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Bioethics and Market: Considerations Regarding the Use of Stem Cells in the Giuridical Field*

Cristiane Avancini Alves

Abstract

The interface between bioethics and law is a current reality regarding the discussion of the use of stem cells and the status of the human embryo in biomedicine. In this scenario, economy and health care are part of this discussion. Historical lines show how the idea of value changed over time, a change that was reflected in the idea of health and in its practice. Culture and profit are two items that also have to be balanced in the connection between market process and human process.

In this context, the use of stem cells and the dilemma regarding the status of the human embryo prompt the discussion concerning the conflict that the market can bring to humanity. The idea that justice can be an important organizing principle for public health is a way to shed light on this new market that is growing in the biomedical field. The current challenge is to understand this genetic movement that represents a constant evolution, not only of the biomedical development, but also a changing of social practice.

KEYWORDS: bioethics, law, economy, human embryo, stem cells, market, social justice

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*Serei eu, porque nada é impossível,
Vários trazidos de outros mundos, e
No mesmo ponto espacial sensível
Que sou eu, sendo eu por estar aqui?*¹

INTRODUCTION

The discussions that involve bioethics field have the taste of diversity. The development of biomedicine brings new themes to the juridical sphere because every discourse related with life is connected with deep values of the human being. It is in the extension of these questions and in the balance between biotechnology and law that is faced the challenge of the jurist nowadays. According to Giorgio Oppo, “Quando dalla conoscenza si passa all’azione, l’azione é soggetta al diritto che é espressione della coscienza sociale e dei valori che la ispirano: é soggetta al diritto come ogni attività dei consociati; é soggetta al diritto nei mezzi e nei fini”. To the author, “Spetta al diritto stabilire non quali risultati siano ottenibili ma se siano socialmente ammissibili ed utilizzabili e da chi siano realizzabili”.²

This paper aims to show the relations between law and economy in the bioethics field, specifically in the issues concerning human embryo research and the use of stem cells. The taste of diversity cited above is also present in considerations regarding culture, terminology and identity. This work will not give a deep analysis of this theme. The idea is to introduce the subject and turn on the discussion regarding this new market that is growing in the biomedical field.

Part One gives some historical lines between medicine and value. The idea is to demonstrate how economy can be connected with the evolution of health care and how it can influence health care development. Culture and profit are two other items related with this evolution. They represent a current preoccupation regarding the relation between physician and patient and with the social context involved in this scenario. Part Two sheds light on the difficulties of the use of terminology connected with the status of the human embryo and the idea of

¹ PESSOA, Fernando. *Mensagem*. São Paulo: Editora Martin Claret, 2001, p. 96. Free translation: “It will be me, because nothing is impossible/many brought from other worlds, and/In the same sensible spatial point/That’s me, been me because I am here?”. The poem’s title is “Hoje que a tarde é calma”.

² OPPO, Giorgio. *Scienza, diritto, vita umana* (“Lectio doctoralis” di Giorgio Oppo). *Rivista di Diritto Civile* – Anno XLVIII – N. 1 Gennaio-Febbraio – 2002 - CEDAM – Casa Editrice Dott. Antonio Milani – Padova, p. 11. Free translation: “When from knowledge we pass to action, action is submitted to law that is expression of social conscience and of the values that inspire it: it is submitted to law as each associates’s activity; it is submitted to law in the means and in the ends”. “It is law that has to establish not the results, but if they are socially accepted and useful and who will manage them”.

identity linked in this discussion. Finally, the creation of stem cells banks and the possibility of introducing the idea of social justice in this context can give a way to manage market and humanity in the juridical field. In this Part Two, it was taken a Brazilian example. It is important to say that this paper will not give an exhausted analysis of the use of stem cells and its connection with social justice as a way to solve the dilemmas regarding their use. The idea is outline some considerations on this field.

In his poem, Fernando Pessoa reflects this transition. In his words, he represents himself as someone brought from different worlds. In this paper, it is viewed a travel through open fields interconnected among them. This work aims to introduce new reflections regarding bioethics and law, specially related with economy and stem cells. A challenge faced in this century.

I – ECONOMY AND HEALTH: AN INTERFACE

1. Historical lines between medicine and value

The understanding of the connection between bioethics, market and law passes through some historical considerations regarding economy. Actually, to comprehend modern economy it is important to view the classical economy, which can be found in the great classical, Greek, Roman and Medieval tracts on the subject. Aristotle gave a huge importance to the subject of the economy in his *Ethics*. According to Diego Gracia, the aristotelian virtue of justice was connected with economy. His thesis was that “things have an intrinsic value and that economy manages this value which is to be found within things and which is expressed in their use”³.

The so-called “intrinsic value” was the beginning and foundation of the “use value” of a thing, transformed in an “exchange value”. This can be expressed in monetary use, but it is important to notice that these are not two separate values but the same use value expressed in monetary units. For this reason, Aristotle defends that prices are not made by the market but a result of the natural function of the things in question. He says that bankers, for example, are immoral because they get benefits from the loan of money.

Land was the truly moral process by which to produce wealth. The owners of the land - that is to say of real wealth - were the highest class society. This economic model also generated a system of health care, where only the upper classes could have access to medicine of a certain quality. Here, the Church established a network of charitable hospitals. Criticism of the economic theory

³ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 44.

outlined above began with the theologians of the last centuries of the Medieval period and continued during the centuries of the modern age.

