

THE STEPS TOWARDS AUTONOMY IN THE WESTERN BIOETHICAL CONTEXT

OS PASSOS DA AUTONOMIA NO CONTEXTO BIOÉTICO OCIDENTAL

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RESUMO

Este artigo consiste em uma análise documental, cujo objetivo é traçar uma revisão crítica do atual conceito de Autonomia da Pessoa perpassando pelo olhar das teorias filosóficas de Kant e Lévinas até a visão bioética na contemporaneidade Ocidental. Kant afirmava que o sujeito deve traçar para si a lei à qual deve obrigatoriamente obedecer. Essa é a autonomia esperada pelo filósofo. De outro modo, Lévinas fundamenta sua ética na heteronomia, isto é, antes de ser consciência pensante, ou mesmo livre, o sujeito é responsável pelo outro. No viés bioético, percebe-se uma preponderância da Teoria de Kant, com destaque da autonomia em detrimento aos demais princípios – Beneficência, não maleficência e Justiça. Conclui-se pela existência da Teoria do Menor Maduro em âmbito brasileiro, porém sem sua efetiva aplicação nos Tribunais Superiores.

Palavras-Chave: Autonomia. Kant. Lévinas. Bioética.

ABSTRACT

This article consists of a documentary analysis, whose objective is to outline a critical review of the current concept of Personal Autonomy, going through the philosophical theories of Kant and Lévinas up to the bioethical vision in contemporary Western times. Kant stated that the subject must draw up for himself the law that he must obligatorily obey. This is the autonomy expected by the philosopher. On the other hand, Lévinas bases his ethics on heteronomy, that is, before being a thinking or even free consciousness, the subject is responsible for the other. From a bioethical perspective, one can perceive a preponderance of Kant's Theory, with an emphasis on autonomy to the detriment of the other principles – Beneficence, non-maleficence and Justice. It is concluded that the Theory of the Mature Minor exists in Brazil, but without its effective application in the Superior Courts.

Keywords: Autonomy. Kant. Lévinas. Bioethics.

INTRODUCTION

Historically, the word autonomy has Greek origins (autos = own + nomos = rule, law, authority). Its genesis referred to a place (ethos) of finitude and vulnerability, referring to the ability of city-states to govern themselves according to their own laws and independently of

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other states or a tyrant. In other words, individual autonomy as we envision it today has its roots in the political autonomy studied by the Greek philosophers (Castoriadis, 2008).

Since then, there has been a huge theoretical tension between the individual and collective meanings of the concept of autonomy. The creation by the Greeks of politics and philosophy was the first step towards the project of autonomy.

Greek individual autonomy was understood as the ability of individuals to reflect and deliberate on the Polis, which meant "self-governing State" (Finley, 1970), a term closely linked to the autonomy of the political community. As the Greeks evolved to apply the integration of decisions, allowing them to be taken beyond the Polis, the economic cost of autonomy became evident. This is why Aristotle proposed that citizens should accept a frugal life (Matti, 1999).

The ethical-political character of autonomy, in its original Greek sense, had its first important historical conceptual variation when it began to be used in the confessional disputes of the 16th and 17th centuries to express the Protestant demand for religious and political freedom. The use it was given is related to the free will to accept, defend, believe and do what everyone considers good in the sphere of their conscience, within the limits of the laws of a state. Thus begins an internalization of the ethical-political sense of autonomy in terms of religious freedom and individual conscience (Urzu, 2016).

The second significant conceptual variation came in the second half of the 18th century by Kant, and it is considered a milestone for the current concept of autonomy, placing it at the center of the conception of the human being, reflective thought and morality, obscuring the more political Greek conceptual dimension of passage.

A third philosophical current of autonomy represented by John Stuart Mill and Gerald Dworkin appears in this study, in which autonomy goes beyond freedom in generic terms and the ability to make decisions in concrete situations.

More recently, in the West, the bioethical vision of Beauchamp and Childress (1998) with regard to the autonomy of the person has come to overlap as that which makes life be its own, which is shaped according to personal preferences and intentions of one.

This study becomes fundamental, since for the Law, autonomy in the broad sense is the foundation for the treatment of freedom as a constitutional guarantee, just as it is central to Civil Law and the exercise of civil liberties. In this context, this article aims to draw up a critical review of the current concept of the Autonomy of the Person, looking at the philosophical theories of Kant and Lévinas up to the bioethical vision in the contemporary West.

1 THE AUTONOMY OF THE PERSON IN THE LIGHT OF KANT AND LÉVINAS

In an era of exaltation of individualization and liquid love (fragile and unstable relationships) between family members themselves, the ‘Kantian’ understanding of autonomy is growing. However, it is important to note that Kant never analyzed the institute of autonomy from the perspective of ageism. In other words, Kant never defended or denied autonomy to children and adolescents in a specific way, as is the case with current Brazilian civil legislation. The author spoke on behalf of the individual, which in that context did not include children, as they were simply ignored from any theoretical-subjective analysis.

For the philosopher, a non-autonomous will is pathologically affected.

