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Alessandra Cordiano*

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1. Author/s information
   * Department of Legal Science, University of Verona (Italy)

2. Contact authors’ email addresses
   * alessandra.cordiano@univr.it

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The most significant dispositions concerning participation of minors in decision-making processes regarding health matters: relevant legislation and Codes of Ethics

Alessandra Cordiano

Alessandra Cordiano
University of Verona (Italy), Department of Legal Science

Corresponding author:
Alessandra Cordiano
E-mail: alessandra.cordiano@univr.it

Abstract

This essay deals with the main issues surrounding the informed consent of minors by reconstructing the theoretical background to the relevant legislation and regulations and illustrating the most significant cases foreseen by Italian law.

Keywords: minors, Italian law, health

1. Hearing minors as an instrument for their protection

The dispositions that acknowledge in various ways the practice of hearing minors as a way of acting in their best interests constitute an ample store and one that is by now widely accepted. However, the approval of the New York Convention, held as far back as 1989, and the ratification of the Strasbourg Convention on the Rights of the Child of 1996 have not led to a satisfactory definition of certain issues, which are still today not fully resolved. Even before the new rules on shared parental responsibility in situations of family break-up were issued and art. 155 sexies of the Italian Code of Civil Law (CCL) regarding hearing offspring was introduced, the renowned New York Convention had stated that “the best interests of the child shall be a primary consideration” (art. 3) and allowed that a child who is capable of forming his or her own views would have the “the right to express those views freely in all matters affecting [him or her]” (art. 12.1), as well as guaranteeing “the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body” (art. 12.2). A very similar theme can be found in the Hague Convention of 1980 on international child abduction, as it obliges Youth Courts to hear the child concerned “when appropriate” (articles 12 & 13). Again, the more recent EC regulation 2201/2003 concerning jurisdiction and the recognition and enforcement of judgments in matrimonial matters and the matters of parental responsibility (art. 11.2) stipulates that the judicial authorities, when applying articles 12 and 13 of the 1980 Hague Convention, must ensure that “the child is given the opportunity to be heard during the proceedings unless this appears inappropriate having regard to his or her age or degree of maturity”.

Although the issue of hearing children has been resolved in the Italian judicial system through the pronouncement of the Grand Chamber of the Supreme Court1, which definitively established the principle of hearing as a duty, a number of doubts remain2, above all about the issue of who should hear the child, how the child should be heard and also about the locations for these sessions. These issues should in part be resolved through the legislative acts implementing law no. 219/2012, which, giving

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1 Grand Chamber of the Supreme Court, 21 October 2009, no. 22238
2 For examples of this, see the National Guidelines on hearing child witnesses issued on 6 November 2010 by the Italian Society of Criminology, the Italian Society of Legal Medicine and Insurance, the Italian Society of Child Psychiatrists, the Italian Society of Neuropsychologists, the Italian Society of Psychiatrists and the Judicial Psychology Society, which can be consulted at: www.psicologiagiuridica.com/pub/docs/numero_1/annoxx%202011/Consensus_Testimonianza.pdf.
equal judicial status to children born within and outside of matrimony, have delegated to the national government the task of standardizing and correctly implementing the regulations on hearing minors.3

2. The principle of children’s self-determination and their participation in decision-making processes as contained in Codes of Ethics

