

THE POWER OF COMPASSION: TRUTH-TELLING AMONG AMERICAN DOCTORS IN THE CARE OF DYING PATIENTS

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Abstract—The perceptions of American doctors about their practice regarding truth-telling in the care of dying patients were examined based on semi-structured interviews with 32 physicians in a teaching hospital. The doctors inform patients of their disease using three basic styles; ‘telling what patients want to know’, ‘telling what patients need to know’ and ‘translating information into terms that patients can take’. These styles are supported by five basic normative principles; ‘respect the truth’, ‘patients rights’, ‘doctors’ duty to inform’, ‘preserve hope’ and ‘individual contract between patients and doctors’.

These styles and principles suggest that physicians adhere to the recent trends of American medical ethics based on informed consent doctrine, and give the impression that patients have control over obtaining information. But close analysis of their accounts shows that physicians still hold power to control information through their management of the information-giving process. The styles and principles are flexibly interpreted and selectively used in the process so that they facilitate a discourse which justifies, rather than eliminates, the information control.

Clinical contexts of information control are analyzed by examining dissimilar manners of providing information about treatment as opposed to prognosis. Physicians give less, and vaguer information about prognosis, citing its uncertainty and lesser relevance to future actions as reasons. Information about treatment is more readily shared in order to counterbalance the negative impact of the news on patients. The analysis reveals that the way doctors control information is closely related to the way they handle aspects of the reality of clinical practice, such as physicians’ own emotional coping, institutional and legal constraints, and power relationships among patients, doctors and other care-givers.

Situating the findings in the historical context of normative discourse in American medicine, discussion focuses on the issues of trust and power of doctors. The humanistic role of the doctor, although suppressed in the currently dominant, contractual ethical framework, is still powerful in doctors’ narratives. It expresses doctors’ commitment to patients while preserving their authority. Implications of the individualistic approach to the doctor–patient relationship are also discussed.

Key words—truth-telling, informed consent, terminal care, American medicine, doctor–patient relationship

INTRODUCTION

Patient–physician communication with respect to disclosure of information about cancer has undergone significant changes over the past three decades in the United States. Studies up to the mid-1960s show that most doctors did not inform cancer patients of their diagnosis [1, 2]. A study done in 1977, however, reported 97% of physicians said they routinely disclosed the diagnosis of cancer [3]. Now, most patients in the United States are informed of their diagnosis and the view that patients should be given information about their illness is widely accepted.

Several factors have been cited as reasons why the practice in the United States on disclosure of cancer diagnosis has changed. These include the development of therapeutic technology, improved rates of survival of cancer patients, involvement of several professionals in care, altered societal attitudes about cancer, awareness of death, physicians’ fear of malpractice suits and increased attention to patients’ rights [3–5].

Among these, probably the most influential factor has been the doctrine of informed consent developed in medical ethics and law, and which is now recognized as one of the most important ethical principles of medicine [6]. According to this principle, patients have a right to make autonomous choices regarding their own care, and physicians have a duty to give all material information to enable them to make such decisions. Physicians must not withhold information even if the information may have a negative effect on patients. It is supposed that by acquiring control over information, patients can secure more control over their own body and life, rather than depend on physicians to act in their best interest. This doctrine has been the major discursive ground on which the struggle for a more equal power relationship between patient and doctor takes place [7].

Although the medical profession seems to display a willingness to accept it [3, 5, 8], it is not clear how much doctors have genuinely accepted this rather new idea of more egalitarian doctor–patient relations. The shift of power may be unwelcome if we employ

an argument that physicians preserve their power position based on possession of esoteric knowledge [9, 10]. In fact, there are a number of critiques which suggest that physicians continue to control information and which indicate patients' dissatisfaction about getting information [11, 12]. Examining truth-telling to cancer patients, Taylor observed that although physicians disclose the diagnosis of breast cancer to patients, doctors experience this task as stressful and routinize it by often 'dissimulating' or 'evading' the true nature of the illness [13]. In another study by Good *et al.* [14], American oncologists they interviewed thought that the disclosure of diagnosis is necessary for treatment and for building a partnership between the physician and the patient but that total frankness about prognosis and treatment is not an operative norm. Good *et al.* argue that American oncological practice, infused with popular notions about the relationship between psyche and soma, draws on distinctive cultural meanings about 'hope', and that for physicians to maintain or instill hope in their patients, the control of information is essential [14].

This paper examines physicians' views about their own practice regarding truth-telling and their ethical standpoints by addressing several specific points of inquiry. Do doctors withhold certain information consciously as the previous studies suggest? If so, how do they resolve the conflict between informed consent doctrine and their information control? Does the withholding imply that doctors do not really believe in the importance of patients' autonomy and resist compliance with the informed consent doctrine? Is the notion that patients need protection from the too-stressful truth still a strong norm among doctors? What factors do doctors attribute to their behaviors which diverge from the new ethical framework which they say they employ? Does physicians' self-protection against the stress of truth-telling influence their behavior, or do they feel threatened by a loss of power if they share information with patients? Does the institutional framework in which doctors interact with patients affect how the information is conveyed?

Physicians' subjective views are indispensable to an understanding of how the discourse of truth-telling takes its shape in contemporary American medicine. The paper is based on an interview survey I conducted with 32 physicians at a tertiary care teaching hospital in the northeastern United States. The interviews focused on information-giving to terminally ill patients rather than to cancer patients alone in order to distinguish information about the true nature of illness from the mere diagnosis of cancer. Although the interview format does not allow a direct view of what doctors actually do, physicians' accounts of their current practice of truth-telling provide a means to examine the values and beliefs they adhere to as well as their view of clinical reality [15].

This paper argues that, taken at face value, physicians' discussions of their styles and normative prin-

ciples on disclosure are very patient-centered, and in the minds of doctors probably reflect their intent. However, the paper's analysis suggests that doctors use styles selectively and interpret norms flexibly, depending on the information in question, and that in this way physicians exercise continuous control over information to meet their own needs and the needs they impute to patients. Physicians exercise power over patients through the continual management of the information-giving process, not through mere possession of information. An individualistic notion of information-giving from the doctor to the patient can work against patients in this process, since it legitimizes the exclusion of family members and other health professionals, and may mean patients can count only on their own ability to counteract the constraints placed by the doctors on the process.

By examining a mode of information control which has been overlooked in previous research—physicians' emphasizing treatment-options information while playing down grim prognosis information—the present study reveals and clarifies the significance of contextual aspects of physicians' information-giving, such as the uncertainty of clinical medicine, institutional and time constraints, the need to deal with their own as well as patients' emotions and the power relations among doctors, patients and other caregivers.

The physicians' narratives in this study, situated in the context of a patient-doctor relationship that is shifting from paternal to contractual, show the ambiguity and tension which define the doctors' new role as a partner of the patient. Preservation of their image (and self-image) as compassionate and caring physicians helps them to manage patient care in emotionally-laden situations like truth-telling as a healer. However, this humanistic model of the physician serves also to maintain the power of the profession, enhancing its 'cultural authority' over patients.

METHODS

This study was designed as the first stage of a comparative study of physicians' attitudes toward truth-telling in the U.S. and Japan. The Japanese part of the study was not completed by the time of writing. Although the present study does not include any comparative analysis, the interpretation of the data necessarily reflects the author's experience of medical training and work as a physician in Japan, where patients are usually not told about the terminal nature of disease.

Thirty-two physicians at a major east coast teaching hospital were interviewed in a semi-structured format for 1 hr by the author. The sample was equally divided between medical and surgical physicians as well as residents and senior staff physicians with 20 years or more clinical experience. Senior staff

physicians were recruited individually by letter and follow-up telephone call. Residents were selected from working shifts during which they had more time available. Mean ages of each group are: medical senior staff physicians, 62.1; surgical senior staff physicians, 59.3; medical residents, 27.6; surgical residents, 30.5. Mean years of clinical practice are, respectively, 38.3, 34.1, 1.4 and 2.9. Three medical residents and one surgical resident are female.

The original interview format was drawn from a review of the existing literature on the issue of truth-telling [3, 5, 13, 14, 16] and the author's 3-year clinical experience. The semi-structured interview format was open-ended, allowing physicians to speak as much as they wanted to. It included very general questions at the outset, such as "what do you tell patients about their prognosis" or "would you describe recent cases", and specific questions such as "do you use statistics" later in the interview. As themes developed in their responses, they were asked additional questions. This method of interviewing allowed eliciting of detailed information, as well as of subtle nuances which constitute an important part of participants' perceptions of the subject.

