

Self-determination, healthcare treatment and minors in Italian clinical practice: ethical, psychological, juridical and medical-legal profiles

Rosagemma Ciliberti¹, Linda Alfano¹, Ilaria Baldelli², Francesco De Stefano¹,
Alessandro Bonsignore¹

¹Department of Health Science (DISSAL), University of Genova, Genova, Italy; ²Department of Integrated Surgical and Diagnostic Science (DISC), University of Genova, Genova, Italy

Summary. *Background and aim:* The social role of the minor, as indeed that of the physician, has changed markedly. This transformation has given rise to new patterns and responsibilities in the management of healthcare procedures that involve minors. *Discussion:* According to international legislation, in the clinical setting, as in other areas of social life, minors have the right to be heard and to have their opinions taken into consideration as an increasingly determining factor, in accordance with their age and degree of maturity and discernment. The authors describe the right to information and the decision-making process when the patient is a minor and underline the role of the parties involved (physicians, parents, under-age patient, judge) in various circumstances. Specifically, the paper analyzes the ethical and legal issues relating to the entitlement to decisions concerning the medical treatment of children and assesses the importance that Italian law attaches to the will of minors in the healthcare choices that affect them. *Conclusions:* Healthcare workers are called upon to face new challenges in order to ensure that healthcare services are able to safeguard the interests of minors while, at the same time, respecting their will. How to evaluate children's competence to consent and how to balance the autonomy of parents and minors are crucial questions which the law courts in the various countries are increasingly being asked to address. These issues require close collaboration among various figures (parents, doctors, psychologists, judges) and imply the ethical need to undergo continuous training. (www.actabiomedica.it)

Key words: healthcare, minor, child, adolescent, autonomy, capacity, competence, pediatrics, surrogacy decision making

List of abbreviations

DSM, Diagnostic and Statistical Manual of Mental Disorders;
NCB, National Committee for Bioethics.

Background

In the light of the enhanced role of minors, policies for their care and protection constitute a topical theme that involves several critical issues (1). Traditionally, references to minors have been associated

with the categories of "protection" and "safeguard". This reflects the juridical incompetence of minors, who are regarded as the "object", rather than the "subject", of the decisions that concern them.

Within the framework of a broader trend of thought towards recognizing and safeguarding the rights of children and minors, international conventions and policies concerning adolescent health (2-4) have promoted a major transformation in the social role of the minor. Indeed, from being simply "protect-

ed subjects”, minors have increasingly been regarded as holders of rights and capable of self-determination. In particular, the Convention on the Rights of the Child of 20 November 1989 expressly envisions (article 12) a fundamental right that is not only closely connected with the self-determination of minors, but is also a vehicle of their will: the right to be heard (5, 6). This new orientation is loaded with moral significance, in that it recognizes the minor as a person “as such”, who is endowed not only with the rights and needs proper to every human being, but also with those specific necessities that the law defines as taking priority over the demands of parents. Moreover, the reference – required by Community legislation (EC n. 2201/2003) – to parental “responsibility”, rather than “authority”, imposes a new ethical value on the adult-minor relationship, in that it enhances the recognition of and respect for the minor’s dignity, otherness, difference and non-belonging – in short, his/her moral equality. In parallel with this reshaping of the responsibilities attributed to parents, the areas of independence of adolescents – who are growing into citizens – are expanding. This development places boundaries on the authority of parents, who, in such areas, are called upon to engage in dialogic discussion with their children (7).

Recognition of the minor’s status as a subject, however, cannot ignore the specific connotations of the “developing subject”. Indeed, the precocious attribution of independence may hinder the acquisition of the true means of achieving it (8, 9). What, then, is independence? What does becoming independent mean, and under what conditions? Through the analysis of actual cases, the authors seek to provide answers to these questions.