The issue of hearing minors forms part of a wider debate concerning their self-determination in the decision-making processes affecting them. From this point of view, the purpose of the 1996 Strasbourg Convention, ratified in Italy through law no.77 of 20 March 2003 on the exercise of children’s rights, is “in the best interests of children, to promote their rights, to grant them procedural rights and to facilitate the exercise of these rights by ensuring that children are, themselves or through other persons or bodies, informed and allowed to participate in proceedings affecting them before a judicial authority” (art. 1.2). The theoretical framework inside which the skein of regulations contained in the Convention is wound provides that a child affected by a proceeding and “considered by national law to be capable of forming his or her own views” has the right to receive all the relevant information, to be consulted and to express his or her views during the course of the proceeding, and also to be informed about the possible consequences of compliance with these views and any decisions he or she makes (art. 3). The child also has the right to apply to be assisted by an appropriate person of their own choice, to apply in person or through other persons or bodies for the appointment of this separate representative (when appropriate, a lawyer) and to exercise some or all of the rights of parties to such proceedings (art. 5). The active participation of minors in proceedings affecting them is encouraged by the dispositions of the Convention, which, in brief, sanction not only hearing the affected child, but also their right to be informed (including about the “risks and benefits” involved), their right to be consulted and the judge’s duty to give due weight to the opinions expressed by the child (art. 6). In the European Council regulations, the principle of hearing, having evidently acquired the content and legislative structure of a duty, is interpreted as a right to participation that becomes clear at the point of the patient expressing their wishes, and especially in the formation of the information circuit affecting the child, who participates actively in the processing of information both received and transmitted (the right to be informed and to express their own opinion). In reality, this happens beyond the strict confines of judicial proceedings in order to give weight to the decision-making and identity-constructing processes of the child in any dialogue or any expression of the physical or immaterial self.

The act of hearing becomes a form of accepting and taking on board the child’s opinion, becoming a process of identity construction (and reconstruction) by transmitting the necessary information for the formation of informed wishes. For these reasons the information to be given to the child – tailored to their age and level of maturity and to their concrete cognitive capacities – must, among other things, present a reality that is comprehensible to them but also illustrates the elements of risk and benefit connected to the specific case (whether court or out-of-court proceedings) affecting them. In other words, the child must be made aware that the outcome of the proceedings (or procedure) affecting them could be rather different from what they have expressed a wish for, but the doctor must also provide suitable grounds for hope or confidence regarding the case. Having said this, it is important to point out that the child’s interests, as they are the theoretical foundation of and basis for the practical application of the hearing procedure, must be accompanied by the further criterion of their capacity for consent, which means not only being able to form their own views, but, in a more complex way, their ability to decide for themselves, or in other words their ability to express themselves, to understand and act as autonomous beings using the complex means at their disposal depending on

3 In the law of 27 November 2012, no. 219, concerning “Modifications to the Regulations Regarding Parental Responsibility and Biological Offspring”, the new 315-bis (Rights and Duties of the Offspring) introduces a “general” regulation which, in the third point, sanctions the right of the “underage offspring who is twelve years of age, or younger if he/she is capable of forming his/her own views” to “have his/her viewpoint heard regarding all the matters and processes that affect him/her”. The same stipulation can also be found in other contexts, such as the regulations for recognizing offspring born outside of matrimony.
their age and their real capacity for self-determination, always within a framework guaranteeing their rights.

This trend towards encouraging the participation of persons lacking the capacity to consent to medical treatments – whether they are of a strictly therapeutic nature or not – as well as a shift towards the self-determination, autonomy and dignity of incapacitated persons, can also be found in more “technical” sources, such as the Codes of Ethics of Italian psychologists (articles 4 & 9), of social workers (articles 11 & 12) and of professional educators (articles 1 & 4). However, it is in the Code of Ethics of Doctors of Medicine that this feature is clearly highlighted in the praxes concerning children and incapacitated adults: art. 32 of this Code stipulates that the doctor must commit to protecting the child and take the necessary steps to ensure that the child can, whatever the circumstances, exploit all the necessary elements for their psychological and physical development, while ensuring that the same child (or elderly or disabled person as the case may be) is guaranteed quality of life and dignity. The guidelines stipulate that the doctor “is obliged to duly inform the underage patient and to take their desires into consideration, depending on their age, capacity for comprehension and maturity.” In the event of irreconcilable differences with the requests of the child’s legal representative, the doctor “is required to report the case to the judicial authorities; he/she shall behave similarly in the case of an adult with mental infirmities” (art. 38.2 of the Code of Ethics, henceforth also “Ethics”). In point of fact, the doctor must communicate with the person in question (at this point regardless of their state of incapacity), taking into account their capacity for understanding, in order to encourage the highest possible level of participation in the decision-making process and adhesion to the diagnostic and/or therapeutic activities proposed (art. 33.2 Ethics).

