

Clinical Narratives and the Study of Contemporary Doctor-Patient Relationships

MARY-JO DELVECCHIO GOOD AND BYRON J. GOOD

INTRODUCTION

In a series of essays published in *JAMA*, David Mechanic, one of the major medical sociologists of our era, addressed the contemporary eroding of traditions of 'trust' that has characterized ideal relationships between American physicians and their patients over much of the second half of the twentieth century (Mechanic 1997; Mechanic and Schlesinger 1996). The recent reorganization of American health services as capitated managed care systems, the shift in the balance of physicians' fiduciary responsibilities from individual patients to larger patient populations or stockholders in managed care groups, and shifts in professional relationships resulting from newly emerging biotechnologies have fostered public controversy and professional unrest (Gray 1997). From an international perspective, these changes in American medicine seem to reflect broader global changes in biomedical therapeutics, the medical profession, and relationships among doctors, patients, and the public. In this chapter, we explore analytic approaches to the physician-patient relationship that have relevance for understanding the contemporary turmoil in medicine in the United States and around the world. We also address those dimensions that reflect deeper cultural and professional forms that appear - as of this writing - to persist despite the radical changes in the organizational structure of health-care services.

The analytic framework we propose here suggests that 'clinical narratives' - stories of therapeutic activities created by physicians for and with patients over time - lie at the heart of doctor-patient communications, and that analysis of clinical narratives provides a means of exploring key dimensions of therapeutic relationships. We draw on recent ethnographic work in American and international biomedicine to analyze how young doctors learn particular narrative forms as they gain professional competence in clinical training, how physicians create and shape patient experience over time through clinical narratives, and how concepts such as clinical narratives have cross-cultural relevance in comparative studies of physician-patient relationships.

The globalization of biomedical cultures and political economies of medicine has had a profound influence on local and cosmopolitan cultures of clinical medicine world-wide. Nevertheless, although biomedicine is fostered through an international political economy of biotechnology and by an international community of medical educators and bioscientists, it still is taught, practiced, organized, and consumed in local contexts. It is our contention that contemporary studies of doctor-patient communications should focus attention on how relationships between clinicians and their patients mediate larger relations of culture, knowledge, and power, globalized political economies of medicine, and local and cosmopolitan dimensions of biomedical cultures. It is our

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argument that attention to clinical narratives provides one important approach to the study of these mediating processes.

ANALYTIC PERSPECTIVES ON THE DOCTOR-PATIENT RELATIONSHIP

Since social scientists began writing about medicine, the doctor-patient relationship has been the site of highly diverse and contested interpretations. In a literature most remarkable for its sheer mass, sociologists and anthropologists, sociolinguists, bioethicists, historians, popular writers, physicians, and more recently management specialists have analyzed and evaluated doctor-patient communications. Researchers have investigated this particular form of communication as conversation, often poorly executed (West 1984), as flawed exchanges of information (DiGiacomo 1987; Gordon 1990; Waitzkin and Stoeckle 1972, 1976), as interrupted narrative performances, with the 'voice of medicine' overwhelming the 'voice of the life world' (Mishler 1986), and as affective exchanges, fraught with transference and counter-transference (Balint 1957). Doctor-patient communications have been interpreted as contributing to the cultural construction of disease (Kleinman 1980), the commoditization of health and healing (Nichter and Nordstrom 1989), and the professional appropriation of suffering (Kleinman 1997; Kleinman and Kleinman 1991). They have been characterized as contributing to the medicalization of oppressive social relations and social suffering (Scheper-Hughes 1992; Taussig 1980) and to social control (Zola 1972), as providing a site for domination and exploitation (Pappas 1990; Waitzkin 1981, 1991), a setting for 'struggle and combat in the very heart of physician-controlled territory' (Singer 1989), and one context for gendered conflict between 'intimate adversaries' (Todd 1989). Despite its contentious and unequal nature, the relationship between clinicians and patients has been viewed as a setting for sustained witnessing of human suffering (Kleinman 1988) and for medicine's soteriological practices (Good 1994). It is through such relationships that physicians are expected to employ medical knowledge in a competent fashion and uphold fiduciary responsibility (Parsons 1978) and, through a variety of medical practices and biotechnologies, to convey hope and shape patient experience of disease and therapeutic processes (Good 1995a, 1995b).

Although medical sociologists, psychologists, and health services researchers have carried out sustained research on 'doctor-patient communi-

cations' since the 1950s, anthropologists are relative late-comers to the study of doctors, patients, and biomedical institutions. In their introduction to *Physicians of Western Medicine* in 1985, Hahn and Gaines called attention to the paucity of ethnographic research on physicians – in contrast to anthropological writing on traditional healers or healing rituals, and in contrast to sociological writing on medicine. Their collected volume was one of the first to draw together a group of studies by anthropologists working in diverse North American health-care settings. However, since the early 1980s, there has been a virtual explosion of anthropological writing about contemporary biomedicine. Collected volumes (e.g., Gaines 1992; Hahn 1995; Kleinman 1996; Lindenbaum and Lock 1993; Lock and Gordon 1988), review essays (e.g., Rhodes 1996), and articles and monographs (e.g., Good 1995a; Gordon 1988; Kaufman 1993; Marshall and Koenig 1996; Martin 1987, 1994; Rapp 1988; Rhodes 1991) have addressed 'biomedicine' in general, as well as particular medical subspecialties or clinical issues – oncology, psychiatry, reproductive technologies, immunology, genetic counseling, bioethics – in the United States or internationally.

Although relatively little anthropological writing focuses narrowly on doctor-patient communications, medical anthropology is relevant to the study of doctor-patient or clinician-client relationships in several ways. Medical anthropology places studies of doctors and patients in the context of comparative studies of medical systems. Since the 1970s, with the development of the study of Asian medical systems (Leslie 1976; Leslie and Young 1992), anthropologists have focused explicitly on pluralistic medical systems. From Kleinman's earliest, seminal formulation of medical systems as cultural systems composed of popular, folk, and professional domains (Kleinman 1980), to more recent studies of medical pluralism (e.g., Brodwin 1996; Good et al. 1993; Nichter 1989), patients are seen as having access to diverse strands of medical knowledge, explanatory systems, and healing traditions. Biomedicine is one form of medical knowledge among many, and transactions between doctors and their patients are complex transactions among systems of meaning, technologies, and power (cf. Rhodes 1996).

