

Patients In The New Economy: The "Sick Role" In A Time Of Economic Discipline

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From the anonymous victim of epidemics as collective scourges, from the traditional image of the alienated and passive "patient" to the "self-provider of medical care" as a new cultural figure, to the "health-care user" as a collective actor in the public-health system, and finally to the militant for whom the body is the basis of a new political action, the "sick person" appears to have travelled a long way, about which a number of questions must be asked (Herzlich and Pierret, 1987: 229).

A system of healing, like any other structure, includes a set of roles for the major agents. Within our modern health-care system, there is a set of social expectations around what it means to be a "patient," how one comes to be a patient and, especially, what one is to do upon becoming a patient. Nevertheless, it is rare that one finds a serious consideration of the role of the patient within the whole practice of medicine. Indeed, one overview of Canadian studies of the sociology of health and illness stated:

we are prompted to note the absence of patients in most Canadian theories, explanations, or descriptions of occupations and professions.... The general absence of patients in the conceptualization of the "health care system" suggests that sociologists have not defined "the system" in sociological terms (Coburn and Eakin, 1993: 100-101).

However, there have been different social roles for patients, each of which has been influenced by scientific, social and cultural shifts. Indeed, the experience of being "sick" is influenced by prevailing social and historical attitudes toward illness. For example, at various times in western history, illness has been claimed to be evidence of sin or guilt or a lack of self-control or just plain bad luck. Each of these conceptions of the causation of illness will affect the treatment of the ill. This essay considers the emerging view of the patient, one which is primarily influenced by economic forces. For example, a part of the retrenchment of medical services involves a conception of patients as more fully responsible (both socially and fiscally) for their sickness, and thus not deserving of total state assistance in their recovery. The major question I wish to ask is: "What is the social meaning of patients in this New Economy?" First I consider Talcott Parsons' concept of a "sick role," and then suggest the ways in which that classic role has been challenged by

the policies of economic restraint. Finally, I argue that a new "sick role" is developing, in response to economic and structural forces, and outline five characteristics of this new role for patients in the New Economy.

The Patient and the Sick Role

One of the most widely-accepted sociological attempts to define the place of the patient in modern health care was that of Talcott Parsons, the prominent American scholar who was a champion of the Structural Functionalist approach to social analysis.¹ For Parsons, individuals played set roles within particular institutional settings, such as the family, the workplace, the legal apparatus, the medical system, and so on. Parsons argued that the ill take on a sick role, which (like all roles) provides them with a set of responsibilities and privileges. As he wrote, "illness is not merely a state of the organism and/or personality, but comes to be an institutionalized role" (Parsons, 1978: 21). Illness represented a legitimate withdrawal into a dependent relationship -- a sick role -- and Parsons outlined four aspects related to this role, two rights and two obligations (Parsons, 1951: 436-437):

- (i) An exemption from normal social role responsibilities. The physician is usually the one to legitimize this right.
- (ii) An exemption from responsibility to get well by one's own actions alone. In other words, the sick person cannot be expected to get better on her/his own, and has the right to assistance.
- (iii) An acceptance that the state of being ill is not desirable, and an accompanying obligation to *want* to get well.
- (iv) An obligation to seek "*technically competent* help, namely, in the most usual case, that of a physician and to *cooperate* with him in the process of trying to get well. It is here, of course, that the role of the sick person as patient becomes articulated with that of the physician in a complementary role structure" (Parsons, 1951: 437, emphasis in original).²

¹ Parsons was not the first to recognize that the ill take up a different position in society than do the healthy. For example, until well into the 19th century, disease was regarded as resulting from "a lack of harmony between the sick person and his environment" and an upsetting of the balance among the four humours (Dubos, 1959: 101). This was very different from the later, and less holistic, approach ("specific aetiology") which held that specific diseases had narrow causes. In these two cases, both the social conception of disease and the roles of the patient would differ. In addition, it is argued that there have been shifts (in Western society) in seeing the ill as either sinful, or as guilty, or as morally-neutral unfortunate victims. These historical shifts in the role of the patient suggest that changes in science, social attitudes, and even economics, affect the role that patients take on in society.

² Parsons initially outlined one "sick role," but he later recognized that a broader social context would have some effect on a society's sick role. For example, in writing of the nationalized health system of Britain,

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While Parsons insisted that the sick role should be characterized as a "deviant" role, he also noted that it differed from other deviant roles:

precisely by the fact that the sick person is not regarded as "responsible" for his condition... and usually the patient got into that condition through processes which are socially defined as "not his fault" (Parsons, 1951: 440).

