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*The Medical Imaginary and the Biotechnical Embrace
Subjective Experiences of Clinical Scientists and Patients*

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The Medical Imaginary and the Biotechnical Embrace
Subjective Experiences of Clinical Scientists and Patients

Mary-Jo DelVecchio Good

Subjective experiences of clinical scientists engaged in producing and delivering high-technology medicine and of patients who are recipients of this technology are fundamental to understanding the political economy and culture of hope that underlies bioscience and biomedicine. In this essay, I examine interpretive concepts linking bioscience and biotechnology and their societal institutions to subjective experience. These are the medical imaginary, the biotechnical embrace, the political economy of hope, and the clinical narrative. Drawing on research and observations on the culture and political economy of biomedicine in the United States and internationally, I illustrate these interpretive concepts through examples from studies of clinical scientists, oncologists and their patients, and venture capitalists, as well as observations of public actions and discourses.

Cultural and social studies of biomedicine and biotechnology lend themselves to examining what anthropologists Fischer (1991) and Marcus (1998) have referred to as "multiple regimes of truth," through multi-sited and comparative ethnographic research in the areas of science and technology. Although acknowledging the importance of "cultural pasts" and "cultural differences," Fischer argues "it is increasingly artificial to speak of local perspectives in isolation from the global system . . . the world historical political economy" and "transnational cultural processes" (Fischer 1991:526). This formulation echoes recent trends in anthropological studies of biomedicine and biotechnology, and of scientific research and clinical culture. Such studies highlight the dynamic relationship, tensions and exchanges between local worlds in

which medicine is taught, practiced, organized and consumed and global worlds of the production of knowledge, technologies, markets, and clinical standards. Although we may speak about a plurality of biomedicines that are socially and culturally situated rather than about a single unified body of knowledge and practice, such local worlds are nevertheless "transnational" in character -- neither cultural isolates nor biomedical versions of indigenous healing traditions. Rather local meanings and social arrangements are overlaid by global standards and technologies in nearly all aspects of local biomedicine.

COMPARATIVE QUERIES

This perspective encourages comparative questions: how do local and international political economies of medical research and biotechnology shape medicine's scientific imaginary, its cultural, moral and ethical worlds, and the structure of inequalities of use, access and distribution of medicine's cultural and material "goods"? How do local and international ideologies, politics and policies influence professional and institutional responses to specific needs of particular societies -- from the disease plague of HIV to scarcity and poverty, trauma and civil strife, to public health and profit-driven health service markets? What form does the "political economy of hope" take? How do the culture of medicine and the production of bioscience and biotechnology "live" in respective societies?

J. Rouse, an American philosopher of science and society, speaks about American science, about the "openness" of science, arguing for an analysis that acknowledges that "the traffic across the boundaries erected between science and society is always two-way." Rouse discusses the idea of destabilizing "distinctions between what is inside and outside of science, or between what is scientific and what is social" (1992:13). Bruno Latour, the prominent French scholar of the biosciences, also contends that "scientific work continually draws upon and is

influenced by the culture 'outside' science." (Rouse: 1992: 13). Although these comments are directed to a long-lived internal debate among scholars of science studies, the concept they propose of two-way traffic across science and society is perhaps even more striking in biomedicine. The flow of knowledge, scientific and medical cultural power, market wealth, products, and ideas is thus not only between local cultures and institutions that create medical knowledge and organize practice, ethics and the medical market, but also between the culture and market of international and cosmopolitan biomedicine and its local variants.

The dynamics of the global-local exchange challenge our notions of "universalism" in clinical science and "local" knowledge in clinical practice, stimulating a rethinking of the boundaries not only between science and society but also between "the local" and "the global." It is with this sense of the transnational fluidity of knowledge and practices, appropriated locally and regionally and integrated into local culture, that I wish to turn to the interpretive concepts that link bioscience and biotechnology to society, and that have grown out of comparative cross-cultural analyses and conversations with colleagues from Europe, Africa and Asia, as well as from my own research in the United States and Indonesia. These concepts are "the medical imaginary," "the political economy of hope," "the biotechnical embrace," and "the clinical narrative."

