

Dying As Medical Performance: The Oncologist As Charon

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I think EVERYTHING in the universe is interconnected. And there are some interconnections we haven't been conscious of, and they'll come out sooner or later. Probably later, because knowing the AMA's grip on things, it's going to take a long time, and it's going to take a lot of people who aren't afraid to speak out for what they really believe in....a lot of people who are simpatico with this new way of living, with this wholeness of living.

-- Margaret Bell

Introduction

In November 1990 a 70-year old woman, whom we will call Mrs. Margaret Bell, entered the hospital suffering from severe dehydration following chemotherapy. She had been diagnosed with colon cancer with metastases to the liver in July of 1990. Having been admitted, she was convinced of her ability to recover. Shortly after she left the hospital after a ten-day stay, she became determined to die. By her own report, the oncologist's words played a significant role in this transformation. As she explained her experience, his dramatically ritualized and repeated pronouncement of her terminal status, reinforced by other aspects of her hospital experience, eventually integrated itself in her mind as a primary "failure" that added heavy symbolic weight to the other "system failures" (of blood sugar and electrolyte balance) she was experiencing. The terminal diagnosis quickly came to form one primary piece of a new reality matrix--a matrix that held her death to be imminent and her task not to attempt further healing but to prepare herself for death.

In an interview, the oncologist primarily involved in her treatment shed light on this transformative moment: he called

the task of announcing terminal status one of the central responsibilities of the cancer physician. In fact, he identified the doctor-patient interaction surrounding this announcement and its reception as a main determinant of "a good death." It was clear to us as observers that the physician, whom we will call Dr. Henderson, had his most profound and anxiety-laden communication with the patient during the three days it took him to get her to accept the message that she was going to die. This freighted communication stood in marked contrast to the kind but brief and distant contacts the doctor had previously had with Mrs. Bell during her examination and chemotherapy sessions. The announcement of terminality seemed to be a key performative element in the oncologist's ritual role.

This inquiry into the performed roles of oncologists has an increasing number of parallel and complementary studies in the anthropology of biomedicine. These studies, both articles and books, deal centrally with issues of communication and empowerment in the relationships among patient, physician, and supporting others (Baer 1987; DiGiacomo 1987, 1992; Fisher and Todd 1983; Good et al. 1990; Good 1991, 1993; Kleinman 1988; Romanucci-Ross et al. 1983). In this article, we address both the humane purpose behind proper communication of the terminal diagnosis--helping the patient to prepare herself spiritually and to make the best use of remaining time--and the role this communication plays in reinforcing the claim laid by the medical establishment to ritual and symbolic hegemony over the bodily processes of life and death.

Interviews with Mrs. Bell were conducted during her last month of life and with Dr. Henderson, the oncologist primarily involved in her treatment. Additional data come from intensive observation of the patient and her interactions with others during the five months between her diagnosis and her death (1), and from conversations with several people, including another physician involved in the case. Specific context for the interpretation of interview data is provided by our observer's account of a central episode--one of two hospitalizations--during Margaret Bell's illness.

The Cancer Physician's Role in Technocratic Social Drama

The cancer physician plays a key role in the social drama scripted by the interplay between the medically defined disease he diagnoses, on the one hand, and the family affected by that diagnosis and its sequelae, on the other. In cases considered terminal, he is often called upon to perform not as healer but as conductor to the other world. In the popular view, oncologists as a class are alternately celebrated for their willingness to play the part of the necessary "bad guy," the bearer of the tidings of death, and condemned for their reputed unwillingness to include the patient as part of the healing team (Buckman 1986; Henriques et al. 1980; GIVIO 1986). Some are further characterized as heartless technical automatons unable to relate humanly to patients and families or as intent on speeding the patient to an early death through self-fulfilling prophecies (Siegel 1986). Still others, however, have come, in the course of helping dying patients, to seem like compassionate and competent conductors to the world of death, performing the important role of lessening pain and fear (Good et al. 1990). Because death is so often not only the literal but also the symbolic--i.e., expected--outcome of cancer, oncologists inevitably take on roles that carry ritual as well as medical freight. A perception that Dr. Henderson's performance encompassed aspects of the role of Charon, who ferried the souls of the dead across the River Styx, occurred ineluctably to us as close observers.

This last comparison illustrates a critical point. Despite biomedicine's departure from shamanism, religious and medical practices align themselves again when an unknown such as cancer, and the fear of its outcome, is involved. Indeed, until AIDS came on the scene, cancer reigned as the most feared disease in America (Sontag 1990:16). We contend that this unity of medical and religious roles is operative for cancer doctors even where individual patients have histories of personal religious practice to help them through the period of dying. The symbolic and ritual dimensions of the cancer doctor's role thus are subjects appropriate for analysis by anthropologists. Mrs. Bell's experience illustrates the ways in which these symbolic and ritual dimensions of the physician's role can both enable the transformative process of dying and reinforce powerful tenets of the American technocratic model.

As one of us has written elsewhere, the technocratic model of life processes is an important part of the American core value

system which conceptualizes the human body as a machine, giving primary responsibility for its repair and maintenance to medical technicians (Davis-Floyd 1987, 1990, 1992). The technocratic model expresses two key dualistic organizing principles of American culture: the Cartesian separation of mind from body, and the belief (growing ever-stronger in the West from the Renaissance on) in the possibility and the benefits of human separation from and control over nature, including the body. The medical management of birth and death are key phases in the development and reinforcement of this model. For example, the rituals that enact this technocratic core value system include the medical procedures through which birth is conducted (Davis-Floyd 1992). Through powerful and expressive symbols (e.g., the IV, the electronic fetal monitor, the epidural) these rituals dramatically show the birthing woman that she is not only separate both from her baby and from her dysfunctional body-machine, but also dependent on the institution's more perfect machines to control the birth of her baby, society's product.

Likewise, a dramatic hospitalization experience focuses enormous socialization pressures on an ill, and thus liminally receptive, individual. It is instructive, then, to observe the elements of performance used by the hospital team, as led by the oncologist, in inculcating the patient with the core values of technocracy and in aligning her own perceptions and models of her illness and its meaning with those of the hospital staff. These performance elements include the "strange-making" (2), time disruption (Zerubavel 1981), and symbolic distancing of practitioner from patient usual in hospital practice (Konner 1987; Stein 1990). In this particular case, they also included other multivalent aspects of her experience such as being awakened in the middle of the night three nights in a row to be weighed, being left helpless in the bathroom until she almost fainted, being kept hungry the night of her admission because a salmonella epidemic had brought in a record number of patients all at once, and feeling obscurely persecuted by the staff for falling sick on a holiday (Thanksgiving).

Melvin Konner (1987) has written eloquently of the pressures on hospital personnel that lead to such omissions and discomforts for patients. But he also identifies such care-less practices, which often are the rule rather than the exception in American hospitals, as part of an intentional pattern of

socialization for medical students. He notes that during their journeys of initiation (residencies), students learn their roles as medical doctors from watching and imitating hospital practice--its manners perhaps as closely as its techniques. Both stem from the American core value principle of separation, as the separation of mind from body is mirrored on a larger scale by the separation of physician from patient. The messages of the relative powerlessness and dispensability of the patient are impossible to ignore.

The fact that most female patients are treated by male physicians also has symbolic repercussions. The relatively higher status of men in American society reinforces the drama of the doctor's role for a woman patient in ways that are further disempowering. In Margaret Bell's case the symbolism was particularly poignant, as she had herself aspired to be a doctor. But on the advice of a male medical school professor, in her early twenties she settled on a career in medical technology. She came rather quickly to the conclusion that medical technology was second best to the primary medical role she wanted, but then she contracted serious viral hepatitis through her technology laboratory and felt set back too much (both physically and through loss of time) to contemplate a full medical school education.