As a result of this complex of elements of the sick role, the patient is generally considered to be entitled to assistance.

One of the prominent characteristics of Parsons' theory is an asymmetry between the roles of patients and healers. Their rights and obligations are not equal, with the more institutionalized and legitimized functions of doctors taking precedence over the role of the patients. Indeed, from a phenomenological standpoint, a doctor and a patient may define the illness in different ways. For example, in a study of elderly patients who were recovering from strokes, Becker and Kaufman (1995) noted that the experience of "living" a disease means that one will construct a different idea of the illness trajectory (the narrative, often quite personal, of the progress and development of a disease) and the expected outcomes of that disease. The acceptance of the sick role implies that the patient takes on some responsibility for getting well, and some patients may be actively advised to take over even greater responsibility (diabetics represent a prime example here). Indeed, much healthcare-related intervention relies on the passive co-operation (usually referred to as "compliance") of the patient. Patient compliance has been a standard feature of medical journals in the last couple of decades. Trostle (1988), who interpreted patient compliance as a euphemism for "physician control," claimed that it was an ideology which reaffirmed and legitimized the unequal doctor/patient relationship. The fascination with patient compliance indicates a particular conception of the patient as an "opponent" of the doctor. This interest in patient compliance was ascending in Parsons' time, and came to full bloom in the 1970s and 1980s (based on the importance of the topic in the medical literature; see Trostle, 1988). In some ways, the concern over patient compliance could also be read as a reaction to the rise of self-help movements, the increasing competition from non-traditional medicine, and the emergence of patient activists of various sorts. These developments represent threats to the established institutions of medicine.

Despite challenges, Parsons' theory provides a theoretical model of how, in one particular medical system, patients were placed within the structure in a particular role.³

Parsons wrote of the "particularly strong British feeling that the sick individual has a right to care... [thus] illness, far from jeopardizing the individual's status, gives him special claims on the collectivity" (Parsons, 1972: 116). These "special claims" are in jeopardy under the current restructuring of healthcare in the New Economy.

³ It should be noted that Parsons' theory of the sick role has been criticized on a number of grounds. For example: (i) West (1989) argued that the asymmetricality of the sick role actually decreased the chances for good doctor-patient communication; (ii) Koos (1954) found that class made a significant difference in whether one would seek medical assistance, with labourers being far less likely to define symptoms as requiring the attention of a physician (see also Kassebaum and Baumann, 1972; Zola, 1989); (iii) Ablon

His model also provides a point of comparison which helps in focussing on the changes which the concept of the patient has undergone since the 1950s, and the ways that the institution of medicine has been able to manage changing demands for services. The following sections will address these changes in some measure, but first another important element must be added into this shifting mix of doctors and patients and structures and roles -- the economic discipline imposed by the New Economy.

The New Economy and the Fiscal Crisis in Medicine

Throughout the 1990s, the phrase "New Economy" rose to prominence in discussions of economic and social policy. It is encountered in numerous discourses disseminated by government and industry, often presenting a gloss of opportunity, freedom, competition and entrepreneurship. This positive rhetoric may hide some of the concrete effects of the New Economy (cutbacks in public services, heightened regional competition, privatization, layoffs, an eroding public sphere, growth without increased employment, economic insecurity, rising Corporate power).

Like many other keywords, the "New Economy" is rarely defined, making it somewhat slippery as a referent. One attempt at definition may be found in a Newfoundland government pamphlet, "At the Crossroads: The New Economy in Newfoundland and Labrador." It claims that the New Economy began with Japan's rise after the Second World War and the move toward a global economy and the increase in information technology. According to Industry Canada (cited in the booklet), the New Economy contains the following characteristics: (i) Globalization (free trade, global competition for businesses); (ii) Prominence of the services sector of the economy; (iii) Knowledge-intensive industry; (iv) Competitive advantage (automation helps short runs to be cost-effective); (v) Niche marketing (customization, to meet specific requirements); (vi) Continuous and rapid change, shorter product life cycles, compressed time for the introduction of new technologies (cited in Economic Recovery Commission, 1994: 5).

