Editorial

Inequalities in scientific publishing – highlighting the current scenario

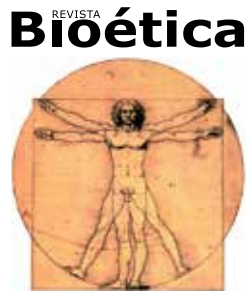
In this editorial, we seek to discuss in general terms the scenario in which are embedded the regional platforms that publish the scientific output in open access in Brazil, Latin America and the Caribbean. In order to, from this point, describe some of the ethical conflicts that directly and indirectly affect periodicals, given that this process also directly affects the field of bioethics. Such considerations are based on a presentation given at a round table at the *XI Congresso Brasileiro de Bioética* (XI Brazilian Congress of Bioethics), held in September in Curitiba, Paraná, Brazil, in which the relationship between bioethics and inequality was investigated.

The decision to present these reflections in this editorial stems from the idea that it is important to think critically about some points that illustrate inequalities in scientific publication between core and peripheral countries, such as Brazil. It isconsidered that such an understanding may help to comprehend the complex framework that supports the dissemination of local and regional production, and to find answers to the dilemmas inherent in the condition of being a peripheral country. It is expected that this process can stimulate the performance of institutions, journals, editors, reviewers, authors, professors, researchers and students, encouraging them to persist in the design and implementation of public policies, strategies and tactics, dedicated to gradually overcoming inequities.

Before turning to the discussion of the topic, it is important to mention that even in September the *Revista Bioética* received an A1 mention in the 2013-2014 evaluation of the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* - CAPES Higher Education Personnel Training Coordination in the fields of Philosophy/Theology, Philosophy subcommittee, which brought us great joy. It was also registered noteworthy improvement in Public Health and Medicine II[1]. With respect to such recognition, it is worth noting that the academic community dedicated to the study, research and teaching of bioethics has proved to be a supportive partner in this achievement. Therefore, it behoves us to thank - once again - the helpful contributors that, following our request, have been acting as peer reviewers and authors of the published articles.

Outline

In early August 2015, the Brazilian scientific editors were in an uproar. In late July, the American Jeffrey Beall published in his blog "Is SCIELO a publication favela?" [2]. In this article, Beall advocates that articles published in open access platforms have no value and that almost no one reads them. Defending methods and work processes adopted by commercial publishers, Beall defends the idea that only commercial publishers would provide a satisfactory "neighbourhood" for the dissemination of scientific knowledge. According to the author, some open access platforms, such as SCIELO and REDALYC are "publication favelas", which do a bad job in the assessment of indexed journals and the dissemination of published content.



Although the blog page of the American librarian and associate professor at the University of Colorado is considered by many as an authority on the matter[3], the negative response to his publication among Brazilian publishers was rapid. Between 7th and mid-August, over 150 scientific editors joined in a petition [4] rejecting

the text. Many criticized the article arguing that the author's position was "biased", "provincial", "colonial", "uninformed" and even frankly "ignorant". In this defence of SCIELO, it was stated that this platform, largely supported in Brazil by the FAPESP initiative, is the most important and innovative political, managerial, technical and academic program in the evolution of publishing and the national and international visibility of Brazilian journals, as well as journals from the majority of the 15 countries that are members of the SCIELO Network [4].

The network consists of South Africa, Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Spain, Mexico, Paraguay, Peru, Portugal, Uruguay and Venezuela [5], and receives financial contributions from local and public institutions [4]. Adopting a cooperative and innovative model - Open Access (OA) has proved to be an important tool to overcome negative discrimination against scientific publications originating from these countries [6]. With decentralized platforms for the publication of scientific knowledge, which allow the release of research, from different areas of knowledge, developed in Latin America, Spain and Portugal. SCIELO and REDALYC have a leading role in Latin America, as recognised by a paper published at the Scholarly Publishing and Academic Resources Coalition (SPARC): it is one of the most progressive regions of the world in terms of open access [7].

Latin American, and especially Brazilian, pioneering in the development of the SCIELO model dates back two decades ago, and happened as a result of meetings of experts, promoted by FAPESP [8] and by BIREME/PAHO/WHO, encouraged by the publication of the article "Lost science in the third world" [9], which points to the limited international visibility of scientific production from the region. The result of those meetings confirmed that only a small fraction of the national periodicals (with the means for international indexing) was effectively accepted.

Given these results, FAPESP started, on an experimental basis, the SCIELO Program, which was rapidly adopted by other countries in the region, starting with Chile. A substantial difference between the SCIELO and REDALYC model and the model diffused by international editors, which had dominated the academic market until then, relates to the purpose of the platform and its strategy to provide access to interested parties. While the Latin American platforms work with open access, the platforms developed by leading international scientific publishers are largely characterized by being a business, a trade that involves selling access to published articles to institutions or researchers.

This means that the commercial platforms hold the copyright on published articles; they charge to receive, review and publish as well as to give readers access to the articles. The open access platforms, in general, allow the total or partial reproduction of published works provided authorship and source are cited. As defined by the adoption of the access attributes of the Creative Commons (CC) system, open access seeks to remove both the barriers to entry, the reuse of content and, thus, has the potential to transform them and formalize them as public goods that can contribute greatly to the progress of research, innovation, education and informed public policy [10].

It should be noted that open access was one of the initiatives taken by Latin American and Caribbean institutions designed to offer an alternative to promote scientific research from peripheral countries and, at the same time, to respond to the recommendations of the World Conference on Science, organized by UNESCO in 1999 in Budapest [11]. That conference reiterates the importance for countries to make efforts to reduce the scientific and technological gap between core and peripheral countries, as confirmed by later documents [12].

The importance of open access to disseminate scientific knowledge has been recognized by researchers, libraries and international bodies such as UNESCO. Its

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merit is to facilitate the publication and dissemination of academic content and promote the visibility of projects and research groups from developing countries, which, for various reasons, find difficulty publishing in conventional media. Without claiming to exhaust the subject, we will endeavour to answer these questions.

Point by point

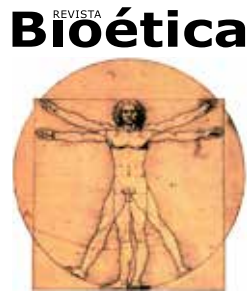
The advent of individualism in modern times definitively consolidated the gap between the collectivist dimension and individual perspective. The notions of equality and freedom that emerged strongly at the beginning of this period gave rise to the resurging discrepancy between these two worldviews. Since then the collectivist dimension and the individualistic perspective began to give specific meaning to the notions of freedom and equality, outlining different strategies to achieve them.

Both worldviews arise from the same sentiments of desire, need and willingness to achieve the "good life" (or quality of life, as defined by human rights), and are based on the same aspirations. However, the freedom to undertake the quest to achieve such a condition, given the characterization of what would be the attributes of such a "good life" and the necessary process that should be followed to reach it, reveal diametrically opposed ethical perspectives.

At the extreme of the collectivist dimension, equality tends to be interpreted as an end, an inalienable right and ideal standard applied through community rules or through a social pact that provides equal opportunities for individuals, groups, sectors and populations to access a good life, but is intended to ensure equal rights for all. At the extreme of the individualistic perspective, equality also stems from the social pact. However, in this case, equality is the means through which each individual exercises their "natural" right to seek a good life and, thus, distinguish themselves – by their own initiative - from others. In the first case, freedom refers to the guarantee of equality for all and, in the second case, it is an indispensable element to ensure opportunities for each individual.

Naturally, the interpretation that the adherents of each of these visions of freedom and equality have, compared to those who choose the opposite perspective, is a marked lack of wisdom and a mutual disregard. Although in principle both sides consider that the opposite view is based on a "selfish" position, each side adds different negative attributes to this underlying sentiment. Those who adopt the individualistic perspective call their opponents "whiners" and say they seek to gain benefits without having truly strived for them. Those who share the collectivist dimension classify those who follow the opposite position as "exploiters", who obtained benefits improperly, through expropriation ensured by the use of force.

As a consequence, for individualists, the requirement of a universal standard of equality goes against empirical reality, which is driven by individual effort and fitness towards individual success. The existence of equality among all would be selfish because it undermines our civilized norms, which should guarantee everyone, without distinction, the ability to independently secure a good life for themselves. As for the collectivist, the individualism of the opposing perspective is ostensibly selfish, because it disregards the fact that we live in a society with equal rights to enjoy a good life, inherent to civilized norms, which should be extended to all without distinction, regardless of any individual trait. This dichotomous panorama, outlined in general lines, paint the scenario which incorporates the challenge we set ourselves to reflect on.



Joining the dots

Currently, the primary difference between rich and poor countries is due to their status as producers or consumers of technology. More importantly, than the absolute material wealth that each may have, is that their ability to produce or their need to consume technology determines their position on the podium of nations.

In this scenario, undoubtedly, science stands out by highlighting the necessary resources to generate technology, which unfolds into wealth and power. As a result of the colonialist role of the British Empire (in America, Africa, Asia and Oceania), and with the United States becoming the leading world power after World War II, as well as being one of the main countries in research development, English has overtaken other languages as the preferred language for science and scientific communication. Today, English has become the 'lingua franca' of international communication. Add to this the fact that new technologies are named in English and, because of the possibility of international dissemination, this same name is used in a similar manner worldwide.

Because the first companies organized to publish and disseminate research findings also used that language, the importance of English grew in the scientific field in such a way that, currently, to seek recognition it is not only indispensable to publish, but to publish in English.

The fact that English has become an almost indispensable requirement for scientific communication gives societies in which English is currently the first or second language a natural advantage over others, even if knowing a language does not ensure that someone has attended school, or guarantees a comprehension of scientific logic or even the ability to produce technology, which are also factors of exclusion. But having the language consolidated in daily life is an indisputable advantage in scientific dissemination. Countries where English is neither the national language nor the second idiomatic option do not have the same advantage.

With regard specifically to academic publications in developing countries, the conflict about the use of local languages or English is intensifying. To fulfil its objective of providing international visibility to local scientific production, the regional databases, such as SCIELO and REDALYC, need to join the major international editors, who make many requirements (including an increasing use of English in published articles) to make the collections of the peripheral countries available on their platforms.

Obviously, this imposition has a direct impact on indexed journals. In fact, the requirement to publish in English can make the scientific production of the region known in the core countries. English publications put authors on the radar of international publishers, which begin to insistently invite them to publish in their journals. There are also invitations to republish articles, translating them into English, which would "assure" higher visibility. This "evidence" of increased output visibility as a function of the language in which it has been published is related to the economic dimension. When authors publish in English, they often receive, in addition to the publishers' invitation, information about translation enhancement services, in which it is explained that it is possible to "improve" a text so that it looks like it has been done by a researcher whose native language is English. This communication class common to researchers from peripheral countries is a reflection of the business dimension.

In addition to this circumstance, one must consider that "the quality journals from Brazil have been, increasingly, publishing scientific papers of other countries" [13], although the reverse is not necessarily true. So, the need for "internationalization"

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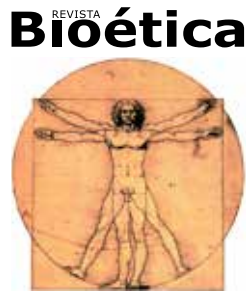
with regard to publication in English ends up motivating Brazilian journals to publish foreign authors, which leads the journals to devote editorial resources from poor countries to make the work of researchers from rich countries available. This situation fuels even further the inequality in scientific dissemination among core and peripheral countries proving, once again, that equally treating those who are unequal can establish further inequality.

A proposal presented in a public notice from CAPES in October 2014 reinforces the view that this matter can, even with the best of intentions, be potentially conflicting. CAPES coordination planned to support the internationalization of Brazilian journals by hiring a foreign commercial publisher who would be able to improve the placement of some national journals (identified by CAPES as the "best" in their field) in the international rankings. In response, SCIELO and the Brazilian Association of Science Editors (ABEC) issued a statement that this strategy would increase the gap between these and others journals, and, worse yet, prioritize once more the support of international companies and of commercial proposals that go against the alternative proposal, which was originated in Latin America, to promote the dissemination of knowledge [13]. Given the situation above, CAPES has reconsidered the proposal.

Although not even the regional databases have identified the following prerequisites as interrelated issues, this analysis considers that the requirement to publish in English could be related to another request that the regional indexes have recently made to periodicals. Journals have been asked to change the license for reproduction of published works. This request is believed to be also due to an internationalization stipulation. Until the middle of this year, most Brazilian magazines adopted (at the advice of SCIELO) the license CC BY NC that allows the total or partial reproduction of content as long as the author and source are cited, but restricting the reproduction for commercial purposes. The request that editors received in an institutional communication from SCIELO suggested changing the license mode for CC BY, which retains the same prerogatives but admits reproduction with financial objectives [10], once again indicating the importance of this international business.

As seen, to awaken confidence in published articles, encourage their acceptance and contribute to their internationalization, concerns much more than the replication of standards and criteria and the requirement of technical proficiency. It requires the delicate process of creating a scientific communication system that communicates with the world and - effectively - promotes the dissemination of locally produced science. In other words, that implies the difficult (but not impossible) task of finding the balance between the pressures and rules of the market and the characteristics and needs of societies, and those of educational and research institutions of the peripheral countries.

Sewing another story



Ethics is not a gift; it is learnt, and can only be truly substantiated through the process of living in a social environment in which ethical standards are reproduced in everyday practice. It is essential that individuals, groups, segments and populations in all societies and communities take their destiny into their own hands and make the present and future a result of their own choices. In order that these expressed preferences can go beyond the selection of brands and products in the market (reaching values and principles indispensable to the reproduction of what these societies consider as a "good life" and quality of life), it is essential to promote

education, not only to ensure actual knowledge domain, but mainly to make every human being agents of their own lives, capable of living in a emancipated, rather than paternalistic, way. This is what the bioethics philosophy advocates, in which freedom is understood to be in close partnership with equality in the broad sense of human rights, which covers all, without distinction, ensuring both learning and critical knowledge, allowing choices to flourish.

This appeal to collectively build knowledge in a way that is not inflexible nor pluralistic, through bioethics, is an attempt to highlight the problems affecting the scientific output of peripheral countries. In this report, it is noted that, despite initiatives such as SCIELO and REDALYC, the prejudice still exists, as Beall's post shows. Although critical, this analysis is limited to pointing out antagonistic perspectives, without delving into other fundamental aspects of hegemonic ethnocentrism, such as the subsumption of the native languages in their own national contexts, which have been discussed in the de-colonial option [14].

The idea of "*libertarianism*", which guides the collective imagination of the North refers to the ability to "negotiate freely" without interference or state regulation. In this model, the "heroes of liberty" play the role of the "winners", "rich", and "successful", which contrasts with the "*losers*", "*poor*" and "*unsuccessful*", as we are labelled. Our claims are considered as the grumbling of those who did not have the strength to win and want to "throw a tantrum". For us, Latin Americans, this rating seems more like a tricky manoeuvre.

This is the picture of a mutual lack of wisdom, of the inability to see others as they perceive themselves and to understand how they perceive us, so that we know how to position ourselves and how to respond in the best and most convenient way. It is essential to understand what role we are expected to play, so that we can pick the best, or maybe the "least worst", of the strategies towards self-determination. What we believe is what we want to be, we feel we should be, and we hope to become.

It is necessary, however, to be aware that, to achieve what we dream, feel and believe, we must, today, take the steps that lead to this condition. The future will come inexorably but what it holds depends on what we do now. With the belief that in this journey we will keep counting on the support of our readers, authors, collaborating reviewers in 2016. We say goodbye with our traditional wishes of "have a good read". To this, we add the wish that next year our country can overcome adversity and move towards ethics and social justice.

The editors

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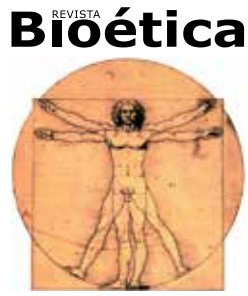

Ten years of the *Universal Declaration on Bioethics and Human Rights*

Salvador Dario Bergel

Abstract

The Universal Declaration on Bioethics and Human Rights of UNESCO, on 2005, represents a radical change between the "classical bioethics", devoid of a social and political view, and the "new bioethics" witch inserts man into a global stage with their peers and other components of the biosphere. Ten years after its entry into force, the paper relates its history, as well as its social and political value of the Declaration, highlighting its more significant contributions and concluding with a vision of the future.
Keywords: Human Rights-Bioethics. Policy-Treaties. International acts-Social justice.

Resumo

Dez anos da *Declaração Universal sobre Bioética e Direitos Humanos*

A Declaração Universal sobre Bioética e direitos Humanos da Unesco, de 2005, significa um ponto de corte entre a "bioética clássica", desprovida de uma visão social e política e a "nova bioética" que situa o homem em um cenário global com seus semelhantes e demais integrantes da biosfera. Após dez anos de sua vigência o artigo relata os antecedentes assim como o valor jurídico, político e social da Declaração, ressaltando seus aportes mais significativos e concluindo com uma visão de futuro.
Palavras-chave: Direitos Humanos-Bioética. Políticas-Tratados. Atos internacionais-Justiça social.

Resumen

Diez años de la *Declaración Universal sobre Bioética y Derechos Humanos*

La Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO de 2005 significó un punto de corte entre la "bioética clásica", desprovista de una visión social y política, con la "nueva bioética" que ubica al hombre en un escenario global junto a sus semejantes y a los demás integrantes de la biósfera. A diez años de su vigencia el artículo relata sus antecedentes, así como el valor jurídico, político y social de la Declaración, subrayando sus aportes más significativos y concluyendo con una visión del futuro.
Palabras-clave: Derechos Humanos-Bioética. Políticas-Tratados. Actos internacionales-Justicia social.

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Declara não haver conflito de interesse.

The history of the Declaration

Ten years after the signing of the UNESCO *Universal Declaration of Bioethics and Human Rights* [1], an assessment has to be made of its importance, the fulfillment of goals pursued and its future projections. The Declaration was not an improvised text, the fruit of an idea launched in one of the many Unesco meetings, but on the contrary, arose from a long process of elaboration through many very enlightened debates.

Going back to its history, we would have to return to the 30th of March of 2001, the date on which the President of France launched the idea of developing a universal instrument devoted to bioethics within the United Nations Commission on Human Rights. Based on this idea, the International Bioethics Committee (IBC) of UNESCO commissioned the doctors Giovanni Berlinguer and Leonardo De Castro to report on the possibility of developing a universal instrument concerning bioethics.

Based on the prepared report, the IBC entered upon the task of its implementation, beginning in January 2004. Three phases took place in this process:

1. Consultations during the first months of 2004, with the Member States of Unesco, governmental and non-governmental organizations, as well as the IBC, on the cover page, objectives, structure and content of the future declaration;
2. Drafting of the text of the declaration by an editorial group of the IBC.

   This phase was characterized by consultations with Member States, governmental and non-governmental organizations, ethics committees and specialists. The work group was made up of specialists from Europe (France, Italy, the United Kingdom and Lithuania), Asia (Japan, the Philippines, Israel and Lebanon), Oceania (Australia and New Zealand), Africa (Morocco and Rwanda), and America (Canada, Mexico, and Uruguay). It should be noted that three distinguished internationalists were included in the group: H. Gros Espiell, M. Ida, and M. Roucosimas;
3. Completion of the text of the future declaration, in the setting of two meetings of governmental experts, extensive discussion within the IBC and finally the approval of the Declaration, which was unanimously ratified by the Member States of UNESCO [2].

As can be observed, the Declaration was carefully prepared and sufficiently debated within UNESCO. The unanimous vote is resounding proof of this. While it was never translated into a treaty, there is no denying the binding force that it has on the internal order of the States, as we present below. The texts, as Badía Martí affirms, mean the consolidation of bioethics in international relations beyond the scientific dimension, its full incorporation in the relations between States with their implications in the economic, political and social fields, entering fully into the international arena.

The author claims that the Declaration still has the indisputable merit of incorporating the subject of bioethics in the international legal order, in the hands of an issue so sensitive and universal in nature, such as human rights, which opens a new scope in this order which is not easily dealt with due to the diversity of interests at stake and the multidimensional character of the matter [3].

The indissoluble link between bioethics and human rights

Beginning with its title, continuing with the explanation of its history, *this Declaration is to be understood in a manner consistent with domestic and international law in conformity with human rights law; the aims of this Declaration are to promote respect for human dignity and protect human rights, by ensuring respect for the life of humans beings, and fundamental freedoms*, the intimate link between bioethics and human rights that it establishes is very clear [1].

In doing so, it did not try to seek a protective shield for bioethics – which it otherwise did not need – but rather emphasized in conveying to its recipients that bioethics provides for a concrete application of human rights in the field that is its own (the life, health and welfare of human beings) and this not only with regard to the progress of the technosciences, but also in a much more open field: that of the social and economic determinants of life and human health. Both constructions speak the same language and note a common objective in the final analysis: the defense of human dignity before the pitfalls of a world that advances precipitously, leaving out large masses of the population which remain trapped through their dramatic exclusion from the most diverse areas of life.

The 1948 Universal Declaration of Human Rights [4] was not the fruit of an invention carried out

by a handful of enlightened people, which while the world was emerging from one of the most grueling catastrophes in history sought to protect human dignity, shielding it with a catalogue of elemental and essential principles for organizing a peaceful and lasting coexistence. It was much more than this: the awareness of this need could perhaps be the most relevant merit of the instrument voted in 1948.

We say that it was not an invention, as much as it limited itself to translating – perhaps masterfully – principles and demands already floating in collective consciousness. The Declaration of 1948 did not intend to constrict human rights into a closed catalogue and if there is anything that may be learned from it, it is the need to move forward in the search for new rights, in accord with the natural preoccupation of human beings with improving the conditions of their existence for their own enjoyment and to transmit to future generations a legacy superior to that received.

In its shadow – as the always remembered E. Rabossi described it - an extremely complex, very dynamic legal, political, ideological and moral phenomenon, of global scope and revolutionary consequences, has been developed. The phenomenon, Rabossi observes, is not anarchy, as it provides a macro scenario in which the interests at play are confronted, logic intersects and solutions (sometimes) are reached [5]. As far as these rights are human, they represent needs, primary criteria, social, economic and cultural material without which the individual cannot develop his life with dignity [6].

Several classifications have been developed over the years, which not only aimed to organize the material, but also intended to establish a hierarchical order of human rights, according to economic capabilities of fulfilling this. All these classifications, deep down, aim to explain or attest the null or diminished validity of economic and social rights, which are – coincidently – the ones most persistently violated. The reality is that all human rights have the same reason for existing and all must be applied and respected on an equal footing. Cataloging only contributes to weaken their practical application. Violation of these rights marks, precisely, a field of struggle, a demand that only ceases with their effective entering into force.

In this picture, proclaims the UNESCO Declaration proclaims, in essence, is a set of human rights that are systematically violated in the field of human life and health. It did so with regard to the reality of the moment at which it was signed, which did not imply that in the future, other rights could be incorporated according to the arising of new demands and the progressive character assigned to them. In short, the Declaration of 2005 is integrated with that of 1948 and other instruments that were generated at the international or regional level through the influence of social and political demands on the field of human rights. Among other rights mentioned:

- the right to respect for personal autonomy;
- the right to respect for personal integrity;
- the right to enjoyment of the highest attainable standard of health;
- the right to quality health care;
- the right of access to essential medicines;
- the right to adequate nutrition;
- the right of access to drinking water;
- the right to the meeting of basic needs (poverty reduction);
- the right to literacy;
- the right to enjoyment of the results of scientific research;
- the right to an unpolluted environment [1].

"In establishing human rights among its principles," Dora Porto points out, "the social dimension was recognized as intrinsic to bioethics" [7]. Bioethics thus incorporated – preponderantly –human rights issues relating to the social and economic conditions of human life and health.

The legal, political and ethical value of the Declaration

It is known that under international law, a declaration does not have the same effectiveness as a treaty or convention. Based on this difference, it has been held that the contents of 2005 Declaration are not binding for the countries that signed it. Faced with this attitude from those who try to relegate the Declaration to a simple expression of good wishes signed by representatives of the States, Héctor Gros Espiell, an outstanding figure in international law and driving force of the three UNESCO Declarations on Bioethics, wonders: *What does 'non binding' mean?, That which does not create links?* And he answers: *It can not be said that a Declaration adapted by the United Nations General Assembly does not create links*. For Gros Espiell and for the majority of the doctrine it is a source of rights [8].