A autonomia da vontade é aquela sua propriedade graças a qual ela é para si mesma a sua lei (independentemente da natureza dos objetos do querer). O princípio da autonomia é, portanto, não escolher senão de modo a que as máximas da escolha estejam incluídas simultaneamente, no querer mesmo, como lei universal (Kant, 1995, p. 85)

Kant said that the subject must define for himself the law that he must obey. This is the autonomy expected by the philosopher. Etymologically, auto means oneself and nomos means law, i.e. “giving the law to oneself”. On the other hand, hetero, of Greek origin, means other. Kant made an important contribution to the reframing of *Aufklärung* in his work of 1784 *Beantwortung der Frage: Was ist Aufklärung*, namely “have the courage to use your own understanding” (Kant, 1995, p. 11).

The concept of adulthood (Mündigkeit) was also the subject of in-depth study, considered to be the ability to use your own understanding without others telling you how to think, how to act and how to decide. In contrast, minority (*Unmündigkeit*) is precisely “the inability to use oneself without the guidance of others” (Kant, 1995, p. 11-12)..

Kant believed that every human being should seek adulthood, i.e. emancipation, by not allowing foreign causes (emotions, feelings, passions and ideas of others) to influence their actions heteronomously. At that time, there is no link between autonomy and biological age, not least because the issue of adulthood is a recent one. It is often said that adolescence is an invention of the late 19th and early 20th centuries, the century of adolescence, according to Ariès (1978). It's possible that Kant didn't even think about children and adolescents in his age concepts, for these reasons.

In this way, to be autonomous is to have the capacity (*Vermögen*²) to think for oneself, to be the own master of one, without interference from others telling you how, where and in

²Na tradução literal do idioma alemão significa “ativo”.

what way to do things. Thus, values or decisions that are not drawn from the internal parameters of the subject cannot be seen as a universal value, since the principle of action has been obtained heteronomously. Therefore, heteronomy occurs when “the will does not give itself the law, but it is a foreign impulse that gives the law” (Kant, 1995, p. 90).

For Kant, heteronomy is the subjection of the individual to the will of others, or to the will of a collectivity, not belonging to reason and moral laws (Bresolin, 2013). In other words, the principle of action is the autonomy of the will, which is determined only by the law.

In contrast to the traditional thinking of Kant on autonomy and heteronomy, we have the writings of Emmanuel Lévinas. However, before talking about autonomy from the perspective of this philosopher's studies, it is necessary to bring up the institute of vulnerability, since, in the voice of common sense, it is the preservation of vulnerability that prevents the development of autonomy. This article will show that Lévinas' understanding is different from common sense.

Vulnerability as an innate, universal (human) condition is a topic that has been treated with favor by the academic community, and much of this is due to the reflections of Lévinas. Since the early 1970s, the author had been developing a new face for vulnerability, which was only disseminated by bioethics theorists in the 1990s. Vulnerability was defined by the philosopher as subjectivity, envisioning the self, always subsequent to otherness, to the other who necessarily exists before the self and who calls the self into existence. So, all subjectivity is in relation, the relationship with another, in dependence on the other that makes it be. Subjectivity is therefore originally and irreducibly dependence, exposure to the other and, therefore, vulnerability (Levinas, 1993, p. 43).

The subjectivity of the human being has two faces: that of vulnerability, which exists because of the simple finitude of the man, and that of responsibility when he responds positively to the call of the other, always as a call for a non-violent relationship, respecting his moral and cultural principles, among others (Levinas, 1993, p. 98). Vulnerability thus enters the philosophical vocabulary as a constitutive reality of man, as a universal condition of humanity and as indissolubly linked to the responsibility of the other in the face of the threat of perishing existence.

For Lévinas, vulnerability came to be understood as a noun, no longer an adjective, i.e. it could not be used to distinguish people or social groups, precisely because it is a universal condition of the living, consolidating itself in the vocabulary of continental European philosophy as an inalienable domain of human action and imposing responsibility as the norm of moral action. To be responsible is to respond to the threat of the perishable (vulnerable).

Lévinas, therefore, saw vulnerability as a positive discrimination of the human being, something that composes him and makes him special. Needing the other is necessary in the face of the perishable condition of the human being, in the same way that it leads to a relational bond that is necessary and important for their own development. It so happens that the bioethical discourse, especially due to the growing use of this term in the language of clinical studies, has introduced the term vulnerability in the light of a negative discourse (Neves, 2001, p. 860), disseminating the idea that to be vulnerable is to be inferior in your decision-making limits.

Kipnis (2001, p.38), a bioethical philosopher and professor at the University of Hawaii, for example, defined vulnerability as the condition of "distinct precariousness of the subject, especially exposed to something harmful or undesirable", and distinguished six types of vulnerability considered ethically relevant and useful for developing a practical checklist of circumstances that could potentially invalidate research.

The types of subject vulnerability referred to by this author are: cognitive (ability to deliberate and decide), legal (degree of submission to the authority of other people), different (differential behavior that could mask unwillingness to decide), medical condition (health problem for which satisfactory treatments are not available), allocation (lack of social goods that could be provided in the research) and infrastructure (integrity and resources of the research environment to manage the study). In all the classifications, there is a pejorative meaning to the word vulnerability.