As a result of these conditions, the New Economic Actor will be a self-reliant information processor, always ready to take another course or to look for another job. All of these characteristics may result in higher levels of stress among workers (and especially non-workers) and increased health problems (as well as more reticence to interrupt work by seeking medical assistance). The Economic Recovery Commission of Newfoundland and Labrador lectured that: "It should be recognized that few jobs are secure in the new economy, and many people will change their places of employment -

(1981) argued that some patients are stigmatized even before they enter the medical system, so that differences in social class, age, gender, ethnicity and sexual orientation may affect the legitimation given to patients; (iv) borrowing from Goffman, one could argue that patients with "discreditable" diseases (such as leprosy or venereal disease), are not provided the sympathy which normally accompanies the sick role (Goffman, 1963); (v) Parsons did not account for the growing tendency to hold patients as being "responsible" for their own illness (see Sontag, 1977); (vi) Segall attempted to apply the concept of the sick role to a group of patients and found that "the respondents' perceptions of the sick role did not overwhelmingly support the Parsonian model" (Segall, 1981: 174).

even their careers - several times during their lifetimes" (Economic Recovery Commission, 1994: 29).

In this economic context, there is increased pressure on our medical system and a resultant shift in conception of patients' roles. There are dire warnings in magazines about the loss of Medicare which is, for many Canadians, a sacred trust. Panel after panel of buffed experts fill the TV screens to tell us we cannot have tomorrow what we've got today. Clearly, one of the major issues in health care today is the crisis in funding, which is sometimes presented as a result of the unrealistic demands of patients. This positions patients as the cause of the funding shortfall and ignores other contributing causes, including: the expansion of medical knowledge and technology, resulting in increased interventions; the heavy reliance on pharmaceuticals, even when they are sometimes unnecessary (Mickleburgh and Nasrulla, 1994); and the way in which doctors get paid, based on the nature of their assistance and the number of patients they see (Canadian Press, 1995).

Proposed solutions to the fiscal crisis intend to affect patient behaviour. For example, one solution is to impose user fees. A 1993 poll found that 73% of respondents were in favour of a \$5 user fee for visits to hospital emergency wards (Came, 1993). While this may not result in significant revenues, it may dissuade patients who are in the habit of using emergency rooms for health care, instead of their doctors. Thus, such fees may be designed more to change patient behaviour than to recover costs, illustrating that changes prompted by the New Economy go beyond the economic sphere. With this brief context of the New Economy in mind, we now turn to the ways in which the "sick role" has changed since Parsons' formulations.

The Sick Role in the New Economy

To paraphrase Marx: "We make our own health, but not always under conditions of our own choosing." This underscores a basic complexity in relation to illness -- that it is a result of both individual and social (or public) factors. To emphasize one source of disease causation and to ignore the other is poor medicine, though it may make for good ideology. What follows are five characteristics of the patient's role in the New Economy. This is not meant to be exhaustive, but simply to bring together some of the changes which the concept of the patient has been encountering since Parsons' initial definition of the sick role. Furthermore, just as the New Economy is only partially set in place, this new sick role is also still in the process of being implemented.

(i) Patients in the New Economy are Responsible For Their Own Illnesses.

The attribution of responsibility for disease has become an important part of the sick role of the patient. Kirkwood and Brown (1995) argue that attribution of responsibility is frequently a rhetorical strategy that is used by medical professionals to promote behavioural changes in their patients, but the effects of this go beyond the walls of the

clinic. While being held responsible for having an illness may make disease similar to a crime, the flip side to an imposition of responsibility is the potential for patient empowerment.⁴ Ideally, the patient who is responsible for her/his health would also be given more control over its maintenance. This would put the locus of control back at the individual level, and there is evidence that people with an individual locus of control will engage in more positive healing behaviours (Kirkwood and Brown, 1995). If people are convinced that their actions have some effect on their illness, then they are more likely to be involved in decisions regarding therapy and to claim more control over the illness experience. Indeed, the rise of "patient's rights" movements may actually facilitate this shift of responsibility from the system to the patient. Such patient-oriented movements are often seen as inherently positive, and as a natural outgrowth of self-empowerment groups (Burston, 1990).

However, an increasingly prevalent effect of holding individuals responsible for their illness is to also hold them economically responsible for its cure. Thus, one result of this "privatization" of responsibility is then a privatization of medical assistance. Some openly question, for example, whether the State should pay the medical costs of people who fall ill due to "lifestyle choices." As Canadian physician R.E. Goldberg stated:

If a patient is injured in an auto accident while not wearing a seat belt or while intoxicated, his or her health benefits should be denied for that accident. This would emphasize personal responsibility for irresponsible lifestyle choices (cited in Francis, 1993).

The belief that individuals are responsible for ill health can lead to a parallel pursuit, that of the attribution of "blame." This is most pronounced in the case of illnesses related to "lifestyle," an ambiguous word which comes to stand in for many things, such as eating patterns, sexual desires, work schedules, leisure pursuits, etc. The word "lifestyle" assumes that we have choice in all of these matters, and this may not be accurate. As a counter, medical research on genetic predispositions to disease may alleviate some of the blame that is placed on the sick. If the disease which will terminate our life is already marked in our genes, then there is little possibility in altering the outcome and patient responsibility is diminished.