These and other aspects of Margaret Bell's history worked to ensure her profound socialization into the technocratic biomedical model, bringing her to the 1990 hospitalization with a predisposition towards a mechanistic approach to diagnosis and treatment. Nevertheless, as a result of years of working for a well-known holistically-oriented nutritionist, she had also developed strong respect for the holistic approach to healing. Where the technocratic model is based on principles of separation and mechanicity, the holistic paradigm is based on principles of interconnectedness and organicity (Davis-Floyd 1992, Chapter 4). This dichotomy set up a structural tension in Bell's own life--a tension that also structured the drama of her death. Yet in turn, this structural tension was ultimately resolved through the manner of her dying, for she partly chose, and was partly persuaded by her family, to live out her remaining weeks at home in ever-deepening connection with her family, and to die there. This resistance to the full application of the technocratic model to her illness and death (which might have resulted in the applying of "heroic

measures" in the hospital, and a lingering death hooked up to machines) led the patient and her family to feel that she had died "a good death" in spite of the disappointments encountered in treatment--a judgment with which the physician too eventually concurred.

Although her death in the end was, finally, a holistic one, along the way she very nearly chose the much more technocratic approach of retaining full control over the dying process through consciously choosing euthanasia. This consideration sheds further light on the symbolism of the oncologist's role. At one point, when euthanasia was most seriously seen as a viable option, his role as Charon seemed on the point of actualization. Although in the end he did not actually "ferry her across," it seemed clear to us that his perception of his role was informed by ancient models transmitted to him through centuries of Western literature and art and subtly codified in medical school pedagogy regarding the treatment of dying patients. There was an old, sure inevitability about the dramatic performance by this young doctor that went far beyond his physical treatment of the illness. Exploring how these ancient models were used in the service of modern American values will be a primary thematic concern of our article.

We will also ask how symbolic analysis can point the way to dynamic new uses of the power of symbol and drama. We suggest that medical paradigms may actually be challenged by restructuring performative models. This is in fact the sort of challenge to the medical establishment presented by contemporary holistic healing philosophy and practice. Holistically oriented medical practitioners and writers like Norman Cousins (1979, 1989), Bernie Siegel (1986), and Simonton et al. (1980), emphasize empowerment of the patient; the social support of friends and family; and good communication among doctor, patient, nursing staff, and religious practitioners. Most significantly, these writers promote dramatic visualization and relaxation techniques to enhance mind-body integration and redefine negative expectations positively. Though few such practitioners are anthropologically sophisticated, what they advocate amounts to a return to concepts of traditional healing and shamanism in which religious and medical healing work is united by

practitioner and ceremony and the healing energy is readily available to all participants (Katz 1982).(3)

Case Study: A Central Episode in the Drama of One Death

Margaret Bell was born in 1919 and grew up in a family that encouraged and enabled her to pursue a college and post-graduate level of education. But the value placed on her education, although high, was not as high as that placed on the education and careers of her brothers. This discrepant valuation was consistent with American historical forces during her formative decades, and is unremarkable except that her family did transcend the general ethos by allowing her to attend a university and work away from home. Her medical career was similarly unremarkable for a woman at that time: having been channelled into medical technology by a professor's remark, the commitment of time she had made to that career would most probably have kept her from full-scale medical education even had she not contracted hepatitis.

Notwithstanding her professional marginalization, Bell was active in the early work on the Rh factor in blood ("A technician walking the rhesus monkeys," she used to fume) and for many decades in the biochemistry of nutrition, she worked hand in hand with physicians and nationally known researchers on the discovery and testing of new vitamins and nutritional therapies. Her academic and career experience on the sidelines of male achievements led her into active promotion of "continuing education for women," before the advent of Betty Friedan and the women's movement. Her three daughters report that, due to their mother's example, they were privileged to experience not a moment's worry over whether their own academic and career aspirations were as worthwhile as any man's. Until her cancer diagnosis at age 70, Margaret Bell still worked every day in a groundbreaking nutritional therapy clinic associated with a biochemical research unit in a major university.

As anthropologist Susan DiGiacomo, herself a cancer patient, has noted:

Biomedicine as commonly practiced in the U.S. simultaneously individualizes its treatment of disease symptoms and routinizes dealings with the

patient, so that the afflicted person is transformed from an integrated and fully functioning adult to a collection of diseased body parts. Further, biomedical opinion holds that sick people are less than fully competent adults simply by virtue of being physically unwell. The first difficulty of the patient, then, is not getting a fair hearing for his or her point of view concerning the illness and its treatment; it is getting the doctor to recognize that the patient, has, in fact, a point of view at all... Thus, from the outset, the afflicted person is required to accept a reduced and defective patient self constructed for him or her by the doctor (1988:4).

Accordingly, when Margaret Bell became a patient, her lifetime involvement in medical science and therapy was suddenly of no consequence to the decision-making associated with her treatment. She was immediately demoted to passive status by the hierarchically structured routines and rituals of her first oncologist's practice (he was later dismissed by Bell and her family in favor of Dr. Henderson). Moreover, in spite of Bell's desire to try it, this first cancer doctor refused to consider the relatively new interferon therapy as an adjunct to chemotherapy in Bell's case (surgery and radiation had previously been ruled out).

Mrs. Bell's husband, Dr. James Bell, taught cell biology and had done pioneering research in cancer chemotherapy and electron microscopy early in his career, yet he was similarly sidelined by the ritual unapproachability and unquestionable aura of authority with which the first doctor surrounded himself. Sidelined and passive they remained during the first frightening weeks after Mrs. Bell's diagnosis until their eldest daughter arrived home. Strongly oriented towards a holistic philosophy and a feminist stance, this daughter immediately began to push for better communication with the physician, and soon Mr. and Mrs. Bell began to feel as if they had a right to be included on the healing team. At that time, through the help of a close friend, the family contacted Dr. Henderson, who agreed after evaluation to provide a new combination therapy of chemotherapy and experimental interferon on a twice-weekly basis--a treatment that was being successfully used in another city by a colleague of Henderson's on cases like Bell's. This colleague, whom we call Dr. Abdul, had also evaluated

Margaret Bell and was glad she was able to find a physician in her own town to administer the treatment.

Bell and her family settled into a routine of chemotherapy ups and downs with the familiar good and bad appetite days of the week. The mood for some time was very positive, as Bell was absolutely determined to combine excellent nutrition, exercise, and positive visualization techniques to help her body and mind work together to fight her cancer. She was surrounded by an extremely supportive group of friends and family. Her primary caregivers soon welded themselves into an efficient team, working hard to leave no stone unturned in investigating the latest research about colon and liver cancer, preparing nutritious meals, ensuring the patient's rest and comfort, and providing both diversion and loving concern. And for several months the medical news was positive, as Margaret responded well to the combined therapy and did not experience undue discomfort. This scenario seemed to all concerned to be a healthy blend of the biomedical and holistic approaches, with each complementing and working to enhance the positive effects of the other.

Sometime in October, however, the side effects of chemotherapy began to take their toll. Also, the indicators of tumor activity reversed their hopeful downward trend and began to rise again. Although Margaret pursued her program of daily swimming and walking, and although each meal was carefully planned and prepared by her family, her health began to go downhill. By the end of November she became dehydrated from uncontrollable diarrhea, and, at the family's suggestion, with which Dr. Henderson concurred, she entered the hospital to have her fluid balance corrected. She was admitted on her 71st birthday, November 20, 1990, just before Dr. Henderson left town on his Thanksgiving holiday.

When admitted, Margaret assumed she would be in the hospital for a few days and then resume her program of combined interferon and chemotherapy. As it turned out, she had an exhausting ten-day struggle in the hospital to regain physical equilibrium. This struggle was not made easier by the fact that for the first crucial days she was seen exclusively by medical students and doctors unfamiliar with her history. Also, it became clear through routine tests that an incipient diabetic condition was beginning to give trouble, and insulin was

started. It took some time for the dosage to be regularized, and during this period Margaret's weakness and instability dictated that she remain in the hospital.

After her first night, which taught her and her family that she needed more constant care than could be provided by the nursing staff, her daughters took turns sleeping on the floor, so that they could help her to the bathroom, make sure she was comfortable, and run interference when there were unreasonable staff interruptions of her sleep, such as the 3 A.M. weighing sessions. (As Zerubavel (1981) has demonstrated, time in the hospital is organized to fit the needs of the staff, not the patient.) There were also difficulties with her IV line which made her family feel that she needed more than ordinary supervision.