For his part, Luna (2008), who has made numerous contributions on "vulnerability", brings together criticisms and positions from various authors and highlights the value of an in-depth analysis that makes it easier to understand why some people can be seen as vulnerable. This author considers the concept of vulnerability as dynamic and relational in order to formulate the idea of "layers", an idea that provides more flexibility, highlighting the possibility of the simultaneity of multiple factors that can be removed one by one, such as social circumstances, degree of autonomy during the informed consent process, advanced age or some degree of cognitive impairment. In other words, the "metaphor of layers", as a representation of vulnerability, implies recognizing different circumstances that can impose such a condition on a subject, which are not permanent, and which, on the contrary, can vary throughout life. It is important to note that the so-called "layers" involve unprotected situations, making the subject more exposed to damage with a greater number of layers.

The positive heteronomy described by Lévinas would only be possible in a fertile field of dialog between the subjects involved in a given decision - the State, family and society.

This is what *Alasdair MacIntyre* (1999) called a support network, because recognizing the vulnerability and dependence of human beings implies recognizing that we need others to flourish, to become what we should be, agents capable of independent reasoning.

As virtudes que nós precisamos, se vamos desenvolver de nossa condição animal inicial até aquela de agentes racionais independentes, e as virtudes que nós necessitamos, se vamos confrontar e responder à vulnerabilidade e deficiência, tanto em nós mesmos como nos outros, pertencem a um e mesmo conjunto de virtudes, as virtudes peculiares aos animais racionais dependentes, cuja dependência, racionalidade e animalidade têm de ser entendidas em relação umas com as outras (Macintyre, 1999, p.5. Tradução nossa.)

In a lecture given at the IV Luso-Brazilian Bioethics Meeting held in the city of São Paulo, Neves (2006, p. 166) summarized the difference between the Anglo-American view of vulnerability (negative, adjective function) and the European view (innate, substantive function) as follows:

de função adjetivante, qualificadora de alguns grupos e pessoas, a vulnerabilidade passa a ser assumida como substantivo, descrevendo a realidade comum do homem; de característica contingente e provisória, passa a condição universal e indelével; de fator de diferenciação entre populações e indivíduos, passa a fator de igualdade entre todos; da consideração privilegiada do âmbito da experimentação humana, passa para uma atenção constante também no plano da assistência clínica e das políticas de saúde; de uma exigência de autonomia e da prática do consentimento informado, passa à solicitação da responsabilidade e da solidariedade (Neves, 2006, p. 166).

It is in this scenario of a natural, positive and necessary understanding of vulnerability that Lévinas reflects on the institute of autonomy. Otherwise, *hetero*, of Greek origin, means other. In the essay *Liberté et commandement* (Levinas; Perpezac, 1993, p. 15-19), Lévinas deals with tyranny as a voice that disguises a “false autonomy”. Thus, it can be understood that man is capable of obeying the tyrant's order, believing it to be his own. This is because tyranny has means at its disposal - from torture to intimidation, from propaganda to a pact of silence, from threats to seduction - that can demolish the power to obey freely, eliminating the very conscience of tyranny. By deciding in the belief that he is exercising his autonomy, man may be obeying the tyrannical order, in a context of subordination, alienation, dependence or even the physical and/or psychological suffering that an illness may present (common in clinical trials). Violence lies precisely in the natural inclination to obey, which is no longer conscious (Levinas; Perpezac, 1993, p.17)

For Lévinas, freedom is the power to renounce decision and to “institute an order of reason outside oneself”. Laws and institutions (including the family) are the voices that prevent tyranny. However, the law that removes this power of renunciation is also a form of tyranny (Levinas; Perpezac, 1993, p.19)

The whole discourse of the mentioned philosopher runs through the idea of ethics. Leaving the self to reach the other. The author states that the other will first be a figure, incomprehensible, generalized, and then recognized individually. The other is what transcends the self, its opposite, and to be tyrannical is to refuse this opposite reality, considering only the general, the figure (Levinas, 1980, p. 218). If you look only at the figure, the general, “the naive right of my powers”, you discover yourself to be tyrannical, arbitrary. The other completes, does not threaten, since it becomes the limit of injustice, of what he could have done and did not do. The moment man refuses to see the other and listen to them, refuses to heed their command in the face of their vulnerability, he is exercising injustice (Levinas; Perpezac, 1993, p.19).

É em nome da responsabilidade por outrem, da misericórdia, da bondade às quais apela o rosto do outro homem que todo discurso da justiça se põe em movimento [...]. Infinito inesquecível, rigores sempre a abrandar. Justiça a se tornar sempre mais sábia em nome, em memória da bondade original do homem para com seu outro, em que, num desinteressamento ético – palavra de Deus! – se interrompe o esforço interessado do ser bruto a perseverar em ser. Justiça sempre a ser aperfeiçoada contra suas próprias durezas (Levinas, 2004, p. 294).

There is also an important point to be emphasized: the responsibility of the self, not only for the fate of the other, but also for the fate of the collective. In this respect, Lévinas does not reject the principle of “resistance to evil”, exercised by violence and the State, since in their absence of the responsibility of the man would have no limits (Levinas, 2004, p. 296).