Interviewees were asked about their styles and experiences of informing dying patients of their diagnosis and prognosis, their reasons for and basic philosophies of informing a patient, the medical training and clinical background which influenced the establishment of their style and their opinions about the shifts in American physicians' attitudes toward truth-telling.

In the interview, 'terminally ill patients' were defined for the physicians interviewed as patients who have a 95% or more chance of dying within 3 years. With this definition, the terminal illnesses the interviewed physicians focused on were mainly various malignant diseases. Some mentioned patients with terminal stages of cardiac, renal, lung, or liver disease, inflammatory bowel disease (Crohn's disease, ulcerative colitis) and AIDS.

All interviews were audiotaped and transcribed. Immediately after each interview, notes on impressions were taken. These were later used to select the focus of the subsequent analysis. In order to avoid forcing the data into a preexisting theoretical framework, the interview data were coded initially by reviewing each line of the transcript by the author following the methods of Glazer and Strauss [17, 18]. The author's initial codes were checked against codes assigned by other researchers. Specific analytic categories were then formulated from the initial codes. In the process of formulating the categories, attention was directed toward the inconsistencies and ambiguities which appeared in physicians' descriptions and justifications of their practices. General statements and the detailed descriptions of their practice in specific contexts were compared. Some of the data were quantified based on the categories, not for

statistical analysis, but to capture the diversity of the subjects' views. Except where specifically mentioned, differences by specialty and generation were not significant. As the number is rather small, difference by gender, race and religion is not included in the analysis.

The categories derived from this process, such as basic styles and basic principles, are neither exhaustive lists nor 'real' facts of physicians' behavior. Rather they constitute a professional discursive framework [19] in which physicians resolve ethical conflicts on truth-telling. To test the generalizability of these findings, further research with a larger group of physicians in different settings and a more structured data collection method would be required.

RESULTS

I will say that 'you have a very extensive tumor' and tell them a little bit more about where the tumor is, then I will pause. At that point they frequently will ask other questions, and *I will give them an honest answer*. If they say, 'is it cancer, doctor?' I will say, 'yes, it is,' *as kindly as I can say it*. And then *if they ask nothing more, that's the end of it*. But if they say, 'is there any cure for it?' I will answer that honestly, if they ask that. I will not say to them, 'you are incurable.' But if they then ask me, 'can it be cured?' I will say, 'I'm very sorry to say that experience has shown that cancer involving thus and such, let's say heart, from the lung, is not curable.' And if there are any positive things at that point, *I try to balance it with something positive*, like saying, 'but, however, this type of cancer'—if it's true—I don't tell them if it's not true—say it's a squamous cancer, 'this type of cancer does respond to radiation treatment and sometimes to chemotherapy.' And *for most people we'll stop there*. But if they ask me, 'what do you mean respond,' I'll say, 'well, it shrinks and gets smaller.' And if they ask me, 'permanently?' I'll say 'no, almost never permanently.' And if they say, 'for how long,' and I won't go into all that with you now, I'll simply tell them, '*it's impossible to predict, which is the truth*. *If the patient has some sophistication* I will explain to them that all statistics are made up of a bell-shaped curve, and for the individual person the prediction of length cannot be made. We can tell you on an average that will give you some kind of a figure if they want it. If they say, 'what is the average?' I will tell them. In other words, *basically the patient asks me what he wants to know and he gets an honest answer*. No matter how bad the answer is. . . . If they don't want to hear the word, even if they know the answer, they won't ask you, 'is it cancer, doctor?' If they can handle the word cancer, they may ask you, 'is it cancer?' And then you can say it. And *I will not, on principle, tell people falsehoods*, even if the family asks me to. But on the other hand I never bludgeon them with their diagnosis. *I simply answer the question that they ask*. And *they ask what they need to know*. [Emphasis by the author.]

Physicians' initial responses to the question, 'what do you tell patients who have a terminal illness?' are generally very 'nice,' textbook-type answers characterized as 'truthful' and 'patient-centered.' However, as they begin to provide more detailed accounts and examples of how they deal with specific information and situations, these initial descriptions become compatible with a range of meanings wide enough to allow doctors' control of information. The statement

above, made by a senior surgeon, captures the coexistence of his subtle control over the information flow with his moral claim that he tells the truth, respects and cares for patients.

First I will describe several 'basic styles' characterizing what physicians say about how they inform patients and several 'basic moral principles' that physicians invoke as a normative basis for these styles. The focus of my analysis is on their ambiguity, which allows a certain mode of controlling information. I will then contrast how physicians handle information about prognosis with the way they handle treatment information, in order to show how these styles and principles are applied to control information in a clinical context.

A. Basic styles of truth-telling

The approach of most doctors in this study to information-giving to dying patients can be summarized as 'we tell what patients want and need in the way they can comprehend.' Positing patients' 'desire' and 'need' as main criteria of information-giving and recognizing the need to adjust knowledge to each patient, the physicians demonstrate their patient-centeredness. However, the following analysis of the approach in terms of three styles will show that doctors' ability to distinguish subtly between patients' 'desire' and 'needs,' as well as to assess the patient's emotional and intellectual capacity, provide opportunities for control.

1. *Telling what patients want to know.* A majority of the doctors explain what they tell terminally ill patients about their diagnosis and prognosis in terms of patients' desire to know, based on a belief in patients' right to know and on respect for their autonomy (Table 1, item 1). For example, one senior surgeon says, "I leave it completely open to them to ask me anything they want to ask me." Although seeming to cede control of information to the patient, how much information is actually given depends on the doctor's assessment of the patient's desire to know. If patients don't ask any specific questions, many doctors interpret this as an indication that the

patient does not want to know. A senior internist says,

If I suspect on my initial consultation that we may be dealing with a terminal illness, I often emphasize to them that I will always tell them the truth. So, I've sort of laid the groundwork before I have the data to say, 'If you ask me a question, I will always tell the truth,' which is part of my technique, so that if they then don't ask me that question, you know, it sort of says to me, 'Well, they're not really all that anxious to hear about it.'

Equating what patients want with what they ask might be a proper 'technique' if patients were under no constraints. It is well known, however, that physicians' behavior, both conscious and unconscious, influences or even restricts patients' questioning [20-23]. Physicians' statements in this study show their varying degrees of openness, willingness to spend time with the patient, sensitivity to patients' subtle cues and active elicitation of patients' desire to know. By changing these aspects of the relationship, they influence and thus control patients' questioning. For example, as shown in the first quote of this section, patients sometimes must extract information from physicians, actively uncovering physicians' mode of operation. In light of this, one might ask how many patients can actually track down the terminal nature of their illness. Through this process, the patient's apparent level of willingness to know can often become just a reflection of the physician's willingness to impart information.

2. *Telling what patients need to know.* Patients' need to know, although subordinate to patients' desire to know, is another major criterion physicians said they use to assess what information to give to patients. If the physician regards it as necessary for the patient to have certain information, s/he will give the information actively regardless of the patient's desire, as expressed in the remark by a medical resident. "The least that I will do, even if the patients don't want to know, is to let them know that they are sick. . . . I wouldn't allow a patient to go out falsely thinking that everything was fine because they didn't want to know." Even when patients explicitly claim that they

Table 1. Physicians' perceptions about truth-telling. Dr = doctors, Pt = patients, Info = information. (N = 32)

Item	Yes	Want + Need	Yes, but not too much	Uncertain
1. Inform Pt as much as they want	23 (72%)	4 (13%)	4 (13%)	1 (3%)
2. Give Pt optimistic/pessimistic estimation, or share uncertainty	Optimistic 21 (66%)	Pessimistic 1 (3%)	Share Uncertainty 10 (31%)	
3. % of dying Pt know diagnosis	All Pt 12 (38%)	Most Pt 19 (59%)	Uncertain 1 (3%)	
4. Withhold Info. if Pt unwilling to undergo a treatment	Yes 1 (3%)	Flavor 2 (6%)	Tell More 6 (19%)	No 23 (72%)
5. % of dying Pt know that they are dying	All Pt 10 (31%)	Most Pt 17 (53%)	Some Pt Deny 2 (6%)	Uncertain 3 (9%)
6. Explicitly tell Pt that they are dying	Yes 15 (47%)	Use Euphemism 7 (22%)	No, But Pt Know 3 (9%)	No 7 (22%)
7. Pt know approx how long they can live	Yes 10 (31%)	In Broad Range 7 (22%)	Optimistic Estimate 6 (19%)	No 9 (28%)
8. Use numbers in telling prognosis	Yes 6 (19%)	In Broad Range 12 (38%)	Avoid 8 (25%)	No 6 (19%)
9. Use statistics in telling prognosis	Yes 8 (25%)	Yes, Some 12 (38%)	No 12 (38%)	

don't want to know, more than half of the doctors say they employ alternative actions, such as giving modified information, giving minimum information, or telling the family. The tendency toward active information giving is more significant in surgeons, reflecting their need to get patients' consent to surgery. If doctors regard information as not necessary for the patient, the information is said to be given only when the patient asks for it very explicitly, as shown in the previous section. In other words, depending on how important physicians think the information is to the patient, their willingness to give it to patients changes.

