

THE PATIENT'S RIGHT TO KNOW: SOME SOCIOLOGICAL CONSIDERATIONS

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ABSTRACT

This is a discussion of the implications of "the right to know" from the perspective of the patient and the physician. Three aspects are explored: Some overlooked premises of the doctor-patient relationship; the assumed benefits of the patient's ignorance; and the link between the right to know and informed consent.

Keywords: Patient's rights, patient's ignorance, informed consent, doctor-patient relationship, the right to know

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"Verbally I don't learn anything definite . . . since in discussing tuberculosis . . . everybody drops into a shy, evasive, glassy-eyed manner of speech."

[Kafka as quoted by Sontag (1)]

The above words were written by Franz Kafka "in a letter to a friend in April 1924 from the sanatorium where he died two months later" (1). Although the advances in medical technology have reached heights not dreamt of sixty years ago, the level of communication between the patient and those who know his prognosis has not improved much since Kafka's days. One could change his reference to tuberculosis for cancer, for example, and his remark would be equally applicable today. Indeed, now we still get together (in different cities, using different languages) to discuss the patient's right to know. The intentions of all concerned are good but, the fact that the patient's right to know is still a topic of discussion rather than a universally accepted principle, reflects the large gap that exists between our technological prowess and our social values.

Nevertheless, the current discussion of the patient's rights is a necessary outcome of at least two positive situations. One is that an increasing number of health professionals is keenly aware of the need to incorporate the patient fully, as a person, into the therapeutic process but what prevents many conscientious physicians from involving the patient fully is the physicians' apprehension that full information may not be in the best interest of the patient. The other positive situation is that the population are better educated today and thus they are becoming more active and discerning in their contacts with the health care system, and less content with the passive role traditionally assigned to them as patients. More importantly, perhaps, is the fact that the confluence of these two situations takes place within the realm of the doctor-patient relationship. In other words, the question of the patient's right to know is equally relevant in the specific interaction between the patient and his or her doctor as it is at the larger social level involving the medical profession and the general public.

It is useful then to begin the discussion of the patient's right to know from the general angle of the doctor-patient relationship. After demarcating the principal features of that relationship, two other aspects will be discussed: namely, the assumed benefits and negative consequences of the patient's ignorance; and the link

between the patient's right to know and informed consent.

The doctor-patient relationship: relevant features

Most medical practitioners may consider themselves well-acquainted with the content of the doctor-patient relationship. This is one of those concepts discussed in medical school and experienced in the professional's daily life. Nevertheless, there are some intrinsic features of the doctor-patient relationship that, although crucial in the context of the patient's right to know, are seldom identified or acknowledged. Three of those features require our attention at this point. They are: common goals; conflict potential; and the "bumpkin" fallacy.

Perhaps the least controversial aspect of the doctor-patient relationship is the assumption that both members in that relationship have at least one common goal, the patient's recovery or maintenance of good health, and thus are expected to work jointly towards its attainment. An overwhelming majority of the doctor-patient encounters fall into this category of a common goal. However, there are instances when this assumption of a common goal is not fully applicable, that is, situations where the doctor-patient relationship is most vulnerable to clashes between disparate goals. One example is a research setting whereby the principal medical goal is experimentation and where medical researchers may, consciously or unconsciously, alter their Hippocratic priorities and put the individual patients' recovery in a second place, behind the goals of experimentation and discovery. Other vulnerable situations are those where the doctor represents an institution or entity upon which the patient depends as an employee or subordinate. In all these cases, doctors need to make a special effort to maintain the Hippocratic tradition of giving the patient's recovery top priority over and beyond any other professional goal.