When the *Universal Declaration of Human Rights* (1948) was adopted, some delegations also

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argued that it was merely a moral text that would serve as an example for domestic law. That same day, the French delegate, René Cassin, one of the authors, said: on the contrary. In a masterful and premonitory speech, he said that the Declaration of 1948, as a projection and refinement of the United Nations Charter, *had its own legal value and would come to be a source of rights*[9].

Later, in the Tehran Conference of 1968 and Vienna Conference of 1993, it was established that the Universal Declaration was obligatory for the entire international community. This materialized in doctrine which is particularly unanimous today on this matter and repeatedly sustained by the International Court of Justice. Concluding his observations, Gros Espiell expresses that the Universal Declaration has a binding character, not only morally and politically, but also binding as an eventual source of rights, from a legal point of view.

In this same line of thought, Maria Yolanda Gómez Sánchez, Professor of the National University of Distance Education (Universidad Nacional de Educación a Distancia - UNED) and former member of the IBC, considers that the Universal Declaration of UNESCO, adopted by the Member States of the United Nations, is *an international legal document, from which commitments are derived, and also legal materials with respect to its content for all of the countries which have adopted it* [10]. In its construction, there is a distinction between the legal value of the Declaration and its internal legal effectiveness in each of the States which have signed it.

When the principles of international law define the concept of a 'binding document' for the States, she states, they are alluding to the internal legal sphere of each of the States subscribing to the international document, but not to the general legal value derived from its adoption by the States within a particular international organization. The legal value of the Declaration applies equally to all the States that signed it and with regard tothe commitment of each state (which is subject to international law) to the international community.

Consequently, the author notes, the content of the Declaration will always be binding, in a general sense, for all of those States which have signed it, with regard to their international commitments [10]. 'Internal effectiveness' alludes to the position of the Declaration in the internal legal systems of the States and their hierarchical relationship (supremacy of some rules over others). Although both the international value and the internal legal effectiveness would be essential elements of the Declaration, the second is a determining factor for the practical implementation of the Declaration in the internal systems of the various States, since it allows the defining of the legislative and executive goals of a given State, and in each particular case, the possible legal protection to be recognized in the Declaration.

The accepting of the "non-binding" thesis to the Declaration, would lead to the legal incongruity that the states can commit internationally to while *not being bound by* to the commitments undertaken. In this direction, Article 3 of the Vienna Convention on the right of the treaties to determine which international accords do not remain included within the scope of the same states:

The present Convention does not apply to international agreements concluded between States and other subjects of international law or between such other subjects of international law, or to international agreements not in written form, shall 'not affect the legal force of such agreements' [11]. This is all the more reason why these principles should be applied to a written instrument signed by the States.

A compelling example of the legal status of an international Declaration in domestic law is offered in article 75, subsection 22 of Argentina's Constitution, the second paragraph of which establishes that the American Declaration of the Rights and Duties of Man, and the Universal Declaration of Human Rights *…have constitutional hierarchy, do not repeal any article of the First Part of this Constitution and are to be understood as complementing the rights and guarantees recognized herein* [12].

In short, the *Declaration on Bioethics and Human Rights*, unanimously signed by the Member States of the United Nations and ratified by the General Assembly of one of its organs (UNESCO), has a tangible legal status in the internal order. While in our country it does not yet have constitutional status, its the corresponding legal value cannot be denied due to the sole fact of it being a Declaration, ratified by the States.

What has not been translated into a treaty does not impede recognition of the legal value of the Declaration, which was widely discussed for two years and passed by the unanimous vote of the signatories. What does not enable the demand of the obligations assumed by one or various states from the non-compliant, does not mean that, in their internal order, the signing of the Declaration amounts to assuming the obligations of the State to its citizens. Moreover, regardless of its legal status, the Declaration has an important ethical value in terms

of its effect on the current agenda, incorporating ethical issues whose importance cannot be ignored, as will be seen in the next development.

From a political point of view, the Declaration provides sufficient tools for those aspiring to a bioethics which is closer to the problems and dilemmas of everyday living for large masses of the global population.

The Contributions of the Declaration

Beyond the depths and heights of the debate that preceded the approved text, it is only fair to recognize the fundamental contribution made by Latin American bioethics, especially Brazilian, to the content of the Declaration. In this direction, it is worth mentioning the grand Congress of Bioethics in Brasília in 2002, which took place under the suggestive slogan "Bioethics, power and injustices".

The Congress of 2002, as noted, "politicized" in actual practice the international bioethics agenda. The principles of autonomy, beneficence, non-maleficence and justice – despite being indispensable and central to bioethics – ceased to be the only theoretical and methodological tool available to researchers and scholars. The practical result has been gradually incorporated into the international epistemological context of bioethics [13]. These contributions were translated into the "principles" of the Declaration. These principles not only constitute the axis along which the "new bioethics" travels, but – essentially – constitute guides to action.

This is how they were understood by the cultivators of bioethics in their meetings and would serve to move the future agenda. From these principles we take those that in our judgment are the most original contributions:

a) Health Promotion

The Declaration refers to various health-related rights: the right to the highest level of health, the right to quality health care, the right of access to medicines, all of these regardless of economic and social health conditions. In its introduction, it stresses that health does not solely depend on the progress of scientific and technological research, but also on psychosocial and cultural factors.

Berlinguer, the illustrious bioethicist and Italian sanitarian, tells us of a society in which the possible does not oblige to medicine the sad duty of engaging itself in reparative activity, which is late and generally useless on the damages caused outside its field of action [14]. Both primary prevention and health promotion jointly propose preventing disease and improving the psychophysical conditions of the individual. These types of prevention tend to mobilize the preventive capacity that is the fruit of decisions made in other areas, the spread of education, the humanization of work, the improvement of housing and urban living and the spirit of coexistence and solidarity between citizens [15].

As outlined, all medicine has health as a goal, but only prevention has as its intrinsic character and specific aim the equality of every citizen in the field of health. Article 14 of the Declaration begins by affirming that health promotion and social development for their people is a central purpose of governments, shared by all sectors of society [16]. The right to quality health care translates into care that guarantees the adequate selection of an indication in accordance with evidence or at least with some scientific support that shows its usefulness; an adequate assessment of risks and possible harms it can cause, a human care that respects the rights of the patient and that complies with the criteria of justice [17].

The rights of access to health services and medicines are essential components of the right to health. When health suffers, the most basic of rights that can be exercised is that of access to health services; access in adequate time and with the required quality according to the type of care. The existence of people who cannot count on the possibility of such access, constitutes an offense to the human species. Parallel to the right to health care is that of access to medicines. The World Health Organization (WHO) periodically draws up a list of so-called essential medicines. Beyond this, the provision of medicines is imperative, without major distinctions – which should be a primary benefit from the State.

The power to heal – returning us to Berlinguer – has become a direct, legitimate and explicit function of money, and due to this there is affirmed in practice, and sometimes in the laws, the right to medical care and health proportional to wealth [18]. These situations, which unfortunately even today many countries display, should be definitively overcome and the Declaration points to this in its Article 14.

Primary prevention and health promotion are often outside the bioethics agenda. The issue of health – it has been noted – is rarely present in bioethical debates. These increasingly favor extreme situations like "artificial" births, organ transplants, the survival conditions of terminal patients, neglecting the fact that health and disease are for all a universal field

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of experience, of reflection and also of moral choices. Health is commonly denied ennoblement as an object of ethics and in the best cases it is attributed only the value (which for some is considered philosophically irrelevant and intellectually plebian)of a social issue [19].

b) Poverty, malnutrition and illiteracy

For the first time, a universal document on bioethics places the focus of attention on these themes which were commonly considered beyond its mandate. Poverty is still the main cause of illness and is a factor which is beyond immediate control. Material poverty (as well as cultural) as well as necessitating insalubrious labor activities, which bring little satisfaction, causes the action of all disease-specific factors, hindering the adoption of preventative measures, and making healing more difficult [20].

Around poverty – as we pointed out on another occasion – a perverse circle is formed, which leads to malnutrition, environmental degradation, marginalization, social disintegration, crime, poverty, illiteracy, and the loss of self-esteem; a circle which makes leaving difficult for those who enter it, since they tend to reproduce these conditions in their descendants [21].

The 1995 World Summit on Social Development, in Copenhagen , had stated that the lack of income and productive resources to guarantee sustainable livelihoods generated hunger and malnutrition, ill- health, lack of access or limited access to education and other basic services, increased morbidity and mortality caused by diseases, discrimination and social exclusion [22]. Closely linked to poverty is malnutrition, which in the first years of life, produces devastating effects. The right to food – specified as safe, healthy and adequate food – presents as the most specific field of global citizenship. Through adequate and safe food, not only the body is nourished, but also the dignity of the person [23].

Fifteen years ago, the illustrious Brazilian geneticist and bioethicist Eliane Azevêdo published a fascinating essay titled “O direito de vir-a-ser após o nascimento” (The right to exist after birth) [24], which stresses the need for adequate nutrition in the first years of life. Malnutrition of children, she noted, slows cell division, DNA synthesis and the total number of cells in the brain, up to the point of interfering with the process of myelination, recalling that in a 1998 UNICEF document [25] it was recognized that malnutrition impairs intellect, productivity and the potential not only of the person, but of the whole society. Azevedo adds that the absence of the minimum conditions of food and shelter, required by the human body, functions as a nullifier of genetic potentialities, driving people to an early death, preceded by a sub-biological life. Denying the essential minimum to anyone is to usurp the most sacred of the essential rights, that is, the right to full development of the biological and mental potentialities that it brings [24].

Years later, Stefano Rodotá, a prominent Italian lawyer and bioethicist – perhaps without having read Azevedo – returned to the issue in similar terms. The right to exist, he expressed, entails surpassing the zero degree of existence, that is, freeing oneself from a biological reductionism which guarantees a minimum subsistence. In the already lengthy discussion that accompanies the recognition and rejection of this difficult right, we often find an overlap, a confusion between survival and existence. This is due to the fact that this discussion is born in the field of poverty that accompanies several of its overt manifestations through time and in varying cultural contexts, dramatically linked to terrible conditions [26].

Since 2001, G. Keyeux reminds us, more than 100 million children were born with severe birth defects and genetic disorders [27]. The impact is particularly serious in low and middle income countries where 94% of births occur in those conditions. Undoubtedly – to be specific - genetic disorders are socially determined; 90% of these children are born in poor households, with degraded living conditions, to parents with low levels of education in the context of systems that provide minimal health packages for the poor and most vulnerable. Birth defects and genetic diseases, the author emphasizes, are not so much diseases of genes as of poverty.

Experience gained over the last 50 years in high income countries shows that mortality and disability caused by birth defects could be reduced by up to 70% in low income countries, if measures were implemented which are relatively simple and low cost, but highly effective, which would encompass from education to prevention, from prenatal diagnostic and pre-conception services to early access to the institutes mentioned [27].

I allowed myself to transcribe these three contributions from illustrious contemporary thinkers, in order to show the effects of poverty and undernourishment on human life and development. In light of these realities, it is easy to conclude that bioethics needed to include economic and social

determinants of health in its analysis and in its programs. Otherwise, the placid contemplation of the damages , caused by poverty, undernourishment, social exclusion, lack of clean drinking water, without warning of their consequences to the health and lives of men, simply means diverting the path of thought.

Without the pretext of applying an aseptic bioethics, which limits itself to borderline problems, excluded from its reach are central themes of urgent importance. The inclusion of social and economic determinants of health and life can be described as an gateway from bioethics to politics, which is nothing bad. The defense of an apolitical bioethics is a political position that is objectively contributes in favor of the reconciliation of interests within the existing social status quo, as Sotolongo says [28].

The Declaration of 2005, with all the edits that had to be accepted for there to be consensus, constituted – without doubt – a strong step towards the integration of economic and social determinants of human life and health. In this sense, Article 14 plays a central role in the achievement of such ends.

c) Protection of future generations

UNESCO had already shown its concern in a specific declaration on the rights of future generations [29]. Now the Declaration of 2005, by reiterating this concern, points in particular to effects that could engender the application of advances in scientific research to the genetic makeup of the individuals who will succeed us.

This is not a minor issue: when Man has managed to penetrate into the innermost secrets of heredity, when he has managed to modify genetic capital through techniques such as recombinant DNA – used today in fields other than human, such as agriculture –concern is born about what limits can be imposed when applying it to the human species.

The human genome is by nature evolving, as recognized by Article 3 of the UNESCO Declaration on the Human Genome; but this variability born of natural evolution of species cannot authorize a "directed variation", since in this case future generations will not be conditioned by natural processes, but the intentional participation of Man would come to play a role. This is obviously dangerous as there are no parameters to determine the limits of such interventions, which could lead to alteration of certain characteristics in future generations.

Science and technology, the adventures of human thought, do not recognize limits and if they are hypothetically fixed, can easily be vulnerable. The destiny of the human being is a distinct thing that imperatively demands respect, beyond and despite the projections of the biotechnical sciences, in the conception of Fermin Roland Schramm [30]. Today the possibility of altering genetic information to enable transmission of hereditary diseases may be debated. This is a topic on which different criteria have been outlined, which must be duly respected and debated.

What should deserve general revulsion is the eventual intent to alter genetic information to incorporate in the offspring certain features of "enhancement" according to the criteria to be determined by those who practice them. Here the prohibition on affecting the rights of future generations plays a strong part.

There are difficult reasons for opposing transhumanist positions, – as Per Puigdomenech teaches – but one of these is to protect the generations that follow us from the problems caused by inequality between individuals that will occur under these conditions. If some day we achieve precise control over the genome modification process on the germ line, this may be one of the most important factors that should be taken into account when making decisions about the use of these technologies [31].

d) Protection of the environment, biosphere and biodiversity

"Classic" bioethics – so to speak – is characterized by accentuated anthropocentrism. It was only interested in man, and where possible, isolated from his habitat and society. In the UNESCO Declaration of 2005, as R. Junges points out [32] – environmental protection appears to be a human right, but this anthropocentric perspective is corrected by the sustainability of the biosphere and biodiversity. In other words, the environment is only preserved when there is a complex vision which comprises the environment as an integral system of interdependence (biosphere) and for this system to be in homeostatic equilibrium, there needs to be biodiversity, which enables these interrelationships. Only this systemic vision of the environment illustrates to organize social coexistence, and around its own ecosystemic vision of health, is a basis for understanding health as a human right and the environment as a basic component in the field of health [32].

The inclusion of this principle, in the midst of an extremely concerning situation, generated by the consequences of irrational exploitation of

the planet, marks the road ahead. In this process, this principle is interconnected with that referring to the rights of future generations. We noted, on a previous occasion, that discourse about future generations involves a broader direction than the defense of Man in the future. In advocating, as the center of the debate, the defense of the quality of life of the generations to come, , there is an implicit tendency to improve the living conditions of all present or future living beings [33].

Final Considerations

The UNESCO Declaration of 2005 took an important step. We have tried to demonstrate that far from being a simple "declaration", a simple intellectual essay formulated by state representatives to justify the reasons for their meeting, it is a legal and political instrument which creates obligations in the States and correlativerights for their inhabitants.

The extirpation of pockets of extreme poverty, access to drinking water, food compatible with development, access to health services and to essential medicines, and an environment neither polluted nor polluting, constitute not only the duties of the signatory States, but also, in parallel, the rights of their inhabitants. The Declaration has the merit of showing these defects, but makes it incumbent on the citizens, in the broadest and most comprehensive sense of the word, to demand and fight for such goals.

If a task is imposed on the basis of the Declaration, it is to deepen the analysis of problems linked to public health and social medicine. Thus, the Declaration constitutes a great battle flag that has the virtue of exposing an issue that for many years was absent from the debates. It is the duty of all who approach a field as fecund as it is fascinating, that of bioethics, to work towards spreading the underlying principles of the Declaration and at the same time to participate in actions which are aimed at expanding them.

To celebrate the 20th anniversary of the UNESCO Bioethics Program, several authors have created a book entitled, *Why a Global Bioethics?* [34]. Among the contributions, H. Ten Have, Director of the Division of Ethics of Science and Technology at UNESCO, wrote a brief essay titled, "Bioethics needs bayonets" [35], noting the need to intensify actions to make effective the principles issued in the Declaration. Here it is worth reaffirming the efforts for bioethics to be conducted within a broad social and cultural movement, directed to defending life and promoting health.

Social movements have demonstrated their effectiveness beyond the existence or nonexistence of legal norms. An unquestionable example given was the social reaction, not only internal but also extended to the international arenas in the case of medicines to combat AIDS, which brought the South Afcrican government to ignore treaties aimed at enabling its inhabitants to have access to essential medicines; an example later followed by Brazil under the Lula da Silva administration, which eventually led to moderating the Doha Agreement (REF) with regard to industrial property.

I consider that the conditions have been met to proceed with the signing of an international treaty on bioethics. The principles of the Declaration have been studied, in depth, and discussed in innumerable international forums, its doctrine has been extended considerably in the directions noted here, and the lack of adequate response to many of the problems which the Declaration articulates, make necessary a stronger commitment in the international order, without prejudice to the intensification of efforts to achieve the proposed objectives in the internal order.

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Ethics of the use of placebos in clinical research: a proposal for decision-making algorithms

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Abstract

The use of placebos in clinical research has been a matter of considerable debate in recent years, notably when the World Medical Association published, in 2002, a note of clarification for paragraph 29 of the *Helsinki Declaration*. Brazil is known for its strong opposition to the flexible use of placebos. Both the Federal Council of Medicine and the National Health Council have published resolutions regulating the use of placebos in Brazil, preventing their use if there is a more effective therapeutic method already in place. The present study reinforces that position and aims to describe the various uses of placebos in clinical research, as well as examining the complex decisions relating to the ethics of their use. Additionally, the authors propose a reflection on the use of placebos through decision-making algorithms based on Brazilian ethical standards.

Keywords: Placebos. Control groups. Bioethics. Biomedical research. Helsinki Declaration. Methods. Decision support techniques.

Resumo

Eticidade do uso de placebo em pesquisa clínica: proposta de algoritmos decisórios

O uso de placebo em pesquisa clínica tem sido motivo de debate nos últimos anos, sobretudo após a Associação Médica Mundial publicar, em 2002, nota de esclarecimento do parágrafo 29 da *Declaração de Helsinki*. O Brasil tem se destacado por sua posição firme e contrária ao uso flexível de placebo. Tanto o Conselho Federal de Medicina quanto o Conselho Nacional de Saúde editaram resoluções que normatizam seu uso no Brasil, de forma a não admiti-lo em caso da existência de um método terapêutico melhor. O presente artigo reforça essa posição e tem por objetivo descrever as diversas aplicações de placebo em pesquisa clínica, bem como trazer à luz a complexa decisão sobre a eticidade de seu uso. Além disso, os autores propõem uma reflexão acerca da utilização de placebo no âmbito da pesquisa, por meio de algoritmos decisórios baseados nas normativas éticas brasileiras.

Palavras-chave: Placebos. Grupos controle. Bioética. Pesquisa biomédica. Declaração de Helsinki. Métodos. Técnicas de apoio para a decisão.

Resumen

Ética del uso del placebo en la investigación clínica: propuesta de algoritmos para la toma de decisiones

El uso del placebo en la investigación clínica ha sido un tema de debate en los últimos años, sobre todo después de que la Asociación Médica Mundial publicara, en 2002, una nota aclaratoria del párrafo 29 de la *Declaración de Helsinki*. Brasil se ha destacado por su firme posición en contra de la utilización flexible del placebo. Tanto el Consejo Federal de Medicina como el Consejo Nacional de Salud editaron resoluciones que regulan el uso del placebo en Brasil, no admitiéndose su uso cuando existe un mejor método terapéutico. El presente artículo refuerza esa posición y tiene como objetivo describir diferentes usos del placebo en la investigación clínica, así como contribuir en la discusión sobre la ética de su uso. Además, los autores proponen una reflexión sobre el uso del placebo en la investigación a través de algoritmos para la toma de decisiones, los cuales se basan en las normativas éticas de Brasil.

Palabras-clave: Placebos. Grupos control. Bioética. Investigación biomédica. Declaración de Helsinki. Métodos. Técnicas de apoyo para la decisión.

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Declaram não haver conflito de interesse.

The use of placebos in clinical research has caused much debate in recent years [1]. In 2002, the World Medical Association (WMA) issued a note of clarification for paragraph 29 of the *Declaration of Helsinki* (DH), 2000 version, permitting the use of interventions known to be less effective than the best proven existing treatments, provided such use was justified by compelling and scientifically sound methodological reasons. Further controversy was generated when, in 2004, the WMA published another note of clarification, this time for Article 30, relaxing the requirement to guarantee post-study access to interventions that proved beneficial [2].

In 2008 the Brazilian Medical Association (Associação Médica Brasileira, AMB) held an event that brought together members of the National Research Ethics Commission (Comissão Nacional de Ética em Pesquisa, Conep), the National Health Council (Conselho Nacional de Saúde, CNS), and the Federal Council of Medicine (Conselho Federal de Medicina, CFM) as well as clinical research professionals, with the aim of discussing the DH. At the meeting, there was a consensus that Brazil should object to the notes of clarification to Articles 29 and 30 of the DH. As a result, it was agreed to submit a proposal to maintain the draft of the original text of the DH in its 2000 version, without the notes of clarification, to the next General Assembly of the WMA in Seoul.

In August 2008, before the General Assembly in Seoul, the CNS issued Resolution 404, which incorporated this position [3]. The Brazilian proposal, however, was not accepted at the General Assembly in October of that year, although the Chairman of the Board of Ethics of the WMA and representatives of other countries such as Portugal, Spain, Uruguay, South Africa and the UK, voted in its favor (the US, however, opposed the motion). The idea that the use of interventions that were less effective than the best available was permitted under certain circumstances was therefore maintained [4]. Since the decision Brazil has no longer been a signatory to the DH.

Shortly after the decision of the General Assembly in Seoul, the CFM issued Resolution 1,885/2008, firmly establishing its position in relation to the use of placebos in research in Brazil. Article 1 included the following wording: *The doctor shall not involve himself in any way with medical research involving human subjects which use placebos in their experiments when efficient and effective treatment for the disease under study exists* [5]. The same deontological ruling was included in 2009 by the CFM, when updating its Code of Medical Ethics (CME), article 106 [6].

The latest version of the DH, approved in Fortaleza in 2013, maintained the same position as the Seoul version, including in Article 33 the following wording *The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best proven intervention(s)*, except in the following circumstances: *Where no proven intervention exists, the use of a placebo, or no intervention, is acceptable*; or Where for compelling and scientifically sound methodological reasons the use of any intervention less effective than the best proven one, the use of a placebo, or no intervention is necessary to determine the efficacy or safety of an intervention *and the patients who receive any intervention less effective than the best proven one, placebo, or no intervention will not be subject to additional risks of serious or irreversible harm as a result of not receiving the best proven intervention*. Extreme care must be taken to avoid abuse of this option [authors' highlights] [7].

In 2012, the CNS enacted Resolution 466, the main current ethical guidelines for research involving humans in Brazil. Attention should be drawn to item III.3.b of this resolution, which states that research must *fully justify, where appropriate, the use of placebos in terms of* non-maleficence and methodological *necessity*, *as the benefits, risks, difficulties and effectiveness of a* new treatment method should be tested by comparing it with the best *proven current prophylactic, diagnostic and therapeutic* methods. *This does not exclude the use of placebo or no treatment studies in which there are no proven methods of prophylaxis, diagnosis or treatment* [authors' highlights] [8].

As a result of these controversial perspectives, the aim of this article was to analyze the main uses of placebos in research and to reflect on situations where there is an ethical justification for their use, in accordance with the regulations in force in Brazil.

Use of placebos in clinical research

Of all the types of study in the field of biomedicine, randomized clinical trials and masked (blind) studies provide the best and most robust scientific evidence. Randomization and masking are different procedures which prevent distortions in a study, providing more reliable results. The first allows research participants to be divided into different groups, with no selection bias, while the second ensures that the outcomes observed in the study are free from the influence of the researcher or research participant [9].