Lévinas bases his ethics on heteronomy, i.e. the other challenges me, and their face constitutes a commandment that makes me responsible for them. There is no option. I am responsible for the other to such an extent that I am even responsible for their responsibility. Thus, the philosopher will not base his ethics on the consciousness of the subject, like Kant, but, before being a thinking consciousness, or even free, the subject is responsible for the other. Ethics is based on the heteronomy of the other (Bresolin, 2013, p. 177).

The ethical relationship is therefore disinterested, an emptying of oneself towards the other. Thus, “to suffer for the other is to be responsible for him, to bear with him, to be in his place, to be consumed by him” (Levinas, 1993, p. 119). Here, it is worth highlighting the theory of radical alterity in the works of Lévinas, which is supported by ethical listening (sensitive, emotional, affective), and not by rational ethics. Radical alterity for Lévinas means not seeing the other as an object of appropriation, of domination, annulling their alterity and transforming them into the self, but rather seeing their individual characteristics in the other, making the decision for them and for them, in their individual conditions.

As the author says:

O outro mantém-se e confirma-se na sua heterogeneidade logo que é interpelado, quanto mais não seja para lhe dizer que não se lhe pode falar, para o catalogar como doente, para lhe anunciar a sua condenação à morte; ao mesmo tempo que apanhado, ferido, violentado, ele é ‘respeitado’. O invocado não é o que eu comprehendo: não está sob uma categoria. É aquele a quem eu falo (Levinas, 1980, p. 56).

Freedom only becomes meaningful through responsibility. That's why responsibility and then freedom, with the former giving meaning to the latter. To be free is to serve the other, it is a disinterest of the self, an emptying with no turning back and no expectation of retribution. As Lévinas says: "If it didn't exist, we wouldn't even say, in front of an open door: 'You first! It is an original 'You first!' that I try to describe [with the ethics of radical alterity]" (Levinas, 1982, p. 81).

What must be defined from this reflection is how to offer the person theoretical, reflective, critical, biopolitical and social support so that alterity leads to an ethical and just autonomy through the positive, real and innate vision of vulnerability. Undoubtedly, the State and the family are fundamental parts of this whole process.

2 THE BIOETHICAL VIEW OF AUTONOMY IN WESTERN CONTEMPORANEITY

The first face of autonomy to be presented in contemporary Western society will be in the light of bioethics. Although the idea of dignity in the Kantian sense is part of the current theoretical construct of autonomy in bioethical discourse, a third philosophical current of the term emerges, taken up by John Stuart Mill and Gerald Dworkin, because autonomy goes beyond freedom in generic terms and the ability to make decisions in concrete situations:

A ideia de autonomia não é simplesmente uma noção avaliativa ou reflexiva, mas inclui a capacidade de mudar as preferências de uma pessoa e torná-las efetivas em ações e, de fato, torná-las efetivas porque se refletiu nelas e as adotou como próprio (Dworkin, 2009, p. 17)

Autonomy as the possibility not only of making decisions in a rational and coherent way, but also of introducing changes and preferences during the course of life of someone, is a key point for the idea of autonomy in bioethics.

The State should only intervene, through the law, in the life plans of the subject when justified in order not to cause harm to third parties, and the individual should act in accordance with their beliefs and preferences, even when they choose something that is not good for them (Mill, 1991). The idea of freedom of Mill, which aims to limit the paternalistic action of the State, is a negative freedom or freedom of non-intervention which, as Isaiah

Berlin (1988) pointed out, differs from a positive freedom that has to do with the connection between democracy and freedom.

For Dworkin, the autonomy of the individual has two types of interest: experiential interest and critical interest. The first concerns the simple pleasures of a good life, while critical interests involve the satisfaction that life is genuinely better based on critical judgments, and not mere preferences about experiences (DWORKIN, 2009).

Autonomy is one of the four principles commonly used in the bioethical analysis model known as "principlism", introduced by Beauchamp and Childress in 1989. These authors propose four fundamental bioethical principles: autonomy, beneficence, non-maleficence and justice.

For Beauchamp and Childress (1998, p. 117), autonomy refers to that which makes life be one own, which is shaped according to the personal preferences and intentions of one. Faced with such a situation, you can argue with the agent to convince them or beg them to do the opposite, without imposing the idea. To be an autonomous agent is to have "a substantial degree of understanding and freedom from some coercion" (BEAUCHAMP; CHILDRESS, 2011, p. 141)

However, the concept of autonomy goes beyond personal preferences, since the concept is linked to its exercise that is, "treating the person in such a way as to enable them to act autonomously" (BEAUCHAMP; CHILDRESS, 2011, p. 143). Being able to understand the situation is the key to being able to make an autonomous choice. This principle is expressed in not intervening in their decisions, valuing and respecting the other person's values, often not identified by the interlocutor, acting in such a way as to guarantee the subject the ability to act for themselves. In other words, it is not enough not to intervene, but to mitigate the elements that take away the power of decision, such as fear or lack of information.

