Physicians' Views on the Level of Medical Information Among Patients

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This paper usefully explores the need and practicability of informing patients about the nature of the current illness.

In organizing medical services for ambulatory patients those planning them often forget the patient in the desire to offer all that is considered necessary for adequate scientific care. Likewise, they may overlook one of the primary purposes of any medical care activity: to provide an optimal environment for the development and continuance of the doctor-patient relationship. Essentially this relationship resolves itself into a give-and-take between two human beings, the nature of the interchange being determined by a number of factors, such as the previous experience and knowledge of the participants, expectations of each toward the other, and ability to communicate. The effectiveness of the doctor-patient relationship should be one of the fundamental considerations in evaluating adequacy of medical care.

To shed some light on the adequacy of patient care in the medical clinic of a large metropolitan medical center a number of studies have been made. This paper will report findings that bear on the question of communication of information between physicians and clinic patients; more specifically, it will focus on the physicians' attitudes and beliefs about patient information. In addition, to provide a context within which physicians' views may be interpreted, a summary of findings on some related questions will be presented.

Methods

In the medical clinic 214 patients were queried about etiology, symptoms, and treatment of ten common diseases, namely tuberculosis, diabetes, syphilis, arthritis, menopause, asthma, cerebrovascular accident, stomach ulcer, leukemia, and coronary thrombosis. A 36-question multiple choice test was used. A sample question follows:

Tuberculosis of the lungs is due to:
1. Prolonged exposure to the cold
2. Infection with a germ
3. Anemia and vitamin deficiency
4. Don't know

These same questions were then made part of a questionnaire administered to 89 physicians in the same clinic which was aimed at determining how much information these doctors thought laymen should know and how much they thought patients in the clinic did know.

The third part of this study consisted of an intensive longitudinal analysis of 50 patient-physician relationships, the 50 patients being randomly selected from among those making new appoint-

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ments in the medical clinic. Each patient visit to a physician in the clinic was observed and a record kept of the activity and conversation that took place; in addition, the patient was interviewed before making the first visit to the physician and after each visit with him. The observations of the patient-physician contacts provided data on the ways the patient's illness was discussed, while interviews with patients revealed their views of what they had been told.

Results

The multiple choice test of knowledge about ten common diseases revealed that, on the average, the clinic patients could correctly answer 55 per cent of these rather routine questions. The range was from one-third correct answers for patients with less than an eighth grade education to two-thirds for those with a high school education. It was also found that knowledge varied considerably by disease; knowledge of coronary thrombosis, for example, was particularly low, with only two-fifths of the information answered correctly.[1]

In addition a random group of 50 new patients were questioned on their arrival at the clinic about the condition they suspected they had. Some of these patients had received care for this suspected illness from another clinic or physician, but the majority had not. Most patients were found to have focused their concern on a particular disease possibility, and the findings pertain only to this group who suspected a particular disease. No patients were found to have a thorough understanding about all three aspects about which they were questioned—the etiology or nature of the illness, the usual treatment, and the prognosis. Four patients were classified as having thorough understanding of the etiology or nature of the illness; but none had a thorough understanding of the treatment or prognosis. The majority were classified as knowing almost nothing about the three aspects of the disease. The minority were classed as having some understanding of it. On the basis of the findings it may be concluded that the patients studied were rather poorly informed about several common diseases and about their own suspected condition.

The next question to be considered, then, is what difference does this make? How does the patient's knowledge of disease influence the way the patient interacts with the physician and the quality of care received from the physician? It was not possible to determine the effect of the patient's level of knowledge, because no patient in the sample was well enough informed about his disease.

What was observed, however, is that the patients in our sample participated with the physician at an extremely low level. They seldom requested information from the physician (one-third of the patients never asked a single question on any visit), they seldom asked the physician to do anything, and seldom even made a statement to direct the physician's attention to something. While it is assumed that the physician should direct the conversation and activity, complete lack of initiative by the patient may be dysfunctional for the physician as well as the patient. While it has been impossible to test whether this low level of participation by the patients was related to their low level of information and understanding of illness, the simultaneous presence of these two conditions is consistent with the notion that they are related.[2]

What are patients' attitudes about re-

1. These findings are reported in more detail in a paper to appear in the Journal of Chronic Diseases titled "Level of Medical Information among Clinic Patients" by Arthur Seligmann, Neva McGrath and and Lois Pratt.

