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SCIENTIFIC CONTRIBUTION

Bioethics in Mediterranean culture: the Spanish experience

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Abstract This article presents a view of bioethics in the Spanish context. We may identify several features common to Mediterranean countries because of their relatively similar social organisation. Each country has its own distinguishing features but we would point two aspects which are of particular interest: the Mediterranean view of autonomy and the importance of Catholicism in Mediterranean culture. The Spanish experience on bioethics field has been marked by these elements, trying to build a civic ethics alternative, with the law as an important support. So, Spanish bioethics has been developed in two parallel levels: in the academic and policy maker field (University and Parliament) and in clinical practice (hospitals and healthcare ethics committees), with different paces and methods. One of the most important changes in the paternalistic mentality has been promoted through the recognition by law of the patient's rights and also through the new generation of citizens, clearly aware on the exercise of autonomy. Now, the healthcare professionals have a new challenge: adapt their practice to this new paradigm.

Keywords Spanish approach · Catholicism influence · Relational autonomy · Bioethics centres in Spain · Bioethics training · Clinical ethics committees · Civic ethics · Patient's rights

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Characteristic traits of Mediterranean bioethics

The Mediterranean view of autonomy

Most authors agree that autonomy has become the central consideration in bioethics. The recognition of personal autonomy, i.e. the individual's ability to take decisions, has led to a radical change in healthcare relations in the last three decades.

Although the meaning and foundations of autonomy have been studied by leading figures in the western philosophical tradition, the principle has been applied to bioethics largely through the influence of the American or Anglo-Saxon tradition, which is somewhat different from the Mediterranean view. The Anglo-Saxon approach is more individualistic, while in countries with a Mediterranean culture autonomy is more relational.

In the Mediterranean context, the patient has always been seen as a subject of the doctor and was treated as "infirm", i.e. lacking physical and moral strength and unable to take decisions. We have called this tendency to treat the patient as a child "medical paternalism". The paternalistic approach, which sought the good of the patient without involving him/her directly, assigned more importance to the family than to patients themselves. Medical paternalism, inspired in the old Hippocratic tradition, was severely undermined when civil society rediscovered the principle of autonomy and began to place greater value on it in the United States from the 1960s on. In the American healthcare context, autonomy was seen, above all, as self-determination, i.e. the patient's ability to take decisions freely in accordance with his/her own value system. The discovery of patient autonomy led to the approval in 1973 of the Patient's Bill of Rights of the American Hospitals Association, the first charter setting out these rights. Central to the bill was the patient's right to receive information and give informed consent.

Interest in this new model spread from the United States to Europe and in 1979 the European Economic Community's Hospitals Commission drew up the Charter of Patients' Rights. This document encouraged national legislative bodies to support patients' rights and to move progressively towards a healthcare system which respected their autonomy.

We have already mentioned the key role of autonomy in western clinical bioethics but, as we have also pointed out, in Mediterranean culture the exercise of autonomy is far from being independent of the family context, as the family continues to play an important role in decision making. This strong bond between the patient and the family conditions the former's decisions, sometimes very markedly. Elizari (2005) refers to the influence of the cultural background on the principle of autonomy in these terms: "its American origins have left the stamp of American society and it owes a great deal to law and a certain type of individualistic philosophy which is not sensitive to the person's social bonds". This individualistic way of viewing autonomy has not really taken root in Mediterranean countries, where the links between the individual and the family are very different from those in the United States, the idea being that we are not isolated individuals and that the exercise of autonomy is related to our social context, in which the family plays a part.

However, this relational view of autonomy involves certain risks. Even today, after the model for healthcare relations has changed, we find healthcare professionals and many families who still subscribe to the old paternalistic model. This reluctance to change can be detected in various attitudes: there are clinical professionals who continue to give great importance to the family when decisions are to be made, sometimes even ruling out the patient's own involvement altogether; there are families that find it difficult to respect decisions by members of their own family, if they do not conform to what they see as right, and that do everything they can to impose their own ideas; other families strictly forbid healthcare professionals to inform their relatives about the diagnosis, etc.

Although great progress has been made in the recognition of patient autonomy, there is still considerable ignorance, on the part of both healthcare professionals and families, of the meaning of respect for autonomy and there are still families that refuse to accept a new model of healthcare based on respect for the wishes of the patient.

The influence of Catholicism in Mediterranean culture

Another aspect of bioethics in Mediterranean countries is the confrontation between Catholic and secular culture. To understand this feature of Mediterranean bioethics we need to remember that Spain, like a number of other Mediterranean countries, has been culturally and religiously linked to Catholicism for many centuries and, despite the movement to secularisation throughout Europe, the church and Catholic culture have a strong influence on bioethical thought, especially in topics concerned with the beginning and end of life.

It is paradoxical that in a Europe where secularisation is generalised, and religion is losing (or has already lost) its social and personal meaning, with declining numbers belonging to or practising a religion, official Catholicism should have so much influence in the field of bioethics. As Grace Davie points out in her book *Europe—the Exceptional Case,* the European secularisation process should be considered an exception rather than the norm, since outside Europe religion maintains its vitality.

In Spain the process of secularisation has been reinforced by the reaction of Spanish people to the national Catholicism imposed under the dictatorship of General Francisco Franco (1939–1975), when a single code of behaviour was imposed, based on the morality of the Catholic Church. The Spanish *Fuero* of 17 June 1945 states in Article 6 that "the profession and practice of the Catholic faith, which is that of the Spanish state, will enjoy official protection. No one will be persecuted for their religious beliefs or the private practice of their religion. No public ceremonies or external demonstrations of faith will be allowed, other than those of the official religion" (Seglers 2009).

In Spain the transition from a society dominated by national Catholicism to a secular society, from Catholic ethics to civil ethics, has involved, and still involves, certain tensions. The dialogue between Catholic culture and secular culture in Spain is difficult because the hierarchy of the Catholic Church is reluctant to accept the separation between the power of the church and the power of the state. In the past it was able to impose its own official doctrine and would like to do so today regarding all matters related to bioethics, even though we live in a society which is culturally, morally and ideologically plural. This attempt by the church to impose its views is seen by many people as interference which should not be tolerated, leading to a permanent state of conflict which only serves to encourage the transition from a secular society to one which is actively hostile to religion.

A secular society, while not being governed by religious principles, is able to appreciate the wealth religion can contribute to a society, when practised sincerely, and respects religious beliefs. A society which is hostile to religion recognises no value in it all, not only rejecting it but also attempting to eliminate any trace of religion in public life.

The bioethical debate in Spain is strained because there is a confrontation between an ecclesiastical hierarchy, which has not been sufficiently flexible to adapt to social change and modify its approach accordingly, and a society in which hostility to religion is on the increase. Bridges for dialogue can only be built if both sides want to understand each other. The church thus has to understand the need to move from Catholic ethics to civil ethics. As Diego Gracia says "the minimum moral standards we can ask of everyone […] can no longer be determined by the precepts of religious morality, but only according to strictly secular, civil or rational criteria" (Gracia 1992). We must accept, however, that those who consider themselves Catholics are also members of society and are entitled to have their beliefs respected, provided that they do not run counter to fundamental rights. What Catholics have no right to do in a secular society is to attempt to impose their beliefs on non-Catholics.

