

Patients' preferences for information

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SUMMARY. *In a study of patients' views of the type of information they would like to receive from the doctor 265 patients from four general practices were given a list of five areas of information — diagnosis, prognosis, treatment, aetiology and social effects of their illness — and asked to rank these in order of importance for that visit. In general, information on diagnosis and prognosis was the most highly valued, while the ways the illness would affect daily activities was the least preferred. Although information on treatment was rarely selected as the first preference it was often the second or third preference. Conversely, diagnosis was the first choice of the largest proportion of patients and the least valued information for 26%.*

Introduction

THERE are now a great many studies examining patients' views about and satisfaction with their consultations, both in general practice and hospital settings.¹⁻³ This work is significant not only because patients' satisfaction and understanding are important for their emotional well-being, but also because there is some relationship with compliance.⁴ Many studies have examined the transmission of information from doctor to patient, particularly the ways in which this process can be facilitated.⁵ A distinction has been made between different types of information. Kinney and colleagues⁶ found that for facts about diagnosis, aetiology, treatment and prognosis 70%, 61%, 77% and 77% of their patients respectively reported that they had received 'enough' information about these areas. Other studies, however, have indicated that the percentages of patients claiming not to have understood the information given are in the range 7-47% for diagnosis, 17-47% for aetiology, 14-43% for treatment and 17-53% for prognosis.^{1,2}

One problem with research in this area is that it tends to be 'doctor-centred' in the sense that researchers decide what information patients are expected to receive. There are few data concerning patients' preferences for information. While it seems that most patients wish to be as fully informed as possible — Cartwright and Anderson⁷ found that the most frequent criticism of doctors was the lack of time and information provided — the weighting given to the various types of information has not been explored. Information about treatment has traditionally been considered by doctors as the most important type to transmit and this is reflected in patients' generally high level of satisfaction with this aspect of the consultation. But treatment may not be the area of greatest significance from the patients' point of view. Patients may be dissatisfied with information about aetiology, for example, because it seems highly relevant to them and this may not be obvious to the doctor. Furthermore, studies of patient satisfaction have generally been limited to the four areas of diagnosis, aetiology, treatment and

prognosis. Medical sociologists place much emphasis on the social consequences of illness, the argument being that patients consult their doctors not simply when a symptom appears but rather when it begins to interfere with their daily activities.⁸ According to this model, a patient may want to know how the illness will affect his or her daily activities, such as work or domestic duties.

The aim of the present study was to examine patients' preferences for these five different types of information. There are two questions of interest: first, what type of information from the doctor do patients put first and, secondly, what is the overall relative importance of the different information areas?

Method

Patients and practices

Each of four practices was visited twice by one of the authors (K.K.) over a two-week period — once during a morning surgery and once during an afternoon surgery. A total of 265 patients agreed to complete a questionnaire while they waited in their general practitioners' waiting areas. There were no criteria for exclusion from the study. Respondents' ages ranged from 14 to 84 years (median 38.0 years) — 91 males and 174 females. For patients under 14 years of age, parents were asked to complete the forms. Occupational status was noted, as was whether they were attending for the first time with their particular problem or if the visit was for a follow-up. The reason for the consultation was not requested, mainly because it was deemed inappropriate to ask about this in a crowded waiting room. An alternative would have been to ask the patient's name and then match this with the practitioner's description of the problem, but this could have been seen by the patients as compromising the confidentiality of the consultation. The practices covered a wide range of social classes; one practice was sited in a tower block estate, one among a mix of privately-owned and council semi-detached housing, the third in a mixed area of privately-owned terraced and semi-detached housing, and the fourth in an area of privately-owned, mostly detached housing.

Questionnaire

The information preference questionnaire consisted of a list of five different types of information that might be given in a consultation. To avoid technical terms such as prognosis or aetiology, five statements designed to illustrate the information types were provided (Figure 1). Patients were asked to list the statements in their order of importance for that visit.