2. An average of 1.4 requests for information per visit, 0.5 requests for action, and 2.7 statements to direct the physician's attention or to volunteer information.

ceiving and demanding information from physicians? Before attempting to modify existing patterns of communication, it would be wise to know what information patients want to obtain from physicians; for if patients expect more information than they are now receiving one would proceed differently than if they expect and want little information. On the basis of our study data it has been concluded that for the clinic patients studied, there was no demand for detailed and fundamental information among the patients; but there is apparently a certain amount of latent interest in receiving more information than they now receive. The findings on this point are summarized: Patients seldom make direct demands for information to the physician, particularly of the sort that would give basic understanding of the disease; their abstract notions about what constitutes a good doctor seldom include information-giving as a requisite characteristic; by and large they evaluated their own clinic physicians as performing satisfactorily with regard to explanations and information-giving; but in contrast to the above findings, which suggested little concern with information, it was found that a majority of patients indicated to the interviewer in some direct or indirect fashion that certain specific pieces of information about the disease process, implications of the test results, and so on, were of some importance to them. In general there was very little conscious demand for a thorough explanation of the illness on the part of the patients; but there was an unformulated, latent need.[3]

At least as important as the patients' views on this problem of communication are those of physicians. The attitudes of physicians determine, in part, what patients are now told. Furthermore, it would be necessary to take their attitudes into consideration in any future plan to change communication practices. This would be especially true if it seems desirable to encourage physicians to devote more attention to this problem, for, according to one study, 19 per cent of the internist's time is now devoted to patient education.[4]

What, then, are the attitudes of physicians about having patients know about medical matters? The findings obtained on this question are based on a questionnaire administered to 89 physicians in the medical clinic. Each doctor was asked to indicate for each of 36 facts about disease whether or not he thought the fact should be part of the layman's fund of knowledge, from his own point of view as a doctor who has to deal with patients. For example, did he think laymen should know that tuberculosis is due to infection with a germ, or that treatment for stomach ulcer tries to cut down on acid stomach juices, and so on. These are the identical facts on which the clinic patients had been tested.

Here are the results. The doctors reported, on the average, that 82 per cent of the facts included in the questionnaire should be known by laymen. Only 9 per cent of the doctors thought patients needed to know no more than half the information; while 18 per cent of the doctors thought patients should know it all. The types of information that doctors most commonly thought laymen should know tended to be facts involving a favorable prognosis for a disease. Thus, the physician is a little more anxious that laymen be given hopeful information than that they be given facts on the etiology, symptoms, and treatment of disease. Nonetheless the preponderant opinion was that lay-

3. Our findings on this problem are discussed in more detail in a paper by George Reader, Lois Pratt, and Margaret Mudd, titled "Clinic Patients' Expectations of Medical Care." Modern Hosp. 89:1 (July), 1957.

4. Dowling, Harry F., and Shakow, David. Time Spent by Internists on Adult Health Education and Preventive Medicine. J.A.M.A. 149:628-631 (June 14), 1952.

men should know most of the information in our test.

These findings must not be interpreted as indicating that physicians feel it desirable to tell a patient the full extent of his illness. On the contrary, when the clinical teaching faculty of the same institution were asked how they would feel if a physician in their specialty were "always to tell patients the full extent of their illness," almost three-fourths said they would disapprove.[5] When these two sets of findings are considered together, it suggests that physicians hold it beneficial for laymen to have a rudimentary understanding of illness, but that in actual practice it is often unwise to give a sick patient all the facts.

Do patients now meet these standards of knowledge of the physician? It is clear from the foregoing figures that patients in general fall far short of physicians' standards of what laymen should know. The physicians thought 82 per cent of the test information should be known by the ordinary layman, while patients knew only 55 per cent of it, with even high school graduates knowing only two-thirds of the facts. This represents, then, one measure of the gap between physicians' standards of what patients ought to know, and the actual level of patients' knowledge. The fact that patients fall far short of physicians' standards underlines the suspicion (reported earlier), that the patients may not be sufficiently informed to communicate with physicians with the highest degree of effectiveness.

The next question considered is: How do physicians perceive patients' level of knowledge about disease? Are they accurate in their evaluations, and do they overestimate or underestimate patients' knowledge? This question is thought to be significant in an investigation of communication problems, because physicians' judgments of patients' current knowledge undoubtedly influence what they discuss with patients and how they discuss it. Concerning the importance and direction of this influence, some limited findings will be presented later.

