

## THE SOCIAL CHARACTER OF ILLNESS: DEVIANCE OR POLITICS?\*

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**Abstract**—Traditional approaches to the analysis of illness as a social phenomenon have regarded illness as a form of deviant behavior. Although many variations on this theme exist, the assumption of illness-as-deviance is retained by virtually all sociological theories. This assumption is not warranted by the experiences of either patients or medical workers, nor has it resulted in any notable contributions to the efficacy of the social sciences. It is proposed here that illness be conceptualized as a political process, concerned with the allocation of patient and medical worker resources and constraints. Such an approach brings to the fore an often-neglected characteristic of illness organization: the inherent conflict of interest between patient and physician. This conflict is generated by the fact that illness is simultaneously the physician's work and a disabling of the patient's self. Authoritative control over work for the physicians is therefore incompatible with the personal independence of patients. The complex work organizations of contemporary medical facilities (with their demands for continual coordination) and the increasingly chronic character of illnesses (with their problems of long-term management) exacerbate this situation in considerable degree. Conceptualizing illness as a political process therefore, allows the beginnings of an analysis which focusses on the problems of practical and theoretical interest, rather than reinforcing an ideologically-based rhetoric of work management.

Since the emergence of medical sociology [1] a major guiding principle in organizing research in the area has been the notion of illness as a form of deviance, a specialized form without doubt, but still one subject to social control. Over the years, the notion has been criticized many times, primarily with regard to the closely associated notion of "the sick role" and its manifestations and consequences [2], but no effective criticism has been mounted against the basic assumption about illness and medical practice which give rise to such a conception. Even scholars who clearly see the major defects of traditional functionalist medical sociology [3] have not directly questioned the assumption that illness *per se* is deviance.

These difficulties have been confounded by the vague character of the sociological concept of "deviance", even within the functionalist tradition, the notion has been used in contradictory ways. Sometimes deviance is claimed to be "statistical" deviance, sometimes "normative" deviance, and sometimes normative and statistical deviance are asserted to be the same thing, a situation which makes any sort of careful analysis of concrete problems problematical in the extreme. The difficulties are further compounded by the emergence of "liberal" critiques of the functionalist position which assert that deviance comes about as the result of "labelling" or a process of social construction, without examining the process itself, or allowing the putative deviant some say-so in his or her definitional fate [4]. This approach, for all it is

an improvement over the functionalist position, does not suggest any obvious procedures for changing social conditions so as to improve the conditions of either deviant or "society at large".

As a result of this confusion, both the study of deviance and large parts of medical sociology languish in the intellectual doldrums. The one-sided approaches to the sociological analysis of medical phenomena have led to two complementary but sterile research traditions. The first, exemplified most recently by Fox and Swayze [5] continues in the tradition of Parsonian medical sociology to accept the occupational ideologies of the medical profession (and their concomitant interpretations of events) at face value. Thus patients are assigned to sick roles and their performance as patients is evaluated according to the degree to which they adhere to the "norms" of the role, i.e. to the degree they make no trouble for the medical staff. The second is represented by a diffuse critical literature [6] which sees things from the point of view of the layman/patient, and conceptualizes medical staffs as heartless, inhuman and often incompetent; prone very much to increase suffering through the systematic enforcement of indignity as they are to relieve it through the use of medical technology.

If we are to develop an effective medical sociology, we must focus upon the *organization* of medical situations and medical work, and not upon the individual characteristics of people (physicians, nurses, patients) in those situations, whether these be explicitly labelled as such (as, e.g. in the use of psychoanalytic categories to describe activity in medical settings), or implicitly defined by such notions as "norm" and "deviance", which relegate the social aspects of social organization to a transcendental otherworld. To this end, I should like to suggest that the social character of illness be conceptualized as a *political process* rather than as deviance.

\* I am grateful to Janet L. DePree, Richard P. Forbes, M. Sue Gerson, and Anselm Strauss for comments and criticism on earlier formulations of the ideas presented here. This work was supported in part by grants from the National Institute of Mental Health (MH 21222) and the Kaiser Family Foundation to the University of California, San Francisco. The views presented here are solely those of the author, and none of these organizations are responsible for them.

