

To flip the coin: around children's and adolescents' capacity to participate in the decision-making process

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A recent article by Robert Wheeler¹ entitled "Must the capacitous young person also be competent to provide consent for treatment and research?" calls on me to share some reflections.

The first, more obvious but essential reflection is that a purely legal approach is likely to bring more confusion than clarity to Wheeler's words. Great Britain and Argentina (and other Latin American countries) are light years apart: a common law system based on judicial precedents is completely different from the Argentine civil law system based on legal codes. In common law, judges create the law through their rulings; in civil law, judges have a legal corpus (codes) on which they base their decisions through judicial and doctrinal interpretation.

The second issue is related to legal procedures and is that British judicial activism leads to judicial intervention in cases that would never occur in this part of the world. In Great Britain, judicial intervention in the medical decision-making process in pediatrics is quite common, whereas in Argentina and most Latin America it is exceptional. This is not the place to delve into the reasons, which undoubtedly enrich the debate and the approach to the subject, and which I am only raising.

The third issue is semantic: although the English language uses the terms *capacity* and *competence*, and both "*capacidad*" and "*competencia*" are used in Spanish, a red light goes on in the face of what would be expected:

it is true that both concepts differ (capacidad/ capacity is not the same as competencia/ competence), but the problem lies in the fact that the concept behind the Spanish definition of capacidad is similar to the English concept of competence, whereas the Spanish concept of competencia is similar to the English capacity... It sounds like a muddle, and it certainly is. Capacity is a term from the medical sciences (in Spanish, it refers to "competencia bioética") that establishes a patient's ability to self-determination in the decision-making process regarding their care and choice (acceptance or refusal) of medical treatments. Such capacity/competencia is dynamic and varies depending on the patient's different individual circumstances and the course of their disease. However, competence is the simile of our capacidad, a person's competence to perform legal acts (any individual of legal age who enjoys their freedom, will, and discernment).

Both in the Anglo-Saxon world and in our Ibero-American setting, *capacity/competencia* especially values the level of maturity and understanding of the child/adolescent to be able to participate in the decision-making process. This is what in Great Britain is known as Gillick competence (based precisely on jurisprudence) and in Argentina is represented by the mature minor doctrine or progressive autonomy, expressly recognized by our legal system since 2015 (Civil and Commercial Code, section 26). Both the British jurisprudence and section 26

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of the Civil and Commercial Code of Argentina establish 16 years of age as the age milestone that marks the acquisition of full *capacity/competencia* to make medical decisions.

Wheeler's paper analyzes a series of British legal precedents in order to determine the existence of clear and precise guidelines on the *capacity/competencia* of adolescents under 16 years of age, through judicial decisions. In particular, Wheeler raises a serious doubt in the age range between 16 and 17 years, where he understands that there may be a clash between the clinical assessment of the maturity and understanding of a young person versus the weighing of a patient's legal competence, and stresses that the absence of (legal) incompetence does not necessarily imply the existence of (bioethical) capacity.

There is another great difference that should be "judicially noticed as public and common knowledge," as we, lawyers, usually say: in Argentina in particular, and in Latin America in general, there is a great development of Hospital Ethics Committees as the appropriate place to deal with the conflicts and dilemmas that arise in the healthcare relationship. Bioethical activism is thus inversely proportional to judicial activism, and allows these decisions to be addressed within the physician-patient relationship, without interference from third parties, as appears to be the case in Great Britain. This does not mean that, in the face of disregard or violation of rights, "justice" should not act.

A significant detail that has caught my attention is that Wheeler's article title mentions consent for treatment and research. However, almost all his brief but very rich text focuses on consent for treatment of young people and only devotes the last paragraph to research, when he argues that "positive affirmation of capacity may be a greater reassurance to the physician than mere confirmation of lack of competence, particularly when faced with the complexity of disclosure of information in research. The use of a better clinical

tool to assess the extent of comprehension and complex information in a competent young person will be helpful to researchers and physicians as they await clarification of the law."

I have previously already referred to the use of the progressive autonomy concept in the field of research and have been absolutely critical of the trends that advocate an extensive interpretation of section 26 of the Civil and Commercial Code (Argentina)² given that, in the name of the expansion of civil rights, it ends up exposing the child who is a research subject to greater vulnerability and lack of protection; it forgets that —although there are points of contact—, there is a big difference between the clinical care relationship and the field of health research, to such an extent that its specific regulation is specific to each area.

Other than these nuances, Wheeler's concern is the same as that of every healthcare provider dedicated to the care of children and adolescents: the permanent tension between ensuring their voice and at the same time, their protection; in other words, the need to find the right balance between benevolent paternalism and the impossibility of finding a tool that provides absolute certainty about that balance. Considering that the law is called upon to be that tool, or even worse, that judges should be its interpreters, is not only an illusion, but also inappropriate. Complexity is the essence of any decision-making process; it highlights the richness of human diversity in the face of life experience. That is why we can only count on more or less precise and more or less broad parameters or guidelines, but which should never become a sentence or a universal law. That is our wonderful yet difficult daily challenge.

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