Ivan Illich claimed that the notion of responsibility for our health, in the midst of our manufactured environment, was absurd. As he contends: "I believe it is time to state clearly that specific situations and circumstances are 'sickening,' rather than that people themselves are sick" (Illich, 1994: 11). This points to a significant effect of holding individuals responsible for their own health -- the obscuring of the social causes of disease. While individuals can no doubt be in certain senses responsible for their diseases, we must be careful not to obscure other causes. We must ask: Are employers responsible when they create a work climate that rewards over-work and stress? Is a society responsible when it creates a social system that keeps people struggling at low-

⁴ Sontag (1977) also explored the ways that illness was used in modern society - how it came to "stand" for particular character types.

wage jobs? A number of researchers have stressed the ways in which the social and economic structure of our society can have effects on health, from its effects on the environment to the manner in which it structures relationships in the workplace (D'Arcy and Siddique, 1985; Schwalbe and Staples, 1986; Livesey, 1989; Taylor, 1993). However, medical intervention tends to focus on individual solutions to disease, rather than fundamental social changes. For example, while stress is often a (dis)product of one's social environment, it is treated through pharmaceutical drugs, thus obscuring and even legitimating underlying social causes of the illness (McKinlay, 1981; Labonte). This tendency to hold individuals responsible for their own illness fits with both the fiscal and ideological needs of the New Economy. It decreases the legitimacy of claims for medical assistance and it depoliticizes the negative effects of social structure on individuals.

The increased focus on a patient's responsibility for her/his own illness, results in both a new conception of the patient and a new conception of the state's responsibility toward the ill. Even before the current fiscal crisis, Crawford (1977) noted that the ideology of "victim blaming" (or seeing individuals as responsible for the onset of their own illnesses) was one result of the threat of high medical costs. In order to lower expectations, and lower the sense of entitlement to health care, Crawford argued that there was a refocussing onto individual responsibility for the onset of illness. It is ironic that we are being convinced to be ever more cautious about our own behaviour at the same time as the social causes of disease (pollution, social disruption, economic insecurity) are increasing. Clearly, behavioural change can affect health outcomes. However, to focus on individual change without also looking at social change is to provide a partial and thus distorted analysis.

(ii) The Patient in the New Economy is Instructed to Tread Lightly on the System.

A part of the current sick role is to use as few medical services as possible. For example, in 1994 the Ontario government undertook a pilot campaign to get people to stop going to a doctor for minor complaints. The government targetted the city of London, and it distributed pamphlets, giving home remedies for the cold and flu (including such time-tested therapies as chicken soup). The purpose was to keep patients from clogging doctors' offices, and in the process spreading their colds even further, through waiting room contacts (Mickleburgh, 1994).

However, a concurrent study found that people overwhelmingly knew that one should not go to see a doctor for a simple cold or flu, even before the government education program had been launched (Breckenridge, 1994). Nevertheless, the fact that a provincial government went ahead with a campaign explicitly to cut down on the number of medical consultations, despite the lack of any evidence showing the necessity of such a campaign, illustrates an underlying conception of the patient as ill-informed, over-serviced and deserving of cutbacks.

(iii) In the New Economy, the Requirement to Get Better Relates to One's Duty to the State, Rather Than One's Duty to Self.

What is our underlying reason to undergo medical therapy (beyond the relief of painful symptoms)? Is it solely for the well-being of ourselves or is it for the benefit of others, especially institutions? In the New Economy, we are told that the government deficit is the fault of all of us, and that we must all do our part in reducing it. This includes reducing the extent to which we rely on medical assistance, and the length of time we might spend as "unproductive" members of society. Thus, we are to get better so that the State does not suffer.

This view of the patient fits with a new moralism about the way in which individuals are held responsible for their own health. Thus, in the New Economy, one has a duty to take care of one's body not just for the good of the self, but also for the good of the State. Furthermore, by shifting the public health and preventive focus onto individual behaviours and individual responsibility, corporate contributions to ill health are ignored and the exercise of social control becomes even more effective. For example, the majority of cancer information to consumers focusses on individual risk factors, rather than societal or cultural risk factors (Breckenridge and Westell, 1995). While individual sacrifice to the public good is not in itself undesirable, in the contemporary situation the ideology of health care is one that is more and more individualistic. And yet, the proposed motivation for maintaining a healthy population relate to issues of productivity and economic advantage, and not to the simple well-being of citizens, or to the common good.

