

Medical information is not enough for patient's participation in clinical decisions

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ABSTRACT

Theoretical Framework: This research was designed to analyze whether patients rate positively doctors' attitudes and information provided favours the patient's participation and involvement in clinical decisions.

Methods: For this, we carry out a cross-sectional analysis of data on 1070 patients discharged from 7 hospitals in Spain.

Results: A total of 82% referred to be satisfied with the information, of which 3% did not have the feeling that their hospital doctor had listened carefully, 27% did not have their doubts clarified, and 76% were not informed of therapeutic alternatives. When the doctor showed a receptive attitude there was actually an increase in the number of patients that still had doubts about their diagnosis and treatment (OR= 1.9, $p= 0.04$). Older patients were less frequently involved in clinical decisions ($\chi^2= 8.05$, $p=0.04$) and often remained with doubts ($\chi^2=9.05$, $p=0.03$).

Conclusion: The conclusion is that a substantial proportion of patients seem to assume a passive role in the interaction with the doctor. There are conditions that may restrict the patient's autonomy which do not ever affect the patient's rating of the information provided by the doctor.

Key words: patient participation, medical information, clinical decisions.

INTRODUCTION.

Clinical decisions of healthcare professionals should be based on scientific knowledge, but also expected to respect the wishes of the patient (Hartzband, Groopman, 2009). The reasons for this are not only ethical: it has also been found that more active participation on the part of patients (asking questions, expressing their concerns, requesting explanations or expressing their preferences) has its advantages: better outcomes (Arora y McHorney, 2000; Benbassat, Pilpel y Tidhar, 1998; Jahng, Martin, Golin y DiMatteo, 2005; Stacey, Samant y Bennett, 2008) and greater clinical safety (Mira et al., 2008).

This is the reason for the proliferation of studies on patient participation in decisions, studies which have thrown light on many relevant aspects of such involvement (Benbassat, Pilpel y Tidhar, 1998; Czaja, Manfredi y Price, 2003; Lee y Hawkins, 2010).

Research has explored whether patients consider themselves correctly informed (Ashbury, Findlay, Reynolds y McKerracher, 1998; Lee y Hawkins, 2010), the usefulness of tools for decision-making (Mira y Rodríguez-Marín, 2001), and how style of practice influences patients' ratings of their doctor (Bertakis, Roter y Putnam, 1991) and their expectations (Arora y McHorney, 2000).

Active participation during the consultation requires both actors (patient and professional) to want it, to consider it in a positive way and to make efforts to interact. Although there may be more and more patients who wish to be actively involved (Coulter y Magee, 2003), not all of them seem to feel comfortable about having the last word (Benbassat, Pilpel y Tidhar, 1998; Czaja, Manfredi y Price, 2003; Ford,

Schofield y Hope, 2003; Jahng, Martin, Golin y DiMatteo, 2005; Mira, Tirado, Pérez-Jover y Vitaller, 2004). We know that older people, the less educated and those with very severe pathologies prefer it to be the doctor who makes the decisions (Arora y McHorney, 2000; Benbassat, Pilpel y Tidhar, 1998). On the other hand, the professionals themselves do not always facilitate patient participation (Loayssa, González y Ruiz, 2007), justifying such behaviour by a desire to avoid doing more harm, by the difficulties they believe patients may have for correctly interpreting the information, or by work overload and the consequent lack of time (Beach, Duggan, Cassel y Geller, 2007; Dickert y Kass, 2009; Mira, Tirado, Pérez-Jover y Vitaller, 2004).

There is broad agreement on the need to overcome paternalism in interaction with patients (Hartzband, Groopman, 2009; Jadad, Rizzo y Enkin, 2003), but deep-rooted behaviours on both sides of the care process relationship hinder progress in this regard (Benbassat, Pilpel y Tidhar, 1998). Up to now there has been systematic analysis of the point of view of professionals (Légaré, Moher, Elwyn, LeBlanc y Gravel, 2007; Légaré, Ratté, Gravel y Graham, 2008), while other research has explored the factors which, from the patients' point of view, contribute to their not being able to participate as actively as they would like. Among the principal reasons adduced by patients are: prescription without explanations, not having the opportunity to ask questions, and not being treated with respect (e.g., not being listened to) (Catrine, Ekman y Ehnfors, 2008).