With Adam Smith, occurred a total inversion of this thesis. Economic value was not determined by function or use but by labour. For this reason, economic wealth was to be identified with productive labour. It becomes moral to leave the market free from external pressures so that it can regulate itself. “External interventions are therefore seen as immoral because they distort just interplay, as in the case of monopolies. (...) Monopoly is immoral because it hinders the free interplay of the market”⁴. This acquired an enormous importance in medicine, that has operated for centuries as a monopoly.

It is interesting to view in this scenario, but not narrowly connected with economy, what Francesco Busnelli called “solidarietà illuministica”, introduced with the *The Declaration of the Rights of Man and of the Citizen*, in 1789. According to the author, it is connected with fraternity and, so, with the liberty and the equality present in French Revolution, that led to a property right regarding the own person. This kind of solidarity should consist in the emancipation of the man of his own solidarity, because it put him in condition to exercise a property right grounded on himself. In other words, “una ‘revisitazione’ della lockiana *property on his own person*”⁵.

In this context, charity was viewed as an “antieconomic” activity and, also, as something that was “unnatural” and “injurious”. But, in 1848, with the socialist movements, it is viewed a passage from charity to social justice. Socialist parties and the trade union movements promote the resurrection of the ancient theory of the intrinsic value of the things, that could not be left to the workings of market forces. There is a return to monopoly, the state was to become transformed into the great economic monopoly power, free market was immorality by definition and health care had to be guaranteed by the state and be equal for everybody. “Where liberals employed the term ‘charity’, now reference was made to ‘justice’. Care was seen as a right derived from the principle of justice and not a mere work of charity. From paternalism, therefore, one moved to social justice”⁶.

According to Diego Gracia, governments address health care questions and issues. The health-care policy expressed itself in various ways, and two may be referred: the increasing importance of “social medicine” and the beginning of the state systems of medical insurance, at least for the poor and the working class. In this way, “Medicine moved from being a private question (the aspiration of

⁴ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 45.

⁵ BUSNELLI, Francesco Donato. *Bioetica e diritto privato – frammenti di un dizionario*. Torino: G. Giappichelli Editore, 2001, p. 239.

⁶ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 46.

liberalism) to being a public and political responsibility”. The author notice that “Health care was transformed into a very important part of the policies of ‘social justice’. This did not mean the old-fashioned contractual freedom of doctrinal liberalism, but, rather, social equality. Justice was now social equality – social justice”⁷.

Gracia affirms that the economic theory which made possible the birth of systems of social security, amongst which is to be listed compulsory insurance for illness, was Keynesianism, that tried to cast off the idea that the liberal economy was the same as *laissez-faire* or a pure and jungle market. “The state had to regulate economic activity, even though this had to be done through the market. This was not a matter of substituting the market but of activating it, and in the final extreme of regulating it”. Continues the author that “The emphasis now became placed upon demand rather than upon production, and this is something which brought about a radical change in moral attitudes”⁸.

History follows its way and also the concept and definition of health care receives a new form. After the Second World War, it was signed in July 1946 the Constitution of the World Health Organization (WHO), placed under the control of the United Nations. The concept of health includes mental and social wellbeing, not only a physical sphere⁹. For Gracia, the definition of the WHO lacks meaning if it is detached from its historical context. “This meant that the correlation previously established between neo-capitalist economics, the consumer society and the political system of the Welfare State had another element added to it, and more precisely: ‘welfare medicines’”¹⁰.

The question of the limits to the right to health care was raised in 1970, following two phenomena: the economic crisis of 1973 (that involved, to a certain extent, the death of Keynesianism) and the technological progress meant that it was possible to keep alive people who until a short time previously were destined to die (ex. of Karen Ann Quinlan¹¹). Questions like “Was there an obligation, in

⁷ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 47.

⁸ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 47.

⁹ The concept of “health” present in the Constitution of the World Health Organization: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity”. Access 28 Oct. 2007 <http://www.who.int/governance/eb/who_constitution_en.pdf>.

¹⁰ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 48.

¹¹ Karen Ann Quinlan, born in 1954, was an important figure in the history of the right to die debate in United States. When she was 21, Quinlan fell unconscious after coming home from a party, and lapsed into a persistent vegetative state. After she was kept alive on a ventilator for several months without improvement, her parents requested the hospital to discontinue active care and allow her to die. The hospital refused, and the subsequent legal battles hit headlines and set

the name of justice, to provide her with every kind of medical care and treatment?” appears in this context.

This fact, it might be observed, was nothing else but a particular example of something that medicine had transformed into a norm – anti-Darwinian action. If nature, as Darwin asserted, selects the fittest and condemns the weakest and the least fit to death, then medicine acts in exactly the opposite way. This meant that the number of the chronically and terminally ill (mentally retarded children, the gravely infirm, the elderly etc.) became ever greater, something which brought with it the so-called ‘cost-explosion’. Once again the question was posed as to whether justice requires that all these sick people are taken care of using all means available. What limits should be placed on their treatment? From what point of departure does the obligation to treat and care for them cease to be total (or one of justice) and become one which is incomplete or a matter of charity?¹².

It is also possible to notice the transformation of the relationship between patient and physician, medicine and society, after the sixties. Usually, before this period, it was the individual physician who decided health care matters at the bedside or in the privacy of the hospital room. During the middle of 1970, it is seen a changing of both the style and the substance of medical decision making. David Rothman, commenting cases like the one of Karen Ann Quinlan, says that “The impact of these events, most generally framed, was to make the invisible visible. Outsiders to medicine – that is, lawyers, judges, legislators, and academics – penetrated its every nook and cranny, in the process giving medicine an exceptional prominence on the public agenda and making in the subject of popular discourse”¹³.

