**CLINICAL "SOUND BITES".
TEMPORALITY AND MEANING IN THE TREATMENT
AND EXPERIENCE OF CANCER.**

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Introduction

This paper develops a series of research questions regarding temporality in illness experience -specifically, the illness experience of cancer patients. The research, to be carried out in one of Boston's Harvard Medical School- affiliated teaching hospitals, is planned over approximately one year beginning late this spring, and has two dimensions. The first stage deals with the perspective from the patient's side of the desk. The Patient Network, a social service to cancer patients seeking assistance in coping with their disease and its treatment, makes use of the experience and insight of former cancer patients who serve as volunteer counselors, attempting whenever possible to match volunteers and patients by diagnosis and treatment. The subjects of the study are the volunteers, rather than patients in treatment, in order to develop an understanding of temporality in survivorship. Two related questions shape this portion of research. The first of these is whether there are any consistently problematic domains of illness experience for cancer patients; and if so, to what extent these domains are generated by the institutional context of treatment in its use of space and time -for example, by the referral of patients by their oncologists to other specialists for treatment of the side effects of chemotherapy and radiotherapy.

If the spatiotemporal fragmentation of illness experience may be a source of distress and even of suffering, volunteer counseling as an aspect of survivorship may be a re-integrating experience for the formerly sick, a pathway toward the creation of personal meaning from the raw materials of illness and treatment. It is hypothesized that in the process of being trained as counselors and in the act of helping others to come to terms with their disease and its treatment, volunteers reencounter their own illness experience and come to new understandings of it.

The second stage of this research project, planned to begin in the fall, is an investigation of the clinical use of professional time. Oncologists -both medical and radiological specialists- will be followed through their work days over two-week periods in order to develop a sense of how their time is allocated and what impact this has on their relationships with their patients. The most recent research (Good, 1988) indicates that oncologists see themselves as engaged in the gradual construction, through conversation, of an ongoing partnership with their patients. The most salient aspect of this "conversation" is the practice of "staging" over time the disclosure of information concerning the patient's treatment and

prognosis, This staging is determined in part by the succession of various forms of intervention: diagnostic testing, surgery, radiotherapy, and chemotherapy. It is also linked to a parallel and complementary "staging" of hope. Oncologists share American cultural perceptions about the benefits of maintaining a hopeful and optimistic frame of mind, if not on the course of the disease then at least on the patient's social experience of illness. Oncologists also feel the need to sustain their own hope in the efficacy of the treatments they prescribe.

The proposed research, based on observation rather than interviews, provides a complementary perspective on physicians' own accounts of how they use their time and why. Attending to structural as well as ideological constraints on the clinical use of professional time will provide insight into the social production and reproduction of forms of clinical discourse -the "discourse of hope" and its linkages to other discourses (discourses of efficacy and of competence come most immediately to mind)- and of forms of patient experience as reflected in the kinds of narratives patients tell about themselves.

In putting together this paper I have made use of primary interview data from a study of radiation medicine patients conceptualized and implemented by my colleagues Byron Good, Mary-Jo Delvecchio Good, and Thomas Csordas at the Harvard Medical School; Stuart Lind, MD; and Steve Seidel (Harvard Medical School class of 1990).

Temporality and Disease Categories

Temporality in biomedicine creates categories of disease: acute vs. chronic disorders. The model for most medical care, however, is the treatment of acute problems. As Kleinman has pointed out (1988:17),

"...practitioners, trained to think of 'real' disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening" because "chronic disease by definition cannot be cured" (1988:229).

And here is the rub: the acute vs. chronic dichotomy, temporal in nature, is also a statement about where biomedical efficacy begins and ends. The acute is treatable; the chronic will persist whatever the physicians do or not do. In their clinical training, medical students' attention is directed toward those disorders that "really make you feel like a doctor". As they review the list of possible causes for a given symptom, their teachers stop them to point out forcefully, "now this one is important, because this one we can treat." (Klass 1987:228). A bit of medical-student humor recorded by Perri Klass (1987:231) reveals the frustration of being unable to cure despite lofty ideals and great expectations:

"Another day in the hospital, subjecting the sick to painful and useless invasive procedures, and curing the healthy".