THE MEDICAL IMAGINARY AND THE POLITICAL ECONOMY OF HOPE

An ethnographic slice through "multiple regimes of truth," narratives of patient experience and of clinical science, and documents on medicine's political economy, suggests ways in which the affective and imaginative dimensions of biomedicine and biotechnology envelop physicians, patients, and the public in a "biotechnical embrace." The medical imaginary, that which energizes medicine and makes it a fun and intriguing enterprise, circulates through

professional and popular culture. Clinicians and their patients are subject to "constantly emerging regimes of truth in medical science" (Marcus 1995:3; Cooke 2001), and those who suffer serious illness become particularly susceptible to hope engendered by the cultural power of the medical imagination. The connection between medical science and patient populations and the cultural and financial flow thus becomes deeply woven; the intensity of such connections may be measured in part through the flourishing of disease-specific philanthropies, through NGOs and political health action groups, and through the financial health of NIH (\$20.3 billion allotted in the 2001 budget; over \$23 billion in the 2002 budget, and a targeted estimate of approximately \$27 billion for 2003), even under a political regime that promotes tax cuts and small government.

Americans invest in the medical imaginary – the many-possibility enterprise – culturally and emotionally, as well as financially. (Freudeheim 2002) Enthusiasm for medicine's possibilities arises not necessarily from material products with therapeutic efficacy but through the production of ideas, with potential although not yet proven therapeutic efficacy. An officer of one of the most successful biotechnology firms in America indicated that biotechnology enterprises are in the business of producing ideas about potential therapeutics, from designer anticancer therapies to the manipulation of damaged genes.

So, think about a biotechnology company as a pharmaceutical company. . . . If you start with an idea and you are by definition working on something in the pharmaceutical industry that is likely to fail 90% of the time. . . . That was one of the myths of biotech. . . . So you are proposing to start a company in which there is a 90% chance of failure, the cost of product development is \$500-900 million, and from idea to the time when you have a revenue stream from product development is 12 to 15 years.

So your question is really, against that fundamental absurdity, how do you build a business, right?

If you start at that purely abstract level, what do you have to sell? You don't have your product yet, so what do you have to sell to feed the beast that you are about to build? Well there are only two things that you have to sell: the one is you can sell things that are or look or smell like equity. . . . What's the problem with that? At the end of the day, the pie is so split up, nobody makes any money on their equity, the dilution is intolerable. So what else do I have to sell? Well, instead of selling pieces of the company, an interest in the home, I can sell pieces of pieces, which I call rights, for example in certain of my discoveries or products, and this is where the pharmaceutical companies come in, and they say we will pay for you to do some research on our behalf, we will take the product that results from it, we the pharmaceutical company will commercialize it and pay you a royalty. So I withstand the dilution, I start generating revenues from collaboration, . . . and then I hand off the more expensive parts of forward integration of manufacturing and sales, I don't have to take on those burdens.

The question then becomes -- so call those your children. Keep the family alive by selling your children. The question is "is the nature of your platform prolific enough that in having sold off some of your children, you haven't sold off all of your future?"

Because if all you are at the end of the day is getting some royalties, from the 10% of your efforts that didn't fail, you are never going to be a big company. (Holtzman 2001)

Such firms seek to make public the scientific imaginary; until very recently, they have been the darlings of venture capital and continue to attract considerable investment. (See the business sections of *The New York Times* and the *Wall Street Journal* for analyses of recent market trends and for documentation of volatility in the financial side of the medical imaginary.) However,

companies whose fortunes appear bright due to remarkable scientific promise of potential and authorized new pharmaceutical products may find that the questionable long term efficacy of once promising drugs, such as HRT, can threaten financial futures and disrupt evolving clinical practices. One such example is Johnson and Johnson's Eprex, an innovative platelet enhancer used for treating anemia in cancer patients. Red cell aplasia, the inability to produce red blood cells, has been associated with this formerly billion-dollar (Pollack 2002; also Tagliabue 2002; Varmus 2002; and on HRT, Kolata 2002) .