In this context, Gracia considers some points of agreement. Affirms that with regard to certain social goods considered as being of primary importance there can be no restrictions in terms of their provision because this would be inhuman. In all other contexts reasonable systems of savings and systems providing for the distribution of scarce resources are necessary. Regarding the previous doctrine, we have a redefinition of the health-care model. “It does not seem that social justice requires us to achieve the ‘perfect wellbeing’ of everybody but only that ‘primary health care’ which allows men to live a ‘life

significant precedents. Although Quinlan was removed from active life support in 1976, she lived on in a coma for almost a decade until her death from pneumonia in 1985. Not only was the case groundbreaking legally, it was remarkable for its rare appeal to religious principles. Because she and her family were Catholics, several principles of Catholic moral theology were critical in deciding the case and thus influencing a development in American law, an influence replicated around the world. The case is credited also with the development of the modern field of bioethics.

¹² GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 48.

¹³ ROTHMAN, David J. *Strangers at the bedside: a history of how law and bioethics transformed medical decision making*. New York: Aldine de Gruyter, 2003, p. 3.

which is socially and economically productive”’. Continues that “This is the move from ‘the medicine of wellbeing’ or ‘pedagogic medicine’ of the previous stage, that is to say from medicine as a consumer good to medicine as a production good”¹⁴.

Many economic theories have conditioned or determined the practice of medicine and, according to the author, it is probable that we have not learned to provide an answer to the great question of economics – that of the value of things. For the author, “The value of things is to be defined in terms of the life possibilities that they generate”, and the same thought is extended to the definition of wealth (“in terms of life possibilities”). “We become richer the more individuals or societies have life possibilities. This is important because it introduces many factors into economic activity which did not form a part of classical theory”¹⁵, like a poem, for example. It is, according to him, an example of a life possibility, although it is not usually seen as economic product.

Following the idea of the importance to notice the total dimension of themes regarding biomedicine nowadays, technology must be faced as an element that operates in the connection between wellbeing and development. In this way, “technology, as it actually operates in concrete situations has a contextually dependent moral quality. Technology creates a moral situation, and this situation should provide the context for decision making”¹⁶. Health care is part of this current scenario.

2. Culture and profit in biomedicine evolution

The idea of profit can be considered part of the improvement and development of health care. Innovation, even the medical one, is frequently driven by the profit motive, and without it – the profit motive – the same level of innovation is not obtained. It is emphasized that greed is a powerful human incentive to create innovative healthcare products and medical services¹⁷.

This is a dangerous line that cannot be simply taken. According to Mark J. Cherry, the open market diffused political and social authority, freeing innovators to compete with each other as well as to challenge the status quo. “Collaborators need not agree regarding the background ranking of values or moral principles,

¹⁴ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 49.

¹⁵ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 49.

¹⁶ BUCHHOLZ, Rogene A. and ROSENTHAL, Sandra B. Technology and business: rethinking the moral dilemma. *Journal of Business Ethics*, volume 41, Nos. 1/2, November (II), December (I) 2002, p. 48.

¹⁷ Considerations of: CHERRY, Mark J. The market and medical innovations: human passions and medical advancement. *The Journal of Medicine and Philosophy*, Volume 30, no. 6, December 2005, p. 555.

cultural or religious assumptions; they need only affirm the content of their agreement”¹⁸.

The changings viewed in biomedicine involve more than a theory of open market. Like seen above¹⁹, economy has a historical background, and the construction of a responsible thought regarding bioethics and, in this work, regarding the use of stem cells, is connected with social formation. In this sense, it is possible to say that the importance of the formation of a community is connected with its welfare, which is the consequence of the welfare of each person. Arthur Dick, referring Stuart Mill, says that “communities persist as long as individuals are able and willing to express their ‘interests’ in the existence and progression into the future of other individuals and communities”²⁰.

This consideration is connected with what Jonhatan Glover calls “moral imagination”, which is our ability to imagine ourselves in the shoes of others and that could enabling us to significantly alter our outlook and actions²¹. It is important to emphasize that individual protection cannot be viewed in a specific perspective, but has to be seen as a part of a total construction. The personal history of each individual is the key to the comprehension of what is society²². According to Norbert Elias, explain the relation between society and the individual and their interdependence requires the perception that is the net of functions established among people that form the so-called “society”.

It is interesting to notice that the presence and importance of interection between disciplines is part of the understanding of these ways taken by biomedicine and its evolution. Even if the rational, logical or, we can also say, utilitarian view of the open market can give its own answers, they are narrowly connected with results, and results cannot clearly reflect the ethical practice. In the borderlines of life, ethics has its space.

An example of this process of combination of areas is viewed in the growing importance given to the understanding of social contexts, multiple ontologies and varied forms of life. Lynn M. Morgan says that bioethicists and philosophers are looking to the anthropologists to see how knowledge about

¹⁸ CHERRY, Mark J. The market and medical innovations: human passions and medical advancement. *The Journal of Medicine and Philosophy*, Volume 30, no. 6, December 2005, p. 558.

¹⁹ See discussion in “Historical lines between medicine and value”, in this paper.

²⁰ DICK, Arthur J. *Rethinking rights and responsibilities: the moral bonds of community*. Washington D.C.: Georgetown University Press, 2005, p. 94.

