Adolescence, autonomy and human research

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Abstract

This article makes considerations on the theme of adolescence as a single stage in people's lives, the phase in which the autonomy gains increasing strength. Although the goal of the study is to discuss issues of epidemiological, clinical or pharmacological research with teenagers, we discuss aspects related to psychological, social and moral development of human beings. At the end, some concepts and guidelines applicable to those different types of researches involving human subjects are reviwed.

Key words: Adolescent. Personal autonomy. Humans subjects. Biomedical research.

Resumo

Adolescência, autonomia e pesquisa em seres humanos

Este artigo tece considerações sobre o tema da adolescência como uma fase única na vida, na qual a autonomia ganha cada vez mais força. O objetivo do estudo é discutir as implicações éticas da pesquisa epidemiológica, clínica ou farmacológica com os adolescentes, abordando aspectos relacionados ao seu desenvolvimento psicológico, social e moral. Ao final, serão revisados os principais conceitos e *guidelines* aplicáveis àqueles diferentes tipos de pesquisas.

Palavras-chave: Adolescente. Autonomia pessoal. Humanos. Pesquisa envolvendo seres humanos.

Resumen

Adolescencia, autonomía e investigación en seres humanos

Este texto hace algunas consideraciones sobre el tema de la adolescencia como una etapa única en la vida de las personas, la fase en la que la autonomía adquiere más fuerza. Aunque el objetivo del estudio es examinar las cuestiones de la investigación epidemiológica, clínica o farmacológica con adolescentes, discutiremos aspectos relacionados con el desarrollo psicológico, social y moral de los seres humanos. Al final, vamos a revisar algunos conceptos y directrices que se aplican en estas investigaciones.

Palabras-clave: Adolescente. Autonomía personal. Humanos. Ética de la investigación.

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The period of adolescence, regarding age and in the context of Western culture, is the one corresponding to the second decade of life, i.e., from 10 to 19 years old. The terminology "adolescence" was embraced by Osório [1] in terms of life stage (age) and, generically, as a concept that encompasses a social construction which is also dependent on time, culture and, currently, the financial status of people.

Punctuating historically the terminology, only since 1950 this social group was recognized as "adolescence". Before that, it was considered the existence of only two social groups: adults and children. Given the number of children and young people orphaned in World War II, experts of several fields (Anthropology, Sociology and Medicine) aimed their approach at that group with different attributes and that was evident in society. Thus, it was recognized that these people had specific features: biological, psychological, social and spiritual ones [1,2].

Puberty is just the first phase of adolescence, lasting approximately two to five years. It is a biological phenomenon exclusively characterized by a stage of physical changes caused by the action of sexual hormones, which create physical changes in boys and girls [1,3]. However, adolescence goes far beyond, both in time and in effect. Nowadays, adolescence is not understood just as a period of crisis, but as an evolutionary and transitional process considered normal for the emotional and cognitive development of human beings [1,2].

In this study, we discuss how the theme of adolescence, considering its social, psychological and moral context. After briefly discussing these issues, the discussion is focused on the participation of adolescents in scientific research, in the light of standards and guidelines in force, ending with a discussion about the ethical issues involved in the question.

Physical, psychological and social development of adolescents

Osorio [1] states that adolescence is a social phenomenon that occurs mostly with people of more favorable social classes. In contrast, those who are considered poor would live only to puberty, which is a strictly biological phase and it depends on hormonal explosion. Thus, adolescence is a phenomenon of construction that encompasses the physical, cognitive, psychological and social maturation of people [1,2].

The World Health Organization [4] defines adolescence based on the following criteria, which were resumed throughout the text: biological development (since the beginning of puberty to full sexual and reproductive maturity); psychological development (from childhood cognitive and emotional patterns to adulthood characteristics); emergence of a step of a total socio-economic dependence to other of relative independence.