At more mundane levels, Americans live in a world in which the medical imaginary has star billing in medical journalism, television advertisements, and globally popular television productions such as *ER*. (*ER* is among the most popular television programs in Indonesia and China; the medical imaginary is a global phenomenon.) The imminent discovery of cancer cure, effective genetic therapy, the manufacturing of new and better mechanical hearts, the engineering of tissue and the genetic alteration of pig cells to offset organ shortages, the latest results of clinical trials on AIDS therapies and the effectiveness, cost, and contested patents -- all become part of the daily global circulation of popular, business and medical knowledge. Our vast interests, financial and certainly emotional, in "the political economy of hope" are evident in daily market reports and public discourses. Recent stories on the Abiomed mechanical heart illustrate the more extreme version of product development tied to the political economy of hope. (See Stolberg 2002 about a patient who lived for 9 months.)

The circulations of knowledge and of the ethereal products of the medical imaginary are of course unevenly distributed. The robustness of local scientific and medical communities, of NGOs and political health activists, influence how this global knowledge is shared, accessed, and used. (See for recent studies: on Brazil, Bastos 1999; on American research oncology, Cooke 2001; on French science, Rabinow 1999; and on medical missions for high-technology treatment

of MDRTB and HIV for the poor, Farmer 1999.) Alternative stories, misuses and failures of medicine's cultural power and possibilities, are also part of the traffic in the medical imaginary: failures (as in genetic therapy leading to patient death); fraud (in clinical trials in oncology); discouragement (when promising therapeutics appear ineffective); greed (physicians trafficking in organs, brokering transfers from the poor to the rich) (*New York Times*, *Boston Globe*, *Organs Watch* (<http://sunsite.berkeley.edu/biotech/organswatch/>) 1999- 2002). Yet these tales are set in the larger optimistic story of the hope and the many-possibility science of medicine.

THE BIOTECHNICAL EMBRACE

The image of the biotechnical embrace emerged serendipitously out of studies of the culture of oncology carried out over the past decade and conversations with my colleagues in medicine, ethics and social science in the United States, Europe, Asia, and Africa. (See acknowledgements.) The concept of "embrace" conjured the subjective experiences and affective responses of many clinicians and their patients when using new biotechnologies, high-technology experimental treatments, and even salvage therapies. Among my American medical colleagues are those who acknowledge the phenomenon, are energized by enthusiasm albeit tempered with irony, and recognize when patients are embraced. (One pediatrician and ethicist has incorporated the term into lectures on the latest transplant therapeutics.) The specifics of popular and professional enthusiasm for biomedicine and nascent technologies may be characteristically American as some of my European colleagues would suggest, but "embracing and being embraced" fundamentally links contemporary high-technology medicine and bioscience to the wider society.

Whether it be new reproductive technologies, effective therapies to treat HIV or MDRTB, innovative organ transplantation procedures, progress in therapeutic gene

manipulation, or efficacious treatments for common life-threatening diseases such as cancer and heart disease, the enthusiasm that sparks the medical imagination also drives the political economy of hope, and our society's investment in medical adventures and misadventures.

CLINICAL NARRATIVES AND ETHNOGRAPHIC FRAMES

The two worlds of American academic clinical oncology -- the therapeutic and the scientific -- provide vivid examples of how patients and their clinicians embrace even as they are embraced by biotechnology, and how American medical culture generates enthusiasm for experimental clinical science and "medicine on the edge." (The success of Jerome Groopman's (2000) essays on cancer patients and experimental treatments exemplifies strong interest for certain groups of Americans.) In our own studies of the culture of clinical oncology, we developed the concept "clinical narrative" to capture the dynamics of clinical interactions that evolve over time between oncologists and their patients, through arduous and often lengthy therapeutic journeys. (See our work on clinical narratives and oncology studies listed in the bibliography; of particular relevance are M. Good 1995a, 1995b; M. Good et al. 1994; see Mattingly for her creative work on therapeutic emplotment: 1994, 1998, and Mattingly and Garro 2000 for additional elaborations).