Chronic diseases, then, represent a challenge to the efficacy of biomedicine, bringing to the fore issues of uncertainty and ambiguity, even of dissonance. cancer is such a disease. It

confounds even the distinction between chronic and acute diseases. It may be life-threatening in the short term, but it may also be chronic, with maintenance therapy, for years. Patients who are free of measurable disease after treatment are identified as having a cancer "in remission", although for some cancers for which the rate of survival past five years after treatment is increasing (notably Hodgkin's disease and some leukemias), even some oncologists have begun to speak cautiously of "cures". However, it remains exceedingly difficult in most cases to know when it is appropriate to talk about one's disease in the past tense.

One way of managing the challenge chronic illness poses to biomedical efficacy is to reconstruct chronic illness as a problem of technical nature, oriented toward a technical solution (Plough 1986). This is the case, for example, for coronary artery bypass surgery, which may relieve the patient's discomfort in the short term but has little effect on the long-term prognosis, since it does not reverse the blood vessel disease. It is also the case for the treatment of kidney failure through kidney transplantation or dialysis (the "artificial kidney").

Another way of approaching the same problem is to break the illness down into disorders that can be referred to other medical specialties and treated as acute problems. I suspect that this is how the multiple problems of cancer patients are handled, for two reasons. First, oncology (from the Greek *onkos*, "mass") is the branch of medicine that specializes in the study and treatment of tumors, and -as is the case with all other medical specialties- any problem not directly attributable to a tumor is of no interest to the oncologist. The development of surgical, radiological, and medical subspecialties within oncology has further narrowed interests, to the detriment of therapeutic research (Cassileth 1983:371).

Second, the language of "side effects" allows the oncologist to bracket a portion (sometimes quite a substantial one) of the patient's bodily experience, which can be treated as epiphenomenal and of minimal (if any) clinical significance; or, if persistent and severe, referred for treatment to another medical specialty. Such strategies serve the "discourse of hope" in both of its dimensions, supporting both physician's and patient's hopes for a positive outcome. The efficacy of chemotherapeutic regimens in the treatment of cancer resides in the fact that these drugs destroy rapidly-dividing cells -cancer cells, of course, but the drugs do not distinguish between these and other, healthy kinds of rapidly-dividing cells, hair follicles, and the cells that form the lining of the gastrointestinal tract. Hence the most demoralizing and stigmatizing consequences of cancer treatment -nausea and hair loss- and the less immediately obvious but more dangerous low white-cell blood counts that leave the patient and easy target for infections. These and other iatrogenic conditions in fact constitute "the illness" for some cancer patients, who experienced little or no physical distress from the disease itself before being diagnosed and treated.

Biologically, there is no difference between the tumoricidal effects of anticancer drugs and hair loss, nausea and other consequences of taking them. It is all the same effect, but

biomedical discourse separates them through the language of "side effects", which are always characterized as temporary and reversible, while the tumoricidal effects of the drugs are represented as lasting, if not permanent. Reality is, of course, messier than this. It is often true that the undesirable effects of chemotherapy reverse themselves partially or completely; nausea ebbs away, hair regrows (though often not in its pre-treatment color, texture, or thickness) and blood counts rise and stabilize. But the immune response may remain diminished, blood vessels used for intravenous drug treatment may remain collapsed, and temporary amenorrhea can become permanent menopause. Cancer cells may reappear, and secondary cancers may grow.

The hippocratic Cath enjoins physicians "First of all, to do no harm." It is evident to oncologists (Good 1988:26) that even successful treatment may be achieved at a high price; as one radiation oncologist put it, "We have this long-term debt you can't take back". Patients and even the general public are also uncomfortably aware of the dangers associated with radiotherapy and chemotherapy. The general perception that "the treatment is worse than the disease" and the continuing popularity of alternative treatments variously labeled "unorthodox" or even "worthless" by physicians are testimony to these anxieties and fears (Cassileth 1984: 110; Brown 1986).

The language of "side effects", then, is not really about the drugs and their impact on the patient's body. It is a statement about the physician's intent and a rhetorical effort to influence the patient's experience of illness and the oncologist's experience of treating the patient. My intention is therapeutic, the reasoning goes; hence the treatments I prescribe are beneficial and fundamentally benign, and the unpleasantness, pain and danger are minor inconveniences to be borne in the short term in exchange for long-term health. An apparently descriptive and referential layer of discourse reveals itself, on closer inspection, to be rooted in a metaphor whose significance is in part temporal: short-term inconvenience for long-term gains.

