Do Spaniards know their rights as patients?

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Abstract

Background. In 2002, Spain introduced new legislation regulating the rights of patients. Spaniards have thus seen an increase in their capacity for decision-making, bringing them into line with many other countries. However, the law changes do not mean to be acquainted with the new legislation and therefore, putting it into practice.

Objective. To analyse whether the rules governing patients’ rights in Spain are sufficiently well known among patients and to identify the profile of those patients most aware of their rights.

Design. Cross-sectional quota-sampled survey study. A total of 790 patients discharged from hospitals or attended in primary care took a telephone survey, 773 replayed.

Results. Twenty per cent had some knowledge of the rules governing patients’ rights. Respondent characteristics that were associated with better knowledge of basic rights included: age of medical responsibility (P < 0.001), cases in which a doctor may inform family members (P < 0.001), whether or not a patient can refuse treatment (P < 0.001) and what is constituted by advance directives (P < 0.001). Patients who opt for a more active role in consultations with medical professionals show greater knowledge of their rights (P < 0.01). Age was related to greater ignorance of these rights (P < 0.01).

Conclusions. Patients’ knowledge of their rights is quite limited, making it difficult for them to assert those rights in specific medical encounters. The youngest patients, the most demanding, and those who prefer to have the last word in decisions are those with the best knowledge of their rights as patients.

Keywords: patients’ rights, clinical decision, patient–physician interrelationship

Introduction

The formal declarations of patients’ rights date back more than 35 years. The rights of patients have evolved, in democratic countries, in parallel with the recognition of the role of citizens in the society, and have been favoured not only by the influence of health institutions and organizations [1, 2], but also by the impetus of civil society [3] and by scientific developments [4].

In Spain, the first formal acknowledgement of patients’ rights took place in 1986, with the passing of the General Health Act (Ley General de Sanidad). Subsequently, in 2002, Law 41 [5], known as the Patient Autonomy Act, updated and extended those rights, recognizing basic elements such as respect for patients’ autonomy and intimacy and their right to reliable and trustworthy information, introducing new rights such as advance directives (living will) and second opinion and reducing to 16 the age of medical responsibility.

As is the case in other countries, patients in Spain today benefit from a more active role, and have noticed an increase in their capacity for making decisions [6]. In the wake of such changes, Spanish research, like in other countries [7–14], has explored the attitudes of professionals to patients’ rights [15] and how they have been put into practice [16, 17], with the aim of ascertaining whether there are sufficient conditions for those rights to be respected. Such studies reveal that the level of knowledge of the relevant legislation is not high, that the principal references are the medical deontological principles included traditionally in professional rules and the styles of practice of each specialty [18]. Among physicians, there is a more permissive attitude where the introduction of the regulations governing patients’ rights is recent [16].

At the time being, little is known about patients’ knowledge of their rights, although the indications, in some cases, are that the information they have is insufficient [12, 13], and that the complexity of information leaflets, which use legal jargon, renders them unlikely to be understood by the vast majority of citizens [14].

The aim of the present study is to explore the extent to which the law on patients’ rights is sufficiently well known among patients and to identify the characteristics of those patients with the best knowledge of their rights.
Materials and Methods

Type of study
An observational cross-sectional quota-sampled survey study was carried out in 2009. A telephone survey using a computer-assisted telephone interview (CATI system) was applied to patients from 3 hospitals and 14 primary care centres in Spain.

Study population
The sample size was calculated for each stratum (hospital and primary care centre) for an error of 3%, $\alpha = 0.05\%$, and $\rho = q = 0.50$. Selection of participants was random by means of self-weighted sampling among patients attended at health centres in the previous 3 months. In each stratum, quotas were assigned by age and sex, in accordance with the demand for care in a similar period reported by each hospital or primary care centre. Patients who refused to reply were substituted randomly by other subjects of similar profile, until the desired sample size was attained. The field study was carried out between October 2008 and May 2009.

Data source and collection
Respondents were asked at home, once they had left hospital, in the case of the first stratum, if they were familiar with the Patients’ Rights Law, and they are presented with specific questions used to assess their knowledge about basic rights of patients in Spain. The survey was developed and refined iteratively by the research team as follows. We drew up possible problem situations in the application of patients’ rights, selected on the basis of recent changes in the Spanish legislation and judicial sentences in relation to the application of such rights. This initial selection of those questions was analysed by primary care and hospital professionals, who selected those situations considered to be the clearest and most relevant to clinical practice. The correct response in each case was in line with the content of judicial sentences, internal health service guidelines on how to apply patients’ rights or the consensus on the correct application of these rights. Those questions refer to (see Appendix):

- Whether they knew what was meant by advance directives.
- Whether they knew that a patient could refuse to accept the treatment offered.
- Whether they knew the minimum age at which a patient could sign informed consent (age of medical responsibility).
- Whether they knew in which cases a doctor could inform the patients’ relatives about his/her diagnosis and treatment.

They were also asked about their preferences in relation to making clinical decisions (the prevailing criterion should be that of the patient, that of the doctor or a joint decision), bearing in mind that this differential level of involvement could have an effect on the results. Satisfaction with the attention provided by their doctor, whether or not they normally received sufficient information, if they were normally left with doubts and their preferences with regard to making clinical decisions (being informed and having the last word, or making the decision jointly). In addition, considering that chronically ill patients in hospital may have different access to information, respondents were asked about their current illness (acute vs chronic), and their perception of their clinical situation. Finally, we encoded age, sex and care level (hospital or primary care centre) at which they had been attended.

