On the Edge of Life, I:
Assessment of, Reaction to, and Management of the Terminally Ill Recorded in an Intensive Care Unit Journal

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Background: In a general hospital, few clinical settings match the intensity of the intensive care unit (ICU) experience. Clinical rotations in ICUs elicit and emphasize the struggles house officers face on a daily basis throughout their training.

Method: These struggles were recorded by hundreds of residents in a journal maintained in the Massachusetts General Hospital's Medical ICU for the past 20 years. We systematically reviewed these unsolicited entries to define and to illustrate how house officers respond to caring for terminally ill patients. The 3 overarching topics that surfaced repeatedly were assessment of terminally ill patients, reaction to their prognosis, and management of their disease or their eventual demise.

Results: House officers record affective reactions and cognitive assessments to cope with the stress and dysfunction associated with the care of the critically ill and to facilitate their management of these patients. Journal entries by residents reveal a deep concern for the welfare of their patients, conflict about the technological advances and limitations of the system, and reflection on how involved physicians should become with their patients.

Conclusion: House officer journal entries reflect a combination of newly gained medical knowledge and coping strategies in managing terminally ill patients. House officers also demonstrate a deep concern for the welfare of their patients. Insight from years of reflection from past house officers can help prepare trainees and residency programs for the breadth and intensity of the ICU experience and for work in clinical practice settings that follow completion of training.

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A good death does honor to a whole life.

—Petrarch (1304–1374)

Physicians are susceptible to feelings aroused in them by their patients. These feelings, whether positive or negative, may interfere with the quality of medical care delivered. Perhaps the greatest level of physician dysphoria is elicited by dying patients. Herman[1] assessed physician attitudes toward terminally ill patients in a department of medicine and found that nearly 60% of respondents felt that they dealt poorly or inadequately with these patients. Herzog and colleagues[2] administered questionnaires to medical, pediatric, and psychiatric house officers and found that dying patients produced the greatest amount of dysphoria in young physicians. Specifically, patients with leukemia elicited feelings of sadness, intubated patients evoked anxiety, and patients who suffered a cardiac arrest or who had metastatic cancer elicited feelings of helplessness and stress. House officers (whether or not they eventually practice in primary care or in some other specialty, e.g., cardiology, oncology, critical care medicine, or gastroenterology), by virtue of their relative inexperience, their high rate of exposure to sick patients, and the occurrence of emotional lability induced by sleep deprivation, may be at greatest risk for these feelings.[3]

In the context of a general hospital, the intensive care unit (ICU) exposes physicians to terminally ill patients more than any other clinical setting. By definition, a patient admitted to an ICU must have organ system failure that is potentially reversible[3]; unfortunately, 20% to 25% of patients admitted to ICUs never leave the hospital alive.[4] Echoing this statistic, surveys of ICU physicians have found that 96% had withheld or withdrawn life-sustaining medical treatment.[5–7] Whether a patient arrives in an ICU with a devastating illness and dies because of the illness, or whether a physician determines that the condition has become irreversible and thus medically futile to treat, the contribution of poor outcomes to emotional exhaustion and burnout among medical intensivists is high[8,9]; among all physicians, stress and burnout are particularly notable in house officers.[10,11]

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One method for exploring the impact of caring for the terminally ill by physicians involves use of a recording mechanism. Keeping track of thoughts, feelings, and associations via a journal or diary allows for further reflection and sparks open discourse. One such journal has been maintained in the Massachusetts General Hospital (MGH) for over 20 years. Representative entries, written by house staff in the ICU, have been included in this article to illustrate overarching principles that highlight house-staff interactions with the terminally ill. It is important to realize that stress, fatigue, and a host of intense and conflicting emotions often color statements made and opinions offered. Their prose reflects real-time commentary made in the privacy of a house staff journal. As such, no attempt was made to refine or edit their prose.

Goals

Our purpose is to describe and define how house officers assess, react to, and manage the terminally ill; we hope to prepare trainees and programs for the breadth and intensity of the ICU experience. We believe that the insights derived from these interactions, through unsolicited journal entries that span 20 years of house officer experience, are invaluable for curricular development. In particular, definition of the stresses particular to house officers and the frequent coping mechanisms house officers use to deal with these stresses can be used in introductory lectures to interns. New house officers will then be made aware of the emotional terrain that lies ahead and of mechanisms (such as support groups or the use of recording mechanisms) that may help minimize stress.