²¹ Considerations published in: BENATAR, Solomon R. Towards Progress in Resolving Dilemmas in International Research Ethics. *Journal of Law, Medicine & Ethics*, Volume 32:4, Winter 2004, p. 579.

²² ELIAS, Norbert. *A sociedade dos indivíduos*. Rio de Janeiro: Jorge Zahar Editor, 1994, p. 13.

culture might apply to ethical decision-making about the beginnings and ends of life. “Culture starts to seem relevant, even necessary”²³.

This interface is a current reality, viewed in the interaction between market, governmental initiatives, culture and religion. For example, many changes associated with China’s development as a market economy occurred in the last quarter of a century. According to Xiao-Yang Chen, in all areas of China there are questions raised regarding the appropriate limitations to be set on the market, as well as to where the market should be further developed. He says that these questions are particularly pressing in health care, because the entrance of market forces has changed the expectations of both patient and families.

The author explains that clinical practice varies greatly across China²⁴. The character of clinical practice is also profoundly influenced by the ways in which reimbursement scales are established in public hospitals. In response to increasing pressures to contain costs, payments for services in governmental hospitals are set at an unrealistically low level. “This state of affairs encourages both prescribing more medications than are necessary to increase volume of sales, and prescribing and selling more expensive forms of medications”²⁵. He also says that because price control makes it impossible to reward directly those physicians known to provide better treatment, informal systems of payment have arisen known as “red packets”, in which an informal extra payment is made by patients or their families to physicians in order to secure quicker or better treatment.

Beside these considerations, emerges another point: the effects of the distorting forces of regulations, according to the author, must be countered by conceptions of trust in the physician/patient relationship that have deep roots and resonance in Chinese culture. “This will require recognizing the ways in which Confucian thought has always placed the concern for a good livelihood and profit within broader commitments to virtue and community service, especially the Confucian virtue of sincerity and honesty”²⁶.

²³ MORGAN, Lynn M. “Life begins when they steal your bicycle”: cross-cultural practices of personhood at the beginnings and ends of life. *The Journal of Law, Medicine & Ethics*, Volume 34:1, Spring 2006, p. 10.

²⁴ According to the author, in “Beijing, Shanghai, and Guangzhou, for example, there are private hospitals of excellence providing medical care to foreign nationals and that segment of the local Chinese business community that can afford to purchase services of a medical quality and scope of amenities roughly equivalent to that available in good hospitals in North America and Western Europe. In contrast, in most places there are few private hospitals. There are only about 1,500 private hospitals, while there are about 70,000 public hospitals across the country”. CHEN, Xiao-Yang. Clinical bioethics in China: the challenge of entering a market economy. *The Journal of Medicine and Philosophy*, Volume 31, no. 1, February 2006, p. 8.

²⁵ CHEN, Xiao-Yang. Clinical bioethics in China: the challenge of entering a market economy. *The Journal of Medicine and Philosophy*, Volume 31, no. 1, February 2006, p. 8.

²⁶ CHEN, Xiao-Yang. Clinical bioethics in China: the challenge of entering a market economy. *The Journal of Medicine and Philosophy*, Volume 31, no. 1, February 2006, p.11.

These considerations regarding Chinese health care system are not so far from American view of the market ethos in this field. The increasing institutionalization of medicine is shaking the notion of integrity as it applies to health care. In a capitalistic vision, the integrity of health care organizations will depend upon compliance with the marketplace and with the forces of commercial culture. Integrity means, in this way, compliance with the organization's economic interests and maximization of profit²⁷.

Rethinking integrity requires a new position of health care professionals. They have to perceive that the corrosive influence of commercial values on their profession is an inevitable implication of its dominance in society as a whole. Says Roberto Dell'Oro that "economists are also becoming increasingly sensitive to both anthropological presuppositions and broad social consequences of the market". In this sense, affirms the author that "The very existence of so many uninsured people is evidence that America still has some distance to go if it is to reach true integration. The *right* to health care is no less important than the right to education or to political participation, struggles that this nation experienced earlier in its history"²⁸.

The connection between economy and health care faces, in the next lines, some considerations regarding the human embryo and stem cell research. The idea of culture and society are re-connected here with the importance with terminology and identity, fields that reflect the challenges that the juridical sphere has in this area of mankind.

II – HUMAN EMBRYO AND STEM CELLS: THE CHALLENGE TO BALANCE MARKET AND HUMANITY IN THE JURIDICAL FIELD

1. Views regarding embryo terminology and identity in law

Italo Calvino, in his book "Seis propostas para o próximo milênio", see a huge epidemic spreading through humanity in its distinctive feature, that is the use of the word. Language, according to him, is losing its force and immediate purpose, it is gaining generic, automated and abstract forms. Meanings are losing their senses and ending the encounter of the words with new circumstances²⁹. It is

²⁷ Considerations of: DELL'ORO, Roberto. The market ethos and the integrity of health care. *The Journal of Contemporary Health Law and Policy*, Volume 18, Issue 3, Fall 2002, pp. 641 and 642.

²⁸ Considerations and citations of this paragraph: DELL'ORO, Roberto. The market ethos and the integrity of health care. *The Journal of Contemporary Health Law and Policy*, Volume 18, Issue 3, Fall 2002, pp. 642 and 646.