Discussion

Decision-making competence in the maturing subject

The concept of decisional capacity is complex and multi-dimensional, and underlies many single capabilities that vary quantitatively and qualitatively in the same person on different occasions and in different situations. In neuropsychology, all the theoretical models, regardless of their complexity, describe decisional

capacity as being supported by four specific abilities; regarded as four key conditions of the entire decision-making process, these are: the ability to express/manifest a choice; the ability to understand the information relevant to the choice; awareness of the meaning of the choice, and the ability to evaluate the choice rationally (10). These competencies are normally acquired at the age of about 11 or 12 years, when the individual’s thought begins to operate within the framework of models of verbal ideation and becomes capable of abstraction and logical operations. Nevertheless, the crucial role of emotions in the decision-making process must be borne in mind. In this regard, the clinical and experimental findings of research in the neurosciences in recent years have revealed that – in contrast with earlier views – the lack of adequate emotional indicators (e.g. a pragmatic disorder of social communication, DSM 5) can interfere with the capacity to act and decide, even to the extent of rendering it impossible (11–13). Thus, the recognition and assessment of the minor’s ability to express his/her own will, desires and opinions concerning aspects of his/her own health, from both a cognitive standpoint and an emotional and affective point of view, are clearly delicate (14).

From the juridical standpoint, Italian legislators have not yet agreed upon valid criteria for determining whether or not a minor is capable of discernment. The notion of the capacity for discernment, which is not present in the current Italian penal code (which refers to the capacity to understand and to will) is derived from Italian Law n° 149 of 28 March 2001 on the adoption and fostering of minors. This latter, in turn, derived the concept from the French text of the Convention on the Rights of the Child: “*enfant capable de discernement*”. However, the English text, which is the official version, does not use the term *discernment*; rather, it refers to the concept of *level of understanding necessary for children to be considered as being capable of forming and expressing their own views* (point 36 of the explanatory report of the Convention). That is to say, it refers to minors who are able to form and express their own views, independently of the pressure exerted by third parties, as a result of the level of understanding they have reached. Moreover, it should be noted that the possession of this capacity does not require particularly well-developed or structured faculties. That

said, in the legislative sphere, in judicial proceedings and in many sectors of private life, the areas of a minor's self-determination have progressively broadened since the 1970s. This development has been accompanied by a concomitant downsizing and, especially, reinterpretation of adults' powers of upbringing and by a reassessment of parenting roles within the family (15). Indeed, although an individual's full capacity to act is legally recognized only at the age of 18 years, several laws attribute broad areas of self-determination to those who are below this age. This is particularly the case with regard to the sexual, familial and affective spheres, decisions concerning the subject's own body and person, creative capacities and status as offspring or parent. Indeed, in accordance with current legislation (Italian civil code, art. 84 and 250), at the age of 16 years a minor - if "emancipated" (children having a higher autonomy due to certain social circumstances) - can undertake paid employment, marry, acknowledge paternity/maternity of a child, and have access to voluntary abortion and contraception^a. Moreover, the freedom and secrecy of a minor's correspondence are safeguarded both by the Italian Constitution (art. 15) and by the Convention of New York of 20 November 1989 (art. 16). In addition, Italian Law n° 281/86 grants a minor attending the second grade of secondary school the freedom to choose optional school subjects and religious education autonomously. Likewise, in accordance with general constitutional principles (articles 18, 39, 49 of the Italian Const.), minors have the right to participate in associations, join trade unions if they are working, and subscribe to political parties. Finally, the law is particularly attentive to the quality and continuity of family relationships and the need to seek the consent of the minor in the setting of those procedures that modify or orient - sometimes irrevocably - the individual's life project and the destiny of his/her personality^b.

Within the category of "minor", there is clearly a diversity of situations. Indeed, it is necessary to distinguish between the case in which the minor is a child and that in which he/she is a pre-adolescent or adolescent. A further distinction must be made between cases in which the minor possesses a given capacity for discernment specific to the issue being dealt with and cases in which this capacity appears to be premature,

still developing or inadequate for the complexity of the situation under analysis.

Examination of the relevant laws reveals that legislators have ascribed ever greater autonomy to the minor, especially with regard to issues of identity, feelings and sexuality, adopting an orientation towards imposing the least possible limitation on the minor's decision-making capability. Striking a balance between the ethical principle of *benefit* and the correlated principle of *autonomy*, between the need for protection and claims to self-determination, however, finds its natural limit in cases in which the minor's choices are deemed to be irresponsible and conducive to harm or danger to the physical and/or mental integrity of the individual; in such cases, restrictive intervention on the part of the adult is invoked in the interests of safeguard and protection (16). In line with this orientation, parent-child controversies are increasingly being tackled with the aim not so much of safeguarding the parent's rights/duties as of pursuing the prevalent interest of the minor. Thus, the parent is endowed not with the power, but with the "responsibility", of bringing up the minor to become an adult capable of exercising his/her constitutional right of freedom.