These tensions between Catholic culture and secular culture in Spain have manifested recently in the legalisation of same-sex marriages, the law on techniques for assisted human reproduction, the law on biomedical research, and the recent reform of the law on abortion.

The national Catholicism imposed on Spain in the Franco era has not only led to religious and ideological problems but also problems on a political level. Spain is a country lacking in democratic culture and this is particularly noticeable in the absence of public involvement in the social and political organisation of the country.

Where are we coming from?

Healthcare being considered as a right is relatively recent. Spain passed the public healthcare act in 1986, and from that point on a whole public system had to be constructed, to serve users who had only just gained the status of citizens with the creation of the parliamentary monarchy in 1978. Democracy had not existed in Spain for 40 years, and the fundamental rights and freedoms which are inherent to a so-called state of law were not recognised during this period.

40 Years of Francoist government was too long for a population which emerged from a 3-year civil war (1936–1939) into an extremely hard post-war period, up to 1975 when Francisco Franco died. By 1975 the population was beginning to enjoy prosperity and economic welfare which discouraged any awareness of rights and duties. The public sphere, laws and schools were dominated by conservative Catholic morality for 40 years. The suppression of all differences in ideas, language and culture was visible in the exile of intellectuals and in censorship. One example of this was the dismissal of Professor J. L. Aranguren from his chair in Ethics in 1965.

The conservatism which dominated all aspects of life prevented any discussion of divorce, freedom for women, contraceptive policies and so on for many years. Spain was under a religious power with conservative legislation and a fairly closed, inward-looking university system. There was no freedom of speech or association and no chance to hear different or dissenting voices, which generated a fairly mediocre atmosphere in political culture: a certain feeling of resignation predominated, made bearable by the economic progress of the 1960s, and the baby boom.

The first task of the new democracy was to make pluralism and tolerance in the public sphere the norm. For many years the communities of Catalonia, the Basque Country and Galicia had suffered from repression of their differences, not only in terms of language but also in the mentalities of many of their inhabitants because of their closeness to, and contacts with, the rest of Europe. This difference was catered for with the emergence of the autonomous communities (whether or not they needed to affirm a separate cultural identity, it was decided that they would all be different for the sake of a "peaceful transition").

Spain was not a country with a tradition of participation in the public sphere: as a country it had sought stability and to give its children the prosperity assured by a job or a university education, and in a few short years, thanks to tourism and other factors, it had become a welfare state and gone from being a country of emigration to a destination for immigrants.

But it was not a country with a population which was conscious of its rights and duties, which in turn determined the type of medicine available. Doctors were very high-status people who practised privately and there were hardly any hospitals in the country. It was a matter of catering for a population with an almost reverential respect for the figure of the doctor, who generally enjoyed high esteem and reputation, because they were professionals with a clear social vocation and well aware of the moral confidence their patients should have in them. Only the most powerful had access to more specialised medicines and services.

It was a young country, with relatively few old people among the population and an attitude of patience and suffering inculcated by scarcity and hard work as the only way to escape from poverty. University was a social and economic escape route, and the middle classes were beginning to enjoy their first cars and holidays, as well as the emergence of many new universities.

What has been done in 25 years in the field of bioethics?

Building a quality healthcare system

Following the passing of the public health act in 1986, the quality of care increased enormously in Spain: there was considerable investment and many universities were founded. Medical faculties now have resources and provide very good training, and very high marks are required nowadays to get into them. But the reputation and status of healthcare professionals are declining. Even though the Spanish population rates the quality of the public health service very highly, and it is one of the best in Europe, this is due to three factors: very good technical training of professionals, a strong public service ethic and very effective, rapid investments which have encouraged professionals to believe they have the chance to establish quality public service.

We have created a welfare state very quickly and both highly positive and other negative effects of this can now be seen.

Among the positive effects are the following: high-quality service, technically proficient medicine which has led to improved health across the country, illnesses which were once fatal have now instead become chronic, healthcare has taken on a social dimension, the population has aged, leading-edge research is conducted and innovative legislation is passed (as will be seen below, in questions of bioethics, Spain has very advanced legislation in European terms and in terms of the medical class itself). This is also illustrated by the fact that many patients have private health insurance, but in the event of serious illness public hospitals are considered to provide the best quality.

On the other hand, with the economic boom we have created hyper-demanding patients. When resources were available they were considered as clients, not just citizens, and nobody imposed limits on them. Moreover, little distinction was made between questions of fairness, rights and personal preferences. Patients got whatever they wanted, whether they merited it or not, and abused the system. This produced an unfair distinction, on the one hand those who asked for a lot and on the other those who did not ask, in which case the system concluded that they did not need anything. Now immigration, the ageing of society, the lack of tradition in managing healthcare resources and so on have led to an unsustainable situation in the public health system. The consequences are waiting lists in a society which is now aware of its rights, and overworked professionals suffering from burnout and a lack of clear policy guidelines.

It is true that the professionals have managed to regulate themselves; there are wonderful professionals who have given their all to patients but seen their social and economic status decline. They now are suffering from a certain institutional punishment in that they are subjected to very strict directives when this had not been the case before. For example, the patients do not know the prices of the medication or treatments they receive, but in many cases neither do the professionals. It is obviously not a matter of confusing price with value, but the lack of management in medicine means that Spanish health professionals are very good technically but suffer from three major weaknesses:

1. Ignorance of the economic side of the profession.
2. Lack of training in more human and ethical issues, such as communication skills or handling dilemmas and respecting the patient’s autonomy: this article highlights these issues because medicine in Spain is still highly paternalistic.
3. Professionals in Spain have little inclination to work in teams; the profession is highly individualistic and has little sense of organisational culture.

It should be added that healthcare policy tends to treat excellent professionals the same as others who, with guaranteed jobs, limit their commitment to not actually being negligent. All this means that excessive demands have been made on public healthcare professionals by the authorities and by hyper-demanding patients, and a defensive form of medicine is beginning to emerge in which the object is not to be reported and to collect one’s salary. Consequently, patient’s continuing satisfaction with the quality of care by health professionals is not matched by satisfaction among the professionals themselves.

The shortfall in bioethics training: major bioethics centres in Spain

One of the key factors in the difficulties in developing bioethics in Spain is not at an academic level but a professional one. This is the obvious shortfall in training in this area which has greatly slowed down the process of applying ethical criteria to healthcare practice by making it difficult to change the mentality of health professionals.