There is a direct link between this fundamental goal and the patient's right to know. For as long as the patient's recovery is the top common goal of the doctor-patient relationship, it is essential that both parties abide by the principle of trust. That principle involves the firm belief in the honesty, reliability and truthfulness of another person. More importantly, to be meaningful and effective, "trust between two people . . . must be reciprocal" (2). As Faulder and others indicate, trust is always seen in terms of the patient's trust in his or her doctor. Unfortunately, the reciprocity of that trust, namely, the doctor's trust in his or her patient, is seldom, if ever, acknowledged (3). In a relationship of trust, both the doctor and the patient are equally entitled to expect and to receive honesty, reliability and truthfulness. Hence, to question the patient's right to know is to ignore the principle of trust.

The second crucial feature of the doctor-patient relationship is the potentiality for conflict. While conflict is inherent in any social relation, the potential for conflict in a relationship between two persons increases if one party

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believes he or she is superior to the other party and acts accordingly while the other party either believes on his or her own superiority, or assumes the relationship is one between equals and acts accordingly.

An illustration of this situation is the relationship between a doctor and his or her educated patient. Compared to patients with no or low formal education, patients who are educated tend to have more information on health matters, to be more confident in expressing their opinions, more articulate in describing their symptoms, and to be less impressed by a medical degree. They approach the doctor-patient relationship from a consumer's perspective: because they pay for the services of an expert, they expect the best possible results. It is, in their view, a relationship of equals, as the patient may consider himself or herself a professional in his or her own field of activity. This situation suggests that the patient is not likely to accept the doctor's orders without question, and that the patient expects to be fully briefed by the doctor on the details of his or her health complaint, the available treatment options, and the possible prognosis. This type of patient is convinced of his or her right to know. I must add that the age or "maturity" gap created when the patient is highly educated and considerably older than the doctor, augments significantly the probability for conflict. The conflict may be open and direct. The patient may express his or her dissatisfaction to the doctor directly and may decide to seek a second opinion or change doctors completely.

When the patient is less educated, articulate or confident, the conflict in the doctor-patient relationship may be produced by numerous factors, three of which are the most important. These factors are: a communication problem (for example, inability of the patient to describe his or her symptoms and fears, or inability to understand the doctor's instructions and explanations); by social class differences between practitioner and patient (with the patient feeling inadequate, ignorant and worried about doing or saying "the wrong thing"); and by cultural or religious differences between practitioner and patient which affect the meaning they attach to illness, their different "beliefs" about disease etiology, and their different approaches to "a cure". These three main factors may also be found when the patient is educated, but their effect tend to be minimised by the similarities between doctor and patient in their levels of information and conceptual comprehension brought about by education.

In contrast to the situation of educated patients, for the uneducated or poorly educated patients, the issue of their right to know is stifled mainly by their lack of information on what are their basic rights as patients, and their apprehension and reluctance to question the doctor whom they perceive as socially superior and wiser. Consequently, the lower educated patient may attempt to resolve the conflict in the doctor-patient relationship by indicating acceptance of whatever the doctor says during consultation and then doing what "makes more sense" to him or her at home, that is, what his or her cultural and religious beliefs dictate, including the advice from family members and consulting traditional practitioners.

The third relevant feature of the doctor-patient relationship in this discussion is what some critics label "the bumpkin fallacy". While the first two features i.e., common goals and conflict potential, focus on both doctor and patient, the bumpkin fallacy addresses two common assumptions held by doctors about their patients. These assumptions are: (a) once under the doctor's care, full control over the patient's body and illness is handed over to the doctor; and (b) the doctor can only treat the patient if the patient obeys doctor's orders.

It is evident that the bumpkin fallacy is related to the potentiality for conflict discussed earlier. The erroneous assumptions of the bumpkin fallacy lead doctors to believe in their superiority over patients and to negate the

patients' right to know. But patients perceive the situation differently. Empirical research on patients's attitudes reveal that patients want to, and actually attempt to, exert control over their condition and treatment in order to normalize their everyday lives (4). It is interesting that while denied or overlooked in regular doctor-patient interactions, patients' efforts to exert control over their condition and treatment have been theoretically legitimized in the 1973 "Patient's Bill of Rights" of the American Hospital Association and in the Resolution on "The Rights of Patients" passed by the European Parliament in 1984 (5). In both declarations, the patient's right to know is presented as a fundamental principle guiding the doctor-patient relationship. Yet, as suggested earlier, those declarations do not have "teeth" as physicians are not legally obliged to follow them.

