

Information Given to Patients and Their Participation in Clinical Decision-Making

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Objectives. To evaluate the information provided by physicians during consultations, the information requested by patients, and patients' participation in decision-making.

Design. Descriptive, cross-sectional study based on observations of visits to the doctor's office and subsequent telephone interview.

Setting. Primary care centers in Toledo, Spain.

Participants. 152 clinical interviews.

Interventions. Questionnaire with items on age, sex, types of information provided by the physician, information requested by the patient, and evaluation of the patient's participation in decision-making and degree of satisfaction.

Main measures and results. Mean age of the patients was 41.1 years, and 55.9% were women. The type of information given most frequently to patients was related to treatment (88.3%). Of the 152 patients whose visits were observed, 55 (36.2%) did not request additional information. The information requested most frequently when not provided spontaneously by the physician concerned treatment (35.3%) and cause of the symptoms (29.7%). Almost all patients (94.0%) considered the information received to be sufficient. However, 22.7% stated that when they left the doctor's office there was something they wished they had asked about, and 18.6% said they understood the doctor's explanations "in part." According to the observers, 69.4% of the patients did not take part in the decision about their treatment.

Conclusions. The information provided by the physician was not as complete as it might have been. Patients usually ask few questions, and a large percentage of patients had something they wished they had asked about, or did not fully understand the information. Patients' participation in decision-making was low.

Key words: Information. Communication. Satisfaction. Physician-patient relationship. Patient's participation.

LA INFORMACIÓN AL PACIENTE Y SU PARTICIPACIÓN EN LA TOMA DE DECISIONES CLÍNICAS

Objetivos. Valorar la información aportada por el médico en consulta, la información solicitada por el paciente y su participación en la toma de decisiones.

Diseño. Descriptivo, transversal, basado en la observación en las consultas y la posterior entrevista telefónica.

Emplazamiento. Atención Primaria de Toledo.

Participantes. Un total de 152 pacientes a los que se realizó una entrevista clínica.

Intervenciones. Cuestionario que incluía la edad, el sexo, la información proporcionada por el médico y solicitada por el paciente sobre diversos aspectos de la entrevista, la valoración de la participación del paciente en la toma de decisiones y su grado de satisfacción.

Mediciones principales y resultados. La edad media de los pacientes fue de 41,1 años y un 55,9% era mujer. La información proporcionada con más frecuencia al paciente estuvo relacionada con el tratamiento (88,3%). De los 152 casos observados, en 55 (36,2%) el paciente no solicitó información. La demanda de información al médico por el paciente cuando aquél no la proporciona de forma espontánea es sobre todo acerca del tratamiento (35,3%) y de la causa del cuadro (29,7%). El 94,0% consideró suficiente la información recibida; no obstante, el 22,7% manifestó haber salido de la consulta con ganas de preguntar algo y el 18,6% dijo comprender «parcialmente» la explicación. Según los observadores, un 69,4% de los pacientes no participó en la toma de decisiones sobre el tratamiento.

Conclusiones. La información que el médico proporciona no es todo lo completa que debiera. El paciente suele preguntar poco al médico; un alto porcentaje de ellos se quedan con ganas de preguntar y/o no comprenden totalmente la información. La participación del paciente en la toma de decisiones es escasa.

Palabras clave: Información. Comunicación. Satisfacción. Relación médico-paciente. Participación del paciente.

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Introduction

Communication is the cornerstone of the physician-patient relationship, and has been the subject of many studies in recent decades.^{1,2} Most of these studies have centered on the (positive) influence of communication on compliance with treatment and user satisfaction,³⁻⁵ within a paternalistic relationship where the physician (the expert) makes the decisions that concern the patient.

More recently, social changes have brought the importance of communication to the fore once again, this time as a prerequisite for patient autonomy^{6,7} (one of the basic pillars of bioethics) and the patient's right to information.^{8,9} This reflects a more deliberative and participatory model of relationship between health care professionals who no longer play the leading role, and patients who may be more like well-informed experts themselves,^{10,11} and whose satisfaction with the relationship may be greater.¹²

Although this trend and the debate certain topics have generated (informed consent,¹³ patients' rights) are clearest in the setting of specialized care—because of the greater transcendence of the decisions that need to be made—we should not neglect that most visits with physicians take place in primary care, where physician-patient communication is the best technology available for the process of diagnosis and treatment.¹⁴

Against this background we felt it would be of interest to evaluate the information supplied by family physicians during consultations, the information requested by patients, and the patient's participation in decision-making.