A review of the degree syllabuses of university courses such as medicine, nursing, clinical psychology and so on shows that in most of them the subject of “bioethics” either does not appear or is included either as an optional course or as a very short compulsory one. At the same time it can be observed that the fact that there is no single or consistent criterion applied by all universities means that the introduction of bioethics to a greater or lesser extent often depends on particular sensitivity or interest on the part of deans or rectors to foster this aspect of training.

Thus, for many years now in Spain new generations have graduated, especially in the case of doctors and specialists, with little or no background in bioethics. As mentioned above, they are not trained in the areas of informing patients or communicating with them, or clinical interviews, error management, respect for people's autonomy and so on. This means that these new generations of doctors often still follow a clearly paternalist model whereby the doctor considers that they know best what is good for patients and either ignore them or treat them like children in the decision-making process. Paradoxically, this attitude is more prevalent today in younger generations of doctors than among professionals who have been practising for years and who experience has taught a different point of view with regard to attention and respect for people, as well as having better-assimilated ethical principles.

This fact led to the appearance in Spain of postgraduate courses in bioethics aimed at professionals interested in the subject, coinciding with the setting up of the first bioethics centres which approached the subject within the academic sphere. The first masters courses in bioethics were created within the university system, and healthcare professionals who were especially sensitive to ethical issues enrolled for them, so that in a few years a considerable number of people received training, though they were still a small minority of professionals at different levels of healthcare (doctors, nurses, etc.). It should be pointed out that many of these trained professionals went on to set up or join the healthcare ethics committees and research groups which have sprung up around Spain, as discussed below (Amor Pan 2005).

The most important centres, which are doing work of the greatest depth and expertise, are mentioned below.

The Borja Bioethics Institute (Universitat Ramon Llull)

This was set up in 1976 at the initiative of its current President, Dr. Francesc Abel i Fabre, a Jesuit and doctor of medicine, specialist in obstetrics and gynaecology, a graduate in philosophy and theology trained as a researcher in the United States, where he saw at first hand—beside figures like Dr. André Hellegers and Daniel Callahan—the establishment of what are still among the world's leading bioethics centres, the Kennedy Institute of Ethics (Georgetown University) and the Hastings Centre. Upon his return to Catalonia he felt it was essential to set up Europe's (and Spain's) first bioethics centre in Barcelona, and this he did together with colleagues from the academic sphere. After working for 8 years attached to the Faculty of Theology of Catalonia, it was set up as a private foundation in 1984. For 10 years, the institute played a part as a founder and an essential part of the International Study Group on Bioethics, established under the aegis of the International Federation of Catholic Universities in order to foster dialogue between the biomedical sciences and the humanities (philosophy and theology) from an inter-faith standpoint. Over this period several working meetings were held in different parts of the world, resulting in relevant publications including "*Human life: its beginnings and development*" (1988), "*Birth, suffering and death. Catholic perspectives at the edges of life*" (1992), "*La mediación de la filosofía en la construcción de la bioética*" (1993), "*Critical choices and critical care*" (1995) and "*Infertility: a crossroad of faith, medicine and technology*" (1997).

Also in 1986, Dr. Francesc Abel, together with other eminent figures from around Europe, founded the European Association of Centres of Medical Ethics, a pioneering body which brought together the most recognised medical ethics centres on the continent, and today has more than 70 members.

Since the year 2000, headed by the jurist Ms. Núria Terribas, it has been a university institute, part of the Universitat Ramon Llull (a private university, Christian in inspiration). Its main aims are the following:

- To reflect on the issues arising from biomedical progress and the life sciences in general, and their repercussions on society and its value system, as well as in relation to healthcare management.
- To provide a service to society in general and in particular to its leaders and administrators, who are constantly faced with new challenges posed by the progress of science and biomedical advances and have to dictate new criteria and draw up regulations on everything that affects life and human dignity.
- To be a channel for dialogue between the Christian faith, different humanisms and cultures and the scientific world, especially in matters pertaining to bioethics in relation to medicine and related sciences.

The Borja Bioethics Institute (URL) pursues these aims through its activities, which fall into four main areas:

- *Research*: Fostering research into philosophical, ethical and legal issues related to progress in the medical and biological sciences.
- *Cooperation and advice on bioethics*: The Institute does important consulting work in the field of Ethics Committees, giving advice and sitting on committees in different hospitals and healthcare centres, as well as on different committees for the Government of Catalonia.
- *Teaching*: It teaches on an interuniversity master's degree in bioethics (with European recognition for 60 ECTS) and postgraduate courses in bioethics.
- *Dissemination and documentation*: The institute produces its own publications on issues specific to bioethics, with more than 30 papers published, and since 1995 it has also produced the journal *Bioètica and debat.*

In 1976 it established its own documentation centre and library specialising in bioethics, which today contains over 13,000 papers and a collection of more than 200 specialist journals published in different countries around the world.

The chair in the history of medicine at the Complutense University, Madrid

In the 1980s Professor Diego Gracia Guillén, holder of the chair in the history of medicine at the Complutense university of Madrid, a disciple of the humanist Pedro Laín Entralgo and the philosopher Javier Zubiri, became involved in the new discipline of bioethics, sitting for several years on the board of the Borja bioethics institute in Barcelona, and began working in depth on the basis and foundations of bioethics. He is the author of two essential works: *"Fundamentos de bioética"* ["Foundations of Bioethics"] (1989) and *"Procedimientos de decisión en ética clínica"* ["Decision-Making Procedures in Clinical Ethics"] (1991). In 1988 Professor Gracia himself created a *Master's degree in Bioethics* at the same university, which on a 2-year course provided systematic training to many healthcare professionals, creating a veritable school of disciples who some years later set up the Association of Basic and Clinical Bioethics. Moreover postgraduate courses were established under the direction of Professor Diego Gracia for qualification in Expert in Bioethics.

1996 Saw the creation of the bioethics institute of the Health Science Foundation, headed by Professor Gracia himself.

The chair in bioethics at the Comillas Pontifical University

In 1987 the Comillas Pontifical University set up a chair in bioethics under the Jesuit Javier Gafo, who for many years—up to his death in the year 2001—performed an important task of reflection through the chair's publications, such as the series on "*Dilemas éticos de la medicina actual*" ["Ethical dilemmas in modern medicine"]. Also, in the academic year 1997–1998 Comillas started teaching a *Master's degree in Bioethics* through which many professionals from different parts of Spain passed.

The bioethics and law observatory at the University of Barcelona

Under Maria Casado, professor of Philosophy of Law at the University of Barcelona, the Observatory of Bioethics and Law was set up in 1991 as a research group into bioethics issues with a special emphasis on legal issues and analysis of the legal framework. This observatory, part of the University of Barcelona Scientific Park, also teaches a *Master's degree in Bioethics and Law* and draws up opinion papers on different issues related to the latest biomedical advances. In 2007 UNESCO awarded a chair in Bioethics to the University of Barcelona, to be headed by Professor Casado herself.

