

## ABSTRACT

In view of the importance acquired by the application of human genome decoding to medicine, it is essential to be aware of the ethical, social and legal issues such applications may give rise to in clinical practice.

Another decisive technological advance for the expansion and development of genetics has been the Internet. On-line updates are vital because of the speed with which progress is made in this field.

Practically all diseases will be diagnosed on the basis of their molecular structures. In fact, this new paradigm is already in use as "*Genomic Medicine*", capable of revolutionizing all branches of medicine just as antibiotics did in their day. As a result, a new concept of preventive medicine, already known as "*Predictive Medicine*", is emerging with the goal of predicting a subject's susceptibility to falling ill with certain pathologies in future. Genetic diagnosis evidently poses specific ethical issues that may affect physical, mental and social wellbeing of individuals and their families. For this reason, this must always be accompanied by correct genetic counselling in order to improve the outcome of its communicative action, humanize and foster patients' exercise of their autonomy when it comes to taking decisions.

In a document entitled "*Twenty-five recommendations on the ethical, legal and social issues of genetic testing*", the European Commission stated in 2004 that specific educational programmes on counselling should be organized at European level and expertise in this area should be exchanged, together with the establishment of mandatory quality standards for those involved so as to avoid the creation of unfair situations of doubtful ethical content.

Aware of the relevance of the role of the professionals today practising genetic medicine and genetic counselling in Spain, we feel it is appropriate to assess from their standpoint the ethical problems they face and the real state of affairs in our country. In addition, bearing in mind the profound change that has come about in the relationship between physicians and their patients in the last twenty years, a relationship that has required specific regulation in order to adapt, such as in Spain's 1986 General Health Act where a duty was imposed on doctors and health-care personnel in general to respect patients' rights in medical practice, based on the principle of their autonomy, as well as the recent Patient Autonomy Act from 2002 which was enacted with a view to giving even better guidance in these situations.

The method used in our study has been a self-completed nationwide survey. The study population comprised all of the professionals engaged in genetic counselling at the officially regulated genetic counselling clinics in each of the seventeen autonomous regions of Spain.

From our study, we have concluded that in Spain there is an irregular distribution of private and public centres among the various regions and that genetic counselling is currently practised by professionals with different qualifications, thus making it necessary to harmonize training and regulate the conditions for access to accreditation in order to provide such counselling. The conflicts most frequently posed are: the emotional reactions of patients, obtaining informed consent especially for notifying relatives of the diagnosis, administrative and economic restrictions and the difficulties in coping with the uncertainty of the test. Confidentiality was detected as one of the problems posing the greatest difficulties for the resolution of specific cases that legislation did not easily clarify.

As for training needs in the ethical aspects of genetic counselling for future professionals, the most important ones identified were: the handling of confidentiality, staying up to date with scientific aspects in the field of genetics and the identification of the main patient.

The recommendations put forward to improve this field of medicine undergoing constant change are: to increase the number of specialists devoted to genetics; to regulate training in genetics as well as the achievement of the corresponding qualification in our country; to contemplate the need for specific training in the ethical, legal and social aspects presented by this field as part of the programmes for obtaining a degree in medicine; and also the acquisition of skills for good interpersonal communication, in order to enable counsellors to address patients, relatives and society with efficiency and empathy.