
ESSAY/PERSONAL REFLECTIONS

A psychiatrist in hospice

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(RECEIVED October 7, 2002; ACCEPTED January 17, 2003)

Dr. Alan Morgenstern joined the psychiatry faculty at Oregon Health and Science University (OHSU) in 1965. He also served as chairman of psychiatry at Good Samaritan Hospital and Medical Center in Portland, Oregon. His many accomplishments include his part in a World Health Organization Travel-Study Fellowship. He served as a senior examiner for the American Board of Psychiatry and Neurology and he published a critique of this process, which resulted in a humanization of the experience for examinees. While teaching at OHSU he had a tremendous impact on generations of students who were impressed by his humane approach to medicine. He received the OHSU Meritorious Achievement Award for Teaching. He also served as a captain in the United States Air Force School of Aerospace Medicine. His close friend, Harold Boverman, M.D., wrote, "He loved his family, his work, his patients, his friends, and his music; his license plate read 'etude.'"

Dr. Morgenstern contacted us regarding his hope that we would facilitate publishing this account of his experience as a hospice patient. This represents an edited version of his manuscript. L.G. and H.B.

Eight years ago at age 60, I suddenly became ill with viral myocarditis. For several years the major limitation of function was shortness of breath with exertion. This did not preclude much pleasurable activity, including piano study, many happy trips, and continuation of an extremely enjoyable professional practice. Somewhat later I decided to retire after a very happy career, which included 10 years as a Professor of Psychiatry at OHSU and then more than 25 years of office practice.

After the decision to retire, a pattern of pain developed as a sequel to knee surgery several months earlier, and the pain began to worsen in spite of physical therapy. In a period of several weeks I was ill enough that I required hospital care, which revealed that my heart had become very enlarged. My knee pain was worsened by leg swelling; I was treated with oxycodone, then methadone.

On the very first day in the hospital the doctor asked my wife and me if we had considered "end of life issues." He used the word hospice. This word "hospice" went in our ears and promptly exited. Memory traces, however, were left behind. Our assumption was that I would be transferred to a convalescent center, receive physical therapy, return home and—with follow-up physical therapy—receive as much rehabilitation as possible. This is exactly what took place.

While I was in the nursing facility, I observed that the great majority of patients in my "convalescent center" were actually elderly women who basically went there to end their lives. Although it was a well-run center, it was a place of great depression for me. I experienced secondhand the helplessness of patients receiving nothing but maintenance care until they died. It became a special horror for me and I decided I would want to end my days in any setting other than that.

I recalled a few people I admired and took their stories as a guide. One was the great operatic composer Puccini, who almost finished a choral work when he died at his desk, still composing. I happened to see in the *New York Times* just a few days ago the obituary of a great paleobiologist who died in his home's library, surrounded by his books and with a view of his garden. This seemed to me, by far, the better way of dying.

Once discharged to my home, I began to fall. On a daily basis, I experienced the dread of another fall, which could result in a broken hip, with the

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inexorable progression from the operating room to dying in the midst of strangers in a convalescent facility. I abhorred this possibility. Utter passivity, pain, and no influence on my destiny were a fate I could not bear to think about. But, after experiencing several falls, anytime that I found myself in a situation of facing a potential fall—such as being in the bathroom—I was filled with dread.

The pain worsened. I was unable to sleep through the night on the prescribed dosage of methadone, although I felt certain that one more dose would get me through the night. Getting out of bed in the early morning I would get to my chair, take methadone no matter what, and experience relief after about 20 minutes. I realized, however, that before long the numbers would catch up with me, and that I would be running out of methadone before my allotment of the medication was used up.

On one occasion, I traumatized a knee and experienced excruciating pain. I reported to my doctors that I had increased my dosage for two nights because of this. I expected a bit of a compliment for being sensible in the use of a medication in response to an unforeseeable symptom. The doctor, however, seemed angry and insisted that my dosage could not exceed a certain quantity per day. If I were to run out of medicine, I would just have to learn to bear it. These were very stringent warnings. On the one hand, I had an intense need for medication early in the morning and, indeed, was awakened from my sleep because of pain. On the other hand, the pain relief from medication brought nothing but stern reminders of how many pills per month I was entitled to use. I had the unfortunate experience of feeling that there was more concern for the number of tablets than there was for me as a person. I hated the experience of having to count tablets every day. It was a frightening and deplorable experience.

One relief from this was marijuana, which I had never employed before, and which was introduced to me by a good-natured friend. He told me of the considerable pain relief marijuana can bring to people. He was good enough to bring a supply of the drug and, indeed, it was effective. I also tried using alcohol for pain relief. Although liquor was effective in helping me sleep, it had no impact in reducing the severity of pain. I stopped the marijuana because it was really discordant with my own self-concept.