In masking, the researcher and/or research participant does not know which product is administered to each group (experimental or control). Despite the relative confusion about the terminology used to define the type of masking, it is generally said that the study is "blind" (or "single-blind") when only the research participant does not know what he or she is receiving. When the participant and the researcher do not know what is being given to each group, the study is called "double-blind". There are even "triple-blind" studies when the participant, researcher, and whoever performs analysis are not aware of the product that each group receives [9-11].

The advantages of performing masking in a study are well established among the scientific community. The process reduces the possibility of the researcher adopting different approaches for the control and experimental groups. In addition, it prevents the survey participants having different or distorted perceptions of their conditions [9-11]. The effects on the experimental and control groups in the event that the researcher and/or the participant is aware of the allocation group are presented in Table 1 of the Appendix at the end of this article.

By knowing the group in which a participant is allocated the researcher may unconsciously favor the experimental group. Even outcomes as objective as death can suffer from researcher interference if he or she has knowledge of group allocation. For example, one can imagine a situation in which patients with an advanced, incurable tumor are admitted into a clinical trial to receive an experimental drug. Upon learning that a participant has been allocated to the experimental group, the researcher may behave in a more obstinate manner toward these participants in comparison with those belonging to the control group. Faced with serious complications during the study, a researcher's behavior may change. He or she may, for example, refer the participants in the experimental group to the intensive care unit, or for hemodialysis, mechanical ventilation, or blood transfusion, or prescribe vasoactive drugs - in short, do everything possible to keep the research participant alive.

In the same situation in the control group, the researcher could be driven towards less obstinate behavior, providing palliative clinical support in the ward in order to relieve the patient's pain without, however, employing the intensive therapeutic measures cited. In this hypothetical, but plausible, situation, the experimental group would be favored, leading the study to the erroneous conclusion that the new drug increases the survival of these patients.

Another example would be the decision to request or not tests for a complaint of "chest pain" described by a participant in a study aiming to evaluate the cardiovascular safety of a drug. With knowledge of group allocation, even if unintentionally, a researcher may underestimate complaints in the experimental group and overvalue them in control groups. This distortion could lead the researcher to request less testing to investigate the complaint in the experimental group, leading to fewer cases being diagnosed with angina. The artificial conclusion of the study would be that the experimental drug is safe from a cardiovascular point of view.

In the case of research participants, knowledge of group allocation leads to different perceptions of clinical condition. For example, upon knowing that he or she has been allocated into the experimental group, a participant may describe an improvement in the intensity of symptoms simply because they believe that the new drug is superior to those otherwise available. Contrastingly, participants in the control group, upon knowing that they will not receive the new drug, may overstate the intensity of their symptoms. The natural but mistaken conclusion of the study is that the new drug is able to improve the symptoms of patients. It is understandable, therefore, that masking is an important tool to avoid distortions being introduced to the study by the researcher and/or research participant.

Masking can occur with or without the use of a placebo. In clinical placebo-controlled trials, the experimental group receives the intervention in question and the control group receives a placebo. The term "pure placebo" is commonly used to show that the control group did not receive any intervention beyond the placebo itself (without an active comparator) [9-11].

However, a placebo-controlled study design does not necessarily imply that the control groups remain without any kind of treatment. There are placebo-controlled trials in which the new treatment and the placebo are added to existing treatments for certain clinical conditions (add-on type studies). There are even dummy type studies, in which the researcher uses more than one type of placebo in both the control and the experimental groups, to ensure masking. This is necessary when, for example, the experimental drug is a tablet with a different color and shape to the control drug.

In this case, so that the experimental group participant does not know which drug he or she is taking, a placebo tablet with the physical characteristics of the control product will also be administered.

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In the control group, the placebo will have the same appearance as the experimental drug. In this example, participants from each group will receive two tablets, one a placebo and the other containing the active drug (both experimental and control). The double-dummy study is one that uses two kinds of placebos to ensure masking [10,11].

A variation of the *dummy* design is performed when the aim is to evaluate the escalation of dosage in a masked form. In such situations, a participant could calculate the dosage administered by counting the number of tablets that he or she receives. To ensure blinding, all participants receive the same number of tablets, but the tablets contain different proportions of placebo and experimental medicine. Figure 1 of the Appendix to this article summarizes the main types of randomized clinical trial, with and without a placebo group.

There are situations where a placebo is administered just prior to study randomization. This is the so-called run-in period, when all the participants (experimental and control) receive a placebo for a period of time in a single-blind system [11]. The goal is to prepare the research participants for the main study (wash-out) which consists of adjustment of drug doses, standardization of procedures, conducting of screening tests etc., so that it can be verified if, in fact, they are eligible for the study before randomization.

Studies of patients with type II diabetes mellitus often employ a run-in period of a number of weeks in order to assess the compliance of participants to non-pharmacological guidelines (diet, exercise and glucose and ketonuria monitoring). At the end of the run-in period, some individuals improve so much that they become ineligible for the study. The run-in period is not always carried out with placebos, but when it is, the aim is to exclude individuals who display a significant placebo effect, or to determine if there is a need to replace the placebo used with another type. The use of a placebo run-in period should be evaluated with caution, with the main issue is being the determination of whether the participant will be deprived or not of the necessary treatment for their clinical condition.

It is worthwhile here reflecting on the position of the CFM regarding the use of placebos in research. CFM resolutions 1885/2008 and 1931/2009 (Article 106) observed that doctors should not maintain a relationship of any kind with studies that use placebos when an efficient and effective treatment for the disease being studied already exists [5,6]. Such a warning applies perfectly to the "pure placebo" scenario, which deprives a participant of an existing treatment solely due to the methodological need to evaluate the efficacy and safety of a new drug - something which is clearly unacceptable.

However, neither resolution is clear on add-on type studies of controlled trials in which the new treatment and placebo are added to an existing treatment. If these regulations are interpreted literally, even this design would be ethically unacceptable to the CFM, which does not seem appropriate.

Justifications for the use of placebos

Despite the fact that the debate surrounding placebos is primarily based on the existence or otherwise of a "best method", the ethics of the use of placebos is not restricted to this criterion, and there exist other factors that deserve equal attention, such as methodological necessity, non-maleficence, beneficence and justice. Figure 2 of the Appendix shows the algorithms that have been proposed to help reach a decision on the ethics of placebo use in clinical research.

Comparison of treatment with the "best method" (non-deprivation of treatment)

CNS Resolution 466/2012 (Clause III.3.b) allows the use of placebos in clinical research provided the experimental method is compared with the best current method (prophylactic, diagnostic or therapeutic). In the absence of a "best method", the use of an isolated placebo ("pure placebo") as a comparator is acceptable[8].

It is worth discussing the concept of a "best current method" as described in the resolution. The expression is often interpreted as a situation where the best method represents, for example, "the most modern", "the gold standard", "the most advanced", "the most effective", and "what is available", among other incorrect settings. Another common misunderstanding is the assumption that the existence of a "best method" of treatment can be defined simply because there may be several classes of drug for a particular disease available on the market.

The fact that several drug options exist does not necessarily imply that one of these represents a best (or most suitable) form of treatment for a specific group of patients. Non-pharmacological measures, for example, are constantly used as the initial treatment for various diseases, with patients with type II diabetes mellitus type an illustrative example.

Consider a group of patients who have recently been diagnosed with the disease and who have not yet been treated. The "best" method of treatment is not to offer the most current drug or the latest of the numerous oral hypoglycemic options available on the market. In fact there is strong scientific consensus and evidence that non-pharmacological measures such as exercise and a strict diet are effective in controlling the disease in its early stages [12].

Therefore, proposing a study that offers only non-pharmacological measures in the placebo group would be perfectly feasible from an ethical point of view, in these conditions. In contrast, the proposition of a study with the same methodological design would be unethical if there was the irrefutable recommendation of the use of oral hypoglycemic agents for the control of diabetes in the control group. Another example is to offer clinical support to patients who are beyond any therapeutic possibility, when palliative care measures represent the best course of action in such cases.

The "best method" is not always the "gold standard" or the "most effective method" in terms of treatment and diagnosis. By way of illustration, surgery is considered the standard treatment for several tumors, but there are situations which make it impossible to carry out, such as in patients with limiting health conditions that make it a risky procedure. In this case, the best available treatment is not that which is considered standard, nor the most generally effective, but what is best suited to that particular stage of the disease and condition. A complicating factor in this assessment is the fact that there are often several treatment options available other than the standard, or even several alternatives, none of which has been proven to be better than another. The definition of what is "best" for a patient is a complex task, requiring expertise and clinical consideration.

Some interpret the "best method" as that which is naturally available in a certain locality or community. Such an understanding is a dangerous error of interpretation and harmful from an ethical point of view, creating an opening for a treatment "double standard". This misunderstanding allegedly justified numerous clinical trials for HIV drugs in Africa, where many participants received only placebos on the grounds that medications for the disease were not offered by local governments (local standard) [13]. Such a situation is unacceptable, and the "best method" cannot, under any circumstances, be considered that which is available due to local logistical or economic issues. Such thinking obviously disregards one of the basic principles of bioethics, equity.

It is also worth remembering Articles 32 and 102 of the CME, which highlight the implications of placebo use, stating that it is forbidden for a doctor *not to use all available means of diagnosis and treatment,* scientifically recognized *and within his or her reach*, *to help the patient* [Article 32, authors' highlights] and *not to use* the correct therapy *when its use is permitted in the country* [Article 102, authors' highlights] [6].

The ethical discussion about placebo use should not focus so much effort on determining what the "best method" is, but instead should be concerned more with whether the participant is deprived or not of treatment that would usually be provided in patients in the same clinical condition. In general, treatments are by therapeutic guidelines developed by organizations that are representatives of classes and associations (guidelines), but can also be the result of practical professional experience. After all, not every therapeutic procedure is planned and described by guidelines.

It is understandable, therefore, that defining a "best method" is a complex task that requires reflection and technical knowledge of the subject being assessed. It should be remembered that the "best method" of treating a disease varies according to the characteristics of a group and a specific situation. Thoroughly evaluating the eligibility criteria (inclusion and exclusion) of a study helps to understand who the participants are, their specificities and the "best treatment" for them, which is not always the "gold standard", "the most modern" or "the most effective", but the one that is the most appropriate for the clinical context in which the these participants find themselves.

Evaluating therapeutic guidelines recommended by representative organizations can assist in understanding treatments. However, the definition of what is "best" for a particular group of people depends on a degree of balance and common sense. The main issue this assessment should examine is whether the group receiving the placebo is deprived or not deprived of a known treatment that should be used.

Methodological necessity

According to Brazilian regulations, the use of placebos in clinical research is permitted only where there is a justification and methodological need for the same [8]. It is worth noting that the use of placebos is a bioethical issue and not solely a question of

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scientific methodology, involving a conflict of values between the interests of research sponsors, professional responsibility and the autonomy of the patient.

While necessary and desirable in clinical trials, masking is not always feasible. There are situations where this procedure is considerably weakened by a particular aspect of the experimental product, such as an adverse reaction, the flavor and format of the medication, the number of pills, the different forms of administration, different infusion times, and non-maskable procedures (different devices) [9]. In such cases it would be evident into which group a participant had been allocated if the experimental drug caused, for example, alopecia, and the control drug did not. Likewise, masking would not be possible if one procedure was performed surgically and the other performed by endoscopy. It can be concluded here that the weakness of the masking process makes it useless, and would therefore not justify the use of a placebo.

However, more commonly, masking failure occurs only in a group of individuals, and not all those who receive a certain medication. Paclitaxel, a chemotherapy treatment used in the treatment of various tumors, can trigger anaphylactic reactions during infusion. It is a known, though very rare reaction (<0.01%) [14]. In this case, although there is masking failure in the detection of the event, it would not be sufficient to completely derail the masking in the study.

More frequent adverse reaction characteristics result in greater and more significant weakening of masking. There is, therefore, no justification for proposing masking when 100% of individuals present characteristics of adverse reactions that may identify their group. The definition of masking fragility is much more complex than it seems, especially when the characteristic event does not occur frequently. Individual weighting should in this case apply when justifying the procedure.

Although there is no cutoff point that exactly stipulates the degree of masking weakening allowed, it is worth noting that the World Health Organization (WHO) considers an adverse drug reaction incidence greater than 10% to be "very frequent" [15]. This number cannot be used as an absolute parameter or as a mathematical decision making tool, as it is an arbitrary definition. The weighting of the degree of masking weakening should include not only the frequency of adverse reactions, but also the type of reaction and the ease the researcher or participant has in identifying it.

The use of placebos in clinical research is often justified by the methodological need to prove the efficacy of an experimental treatment [10, 16]. It is not enough, however, to simply recognize this need, nor does it always translate into a plausible ethical justification. Consider, for example, a researcher who wishes to study the effectiveness of a new model of parachute to prevent injury produced by free falls. So that the effectiveness of the device can be demonstrated in statistical terms and produce robust scientific evidence, the study design would require a randomized trial with a group of people jumping from the plane with parachutes, and another group doing the same without parachutes.

The difference in the number of deaths would surely result from the use or not of the new device. This would demonstrate the unquestionable effectiveness of the parachutes. In this study, while the methodological necessity of a control group is evident, there is no ethical justification for it. Smith and Pell used this example in a provocative article which demonstrated the obstinacy of clinical trials to prove, at any cost, the effectiveness of a treatment [17].

In recent years, the pharmaceutical industry has not invested enough in research that includes genuine pharmacological innovation, instead preferring to focus its efforts on the production of imitation drugs (*me too*) for the renewal of patents [18]. The use of placebos in clinical trials with imitation drugs has nothing to do with scientific or methodological issues. In reality, economic and regulatory issues prevail, as it is much simpler, faster and cheaper to demonstrate the superiority of a new drug by comparison with a placebo than by comparison with standard or similar medicine. This clearly greatly facilitates the process of registering the drug with regulatory agencies [19].

The ethics of placebo use in clinical research are directly related to the justification of masking, and not to the necessity of proving effectiveness. If there is no reason for masking, equally there is no need for the use of placebo.

Non-maleficence

A placebo should not result in additional risks or harm to those who receive it. Item III.3.b of CNS resolution 466/2012 clearly warns of the issue of non-maleficence in studies using placebos. Furthermore, Item III.1.b states that the *ethics of research imply (...) weighing risks and benefits, both known and potential, individual or collective, committed to*

maximizing benefits and minimizing harm and risk [authors' highlights] [8].

It is noteworthy that even the most seemingly innocuous placebos, such as tablets, may have adverse effects. These are called "nocebo effects", defined as negative responses to intervention with a placebo [20]. The belief that the use of a placebo does not bring risks and harm to research participants is therefore misguided.

There are two fundamental aspects to be examined in the assessment of risks and possible damage caused by a placebo: the type and period of administration. It is easy to accept a study that proposes taking a placebo tablet once per day for a week. However, not all situations involving placebo use are as simple when it comes to weighing the potential risk and harm to a research participant. Would it be unethical, for example, to ask someone to ingest a placebo tablet daily for ten years? Would it be ethically acceptable to request the infusion of a placebo subcutaneously, which causes less discomfort than when administered in small amounts, in a single dose? Perhaps most people would answer yes to this last question. But if the study involved the subcutaneous administration of a placebo three times a day for 12 months, it is likely that a considerably smaller proportion of people would judge the study as ethical.

Considering other situations, what would the reaction be to a placebo administered intravenously? Would it be acceptable from an ethical point of view to propose the intravenous infusion of a placebo to patients who were already using an indwelling catheter? On the one hand, the discomfort of venipuncture is avoided because of the existence of the catheter, on the other, the more frequent use of the device increases the chance of contamination, which would result in its removal. And in the case of participants who do not have a catheter, would it be ethically justifiable to propose installing the device so that the participant could receive the placebo more comfortably (for example, a long-term venous catheter)? All these situations become even more complicated when it comes to the study of children.

There is no single or correct answer to the above questions. In fact, the decision about the ethics of placebo use, with respect to the aspect of non-maleficence, depends on the weighing of its potential risks. Often there is no objective assessment criteria, but only consideration of the route of administration and time of exposure to the placebo and the age range of the participants. While subjective, one way to reflect on this issue is to put oneself in the place of the participant and ask "*would I accept the risks, discomforts and harm caused by the placebo for myself or someone in my family?*"

The answer to this question is obviously subjective, yet it contains a fundamentally guiding character. It cannot in essence, be weighted by the individual or guided by interests. If a researcher, for example, puts himself in the participant's position, he or she may be willing to assume greater risks and discomforts for himself or herself due to being motivated by the success of the study and convinced that the experimental drug will bring benefit. The assessment of the risks, discomforts and harm caused by the placebo must be free of conflicts of interest, and based, above all, on a consensus among peers who analyze the ethics of its use.

Beneficence and justice

The most obvious benefit that individuals in the placebo group may gain from participating in a survey is post-study access to the product being investigated, should it prove beneficial. On this subject, CNS Resolution No. 466/2012 (item III.3.d) defines a role for the study: to guarantee for all participants *at the end of the study, provided by the sponsor, free and unlimited access to the best prophylactic, diagnostic and therapeutic methods found to be effective* [authors' highlights]. Item V.4, meanwhile includes the following wording: *In the area of health research, as soon as the significant superiority of one intervention over another or other comparative intervention(s) is proven, the researcher should assess the possibility of adapting or suspending the study in order to offer the benefits of the best regime to all* [authors' highlights][8].

It is, however, necessary to consider the possibility of situations where it is not feasible to provide the investigational product at the end of the study, and there is therefore no reason to ensure post-study access to the control group. This is the case, for example, in clinical trials with devices used during surgery, where the benefit is only valid during the procedure, or, in placebo-controlled clinical trials for the treatment of an acute but self-limiting condition, such as a cold or a similar infection. At the end of the study, research participants from both the control and the experimental group, will no longer suffer from the medical condition that led them to take part in the survey; therefore, the provision of the investigational product is no longer applicable.

Fatal diseases with a high demand for new treatments, such as cancer, for example, are often

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the subject of simultaneous studies with different drugs but the same goal. However, the conclusion of one study may occur before the other, changing the current treatment guidelines and sometimes generating a new therapeutic standard. If the last study to be completed shows positive results which are inferior to the first, it is necessary to weigh the benefit and justice of providing post-study medication when there is a more favorable option available. Again, the ethical position will depend upon a technical and expert judgment of the disease treatment options in question at that time.

Ensuring that the investigational product is provided free of charge to the placebo group at the end of the study is not just a matter of charity, but above all of justice towards those who collaborated as a control group. Therefore, the guarantee of post-study access to the control group is another element to be considered in assessing the ethics of placebo use in clinical research.

Final considerations

This paper presents a proposal of systematization of the analysis of placebo use in clinical trials in the light of CNS Resolution 466/2012. It is essentially based on the analysis of five inseparable criteria: non- deprivation of treatment, methodological necessity, non-maleficence, beneficence and justice. For a study to be deemed ethical, it is necessary that the previously mentioned criteria are fully complied with. If one fails, the use of placebo cannot be justifiable.

The epistemological keys set out in this work have their roots in the principlism of Beauchamp and Childress [21]. It should be noted that the discussion about the use of placebos in clinical research should not only take into account biological vulnerability, as highlighted by Garrafa [1]. In a Brazilian context, social vulnerability is as or more important than biological vulnerability, although the two are also inseparable. This concern is at the heart of intervention bioethics, which has as one of its focuses the criticism of the double standard in clinical research [22].

The alleged objectivity of the four traditional principles is a limiting factor for a more comprehensive analysis. Intervention bioethics requires a socio-political context, taking into account other categories of bioethical practice foundations, such as “care”, “responsibility”, “solidarity”, “commitment”, “otherness”, “tolerance”, “prevention”, “caution”, “prudence” and “protection” (of the socially excluded) [23]. Paranhos, Garrafa and Melo [24] argue that the UNESCO Universal Declaration on Bioethics and Human Rights [25] is a key document for supporting bioethical analysis involving the harm and benefits of clinical research.

In the present study the proposed algorithms are a long way from representing the truth, being open to criticism and adjustment. They are additional tools which will bring more objectivity to a discussion that is guided in most cases, by passion and even by a misguided preconception regarding the use of placebos. There is no intention to reduce ethical analysis to algorithms or Manichean debate. Bioethical decisions are multifaceted, and depend on a significant degree of weighting. The intent of the proposed algorithms is to assist in the complex decisions that surround the ethical use of placebos in clinical research, without replacing human judgement regarding such resolutions.

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Participation of the authors
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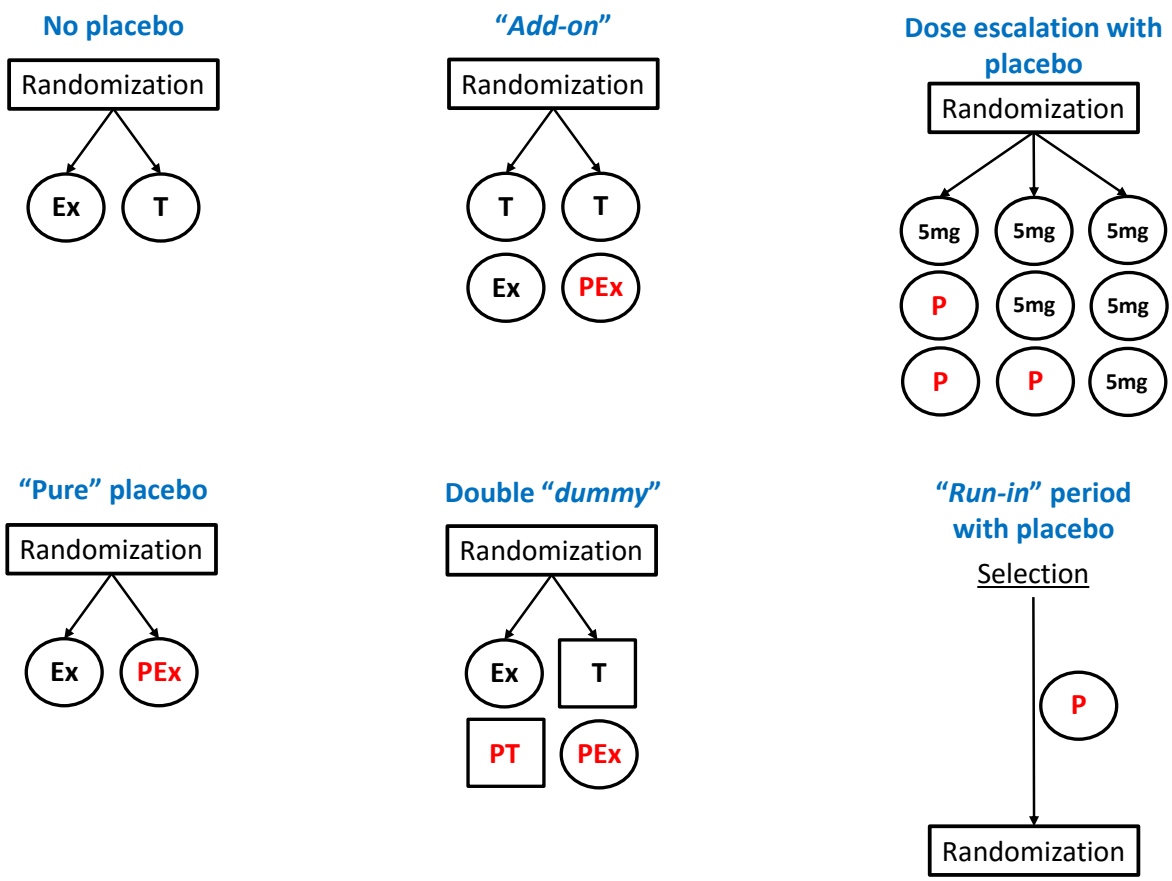
Appendix

Table 1. Effects on experimental and control groups when the allocation is known by the researcher and/or research participant in a clinical trial