Diverse interpretive theories have been developed within medical anthropology to analyze these transactions. In his earliest work, Kleinman described clinical conversations as transactions across explanatory models, leading to the clinical construction of reality (e.g., Kleinman 1980; Kleinman, et al. 1978). In our own early work, we focused on the hermeneutic

or interpretive dimensions of such transactions (Good and Good 1981a, 1981b; cf. Good 1994). Others have analyzed medical knowledge as hegemonic, portraying social inequalities as arising naturally from human nature or biology, and have gone on to interpret doctor–patient communications as an important site for making the hegemonic appear real to those seeking medical care (e.g. Martin 1987).

In addition to conducting studies of doctors and patients in the context of comparative research on pluralistic medical systems, medical anthropologists have also written about doctor–patient communications in a critical and normative literature directed explicitly to clinicians and educators. One goal of such writing has been to make explicit ‘the relevance of social science for medicine.’ In an edited book of this title published in 1981, Eisenberg and Kleinman gathered together a series of essays aimed at demonstrating ‘the relevance of social science concepts, and the data derived from empirical research in those sciences, to problems in the clinical practice of medicine’ (1981: ix). The book included explorations of ‘cultural influences on illness behavior’ (Lewis 1981), illness ‘attributions’ (Stoeckle and Barsky 1981), ‘social labeling’ (Waxler 1981), and other concepts which could be translated for clinical research and teaching. Our own essay in that volume – ‘The meaning of symptoms: A cultural hermeneutic model for clinical practice’ (Good and Good 1981a) – outlined a critique of empiricist or positivist epistemologies of clinical medicine and argued for rethinking medical practice in interpretive or hermeneutic terms. Grounded in the broad tradition of hermeneutic philosophy and interpretive social sciences (Ricoeur 1981a), the paper argued that clinical interactions should be understood as belonging to the world of meaning, aesthetics, and experience, rather than narrowly to the world of biology and instrumental communications about physical symptoms and diseases. Although theoretical in vein, the paper aimed at making explicit the relevance of a cultural interpretation of medical knowledge and clinical transactions for teaching medical students and residents alternative approaches to interviewing patients. The paper belonged to a genre of medical anthropology, which included empirical studies in ‘clinically applied’ anthropology (Chrisman and Maretzki 1982) as well as studies of ‘the politics of medical encounters’ (Waitzkin 1991), that aimed explicitly to criticize aspects of clinical medicine and to translate social science concepts and research into tools for clinical teaching and practice.

The decade of the 1990s has seen the emergence of new modes of anthropological analysis of medical knowledge, medical institutions, and

clinical transactions. These are a result of both the sheer magnitude of changes in the world of medicine and changes in anthropological theory. Advances in molecular biology, investigations of the human genome and its role in disease, and the development of new biotechnologies – from reproductive technologies to imaging devices to new therapeutics – raise issues hardly conceived as recently as a decade ago. In addition, the rise to dominance of the for-profit managed care sector of the health-care system – particularly in the United States – has increased demands for efficiency, brought economic considerations into clinical transactions, and involved management specialists in clinical decisions, thus, dramatically altering relations between doctors and patients. Also, the transnational production and exchanges of medical knowledge, standards of care, and therapeutics have added global dimensions to medicine and medical practice in ways seldom imagined by earlier medical anthropologists. These changes have radically altered the world of clinical medicine, provoking new questions and offering new challenges for anthropological writing about ‘doctor–patient relations.’

At the same time, the theoretical landscape for medical anthropology has also shifted. More than ever, anthropologists reject any account of doctor–patient relationships and communications that fails to link them systematically to broader social, political, economic, and cultural processes. Diverse forms of critical theory are now a part of any discussion of medical knowledge and clinical practice. Anthropologists routinely explore how medical systems reproduce hegemonic views of the body, the person, gender, and social relations. At the same time, new forms of poststructuralist theorizing have moved beyond exclusive attention to hegemony as an analytic approach. Medical anthropology has also come into conversation with ‘science studies,’ with anthropologists, sociologists, and historians carrying out innovative studies of late-twentieth-century science. Theoretical developments in the study of culture – in interpretive anthropology, subaltern studies, theories of the body, feminist writing – have all changed the way medical anthropologists write about ‘the clinic,’ and recent theories of transnationality and globalization, as well as new ‘multisited’ approaches to ethnographic research, provide diverse and innovative theoretical resources to study ‘doctor–patient communications.’

Rather than attempt a broad review of this highly diverse field, our goal in this chapter is to outline a specific approach to the study of doctor–patient communications from the perspective of ‘clinical narratives.’ After providing a brief account of this analytic framework, we draw on small pieces of data from larger

ethnographic studies to address three sets of questions. First, how do physicians in training enter into the world of medicine? How is medicine learned as a set of narrative practices? How does the learning of doctor-patient communications mediate entry into a complex set of social, political, economic, and biotechnical relations? Second, in cases of high-technology medicine and the treatment of serious medical conditions, how do relations between doctors and patients mediate emerging technologies and new political economies of research, biotechnologies, and health services? How are clinical narratives developed and sustained in such settings? How are issues of suffering and soteriology engaged via elaborate advanced technologies? Third, how do these issues translate cross-nationally? How do doctor-patient communications mediate local and global flows of knowledge and biotechnologies in low-income societies? How is the essence of doctoring threatened in societies that combine overwhelming disease problems with terrible scarcity of resources? The goal of these analyses will be to illustrate, rather than fully develop, an approach to analyzing doctor-patient communications consistent with current theoretical and analytic concerns of medical anthropology.

CLINICAL NARRATIVES: AN ANALYTIC APPROACH

In a series of studies, we have explored the idea that doctor-patient communications may be investigated as 'clinical narratives.' That is, stories created by physicians, for and with patients over time, about the course of disease and the progression of therapeutic activities (Good 1995b, 1998; Good et al. 1994; cf. Good and Good 1994; Good 1994). This approach focuses attention on on-going narrative processes that lie at the heart of clinical communications, thus making analytic concepts from literary criticism and narrative approaches to the social sciences relevant to the study of doctor-patient communications. At the same time, it provides a means for analyzing how larger social and cultural processes are made relevant to the experience of patients, suggesting that clinical conversations are a form of traffic not only among doctors and patients, but also among diverse local and global sites that produce biomedical knowledge, therapeutic technologies, and the scientific imaginary.