METHOD

To combat the stress and dysfunction known to be associated with being a house officer, institutions have created programs to help those at risk and those negatively impacted by their work environment. Programmatic efforts have included individual and group meetings; weekly support meetings; psychiatrically oriented, case-centered discussions of patients; and 1-time retreats with formal, process-oriented group discussions.[12] At the MGH, weekly autognosis, or self-awareness, rounds have been held in the Medical ICU (MICU) for more than 20 years.[12] As an adjunct to these meetings, a journal was created to enhance awareness of the stressful nature of internship and to facilitate open discussions (intended to improve function).

Since the inception of the journal, more than 7 volumes have been filled with writings by hundreds of house staff. It has, we believe, served to stem the tide of isolation and provide an outlet for emotional expression. Examples from the journal highlight what the initial rotations in the ICU and the time sequestered in the hospital have been like for a generation of house officers (dates of entries have been modified to maintain anonymity). Keeping track of thoughts, feelings, and associations, via a journal or diary, allowed for further reflection and sparked open discourse. The “MICU journal” or “Red Book” (as the first of the journal volumes had a red cover) was kept in an MICU conference room used only by physicians for 20 years. We (M.A.S. and T.A.S.) systematically reviewed all of the entries in the journal individually, each identified “significant” entries (i.e., those entries that were particularly lengthy, emotional, humorous, angry, or stressful), and met periodically to determine which culled entries overlapped and to identify overarching principles that highlighted house staff stressors. Entry choice was based on our collective experience of entries that elicited reactions in subsequent house officers who read and discussed the book. The rare instances of disagreement were discussed, and a consensus was reached to either include or exclude an entry from an overarching topic head. We then defined 3 overarching topics that surfaced repeatedly within the general category of “care of the terminally ill”: assessment of terminally ill patients, management of the terminally ill, and reaction to the death or the impending death of a patient. All identified “significant” entries were classifiable under at least 1 topic head. All entries were unsolicited, documented in real-time, and recorded without knowledge of this analysis.

RESULTS

Assessment of the Terminally Ill

For physicians, the first steps involved in determining which treatments to recommend (and how aggressive those treatments will be) to patients and their families are to assess the severity of illness, its reversibility, and the patient’s wishes regarding treatment. Assessment of a patient’s wishes, however, can be difficult in the ICU, as many patients are unconscious or incapable of making decisions.[13–15] Regarding the severity of illness and its reversibility, scoring systems exist that can help predict survival on the basis of objective criteria.[16,17] Similarly, criteria based on serial neurologic examinations have been developed to predict prognosis in nontraumatic or hypoxic-ischemic coma.[18,19] In their journal entries, house officers often make oblique or direct references to these assessment tools as they grapple with their reactions to the patients’ conditions.

> *1980s:* Tonight we admitted a man, a nuclear power engineer, who had a VF [ventricular fibrillation] arrest at a conference in Boston, away from his family, who are in California. They can’t come because it’s snowing and the airport is closed. He’s decorticate. They feel afraid and helpless. It’s pretty sad. This unit can be full of sadness like that. That’s part of the intensity of it.

> *1980s:* To share one of the unpleasant ICU experiences—telling a close friend with an Italian-speaking mother that their father/husband is "brain dead" when they can see full well that his breathing and heart will stop only when I turn off the vent. Wanting to say that it is indecent to breathe for someone who has been dead for 4 days when they ask, "What's the rush?"

> *1990s:* Dr. Z, pulmonary fellow, assesses comatose patients in neurovegetative states' withdrawal to pain with an easily reproducible test. . . . In reviewing Levy's criteria (JAMA, 1995), we found that no response to [his test] was only predictive of no recovery vegetative state in conjunction with the gold standard: no spontaneous eye movement to [pain stimulus].

Journal entries such as those cited above often are cryptic. Moreover, when taken out of context from the experience and from the entries that precede and follow them, they can be jarring. They do, however, reflect the range of emotions experienced in the ICU (sadness, arrogance, and anger) and indicate a variety of coping strategies (e.g., use of sarcasm, gallows humor, and intellectualization). Yet, they reflect knowledge of brain-death criteria, awareness of studies on predictors of poor outcomes, and a sense of how the patient and his/her family must be managed in difficult times. Gallows humor serves not only to demonstrate knowledge of the appropriate brain-death criteria, but also to express horror at the clinical situation to which they are applied. Humor often is extended to the point of absurdity. Terms such as *decorticate, brain dead,* and *neurovegetative state* convey knowledge of the neurologically devastating process that has occurred (i.e., assessment) and to which the residents are reacting.