Material and Methods

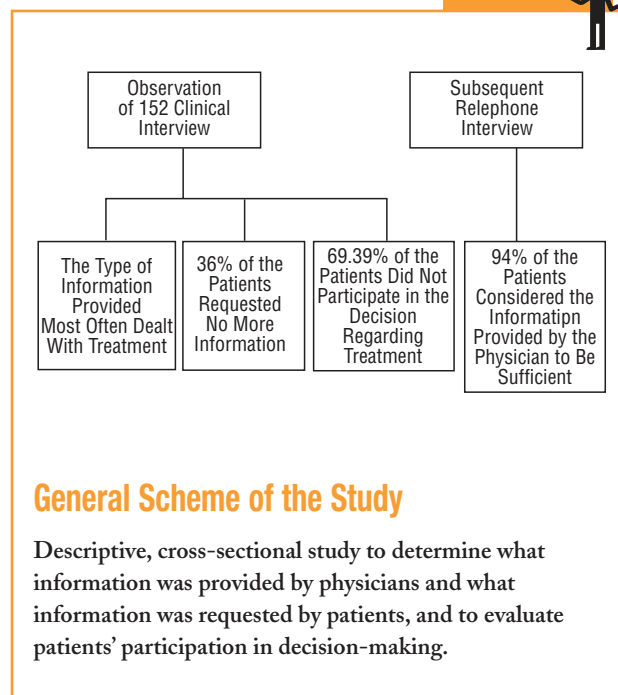
The descriptive, cross-sectional study involved 3 health centers in the Toledo health care area, one rural (Polán) and 2 urban (Santa María de Benquerencia and Sillería). Both urban centers were located in the city of Toledo.

The study population consisted of visits to the doctor by patients who sought care for an acute illness. We included the first patients to arrive on each day between 15 January and 15 March 2003 at walk-in offices staffed by 6 family physicians accredited as tutors for residents in training. To estimate the percentage participation of patients during the visit, 143 visits were considered sufficient assuming an expected frequency of 30%, a *P* value < .05 and a precision of ±8%.

The study was based on observation of the visit by a resident in family medicine without the tutor's knowledge. Patients whose examination was performed in whole or in part by a resident were excluded from the study population, and the next patient to fulfill the inclusion criteria was included.

The resident then completed a questionnaire with items on the following variables: age, sex, information provided by the physician and requested by the patient (cause, diagnosis, complementary tests, treatment, dosage, complications of treatment, prog-

Material and methods



nosis), and an assessment of whether the patient had or had not participated in decision-making regarding complementary tests or treatment.

Later, the patients were interviewed by telephone to determine their degree of satisfaction with the information received and comprehension of the information. For patients younger than 14 years of age the telephone interview was conducted with the person who accompanied the child during the visit to the physician's office.

Before the study was begun the observers were trained with simulated interviews.

Statistical analyses of the data were done with the SPSS v. 10.0 program, using descriptive and analytical tools. Percentage values were compared with Pearson's χ^2 .

Results

A total of 152 clinical interviews were observed, all of which were considered valid. Mean age of the patients was 41.08 years (SD 18.56 years), and 55.90% were women.

None of the visits was characterized by a complete lack of information provided spontaneously by the physician. The type of information supplied most frequently to patients (Figure 1) was that regarding treatment, recorded in 88.28% of the interviews (95% CI, 81.63%-92.82%), and the type least frequently provided was that regarding possible complications of treatment, recorded in 9.35% (95% CI, 5.28%-15.77%).

Of the 152 interviews, the patient requested no further information in 55 (36%-18% [95% CI, 28.67%-44.41%]) re-