Thus, Beauchamp and Childress make a distinction between the capacity of the subject to be autonomous and the effective realization of autonomy. With this distinction, they introduce nuances in relation to more abstract theories, such as the one of Dworkin, which make the autonomous subject still an ideal construction (BEAUCHAMP; CHILDRESS, 1998, p. 115). Autonomy as a power or faculty is one thing and autonomy as an act or choice is another.

An autonomous person can make non-autonomous choices and vice versa. At the level of the analysis of the agent, an action is autonomous when it is carried out: i) intentionally (not gradable); ii) with understanding (adequate and complete information); in the absence of

external influences that seek to control and determine the act (coercion or manipulation). The latter two can vary to varying degrees (BEAUCHAMP; CHILDRESS, 1998, p. 116).

Despite the fact that the principle of autonomy has a strong basis in respect for values and beliefs, autonomy is also anchored in the right to privacy, which encompasses the way individuals perceive themselves and their personal relationships (BEAUCHAMP; CHILDRESS, 2013, p. 106). In addition, there is a duty to protect confidential information, tell the truth, collaborate in the decision-making process and request informed consent from patients for interventions or treatments.

3 THE PROMINENCE OF AUTONOMY TO THE DETRIMENT OF OTHER BIOETHICAL PRINCIPLES

Autonomy should be seen as complementary to the other bioethical principles - non-maleficence, beneficence and justice - forming an integrated support network for making the final decision. The fact is that in the face of as many principiologial and theoretical nuances as the principles themselves, autonomy in the light of bioethics does not have precise conceptual limits, as is usually the case in legal and political venues, which calls into question its supposed central normative function as a guide for moral conduct, in other words, that of an ethical principle.

A necessary confrontation is between the Principle of Beneficence (or non-maleficence) and the Principle of Autonomy of Will. For decades, the former has reverted to an image of paternalism on the part of health professionals or researchers, who use the maxim that both medicine and research are used for the benefit of the subject; thus, reducing their autonomy is understandable when there is a greater good to be offered, even if the person doesn't want it (WETTERNICK, 2005).

To advance in the defense of autonomy is, in some cases, to reduce the role of beneficence when, for example, in a clinical study the researcher knows the good that the results of the research will bring to the child as a person, but does not have favorable decision-making support from the family or the child himself and, for this reason, does not include him as a participant in the research. When there is a clash of principles - autonomy vs. beneficence - which one should prevail?

Even more obscure is the situation in which the child wishes to take part in the research, but the family does not authorize it. In this case, would the Principle of Beneficence,

combined with the Principle of Autonomy of the child, be enough to overcome the lack of consent from those responsible?

The fact is that in the two problems raised above, the reflection of Lévinas must be taken into account, in order to analyze whether this supposed “autonomy” of the child is the expression of tyranny.

Apparently, guaranteeing the application of both principles in their entirety is impossible. As Professor Daisy Rafaela aptly put it, “(...) it's like having a small blanket; choosing whether to cover your foot or your head will always be a flawed action, because both parts are unique parts of an indivisible whole” (RAFAELA, 2014).

In cases such as these where fundamental principles clash, doctrine and case law have followed the path of conciliation between the principles, so that each one is applied to varying extents, according to its relevance in the specific case, without, however, excluding any of them. To this end, it is accepted that each principle has an abstract weight, which varies according to the case in question.

Conflicts between principles must be resolved by weighing them up, through an analysis of proportionality, in order to define which of the clashing interests is more relevant (WANDERLEY, 2014). The application of both conflicting rights must be sought, even if one of them is attenuated. Mendes and Branco (2014) put it this way:

(...) [o princípio da proporcionalidade] exige que o sacrifício de um direito seja útil para a solução do problema, que não haja outro meio menos danoso para atingir o resultado desejado e que seja proporcional em sentido estrito, isto é, que o ônus imposto ao sacrificado não sobreleve o benefício que se pretende obter com a solução. Devem-se comprimir no menor grau possível os direitos em causa, preservando-se a sua essência, o seu núcleo essencial (modos primários típicos de exercício de direito). Põe-se em ação o princípio da concordância prática, que se liga ao postulado da unidade da Constituição, incompatível com situações de colisão irredutível de dois direitos por ela consagrados.

It is very difficult to establish a consensus in the field of ethics, especially when the aim is to achieve universally accepted ethics, as can be seen in the main North-Western theories. Apart from the consensus on the existence of the four basic principles of bioethics, there are few other consensuses in bioethics, starting with the lack of consensus on the absence of hierarchy between them. Although autonomy was the last principle to be incorporated into bioethics, since it is related to individual freedom (of the patient), and this is a modern concept, the fact is that in many situations there is a preponderance and exaggerated protagonism of formal autonomy in the Western world, without any concern for the capacity to exercise it. This is no different in Brazil.

Bioethics may be paying a high price for practically making the defense of autonomy its *raison d'être*. This price has to do with promoting (or colonizing) the individualistic biopolitical vision that prevails in most North-Western countries, unaccompanied by an effective support network and reflection on otherness and its genuine nature.

In the same line of debate, seeking to deepen the institute of autonomy and the possibility of the vulnerable participating in bioethical decisions, various theories emerged from the 1990s onwards, including the Ladder of Participation Theory of Hart.

