. Denton clearly in front, with her children and her in-laws immediately surrounding her. Although I was free to stand anywhere, I now wasn't sure where to stand so I moved off to their right as Tom took his place in front of them, his team of residents and two medical students slightly behind him. I noticed nurses grabbing boxes of Kleenex. Everyone else seemed to be focused directly on Tom; he began to speak.

In that steady monotonous cadence I've come to recognize as the one many physicians use when talking to families about their loved one's dying, Tom reviewed the events of this hospitalization, including the discussions with me and the family's decision to withdraw interventions. In a soft and slow voice, he asked Mrs. Denton to explain how she understood things, and briefly to recount why the family believed it appropriate, at this point, to initiate the withdrawal.



I turned toward her as she spoke. She appeared calm. I heard her words, and unbidden, the thought occurred whether I could be so calm were I talking about my wife; I restrained that thought, tried to push it aside and listen more closely to her words. She recounted how a few years ago her husband, after watching a TV show about someone on life-support, had said that he'd never want that. It was the same thing that she had told me earlier, almost to the word. As this scene unfolded before me – part of which I had already gone through with Mrs. Denton and her family, and with Tom and his team – I had the fleeting, and slightly uncanny, sense that it was a performance for which the previous conversations now seemed rehearsals; the words flowed and we all hung on them in anticipation of what would happen next.

Tom then began to tell them the steps he planned to take as part of the actual removal of the ventilator. As he spoke, several of the family members towards the outside of the group moved further away; several hugged one another. I became aware of how quiet the Unit now seemed, the usual beeps and hums seemingly not present. The nurses were passing the boxes of Kleenex through the group of family members. Tom reached the end of his description, and paused: “Are you ready then?” He was looking directly at Mrs. Denton as he asked; she was gazing back to him. I was watching Tom look at her. The moment of his question hung in time just long enough for me to be acutely aware of it.

Mrs. Denton shook her head “yes.” Tom turned quickly and briefly in my direction. His face was taut; mine felt like it too. I had the sense that everyone's did. Tom turned to the senior resident and told him to draw-up 10 cc's morphine as pre-extubation sedation. As the resident walked towards the SureMed, I noticed two elderly men in suits come walking down the hall, and those at the edge of the group greeted them. One carried a fat black book, well worn, and I guessed (correctly, as it turned out) that it was a Bible. Tom then explicitly stated to no one in particular, to the family gathered in general, that “the removal of life support is meant to remove what we have provided as intervention. We don't expect Mr. Denton to live very long after we do so, but that's not up to us. I want to reiterate that we will do everything we can to make sure that he's kept comfortable.” I was struck that there was a pageant-like element to Tom's pronouncement, and I wondered if Tom meant it to feel this way. As he finished, he again turned to me, this time asking, “Is there anything you'd like to add?” I felt a slight flush.

I also felt the compression of thoughts racing together; was there anything I wanted to say? Did I need to say anything? Could I add something that might help? I remembered something that I had already told the family during our last conversation, but which I hadn't discussed with Tom and his team. And, I didn't recall hearing it in what Tom had said, so I repeated myself, "For some people, it's important to actually be in the room when life support is withdrawn; for others it's not. I think Dr. Jackson is fine with anyone who wants to be in the room to be there, but don't feel obligated." Again, as I spoke, I felt I was acting in a play, or was it playacting? All of the lines sounded fitting when delivered, but they might not have been – and there was no way to pause and try it again.

Tom echoed what I had said, and Mrs. Denton said she wanted to be with her husband, as did Mr. Denton's parents. The children remained silent, but then shifted towards the room, along with Tom, the resident, and the nurse. I too walked with them into the room. Being an intensive care unit room, we were tightly packed in, and we could not avoid touching one another.

After the resident provided the bolus of morphine, Tom himself began to remove the tape that held the ET tube in place in Mr. Denton's throat. Standing on the right side of the bed, Tom gently pulled the strips off, one by one. He lifted Merle Denton's head, as if Mr. Denton was a baby and Tom was going to shampoo his hair, then pulled the strips that wrapped around behind his ears. When all the tape was removed, the room was pretty much silent except for the sound of the machinery still doing its work and stifled sniffles. Tom asked the nurse for a washcloth and then wiped around Mr. Denton's mouth and nose. His touch was gentle, and I noted the way his countenance, his look, was focused on Mr. Denton's. I saw Mr. Denton's youngest son move into the left corner, to someone I guessed was an older cousin, with her holding him in her arms; Mrs. Denton held the hand of her daughter, and the oldest son was standing with his grandparents.