In order to ascertain whether the statements did indeed reflect the kinds of information attributed to them, 23 trainers and trainees on the local vocational training scheme were given the list in Figure 1 and asked to indicate whether each referred to diagnosis, treatment, prognosis, aetiology or social effects. A sixth category — 'none of the above' — was also provided.

Results

The responses of the general practitioners from the local vocational training scheme indicated that the statements accorded with the five information types. There was complete agreement that statements 2 and 5 referred to diagnosis and aetiology respectively, 22 of the 23 practitioners believed that statements 1 and 4 referred to social effects and treatment, and 21 felt that statement 3 referred to prognosis. In no case was a statement classified as 'none of the above'.

When you feel ill and go to the doctor, he may tell you various things about your illness. The following is a list of different kinds of information that a doctor might give you:

1. How it will affect your daily life, for example, work, looking after the children.
2. What is wrong with you and the medical name for it.
3. The seriousness of your illness, its likely outcome and time before you will be well.
4. What the treatment is, how it works, and possible side-effects.
5. The cause of your illness and what you might do to avoid it in future.

Please list these in their order of importance for today's visit.

Figure 1. The five statements designed to indicate patients' preferences for information about the five factors: 'social effects of the illness', 'diagnosis', 'prognosis', 'treatment' and 'aetiology' respectively.

The patients' responses on the preference questionnaire are shown in Figure 2. Information about the diagnosis was placed first in importance by most patients (37.9%) followed by prognosis (29.5%), aetiology and prevention (17.7%), treatment (8.8%) and social effects of the illness (5.9%). These results differ significantly from what would be expected by chance ($\chi^2 = 89.7$, 4 df, $P < 0.001$). Diagnosis and prognosis were chosen more frequently than would be expected by chance, while treatment and social effects were chosen less frequently.

The overall rankings for each type of information are also shown in Figure 2. Again, patients' preferences were not randomly distributed among the categories of information (Friedman's $\chi^2 = 120.7$, 4 df, $P < 0.001$). In taking all of the rankings into account, prognosis is the information most highly preferred by patients, followed by treatment, aetiology and diagnosis (which were not significantly different from each other) and then, finally, the social effects of the illness. Although information about treatment was selected as a first preference relatively infrequently, it was often the second or third preference. Conversely, diagnosis was the first choice of the largest proportion of patients, but it was also the least valued type of information for 26%.

The bimodal distribution in patients preferences for diagnosis is consistent with clinical impressions that although some patients wish to know everything about this aspect of the consultation, others are much less concerned, only wanting the doctor to cure the difficulty. None of the demographic information collected from the patients could account for this difference: the patients' sex, age, social class, practice attended or whether the problem was a new one or if the visit was a follow-up were unrelated to the placing of diagnosis first or last in the list of preferences. For example, there was no difference in the rankings of diagnostic information for first time or subsequent attenders ($U = 6768.0$, $P > 0.15$), or between different practices ($\chi^2 = 5.80$, 3 df, $P > 0.10$).

Discussion

Several points can be made about these results. First, it seems that asking patients about the type of information they want the most may obscure their second or third choices, which could be almost as important. Few patients placed information about treatment as their first choice, but it was nevertheless of much