Before conducting the study, we checked with a small sample (11 patients) all the questions for understanding, facial validity and response time required. Given the results of this pilot study, no changes were introduced in the questionnaire.

Statistical analysis
The results are expressed as frequencies. We used the $\chi^2$ test for categorical variables. In these analyses, we considered as possible control variables sex and age. We carried out a binary logistic regression analysis, with simultaneous inclusion of all the variables, considering as dependent variable the dichotomized response as to whether or not they had prior knowledge of the relevant law, and as independent variables: patient satisfaction, understanding of the information provided by the doctor, preferences about patient participation in decisions, perception of state of health, age and sex. In all cases, we considered differences as statistically significant when $P < 0.05$.

Results

Patient characteristics
A total of 773 patients responded and 9 questionnaires were discarded because they could not finish the interview, leaving a final total of 764 responses to be analysed. The proportions of patients discharged from hospital and attended at primary care centres were the same (Table 1). The reasons for seeking primary care were comparable with those commonly found in primary care settings [19].

Patients’ knowledge of their rights. Of all those surveyed, only 147 patients (19.7%, 95% confidence interval 17–22) had information about the Patients’ Rights Law. The fact that 16 is the age of medical responsibility was unknown to practically all respondents (Table 2); the majority believing that it coincided with the age of criminal responsibility in Spain (18 years). Only 11.8% attempted to answer the question on whether a doctor may inform the parents of a patient aged 16 or over. Of this group, 77.1% gave the correct answer. The errors most commonly found were due to a belief in the prevalence of parents’ right to know what is happening to their relative by virtue of the family relationship or of living together.

What influences patients’ better knowledge of their rights? Those who reported knowledge of the Patients’ Rights Law are
Discussion

We found that the legislative reform carried out in Spain in 2002 has gone practically unnoticed among patients, and it can be assumed that among citizens in general, too.

The majority of those surveyed had not even heard of the Spanish legislation governing the patients’ rights. Although we might assume that citizens have a right to information, to
people believe that immediate family members have the same right to information as the patients themselves. Moreover, the age at which a patient can request a treatment or participate in clinical decisions is unknown to the vast majority. On the positive side, more than half of our sample patients—in a result considerably better than that obtained in Turkey with oncological patients [12]—are aware of the patient’s right to refuse a treatment.

In other studies, almost one-quarter of doctors were found to be ignorant of the law governing their relationship with patients [15, 16, 20]. However, in an additional study, we found that half of doctors did not know how to explain to their patients what advanced directives were, and over half of them were unaware that the age of medical responsibility was 16 [18]. In order to avoid the new legislation coming to naught, specific action is needed (and, as the data show, not only in Spain) to increase knowledge of the legislative changes.

Those who have had some previous information do better in terms responding correctly to the survey, and demonstrate greater knowledge of their rights. In this sense, traditionally Spanish women were deeply involved attending medical family needs, which is the reason that might explain the knowledge differences between older men and women [21]. This gender difference in the Spanish context makes women often informed on health system performance and this result confirms it. However, the only aspects that emerge as predictors of better knowledge about patients’ rights are, on one hand: youth and a more demanding attitude to their assigned doctor, and on the other, a preference of the patient to make the final decision. A higher knowledge, in this case, was isolated among those patients who seek a more active role (before–during–after consultation) in the interactions with physicians and health system. This greater concern with rights in those patients who tend to have a more active attitude can be understood as positive in an environment in which patient autonomy is sought [22], but may represent an obstacle in the relationship with professionals. It is not always considered positively that patients assert their rights [23, 24]. This point is particularly relevant in our case, given that in addition to the information shortcomings detected, there are other barriers bringing to bear these rights as they should be: greater caseloads and the sensation among professionals of being harried to change the doctor–patient interaction model, away from paternalism and towards the more active participation of the patient.

We are aware that it is fundamental for patients to have the right to information and to be able to participate in clinical decisions [12]. However, in the light of these results, we might expect some bias in responses, given patients’ lack of knowledge about the deployment in practice of basic rights to information, to confidentiality or to autonomy. This is an aspect for future analysis.

Patients may be overwhelmed at entry to the hospital with many different information items, including patients’ rights. On admission to hospital in Spain, it is common for patients to be informed of their basic rights. However, given the results of the present study, such information no longer
appears to be of much use—a situation also found in other cases [13]. An alternative to this practice might be to provide customized information based on the patient profile. In practice, this information seems to be limited to matters that are too general (information, confidentiality, being treated with respect etc.) and obvious or widely known and fails to cover significant legislative changes, specifically the least known aspects. These timing modifications, form and content of such information may help to improve patients’ knowledge of their rights.

**Limitations of the study**

The questions in the survey do not cover all patient rights, representing only some of the situations commonly occurring in the clinical context. Moreover, the results should not be extrapolated to other countries.

**Conclusion**

Spanish patients have quite limited knowledge of their rights, making it difficult for them to assert those rights in specific medical encounters. The youngest patients, with the most demanding approach, and who prefer to have the last word in decisions are those with the best knowledge of their rights as patients.

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**Appendix: Questions used to assess the knowledge about basic rights of patients**

Have you heard of advance health-care directives or living wills? Could you explain me what it is?

Can a patient refuse to receive a treatment?

Do you know how old a patient has to be to sign an informed consent document?

Would you be able to tell me in what cases a doctor could inform the parents of a 22-year-old patient who lives with them what is wrong with him and what treatment he should have?

**References**