Biomedical discourse, then, denies the wholeness of the physical body by fragmenting the patient's lived bodily experience synchronically into "therapeutic" (i.e., tumoricidal) effects and "side" effects (see Figure 1). Then the "side effects" serious enough to be reinterpreted as "medical complications" are fragmented diachronically by biomedical practice, as the patient is referred for treatment to a variety of specialists in other diseases and/or organs and organ systems. Thus do "side effects" seem to become separate diseases, as if they were unrelated to the treatment regimen. The fragmentation of time and the fragmentation of the body reproduce each other. A third level of fragmentation has its origin in the biomedical "discourse on hope" (Good 1988), in which oncologists gradually disclose information to their patients about treatment options and prognosis in the interest of inspiring and sustaining hope - if not the hope of recovery, then of improving the quality of life - and maintaining the doctor-patient "partnership" through successive "conversations".

Temporality and the Experience of Illness

Given this state of affairs, how can we characterize cancer patients' experience of their trajectory (Strauss 1985) through the spatiotemporal order of the hospital? (I should emphasize at this point that it is the tertiary-care university teaching hospital I am concerned with here; small-town or suburban community hospitals may be quite different). The experience of one patient is revealing of how the process I have outlined may operate in practice, and how it may affect the experience of illness. The interview excerpted here is drawn from the materials used in a course I am teaching this year at the Harvard Medical School, entitled "Patient-Doctor". The patient is an elderly woman who has been treated in this hospital for approximately five years, during two of which she received chemotherapy. This interview was recorded on videotape in the outpatient department of the hospital, where she saw a primary care physician.

DR: And now, now that --let me just say this-- now you've come down to see all these doctors at the hospital, you've got Dr. Y. you know Dr. W. and you've seen Dr. C. and then you had this Dr. H. out in Chestnut Hill.

PT: Dr. Y. sent me to him.

DR: Yeah. O.K. Now let me ask you this question, then. How often do you come down here to be seen by the doctors?

PT: Dr., ah W. operated on me for a bladder, years and years ago.

DR: Do you see him once a year, or anything?

PT: I've been seeing him but I haven't been getting answers, and that's why I've been going from one doctor to another, more or less.

DR: Yeah.

PT: I went to M. He operated on my spleen.

DR: Uh hm. so you know M. too, then, here. So you know M. C., Y., and W.

PT: I tried to keep the records together, what I was -- got in the end I wasn't getting anywhere.

DR: Yeah.

PT: And this is what the social worker, gave me that.

DR: Uh hm.

PT: Those are the doctors I've seen.

DR: Uh hm. You've got Dr. F., too.

PT: Oh, I had my eye just done, I'm going to pick up my glasses.

DR: Yeah, I know all these doctors, every one of them.

PT: Well, we've been coming here for quite a while, my daughters been --

DR: -- O.K.

PT: -- taking, four or five years now, or even longer.

DR: I'm going to borrow this and send it back to you.

PT: Oh, you're welcome to have it.

DR: O.K. Now look at me. Tell me what it is you'd like us to do? You said you'd want to get things straight, but what was it that was puzzling you, anyway, about yourself?

PT: Just one doctor instead of trying to get an answer here and there. I don't feel as though Dr. Y. was doing enough for me.

DR: Yeah.

PT: I, I was coming for chemotherapy for over two years. When I came in for urinary infection, they said he wasn't around at that time, for an answer more or less. They did give me the pills, so I took for ten days

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DR: Uh hm.

PT: Dr. -- I forget the doctor's name that saw me, she was very --

DR: C.

PT: No, no. When I came in for --.

DR: Woman doctor?

PT: -- a woman doctor. For emergency, when I came in for emergency. She spent the whole day with me and she was very good with me. That's not answering any questions, but anyway, that's when I had the urinary infection.

DR: Yeah, well let me ask you this question. Have you ever looked, when you want answers, do you speak up and ask for them? Do you speak up to the

doctor and say to the doctor, now listen I want to know the answer to this? Or are you too shy to do that?

PT: I gave up. I tried to talk to them and I gave up. So I just keep quiet and say nothing, more or less.

DR: Yeah. Because there's no reason you can't speak up to me or anybody else, and say look doctor, I want to know the answer to this question. You know, because it's on my mind or I want to know what you think. You should feel free to do that, you know. I don't think any of us would ever criticize you for that, or shame you for doing that sort of thing.