NARRATIVE ANALYSIS

When literary concepts such as narrative are introduced into observations of everyday clinical life, new aspects of medical work and therapeutic processes become evident. Concepts drawn from narrative analysis -- plot, emplotment, and narrative time -- illuminate how affect and desire play in clinical narratives, seducing patients and clinicians, enveloping both in a world of the medical imagination, with a many-possibility regime of truth, with fantastic but apparently

purposeful technical acts. This analytic approach highlights not only how clinical stories are made and how narrative strategies are developed by oncologists, but it also identifies anti-narrative clinical talk, when events are given no meaning, strategies of communication fail, and clinical plots fragment or fail to emerge. This is common to medicine globally. (See B. Good 1994, B. Good and M. Good 1994, 2000; M. Good and B. Good 2000; Mattingly and Garro 2000, Ricoeur 1981a and 1981b, Brooks 1984, Iser 1978, Eco 1994 among others for references on narrative analysis.)

Narrative analysis enables disaggregation of specialty power and its economic underpinnings; it leads us to ask how the cultural power and scientific robustness of clinical medicine at the academic medical center where our projects took place come into play, to "plot" a coherent therapeutic course, to structure clinical time, to instill desire for treatment, to give hope, and in the case of disease resistant to standard treatment, to invite patients to open their bodies to experimental treatments that are often of questionable efficacy. In the American case, it is through clinical narratives that oncologists incorporate evidence-based medicine into clinical culture, and introduce therapeutic meaning through reliance on the findings of clinical trials and relevant research in the biosciences. And it is through the clinical narrative that the aesthetics of statistics -- how odds and chances of particular treatments are conveyed to patients -- emerge as culturally shaped and institutionally sanctioned, taking on a centrality in the narrative discourse even as ultimate questions of death are skirted, and the immediacy of therapeutic activities is addressed.

Patients' ironic engagement with their clinicians, as they negotiate the meanings of these clinical narratives, of the odds and statistics, of the fantastic and questionable, affords a glimpse into how the medical imaginary engenders a certain bravado, an experience with many

possibilities, that supports and sustains the emotional, financial, and cultural investment in experimental procedures and treatments (Gould 1996).

WORLDS OF ONCOLOGY

Case examples drawn from our oncology studies illustrate how clinical narratives connect the public, and in particular patients, to high-technology medical science; how patients experience and discuss invitations into a biotechnical embrace. Complementing these clinical examples are illustrations from a forum created and dominated by patients, "BMT-Talk," a cyberspace network connecting bone marrow transplant patients, friends, kin, researchers and curious clinicians, some of whom dispense second opinions from as far away as Brazil. The global connection is evident.¹ In addition, public documents from insurance hearings open additional perspectives on oncology's multiple "regimes of truth."

In the American culture of high-technology medicine, oncologists are expected to invite patients to enter the world of experimental therapeutics when cancer is resistant to standard treatments. It is through an invitation to "salvage therapy" (a clinician's term) that a clinical narrative that weds the experimental to the therapeutic begins to unfold. Clinical narratives direct action and technological interventions. Treatment experiences are inscribed on a patient's psyche and soma, under the guise of multiple plots and subplots that the professional subspecialties envision for patient and clinicians.

"RULES CHANGE": ABMT AND HIGH-DOSE CHEMOTHERAPIES

The current controversy over autologous bone marrow transplant treatment for metastatic breast cancer poses an ethical dilemma in terms of societal and individual costs, both financial and personal. As a medical oncologist noted in conversation in 1993, this expensive 'salvage

therapy' had dubious therapeutic credentials; and in clinical trials to that date patients who initially responded positively to transplants "were all relapsing at six or eight months after the transplant." Yet, in 1994, some patients sued their insurers who refused coverage for these treatments and many more medical oncologists encouraged their use. (A now infamous suit brought by a California Kaiser patient who was refused coverage in 1994 helped to establish this "experimental treatment" as a standard of care by 1995-96. "No HMO would be able to refuse coverage now because of that suit," claimed the chief of surgery at the Harvard teaching hospitals in 1996.)

By 1995, clinical studies indicated mortality from the procedure decreased from 30% to 3%, as innovative post-treatment care was introduced and healthier patients were recruited. Although the cost of providing autologous stem cell/ bone marrow transplants declined quickly and dramatically (from approximately \$150,000 in 1993 to \$60-75,000 today), as the technological fix became "technically sweet," increasingly efficient and standardized, and as treatment locales shifted from lengthy hospitalizations to outpatient services, long-term therapeutic efficacy continued to be questioned. As the bioscience of the field alters and decisions to choose competing therapeutic options (such as platelet treatments with new pharmaceuticals) become ever more complicated, especially given the uncertain efficacy of many treatments and the potential for serious clinical errors, the medical imaginary has to be carefully orchestrated. Yet, even with questionable efficacy, we see patients and physicians captured by the biotechnical embrace, enthusiastic about the possibilities of the therapeutics of the experimental. "ABMT" for metastatic breast cancer is a prime example of enthusiasm with questionable clinical science.