One of the older men with the Bible, who looked at my hospital ID, began asking questions just as Tom disconnected the vent tubing from the ET tube. Mr. Denton bucked a tiny bit and I immediately wished that they had given him enough morphine, so that he wouldn't start gagging and gurgling as we all stood there, watching.

"Is Dick Zaner still around? Do you work with him?" he whispered. I turned to look at him. From the corner of my eye I saw

Tom pull out the ET tube and heard Mr. Denton gag and cough. I felt a wave of anxiety. I knew I couldn't, but I wanted to blurt out to Tom, "Did you give him enough morphine?"

"Yes, he is, and I do," I replied to the man's question, not wanting to be rude but not wanting to be talking, even in hushed tones, just at that moment. I heard some more coughing and saw Tom reach, smoothly and deliberately, for the suction catheter and suction Mr. Denton's mouth. "Oh, good for him. I've always enjoyed hearing him speak, 'though its been a number of years," the man said.

Mrs. Denton began to say, in a gentle, breathy voice, "Breathe, Merle . . . breathe baby." There were now several people sobbing, and two other nurses from the unit were again passing around Kleenex. Tom asked one of the nurses to turn up the suction pressure, his voice with a slight strain of irritation and his face again drawn taut. "I'll tell him I saw you," I said, again trying not to be rude, and aware that I wouldn't actually do so; I didn't even know who this man was, nor, at the moment, did I care. He seemed pleased at my response and turned away from me. I refocused.

"Breathe, baby, come on and breathe."

Tom reached up and turned off the monitor, then reached over and turned off the vent. He asked the nurse to get another 10 cc's morphine ready in case he needed it. The senior resident, standing to Tom's right, turned off the IV pumps while another nurse disconnected several of the tubes from the IVs in Mr. Denton's arms.

"Breathe, Merle."

Three family members now moved out back into the hallway, and one walked halfway down the hall before pulling out his cell phone and answering, "Hello?" The two men with the Bible moved towards Mr. Denton's parents, and both nurses were busy straightening the sheets around Mr. Denton, who no longer was coughing, his chest rising and falling in short, but regular movements. Tom again gently wiped down Mr. Denton's face, and Mrs. Denton continued the chant for her husband to breathe, still in the same breathy tone with which she had begun. I stayed right where I was. Five minutes had passed since Tom had pulled the ET tube.

Tom made his way out of the room, and stood to the right of the door. He looked over toward me and I joined him. What do you say at a time like this? Do you say anything? I realized that I was again aware of how gentle Tom had been when he pulled the tape off. We both stood there, looking through the windowed-wall into Mr.

Denton's room. Then, Tom walked over to the monitors at the nurses station and looked at Mr. Denton's vital signs: heart rate at 110, blood pressure at 160 over 95, respiratory rate at 32, sats at 85%. He called to the junior resident, who was also exiting the room, "Brad, put on the face mask, 40%." I walked over to the monitors. Tom turned to me, his face slightly flushed, a moist sheen to his eyes. I felt compelled to say something.

"This may sound strange, and I'm guessing that people don't usually talk this way, but I couldn't help but notice how gently you held Mr. Denton's head when you were getting ready to pull the tube. I don't know if anyone else noticed, but I did, and, well, I just want to let you know that." Tom kept looking at me. "I guess it really struck me 'cause it doesn't fit your image," I continued awkwardly. I was aware that what I was trying to say was, "Thank you for being so gentle," although I was also aware that saying that would have been even more awkward.

"Yeah, well, there's a lot that doesn't fit my image," Tom replied in a quiet voice. Which caused me to wonder if I shouldn't have said that last bit; why had I said it that way? Mrs. Denton continued her chant.

"Well; um, I guess I just wanted to let you know that you did a good job," I replied. Of course, how would I know? Tom wiped his forehead with a handkerchief. He didn't say anything.

"So what do you think is going to happen now," I asked. Tom looked at the monitor again. Mr. Denton's numbers were virtually unchanged. "I'm going to see if we can move him out of the Unit to a regular room so the family can be with him in a more comfortable atmosphere." Tom then called out to the charge nurse, to have her see if there were any beds available. I continued to stand with him. The residents, who also had been standing around with us, now drifted over to another room and another patient. Mrs. Denton was still telling her husband to breathe. When I looked over into the room, she was holding his hand, her in-laws and oldest kids standing behind her, not saying anything. Her youngest son was still standing in the corner with the cousin, and one of her brother-in-laws and his wife were also in the room. Everyone else was making their way towards the waiting area. "Thanks for your help," Tom said to me, not waiting for a reply, before going over to where the residents had gathered.