Striking the right balance between the doctor’s twin duties of care and diligence and the free processes of the dignified self-determination of the incapacitated subject emerges as a particularly complex task in the field of medical care; here the issue is not so much whether the person is of sound mind and able to express their will but rather what their overall state of being is when they are effectively deprived of the distinguishing characteristics of personal subjectivity in terms of information processing, growth and development and interpersonal relationships. In an emergency situation, the doctor must provide any vital medical treatment (art. 36, final point, Ethics) and, in the event of the patient having lost consciousness, must proceed with life-supporting therapies as long as they are considered to be reasonably useful, but avoid any form of aggressive treatment (art. 39.2, Ethics), while taking into consideration any desires expressed before the onset of the incapacity and not only those expressed by a patient who has already become incapacitated (art. 35, final point, Ethics). If the patient is unable to express their wishes, the doctor must take into account any choices made previously by the patient – as long as they have been expressed clearly and been documented (art. 38, final point, Ethics) – regarding their freely expressed wishes for treatment options. The furthest point this encouragement of the patient’s participation in expressing their choices is pushed to is the obligation for the doctor to provide the patient – whether a child or an adult incapable of expressing their wishes – with adequate information and to respect their wishes, when compatible with an appropriate initial assessment and the subject’s effective degree of understanding (art. 37, Ethics). The acknowledgment of considerable scope for the self-determining capacities of the child – divided into the two aspects of receipt of information and manifestation of willingness (or refusal) – does not, however, exhaust the possible cases pertaining to treatment of minors; naturally, this area is often highly complex as the positions of the doctor, the parents and the child herself are at times in complete contrast and involve either opposition to or the request for a certain form of medical intervention. The issues, although at times resolved on a legislative level by giving greatest weight to the wishes expressed by the child, more often than not have to be dealt with by finding a delicate balance that does not debase the self-determination of the formally incapacitated patient, acknowledges the presumably reasonable position of the adults with parental responsibility and, lastly, protects the doctor’s function as someone working to care for and protect their patient. The concrete development of such conflicts – often with dramatic outcomes – is formally a judicial proceeding

4 If we look at the international conventions concerning this area, the Oviedo Convention “For the Protection of Human Rights and the Dignity of the Human Being with Regard to the Application of Biology and Medicine”, in the rules about intervention on persons who do not have the capacity to consent, stipulates that the opinion of a child should be taken into consideration as an increasingly determining factor, depending on their age and degree of maturity, and that the person incapable of consenting should as far as possible take part in the procedure for authorization of the medical intervention (art. 6).
which is held in compliance with a provision of art. 333 CCL but which does not neglect to apply the necessary awareness of the difficulties of the case, at times favouring the child’s will over that of their parents.

3. The patient-doctor relationship and informed consent in paediatrics

The accepted legitimization of a third actor in a person's sphere of existence, which is typical of the doctor-patient relationship, arises principally from the issue of consent as an instrument authorizing the actions of others, which would otherwise be prohibited by the prevailing concept of *neminem laedere* (duty of care) as sanctioned by the combined dispositions contained in art. 32.2 of the Italian Constitution and art. 5 CCL. In the field of medicine, the instrument of consent/refusal – alongside the overruling criterion of the usefulness and therapeutic advantages of the intervention – naturally constitutes the smoothest path when handling the matters in question here.