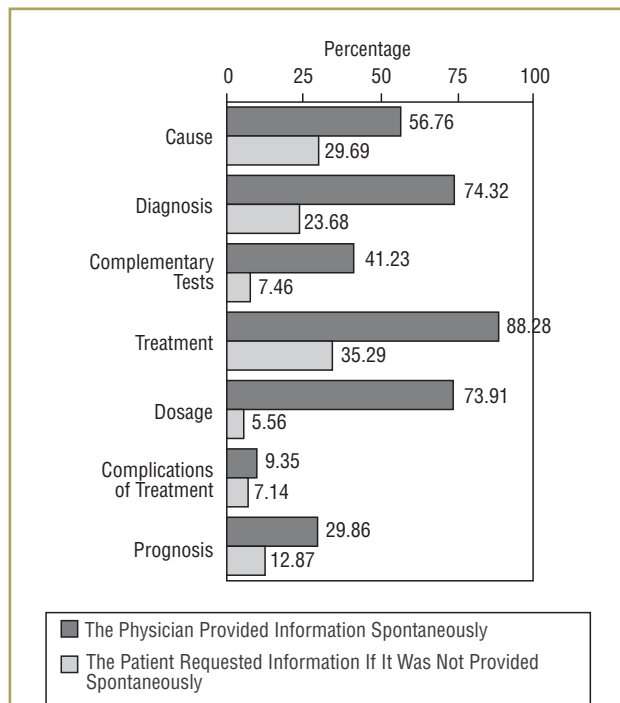


FIGURE 1 Percentage of cases in which the physician provided and the patient requested different types of information (if not provided spontaneously).

regardless of whether the physician had previously provided information spontaneously or not. The topics patients requested information about most often were, in decreasing order, cause (29.6%), treatment (28.9%), diagnosis (21.7%), complementary tests (16.4%), prognosis (13.2%), dosage (11.2%) and complications of treatment (8.6%). The types of request for specific information made when the physician did not provide this information spontaneously are shown in Figure 1. The most frequent requests were for information about treatment (35.29% [95% CI, 15.26%-61.38%]) and cause of the symptoms (29.69% [95% CI, 19.25%-42.58%]).

In the telephone interview (Table 1), 94.0% (95% CI, 88.58%-97.04%) of the participants considered the information they received to be sufficient; however, 22.7% (95% CI, 16.41%-30.36%) said that when they left the doctor's office there was something they wished they had asked about. We found no significant differences between sexes or age groups for these two variables. Of the 34 patients who had something they wished they had asked the doctor, 10 (29.4%) requested no further information.

The results for comprehension of the information were similar: 18.67% (95% CI, 12.96%-26.02%) of the patients we interviewed said they had not fully understood the information provided during the visit. There were no statistically significant differences between men and women (22.73% vs 15.48%; $\chi^2=1.73$ [$P>.05$]), nor did we find any relationship between this variable and age. Of the 28 patients who said they had not fully understood the information, 11 (39.28%) did not ask the physician for any further information.

The observers considered that 69.39% (95% CI, 61.17%-75.57%) of the patients did not participate in decision-making about their treatment. This figure increased to 75.41% (95% CI, 66.63%-82.55%) with regard to decision-making for complementary tests.

Discussion

Before we begin the discussion of our results, we should clarify a few points about the study. We opted to include only visits for acute illness because patients with a chronic illness receive information gradually, and this makes it more difficult to evaluate the information provided or requested. In contrast, acute processes are often a new experience for the patient, and their need for information on the spot is clearer. This makes it easier to observe which types of information are provided and requested.³ Possible sources of bias should also be noted. One such bias is that arising from the small number of physicians we were able to observe, given the nature of the study. In addition, the participating physicians were tutors responsible for training the residents who acted as observers, and thus

TABLE 1 Results of the Telephone Survey of Patients Who Were Observed During Their Visit With the Physician

Questions	Responses			
	Yes N %	No N %	In part N %	Completely N %
Did you understand the explanations the doctor gave you?	102 (82.9)	3 (2.4)	18 (14.6)	123 (100)
Did you feel the information the doctor gave you was sufficient?	116 (94.3)	7 (5.7)		123 (100)
Was there anything you felt like asking the doctor?	23 (18.7)	100 (81.3)		123 (100)

Of the 152 participating patients, 29 (19%) could not be located. The sample for the telephone survey therefore consisted of 123 patients.

Discussion
Key points

What Is Known About the Subject

- Information and physician-patient communication have a positive influence on compliance with treatment and user satisfaction.
- Communication is important because it is now considered a prerequisite for patient autonomy and the right to information.

What This Study Contributes

- Information provided by the physician is not as complete as it might be.
- Patients usually ask the physician few questions, and a large percentage of them wish they had asked about something or do did not fully understand the information they are given.
- Patient participation in decision-making is low.

may have been more likely to give particular consideration to the importance of the clinical interview and the information provided to patients. Moreover, despite the considerable training the residents received, a non-negligible degree of observer subjectivity is involved in interpreting a generally complex event such as the clinical interview. For these reasons we believe our results, while valid, should be considered with due caution.