According to these ideas, adolescence is a period of transition and the challenges faced by teens would be development challenges. These include the anatomical and physiological adaptations, changes related to puberty, and also the integration of a sexual maturation in a personal role model, i.e., the gradual separation from parents and family and the establishment of an individual, sexual and social identity through relationship with their companions, the use of an enriched individual skill development and the potential for occupational and developmental activities.

This way of noticing the facts is corroborated by Osório [1] & Osório and Baptista Neto [5], who consider the period of adolescence as a primarily cultural process, long and complex with multiple synergisms and multifaceted perspectives. This period would be a universal and transcultural phenomenon that varies from culture to culture, from age to age, shaped by political and economic influences. The same authors reiterate that adolescence would be even a cultural and social class process as a possibility only available to higher social strata and better purchasing power.

It is prudent to point out that, from the physical and mental view point teenager goes through a metamorphosis that occurs in their body and their psyche, produced by forces unknown to them, but they operate in their body and mind regardless of their will.

In the psychic and social aspects existed in the childhood of these people there was a state of too much dependence on others, especially on parents and family. Throughout time this dependence tends to decrease progressively. The adolescent starts to miss their child identity and, little by little, they move from a state of total dependency to increasing autonomy over the years, if they find a favorable environment. This last phase which involves factors such as education, social interaction, social relationships, maturity and intelligence, among others, adolescents begin to seek relationships outside the family – friends – which features the gregarious aspect of youth. Thus, the new group plays an important role, acting as liaison between the family of origin and the outside world. This fact is crucial to their future way of life [1,3,6].

Adolescents, who are supported these relationships, they look forward to take their first steps out of their house, usually establishing, at that time, coping and escape behaviors from parents or their substitutes, their first models [1]. This process is important to face the new and the unknown and that people can be, in future, asserted as adults and independent individuals. In this way, if it is well conducted and lived, adolescents begin to build, gradually, their own world of values, beliefs and abilities to assert their identities as independent individuals.

Moreover, according to Osorio [1] and Osorio and Baptista Neto [5], changes in which children spend also determine changes in parents. In fact, their children are no longer children but young teenagers. For parents, the recognition that teenagers are almost adults means that they are losing the youth, forcing them to confront their own aging. This is an ambivalent relationship which is established and requires mutual acceptance and understanding between parents and future adults. This period is therefore difficult and confusing for parents and their children. By becoming aware of the conflicting values that the growth of the children generates, it is important that parents do not resist the emotional development that resulted of the inner fighting of young for their independence [1,6].

The independence process then occurs in two directions, i.e., the children establish new relationships with parents and they need to accept the process of maturity of the child as a subject whose autonomy is increasing and may lead to independence. This experience is arduous for both, and it is considered relevant by the experts, for the psychic evolution of human beings [6]. Its is important to indicate that the evolutionary process of the human being is not tight. On the contrary, it is dynamic, unfolding itself from childhood to old age, since further amendments and understandings always arise.

According to Cohen [7], *nor adult values are definitive. Moreover, it is not desirable that the values are stuck; we have to be aware of changes that occur through changes in personal and social life over time*. In other words, the understanding of the world is not closed to new understandings, proposals and events, because the paths of people change, and may require lengthy deliberations, adaptations, reflections.

Therefore, the transformation process inherent in the very course of life often involves changes of ideas and directions. In the case of adolescents they are the other teenagers because they are the same age and share coexistence groups, which have a high degree of influence over their thoughts and actions. From the time when the adolescent is identified with the group, they feel more confident regarding their actions, which can bring good or bad consequences.

Whatever those consequences are, teenagers present their own aspects of behavior, disease and needs; for this reason they constitute a specific study group in the medical and scientific community [7]. Experts in adolescent health state that they are generally healthy people, i.e., free of disease. However, Melamed says: *There are a considerable number of changes that affect adolescents and can severely compromise them. The health of children and adolescents may be interrupted by conditions that appear in childhood and may continue into adulthood, and if these changes are not taken into account, it will continue and may even become more pronounced in adulthood* [8].