Reactions to the Terminally Ill

A number of journal entries by house officers detail (often in quite eloquent prose) personal reactions to the dead and the dying. Two major themes emerge from these writings: conflict over the degree to which technology in the ICU should be used to prolong life in those with poor prognosis (i.e., quality of life vs. length of life) and the emotions that arise when house officers relate to or identify with terminally ill patients and their families (i.e., seeing oneself in the patient).

Originally, ICUs were designed to provide expert assessments and effective interventions in acute, life-threatening illnesses. Technological advances and improved nursing care over the past 30 years enable lives to be prolonged in the face of certain death.[20,21] Ethical and treatment conflicts have arisen as technology has been developed to support organ function long after the possibility of life independent of that support system has ceased.[20] Strictly speaking, criteria for ICU admission include (1) a requirement for life support for organ system failure that may be reversible or remedial, (2) irreversible organ system failure that cannot be treated appropriately in another setting, (3) risk of a life-threatening complication that requires monitoring or treatment, and (4) need for a trial period of monitoring or treatment when there is doubt about the prognosis or the effectiveness of therapy.[4]

Conflict arises when the "doubt about the prognosis" in the fourth criterion disappears as the prognosis becomes grim. Yet, not all members of a patient's care team, family, and other supports reach the same conclusion at the same time.[22] Some resent the physician or team of caregivers for not being able to save a patient,[23] while others, including the patient, hope for an "appropriate death." When death is imminent, several principles should be invoked. The patient should have good pain control, function on as effective a level as possible given the constraints of his or her illness, recognize and resolve residual conflicts, satisfy remaining wishes as much as possible given his or her condition, and be able to yield control to others in whom he or she has confidence.[23,24] House officers, who are often caught in the middle between a patient, a patient's family, and the patient's attending physician, bear the brunt of everyone's frustration.

> *1990s:* After a month in this ICU, I am now forced to condemn it as an embarrassment to a modern ethical society. Designed as a vehicle for aggressive therapy for otherwise healthy individuals with acute and potentially reversible medical problems, it has become instead a long-term care facility for individuals permanently incapable of contributing to or deriving enjoyment from the life and community outside. It is an engine of false hope, misperceptions, and overall moral negligence. We, as its captains, are universally guilty of prolonging the suffering of those unable to comprehend the complete extent of their decisions while consuming the resources entrusted to us by society as a whole. "Doing more" remains the path of least resistance—doing less ought to be the challenge to face up to. We inflict harm in the guise of treatment. We violate our past as entrusted compassionate physicians on a daily basis. As an alternative, perhaps we might devote more effort to overall treatment goals. Place ourselves in the patient's position—we know what the right thing to do is—we need to explain to the families that we understand and give them permission to draw back. We abuse our power by doing otherwise. Lastly, we might work on physicians to avoid letting our patients get to this point. Few of the millions of people we meet truly want all that is done here. How often do these people change their

> minds while unable to communicate—how many hate us for what we do?

> _1980s:_ There are only so many ways coronary artery disease can present, and we've seen them all. Watching people die . . . is neither educational, nor fun, nor particularly humane. Whoever invented the ICU should see some of the patients we have here. With reference to the atom bomb, Einstein said, "With the development of the bomb, everything has changed save our mode of thinking, and thus we drift perilously." I propose that with the invention of the ICU we also need to change our way of thinking. Just because we have the capacity to prolong death in elderly people doesn't mean we have to, and yet we do; everyday in this place we prolong suffering at little benefit. Bring back the house call and a hold of the hand. Final score—buried hundreds; saved one or two; cured zero; flog on, comrades!

The following entries seem to respond to this entry almost directly, though they are separated in the journal by a decade.

> _1990s:_ I got to see a lot in the past 31 days, but a few cases stand out: I got to meet a nice older woman, walking and talking (rare to the MICU). She had a stream of family members in and out. They were worried about Grandma. . . . She was smiling through the night, until she woke at 5:00 in the morning with the sense of impending doom. I got to know that look well. Right before our eyes, she lost her blood pressure. She was DNR [do not resuscitate] by previous wishes. All we could do was stand by her bedside and hold her hand as her heart slowly stopped beating and she drifted off. No morphine drips, no withdrawal of support. She just died naturally, and we let her. Although hers was an unexpected death, we knew that she had had a recent MI, and she wasn't a well person by any means. It struck me as not a bad way to go.