NORMALIZING THE EXPERIMENTAL

Clinician-scientists such as Dr. William Peters of Duke University Medical School were among the early public promoters of experimental therapeutics, normalizing the technologies and the apparent high-tech oddities, turning the unusual into an event no more odd than a coffee break; the housekeeping metaphors of daily life. In his persuasive presentation to the federal government hearings on whether Medicare/ Medicaid would support coverage of ABMT for metastatic disease, Dr. Peters characterized the procedure as follows:

As our famous philosopher once said: "the future just ain't what it used to be" -- this is what most people think of bone marrow transplants as being -- a high-technology facility with isolation procedures, use of high-tech equipment, multiple supportive care efforts and so on. What is really happening is that, in the last few years, this is occurring more frequently. Two women from our institution (post transplant day two and day six) -- are waiting for coffee to be delivered to the hotel where they are staying during their bone marrow transplant. We now essentially do all our bone marrow transplants as outpatient procedures. If one looks at the 100-day mortality in patients undergoing transplants, you can see that, back in the mid-1980's, the therapy-related mortality in the first hundred days was at over 30%. Now, it is in the range of about 3%. In fact, if you look at the 30-day mortality [it has dropped] from 15% down to the 3 to 4% realm. This represents massive change in therapy-related mortality. (Peters 1994)

IRONIC HUMOR: THE TWILIGHT ZONE AND THE MEDICAL IMAGINATION

Patients, like clinicians, play the numbers. Ironic humor and an edge of cynicism (hope against hope?) mix with the medical imagination and the slightly bizarre imaginary of what the

future might hold. The following comments by patients about the clinical narrative created for them are illustrative.

Mrs. R, a witty 54 year old educator, suffers from metastatic disease and is a candidate for autologous bone marrow transplant and high dose chemotherapy (Cytosan). She discusses therapeutic choices with her medical oncologist and the transplant surgeon. The excerpts included in this example cover several meetings over a period of nine months. When we first met Mrs. R., she was with the medical oncologist. It was then that she learned she had metastatic disease secondary to breast cancer.

The excerpt is from her third visit with the medical oncologist with whom she discusses "choices" and recommendations from the transplant surgeons. The patient's sense of humor is dry; her comments nevertheless capture the strangeness and uncertainties of experimental treatments and medicine on the edge.

August

Patient (Mrs. R.) comments to the interviewer about ABMT: I guess if I had a concern, my concern is -- is it going to damage my immune system so that it's going to make things worse? It seems like a very archaic sort of technique. [Speaks about postponing a vacation]. I don't want to jeopardize this great 15-20% chance. I really don't have a choice, do I?

Medical Oncologist: Yes you do have a choice. You don't have a choice if you're only focusing on the big picture and ten years down the road. Then you don't have a choice because these choices can give you a chance. But if you focus on the next five years ---

Patient (Mrs. R): Five years is nothing.

Medical Oncologist: So you don't have a choice. It's your choice.

Mrs. R: He [the transplant specialist] said it is not a choice.

February

The second encounter begins with an interview between the patient and the researcher; it then focuses on the clinical encounter as the physician removes the stem cells.

Mrs. R: This is supposed to stimulate the stem cells to grow... and then they harvest them in ten days. It's kind of like gardening.

Interviewer: It's just a very short growing period. Like radishes.

Mrs. R: That's right. Like radishes. That's right. These little radishes. That's right.

***** (Gap) *****

Interviewer: So, I have my usual question, how does all this feel at this point?

Mrs. R. Like a giant mistake. The truth? Like I made a mistake. I shouldn't be doing this. . . . I wasn't feeling sick. And, you know, right now it's getting toward the big time, and I don't want to do it. I don't want to be here. I want to be on with my life. This is inconveniencing my life, and I don't like that. Does that sound adequate enough? So I am saying why the hell did I decide to do this? This is stupid. Besides, the whole thing is Twilight Zone.

