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Therapeutic choices and care of minors: a recent story

Linda Alfano, Alessandro Bonsignore, Rosagemma Ciliberti
[1]Department of Health Sciences (DISSAL), University of Genoa, Genoa, Italy

Abstract. The profound social, ethical and juridical transformations that have invested the condition of childhood have also affected the consideration of the existential interests of the minor in the care relationship and his role in the adoption of the therapeutic choices that concern him. If the history of children's rights is recent, that of children's rights in the health field is still at the outset. The legal status of the minor in the medical field expresses all the complexity of a *status* that, for a long time, has been subject to profound reconsiderations and which concerns various and different stages of growth and the formation of his personality. The participation of the child is an important factor to condition the therapeutic path and improve the curative results. However, the participation of the minor in his/her health path still has obstacles and shortcomings. The promotion of a specific communicative competence of health professionals can represent an important factor capable of contributing to the growing autonomy of the child and positively influencing the therapeutic path.

Key words: self-determination, healthcare, minor, child, autonomy, competence, paediatrics, decision making

The evolution of child protection

Minors have always been subject to violence, sometimes unprecedented violence (1). In all cultures and in all kinds of societies parents have beaten, exploited, abandoned, tortured and killed their newborn children. The female sex of the child, the lack of economic resources for his livelihood, the clandestine state of the relationship and disability were all valid reasons to support this practice. In a study on human cultures, the anthropologist Laila Williamson (2) reveals that infanticide was a widespread practice in almost all types of society (the number of suppressed babies fluctuated between 10 and 15%), and this is also evident in our humanistic repertoire that recounts the exploits of great personalities of history who all have in common the fact of having been abandoned children, exposed to the forces of the elements or destiny (Moses, Remus and Romulus, Cyrus the Great, Oedipus, Gilgamesh and so on). For a long time, childhood life had no specific recognition by adults who considered the "minor" (from the Latin *parvus - minor*: small/smaller, as being worth less; *infans-infantis*: who cannot speak) a being without rights, a subject to be educated and shaped.

Minors were juridically the property of the *pater familiae* who could impose every decision on them, in any field; the public authority could not violate the boundaries of the family, nor overlap or replace the authority of the father, not even to prevent violence, abuse of power or mistreatments. The first institutional intervention to protect abused minors took place in 1874, in the United States, in favour of the child Mary Ellen Mc Cormack, brutally beaten and abused by her family. In the absence of specific legal instruments, the minor's neighbours were forced to turn to a society for animal protection, as the only reference that could provide assistance to her. On the basis of the analogy between the vicissitudes of the child and those of the horses saved from the violence of the farmers, the founder of the company presented an application to the Supreme Court of the State of New York. Through a creative interpretation of the legal institution of the

Habeas corpus (an Anglo-Saxon legal institution of very ancient origin, aimed at protecting the citizen's personal freedom), the applicant thus obtained the first judicial hearing of a minor against his parents and a subsequent provision of protection. This trial was followed with great interest by public opinion and gave rise to a series of significant debates, which led to the birth in New York of the First society for the prevention of cruelty to children and, in Chicago (1899), of the first Juvenile Court in history. Also in England, the defence of minors was initially undertaken by animal protection associations (3).

From the first half of the 20th century, a different sensitivity towards the child has gradually promoted a profound transformation of his social role and has increasingly attracted the attention of states and supranational organizations towards the minor and the fundamental rights of which he is bearer, albeit with great initial ambivalences. In fact, still in 1911, an English doctor, Charles Mercier, presented some arguments to support the idea that infanticide had to be considered a less heinous crime than the murder of an older child or adult, writing:

"The mind of the victim is not sufficiently developed to allow her to suffer from the contemplation of the approach of suffering or death. She is incapable of feeling fear or terror. Nor is her consciousness sufficiently developed to allow her to feel the pain appreciably. Her loss leaves no void in the family circle, does not deprive any child of the breadwinner or mother, no human being of a friend, a helper or a companion" (4).