Other initiatives

Although there are other universities which offer training in bioethics with masters or postgraduate courses, they do not go beyond a qualification by the university itself, without a structured institution behind it, the main function of which is reflection and analysis of bioethics. Mention could be made of the interuniversity master's programme taught by La Laguna University (Canary Islands) together with five other Spanish universities, or of the University of Navarre, but these do not have an institutional background like the others discussed above.

Likewise, Spain has other institutions which, while they do not run approved training programmes in bioethics, nevertheless have a background of many years fostering activities, research and reflection on bioethics in the form of publications, congresses, seminars, prizes or scholarships, etc. Among these mention must be made of the interuniversity chair in law and the human genome (Bilbao), headed by Dr. Carlos Maria Romeo Casabona; the International Society of Bioethics (Gijón), chaired by Dr. Marcelo Palacios, and the Víctor Grífols i Lucas Foundation (Barcelona), headed by Dr. Victòria Camps, among others.

However, the challenge for the future is for bioethics and ethics applied to different fields to become part of degree curricula, so that future generations of professionals will graduate with specific training in this area as part of the basis of the profession.

Changes in Spain through the laws on bioethics

In Spain the transition to democracy culminated with the Spanish Constitution taking effect in 1978. The constitution recognises as basic rights the fundamental right to life and physical integrity (art. 15), the right to freedom (art. 17), the right to honour and to personal privacy (art. 18), the right to scientific production and creation (art. 20), the right to form a family (art. 32), and the right to healthcare (art. 43), and others. Thus began a very important period of regulatory development which directly affects very specific topics in bioethics, such as Spain's leading role in Europe in the regulation of organ transplants (1979) and assisted human reproduction (1988), for example.

During this period of transition and the following decades, many provisions and laws have been enacted.

The areas of regulatory development which stand out most for their significance are those regarding biomedical research, assisted human reproduction, transplants, organ and tissue use, and those regarding patients' rights. It must be said that some of the contents of the latest laws have been inspired by the *European Convention on Human Rights and Biomedicine* (1997), which was enacted in 2000.

Of the specific regulations, we will present a more concrete commentary on some which have had special relevance as they have meant a paradigm shift at the social and professional levels.

Patients' rights

A process of recognising rights has been begun in Spain, based on the recognition of the right to health protection as a basic right of all citizens (art. 43), which was formulated initially as a Patients' Bill of Rights and subsequently as a positive law. Despite that, in order to understand this regulatory development in Spain, the territorial and political organisations of the autonomous communities should be mentioned. As stipulated in the constitution, they have their own legislative capacity within their territories. Patients' right is one of the areas which have been specifically regulated by these autonomous territories.

The first Rights and Duties Chart was approved in the territory of Catalonia in 1983, and then in 1984 for all of Spain, under the aegis of what was then the Instituto Nacional De Salud (National Health Institute) and which joined the public healthcare system of the rest of Spain.

Shortly thereafter, the General Health Law of 1986 (Ley General de Sanidad, LGS) went into effect, and for the first time a list of patients' rights was set forth in a law (art. 10 and 11) which was applied to all of Spain. This is the law that introduced the new obligation of Informed Consent (IC), amongst others, though in a manner so defective and ambiguous that it invited very diverse applications of the precept due to maximalist interpretations of the text, none of which are satisfactory for the users (written consent for everything, an exhaustive and incomprehensible text due to its technical language, etc.). The consequence of this legal imposition was that IC became an obligation which could lead to lawsuits in the case of failure to comply. It lost the essence of what it should have been, i.e. a tool which, through a process within the doctor-patient relationship, would favour respect for the patients' right to be informed, to comprehend this information, and ultimately, to give their authorisation for a given procedure. However, in the context of this law, the only important thing was that the signed IC form appeared in the patients' file, and nothing else… whether or not the patients had been informed or if they had understood the information was completely irrelevant.

This point seems especially relevant, given that these are questions which affect all levels of care (primary, hospital, social services, healthcare, etc.), despite it being applied initially and in an especially severe manner at the hospital and specialised care levels. Based on this legal imposition—which was not accompanied by a change in the mentality of healthcare professionals, who had been trained under a very paternalistic model—an increase in litigation also began, such that there were many reports filed before the courts against health professionals and centres seeking compensation for improper information or lack of an IC. Thus, between 1990 and 2002, the increase in lawsuits grew steadily, clearly generating a defensive attitude in healthcare professionals who, in order to avoid legal problems, simply supported the correct "formal" completion of the IC, leaving aside the ethical aim of respecting patient autonomy.

After many years of the General Health Law of 1986 being in force and with the criteria set forth in the European Convention already approved and in force, the Parliament of Catalonia created and promoted a Law (21/2000, on the right to information, patients' autonomy, and clinical documentation), and it was the first autonomous community in Spain to set forth in law a more detailed and concrete process of everything related to the right to information, exercising patients' autonomy, and rights regarding clinical documentation. Subsequently, other autonomous communities copied the Catalan model (amongst them Galicia, La Rioja, Madrid), introducing some changes and nuances, but conserving the same fundamental content. It should be noted, as we have mentioned above, that before the creation of this law in Catalonia there was already a provision for patients' rights in the 1983 Rights and Duties Act, which was later (2002) revised and updated (Bioètica and Debat 2003).

After the law took effect in Catalonia, the Spanish Parliament proposed following Catalonia's model and created a regulation (41/2002, on patients' autonomy, information, and clinical documentation), giving it the standing of "basic law", so that all of the autonomous communities in the territory which developed legislation on this subject were required to do so respecting the basic principles and criteria established therein.

When the law on patients' rights took effect, it meant an important change in improving the law in all aspects of patients' autonomy, specifying elements such as the regulation of informed consent, the right to information, access to the patient's clinical documentation, the withholding, withdrawal, or refusal of treatment (of special importance regarding end-of-life care), the implementation of advance directives, the recognition of the capacity to take decisions of a competent minor, etc. The change in the law also meant a better acceptance by professionals of criteria governing the doctor-patient relationship, which must be based on respect for the autonomy of the person while adhering to the principles of welfare and justice in the context of a universal-coverage public healthcare system with limited resources.

It must also be said that the recent years of evolution and change to the paradigm in the clinical relationship, aided in part by the evolution of the legislation, have led to a reduction in lawsuits brought against professionals in Spain—at least in those related to questions regarding patients' rights. Lawsuits now tend to be more limited to questions of physician error or mal practice. Despite that, the reality of how patients' informed consent or the right to information is applied, despite having improved in the last 10 years, is still very far from the ideal, since it is understood and applied as a legal duty before an ethical duty, and still observes some very paternalistic practices with little patient participation. One of the key elements in attaining this change in attitude is training healthcare professionals in bioethics and specifically in these subjects, as a basis and foundation for their practice. As we stated previously, however, this training in the different degree programmes is still a theoretical aspiration and not a reality.