This was the situation before hospice: terrible pain and terrible fears. I felt myself to be a trapped and broken man with unbearable pain, who was physically defeated in every way possible. My ability to cope with the everyday needs of life was very badly diminished. My wife and I had often dis-

cussed our views about the inherent right to end one's life when daily existence has become intolerable, and there had been appropriate discussions with colleagues and wise friends and I initiated the application for "physician-assisted suicide" through the Oregon Death with Dignity Act. I felt my only relief could come from suicide.

I insisted upon an emergency visit with my primary care doctor during which he experienced the full weight of my illness when he saw me crouched down in a wheelchair, obviously in pain, and behaving very much like a lost child. My wife and I reminded him of his use of the word hospice, and I said that it was time for me to get whatever help they might have to offer. My doctor promptly made the referral. Four days later, on a Sunday morning, my wife and I were surprised when a senior hospice nurse came to evaluate me regarding my suitability for home hospice care. The care itself began at a very rapid tempo. Then next day brought a welcome visit devoted to psychosocial matters by a skilled social worker from the hospice program. We were off and running before we had a chance to catch our breath, and it was an enormous relief to both my wife and me.

Once in hospice, I was startled by the rapid attitudinal change in my doctor. I was now a "hospice patient," and the goal of treatment was freedom from pain. It had been so long since I had been free from pain that I could hardly grasp the idea. I embarked on a search for analogies, and I needed help in organizing my thoughts about the changes in attitude and behavior that I was witnessing. For me, the experience was something like a misplaced envelope in a mailroom finally being put into the correct slot. The contents have not changed, but the labeling has changed and everything is seen in a different light. A most dramatic example of this is encouragement of the liberal use of opioids. The dosage of methadone was increased by almost 50%, and my goal of "staying ahead of pain" was now feasible.

My first use of hospice actually occurred before the initial visit from Ann, my hospice nurse. It stemmed from anxieties over picking up a methadone prescription and basically was an arithmetic problem, heavily imbued with anxious fears of running out of methadone and my wife's concerns about encouraging a drug abuse habit. I vividly recall the sense of humiliation I experienced each night as my anxiety forced me to count the tablets to be sure there would be enough to see me through until they were refilled. It was something akin to a questionnaire which the pain doctor gave to me and which was seen much more suitable for the entry of a felon into a penitentiary than for a man seriously ill with

a painful and dreadful disease. My wife and I rarely argue but such was the case around 7:00 a.m. that Monday, and she suggested that we call the hospice telephone number affixed on a red label to our kitchen phone and ask for help. The nurse settled us down and made a few very practical suggestions. She helped determine that the error was due to my own anxiety. But the experience of calling, even before the first hospice visit indicated, I believe, an attitudinal shift and an ability to form a kind of working alliance with hospice even before I had formally had any treatment by the program. The nurse on the telephone simply helped with the arithmetic part of the problem and promised to contact my primary care physician at a certain time. She followed through on this, and at that point the term "mother hospice" became an intuitive part of my vocabulary. I began to see my relationship to my hospice providers through the vocabulary and viewpoint of John Bowlby, the psychologist who wrote about "attachment and its manifestations." Asking for help, even before the first visit by my nurse, indicated my attitudinal readiness.

The following morning, nurse Ann arrived for the initial visit. She carried a "doctor's bag" and was a pleasant and obviously experienced person. Her visit made for a very happy experience for my wife and me. Since a fundamental goal of hospice is freedom from pain, the medications would be discussed and recommended to my primary care doctor, and he would write the orders upon such recommendations. Needed changes were implemented with great rapidity. In addition to Ann's twice-weekly visits, an aide took care of my shower and dressing needs. In all of the visits, and especially those associated with the showering, I have been very impressed that, like a child, I have not felt any trace of shame at being bathed—simply relief in the safety of a shower and comfort in her assistance.

In the 1940s and 1950s, before the development of corticosteroids, a novel approach to the treatment of hemorrhagic gastrointestinal disease was attempted by a psychoanalyst named Sydney Margolin. Relying on concepts of transference, he developed an approach called "anaclitic therapy." He thought that providing all of the needs for a patient's "body ego" might be enough to turn the tide in stemming the high death rate from ulcerative colitis. The Latin root of anaclitic is "to lean against," and that is exactly what was done in a treatment plan, which encouraged complete dependency and regression by the patient. The workload was shared by a cadre of experienced nurses, who were instructed to deal with a patient much as one does with a baby or toddler. Every effort was made to

anticipate needs, and there was no discussion about choices. Needs were simply anticipated and appropriate actions were taken. There would be vocalizations, but they were generally of a rather cooing sort, as between a mother and a young child. Back rubs were generously employed and the nurse, behaving like a caring mother of a very young child, soothed the patient. The results were very encouraging; hemorrhagic episodes were often terminated by this regression.