Evolution of the minor's rights and the right to health protection

The legislation on children's rights is, however, recent and closely linked to the progressive transformation of the family and the concomitant redefinition of the nature and social role of children (5). The first international organization to protect children was the Committee for Child Protection, established in 1919. However, the Declaration of the Rights of the Child signed by the League of Nations in 1924 (also known as the Geneva Declaration) represented the first significant attestation of the needs of children, which also established a precise and clear responsibility of adults towards them. The approval of this Declaration, in which Eglantyne Jebb (member of the Red Cross, who had founded Save the Children in 1919) participated, among others, is linked to the dramatic events related to World War I, that also called for the question of the protection of children and adolescents. The text of the Convention, deliberately brief and concise, has a system substantially based on welfare, aimed at affirming the material and affective needs of minors, considered not as holders, but only as passive recipients of rights.

With the subsequent birth of the United Nations Organization, the UN General Assembly approved, on November 20, 1959, the Universal Declaration of the Rights of the Child. The document, structured in 10 principles, considers the particular fragility of the child including a series of health related rights, not foreseen in the previous Universal Declaration of Human Rights, such as: the prohibition of children insertion into productive activities that may harm their health or hinder their physical or mental development and the right of the disabled child to receive special care. Although not a binding instrument, the Declaration assumed considerable moral authority, thanks to the unanimity of its approval and the innovativeness of its contents.

In the evolution of international child law, these international documents have undoubtedly been very important steps. However, in a world that recognized ever more complex spheres of human rights, the rights of the child continued to be lacking. As "human beings" in formation, the minors continued not to be holders of independent rights, but the object of care and protection.

Only in 1989, with the New York Convention, the child finally became the owner of subjective legal situations that required parents, the State and the international community to commit themselves concretely, with different levels of responsibility, to preparing a system that would realize his *superior interest*. In his regard, the parents continued to perform the traditional tasks of rearing, caring, education and supervision, but in compliance with his abilities, natural inclinations and aspirations.

The recognition of the subjectivity of the child and, together, the best interest of the child thus became the guiding principles for any intervention activated to protect children. The recognition of the child's subjectivity has been expressed, in particular, in the provision of the fundamental right of the child to be heard and to express his opinion in any judicial or administrative procedure that concerns him.

Subsequent international documents have enhanced the role of the child in the information and decision-making process by progressively affirming a new image of the minor: one that sees him as, at least potentially, autonomous, competent, capable of self-determination and of freedom. According to these important international Acts the obligation to take into account the opinions of the child applies in cases where it is a "child capable of discernment" and also "in relation to his age and degree of maturity" (6).

Moreover, the protection of health also falls within the scope of these norms that therefore introduce the direct and unavoidable participation of the minor in the health treatments that concern him. The involvement of the minor in the information and decision-making process is, moreover, closely related to the careful evaluation of his ability to understand and self-determine himself in relation to the health pathways. In this perspective, listening to the minor plays a fundamental role of important ethical value. The implementation of a participatory health model also makes it possible to increase the child's adherence to the therapeutic path and favour the offer of appropriate health care according to the subjective, cultural and systemic perspectives and needs of the assisted children.

However, these documents do not indicate the benchmarks for assessing the capacity for understanding and self-determination, but merely suggest certain verifications and a broad assessment that includes a plurality of factors, such as age, personality characteristics, complexity of choices to be made and the values at stake. Actually, this assessment is left to the discretion of the professionals and to their training competence.

Several researches suggest that the formal operational stage begins at approximately age twelve and lasts into adulthood. As adolescents enter this stage, they develop the ability to think in a theoretical manner by manipulating ideas in their head, without any dependence on concrete manipulation (7, 8). However, the role of emotions in the development of decision-making processes must be taken into account. For centuries, passions and feelings have been considered sources of disturbance or even suppression of human rationality and freedom, while more recently, evidence deriving from the clinic and ethology has allowed us to understand how, contrary to what was believed in past, precisely the absence of adequate emotional indicators (for example due to brain injuries or particular mental disorders) can interfere with the ability to act and decide, even to the extent of making it impossible (9).