Biomedical research

In terms of biomedical research, Spain was for many years at the tail end of European countries. It had a very restrictive regulatory framework, especially in terms of the possibilities for research in the field of biomedicine, with embryonic stem cells, and in molecular biology. Paradoxically, it had been a pioneer in the field of assisted reproduction (these techniques have been regulated by law since 1988), but the restrictiveness of the law had given way to a situation of "corralling" with no exit for the thousands of unused embryos. The law had established a maximum term for the preservation of the frozen embryos of 5 years, but it did not establish what to do with them after this period expired. Over the years, thousands of frozen embryos were accumulated in assisted reproduction clinics, abandoned by their progenitors and therefore without a reproductive function. However, these could not be used for research since the law had not specifically stipulated this.

It wasn't until a reform of the Law on Assisted Reproduction was approved in 2005 that the use of all of the unused frozen embryos for research was authorised if the progenitors so chose. Subsequently, in 2006, a new law on assisted reproduction took effect which specifically laid out the need to specify, through informed consent by the progenitors, the potential fate of the remaining embryos, with research being one of these ends.

It should be mentioned that the 2006 version of this law introduced new elements in assisted reproduction such as authorising genetic diagnosis prior to implantation in order to avoid passing on serious hereditary diseases, those that are early-onset, and those for which there is no postnatal curative treatment, and to authorise this diagnosis when it would benefit third parties for the histocompatibility in a future recipient of cells or tissues (Lacadena Calero 2011).

In addition to this law, in 2007 Spain approved the current law on Biomedical Research, specifically designed to regulate all research procedures which are carried out on human subjects using cells or tissues, with special attention paid to the handling of genetic data and to the creation of biobanks as a tool for collection and providing biological specimens for research. The law established very rigorous criteria for using any sample, requiring explicit and detailed informed consent on its fate and uses with the aim of maintaining proper handling of genetic information contained in any biological sample.

Similarly, and as an important new addition, the law accepts the technique of nuclear transference as a procedure for obtaining stem cells.

All of these procedures, as long as they are conducted for research and not yet applied to clinical medicine, must pass strict ethical correctness controls under the supervision of research ethics committees. More novel projects with stem cells are under the direct control of a national committee for the use of human cells and tissues. The purpose of this was to avoid having lines of research begun without the knowledge of health authorities, and to be able to conduct exhaustive monitoring of the projects underway, regardless of whether they were financed with public or private funds.

With this legal framework, Spain has placed itself amongst the leaders of the European countries with more open biomedical research laws. This was aided in the initial years by significant investment in research and development, and the creation of new infrastructure and scientific parks. It was hoped that this would help to convince many Spanish researchers who had gone to work in other countries to return home, and that research activities in Spain would rise to the same level as in other European countries. The policy was effective, although currently it has been slowed somewhat by the current financial crisis, in which research and development has been one of the fields most affected by budget cuts.

In addition to basic biomedical research, Spain has had specific regulations on pharmacological research and on new health products since 1990. This regulation has been updated and adapted to European regulations, and has always respected the directives established in benchmark documents on research with human subjects, such as the Belmont Report or the Declaration of Helsinki, and internationally accorded guidelines on Good Clinical Practice. In terms of supervising pharmacological research, as of 1990, committees on ethics in clinical research have played a central role in promoting the ethical correctness of projects and protecting rights.

Creation and accreditation of HECs and CRECs

In the development of regulations in medical practice—the application of which entails many ethical conflicts for medical professionals in their work with patients—we would like to highlight the birth of the Health Ethics Committees (HECs), organisations created to help professionals with consultation and reflection on these issues.

The first experience in implementing these in Spain was thanks to the efforts of Dr. Francesc Abel, founder of the Institut Borja de Bioètica, who in 1976 began the first hospital health ethics committee in the maternity ward at the Hospital de Sant Joan de Déu in Barcelona. Initially, the committee focused on problems related to family planning and human reproduction. It then gradually extended its competence and counselling activity to other fields of care (therapeutic limitation in newborns, paediatric oncology, etc.). For many years it was the only committee in Catalonia and Spain, until 1985 when other initiatives emerged. Beginning in the nineties, the creation of committees in other hospitals and health centres began to rise.

As far as legal regulation, Catalonia once again led the way, and in 1993 it established regulations for the creation and accreditation of the HECs in Catalonia. Subsequently, similar, more general regulations were approved for all of Spain. After that, from 2000 on, other autonomous communities followed the initiative. Today the creation of HECs is legally recognised in most of the Spanish territory and their expansion has been openly and widely promoted throughout most of the Spanish healthcare system. At a quantitative level, the Catalan model is a good example. With a population of 7 million people who are users of the healthcare system, it has a network of 57 HECs, not only in tertiary hospitals, but also in minor health centres, in primary healthcare, and in the fields of social services and general healthcare.

However, it must be noted that the model that has been established and accepted is that of the committees as collegiate and multidisciplinary organisations, including professionals from different fields, in which dialogue and the deliberative method prevail as tools for the analysis of the cases considered and for the creation of guidelines and protocols, etc. (Montero Delgado and Morlans 2009). The model of an individual person as the ethics consultant has not yet been accepted, except for very few initiatives in a small number of centres.

This fits with the Mediterranean culture and the Spanish healthcare system, which has strongly promoted teamwork in order to foster cooperation between primary and hospital healthcare and to respond to the necessity of comparing criteria and second opinions. So, the dialogue and reflection method prevails over the individual criterion of the ethics specialist, with the former being that which best responds to professional working and collective decision-making plans.

It is important to highlight the fact that, despite laws for the creation and accreditation of this type of committee, these committees have generally not been decreed by regulation. As such, if a health centre decides to implement an HEC it is essentially because the employees at that centre have perceived a need to have an advisory body, and not due to the fact that they are being obligated to do it as a result of administrative or legal requirements. We understand that this adds much more value to the existence of the HECs, as their founding is the result of a genuine desire and is due to the necessity in the profession for the resolution of the ethical conflicts encountered.

In terms of the composition of the HECs, it must be said that the regulations almost universally have a multidisciplinary composition and include the participation of doctors, nurses, social workers, jurists, specialists in bioethics, representatives of the users, etc. The dynamic generally consists of monthly meetings with potential extraordinary meetings when issues demanding urgent review arise. HECs in Spain also create guidelines and ethics protocols for the centre's regular procedures and promote the training of all members and professionals at the centre.

Clinical Research Ethics Committees (CRECs) have a different approach. This type of committee has been legally mandated since 1990 with the explicit purpose of supervising the ethical, legal, and methodological correctness of clinical research projects with human subjects, and ensuring the protection of their rights. The medical law at that time stated that all clinical research projects had to go undergo prior screening and were subject to the binding rulings of a CREC. So all university hospitals and research centres had to obtain this certification from a committee. This led to the creation of the first CRECs, which generally acted as reference committees for the supervision of research projects which were carried out in one or more centres. There have also been other experiences in this field in Spain. For example, in 1992 Catalonia published the CRECs' accreditation regulations, and committees were created according to the needs of the centres. As a result of this, there are 37 accredited CRECs in Catalonia. In contrast, other autonomous communities chose a single committee model for an entire autonomous territory, and every project had to go through the same committee. It should be noted that in Spain research is distributed very unevenly;

the areas with the highest concentration of universities and research centres are the autonomous communities of Catalonia and Madrid, where it would be almost impossible for just one autonomous committee to take on all of the research projects that are conducted every year.