²⁹ CALVINO, Italo. *Seis propostas para o próximo milênio: lições americanas*. São Paulo: Companhia das Letras, 1990, p. 72. "Às vezes me parece que uma epidemia pestilenta tenha atingido a humanidade inteira em sua faculdade mais característica, ou seja, no uso da palavra,

possible, here, to make a bridge between literature and an adequate terminology regarding stem cells, specifically the embryonic ones.

How we define an embryo is a controversial field. According to E. D. Pellegrino, a group of modern biologists regard the embryo to be present from the zygote stage or right after it begins to divide. Some embryologists and bioethicists speak of the “pre-embryo”, postulating a stage from the zygote until the fourteenth day before which they do not consider the developing cells an “embryo”. For the author, “There is no biological warrant for such an arbitrary distinction. Rather, it has the earmarks of a convenient means for justifying treatment of the developing human with less respect than one would grant it after fourteen days”. Affirms that “The nature of the organism is not changed by changing its name”³⁰.

Alerts Pellegrino that terminology is essential in the stem cell controversy. Those who favor the destruction of embryos as a source want to avoid use of the term “embryo” because they think it is too inflammatory and generates resistance. They suggest a variety of euphemisms: “nuclear transplantation” or “therapeutic cellular transfer” for cloning humans. “These euphemisms are intended to confuse the non-scientist public and decision-makers and divert their attention from the fundamental fact that human embryos are produced to be destroyed, - a practice currently at least subject to congressional ban. All terms used to support or denounce embryo sacrifice should be defined clearly”³¹.

Societies are facing the challenge of the definition of these borderlines connected with the beginning of life. In this context, information plays an important role, independent if this definition is concerning ethical, political or economic issues. Alerts Hans-Martin Sass that it is not a prerogative of political leaders to answer questions like “what is a zygote, what is an embryo, what moral recognition do I owe them as compared to living fellow humans”, but “it is their obligation to help us via information, precise terminology, and a cultural environment of open discourse to form our own opinion and follow our conscience as good as we can”³². He cites an interesting thought connected with

consistindo essa peste da linguagem numa perda de força cognoscitiva e de imediaticidade, como um automatismo que tendesse a nivelar a expressão em fórmulas mais genéricas, anônimas, abstratas, a diluir os significados, a embotar os pontos expressivos, a extinguir toda centelha que crepita no encontro das palavras com novas circunstâncias”. The English title is: “Six memos for the next millennium”. This part is extract from the lecture regarding the “exactitude” in the portuguese version.

³⁰ PELLEGRINO, E. D. Balancing science, ethics and politics: stem cell research, a paradigm case. *The Journal of Contemporary Health Law and Policy*. Volume 18, Issue 3, Fall 2002, p. 595.

³¹ PELLEGRINO, E. D. Balancing science, ethics and politics: stem cell research, a paradigm case. *The Journal of Contemporary Health Law and Policy*. Volume 18, Issue 3, Fall 2002, p. 596.

³² SASS, Hans-Martin. Ethical dilemma in stem cell research? *Formosan Journal of Medical Humanities*, Volume 7, no. 1 & 2, June 2006, p. 36.

the situation in the Republic of Singapore, that will be here reproduced to show the different influences and contexts in this discourse:

The price of freedom is responsibility. Sometimes we might regret what we have chosen or others might disagree with our choice; but been not allowed to choose is worse, uncivilized, inhumane. You own your stem cells as your real property and you may do with those, whatever you want as long as you do not hurt me directly similarly, I own my own stem cells and reserve the same right for me. We make laws and regulations, we form customs and attitudes, but what counts is the free space we and our fellow humans need to breathe, to prosper and to serve. Once the Tao said 'We make doors and windows for a room, but it is these empty spaces that make the room livable'.³³

Doors and windows that were not constructed in Brazilian discussion regarding the regulation of stem cells research. The Brazilian law³⁴ concerning the use of stem cells was approved with a media and society pressure, but without a critical discussion about the real possibilities of their use. "Most of the public's information come from the popular media, which customarily celebrates whatever is new and sensational, or represents 'progress'". The words of Pellegrino can be connected with the Brazilian scenario. Disability groups³⁵ claimed for the approval of the law in the National Congress, and the media focused the debates based in the emotion of these images.

Another criticism is that the so-called "Biosecurity Law" involves the use of embryonic stem cells and, also, the regulation of genetically modified organisms (GMO). Two different themes in the same juridical instrument, subjects that "son ontológicamente diversos, participan de distinta naturaleza".³⁶ In this way, it was broke up an effective discussion regarding the consequences of the research with stem cells, keeping the society aside from the debate.

³³ In SASS, Hans-Martin. Ethical dilemma in stem cell research? *Formosan Journal of Medical Humanities*, Volume 7, no. 1 & 2, June 2006, p. 36. SASS refers: Republic of Singapore. Parliament (2004) The Human Cloning and other Prohibited Practices Act 2004 Gazette Electronic Edition No. S 592, Sept 27, 2004 [Nr 35 of 2004].

³⁴ Law 11.105/2005.

³⁵ The author of this paper prefers the use of the expression "group with special necessities". This is an expression currently used in Brazilian discussion, and it shows the power of terminology. "Special necessities" and not the word "disability" gives the right idea of people that are not unable to many life activities, but that only need special attention to a correct adaptation of daily routine. They are not kept out of the "able" world. Anyway, it was maintained "disability groups" in this article because it is the expression followed in the bibliography in English language used to this work.