Some predictable problems arose, such as patients not wanting to reassign themselves to a more adult view of the world and the impossibility of a nursing staff allocating so many of its resources to one patient. This dilemma was ended by the new availability of steroids. It seems to me, however, that some principles of anaclitic therapy occur with hospice care, even home hospice. Dependency fears disappear and, indeed, doing more becomes possible.

After 4 weeks of hospice care, I began to experience its reality and what it meant to be basically free from pain. A schedule was established and included the very useful visits of a clinical social worker. I noticed that her use of euphemisms for the word "death" sharply diminished once I was firmly established as a hospice patient. It became possible to get on with the current task of writing this paper, as well as more involvement in intellectually stimulating readings. Every evening my wife and I had a chance for a good discussion about what was happening in our lives. We sought to be realistic and as loving as humanly possible.

Ann arranged for the delivery of a lightweight wheelchair, and its prompt arrival the very next day reinforced her esteem in my eyes. The shower aide had enormously high regard for her, and she says, from time to time when asked a question, "Ann knows everything." I am a member of the same admiration society, and I find that her "knowing everything" is based upon her 30 years of experience, as well as her great talent in hospice nursing. It is very clear that there is a strong transference that has developed between me, my wife, and Ann. I see her as a kind and wise helping person, who will be effective in my care for as long as is required. Feelings, however, go deeper than that: They include wisdom, omniscience, and omnipotence. In the little world that has become my universe, she looms very large. Since the burden and paralysis of pain has been lifted, I have been able to write; this memoir is the primary example. I know that Ann is very approving of the fact that I am engaged in writing, although she has no idea about the contents of this paper. I still have a need for approval for doing "good deeds." The lifelong need to prove

that I am “an okay person” continues to manifest itself, although it is now utterly unnecessary.

Aspects of sibling rivalry are also showing themselves. My wife has very positive feelings toward Ann and, as they have gotten to know each other and engage in conversation, my wife has gone as far as showing Ann a wonderful piece of Indian cooking which she had just prepared. I find myself thinking: “Ann, don’t bother with her. Pay attention to me!” It would be hard to find a statement more characteristic of a sibling rivalry than that.

Once I became comfortable with the role that hospice asked me to play, I found that my energies were freed for other ambitious tasks. I know that I will be well attended to and that through hospice my needs will be met. There is energy for less selfish thoughts, such as the allocation of funds for care amongst our youngest and most vulnerable citizens, and our oldest citizens like me. None of this is possible when focused on terrible pain, and it reminds me of the French saying, “No philosopher can exist when that person has a toothache.”

Inexorably, however, the physiology is turning against me and there are signs that now my right ventricle is failing. This leaves me with sadness, resignation, and yet a certain degree of peace of mind. The words on my wheelchair voucher include “End-Stage Cardiac Disease.” I know this to be an accurate statement, but as a physician I know that there are many possible outcomes in end-stage disease, and I feel a sense of both resignation and a need to hope. Even at this time, I find myself not wanting to dwell on the “end stage” idea too long for fear of becoming paralyzed in my everyday life behaviors.

There have been moments of anxiety, which I decided I could at least use as small “experiments of nature.” On one occasion I was awakened by pain in the middle of the night and then wondered if the methadone supply Ann had ordered for me was

adequate. In my 2:00 a.m. calculations, I concluded she had made a mistake, and I was getting too little. (It subsequently became clear she had made no mistake.) I thought my model of omniscience had made a mistake. What was I to do to maintain my total positive regard for her? I immediately and uncharacteristically began to ruminate about an earlier experience of abandonment, and I recalled the abrupt shock and pain of those very difficult times. It seems that any negative feelings were instantly activated to be felt toward a third party rather than toward Ann herself. There is an English school of psychoanalysis which was developed by Melanie Klein in which the emotional reaction toward the mothering figure is split into the “good” and the “bad” mother. I have always been skeptical of the psychodevelopmental aspects of Ms. Klein’s work, but I think I found myself in a “Kleinian split” that night.

I mention this abstruse fact to illustrate that thanks to hospice care and to their fulfillment of my needs, I am still able to learn in spite of the great difficulty at this time in my life. I thank hospice for the opportunity to keep on learning, and I know that their attention to my basic needs has allowed me to grow rather than to diminish. The generous fulfillment of my own needs is at the heart of my hospice experience. It is very helpful to know one has the capacity to die gracefully.

I met with Dr. Morgenstern at his home on May 28 and again on May 31, the day he completed this manuscript. Despite the fact that through hospice he renewed his energies and focus, he continued to fear future decline, increasing dependence, and lack of control. He spoke of having completed the necessary requirements under the Death with Dignity Act and anticipated receiving a lethal oral prescription under the act the following day. He died June 4, 2002.

L.G.