Research results associate patient satisfaction with being able to interact with the doctor (Benbassat, Pilpel y Tidhar, 1998; Joosten et al., 2008), but some observations should be borne in mind. Patient satisfaction is greater when there is agreement between the level of involvement desired by the patient and the doctor's attitude and the information he or she provides regarding the medical problem and its treatment (Ryan y

Sysko, 2007). Some data suggest that it is those patients who do not wish to participate in clinical decisions whose expectations are more easily satisfied (Ford, Schofield y Hope, 2003). The present study examines some of the reasons behind these findings and analyzes whether patients actually rate more positively those attitudes in doctors (and the information they provide) which we know to favour more active patient participation and involvement in clinical decisions.

METHOD.

Type of study

A cross-sectional descriptive study was carried out in 7 hospitals belonging to 7 Health Districts in Spain between May and July 2009. These districts are representative with regard to discharges, resources and proportion of rural/urban population.

Study population

We carried out a telephone survey on 1070 patients attended at 7 hospitals from the same Autonomous Region in Spain. The hospitals were located in both urban and urban/rural health districts, and number of beds ranged from 300 to 500. Selection of the sample was made at random from among all the patients attended in the 3 months prior to the field study, assigning quotas to medical and surgical specialties, and to accident/emergency and outpatient care in proportion with that hospital's habitual activity. Those who denied participating in the study were substituted by patients of similar profile.

Data source and collection

The data were collected by means of a validated telephone survey after discharge (inpatient and accident/emergency department patients) and after consultation (outpatients). Respondents were asked, once they were back home, about their satisfaction with the information provided by the doctor (during the stay at the hospital, or accident/emergency Department) whether they had had any complications in the course of that treatment, and 3 questions identified in previous studies (Catrine, Ekman y Ehnfors, 2008; Mira, Lorenzo, Pérez-Jover y Ortiz, 2010; Siminoff, Ravdin, Colabianchi y Sturm, 2000) as relevant to the patient's involvement to implementing shared decision-making in clinical practice:

- If you had the feeling that the doctor was listening to you when you spoke.
- If you left the consultation feeling like you wanted to ask the doctor something else, about something you hadn't understood or that was worrying you.
- If the doctor explained them on alternatives to the prescribed treatment.

In addition, we coded the variables: age, sex and care setting.

Those questions belong to a previously validated questionnaire (Mira, Nebot, Lorenzo y Pérez-Jover, 2010).

Data analysis

We calculated the probability of a patient reporting satisfaction (positive predictive value) or dissatisfaction (negative predictive value) with the information

provided by their doctor, whether they had felt listened to, whether they remained with doubts, and whether they had been informed about therapeutic alternatives.

Chi-Squared was applied for analyzing the relationships between categorical variables (calculating the Yates correction), adjusted for age, sex and care setting. We used a logistic regression analyses (enter model), considering as dependent variable in successive analyses: satisfaction with the information and whether the patient had been able to ask the doctor about his/her doubts, and as independent variables: responses to the questionnaire items.

Differences were considered statistically significant when $p < 0.05$.

RESULTS.

Patient characteristics

1070 patients responded to the questionnaire, so that the sample size requirements were met. The proportions of men/women, age groups and care setting were balanced. Even so, after the final purging of the database, two hospitals remained slightly under-represented. Table 1 shows the sample characteristics.

Patients' satisfaction with the information provided

The majority of respondents reported feeling satisfied with the information their doctor had provided (82.1%, 95% CI 81-85). “Feeling listened to” (OR 29.4; 95% CI 15.6-55.4), “asking about doubts” (OR 5; 95% CI 2.9-8.6) and “being informed about therapeutic alternatives to the prescribed treatment” (OR 3; 95% CI 1.6-5.7) increased such satisfaction.