Criteria used to decide what information is needed by patients vary among the doctors. Issues commonly taken into consideration include availability of treatment, seriousness of the disease, the patient's family and social responsibility, the patient's financial arrangements and the patient's personality. Clearly, the physician's assessment of these criteria for judging what needs to be known may be different from the patient's, especially when the physicians do not know patients well. Moreover, the 'need' can be the need of physicians themselves to have the patients know. Some doctors say they need to tell patients about how the symptoms will progress so that patients know physicians understand their illness. They believe that maintaining the patient's trust in the physician's competence (and, presumably, preserving the doctor's authority) are important for the management of patients care.

Legal obligation is also important in physicians' definition of 'need'. A senior surgeon states,

If they don't want to know, they don't get any information. I've had people say, 'I don't want to know anything, Doctor. I don't even want to know what the operation is. Don't tell me about the operation.' Now, we have to tell them certain things because the lawyers in the United States have made that necessary. It's part of the law that we have to tell them about certain complications and, to a degree, what operation we're going to do.

The point here is that the 'need' of patients is assessed by the doctor, not by the patient, often being infused with the physician's own perceived needs, such as keeping patients' trust or avoiding legal problems. Decisions about how much information is to be given are still the doctor's.

3. *Translation of information into terms that patients can take.* A majority of the physicians consider it necessary to modify information to a certain extent, given the gravity of information and the unequal medical knowledge possessed by doctor and patient. As a medical resident states, "we have to use our judgment in terms of how we present the information to the patient." Crucially, how and to what extent information becomes modified is up to the physicians.

First, this style mandates that the physician's professional knowledge about the patient's disease be translated into terms that the patient can take *intellectually*. Most physicians say they decide how much

medical terminology to use, and how much to simplify the explanation by evaluating patients' ability to understand in terms of age, gender, occupation, educational level and the precision and assertiveness of their questioning. But in the light of the following statement, one might ask whether this style helps every patient to acquire appropriate information. It may mean that a sophisticated patient gets detailed information, but that patients who need more help to grasp their situation are in practice denied it.

You have to tailor your information to the abilities of the patient and his education and his comprehension. Some people simply cannot understand what you say, so you have to simplify it. And those are the people who often ask very few questions, so the problem takes care of itself. It's the university professor from the Harvard Business School who wants to know everything. And I've had them sit where you're sitting with a tape recorder because they want to be sure they know what I said, so that they can go home and play it back and forth, you know, to the husband or wife. And it's a good way. For them, it works.

Second, physicians' knowledge has to be translated so that patients can take it *emotionally*. Many physicians say they often try to avoid certain 'dirty words' such as 'cancer' or 'malignancy' and try to use 'unthreatening terms'. They also use euphemisms very often. A medical resident says, "I will convey prognosis by alluding to how serious—'might be difficult for us to control it,' but I never say 'your prognosis is terrible, or bad or favorable'." The degree to which information is modified or softened depends on physicians' evaluation of the patient's ability to cope with the information. Factors influencing physicians' evaluation are patients' age, gender, personality and emotional state. If the patient is anxious and appears insecure, more than three-quarters of the physicians say they tailor the information they give to patients or give it more gradually and carefully. Some physicians, however, think it is very difficult to evaluate patients' ability to cope, and they think it should not be the reason for not informing patients.

B. *Basic moral principles*

The reasons physicians give for employing the basic styles are usually internal norms, rather than external strictures such as legal rules. In other words, they are presenting themselves as autonomous moral agents. They claim that what they do stems from the belief that it is the correct thing to do.

In this section I summarize 5 principles the physicians commonly mentioned as a basis for their behavior: (1) respect the truth; (2) patients' rights; (3) doctors' duty to inform; (4) preserve hope; (5) individual contract between patient and doctor. These are not particularly new to the current discourse in American medical ethics. Nonetheless, the fact that these moral principles often exist in conflict will show that the paternalistic view has not totally disappeared. Furthermore, to grasp the context-dependent meanings of certain critical terms such as 'truthful-

ness' and 'hope,' it is worth noting what the principles *mean* when doctors apply them in the actual process of information-giving.

1. *Respect the truth.* Most of the doctors I interviewed support the principle of respecting the truth, which underpins their styles of telling based on what patients want and need to know, and none advocates lying. But this does not mean that they tell the whole truth.

First, several physicians assert that there is no 'whole truth' available even to physicians: they stress that most medical information itself is uncertain and revealed gradually in accordance with the natural course of a disease, intervention with diagnostic tests and treatment. A surgical resident says, "We as physicians, . . . personally I don't know all the information, and I also don't know the truth, I don't know how good the information is. Using statistics and all that, I really don't know what the truth is in terms of what this disease is going to do."

Second, as described in the previous section, some physicians argue that even if the whole truth is available, the truth to be told to patients is the relevant truth which patients want and need.

Third, many doctors justify withholding information by an assertion that 'I haven't told that yet,' because information-giving is not done at a single moment in time, but is a continual process in the therapeutic relationship. This delaying of information-giving is discussed in Good *et al.* [14] in relation to physicians' conscious efforts to help the patient to maintain an appropriate degree of hope at each stage.

Finally, few physicians consciously categorize different modes of speech, such as sweetening, softening information, avoiding certain words, using euphemisms, giving hopeful information selectively, as 'lying.' They are rather seen as a necessary part of 'translating information.'

How we present the numbers to patients, will dictate how they hear it, so it makes sense, in other words, if I say 90% will die, or 1 in 10 do better, then I think patients hear different things. And so the physician has a lot of power in terms of how they present the information, so I can withhold, I think withholding information is different, but to tell a lie, 'oh, no you are going to do fine,' or 'you will be dead in a year,' those are both lies, because there is no way you can know.

This conception of lying corresponds closely to the research findings by Novack *et al.* on physicians' use of deception, that physicians have different personal definitions of deception [24].

The consequentialist approach by physicians noted in the same research is also apparent in the present study: only a third of the doctors judge the value of the truth in terms of truth itself rather than in terms of consequences. The other two-thirds say they modify the information, if they think the truth-telling will have a seriously bad outcome. It is important to note that, just as in assessing the patient's desire and need

to know certain information, it is the physician who makes the crucial assessment as to the 'goodness' or 'badness' of outcome. Certain outcomes, such as losing patients' trust or facing legal liability, might be more important for the doctor than the patient.

In summary, 'respect for the truth' is often very different from 'telling the truth,' and the meaning of the truth itself is very flexible. A senior internist says, "I will always *respect* the truth, but I may not *tell* the truth because of the consequences" [emphasis in original].

2. *Patients' rights.* The language of rights is quite often used by the doctors interviewed in terms of the right to know, to make a decision, to self-determination. A statement by a surgical resident is exemplary: "my main reason is that I think that people have a right to know what their medical problem is and how it will affect their lives."

Paternalism is severely criticized as a violation of these rights. Even if patients don't follow the doctor's advice, if they are given relevant information and understand it correctly, eight-tenths of the doctors say they respect patients' decisions. Other doctors think that patients' self-determination can be restricted, but only in an extraordinary case such as suicide, or escape from the hospital on the day of operation. However, as we have seen, patients' decisions are affected by the way doctors give information, such as emphasizing the uncertainty of results, recommending specific treatment or persuading patients to change their choice as shown in the 'translation of information' style. Although the 'rights talk' reflects concerns with legal aspects of informed consent, it often lacks specific legal standards of information disclosure. The doctrine of informed consent requires that all relevant information be given to patients in a way they can understand, so that they can make an autonomous decision [25]. As long as it is doctors who define what information is 'relevant' and 'understandable to patients,' patients' autonomy and rights are subject to limitations beyond their control.

3. *Doctors' duty to inform.* The notions of the doctor's duty, obligation and responsibility are also commonly mentioned. Compared to the doctors' use of 'rights talk,' these have a moral and ethical, rather than legal, resonance. Most doctors regard the task of informing patients as "an obligation that I want to fulfil, because it's one of the most important things that I have to do as a patient's doctor," and "one of the responsibilities that you bought when you became a physician." Another physician says,

I don't enjoy it, but they came to me for medical advice and opinion and I feel I have to do the job that I'm supposed to do. It's, you know, it's—I can't think of a word for it. It's a sad duty, but it's a duty.