³⁶ SESSAREGO, Carlos Fernández. Hacia una nueva sistematización del daño a la persona. *Revista de Direito Civil, Imobiliário, Agrário e Empresarial*, nº 75, ano 20, janeiro-março/1996, p. 10. Free translation: "(...) they are ontologically different, they are part of a distinct nature".

The use of ambiguous terminology also creates a real confusion regarding the status of the embryo. For example, the law permits the use of embryonic stem cells originate from cryopreserved embryos, but with parents authorization. Some lines after, says that is prohibited the commercialization of the “biological material” that is refered in the law. The “biological material” are the embryos. But embryos that have parents. So, the use of the word “material” gives the idea that “materials” can have “parents”³⁷.

It is possible to say that the law’s response in this area can be one way to find an answer in this complex scenario because law is a field which constantly evolves. Cultural, social, economical and political aspects are involved in this discussion. It is also outstanding, anyway, to perceive that “It is important to be very clear about what is supposed to be achieved by making regulations of some kind. Legislation does not necessarily make people ethical”³⁸.

Bioethics, as an interdisciplinary field, considered a meeting ground for a number of disciplines, discourses and organisations concerned with ethical, legal and social questions raised by advances in medicine, science and biotechnology³⁹, naturally opens the debate and, consequentially, the possible need of regulations related to the medical practices in each country.

It is interesting to view that healing people from suffering disease and protecting health never has been called immoral. “On the contrary, all cultures put high emphasis to help the sick and the poor and experts in healing and those who advance the healing science have always been given high credit and respect”⁴⁰. However, communities have different positions in regard to the intensity of the intervention, limits in manipulating or fighting nature and natural developments. According to Hans-Martin Sass, whatever these difference in prioritizing values

³⁷ Art. 5 of the Law 11.105/2005, regarding embryonic stem cells: “É permitida, para fins de pesquisa e terapia, a utilização de células-tronco embrionárias obtidas de embriões humanos produzidos por fertilização ‘in vitro’ e não utilizados no respectivo procedimento, atendidas as seguintes condições: I - sejam embriões inviáveis; ou II - sejam embriões congelados há 3 (três) anos ou mais, na data da publicação desta Lei, ou que, já congelados na data da publicação desta Lei, depois de completarem 3 (três) anos, contados a partir da data de congelamento. § 1º Em qualquer caso, é necessário o consentimento dos genitores. § 2º Instituições de pesquisa e serviços de saúde que realizem pesquisa ou terapia com células-tronco embrionárias humanas deverão submeter seus projetos à apreciação e aprovação dos respectivos comitês de ética em pesquisa. § 3º É vedada a comercialização do material biológico a que se refere este artigo e sua prática implica no crime tipificado no art. 15 da Lei nº 9.434, de 4 de fevereiro de 1997”.

³⁸ NIELSEN, Linda. From Bioethics to Biolaw. In: MAZZONI, Cosimo Marco (Ed.). *A Legal Framework for Bioethics*. The Hague, The Netherlands: Kluwer Law International, 1998, p. 40.

³⁹ O’NEILL, Onora. *Autonomy and trust in bioethics*. United Kingdom: Cambridge University Press, 2002, p. 1.

⁴⁰ Considerations and citations of this paragraph: SASS, Hans-Martin. Ethical dilemma in stem cell research? *Formosan Journal of Medical Humanities*, Volume 7, no. 1 & 2, June 2006, pp. 20 and 21.

or selecting certain unwelcome or forbidden products or procedures are, “all civilized individuals and all respected moral or religious worldviews agree that the ‘golden rule’ of caring for a fellow human in need is a prime indication of culture, commitment and morality”⁴¹. The central point of each of these communities is the recognition of and respect for humanity.

We can say that each human being has a personal identity, which has two dimensions. One of them is an absolute or individual dimension because each person has their own particular reality, with an individuality that makes the difference among all the others, that distinguish every person. The second one is a relative or relational dimension, defined through family memory inherited from the past, by our forebears, when we can talk about as a “right to a personal historicity”⁴². In the bioethics field, specially regarding issues about human and embryo experimentation, the modification of genetic information and the experimentation itself, in the measure that changes this identity, modifies social formation.

This idea can be extended to the market process and the interface between technology and humanity. “The problems surrounding the misuse of technology lie in a lack of understanding of technology’s inherently social and moral dimensions”⁴³. Here, it is possible to cite Gracia when he says that “The economy must be seen for what it really is – an instrument at the service of the goals of human life. Here, indeed, we encounter the great philosophical and ethical question: the ends of human life”. In this sense, the author affirms that the economy is nothing else but the reasonable management of the means which serve these ends. And whatever they may be, what is clear is that one cannot fall into the error of confusing ends with means or means with ends⁴⁴.

⁴¹ The author, regarding the “golden rule”, cites: “ ‘Do not do to others what you would not desire for yourself (Confucius); ‘Love God by loving your neighbor’ (Jesus); ‘Do not use fellow humans as means only as you would do with horses’ (Mohist); ‘Do not do to others what you would not to be done to you’ Kant). Buddhist reasoning and life centers around reducing suffering; Jewish, Muslim and Christian call is the service to the poor and sick”. SASS, Hans-Martin. Ethical dilemma in stem cell research? *Formosan Journal of Medical Humanities*, Volume 7, no. 1 & 2, June 2006, p. 21.