Traditional conceptions of deviance postulate a system of authoritative norms to which adherence is expected by all. Failure to meet these expectations then constitutes deviance, and such failure is supposed to call out actions from others designed to enforce conformity to the norms violated, and possibly punish the violation as well. Such conceptions of "norm" implicitly put the cart before the horse, and leave us with a rarefied social fact which cannot be located in the ordinary conduct of affairs. Even when the norms in question are codified and embodied in a formal canon of law or administrative procedure, the important point in sociological analysis is the process by which these rules come into being and are maintained in force, and *not* in their mere existence *per se*. This process is necessarily political within the usual definitions of the term, the process of establishing and enforcing rules of conduct is quintessentially one involving "authoritative allocation of values" or the exercise of power.

The attribution of "deviance" to a person therefore, constitutes a bargaining position taken by one party (participant or sociologist) to an on-going process of allocating resources and constraints in particular situations. This strategy may, or may not, prove effective, depending upon the interests of other parties to the interaction. The crucial point is that the applicable rule in a situation is always the result of some political process (whether proximate or remote) and that the rules are always changing because the political situation is constantly being revised. Strauss, Bucher, Schatzman and their associates have used this notion of "negotiated order" in a number of studies of medical organization [7]. The same ideas can be fruitfully applied to the analysis of interaction between medical workers and patients, as well as among medical workers.

Such an approach allows us to begin with the assumption that medical personnel are (by and large) both reasonably competent technically, and sincerely dedicated to the relief of pain and suffering and the cure of illness. It also allows us to assume that people become patients because they don't feel well, and want to get better for their own purposes. With these very ordinary—even naive—assumptions to begin with, we may then go on to enquire as to how things go wrong when they do. Thus, we may begin to analyse and suggest corrections for defects in medical organization, while acknowledging the undeniable fact that medical procedures do in fact achieve a rather large number of successes.

We may begin by noting a fundamental flaw in the traditional conceptualization of the relationship between physician and patient, the assumption, first made by Henderson in 1935 and since enshrined in the medical sociology literature, that the interests of physician and patient are harmonious if not congruent. In fact, this situation applies only in a limited circumstances, and the relationship is fraught with inherent contradictions which may appear—to the detriment of physician, patient, or both—in most contemporary medical settings. The failure to recognize these contradictions is in large part responsible for both the sterility of traditional medical sociology and the ineffective public policies of the physicians who have sponsored it.

The physician-patient relationship has a dual nature, even in its simplest form. On one side, practicing medicine is the work of the physician, and he must necessarily be as concerned with the conditions of his work as with the particular medical situation of particular patients. By this, I do not mean simply the problem of fixing fees, but rather the more general problem of defining the circumstances under which he must work, circumstances which include the fixing and collection of fees, determining hours of work, the distribution of honor and prestige for exceptional accomplishment (and of opprobrium for misfeasance), the nature of working relationships with a host of colleagues and other professionals, and the character of relationships with a wide variety of complex organizations (hospitals, insurance companies, government agencies, and so on). Furthermore, physicians do not exist simply in some "professional role" divorced from other aspects of ordinary life—they are spouses and parents, they live in complex communities, they have hobbies and debts, friendships and enmities. All of these make for differing assessments of work and work contingencies, and for different patterns of risk in making decisions about working conditions. Finally, physicians must handle the problem of emotional involvement with patients and emotional response to their problems, despite what their teachers and sociologists have told them. Styles, tactics and strategies for doing this vary enormously from physician to physician, although certain broad patterns can easily be identified.

From the perspective of the patient, an illness is *not* work in the sense of "making a living", it is a grossly uncomfortable, often painful, often embarrassing, frequently terrorizing experience involving the fundamental character of the self. That is why patients approach physicians in the first place. They may approach with an attitude ranging along a broad continuum from total unreasoning trust to total unreasoning suspicion, but they approach in, and because of, a cloud of pain and fear. Along with the illness and the patient's reaction to it come a wide variety of other concerns and considerations. The patient wants, not only relief of suffering, reassurance, and information on his physical condition, he wants them at a minimum of monetary cost, he wants them in a minimum amount of time, he wants them with a minimum of disruption to his usual activities, and he wants them with a minimum of further discomfort, fear, and inconvenience. In addition, patients have families, friends, jobs, and other interests as well, and an illness impacts these settings to the degree that the patient is prevented from operating effectively in them. Such interference is as often a result of the prescribed regimen as it is of the disease proper, and patients do not often bother to distinguish too carefully between the two, indeed, it is often difficult for the physician to do so in the face of the extreme side effects of many kinds of drugs and procedures.