This strong moral sense of duty has some interesting aspects. First, it sustains the physician's self-image as an autonomous moral agent. External constraints,

such as fear of malpractice suits and knowledge about the legal concept of informed consent, however influential for their practice, are kept implicit as determinants of what information they give to patients. Second, the moral duty is not a mere reflection of patients' rights. It connotes heavier responsibility on the physicians' side, reflecting their recognition of their authority over patients. It assumes physicians' loyalty to patients. In spite of their rejection of paternalism, and its contradiction with the patients' rights principle, many physicians express the belief that they have a moral duty to protect patients. Third, since it is the physician's duty, the information that physicians perceive as necessary to patients acquires priority over the information patients merely want.

4. *'Preserve hope' principle.* Maintaining hope [14], is another very frequent statement. Most doctors think that whether patients lose their hope or not is the doctor's responsibility. Two-thirds of doctors say they inform patients optimistically when things are uncertain (Table 1, item 2). A surgical resident who chose to give pessimistic information seems to try to give patients hope through a different logic:

I share my uncertainty, but I tend to favor the pessimistic approach. I make it sound worse. If it is someone who, even if it is someone who hinges on every word, I think it is better to paint a worse picture, because it is better to get things in order and to have bonus time, but to be thinking about 3 years, and all of a sudden in 1 year have that time snatched away from them. I think it nicer to be surprised with extra life, than it is to be surprised with less life.

The principle of hope conflicts with other principles, because it sometimes mandates withholding or modifying the truth, an action which can be criticized as paternalism. However, the ethical conflicts do not emerge very obviously in the doctors' accounts. In fact, most doctors say truth-telling itself does not necessarily deprive patients of hope, expressing views such as "only a few patients cannot cope," "most patients regain hope even if they are in shock temporarily," "many patients feel relieved when they know the truth" and "it is easier for patients to fight the enemy which is known to them." But some doctors say "it depends on how it is told." Very often, doctors seem to mediate the conflict between truth and hope by the way they represent 'the truth' to patients and through utilization of 'the translation' style. If the news deprives patients of hope, half of the doctors say they withhold information, soften information, give miracle anecdotes, or counterbalance with the possibility of treatment, which, as described in the 'respect the truth' section, they do not think is telling a lie. When doctors describe their behavior as optimistic, they quickly add a phrase like, "but not unrealistic" or "emphasizing uncertainty at the same time."

It is important to note that the doctors mention different kinds of hope, which influence how the doctor presents the truth: for example, hope for cure, hope for freedom from pain, hope for accomplishing

something before dying, hope for dying a good death. What is hope for patients is partly related to the doctors' own philosophy about life and their own perspectives on the role of medicine and the doctor, and can be confused with the doctor's own hope. As discussed in Good *et al.* [14], physicians interviewed in this study expressed similar confounding of patient and physician's hope.

I do not think that any patient should ever have all hope taken away. I think that's a very difficult position to be in. And I think there are a few situations, where there is really no hope. I think that a lot of that has to do with my own personal beliefs and by that I mean, that if the physician is a very optimistic person, they don't see situations very often as having little hope. If the physician happens to be a very pessimistic person, you know some physicians see the glass as half full and others see it as half empty. If you're in the half-empty group, you may be confronted with many more situations which you see as hopeless and I think life in medicine for those physicians is much more difficult.

5. *'Individual contract between patient and doctor' principle.* As in the study of oncologists by Good *et al.* [14], most physicians in this study also state that the primary therapeutic relationship is a dyad, and that communication about illness is primarily between physician and patient. An individualistic understanding of the doctor-patient relationship is a presupposition of the three styles and the other four principles: rights are possessed only by the patient, the hope to be maintained is the patient's, the physician's duty is only to the patient, and the truth goes between the two.

When asked about the family's involvement in information exchange, many doctors mention their sole commitment to the patients, although about 90% of the doctors reply that taking care of terminally ill patients is a team effort including other health professionals and family members, and a few doctors even mention the major importance of family members. They say, "it's up to the patient," "my role as a physician would be to tell the patient," and "It's his body, and his life, and his death that's at stake." Three-quarters of the doctors, therefore, disagree with the family's restricting information to patients. More than half of physicians say they usually disclose bad news to the patient for the first time when the patient is alone. Some physicians mention the family's need to know, but this is minimized by the priority given to patients' control over their life and death. The family's emotional coping with the patient's illness is left out of the picture and it is simply 'unethical' for physicians to consider the family's financial concern over treatment options. Viewing patients as isolated from a social network such as their family is often said to reflect the patient's own philosophical standpoint. Physicians' basic commitment to the patient alone and the delegitimization of family members' participation in a therapeutic relationship, however, seems to reinforce a view which not all patients share.

Family members are often perceived negatively as interlopers or confounders of smooth and straightforward communication, and their exclusion is thus justified by doctors. A general distrust of family members is also often expressed:

It is so hard to tell what a family wants, so if they want to get the money, to be the beneficiary of the will or not, you just never know what someone's motive is, and not that I'm a suspicious guy, but sometimes you see family members who have been far away for twenty years, and they hear someone is dying, and they run in and then shower them with flowers, and all this kind of stuff. It may be guilt, but it also may be manipulative.

Several physicians say that family members are less capable of coping with patients' diseases and tend to be less rational. It is unclear whether these are valid observations or a reflection of the physicians' frustration with the actions of family members when the latter act as the patient's advocate. Interestingly, however, in contrast with their descriptions of family members, no physicians in this study mentioned patients negatively, e.g. as manipulative or irrational. This suggests that although the question of who gets information is closely related to the complicated power relationship among doctors, patients and family members, power issues may be masked by a discourse which is exclusively ethical.

As in the abstraction of patients from their social relations, the individualistic approach also appears in physicians' self-portrayal, depicting themselves as separate from their professional milieu. Physicians describe care of the terminally ill as a 'collaborative effort,' 'multi-disciplinary follow-up' and a 'multi-faceted thing,' involving other health professionals such as hospital and hospice nurses, social workers and sometimes psychiatrists. However, when the issue becomes information-giving, the picture shifts sharply, and the doctor's role as principal information-giver is justified by statements such as, "the doctor is the team leader," or "patients will be confused if more than one person gives information." When there is more than one doctor involved in patient care, what is told to patients is up to the attending physician. This additional hierarchy is revealed by a senior surgeon who says, "unfortunately, many young people in medicine, whether they're doctors or nurses, get a peculiar sense, I won't say of power, but somehow of maturity, by giving information to patients about things like this." He goes on to say, "when a patient says, 'how long have I got to live?' the wise surgical resident or medical resident or the wise nurse, will say, 'that's a difficult question to answer. Why don't you talk to your doctor about it?'" This again suggests that the question of who controls information is closely related to power relationships among care givers.

Not only do doctors portray themselves separated from other care givers, they also respect other doctors' autonomy very highly. How to inform patients is viewed as a highly individual decision. The

main factors reported as influencing doctors' style of telling are their personal philosophy, upbringing and their own clinical experience. Role models and peer culture are viewed as having a certain influence but not very strong, and many doctors say they don't know how other doctors handle these issues. Moreover, physicians who teach in a formal curriculum on truth-telling say they usually avoid giving definite answers, and stress the importance of the individual doctor's judgment. Less than half of the doctors think formal training about conveying information is necessary; learning through clinical experience is more emphasized. Some doctors said that formal training is not helpful because most of the physician's style is determined by the personality and philosophy of the individual. A surgical resident says,

[Do you think doctors should have formal training about how to inform patients of bad news and how to care for patients after breaking the news?] I disagree. You are not going to teach somebody who doesn't know, who isn't, to be good at it by giving them lectures and letting them practice. It has to be a personal thing. You have to have the ability to reach people and to do it. Then you can't take a cold fish and make a ham sandwich out of him.

Since control of professional standards is carried out mainly among peers [26], the fact that the medical profession relegates the matter of how to inform patients to the sphere of a 'personal thing' may either mean that it is considered not important enough for a professional standard, or so important to physicians' work as an 'art' that full discretion must be maintained.

To summarize, the individualistic view of both doctor and patient, excluding as it does the complex power relationships involving family members and other health professionals from the ethical framework, may be effective in making certain forms of doctors' information control feasible.

C. Information control and its context

The analysis of physicians' basic styles and principles has highlighted the sharp contrast between their egalitarian appearance and the subtle ways in which they can control the process of information-giving, and thus the information itself. In this section, I will show how the styles and principles are actually deployed in a concrete situation of information control, and examine how certain aspects of clinical contexts have necessitated the information control and shaped it into a particular form.