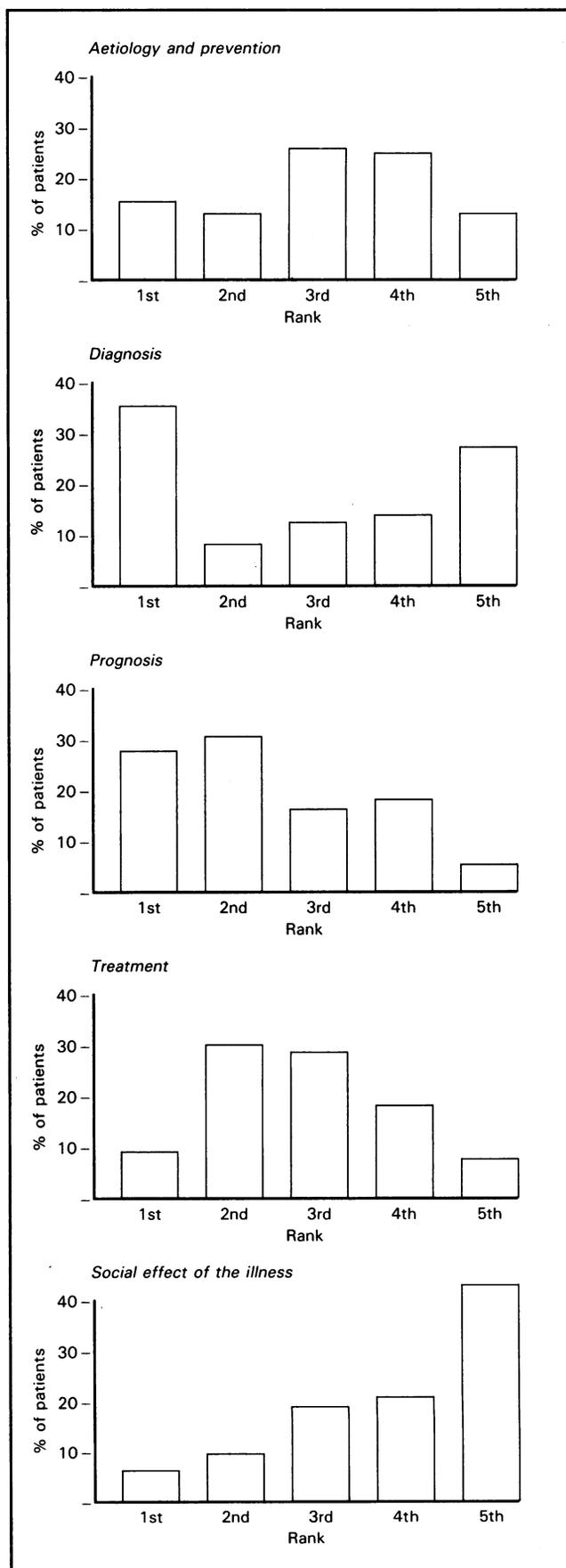


Figure 2. Rankings given by patients for the importance of each type of information from the doctor.

importance, being rated second or third by the majority of patients. This may have practical implications. For example, it is commonly argued that doctors should ask their patients at the end of the consultation if they have any further questions. It should not be assumed that simply because questions are asked about one area, say diagnosis, there are no further queries about others, such as treatment.

Secondly, information about the social effects of the illness was rated relatively low by most patients. There are several possible explanations for this. One possibility is that this is simply due to the design of the survey. Thus although the social effects of illness were rated low when compared with the other types of information, they could still be important for a patient's well-being. If patients had been asked to rate the importance of each type of information independently (for example on a seven-point scale ranging from 'very important' to 'not at all important'), the absolute differences between this type and the others could have been small. Another possible reason is that the emphasis placed on the disabling effects of illness has been misplaced, and that patients are relatively uninterested in how the illness will affect them in the future. A more likely explanation, however, is that patients make inferences about their future incapacities from prognostic information. This suggestion is supported by the consistently high ranking given to prognosis. Once they know the course of a disease they feel able to judge its social effects for themselves.

Finally, these results raise some further questions. One is the extent to which doctors are able to judge patients' preferences. The type of information which is most sought after by some patients may be much less important for others. In the present study the clearest example of this is diagnostic information, which was placed both first and last by large numbers of patients, but the point applies to the social effects of the illness as well. Although this was the least preferred type of information for the majority, it was nevertheless most important for a number of patients. Byrne and Long⁹ found that the most frequent reason for a consultation becoming 'dysfunctional' was that the doctor did not discuss the main reason for the patient's visit. Perhaps patients would be most satisfied if their prime reason for visiting the doctor was recognized and dealt with.

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Acknowledgements

We would like to thank the general practitioners and patients for their cooperation and particularly Dr A. French for his helpful advice. K.K. was funded by the Medical Research Council.

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