Studies of clinical narratives begin with the basic notion that physicians, in conversation with patients, 'emplot' disease and its treatment,

constructing meaningful stories linking the past and the present to potential futures and plotting courses of action.¹ In high-technology medical settings, physicians are nodal, directing the story, shaping patients' experience of treatment and disease course, and managing the treatment team. Clinicians establish therapeutic plots for patients, as a course of treatment is set in action, and they 'read' the unfolding 'medical plot' determined by disease process and patient response. Although clinical narratives are given directionality by physicians, and the 'voice of medicine' (Mishler 1986) and biomedical actions dominate, patients are also critical 'readers' and 'interpreters' of treatment plots, directing - often in collaboration with their clinicians - how the shifts in therapeutic course will affect their lives.

Physicians, even within the same subspecialty, hold a variety of opinions about how best to devise appropriate clinical narratives that are 'therapeutic,' caring, and productive of desired responses from patients. As creators of clinical narratives, physicians also develop multiple and parallel subplots, each tailored to specific actors. These include stories formulated for professional colleagues, the treatment team, and patients and patients' families, and also for the research groups and scientific communities to which they belong. The dimensions of temporality, outcome, and ending may differ for each audience and subplot of the clinical story (Good 1995b, 1998). A single, clear plot or theme seldom characterizes a clinical narrative; multiple and alternative readings, contributing to 'subjunctivity' and an openness to unexpected sources of healing, are the norm (Good 1994; Good and Good 1994; Good 1995b, 1998). Institutional forces, irrationalities in a health-care system, and fraud in research medicine can disrupt and fragment the progression of a clinical story and wreak havoc with professional intent. In addition, patients may choose to step out of a professionally devised 'plot,' to abandon treatment or seek alternative medical care.

Physicians are readers not only of the stories of their patients and the partially hidden course of the 'disease' as it is clinically manifest, but of the cultural flow from the biosciences. Bioscience narratives are occasionally brought into clinical practice through rank and file clinicians; more often they are introduced through clinician-investigators and teachers who conduct clinical trials and set standards of competence in specialty medicine. Such definitions of standards influence how competence is regarded in the evaluation of physicians' work as well as in physicians' construction of clinical narratives. Narratives of bioscience and technological expertise parallel even as they inform clinical

narratives designed for patients, and many patients, at least in the American context, are aware of biomedical innovations and treatments (through television, science news articles, and even the fiction and films that feed Americans' insatiable interest in biomedicine). Nevertheless, bioscience narratives often introduce 'facts,' ambiguities, and uncertainties that are selectively employed by clinicians depending on the clinical culture in which they work. Thus, physicians articulate not only local cultural values, but the sciences and therapeutics that create standard frameworks for specialty narratives.

The teaching and practice of medicine and the production of clinical narratives draw from both global and local political economies and cultures of biomedicine. What happens in clinical contexts among patients (and their kin) and physicians (and other health-care workers) may be profoundly local, shaped by cultural assumptions about the appropriate role of physicians and their obligations to patients and by dominant conceptions of the person. How – and how long – physicians speak with patients in clinical contexts and how they construct clinical narratives varies across cultures and in different treatment settings. Nevertheless, comparative studies of patient-doctor communication document how even the more culturally resilient patterns of medical practice, such as assumptions about professional obligations, modes of disclosure of information about disease state and treatment, and the bases for trust, are affected by rapid changes in the biosciences and in the organiz-

ation of health-care delivery. Thus, medical culture and the political economies of biotechnology and health-care fuel constant shifts in definitions and meanings of clinical competence, standards of care, and ethical behavior. Such changes influence the physician-patient relationship as choices of therapeutic options and the use of new biotechnologies introduce unforeseen ethical and economic dilemmas, even as they alter the narrative strategies physicians employ in the treatment of patients.

Figure 1 provides an overall schema of the approach outlined here, suggesting ways in which the patient-doctor relationship and clinical narratives are influenced by domains beyond the actual dyadic interaction in clinical settings. The approach suggests a number of questions for the study of doctor-patient communications. For example, how do physicians learn to create competent clinical narratives that are meaningful for patients? How do they come to treat patients as partners in the creation of these clinical stories? How do parallel plots – for other clinicians or for bioscientists and researchers – influence the jointly constructed stories of physicians and patients? How are therapeutic stories set in motion? In what ways do various forms of clinical narratives shape patient experience? How, in the face of serious illness, does the doctor-patient relationship mediate new knowledge and biotechnologies and bring them into clinical practice? How does the 'political economy of hope' influence clinical interactions? What are the aesthetic structures of scientific images,