In the contractual relationship between doctor and patient, the problem of consent is a rather unique one (especially considering the traditional relationship of trust that distinguishes this type of relationship) and can be defined as the doctor’s duty to inform the patient and the latter’s subsequent consent, which becomes “informed”. A significant change has produced a general shift in the relationship from one that was traditionally viewed as *paternalistic* to a relationship between persons who are in an (at least symbolically) equal position leading to the creation of a *therapeutic relationship* that will overcome both the congenital imbalance of information that characterizes this type of relationship and the inevitable condition of emotional subjection affecting the patient. The idea behind this therapeutic relationship is that the relationship is not marred by conflicts that are as frequent as they are bitter, but is imbued with a spirit of joint cooperation and service to the patient. Essentially, this comes about through the use of two instruments: diligently provided healthcare and compliance with the principle of informed consent.

As has been said, informed consent constitutes a specific component of the healthcare relationship and, at the same time, represents a way of implementing the concept of individual self-determination. In terms of the definition of its content, informed consent has traditionally been divided into two separate aspects: the right to be informed (which allows the patient to perform their acts of self-determination and negotiation consciously) and the healthcare provider’s duty to provide the information that will allow these acts to be performed. As far as the first aspect is concerned, the patient’s consent must be *specific* in its contents. The specificity of the content is an expression of the need for patients to consent to treatment of their personal information through a conscious and concrete manifestation of their will, which is fully described in art. 33 of the Code of Ethics of Doctors of Medicine, where it states that “the doctor must provide the most appropriate information about the diagnosis, the prognosis and the future prospects, and about any alternative diagnostic or treatment methods, as well as the predictable consequences of the chosen options”; the doctor must also “take into consideration the patient’s capacity for understanding in order to facilitate their adhesion to the diagnostic and treatment methods proposed” and also satisfy “any further requests for information from the patient”.

Nevertheless, in the field of healthcare relationships, this same need for specificity can take on a crucial role, both regarding the *quality* of the information given to the patient (when it is “information regarding prognoses that are serious, unfavourable or such that they may cause worry and suffering to the individual”) and when the “desire of the individual receiving care not to be informed or to delegate receipt of the information to another individual” has been documented. The right to be informed is a demand that can be extended and expanded to affect the structure of other people’s power: the right to be informed, the representation of the right to self-determination and individual identity, is not structured only as a right to knowledge, but also as a right to have control over the information itself or, conversely, to be excluded from the information-giving process, *i.e.* the right *not* to know. Therefore, the specificity of the consent expressed must go hand in hand on the one side with the delicacy that marks the doctor-patient relationship (which undeniably may require that if the information is likely to cause upset it is therefore “provided with prudence, using non-traumatizing terms and not failing to express any elements of hope”), and on the other side with the explicit wish for lack of knowledge.

From this arises the need for consent, if it is to be described as ‘informed’, to adequately blend the process of self-determination – thereby allowing the *an* of one’s self expression and promoting the highest possible levels of adhesion to the diagnostic and treatment options proposed – with the
situation of emotional weakness patients finds themselves in. The delicate arrangement characterizing the information-giving stage becomes evident when, for example, the healthcare provider is requested to give further information to the patient and this information is irremediably serious or unfavourable. The Code of Ethics of Doctors of Medicine provides a clear expression of the ambiguity and complexity of the twin concepts “duty to duly inform – right to be informed” when it states that the information must be “provided with prudence, using non-traumatizing terms and not failing to express any elements of hope”. The core of the problem, therefore, shifts from the area of the patient’s rights to the area of the duty to duly inform, more specifically to the scope for discretion of the same.

The consent must also be given freely and as the result of the patient’s own choice, in no way influenced by any event that could in any way upset the patient’s decision-making process. From this perspective, the consent can be defined as freely given and valid when it has been expressed under objectively normal conditions.