The physician then, must manage both his work and the disease as best he can simultaneously, while the patient must manage his disease *and the physician's work*. And therein lies the essential contradiction in the physician-patient relationship: there is an inherent conflict of interest which can rebound with enormous damage to both parties if it is not adequately

tely managed. And here lies, in turn, the principal defect of medical sociology: for to say that the patient must adhere in his conduct to the norms of the sick role is merely to take the side of the physician, while to assert simply that illness is "labelling" is merely to take the side of the patient. One task of medical sociology therefore, is the analysis of the processes by which the inherent contradictions in the physician-patient relationship are managed by all parties to the relationship. These include not only patient and physician, but the enormous complex of commitments and obligations which both have in their surrounding social organizations.

There are a variety of circumstances which tend to "mask" the contradictory nature of the physician-patient relationship, while at the same time compounding the difficulties of management. Two of these have overwhelming importance: the fact that medical care is increasingly provided in very large complex settings, and the fact that many illnesses are short-term and relatively inconsequential in their "social side effects" to the patients. Traditional medical sociology has tended to focus rather arbitrarily, on relatively short-term acute conditions, often treated by the physician in his office. Thus, the "model" disease has been the common cold or influenza, with an occasional nod to the possibility of acute appendicitis, surgical correction of hernia, and so forth. Under such circumstances, the pain, discomfort, and fear of the patient are at a relative minimum, he can look forward to resuming a normal life in a few days, essentially "cured" of the problem which drove him to the physician. These are however, the very procedures and problems which are most highly routinized in medical practice, which have the lowest rates of error, which are best understood by the general public, and which allow for a relatively smooth and efficient processing by the physician and the hospital, as well as "third-party" insurance carriers and other interested bureaucracies.

Catastrophic, long-term, and chronic illnesses which require elaborate continuing management by a complex medical organization and which severely impact (if they do not eliminate) the normal activities of patients are an entirely different story. It is, in fact, from sociological studies of such diseases [8] that the notion of illness as politics rather than deviance clearly emerges. The process of managing such illnesses requires a different order of skills and procedures on the part of both patient and staff. The patient must become medically quite sophisticated in order to "hold up" his end of the treatment, he must somehow reconcile himself to a lowered level and restricted range of activity, to the loss of friends, and other social consequences of his disease, and to his potential pauperization by the high costs of the treatment. He must often learn to live with some specific chronic pain or discomfort, and (certainly not least) he must learn to deal with a host of complex bureaucracies which are notably idiosyncratic in their procedures.

The physician, on the other hand, must reconcile himself to "managing" rather than "curing" the illness, to surrendering much of his technical autonomy to a host of specialists and consultants, to developing and managing relatively extensive and intimate rela-

tionships with patients and their associates, to suffering the endlessly repeated failure of procedures which do not work, treatments which damage more than they help, and the bitterly fought loss of patient after patient. In addition, there are the compounding difficulties of ethical dilemmas: the precise definition of death, the moral burdens accompanying the use (or non-use) of heroic measures, and the management of involvement with patients. And finally, physicians must learn to deal with a host of complex bureaucracies which are notably idiosyncratic in their procedures.

In such situations, the contradictions inherent in the fact that a single organism embodies one person's work and another person's self, come rapidly to the fore and generate a host of detailed management problems for both physician and patient. These problems are inherently political—they are concerned with "who gets what, when, where, how." They involve extensive maneuvering on the part of all concerned to maximize advantage and minimize disadvantage under conditions in which "advantage" and "disadvantage" vary both across parties and over time for each part. They involve the exercise of power, sometimes subtly and indirectly, sometimes coercively, even brutally.

The balance of power is usually with the medical organization (which may or may not be *politically* separable from the attending physician) while the important outcomes and consequences are with the patient. Patients of course, come to realize this very quickly, and react in a variety of ways. Generally, the immediate effect is to increase the patient's fear and helplessness. In turn, this may make for more difficult "management" problems for medical personnel, as they confront an ever-intensifying series of worries, complaints, and even threats. One of the most powerful strategies for handling this situation is the ability of the physician (and often nurses as well), to define the problematic conduct of the patient as "symptomatic" rather than political, and thus react by prescribing rather than negotiating. Thus, often the consequences of the organizational defects of medical practice are passed on to the patient in doubled form: once through direct impact on patient quality of life, and again through oppressive responses to legitimate complaint. This is known in traditional sociology as "sanctioning conformity to the norms of the sick role", and occurs precisely when the technical capacities of the medical institutions are *least able to deliver their "normative" service*. The *reductio ad absurdum* of this situation occurs when the patient is himself a physician, or at least medically knowledgeable. The increased technical sophistication of the patient on the one hand, combined with the increased involvement of the medical staff with "one of their own" on the other, naturally heightens both the probability and the potential damage of the general process.