Who knows allocation	Item affected	Group affected	
		Control	Experimental
Researcher	Conduct related to treatment, dose adjustment, instructions etc.	Less obstinate	More obstinate
	Interpretation of information supplied by the participant	Less favorable	More favorable
	Evaluation of participant by researcher	Less favorable	More favorable
Participant	Perception of participant of own condition	Less favorable	More favorable
	Participant's adherence to instructions given by researcher	Less adherence	More adherence
	Participant seeks alternative treatment	Greater chance	Less chance
	Participant abandons study	Greater chance	Less chance

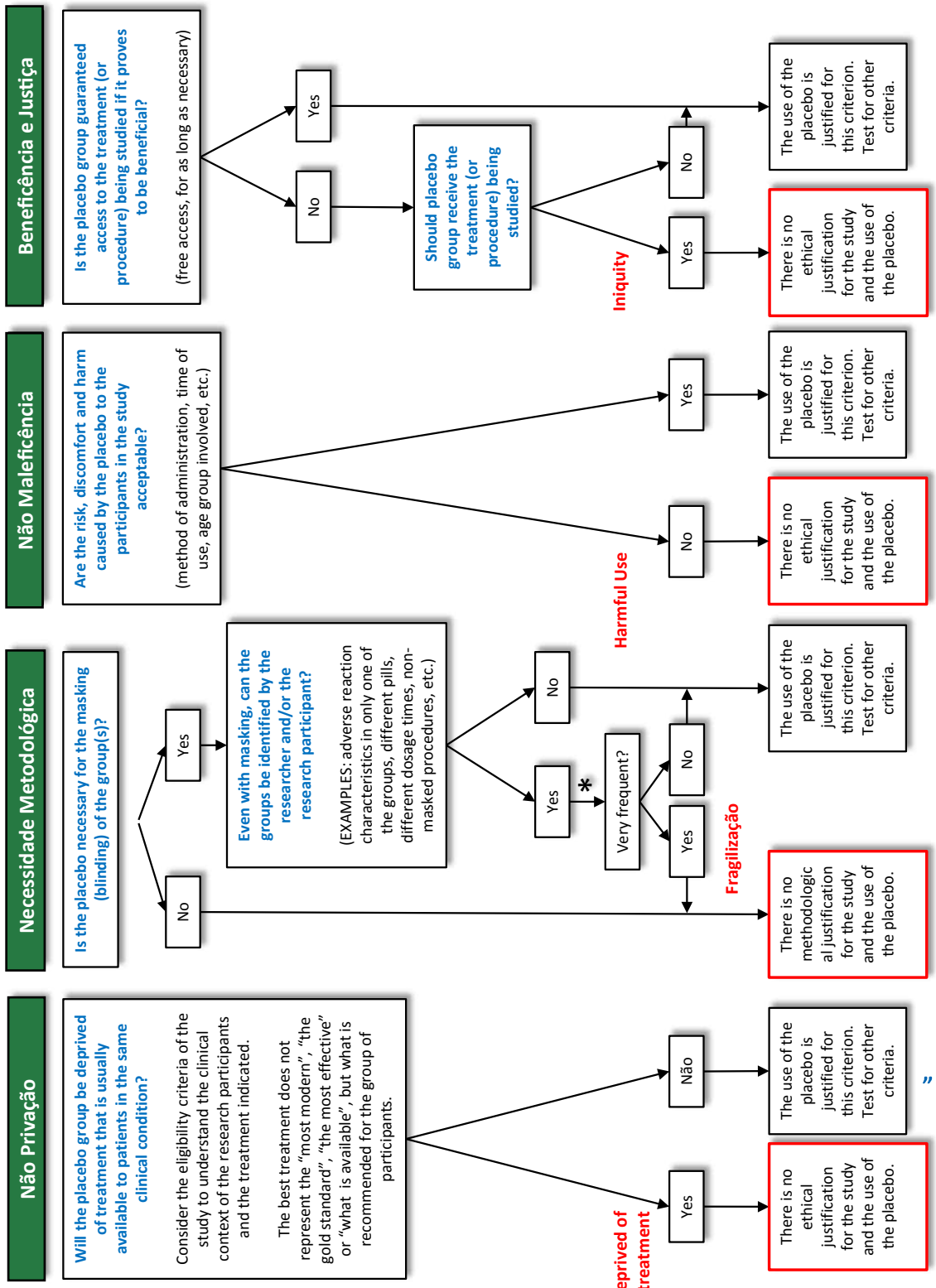
Source: based on Schulz and Grimes [9].

Figure 1. Schematic representation of the main designs of randomized clinical trials with and without placebos



Key: (Ex) experimental treatment; (T) most appropriate treatment for clinical condition of a specific group of participants; (PT) placebo of T; (PEx) placebo of Ex; (P) Placebo

Figure 2. Algorithm for the decision about the ethics of placebo use in clinical trials



* The World Health Organization (WHO) considers an adverse drug reaction incidence greater than 10% to be "very frequent". However, this number cannot be used as an absolute parameter about the fragility of masking, as it is an arbitrary definition.

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To think about ethics in *influenza* surveillance?

Ligia Cantarino [1], *Edgar Merchan-Hamann* [2]

Abstract

Epidemiological surveillance, important in the indication and implementation of public health policies and decision-making, constitutes a link between health services and research. In this context, the ethical issues found in daily surveillance practices require in-depth reflective processes and specific qualified discussions. Some ethical questions related to *influenza* surveillance were considered for the elaboration of this reflective essay. Those questions were held up against a range of bioethical, human rights, right to health, public health and ethics' concepts. The proposed reflections address the principles of bioethics, relating them to the characteristics of surveillance actions directed to the participants of the survey on respiratory viruses circulation.
Keywords: Ethics. Bioethics. Epidemiological surveillance. Influenza, human.

Resumo

Pensar a ética na vigilância da *influenza*?

A vigilância epidemiológica, importante na indicação e execução de políticas de saúde pública e nas tomadas de decisão, constitui um elo entre os serviços de saúde e a pesquisa. Nesse contexto, as questões éticas presentes nas práticas diárias de vigilância demandam processos reflexivos aprofundados e discussões específicas mais qualificadas. Para a elaboração deste ensaio reflexivo, tomaram-se algumas indagações éticas relacionadas à vigilância da *influenza*, confrontando-as com uma gama de conceitos bioéticos, de direitos humanos, de direito à saúde, de saúde pública e de ética. As reflexões propostas enfocam os princípios da bioética, relacionando-os às características das ações de vigilância direcionadas aos participantes da pesquisa de circulação de vírus respiratórios.
Palavras-chave: Ética. Bioética. Vigilância epidemiológica. Influenza humana.

Resumen

¿Pensar la ética en la vigilancia de la gripe?

La vigilancia epidemiológica, importante en la indicación e implementación de políticas de salud pública y toma de decisión, constituye una conexión entre los servicios de salud y la investigación. En este contexto, las cuestiones éticas presentes en las prácticas diarias de vigilancia requieren procesos reflexivos profundos y discusiones específicas más calificadas. Para el presente ensayo de reflexión se consideran algunas indagaciones éticas relacionadas con la vigilancia ejercida a la influenza, abordándolas frente a una gama de conceptos bioéticos, de derechos humanos, del derecho a la salud, de salud pública y de ética. Las reflexiones propuestas abordan los principios de la bioética relacionándolos con las características de las acciones de vigilancia dirigidas a los participantes de la investigación de circulación de virus respiratorios.
Palabras-clave: Ética. Bioética. Vigilancia epidemiológica. Gripe humana.

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Declaram não haver conflito de interesse.

Influenza, or cold, is an acute viral disease of the respiratory system of rapid dissemination and global distribution. An individual may contract the flu several times throughout his or her life. The flu is most serious in risk groups such as the elderly, children, immunocompromised individuals, people with heart disease and lung disease. From the public health perspective, this virus presents a combination of different problems that require specific care surveillance and control, given the severity of its clinical manifestations and its pandemic and zoonotic potential [1-3].

Influenza causes concern to world health authorities for its impact on morbidity and mortality, its similarity to highly contagious atypical pneumonias and its severity and the probability of emergence and spread of strains with pandemic potential [4]. Thanks to these characteristics, the virus has been the target, since 1947, of a world-surveillance program now called Global Influenza Surveillance and Response System (GISRS), created by the World Health Organisation (WHO) [5].

The Brazilian government, through the Ministry of Health, introduced influenza surveillance nationwide in 2000. Vigilance is grounded in sentinel units and in the monitoring of indirect morbidity and mortality data associated with influenza. The records of consultations for flu-like illness are considered together with information about the circulation of viruses, which are the etiological agents of acute infections of the respiratory system. The surveillance of respiratory viruses aims to know which strains are circulating in Brazil, respond to unusual situations, assess the impact of vaccination, follow the trend of morbidity and mortality, in addition to producing and disseminating information on epidemiology with a view to strengthening surveillance through the elaboration of contingency plans to deal with pandemic situations [1].

Epidemiological surveillance plays an important role in the indication and execution of public health policies and in the decision-making process. In a broader concept, epidemiological surveillance works as a link between health services and research [6]. The role of research in health surveillance is critical to the building of knowledge and elucidation of health risks. The research in public health and research in health services are intertwined and, although they have different approaches to the traditional academic research, the ethical aspects in common should be considered.

The need for influenza surveillance is indisputable. However, some ethical questions require reflection. The purpose of this article is to reflect on aspects of the permanent action of respiratory virus surveillance, an essential part of the influenza surveillance from the perspective of bioethics.

Practices, guidelines and surveillance standards

Brazil belongs to the global network of *influenza* surveillance with the participation of three laboratories accredited by the WHO as National Influenza Centers (NIC). The information generated by this network is analysed and discussed each year at a meeting at WHO headquarters which, among other decision-making, indicates the composition of the vaccines to be used the following year.

To place the surveillance of influenza in the broader context of health surveillance activities, it should be clarified that there are different ways to monitor events. The traditional approach, centered on the disease and known as universal surveillance, is based on mandatory reporting and it is called passive surveillance. However, alternative approaches have been advocated in recent years focusing on other moments of the event, or biological cycles, which requires the promotion of diversified actions, called active surveillance. This approach includes the sentinel surveillance strategies.

In the sentinel surveillance of influenza, samples are taken from patients with flu-like illness symptomatology who sought medical care in health facilities, even if the complaints of these patients were not related to the syndrome. It recommends a convenience sampling, and health units should collect samples of five patients per week, every week of the year. Thus, samples are taken after a screening and brief interviews with citizens present in the waiting room, provided that they confirm they are carriers of clinical signs consistent with flu-like illness. Samples are, in order of preference: 1) nasopharyngeal aspirate, or 2) combined swab (nasal and oral), obtained within five days of the early onset of symptoms (acute phase) [1]. These samples are forwarded to laboratories of the influenza surveillance network, and not for diagnosis related to patient care.

On the approach and attention to ethical aspects related to patients who are subjects participating in viral research, there is a reference on the subject in the "Epidemiological Surveillance Guide" of the Ministry of Health [1] (page 23), expressed by the statement that the notification must be confi-

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dential and should only be disclosed outside the medical and health field in the case of risk to the community, respecting the citizens' right to anonymity. There are no references to ethical aspects in the Ministry of Health Ordinance 2693/2011 [7], which deals with the transfer of funds for the introduction, implementation and strengthening of epidemiological surveillance of influenza.

In the practice of disease surveillance, normative documents are not followed in their entirety, such as the guidance to patients about biological samples, laboratory flow and results. The ordinance 788/2002, issued by the Secretary of Health Assistance (abbreviated as SAS in Brazil - Secretaria de Assistencia a Saude) from the Ministry of Health , recommends that among the main functions of a collection point are the *care and guidance of patients for the collection, identification and receipt of biological materials, as well as proper storage of biological fluids for transportation, release and delivery of report* [8]. Accordingly, the SAS Ordinance 787/2002, as well as establishing basic parameters and technical rules for the organisation of the network of clinical laboratories, recommends the correct identification of samples, an efficient transport system and secure packaging, as well as a clear flow of routing of examination reports to the collection sites and/or unit of origin of the patients, in a safe and reliably way, in order to ensure that the patient has a timely access to the result [9].

The Resolution 302/2005, from the Executive Board of the Brazilian Health Surveillance Agency (Agência Nacional de Vigilância Sanitária - Anvisa), also supports that concern and aims for a technical regulation for the operation of clinical laboratories. The resolution applies to all public or private services that perform laboratory activities in the field of clinical analysis, clinical pathology and cytology. According to this legislation, the sample collection unit and the laboratory must meet the expected operational processes and, among other duties, *shall make available written and/or verbal instructions, in accessible language, to the patient or responsible, advising on the preparation and collection of samples having as objective the understanding of the patient* [10]. In addition, the resolution states that the patient in ambulatory care or the responsible must receive a proof of the service containing registration number, full name of the patient, date of the service, expected date of delivery of the report, list of requested tests and contact information for the laboratory.

However, despite the existence of these guiding norms, situations still exist where patients do not know which laboratory will process the sample, is not given a receipt to monitor the laboratory analysis of their biological sample, nor receive the analysis results. Once the collection of the clinical sample is done, it is the duty of the public service (or private) to ensure the identification, the packaging and adequate and timely submission of the sample for laboratory analysis. Likewise, one must ensure the processing of the sample within the given deadline and the delivery of laboratory results to patients on an individual basis (for each patient, a report). In the practice of surveillance, what is observed is that the results of laboratory tests are disclosed, in aggregate form, by epidemiological week, in the "Bulletin of Influenza Epidemic", available on the website of the Surveillance Secretary of the Health Ministry.

In *influenza* surveillance activities at the time of collection at the health unit, the consent or assent for viral investigation is informed orally by the patient, after having received a brief explanation. There isn't a free and informed consent, the same as there is no formalised signing of a document similar to the free and informed consent as it happens in scientific researches, or a recording of a manifestation of acceptance. And there is not any clear evidence that the information was correct and timely provided by the health professional and understood by the patient. And, as it is known, the information must be understandable in order to produce an informed consent, it is not enough that the person is simply a recipient [11]. There isn't here a suggestion to formalise the documentation, but a questioning about the information and proper communication to the research subjects. Formal procedures, mere compliance with bureaucratic determinations lacking reflection and conscious choice [12], do not contribute to the respect for the rights of the citizens taking part in the research.

In surveillance research, even when based on a different understanding, in the light of the Resolution 466/2012 [13] of the National Health Council (abbreviated as CNS in Brazil - Conselho Nacional de Saude), which establishes the guidelines and regulatory standards for research involving human beings, patients participating in viral investigations, who are the subjects of the research, may be considered vulnerable. Or, patients may be counted as vulnerable, given their living conditions, including their health condition [14]. After all, these patients sought a health facility for medical care, not specifically a respiratory problem, and then during the screening, they are asked by a health care professional to perform a collection of material for examination

because that specific medical service unit happens to be part of the sentinel network for *influenza*.

While individual and social effects of researches on respiratory viruses are highly relevant, as they will benefit directly or indirectly, immediately or later, the participants and/or their community, those participants must be informed about the nature of the research, its objectives, methods, expected benefits, potential risks and the discomfort that such research may cause to them. The information should consider the participants' understanding and respect their singularities, as it is recommended by the Resolution CNS 466/2012 [13].

We are not proposing here the use of the CNS Resolution 466/2012 [13] to support aspects about the ethics of influenza epidemiological surveillance . The academic biomedical research is different from the investigation or research in health surveillance; however, it is necessary to observe surveillance practices. It is well known that the decision-making in epidemiology involves both technical knowledge and reflection on important issues for the public health service. Similarly, the relationship between ethics and epidemiology unfolds between political commitment and practice in health services as well as production of knowledge. Besides the political commitment or the social relevance of knowledge and interventions, it is essential to highlight the need to elect priorities for individuals in the society. Add to this the issues of ethics in research involving human beings and concepts of risk and vulnerability, which raises the question of informed consent and return of results to the society [12] - Return discussed here both as an individual result and as a benefit of the research to the community.

While individual principles do not apply to public health or to epidemiological studies, it is important to observe rules and practices that consider the particularities of groups and populations. In epidemiological studies, even with a commitment to acquisition and application of scientific knowledge for the maintenance and restoration of public health, individual rights must be respected [15].

To set criteria and standards for ethical conduct in epidemiological research is a constant concern of scholars and researchers , whose discussion topics are contained in international documents aimed at epidemiologists, such as in the following examples, mentioned by Coughlin[16]: the "International Ethical Guidelines for Epidemiological Studies", prepared by the Council for International Organisations of Medical Sciences(CIOMS) in collaboration with the WHO and published in 1991; the "Ethics Guidelines" of the American College of Epidemiology (ACE), published in 2000; and the guidelines of the "HIPAA privacy rule and public health", guidance from the Center for Disease Control and Prevention (CDC), published in 2003.

About the rights

Whereas the surveillance strategy should be based on the concept of the citizen as a subject of rights, it is vital to establish instruments that protect the health of the individual integrated to the population group, recognised as equal in the rights, even when defending differentiated positions or socio-cultural values . It is rather important that ethics is closely linked to public health practices, since ethical issues are confined only to technical, legal or administrative areas. Ethical interference, whether direct or indirect, can affect people in their decision-making [17].

According to the WHO document [18], which discusses solutions for pandemic *influenza*, human rights are universal legal guarantees that protect individuals and groups against actions which confront fundamental freedoms or human dignity. One of the most important characteristics of this document, the international consensus on guarantees that individuals and peoples should enjoy in the health sphere, has been ratified by the governments of the signatory countries, which thus undertake to apply international standards in their local contexts. Thus, both by the force of the law in national dimension as well as a result of moral consensus among countries, human rights can not be disowned or withdrawn.

The right to health is a primary requirement of the right to life [19]. To a large extent, the development of the right to health stems from the increasing urbanisation that came with industrialisation since the nineteenth century as well as the fact - defined by law - that health has become the responsibility of the State [20]. Similarly, epidemiological surveillance is a function of the state, and should be a prerequisite in the development of health programs and an evaluation tool of the impact of their implementation. Disease and injury surveillance systems should be subject to frequent reviews and adjustments as well as any necessary changes in order to ensure good performance, quality, efficiency and effectiveness of their actions. Only then will it be possible to show the epidemiological situation of the problem, its trends, the impact of control measures and the

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proposition of new actions. The epidemiological surveillance system remains efficient when its running is measured regularly with a view to opportune adjustments [21].

It is therefore important to have the collective good in mind when assessing epidemiological research, but with a point of view which respects individual rights. The improvement of public health has been marked by the incorporation, by the State, of roles and responsibilities based on the consideration that collective rights, and even diffuse social rights, are defined as inexorable conditions of citizenship. Sanitary control measures stem from the set of measures that societies established in the course of time, in order to prevent or reduce risks and damage to the health of the population. Relations between public health and human rights permeate the political aspects, programs and public health practices. It is essential, therefore, to find a balance between the collective good and individual rights [22].

Bioethical principles

Bioethics may be defined as ethics directed to human survival, since it covers social and environmental issues, in addition to biomedical and biotechnological conflicts [23]. The field is a discipline committed not only with the moral in the area of health and disease of humans and animals, but also with the reflection and discussion of ethical conflicts indicated by bioethics, conflicts which have always been present throughout the history of human society [24].

The Universal Declaration on Bioethics and Human Rights [25] meant a new phase for the field of bioethics, which left the narrow confines of the clinic and research to consolidate itself as a discipline which provides a framework of human rights. The document contains a number of principles: human dignity and human rights; benefit and harm; autonomy and individual responsibility; consent; persons without the capacity to consent; respect for human vulnerability and personal integrity; privacy and confidentiality; equality, justice and equity; non-discrimination and non-stigmatisation; respect for cultural diversity and pluralism; solidarity and cooperation; social responsibility and health; sharing of benefits; protection of future generations; protection of the environment, the biosphere and biodiversity.

In Brazil, ethical motivation is seen by principles similar to each other: a) respect for people, be it obtaining an informed consent or on confidentiality and protection of those who are unable to take decisions; b) beneficence or "do no harm" (non-maleficence), maximising benefits and reducing risks; c) distributive justice, with a favourable balance of risk-benefit and an equitable selection of patients. This motivation was discussed in a study by Novaes and collaborators [26], and its principles are regulated by the Resolution 466/2012 13 of the National Health Council (Conselho Nacional de Saude)

Bioethical challenges with a focus on public health deserve critical reflection *on key topics such as global health and global bioethics, social justice and health equity, vulnerability factors in the poorest countries, respect for cultural autonomy of the people, responsibility towards solidarity and cooperation among nations, universalism versus ethical relativism in the face of human dignity* [27].

Considering the changes experienced by society, we must think of a bioethics guided by respect and encouragement of individual freedom in decision making, in addition to the principles of solidarity, justice, equity and accountability, reinforcing the need for protection of the disadvantaged or vulnerable. We have to think of a bioethical action able to assist in the search for balanced solutions between individual freedoms and collective interests [28].

Bioethical principles should be observed even in the interdependence between surveillance and health research. These interfaces in *influenza* surveillance activities should be detailed in order to guide and regulate the decision-making about the service actions, which should prioritise the respect for citizens. The ethics of life should guide the surveillance actions, as they turn to the collective, in order to ensure, by the State, the citizens rights.

Final considerations

This paper presents some reflections on influenza surveillance from the perspective of ethics. What is observed is that services and health professionals have not expressed explicit interest in changing the system, while participant patients don't show concern about the obtention of diagnostic results nor with the progress of the research.

The considerations about the resizing of surveillance activities included, as a starting point, the fact that they constitute a duty of the State and the fact that they affect the community. These reflections occurred, in part, during the period of the surveillance

decentralisation and at the time when it was realised that traditional surveillance - passive, based on compulsory notification - was insufficient and often not opportune [6]. This fact reinforced the need to innovate the forms of surveillance by introducing active sentinel surveillance strategies, which affected the very concept of surveillance. At the same time, the role of research both induced and expedient (*ad hoc*) has been emphasised to elucidate events relevant to health surveillance, either on a serial or continuous basis, in order to strategically monitor the progress of diseases and practices or risk habits. Such investigations can be carried out either by the health service or by academic institutions and research institutes. In epidemiological research, in general, there are important ethical considerations [15,16]. It is important to consider that the interface and the profound connection between epidemiological research and surveillance practices entail new challenges in addressing the ethical aspects, and, given its social and political relevance, should take into account their relation to the care or health care.

Issues related to ethics often go unnoticed by services and health surveillance professionals; consequently, they are not included in their programs and protocols. Ethical aspects in the practice of *influenza* surveillance are important and should be observed as any other necessary factor for its management.

The procedures adopted for the taken samples, timely and necessary explanations about the use of biological material obtained, and the duty and the right relating to the results of laboratory tests are of interest for further study. Other issues relating to contingency plans should also be checked from the perspective of ethics, such as measures restricting freedom (quarantine), the use of antiviral drugs and vaccines (to ration or to rationalise?), access to health care and its physical resources, the risk and tiredness imposed on health professionals and their responsibilities, as well as communication of the risk and the role of the press.

It is necessary that rights and responsibilities are discussed from an educational focus, in the area of continued education [29] and in the training in the services and technical supervision. In the production of epidemiological knowledge, ethical issues in research involving human beings, as well as the social significance of risk and vulnerability are important aspects of reflection for guidance of epidemiological surveillance practices.

Here we portrayed some points about the *influenza* sentinel surveillance as an exercise of reflection. Ethical concerns are indispensable in everyday surveillance practices. As rights of every citizen-patient, the obtainment of clear information about the laboratory processing of the sample at the time of collection and the adequate communication of the examination results are examples of situations that need to be reviewed in the context of health services. In addition, it is necessary to take into account the creation and adherence to routines based on ethics in the relationship with participants studies. Such concerns should be foreseen in the guidelines as well as surveillance guidelines and ethical regulations aimed at the research in public health surveillance.

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The Belgian case of euthanasia for children, solution or problem?

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Abstract

By extending its euthanasia law to minors in 2014, Belgium has fuelled the international debate on this issue. In fact, Medicine does not always have something to offer when it comes to a child's serious disease. Nevertheless, should euthanasia be considered a viable solution? Keeping in mind the Belgian reality, this article analyses the relevance of the new law, considering, on one hand, children's growing self-determination capacity and, on the other hand, their lack of "life experience". Let's not forget, in addition, classical arguments against euthanasia, such as the disrespect for the value of human life and the eventual approaching of the slippery slope. An obvious solution for this problem is the implementation of a proper palliative care system. However, evidence about the quality of pediatric end-of-life care is scarce. Therefore, additional investigation is necessary in order to formulate and propose an appropriate public policy on the matter.
Keywords: Euthanasia. Child. Belgium. Palliative care.