For this purpose, I will compare physicians' ways of informing patients of treatment with those used for prognosis. The majority of the doctors in this study selectively emphasize information about treatment over prognosis. They justify their almost contradictory attitudes in handling the two kinds of information by invoking principles or employing styles which suit their purposes. However, the reasons they treat the two kinds of information differently are

contextual and cannot be reduced to the normative discourse of styles and principles. The criteria they employ for the differentiation, like 'uncertainty,' 'action-relevance' and 'counterbalancing,' have been shaped in and emerged from clinical trials. In order to understand why physicians control information in the way they do, a close look at these criteria is essential.

1. Prognosis and treatment. The issue of truth-telling has focused attention on the diagnosis of cancer, and it is not a surprising fact that most doctors in this study say they inform dying patients of their diagnosis (Table 1, item 3). However, information about treatment and prognosis, rather than simply a diagnosis, is the principal thing that patients want from physicians [16] and that physicians give to patients in an evolving relationship [14]. When we begin to analyze the doctors' information-giving as an ongoing process, we can find a remarkable difference in their handling of the two kinds of information.

When asked about treatment, most doctors say they try to give patients a lot of information, mentioning principles of respect for the truth, patients' rights and the physician's duty to inform patients. More than 90% of the physicians answer that they do not withhold or sweeten some information even when they think that the information will make the patient unwilling to undergo a treatment (Table 1, item 4). Some answer that they provide more information to persuade the patient. Many of them argue that withholding information is unethical and unfair to patients:

[Do you withhold information if disclosure would make patients unwilling to undergo a treatment that you felt necessary?] No. No. No, I do not do that, because I think the patient must make decisions based on true and valid information. And if he chooses not to have a certain kind of treatment, I really strongly believe he has a right to make that choice, because sometimes we're wrong.

In contrast, when the issue is about prognosis, many physicians try to give patients very vague information. Although 84% of the doctors think most patients know that they are dying, half of them do not explicitly tell patients that they are dying (Table 1, items 5 and 6). They often give optimistic estimations and use euphemisms to describe patients' prognosis. They also tend to give patients the estimation of prognosis within a broad range, not using specific numbers or statistical data (Table 1, items 7, 8 and 9).

I wouldn't tell an old mother, or a child, and if the person is, in my opinion, likely to take it badly, I will delay telling them until they gradually begin to learn the truth. A lot of them, for example, will go out and read a book and the book will say, 'this is always fatal,' then they'll come back and say, 'hey, what about that?' and I'll say, 'well, that book was written 10 years ago and it isn't always fatal.' As a matter of fact, none of these diseases is always fatal, but they'll soon realize what the game is. As I say, I can usually tell, because they stop asking questions.

As this senior internist's reference to the 'game' implies, there is much that remains unspoken between patient and doctor, including the terminal nature of the illness. He assumes patients' understanding of the truth because "they stop asking questions." Another doctor says, "I let the patients make their own conclusions about that. I don't tell them that they're dying. I think they know they're dying." This preference for verbal vagueness, however, may ignore a significant gap between the patient's perception and the physician's. This also contradicts the views expressed by three-quarters of the physicians opposing as a matter of general principle non-verbal communication because of its ambiguity and the possibility for misunderstanding. A medical resident states,

Unless you tell them directly, there is no way of knowing that they are getting the information. So, you just can't rely on nonverbal ways of communicating the information. I just don't think it is possible. You may think you have conveyed your message, you may have used terms that the patient didn't understand, and I found that patients want to please their doctors when you tell them some things, mm-hm mm-hm (yes, yes), and you go back in the room a few minutes later, and they didn't understand a thing you said. They want to make you think they understood and we tend to speak to them in very sophisticated terms . . . I think you have to spell it out pretty explicitly.

To summarize, a majority of the physicians apply the 'patients' need' style for treatment and insist on active and forthright information-giving. For prognosis, on the other hand, they use the 'patients' want' style, but patients' 'want' to know is assessed quite passively. The absence of questioning is interpreted as a sign of patients' unwillingness to know as well as of their understanding. When there are direct questions about prognosis from patients, the information can be considerably modified through the application of the 'translation' style. However, doctors do not openly advocate that patients do not 'need' to know their prognosis. Principles of 'truth,' 'patients' rights' and 'doctors' duty,' which are more unambiguously applied to the treatment information, have a more equivocal meaning for prognosis information. 'Patients' rights' are overshadowed by the 'patients' hope,' and 'doctors' duty' shifts its meaning to privilege the moral and protective role of doctors. These differences can thus coexist within the ethical framework.

However, the reasons physicians give for emphasizing treatment and evading prognosis information are not confined solely to the ethical discourse mentioned above. They provide a more particularized picture of the context in which doctors' information control occurs. Physicians' accounts reveal important aspects of the clinical reality they face [15] such as their own emotions, institutional constraints and the power relationships in care. I will explore these factors using the three criteria physicians employ for the differentiation of treatment and prognosis. 'Uncertainty,' 'action-relevance' and 'counterbalancing' will turn

our attention to contextual, particularized facets of information control.

2. *Uncertainty.* The most frequent reason the physicians give for emphasizing treatment over prognosis is that prognosis is hard to predict and it is dependent on treatment choices:

You can't tell for sure what the outcome will be from your surgery. And you may well get unexpected complications. And the other is, of course, sometimes you get an unusually good result and the patient does fine. And so you can't—it works both ways. You can't tell the patient 'you're going to die' all the time, because you could be wrong. And you can't tell them 'you're not going to die' and have them die unexpectedly.

The unpredictability of prognosis and its dependence on treatment are certainly true, but the consequences of treatment are no less uncertain. A medical resident who prefers to tell the prognosis to patients explicitly, says:

There is no treatment that we know of currently, that is completely risk-free. And I think once they accept their illness, it is up to them to decide when the benefits outweigh the risks. For certain patients, they would rather be not having side effects of cancer, and living less time, than to be living for a year, but be nauseous, vomiting, and really being miserable. And I think that once you give them all the information, let them know what percentage of people live, and what percentage don't, how sick they are, and how not sick they are, that is a decision that they have to make.

In fact, most medical information is based on probability, and informed consent stems from a theory of decision making in which patients assess pros and cons of each option in a probability sense [27, 28]. If statistics could not tell anything about individual cases, physicians would not be able to inform the patient at all.

The selective invocation of uncertainty of prognosis is interesting because it suggests a new relationship between doctors' power and knowledge in a new type of ethical framework. Uncertainty has been mainly discussed as a possible threat to the authority of doctors and something which doctors try to manage desperately in their clinical situation [29]. But in the era of the doctrine of informed consent, in which physicians must disclose the truth, including the uncertainty of their clinical data, to patients, the uncertainty can also be utilized to justify their information control. They must disclose the truth, but they can emphasize the uncertainty of 'the truth' itself. For example, some physicians emphasize the uncertainty of the terminality. A senior internist says, "you know, we're all terminally ill in one way or another. I mean, you're going to die of heart disease or cancer or stroke. Now, if a patient had a cancer, it doesn't necessarily mean he's going to die from it. He may survive a long time, even if he has residual disease in his body."

When the uncertainty of 'terminality' is connected to the rapid development of biomedical technology, it becomes a 'possibility' of and 'hope' for cure. The following remark by a senior hematologist who has

witnessed many diseases become curable with new treatment, shows how the shift from uncertainty to possibility resolves the conflict between truth and hope.

I think you can say there's hope and still be truthful. Because we're not fortune tellers. I can't foresee the future. I've seen too many cases where surprising things happen. So I would never say there's no hope. . . . At least in my field, with some of these fatal diseases, the picture changes from year to year, and I think that I'm not lying if I say, 'just hang in there. Something may turn up.'

The important point here is that there are specific contexts in which physicians admit or even emphasize their uncertainty and ignorance and others in which they do not, especially in relation to patients' expectations of physicians and the physician's own notion of competence [30]. In this sense, predicting accurate prognosis is not really included in professional competence. It suggests the denial of terminality is a widespread phenomenon among the majority of the medical profession.

I usually give them a range of time, not a specific number of months, and I always indicate that there's a wide range of variability, and I can be very wrong on what I say. It's been my experience that I am apt to be most inaccurate at times when people ask me 'how much time do I have?'

3. *Action-relevance.* Another ground employed by physicians for selective attention to treatment information is action-relevance: whether the information makes any difference in the patients' choice, the physicians' action and in the overall result. This criterion offers an insight into what information doctors actually value when they evaluate patients' need and wants. First, the actions doctors take into consideration are very much confined to a medical sphere.