Because of the methods used in this study, it was difficult to compare our findings with those of other studies, most of which were based on opinions provided by patients and which did not attempt to describe the information interchange. In general, we believe the information health care professionals provide to patients is not as complete as it might be, especially with regard to specific aspects of the symptoms such as their possible causes, the prognosis, and the possible complications of treatment. The types of information provided most frequently dealt with the diagnosis and treatment (although the actual information provided also showed room for improvement), possibly because these aspects are considered more basic. This assumption is supported by the fact that, as others have noted previously^{3,15} and as seen in the present study, the patient's interest usually centers on these two aspects of his or her illness.

The main reason that is likely to explain why information provided to patients is inadequate is the shortage of time available to primary care physicians to see all their patients.¹⁶⁻¹⁸ Another possible cause is the fact that many visits were motivated by a mild illness for which the physi-

cian may have felt extensive explanation was unnecessary. In any case, a consequence of these factors may be that patients acquire insufficient knowledge of their illness, and are thus more likely not to comply with or adhere to treatment. This in turn may lead to further requests for care.¹⁹ In general, we found that patients usually ask few questions even when the physician has not provided information beforehand. The explanation for this may lie in the fact that the patient is already familiar with the illness, or considers it not to be serious. However, the fact that almost one third of the patients who admitted there was something they wanted to ask the physician failed to raise any questions suggests other motives. These might involve, among other things, a degree of passivity on the patient's part (patients who want only that information which is indispensable),^{20,21} blind trust in the physician,²² or impediments to communication (specialized medical language, highly directed interchange).^{3,23} If we accept that one of the main aims of the clinical interview is to inform the patient, and although the great majority of patients responded that they found the information provided to be sufficient, this aim was not fulfilled in one out of every five consultations. Some patients had questions they wished they had asked, or did not fully understand the information.

Despite the trends experts have predicted,^{15,20,24-26} we believe that participation by patients in decision-making remains poor at the present time. Very few patients are asked their opinion on the diagnostic process or the treatment they are to follow,^{23,27} even though it has been shown that participation in decision-making has a favorable effect on the efficacy of treatment.²¹ This situation shows how far we are from the model of shared deliberation in which information flows in both directions, favoring joint decision-making between the physician and the patient.^{6,12,15} It would be interesting to investigate in greater depth the reasons that make it difficult for patients to participate more fully in consultations with their primary care physician.

In closing, we wish to restate our conviction that family physicians should play the role of information provider that society has already begun to demand of us.^{9,21,28} In the words of Meneu,²⁰ "sharing information is not the same as making decisions, but the former is a prerequisite for the latter."

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COMMENTARY

The Challenge of Information for Patients

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The need to inform patients and their families appropriately is now one of the principal challenges faced by all physicians. Almost all patients now demand more complete and better quality information. Studies in Spain have noted that elements of consultations which patients value most highly include receiving clear and comprehensible information especially regarding treatment and its effects; reassurance by physicians on matters the patient has questions on¹; and knowledge about and comprehension of the patient's problem.² One of the main expectations on the

part of patients who seek primary care is to receive appropriate information and advice.³

The desire to be better informed might be best understood in the light of new social trends: changes have broken down social and class barriers, and rights are being demanded for minorities and other groups (sexual orientation, ethnic identity, women and consumers, among others). Greater freedom of expression in all areas, and greater availability of medical information mainly on the Internet, contribute to greater expectations by patients to partici-

Key Points

- Physicians should provide patients with more information that makes sense and is clear.
- The responsibility to provide information is one of the family physician's main responsibilities.
- The type of information and manner in which it is communicated are related with the patient's ability to cope with health problems and other consequences of the visit to the physician's office.
- The research agenda for family physicians concerning these issues is currently as broad as it is ineludible.

pate in their own care, especially for chronic illnesses and other, lesser illnesses that make up the majority of cases. In addition, medical ethics is acquiring a central role in patient autonomy, and the physician-patient relationship is coming to be viewed as an act of deliberation and collaboration between both parties. These factors have eroded the traditional view of the physician-patient relationship characterized by the physician's paternalism and the patient's lack of information. In the process, some of the more confessable assumptions that underpinned the old model have been overturned. On one hand, the purportedly unbridgeable competence gap made it difficult to provide patients with an appropriate explanation of complex subjects, owing to the physician's vast expertise and the patient's lack of suitable background knowledge. In addition, the emotionally charged environment created by illness was assumed to make rational communication and comprehension difficult.