Resumo

Caso belga de eutanásia em crianças: solução ou problema?

A aprovação da extensão da prática da eutanásia a menores de idade em 2014, pela Bélgica, reacendeu o debate internacional sobre as decisões médicas em fim de vida em crianças. De fato, a medicina nem sempre tem resposta para a doença grave de uma criança. No entanto, será a eutanásia uma solução equacionável? Partindo da realidade belga, este artigo analisa a premência da nova legislação, considerando, por um lado, a capacidade crescente de autodeterminação das crianças e, por outro, a sua falta de "experiência de vida", não esquecendo argumentos clássicos que contrariam a prática da eutanásia, como o desrespeito pelo valor da vida humana e a eventual concretização do argumento da ladeira escorregadia. Uma solução óbvia passa pela realização de cuidados paliativos apropriados. Todavia, sendo escassa a evidência sobre a qualidade dos cuidados pediátricos em fim de vida, é necessária investigação adicional para que se possam formular e propor políticas públicas adequadas a respeito da matéria.
Palavras-chave: Eutanásia. Criança. Bélgica. Cuidados paliativos.

Resumen

Caso belga de la eutanasia en niños, ¿solución o problema?

La aprobación de la práctica de la extensión de la eutanasia a menores en 2014 por Bélgica ha reavivado el debate internacional sobre las decisiones médicas en el fin de la vida de los niños. De hecho, la medicina no siempre ha de responder a la enfermedad grave de un hijo. Sin embargo, ¿debería considerarse la eutanasia como una solución viable? Partiendo de la realidad belga, este artículo analiza la emergencia de la nueva ley: considerando, por un lado, la creciente capacidad de autodeterminación de los niños y, en segundo lugar, su falta de "experiencia de vida", sin olvidar los clásicos argumentos que contradicen la práctica de la eutanasia, como el desprecio por el valor de la vida humana y la eventual realización de "rampa de deslizamiento". Una solución obvia es implementar los cuidados paliativos adecuados. Sin embargo, puesto que las pruebas sobre la calidad de la atención con el fin de la vida pediátrica son escasas, se requiere investigación adicional para poder formular y proponer políticas públicas adecuadas en esta área.
Palabras-clave: Eutanasia. Niño. Bélgica. Cuidados paliativos.

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Authority and responsibility, once an exclusive domain of the physician in medicine, are now shared with the patient , who is given, as a mentally and emotionally capable individual, the freedom to choose from several options. The risks and benefits related to those options should be explained in advance[1]. Add to that scenario technical advances and demographic changes which have given medicine a relevant role in determining the circumstances of death. Increasingly, death derives not only from the natural course of a deadly disease, but also from a number of medical decisions, such as the assignment of treatments that prolong the life of critical patients or the suspension of those treatments (life-saving technology can sometimes only delay the process of death) and the relief of severe symptoms by the use of drugs which can cause, as possible side effects, acceleration of death. This scenario can create difficult situations such as when patients feel hopeless, after realising that their suffering is unbearable, and ask the doctor to help them to end their lives [2-5].

To provide appropriate care to a dying patient implies, therefore, to be able to handle complex situations and requires knowledge of ethical rules and controversies, pharmacological and non-pharmacological tools to manage symptoms as well as the risks and benefits of medical technology. Equally important, it is necessary to know how to discuss these issues with the patients and their families, while continuing to support them in what is probably one of the most difficult times of their lives [5].

Over a third of all deaths are preceded, in several european countries, by end-of-life medical decisions [6]. The assignment or suspension of treatments and the relief of severe symptoms are generally considered common medical practice [7]. Still, in most countries, doctors are not allowed to accept a request for euthanasia (death resulting from the administration of drugs by a physician, with the explicit intention to hasten death) [2], although this is a topic which is being increasingly debated [2-4,8].

In 2002, The Netherlands and Belgium had adopted a law decriminalising euthanasia in certain conditions. A similar law was adopted in Luxembourg in 2009. This situation differs from the physician-assisted suicide, procedure decriminalised in the Netherlands, Luxembourg, Switzerland and four US states (Oregon, Washington, Montana and Vermont). In this case, the doctor prescribes a lethal drug but the patient will carry out a self-administration [3,8-10].

End-of-life medical decisions about minors are an even more complex matter and, although it has received less attention, the subject is of growing interest in the scientific community [8]. In fact, the international debate on end-of-life medical decisions about children was reignited after Belgium approved, in February 2014, a law on euthanasia without reference to age limits [9].

Despite the great scientific and technological advances, medicine doesn't always have the answer to children's serious illnesses . Therefore, minor patients and their families may have to face the reality of death in childhood [6]. The child, as a vulnerable individual, requires special care and, for this reason, end-of-life medical decisions concerning minors represent additional clinical and ethical challenges. The Convention on the Rights of the Child [11], adopted by the UNICEF, mentions four relevant rights about this subject: the inherent right to life (Article 6) ; the right to express their opinions freely (Article 12), the best interests of the child (Article 3) and the right to health care and education (Articles 24 and 28) [12].

The triangular interaction between health professionals, parents and patients makes the decision making particularly difficult. Parents - who in general are unprepared to deal with the devastating possibility of death of their child and act as the child's advocates - are usually the main intermediaries in communication with health professionals [5,8]. When it comes to adults, there is often some prior information of the patient's wishes regarding decisions about end-of-life, decisions that family members might be aware of and use in order to make up their minds [13].

In the case of minors it turns out that they don't always have the cognitive capacity to reflect and verbalise such desires and, therefore, parents and doctors have to make decisions in accordance with the best interests of the child [14]. In fact, the involvement of minors in the decision making process is not linear and depends on age, level of competence, nature of decisions and experience with chronic diseases. In ethical terms, this interaction between the role of parents as legal representatives and the child's decision making capacity raises important questions about the rights of minors to self-determination, the limits of parental control and the balance between the best interests of the patient and his or her wishes [5,8].

Studies show that [5,6,14] most end-of-life care of children occurs in hospitals, especially in pediatric intensive care units (PICU). The decision to suspend the life support treatment is the most common - 30% to 60% of deaths in the PICU are preceded by a process of active suspension, usually starting with

the decision to not resuscitate, progressing then to the removal of assisted ventilation . Sedatives and analgesics are also regularly used, mainly after the decision to withdrawal treatment, emphasising the patient's comfort and palliation of symptoms [5,6,14]. In about 3% of the cases, the death of the child is preceded by an euthanasia request (about a third of the cases are requested by the minor and the rest is requested by the family) [6].

The causes of death in children depend on age: 50% of children with serious illnesses die during the first year of life; children older than one year die mainly due to external causes, such as traumatic injuries, followed by chronic diseases such as cancer, which is the most common cause of death by disease in children over 1 year. Situations such as frequent hospitalisation of chronic patients, gradual loss of vital functions and increased need for technical or medical support, considering the risk of death that they entail, must motivate the reflection on the goals of the treatment [15].

In this context, this article aims to analyse the complexity of end-of-life medical decisions regarding children, in order to understand if euthanasia is a possible solution or, on the other hand, worsen the complexity of the decision making. Starting from the Belgian reality, the urgency of the new law will be evaluated, highlighting its advantages and disadvantages in the light of the doctrine of human dignity. It will be considered, for that purpose, the principles and the current practice of pediatric palliative care as well as how medical ethics should position itself in the face of social transformation resulting from the approval of this law.

Euthanasia: the Belgian case

In 2002, a few weeks after the Netherlands new legislation, Belgium adopted a law decriminalising euthanasia under certain well defined conditions. These conditions include the voluntary request, thoughtful and repeated by a patient in unbearable and not mitigable suffering resulting from serious illness and incurable . The doctor must discuss other possible options with the patient, including palliative care [9].

It is also necessary that the patient consult with another doctor before taking a decision on euthanasia. Under this law, euthanasia is a medical procedure, and the patient must be of legal age (*i.e.*, have completed 18 years of age) or an emancipated minor (usually as a result of marriage or, more rarely, a court decision declaring the minor competent to deal with the situation) [9].

A study in Belgian Flanders 8 shows that, between June 2007 and November 2008, end-of-life medical decisions preceded 36.4% of deaths of children aged 1 to 17 years (which is consistent with findings in Holland). Excluding sudden deaths, these decisions were taken in 78% of cases. The decisions of no treatment (10.3%) are generally associated with the administration of drugs for relief of symptoms, the latter being the most frequent decision (18.2%).

There was involuntary euthanasia (poor prognosis and expectations of lower quality of life were the reasons used by doctors for this practice) in 7.9% of the cases studied in this region, against 7.2% in the Netherlands. It should be noted that, according to this study [8], medically assisted death is not an isolated practice in Belgium, but rather part of a comprehensive process of care, usually resulting from the decision to increase the dose of morphine, with the consent of the parents, after a long disease period.

During the period of study, there had been no request for euthanasia in minors whilst four cases of people under 20 years were registered between 2002 and 2006. On the other hand, there are about 5 cases per year in the Netherlands . This disparity may be due to differences in how the cases are reported, and this information about the number of requests for euthanasia in minors in Belgium might not be reliable. [6,8,9].

The analysis of doctor's attitudes in the monitoring of under-18s who died showed that most of them seem to accept medically assisted death in children in certain circumstances, revealing to be favourable to the extension of the law to minors, as long as the law takes into account the capacity of decision of the child [16]. With regard to other health professionals, the 2009 study shows that PICU's nurses are often involved in end-of-life medical practices (including administration of drugs that cause death), although they have limited participation in the decision making . The termination of life presents two controversies: on the one hand, euthanasia in children was illegal at the time and, on the other hand, the law stipulates that euthanasia must be performed by a doctor. Most nurses are also in favor of extending the euthanasia law to minors [6].

In parliamentary debates in Belgium, age was considered less relevant when compared to the capacity to understand the situation and its impli-

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cations. Thus, the bill which was approved by the Senate on December 12, 2013 and promulgated by the House of Representatives on February 13, 2014 (after two days of debate, with the majority in favor - 86 against 44 - and 12 abstentions) does not mention age limits [9, 12]. In this way, Belgium becomes the first country in the world to legally abolish all age restrictions for the performing of euthanasia 17. This situation differs from the Dutch law , which allows terminally ill children who are older than 12 years to require euthanasia but with a mandatory parental consent if they are younger than 16 years old. From that age it is only necessary to inform the parents but their authorisation is not required [9,12]. Euthanasia is only allowed if the patient is older than 18 years old in Luxembourg [17].

The extension of the Belgian law to children rests on the same assumptions as that of adults and some specific criteria must be met:

1) "capacity for discernment" - carefully evaluated by a multidisciplinary pediatrics team, including a clinical psychologist or psychiatrist and the presentation of a written opinion;
2) the context of terminal or incurable disease that will lead to death within a short period of time (which should be agreed by the paediatrician and an independent doctor) with constant and unbearable suffering of the child;
3) written request from the child;
4) consent of the parents or legal representative;
5) The physician's responsibility and provision of psychological support to all involved [9,12,17].

Although extended to children, this new law restricts its application when it omits psychiatric disorders and, more importantly, when it specifies the need of a capacity of discernment , which unequivocally excludes children with consciousness changes, children with intellectual deficits, very young children and newborns [9]. Minors without cognitive or motor ability to express and write their request are also excluded [12]. The law contrasts, therefore, with the Groningen Protocol [18], a practice resorted to in the Netherlands and which results in active euthanasia, with parental consent, of a newborn with very severe prognosis or unbearable suffering [9,18]. Although parents have to agree with the request, the Belgian law also excludes ,undoubtedly, all requests by someone other than the patient , such as parents or professional health carers [9]. There is a committee that oversees the practice of euthanasia to ensure that the criteria are being properly fulfilled [19].

The need for pediatric palliative care

One option to minimize the need for patients to request euthanasia is to improve palliative care and increase psychological support. These practices might make life tolerable although it doesn't necessarily prolong it [12,20]. An appropriate palliation implies that the disease runs its natural course whilst the treatment seeks to promote the maximum quality of life for patients, as the time to death is in general uncertain (the outcome of this episode of disease, especially for patients without cancer , might not necessarily be fatal) [5].

In fact, after controlling the symptoms, patients occasionally live longer than expected. Often a request for euthanasia is motivated by the desire to control the circumstances of death, but as we saw, both the patient and the family as well as the medical staff can benefit by admitting that there is not a total control over the timing of death [5]. Although the benefits of pediatric palliative care are indisputable, the recognition and dissemination of palliative care is still at an early stage, in which currently available services for children with incurable conditions and their families are precarious and fragmented. The precipitating causes of this situation are multiple and complex: the number of children who can benefit from palliative care is much lower when compared to the number of adult patients, plus there is inefficiency in organisational policies and management, shortage of qualified health professionals and emotional and cultural embarrassments related to child care in end-of-life, which conditions the social acceptance and understanding of the phenomenon of death in children.

There are inconsistencies about the time in the evolution of the disease when medical care should be restricted to palliative care for the own good of the patient. There are also inconsistencies about its meaning for the child and for the family, whereby the criteria must be standardised. This is an area that lacks research, focused either on the individual needs of the child or on the child's environment. Therefore, it is important to define clinical outcomes [5,14,15,21-23]. Institutionally, the obstacles to the provision of appropriate palliative care can be overcome by the development and conduct of clinical protocols that adequately meet the needs of children and their families. It is also important to promote appropriate training to the providers of palliative care [22,24].

The Association for Children's Palliative Care (ACT) defines the paediatric palliative care as an active approach focusing on the longitudinal care:

from the diagnosis of the disease, along the child's life until death and even in the mourning stage [15]. It includes physical , emotional, social and spiritual elements, with a focus on improving the quality of life of the child or young person, including the management of symptoms of discomfort, the support to the family at the death and during the mourning [15,22,25]. The prolonging of the life of children, unlike in the palliative care to adults, may be an important goal. The palliative care is, therefore , directed not only to a child suffering from an illness, but also to a child who lives with an illness [15].

The prevailing model of palliative care in hospitals is the consultation service, although formal units of multidisciplinary palliative care are starting to emerge. By keeping the primary care team involved, this model ensures the continuity of the care in the hospital and saves financial and human resources. The goals are redefined according to the needs of the child and family, integrating palliative and interventionist care [14,21]. The palliative care team should be multidisciplinary, with at least one doctor, one nurse, a psychologist and a social assistant [15, 22].

The ACT advocates the discussion of such care in children with specific diagnoses, regardless of the stage of the disease and additional events, because of the advantage of starting the approach when the patient is still stable , making it easier for the family to discuss treatment objectives since the diagnosis of a life threatening condition [15]. Therefore, care is offered to patients at different times of the evolution of their diseases, so as not to deprive patients of the diagnostic and therapeutic resources that medical knowledge can afford. The early approach also allows the prevention of symptoms and complications related to the main disease, besides providing proper diagnosis and treatment of diseases that may develop in parallel with the main illness.

A good evaluation, based on the required exams in addition to the definition of the patient's behaviour , is essential for preparing a comprehensive plan of care, tailored to each case and adapted to each period of the disease progression [24]. In practice, however, the most common reason for contact with the palliative care team is not the diagnosis, but rather events or additional needs. The palliative care in children with cancer, is commonly initiated when the disease stops responding to treatments [15].

In general, children who die under 1 year spend much of their lives in the hospital but older children and adolescents live predominantly outside the hospital during their last year of life [26]. It is, therefore, essential to adapt the care (with integration and coordination of hospital and home-based services) and individualise it, taking into account the particular needs of the child and the family, without nurturing any prejudices regarding the location of the provision of such care. If the location changes, a professional should be designated to ensure the continuity of the care (an universally known need which is not always guaranteed) [15,26].

Pediatric palliative care can be divided into five phases: 1) first contact with the care team, be it due to recognition of treatment failure or due to impairment of the child's condition, having in mind that early palliative intervention should be considered for all patients whose condition presents risk of life, since the relationship between palliative care and curative care is not one of mutual exclusion and, in addition, the curative therapy and the one that maximises the comfort and quality of life should overlap as components of the care; 2) first contact between the palliative care team and the child and family, in order to develop a holistic support plan (having in mind that an advance planning is vital for the relief or a satisfactory control of the symptoms); 3) maintenance of the palliative care, providing stability to the child and the family, who should take advantage of their valuable time together; 4) terminal phase (end- of-life), in which the child can tolerate contact with only few people, being important to control the symptoms and to have a prior consideration about the mourning, by preparing for the fatal event (which may include the child's wish to say goodbye or leave messages to loved ones) and the planning of the death (including location and circumstances); 5) mourning phase, for which parents should have been prepared in advance. At the beginning of this phase the availability of caregivers is essential as witnesses of the loss. After all, what parents usually look for after their child's death is to share details of this common experience [14,15,22,24,25].

Mourning is an individual process of "relearning the world." The death of a child can never be overcome, but parents will learn to live with the loss despite of it. These phases are In general shorter in neonatology and there is little time to prepare for the mourning. Nevertheless, it is important to plan this phase before the parents leave the hospital. Despite its great importance, such sort of support during the mourning is still rare in many European countries [14,15,25].

The communication capability is particularly important in palliative care [15,22,24]. Communication, beyond its immediate effects, could have a long-term consequence on families which should not be

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underestimated. To be able to explain to the dear ones what one can and can not do , whilst it is ensured that the medication will be adjusted in the doses required to make the child comfortable, helps to build and preserve the family confidence in the palliative care team [5]. An important goal of communication is the redirection of the hope to realistic scenarios [15].

Even so , the hope of a miracle (even with knowledge of the reality), which sometimes gives some stability to the parents, can be seen as "healthy denial." However, some of the parents insist on aggressive treatment because they understand that other attitudes toward the disease would mean "do nothing" or, at least, don't do all that is possible [15]. It may be easier to discontinue certain treatment if it is known that the discontinuation does not imply the immediate death of the child [5]. Besides, if palliative care professionals are able to share their emotions with the parents and reflect with them on what more could be done for the child who is dying - how to hold the child, stand by the side of the child, sing, pray - the idea of "do nothing" can be subtly changed to an image of love, closeness and peace [15].

The involvement of children is recommended, as much as possible, in the decision making process in accordance with their maturity. The minor has the right to know the procedures that he or she will be submitted to, and if the parents refuse to share with the child this information, it is important to explore the reasons and underlying fears. It may be useful to mention cases of parents who involved the child in the decision making and felt well with it, while others who have not involved the child in the process repented. There are studies that show this fact [27]. Besides, it may be emphasised that children should trust health professionals, hence it is essential to have an honest attitude towards the children [15].

Studies conducted in Belgium and the Netherlands [8,28] reveal that, in most cases, the decision making is shared with the parents, but patients are rarely involved in the process, as incompetence of the minor is given as a justification(most often because of comatose state or because the child is too young). According to these studies, the decisions about treatment and medically assisted death are always discussed with the parents, which may result from the effect of short course of life in both cases. A discussion with parents appears to be less common when it comes to the administration of drugs for relief of symptoms with possible hastening of death, which can be credited to the fact that doctors consider it their duty to relieve suffering. On the other hand, this practice has been discussed with the patient more often, being usually requested by the patient, possibly because of a worsening of the symptoms [8].

The alleviation of suffering is the priority in palliative care, even if it accelerates death, whichcan be justified by the principle of double effect. According to this principle, an unwanted effect (death) can be ethically acceptable if the desired effect (relief from pain) is intended, provided that the unwanted effect is not the medium to achieve the desired effect and there is proportionality between the benefits of the desired effect and risks of the undesired effect. Thus, it is acceptable that the pain relief results in the death of a patient who is about to die, but not of a patient who might otherwise live for a long time. However, it is proved that the proper medication to control symptoms does not significantly accelerate death. There is, in fact, a greater risk of under treatment of symptoms, causing needless suffering [5,20].

The understanding that to treat pain and reduce suffering is ethical and desirable helps the medical team to do their best without the worry of "crossing the line". Indeed, the line between palliation and euthanasia can sometimes appear to be rather thin, since both aim to relieve the suffering. However, in palliation, the primary objective is to treat the symptoms, knowing that there is some probability of accelerating death whilst with euthanasia, death is the means to alleviate the suffering [5].

Despite this difference being clear in theory it can be difficult to discern between them in practice and to know if the doctor had intended to mitigate the suffering or to cause death. It is necessary to analyse the doses prescribed according to the clinical situation and verify if the medication had been properly prescribed based on signs and symptoms of the patient [5]. Other practices that may raise doubts in ethical terms are the suspension of artificial nutrition and hydration as well as the palliative sedation. The first may be reasonable in situations aimed to diminish the suffering, for example, when it is the feeding itself that is causing the pain or in a patient who is clearly in the last hours or days of life (it is unlikely that suspension of nutrition accelerates death) [5].

Palliative sedation refers to the administration of sedatives in end-of-life to treat symptoms resistant to all other treatments. Commonly referred to as "terminal sedation", the term "palliative", however, is more suitable because it reflects the purpose of the medication. The treatment should be titled according to its effect. One should recur first to

safer alternatives, progressing later to riskier interventions in case the first ones had failed. Thus, the medication should be adjusted just enough to ease discomfort and it is unlikely that in this way, death will be accelerated [5,20].

According to that, it is important to improve the quality of pediatric palliative care, thus minimising the need to request euthanasia when children are in end-of-life situations. Howsoever, and even if they are properly developed, such palliative care can fail [12], making important the perception of the role that euthanasia in children should take in such cases.

The debate on pediatric euthanasia

One of the arguments put forward by pediatricians and politicians for the change in the Belgian law is the fact that , as long as the children's capacity of discernment is evaluated , they should enjoy the same rights as adults and, if they so wish, in a context of suffering from an incurable disease and likely death, put an end to their life [12]. This way, the Belgian euthanasia law seeks to respect the moral status of children as agents of an increasingly self-determination capacity (which, as we have seen, has to be carefully assessed) [29]. Some see this measure as the ultimate gesture of humanity: the relief of suffering, when the most advanced medicine has failed [12,30].

Although most of the public approve the change in the law, the medical, legal and political professionals are divided about it . So much so that a group of over 170 pediatricians signed an open letter before the vote of the law, asking members of the Belgian parliament to postpone the decision [12,17]. Some of the authors who are opposed to this new legislation have doubts about the child's ability to make a lucid decision [12], since adults opt for euthanasia for reasons that go beyond pain, including the fear of loss of control, not wanting to be a burden to others, or the will to not spend their last days of life under sedation (wishes usually based on their life experience). According to those authors, children seem to have to choose between unbearable suffering on the one hand and death on the other, because they don't have the experience and sense of dignity and self-determination that adults commonly invoke(rightly or wrongly) at the end of their lives [29]. However, it is shown that generally a child with terminal disease develops faster than other children of the same age 12.

Yet, this fact should never be taken as the norm, hence the need for careful assessment of the child's sense of judgment by a multidisciplinary medical team and in accordance with the maturity of the child, not the child's chronological age. Although nowadays the Belgian law applies to all ages, in fact, euthanasia for children is likely to be limited to pre-teens, considering the requirement of "capacity for discernment" [12,31]. As we have seen, the debate over medical decisions about children and young people focuses in general on this conflict between the competence to make decisions and the need that adults feel to protect children, even though, for some young people who are living with a serious illness for many years, this position may seem condescending [19]. In addition, the perspective of parents, manifested by their consent, can translate the notion that suffering is unbearable only for them, not for the child. Added to this the fact that the parents' decision requires the prior presentation of the options by the doctor, making their decision dependent on the information provided and the way it is given [30].

The historical connection between medicine and law led most societies to promote respect for life (though the answers to the "why" of the need to respect, maintain and protect life are usually given by religion, philosophy or politics). Opponents of euthanasia argue that the legalisation of this practice replaces the "treatment" for a mitigating "relief of suffering" or "avoidance of harm" , restricting the scope of medicine as a treatment tool and the resulting disregard for the value of human life [19,30].