When the issues of health and prevention are addressed, the so-called "risk behaviors" – one of the most important events in adolescence – often appear and if they are not properly maintained, undermined and/or controlled, they can promote severe disruption in youth training [8,9]. This disruption can occur because adolescents generally still have difficulties to predict the future consequences of their actions performed in the present [1,3].

The moral development of adolescents and the mature minor doctrine

There are several theories that attempt to explain and understand the psychological and moral development of adolescents. Studies report different aspects related to progressive evolution and organization of human structures at various levels, such as mental, cognitive, affective, social and moral [10,11].

In most cases, authors who have addressed the study of moral, cognitive and psychological development of adolescents report that human development, in all its facets, occurs in synchronous way and it is very complex [1,3,6,12]. It should be emphasized that the term "mature" refers to the possibility of achieving a degree of development of psychic structures, which is done gradually and progressively. Since then, the ideal goal of human evolutionary process is the convergence and integration of all aspects in a structured and defined personality [9,11].

In his thesis, Brusa [13] stated that the issues of bioethics and research ethics, especially in relation to adolescents, it is important to have some knowl-

edge about the theories of moral development and cognitive development of people [6,14], as well as social learning (Durkhein, Bandura) and psychoanalytic theory (Freud, Erikson) [6].

In this paper, however, we will not expose in detail all these theories, but we will stress the importance of some such as elaborated by Kohlberg [14] and Gilligan [6], who strengthen the bioethical discussions and perform theoretical support for the construction of the guidelines related to the autonomy of adolescents. However, it is necessary to reaffirm the outset the complexity of the studies involving the moral development of human beings. Also, it is important to emphasize that moral development continues throughout life, although it is most important in the early decades, because during this period structure is the fundamental core of the individual who will interact with the outside world [1,3].

Historically, it was in the United States that the legal doctrine of mature adolescents was originated. The expression mature adolescent means that person who has not reached the legal age yet, but that is humanly and psychologically mature to enjoy and exercise their rights [7]. Another concept that it is added to this is the capacity. For Brusa [13], capacity is a term that belongs to the legal field.

Although countries have legal rules establishing different standard ages for civil capacity and they are in the ideal plan applicable to the clinical context some adopt the call capacity per task, recognizing the ability to make decisions about health behaviors and medical treatment before full civil capacity, as defined by Denmark and Norway at 15 or Spain to 16 [7,8,13]. In Argentina, for example, people aged between 18 and 21 years old are considered capable, according to acts that may legally practice and decide; in Brazil, the rule is the full civil capacity after 18 years old. However, for a significant portion of the experts who work with teens in general young, at 14 years old, would present the necessary conditions for making decisions on some tasks and, significantly, skills on their own health [10,11,13].

There are several theories that discuss different types or models for promoting autonomy. One of the most recent trend is the person-centered model – which aims to promote the right to self-determination of minors and seeks to promote the rights of children and adolescents by encouraging autonomy and ability to make decisions. This fact is reflected in official positions, such as the American Association of Pediatrics and the Society for Adolescent Medicine, which issued the document entitled Guidelines for Adolescent Health Research [10,11,13].

The theory of moral development Kohlberg [14] is one of the best known and, for its innovative, in-depth study of the subject, psychologist achieved significant international recognition. It is considered a universalist theory. Accordingly, he believed that human beings could reach a full moral, autonomous and independent consciousness of culture of the country or social group to which the person belonged [14-17]. The author discussed that moral development would take place in six stages, where each has its own characteristics and would depend on the age of people.

In the last stages proposed by the psychologist, that would be the highest levels of the evolutionary scale, the moral principles of individuals would be grounded in principles of autonomy and justice. He believed, therefore, that through an interactive maturity process and all human beings would have the ability to reach full moral competence assessed then by the characteristics that qualify the criteria of post-conventional morality [16,17].