> _1990s:_ I would hope and pray that in this long month I have helped at least one family to come to grips with the loss of a loved one; have dampened the horror/fright of the enveloping lights and buzzers in the mind of one critically ill old person fallen victim to our technological "marvels." If I have done this, my month wasn't wasted.

These entries place the conflict in a global perspective, depersonalizing the issue of what the house officers consider the inappropriate use of technology by viewing it (correctly) as a problem extending beyond the confines of the ICU. The latter entries, which appear almost wistful, recall simpler, nontechnological times, as if the resident is removing himself or herself from the daily conflicts imposed by modern technology.

The emotions that arise when house officers relate to and identify with terminally ill patients and their families (i.e., seeing oneself in the patient) also influence the tenor of the journal entries. Cassem[23] has written that a dying person poses a threat to the professional's own human attachments for 2 reasons. First, the physician is reminded that death means loss of the relationship with the patient and all of the investment and caring that have gone into it. Second, the imminent loss of a patient reminds the physician of his or her own losses and threatened losses. A particular patient or illness may provoke a physician's anxiety about death and disease, sometimes because of common features of age or life situation, or be a reminder of a painful event in a physician's life, such as the terminal illness of a parent.[25]

> _1990s:_ I just called another patient's daughter to tell her: "Your mother looks worse, you may want to come spend time with her."
>
> "Do you mean my mother is going to die?"
>
> It is hard not to feel a certain amount of responsibility or culpability in making such a phone call. Much easier to say: "She's doing well," and see them smile, than to see the horror and the dread. My father still remembers, 30 years later, the words used by the doctor on the night my grandfather died.

> _1990s:_ Mrs. P died yesterday. Her mother, who had made the decision to pull back and has been by her side every day of her course, can now rest and mourn. I cannot even begin to imagine what it must be like to mourn for a child. But as I await the birth of my first—I have a sense that there could be nothing worse.

While the house officers in these entries identify unabashedly with the plight of their patients, phrases in other journal entries imply a process of depersonalization by referring to patients by the names of their moribund diagnoses: "We have 2 status-post cardiac arrest anoxics . . . ," "Dr. S, referring to the DNR in Room 927 . . . ," and "The ICU is filled with broken bodies. . . ." Depersonalization is a defense against sadness and loss, but it comes with a price, i.e., a lack of empathy and an interpersonal distancing that, arguably, may improve objectivity, but at a price of a humanistic approach and relationship to one's patients.

Other entries focus on the house officer's attempt to obtain a patient's or family's agreement to forgo aggressive life-support measures. This issue is stressful for residents for several reasons. First, although discussions with patients regarding advanced directives should occur in the pre-ICU phase, before critical illness or deterioration of mental status compromises a patient's ability to express his or her wishes,[4] these discussions often begin in the ICU. Here, the house officer may be forced to initiate such a discussion. Second, it is psychologically difficult to stop a treatment once it is started[26]; ethically and legally, however, there is no difference between withholding and withdrawing a treatment; such actions are sanctioned in all 50 states.[4,27,28] Finally, house officers are less experienced than attending physicians at conducting end-of-life discussions and thus become notably anxious when these discussions become necessary. House officers use the word *status* to indicate a DNR order.

> *1990s:* Tonight, a daughter requested I talk to her father about the futility of her mother's care—dense left stroke, severe COPD [chronic obstructive pulmonary disease]. No progress after hours of conversation. I tried hard to get him to understand we should not unnecessarily prolong her suffering and tried for a DNR status, i.e., don't shock. He is now very angry, and the rest of the family is upset. How could I have handled it better? Will I ever know? The MICU goes on. . . .

> *1980s:* The ICU is the only place where having status is bad for you. Mr. T, nice man, tough, denies his ejection fraction of 11% (tough to deny that). Improving a little on dobutamine, captopril, IVTNG, bumex, kitchen sink. Family, having a hard time coming to grips with his illness (he worked up to the day of his MI), tries to understand. The nurse mentions on rounds, "Where are we going here, we need a status." I see Dr. Y speaking with Mr. T, then Mr. T and wife, then just the wife, off and on all day as the nurse leaves at 5 p.m. (another hard day). Later tonight, while I'm putting in an A-line, I hear of a transfer from the emergency department and the need to rearrange beds. A nurse says, "Oh, move the DNR in [Room] 27, he's no work." Mr. T has attained a "status." Tomorrow will be better.