(iv) Patients in the New Economy are not to see Health as an Experience, but as a Commodity.

In the New Economy, which is solidly permeated with marketing, health has ceased to be simply a condition of one's body, but it has become a commodity -- a thing to be purchased and even traded for further gain. This fits with the general government emphasis on privatization (which is really an expansion of commodification, or the invasion of the cash nexus into more and more spheres of life). Illich (1994) argued that "life" itself has become an idol in today's Western culture, a fetish. It is talked about as if it were property -- a commodity rather than an experience -- which then fits in with our bias toward possessive individualism

Along with this commodification of health, there is also an alienation of the patient from the process of medical intervention itself. New techniques of diagnosis and observation can "identify symptoms without depending on the subjective perceptions of the patient" (Doyal and Doyal, 1984: 90). For example, in relation to people with HIV, the decision regarding when to begin prescribing drugs such as AZT or DDI may depend on the results of laboratory testing (such as a T4-cell count or a CD4 count), rather than a consideration of how the person is "feeling." A patient may arrive at a doctor's office with few complaints and in a positive frame of mind (thus, they are "feeling" well), but will

leave with a new prescription due to test results. Some have argued that the discourse around hypertension ("a symptom without a disease") likewise subjects patients to treatment when they receive certain test results, regardless of how they "feel" (Banerjee, 2000).

(v) Patients in the New Economy are Not to be Trusted.

The concern over the abuse of the medical system is an ideological plank of the New Economy, and a further attempt to shift the blame for the fiscal shortfall on to the patients and off of the system.

In an article summing up a week's special coverage of the health care funding crisis, the *Globe and Mail* noted that: "There will be more public education aimed at ending abuse of the health-care system" (Valpy, 1992: A5). This, despite the fact that there was no significant evidence in the stories of any such "abuse." The only thing mentioned, in the summation, was the number of people with a cold seeing a doctor (and this figure was later disputed).

Mickleburgh (1993) reported that, according to studies, less than one percent of health-care spending could be due to the provision of "unnecessary" services. Thus, the introduction of user fees would be of little value, and would deter many who truly need medical care (thus resulting in a net decrease in the nation's health status). So, while we have no solid evidence of abuse, we see it used as a justification for stricter surveillance of patients in the New Economy.

In sum, in the New Economy, the doctor has two patients -- the ill individual who comes looking for physical relief, and the ill economy, which is in need of some fiscal relief. Medicine has been asked to balance these two in some way. It is thus no wonder that the conception of the patient has been altered as well.

Conclusions

(M)edicine itself, and not illness, has become a metaphor and ... medicine has become the focal point of certain of our most fundamental questions concerning the future for which our society is headed (Herzlich and Pierret, 1987: 239, emphasis in original).

This paper has argued that our conceptions of the ill, and the roles they are given to play, are affected by social factors. Thus, the sociology of medicine is not the analysis of a static social institution, but is an attempt to study the shifting values of society itself (using the site of medicine as its focus).

I have not only identified some of the ways in which economic discipline is changing the view of patients, but I have also tried to identify the positive aspects of current shifts

in health-care thinking. Maybe we *will* become more empowered as patients. Maybe these shifts *are* in our own interest, and not solely in the interests of the government of the day. Or maybe the sociobiologist's dream will come true, and we will begin to see ourselves as fractured, atomistic collections of genes, each one plotting a possible treason.

As for a remedy to this situation, there is a temptation to focus possible solutions on the individual level -- to further empower patients through new models of public health education. For example, Homans and Aggleton have called for a "socially transformatory" model of health education, which would provide a critique of the "pervasive inequalities of power in society which affect the choices people make and limit opportunities for healthier forms of living" (Homans and Aggleton, 1988: 168). The resulting social transformations would not only change the nature of our society, but it would give the patient another (maybe more humane) sick role to play. This time, a role which recognizes the complexities of maintaining one's health within a structure that is itself sometimes ill.

And yet, to believe that a new model of health education will solve these problems is to be naively idealistic. One cannot simply call for more patient adaptations if the causes of the problem are structural. The new model of health education would not alter the discipline of the New Economy. Social transformation is occurring, but it is a transformation toward the New Economy, not away from it. It is unlikely that a significant cultural shift (which would be needed for the above model to work) could be negotiated against the grain of the "teeth-gritting harmony" of economic trends. The altered conceptions of patients in the New Economy will likely be with us for some time to come.

We do, indeed, make our own health, but not under conditions of our own choosing. Nor, I might add, do most of us have the luxury to choose the sick role which we shall inevitably play.

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