⁴² Observations about absolute and relative identity in: OTERO, Paulo. *Personalidade e identidade pessoal e genética do ser humano: um perfil constitucional da bioética*. Coimbra: Livraria Almedina, 1999, p. 64.

⁴³ BUCHHOLZ, Rogene A. and ROSENTHAL, Sandra B. Technology and business: rethinking the moral dilemma. *Journal of Business Ethics*, volume 41, Nos. 1/2, November (II), December (I) 2002, p. 47.

⁴⁴ GRACIA, Diego. The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 49.

2. Stem cells banks and social justice

The goals of human life proclaimed above concern juridical aspects connected with human life. They also draw on the aspects that are emerging from biomedical development regarding this theme. Stem cells banks are part of this scenario. Their movement from the laboratory into the clinic can raise some concerns about identity and justice.

A huge discussion is occurring regarding the use of stem cells banks around the world. It is faced not only the ethical problem concerning the status of the embryo (and, so, the use of embryonic stem cells) but also who will receive the benefits of this procedure. And, here, it is faced another challenge: american studies show that stem cells lines currently available might benefit primarily white Americans depending on how is addressed the problem of biological access⁴⁵.

A paper published in the Hastings Center Report shows that immune rejection is the principal reason that a given stem cell-based therapy for a specific disorder might be biologically less available to one patient than to another. Immune rejection, according to the authors, is mediated by our genetic makeup, specifically the set of genes which code for a type of protein called human leukocyte antigens (HLA). HLA has been demonstrated to track with geographical ancestry. The work cites the example that persons of sub-Saharan African ancestry have a greater variety of HLA types than do persons of any other geographical or ethnic grouping. A person's ancestry may significantly diminish (or increase) the odds of locating an HLA match – whether of certain solid organs, bone marrow, or stem cells. “HLA matching and transplantation raise serious question of public policy and justice. In the American context, there have been many attempts to address one such issue: the relative unavailability of good matches for African American transplant recipients”⁴⁶.

The authors also say that a particularly worry from the perspective of justice is how fairly to accomodate the world's population as stem cell medicine progresses. The work indicates that “economic considerations would clearly come into play for countries in the global South, whose health care and health research budgets are already severely constrained (...)”. Allerting that this subject merits a separate analysis, the authors “assume that relatively rich countries will develop

⁴⁵ This is a North-American example that can be useful to view the same situation in other contexts.

⁴⁶ FADEN, Ruth R.; DAWSON, Liza; BATEMAN-HOUSE, Alison S.; AGNEW, Dawn Mueller; BOK, Hilary; BROCK, Dan W.; CHAKRAVARTI, Aravinda; GAO, Xiao-Jiang; GREENE, Mark; HANSEN, John A.; KING, Patricia A.; O'BRIEN, Stephen J.; SACHS, David H.; SCHILL, Kathryn E.; SIEGEL, Andrew; SOLTER, Davor; SUTER, Sonia M.; VERFAILLIE, Catherine M.; WALTERS, LeRoy B.; GEARHART, John D. Public Stem Cell Banks: Considerations of Justice in Stem Cell Research and Theraphy. *Hastings Center Report*, Volume 33, no. 6, November-December 2003, p. 17.

stem cell-based therapies and that eventually these products will be made financially available to those in poor countries”⁴⁷.

According to E.D. Pellegrino, most of the existing lines have come from small segments of the human population. “In the West, most of cells now available come from the U.S., Sweden and Israel; in the East, they come from South and East Asia. This is a limited representation of the racial, genetic and ethnic diversity of today’s world”. The autor affirms that a new field of pharmacogenetics has emerged to study some of these differences in drug reactions by individuals and ethnic groups. He affirms that “The narrowness of the ethnic and genetic spectrum of existing cell lines means that research on fundamental mechanisms may not be readily transferable between and among ethnic groups”. Continue saying that “If there were therapeutic benefits forthcoming, they would be limited, at present, to those of European and some small number of Asian ancestries. This differentiation is also a matter of justice”⁴⁸.

All these considerations are connected with healthcare and the idea that justice can be an important organizing principle for public health. This is the point defended by Lawrence O. Gostin and Madison Powers, that vindicate an interventionist social justice, “not passive or market-driven, vigorously addressing the determinants of health throughout the lifespan”. For them, “It recognizes that there are multiple causes of ill and good health, that policies and practices affecting health also affect other valued dimensions of life, and that health is intimately connected to many of the important goods in life”⁴⁹.

Lawrence O. Gostin affirms that social justice demands more than fair distribution of benefits and burdens. According to him, a failure to plan, and act, in support of the disadvantaged and with equal concern for all citizens harms the whole community by eroding public trust and undermining social cohesion. It

⁴⁷ Continue the article that “To achieve biological access on a worldwide level, concerted effort and collaboration will be needed among developed nations pursuing stem cell-based therapies in order to consider genetic diversity in sufficiently broad terms to meet the needs of patients in resource-poor, as well as resource-rich, countries”. FADEN, Ruth R.; DAWSON, Liza; BATEMAN-HOUSE, Alison S.; AGNEW, Dawn Mueller; BOK, Hilary; BROCK, Dan W.; CHAKRAVARTI, Aravinda; GAO, Xiao-Jiang; GREENE, Mark; HANSEN, John A.; KING, Patricia A.; O’BRIEN, Stephen J.; SACHS, David H.; SCHILL, Kathryn E.; SIEGEL, Andrew; SOLTER, Davor; SUTER, Sonia M.; VERFAILLIE, Catherine M.; WALTERS, LeRoy B.; GEARHART, John D. Public Stem Cell Banks: Considerations of Justice in Stem Cell Research and Therapy. *Hastings Center Report*, Volume 33, no. 6, November-December 2003, p. 23.