I walked back to the doorway of the room; all was as it had been moments before. Twenty minutes had passed since the ventilator had

been withdrawn from Mr. Denton. The Unit (or was it my awareness of the Unit?) was shifting back to normalcy; the nurses were back to caring for their own patients, and even Mr. Denton's nurse was occupied with something else. Mr. Denton was stable, for the moment, and his family was settling into whatever it was they were going to do now that the "withdrawal" had occurred. I turned back towards Tom, who was talking with his residents in his normal tone, that loud and commanding voice that so many found intimidating. I looked back into Mr. Denton's room and wondered what would happen. I walked back over to Tom and the team. Feeling a bit intrusive, as they were now talking about a different patient, I waited for a break. "What do you do once he's transferred out?" I asked. "He won't be ours then, but we'll write orders to keep him comfortable." "Oh, OK, thanks."

As I walked out of the Unit, I remembered my conversation with Jonah earlier in the day. He'd said he knew that withdrawing interventions from Mrs. Mercer was the right thing to do, but he was still struggling with it. Struggling, I guessed, with the responsibility for a situation like the one I'd just witnessed. I was glad to get into the stairwell and start descending.

### CROSSING BOUNDARIES

"Clinical encounters" involve the same moral risk contained in most if not all human interactions: even if we grant that all participants (including loved ones) genuinely seek, at times desperately, to know and understand, there is no guarantee that anyone, the physician or ethics consultant included, is actually prepared to help (even if they appear to be in position to help). More to the point, to "draw out" the vulnerable other, and then not "listen" or respond, is a transgression. As we try to anticipate where "boundaries" might be in a clinical encounter, this is especially noteworthy given that relationality, or affiliation [27: 315–319, 28], is available in the many interactions typical to clinical encounters. In that typicality, an apparently "professional" concern for the individual can actually remain indifferent to the unique person obscured behind the role of dying patient, or spouse, or family member, due to the taken for granted application of a number of ready-made strategies: diagnostic, therapeutic, ethical, social, economic, and political, to name a few. Thus, a problem can arise in our frequent utilization of roles in these end-of-life situations. We may selectively interpret our relationships with others, i.e. "relationality," not as we

*are* in those relationships, but as we would prefer to be: for instance, to be identified primarily, if not only, in terms of the familiarity of one's professional role which, being repetitive, appears to remain stable over time and thus resists transformation. Therefore, an additional element must be considered in this "being bound-up" with another – especially when that other is the one who is dying, soon to be dead.

#### SUNDERING BOUNDARIES WITHIN ROLE BOUNDARIES: RESPONSIBILITY AND REFLEXIVITY

In that light, consider this question: *What does it mean to take the responsibility for saying "we need to stop medical treatments"?* Already contained in that statement is the placement of a boundary in the relationship to that patient. This arises in the ethics consultant's experience because the typical concept of decision and responsibility in clinical situations seems to partition the moment of choice from the act of withdrawing treatments. What we are noting is that the history of decisions and other actions leading up to that choice – bounded as these are by the various roles of the participants in that history – appears to be compartmentalized, or shunted off in some way. For the ethics consultant, this means becoming a witness who, while previously responsible for guiding conversation, now may not be able to find the language to speak.

The point is not merely that the ethics consultant may get subsumed in the detailed moments of action; no, there is the arresting detail that among the possible futures for that individual – right there in front of you – he or she has no future other than death (whether that occurs immediately after withdrawal, a few minutes or hours later, or the next day; death is the result). That issue of responsibility, at the core of an ethics consultant's participation in the actions of withdrawing medical interventions, reveals the disruption of the boundaries modeled by the "external" – social, institutional, political, legal and professional – authorities [22]. Furthermore, evoked in such moments are the personal and interpersonal meanings we take up in relation to, in addition to, and sometimes in contrast to, those social, institutional, political, legal and professional roles we inhabit.

Our thought is that during these occasions, 'responsibility' binds me to the dying other – as other – thus connecting *me* to the other *as other*, even when that specific connection might be obscured or otherwise defined according to *other relationships* configured in accordance with some *type of role*. And so the point: each instance of such binding, let us hope, reveals to the ethics consultant, and the others involved in the act of withdrawing medical interventions, the inadequacy of mere roles to support

the moral weight of that act. Furthermore, in that revelation something emerges, which may be what we are pointing to when we talk about moral experience.