***** (Gap) *****

Transplanter: Good, good, good. Okay. So the fun part starts.

Mrs. R: (To interviewer) He's got this sadistic humor

Interviewer: You know you're in trouble when he starts rubbing his hands.

Mrs. R Oh, that's a sign? Okay. He's kind of got that Frankenstein look. What are we going to make today? . . .

***** (After procedures are complete) *****

Mrs. R: You know what the hardest part -- not even the hardest part, but -- I guess the irony of the whole thing is to go through all this and have absolutely not only no guarantee at the end, but not even an indication. . . . No way to have any idea whether it worked or didn't work. When you think about it, it seems like at the end they should be able to say, "it looks good," or "it doesn't look good."

Interviewer: What did they say about that? . . .

Mrs. R: If I'm alive and well in five years they'll call it a success, and I'll follow the 20% success rate. It's a hindsight thing. And it's funny, one of the things that we did do initially that we've gotten off that we have to get back on, I think, was to go on a diet and become vegetarian . . .

[Referring to Tamoxifen and soy being a natural tamoxifen] . . . You listen to the medical

profession but you must do your own thing. So I'll keep eating tofu. So, I'll keep eating tofu. So, I don't know. It's all so interesting. The teachers gave me a huge party. Very nice, a surprise party. And they sent out invitations and they called it a shower. They had a shower for me, a shower of friendship, they called it.

Five weeks after this interview, the patient returned for a follow-up treatment just after news articles revealed that a competing institution, the esteemed Dana Farber Cancer Center, had inadvertently overdosed two women during high dose chemotherapy, leading to one patient's death. (*Boston Globe*, March 22, 23, 24, 1995). The Joint Commission on Accreditation of Hospitals placed the Dana Farber on probation.

April

Mrs. R evaluates for her oncology nurse her physicians' skill at extracting bone marrow (not only for therapeutic purposes but for a clinical observation study). She scores each of them: "a five, a seven, a three!"

Nurse: Not a ten?

Mrs. R: Ten does not exist, nobody can get a ten.

Just as no ABMT patient can be assured of a cure.

Mrs. R: I decided that [cancer] can be a chronic disease. It doesn't have to be a -- I always believed it was a death sentence. . . . Now my next big decision is, they did the second bone

marrow for their research. . . to see if there's any breast cancer cells in the bone marrow. So do I want to know the answer to that?

Nurse M: I don't think they can tell you the answer to that.

Mrs. R: Yeh, he said he could.

Nurse: Right. . . . and you don't know what to do with the information . . . he shouldn't have even told you there was an option.

Mrs. R: I'll have to think about that.

The oncology nurse and patient conclude with additional talk about the 15-20% cure rate, the uncertainty and ambiguity of what the future holds.

Narrative strategies in this type of clinical encounter draw heavily on humor, and many patients in our study responded in kind. Humor lends irony to ambiguity. Nevertheless, the experimental nature of the procedure was fully experienced by clinicians and patient. Notably, in May 1999, the American Society for Clinical Oncology released data from five clinical trials comparing ABMT with high dose chemotherapy to standard treatment protocols. No difference was detected in longevity in four of five studies, although one study indicated a small difference in quality of life. (www.ASCO) The single trial that reported greater effectiveness was discovered to be flawed by fraudulent research and science. The clinician investigator responsible, Dr. Werner Bezwoda, chair of the oncology and hematology department of the University of Witwatersrand Medical School in Johannesburg, South Africa, acknowledged he

adjusted his data in order to gain fame (Waldholz 2000). Clinical narratives may inadvertently introduce fraudulent science and treatment of questionable efficacy and high toxicity, even as they offer the power of scientific discovery and biotechnical innovation.

WILE E. COYOTE ON BMT-TALK IN CYBERSPACE

BMT-Talk is filled with the fantastic -- with images of the archaic, the Frankenstein, the cyborg, and the bizarre aspects of treatment. A young patient writing about bone marrow transplant for his/her multiple myeloma also draws on American metaphors of the flexible cartoon-like and regenerating body (the coyote appears in many forms and like a cat has multiple lives).