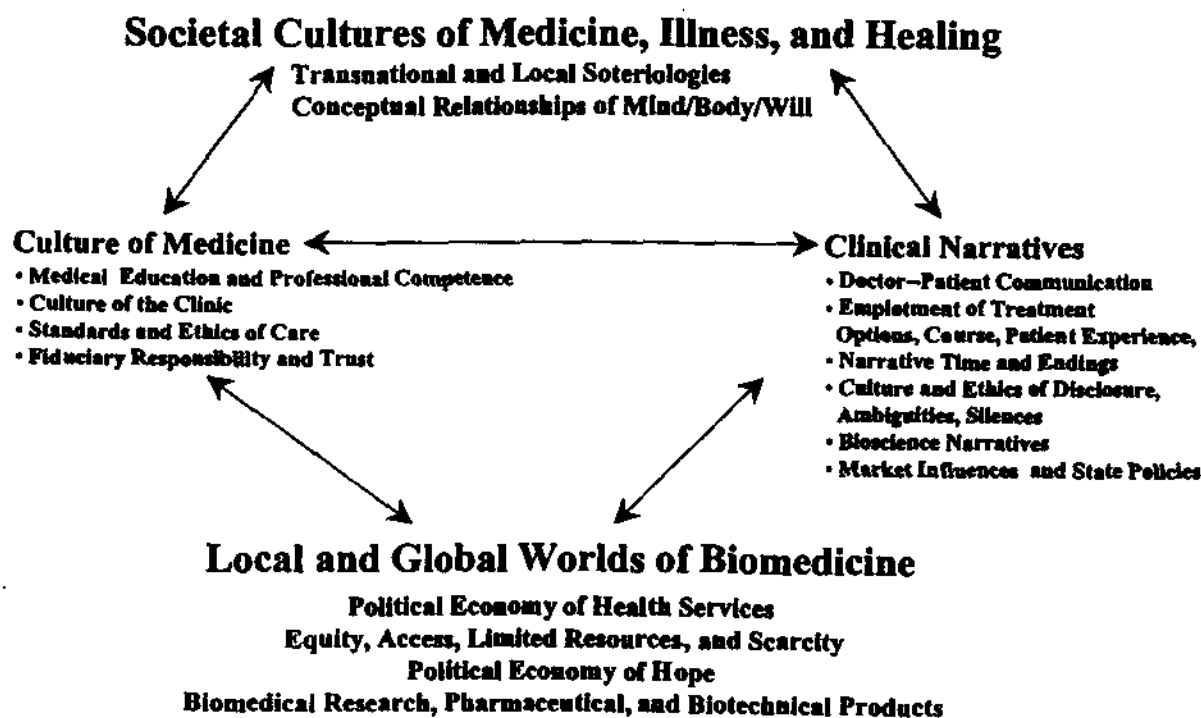


Figure 1

such as statistics, data from clinical trials, and other knowledge forms through which clinicians bring the world of research medicine and biotechnology into everyday clinical conversations, and how are these received and interpreted by patients? What does 'treatment choice' and 'decision making' mean in emotionally charged contexts of serious and life-threatening illness? What remains unspoken, masked, actively silenced, or ambiguous within the clinical narratives? In what ways do clinicians and patients encounter the ultimate limits of lifetime and engage soteriological issues through the technological treatments offered?

These and other questions provide a broad agenda for research on clinical narratives, reshaping classical approaches to studying 'doctor-patient communications.' In what follows, we provide brief examples from our research, illustrating how this analytic approach may be employed in several settings. We begin with research on medical education that asks how students learn to construct clinical narratives, and how such learning mediates entry into a complex set of medical relationships.

STUDIES IN MEDICAL EDUCATION: ENTERING THE WORLD OF CLINICAL NARRATIVES

Learning to interview patients is a critical step for American medical students entering the world of medicine. Early encounters with patients are often among the 'primal scenes' of medical education, and stories of these encounters are retold with great emotion. One medical student told us:

I never anticipated what a terrifying experience it was emotionally to see patients. I couldn't believe it! I'd even seen patients before [when he was a research interviewer]. But I was frightened. It was as if a woman came in a room you were in and started taking her clothes off! This time I was going to have to do the exam. I was the only one who was going to do it, and it happened too fast. I didn't get anything that I needed. I couldn't believe how anxiety-producing it was.

In American medical schools, enormous energy is devoted to teaching interviewing, and efforts to reform or 'humanize' medical practice often focus on teaching communications skills to doctors in training. Why then do both popular and social science reports continue to criticize physicians for their communications skills – for their failure to listen to, or provide adequate explanations to, patients?

Our research with Harvard medical students (see Good 1994: Ch 3; Good 1995b: Ch. 6–7. Good and Good 1989; Good and Good 1993) suggests that conversations between doctors and patients and the clinical narratives they construct mediate a complex set of social, cultural, economic, and biotechnical relations, and that learning to 'interview' and interact with patients is one means of entry into this complex set of relations. These broader structures are resistant to reform, and thus constrain the best-intended efforts to reform doctor-patient communications. What is the basis for this argument? How does the learning of a distinctive form of constructing clinical narratives mediate entry into the medical life world?

In early encounters with patients, medical students are often taught to listen in a common sense way, to encourage patients to tell their stories and to learn to hear what patients tell them. However, these 'interview skills' are quickly linked to a larger set of speaking and writing practices, particularly as medical students enter their clinical rotations and the social relations associated with joining a medical team. Students learn to interview patients, to take a medical history along with doing a physical exam, in order to provide data for presenting patients to other physicians during rounds and for writing-up patients in medical charts. These practices – presenting patients and writing charts – precede and provide the structure for learning to interview.

Case presentations are organized as a distinctive form of medical narrative. A medical student we interviewed described it as follows:

Telling a story is definitely one of the things, I mean that's often what you're kind of told . . . you have to organize things into some kind of a story, whether you choose to do it chronologically or whether you choose to do it from the basis of one particular disease process or something, even though it might not be exactly a chronological progression or something, but definitely you're often told to, encouraged to tell a story in some way.

Students enter the world of medicine by learning narrative practices – by learning to tell patients' stories to other doctors. These stories are not simple reports of patients' narratives. 'They [other doctors on rounds] don't want to hear the story of the person. They want to hear the edited version,' a student told us. Patients' stories are edited and retold as diagnostic stories, or as stories of the progress of a disease or treatment. They are stories that construct the patient as a medical project – a problem to be solved, a condition to be treated medically. Thus, clinical narratives are first learned as a form of stories told to other physicians.

Medical students are taught to construct clinical narratives in the context of diagnostic and therapeutic procedures. A case presentation or reporting on a patient in a chart leads directly to other medical acts, to interventions. By learning to construct clinical narratives, students enter the medical world as active participants. One student described a rotation in a pediatric emergency room.

After a while you just become totally at home because you have to, walking into a room, introducing yourself to a complete stranger, doing a history and physical and trying to make sense of the situation, and come up with a diagnosis, and come up with a treatment plan and write it up very concisely on one sheet of paper because that's the way the ER works, deciding whether they need to be admitted or not, what tests to order.

In such settings, medical students learn to tell prototypical disease stories, to act upon those stories, and to observe the consequences. Narrative, diagnostic, and therapeutic practices are closely intertwined, and clinical narratives are seen to be linked to practical effects in the real world. Learning to produce clinical narratives is experienced, in turn, as a sign of increasing maturity and competence on the part of the student.

These narrative practices position medical students in a complex set of medical relationships. Case presentations situate medical students among a hierarchy of physicians during rounds. Writing in a chart constitutes the medical student as an authorized actor, even as it constitutes the patient as a medical project. As one student told us,

To a large extent, you're authorized through your writing. That's sort of what justifies everything else, is you are actually now communicating important information, and that entitles you to poke and prod. . . . spiritually, verbally, and physically.

More than that, this set of speaking and writing practices situates the medical student in a complex social field of physicians, nurses, case managers, hospital administrators, and, potentially, lawyers. It also situates students in a field of biotechnologies, of imaging and diagnostic tools and a wide variety of therapeutic technologies. Learning the most fundamental narrative practices of communicating with patients thus draws medical students into the medical world, into this complex set of relationships, in ways that are highly constrained. Indeed, such constraints are what constitute this world as a medical world, even as they resist efforts to reform styles of doctor-patient communications.

Research on how medical students communicate with patients thus leads directly to investigations of how students learn to communicate clinical narratives to other physicians, and how this, in turn, shapes their relations with patients. It also reveals a process of maturation, a growing competence that is linked to an ability to construct complex clinical narratives in their interactions with both patients and other physicians. Our research in high-technology cancer treatments has focused specifically on such complex clinical narratives and their role in mediating broader social and biotechnical relations.