The criterion of the consciousness of decisions, furthermore, hints at a tendency to resist a manifestation that can be defined on the one hand as presumed and on the other as implicit. In this context it is an arduous task to establish a definite dimension for the concept of consciousness. Art. 35 of the Code of Ethics states that “the doctor must not embark on any diagnostic and/or therapeutic activities without first obtaining the informed consent of the patient” and that “in the event of a documented refusal on the part of a person able to form and express their opinions, the doctor must refrain from performing any related diagnoses and/or treatments”, as no medical treatment may be administered against the will of the individual, except in certain cases foreseen by Italian law. When a person incapable of giving their consent is involved, the doctor must act “according to science and conscience” (art. 35 Ethics), respecting the dignity of the individual and therefore avoiding the use of any aggressive treatments, while respecting any wishes expressed previously by the patient. On a different note, although one that does not completely contradict the above, art. 36 of the Code of Ethics declares that, in the event of an emergency situation, the doctor must treat the patient and provide vital care but at the same time “respect the subject’s desires if they have been expressed”. In any case, the doctor’s intervention must pass through a hermeneutic procedure interpreting the will of the sick person, and reconcile the need for participation in the treatment process with the unique features of the same. Consciousness may be gleaned indirectly from expressed (in other words, unequivocal) consent: the written form can represent an indication of the general guarantee that the duty to inform will be fulfilled; however, consent expressed in this way is entirely supplementary to the main information-giving process and does not substitute it in any way. Therefore, obtaining consent to medical treatment does not preclude or exempt the doctor from fulfilling the obligation to duly inform the patient about the medical procedures.

In the case of patients incapable of giving their consent – whose desires cannot in any way be interpreted or deduced from external sources – the issue of medical treatment and manifestation of will emerges as a rather problematic one, although as we have already seen the doctor has the duty to provide vital medical care in situations of urgency (art. 36, final point, Ethics) and, in the event of a loss of consciousness, must proceed with life-supporting therapies as long as they are considered reasonably useful but avoid any form of aggressive therapy (art. 39.2, Ethics). Medical treatment of child patients also comes under this category; at first sight, this may appear simpler, except when no wishes emerge and it is impossible to deduce them despite attempts to reconstruct the young patient’s personality, as legally children are considered unable to decide for themselves. This apparent simplicity is due to a distinct contrast in the duality of the relationship: the two players are the healthcare provider and the legal representative (parents or legal guardian), who completely replaces the patient. In this relationship, whenever situations of conflict arise the doctor has the duty to forward the information to the judicial authorities and, as in all other cases, to provide emergency medical care.

\[\text{In cases where there is no current manifestation of the wishes of the incapacitated patient, the Supreme Court of Italy (e.g. judgment no. 21748 of 16 October 2007 on the famous Englaro case) adopts the criterion of the best interests of the patient instead of the parameter of the advantageousness of the proposed intervention, together with the well-known procedure to reconstruct the wishes and the personality of the patient who has consented to legitimize other people’s management activities; this is done by moulding the ruling around the overall personality of the ill individual even when their wishes have not been made explicit or have been expressed not currently but reliably. Therefore their wishes are presumed only in the sense (taken technically) that they have been extrapolated from a series of clear and definite pieces of evidence and can be deduced from the overall personality of the currently incapacitated person.}\]
when necessary: art. 37 of the Code of Ethics states that “when a minor or person certified as incapable of giving their consent is involved, consent for diagnostic activities or treatment, as well as for the handling of sensitive data, must be given by that person's legal representative. In the event of a personal administrator having been appointed by the courts, the doctor must provide him or her with the appropriate information and give full weight to his or her claims and wishes. In the event of legal representatives expressing opposition to necessary and urgent treatment for minors or adults incapable of giving their consent, the doctor has the duty to inform the judicial authorities; if the minor's or adult's life is in danger or their health is at serious risk, the doctor must proceed regardless with the vital treatment, without delay and according to necessity”.