We shall see how these committees are organised in the coming years, since the approval of the law on Biomedical Research involves the extension of their competences, they will also have to supervise all of the biomedical research projects, in addition to the pharmacological projects or projects with health products (cellular therapy, use of tissues and biological samples, etc.). It seems obvious that it will be necessary to strengthen the structures of the current CRECs, conferring on them a more professional character, and providing them with employees who are solely dedicated to the CRECs, since so far they have been comprised of professionals who have combined their health practices with their work on the CREC, avoiding potential conflicts of interests.

At the same time, we need to consider the criteria imposed by the regulations of the European Community, which also define the course these committees should be following. The most recent directive to date is from 2001; presumably this will be revised and adapted to the evolution of research in pharmacogenetics, gene therapy, etc.

Social rights

Spain has also progressed in the field of social rights in recent decades, with clear, explicit recognition of comprehensive social rights (right to association, freedom of expression, etc.), already recognised in the Spanish Constitution. Specifically, an important field in which Spain has progressed is in social services, which have played an important role as one of the pillars of the welfare state, together with healthcare. Regulations governing citizens' rights in cases of necessity or conflict have been developed, under the basic criteria of respecting rights. It must be noted that this is also a subject whose field of competence in Spain is divided by territories (the autonomous communities), and thus regulations have been progressively adopted that develop social services at different levels, depending on the territory.

Catalonia has first-hand experience in this, having approved the Law on Social Services in 2007, which establishes different degrees of social intervention based on people's circumstance and need. It outlines the administration's responsibility for homecare, financial aid in marginal situations, support for women who are victims of domestic violence, aid for the homeless, measures to protect at-risk children and teenagers, aid for immigrants, etc. The Catalan model takes into close consideration the ethical aspects and the training of the professionals in social services in respecting people's rights. In following with this, a training programme in ethics and social services has been implemented. This programme is intended to reach professionals throughout the entire territory. At the same time, the Social Services Ethics Committee of Catalonia been created as a government advisory body in this field.

Other autonomous communities have also developed their social services as one of the pillars of the welfare society, and have also created advisory organisations in the autonomous government on the ethical aspects of social services (the Basque Country and Navarra).

At the national level, Law 39/2006 on the promotion of personal autonomy and care for dependent persons has been the most important regulation in the social field in recent years. This law is intended to cover the different needs of the many people who obtain recognition of their degree of dependence, based on their level of dependence, in order to receive benefits such as in-home assistance, placement in a day centre, financial assistance for familial caregivers, etc. The greatest difficulty posed by the development of this law is the fact that its application and financial provisions have been delegated to the autonomous governments, which has made application very difficult, especially during the serious financial crisis of the last 2 years. It is also being implemented very slowly and with very few resources, which is creating great inequalities amongst the citizens in the different territories (Amor Pan 2010).

Even so, demographic data shows that the Spanish population is aging while life expectancy is increasing, leading to an increasing number of elderly people with multiple pathologies who are dependent on the healthcare system. This has led to an urgent need to coordinate social and healthcare services, which is not always done quickly enough, or governed by parameters which make streamlining resources possible. This is one of our most compelling challenges, one which requires acting with the ethical criteria of justice, equity, and respect for the rights of citizens.

Challenges and the agenda for the future of bioethics in Spain

Promoting patient autonomy in a context where the family is still very influential

In this article we have demonstrated that recognition of patient autonomy has advanced greatly in Spain and across the Mediterranean over the last three decades. This is especially due to the influence of bioethics in North America. We have also indicated that the relational concept of autonomy which prevails in Spain still creates situations of paternalism, by both health professionals and the families of patients. Thus, one of the most important challenges of Spanish bioethics is to find a way to overcome paternalism in clinical medicine.

The profusion of declarations, acts, laws, and deontological and ethical codes, etc. in favour of patients' autonomy which have been approved in recent years, and which have led to a paradigm shift in healthcare relations, is an important milestone for our society. However, it is also true that even today a great deal of ignorance persists amongst health professionals, patients, and patients' families as to the spirit on which these documents are founded.

Overcoming paternalism cannot be done solely with the approval of declarations and laws. Rather, this change must be accompanied by pedagogical actions. If this is not done in this way—if the ethical and legal regulations do not have social recognition—it is likely they will not achieve their purpose; the laws will be relegated to a theoretical realm and will not be put into practice. In order to give patient autonomy the respect it deserves, we must support bioethics training for all healthcare professionals, and at the same time develop educational projects for all citizens, with the objective of informing them of their rights, and of the scope of these rights.

Making this respect for autonomy a reality will be brought about through informed consent, but this approach has two potential drawbacks:

(a) It could become just another bureaucratic act, a mere paper to be signed so the healthcare professional is legally protected (this is called "defensive medicine"). Procedures in defensive medicine cast aside any concern of respecting patient autonomy. As V. Camps stated, the purpose of informed consent "should not be the signature with which one gives consent, it should be the information which precedes the signature. It is obvious, then, that without information, consent cannot be valid. How can someone who is not informed—someone who turns to a healthcare professional precisely because he is sick and does not know what to do to get better—give his consent? Informing, in this case, cannot be reduced to demanding a signature after reading some pages which attempt to make the patient understand the possibilities he has for treatment, at any cost" (Camps 2001). The author then poses the true challenge of the process of informing: "Informing must be a dialogue and, where necessary, deliberating together, because only in this manner—by talking—will the information become comprehensible and help towards taking the appropriate decision" (Camps 2001).

(b) Another risk of the informed consent formula—in a context in which the family is very influential—is that of carrying out processes of informed consent by representation, without the health professionals having truly explored the patient's capacity. As P. Simón and I.M Barrio state, "as a general rule, informed consent cannot be substituted when the patient has the capacity" (Simón and Barrio 2004).

This tendency for the family to decide for the patient is quite widespread in Spanish culture. The usurping of the patient's capacity to decide by the family should not be seen as a disrespectful attitude towards the patient—although that may be the case—, rather as the traditional way in which families protect the patient. When faced with this situation, healthcare professionals have the challenge of helping the families understand that the best way to protect their loved one is by respecting his or her decision. This absolutely does not mean that the family cannot play a role in decision-making, simply that they must help the families to understand that their degree of involvement in the decision is not determined by the simple fact of being related to a patient, rather it is the patient himself who should determine the family's degree of participation in decision-making.