Many of the interruptions took the form of what seemed to the family to be a kind of "hazing" of Mrs. Bell as a patient. For example, a male nurse exhibited total disregard for the pain of a chemotherapy rash on her hands, grasping them roughly after she had begged him not to, saying "Of course it doesn't hurt!" The rapid turnover of staff, which meant that each new nurse who came on the ward had to be familiarized with her weaknesses and special needs, gave her and her family a profoundly uneasy feeling that it was "us against the world" of the hospital. Some nurses seemed friendly and compassionate, but more were bored, indifferent, condescending, and even hostile. Especially upsetting was the sense the patient felt of being punished for having "difficult veins." Every time one of the nurses had a hard time replacing the IV line, an expert was called in who brooked no failures and whose very stance bristled with disapproval and censure. A huge woman known to the family as "the IV nurse from hell," she struck terror into the hearts of all, looming as a truly frightening possibility every time a change in IV had to be made.

Socially, Mrs. Bell's hospital stay was all that could be desired. She was never left alone for more than a few minutes, and when she was napping there was a vigilant family member on guard outside her door to request visitors to come back another time. When awake and feeling well enough, she gladly received many visitors, as well as a wallful of cards and a roomful of flowers and gifts. Though she realized she had had a serious setback, she assumed that she was on track with her

original plan of treatment, and was determined to keep right on listening to her visualization tapes, reading Bernie Siegel, taping her memories for her daughters, making lists of gifts to give at Christmas, and anticipating how good it would be to get back to home cooking after the boring hospital food. She greatly enjoyed visiting with her daughters, who clearly had all inherited their mother's ability to see humor in adversity. By the time Thanksgiving was over, her room was quite the party place on the oncology wing.

Thus it came as a shock to hear from Dr. Henderson on Monday when he returned from his holiday that there would be no more treatment. After examining her and reading her charts, he told Margaret without preamble that "resistance had developed," that she couldn't handle the treatment, and that there was nothing else known that could help her.

This was Act I in a dramatic three-day attempt to get Mrs. Bell to accept the "fact," as Dr. Henderson saw it, that she was going to die. On this first day, the stage as one of us (Biesele) observed it was set as follows: the eldest daughter sat on the window ledge at her mother's bedside. The doctor sat slumped in a chair in the furthest corner of the room, his posture suggesting both earnestness and a lack of ease. Mrs. Bell and her daughter became suddenly anxious, both because they had waited six tension-filled days for this particular doctor to answer some questions about acute problems that had developed in the hospital, and because this was the first time in their three-month association with him that they could remember him actually sitting down with them. (His earlier talks had been careful and calm, not lacking in communicative mutuality, but he had conducted them on his feet, while examining Mrs. Bell on a raised table, for instance, or passing by in the hall while his nurse administered chemotherapy.)

After briefly discussing her blood sugar and dehydration problems, Dr. Henderson said that Margaret Bell was "in a terminal phase." He said that she would be getting no more chemotherapy because of the resistance, as seen in the elevated CEA level (a blood indicator of tumor activity) and on the CT scan, which revealed no appreciable shrinkage of tumors. Mrs. Bell drew herself up with what dignity she could muster, and said that she accepted the diagnosis but did not consider herself "terminal." She said that she was still fighting.

The daughter by her own admission was "glaring" at the doctor and silently applauding her mother's spirited answer. Mrs. Bell then asked the doctor, with a sourness quite uncharacteristic of her, whether he thought nutrition could play a role in healing. The unwillingness of the medical profession to consider nutritional approaches had been a long-time sore topic with her both professionally and personally, so when Dr. Henderson answered with the single word "No," the atmosphere became very quiet--and very charged. Mrs. Bell said, "Then that's all I have to say to you for now," and Dr. Henderson stood and went out the door.

Early the following morning he returned for Act II. He seemed more rested than the previous day and quite energetic, like a person who knows he has a job to do and feels equal to the task. He said clearly that she was "terminal, and that isn't necessarily bad. One can prepare oneself for death." Mrs. Bell's response surprised even her daughter, who (though she had long ago thrown in her lot with the self-healing philosophies and had been listening to the personal empowerment tapes right along with her mother) thought that by now the diagnosis of terminality was quite clear. "What I want to know," said Mrs. Bell, "is how are you and Dr. Abdul going to build me up so I can continue chemotherapy?" Dr. Henderson appeared to realize at that point that Mrs. Bell and at least some of her family were still reacting at that point with denial, and he just left it. Indeed, her daughter said that "It was as if she had not heard what he said." Before he left the room, Mrs. Bell requested a look at the CT scan taken a few days earlier and the addition of a vitamin C infusion to her IV bottle. Dr. Henderson quietly agreed to both requests and departed.

Later that day, when Dr. James Bell was sitting with his wife, Dr. Henderson returned with the CT scan of her abdomen. In technocratic diagnosis, the CT scan, as external, "objective" evidence obtained by tests and machines, constitutes a defining source of "authoritative knowledge" (Jordan and Irwin 1990), that is, knowledge that forms the basis for decisions made and actions taken. It was apparent that the liver was largely taken over by tumors. The nursing staff did add an ascorbic acid solution to the IV, though at a much lower percentage than that recommended by Mrs. Bell's nutritional therapy colleagues. Mrs. Bell spent a quiet afternoon listening to her husband read to her: her eyes were bothering her and

reading was difficult, though it never had been before. She seemed untroubled by this annoyance.

Meanwhile, the family "cheering squad" (as they called themselves) went into action and rallied around the telephone checking out every possible lead. Much of the activity centered around the question of whether Dr. Abdul in the neighboring city concurred with Dr. Henderson's assessment of "resistance." When at last it was ascertained that he did, and had in fact already told Dr. Henderson that further treatment seemed counterindicated, Mrs. Bell's daughters began to confront for the first time the probable reality that their mother was going to die. This is how the stage was set as Dr. Henderson and Mrs. Bell went into the last act in their joint drama: acceptance of terminal status by the patient.

Early on Wednesday morning, when Mrs. Bell's middle daughter was with her, Dr. Henderson came back a third time. Mrs. Bell asked him what treatments she would be getting when she got out of the hospital. The question was in the context of possibly continuing Vitamin C infusions via a periodic IV drip. He said, "I'm not recommending any. It's important for you to not just keep trying quackery but to think about your death." Margaret then said, "Oh, so you're saying I'm really terminal?" Dr. Henderson replied, "You've been terminal since you got your diagnosis in July."

Later the middle daughter encountered Dr. Henderson in the hall, and said "She's finally accepted it." He said, "I was beginning to get worried."

On the afternoon of the same day, when the eldest daughter was with her mother, Dr. Henderson again came in and repeated for a fourth time that she was terminal. It was as if he needed to reassure himself that she had indeed accepted her status. And perhaps he also wanted to make sure that the eldest daughter, who had been the primary caregiver, had, like her sister, accepted it too. To this eldest daughter, it seemed as though her mother was behaving as if she were receiving the news for the first time. When the doctor left, Mrs. Bell said, "I wish he'd told me before, so I could have gotten my study in order." The daughter, who later said that leaving a chaotic study behind after her own death had always been an uneasy thought, began to feel guilty for her own part in promoting--

perhaps overpromoting--the stance of positive resistance to a grim prognosis. Had she robbed her mother of enough time to put her affairs in order? If the doctor had "known" her mother was terminal ever since her diagnosis, had her own positivism kept him from informing the family until now?

Yet the family remained open, even after that third day, to any desire Mrs. Bell expressed to try alternative therapies in keeping with her nutritional convictions. Dr. Bell and the eldest daughter made an appointment with Dr. Henderson on Thursday morning, largely for the purpose of obtaining his blessing on such alternative therapies. He agreed readily, but repeated that she was terminal and all that was realistically left as an option was "symptom management." The daughter asked whether great pain was to be expected or rather a quiet death from liver failure. Dr. Henderson said the latter, and that it would be relatively "comfortable."