CLINICAL NARRATIVES IN HIGH-TECHNOLOGY MEDICINE: EXAMPLES FROM ONCOLOGY

The following examples are drawn from a recently completed study on clinical narratives and the treatment of breast cancer. We followed forty American women through their course of treatment at a major teaching hospital. Taped observations of clinical interactions, discussions with oncologists about therapeutic intent, interviews with patients about their interpretations of these interactions during and after their course of treatment, and interviews with the academic oncologists who care for these patients about their clinical science provided the basic ethnographic elements of the study.

Setting the Story in Motion

An interview with a female surgical oncologist.

If it's malignant, I want them to have enough information so that they have the truth, but also so that they have some hope. They know that there are things that can be done that will help them. I think the hardest thing is uncertainty, and also I think it's extremely hard if you begin to think that your doctors are not telling you things. Then you don't know if you can ever believe them. So, I find being very frank, but not discouraging, from the beginning seems to be best. . . . Women are adults, women can deal with breast cancer, and . . . you start out with that assumption and you deal with them that way. . . . When patients start out being involved from the beginning and being in *control* from the beginning, it's much better. The whole way. And treating breast cancer is a long process these days.

Setting the clinical story in motion and beginning the therapeutic process are paramount to an oncologist's clinical task, and this 'beginning'

engages most patients intensely. The surgical oncologist quoted above remarked how she deliberately shapes the therapeutic story for patients, consciously designing early clinical interactions to give patients the experience of control over their treatment course and ultimately over their illness. These early interactions, she contends, influence how patients cope with the lengthy process of therapy. In the example noted below, one of the patients in our study discusses how she chose her treatment team in response to the clinical narratives set forth in initial meetings with this surgeon and her colleagues.

Oncologists have long debated how best to carry out their clinical and informational tasks with patients. Conscious consideration of how to shape patient experience has become an expected part of clinical work. Although contemporary clinical standards vary in patient care, oncologists invest a high degree of professional attention to this aspect of their work, as evidenced by journal articles, essays, books, and interviews.

In a complex and uncertain field like contemporary American oncology, much more than a good 'bedside manner' is at stake. Given the current state of knowledge and available therapeutics, patients must rely on the clinical judgment and skilled actions of their physicians. However, in many situations, several alternative courses of action may be appropriate. Good care includes not only helping patients select a therapeutic option but also helping patients feel that a chosen course constitutes the best possible care for them. This work is accomplished through the medium of clinical narratives, and it is through this medium that clinicians mediate emerging technologies and protocols for patients.

Skilled clinicians are often quite conscious of the importance of this aspect of their work, especially women oncologists who treat breast cancer patients. This awareness reflects the challenges for this specialty; a challenge to treat life-threatening disease, often over long periods of time, in a context of high-technology medicine fraught with the uncertain efficacy of diverse therapeutic modalities and an unfolding array of treatment pathways, which at times appear to patients to be part of a never-ending journey.

Most patients in our study were aware of their diagnosis of breast cancer when they made their initial appointments at the Massachusetts General Hospital (MGH). Primary care physicians had often found cause – through routine mammograms or because of suspicious lumps – to order biopsies. Patients then began the search for a treatment setting and treatment team. Of those who agreed to participate in our study, many had sought opinions elsewhere. In the following example, we find that patients too set the

therapeutic story in motion. The choice of a treatment pathway is often entwined with choosing a team and a place that engender particular feelings about the therapeutic journey, and its many challenges, upon which patients are about to embark. It also is a choice of a particular kind of clinical story.

Choosing an Affect, Choosing a Team

In this first example, the patient chooses a team, and a comforting and calming feeling is conveyed by members of the team, rather than an explicit and bounded treatment plan. Mrs M's initial therapeutic decision – to have a mastectomy – is overridden by the particular team she has chosen. She recounted to us:

I found my lump May 14, at 1:32 p.m. and went the following day to the clinic, where I have been treated for other things. And I – they confirmed the fact that I had a lump . . . and then I think it was the next day, I had a fine needle aspiration, and they called while I was in my car and told me I had cancer – that's how I found out I had cancer, I was driving my car . . . we went back . . . we had a meeting with a surgeon, and oncologist, and a radiation person and they described the course of treatment, and we decided that we needed a second opinion, so my husband called up everyone he knew. . . .

Although Mrs M. thought she would have a mastectomy, after having read 'all those books . . . maybe easier, getting rid of the cancer,' and remarked that 'I've had that phobia, for chemotherapy for a long time because I've seen a lot of people take it and be very sick and die after going through all that,' she entered a treatment path that began with breast conserving surgery, went on to 6 months of chemotherapy, followed by hormonal therapy, and concluded with 6 weeks of radiation. She selected the third medical group she 'interviewed' for 'opinions.' All three surgeons interviewed at each of the hospitals were women, all noted she was a candidate for 'lumpectomy.' Yet Mrs M., a lively primary school teacher, told us what led her to choose the MGH team.

When I went into that room, I said "That's it," I said to my husband and daughter, "That's what I'm having. I'm going to have a mastectomy." And when we left, I said "All right, I'll have a lumpectomy." [laughs].

She scheduled the surgery that day. What Mrs M. chose was the effect conveyed by the treatment team. She commented about her surgeon:

I found her very soft-spoken . . . she had a very calming effect on me. She could tell – she told

me – bad news, and the way she tells you, she has a wonderful manner about her and her credentials I thought were great. And as soon as I spoke to her, even though the other surgeons I had spoken to – I was so impressed with at the other hospitals. I just felt very comfortable with Dr S.

Regarding her medical oncologist:

I had very negative thoughts about chemotherapy, so when she came in, I had this wall. . . . She was very good at calming me also. She said, "I'll get you through this." And she assured me that it wasn't as bad as I thought it would be, and I believe her. I still believe her. I'll let you know next week. . . .

Her radiation oncologist:

He's young, probably in my children's age group, and I really don't have a lot of thoughts about him . . . he explained very well, and he explained how he would do it, and I figure that's off in the future, if I get through chemo I'll worry about that.

She concluded, 'I was happy to have two women on the team. Very happy.' She may also have chosen a team unassociated with the initial disclosure of the diagnosis, told to her as she was driving in her car (cf. Lind et al. 1989).