At any rate, it is important to remember that we must educate the citizenry so as to not confuse patient autonomy with patient preferences. We must insist again on social instruction on subjects related to bioethics, to make it clear that health institutions are at the service of the rights of the citizens (as is just), not of the individual preferences that they may have (for their options for quality of life). This occurs when we do not have a shared criterion for distinguishing the publicly-supported option, which understands and has the competence to weigh risks and benefits, from an option which may be subject to distortion due to a psychological disorder, to depression suffered because of the patient being diagnosed with a serious disease. Only from a post-conventional level of consciousness can individuals and representatives of institutions and countries distance themselves from their personal options and place themselves in a secular and plural public space.

Promoting civic ethics and re-educating the citizenry and professionals

Promoting civic ethics: de-idealisation of the laws in a secular state

The quality of professional and organisational service must be in accordance with minimum civic rights, the right to healthcare is a decent minimum right; but quality of this will also depend on the citizens using it responsibly, in line with their needs, and fully, accepting that the system must satisfy rights, not individual preferences. And if a quality service is to be achieved, we must feel part of a shared world. We must reconcile the four areas of ethics: civic; organisational; professional; and the last—which is important for motivation—personal (the professional and that of the citizen whose service the professional is at). If we want to gain people's confidence—and this is much needed in Spain during this time of serious financial crisis—we will need to begin to re-classify our decisions in the corresponding areas. This means not giving priority to personal preferences or the preferences of the "clientele" when making professional or organisational decisions, and weighing before-hand whether they are in line with the civic, organisational, and professional values.

Even though bioethics should be a civic, secular ethic which respects personal options, in Spain it is even difficult for the national government to maintain neutrality in its view of the world as it should in a morally pluralistic society. Sometimes it even goes from secularity to secularism.

It is one thing to decriminalise a practice (for various reasons, including the impossibility of supervising it or, precisely the contrary, the impossibility of guaranteeing efficiency in its supervision); it is a completely different thing to consider it a good practice and a duty to be promoted by the national government, as if it were a universal right. For example, it is one thing to respect religious and moral pluralism, in the name of the freedom of worship, but it is quite another to oblige the State to assume the costs which may be derived from personal options. Something similar has just occurred with the inclusion in the public health system of elective abortion within the first 14 weeks of pregnancy. Not penalising it cannot be equated with converting it into a right in the name of women's reproductive autonomy when no changes are made to other reproductive issues, such as the administration of oral contraceptives, etc.

Re-educating the citizenry and healthcare professionals

In times of prosperity when the public health system was being created, there were three factors in favour of the quality of the care for users of the healthcare system (financial resources, professionals who were enthusiastic about the project they were working on, and users without many previous models on which to draw a comparison); now things have changed. With the crisis of the welfare state, which was intended to create social protection for the citizens, we find ourselves facing the need to curtail spending and prioritise resources in an economically unfavourable environment. We find ourselves with healthcare professionals who feel pessimistic in their view of professional excellence; and we find ourselves with users who have clear models, because they had gotten used to not only quality standards, but also—and this is not as good—a dependence on the healthcare system, perhaps because it was excessively accessible (at any time and on demand), or too complacent with their demands.

However, the solution for managing the crisis of the welfare state does not lie in throwing the baby out with the bath water, which would mean abandoning the achievements of the welfare state, conscious as we are of the fundamental right to healthcare which must be satisfied. We must go from a welfare state, one which is overly focused on the demands of the users and on the electioneering policies of those in charge of healthcare, to a justice state. And in the justice state, the fundamental right to healthcare is guaranteed, but with three clear objectives: co-responsibility, vocation of service, and accountability, which is defined by the following:

- Educating responsible citizens on the use and demand of public goods.
- Training professionals who are conscious of their mission and vocation, professionals committed to attentive care and to serving the citizens.
- Creating organisations which are accountable for satisfying the expectations of these two.

If in the welfare state it was the criteria of supply and demand and the populist policies which often governed, in the justice state we will need to consult those affected by the decisions (that is, the citizens and the professionals) from information and symmetry. It is based on justice—and not Christian charity or Hippocratic duty—that we must attend to people. A service which covers the civic minimums in terms of justice and the recognition of the respect which personal dignity deserves must guarantee care for these people.

For that, we must first clarify a series of questions which we must address as a society. Indeed, we must clarify whom the public healthcare is serving: the citizen, the user, or the customer. We must clarify where we are headed and at which speed, the speed of the electoral campaigns or at the prudent speed that justice, quality, and efficiency require. We must have a social consensus on the citizens' model, the model of the just society towards which we wish to move and support. We cannot forget that healthcare organisation will always be a reflection of the society it serves.

We need instruction on the correct expectations for healthcare organisations and related professions, apart from scientist euphoria and disregarding the expenses that go along with it. This means making the health system (its organisational structure and how it operates) known to the citizens, so that equity of access and use are a reality and not just a well-intentioned declaration of ethical principles.

We must insist more, and more effectively, on the use of advanced directives and informed consent, as these tools are much more than documents and papers, they are the logical result of the inevitable dialogue between the patient, professionals, and the organisation.

We must remind the professionals not to infantilise their care either towards mature minors or the elderly, who, despite their years, have not necessarily lost their maturity and who may be humiliated by infantilised treatment.

We must improve the citizens' participation in decision making, not only regarding their own individual health, but also on that which requires having their "representation" as health policies are proposed.

Promoting the participation of the citizenry in public institutions

The ethics of organisations and health policies

In Spain, the emphasis in bioethics has been focused mainly on the ethics of healthcare professionals and little on the ethics of organisations, which are excessively bureaucratic, vertical, and rigid, and which have very little tradition of teamwork in the sense of the participation of the professionals in the decision-making process.

Indeed, in Spain it is common to deal with questions related to healthcare from a *micro level*, that is, from the reduced core of the interpersonal relationship between the patient and his family and the healthcare staff. There is no doubt that this is the common way of handling the situation, as the interpersonal relationship between the professionals and the patients is the basis of healthcare. However, this approach is also inadequate, and not only because it does not explain other equally important dimensions, but also because by not doing so it makes it impossible to solve some of the problems that arise in the healthcare.

Therefore, a reflection on the *meso* and *micro levels* is required. The *meso level* is the middle level of the organisation which mediates and intermediates, where the interpersonal relationship which is healthcare is established. Certainly, the organisation makes such interpersonal encounters possible, but as a mediator in the relationship, it can either hinder it or facilitate it: the organisation is *essential* in order for the interpersonal relationship of the healthcare to be a successful encounter for both parties. The *macro level*, which appeals to the political and social framework in which the organisation resides, must also be considered.

The *meso level* covers the ethics of the organisation, since decisions are taken in, and from it, by the people who represent it, promoting—or not promoting—quality in the service, the purpose for which they are created and which gives them social legitimacy, i.e. healthcare. On the *meso level*, the organisation must confront different ways of understanding and exercising the various professions, which requires the coordination and the organisation of different people pursuing the same goal.