The patient's ignorance: assumed benefits and real consequences

The preceding section has looked into the patient's right to know from the viewpoint of the doctor-patient relationship. But that right may also be examined from an alternative perspective, that is, the assumed benefits of ignorance. More specifically, one can ask the question: What can be gained by maintaining the patient ignorant about some or all the details of his or her condition, treatment and prognosis? There are many possible answers to that question depending on who is answering it. In the context of the present discussion, the answers of two groups of professionals, doctors and social scientists, are particularly relevant.

As suggested earlier, caring physicians who are against the patient's right to know may argue that full information may not be "in the best interest" of the patient as it may cause "unnecessary anguish" or "confuse" the patient. These opinions have been commonly found in empirical research on physicians' attitudes. Some illustrations will suffice. In 1961, Donald Oken, a physician and the then Assistant Director of the Institute for Psychosomatic and Psychiatric Research and Training at the Michael Reese Hospital in Chicago, conducted a survey on the "policy" of "physicians about 'telling' their cancer patients" their diagnosis (6). He sent questionnaires and interviewed 219 physicians and found that "ninety per cent indicated a preference for not telling" (7). What is most revealing is the doctors' rationale for not telling their cancer patients. Oken reported that:

The modal policy is to tell as little as possible in the most general terms consistent with maintaining cooperation in treatment . . . Questioning by the patient almost invariably is disregarded and considered a plea for reassurance unless persistent and intuitively perceived as "a real wish to know". Even then it may be ignored. The vast majority of these doctors feel that almost all patients really do not want to know regardless of what people say . . . Every single physician . . . indicated his resolute and determined purpose . . . to sustain and bolster the patient's hope (8).

During the course of the interviews, Oken also looked into "the doctor's wish to be told if he were the patient". He found that 60 per cent [73 out of 122] "said they wished to be told". The usual argument given was "I am one of those who can take it" or "I have responsibilities" (9).

Oken's study was replicated in 1979 by a group of six medical researchers from the University of Rochester. Their findings are also highly revealing. Using the same questionnaire designed by Oken, they collected information from 264 "university-hospital medical staff" and found that "97 per cent indicated a preference for telling a cancer patient his diagnosis — a complete reversal in attitude" (10) compared to Oken's findings some eighteen years earlier. Novack and his colleagues indicated that all of the 264 physicians in their study "thought that the patient has the right to know" (11). In their view, this unanimous

agreement could be explained by:

. . . sweeping social changes. The rise in the consumerism movement and increasing public scrutiny of the medical profession have altered the physician-patient relationship. In this era of "patients' rights," an attitude of frankness feels right and, indeed, given the current disputatious atmosphere of medical practice, may be the safest one to adopt (12).

Novack and his colleagues were accurate in their description of the social changes taking place in the United States concerning an increasing public awareness of the rights of patients. This awareness did not appear in the vacuum. Its background is interesting and I will return to this point after mentioning some other relevant views of physicians on the assumed benefits and consequences of the patient's ignorance.

An insightful and informative article on "Some thoughts to be delivered to House Officers on the first day of Clinic" written in 1987 by three American senior physicians involved in medical education, reveals the ambiguity and difficulty of the current medical position concerning the assumed benefits and consequences of the patient's ignorance. Departing from the premise that today "the inpatient model simply isn't relevant for outpatient practice", the authors advise young housemen on the different approach they must take when dealing with outpatients.