Finally Mrs. Bell's condition stabilized and she asked to end her ten-day hospital stay and go home. In the days that followed her discharge from the hospital her family continued to strive to balance her diet and regime of care with her ever-more-complex physiological needs. She went by car and wheelchair to the one doctor in town who would agree to provide the high concentration of Vitamin C infusions she wanted to try. These infusions, along with the soothing atmosphere of this "New Age" doctor's clinic, had a restful and apparently cleansing effect on Mrs. Bell's state of mind and body. But by about mid-December even this doctor was unable to find a vein capable of holding a needle, and he suggested that it would be best to "take a rest and come back after Christmas." This news was received gravely by the whole family. Mrs. Bell began another alternative therapy she learned of through the nutrition clinic, one she could take at home orally, but this time she seemed to act without conviction. In the oral history her daughters had been recording for some months there suddenly appeared the motif of acceptance of death.

At this time, one of us (Davis-Floyd) asked to move beyond the observer's role, to formally interview Mrs. Bell about her current experience. This interview turned out to be decisive. With her main caregiver, her eldest daughter, absent, Mrs. Bell was able to speak without hesitation about her readiness to die. She spoke of having no fear of death, only of the messiness

of dying and the burden she was putting on her family. Reaching over and emphatically tapping the anthropologist's tape recorder, she said repeatedly "If I could, I would just push this button and turn myself off." She confessed that she was only continuing with the latest alternative nutritional treatment to please her family and her community of holistically-oriented friends. After saying this in an interview, she found the courage to say it to her friends and family as well. (As the anthropologist left, teary-eyed, the eldest daughter asked her at the door, "Are you telling me it's time to stop cheerleading?" and the anthropologist answered "Yes.")

Sometime between her discharge on December 2 and the interview on December 21, Margaret Bell had completed the process of cognitive restructuring that accompanies all lasting major perceptual shifts (d'Aquili et al. 1979; Laughlin et al. 1990); in other words, her cognitive system had reconstellated around the diagnosis of terminality. (When asked in the interview what were the deciding factors in this process, she answered that it was the combination of seeing the CT scan and the many repetitions by the doctor that she was terminal.) In the days following the interview, her behavior consistently expressed the thoroughness of this process of cognitive restructuring. Her clear-eyed acceptance of death's inevitability enabled her family too to relax into the next phase. Said one family member, "It was as if the whole house stopped fighting and gave a sigh of relief."

The routines of care did not cease, but they were carried out under a different aegis, that of easing a loved one the best way possible into another life. Norman Cousins died at this time, and though they found that "very sad," it did not cause the family the consternation it might have a month before. No longer was Bernie Siegel read in the house; his new videotape arrived and remained unopened. Instead, family members took turns reading from books about near-death experiences and what they can teach us about "the other side." Mrs. Bell found it soothing to hear this sort of thing read to her before she napped.

The oral history was completed with all that she found important, and was transcribed by a family friend. The rituals of Christmastime, particularly caroling and church music, were brought to the house by the choir in which Mrs. Bell had sung

for twenty years. Mrs. Bell talked more and more often of the plans for her memorial service, and Christmas music figured prominently in them.

At this time too, Mrs. Bell told her eldest daughter, and some of her friends, of her interest in euthanasia. She had a conviction of its rightness in "hopeless cases" (her words) like her own, and even a vision of its aesthetic potential. She spoke about this with conviction with the clergyman she had chosen to conduct her memorial service. In general, people were awed but respectful of her views. Shortly before Christmas a good friend close to medical networks made the family aware that Dr. Henderson himself was not unwilling to discuss the matter. Mrs. Bell made an appointment to see him, saying that she had just enough strength to leave her house one more time.

In the end, after this consultation, family debates, and a pivotal conversation with a compassionate woman doctor/friend, Mrs. Bell's decision was made in favor of her family's peace of mind and legal safety. But she had made her convictions fearlessly known. And through the discourse surrounding this decision she finally came to terms with allowing herself to be taken care of to the end, at home, by her family (who firmly desired that). Throughout, she insisted that heroic measures never be taken on her behalf and had filed a "Durable Power of Attorney for Medical Care" under Texas law with her lawyer and her physician. Her desires were honored, and after last visits from virtually everyone she wanted to see, she died peacefully at home on Jan. 1 with her eldest daughter by her side.

But the debate about euthanasia nevertheless illuminated the symbolism of choice and empowerment involved in the dying process. Margaret Bell had resisted her dismal and eventually terminal prognosis stoutly. Only twice during the difficult five months she lived after her diagnosis did she give in to brief expressions of dismay when anyone else was around. She took just as positive an orientation toward her death once she had accepted its inevitability:

It's that I'm a realist, and I know enough about what the body does under different circumstances to be able to see myself going down day by day, in the strength department and in every department--my

eyes are really bad...I'm a realist, and I call things as I see them.

Partly this attitude was connected with Mrs. Bell's unstoppable research orientation. She was interested in monitoring her condition up to the last in order to understand it, even to the final phases of systemic breakdown. She said that she found the ways in which her vision was distorted at the end, for instance, "captivating to watch. It doesn't bother me that I can't read any more." The existence of the euthanasia option, she said, means that one doesn't have to be afraid of carrying this learning process so far that one's quality of life becomes intolerable.

Dr. Henderson and Mrs. Bell:

A Contrapuntal Dialectic Between Philosophy and Performance

In a telephone conversation with Mrs. Bell's eldest daughter after the last office visit, Dr. Henderson opened the topic of his own understanding of Mrs. Bell's views on euthanasia by saying, "I know what she wants--she wants to exit stage right." The performative reference of this statement, combined with the discovery that Dr. Henderson was working toward a doctorate in philosophy in order to pursue a strong academic interest in the ethics of euthanasia, led us to request a formal interview with Dr. Henderson.

The interview was conducted a week after Mrs. Bell's death. Early on, Dr. Henderson had remarked, "Dying is not something that happens to you. It is still something you can participate in." It quickly became clear that Dr. Henderson was committed to the social support of the dying in a profound way, and that he found his own niche as a cancer doctor to be just there, defining the limits of science clearly so that patients could prepare themselves for their deaths by completing their connections with life. What galvanized him was practicing "medicine," which for him included taking full responsibility for "taking care of them until they die" as opposed to surgery, which he said was "just slice-of-time oriented....where you do not have to take care of the whole patient, where you are

either successful or not in that limited slice of time. It does not seem to be as rewarding."

He said that medicine, as opposed to surgery (4), "should be good at knowing when the battle is lost and you need to change directions and provide some comfort....It is trying to do everything you can and still be the court of last resort for a lot of people." A period of practice in a small Mennonite community had helped form his outlook in this regard: he characterized it as a community with "no loss of connection....The diagnosis of cancer was a signal that someone needed to be taken care of and hardly anyone went out of this little community to be taken care of." He went on to say that had he been in a big city he would have continued in academic medicine--doing hematologic cancer protocols, etc. "But I don't think I would have been as satisfied as I could be now because academic communities are so disjointed from the community of the patient that you can't provide total care. All you can do is provide heroic care." He preferred, he said, that there be "some look over the long term even if it's only a couple of weeks. I'm not here to say well, I have nothing to offer you and you need to go someplace else." It was clear that the "long-term look" and "total care" meant for this doctor something different from what such terms might mean coming from a family pediatrician, for example. They had a great deal to do with mediation of the dying process once curative medicine had reached acknowledged limits. In Mrs. Bell's case it was clear from the way Dr. Henderson went into action at the time of his announcement of the diagnosis of terminality that his sense of his role was centered just there--an observation confirmed by his own words in the later interview:

What the patient's whole life is has a lot to do with how they are going to live the rest of their life. Some will be satisfied with facing the end of treatment and some won't. They will want to do other things....The greater likelihood a patient has of being cured the more adamant I am about trying to get them to take chemotherapy. But if there is no cure rate we are really just talking about quality.

Dying is an event we all have to go through and it seems to me you are shortchanged if you don't [have the chance to] do the things you would regret

not doing if you didn't know about it... You look at what you have to leave people. And that is all you can do. You leave something. You leave whatever you do through your connections....

So, I do believe a lot can be made of the death. It can be a good death. [But in our culture] it has been hidden. It has been suppressed by medicine. Medicine has held out a hope that has been unrealistic....People still die...too often in the hospital, too often not aware of what has happened to them. And they are older, and separated from their families. It's partly medicine and it's partly society.