⁴⁸ PELLEGRINO, E. D. Balancing science, ethics and politics: stem cell research, a paradigm case. *The Journal of Contemporary Health Law and Policy*. Volume 18, Issue 3, Fall 2002, pp. 598 and 599.

⁴⁹ GOSTIN, Lawrence O. and POWERS, Madison. What does social justice require for the public’s health? Public health ethics and policy imperatives. *Health Affairs*, Volume 25, Number 4, July/August 2006, p. 1054.

signals to everyone that the basic human needs of the disadvantaged matter less, and it thereby fails to show respect for all members of the community. Social justice therefore requires action to preserve human dignity for all, particularly those who suffer from systematic disadvantage⁵⁰.

It is important to connect these ideas of social justice with a Latin American example, that is the Brazilian Constitution. The *caput* of article 170 cites the fundamental principle of the economic order. It says that the economic order, founded on the valorisation of human labor and in the free initiative, has the goal to give to everyone a worthy life, according to the lines of social justice⁵¹. The economic activity doesn't have as its aim the economic development or the national power, but the warrantee of an existence with dignity to every citizen. The social justice is directed to the welfare of the population.

In this context, the economic order is a mean to the achievement of this welfare⁵². The Brazilian Biosecurity Law goes against this value, because it shows the preponderance of economic interests instead of a real preoccupation with the embryonic research and the consequences of this research to the population⁵³. It was not viewed a real preoccupation with the welfare of many citizens that are waiting for honest and efficient results regarding the use of stem cells. It also didn't discuss an important topic of this argument: the status of the human embryo.

This is not a demagogic point. "The most obvious, and most formidable, challenge to creating stem cells banks in the United States is the widespread disagreement about the moral status of early human life"⁵⁴. For the authors, it is certain that a significant portion of the population will be opposed to the creation of such banks solely because they necessitate the creation and destruction of embryos.

Beside all these views, Sass affirms that a prudent and morally authentic response in political ethics would be the recognition that globalization of research, reasoning, services and production suggest that national legislation will be less

⁵⁰ GOSTIN, Lawrence O. Why should we care about social justice? *Hastings Center Report*, Volume 37, no. 4, July-August 2007, p. 03.

⁵¹ Art. 170, *caput*. A ordem econômica, fundada na valorização do trabalho humano e na livre iniciativa, tem por fim assegurar a todos existência digna, conforme os ditames da justiça social, observados os seguintes princípios (...).

⁵² Here, it is important to remember the words of Diego Gracia related to footnote 44.

⁵³ See discussion in "Views regarding embryo terminology and identity in law", in this paper.

⁵⁴ FADEN, Ruth R.; DAWSON, Liza; BATEMAN-HOUSE, Alison S.; AGNEW, Dawn Mueller; BOK, Hilary; BROCK, Dan W.; CHAKRAVARTI, Aravinda; GAO, Xiao-Jiang; GREENE, Mark; HANSEN, John A.; KING, Patricia A.; O'BRIEN, Stephen J.; SACHS, David H.; SCHILL, Kathryn E.; SIEGEL, Andrew; SOLTER, Davor; SUTER, Sonia M.; VERFAILLIE, Catherine M.; WALTERS, LeRoy B.; GEARHART, John D. Public Stem Cell Banks: Considerations of Justice in Stem Cell Research and Theraphy. *Hastings Center Report*, Volume 33, no. 6, November-December 2003, p. 24.

and less efficacious and that coordinated transnational legislation intertwined with legislative and cultural initiatives in protecting individual choice, vision, values and wishes of citizens – as long as they do not hurt other citizens – would be the politically and morally right thing to do⁵⁵. This is the current challenge concerning the interface between bioethics and law.

CONCLUSION

The proposed travel made in the introduction of this article has arrived in its end. Fernando Pessoa had his own questions regarding his journey. In this paper, some questions were raised. They are an important way to face the dynamics regarding the connection between bioethics and law and their relation with the market process. The claim of this work is that the economic influence in the practices concerning biotechnology has to be balanced with a genuine development of the concept (and, so, practice) of social justice.

It is fundamental to remind that justice has to be connected with dignity. A real social justice cannot be an empty discourse, but a responsible construction of ideas and clear practices concerning society's development. The improvement of technologies affecting human issues, such as the use of stem cells, has spread not only benefits, but doubts in society. As seen above, information is an important way to achieve an open discourse. In bioethics field, this is a crucial point.

We have seen that the idea of value in an economic sphere has changed during history. It is natural that also the development of biomedicine will bring changes to concepts and practices inside society. This movement will naturally tap into law. Here, it will be important to notice that “No matter how much good we envision, we cannot allow our zeal for knowledge, power, profit or even cure to display our humanity”⁵⁶. A value that cannot be forgotten in law and bioethics research.

⁵⁵ SASS, Hans-Martin. Ethical dilemma in stem cell research? *Formosan Journal of Medical Humanities*, Volume 7, no. 1 & 2, June 2006, p. 35.

⁵⁶ PELLEGRINO, E. D. Balancing science, ethics and politics: stem cell research, a paradigm case. *The Journal of Contemporary Health Law and Policy*. Volume 18, Issue 3, Fall 2002, p. 592.