As we followed Mrs M. through a course of chemotherapy ('I'm off to chemotherapy,' she sang for us to the tune of "I'm off to see the Wizard, the Wonderful Wizard of Oz") – followed by radiation treatments – a course that took over 9 months, she continued to question her oncologists about the reasons for each new treatment decision. The clinical narratives of her team not only addressed the 'why' of therapeutic decisions, but also gave scientific legitimacy to the biotechnical embrace within which Mrs M. lived for over a year. 'Why do radiation?' she asked her young radiation therapist. He justified the choice through the story of clinical evidence – the three arms of the famous and infamous clinical trials – legitimizing his recommendation in statistical terms '40 per cent recurrence without radiation, only 8 per cent recurrence with radiation, as good as mastectomy.' No mention was made of the scandal and research fraud that had momentarily cast the trials in questionable light at that time (Angell and Kassirer 1994; Rennie 1994).

Emergent Technologies and Experimental Treatment 'Rules Change': ABMT and High-Dose Chemotherapies

High-dose chemotherapy with autologous bone marrow transplantation and stem cell rescue

(HDC/ABMT/ASCR) is one of the emergent technologies and therapeutic options that patients with metastatic disease are now frequently offered (Kelly and Koenig 1998). As one medical oncologist noted in 1993 at the very beginning of our project, this expensive 'salvage therapy' had dubious therapeutic credentials. She recalled at the time that in clinical trials patients who initially responded positively to transplants 'were all relapsing at six or eight months after the transplant' (Good et al. 1995: 148). Yet in 1994, a now infamous suit brought by a California Kaiser patient who was refused coverage for ABMT helped to establish this 'experimental treatment' as a standard of care by 1995–96 (Good 1995b: Ch. 8). The chief of surgery for one of the large networks in Boston noted in 1996, 'No HMO would be able to refuse coverage now because of that suit.' In addition, the cost of providing autologous stem cell/bone marrow transplants declined dramatically – from approximately \$150 000 in 1993 to \$60–75 000 in 1995 to as low as \$50 000 in 1997. As costs declined, promoters of the procedure (HDC/ABMT/ASCR), such as Dr William Peters, who directed the Duke University Bone Marrow Transplantation Program, sought to normalize the experimental work. At a 1994 hearing of the Federal Insurance Commission in New Orleans (5 December 1994), Dr Peters argued:

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 – [one] on Day 2 and [one] on Day 6 of their bone marrow transplants – are waiting for coffee to be delivered to the hotel where they are staying during their bone marrow transplant. [Shows two slides of women; how routine, how normal, how unremarkable.] 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-1980s, the therapy-related mortality in the first 100 days was at over 30 per cent. Now, it is down in the range of about 3 per cent. In fact, if you look at the 30-day mortality shown here, again, from 15 per cent down to the 3–4 per cent realm. This represents massive change in therapy-related mortality.' (Federal Insurance Hearing transcript, New Orleans, 5 December 1994)

Even as this technological fix became increasingly efficient and standardized, and as treatment locales shifted from hospital to

outpatient services, many oncologists continue to question the procedure's therapeutic efficacy. As the biotechnological activities alter and decisions to choose competing therapeutic options become ever more complicated, especially given the uncertain efficacy of many treatments and the potential for serious clinical error, clinical narratives have to be carefully orchestrated. Yet, even with questionable efficacy, we see how the traffic between research medicine and clinical practice leads to a kind of 'biotechnical embrace' which captures and enthuses both patients and physicians in imagining the possibilities of the therapeutics of the experimental (Good 1996).

When patients enter the embrace of the high-technology world of clinical oncology, choice of treatment often recedes and choice of place, of the culture of clinical oncology, predominates. In our study, several patients with advanced or metastatic disease who were 'good candidates' were offered ABMT and high-dose chemotherapy by 1994. Invitations to experimental treatment often appeared to hold 'no choice' if one was to take the only 'chance' for cure.

The following example illustrates how patients encounter the dilemma of 'choice, no choice' and how, through the clinical narrative, clinicians create meanings of 'hope' and 'chance' through the aesthetics of medical statistics. A 54-year-old patient, Mrs R., with metastatic disease, who appeared to 'be doing quite well' according to her medical oncologist, was offered the ABMT/HDC option.

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. . . .

Thus, Mrs R. described her worries to her medical oncologist after meeting with the transplant specialist. As she debated whether to take up the invitation to undergo experimental treatment ('an opportunity' as she and her husband labeled it), she remarked that perhaps she should not go on vacation as planned. She remarked with irony and humor on the statistical odds given for the success of the recommended treatment: 'I don't want to jeopardize this great 15–20 per cent chance.' As she continued her discussion with her oncologist, she asked, 'I really don't have a choice, do I?' Her oncologist, in her gentle educator voice, but again employing the irony of life-span talk responded:

Dr: Yes, you do have a choice. You don't have a choice if you're only focusing on the big picture and 10 years down the road. Then you don't have a choice because only one of these choices can give

you a chance. But if you are focusing on the next five years. . . .

Mrs R.: Five years is nothing.

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

Mrs R.: He [the transplant] said that it's not a choice. . . .

In a subsequent interview with us, Mrs R. noted that the specialist 'gave me all the details. He was excellent. What he wasn't able to give me is the patient's perspective, only the medical perspective.'

Mrs R. is remarkably articulate, aware of the uncertain efficacy and cognizant of the potential toxicity of this experimental treatment. Yet, similar to most patients who participated in our study, she accepted the invitation with enthusiasm, albeit tempered with fear and what she noted was an underlying depression. As she proceeded to ABMT treatment (6 months after the initial invitation), she engaged her physicians with high humor, participating in the strangeness of the medical imagination and the irony of statistical odds and chances (questionably construed given the lack of clinical trials) – wondering whether she would make it into the '20 per cent success rate.' To the interviewer on her first day when stem cells were taken from her hip, she joked, 'why the hell did I decide to do this, this is stupid. Besides, the whole thing is Twilight Zone.' As her specialist entered her room, she went on, 'He's kind of got that Frankenstein look. What are we going to make today?' The discussion between patient, interviewer, and clinician evolves from the clinical event to soteriological issues of the life world and concerns with the ultimate outcome.

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? . . .

Patient: If I'm alive and well in 5 years they'll call it a success, and I'll follow the 20 per cent 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. (She was referring to Tamoxifen and soy being a natural tamoxifen.) . . . You listen to the medical profession but you've gotta 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.