Asked how he thought modern physicians--particularly oncologists--might help alleviate this problem in the social dimension of dying, Dr. Henderson said, "You have to develop some kind of philosophy that allows you to...get into somebody's life, to participate in someone's life...". But he went quickly into the difficulties this approach involves for physicians:

There are certain penalties you have to pay for being connected. One of them is that you will have feelings for a person, whatever happens to them. On balance that is okay...but it's just not easy sometimes. I can't see not doing this but I can see doing less of it. It is where I keep contact with what happens. I'm not sure it's a strength. It's just something I do....The greatest amount of suffering in someone's life may occur toward the end of that life so there is a need. And filling that need is what I feel fairly comfortable with. It's a good sense, you know. You get reinforced every now and then. We have had people who have had good deaths and we have participated in that to some degree. I think people's lives are better for that--it's just not as dramatic or visible as getting your appendix out. So there is reinforcement. There is a commitment to helping people at that time in their lives.

When asked about the limits he had to set in order to keep on doing this difficult thing, he responded that the main limit was

an adherence to scientific facts. He named these same scientific limits as a source of occasional escape from the personal emotional pressures of oncology. He called clinical medicine

a detective game requiring...understanding of the whole patient....I took a hematology/oncology rotation when I was a senior medical student. I don't know why I was particularly struck by it except that it was exciting medicine. You could make diagnoses right away just by looking at blood films....Hemologic malignancies: it's intellectually challenging. There are obscure diseases like certain kinds of anemias--interesting. Sickle cell disease is the best-defined genetic disease there is...So that is scientifically pure to some degree. Some of the hereditary anemias and some of the clotting disorders are almost pure science. You can see a defect and you know what the molecular effect is and you can follow it all the way up to what happens on the physiological level. So that's fun and is a good foil for some of this other stuff. A relief. I enjoy it and it's fairly simple. There are some sophisticated tests you can do but still you don't always need an NMI scan. You can just look at the blood and take a person's history and physical exam, so it fits together well for me. However, a lot of the hemologic diseases are fatal.

At almost every point in the interview, as here, the narrative arrows, returning, pointed toward death. As this was clearly a focal point in Dr. Henderson's perception of his role, we asked how his medical school training had prepared him to handle it. He answered that in medical school "it's not as intense since you are not the one who is primarily responsible....Now I find since I am primarily responsible for patients that it has become difficult, an emotional effort, to help people die." The age limit he placed on his practice was born of hard experience with himself: "I couldn't stand to see kids die. I couldn't stand to deal with their parents. It was just overwhelming--it was just too much for me. I just couldn't stand to see children who were terribly disfigured and disabled, probably because I didn't know enough."

He also admitted limitations in the area of interacting with patients, speaking admiringly of "Sandie," the nurse who administered chemotherapy in his clinic. "She's wonderful. She is a buffer for me: she has much more physical contact with the patients." He surprised us by saying he had found her by placing a personal ad for a cancer clinic nurse. Sandie seemed a highly approachable pillar of human strength, performing routine chores and tests with the outpatients which clearly would have taxed Dr. Henderson beyond his specialist's role. She "ran interference" with a vengeance, making it virtually unnecessary for Dr. Henderson to have contact with patients or families as often as was usually necessary during the course of chemotherapy. We talked with her and found that she connected her own ability to do what she did with her experience in taking care of a father who died of cancer.

In a recent study of American oncologists, Good et al. (1990) find that these oncologists perceive themselves as mandated "to instill and maintain hope." In contrast, in Margaret Bell's case, both Sandie and Dr. Henderson seemed to have developed into professional hope-withholders. They worked in structural symmetry: Dr. Henderson ran interference for her (as she for him) by acting out his role as the scientific arbiter for treatment decisions. However, he was somewhat "unavailable" (at least on Mrs. Bell's twice-weekly session basis) to discuss the case as it progressed. Sandie herself could be asked questions at each session, but the answers took time to come back, as most of them had to go through Dr. Henderson. By the time the answers did come back, the original impetus for the question had often faded and the emotional charge lessened, making Sandie's "patient contact" less trying for her than it might otherwise have been.

Meanwhile, Sandie performed the maintenance and treatment tasks routinely, and this in itself was patient therapy, as it at least acknowledged the ongoing physical needs of the patient. The performance aspects of Sandie's job made it highly didactic: her kind but businesslike demeanor conveyed, more clearly than words could, what kind of job she saw herself engaged in. It was, like Dr. Henderson's job, one of facilitating dying more often than fostering life. She silently taught the patient and family what their job was too.

Sandie's lesson at first was not easily absorbed by the Bells. Mrs. Bell was distressed that she was not able to discuss with Sandie or Dr. Henderson the holistic healing philosophy that was animating a whole other side of her self in her struggle against her disease. She and her family were shaken by the realization that in the entire oncology profession of their large city they had been able to discover only this single young doctor willing to administer an experimental treatment combination, but that even he stopped short of enthusiasm for "mind-made health." They were uneasy with the split between home, where one could take a hand in one's own healing, and clinic, where one could not. It wasn't that their holistic views were overtly denigrated in the clinic, but rather that the atmosphere at the clinic allowed them no conversational room to even bring up the philosophies of Bernie Siegel and Norman Cousins.

Characteristic features of biomedicine as described by a number of social scientists include a hierarchical physician-patient relationship in which the physician protectively contains his authoritative knowledge within the community of biomedical practitioners, doling out small pieces of information to the patient while maintaining a general unwillingness to share this knowledge and information (Fisher and Todd 1983; Jordan and Irwin 1990; Klein 1979; Lyng 1990). Susan DiGiacomo (1987) poignantly describes her five-year struggle not only with Hodgkins Disease but also with the resistance her physicians demonstrated toward keeping her fully informed. An anthropologist and PhD candidate at the time of her initial diagnosis, she desired a collegial relationship with her physicians in which knowledge and information would be shared and treatment decisions mutually decided upon, while they sought to enforce a strict hierarchy in which she would follow the treatments they prescribed without asking too many questions. So pervasive is this approach in biomedicine that Stephen Lyng, in envisioning an ideal "countersystem," suggests that in such a system, "the practitioner's primary role would be educational, while the patient would assume primary responsibility for selecting a diagnosis and treatment regimen from among the various alternatives presented" (1990:61).

Like DiGiacomo, throughout the course of her illness Mrs. Bell keenly felt the disjuncture between the technocratic approach to healing and her own. This sense of disjuncture was

intensified by her personal lifetime commitment to the idea of nutritional support for the immune system. She had doubts throughout the course of chemotherapy about whether she could fruitfully discuss nutrition with either her doctor or her nurse, doubts that were finally confirmed in the hospital during the dramatic announcement of terminality. The question she blurted out, "Do you believe that nutrition can play a role in healing?" was one she had been longing to ask for months, as the answer would precisely define the limits of their system of shared beliefs. Dr. Henderson's flat "No" cemented the disjuncture, making impossible any kind of conceptual reconciliation between Margaret Bell's own beliefs and those of the medical personnel treating her, ultimately augmenting her sense of hopelessness.

In other words, although Mrs. Bell and her family continued to pay every good attention to her diet, the sense of dissonance created by the total devaluation of this practice by the medical profession intensified her alienation from a part of herself. In Kleinman's (1988) terms, this situation constitutes a failure of conversation, a failure of the healer to empathetically enter into the patient's own discourse concerning her lived experience:

Of all the tradecraft of the physician, nothing more effectively empowers patients. The very act of negotiation, if it is genuine....necessitates that at the very least the physician show respect for the patient's point of view. The real challenge is for the physician to engage in negotiation with the patient as colleagues involved in care as collaboration. The practitioner begins this phase of care by elaborating an explicit comparison between the lay model and the professional biomedical model. The physician can determine points of disagreement....he must be prepared to hear out their criticisms....he must expose his uncertainty and the limits of his understanding, as well as his critical reaction to relevant popular and commercial images....The negotiation may end up in a compromise closer to the patient's position, a compromise closer to the doctor's position, or a joint lesson in demystifying professional and public discourse. (Kleinman 1988:243)

Such a joint lesson in demystification was precisely what Bell was longing for. The psychological trauma of her illness experience stemmed from the ultimate and total lack of this kind of mutual negotiation, which she experienced as an extreme philosophical tension and an ultimate putdown--a powerful argument in support of Kleinman's conversation-centered approach to healing.