What emerges is the task of the individual – *in relation to the other who is dying* – to work him- or herself out of dwelling within a role (for instance, that of “ethics consultant”) – if for no other reason than to come to grips with the issue of ‘responsibility:’ *i.e.* “*out of hiding*” into “*facing it.*” Faced with that sort of recognition, I – myself – am confronted with something vital to one’s “self,” namely, the struggle to determine *what do I do* when I recognize that the role – ethics consultant – which leads me to this responsibility cannot satisfy it: How, then, do I proceed? The role that has led me into this experience – itself composed of other roles that I have learned from the past will re-cohere as the moments of this experience fade – is yet exceeded by this experience. What I do now – even ‘*in*’ my role – *I do* beyond my role. Even as I confront questions about my continued involvement with this role, I know how easily I can revert to my own dwelling in it. Although it may not support the momentous action taken, it still enables me to move through the situation. Finding a vocabulary, some way to talk about and acknowledge the astonishment, even awe, in this sort of experience may be helpful, because among those things disclosed is a complex wonder about the self “coming out of hiding” and finding “its self,” not in the terminus of the specific actions of withdrawing that apparatus which “supports” the life of this other, but rather “in” that there is no real sense of “my” self ending.

These intimations of responsibility take us right to the crucible, for *death demands recognition in the temporality of a moment*, without even constituting a present: it cannot be stabilized, established, grasped, apprehended or comprehended, yet it establishes an unmistakable singularity, for instance my inability to replace that other dying in the bed with my self [8: 65, 42–44]. And here we need to acknowledge the boundary between self, or “individual,” and singularity, because an individual always already entails relationships and relationality, whereas singularity is defined by death (in that death remains irreducible): I am not able to reduce my presence to singularity, given the wondrous burden of “I” continuing; so too am I unable to grasp singularity in the presentation of the other, nor even in the grave astonishment, the trembling awe, in the “not-being-there,” of the other in death.

At this point we are exceedingly aware that perhaps what we bump up against with these intimations are the issues of secrecy and responsibility [8: 60–61], referred to also in different terms, like “the mystery of human being,” “the mystery of the sacred,” or as Hans Jonas stated in one of his

final essays “the burden and blessing of mortality” [15]. So be it! Because, in the strongest sense of those words, in order *to help* in such circumstances we inevitably come into contact with that sundering experience, grave astonishment, and trembling awe – and the moral significance these hold – which accompany that forecast of the end to a relationship. Precisely in this way responsibility is reflexive in character – it is bound up with relationality – evoked in the sense of affirmation (of one’s own otherness) as well as in a sense of otherness *of that other*.

## NOTES

<sup>1</sup> *Søren Kierkegaard’s Journals and Papers*, Vol. 3, L-R (2809), H.V. Hong and E.H. Hong (eds. and trans.) (Bloomington and London: Indiana University Press, 1975), 245. Translation liberalized following Paul Ramsey’s epigraph to *Ethics at Edges of the Life: Medical and Legal Intersections* (New Haven and London: Yale University Press, 1978).

<sup>2</sup> See Quill’s (1993) discussion about the ambiguity of clinical intentions as well as the need to “explore the gap between idealized ethics and actual experience” (1039), regarding the provision of adequate narcotic medication to patients who are dying. See also Edwards and Tolle (1992), for a rare discussion by physicians who became involved as ethics consultants and eventually were involved, as physicians, in disconnecting a ventilator from a patient. More recently are discussions such as “‘Terminal sedation’ and existential distress” by Shavia (1998), accompanied by commentaries from Cherny (1998) and Rosen (1998).

<sup>3</sup> Evidence for the broad acceptance of this equivocation is strongly implied by the more recent focus on attempts to justify physician assisted suicide. As one example the articles included in the “Special Section: Euthanasia and Public Policy” of the Fall 1998 issue of *Cambridge Quarterly of Healthcare Ethics*.

<sup>4</sup> This difference in the “feel” of these actions has been noted by physicians and nurses alike; see for instance Edwards and Tolle (1992) and Campbell et al. (1998).