Roger Hart is an American academic, known worldwide for creating the symbolic example of the 'ladder of participation' of the subject, published by Unicef in 1992 in the document entitled "participation of children: from tokenism to citizenship", considered one of the pioneering works in the field of studying child participation.

Amstein (1979), through his theory of participation, was the main theoretical reference for the creation of the ladder presented by Hart, who created eight levels of participation: manipulation, decoration, tokenism, delegation with information, consultation and information, process initiated by the adult but shared with the children, process initiated and directed by the child and process initiated by the child but shared with the adult (HART, 1992).

The 'ladder of participation' has two parts. The first integrates the first three levels (manipulation, decoration and tokenism), in which the child does not participate. On the first level, the lowest rung of the ladder, called 'manipulation', adults feel that the end justifies the means. An example given by the author is that of pre-school children carrying political posters about the impact of policies on children. If children don't understand the issues and therefore don't understand their actions, this attitude is being induced by adults, probably because they are unaware of children's capacities to participate, which makes them closer to being mistaken than manipulative, but in any case there is certainly a need for better awareness on the part of adults (HART, 1992, p. 9).

The author warns that many organizations have begun to conduct opinion searches and referendums with children in order to "give them a voice"; however, despite being a method with considerable potential, they are susceptible to manipulation, especially in the case of pre-adolescent children, who become easy prey for this technique due to their varied abilities to interpret the meanings and purposes of such instruments (HART, 1992, p. 9).

At the second level, which is called 'decoration', children are used as decorative figures, with no knowledge of the causes in which they are involved, for example, an adult puts a shirt of a certain political party on their child and takes them to campaign in the streets.

In other words, although they are taking part, they have little idea of what it's all about and have nothing to say about the cause.

The level called 'tokenism' translates into a situation where the child is apparently given a voice, but in fact has little or no choice in the matter or little or no opportunity to formulate their own opinions. This situation seems to be common in the Western world due to progressive ideas about child-rearing that are often acknowledged but not truly understood. As you can see, at these first three levels of the participation ladder, real participation is not considered to exist.

The second part, which brings together the remaining five levels (delegation with information, consultation and information, process initiated by the adult but shared with the children, process initiated and directed by the child and process initiated by the child but shared with the adult), already refers to genuine participation by the children (Hart, 1992, p. 11).

The fourth level, called 'delegation with information', points to the intervention of the children in the planning of projects, being informed about the actions they take, unlike the next level (fifth), called 'consultation and information', where the children are consulted, not just informed about something, and their opinion is taken into account for the act.

The sixth level is called 'shared decisions, initiated by adults with children', and deals with the process initiated by the adult, but shared with the child, by listening to them and truly participating in the decision-making process. At the seventh level, 'child initiated and directed', the process is initiated and directed by the child, who guides the whole process, with the adult merely facilitating it. And finally, at the eighth level, called 'process initiated by the child but shared with the adult', the child takes on the role of the adult, guiding the projects and sharing the decisions with the adult (Hart, 1992, p. 12-14).

In view of these levels, it can be concluded that the participation of the children in the decision-making process regarding their learning, level by level, increases and, as they move up the ladder of participation, their dependence on the adult decreases. For the author, the 'steps' on the ladder do not mean that one level must lead to the next, and that the ultimate goal of each project is to reach the eighth level. The reality is that initiatives involving children have such different objectives, and the level they start at can vary widely (HART, 1992, p. 11).

It can be concluded that the reason behind the classification by levels has to do with a conception that there are factors that condition the modes of participation, such as cultural contexts, for example, as well as the degree of autonomy, competence and interest of the

children. Although the ladder does not refer to the notion of progressivity associated with the age issue, for the purposes of analyzing how younger children participate, for example, these classifications can assume that their social and linguistic competence has an impact on the forms and levels of participation, placing early childhood at the symbolic, simple or consultative participation levels.

Otherwise, participation should not be a decree, an imposition, a decoration. In this way, Hart looks more closely at experiences with children in which they can engage in genuinely participatory processes. The ladder indicates the starting point for thinking about participation of the children in projects, rather than being the final model (HART, 1997).

The image of the ladder can be a useful guide for assessing the extent to which children are or could be participating, with so many interpersonal and structural barriers to overcome. One of the biggest of these is the fact that funders rarely support the initial and follow-up stages of research, described earlier as so important for young people.

The fact is that there is no society that fully offers children the maximum opportunity for real participation at all times, especially considering the democratic political and social system, in which children are expected to participate effectively, but which also carries the contradictory possibility of non-participation as a right.