The minor's opinion, discernment and consent: laws, principles and clinical practice

The informed participation of the patient is deemed to be essential to the success of medical treatment (17). Thus, the awareness and involvement of minors in therapeutic decisions, in accordance with their degree of maturity and discernment, are central to their interests. In keeping with this notion, the European Convention on Human Rights and Biomedicine of the Council of Europe (Council of Europe 1997) sets out a specific disposition regarding healthcare treatments for minors. Specifically, the text requires that "*the opinion of the minor be taken into consideration as an increasingly determining factor, in accordance with his/her age and degree of maturity*". A similar provision is contained in the latest version (2014) of the Deontological Code of Italian Physicians, Surgeons and Dentists, article 33 of which states: "*The physician is to provide minors with any information that can enable them to understand their health condition and the diagnostic and*

therapeutic procedures planned, in order to involve them in the decision-making process". Similarly, article 4 of the Nurse's Deontological Code (2009) states that: "The nurse is to urge that the minor's opinion regarding therapeutic decisions be taken into consideration, in accordance with the individual's age and degree of maturity". These documents, however, do not provide reference parameters for assessing the relationship between the age of the subject and his/her ability to understand. The commitment to involving the minor therefore seems to be left to the discretion of individual healthcare workers and their subjective professional resources.

This issue has been tackled with greater precision by the Italian National Committee for Bioethics (NCB) which has identified the following developmental stages (18):

- 1) a threshold age of 7 years, below which it is difficult to attribute to the minor the ability to understand;
- 2) the period between the ages of 7 and 12 years as the phase in which children begin to explore their own motivations and to compare these with what others say or do; hence the need for consent to be expressed jointly with the parents;
- 3) the period after the age of 12 years has been reached, during which the minor's consent or dissent can be deemed to be progressively informed.

In assessing scientific and ethical issues about reconstructive surgery in young people, the Italian NCB has highlighted the need to consider the specific vulnerabilities of these patients in relation to the particular age and physical, psychological and cognitive ongoing changes (19). Sometimes aesthetic impairment, however, may create a state of anxiety in patients and, even before that, in their parents; this condition may undermine a proper formation of a solid body image by reducing self-esteem of these patients (20). Nevertheless, legislative contributions regarding the minor's ability to express consent to medical procedures are somewhat heterogeneous and discordant.

With regard to the sphere of sex and procreation, Italian Law n° 194 of 22nd May 1978 recognizes the minor's will regarding access to the means of contraception, and grants female minors the right to request

abortion, within the first 90 days, even without the consent of those exercising authority or guardianship, *when there are serious reasons that prevent or advise against consulting those persons who exercise authority or guardianship, or when such persons deny their consent or express discordant opinions*. In such conditions, the judge supervising guardianship may, *after taking into account the young woman's will and the reasons she adduces*, authorize her to decide autonomously.

Legislation concerning the transfusion of blood and blood components (Italian Law n° 219, 21st October 2005) allows *the donation of blood or blood components and the harvesting of stem cells and hematopoietic stem cells from the umbilical cord* in persons of at least 18 years of age, once informed consent has been obtained and their physical suitability has been verified. With regard to persons below the age of 18, consent must be obtained from those exercising parental responsibility, or from the legal guardian, or from the judge supervising guardianship. However, a minor who gives birth may donate hematopoietic stem cells from the umbilical cord after having provided informed consent.

Harvesting bone marrow for the purpose of transplantation, which is regulated by Law 52 of 6 March, 2001 (instituting the National Registry of Bone Marrow Donors) is apparently forbidden to minors. In reality, however, the doctrine holds that, in such cases, the above-mentioned Law 219/2005, which regulates the production and transfusion of blood derivatives, is to be applied. Indeed, the requirement that the subject be over the age of majority is deemed to apply only to non-consanguineous donors, while in the case of consanguinity, Law 219/2005 would be applicable. This broadens the spectrum of potential bone-marrow donors to encompass minors who have the consent of their parents, legal guardian or judge supervising guardianship; this is in line with the dispositions of the European Convention on Human Rights, which expressly allows minors to donate hematopoietic stem cells, though not organs, the donation of which continues to be forbidden. Allowing bone marrow to be taken from minors, without any age limit, once parental consent has been obtained, raises major ethical questions. Indeed, donations between consanguineous subjects may potentially arouse suspicion of constraint – moral constraint at least – within the family