It was not until after Mrs. Bell's death that anyone involved in the process was to hear Dr. Henderson speak the word "holistic." During our interview with him, Dr. Henderson spoke favorably of humanizing trends in medicine's approach to death stemming from the hospice movement and a "network of holistic medicine." Yet two of his main judgments about holistic medicine were decidedly negative:

If you ask, "Do these [alternative treatments] have a function for the patient?" the answer is that they do. They provide a level of proof that no matter what they do this disease is not going to go away....One study in the New England Journal of Medicine showed that non-traditional and traditional treatments had the same success rates. The proof is...the lack of effectiveness, the fact that they are going to die...It is a proof of mortality, basically, and there is nothing we have that will rescue them from it. (5)

At one point in the interview, Henderson added,

I think people do get the idea that what [Siegel] is saying is that if you can think about it you will get better, if you will it enough, when in fact this is not the case. In fact, that gives even the wrong meaning in that you end up with patients who blame themselves for their disease, which is just entirely wrong. (6)

This potential for creating guilt in patients, he said, together with holistic healing's mindless positivism (which he characterized as "ice cream sundaes") obscures the real message:

What Siegel is saying is that whether you have a diagnosis of a cancer or not, that should not keep you from living your life. There are still things to do, and [you] may be able to tune into the connections you do have. Relationships are still important, maybe more important....[And Siegel] is emphasizing the emotional content by shaving his head to be sympathetic with those patients having chemotherapy, hugging his patients, and being in contact, sharing their feelings.

There was a certain wistfulness detectable in Dr. Henderson's acknowledgment of his own very different orientation to patient treatment, as he noted, "I haven't come to that point...I just recommend hairpieces instead."

This acknowledgment points up the structural tension in Dr. Henderson's own working philosophy--fascinatingly, the same tension that structured Margaret Bell's experience of illness and death. In his own words, he values connectedness and seeks for patients to be connected with both their families and himself. Yet his orientation to diagnosis, treatment, and interaction with patients is highly technocratic; his words express, and his behavior enacts, a more-deeply held valuation of distance and separation. The pure science of complex tests is "fun," "a relief" from the strain of human commitment. And although Dr. Henderson verbally expresses human commitment both to patients and their families and in professional writings and talks, he does not physically enact this commitment through companionship, or conversation, or head-shaving, or loving touch. In other words, he does not engage patients in two-way explorations of the experience or meanings of their illnesses.

In this, he is not alone. As Arthur Kleinman notes in [The Illness Narratives](#), at the heart of healing lies the potential for a powerful dialectic that can draw the practitioner into the patient's experience and so can make of illness and treatment a rare opportunity for moral education. But instead, the modern medical care system

does just about everything to drive the practitioner's attention away from the experience of illness. The system thereby contributes importantly to the

alienation of the chronically ill from their professional care givers and, paradoxically, to the relinquishment by the practitioner of that aspect of the healer's art that is most ancient, most powerful, and most existentially rewarding. (1986:xiv)

Charon's Discourse:

A Conversation-Centered Approach to the Issue of Euthanasia

Participation in dying through consciously living the last months or days of life seemed a cornerstone of Dr. Henderson's philosophy, whether he was referring to his own or to more holistic approaches. It was of a piece with his attitude toward euthanasia, though this attitude was far from simple or completed in his mind. "Euthanasia is interesting," he began. "Euthanasia is a good death, bringing about a good death. That's what we do." He went on to explain the legal constraints and ultimately to illuminate through his own ambivalent musings the moral confusions that keep most doctors from active involvement with what they may humanely believe in:

I think the difference between passive and active is artificial. I don't know if you know what they generally consider the distinctions....Actively agreeing about somebody's death is allowed if you meet certain criteria. Actually it's done much more sub rosa than you might consider. If you meet certain criteria of intractable suffering and a terminal disease, then a physician under certain circumstances is allowed to end that patient's life. We are [legally] allowed to do that [in the U.S.]. We also have something called passive euthanasia which is if death is inevitable and you are taking steps to relieve suffering and that speeds up the time of death, then that is okay...[But] if you look at intent, then there is no difference between passive and active euthanasia.

I have a lot of difficulty with killing patients, ending suffering by putting the patient to death, mostly because I don't think the patient is likely to be suffering if his other aspects of medical care are

handled properly. Another issue in a good death is whether timing is important. To my way of thinking, timing isn't that important, that a physician should participate in hastening a patient's death....It's important to the patient not to be a burden any more. You have fulfilled all your obligations, you've taken care of all your connections, life is not going to be worth a damn any more...and it's time to check out. That's not metaphysical. That is very much tied into what that person is, and that is assisted suicide, [an act that] is for convenience and I'm not willing to do that...Whether society should say at some point that a patient has a right to do that is probably something I would not object to, but that has to be a societal decision...not a medical decision....I think there is something about the separation between medicine and society that has to continue.

These and other considerations were in the background of Dr. Henderson's interaction with Margaret Bell in the final days before Christmas, 1990, when she made the appointment to discuss euthanasia with him. At that time he did not make these issues clear either to the patient or to her family, partly because another physician came on stage at this moment. A compassionate woman doctor, whom we will call Ann Walker, was a colleague of Dr. Henderson's and thought very highly of him. She offered to discuss the issue of euthanasia and the practical problems involved with the family at home after Mrs. Bell had expressed her views to Dr. Henderson at the clinic. Dr. Henderson appeared happy to have Dr. Walker take on this chore. In the absence of full information at that time regarding his views on euthanasia, the family assumed that Dr. Henderson was taking the easy way out to protect himself legally. This assumption was reinforced by Ann Walker's surprisingly ready acknowledgment that she knew she was being "used" in this way; however, she pointed out, she didn't care, as she had her own strong convictions about patients' rights.

When Ann arrived on December 22 to talk to Dr. Bell and his eldest daughter, her words hit them "like a bolt of lightning." She was compassionate and caring, but this was "the most intense family learning experience we had ever had." The eldest daughter woke up very quickly to the fact that the

practical details of her mother's intention were far from easy and that they would not, as she had assumed, be carried out by a physician or a nurse, as Mrs. Bell was no longer hospitalized and was choosing to die at home. They would become the responsibility of the family, but as primary caregiver, she herself would have to carry them out. Even more astonished was Dr. Bell's response, "Are we actually talking here about shortening her life?"

Swiftly it became apparent that Dr. Bell either had not been given or had not taken in the implications of Dr. Walker's visit. Just as swiftly he reacted with a perspective that had not been considered by the eldest daughter--the legal liability that could become a problem for family members. A recent case was in the news about a man who received a life sentence for helping his wife, who was suffering from AIDS, die. Dr. Walker explained her view that one way to resolve all this was to reassure Mrs. Bell that her natural course of death at home, no matter how long it took, would be no burden but rather a blessing in the eyes of her caregivers. Perhaps, she suggested, Mrs. Bell could perform this final act of trust in the love of her family. She also implied, but did not state, that Mrs. Bell's decision would be based as well on compassion for the difficulty a family member would find in actually physically assisting a beloved one to die. Enacting her stated high value on connection and patient empowerment, Dr. Walker hugged both husband and daughter as she left; she also left them with a prescription for morphine sufficient not only to ease pain but to cause death.

The turning point in this family drama came the next day when the eldest daughter was able to convey the substance of Dr. Walker's visit to her mother. She did so in the context of a simultaneous illumination she was having about the necessity of her seeing the processes of caregiving through, for purposes of her own growth:

I explained to my mother that I was experiencing the completion of our bonding by taking care of her as she died, and in so doing was eliminating a lifelong sense of incompleteness. I asked my mother to trust my desire to care for her to the end at home. I said that either of the other alternatives--giving her over to hospital care or helping to hasten her

death--would be much harder for me personally than seeing it straight through.