However, recent studies indicate that children are generally excluded and not sufficiently involved in individual healthcare decisions in many European countries (10,11). The scarce participation of minors in the communication and decision-making process of the therapeutic path is related to the lack of a specific formation of physicians and specialists working with children on how to communicate with them in a child-friendly and professional way, particularly in clinically difficult situations, building relationships of trust (12). Delegating this task to psychologists, social workers, nurses, and other workers risks further marginalizing the role of physicians in the creative process of mutual understanding and trust (13). Most European children often feel they are mere spectators of a process in which their participation is not at all solicited, but replaced by their parents (14,15).

Ehrich et al. (10) indicate that the success of medical treatment depends not only on the severity of the disease and the quality of care, but also on children's participation in therapeutic measures. In particular, external determination and attempts at autonomy influence the result both positively and negatively. The survey carried out in the context of the health research project of the European Paediatric Association (EPA) revealed that in 30 of 35 European countries, chronological age has been considered the only parameter for allowing children to participate in decision-making (10). Indeed, when we refer to acts of autonomy of minors relating to personal and existential interests, such as those relating to the exercise of the right to health, due consideration must be given to the complexity of situations that, from a subjective point of view, do not lend themselves to being framed only with the mere identification of an age threshold.

Recent study indicates that European adolescents, even though they have different preferences regarding health communication, all wish to be involved as partners (14). Coyne et al. (16) show that children with cancer generally prefer to be involved in decision-making and consider it important to have the opportunity to take part in decision-making concerning their health care, even in the case of end-of-life decisions. The enhancement of the communicative and participatory involvement of the child also constitutes one of the indispensable elements in the process of humanization of medicine that has its roots in the rigorous selection and full training of the new nurses for "sick children" (17,18).

The value of the minor's choices in the medical field between rights and over-treatment

The consideration of the issue of the self-determination of the child, with respect to health care choices, lies within that path that has, with difficulty, introduced the ethical principle of autonomy of the assisted person into the medical field. This principle, in fact, was initially extraneous to both medical tradition and practice, which were governed exclusively by the principle of beneficence (19), that required attention only to the "objective" good of the patient, judged presumptively incompetent to make appropriate health choices. The gradual affirmation of the principle of autonomy is connected to the introduction of surgical anaesthesia, in the second half of the 19th century, which raised important problems of informed consent. The application of surgical anaesthesia, in fact, allowed not only to avoid pain, but also to overcome the resistance of patients against operations. At the end of the 19th century, however, complaints from patients who considered themselves to be involuntary victims of surgery increased significantly. The absolute need for consent to the medical act was universally declared only by Nuremberg Code (1946).

In recent decades, the particular nature of the right to health protection and, above all, its very close connection to the body and to the freedom of the person have prompted the question of consent also with regard to underage patients, traditionally considered subject to their parents' will even for what concerns health treatments. Moreover, clinical practice highlights the difficulty of marking a clear demarcation between specific properties of a certain age compared to another, since maturity, competence, autonomy, responsibility, or their opposite (immaturity, incompetence, dependence, irresponsibility) are characteristics that no longer belong only to a certain age, but that characterize in a transversal way every phase of development.

In a perspective that considers the consent to the medical act the expression of a very personal right and that identifies conscious participation in care as an essential element for the success of the therapeutic project, there is also in this context a general rethinking of the condition of minors, and more generally of legally incapacitated subjects. From a purely evaluative, incapacitating and even exclusive logic of the person presumptively deemed unsuitable, international law is increasingly directed towards a dynamic and propulsive role aimed at including subjects, emphasizing and enhancing their capacities and abilities, rather than compressing and repressing them, also taking into account, on the one hand the emancipation of the child world, on the other hand the revisitation and reinterpretation of adult models.