Several weeks later, Mrs R. returned for a follow-up treatment just after news articles revealed that the esteemed Dana-Farber Cancer Center (a competing hospital) had inadvertently poisoned two women during high-dose chemotherapy when four times the dosage of the highly toxic drug Cytosan was administered. One woman died of heart failure directly caused by the treatment; she was 39 years old, a mother, wife, and a health and medical columnist for the *Boston Globe*, and Dana-Farber was placed on probation by the Joint Commission on Accreditation of Hospitals (JCAH). These events influenced the interpretation of cancer caregivers and patients by the community, suggesting that indeed the treatment Mrs R. was undergoing could be 'in the Twilight Zone.'

At a clinical-research related visit 3 months later, Mrs R. evaluated for her oncology nurse her physicians' skill at extracting bone marrow (not only for therapeutic purposes but for a clinical observation study). She scored each of the three '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.

She continued to reflect on her very lengthy treatment experience over the course of 22 months:

Mrs R.: 'I decided that [cancer] it 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, and their research is to see if there's any breast cancer cells in the bone marrow. So do I want to know that answer to that?'

Nurse: '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.'

Their conversation concluded with the difficulties of the uncertainty, the ambiguity, the not-knowing conveyed in the statistics and odds of a '15-20 per cent' cure rate and in the silences surrounding the clinical observational studies.

Hope in terms of odds and statistics dominates oncology narratives and becomes part of physician, patient, and family talk. Husbands in particular appear to try to master the odds talk;

patients, such as Mrs R., who are well educated, play with the odds talk, and buffer fear with the ironic humor that we observed over and over again in interactions with physicians and in our research interviews. The oncologists in the study note that at times, when alone with patients, the humor drops, the fear and tears and ultimate questions flow. In taped clinical interactions when no researcher was present, emotions were often intensely expressed, as they were in many of the one-on-one research interviews as well. Yet, hope and irony, odds and chances – these themes are not only present in many of our conversations with patients and physicians, but they arise very frequently in the clinical narratives physicians and oncology nurses use to justify and explain treatment recommendations. This deployment of clinical statistics is markedly 'American,' perhaps most characteristic of oncology narratives in American teaching hospitals.

As we examine the exchanges over time between oncologists and their patients, we find that concluding treatment appears to be one of the most difficult chapters in the unfolding clinical story. Cancer patients speak about being 'thrown from the nest,' of the sense of loss and anxiety they feel when they are no longer able to 'do anything.' Oncologists, reflecting on this concluding stage, acknowledge it as one of the classic and most difficult phases of treatment. Good clinicians reassure their patients that they will continue to see their physicians, seeing them in 'follow-up' appointments. Some patients choose to set the experience in their past, to simply 'get on with their lives'; others not only wish to 'get on with their lives,' but also seek continued connections to the clinicians who have shaped so much of their life experiences through lengthy treatment journeys, many of which have exceeded 2 years. Patients who have relapses or who are not cured of disease remain actors in the clinical stories, embraced by the experimental or salvage treatments offered, participating in a slowly unfolding treatment pathway that is marked by the uncertainty of endings.

Clinical narratives in high-technology cancer care thus mediate relations between patients and their caregivers. However, as suggested in Figure 1, they also mediate a broader set of cultural and technological relations. Newly emerging technologies and therapeutics, data from clinical trials, popular culture, and the 'technoscientific imaginary' all flow through the conversations between doctors and patients and are played out in the bodies of the patients.

CLINICAL NARRATIVES IN TRANSNATIONAL PERSPECTIVE

The perspective outlined in this chapter is intentionally comparative. Doctor-patient communications are analyzed in societal context – as embedded in distinctive cultures of the body and medicine, in particular organizational structures of health-care and biomedical research, in political economies that have powerful influences throughout the health-care system. Doctor-patient communications are also analyzed as belonging to a transnational field, as a site for the flows of knowledge, technologies, and practice forms through which local and global elements enter into conversation and conflict. How then do these issues translate cross-nationally? How do doctor-patient communications mediate local and global flows of knowledge and biotechnologies in low-income societies? How is the essence of doctoring threatened in societies that combine overwhelming disease problems with scarcity of resources? The study of clinical narratives provides a means for cross-national comparisons and analysis of high-technology medicine, as well as research on the influence of economic scarcity and disease patterns on the ways doctors and patients relate and communicate in poor societies.

Recent research on the practice of oncology in countries other than the United States provides an example of comparative studies of high-technology medicine and doctor-patient communications. Gordon and Paci's work in Italy (1997), Tana Nilchaikovit's studies in Thailand (Nilchaikovit 1998; Nilchaikovit et al. 1993), Hunt's work in Mexico (1992, 1994), our comparative work with colleagues in Japan, Indonesia, and the Philippines (Good 1995a; Good et al. 1993, 1994; Kusumanto et al. 1997; Ngelangel et al. 1995), and studies of ethnic differences within national medical cultures (Kagawa-Singer et al. 1997) document a wide variation in the culture and ethics of clinical practice, in particular in the way physicians shape clinical narratives for their patients throughout the lengthy course of treatment. More recently, essays written by clinicians from around the world and assembled by editors from the Memorial Sloan-Kettering Cancer Center have examined the diversity of the ethics of doctor-patient communications in different medical cultures (Surbone and Zwitter 1997). These essays wrestle with the difficulties and ethics of communicating information and 'truth' to patients, and with how 'truth' is defined in particular cultural contexts. However, it is not only explicit disclosure practices that vary widely. Ambiguity and silences are main-

tained and information is conveyed in culturally distinctive ways. Therapeutic choices and patient experiences are also diverse, dependent upon clinical culture and the resources available to pay for advanced treatments. Access to the latest chemotherapies or innovative treatments may be limited by government policy (e.g., in Norway bone marrow transplants are restricted according to patient age as well as health status) or by the economic situation of a country and members of its population. Current research in Indonesia provides one example of the latter (Good, forthcoming). In the pediatric oncology center in Yogyakarta, Indonesia, protocols for treating childhood leukemia (ALL) are in place. Yet, the cost of cycles of chemotherapy and of the antibiotics necessary to handle the infectious load is very high, often several times the cost of the same chemotherapies in The Netherlands (Kusumanto et al. 1997). Thus, responses to anticancer therapy are characterized by pediatric residents in training in Yogyakarta as governed by 'the economic gene.' However, levels of utilization of aggressive therapies do not depend on income levels alone. Japanese oncologists have long preferred treatments with minimal side effects (Good et al. 1993). Nilchaikovit et al. (1993) have noted, for example, that cancer patients in Europe and Asia seek care at later disease stages than do patients in the United States. This affects therapeutic options and thus the type of clinical narrative oncologists may develop for their patients.