However, other much more unsavory factors have also been involved. One such factor was physicians' desire to retain power by controlling information. Work by Ley⁴ on the effects of information provided to patients and their recall of this information lent support to this view by emphasizing that the more information given to patients, the less they remembered. The inevitable conclusion reached by a large part of the medical community was that it was not worth it to give patients too much information.

This conclusion, however, was refuted in research by Tuckett et al,⁵ who found that only 10% of the information was forgotten, in contrast with the 30%-50% figure in Ley's study. The classic work of Tuckett and colleagues, who studied 1302 consultations,⁵ led to important methodological improvements. The most noteworthy of these were the consideration that not all information is of

the same importance, and that recalling does not necessarily mean comprehending or agreeing. Their study concluded by offering advice to physicians who wished to inform effectively. Doctors were advised to explore the patient's ideas and beliefs, negotiate and share an explanatory model, and check the patients' interpretation of and reaction to the information provided. In addition, the information physicians offer should be clear enough for the patient to understand it and to realize when he or she and the physician see things differently. In other words, we should offer more information that makes sense to the patient, not only because this is what patients want and because times change, but also because it allows us to hold consultations that are more cooperative and effective for both.

Recent studies in Spain, of which the article by Barca Fernández et al⁶ is a part, note that patients currently receive vague, unspecific information that keeps them from coping appropriately with their problem,² that physicians do not explain the diagnosis,⁷ and that many patients do not understand the information they are given but cannot bring themselves to ask their doctor questions.⁶ Another finding of interest reported by Barca Fernández et al is that most of the patients did not participate in decision-making regarding their diagnosis and treatment. This, together with the physicians' lack of concern for their beliefs and preferences concerning the diagnosis and treatment,^{7,8} suggests that the quality of the relationship during the consultation remains questionable. As a result there may well be direct effects on the physician's clinical and advocacy efforts. The results of the studies mentioned earlier do in fact seem to suggest a relationship between low participation on the part of the patient during consultation, lack of interest in the patient as a person, and the fact that information provided to the patient is scarce and definitely inadequate. This probably makes it impossible for the patient to become truly capable of cooperating more fully and more effectively in his or her own health care.

The research agenda in this area is wide open: we need larger studies with more sophisticated methods that will give us a more accurate idea of the actual degree and impact of these factors, how they are related, and how they affect the outcome of consultations. We should focus our attention on determining in greater detail what transpires during consultations, and on how to record patients' opinions regarding their relationship with the physician. For example, the study by Barca Fernández et al notes that most patients felt the information they had received to be adequate. However, this does not seem credible in the light of data from this study and an earlier report by Makoul et al,⁹ who found an "illusion of competence" in patients who felt that important matters had been discussed when in fact they had not been dealt with at all.

Reliable, validated instruments should be developed that can provide direct information on patients' opinions, so

that this information can be compared with the opinions expressed in appropriately designed questionnaires or qualitative studies, which are unfortunately rare. Both perspectives would make evaluations of the clinical relationship and its consequences more complete and accurate.

We also need to learn more about the information given to patients and their participation in decision-making. For example, how do we actually inform our patients when we do inform them? What techniques do we use, and how effective are they? Does the information we provide them with make sense to them? How and whom do we inform about difficult subjects (cancer and other serious diseases)? Nevertheless, we know that although most patients want more information, not all patients do. We do not know what factors determine this behavior, and we know hardly anything about family influences and information-related factors in the primary care setting in Spain. What do patients' families wish to know about their disease and the care they will need? We do not know what information we should share with patients, especially in cases of serious illness. We lay most of the blame for our mistakes in providing information and our inability to make consultations more cooperative on the lack of time, yet what we lack are studies that investigate these issues.

Much remains to be explained regarding the impact of training in these subjects on physicians, and regarding the most effective and practical teaching methods. However, we also need to know how to train patients to obtain more and better quality information from their physicians, and how this affects the physician-patient relationship and the efficacy of consultations. These topics are just a sampling

from the vast research agenda in this crucial area of information. But they are topics that primary care professionals should consider in framing our long-overdue response to the challenges these problems pose.

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