However, this form of conflict resolution (i.e. with the judicial authorities being informed in the event of open conflict between the healthcare provider and the legal representative and where there is an urgent need for care) obviously cannot cover all the problematical issues intrinsic to this topic. On a purely theoretical level, we cannot fail to consider the fact that the person with legal responsibility can express their wishes only in reference to acts of assent to medical treatments and not to acts of refusal. This reveals a gross presumption that acts of refusal – and not those of assent – belong to a subjective sphere that cannot be left open to the unconditional power of a legal representative. Regarding these conflicts (to which we will return later), we must nonetheless point out that a significant renewed cultural awareness has emerged both towards diseases that completely invalidate the sufferer's intellectual processes (see the regulations on personal administrators) and towards childhood as a time when the individual is essentially growing and developing, therefore the exact opposite to a limiting situation (e.g concerning hearing minors, see art. 7 of law no. 184 of 4 May 1983, as amended by art. 7 of law no. 149 of 28 March 2001, and art. 155 sexies CCL introduced by the regulations on shared parental responsibilities). Within this framework, which at least in theory has been restructured, the general (but not absolute) dominance of the role of the parents or guardian is certainly not disavowed in conflict situations like those described above and their resolution in court, which often comes about through one of the provisions in art. 333 based on the provision of guarantees. Nevertheless, the classic relationship between the treating doctor and the legal representative, which generally informed the dialogue with the judge in the event of a dispute, when possible is now suitably enriched by the active role of mature minors; they participate actively and consciously in making choices regarding their own health, thereby further encouraging the “growing” principle of the child’s right to self-determination.

When the patient is a minor, the matter of fulfilment of the duties regarding informed consent also displays some distinguishing features, different from the classic ones, especially when the minor shows concrete characteristics that demonstrate a capacity to form their own opinions in reference to the treatment being proposed for them. In this light, the disposition contained in the second point of art. 38 of the Code of Ethics is significant: “consistently with the age, the level of understanding and the maturity of the child, the doctor has the duty to duly inform the child and to give weight to his or her wishes. In the event of an unbridgeable divergence from the requests of the child's legal representative, the doctor must report the case to the judicial authorities; the doctor must behave in a similar manner when faced with a mentally incapacitated adult”. As we have seen above, the doctor must communicate with the person concerned (even when in a state of incapacity) and take into account their level of understanding in order to encourage the highest possible degree of participation in the decision-making process and adhesion to the diagnostic and therapeutic activities proposed (art. 33.2 Ethics).

On another note, the general content of informed consent and its mirror duty to inform is destined to transform itself and become more specific as far as the characteristics of the quality and quantity of the information given to the minor are concerned. The right to know, which a child can exercise just like any other patient, naturally does not contradict the principle of respect for the person's dignity, the principal aim of benefitting the patient and the general principle of the therapeutic aim of the intervention, even when said intervention is configured in terms of omission but still acknowledges the underage patient's healthy sense of identity and self-determination. At the same time, the very principle of consent as expressed by the child in a hearing, for which the highest possible level of adhesion to and participation in healthcare and treatment choices must be obtained, is not contravened.

On this particular matter, the scientific literature available appropriately reveals that, rather than written documents and questionnaires, there is a preference for an open and real dialogue with the treating doctor, who should be able to grasp the fragility and uniqueness of each single patient and
each couple of parents, using a form of communication that is simple but always open. The doctor should provide clear and adequate information that will avoid confusion and aid understanding, as part of a continuous process of dialogue that goes beyond the confines of the usual formality of medical questionnaires. Therefore, it is necessary for the doctor's duty to inform and the patient's (and parents') right to be informed to be adapted and tailored to each specific context and for the provision of the information to adhere to different canons: in terms of quality and quantity, the information must be provided using simple and comprehensible language modulated to suit the age of the child and their individual, concrete capacity to decide, while also bearing in mind the possibilities for assessment and development on a psychological level and respecting the dignity and best interests of the patient. On the other hand, the doctor has to strike a delicate balance between the child's self-defence mechanisms and, quite in an opposite direction, the feeling of omnipotence they can develop as a result of deciphering (albeit only in part) the fabric of the family relationships they perceive. The act of adhering to proposed diagnostic and therapeutic activities by a minor, even a mature one, must present the same with a reality that for him or her is comprehensible and acceptable, by favouring the quality of the appropriately tailored information rather than the specificity or the quantity of the information, even when it comes to information that is explicitly requested. The ability demonstrated by the doctor, therefore, will be measured in terms of his ability to direct the information-giving process and any unfavourable or uncertain prognoses towards concrete elements (not so much of hope as) of a form of normality acceptable to the child.