Table 1. Characteristics of the study sample (n=1070)

<i>Age, mean (SD)</i>	51.4 (20.7)
<i>Age (%)</i>	
18 to 35 years	26.5
36 to 50	21.6
51 to 65	20.9
> 65	31.0
<i>Gender (%)</i>	
Male	43.5
Female	56.5
<i>Medical Specialty (%)</i>	
Medical	18.4
Surgical	21.1
Accident/Emergency	24.0
Outpatient services	36.4
<i>Health Districts (%)</i>	
HD 1	13.8
HD 2	4.7
HD 3	17.4
HD 4	13.7
HD 5	4.9
HD 6	14.1
HD 7	31.4

HD Health District

Older patients were the most satisfied with the information from their doctor ($\chi^2=10.0$; $p=0.02$). Males and females gave similar ratings of the information provided ($\chi^2=0.1$; $p=0.9$). Although in the Accident/Emergency context (78.9%) the satisfaction level reported by patients was slightly lower than those reported for inpatient care (85.3%) and by outpatients (82.3%), the differences were not statistically significant ($\chi^2=3.9$; $p=0.1$).

Information that favours patients' involvement

A total of 90.8% of the respondents said they felt that the doctor listened to them (Table 2), while 21.3% received information about possible therapeutic

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alternatives to the prescribed treatment and 25.7% had remaining doubts because they failed to ask. No effects of the control variables sex, age and care setting were detected.

Table 2. Frequency with which the doctor shows an attitude and provides information that favour patient participation in clinical decisions

	% (n)	95% CI	Sex (%)		Age (%)				Setting		
			Fem	Male	18-35	35-50	51-65	>65	Hosp	Emerg	Out
Had the feeling that the doctor listened when they spoke	90.8 (972)	89.7 – 93.2	90.7	92.5	88.8	88.5	95.0	93.5\$	93.3	87.1	93.5\$
Left wanting to ask more questions of the doctor, about something they hadn't understood or that worried them	25.7 (275)	25.3 – 30.9	26.6	29.4	22.8	26.2	37.7	26.6\$	32.1	20.8	28.3\$
They were explained about the different therapeutic alternatives so that they could give their opinion	21.3 (228)	19.3 – 24.5	19.0	24.8*	21.3	25.0	24.3	17.5	14.2	18.0	29.6\$

95% CI 95% Confidence Interval

Hosp: Hospitalization – Emerg: Emergency – Out: Outpatients

\$p<0.01

*p<0.05

Where doctors showed a receptive attitude to what the patient said (Table 3), there was an increase in the number of patients who remained with doubts or worries about their diagnosis and treatment ($p=0.04$). Among women there was a higher proportion of patients who, despite feeling that they were listened to, remained with doubts and/or the desire to ask more questions ($\chi^2=5.8$; $p=0.02$). Also, although there may have been complications in the course of their treatment, this did not make patients more likely to ask their doctor to clear up their doubts or concerns ($p=0.2$). No effects were found of the adjustment variables sex and age.

Table 3. Variables influencing patient interaction with the doctor

Left wanting to ask more questions of the doctor, about something they hadn't understood or that worried them			
	NO (795)	SI (275)	OR (95% CI)
Had the feeling that the doctor listened when they spoke			
YES	712 (73.3)	260 (26.7)	
NO	83 (84.7)	15 (15.3)	1.9 (1.0-3.7)
They were explained about the different therapeutic alternatives so that they could give their opinion			
YES	161 (70.6)	67 (29.4)	
NO	634 (75.3)	208 (24.7)	1.2 (0.9-1.7)
Level of satisfaction with the information provided by the doctor			
HIGH	645 (73.4)	234 (26.6)	
LOW	150 (78.5)	41 (21.5)	1.1 (0.7-1.6)
Were there any complications in the course of your treatment?			
YES	172 (72.0)	67 (28.0)	
NO	623 (75.0)	208 (25.0)	1.3 (0.9-1.7)
The OR (odds ratio) for being left wanting to ask questions about doubts or concerns. 95% CI 95% confidence interval			

A receptive attitude in the doctor was positively and significantly associated with the frequency with which patients were informed about therapeutic alternatives to the prescribed treatment ($\chi^2=10.3$; $p=0.001$) (Table 4).