Clinical narratives in high-technology medicine are a curious mix of local and cosmopolitan cultures. They are driven by what we have previously labeled 'the political economy of hope' (Good 1995b) and by advances in anticancer therapies, which are shared by the global community of cancer specialists and researchers through pharmaceutical markets and participation in clinical trials and new protocols. Clinical narratives are also shaped by local professional cultures, including the ethics of doctoring and patient care. Local and transnational political economies also have profound influences on clinical practice that give rise to distinctive clinical narratives and forms of communications between treatment teams and cancer patients and their families.

ANTINARRATIVE AND THE LIMITS OF ANALYSIS

The analytic concept of the clinical narrative makes sense in medical systems in which physicians are expected to communicate with patients

or with family members, over time, about diagnostic, prognostic, and therapeutic processes. Whether cultures of disclosure are more open partnerships or ambiguous, protective, and paternalistic, the relationship of patients with physicians is at least partially grounded upon an assumption of professional responsibility, a trust that one's physician will recommend an optimal treatment pathway given a particular disease and the limits of available therapeutics. However, when scarcity and disease entities overwhelm ideals of clinical practice and the basic ethics of patient care, even minimalist communication with patients may be compromised. A Kenyan physician colleague recently noted that in his teaching hospital, the ideals of the profession of medicine in the HIV era have been 'overwhelmed by disease entity.' Remarking on the difficulties of teaching medicine and patient-doctor communication when medicine wards are populated with as many as 60 per cent HIV patients, he worried about a 'numbing' that afflicts the clinical faculty and medical students and distances them from their patients. Silence and withdrawal rather than narrative come to the fore when patient care appears hopeless and potentially dangerous to the caregiver. He argued that the effects of the AIDS plague are of a different magnitude than that of poverty, economic scarcity, or shortage of medical resources.

Not only is there scarcity, but the essence . . . the principle of [doctoring] is to save life. So it comes to it that lives are no longer being saved. You have people dying much more than they used to and I really do not know how it affects me. . . . You don't get so bothered that you had a ward which was just full . . . and then at the end of the week it has been reduced . . . due to people who have died, and death no longer becomes a very serious affair. Before you would get worried when one of your patients died, but now it seems to be a usual thing. When AIDS comes in, death [regardless of cause] is so encompassed in the AIDS deaths, so that death looks the same. Even sometimes deaths you used to get so worried about - for example a young person dying - it is no longer having that amount of impact.

Scarcity in the context of whether you can do something [is different from this] - even if I gave you everything, how much of a difference would it really make? People come, and they are just dying, it is just impossible to try to comprehend what to do.

HIV obliterates, he argues, what medicine is supposed to be about and what energizes teaching and professional practice.

It makes you feel you may lose your proficiency [in your own specialty] and even your particular [ability at] solving diseases. Because you have one pattern

that comes all the time . . . diarrhea, cough, fever . . . and that pattern is all over. Even in ward rounds, it is no longer interesting because there is nothing challenging. Because medicine is supposed to challenge your mind - OK, this may be this disease, that disease, and lead to some kind of discussion. Now it goes to the extent where you arrive at the door and the diagnosis is obvious. . . . Now patients, who are in sight but . . . you don't really see them . . . *like so much wheat you don't see the other important crops for that.*

Students fear - their biggest worry is that they will not be recognized (as competent physicians with requisite skills acquired in patient care). The recognition is more frightening - doing something for somebody is no longer the norm. And when you come out of the system, you are so numbed at that initial level because there should be an ideal - so you are seeing the worst. And the people complain that new doctors don't care about their competence and training.

These comments are exceptionally frank. Although our colleague and his fellow physicians in East Africa are combating the professional 'numbing' (the 'antinarrative' response of physicians to HIV patients) by teaching students how to counsel AIDS patients and families, the point made highlights the limits of narrative analysis of doctor-patient communications.

CONCLUSION

We began this chapter on doctor-patient communication with reference to the question of trust. The issue is central in current discussions of the financing of American health care. 'Many contend,' Gray (1997: 34) argues, 'that [the] intimate dynamic of the relation between physicians and their patients has been forever altered by managed care,' but the issue of trust is hardly limited to American discussions. Kenyan physicians, as we have seen, discuss the threat to the essential fiduciary qualities of medical practice that results from their being 'overwhelmed by the disease entity.' The appropriateness of disclosing the diagnosis of cancer in societies such as Italy and Japan is debated in terms of maintaining patients' trust in their physicians. Our most basic claim in this chapter has been that fundamental aspects of doctor-patient relations, such as trust, cannot be adequately understood using models of a former era of research that focused narrowly on conversational aspects of doctor-patient communications. Any analysis of doctor-patient relations opens immediately onto discussions of managed care, the global AIDS epidemic, the appropriateness of ad-

tives for addressing such issues. The model focuses on narrative dimensions of clinical communications, on the role of story-making in giving meaning to life-threatening experience and medical efforts to respond to a changing course of illness experience. At the same time, it views such narratives as a site that mediates broader, transnational relations of social class, gender and ethnicity, of biotechnologies, professional cultures, and political economies of health care. We believe such a model has importance for comparative studies of medicine, as well as for social science interventions aimed at improving the human quality of medical care.

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NOTE

¹ Literary theorists have argued that plot provides the underlying structure of narrative, constructing 'meaningful totalities out of scattered events' (Ricoeur 1981b: 278). Reader response theorists, such as Iser (1978) and Eco (1994), have focused attention on the activity of 'emplotment,' on the response of a reader or hearer of a story who engages imaginatively in making sense of a story. Readers try to 'uncover the plot' to determine what is really going on, what is likely to happen as the story progresses (Bruner 1986). 'Narrative time' is also a central dimension of all plots, with a sequential dimension of beginnings and endings, a directionality, an outcome or conclusion that bestows sense on what has occurred (Brooks 1984). Concern about how the story will turn out, about how the present will be seen retrospectively from the vantage of the ending, is present as a structuring quality in all storytelling and emplotment. Mattingly introduced the notion 'therapeutic emplotment' (1994) and has gone on to develop full analysis of the relevance of the literature on narrativity to therapeutic encounters (1998). See Mishler (1986) for an early statement of these issues. See Good and Good (1994) for a development of these ideas as we use them here.

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