The thing that is weird to me is that the transplant, unlike a liver or kidney or other organ transplant, isn't what's supposed to help against the disease [multiple myeloma]. What's supposed to do the damage to the cancer/tumor cells is the chemotherapy. The transplant is a rescue technique because without it the chemo would be fatal. Wow. It's a really bizarre idea -- like if the water in your aquarium were tainted somehow, you'd put a ton of salt or other medicines in it, then pump it ALL out (leaving the fish inside the aquarium), waiting for it to dry out, and then pumping the water back in and hoping the fish could still swim (and not just float upside down!). Hmmm . . . well I just thought up that analogy, and it's not quite right, but it's kind of how I feel about it. We'll drop a 16-ton weight on you. That'll kill all the cancer. Then, you'll walk along like an accordion, as though you were Wile E. Coyote in a Road Runner cartoon, until you pump the air back into yourself. In fact, we'll pump it in for you! . . . I know it's the best chance I have, but I can't help feeling that it's going to seem awfully primitive in (hopefully) not

many years. It feels like with all the technological and medical advances we've made, we're not that far removed from bloodletting!

Patients' subjective experiences with BMT procedures -- from enthusiasm to disappointment and struggle -- contrast with that of physicians who have cared for BMT patients when the procedure has failed. In our recent study of internists' emotional responses to patient deaths, we found an alternate and chilling version of the bizarre "BMT-Talk" as illustrated in the following interview excerpts, presented by clinician rank -- faculty physicians (attendings), second- to fourth-year residents, and interns.²

Attendings:

Commenting on training in bone marrow stem cell transplant: "The big hope -- there are incredible highs and lows -- the high is when you get the disease to go away with the transplant and you have done good."

"Sometimes transplant units are like a morgue; the transplant people don't see it that way; house staff rotate through and comment about it all the time."

"It's a big risk, an up-front risk, a 20% mortality rate from the procedure."

"Intellectually, bone marrow transplantation is a numbers game -- I firmly believe in the ability to cure the other 60%."

"We threw everything we could at her and she died anyways, which is unfortunate, but that was the standard of care with transplant."

"It was the standard transplant story, go in, get chemotherapy, radiotherapy, get the transplant, get sick in a couple of weeks later, get sicker, get sicker, get sicker, wind up in the ICU, died a week later."

"I don't expect transplants to work."

“Although you haven’t killed them theoretically, you have at least contributed to their death prematurely.”

Residents

“I finished off my responsibility, but the next year I did not want to go back to the bone marrow transplant unit.”

“Bone marrow transplant is such an odd realm of the medical world, and frankly other programs don’t even see any of it.”

“And this 35 year old woman, like all people who enter transplant, looked good, then died of it.”

“Being given high doses of chemotherapy and bone marrow transplant is not a natural event.”

“Sometimes oncology in general kind of bugs me, in that it seems – especially for bone marrow transplant patients – I was feeling ‘why are we doing this?’”

Interns

“They come to the ICU and we have to tell them, to tell their families, it’s just so frustrating that the people don’t know [the high rate of failure of BMT procedures].

I’m on a bone marrow transplant team, so this is like the worst of ...I don’t know.”

These excerpts exemplify physicians’ internal critique on practices they regard as clinical irrationalities. Their experiences with patients’ deaths rather than recovery convey the negative side of the medical imaginary and the biotechnical embrace.

METAPHORS OF ENTERING THE BIZARRE

Patients in our studies also used metaphors of the bizarre. Even standard chemotherapy feels like one is "off to see the wizard." A primary school teacher, 53 years of age, sang us a

little ditty to the tune of "I'm off to see the Wizard, the wonderful Wizard of Oz," a song she sings with her daughters as they drive to chemotherapy treatment:

I'm off to see the wizard, I'm off to chemotherapy.

Other patients, especially those who seek every possible treatment, articulate their ambivalence in succumbing to the embrace of oncology's power:

It makes me wonder what people are willing to accept when they think of something, some institution or doctor as being the best. Is it how bad you feel? [laughs] Is it how absolutely miserable and sick you are made as a result of a treatment they are willing to invite you to have? Is that what being a good patient is all about? Not complaining . . . I wonder, when will it be enough?