setting^c. As has rightly been pointed out by the National Committee for Bioethics, *current legislation does not seem adequately to consider the importance of the minor's will, which may conflict with that of the parents, nor the problem of possible abuse by parents of their power to consent to donation* (18). The doubts and controversies raised by the donation of organs and tissues by living donors persist in the case of harvesting from cadavers, not least on account of the underlying issue of the ascertainment of death. With regard to minors, the will of the individual is certified by the parents responsible; if there is disagreement between the parents, no availability for donation can be manifested. In order to avoid any abuse, the Italian law establishes that no statement of will can be provided for subjects who lack the capacity to act, nor for minors who are fostered or placed in care institutions (21).

A further area in which the minor's decision-making capability is relevant is that of experimentation. Specifically, Italian Legislative Decree 211/2003 *Implementation of the 2001/20/CE directive concerning the application of good clinical practice in the clinical experimentation of medicines for clinical use* establishes that *"the experimenter must take into account the minor's explicit will to refuse to participate in the experimentation or to withdraw from it at any time, if the minor is capable of forming his/her own opinion and evaluating the information received"*. Thus, the growing attention paid to the will of the minor finds only partial recognition in current legislation. What is seen is a weak form of self-determination which is manifested more as a right to resist healthcare treatment than as an exclusive entitlement to the right to refuse or consent to it. In Italy, unlike other countries, there is no law providing a precise indication of the age at which parental consent to decisions concerning a minor's health can be dispensed with^d. While the indication of a general principle may leave excessive leeway for discretion in the application of the law, it nevertheless ensures the flexibility that the healthcare setting requires.

Parents in conflict over their children's health

When a parent's decision is clearly in conflict with a minor's interests, the juvenile court (JC) may impose restrictive measures on parental responsibility

(articles 330, 333, 336 of the Civil Code) in order to safeguard the minor's health. If responsibility is to be limited, the JC will appoint a special guardian who, after consultation with healthcare personnel, will express the healthcare decisions deemed most suitable, and with which the parents must comply. This frequently occurs in the event of refusal of treatment, chiefly for ideological, religious or cultural reasons of the family, or when, as a result of psychiatric disorders, parents subject their children to continual treatment that is absolutely unnecessary. In this regard, the Italian Court of Reggio Emilia, when dealing with the question of the entitlement to take decisions on healthcare issues in the event of disagreement between the parents of a minor, recently adopted an absolutely innovative approach (22). The case involved a couple of separated parents who strongly disagreed between themselves as to who should take decisions concerning the health of their autistic son, thereby risking aggravating the boy's condition. The judicial authority confirmed that custody should be granted to both parents. At the same time, however, two independent subjects (the head of the institute for autism frequented by the boy and the director of the neuropsychiatry service of the Local Health Authority) were appointed to take the principal decisions concerning the process of rehabilitation and support undertaken on the basis of the minor's health. In addition, the Court entrusted implementation of this process to the social service responsible. This conclusion was motivated by the realization that the care required by the minor was so onerous and psychologically tiring as to be unsustainable by either of the parents. Custody of the minor was therefore granted to both parents, with the sole exception of the medical decisions to be taken in the interests of their son. This example, however, reveals the difficulty of actually implementing international and constitutional principles that are universally agreed upon. In practice, disagreements over healthcare choices are often settled by delegitimizing the will of parents and minor alike and assigning decisional power to the technical knowledge and medical culture prevailing at the time. Indeed, in the case cited, the judicial authority did not attach sufficient importance to the opinions of either the autistic minor or his parents, even though the etiology and treatment of the pathology in question are

frequently discussed. Further examples can be found in a whole range of cases in which minors' psychiatric and behavioral problems are dealt with by imposing restrictive measures on parental responsibility and by forcibly placing the young person in a therapeutic facility.