4. The most significant cases foreseen by Italian law

In cases of routine medical treatment (examinations, first aid), the consent of just one of the child's parents is sufficient, given the general principle of the separate exercise of parental responsibilities. In these cases, joint consent is considered implicit. However, there are cases where it is necessary to obtain the explicit consent of the parents, for example in the event of both parents being present and agreeing to the treatment or, more importantly, when the treatment being proposed is not of a routine nature.

Joint consent is always required in the event of parents who are separated, divorced or non-cohabiting, based on the principle that the decisions that most greatly affect their children regarding education, welfare and health are taken by joint agreement (art. 155.3 and art. 317.2 CCL). According to the principles expressed by the new regulations on shared parental responsibility, when there is a lack of agreement between parents who are divorced or separated the decision will be made by a judge. The doctor cannot proceed with providing medical care, unless a state of necessity subsists in compliance with art. 54 of the Code of Criminal Law.

In the event of both parents opposing the treatment, the doctor, if they maintain that the medical care is vital for the child, must anyhow proceed with reporting the matter to the Public Prosecutor's Office for Minors so that the case can be brought before the Youth Court and one of the measures stipulated in art. 333 CCL can be adopted (when considered appropriate) in order to relieve the parents of their responsibility only for that specific act of medical care and to authorize the doctor to proceed without their consent.

Another case arises when one of the parents cannot be present, whether because of geographical distance, obstruction or temporary or certified incapacity: as a general rule, it seems that it is sufficient to obtain the consent of the one present and capable parent (art. 317.1 CCL). The possibility to omit the informed consent of the distant or obstructed parent should be assessed in relation to the urgency of the treatment and the time it would most probably take said parent to intervene in person, providing proof of their effective distance, obstruction or incapacity (and/or offering the parent present the possibility to fill out and sign – under their own responsibility – a form declaring that the other parent is either too far away or obstructed from being present; this document must be conserved alongside the consent form). Whenever such proof is missing, the Court for Minors must, upon the request of the other parent, a relative or the Public Prosecutor, take measures to substitute the missing consent of the parent, or to overcome the (unmotivated) dissent of a parent who is incapable of giving their consent but has not formally lost their parental responsibility.

If the child does not live with their parents, the means of obtaining their informed consent change according to each situation: if the child is in foster care, an institution or a correction facility, the foster parent (whose position is on a par with that of the wardens in institutions and correction facilities)
exercises the powers connected with parental responsibility when it comes to everyday interaction with the healthcare authorities, including routine medical treatment; therefore the doctor can proceed with the medical procedure with their consent. For “non-routine” procedures, it is necessary to request the consent of the parents or guardian, or report the case to the Public Prosecutor's Office for Minors in order to apply for a ruling from the judge at the Court for Minors.

In the event of a minor living on the streets whose parents cannot be contacted, or an unaccompanied foreign minor whose welfare has not yet been provided for, the Public Prosecutor for Minors must again be informed so that they may apply to the Court for Minors for an emergency ruling authorizing the treatment. The case will then have to be reported to the tutelary judge so that provisions may be made and a guardian appointed.

Given this general background, it would be useful to mention a significant kind of case, which can be found in certain special disciplines that adhere to the regulations regarding the health of minors.