Table 4. Relationship between variables that describe a style which empowers the patient to participate in clinical decisions

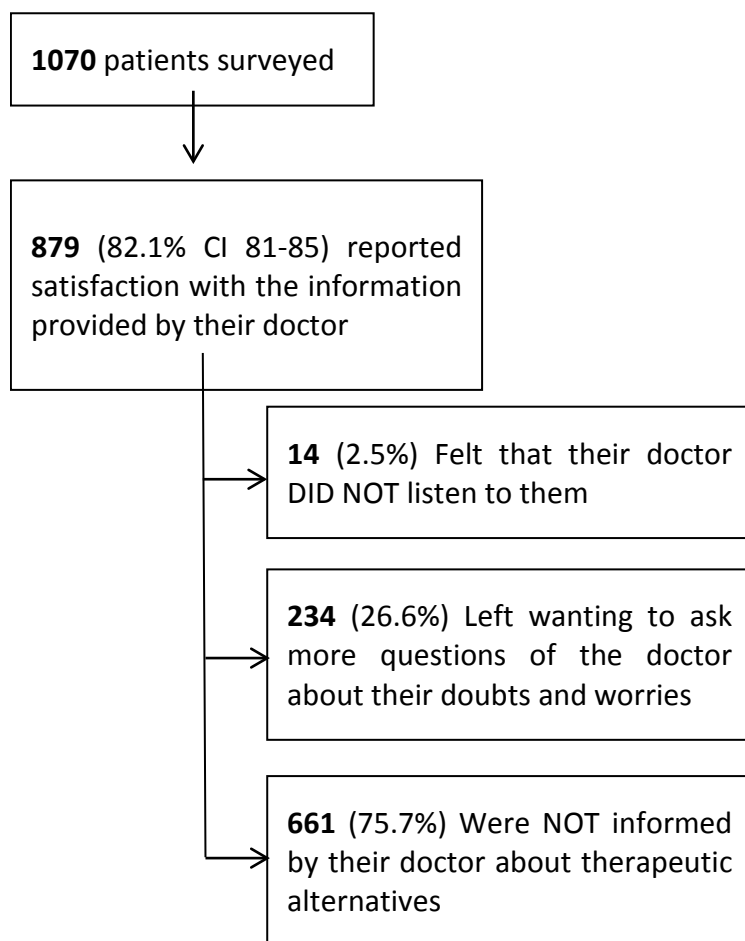
	Doctor informed patients about different therapeutic alternatives so that they could give an opinion	
	NO (%)	YES (%)
Did not have the feeling that the doctor listened when they spoke	90 (10.7)	8 (3.5)
Had the feeling that the doctor listened when they spoke	752 (89.3)	220 (96.5)
Differences are statistically significant at $p<0.05$		

Satisfaction/dissatisfaction and style of practice that facilitates patient implication

Considering only those patients who reported satisfaction with the information they received, we find that: 2.5% (95% CI 1.5-3.5) did not have the

feeling that their doctor listened to them attentively; 26.6% (95% CI 23.7-29.5) remained with doubts about the diagnosis or treatment; and 75.7% (95% CI 70.4-76.3) were not informed about therapeutic alternatives to the treatment prescribed by the doctor (Figure 1).