Becoming "uncooperative" however, is not the only strategy open to the patient in these situations, and defining the patient as psychologically or (what is tantamount to the same thing) morally defective is not the only strategy open to the medical staff. Indeed, the emergence of such a situation is relatively rare, and such strategies are often last resorts on the part

of physicians and patients alike. Patients may in fact cultivate a studiously ignorant and deferential helplessness, which thrusts upon the medical staff the necessity of vastly more intense monitoring of the patient's condition and adherence to the prescribed regimen. Thus, such patients may effectively force the commitment of a disproportionate amount of time and emotional involvement from the medical staff, at the same time they jeopardize their own chances of success through their inability or unwillingness to manage the details of their own illness careers.

Pediatric situations are of course particularly subject to this kind of problem. Glasser [9] in fact notes one case in which a leukaemic child brought along an exceptionally knowledgeable parent, who promptly precipitated a major management crisis on the service by using his knowledge to "supervise" the case. This is an interesting juxtaposition of both strategic patterns, and is not so uncommon but what most hospital-based pediatricians cannot recognize—and dread—it.

Before such extreme situations occur however, there is usually a long history of negotiation and maneuver on the part of all concerned, together with a series of false starts, misbegotten alliances, and ineffective arrangements. It is in this broad central range of chronic disease situations in which the impact of variations in organizational processes make themselves felt most subtly and yet most importantly. At every point in the career of the relationship between physician and patient the context of negotiation between them is constrained—often subordinated—to the larger scale organizational arrangements which surround the relationship. For chronic diseases, the impact of these influences on the course and ultimate outcome of the illness career is no less important than the physiology of the patient and the pathology of his illness.

Adequate management of illness therefore, requires an understanding of these organizational problems and contingencies. It also requires the availability of political technology adequate to avoid or overcome their detrimental implications and take advantage of their potential benefits. Clearly, the job of the sociologist in this situation is to perform the analysis leading to such an understanding, and to advise on the development of such technology. In such a view, the oft-cited distinction between "sociology *in* medicine" and "sociology of medicine" [10] disappears. Sociology "in" medicine has little purpose beside the improvement of the character and results of medical work, and this can be achieved only by the practice of sociology "of" medicine. In other words, medical sociology (as, equally, other sorts of social science) will improve sharply in technical quality to the extent it abandons the specious myth that it is divorced (in practice, but not in theory) from the problems of the world.

Medical services are organized in a wide variety of ways. The most fundamental distinction is between "in-patient" and "out-patient", the formal organizational embodiments being (typically) hospital wards and clinics respectively. A given ward often serves patients with a variety of more-or-less closely related problems; at the very least "medical" wards are separated from "surgical" and "psychiatric" services. Except in the rare case of specialized research ser-

vices, wards and clinics both have a number of different medical specialties in attendance upon their patients, and the "mix" changes continually as the problems of particular patients come and go. In teaching hospitals, the physician who is routinely "on the service" is the house officer, an intern or resident. House officers' periods of service however, often last only a month or two, and rarely for more than a year. The major continuity of medical care on a service (such as it is) is provided by the nurses, who are nominally permanent in their positions. In fact however, there is a very large turnover in nurses on most services [11].

As a consequence, we have a situation in which the working arrangements among the professional staff of a service are constantly in process of re-negotiation as established relationships dissolve with the high turnover and new relationships involving new people and different specialties are obliged to form. Strauss [12] has analysed a variety of the work contingencies which can arise as a result of the rotational system for house officers. When combined with the more irregular turnover of nurses, administrative personnel, and attending physicians, the maintenance of stable working relationships on a service is clearly a complex and resource-consuming problem [13].

The patient of course arrives in the midst of this situation knowing little or nothing about it. If he is lucky, he will not arrive at the beginning of the rotational turn of a slightly undertrained intern, coincident with the departure of a respected longterm head nurse and the emergence of serious disputes over procedure and philosophy among the senior physicians on the service.