What's wrong with this picture? The physician, although he tries to affirm the patient's right to question her doctor(s), has missed the point. This patient is less in need of assertiveness training than she is of continuity in her medical care.

Over the course of five years, she has been referred to as many physicians, and the fragmentation of her care has made her feel thoroughly disoriented. When she says, "I haven't been getting any answers" the doctors interpret this narrowly and literally to mean that she does not get specific answers to specific questions. For the patient, however, this statement seems to mean not one but several things. It does, at one level, mean a specific answer to a specific question, but it is also a more general distress signal; she is confused because she has been in the care of so many different doctors that it seems no one in particular is in charge, and she hopes to resolve the ambiguity by having "just one doctor" who is responsible for her care. She also feels that "Dr Y wasn't doing enough for me", which suggests that "not getting any answers" may mean "not getting cured" as well. The patient remembers with gratitude the emergency-room doctor who treated her for a urinary-tract infection and "spent the whole day with me". The patient acknowledges that didn't "answer any questions" in the narrow and specific sense, but that particular encounter answered another need, that of temporal continuity in care, at least over the course of one day.

Unfortunately, the lesson the patient probably draws from this interview is that the best strategy really is to "just keep quiet and say nothing", at least about the problem of continuity. Her questions imply a challenge to the institutional structures of the hospital and to biomedical common sense, a challenge that goes unrecognized here as it has in her past experience.

How can the temporal fragmentation of patients' bodily experience (through the language of "side effects") and knowledge about their condition (through the "discourse on hope") --what I have characterized in the title of this presentation as "clinical sound bites"-- affect their experience of illness? This remains an open question, one to be explored in research, but a reading of some extended interviews done by several of my Harvard Medical School colleagues with cancer patients suggests some possible connections.

Time is quite explicitly an issue for some of these people. One woman reported being very dissatisfied with her husband's cancer treatment at another hospital because he "never had the same doctor for longer than six months". One patient, who wished his doctor could "spare a few minutes" to telephone him at home and inquire about how he was managing, compared the hospital to

"a factory" in the way it processes people. A woman with breast cancer resented feeling that her doctor was trying to stampede her into immediate surgery before she'd had time to absorb what was happening to her. A lung cancer patient was shocked, when she finally worked up the courage to call her doctor and report her intractable pain, that the soonest he could see her was the following week. Another patient expressed a desire for advance warning about painful tests so that he could steel himself against both the pain and its emotional consequences.

These patients are not uniformly happy with doctors or the way their care has been managed. A number of them are quite specifically angry about receiving confirmation of a cancer diagnosis while coming out of general anaesthesia after a biopsy, or being told the pathologist's findings over the telephone. However, they are, in general, confident that they are getting the best treatment available anywhere, and often contrast the local practitioners who referred them to the hospital unfavorably with the specialists who are now treating them. The expertise concentrated in a research and teaching hospital is reassuring to some, not only because they hope to benefit personally from it, but because they hope knowledge gained in treating them may help someone else. But one patient described feeling like a "spectator" of his own illness, and said of his attempts to tell his doctors about the pain and nausea caused by radiotherapy, "they'll all tell me I'm doing fine, and they all disappear. ...What I should have told him was 'I feel great'".

Many, when asked how and what they believe physicians should tell patients about their illness, say, "Everything", all the cards on the table at the outset, although some, when pressed to consider whether there may be harmful ways of communicating such information, suggested that perhaps everything all at once is too much for some people. They stress that it takes knowing the individual patient to be able to judge how much time the person needs to absorb this kind of information.

Many patients do not believe their doctors understand, at an empathic level, what they are experiencing; yet they themselves often seem reluctant to talk about the emotional aspects of having cancer even when invited to do so by a sympathetic interviewer. At some point, almost everyone says something like, "I don't worry about it. I just put my life in my doctors' hands, and try to live one day at a time". In general, they have little in the way of mental images of what the cancer looks like or does inside their bodies, and when asked what they believe caused their disease, sometimes, suggest "heredity" or "environmental pollution", or -more rarely- "stress", but many also say they have no idea, and beyond these three concepts, there is no elaboration of theories of cause. Many have deliberately avoided joining support groups for cancer patients because they feel it would only "get you down". Many also resist talking about their fear upsetting the other, sometimes because they fear upsetting themselves; yet at the end of the interview, these same individuals sometimes express their gratitude and relief at having the chance to talk to the interviewer about their feelings.

