



Review

Health management and patients who lack capacity: Forms of guardianship in European health policy



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ABSTRACT

The focus of healthcare debate has in recent years shifted from doctors and healthcare professionals in general to patients and the principle of patient self-determination. Patient competence therefore plays an increasingly central role in the legal framework of many European countries.

Consequently, healthcare policy has to address the possible repercussions of a non-systematic approach to cases of patient incapacity. The diverse nature of the experiences of the mentally or physically disadvantaged clearly raises problems for the healthcare professional. In this setting, we examine Italy's Law no. 6/2004 from a comparative perspective, in particular analysing legislation in the same area from Spain, France, Great Britain and the Netherlands.

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1. Introduction

In order to safeguard the interests and needs of all disadvantaged individuals, it is extremely important to identify measures that protect an incapable person whilst at the same time respecting his right to self-determination and health.

For that reason, patient competence plays a pivotal role in the legal framework of many European countries [1]. Competence, which should be distinguished from criminal responsibility and legal capacity, can be defined as the ability to exercise rights, more in particular the ability to exercise one's right to give or refuse informed consent. A patient's competence determines whether or not he/she has the final say in a healthcare decision and whether or not he/she can legitimately be subjected to compulsory interventions in that context.

Consequently, healthcare policy has to address the possible repercussions of a non-systematic approach to cases of patient incapacity. The diverse nature of the experiences of the mentally or physically disadvantaged clearly raises problems for the healthcare professional.

As regards mental health, there has been considerable debate on the protection of individuals with serious and lasting mental health problems as well as on legislation both in Italy and in other countries based on liberty deprivation measures (e.g. *interdizione* and *inabilitazione* in Italy, which will not be part of the author's evaluation because a number of papers have been already published on it).

Our analysis begins then with Law no. 6/2004, which foresees the possibility for the patient to have a court-appointed administrator – *amministratore di sostegno* (AdS) – to make decisions on his behalf (Italian Civil Code articles 404–411). The AdS represents the culmination of a long process towards the recognition of an individual's residual capacity to judge also when in care. More or less at the same time in other Western countries two distinct models of substitute decision-making for incompetent patients were being developed, i.e. best interests and representational models [2,3].

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In both models doctors enjoy wide powers in relation to decision-making for incompetent patients.

The difference between these two models may really be quite insignificant, presuming that healthcare professionals operating in jurisdictions characterised by a best interests model, will have to consult family members, friends or other close relatives of the patient where necessary in order to form an idea of the patient's best interests.

However, even in the representation model the healthcare professional can still profit from the presence of a potential representative by involving this person as an interlocutor in the decision-making process and thus improving the quality of the service offered. This could justify an obligation on the part of the healthcare professional of an incompetent patient to hear a representative of the patient.

In Spain, for instance, Law no. 41/2002 establishes that an individual may by means of a notarial deed make his wishes known concerning the management of his life and affairs, and the possible appointment of a tutor or guardian [4].

In France, the *Code de la Santé Publique* foresees for persons with permanent incapacity the possibility to appoint in writing a *personne de confiance*, who shall be consulted by doctors whenever treatment is to be either initiated or interrupted [5].

In England and Wales, the Mental Capacity Act, 2005 introduced lasting powers of attorney (LPA) in which the donor confers on a donee or donees the power of make decisions on his behalf [6].

Finally, in the Netherlands, specifically for the field of healthcare, the Contract of Medical Treatment Act (part of the Dutch Civil Code) establishes four, hierarchically ordered categories of possible representatives [7].

All these pieces of national legislation passed around the same time derived from a raft of international regulations such as the Declaration on the Promotion of Patients' Rights in Europe (Amsterdam, 1994), the European Convention on Human Rights and Biomedicine (Oviedo, 1997), Recommendation no. (99) 4 of the Committee of Ministers of the Council of Europe to Member States on Principles Concerning the Legal Protection of incapable adults (Strasbourg, 1999), and the Convention on the International Protection of Adults (2000).

To be highlighted is the fact that patient competence as it appears in the legislations of the countries analysed could be related to the concept of legal capacity in both civil and criminal actions.

We will discuss about the civil concept of patient competence which provides for those individuals unable, due to mental or physical reasons, of taking care of themselves. In our opinion, indeed, such a concept should represent a key issue in the debate on safeguarding health.

We will therefore analyse the functional differences between the above-mentioned models by using a systematic comparative law analysis of several European models in the light of prototypical cases [8].

2. The safeguard of incapable persons in European legislations

2.1. Italy

Measures aimed at identifying and satisfying the needs of persons lacking the capacity to make decisions were modified by Law no. 6 of the 9th January 2004 [9]. Article 404 of the Italian Civil Code establishes that 'any person who, due to an impairment in the functioning of the mind or brain, permanently or temporarily lacks the capacity to take care of his own best interests can be assisted by an administrator (*amministratore di sostegno*) appointed by a judge (*giudice tutelare*) in the place where the person resides or is domiciled' [10,11]. The AdS provides support to the person when he/she no longer has the capacity to determine his best interests [12]. The persons who may require the appointment of an AdS are the mentally infirm (defined as any condition that prevents either totally or partially a person from performing normal relational activities) and persons suffering from disabilities to the body or brain that prevent them from looking fully after themselves (including the blind, the deaf and mute from birth). Fig. 1 summarises the flowchart on the question of patient consent according to the Italian legislation.

Article 405 of the Italian Civil Code establishes the following contents of the decree appointing the AdS: (a) personal details of the person requiring the appointment ('beneficiary'); (b) personal details of the AdS; (c) the term of appointment, stating that this may also be open-ended (i.e. without a predetermined date of termination); (d) the purpose of the appointment with details of the actions that the administrator may or must perform on behalf of the person lacking capacity (importantly, the appointment of the AdS does not concern automatically the beneficiary's healthcare questions, which are assessed in every single case); (e) the acts the beneficiary can do solely with the assistance of the AdS; (f) the maximum amount of the beneficiary's money that the AdS can spend on the beneficiary's behalf; (g) the calendar of reports to the judge providing details of the beneficiary's personal and social condition.

Article 406 prescribes that the AdS can also be appointed at the suggestion of the beneficiary, also if under the age of 18, at the suggestion of a spouse or person residing with the beneficiary on a stable basis, of relatives up to the fourth degree, of in-laws up to the second degree, and at the suggestion of legal guardians or a public prosecutor (*pubblico ministero*).

As we have seen, a specific judge – *giudice tutelare* – established in every court is responsible for appointing the AdS [13]. The judge can ask at any time the AdS for details regarding the administration of the beneficiary's affairs or can give instructions regarding financial, moral or healthcare issues.

The judge can also supplement and/or change decisions taken by the AdS and where necessary replace him/her in the event the judge believes the beneficiary's best interests are not being fully safeguarded [14].

The new system foreseen by Law no.6/2004 gives priority to the beneficiary's interests as a whole rather than concentrating solely on protecting his financial situation.

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