She spoke of her own concern that since death is "the final stage of growth," there may be some reason for not hurrying that process. Mrs. Bell's final protest was that she was afraid her daughter's back would be hurt: "You will not be able to lift me tomorrow." Her daughter told us that "somehow the strength in my eyes convinced her otherwise, and then she gave herself over completely to trust in her family's ultimate care. The prescription was never filled."

Though the family's final decision was made in a context of poignant personal relationships, it mirrored in interesting ways the societal ambivalences outlined by Dr. Henderson in the interview after Mrs. Bell's death. At least some of the family members were clear on the humane intent of both active and passive euthanasia, and had supported Mrs. Bell's wishes throughout the course of her illness regarding avoiding intrusive or heroic measures. They were in tune with both Dr. Walker's and Dr. Henderson's views that the administration of progressively higher and eventually fatal doses of painkiller was acceptable and even expected in the hospital with terminal patients, comatose or not. But their ambivalence about personally "assisting suicide" coincided strangely with the legally disputed gray area in American society where some cases of "mercy killing" reached prosecution and others, perhaps many others, carried themselves to their conclusions in private.

By their own report, the family's courage in this regard never matched that of Margaret Bell, the uniqueness of whose attitude was attested to by her clergyman and many others. Her vision of euthanasia was an utterly positive and even joyful one, and if it had not been for her consideration of family members' feelings it might have been her final act of self-realization--an act she considered not only because she had not wanted to be a burden, but also because she "never liked messiness" and wanted to control the aesthetics of her death.

Yet the important point here is that the decision against euthanasia was reached in just the sort of egalitarian conversational context that Kleinman (1988) recommends. The consensual nature of that decision, the mutuality of its

acceptance, and the family healing that the process of reaching it achieved stand as a powerful endorsement of the value of Kleinman's conversation-centered approach.

The Oncologist as Charon: Ethnoconcepts as Cultural Containment

Anthropologists have identified the most destructive concomitant of illness as fear of the unknown. For example, drawing on the works of such earlier theorists as Levi-Strauss (1967) and Turner (1967), Schieffelin (1985) describes Kaluli healing seances in Papua New Guinea as emergent social constructions that draw upon and actualize group knowledge about the unknown. He emphasizes that removal of chaotic fear through such dramatic social ordering processes lies at the heart of shamanistic cures.

Although in official American ideology, religion and medicine, like religion and state, split off from each other long ago, in praxis the physician, laden as he is not only with responsibility for the body but also with heavy ritual and symbolic weight, has enormous influence over the psyche as well--a shamanistic function of which American physicians themselves are often aware, and whose potential they sometimes consciously exploit (Spiro 1986). (7)

Correspondingly, one of the main services this American doctor provides is a cognitive system emergent in diagnosis and treatment (or lack thereof) that organizes and alleviates the chaos of fear. Perhaps he does this partly by taking into himself as a ritual figure all those unknowns of a mysterious disease process and of death, thereby relieving the patient of that wondering that is beyond her capabilities. As he is himself untrained in shamanic myth and mystery, the full alleviation of such wondering is beyond the oncologist's capabilities, as well. Nevertheless, the ritual function of these doctors in Western society is consolidated by their exclusive control of authoritative knowledge--highly specialized scientific information--in spite of its conceptual emptiness/inability to explain. Yet the function itself is as simple and as old as the Christian idea of carrying another man's burdens for him, an idea shared by many ancient religions and healing traditions. It is as simple as piling symbolic unwanted baggage--disease,

trouble, fear--on a symbolic camel and watching it walk off into the sunset.

"Man," wrote Suzanne Langer "can adapt himself somehow to anything his imagination can cope with, but he cannot deal with chaos" (1974:23). It was Malinowski (1925) who first made clear the roles of religion and magic in inducing socially-agreed-upon confidence in observances designed to keep chaos at bay. Expanding on Malinowski's insights, Turner (1967, 1974) and Geertz (1973) emphasized the processual nature of "reality," showing that ritual performances are not only models of what humans believe, but models for ensuring that they will believe it. "In these plastic models, men attain their faith as they portray it" (Geertz 1973:114). The metaphor of a camel loaded with symbolic baggage, for example, or any other metaphysical image used in a therapeutic context, can have the effect of lightening the load of mystery upon the ill person. The physician/healer whose ability to assume the load of chaos is consonant with general social belief in the effectiveness of such a maneuver will demonstrate a capacity to heal which may have little or nothing to do with specific knowledge of treatment or cures.

Seen this way, the oncologist's role must finally be understood as having profoundly mystical dimensions. This doctor is Charon in no mechanistic sense: morphine is ultimately no way out of the ethical dilemmas of his mandate. His task remains as hard as the task of the mythic thaumaturge has always been--harder, because he is also charged, today, with probing the furthest reaches of proliferating scientific fact to leave no healing possibility unexamined. Yet despite its medical connotations and emphases, the oncologist's role remains basically a social one. In effect, he does address the lived experience of illness as well as the mechanics of disease. As arbiter of both the potentials and the limitations of scientific medicine against a disease virtually synonymous with death, he holds the reins on what the unassisted patient and family both fear and dare to hope. The mystery they fear is clear; what they dare to hope for--new discoveries in the nick of time, the power of the mind to transcend statistics, the possibility that choosing the time and the manner of death may be an affirmation of life, the ultimate rightness of their hunch that death will be an opening-out rather than a closing-in--may be much more individual, a result of their histories as persons. But all

individualism must be culturally contained, and this is where the cancer doctor's role has what is perhaps its central defining power.

The Greeks' model "of and for" dying was the Charon myth, the conceptual reality of which they expressed by burying their dead with oboli on each eyelid to pay the ferryman for passage to the Underworld. Just so does a modern cancer patient internalize her relationship to the cancer doctor's ritual power, once her own beliefs come into alignment with the technocratic model/myth. She gains, ultimately, the treasure of conceptual clarity, even if she must pay for it with the loss of individual hope.

We suggest that the power operating here is both social and religious. If a central act for many oncologists is the announcement of terminality and getting the patient to accept that diagnosis in the interests of "a good death," it is clear that defining "a good death"--known by anthropologists to be a social and religious preoccupation of societies in general (Fox 1973; Needham 1973)--has become at least partly the province of these specialists. If one realizes further that under certain conditions medical euthanasia may be permitted by our society, that these conditions are most often met in cancer cases, and that providing the means for euthanasia under these conditions is defined by at least some oncologists as "bringing about a good death," the implications of a role far beyond the medical one as contemporarily conceived are inescapable.

In the end, in Mrs. Bell's case, the question of who does Charon's actual ferrying, and to where, is left open. But some boatman figure standing ready to meet the dying passenger and carry her across seems just as necessary in our age as in ancient times.(8) If dying has become medicalized in America it has not done so without bringing elements of performance into the medical profession along with it. If "exiting stage right" is not yet actually condoned medically in America as a good death, it is at least a ready metaphor for evoking the performative aspects of dying and of attending those who die either as actor or audience.

Ideas about illness and healing are as precisely idiosyncratic to specific cultures as is verbal language. Ethnoconcepts form part of the cultural signature: though there may be variation

within traditions, part of what holds the members of a culture together is the containment provided by such ideas. This containment holds true for people whether they live in traditional or in highly industrialized societies.

The heritage of the Classical cultures of Greece and Rome held powerful sway in Euroamerican thinking for centuries. Economic fields such as medicine, politics, and law which have invested heavily in, and gained much from, this intellectual heritage, are slow to move toward "multicultural" (or even ethnohistorical within European traditions) awareness. They have the investor's unwillingness to learn of a possible threat to the return on their worldview. The science of anthropology goes largely unheeded by the science of medicine, for example, and a fortiori the ethnoscience of traditional peoples has little impact on medical practice, even as comparison or perspective.

But, as anthropologists often point out, a biomedicine that is trying to humanize itself could learn much from other conceptual systems and practices. The !Kung (Ju/'hoansi) of Botswana and Namibia, for example, have a long and trusted heritage of altered-state healing by laying on of hands. In this tradition, religion and healing are inextricably linked--by the practitioners, the n/omkxaosi or "owners of medicine," who are seen as both doctors and religious technicians, and by the expectations of all who participate. Such high value is placed on n/om (an intangible potency or energy which is activated both from within the healers' bodies and from within the highly social context in which they work) that herbal medicine, though known, is relatively little elaborated. Faith is put instead in the transformative experience shared by patient and healer.