Sometimes what I say is determined by the need for action. In other words, if I have to, let's say, undertake a big treatment, like bone marrow transplant, I have to present it to them in a certain way. If there's no treatment, or no decisions have to be made, that's a different story, and so what I say and how I say it is determined a little bit by the options.

Second, institutional arrangements of the clinical situation shape this criterion. Decisions about cancer treatment have to be fairly quick because of the disease's nature, and in current complex medical care, different health professionals have to organize their schedule around the principal physician's treatment plan. Recognizing this, many physicians say they try to inform patients of treatment options as early as possible, but there is no clear deadline for the disclosure of prognosis. While no physicians discuss action-relevance in relation to legal concerns, interestingly the legal doctrine of informed consent shares a similar value: to claim successfully that someone is liable because of an act or omission, one usually has to prove that the act or omission produced different consequences [7, 31].

Doctors' time constraints are also important. If physicians' work is conceptualized as work within organizations [32], truth-telling is just one of the tasks they have to accomplish in their institutional settings. Two-thirds of the physicians think truth-telling is more time-consuming than not telling, especially if it is done 'sensitively' and 'in the proper fashion.' More than half of the physicians say they take special care afterwards, such as visiting more often, being with patients, giving them support, calling and so on, and criticize other physicians who don't spend enough time with patients. But the actual time physicians have for informing and being with patients is not determined by the autonomous choice of each doctor, and may be dramatically different depending on where they are: in private practice, in an emergency room or in a 15-min HMO clinic, and whether they are house officers or are private practitioners. Time constraints inhibit physicians from exploring patients' need and desire to know, thus not only limit the amount but also the quality of information they give. Doctors' time constraints also contribute to the attitude that physicians' time is more precious than patients' and given by physician to patient. This enhances the hidden hierarchy in the physician-patient relation.

Now this [truth-telling] is terribly time-consuming. And time is the one thing that none of us have very much of. So there is this pressure to carry on with all the things you're supposed to be doing, and yet the dying patient wants to spend time, wants to be with his doctor as much as he can. And it's very difficult. But time is a very constraining factor.

4. Counterbalancing. One other ostensible reason why most physicians prefer to speak about treatment rather than prognosis is their wish to counterbalance the bad news with hopeful information [33]. Although counterbalancing is inseparable from the principle of preserving patients' hope, it reveals a more nuanced picture of physicians, including their own emotions, their ideal roles and their power relationship *vis-à-vis* patients.

Most doctors in this study dislike giving bad news to patients, although they think it is an important duty. They realize the tragic impact of their news for patients, describing their practice with phrases such as "hit the patient over the head," "bludgeon the patient with diagnosis" or "dropping a bomb." And yet, informing patients has to be routine for physicians. Dealing with this tension between the tragic impact on patients and routinization of the events in clinical practice requires an effort by physicians. A senior internist states, "you have to somehow become unemotional and try to get rid of that aspect of what you're telling the people. Depersonalize it as best you can and still be empathetic." But for inexperienced physicians, this is not an easy task and a counterbalancing strategy becomes more attractive. A second year medical resident's remark is illustrative.

[How do you feel about conveying bad news to patients?] I don't like it. I don't enjoy it. It's very difficult for me because I have very little experience with it. And because of that I think I'm very uncomfortable with a patient, I don't feel very at ease and I don't have a lot of experience comforting patients who have bad news. I tend to try to find some of the positive aspect, any positive aspects I can think of to tell them about it, and leave it open for them to discuss things with me if they wish, but otherwise I just would let them on their own.

Furthermore, existing accounts on physicians show that physicians often feel powerlessness, frustration and guilt about not being able to cure the patient when they deliver bad news [34, 35]. Some doctors in this study give similar accounts in relation to counterbalancing. A senior surgeon who says he gives optimistic estimations to patients states,

That's the hardest thing in the world for a surgeon to stay with a patient who's dying and to work through them, because it represents failure, and I feel as though I've failed, perhaps. Maybe we didn't get to the patient early enough, maybe we didn't do the right operation, maybe the operation didn't work very well, but it's very hard for doctors to deal with failure. We are oriented towards success, but not failure.

Just as the definition of hope, shown in the use of the 'hope' principle, varies among doctors, physicians' emotions in giving bad news and the level of counterbalancing also vary depending on what doctors think is the role of physicians. Taylor reports that 'therapists' who stress humane kindness employ more efforts to reduce the impact after the cancer diagnosis was disclosed to patients, than 'experimenters' who emphasize scientific clarity [13]. Confirming the finding, half of the physicians in this study who prefer clarity say truth-telling is emotionally easier than not telling because "it takes away that much off my shoulders," rather than "taking more energy in trying to circle around the issues." Another dimension of doctors' role found in this study is the degree of orientation to curative medicine. As the previous remark suggests, physicians who regard their task as the eradication of disease, whether 'therapists' or 'experimenters,' are prone to counterbalancing. 'Quality of life' oriented doctors can be very candid, even if they prefer kindness to scientific straightforwardness, recognizing how important the information is for the patients' life planning. They resist counterbalancing bad news and find positive meaning in delivering bad news. A senior internist who says "I feel good" in conveying bad news, explains, "although it is very sad to have to convey it, I also think it's an opportunity for the physician to really just become purely a patient's advocate. . . . It's really the pure art of medicine at its best because you've tossed away the whole curative science side of medicine."

The physician's ideal notion of his/her role is not exclusively the result of individual choice. Physicians' orientation towards curative medicine is closely related to the change in medical technology and the

availability of new therapeutic technique in their own speciality [14]. The current legal climate has shifted the physician's role toward 'experimenters,' in spite of the ambivalence on the part of physicians, as expressed in the remark by a senior surgeon. "Lots of times the patients don't want to hear it, but . . . we face the problems of malpractice and operating on people without consent, if we don't tell them everything nowadays, so we do it. It's funny that the lawyers have defined the nature of the role between the doctor and the patient, and that the doctors haven't had much to say about this." Thus, these social factors also affect doctors' emotions and the level of counterbalance.

Whether aimed at protecting patients' or doctors' emotions, counterbalancing can distort doctors' assessment of what information to share with patients. A statement by a surgical resident suggests that physicians' offer of treatment options is closely related to the effort to maintain their powerful status *vis-à-vis* patients.

I don't think in the 1950s that we knew as much as we know now. We didn't have the kind of treatment options that we have now. And then when you told someone that they had cancer, you didn't have anything to offer them. And you didn't know how long they had to live. So I think in that time frame, that [not telling the truth] was perfectly appropriate. Because you didn't know, and it didn't inspire confidence in your patients, I mean, it would make you look like you didn't know what you were doing. So I think in that situation, it protects the patient, but it also protected the medical profession. It didn't make us look like idiots, basically.

While the level of counterbalancing may differ with each doctor, counterbalancing seems to be indispensable for most physicians to preserve their own power over patients. Many physicians in this study see information about treatment as something they can uniquely offer. Some physicians regard treatment information as their message to a patient that "I am not abandoning you. I am here to help you." Even if the intention is to be compassionate to patients, physicians also know the power of counterbalancing in a situation in which patients do not necessarily appreciate, and may even blame the physician for giving truthful but bad news.

Counterbalancing may have consequences which do not benefit patients, however, if physicians are unaware of underlying incentives. In the following statement, the oncologist's 'magic words' may be encouraging to patients but may also expand doctors' power beyond the territory they can rightly claim as professionals [36].

I would bring an oncologist in consultation to give us an opinion about what to do. The oncologist was called in, and saw him and I don't know the final theme that the oncologist recommended, but the magic words that he said to the patient were, 'Well, I think I've got something I can help you with.' I think I can help you was what the oncologist said to the patient, which the patient felt was very encouraging. Ahh . . . from my own experience I would say that the benefit of chemotherapy in this situation is very limited, and

that radiation therapy has nothing to offer, but that was basically what you would say.

DISCUSSION

Physicians' narratives revealed a very complex web of connections—linking their perceptions of their own styles, their moral principles and the ongoing control of information in the context of their clinical settings.

The question whether doctors tell the truth or not can be answered, 'yes and no'. Certainly, they advocate information-giving styles in which the patient's desire, need and understanding are ostensibly centered. But we also find a striking difference in their handling of information about treatment from information about prognosis.