While the young doctors are used to deal with the captive audience represented by hospital inpatients whose situation made them more dependent on the doctor's willingness to communicate and share information, outpatients "live in their own worlds, worlds over which you have much less control than you are used to having in the hospital". Consequently, they add, "you won't be able to make decisions in the same way you are accustomed to in the wards" (13). The implication seems to be that the stronger control doctors have over patients is accepted as a natural part of the doctor - inpatient relationship which involves, among other things, the doctor's stronger hold over their monopoly of information. In contrast, Howell, Lurie and Woolliscroft instruct housemen to change this legitimate (in their eyes) model of the doctor - patient relation significantly when dealing with outpatients. Their advice is explicitly in favour of more communication and sharing of information for the sake of a more successful treatment. In their own words,

In the clinic, forming an alliance with the patient is critical. You can do nothing except give advice; the patient then decides whether to take it. This partnership will work better if you explain the problem and plan clearly . . . and complete the interaction by inviting the patient to ask questions or express feelings . . . You will have to adapt to having less data and less control . . . But the payoff will be great. You'll have the chance to be more thoughtful and less technical . . . and . . . to see the world through the eyes of your patients (14).

It is revealing that the switch in systems is presented as a practical and useful technique of patient management. The authors appear oblivious to the inherent contradiction of the two systems or approaches with respect to the patients' right to know. The same positive attitude and acceptance of the right to know that they recommend towards outpatients is required from all patients irrespective of the setting where the doctor-patient relationship takes place.

There is yet another angle of the problem of the assumed benefits and real consequences of the patient's ignorance as discussed by Miles (15), a physician working in the field of medical ethics. Miles feels that the principle of patient autonomy involving the patient's right to know and right to say no to a proposed treatment, although "serving many persons well" may not apply in all situations and may actually cause hardship to some patients. To illustrate his argument, he cites two examples of elderly patients who had steadfastly refused to undergo cataract

surgery although they were getting blind. One of the patients had no relatives, was paralysed and was living in long-term care hospital and his diminishing vision was increasing the "tedium of institutional life" which "became intolerably burdensome" (16). The doctors, following the principle of patient autonomy, accepted his refusal to undergo the operation and he eventually became blind. The other patient, although living in a home for the aged, had a caring family and one of her nephews was a doctor. Her family tried for some time to persuade her to accept the surgery and finally her nephew took charge of the details. Says he ". . . the night before surgery . . . resignedly, she spoke of being 'railroaded' to surgery. She did not ask that the surgery be cancelled; I did not offer to do so" (17). She recovered her eyesight and, according to Miles, she also regained the will to live and her enjoyment of life.

Miles concludes that there are times when patients need their families' pressure to accept treatment. He suggests that one such exception to the principle of the patient's right to say no (which is linked to the right to know) is the case of elderly patients who may listen to the information on the benefits of treatment but may require the intervention of their families or someone who cares, to overcome their misgivings.

Miles provides us with a serious point to ponder. The principle that the patient has the right to know and the right to say no, is based, among other things, on the assumptions that as an informed patient in possession of all your faculties, you should decide what is in your best interest, and that no one can judge what is in your best interest but yourself. Given the importance of these assumptions, one must also look into their limitations. The discussion of this point leads me to focus in the next section on the views of social scientists on the question of informed consent, a concept that furthers our understanding of the consequences of patients' ignorance as well as of patients' knowledge.

Informed consent

As indicated earlier, the open debate on the doctor's privileged access to information and the patient's right to know, has not appeared in the vacuum. The issue of patients' right to know and right to say no, is the corollary of a wider social awareness involving moral and political values. Throughout the 1970s and 1980s, intensely hard questions have been asked in industrialised nations about the role of information (official and unofficial) in a democratic society (18, 19, 20); the citizens' right to know encompassing all aspects of a nation's life and the issue of national security (21, 22); access to information as a human right (23); and the link between professional authority and democratic accountability (24).

Thus, it is not surprising to find a parallel development in the realm of the citizens' utilization of medical services. For example, in the United States, where litigation is now very much part of everyday life, the social value of the right to know is manifested in the concept of informed consent. As a "legal doctrine", informed consent actually "evolved gradually since the late 1950s through a body of court decisions" (25) and has become particularly strong during the past decade.