In Ju/'hoan healers' ideas of death and fate lies an even more striking contrast to Western medicine. For them, the power to kill a person lies in the hands of !Xu (God). A healer has no foreknowledge of what he can cure and what he cannot cure. He must just try to the limit of his strength and if he is defeated, the patient will die. No fault accrues to him if this happens: instead he is socially rewarded for having tried his best. For Ju/'hoansi or for Ju/'hoan healers, the strength of n/om is not a thing that one can augment by wishing or trying. It is a given. It is God-given. N/om is given to the healers through the whim of !Xu. It does not set its owners apart or

above others in the society, and they do not receive material benefits for using it. They participate, as do all the people, in the dancing and singing which accompanies healing, for the pleasure of participation in a beautiful social event.

Next, n/om is conceived as a thing only multiplied, never divided, by being shared. Thus Ju/'hoan healers are not concerned that when someone dies they have not tried hard enough (as a physician who has not kept up with the latest medical journals might feel) since a certain equable fatalism releases them from personal responsibility. These factors, it seems, have important correlates in the realm of individual psychology and social structure.

First, n/om is not jealously protected, because sharing it redounds to the good of all. Nor are there material rewards to be had for exclusive control of n/om or its secrets. So a priesthood doesn't form, and egotism in the defensive sense does not characterize the social interactions of the n/omkxasi with the ill. Second, the ultimate responsibility for life and death is far removed from these practitioners. Unlike practitioners of biomedicine, with its stoutly defended turf (and concomitantly highly contested legal responsibility), Ju/'hoan healers are not assailed by accusations of ill-preparedness, coming either from others or from within themselves. They do not have to know everything. They can help ease the fear of sickness or of death, just as some biomedical doctors do, but they do not have to perform expert prognoses.

For these reasons, their role, even when dealing with grave illnesses like the recently introduced tuberculosis, does not define itself around an announcement of terminality or urgings to the patient to order her affairs. It is life- and hope-affirming throughout, holding to one source of hope--the patient's will to keep trying--as the indicator that effort should still be expended, that the patient should not be given up for lost.

It is here that Ju/'hoan traditional practices and newer holistic medical approaches in the U.S. most significantly converge. Neither treats the living patient as a "case." In both approaches the patient is an autonomous actor, her individuality valued, her inclusion on the healing team a given, her will and beliefs assumed to play strong roles in the healing process. But, contrary to the American holistic tradition's

emphasis on acceptance as an important part of the dying process (Kubler-Ross 1975), in the Ju/'hoan tradition the sick are alive until proven dead, given the benefit of the doubt as long as they are still breathing (and sometimes even afterwards): they are culturally allowed the ability to make the miraculous recovery if it is in them--or if, as the Ju/'hoansi believe, it is in !Xu's will.

Seeing the ease with which Ju/'hoan healers accepted that death was ultimately out of their hands, Biesele was filled with compassion for doctors whose techno-scientific tradition forces them to incur so much personal responsibility. She remembered Dr. Henderson's words, "Since I have become primarily responsible for patients...it has become difficult, an emotional effort, to help people die."

Upon her return to the Kalahari, Biesele told the story of Margaret Bell's death to the Bushman healer she had known and worked with the longest, a man in his fifties we'll call Komtsa Kxao. Komtsa listened gravely to the story of how the last afternoon of Mrs. Bell's life was spent quietly at home in a coma with her family present, and how she quietly slipped away in the evening. "Where was the doctor?" he wanted to know. "Well, they all knew she was dying so he wasn't there." Then Komtsa said, matter-of-factly and without a trace of criticism for the other medical tradition, "It's too bad she was so far away. If it had been me, I would have still been trying. If she could have been brought back, I could have done it."

Shortly after her mother's death, the eldest daughter had told us a strange story about hearing "garbled voices in the wall" above her mother as she lay dying, speaking incomprehensibly but so audibly that she actually went outside to see who was there, but found no one. It occurred to Biesele to ask Komtsa Kxao if he had any idea what these voices might have been. He responded, "Of course I know. It was the spirits coming to take Mrs. Bell. If I had been there, because I'm a n/omkxao I would have been able to speak their speech and ask them to bring her back."

We believe that what we can learn from non-"experts" ministrations to the ill, through their spiritual or humane approaches to the whole person, is profound. Other cultures, other traditions, suggest more open paradigms of the healer

than the technocratic biomedical model: in other models, it seems, the ferryboat to the other side can run both ways.

Perhaps the role of Charon for Western physicians much involved in terminal illness has a great deal to do with the privileged Classical heritage in which they have invested. It's not just the myth, though myths are powerful; it is the whole complex of ideas about Cartesian rationalism and the human potential for control of both nature and fate which come down to us with the strength of unassailable Truth. Yet these ideas, like any ideas, are cultural constructs, and the physician who enacts the matrix they form by diagnosing in its terms only is imposing a very narrow and culture-specific view of reality on the life/death of his patient. Fascinatingly, the attempt to meaningfully move beyond this narrow matrix informs not only the philosophies of physicians and medical anthropologists who advocate conversation-centered approaches to healing (DiGiacomo 1987; Kleinman 1988), but also those of the advocates of holism so admired by Margaret Bell (Cousins 1982, 1989; Siegel 1986).

Dying is a physiological and often interactional event with profound religious, social, spiritual, and individual ramifications. Enactments of their cultural matrix by practitioners who wrestle with, talk to, or wait upon death, be they technocratic Western physicians, holistic Western practitioners, or traditional Ju/'hoan healers, work to ensure that, like giving birth, dying will also be a cultural performance.

Endnotes

1. Our complete acceptance by Mrs. Bell and her family as anthropologists was certainly related to the fact that we were also close family friends.
2. Abrahams (1973) defines strange-making as making the commonplace strange by juxtaposing it with the unfamiliar.
3. We rely here on insights derived from our work with healing practitioners in more traditional contemporary societies whose

roles combine the religious and medical, Biesele's with !Kung Bushmen of Southern Africa (1979, 1987, 1990a,b, 1992; Biesele and Katz 1986; Katz and Biesele 1980, 1987) and Davis-Floyd's with Mexican shamans (1982).

4. In biomedical parlance, "medicine" means generally and generically internal medicine, the central specialty of the field (Hahn 1985). Hahn reports that to "go medically" is to be conservative, to intervene more cautiously, to act non-invasively out of an ideal of "physiological wholeness." "Surgery" is perceived by biomedical practitioners as the extreme opposite, a mode of practice based on "invasive procedures, direct looking at and handling of the body's organs, and the virtues of aggressiveness, action, doing, mastery, conquest" (Stein 1990:40).

5. A recent study of oncologists and their discourse on hope found that, although they stressed the advantages of instilling hope and a positive attitude in their patients, they did not associate these with increased longevity but only with a better illness experience (Good et al. 1990).

6. This notion that we can make ourselves both sick and well--the "New Age" concept of patient responsibility for illness (Ferguson 1980)--has been interpreted by social scientists as "blaming the victim" (DiGiacomo 1992; Farrer 1988). DiGiacomo (1992) points out how neatly this concept articulates with the pre-existing tendency in biomedicine to "blame the victim" in a different way--"she failed her chemotherapy," "he ruptured his scar." Thus it can be easily coopted into the biomedical discourse, providing technocratic practitioners with yet another means of retaining control by separating themselves from the patient and then defining the patient's experience.

7. Kleinman himself advocates such exploitation. He recommends that physicians try to achieve "the highest possible placebo effect rates" (1988:245). His approach to psychotherapy involves establishing relationships that "patient and family come to believe in as of practical help and symbolic significance" (1988:245).

8. It is noteworthy that in this context some holistically-oriented practitioners have begun to specialize in facilitating

death in much the same way as midwives facilitate birth. For example, harpist Theresa Schroeder-Sheker plays music and sings songs for the dying created by French monks in the 11th century to help the dying make a peaceful transition, as part of what Schroeder-Sheker terms "musical sacramental midwifery" (Harrington 1990).

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