In his textbook on cancer care, Billings emphasizes the importance of giving both information patients want to know and information patients need to know, concluding with the remark that, "once patients have had a chance fully to explore their concerns, this second category of information has often already been addressed" [5]. While the physicians in this study report that they first tell patients what they want, then what they need to know, closer examination of their narratives reveals that the patient-centeredness itself is regulated by physicians. For example, it is doctors who draw the boundary between 'need' and 'want' of patients and decide how actively they provide information. Each patient's desire to know and need to know are assessed by doctors, who often confine patients' questioning and conflate these desires and needs with their own. Doctors translate information into terms that patients can take, but the evaluation of patients' ability to comprehend and cope as well as the decision as to how much the information is to be modified are primarily in the hands of the doctors. Through this process, doctors often end up giving priority to what they need to tell (projected as what patients need to know), in effect reversing Billings' patient-centered approach. Doctors can hold power over patients even if they accept the idea of sharing information with patients. Patients may be able to get more information than before, but they are still dependent on doctors as long as the information-giving process is assessed and managed by the latter.

The physicians' ethical principles do not preclude this information control, despite the fact that they advocate respect for the truth and patients' rights, suggesting their adherence to more egalitarian medical ethics. The principles, instead, provide particular discursive form which justifies the ongoing information control. Paternalistic attitudes are still found in physicians' notions of duty and endeavors to maintain patients' hope, but the contradiction between physicians' moral duty to protect patients and respect for the patient's autonomy is 'resolved' by a flexible interpretation of 'truth,' 'rights,' 'duties' and

'hope.' Selective use of contradictory principles and the resultant information control are thus legitimized.

This particular way of formulating the discourse by doctors, reconciling the gap between patient-centered care and information control, is intriguing when it is situated in the specific U.S. social and historical context. The controversy over truth-telling is often framed in terms of the paternalism/patients' autonomy dichotomy: physicians acting for the patients' benefit versus a contractual agreement between two equals [37]. In the United States, the shift from the 'old' paternalistic model to the 'new' contractual one occurred in the late sixties and seventies. Patients' rights were advocated during the period when the consumer movement and other movements for civil rights including women's rights, rights of prisoners, of the mentally ill and of the handicapped, embodied and fueled a general anti-authoritarian trend in American social life [38].

The shift was supported and enforced by the recognition of the notion of informed consent in law and medical ethics. Lawyers stressed the written form of contract rather than relying on the physician's 'good will.' American courts have helped to redefine the relationship between patient and physician through their decisions. Medical ethicists severely criticized paternalism as a logical consequence of their argument that the principle of autonomy supersedes other principles such as beneficence, nonmaleficence and justice [6, 37]. The trend seems to continue in the direction of the contract model, and the physicians in this study, sensitive to this, are trying to conform their narratives to the trend.

But an extreme contract model, where the trend logically leads, is not uncontroversial. It would require telling as much as patients want, with no distortion. In this model, patients have total responsibility for their care and physicians have no duty or responsibility other than to impart the raw information which patients want. Values such as mutual trust and physicians' loyalty in the patient-doctor relationship are marginalized, which some social scientists have criticized as resulting from an overemphasis by current American medical ethics on formalistic logic [39]. The question whether the principle of patient autonomy is always paramount or can be overruled by other principles is still hotly argued, and some defend certain kinds of paternalism [40]. Legal arguments support some degree of withholding of information by physicians based on the notion of therapeutic privilege [41, 42], although it is controversial [43]. Even medical ethicists and jurists who emphasize the equality and autonomy of patients *vis-à-vis* physicians, often use words like 'partnership,' 'shared decision making,' or 'therapeutic alliance' [7], implying that there is something more than contract in the patient-doctor relationship.

One of the important issues here is how to deal with trust and power of physicians. Starr notes that the implicit belief which supported the historical shift was that the interests of doctors and patients frequently diverge, and hence that patients needed protection. The new model has been developed on the assumption that the doctor, who has power, is potentially harmful. "Once a hero, the doctor has now become a villain," he notes in describing the concurrent change of the intellectual portrait of the physician during the period. This signal of distrust has caused resentment of and ambivalence toward the new model on the physician's part [38]. It is clear that the old, god-like role of the doctor is no longer acceptable, but the doctor cannot be just an ordinary, fallible human being. Most patients and their family members still expect physicians not only to fulfil legal obligations to respect patients' rights, but also to devote themselves to caring for patients compassionately [44]. The developing norm of partnership requires this humanistic role of physicians so that patients can rely on them, while it simultaneously gives the message that doctors' good will may not be trustworthy.

These tensions and ambivalences become especially acute in situations of extraordinary psychological impact on patients such as disclosure of terminal illness. Physicians express a strong notion of duty and responsibility for patients' coping with bad news. They try to give patients hope and support, and to soften the shock of the news. Expressing physicians' own self interests or emotional needs is simply inappropriate in such situations. This study, however, found these factors are important in understanding why doctors control information.

Analysis of the doctors' emphasis on treatment over prognosis in information-giving in this study shows the influences of the physician's need to deal with day-to-day clinical reality [15] on their decisions about what information to share with patients. Uncertainty, action-relevance and counterbalancing, the reasons for separating information about treatment from that of prognosis, reflect physicians' emotions, structural constraints of medical institutions, development of biomedical technology, legal concerns and power relations among care givers and patients.

Nonetheless, these contextual factors are hardly incorporated into physicians' normative discourse [8]. Doctors are not willing to abandon the role of doctors as possessors of altruistic devotion and compassion or to portray themselves as surrounded by constraints imposed by the clinical situation. This humanistic and highly moralistic role of the physician is an important source of the patient's healing in a therapeutic relationship [15], but this study indicates that it is also crucial to preserving physicians' power, or what Starr calls "cultural authority." According to him, physicians' power originates not only from their regulation of action but also their construction of

reality, with which patients' experience is defined in a particular field. It creates patients' dependence, including emotional dependence, on physicians. For physicians to maintain their authority, in addition to the possession of scientific knowledge, it is essential that they show they are humanistic and trustworthy enough to use that knowledge.

Physicians' reluctance to accept the notion of 'terminal' illness and their hope for curative treatments are understandable in connection with their optimism about advances in biomedical technology and their valuing fighting spirit. In the United States, these views may well be widely shared by patients and society [45]. But doctors' omission of the terminal nature of illness, i.e. prognosis, from the information-giving has more consequences than just the encouragement of patients. As long as doctors' cultural authority permits the construction of reality, their optimistic view defines "reality" for the patient in the sphere of medicine, expanding their professional territory beyond that in which they can actually be effective [36]. When patients are terminally ill [7, 25], and especially where research and clinical care are closely linked [46], physicians' heroic attempts to cure patients can prevail, and the result might be a prolongation of patients' suffering without provision of real options [47]. It may be also contributing to the growing dissatisfaction with American medical care, and to its soaring costs [48].

Previous studies about truth-telling have focused on cancer and its diagnosis [3, 16, 49], equating telling the cancer diagnosis to telling the truth. As a result, they have left intricate modes of information control unexamined and disguised the omission of specific content as just a matter of style, of 'how well to tell' [8]. But physicians' focusing on treatment options and leaving out prognosis (the worst part of the information) is the key to understanding the coexistence of information control with patient-centered ethical norms in the context of current American medicine. Physicians can proclaim that they tell the truth, even if the truth is considerably modified. They can manage their need in a day-to-day clinical reality while keeping their prestige and power as a care-giver. They can preserve patients' hope as well as continue their innovative therapy. It will be important to see whether this tendency is observed in primary care oriented or rural hospitals in the United States or is confined to the urban tertiary teaching hospital.

Finally, implications of the individualistic notion of information giving from the doctor to the patient can be mentioned. The individualistic view of patients and doctors as atomistic, autonomous selves [50] held by law and medical ethics is supposed to give more power to the patient and contribute to the creation of a more equal relationship between doctor and patient. But this study shows that this is not necessarily so. In light of the finding that the doctor's control originates not from mere

possession of knowledge, but from the management of the information-giving process, the exclusion of family members and other professionals from that process may leave the patient more vulnerable to the doctor's control in their interaction as two 'equal' individuals.

This study shows the importance of patients' characteristics, such as age, gender, educational level, and occupation, for physicians' assessment of patients' needs and wants, and for the way in which they actually give specific information. Doctors seem to give more detailed, specific explanations to patients with higher education and an influential role in society and in the family. Corresponding to the findings here, empirical studies have shown that more information is given to patients who are upper-middle class, more educated and middle-aged [12, 51]. In terms of the interactional nature of information-giving between doctor and patient, other empirical studies also confirm the complex modes of controlling information found in this study. Physicians give more information to patients who are more affectively expressive and verbally assertive [52]. Conversely, physicians' attitudes considerably influence how much patients can ask questions, assert their opinions and express their feelings [21-23]. Facing highly professionalized medical knowledge, many patients, especially those at a social distance from doctors in terms of class, gender, ethnicity etc., avoid asking questions of doctors, fearful of appearing ridiculous, bothersome, and of not being able to understand [20, 44]. Patients' not questioning does not mean patients understand or are unwilling to know the information. While it is important to adjust information-giving based on each patient's characteristics and capacity to comprehend, this should not mean that physicians volunteer more explanations to sophisticated patients with social backgrounds similar to theirs.