A first attempt to measure physicians' judgments about patients' level of knowledge was made by asking 89 clinic physicians to estimate the proportion of the clinic patient population who knew each of the 36 facts about disease. The estimates were then compared with the actual results on the knowledge test for the patient population. This is admittedly a gross measure of physicians' judgments because they were asked to evaluate an entire group rather than specific patients. Nonetheless, it provides an indication of how they perceive the clinic patients. It was found that well over half the estimates made by doctors were in error by at least 20 per cent, the median error for doctors being 23 per cent. Eighty-one per cent of all doctors had an over-all tendency to underestimate patients' knowledge. This tendency to underestimate occurs in spite of the fact that patients' actual level of information is quite low.

What effect do these perceptions by physicians of the patients' knowledge have on their discussions with patients about illness? The data available on this problem consist of a measure of the physician's tendency to underestimate, overestimate or accurately judge the knowledge of the patient population, and a rating of the amount of explanation given by the physician to one or two patients.[6] It was found that those physicians who seriously underestimated the knowledge of the patient population tended to have more limited discussions with the patient about his problem, than

5. From a study now in progress at the Bureau of Applied Social Research of Columbia University, by David Caplowitz.

6. The first measure is based on the questionnaire study of 89 physicians, and the second on observation of 50 patient-physician relationships.

did the physicians who more accurately evaluated patients' knowledge or overestimated it.[7]

In addition to this statistical relationship, the intensive observation of 50 patient-physician relationships provided countless clues that the dynamics of the situation were somewhat like this: when a doctor perceives the patient as rather poorly informed, he considers the tremendous difficulties of translating his knowledge into language the patient can understand, along with the dangers of frightening the patient. Therefore he avoids involving himself in an elaborate discussion with the patient; the patient, in turn, reacts dully to this limited information, either asking uninspired questions or refraining from questioning the doctor at all, thus reinforcing the doctor's view that the patient is ill-equipped to comprehend his problem. This further reinforces the doctor's tendency to skirt discussions of the problem. Lacking guidance by the doctor, the patient performs at a low level; hence the doctor rates his capacities as even lower than they are.

What are the actual practices of physicians in giving explanations to patients about their illness? Our findings on this question are based on observations of 50 patient-physician relationships during the entire course of these relationships.[8] On the basis of examining all the conversation between patient and physician, an attempt was made to code the amount and type of information given by the physician to the patient as objectively as possible. Five types of information about the patient's illness were considered: (1) reasons for tests; (2) test results; (3) etiology of the illness or what the illness consists of; (4) what the treatment is supposed to do; and (5) prognosis, possible complications, or other statements of what can be expected in the future.

It will not be possible at this time to report on the ways each of these areas were handled by physicians. The findings will be illustrated by discussing just one area—the reasons for tests: one-third of the patients were told nothing beyond the fact that tests x, y, and z were to be done (that is, they were given no explanation of the tests on any level); one-half of the patients were told, with regard to at least one test, what organ or possible disease was being investigated by the test (for example, they might have been told they were to have an x-ray of their chest); the remaining 14 per cent of the patients received an explanation, with regard to at least one test, of the type of evidence the tests would provide, or what the test means in terms of a possible disease.

The findings for the physicians' handling of the other information areas were similar. Physicians were significantly more likely to give some explanation rather than none at all. A small minority received what could be called a rounded explanation, while the majority received a limited number of isolated facts. It was further found that physicians were more likely to avoid completely discussion of the prognosis and etiology, than they were to bypass the more immediately practical issues of tests and treatment. It is strongly suspected that the limited explanations given by physicians in this sample is bound up with the low level of knowledge of the patients and the lack of overt interest shown by the patients in receiving information.