Metaphors of living are of course equally central to the way patients address the medical imaginary and the seduction of the biotechnical embrace, the desire for hope. The aesthetics of science are wed to art in the poignant reconfiguration of Botticelli's *Venus in Art.Rage.Us* (Tasch 1998). *Venus* is refigured with a subtle, surgically elegant mastectomy, still beautiful. Thus as life continues, beauty too may endure despite the inscriptions on the body of consequences of clinical narratives, medicine's technically sweet fixes, and life's illness traumas.

CONCLUDING REFLECTIONS

As we deconstruct American clinical culture, particularly worlds of oncology, we find a persistent rhetoric of humanism contrasted with that of technology. Such public and professional dichotomies may lead us astray, endorsing professional power over against lay knowledge. And yet the metaphoric language of many patients is profoundly affective, expressing hope and interest in the possibilities of biotechnical innovations and therapeutics, whether in consultation with their clinicians discussing therapeutic choices, results, and ambiguities or in the less

structured interviews with researchers. In BMT-talk, cyberspace connections often appear to heighten the emotionality of discourses and graphic debates with other patients over limits to therapeutic options. The affective dimensions of high-technology medicine are clearly soteriological (see B. Good 1994), a salvation ethos that is fundamental to bioscience and biomedicine, and to the political economy and culture of hope. The biotechnical embrace creates a popular culture enamored with the biology of hope, attracting venture capital that continues even in the face of contemporary constraints to generate new treatment modalities.

I began this essay with considerations of the relationship between science and society and its connection to the relationship between the global and the local in biomedicine, particularly high-technology medicine. A global moral dilemma arises when the cultural traffic from the biosciences and its attendant marketing of biomedical products influence the practice of clinical medicine in societies of scarcity. While the world's dominant economies invest private and public monies in the production of biotechnology and aggressively seek to integrate these advances into clinical practice -- thereby reaping financial as well as scientific returns on capital investments -- all societies are confronted with difficult questions about rationing biomedical interventions assumed central to competent clinical medicine. Local clinicians are thus subject to constantly shifting and competing claims and regimes of truth from the worlds of scientific power and transnational biomedicine. (See Bastos 1999 for discussion of similar issues in AIDS science.) As metaphors of science and society merge, ethical questions of how best to serve all patients arise. Integrating cultural, ethical and political economy analyses of contemporary popular and professional biomedical cultures is critical to unmasking links between interests, be they economic or cultural, and policies on "best medical practices" for the global medical commons. How medicine serves humanity in the third millennium may be at least marginally affected by how anthropology assumes this interdisciplinary analytic project.

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¹ To illustrate, the following describes a bone marrow transplant for Acute Lymphocytic Leukemia: “Treatment begins with chemotherapy designed to kill as many cancer cells as possible. If the cells have spread to the brain, the patient will also undergo radiation therapy and chemotherapy injected directly into the spinal fluid. Generally, 70 to 80 percent of the patients achieve remission after chemotherapy. To reduce the risk of relapse, the patient is given maintenance chemotherapy treatments. Sixty-five percent of the patients relapse after remission, and begin aggressive chemotherapy again. Bone Marrow Transplants are usually performed during the second remission. Studies have found 60 percent long term survival rates (survival beyond three years) for those patients who receive BMT in the first remission, and 40 percent long term survival rates for those who receive them in the second. (Many doctors prefer to wait to see if a patient relapses after the first round of chemotherapy before deciding to perform BMT).” (<http://www.peds.umn.edu/centers/BMT/all.html>)

² The study, *Physicians’ emotional reactions to their patients’ deaths*, was funded by the Nathan Cummings Foundation; the primary investigators are Susan D. Block, M.D., Dana Farber Cancer Institute and Department of Psychiatry, Brigham and Women’s Hospital, and Robert M. Arnold, M.D., University of Pittsburgh Medical Center. Research was carried out during 1999-2001. In addition to myself, the Boston research team included Patricia Ruopp, Ed.D., Nina Gadmer, Matt Lakoma, and Amy Sullivan, Ph.D. (See Good et al., “Narrative Nuances on Good and Bad Deaths: Internists’ Tales from High-Technology Workplaces” [in press] for project description.)