The regulations on voluntary termination of pregnancy allow (under art. 13) that, for both the procedures described in articles 4 and 6, the application for medical treatment may be made in person by an incapacitated woman, by her guardian, or by her husband even when not her appointed guardian, as long as they are not legally separated. Any application made by the latter two must be ratified by the woman and the healthcare provider has the duty to report to the tutelary judge regarding the application, the attitude assumed by the woman, the pregnancy and the type of mental infirmity she suffers from. Similarly, if the woman is under eighteen years of age, art. 12 of the regulations requires the consent of whoever has parental responsibility for or guardianship of the young woman. However, in the first ninety days, when serious reasons inhibit or advise against consulting the responsible adults, or if they, when called upon, refuse to give their consent or each express contrasting opinions, the family planning clinic or healthcare/welfare institution, or even a trusted doctor, must lodge a report containing their professional opinion with the tutelary judge within seven days of the application. The judge, having heard the young woman and given due weight to her wishes, to the reasons given and the report received, may authorize her to decide on the termination through an unchallengeable ruling.

Looking once again at law no. 194/1978, under the final point of art. 2 we see that, “The necessary means to achieve the freely chosen aims relating to responsible procreation may also be administered to minors, in healthcare structures and family planning clinics, on condition that they have a doctor's prescription”. Therefore, the regulations allow the young man or woman the freedom to make choices concerning procreation (but from what age?), including the freedom to use contraceptive methods once they have reached sexual maturity. The obligation to have a prescription is an implicit acknowledgment of the fact that use of these methods depends on an initial clinical assessment and an initial diagnostic procedure aimed at prevention or cure; at the same time, the healthcare provider whom the young man or woman asks for contraceptives must always evaluate any clinical contraindications to the use of the medicines and what risks there may be, including those relating to previous states of health and the age of the person concerned. Therefore it is necessary to be prudent, painstaking and diligent and to avoid any hasty actions or lack of attention to the reasons for the intervention being requested.

Furthermore, the specific cases described under articles 4 and 5 of Legislative Act no. 211 of 24 June 2003 on “Implementation of EC Directive 2001/20 Regarding Application of Good Clinical Practices in the Conduct of Clinical Trials on Medicinal Products for Human Use”, allow medicines to be tried on minors and adults incapable of giving their consent, as long as it is solely for their benefit and the informed consent of their legal representative has been obtained. This consent must represent the presumed will of the patient and be able to be withdrawn at any time without prejudice to the patient. At the same time, a capable person must have received information adapted to their capacity for understanding regarding the experimental trial and its related risks and benefits, while the healthcare provider has the duty to give due weight to the patient’s explicit wish to refuse their consent to participate in the trial or to withdraw from it at any time, as long as they are considered able to form their own opinions and to assess the information given to them.

On the topic of diagnostic tests and therapeutic and rehabilitative treatment for a minor who makes non-medical use of narcotics, it is stipulated that the minor in person can access drug addiction services, receive therapeutic treatments and give their consent to have urine and hair samples analyzed in complete confidentiality. Article 120 of Presidential Decree no. 309 of 9 October 1990 provides that, “Anyone making use of narcotics or mind-altering substances may request the public drug addiction services or an authorized private institution to perform diagnostic examinations and to carry
out a programme of re-socialization and rehabilitation”. The second point goes on to specify that, “Whenever the person involved is under the age of eighteen or incapable of forming and expressing his or her opinions, the request for intervention may be made not only by the person concerned, but also by those who have parental responsibility for him or her, or are his or her appointed guardians”.

Therefore we have seen that a minor requesting treatment has the right to remain anonymous, with healthcare providers obliged to keep the patient’s identity secret even from their parents; the treatment and rehabilitation programme can take place without the parents’ consent, at least when the minor is of a certain age. The reasoning behind this provision is evident and appreciable: it is considered a good thing to respect (at least in part) the wishes of a young patient and their right to confidentiality, partly because this is deemed to encourage minors to access the services; however, the healthcare providers are authorized to reveal the situation to the parents when they believe the parents’ cooperation is necessary to achieve the desired results, thanks to the provisions of art. 622 of the Code of Criminal Law which exempts them from their obligation for confidentiality when there is just cause.

References

The most significant dispositions concerning participation of minors in decision making process regarding health matters: relevant legislation and Codes of Ethics

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