However, a striking point of this theory would be by Kohlberg, on the irreversibility of the stage reached by the people, i.e., with no possibility of regression in them – at least significantly –, because each stage was associated with distinct characteristics and wider than before. Moreover, for the same reasons we could not get through a stage before the other [12,15].

Carol Gilligan [6], when she studied more specifically the developmental psychology of women, analyzed and described the formation of feminine identity and the evolution of its moral judgment from adolescence to adulthood. In her studies, she included men and women, contrary to what Kohlberg did [14] – her teacher –, who considered only males in his research.

Gilligan [6] dissented in part, the ideas of Kohlberg stressing the existence of a gender bias in surveys of her predecessor. In some of her conclusions, she states that, for men, identity formation precedes intimacy and the generation of separation cycle and human attachment and separation cycle. For women, these tasks – identity formation, intimacy, separation and attachment – seem to arrive together. The issue of intimacy and relating accompanies the formation of feminine identity. When a woman comes to know herself, she does so through her relationships with others.

According to Gilligan [6], the woman learns to exist for others and care for others. Only in more developed and mature emotional stages she learns to recognize the perception of her own self and her

inner voice, as relevant as that of others, and learn how to take them into account. It would not occur to men in the same way. The timing would be different. Overall, first of all they form their own identity. The sense of relationship comes later and does not constitute the main aspect of their lives, as it happens with women.

Gilligan [6] also notes that women are socialized in an ambiguous moral standard, distinct from the ascribed to man, which remains the ambivalence between ethic of care for others and ethics care herself. In socialization of women something that causes great inner turmoil that often hinders or disrupts her entire development process is taught: the existing dilemma between what she is taught about the selfishness and what is taught about not harming others. That is, for a woman any personal option that meets the option of others, even if that choice is legitimate, can be taken by herself and by others as a selfish attitude. Taking care of herself can, in this sense, be seen as selfishness. For the male socialization that does not work as truth. The concept of taking care of himself is generally legitimate for men and so they understand.

The psychologist [6] recalls that predicting consequences of their own acts also means mature. Thinking and reflecting on life itself can initiate a crisis, but they can also, most likely, contribute to a transition to development. Furthermore, she emphasizes that understanding the truth about their own involvement in the events that lead to satisfaction, accomplishment or defeat is part of the human psychic maturation process. Without this awareness and understanding, little or nothing changes. After that, there is still long way to go.

By taking into account part of these theories, it is important to take and analyze pursuant to some current concepts mature minor theory. According to Partridge [18], *the category of the mature minor has developed in American law as a legal device designed to equip adolescents with decision-making authority concerning medical treatment equivalent to that of adults*. He adds that in the legal field, at present, such a statement is considered controversial.

Thus, many lawyers consider adolescents as not capable to make many decisions as if they had the maturity of adults. Emphasized by the abovementioned author, the mature minor doctrine would be restricted to the area of clinical health decisions, with exceptional applicability. However, Partridge interprets that in recent years the exception has expanded, in addition to clinical health decisions, adding that there were *decisions to participate in medical research therapeutic nature* [19].

The premise of Partridge is guided into new epidemiological, psychological and neurophysiological studies – the latter even performed with the aid of brain imaging – which corroborate the statement that *decisions of people under 21 years old usually are, although functionally equivalent in the case of purely intellectual decisions, qualitatively inferior to the decisions of competent adults when these involve affective content* [20].

These hypotheses would be in line with Knobel [3], who has already thought that teenagers have no brain maturity enough to perform duties to assess at the present time, the future consequences of their actions and decisions. Among them, there are very customary behaviors. According to Partridge [20], *the choices of adolescents are marked by impulsivity and that the brains of people under 21 years old are qualitatively distinct from mature people when risks are weighed and decisions are made*.

From the foregoing, the strong controversy on the subject becomes clear. If the issue of health decisions by adolescent brings controversies to the fore in different areas, what can be said when the dispute involves a voluntary and autonomous participation in research?