In Brazil, the theory that comes closest to the lines of reasoning of Ladder of Participation Theory of Hart is called the Mature Minor Theory, which defends the autonomy of the subject not in any situation, but when it comes to fundamental rights to health and well-being. Or, going further, when it comes to personality rights, especially rights over the own body of someone. In these situations, it can be said that the mature minor has the capacity to judge. The fundamental difficulty lies in the need to assess the capacity of the child, which must allow them to discern clinical and therapeutic information (capacity for autonomy), that is to say that they sufficiently understand and rationalize the decision they are going to make, and this requires a cognitive level in which abstract thought and rationalization appear:

[...] Uma vez iniciado, o profissional de saúde pode ajudar, alertando que as práticas de risco, frequentes entre os adolescentes, devem ser evitadas, embora tenham recebido informações a esse respeito. Justamente por isso, é aconselhável estar atento para detectar possíveis doenças sexualmente transmissíveis (DST), gravidez ou alterações do humor. Se for um adolescente com maturidade suficiente para sua idade, não haveria necessidade de quebra de sigilo, mas seria preciso considerá-lo em alguns casos, como: parceiro adulto (com diferença de idade, por exemplo, por volta dos 10 anos), parceiro com risco (conhecido) de DST, promiscuidade, adolescentes muito jovens (12 ou 13 anos). Nestes casos, se o menor se recusar a informar os pais, é necessário considerar a quebra do sigilo, pois existe um risco elevado de danos ao paciente (ESPÍLDORA; TROTA; MARROQUÍN, 2010, p. 347-348).

As for the need to apply heteronomy, due to the lack of maturity of the subject, in principle, it is considered that the parents are the most appropriate people to make the decision. However, in practice, there are situations where this is not the case, and others where it is difficult to prove. Some families are so dysfunctional that it's not easy to turn to the parents to look after their children, hence the importance of strengthening the support network and public social policies to structure the family. There are also situations where there is a lack of mental health or serious social problems that make it difficult for legal guardians to make decisions in these situations. Therefore, in certain cases, it may be advisable to turn to other family members, as well as social services (MARTÍN ESPÍLDORA; ALTISENT TROTA; DELGADO MARROQUÍN, 2010, p. 348-349).

Thaís Sêco (2014) criticized this theory, pointing out that its proposal consists of evaluating situations in which the maturity of children would be confirmed based on decision-making behaviors that would be close to the standard established for the 'average adult male'. For this author, the theory of the mature minor is not consistent with the perspective of effective protection of freedom and autonomy, since this criterion would seek an average standard, homogenizing and unable to promote pluralism.

The fact is that Brazil has never confronted the 'Mature Minor Theory' in its Superior Courts, neither to remove it from concrete situations, nor to support it, which can be proven by a quick search on the official websites of the Superior Court of Justice and the Supreme Federal Court, which demonstrates how much the traditional model of parental heteronomy is still the foundation of everything that is known about civil capacity in Brazil.

CONCLUSION

The institute of Autonomy is something robustly studied by several areas of knowledge for centuries, which does not rule out the antagonism in the conclusions and failure in the search for a perfect concept. While for Kant autonomy is the absence of external influences to the subject, Levinas believed that only heteronomy could bring ethics into the decision process.

In the western world bioethical debate, it was verified the protagonism of the Kantian understanding, being considered the autonomy by the percussionists Beauchamp and Childress as what makes the life is own, that is shaped according to their personal preferences and intentions. In recent decades, autonomy has become the most valuable and prominent bioethical principle in international decisions, to the detriment of the classic beneficence and

not maleficence. It is the reflection of the neoliberal economic system, in which the separation of the state from economic relations guarantees the advance of capitalism.

In this line, when it comes to the autonomy of the child, several theories have emerged in the West in order to move away from the purely age-related approach, imposing a flexible system of subjective analysis of the aspects of maturity and as is the case of Ladder of Participation Theory of Hart and Mature Minor Theory.

Although there is no decision of the Superior Courts that supports the application of modern theories in the autonomy of the person, there was a range of Brazilian doctrinaires who raise the flag of the prevalence of autonomy of will in cases involving fundamental rights of the infant. Thus, principles such as the Constitutionalization of Civil Law, the Best Interest of the Child and the Protection of Human Dignity have been founding the theoretical possibility and moving away from the cold and dry application of the current theory of disabilities in Brazil.

REFERÊNCIAS

ARIÈS, Philippe. **A História social da criança e da família**. Rio de Janeiro: Guanabara, 1978.

BEAUCHAMP, Tom L.; CHILDRESS, James F. **Princípios da ética biomédica**. 2^a ed. São Paulo: Ed.Loyola, 2011.

BEAUCHAMP, Tom L.; CHILDRESS, James F. **Princípios de ética biomédica**. São Paulo: Edições Loyola, 2013.

BERLIN, Isaiah et al. **Cuatro ensayos sobre la libertad**. Madrid: Alianza, 1988.

BRESOLIN, Keberson. Autonomia versus heteronomia: o princípio da moral em Kant e Levinas//Autonomy versus heteronomy: the principle of morality in Kant and Levinas.

CONJECTURA: filosofia e educação, Caxias do Sul, v. 18, n. 3, p. 166183, set./dez. 2013.

CHILDRESS, J. A Principle-based Approach. In: *A Companion to Bioethics* (H. Kuhse & P. Singer, eds.), Oxford: Blackwell Publishers Ltd. p. 67-76, 1998.

DWORKIN, Ronald. **Domínio da vida**. São Paulo: Martins Fontes, 2009.

FINLEY, Moises.I. **Os Gregos Antigos**. Lisboa: Edições 70, 1970.