One of the most relevant arguments against the decriminalisation of euthanasia is the slippery slope argument, which trivialises the act of ending the life, implying the risk of misuse of the practice and the elimination of the most vulnerable patients [9,32]. It is even suggested the possibility that a focus on the idea of "relief of suffering" could evolve into a "relief of abnormality," slipping to the danger of using perfection as a standard [30]. From the example of the adoption of the euthanasia law in the Netherlands, it can be concluded that there wasn't an abusive increase in numbers nor, apparently, the extent of the practices to vulnerable patients. On the contrary, there was an intensification of symptom relief, that is, the improvement of palliative care [33].

The Belgian Law of 2002 was accompanied by an increase in all types of end-of-life medical practice (attributing the increase of euthanasia to a likely increase in the number of reported cases), with exception from involuntary euthanasia, and an extension of these practices to vulnerable groups [34] was not verified. On the other hand, some authors

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mentioned the reduction of the legal scrutiny over time and the delegation of the practices to nursing professionals [30].

Although the frequency of medically assisted death without explicit request has declined in both countries over time, attention and thorough study of cases that still exist are necessary, in order to check for conceptual confusion or serious flaws in practice. The failure in the record of euthanasia in minors being around 20% of the cases in the Netherlands and about 50% in Belgium also raises an additional concern 32,33. Some authors suggest that what the legalisation of this practice for children really means is the implementation of a process that approaches a slippery slope[12].

It is anticipated that cases of euthanasia in children are very few in number [9], which questions the urgency of the amendment of the Law [12]. However, the practice advocates argue that, despite the small number of euthanasia requests, these will be of immense importance, since, with this option now available, open discussions on early death will be possible, allowing the appearance of solutions to a situation that may be intolerable [12.] Ultimately, it is the rare situations that fail to be addressed, although euthanasia in such cases, even if it's not a positive solution, consists in a way to prevent that these children remain suffering [17].

According to this perspective, the extent of the law to minors was a matter of principle, not necessarily of an immediate need 31. Nevertheless, the lack of evidence as to the definition of "hopeless" and "unbearable" suffering, without an objective quantification, is a major problem 30. In addition, to raise the issue of euthanasia in the context of end-of-life of a child in pain may further increase the emotional stress experienced by the parents . Indeed, it is known that in countries where euthanasia is permitted there is an emotional burden on doctors and family, with many professionals refusing these requests [12,17].

Final considerations

In short, in this ethical and social framework, the need for a law on euthanasia for children, as the example of the law passed in Belgium in February 2014, would be much more debatable if palliative care were available and developed enough to meet the needs of children, youths and families who face terminal life situations. However, with sparse evidence about the quality of pediatric care at end-of-life, the discussion of child euthanasia requires multidisciplinary research so appropriate public policies concerning this subject can be formulated and proposed [19]. Namely, it should be adequately clarified whether euthanasia of minors is or is not an, albeit covert, involuntary euthanasia [35].

In any case, by way of conclusion, it seems that the international debate on decisions about end-of-life in children, fostered by this recent political and social change in Belgium, could result in an investment in the improvement and accessibility of pediatric palliative care [9].

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Filipa Martins Silva was responsible for the conception and design of the study, the research and literature review, as well as the wording of the original text; Rui Nunes proceeded to critical analysis of the intellectual content of the work. Both changed the final version submitted for publication.

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Brain death: a finished discussion?

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Abstract

This article is a narrative review of the main authors who establish objections to the use of the concept of brain death as a synonym for death. It focuses on their biological and philosophical inconsistencies of the concept and proposes the discussion of the topic using the epistemological concepts of Popper and Kuhn. The article adopts the concepts of biopower and biopolitics as tools in the analysis of brain death, especially in relation to the inevitable intersection with organ donation and transplants.
Keywords: Brain death. Bioethics. Transplantation.

Resumo

Morte encefálica: uma discussão encerrada?

O presente artigo faz revisão narrativa dos principais autores que estabelecem objeções à utilização do conceito de morte encefálica como sinônimo de morte, com foco em suas inconsistências biológicas e filosóficas. Propõe a discussão do tema recorrendo aos conceitos epistemológicos de Popper e Kuhn. Utiliza os conceitos de biopoder e biopolítica como ferramentas de análise da morte encefálica, especialmente no que concerne a sua inevitável intersecção com a doação e transplantes de órgãos.
Palavras-chave: Morte encefálica. Bioética. Transplante.

Resumen

Muerte cerebral: ¿una discusión cerrada?

Este artículo es una revisión narrativa de los principales autores que establecen excepciones a la utilización del concepto de muerte cerebral como sinónimo de muerte, centrándose en sus inconsistencias biológicas y filosóficas. Se propone la discusión del tema usando los conceptos epistemológicos de Popper y Kuhn. Utiliza los conceptos de biopoder y de biopolítica como herramientas en el análisis de la muerte cerebral, especialmente en relación con la intersección inevitable con los trasplantes de donación de órganos.
Palavras-clave: Muerte encefálica. Bioética. Transplante.

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Declaram não haver conflito de interesse.

Death was recognised only by cardiorespiratory criteria in the past. The techno-scientific advances of the twentieth century, such as the advent of mechanical ventilation and intensive care, made possible the support of cardiorespiratory function in victims of severe and irreversible neurological damage. Parallel to that, the development of organ transplants also influenced directly and indirectly the discussion on the fate of those patients, leading to the creation of a neurological death criteria. In Brazil, the diagnosis of brain death is confirmed by two clinical exams and a supplementary examination, as required by the Resolution 1,480 / 97 of the Federal Council of Medicine (Abbreviated as CFM in Brazil - Conselho Federal de Medicina) [1].

Most advocates of brain death as a synonym for death of the organismo share the same paradigm that the term "cerebral death" refers to an irreversible biological phenomenon, which results in the permanent interruption of the life of the organism [2]. This premise provides moral support for the removal of organs from people considered dead, what is known as dead donor rule [2]. The idea that death is the permanent cessation of the integrated functioning of a body and that brain death is a sufficient criterion for determining when such interruption occurs is also part of this vision.

The main reason for this belief comes from the fact that the brain is considered irreplaceable, as well as being the main integrator of the whole organism [2]. Another argument is that, ultimately, every death is cerebral, causing irreversible cessation of cardiorespiratory functions [3]. However, despite being widely used and established in several countries as a criterion for death of the organism, both for the suspense of vital support as well as organ donation, the diagnosis of brain death still remains a subject of controversy as a synonym for death of the organism [4].

These divergences manifest themselves in the different criteria that are used worldwide to define brain death. Based on various philosophical principles, these parameters stipulate variable intervals between clinical trials, various assignments of the professionals in charge of carrying out such tests and whether or not the execution of additional procedures are necessary [5]. A certain uneasiness is still frequent among the professionals involved, especially among critical care physicians, at the time of suspension of life support or at the time of filling in the death certificate [6,7].

Despite the fact that this uneasiness is generally attributed to the lack of knowledge about the method [8], philosophical and biological doubts persist and should not be underestimated as they can, even if intuitively, be the answer for this discomfort. In this review, we discuss the concept of death, especially the brain death, the biological and epistemological inconsistencies of this classification, in addition to the "necessity" of this diagnosis as a way to provide organs for donation and transplantation purposes.

What is death?

Every definition of death should grasp the common sense of the word used by anyone, not being primarily a legal or medical term [9]. But here we will hold to the biological paradigm, which definition is the permanent loss of critical functions of the organism as a whole [10]. Organism as a whole is an old concept of theoretical biology [11] regarding the unit of an organism and its functional integrity, and not simply the sum of its parts - a concept that brings in its core the notion of critical functions [12].

Critical functions are those without which the body can not function as a whole, namely the control of respiration and circulation, the homeostatic and neuroendocrine regulation as well as the conscience. Death, therefore, would mean the irreversible loss of all these functions [13].

The current concept of death implies the irreversible loss of cardiorespiratory or brain function (brain "as a whole" or brain stem, according to the country in question) as a condition to attain the loss of all these critical functions [10]. It is interesting to highlight that the irreversible loss of cardiorespiratory function must be natural, since it is possible to keep it artificially - which often happens in practice - for varying periods of time [9].

Another key aspect, but difficult to answer, is whether the death is an event or a process. The Harvard Medical School Committee had a decisive influence on this issue when, in In 1968, they chose to define it as an event [14]. It is not surprising that several laws and medical guidelines have adopted the same classification after that decision [15].

One of the problems that can afflict the professionals involved in such situations is that the idea of death as an event seems to hurt the common sense. This is also reflected in the literature, in view of the extensive resumption of the discussion of death as a process [16-19]. In a very general way, it can be said that death begins at birth. More practically, however, it would be possible to consider that ,

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even when extremely short, this process still takes a lapse of time, not exact, in the linear view of time.

Inconsistencies of the biological diagnosis of brain death

There are several ways in which functions of various organs of the body and subsystems may be integrated in order to maintain homeostasis and resist entropy. Integration may occur from a central integrator, an organ which receives signals from various other organs and subsystems, processes them, and then returns these signals to the subsystems, coordinating the various functions of the parts of the organism [2]. Proponents of brain death argue that the only central integrator possible is the brain because it is irreplaceable in implementing these regulatory functions [10].

Another possible way to integrate the functions of various organs is through the decentralised interaction in which the parts are coordinated through the ability to feel, receive and process signals between each other [2]. Shewmon [20] argues that this form of integration and decentralised operation can occur between the parts of an organism without any participation of the brain. The author cites numerous cases involving the high neck section, isolation of the brain by Guillain-Barre syndrome or even death brains with artificially-induced respiration, in which there was a high degree of functional integration in the absence of regulation by the brain or by any other central integrator.

Shewmon [20] completes his examples mentioning that organisms with dead brain have the same functions of unquestionably living patients in intensive care units (ICU), and managed to keep these functions with little external support. It is also noteworthy that a study conducted by histopathological findings suggested that even when clinical guidelines for brain death were properly implemented, more than 60% of donors didn't have or had only minor structural changes in the brainstem in autopsies [21].

The risk of an incorrect declaration of brain death increases as the pressure increases to "gain" time in the removal of potentially viable organs for donation. In this scenario, it is not surprising that supporters of transplants are advocating that confirmatory tests should not be performed in order to avoid delay [22]. More worrying is what was revealed in a study involving 142 pediatric donors with beating heart, in which, after having passed through 294 neurological examinations, it was found that in only one of them the documentation of all components of the test was complete, only 26% had the apnea test properly performed, only 15% had two clinical examinations with appropriate time interval between them and only 58% had undergone confirmatory angiography [23]. Similar results were also found in studies with adult donors [24]. Published data showing such inconsistencies in Brazil was not found.

The basic issue is that the diagnosis of brain death can actually be only a prognosis of irreversibility which is arbitrarily set in a period preceding the biological death and extending in a spectrum that ranges from simple completion of a clinical examination consistent with brain death , as in Finland, until the completion of three clinical tests over a period of 24 hours, together with further examination, as it happens in Greece [5,25]. Therefore, to describe the same situation, this range goes from the simple acceptance of brainstem death as a diagnosis of brain death and therefore the death of the organism, to the demand of the death of the brain as a whole [5].

Death of the brain as a whole as a criterion for brain death

The point of view of the death of the brain as a whole professes that the loss of integrative activity of this organ with other subsystems leads inexorably to cardiorespiratory collapse, since this loss establishes a progressive state of entropy and organic disintegration. However, several other functions resulting from activities between integrated subsystems of the organism which are not dependent on cerebral control persist for indefinite time, according to the type of neurological insult and level of critical support offered. It is worth mentioning the functions that remain despite the diagnosis of brain death: circulation, hormonal balance, temperature control, digestion and metabolism, waste disposal, deep healing, combat to infections, growth and sexual maturation in children and adolescents [26], and even the ability, in victims of catastrophic brain events, to carry out a pregnancy to term [27].

A fundamental paradox of the definition of death through brain criteria, identified by Joffe [28], consists in stating that the arrest of cerebral functions is the final event of the three forms of death (cardiac, respiratory and cerebral itself) and, at the same time, affirming that brain death leads to death by loss of integration with consequent respiratory arrest and circulatory collapse, because if brain

death leads to death, then it is not the death of the organism properly said.

Shemie [29], for example, opposed the arguments of the critics of brain death, stating that these would wish that there is a clear dividing line of death, which, as required, could only happen, according to the author, with the death of all cells. But, apparently, what is desired by critics of the brain death concept constitutes a clear dividing line of death of the organism by irreversible loss of integrative capacity, a condition which today can be defined only through circulatory arrest [28].

Brainstem death as brain death

Joffe [30] discusses the criterion of death of the brain stem as a sufficient criterion of brain death, characterised by the irreversible loss of consciousness capacity also associated with the irreversible loss of ability to breathe. This criterion proves to be problematic as it is disturbing that consciousness may be preserved but be inaccessible due to the etiology of neurological damage. In addition, according to the author, it is not always clear that the loss of the ability to breathe should be spontaneous.

Ontological criteria of brain death

According to Joffe [30], the ontological criterion of death, also known as neocortical death, is not without its problems when one wants to diagnose death by the loss of the characteristics that make us human beings. There are no reliable methods to assess the absence of these features, according to the author, and it is impossible to determine the potential of reversibility of such cases.

Objectively, this parameter requires only irreversible loss of consciousness. However, accepting such a concept would result in numerous theoretical and practical problems, such as to admit that the individual could be declared dead before his or her organism was dead, a situation that would imply to authorise the burial, cremation or performing of autopsies on ill patients who are in permanent vegetative state, despite breathing and display movements or even spontaneous eye opening [31].

Donors with stopped heart

The possibility of using donors with stopped heart and assisted death brings even more debatable dimensions of the ethical point of view, as it seeks to interfere directly in the dying process, anticipating the final event with a view to the removal of potentially viable organs for donation. The question of the removal of organs after death of the organism in such cases is "resolved" by the establishment of an arbitrary time criterion of absence of auto resurrection after an assisted cardiorespiratory arrest [28].

This period, according to Joffe [28], can go from 2 minutes, in Pittsburgh, USA, to over 20 minutes, in Sweden. For the author, this death linked to organ donation, time manipulated , also hurts the criterion of irreversibility, which must be understood as the inability to reverse the fact, not as a prior decision not to try to reverse a cardiorespiratory arrest. Bernat [10,32] suggests the term *irreversible* for the impossibility of reversion characteristic of brain death, and the term *permanent* for situations in which the reversion will not be attempted, a condition which would classify the donation as stopped heart.

It is important to highlight that the reintroduction of the concept of donor with stopped heart results from the progressive reduction of brain-dead donors in some countries, consequent to the requirement of use of helmets by cyclists and motorcyclists and the improvement of the care of severe traumatic brain injury victims [33].

Is brain death a dogma?

It is possible to search in the philosophy of science some epistemological considerations to support this argument. Initially, the unique contribution of Karl Popper [34] in addressing Hume's induction problems and Kant's demarcation can be highlighted. At the confluence of these two analyses, Popper concluded that induction would not be a reliable scientific method in the field of natural sciences, since the repeated occurrence of events in the past is no guarantee of repetition in the future.

As for the problem of demarcation between science and pseudoscience, the contribution of Popper34 was to understand that knowledge, to be considered science, can never be permanently validated and must always be open to potential rebuttal. When the refutation (or fallibility) does not occur, according to the Austrian born British philosopher, the theories would not be considered definitely true, but only temporarily corroborated. A knowledge that is not open to a hypothesis test, in his view, can not be conceived as scientific.

While it is hard to imagine to what extent the theory of brain death as death of the organism can

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be submitted to hypothesis testing, the fact that it can not be widely discussed brings a question as to its scientific status, considering Popper's view on what is and what is not scientific [34].

Later, Thomas Kuhn [35] also contributed decisively and originally to the philosophy of science, when he added a generous dose of irrationality to the scientific procedure. According to him, certain knowledge often takes the characteristics of a dogma (paradigm) called normal science. It is a stage of science when new hypotheses able to refute the dominant theories are not created, therefore scientists work in pre-established lines of research, which quite often had been started by other researchers. It is worrying that the current status acquired by brain death, as a synonym for death of the organism, has become a dogma in our area.

Another form of acceptance of brain death as a synonym for death of the organism occurs in bad faith. The meaning of "bad faith" here refers to the form originally described by Jean-Paul Sartre in the famous chapter 2 of "Being and Nothingness" [36]. In the context of this work, the bad faith is the masking of an unpleasant truth [37], seen in our midst as the early closure of the discussion of brain death as synonymous with indisputability. If, on the one hand, it promotes the donation and transplantation of organs, on the other hand, restricts a continuing scientific debate.

The paradox of the bad faith, which makes it different from lie, is in the fact the deceiver and the deceived are the same person, since it is a lie that one tells oneself. The real problem, according to Sartre [36], comes from the bad faith being a dogma [37].

Biopower, biopolitics, brain death and organ donation

The "need" to reify this dogma, hiding unresolved doubts, due to the use of the concept of brain death as a synonym for death of the organism, operates in parallel with the promotion of organ donation and transplantation. This need can be addressed by the help of the theoretical framework of the concepts of biopower and biopolitics.

These concepts were originally coined by Michel Foucault [38] in the first volume of "History of Sexuality". The idea of biopower joined the reflections of this author on disciplinary practices as techniques of exercise of power , particularly since the eighteenth and nineteenth centuries. Foucault called biopower the management of life as a whole through the power techniques on the biological dimension, and biopolitics the human activity on natural life and the biopower mechanisms to control it.

In the beginning of this period, the power exercised by medicine on human life was not restricted to the adoption of several specific measures, such as establishing rules for birth control, containment of illnesses and endemic diseases, hospital construction and allocation of the "mentally ill in " insane asylums ", but it was extended to sexuality in general. Subsequently, the biopower started to penetrate the very body of the subjects and their different ways of living [38]. The body was subjected to the dictates of biopower and biopolitics, with the interconnection of ideas of life to the idea of death. On the other hand, biopolitics has become the means by which to carry out resistance to biopower attempts to neutralize people [39].

In the past, to die or kill was a gift from the rulers, who hold the power on the life and death of the population. The change in the concept of death in the West established the power of death over life, according to Foucalt, through the biopower. In a brief, it can be said that biopower refers to the actual devices to which one recurs to obtain power over life, while biopolitics is the politics whose objective is to implement and manage the biopower [40]. With regard to death in a general sense and the brain death in the case of this article, biopolitics takes on the role of thanatopolitics.

In the first volume of "Homo sacer: sovereign power and bare life," Giorgio Agamben [41] resumes Foucault's concept of bio-politics 38, taking advantage of an obscure figure of the Roman law, *homo sacer* ("holy man" in Latin), a person deprived of all civil rights, and who may be killed by anyone without a punishment for his or her death; Paradoxically, however, that life was considered "sacred" and could not be sacrificed in religious rituals [41].

Agamben named this condition "bare life", a way of life which does not reflect any rights or duty, and that goes beyond its biological form. Bare life examples can be found in refugees, prisoners of concentration camps, in human subjects, political prisoners, or in people whose autonomy over their life is no longer possible: the case of individuals in a coma and with brain death [41].

Foucault [38] identified that, in the course of modernity, natural life started to be managed by the power of the state and politics became biopolitics, as the biological dimension of life was gradually occupying the center of the modern political scene.

Agabem [41] is interested in how this transformation of life in biopolitics happened. If, before, the power of the sovereign *could order death or let live*, now, the state *can order to live and let die* [38].

It is this idea of sovereignty and "sanctity" of life that Agamben [41] uses to define the concept of bare life, making use of the Holocaust phenomenon as an example where the biopower and the sacred man were markedly demonstrated. The bio-political power over life and death has been transferred to the State through medicine. Agamben believes that the politicisation of life and especially the politicisation of death occurs from the moment when one comes to understand the biological dimension of life and its needs as an integrant part of politics, to the extent that the body is the new subject of politics in modern democracy.

For Agamben [41], with the valorisation of the biological body, biopolitics has become thanatopolitics, understood as a set of devices that allow interaction of medicine with the law through the use of new technologies to prolong life, transforming death in an epiphenomenon of the technology. As a result, the biopower passed from the hands of the sovereign into the hands of the physician and the scientist, and from these, into the hands of the state. The state, in turn, converted biopolitics into biopower and then thanatopolitics, deciding who can live and who shall die, making believe that living organisms belong, in fact, to the government.

The thanatopolitics brought as a consequence the "need" to legislate on life and death, which is the main point of our discussion about what is biological death, especially brain death. The situation of the donor in cases of brain death reminds of the situation of the Agamben's *homo sacer* [41]: is sacred, to the extent that it can save several lives in this situation, and at the same time can be declared dead without this meaning an infraction; that is, the condition of the person is so inviolable as violable. It is as if the individual were a mere body without meaning, liable to become a means instead of an end in itself.

Agamben [41] understands that individuals identified with the bare life, the sheer physical life, are exposed to the dynamics of biopolitics. Following this line of thought, it can be said that the person declared brain-dead is reduced to bare life as it loses its right to personality, which is transferred to the family, as defined in Article 4 of the Federal Law 10,211 / 2001 [42]. This means moving to the scope of biopolitics actions.

The relationship between bioethics and biopolitics is narrow, since the birth of both concepts is related to the context of Nazi experiments. However, the paths they followed are irreconcilable: biopolitics is generalising and strips the man, consisting of the most extreme and aggressive manifestation of politics, whilst bioethics is concerned about the natural life and the autonomy of individuals [43].

Maldonado [44] also considers bioethics and biopolitics irreconcilable because it considers the first from the humanitarian perspective and the second as associated with the idea of violence [44]. It should also be noted the position of Schramm [40], who advocates the role of bioethics resistance before the attempt to subject it to the pragmatic "needs" of the political reality, which we understand to be the focus of this discussion, as we try to discuss a theme that can be viewed as a way to disturb the process of organ donation and transplants.

Final considerations

Initially, there were two basic reasons why the definition of brain death had become accepted by society: to allow discontinuation of life support in patients with extremely severe neurological injury and to provide organ donation for transplants without the one responsible for the decision being charged with murder [14]. The first reason is no longer necessary, since the suspension of life support in patients with prognosis of irreversible neurological damage and unacceptable quality of life can be done through the prior consent of the patient or the patient's family (in the absence of an instruction previously signed by the patient). However, the second reason remains necessary to comply with that "dead donor rule" [30].

To equate brain death to death of the organism has become a "necessary" mechanism to facilitate society's acceptance and to legalise the search and removal of organs from donors with a beating heart [45]. Although brain death and organ transplantation have presented distinct historical trajectories [46], from the moment that these two concepts converged, the impact of the latter over the former could no longer be underestimated.

Doctors who work in institutions which are renowned for saving lives through transplants are often faced with candidates for transplants who are suffering and dying whilst waiting for organs as well as with the significant improvement in quality of life of patients submitted for successful transplants [30].

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Moreover, they are also influenced by the feeling of futility to continue the cardiorespiratory support in patients with brain death, as many times these professionals work pressed by a context of lack of resources [30].

These issues operate consciously or unconsciously as conflicts of interest, inhibiting the dispute, by the professionals, of the brain death criterion as death of the organism30. It is also possible that doctors simply accept the definition of brain death as true, without knowing its theoretical basis and its potential conceptual problems [30]. Death determined by neurological criteria is a paradoxical death, because it is associated with the physical image of the body's normal functioning, which creates emotional and cognitive conflicts for many health professionals and relatives of the patient [47].

For Miller and colleagues [48], these unspoken conflicts may have the practical effect of the discomfort present among professionals and the discrepancy between practices and standards on the issue of donation after brain death or cardiac arrest, that is, the use of organs according to " the dead donor rule ". The authors qualify this discrepancy as a moral fiction, identified by the assertion that organs are only removed from organ donors with diagnosed death, since, when making such a claim, one is either denying reasonable doubt of the biological basis of the diagnosis of brain death as death the body, or is admitting to confuse irreversibility after cardiac arrest with the decision not to try to stop the cardiac arrest, concerning the donor with heart stopped.