What is informed consent? This concept has been defined in numerous ways but always centering on the doctor's "affirmative duty to acquaint patients with the important risks and plausible alternatives to a proposed procedure" (26, 27). More specifically, two main principles serve as the bases of informed consent: the patient's autonomy or "freedom to decide his or her goals and to act according to those goals"; and veracity or truthfulness on the part of both doctor and patient (28, 29). Bayles considers truthfulness or "the right to be told the truth" as one of three key concepts of justice. He argues that "As a right of justice, it [truth-telling] imposes an affirmative duty

upon medical personnel to disclose fully information about a patient's condition" (30).

Bringing back the point raised by Miles (31), one then confronts the possibility that some patients may not be competent to give informed consent. When is the patient competent to give informed consent, that is, to exercise the right to know and the right to say no? As suggested by Faulder (32), the patient must be aware that he or she is giving consent and he or she "must understand what it involves". There appears to be an agreement among social scientists on the most crucial prerequisites to the exercise of these rights (33, 34, 35, 36, 37, 38, 39, 40, 41).

A summary of these preconditions may be stated thus: the patient's autonomy to decide presupposes that the patient is well informed about (a) the nature of his or her problem; (b) the suggested procedure to deal with the problem; (c) available alternatives to the recommended procedure; and (d) the positive and negative consequences of each possible course of action. A patient may be said to be competent to give informed consent to the extent that these prerequisites are met.

Correspondingly, there are some patients who may not meet these requirements themselves and doctors then need to seek informed consent from the next of kin or legal guardian. The most obvious types in this category are "children, the severely retarded, the elderly senile and people in a coma" (42), and some types of mental patients. The mentally ill, however, present a particularly difficult dilemma. Given the fact that some mental illnesses are discontinuous and thus only incapacitate patients temporarily, these patients may be competent to exercise their right to know and to give informed consent during their lucid intervals. When is such a mental patient lucid? This requires a medical opinion. As decided in a relevant court case in Britain, "the main issue in this case was the doctor's competence, not the patient's" (43). At the same time, a rather significant consideration needs to be mentioned:

... a patient's apparently irrational refusal of consent should never be taken as a sign of incompetence [in judgement] if, were it to have been given in the same circumstances, the consent would have been regarded as valid (44, 45).

The salience of this warning is underscored by "the bumpkin fallacy" mentioned earlier, that is, the belief among some physicians that patients must obey doctor's orders. Even if a non-mental patient refuses a suggested procedure, these doctors are inclined to conclude that

there must be something "wrong" with the patient's judgement and thus dismiss the patient's opinion.

CONCLUSION

I have discussed the patient's right to know from three perspectives namely, the relevant features of the doctor-patient relationship; the assumed benefits and consequences of the patient's ignorance; and the concept of informed consent. It is evident that these aspects are closely intertwined. They have been addressed in three separate sections simply for heuristic purposes. In the process of dealing with these principles and concepts, I have presented views from medical and non-medical professionals in order to provide, as far as possible, a balanced picture of the current situation.

One may draw three conclusions from this discussion. First, while most research published today have been conducted in Western countries, the issue of the patient's right to know is not confined to the geographical boundaries of specific nations but, rather, it is an issue that includes us all, patients, doctors and non-medical professionals alike, irrespective of nationality, ethnicity, gender or creed.

The second conclusion is that the public pressure to change the "traditional" values of professional authority over patients and doctors' privileged access to information is strong and it is supported by the wider trend towards democratic accountability in many other aspects of a nation's life.

The final conclusion is that, although there is no consensus among the medical profession on the question of the patient's right to know, the position of doctors who reject that right is becoming increasingly difficult to defend. Conversely, the patients' right to know appears to be a logical premise among social scientists, and our acceptance of this principle includes the acknowledgement of exceptions to every rule. However, any exceptions should be fully justified following the community standards of justice.

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