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Commentary

Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care?

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ABSTRACT

The purpose of this article is to provide policy guidance on how to assess the capacity of minor adolescents for autonomous decision-making without a third party authorization, in the field of clinical care. In June 2014, a two-day meeting gathered 20 professionals from all continents, working in the field of adolescent medicine, neurosciences, developmental and clinical psychology, sociology, ethics, and law. Formal presentations and discussions were based on a literature search and the participants' experience. The assessment of adolescent decision-making capacity includes the following: (1) a review of the legal context consistent with the principles of the Convention on the Rights of the Child; (2) an empathetic relationship between the adolescent and the health care professional/team; (3) the respect of the adolescent's developmental stage and capacities; (4) the inclusion, if relevant, of relatives, peers, teachers, or social and mental health providers with the adolescent's consent; (5) the control of coercion and other social forces that influence decision-making; and (6) a deliberative stepwise appraisal of the adolescent's decision-making process. This stepwise approach, already used among adults with psychiatric disorders, includes understanding the different facets of the given situation, reasoning on the involved issues, appreciating the outcomes linked with the decision(s), and expressing a choice. Contextual and psychosocial factors play pivotal roles in the assessment of adolescents' decision-making capacity. The evaluation must be guided by a well-established procedure, and health professionals should be trained accordingly. These proposals are the first to have been developed by a multicultural, multidisciplinary expert panel.

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Carlos, an adopted 15-year-old adolescent, was found to be infected with HIV on his arrival in his country of adoption. Until recently, he has performed well at school, and the infection was under control with the parents making sure that Carlos was taking his medication. For the last couple of months, however, Carlos has become rebellious at home as he feels that his parents are overprotective and too concerned about his life and his medical condition. Moreover, his medical situation has deteriorated. Carlos feels different from his peers, who do not have to

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take a medication everyday, and admits that he has stopped regularly taking his medication; as a result, his blood test results have worsened. He wants to stop his medication for a while as he thinks he will feel better. Carlos has recently met a girlfriend with whom he has had sexual intercourse on several occasions. His parents do not know that he has a girlfriend and ignore that he has had sexual intercourse with her. Moreover, the girlfriend does not know his HIV status, but Carlos says that he always uses a condom. Although Carlos asks for total confidentiality on all these issues, his parents insist that the doctor give them some insight into their son's situation. Additionally, the doctor thinks his girlfriend should know about the HIV status of Carlos.

Carlos condition raises clinical, psychological, legal, and ethical questions. Poor adherence to HIV treatment may increase the virus' resistance, and the question arises whether it is advisable for him to cease treatment for a while. What are the long-term risks of stopping medication? What are the rights and responsibilities of this 15-year-old adolescent and to what extent is he able to consider the potential short- and long-term consequences of stopping his treatment? Should his parents be informed about their son's medical situation? Should the doctor insist that Carlos disclose his condition to his girlfriend? Health care providers are faced with many clinical situations which pose psychological and ethical questions, and the response to these issues is complex. One of the most critical questions that health care professionals and health care teams face is the one regarding the involvement of adolescents in decisions affecting their health. From a legal point of view, the right to give an opinion (e.g., assent to a procedure) or to make an autonomous decision (e.g., benefiting from confidentiality and consent for an intervention or a treatment) is referred to as competence. The cognitive and psychological capacity to make autonomous decisions refers to the context of clinical care. Thus, the two words refer to the same concept, but one is used from a legal point of view, whereas the other is used to clarify the adolescent's ability to give his opinion and make decisions in the field of clinical care or research.

Although individuals having attained their majority, usually 18 years, are in most countries legally considered as competent (unless they suffer from a severe psychological disturbance or intellectual impairments), in many parts of the world, minor adolescents or even children can be considered competent, as long as, in a given situation, their health care provider and health care team deem them so. In some countries, the assessment of the minor's competence is in the hands of lawyers, but in many countries, especially in Western Europe, the capacity to give an informed opinion or make a decision is usually assessed by clinicians or health care teams, who thus have the responsibility to state whether a minor can be legally considered as competent or not [1-4]. Such capacity depends on many factors such as the stage of development, the social and cultural environment, and of the complexity of the clinical situation. Some well-validated and largely if not universally accepted instruments and guidelines are available for the assessment of the adults' capacity who suffer from diseases which hinder their cognitive abilities [5-7]; but even if several authors have developed advice as how to assess autonomous decision-making capacity among minors [2,3,8], no universally applicable approach is yet available.

The objective of the present article is to offer health professionals who provide care to adolescents and guidance to assist them in assessing the extent to which their patients aged <18 years possess autonomous decision-making capacities without a third party authorization in the field of clinical

practice. It summarizes the results of an international 2-day meeting which took place in June 2014 under the auspices of the World Health Organization (WHO).

Methods

Participants

The meeting was organized by the Centre Hospitalier Universitaire Vaudois, a WHO Collaborating Center, as part of the implementation of their collaborative work plan. The five organizers of the meeting, coauthors of this article including a WHO representative (V.B.), established a list of professionals working in one of the disciplines related to the theme of the meeting, e.g. adolescent medicine, adolescent gynecology, nursing, epidemiology, public health, law, developmental, forensic, and clinical psychology, psychiatry, sociology, and bioethics. Participants were selected on the basis of their publications and area of expertise, as well as their country of origin to ensure broad international participation (a list of the participants with their affiliation is provided in the Appendix).

Process and outcome of the meeting

The meeting was organized around a mix of formal, theoretical presentations on specific topics (e.g., legal framework; research on adolescent brain development, developmental psychology, ethics as applied to young people; sociological perspectives of children and adolescents' decision-making capacity) and case-based small group discussions. After several small- and large-group deliberations based on the formal presentations and a discussion of clinical cases, a last plenary session allowed for the production of a set of proposals, applicable in different countries and contexts on which all participants agreed. Interestingly, despite the heterogeneous composition of the audience, there was high consensus on the principles providing the scaffold for the proposals. The participants have agreed to the publication of a summary of recommendation.

Legal Aspects for Consideration

Legal frameworks are highly heterogeneous across countries and at times within countries [4]. Some countries or states have defined in the law at what age minors can make decisions regarding their health, but in most countries, such age limits are not defined, and it is then necessary for the health care provider and team to assess the young patient's competence. In Great Britain, for instance, as a result of a political intervention after a highly publicized case of request for contraception by a girl aged <16 years, an adolescent who is deemed "Gillick competent" is able to prevent their parents viewing her medical records [3], and this competence is usually assessed by the practitioner.

In the United States, many professionals may ask for the assistance of specialists, such as bioethicists, an ethical commission, a psychiatrist, or a psychologist or even a lawyer or tribunal to decide if the minor patient is competent [9–13]. In Europe and most low- and middle-income countries, health professionals and clinical team normally do not delegate the assessment to specialists, and it is important for them to know their country's legal context (Table 1).

In countries which do not provide any guidance, the persons in charge of the situation can at least rely to the Convention on

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