There are three possible solutions to overcome this moral fiction: change practices, change the rules, or, what usually occurs, continue to act as if these bioethical conflicts don't exist 48 - a measure that is likely responsible for frequent maintenance of individuals, who are not donors, in brain death under intensive support until cardiac arrest. A shift of the standard alternative would be to define brain death as an undoubted prognostic death of the organism, and not as a diagnostics of death itself. Another possible change from the norm is the solution adopted in Japan since 1997, which allows individuals and families to define the kind of death they think is acceptable according to their beliefs and values, and in an independent way, whether they want to donate organs or not [49].

It remains paradoxical that the biologisation of death diagnosis in order to objectively define it shattered the concept of death in four possible alternatives: cardiac death, death of the whole brain, rainstem death and ontological death. Another paradox of this search for objectivity is that death has become a subject in the first person, as the irreversible loss of consciousness is important only for those who die - which, according to Holland [50], had already been perceived by Schopenhauer in "The World as Will and Representation" - without becoming objective in the third person, that is, one where a different person should recognise someone else's death.

Therefore, brain death, technically defined as an event at the end of the third examination (either clinical or complementary), remains a challenge as a valid concept of human death, since the scientific evidence is insufficient and the philosophical thought is even less convincing [33]. Some authors even consider that neurological or circulatory parameters currently used for the confirmation of death and search for transplantable organs conceals the practice of physician-assisted suicide [33]. The term "physician-assisted death" means intentional actions at the end of life, performed either by consent (such as euthanasia or suicide physician-assisted) as those practiced without explicit consent [51].

To reduce any definition of death to exclusively neurobiological criteria implies to ignore its anthropological, cultural and religious dimensions, to which many people give more value. Thus, the policies and practice of searching for organs should be consistent with aspects deeply rooted in these dimensions [33]. The concept of death is not simply of biomedical nature, but it is also a result of major sociological influences [52], being partly a social construct. The elaboration of the idea of brain death as synonymous with the body's death follows the utilitarian view of death, maybe way too much. To paraphrase Bernard Williams if utilitarianism is right, it will be better that people do not believe in utilitarianism [53].

This article is not meant to be an indictment of the donation and transplantation of organs, but a proposal for a resumption of discussion, made tacit, concerning the basis the premise of brain death as a synonym for death of the organism. It also aims to warn about the limits that must be guarded against biopower and biopolitics, regarding their influence on life and death. It also seeks to point out another negative aspect of biopolitics: the fact that even when brain death is accepted as a diagnosis of death of the organism, in practice the life of the patient is perpetuated - not infrequently - through the intensive support of those non-dead donors.

However, it is these same biopower and biopolitics that , while managing the fate of the bo-

dies, allow lives to be saved by organ donation and transplantations. Such ambiguity reinforces the theoretical potential of these concepts in the analysis of bioethical issues. The primary questions, how could they not be, remain unanswered: what is death? Is brain death synonymous with death of the organism? Who owns the right to define the outcome of the process of dying? Do organ transplants, though instrumental nowadays, have to be socially constructed on a cloudy premise?

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Anencephaly and congenital abnormalities: the pathologist's contribution to Judiciary

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Abstract

The Federal Supreme Court of Brazil in 2012 issued a historical decision in the context of Arguição de Descumprimento de Preceito Fundamental – ADPF 54, based on the premise that only the fetus that has the capacity to be a person can be the victim of the crime of abortion. The topic is important because it involves dignity, liberty, self-determination and individual rights. It was decided that performing the delivery earlier, in this situation, is not abortion, because this crime supposes potential for extra-uterine life. In this context, several malformation syndromes are underlined, also incompatible with extra-uterine life, which must be topics for regulations, anchored in isonomy. Intra-uterine diagnosis is essential, as well as the thorough study of the fetus, by the means of necropsy performed by pathologists. It is important, still, to grant equal judicial treatment to fetal conditions which, although not as well known as anencephaly, carry the same social impact and have analogous judicial situation.

Keywords: Anencephaly. Abortion, legal. Autopsy. Pathology. Congenital abnormalities.

Resumo

Anencefalia e anomalias congênitas: contribuição do patologista ao Poder Judiciário

O Supremo Tribunal Federal, em 2012, proferiu decisão histórica no bojo da Arguição de Descumprimento de Preceito Fundamental 54, baseando-se na premissa de que somente o feto com capacidade de ser pessoa pode ser sujeito passivo do crime de aborto. O tema é dos mais importantes, pois envolve dignidade, liberdade, autodeterminação e direitos individuais. Decidiu-se que a antecipação terapêutica do parto, nessa situação, não constitui aborto, uma vez que esse tipo penal pressupõe potencialidade de vida extrauterina. Ressalta-se a existência de numerosas síndromes malformativas, também incompatíveis com a vida extrauterina, que devem ser objeto de regulamentação, com base na isonomia. É fundamental o diagnóstico intraútero, além do estudo minucioso do produto da concepção, mediante necropsia realizada por equipe especializada. Importa, ainda, privilegiar o debate e conferir tratamento jurídico semelhante a condições fetais que, embora não tão conhecidas como a anencefalia, acarretam o mesmo impacto social e condições jurídicas análogas.

Palavras-chave: Anencefalia. Aborto legal. Autopsia. Patologia. Anormalidades congênitas.

Resumen

Anencefalía y anomalías congénitas: la contribución del patólogo al Poder Judicial

La Suprema Corte brasileña ha proferido decisión histórica en el ámbito de Arguição de Descumprimento de Preceito Fundamental – ADPF 54, con basis en la premisa de que solamente el feto con capacidad de ser persona puede ser sujeto pasivo del crimen de aborto. El tema es importante porque envuelve cuestiones como libertad, autodeterminación y derechos individuales. Se ha decidido que la anticipación terapéutica del parto, en esa situación, no constituye aborto, ya que ese tipo penal presupone la potencialidad de vida extrauterina. Se resalta la existencia de diversas síndromes malformativas, incompatibles con la vida extrauterina, que deben tornarse objeto de regulación. Es fundamental hacer diagnóstico intraútero, a parte de un estudio del producto de la concepción, a través de necropsia realizada por equipo de expertos. Es necesario que se haga una discusión del tema y que se de tratamiento jurídico similar a condiciones fetales que resultan en el mismo impacto social y en condiciones jurídicas análogas.

Palabras-clave: Anencefalía. Aborto legal. Autopsia. Patología. Anomalías congénitas.

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Declaram não haver conflito de interesse.

The legal possibility, in Brazil, of allowing the interruption of pregnancy in cases of lethal fetal congenital malformations is a recurring subject in legal doctrine and jurisprudence. That is because the Brazilian Criminal Code of 1940 [1], published according to the dominant habits and values of the 1930s, does not predict the possibility of abortion in situations besides the ones predicted and considered special. These exclude the illicitness from the necessary abortion (when there is no other way to save the life of the pregnant woman) and humanitarian abortion (when pregnancy results from rape and there is consent of the pregnant woman or her legal representative).

In more than thirty years of the publication of the Brazilian Criminal Code, in 1940, with its "Special Part" still in power, the values of society have changed also with the significant evolution of science and technology, which produced a revolution in medical sciences. Therefore, criminal law cannot be indifferent to the development of science or to the historical evolution of thought and sociocultural aspects of present day society. Frequently, questions claiming the application of criminal norms edited formerly, which must be analyzed hermeneutically, in order to find its real sense, adjusted to the present time.

In the current days, medicine is capable of defining, with significant degree of precision, the occasional fetal anomaly incompatible with extra uterus life, being it defensible, from the standpoint of the physicians studying the subject, that the law allow for the "abortion" when the unborn child presents serious and irreversible anomalies that make life outside the mother's womb unfeasible, as occurs in several other countries. In Brazil, courts of justice frequently analyze requests for therapeutic anticipation of parturition in cases of lethal anomalies of the fetus. There is jurisprudential understanding that corroborates this understanding, as can be inferred from the analysis of the judgment published by Tribunal de Justiça do Rio Grande do Sul (Rio Grande do Sul Court of Justice):

Considering that, by the time of the promulgation of the present Criminal Code, in 1940, there were not the present day technical resources that allow for the detection of malformations and other fetal anomalies, including the certainty of death or physical or mental impairment of the unborn and that, therefore, the law could not include eugenic abortion among the causes of exclusion of the illicitness of abortion, an update in thought on the matter imposes itself, as the Justice is not limited to the law and is not stagnated in time, indifferent to the technological advances and to social evolution. Moreover, present jurisprudence has performed extensive interpretation of art. 128, I, of that law, admitting the exclusion of illicitness of the abortion, not only when it is performed to save the life of the pregnant woman, but also when it is necessary to preserve her health, including mental [2].

Based on these premises, the present study intends to analyze the theme in a neutral way and, as much as possible, devoid of ethical, moral, religious or emotional biases, without the intention to exhaust the topic, due to its amplitude, but only to contribute to the debate. The decision of the Supremo Tribunal Federal (Federal Supreme Court of Brazil - STF) in the framework of the claim of non-compliance with a fundamental precept (Arguição de Descumprimento de Preceito Fundamental - ADPF) 54, which not only mobilized the public opinion and sectors of civil society but also treated and settled the question within the Brazilian Judiciary, shall be briefly analyzed. Besides, it supplied subsidies for Resolution 1,989/2012 of the Conselho Federal de Medicina (Brazilian Federal Council of Medicine - CFM), which, in turn, defined the guidelines for the diagnosis of anencephaly.

Lastly, the authors, university hospital pathologists pathologists with solid experience in fetal and perinatal pathology, shall approach other malformation syndromes that cause fetal inviability. These, although nos as widely known as anencephaly, bring the same social and medical impact, thus deserving analogous legal treatment.

The STF and the ADPF 54 decision

Filed by the Confederação Nacional dos Trabalhadores da Saúde (National Confederation of Health Workers), the ADPF 54 requested the interpretation of the 1940 Criminal Code according to the Federal Constitution of 1988 [3], on the grounds that only a fetus with the ability to become a person can be passive subject of the crime of abortion. It was intended that the characterization of the therapeutic anticipation of parturition of anencephalic fetuses as a crime be declared unconstitutional.

In public In public hearings held in 2008, during the restructuring phase of the process [4], medical arguments were raised in order to subsidize the possibility of anticipation of parturition in cases o anencephalic fetus pregnancy, among which the

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argument that this fetus may be considered a biological stillborn and that there would be increase in the risks to maternal health in cases of pregnancy maintenance, considering the possibility of complications in labor as well as increased vulnerability of the pregnant woman to pathological states of depression and other psychiatric conditions.

At the time, physicians representing the CFM, the Federação Brasileira das Associações de Ginecologia e Obstetrícia (Brazilian Federation of Gynecology and Obstetrics Associations - Febrasgo), the Sociedade Brasileira de Medicina Fetal (Brazilian Society of Fetal Medicine - Sobramef) and the Sociedade Brasileira de Genética Clínica (Brazilian Society of Clinical Genetics - SBGC) were unanimous in stating that there are countless repercussions of an anomalous pregnancy to the life of the pregnant woman: increase in morbidity; elevation of the risks during pregnancy, due to the presence of polyhydramnios (excess in the amount of amniotic fluid); higher probability of hypertension, diabetes, placental abruption, blood transfusion and premature parturition; increase in the obstetric risks in parturition, with dystocia and severe psychological consequences (high rates of depression, anguish, suicidal thoughts, compromise of wedlock).

On April 11, 2012, the STF started judgment of the referred ADPF. In the plenary, the then attorney Luis Roberto Barroso supported the evolution of the rights of women in contemporaneous society, for the request. Barroso argued that the juridical possibility of licitly anticipating parturition of anencephalic fetuses does not consist in abortion and this has been the position of all democratic and develop countries in the world, and *growing criminalization is a symptom of underdevelopment* [5].

On this date, the Brazilian supreme court, in uttering a historical decision by majority (eight votes against two), settled that the therapeutic anticipation of parturition, when there is diagnosis of anencephaly, is atypical criminal fact and does not constitute abortion, since this criminal type assumes the potential for extra uterus life. *Anencephaly and life are antithetical term*, stated the rapporteur of the action, Minister Marco Aurélio Mello, in uttering his vote in the plenary, deciding for the merit of the request [5].

It was then decided that the articles of the criminal code which criminalize abortion must not be applied to these cases, since the term "abortion" assumes the possibility of extra-uterine life. The very term "abortion" would not be adequate in these situations, as they refer to a lifeless fetus, or, in modern medical language, a fetus with brain death. It would, in fact, be the therapeutic anticipation of parturition, to the extent that the anencephalic fetus, as the brain dead, does not present cortical activity. The phenomena of mental life, sensibility, mobility and the integration of all bodily functions which, in this case, are only rudimentary. It is, with no scientific doubt, a lethal congenital disease.

It was highlighted that the so-called law of organ transplants (Lei dos Transplantes de Órgãos [6]) authorizes the extraction of tissues and organs with basis on the diagnosis of brain death – considered as legal death –, reinforcing the recognition that life does not end only when "the heart stops beating". Thus, there being a definitive medical diagnosis stating the inviability of life after the normal gestational period, the anticipation induction of parturition does no constitute the crime of abortion, because the death of the fetus is unavoidable as a result of its very pathology.

It was also rightfully stated that it does not constitute eugenic abortion, to the extent that the ideological or political bias of the word "eugenics" are not present. Besides their mere descriptive purpose, words carry emotional meanings, which may cause emotional reactions in those who hear them. "Eugenics" is one of these words whose meaning carry bear a high degree of emotional rejection, linked to the use made of it in Nazi Germany, turning it into a "taboo term". This is not about eugenic abortion, whose practice has the purpose of obtaining a superior, pure race. It is not about this.

Nelson Hungria, quoted in the plenary by the rapporteur, Minister Marco Aurélio Mello during the judgment of the ADPF 54, specified, in the 1950s, situation in which the term "abortion" should not be employed. His words are elucidative:

In the case of extra-uterus pregnancy, which represents a pathological state, its interruption cannot constitute the crime of abortion. The life of another being is not at risk, if the the product of conception cannot reach its own life, so that the consequences of actions performed are resolved only against the woman. The expelled fetus (for abortion to be characterized) must be a physiological product, not a pathological one. If the pregnancy presents itself as a truly morbid process, in such a way as to not allow even a surgical intervention that could save the life of the fetus, there's no speaking of abortion, for which the possibility of continuation of the life of the fetus is presumed [7].

There is no doubt, then, that the therapeutic anticipation of the parturition cannot be mistaken with abortion. The STF, thus, has not examined the decriminalization of abortion, but the interruption of the pregnancy in the cases of anencephaly, a situation that anticipates the moment of parturition, that is, the natural end of the pregnancy. It was added, also, that the this was one of the most important themes assessed by the STF, for it involves human dignity, liberty, self-determination, health, and the recognition of full individual rights. It' is not a duty of the pregnant woman to interrupt the pregnancy; the STF only authorizes the cessation of the pregnancy for the dignity of the woman and with the objective to minimize her probable suffering, in case that is her wish. The autonomy of the patient and the respect to the human person were some of the most relevant and most discussed issues during the trial.

Lastly it was reinforced that the Federative Republic of Brazil is a secular state and that, the Constitution, in consecrating such secularity, keeps the state entity from intervening in religious issues, it also means that faith dogmas cannot determine the contents of the acts of the State. Thus, moral or religious conceptions, be them unanimous or majority, cannot guide state decisions, being circumscribed to the private sphere. Thus, the authorities with the duty to apply the law must also devoid themselves of their religious convictions.

Strictly for the record within the scope of the present study, there were two diverging votes in the plenary, uttered by Ministers Ricardo Lewandowski and Cezar Peluso, who based their votes mainly on the argument of the impossibility of the judiciary to usurp the sole competence of the National Congress to create a cause of exclusion of illicitness, not being the duty of the court to act as positive legislator, as well as on the existence of life in the anencephalic fetus. In summary, the STF, by majority, upheld the ADPF 54 and declared the constitutionality of the therapeutic anticipation of parturition of the anencephalic fetus, which does not characterize abortion in the articles 124, 126 and 128 (items I and II) of the Criminal Code, and it cannot be mistaken by it.

From this decision, thus, it is up to the physicians to perform the diagnosis of certainty of anencephaly, as well as the Unified Health System to promote the adequate public health policy to the support and treatment of the pregnant woman trough guidance and psychological and obstetric support, for her to have the liberty to adopt the resolution that best suits her particular conviction.

Today, interruption of the pregnancy of an anencephalic fetus is no longer a strictly judicial decision – as occurred in the country over 20 years ago, in which these requests depended on the appreciation of the Judiciary – but part of the protocol of public health programs, which requires the definition of diagnostic criteria by the competent organ for regulation of professional practice.

Guidelines of the CFM for the diagnosis of anencephaly

During the plenary debates in the Supreme Court, Ministers Gilmar Mendes and Celso de Mello highlighted the need for diagnostic criteria for the woman pregnant of an anencephalic fetus to have the right to interrupt pregnancy. In the judgment, it was stated that the fetal malformation must be diagnosed and identified with proof by a legally certified professional physician. After the STF decision mentioned above and facing the need to guarantee safety to the diagnostic criteria of anencephaly, in such a way as to permit the interruption of the pregnancy by the request of the pregnant woman without the need of authorization by the State, the CFM approved – unanimously – Resolution CFM 1,989/2012, fulfilling this important juridic and social demand [8].

This norm defined guidelines for the diagnosis of fetal malformation, highlighting that this must be performed by means of ultrasonography, from the 12th week of pregnancy. This exam must contain two pictures of the fetus, dated and identified: one must show the face of the fetus in sagittal position and the other showing the cephalic segment (head) in crosscut, to demonstrate the absence of the skullcap and identifiable brain parenchyma (tissue). The report must, also, be signed by two physicians qualified for such a diagnosis, in order to assure the right to a second opinion and not to withdraw the sufficiency of the diagnosis made by only one physician.

In the face of this image diagnostics, the pregnant woman shall have the right to search for another opinion or plead a medical panel, so that all due clarifications are supplied to her, as well as those she may request. This way, the CFM highlights the importance of supplying ample knowledge to the pregnant woman, in order to assure her right to freely decide on the conduct to be followed. In the case she chooses to maintain her pregnancy to its term, she must have assured prenatal medical medical assistance compatible with the diagnosis, as this pregnancy is considered high risk.

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In the normative text, the CFM highlighted that the pregnant woman, once informed of the diagnosis, has the right to interrupt the pregnancy immediately, independent of the time of pregnancy, or may postpone the decision for a later time. In case she opts for the therapeutic interruption, a record of the procedure must be kept, with her written consent, which shall integrate the medical records, along with the report and the pictures of the image exam. Such conduct may only be performed in hospitals with proper structure for the management of occasional complications inherent of this medical act.

Lastly, the CFM alerts that patients pregnant of anencephalic fetuses must be informed of the risk of relapse of the malformation in future pregnancies, condition which, according to medical science and the statement in the "Exhibition of reasons" of the Resolution CFM 1,989/2012, has around fifty times higher chance of occurring. They may, also and if they wish so, be forwarded to units of family planning in which they will receive multidisciplinary support and assistance for contraception, if needed, and to conception, when freely wished (as the daily use of folic acid, which may reduce the risk of anencephaly by half).

Perinatal necropsy, diagnosis of anencephaly and other congenital brain anomalies

Necropsy, or autopsy is the systematic *post mortem* exam of the organs or part of them in order to determine the cause of death or to know the lesions and diseases present in the individual.

With the emergence of the diagnostic imaging techniques in the 1970s and their growing improvement in subsequent decades, a significant decline was observed in the interest for the performance of necropsies in several parts of the world, inclusive in Brazil. A proof of this is the great reduction in the number of necropsies performed in the large centers of medical teaching and research. However, despite the undeniable progresses reached with the application of the diagnostic resources on living patients, an expressive rate of discordance between clinical diagnoses and the necropsy are still observed, in a proportion ranging between 10% and 50%, reason why the necropsy still has great value for the systematic study of pathology and the improvement of medical practice [9].

In the realm of fetal and perinatal pathology, this importance is even more visible, because the necropsy is able to perform a detailed study of fetal malformation syndromes, supplying detailed analysis of the syndromic alterations and favoring genetic counseling to patients. Even if there is precise diagnosis in the prenatal period, through imaging exams, after the interruption of the pregnancy (spontaneous or not), the parents wish to know if such diagnosis is correct and what the implications are for future pregnancies. This is particularly observed when the prenatal diagnosis was performed only through imaging exams, without the aid of genetic studies and the information of these exams may be obtained through the necropsy.

This way, perinatal necropsy remains as "golden standard" for the diagnostic of congenital anomalies and has vital importance for the confirmation of prenatal diagnosis, the recognition of additional internal anomalies, favoring associations with genetic and chromosomal syndromes, as well as in genetic counseling for future pregnancies [10]. Genetic counseling is a non-directive and non-coercive process of communication, dealing with problems associated to the occurrence or the possibility of occurrence of genetic disorder in a family.

It is worth highlighting, within the realm of diagnosis of congenital anomalies, the action of the Serviço de Patologia do Hospital das Clínicas da Universidade Federal de Minas Gerais (Pathology Service of the Clinical Hospital of the Federal University of Minas Gerais -HC-UFMG), which has a specialized laboratory for fetal and perinatal pathology, whose team works in close collaboration with the Serviço de Obstetrícia e Medicina Fetal (Obstetrics and Fetal Medicine Service) of the same hospital, regional reference as to the study of fetal malformations. The case series of this service is solid and broad, composed of representative cases of the more diverse congenital fetal syndromes.

It is not the purpose of the present study to perform statistical analysis of the frequency of such syndromes in our midst, but only to supply a punctual report that may interest the medical and juridical community on the subject. Next, some situations will be focused in which the medical and social unfolds resulting to the fetus and to the pregnant woman may be identical to those described for anencephaly.

Being responsible for high prenatal and postnatal death rates, congenital anomalies of the central nervous system are spectral diseases, with a broad range of known morbid conditions with significant frequency. The so-called "dysraphism", in which theres is a defect in the closing of the neural tube, may range from lethal anomalies to asymptomatic

anomalies fully compatible with extra-uterine life, such as "Spina bifida occulta". The inability to close part of the neural tube or its reopening after being successfully closed, may generate one out of many malformations. All of them present anomalies of the neural tissue and the bone or overlying soft tissues and, as a whole, constitute the most frequent anomalies of the central nervous system [11].

Anencephaly is a dysraphism that is incompatible with life, characterized by the absence of most cephalic structures (cerebral hemispheres, cerebellum and only rudimentary brain stem) and the bones of the cranial vault, which remains open and devoid of skin in its upper portion. There is an irregular mass of residual nervous tissue and rudimentary blood vessels adhered to the base of the cranium. The eyes are apart and protruding, and the eyeballs elongate directly to the base of the skull, giving the face an appearance commonly called "batrachian aspect".

Anencephaly is a lethal disease that occurs in 1 to 5 out of 1,000 born alive, more frequently in girls. It is believed to arise around the 28th day of pregnancy. According to Cotran, Kumar and Collins [11], its global rate of recurrence in subsequent pregnancies was estimated in 4% to 5%. Folic acid deficiency during the first weeks of pregnancy is a risk factor. It is a defect of the closing of the anterior portion of the neural tube, with diverse secondary alterations, such as incomplete development of the calvaria, cleft palate and frequent abnormalities of the cervical vertebrae [12].

Anencephaly is frequently associated with other congenital anomalies in distinct organs, such as the osteoarticular, renal and cardiovascular systems. This is one of the reasons why transplants using organs of anencephalic fetuses are not possible. Another reason is that these organs are usually smaller than normal, affected by hypoxia (low oxygenation), besides the fact that transplants in newborns are not performed before the seven days of extra-uterine life, which, in itself, makes transplant of organs of anencephalic fetuses inviable.

Other lethal anomalies of the fetus: the need for isonomic judicial treatment

The Judiciary has been facing some cases in which other diagnoses of fetal anomalies incompatible with life (besides anencephaly) subsidize requests of therapeutic anticipation of parturition. This way, it is important to inform jurists of the existence of such syndromes to, after this, discuss some cases capable of generating jurisprudence in this area.

Congenital anomalies incompatible with extra-uterine life

A congenital anomaly constitutes a structural defect present at birth. It may be isolated or multiple, of higher or lower clinical importance. A study performed by researchers form Pernambuco demonstrated that over 20% of the pregnancies of fetuses with congenital anomalies end in spontaneous abortions (miscarriages), and that the remaining 80% will be born alive or dead, resulting in a 3% to 5% proportion of newborns with these anomalies that remain alive after birth [13].