## REFERENCES

1. Aulisio MP, Arnold RM, Youngner SJ, eds. Special issue: Commentary on the ASBH core competencies for health care ethics consultation. *The Journal of Clinical Ethics* 1999; 10: 3–49.
2. Bliton MJ, Finder SG. The eclipse of the individual in policy (Where is the place for justice?) *Cambridge Quarterly of Healthcare Ethics* 1996; 5: 519–532.
3. Bliton MJ, Finder SG. Strange, but not stranger: The peculiar visage of philosophy in clinical ethics consultation. In: Zaner RM, ed. *Performance, Talk, Reflection: What is Going on in Clinical Ethics Consultation*. Dordrecht: Kluwer Academic Publishers, 1999: 69–97.
4. Campbell ML, Bizek KS, Stewart R. Integrating technology with compassionate care: Withdrawal of ventilation in a conscious patient with apnea. *American Journal of Critical Care* 1998; 7: 85–89.



5. Cherny NI. Commentary: Sedation in response to refractory existential distress: Walking the fine line. *Journal of Pain and Symptom Management* 1998; 16: 404–405.
6. Churchill LR. Are we professionals? A critical look at the social role of bioethicists. *Daedalus* 1999; 128: 253–274.
7. The Council on Ethical and Judicial Affairs, American Medical Association. Decisions near the end of life. *Journal of the American Medical Association* 1992; 267: 2229–2233.
8. Derrida J. *The Gift of Death*, D. Wills (trans.), Chicago: The University of Chicago Press, 1995.
9. Devettere RJ. Reconceptualizing the euthanasia debate. *The Journal of Law, Medicine and Health Care* 1989; 17: 145–155.
10. Edwards MJ, Tolle SW. Disconnecting a ventilator at the request of a patient who knows he will then die: The doctor's anguish. *Annals of Internal Medicine* 1992; 117: 254–256.
11. Fox E, Stocking C. Ethics consultant's recommendations for life-prolonging treatment of patients in a persistent vegetative state. *Journal of the American Medical Association* 1993; 270: 2578–2582.
12. The Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. Indianapolis: Indiana University Press, 1987.
13. Howe EG. Ethics consultants: Could they do better? *The Journal of Clinical Ethics* 1999; 10: 13–25.
14. Husserl E. *Formal and Transcendental Logic*, D. Cairns (trans.). Martinus Nijhoff: The Hague, 1969.
15. Jonas H. The blessing and burden of mortality. *Hastings Center Report* 1992; 22: 34–40.
16. Jecker NS, Emanuel L. Are acting and omitting morally equivalent? A reappraisal. *Journal of American Geriatric Society* 1995; 43: 696–701.
17. President's Commission for the study of ethical problems in medicine and biomedical and behavioral research. *Deciding to Forgo Life-Sustaining Treatment: A Report on the Ethical, Medical and Legal Issues in Treatment Decisions*. Washington, D.C.: U.S. Government Printing Office, 1983.
18. Quill TE. The ambiguity of clinical intentions. *The New England Journal of Medicine* 1993; 329: 1039–1040.
19. Rosen EJ. Commentary: A case of Terminal Sedation in the family. *Journal of Pain and Symptom Management* 1998; 16: 406–407.
20. Scott CE. Responsibility with memory. *Research in Phenomenology* 2000; XXX: 240–251.
21. Shaivoo L. Case presentation: Terminal sedation and existential distress. *Journal of Pain and Symptom Management* 1998; 16: 403–404.
22. Solomon MZ, et al. Decisions near the end of life: Professional views on life-sustaining treatments. *American Journal of Public Health* 1993; 83: 14–23.
23. Special Section. Euthanasia and public policy. *Cambridge Quarterly of Healthcare Ethics* 1998; 7: 339–401.
24. Spiegelburg H. Putting ourselves into the place of others: Towards a phenomenology of imaginary self transposal. *Human Studies* 1980; 3: 169–173.
25. Tolle SW, Girard DE. The physician's role in the events surrounding death. *Archives of Internal Medicine* 1983; 143: 1447–1449.

26. Weir RF. Options among ethicists. Chapter 6 in his *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits in the Medical Prolongation of Life*. New York: Oxford University Press, 1989: 214–289.
27. Zaner RM. *Ethics and the Clinical Encounter*. Englewood Cliffs, NJ: Prentice Hall, 1988.
28. Zaner RM. *Troubled Voices: Stories of ethics and illness*. Cleveland, OH: The Pilgrim Press, 1993.
29. Zaner RM. Listening or telling? Thoughts on responsibility in clinical ethics consultation. *Theoretical Medicine* 1996; 17: 255–277.

*Center for Clinical and Research Ethics*  
*319 Oxford House*  
*Vanderbilt University Medical Center*  
*Nashville, TN 37232-4350*  
*USA*  
*E-mail: mark.bliton@vanderbilt.edu*