Adolescents as research subjects

According to Guilhem [21], one of the main objectives of the guidelines on research ethics is the process of incorporating these standards by researchers, which therefore brings obvious support for the respondents, in order to protect them with responsibility, fairness and respect for human rights. However, with regard to adolescents, when they are focused as research subject, it is necessary to consider that they are living in unprecedented situations that permeate, in most cases, their everyday lives.

Epidemiological research shows, for example, that sexual initiation of young starts earlier and earlier, especially in Latin America – in Brazil and Argentina, the first sexual contact of adolescents begins around age 15. Studies with adolescents show that, after the first sexual intercourse, the occurrence of pregnancy is common, with rates between 20% and 30%. This problem can have serious consequences in the short and long term to the lives of young and for people of their coexistence [8,10,22].

Other problems that violate this particular age group are sexually transmitted diseases, especially AIDS, as well as the use of alcohol, tobacco, illicit drugs, violence and mental illness – all of them are provided by serious consequences throughout life. These factors can be added simultaneously, further increasing their vulnerability [7,8,22].

In this sense, Melamed argues that *vulnerability is a concept often used in adolescent health to characterize a state of greater exposure of young people to risky situations that may compromise their development and harmonious development. The vulnerability is associated with some form of addiction, resulted from different levels of cognitive and emotional maturation that influence the ability of decision-making in general, and specifically in the context of possible research* [8].

Given the countless heavy experiences that young people can spend in real life, in their daily life – and which they often cannot be protected –, many advocate that their participation in an ethically well-conducted research, whether epidemiological or clinical line, can be acceptable and less risky than their daily life. The question underlying this argument is: is living simply in the everyday risks that violate the young (sex in its negative exercise, violence, crises of age, depression, suicide) more acceptable than allowing them to participate in research, since they are ethically appropriate and well-conducted?

Despite – moral, ethical, legal – difficulties to conduct scientific research with adolescents, the fact is that they are necessary because these may result significant expertise to properly guide the reduction of vulnerabilities programs, prevention and health education for the age range itself. The fact is that, many times, it is not possible to apply to adolescents knowledge from research conducted with adults, since each group has its own peculiarities. In fact, it is about the psychological, social and biological characteristics of this group that studies should be focused to provide scientifically valid information for the definition of individual interventions and public policies.

In a first step, the research is conducted to uncover the appropriate circumstances; in a second, it generates the knowledge of what is intended to study and, finally, in a third step, there will be appropriate proposals targeted at knowledge produced. However, often, the bodies responsible for health programs do not sufficiently consider the reality of teenagers. Therefore, many health programs are imposed on young people, but because of their origin inconsistency they are inconsistent and ineffective [11,22].

Thus, it is important to remember that since the bioethical perspective that underlies the main guidelines on research ethics, in addition to autonomy, beneficence, i.e., the obligation to maximize benefit and avoid harm, should also be considered directive of scientific practice. Moreover, the conception of justice imposes the need to make all involved and even the society the benefits acquired in research. These basic principles do not justify depriving the participation of adolescents in research, and hence their possible direct and indirect benefits.

As noted, adolescents are linked to the acquisition of increasingly complex skills and their ability and autonomy are involved in cognitive development and personal experiences. Anyway, as several studies show, those aged 14, when they are compared to adults, are able to take appropriate decisions on various aspects of their life and health [10,11,13,23,24]. Paraphrasing Diego Gracia, one wonders *how this effect could occurs much distinction and inconsistency when we treat adolescents, and which they are not able to clinical practice in hospitals or doctors' offices, and as they are not as capable in matters that might even involve research? Why the occurrence of such a discrepancy?*. [25]

Many authors agree with the guidelines of the Society for Adolescent Medicine (SMA), which considers them as therapeutic orphans due to the difficulties imposed on them when they act as subjects of research [11]. In this context, although there are no biological, psychological and social behaviors that are typical of teenagers, research centers often reject investigations in this area due to the legal problems that may result. So, permission from parents or guardians becomes necessary for the young person is subject or a research subject.