Figure 1. Patients with insufficient information to participate in clinical decisions among those who reported satisfaction

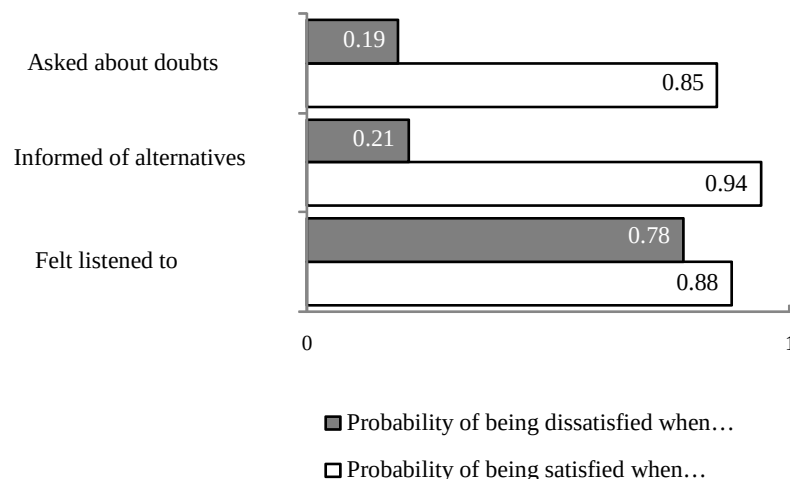


With increasing age of patients it was much less likely to find, among those who reported satisfaction, that they had been informed about therapeutic alternatives to the prescribed treatment ($\chi^2=8.05$; $p=0.045$) or that they had asked the doctor

about their doubts or worries ($\chi^2=9.05$; $p=0.029$).

Positive predictive value (reporting satisfaction when they had asked the doctor about doubts or been informed about therapeutic alternatives) is high, though negative predictive value (probability of dissatisfaction when they had not been able to ask questions or were not informed about alternatives to the treatment prescribed by the doctor is very low (Figure 2).

Figure 2. Probability of being satisfied/dissatisfied and information provided by the professional (n=1070)



DISCUSSION

Respect for the patient's autonomy goes beyond the sharing of information, to involve an attitude in the professional that facilitates the patient's potential involvement in decisions (Dickert y Kass, 2009; Dillon, 1992). In this study, the number of patients remaining with doubts and concerns about their diagnosis and treatment, and for participating actively in clinical decisions during their stay at hospitals emergency and outpatient is greater than would be desirable, especially

among the more elderly patients, which are those with the greatest healthcare needs. These results, in combination with those found in other studies in which primary care patients were interviewed (Barca et al., 2004), suggest that patients come up against substantial barriers (relating to healthcare organization, to health professionals and to themselves) for adopting a more active role and interacting with doctors (Dillon, 1992; Schoen et al., 2005) and other healthcare personnel (nurses, physiotherapists, auxiliary staff, social workers, and so on)(Lorenzo, 2008).

As would be expected (Arora y McHorney, 2000; Benbassat, Pilpel y Tidhar, 1998; Bertakis, Roter y Putnam, 1991; Catrine, Ekman y Ehnfors, 2008), the good practices in communication with patients identified in this study are related to patient satisfaction. However, we actually found that among those who were not informed about possible therapeutic alternatives, or remained with doubts and concerns about their diagnosis and treatment, there is a large percentage of patients who nevertheless give a positive rating to the information their doctors provide. It seems that the limitations in the patient-physician interaction respond to patient expectations and that might be reason why they do not reduce patient satisfaction, suggesting that some of the characteristics of a paternalistic style are accepted as normal by a substantial proportion of patients.

The possible explanations for these results are various. Firstly, that over half trusted their doctor, and despite rating as positively the idea of the doctor informing them about what is happening and indicating treatment and dosage, they do not expect to interact with him or her as equals (Williams, 1994). Secondly, that these patients simply do not want to play an active role (Bertakis, Roter y Putnam, 1991;

Jahng, Martin, Golin y DiMatteo, 2005). Third, that in some cases their predictive expectations (Hsieh y Kagle, 1991; Thompson y Suñol, 1995) (expectations about what will probably happen in the interaction with the doctor) do not include asking questions or that the doctor will inform them about alternatives. In other cases, we might suppose that patients fail to interact with the doctor simply out of custom or for fear of bothering him/her, thus blaming themselves for this passive attitude to the interaction (Barca et al., 2004). Moreover, the findings of this study highlight the fact that even when patients report a positive attitude in their doctors (they are listened to attentively), they still may not ask them questions to resolve their doubts and worries. Even the experience of some complication does not show a relationship with frequency of asking the doctor questions. It can also be assumed that chronicity, trust in one's doctor, self-perceived health or the availability of sources of information other than the doctor may be modulating the desire to participate actively in the consultation (Mira y Rodríguez-Marín, 2001). Future research might explore this issue, differentiating between patients' predictive and normative expectations about the interaction with their doctor, considering locus of control and interest in obtaining medical information.