> *1990s:* The death toll for the month is already up to 12, many of whom probably should have been allowed to die before ever coming here. Just once in a while, it would be nice to treat someone who was sick, but had a decent long-term prognosis. We have had our surprises . . . but it is like our efforts have made very few people become long-term better. Did they live because of us or in spite of us? Did they die because of us or in spite of us? How should I know? I just work here. . . .

These entries emphasize the frustration house officers experience around issues of terminal care and absolute helplessness, again and again questioning their medical skills and their ability to communicate with patients and families.

While many physicians have learned to protect themselves from identifying excessively with a patient's fate, that protection may fail in the face of an especially poignant clinical situation or during a period of illness or personal crisis in the physician's life.[25]

Management of the Terminally Ill

Is *not* protecting oneself from identifying excessively with a patient's fate truly a failure? Cassem et al. elucidated essential features in the care and management of the dying patient.[26,29] Qualities sought in caregivers by patients include physician competence, concern, comfort, communication, cheerfulness, consistency, perseverance, and equanimity. A recent survey of 340 seriously ill patients identified 5 items rated as important in patients' relationships to health care professionals. These items included receiving care from one's personal physician, trusting one's physician, having a nurse with whom one feels comfortable, knowing that one's physician is comfortable discussing death and dying, and having a physician with whom one can discuss personal fears.[30] Patients clearly value physicians who become involved with their plight.[25]

Others argue that physicians develop defenses to avoid the repeated stresses of becoming involved with dying patients.[23] Presumably, these defenses result from feelings of discomfort and are created to avoid burnout. These physicians try to avoid dying patients altogether and are seen as being uninvolved or aloof by patients and their families. Several journal entries reveal a mix of the "involved physician" and the "aloof physician." This mix probably reflects a combination of the adolescent nature of the house officer (being somewhat between an immature and a mature practicing doctor) and the increasing acceptance of greater involvement with the nonmedical aspects of a patient's care.

> *1990s:* One of the youngest and, seemingly, the most normal patient on our service was patient A. We would wave to her as she pushed her IV pole around the unit—"this is not an MICU player," we would say on rounds. . . . Then—she had a VT/VF [cardiac] arrest refractory to cardioversion, and the code was called at 6:00 a.m. The patient's family and attending were notified. The team was devastated. I was exhausted. We had essentially been coding another patient for the past 24 hours straight, and we lost patient A on top of that. For most, it was an emotional time. We had worked hard on her case, gotten close to her personally. Her loss is one that we all took to heart. But for me, I didn't feel it at all—too little sleep, too much work,

> too many responsibilities. I was totally numb. It was only after the event—after a decent night's sleep, a good meal, a shower—that I could feel human again—and thereby start to feel for her as well.

> *1980s:* Mr. B, a 30-year-old man, continuing to bleed overnight from his abdominal wound, despite the efforts of Dr. H and myself. He was . . . still bleeding, and very scared, as he knew, as we did, that the end was near. It was way too overwhelming to contemplate this patient's thoughts.

Despite the numbness and the feeling of being too overwhelmed to contemplate the patient's thoughts, residents are deeply affected by their interactions with patients—affected enough to talk with patients about their feelings and visit frequently as a patient dies. In action, these house officers fulfilled Cassem's "qualities sought in the caregiver by the patient," even if in words they tried to invoke the distance that they were, in all likelihood, taught to assume in such situations.

CONCLUSION

Assessing, reacting to, and managing terminally ill patients is difficult for any caregiver.[25] It is harder still for the doctor-in-training in an intensive care setting.[3] Journal entries by residents reveal a deep concern for the welfare of their patients, conflict about the technological advances and limitations of the system, and reflection on how involved physicians should become with their patients. Journals such as ours can provide a medium through which residents can gain acceptance of their insecurities about their skills as physicians, particularly as current house officers recognize the same emotions in entries by past house officers (many of whom have since become attendings) and come to the realization that those emotions are normal sequelae of training in a stressful environment. Support can thus be gained through the collective voice and experience of colleagues. Programmatic efforts on the part of residency programs could include using the insights into house officer emotional distress and coping mechanisms gained from the collective experience of 2 decades of house officers to educate new house officers and provide appropriate support mechanisms.

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