How much do patients learn about their illness from physicians? If a physician explains the problem carefully, does the patient always learn more than when the physician does not give a careful explanation? Are other factors—such as the patient's anxiety, in-

7. Too few physicians overestimated patients' knowledge to analyze this group separately.

8. Both junior physicians and attending physicians were observed. While certain differences were found in the explanations given by these two groups of physicians, the patterns to be reported below apply to both groups.

terest, or education—such crucial determinants of what the patient learns from the physician, that undue emphasis should not be placed on the physician's giving elaborate explanations to all patients? The limited investigation made of this problem consisted of classifying patients in terms of how thorough an explanation their physicians gave them and then cross-classifying patients in terms of whether they improved in their understanding of their condition after interacting with the physician. It was found that the patients who received some explanation were more likely to increase their understanding of their problem than were those who did not receive explanations, but there was by no means a perfect relationship. While the measures are crude, it appears safe to conclude that what the doctor tells the patient is certainly not the only factor determining how much the patient learns about his condition. Because of the small number of cases in the sample, it is not possible to trace what the most significant other factors are which intervene between what the doctor says and what the patient actually learns. Furthermore, it was not possible to ascertain definitively what patients can learn when they receive well rounded explanations, for so few received systematic explanations.

The final consideration is: what difference does it make if a doctor gives or does not give a thorough explanation to the patient about his illness? That is, does it affect the patient's health? It is not feasible at this stage of the research to attempt to determine whether patients who are informed by their physicians actually make better recovery from their illness than those who are not informed. It was thought more practical to attempt to specify some of the more direct and specific effects that the doctor's explanations might have. First, were patients who received thorough explanations able to participate more effectively in the conversation and planning with the physician? It had been strongly suspected from the observations that the patients who were most confused about their condition and about what the doctor was doing or thinking, were the ones who participated least actively in discussions with the physician. Therefore, the number of requests for information made by the patient was used as a crude index of the extent of the patient's participation. It was found that the patients who received some explanation from the physician tended to ask slightly more questions than did those who were given almost no explanation. This finding is far from conclusive, but is consistent with the notion that the patient is able to interact more productively when the physician provides at least a minimum framework of information within which the patient can arrange his thoughts and formulate his questions.

Another possible effect of the physician's explanations might be the extent to which patients accept the physician's diagnosis and plans for treatment. It was found that the patients who received some explanation of the problem from their physicians were slightly more likely to agree fully with the diagnosis and plans of the physician, than were those patients who received negligible information about their condition. The relationship is far from perfect, partly, perhaps, because refined measures have not yet been developed. However, the relationship found does suggest that the patient who receives regular explanations from the physician about what he is doing and what he is finding, may accept more fully the physician's plans and goals, and hence this patient may be better cared for. As reported in another paper, agreement with the physician's diagnosis and plans is apparently a crucial factor; for the patients who agreed with the physician's diagnosis and plans were found to complete their care in every case, while a significant

number of those not agreeing completely with the doctor's formulation, left the physician.[9]

Summary and Conclusions

This paper has reported on findings from studies of problems of communication between patients and physicians in a medical outpatient clinic. It was found that:

Patients were quite poorly informed about their own condition when they came to the clinic and about ten common diseases. It was suggested that this might be partly responsible for the almost complete lack of initiative shown by the patients with the physicians.

The patients gave little evidence of conscious, aggressive demand for information about their condition from the physician; but there appeared to be an unformulated, latent desire for more information among the majority.

Physicians working in the clinic thought that basic facts on the symptoms, etiology, and treatment of common diseases should be known by laymen. The fund of information that physicians indicated should be known by laymen was considerably more extensive than patients were actually found to have.

Physicians apparently cannot judge very accurately the level of medical knowledge in a patient population. The direction of their error was rather consistently to underestimate patients' knowledge, despite the low level of knowledge among patients. Physicians who seriously underestimated patients' knowledge were less likely to discuss the illness at any length with the patient, than were the physicians who did not seriously underestimate patients' knowledge.

A majority of patients were found to have been told a limited number of isolated facts about their condition; few were given a systematic explanation of either the etiology, prognosis, purpose of the tests, test results, or treatment.

Finally, patients who were given more thorough explanations were found to participate somewhat more effectively with the physician and were more likely to accept completely the doctor's formulation, than were patients who received very little explanation.

9. Pratt, Lois, and Mudd, Margaret. Patients' Medical Care Expectations as Influenced by Patient-Physician Interaction. Paper read at American Sociological Society Meetings, Sept. 7, 1956.

1,532 Communities Receiving Fluoridated Water

A Public Health Service report on the status of fluoridation in the United States as of September 1 showed that 1,532 communities, served by 798 water supply systems, are receiving fluoridated water. The population served is 32,319,603.