Clearly, there are many contested domains here. Patient experience is far from uniform, but there is a thread of

continuity linking all the interviews. It has less to do with substance than with tone, a manner of speaking rather than the substance of what is said. One of my colleagues (Mary-Jo Good, personal communication) suggested "matter-of-factness" as a way of conceptualizing this tone. In a few interviews the patient's struggle to hold introspection at arm's length and appear self-contained and self-reliant is clearly visible, as in the case of the man who denied eight times within the first few minutes of the interview that he was afraid, worried, or even concerned, and finally mentioned his painful memories of the deaths of his father and sister-in-law from cancer and his fears that his own death would resemble theirs -- then said, "I'm meandering" and changed the subject. Some retreat into prefabricated accounts of illness experience, like the woman who, when asked to describe what it was like to have cancer, said, "It makes you think things over... appreciate things more intensely than you might have otherwise... your friends. Things that are pretty, like ... springtime. Going to museums, all that stuff." Then she added, as if aware that this was the culturally appropriate, "correct" response, "Is that enough?"

Other rhetorical strategies achieve the same purpose: a matter-of-fact attitude towards the possibility of one's own death from the "master disease" (Sontag 1978) of our century that drains the situation of its inherent drama and renders it pedestrian and routine. This requires some explanation. I am still a long way from being able to produce one, but I see the beginnings of one in the pervasive temporal discontinuity to be found in clinical discourse and clinical practice, which fragment the patient's bodily experience and knowledge about bodily experience. Cancer patients step into a looking-glass world where they lose sight of themselves as the persons they used to be. Now, as patients, they catch only fragmented reflections of themselves.

There are, to be sure, cultural styles of being sick, and our places a high premium on stoicism. Stylistic issues apart, however, it seems possible that pervasive cognitive and experiential discontinuity and fragmentation may have an anesthetic effect on sick people, raising obstacles to the creation of personal meaning in illness experience. I make no judgements here about what is the "right" or the "best" way to confront cancer. My observation is simply that the structuring of experience may leave people little choice in the matter.

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Abstract: This paper develops a series of research questions regarding temporality in illness experience to be addressed in the course of fieldwork among cancer patients in a major East Coast (U.S.A.) teaching hospital. Temporality in biomedicine creates categories of disease: acute vs. chronic disorders. It is hypothesized that the tendency of physicians to treat a long-term disease process as if it were a series of disease events helps to shape the clinical use of professional time as a highly limited resource. This, in its turn, structures clinical discourse -the gradual disclosure of diagnosis in an effort to inspire and maintain hope- and the kinds of narratives patients tell about their illness experience.

Resum: Aquest article desenvolupa una sèrie de temes de recerca relacionats amb la temporalitat en l'experiència viscuda de la malaltia, i que s'investigaran en el transcurs del treball de camp entre malalts del càncer en un dels principals hospitals del nord-est dels EUA. La temporalitat en la biomedicina origina la classificació de les malalties en dos grups: agudes i cròniques. S'hi totetitzta que la tendència dels metges a tractar una malaltia crònica com si fos una sèrie de malalties agudes condiciona l'ús del temps professional com a recurs molt limitat, i això, pel seu torn, estructura el discurs clínic -la progressiva divulgació del diagnòstic per inspirar al malalt la confiança i l'esperança- i també els tipus de narratives que expliquen els malalts sobre la pròpia experiència de la malaltia.

Resumen: Este artículo desarrolla una serie de temas relacionados con la temporalidad en la experiencia vivida de la enfermedad, y que se investigarán en el transcurso del trabajo de campo entre enfermos de cáncer en uno de los hospitales principales del noroeste de Estados Unidos. La temporalidad en la biomedicina crea la clasificación de las enfermedades en dos grupos: agudas y crónicas. La hipótesis es que la tendencia de los médicos a tratar una enfermedad crónica como si fuera una serie de enfermedades agudas condiciona el uso del tiempo profesional como recurso muy limitado, y eso, en su turno, estructura el discurso clínico -la progresiva divulgación de la diagnosis para inspirar al enfermo la confianza y la esperanza- y también los tipos de narrativas que explican los enfermos sobre su propia experiencia de la enfermedad.