Exclusion of family members and other professionals [53, 54], may be important to protect the patient's interests and privacy, if we accept the reigning assumption in contemporary American society that the family is no longer a reliable source of support for patients, and possibly exploitative. However, such a view denies their potential role as patient advocates, and too much emphasis on the individualistic image of the patient as someone who single-handedly gets information, makes decisions and fights the disease may keep patients struggling in isolation [20].

Truth-telling occurs in the period when the patient must cope with physical as well as emotional suffering, and with the existence of doctors' power based on their cultural authority as well as institutional arrangements. While the individualistic informed consent model has been useful in developing ethical reasoning which supports a more egalitarian doctor-patient relationship, the ethical discourse will mask and legitimate ongoing information control if

it does not embrace a more contextual picture of truth-telling as an ongoing process involving patients, family members, doctors and other care-givers.

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REFERENCES

- Oken D. What to tell cancer patients—a study of medical attitudes. *JAMA* 175, 1120–28, 1961.
- Glaser B. G. and Strauss A. L. *Awareness of Dying*. Aldine, Chicago, 1965.
- Novack D. H. *et al.* Changes in physicians' attitudes toward telling the cancer patient. *JAMA* 241, 897–900, 1979.
- Taub S. Cancer and the law of informed consent. *Law, Med. Hlth Care* 10, 61–66, 1982.
- Billings A. J. Sharing bad news. In *Outpatient Management of Advanced Cancer*. Lippincott, Philadelphia, 1985.
- Faden R. R. and Beauchamp T. L. *A History and Theory of Informed Consent*. Oxford University Press, New York, 1986.
- Annas G. J. *The Rights of Patients: the Basic ACLU Guide to Patients Rights*. Southern Illinois University Press, Carbondale, 1989.
- Holland J. C. Now we tell—but how well? *J. clin. Oncol.* 7, 557–559, 1989.
- Waitzkin H. A critical theory of medical discourse. *J. Hlth soc. Behav.* 30, 220–239, 1989.
- Friedson E. *Professional Dominance: the Social Structure of Medical Care*. Atherton, New York, 1970.
- Todd A. D. *Intimate Adversaries: Cultural Conflict Between Doctors and Women Patients*. University of Pennsylvania Press, Philadelphia, 1989.
- Waitzkin H. Information giving in medical care. *J. Hlth soc. Behav.* 26, 81–101, 1985.
- Taylor K. M. 'Telling bad news': physicians and the disclosure of undesirable information. *Sociol. Hlth Illness* 10, 109–132, 1988.
- Good M.-J. D., Good B. J., Schaffer C. and Lind S. American oncology and the discourse on hope. *Cult. Med. Psychiat.* 14, 59–79, 1990.
- Kleinman A. *The Illness Narratives*. Basic Books, New York, 1988.
- Lind S. E., Good M.-J. D., Seidel S., Csordas T. and Good B. Telling the diagnosis of cancer. *J. clin. Oncol.* 7, 583–589, 1989.
- Glazer B. and Strauss A. *The Discovery of Grounded Theory*. Aldine, New York, 1967.
- Strauss A. L. and Corbin J. *Qualitative Research: Grounded Theory Procedures and Techniques*. Sage, Newbury Park, CA, 1991.
- Kuipers J. C. "Medical discourse" in anthropological context: views of language and power. *Med. Anthropol. Q.* 3, 99–123, 1989.
- Saillant F. Discourse, knowledge and experience of cancer: A life story. *Cult. Med. Psychiat.* 14, 81–104, 1990.
- Street R. L. Jr Information-giving in medical consultations: The influence of patients' communicative styles and personal characteristics. *Soc. Sci. Med.* 32, 541–548, 1991.
- Hall J. A., Roter D. L. and Katz N. R. Meta-analysis of correlates of provider behavior in medical encounters. *Med. Care.* 26, 657–675, 1988.
- Cox A. Eliciting patients' feelings. In *Communicating with Medical Patients* (Edited by Stewart M. and Roter D.). Sage, Newbury Park, CA, 1989.
- Novack D. H. *et al.* Physicians' attitudes toward using deception to resolve difficult ethical problems. *JAMA* 261, 2980–2985, 1989.
- Katz J. *The Silent World of Doctor and Patient*. Free Press, New York, 1984.
- Bosk C. L. *Forgive and Remember*. University of Chicago Press, Chicago, 1979.
- Andrews L. B. Informed consent statutes and the decision making process. *J. Legal Med.* 5, 163–217, 1984.
- Merz J. F. and Fischhoff B. Informed consent does not mean rational consent: Cognitive limitations on decision-making. *J. Legal Med.* 11, 321–350, 1990.
- Fox R. Training for uncertainty. In *The Student-Physician* (Edited by Marton R., Reader G. and Kendall P.). Harvard University Press, Cambridge, MA, 1957.
- Good M.-J. D. Discourses on physician competence. In *Physicians of Western Medicine* (Edited by Harn and Gaines). Reidel, Dordrecht, 1984.
- Nolan J. R. and Sartorio L. J. Informed consent. In *Tort Law*. West, St Paul, MN, 1989.
- Straus A., Fagerhaugh S., Suczek B. and Wiener C. *Social Organization of Medical Work*. University of Chicago Press, Chicago, 1985.
- Maguire P. and Ann F. How to do it: Communicate with cancer patients: Handling bad news and difficult questions. *Br. Med. J.* 297, 907–909, 1988.
- Buckman R. Breaking bad news: why is it still so difficult? *Br. Med. J.* 288, 1597–1599, 1984.
- Higby D. J. The doctor and the cancer patient: Sources of physician stress. In *The Cancer Patient and Supportive Care* (Edited by Higby D. J.). Martinus Nijhoff, Boston, 1985.
- Finkelstein J. L. Biomedicine and Technocratic Power. *Hastings Center Report.* 20, (4), 13–16, 1990.
- Beauchamp T. L. and Childress J. F. *Principles of Biomedical Ethics*. Oxford University Press, New York, 1989.
- Starr P. *The Social Transformation of American Medicine*. Basic Books, New York, 1982.
- Fox R. C. and Swazey J. P. Medical morality is not bioethics: Medical ethics in China and the United States. *Perspec. Biol. Med.* 27, 340, 1984.
- Childress J. F. The place of autonomy in bioethics. *Hastings Center Report* 20, (1), 12–17, 1990.
- Canterbury vs Spence., 464 F.2d 772, 783 n.36 (D.C. Cir.), 1972.
- Miller L. J. Informed consent II. *JAMA* 244, 2348–2349, 1980.
- Katz J. Informed consent—a fairy tale? Law's vision. *U. Pitt. L. Rev.* 39, 137–174, 1977.
- Lehman B. A. Bridging the doctor-patient divide. *Boston Globe*, pp. 45–47, 5 Nov. 1990.
- Hayes B. E. Who knows? You could outlive your doctor. *The New York Times Magazine*, pp. 31–36, 17 March 1991.
- van Eys J. Clinical research and clinical care: Ethical problems in the "war on cancer". *Am. J. pediat Hematol./oncol.* 4, 419–423, 1982.

47. Goodin R. E. Heroic measures and false hopes. In *Philosophy and Medical Welfare* (Edited by Bell J. M. and Mendus S.). Press Syndicate of the University of Cambridge, Cambridge, 1988.
48. Hiatt H. H. *Medical Lifeboat—Will There Be Room for You in the Health Care System?* Harper & Row, New York, 1988.
49. Holland J. C., Geary N. A. and Tross S. An international survey of physician attitudes and practice in regard to revealing the diagnosis of cancer. *Cancer Invest.* 5, 151–154, 1987.
50. Sandel M. *Liberalism and the Limits of Justice*. Cambridge University Press, Cambridge, 1982.
51. Pendleton D. and Bochner S. The communication of medical information in general practice consultations as a function of the patients' social class. *Soc. Sci. Med.* 14A, 669–673, 1980.
52. Greenfield S., Kaplan S. and Ware J. Expanding patient involvement in care. *Ann. intern. Med.* 102, 520–528, 1985.
53. Hardwig J. What about family? *Hastings Center Report* 20, 5–10, 1990.
54. Alexander L. Illness maintenance and the new American sick role. In *Clinically Applied Anthropology* (Edited by Chrisman N. J. and Marezki T. M.). Reidel, Boston, 1982.