HART, Roger A. **Children's participation**: the theory and practice of involving young citizens in community development and environmental care. London: Earthscan/UNICEF, 1997.

HART, Roger A. **Participação de Crianças**: da indicação falsa até a cidadania. UNICEF, 1992.

KANT, Immanuel. **Fundamentação da metafísica dos costumes**. Lisboa: Edições 70, 1995.

KIPNIS, Kenneth. Vulnerability. In Research Subjects: A Bioethical Taxonomy. En N. B. Commission, Ethical and Policy Issues in: **Research Involving Human Participants**. Commissioned Papers and Staff Analysis. Vol. II. 2001.

LEVINAS, Emmanuel. Entre nós: ensaios sobre a alteridade. 3 ed. Petrópolis: Vozes, 2004.

LEVINAS, Emmanuel. **Humanismo do outro homem**. Petrópolis: Vozes, 1993.

LEVINAS, Emmanuel. **Ética e infinito**. Lisboa: Edições 70; 1982.

LEVINAS, Emmanuel. PEPERZAK, Adriaan. **Ética prima come filosofia**. Milão: Guerini e Associados, 1993, p. 15-19.

LEVINAS, Emmanuel. **Totalidade e Infinito**: Ensaio sobre a exterioridade. Milão: Jaca Book, 1980.

LEVINAS, Emmanuel. **Humanismo do outro homem**. Petrópolis: Vozes, 1993.

LUNA, F., & SALLES, A. **Bioética**: Nuevas reflexiones sobre debates clásicos. 1 ed. Buenos Aires: Fondo de Cultura Económica. 2008

MACINTYRE, Alasdair. Dependent Rational Animals: **Why Human Beings Need the Virtues**. Chicago: Open Court Publishing Company, 1999. (The Paul Carus Lectures Series, 20).

MARTÍN ESPÍLDORA, M. N.; ALTISENT TROTA, R. DELGADO MARROQUÍN, M. T. La intimidad, la confidencialidad y el secreto médico en la relación clínica con adolescentes. In: LÓPEZ, M. de los R.; JACOB, M. S. (Ed.) **Bioética y pediatría**: proyectos de vida plena. Madrid: Sociedad de Pediatría de Madrid y Castilla, 2010, p. 341-349.

MATTLI, Walter. **The Logic of Regional Integration**. Cambridge: Cambridge University Press, 1999.

MENDES, Gilmar Ferreira; BRANCO, Paulo Gustavo Gonet. **Curso de Direito Constitucional**. 9^a ed. Rev. e Atual. São Paulo: Saraiva. 2014.

MILL, John Stuart. **Sobre a liberdade**. 2^a ed. Petrópolis, RJ: Vozes, 1991.

NEVES, Maria Patrão. Na senda da responsabilidade moral. In: **Poiética do Mundo**. Homenagem a Joaquim Cerqueira Gonçalves. Lisboa: Edições Colibri, 2001.

RAFAELA, Daisy; FERNANDES, Thais. A polêmica das biografias não autorizadas: O limiar entre o direito à intimidade x liberdade de expressão. In: **Direitos Humanos e Sociedade Contemporânea**. III SEMIDI/UNISAL; coordenadores: Daisy Rafaela da Silva, Regina Vera Villas Boas, Raul Fernando Nunes Marín - Lorena: III SEMIDI, 2014. Disponível em:

<http://www.lo.unisal.br/direito/semidi/publicacoes/livro5/Daisy%20Rafaela%20da%20Silva%20e%20Thais%20Cristina%20Fernandes.pdf>. Acesso em: 18 fev. de 2025.

Ribeiro, Diaulas Costa. **Autonomia: viver a própria vida e morrer a própria morte**. Cad Saúde Pública. 2006;22(8):1749-54.

SÊCO, Taís Fernanda Tenório. Por uma nova hermenêutica do direito da criança e do adolescente. **Civilistica.com**, [s.l.], v. 3, n. 2, p. 1-26, 10 dez. 2014. SEDU. Secretaria de Educação do Estado do Espírito Santo. Disponível em <https://sedu.es.gov.br/calendario-escolar-2022>. Acesso em: 24 nov. 2024

URZÚA, Alberto Lecaros. Hacia una autonomía encarnada: consideraciones desde un ethos de la finitud y vulnerabilidad. **Revista Latinoamericana de Bioética**, [s.l.], v. 16, n. 2, p. 162-187, 2016.

WANDERLEY, Natascha Tavares de Melo. **Colisão de direitos fundamentais na questão das biografias não autorizadas: Uma análise no contexto do estado constitucional.** 2014. 83 f. TCC (Graduação) - Curso de Direito, Faculdade de Ciências Jurídicas e Ciências Sociais, Centro Universitário de Brasília, Brasília, 2014. Disponível em: <http://repositorio.uniceub.br/bitstream/235/6073/1/21011927.pdf>. Acesso em: 2 fev. 2025.

WETTERNICK, Ernani Miguel Lacerda. **Alcances e limites do principlialismo em bioética clínica.** 2006. 214 f. Dissertação (Mestrado em Filosofia) - Pontifícia Universidade Católica do Rio Grande do Sul, Porto Alegre, 2006.