In Spain, healthcare staff is normally very vocational and very aware of the necessity of this implication in attending to the citizenry. However, they usually experience their vocation and their implication as a dilemma, and their desire to serve excellently meets obstacles that are beyond their control, their power, and therefore, their responsibility. These obstacles come from the *meso* and *macro levels*.

So the user of the healthcare system does not know that the expectations that he, as a citizen, has of the system, and more specifically of the health staff, might be unfounded, i.e. impossible to meet. And these expectations cannot be met because sometimes citizens demand services which are not considered by the law (they demand what might even be considered privileges, that is, private laws which clash with the universalisation required by justice). In other cases, they cannot be met because limited resources and the unavoidable prioritisation of demands creates the need to disregard some reasonable expectations. So, it is possible, for example, that the citizen is not sufficiently aware of all the different services, or that by being in another autonomous community he encounters discrimination, or that some public centres give him prescriptions from private clinics and others in the same city do not. It is also important to note that citizens have not been educated on expectations (on what can be reasonably and legally expected from the health system) or that this education has been poorly executed.

It is due to this that the ethics of organisation is important: there must be an *ethos,* a nature, a coherent way of acting and taking responsibility for errors and contradictions, which follows simple guidelines and not electioneering political changes.

When the ethics of organisation is disregarded, and therefore there is no organisation, but just a sum of the parts, the professionals themselves lose courage in their search for excellence and become strange figures which they do not even recognise: they end up doing a non-negligent job, doing the minimum so that neither the "bosses" nor the patients complain. In homogenising the treatment of the professionals acting against excellent professionalism, healthcare is homogenised by the common and simple measuring stick of mere non-negligence. Or they assume an excessive responsibility and end up defeated and demoralised.

Drucker (1995) reminded us that the society of the twenty-first century will be a society of organisations or it will not be. The organisations of the knowledge society are organisations formed by professionals who are experts in their fields, like a symphony orchestra where each person masters an instrument. The orchestra of virtuosos, of excellent professionals, needs a conductor who is aware of the power of the orchestra and brings out the best in each of the experts and makes them shine like musicians in an orchestra. But the orchestra also needs a public programme and the audience must be reminded that it is a symphony orchestra, and not just any musical group or a festive orchestra which plays only what the audience wants to hear. And in Spain the ethics of organisation is most notable for its absence.

Therefore, it is very important that the health organisation be able to create an identity and a sense of belonging. The health organisation must be capable of understanding itself like a symphony orchestra, where professionals master an instrument, perfect the piece that they have to play, and adapt to the listening audience, without forgetting that all the members must play the same piece.

Spanish organisations must fight against indifference and the victim mentality—the symptoms that, according to P. Bruckner, are linked to the temptation of innocence (Bruckner 1992). If we are part of it, we need to want to be part of it, take part in it and participate in the deliberation, in the imagination, in the involvement of the people in the organisations, and the involvement of the organisations in the society as a whole: the *micro*, *meso* and *macro levels* must be related in a better way.

Another challenge of the ethics of organisation is that of being capable while respecting individual and professional autonomy, and of creating a sense of belonging, of voluntary belonging in the group. This is difficult to achieve, because the relationships underlying this are often contractual or financial, and therefore affected by the vulnerability of all paid relationships. However, if we are to have ethics and not just internal legal regulations, with the consequent elimination of the personal, organisations will have to struggle to integrate individual autonomy into the organisational environment through the development of the concept of *belonging*. There is no ethics of organisation without that voluntary joining, without that sense of belonging. This sense is best developed by how decisions are taken in environments of dialogue and deliberation with the consent of the affected parties. In Spain the lack of democratic tradition is also reflected in health organisations; they are pyramidal, obscurantist, and classist.

Yet another challenge will consist of improving teamwork. One person alone cannot be responsible for everything that needs to be covered, or control all aspects of complex issues; the individual needs the team and its confidence. Quality, just, and good patient care is provided as a team, delegating responsibility and power based on ability, bearing in mind that everybody is in the same boat, sailing in the same direction and at the same speed.

If the patient's right to autonomy and the resulting increased decentralisation and flexibility of the decision making authorities is considered an achievement, then the organisation must change from a pyramid to a network, and overcome the reluctance to assume power in those people who do not want to take on responsibilities, and the excessive desire for power in those who would latch on to it and not let go. We are not interested in seeing a return to paternalism in organisations, since decision-making requires courage and efficiency, both of which have been greatly reduced with centralist and bureaucratic plans which lack autonomy. This illustrates the true importance of teamwork.

Responsibilities must be delegated based on knowledge and capability. It is not responsible to put someone in charge of managing a team, for example, and not give this person the power to punish the unprofessionalism or the ability to award excellence based on merit.

More emphasis must be placed in the understanding of quality, ethics, and service provided by patient attention services (information, claims). Thanks to these services, which are now sufficiently specialised and prepared, the health system is able to have a broad and complete vision of the primary challenges problems to be addressed and the successes that must be reinforced or maintained. However, these services are seldom used, and frequently they are reduced to complaint services for indignant users, or act as a means of enabling permissiveness for ethically lax professionals.

Improvement in risk management: errors and contradictions

Bioethics needs confidence, which cannot flourish without coherence. When organisations or institutions address the citizenry with messages which are full of ethical vocabulary which do not reflect coherent real-world applications, both the citizenry and the professionals take them as cynicism, and distrust arises.

There is a need for public discussion forums on purposes, justice, solidarity, professionals… these are all vague words if we do not fill them with content from the organisation and its accorded, coordinated, and defined policies on what quality citizen assistance means.

If we talk about it, we must do it. And we must be aware of our responsibility of being accountable for what we have said we will do, but didn't do; as well as what we have done, but have failed to mention, and have no intention of mentioning. Sometimes discourses appealing to ethics have been made that disregard the repercussions that they would entail, avoiding the contradiction between what is said and what is done, the contradiction between what is done today and what will be done tomorrow, the contradiction between what we do in a specific area and what we do outside this area within the same organisation, the contradiction of orders received, the contradiction in the organisation between what is decided "higher up" and what is done "down below", or the contradiction between the ends and the means. There is a need for processes of transparency that deal with the efficiency of the system, and for clear criteria regarding what is to be included in healthcare and social services, and why, and who decides it.

The purpose of ethics in health organisation is to attend to the patient justly and equitably. This requires confidence and respect, which is found in informed and participative citizens who are necessarily aware of their rights and duties; in dedicated and involved professionals who are devoted to their task, to their vocation, and are free from being exploited or overworked. Organisations persist while people come and go, but the organisations are positively or negatively affected by the people who have worked there or who have directed them. What the professionals achieved was only possible thanks to the support of their colleagues, the trust of the people who received the service, and because they had a project which they respected for which they made decisions.

As Jonas (1995) reminds us in *The Principle of Responsibility*, "We only learn what is at stake when we realise that it is at stake". In Spain, we have done a lot in a short time for justice and quality assistance in the field of bioethics. Being aware of what we could lose puts us in a good position to manage the risk.

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