Conclusions

The issue of a minor's self-determination and of the legitimacy of medical procedures raises crucial problems. Not only does it touch upon the basic rights of minors, it also has legal-medical and ethical implications with regard to the questions of consent, privacy and compliance with professional secrecy (23, 24). Analysis of the literature reveals that the increasing importance assigned to the minor's opinions and will is exerting a growing influence in many spheres of civil life. Thus, in the healthcare setting, doctors are called upon to involve pediatric patients more actively in the therapeutic process, in accordance with the minor's capacity for discernment, which may even be recognized at a very early age. However, there is also an ethical imperative to ensure that this presumed autonomy does not result in the neglect of parental and medical duty or in the assignment of excessive responsibility and/or adult status to the minor. Indeed, in the absence of proper support in the making of healthcare choices, the risk is that of abandoning the minor in a state of anguished solitude at the very time in life when he/she is most vulnerable. On the other hand, we must not overlook the solitude of healthcare personnel and judges, who are increasingly obliged to take decisions, often in emergency situations, regarding highly intimate and subjective aspects of the person. On the one hand, the absence of specific legislation allows flexibility in decision-making and therefore fosters respect for the person's individuality. On the other hand, it imposes an attitude of humble prudence and the need to undertake ongoing major training.

In order to evaluate the minor's decision-making capacity in each specific situation, we need to implement measures of environmental support aimed at improving and strengthening the competences necessary for the subject's involvement. Whenever possible,

the expression of the minor's will and his/her choices should always be deferred until a mediatory function has been assigned to the relationship between the doctor, the minor and his/her affective references (and legal representatives), a process that may be long and complex. This mediation should not sacrifice the will of the minor to the rights of parental responsibility and should aim to balance the interests of all the parties concerned.

Authors' contributions:

All the authors equally participated in the design of the work, drafted the manuscript and approved the final version of the manuscript.

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Correspondence:

Ilaria Baldelli, M.D. Ph.D,

Department of Integrated Surgical and

Diagnostic Sciences (DISC) - University of Genoa

Largo Rosanna Benzi 10 – Pad 15 - 16132 Genoa, Italy

Tel. +39 0105558827

Fax +39 0105556351

E-mail: ilaria.baldelli@unige.it

Notes

^a Other competencies (prerogatives, liberties, duties, responsibilities) are granted to minors under 14 years of age, such as the autonomous right to sue, the possibility of facing legal charges, and consent to sexual intercourse. ^b The right to be heard is granted to a minor who has reached the age of 12 years (or younger, if capable of discernment) in proceedings concerning the separation of the parents (Italian Law n° 54/2006); at all stages of the adoption procedure (Italian Law n° 183/1984 and subsequent modifications); and in questions of filiation (Italian Legislative Decree 154 of 28 December, 2013). ^c We may remember the debate following the Decree of the Juvenile Court in Perugia on 26 April, 1999, which declared its lack of authority to issue a provision requested by the parents of a 14-year-old who asked to be authorized to donate bone marrow to his mother, who was suffering from a severe form of acute leukemia at high risk of recurrence, and whose bone marrow was compatible only with that of her younger son. The court ruled that Law 107/1990 did not allow this type of authorizing provision and, citing a potential conflict of interest between the parents and their son, appointed an independent guardian (with specific medical competence) who could provide consent on behalf of the young donor. This decision, however, proved controversial, in that article 3, clause 3, of Law 107/1990 allows platelets, leukocytes and bone marrow and peripheral stem cells to be harvested even from minors, once consent has been obtained from those exercising parental responsibility, the legal guardian or the judge supervising guardianship. In such cases, there is no necessity to appoint a guardian to provide consent in lieu of the parents, at least not when these latter have already explicitly expressed their consent. Others pointed out that the decision had not taken into account the will of the minor and the situation that might have arisen if the mother had died of the disease for want of transplantation: i.e., the minor's sense of guilt, the pain of bereavement and the deleterious effect of growing up without the mother. Mastrangelo G, Sellaroli V, *Trattamento medico e lesioni all'integrità fisica del minore*. Maggioli Editore, 2014. ^d For example, legislators in the UK and Quebec have established that minors cease to be deemed incapable at the ages of 16 and 14 years, respectively, with regard to healthcare treatment. Under Austrian law, a minor aged 14 years or over is presumed to be able to understand and to will, though parental consent is required in the event of medical intervention that may cause serious harm to the minor's physical integrity or personality. In other countries, such as the United States, Spain and Switzerland, evaluation that a minor's discernment is sufficient for the formulation of consent to highly personal acts is made on a case-by-case basis.