He will be luckier still, if his problem requires the attention of only a single physician. When diseases become complex and multifaceted, they require the services of a wide variety of medical specialties, each with its own perspective on treatment and the evaluation of the myriad trade-offs and contingencies among alternative treatments. Patients with many physicians run the risk of becoming embroiled as innocent victims in disputes over whether surgery or chemotherapy is the appropriate procedure; over the advisable dosage limits to powerful or dangerous drugs, over the jurisdictional boundaries between physicians whose work overlaps; and in a variety of other possible disputes. These problems arise because the work is inherently uncertain, and because it intrinsically requires a wider variety of skill than any single person can hope to attain. This in turn inevitably makes for jurisdictional and philosophical disputes among physicians in situations in which segregating them from one another is impossible. Thus, a patient may find himself rapidly taken off and returned to and again taken off a potentially habit-forming drug, or discover that an intrusive and uncomfortable diagnostic procedure has come to naught because of technical disagreements among physicians on the appropriate methods of analysis. That such occurrences are *relatively* rare is a tribute to the generally high level of dedication and responsibility in the medical profession. That they occur in the first place (and the *absolute* frequency of such occurrences is large), is a tribute to the gross misorganization under which the institution labors.

The elaborate hierarchy which exists on medical services serves to compound these difficulties enormously. Medical services may well be unique in the number of different ranks of office they can cram into a "production" setting. In a large teaching hospital it is possible to find eight different ranks clustered around the bed of a single patient: orderly, nurse, head nurse, intern, resident, chief resident, attending physician, chief-of-service. Of these, seven claim to be professionals, and have at least some means to enforce the claim. They also each claim to provide care of the patient according to technical criteria. Yet each of these must also take orders from or give orders to the others, and each claims some ethical and moral responsibility for the welfare of the patient. That all of these people have rather different conceptions of their relative strengths and weaknesses—technical and moral—there can be no doubt. When these alternative conceptions become explicit, the risk to the patients' welfare rises rapidly. Because precise analysis of medical service hierarchies is still in its technical infancy, relatively little can be said at this point about the impact of specific hierarchical patterns on patient care and welfare. Nevertheless, it is clear that the potential for mis- and non-coordination is extremely high.

A frequent result of these organizational complications is the exacerbation of a tendency already present in work of this kind: the medical staff begins to treat the patient like a "case", and not like a person. That is, as the problems of managing the work (as over against the illness) multiply, there is an increasing tendency to fall back for support upon more-or-less well-understood routinized procedures (often rooted in abstract theory or ideology) which may apply regardless of the particular circumstances involved. This applies as much to the social control of patients as it does to the choice of technical procedure, and it applies most of all to the settlement of jurisdictional and other "administrative" disputes. Professional prerogative in these latter situations often overrides the interests of the patient, especially if the cost to the patient is measured in inconvenience, uncertainty or monetary expense rather than severe pain or threat to life. Thus, a patient who is a "management problem" ("turkey", "crock") may receive tranquilizing medication at the request of nurses or house officers, and it is not unheard of for mild doses of such medication to be increased through "accidental" multiple administration. The extreme (but not unique) example of such practice is described by Strauss and Glaser [14].

The degree to which a particular patient may have to face some or all of these contingencies in his medical career varies widely with circumstances—the problems are clearly more intense in larger, research-oriented teaching hospitals, especially those connected directly to medical schools. Contingent circumstances also might include the season of the year, the social characteristics of the patient, the type of service, and so on. Whatever the particular situation faced by the patient however, he is faced with the problem of somehow managing his illness (and the rest of his life) despite the problems presented directly or indirectly by the organization of the service. Few patients are sufficiently familiar with the complexities

of hospital and clinic life to manage the various contingencies effectively. Fewer still are physically up to it—illnesses have a tendency to distract people from the relatively delicate nuances of their immediate situations. To consider the patient as "deviant" in such situations (whether he is "really" deviant or whether "society" just "says he is") is to completely miss the point of what happens to the patient, and to the medical staff. The patient in such a situation is faced with a complex political order, constantly in flux and constantly throwing up new problems and contingencies which have important implications for the patient's life, liberty and capacity to pursue happiness. Patients tend to respond to these situations with a varying mix of political tactics and strategies, some successful, others unsuccessful. In this perspective, the assignment of the patient to a "deviant" category is one more debilitating *symptom* of his illness career, one imposed by the social order he is supposed to uphold rather than by a defective physiology.

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