Results reinforce the logic of health education logic on clinical safety, like AHRQ presenting videos of patients buying cellular phones, or having dinner at a restaurant. In those examples customers keep asking about any details related to the phone or the menu, while they keep silent when visiting the doctor. These situations makes the clinician manage consultation timing differently, making sure that he/she leaves time enough to the patient to talk. In practice suggests the convenience of

modifying health care professionals training contents including communication skills so that they learn to listen and not only to express themselves clearly.

We know that “feeling listened to” is an antecedent of patient satisfaction (Mira, Lorenzo, Pérez-Jover y Ortiz, 2010), and in this case, in which a large majority of patients reported that their doctor listened to them attentively when they spoke, it may be acting in the direction of increasing satisfaction, making up for informational shortcomings, as the data suggest. It should not be overlooked that the interaction processes occurring during the consultation are more complex than a simple exchange of information (Czaja, Manfredi y Price, 2003; Jahng, Martin, Golin y DiMatteo, 2005).

In the light of these results, interventions that seek to involve the patient in decisions with a view to reducing adverse effects come up against the barrier of the passivity of patients, so that there is a need for the type of direct intervention suggested in other studies (Benbassat, Pilpel y Tidhar, 1998). Indeed, these results suggest that the number of patients who fail to assume a more active role and who trust the decision of their doctor is higher than might be expected, which corroborates the findings of other researchers (Ford, Schofield y Hope, 2003; Barca et al., 2004).

Up to now, analyses of models of interaction between professionals and patients have considered doctors' attitudes and behaviours (Dillon, 1992; Ford, Schofield y Hope, 2003; Loayssa, González y Ruiz, 2007) and patients' points of view and preferences (Coulter y Magee, 2003; Feldman-Stewart, Brundage y

McConnell, 2000). The present study suggests that certain characteristics of the long lasting paternalist model, deeply interiorized by patients, representing an additional barrier to their involvement in the interaction. These data are in the line of others (Arora y McHorney, 2000; Ashbury, Findlay, Reynolds y McKerracher, 1998; Ford, Schofield y Hope, 2003; Jahng, Martin, Golin y DiMatteo, 2005) which reveal that patients who do not expect to interact openly with their doctor are those who are more likely to have their expectations satisfied.

We are well aware that not all patients can be expected to be informed in the same way, and that in different circumstances the same patient may desire different information (Arora y McHorney, 2000; Janssen, 2009). We also acknowledge that the “paternalism vs shared decisions” dichotomy does not reflect the true complexity of the doctor-patient interaction (Schildmann, Grunke, Kalden y Vollmann, 2008). The data presented here show that a positive rating of doctors’ efforts to provide information does not presuppose that the patient has resolved his or her doubts, which are the bases for adopting a more active role.

This study has several limitations. The results should not be extrapolated to other countries or to settings outside of the Spanish public health system, given the context in which the study was carried out; nor should they be considered applicable to the cases of other types of professional. Patients’ quality of life and his/hers perceptions about his/hers health care might be relevant variables that have not been considered in this study, and might be analyzed in future research. However, patients that currently require hospital admission or attend outpatient clinics are usually older and their profile might be different in a few years, producing different results.

It is clear that the provision of information is not sufficient to enable the patient's active involvement in the consultation, but it does seem reasonable to suggest that it is a necessary condition. Exploring the patient's preferences requires sufficient consultation time and an attitude in the health professional that empowers the patient to interact without too many complexes (Lorenzo, 2008). Doctors now face the dilemma of taking a more leading role and holding shorter consultations or seeking the involvement of the patient and enduring a greater burden of work.

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