The confidence of the young doctor and the researcher is an essential factor. With confidentiality and respect, youth may reveal issues and problems, the so-called "sensitive issues", which are fundamental for much research. If confidentiality is one of the basic requirements for the proper construction of the therapeutic relationship or research with anyone [26], yet it becomes even greater when respondents are teenagers.

Breaking this assumption means fragmenting a very significant chain, created in long term and with great emotional investment by both: the researcher and adolescents. For this reason if there is any feeling of embarrassment by adolescents, research can become distorted and present inadequacies. Diane Cohen emphasizes the need to consider that adolescents have a set of values that are transient, among

which the imposition of a decision can mean a form of paternalism, which requires justification [24].

With respect to research involving pharmacological trials with adolescents, one should be even more cautious. Such research raises questions and issues that may have serious ethical, medical and legal implications. Not by chance, even in countries where teenagers can decide about their health issues, i.e., where they are considered mature and legally able to do so, they are not allowed to have the power to decide alone on participation in clinical or pharmacological research.

In those cases, such as in Brazil, it is mandatory consent of parents or guardians, evidenced in writing, by obtaining and signing consent and informed form previously evaluated and approved by research ethics committees. Importantly, by the side of the parents or guardians, adolescents should also express agreement to participate in the study, providing their consent – i.e., exercising their autonomy.

Final considerations

Given the above, we emphasize that it is essential to differentiate the epidemiological and non-clinical areas of those more invasive searches. Rescuing the theories of moral development briefly described in this article and which allowed, in part, the basis of statements or propositions outlined therein, we connected ideas of Kohlberg 6 and Gilligan [14] which point stages of moral development to people with the appropriate development and moral insight that adolescents may have to make choices and manage their consequences. Such choices may be the decision to participate, autonomous and independently of certain types of studies, since previously evaluated by committees of ethics in research.

We stress the importance of clinical and pharmacological researches for the control/cure diseases that affect more frequently youth and adolescents, and we agreed that they should be properly conducted with the participation of this group. However, regarding the decision to participate in studies, we defended the need to separate the types of research and assign their precautions.

For certain types of epidemiological research, for example, according to the mentioned in this work, it would be reasonable to agree with the participation of adolescents without the consent of parents and/or guardians, but only with permission from CEP and of course with their own consent . We start from the idea, supported by other authors mentioned, that teenagers already have personal and private life that gives them their own identity, and that they can even include deep experiences that severe participation in certain well-conducted studies [10,11,13,27].

We also share ideas de Gracia and collaborators [27], according to which if the adults are considered capable until proven otherwise, it would be wise, considering numerous exceptions that can occur in research, reverse the judgment of disability in relates to adolescents. The authors state that such a thought would be a reversal of the presumption, because it would be considered that young people aged equal or over than 14 years old would, in principle, capable and competent in relation to matters relating to health. According to these criteria, were even able to participate in research. In order to reconsider these assumptions, these researchers claim: *the judgment of incompetence is that it would be justified* [27].

The three authors are members of the Bioethics Committee of the University Hospital of Santa Maria (Cobi/HUSM) and have no connection with research involving medicinal and therapeutic methods and techniques. Maria Teresa works with adolescents in epidemiological and/or qualitative research design.

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Participation of the authors

The three authors were responsible for the coordination and implementation of the study design. Maria Teresa Aquino de Campos Velho contributed to the bibliographic research, preparation and execution of the project, wording of the paper and proposals for reflections on the topic. Alberto Manuel Quintana contributed to the bibliographic research, preparation and execution of the project, wording of the article, reflections on the topic and review/structuring of topics involving psychology. Alvaro Garcia Rossi contributed to the bibliographic research, preparation and execution of the project, wording of the article and reflections on the subject, besides proofreading of the written text and proofreading of the abstracts in foreign language.

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