On the basis of these premises it was excluded that parents could represent, in an exclusive way, children in relation to their medical choices, particularly when the child has reached an age close to the full capacity to act. The introduction into community framework of the concept of parental responsibility, rather than authority, better describes the commitment of adults to promote the progressive autonomy of children, based on their inclinations, capacities and interests.

The condition of "minor" contains, moreover, within it, heterogeneous situations that make it necessary to distinguish between:

a) the case in which the minor is a child and the case in which the minor is a preadolescent or adolescent;
b) the cases in which a specific capacity for discernment appropriate for the task being analysed is present and those in which it appears premature or in progress or not adequate to the complexity of the situation under examination.

An essential ethical principle of child rights is that information must be provided in a language and/or form of communication that is congruent with the child's evolving capacity to understand and respond (20). The recent Italian legislation on consent and end-of-life provisions has introduced a norm of particular ethical significance that states that "the time of communication is time of treatment" (21). This provision constitutes a valuable principle in the hypotheses of conflict between doctor-child; child-parents; doctors-parents.

Particularly significant are some decisions of the Italian juvenile judiciary in cases of very serious disease with uncertain prognosis that have identified in the principle of self-determination of minors an important criterion of orientation in the resolution of conflicts between physicians, who believed it was necessary to implement therapeutic programs indicated by official medicine, and parents, who refused the medical decision and preferred other therapeutic strategies (22). In these cases, judges have enhanced the negative will of the minors and have denied the forced imposition of the experimental treatment. Such decisions of the Italian judges on the events, tragically concluded with the death of the involved_children, are in line with the provisions of Directive 2001/20 / EC of The European Parliament, which in Article 4 states that "the explicit wish of a minor who is capable of forming an opinion and assessing this information to refuse participation or to be withdrawn from the clinical trial at any time is considered by the investigator".

The conflict and balance between the principle of beneficence and the related principle of autonomy, between the need for protection and instances of self-determination, could therefore find natural limitations in cases in which the choices of the minor appear imponderable or irresponsible and likely to lead to situations of damage or danger to his/her physical and mental integrity.

In such a context, as in every other aspect of the wider debate relating to the self-determination and autonomy of the minor, a risk still remains where a greater flexibility of the rule may cause arbitrary, personal, subjective assessments, which may forget and sometimes go beyond the epistemological boundaries and ethical aspects of the question.

In assessing the decision-making capacity of the child, specifically for that particular situation, case by case, it is also necessary to provide adaptation interventions and environmental supports aimed at improving and enhancing the skills necessary for his/her involvement.

Conclusions

The child's participation in care choices is an important factor capable of conditioning the therapeutic path and its effectiveness. A specific competence in communication with children that takes into account, in addition to age, also maturity and their different cultural backgrounds should become an integral part of the curricula of physicians, nurses and specialists that work with minors.

The process of empowerment of minors can also be positively or negatively influenced by the family which seem to underestimate the child's ability to express himself. In addition to the family, it is also well known that there are also other social institutions (such as schools), delegated to fully develop the potentialities of humans and the promotion of an authentic autonomy of individuals.

Moreover health professionals may become more involved in the process of implementation of decision-making capacities, taking into account the state of illness, which if not carefully treated, can represent a significant existential limitation (23).

Autonomy, should not be considered, especially in the clinical setting, as a prerequisite, but as a goal to be sought and constantly built within the relationship, in that encounter between the principle of autonomy and beneficence, expressed in the therapeutic alliance (24). An autonomy vitiated by assumed presuppositions and by no means obvious, risks becoming the instrument of a defensive medicine both in the case of adults and, even more dramatically, in that of minors.

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Correspondence:
Alessandro Bonsignore
Department of Health Sciences (DISSAL),
University of Genoa,
Via De Toni 12, 16132, Genoa, Italy
E-mail: alessandro.bonsignore@unige.it