The brain is frequently affected during the intra-uterine life due to its formation, which, besides being complex, extends over a long period, making it susceptible to developmental abnormalities from the 3rd to the 16th week of pregnancy. Several congenital malformations of the central nervous system may result in extreme forms, incompatible with full extra-uterine life. Among them, them least rare are holoprosencephaly and the forms of craniorrhachischisis, rachischisis and total meningoencephalocele. Such defects in the closing of the neural tube are spectral anomalies which can be present isolated or associated wit other alterations in different organs, originating multi-system malformation syndromes of various etiologies.

Note that anencephaly itself may be associated to chromosomal problems such as trisomies of chromosomes 18 and 13, triploidies and structural changes, as well as several other congenital anomalies, with bone defects, cardiac, renal and abdominal wall malformations.

Holoprosencephaly is a spectral disease with several extensions of the defect in the closing of the neural tube, characterized by an incomplete separation of the brain hemispheres in the medium line. The extreme and lethal case called "sequence of holoprosencephaly" is cyclopia, malformation that presents a serious defect in the early development of the face, with fusion of the eyeballs and a single eye, or two partially fused eyeballs, over which projects a small protuberance (rudimentary proboscis). Such anomaly is frequently associated with trisomies of chromosomes 13 and 18, besides other genetic alterations (like deletion of genes), and its higher incidence is observed in fetuses of diabetic mothers.

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It is also important to highlight the existence of multi-systemic malformation syndromes which can also result in serious and extreme forms, as observed of skeletal dysplasia with lethal forms, which include thanatophoric dysplasia and lethal osteogenesis imperfecta.

Thanatophoric dysplasia consists in a lethal congenital disease related to genetic mutations with bone and neural repercussions and it is characterized by bone dysplasia with shortening of the limbs, hypo-plastic ribcage and macrocephaly. Its approximate incidence in the population is of 1 to 35,000-50,000 births, being a disease with low rate of recurrence in following pregnancies [14]. Most cases are stillborn and those who are born alive die shortly after birth.

Osteogenesis imperfecta is a spectral disease, with nine types of malformations (types I to IX). The lethal osteogenesis imperfecta syndrome, or type II, is characterized by shortening of the limbs, serious bone fragility with multiple fractures, inguinal hernia, hydrocephalus and other bone abnormalities. Most cases result form sporadic genetic mutations, with a relatively high recurrence rate in the next pregnancies, of 6%, reason for which, in cases like this, genetic counseling and monitoring of the family are fundamental [15].

It must also be highlighted the existence of several chromosomal multi-system malformation syndromes, which may result in lethal forms, of which the trisomies stand out. Trisomies consist in the presence of three chromosomes of a specific type (and not two as would be normal), resulting in several types of congenital anomalies. The most common anomalies are the ones of chromosome 21 (Down's syndrome), chromosome 18 (Edwards syndrome) and chromosome 13 (Patau syndrome) [16]. Edwards syndrome, for example, has an incidence of 0.3 in each born alive. Over 130 types of abnormality are described in bearers of this syndrome, whose survival ability is very limited [12].

Requests for isonomic juridical treatment

In a jurisprudential search for the terms "abortion"and "anomaly" in the public websites of of several courthouses across the country, the main decisions reveal requests for therapeutic anticipation of parturition due to the diagnosis of anencephaly; however, there are decisions – the examples follow – that focus on diverse malformation syndromes. Despite the fact that, according to what was previously exposed, the term "abortion" is inadequate to such issues, as it is not properly a fetus with possibility of full extra-uterine life, it was used in the jurisprudential survey because it is frequently cited in these cases.

The Minas Gerais Justice Court judged a case in which the diagnosis was of thanatophoric dysplasia, having the therapeutic anticipation been authorized, is a decision of which the minutes are as follows:

Judge award - therapeutic anticipation of parturition - fetus with congenital anomalies incompatible with life - Thanatophoric dysplasia - supporting medical examinations - Balancing of values - Concession – Partially losing vote. The secure finding of the development of pregnancy of fetus with congenital anomaly incompatible with life puts in confrontation many values consecrated by our Federal Constitution, life being the most precious one, followed by liberty, autonomy of will, and human dignity. There being little probability of survival at birth, certified by the physician who assists the applicant, corroborated with the report of the medical judicial expert, the applicant has the right to exert her liberty and autonomy of will, performing the abortion and abbreviating the serious clinical and emotional problems that affect her, the father and all family members. Facing the medical certainty that the fetus will be stillborn, protecting the the liberty, the autonomy of will and the dignity of the pregnant woman, she must be permitted tom interrupt the pregnancy [17].

The diagnosis of Edwards syndrome (trisomy of chromosome 18) also subsidized the request of therapeutic anticipation of parturition evaluated by the São Paulo Justice Court, as is understood of the minutes that follow: *Habeas Corpus – Request by pregnant woman to interrupt pregnancy due to the fetus bearing Edwards syndrome – Injunction granted – Inviability of fetus survival – Risks to the health and possible psychological damage to the pregnant woman – Therapeutic abortion – Maintenance of the definitive concession – Necessity– Impossibility of the Judiciary to make moral judgment, being limited to the legality or not of the conduct – Definitive order granted* [18].

However, there are decisions in the opposite direction, based on the possibility of extra-uterine life, even if for a short time, in cases of malformation syndromes that can also result in lethal forms. An example of this is the Patau syndrome (trisomy of chromosome 13), also a spectral disease, for which the specialized medical literature reports and average of seven days of survival to patients [12].

The Minas Gerais Court of Justice evaluated a case with the same diagnosis, deciding for the impossibility of therapeutic anticipation of the parturition in the following terms:

Authorization to perform abortion – Fetus malformation – Absence of proven risk of death to the mother – No place– Article 128, I, of the Criminal Code – Eugenic Abortion – Absence of legal provision – Preservation of the right to life guaranteed by the Constitution – Denial of appeal. Although not controversial, according to the medical reports annexed to the process, the nonexistence of post-parturition life of the fetus, which has "serious morphological alterations with characteristics of Patau Syndrome (Trisomy of 13)" (p. 22), the fact is that this does not imply imminent danger to the life of the mother, i.e. that the abortion is the only means to save her life, as provided by article 128, I, of the Criminal Code. In this case, by legal impediment, there is no place for the judicial authorization for the interruption of the pregnancy. Once the hypothesis of necessary abortion is dismissed, its consent would be illegitimate with base on the thesis of eugenic abortion, as the right to life in assured by the constitution, there not being legal permission for the interruption of pregnancy in the case o malformation of the fetus [19].

The existence of several other fetal anomalies besides anencephaly which can result in lethal forms and the need of their knowledge and isonomic treatment by the Judiciary were also issues approached at the time of judgment of the ADPF 54 by the STF. Minister Ricardo Lewandowski, who uttered a diverging vote, in which he was followed by Minister Cezar Peluso, then president of the Supreme Court, mentioned the issue in his vote, saying that the decision favorable to the abortion of anencephalic fetuses would, in theory, have the power make licit the interruption of pregnancy of any embryo with little or no expectation of extra-uterine life.

Therefore, what is defended here is the importance of increasing the debate of this issue in the sphere of the civil society and its legitimate instances of representation, given that, in the face of the decision object of the present study, it is necessary to provide isonomic treatment for situations in which the chances of survival of fetuses are null or negligible. For its relevance, the matter deserves careful and prompt regulation in the Legislative sphere, in order to confer the legitimacy, the certainty and the juridic safety necessary to the matter and not to legitimate occasional irresponsible abortion practices.

Final Considerations

At the time of the judgment of the ADPF 54, based on the incompatibility of anencephaly with full extra-uterine life, the Supremo Tribunal Federal decided that the therapeutic anticipation of parturition, when there is the diagnosis of this anomaly, is a criminally atypical fact and does not constitute abortion, since this type of crime assumes the potential for extra-uterine life.

The decision for the possibility of the therapeutic anticipation of parturition in cases of pregnancy of anencephalic fetuses does not constitute obligation to the pregnant woman, but makes it facultative, based on the juridical ordainment, preventing social disapproval or reprehensibility of the conduct of those who interrupt the pregnancy of an inviable fetus. As stated by Cezar Roberto Bitencourt, *the pregnant woman will only use this faculty if she so wishes, which is very different form its prohibition, imposed by cogent legal norm, increased by deprivation of freedom criminal sanction* [20].

This way, the recognition that, in Brazil, the voluntary expelling of the anencephalic fetus does not constitute abortion (criminal or not), but atypical behavior in the absence of elementary circumstances of the crime of abortion, since the so called "legal death" is equivalent to brain death, implies the knowledge of other clinical syndromes in which fetal inviability, as well as brain death, are also present.

The Judiciary has been facing the knowledge of this matter in some decisions that involve malformation syndromes other than anencephaly. Such decisions are almost always permeated by uncertainty and lack of specific knowledge on the issue to the extent that, oftentimes, full knowledge of the matter as well as is broad process instruction are not possible, since the time for the proceedings is absolutely incompatible with the necessary promptitude of analysis of the theme in concrete cases. It is very probable that the decision uttered within the ADPF 54 will subsidize a growing number of requests to the Judiciary for isonomic treatment in case of identical or very similar medical and social repercussions to those caused by anencephaly. For this reasons the juridical community must be familiarized with this still polemic question.

Thus, in order to prioritize juridical safety and legitimacy of the treatment of an issue that is still delicate and stormy, the theme claims isonomic

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juridical treatment and detailed legislative regulation, so that the same rights be granted to pregnant women bearing anencephalic fetuses and those carrying in their wombs fetuses with other congenital anomalies that result in the same medical psychological results now agreed upon.

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Participation of the authors

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Transhumanism, neuroethics and human person

Jorge Walker Vásquez Del Aguila [1], *Elena Postigo Solana* [2]

Abstract

Attempting to create new people, Transhumanism advocates deep structural changes in our concept of "human". Some of the most significant changes are related to the central nervous system and would be achieved through different technologies. In this paper, we present an overview of this philosophical tendency and the concept of Neuroethics, thereby presenting the practical problems of those presumed neurological enhancements and analysing the ethical issues arising from these practices. Finally, we discuss what we believe to be the fundamental cause of the problem: a misconception of Person.

Keywords: Ethics, clinical. Personality. Humanism.

Resumen

Transhumanismo, neuroética y persona humana

En el intento de crear nuevos individuos, el transhumanismo propone profundos cambios estructurales en nuestro concepto de "lo humano". Entre los cambios de mayor relevancia se encuentran los relacionados al sistema nervioso central, que serían implementados a través de diversas tecnologías. En el presente artículo, presentaremos una descripción general de dicha corriente filosófica y del concepto de Neuroética, para con ello abordar los problemas prácticos de las supuestas mejoras *o enhancements* neurológicos y analizar los problemas éticos derivados de dichas prácticas. Por último, estudiaremos aquello que consideramos la causa fundamental del problema: un concepto errado de Persona.

Palabras-clave: Ética clínica. Personalidad. Humanismo.

Resumo

Transhumanismo, neuroética e pessoa humana

Na tentativa de criar novos indivíduos, o transhumanismo propõe profundas mudanças estruturais em nosso conceito de humanismo. Entre as mudanças de maior relevância estão aquelas relacionadas ao sistema nervoso central e que seriam implementadas por meio de diferentes tecnologias. Neste artigo, apresentaremos uma descrição geral dessa corrente filosófica e do conceito de Neuroética, abordaremos as questões associadas ao suposto aprimoramento ou *enhancement* neurológico e analisaremos os problemas éticos decorrentes de tais práticas. Finalmente, discutiremos aquilo que consideramos a causa fundamental do problema: o conceito errado de Pessoa.

Palavras-chave: Ética clínica. Personalidade. Humanismo.

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Declaram não haver conflito de interesse.

Transhumanism is defined according to its supporters as *the intellectual and cultural movement that affirms the possibility and desirability of fundamentally improving the human condition through applied reason, especially through the development and implementation of technologies available to eliminate aging and greatly improve intellectual, physical capabilities and psychobiological aspects of the human being* [1]. Also, *as the study of the ramifications, promises and potential dangers of technologies that will allow us to overcome fundamental human limitations, and the related study of the ethical aspects involved in developing and using such technologies* [1].

In 1998 the World Transhumanist Association (WTA) was established. This international organ began an extensive project entitled "Transhumanism: Frequently Asked Questions" [1] and published a statement [2]. In 2008, the WTA was renamed Humanity (+). Its greatest exponent is the Swedish philosopher Nick Bostrom, who in his article entitled "A History of Transhumanist Thought" [3], explores the origins of the ideology, going as far back as the epic of Gilgamesh and other searches for immortality, including that for the philosopher's stone.

The concept of "Transhumanize" was used for the first time by Dante Alighieri in his work, "La divina commedia", who believed it to be the experience elevated by grace, beyond humanity, towards the total and transcendent realization in God [4]. However, the concept of the word transhumanist given by biologist Julian Huxley in 1927 adds a new perception of the word: …*man remaining man, but transcending himself, by realizing new possibilities of and for his human nature* [5]. To put it another way, Huxley spoke of the superseding of humanity by virtue of technology as a purely human work, moving away from religion.

According to Bostrom, the ideological underpinnings of transhumanism are based on the empiricism of Hume, the materialism of La Mettrie (the "man-machine") and the evolutionism of Charles Darwin (humanity not as an end point of evolution, but as an early stage) [3]. In addition, it was influenced by Nietzsche's doctrine of the superman (…) *man is something that shall be overcome* (…), giving a particular, technological and biological interpretation to that originally proposed, which was, in terms of personal growth and cultural refinement, closer to the thoughts of John Stuart Mill than those of the author himself.

Transhumanism *seeks to improve human nature, overcoming its limitations and prolonging its existence through reason, science and technology*. In this path towards the future there needs to be an intermediate stage (transhuman or human+) to reach the posthuman (human++) [6]. To achieve this, he promotes three suggestions: (1) that the technologies for "improving" or the enhancement of humans must be widely available; 2) that individuals should have the right to transform their own bodies as they wish; and 3) that parents should have the right to choose what technologies to use when deciding to have children [7]. The transhumanists advocate the redesigning of the human condition, including parameters such as aging, intellectual limitation, undesirable psychology, suffering, and confinement to Planet Earth [2].

Since its creation, transhumanism has received many criticisms. The philosopher and political scientist Francis Fukuyama [8] called transhumanism *the most dangerous idea for democratic systems* and describes it as a threat to human essence that contravenes the principle of equality of all men. Also, Habermas criticizes it for leaving the moral autonomy of the individual subjected to social, political and economical interests [9]. Others argue that the eventual bifurcation of humans into posthumans would lead to slavery and genocide between both groups [10] or even that its ideas could lead to the extinction of Man [11].

For all practical purposes, the implementation of transhumanism would be based on four convergent areas: nanotechnology, biotechnology, information technology and cognitive science. From the neurobiological point of view, transhumanism seeks to improve sensory capabilities, increasing memory, accelerating reasoning processes and reducing the number of hours of sleep. For this, transhumanism seeks technological mechanisms, either pharmacological or from the field of engineering, ultimately seeking the development of artificial brains with the capacity for natural intelligence. It is precisely these "improvements", their dangers and their neuroethical implications, which we will be discussing in the present work.

General concepts of Neuroethics

The term "Neuroethics" was coined in 1973 by Dr. A. Pontius of Harvard University in the article entitled "*Neuro-Ethics of Walking in the Newborn*" [12]. However, its actual meaning is credited to writer William Safire, who defined it as *the examination of what is right and wrong, good and bad about the treatment*

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of, perfection of, or unwelcome invasion of and worrisome manipulation of the human brain [13].

In other words, Neuroethics could be defined as the study of ethical, legal, and social aspects that arise when scientific discoveries about the brain are brought forward in medical practice, legal interpretations and health and social policy [14]. A broader definition is given by Häyry: *Neuroethics is a field where the strict interpretations of the science that is being studied may conflict with the alleged metaphysics of the methods by which the supposition wasmade* [15].

In a simpler way, one could say that Neuroethics was established in order to cope with the rapid development within cognitive neuroscience and neuropsychiatry and findings specifically related to the sciences of the mind, including the central nervous system and the brain mechanisms underlying human behavior [14].

As indicated by the philosopher Adina Roskies, it is possible to speak of two divisions in Neuroethics: 1) the ethics of neuroscience or the ethics of its practice, which involves the ethical issues and considerations that must be evaluated in the course of design of neuroscientific studies and which include optimal design, guidelines for investigative practice, privacy, informed consent, etc.; and 2) the ethical implications of neuroscience, which involves evaluation of the social and ethical impacts that the results of these studies may entail [16].

Martha Farah [17], for his part, believes that Neuroethics, when covering the multiple ways in which developments in clinical and basic neuroscience intersect with ethical and social issues, could also be divided into two categories: "what we know" and "what we can do". In the first category would be the ethical problems generated from growing knowledge of the basis of behavior, personality, and consciousness, among others. In the second would be those issues related to advances in functional neuroimaging, brain implants, man-machine interfaces and psychopharmacology. These last three items, to be advocated through transhumanistic ideas, are the ones we will be discussing.

Neurobiological Transhumanistic "Improvements"

Among the improvements or enhancements suggested by transhumanism, cognitive improvement [18] can be included. This can be defined as the amplification or extension of the mind's basic capabilities through the improvement or expansion of internal and external information processing systems [19].

Its final objective would be the pursuit of superintelligence or ultraintelligence understood as the radical capacity to overcome the best human brains in virtually every field, including scientific creativity, wisdom in general, and social skills. Transhumanistic vision is so optimistic of this that it relates: *Creating superintelligence may be the last invention that humans will ever need to make, since superintelligences could themselves take care of further scientific and technological development t* [20].

Although they accept that it is an uncertain and long-term objective, they say that it could be accomplished through subsequent improvements or increments such as: drugs for cognitive improvement or "*nootropics*", cognitive techniques, instrumental tools as implantable computers, information filtering systems, etc.; brain-computer interfaces, implants, etc. In our view, these lines could be grouped in the following way: electronic brain improvement and pharmacological brain improvement.

Electronic Brain Improvement

This type of improvement includes, among others, cerebral neurostimulation. It is currently at different degrees of clinical acceptability in the treatment of diseases such as Parkinson's disease, epilepsy, refractory depression, etc.; from where its use would be extrapolated for cerebral improvement. It consists in the use of invasive and non-invasive methods that through the application of electrical or magnetic currents, seeks to alter spontaneous neural activity.

Anodal stimulation brings the action potential of the neuronal membrane toward its trigger point, increasing its excitability. Cathodal stimulation, on the other hand, inhibits it, reducing neuronal excitability. Its long-term effects would be based on protein synthesis accompanied by modifications to the AMPc and intracellular calcium levels; in addition, promoting changes in local concentrations of the neurotransmitters GABA and glutamate which are important in the synaptic mechanisms for implementing, for example, learning and memory [21].

Also included in this classification are the man-machine interfaces which would seek for information from the outside world able to be translated into neuronal activity and of which neuronal activity can be transmitted as external information for communication or for robotic control.

Even the brains of "cyborgs" (cybernetic organisms) can be cited, and postbiological existence in computers. A cyborg would be a superintelligent being resulting from the combination of organic and cybernetic elements. In addition, some authors suggest the possibility of a postbiological existence through scanners that allow all the synaptic matrix to be obtained from the brain of an individual and which can be reproduced on a computer. This process is called uploading.

Pharmacological brain improvement [22]

In the late 1990s, the growing use of Prozac (fluoxetine) triggered a debate on the possibility of feeling "better than well" [23]. Today, these possibilities for pharmacological improvement have multiplied, often driven by clinical studies, and marketing campaigns sponsored by the pharmaceutical industry [24].

The use of psychotropic drugs for brain improvement is based on the discoveries made as a result of preclinical and clinical studies for the treatment of neuropsychiatric pathologies. The question is raised: "*If X treatment can relieve a significant deficit in psychological function Y, what can it do for healthy people?*"

From these studies some theoretical and practical benefits could be deduced. For example, serotonin reuptake inhibitors (SIRS) promote affiliative behavior in healthy situations; dopamine agonists can improve the acquisition of motor skills and are associated with an increased neural plasticity; cholinesterase inhibitors can improve normal performance under certain circumstances. New non-addictive stimulants, such as Atomoxetine, seem to improve levels of excitation in normal subjects [25].

The development of new classes of drugs that do not seek to improve a disease, but are targeted directly to the healthy subject such as the AMPAkines and modulators of protein binding to the response element of CAMP (CREB) [25],is particularly intriguing. These drugs promote a cascade of intracellular events that lead to neuronal structural changes related to the acquisition of long-term memories.

Neuroethical Problems Derived From These Practices

Chatterjee, pursuing the problem of cosmetic neurology and which in my opinion can be extrapolated to the subject in question, finds that there are four reasons that would halt its practice[25]: 1) problems of security; (2) problems of justice; 3) issues of autonomy and; 4) problems of character.

Problems of Security

These include unwanted adverse effects in the short and long term; and problems of physiological and psychological addiction [26]. The aura of high technology by which such "improvements" would be developed could lead many people to accept them without any criticism [19]; it must, however, be taken into account that involved systems are far more complex than the simple synaptic interaction of neurotransmitters, which would put the subject at risk of unanticipated problems, so its real impact could be very unpredictable and involve unwanted cognitive and personality changes [17]. For example, in Transcranial Neurostimulation, when power is applied to any part of the cerebral cortex, other areas causing adverse effects in the long term could be included.

Another problem would be of aggravating previously undiagnosed Comorbidities. Some studies have reported worsening of depression by up to 18% in patients who underwent deep brain stimulation, particularly in patients with depressive episodes before the procedure [27]. Other studies have shown that SIRS may trigger bipolar disorders in susceptible patients.

In a study published in the journal World Neurosurgery, in which an interview was carried out with professionals from five hospitals in Canada, where deep brain stimulation was performed for the treatment of refractory medical pathologies, revealed that the majority of specialists saw the use of nerve stimulation for brain improvement as a definitive risk.

To this we can add the important statement of Echarte: *If the nature and probability of adverse neurological effects occurring is a matter difficult to evaluate, much more difficult to identify and assess are its effects on the maelstrom of the human psyche* [28].

Problems of Justice

The use of these procedures and drugs would require equity in the distribution of resources. An inadequate distribution could increase disparities at the extremes of the economic spectrum, above all in the field of education and employment [17]. In view of this, however, Bostrom raises an extremely optimistic time-dependent solution: the typical pattern

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with new technologies is that over time they become cheaper [29]. In addition, he presents a number of solutions dependent on public policies, as well as technical, social and economical aspects that Governments should observe to avoid inequity [18].

Problems of autonomy

Caplan refers to this as the individual right to determine whether or not drug for cosmetic purposes [30]. However, what starts as a matter of choice can lead to coercive force, especially in some social sectors. How will life be for those who choose to not "improve" in a society full of "improved" people?

Transhumanism justifies its "improvements" on the basis of a frank imperialism of autonomy [31], understood in this context as free will [32]. In this regard, we could propose some practical questions. For example, if these procedures affect the way people think and feel, would this not go against their cognitive liberty? If the answer were negative, then when and how would the privacy of the individual's mind be ensured? And if this were not done, would it not in itself affect their autonomy? This is to say: without privacy would their autonomy not be the victim of coercion? Going beyond this: in the creation of a different human being (posthuman) to which consent was given, is the original authorization valid to continue experimenting on or "improving" this new being? How would they themselves find their autonomy to be affected? Or even worse: would they still have autonomy?

If we take autonomy as the principal moral priority, it is possible to go so far as to justify dangerous and futile practices like those presented. Also, this overvaluation of autonomy, does not do any more than transfer responsibility for the consequences to the individuals who granted their permission.

As a sample of their pragmatic, utilitarian, liberal and individualist morality, while speaking about autonomy, the transhumanist seems to think that another moral theory is not necessary. Problems can be resolved "case by case", by employing it as a sole criterion. This can give answers to relatively simple ethical questions. Nevertheless, its use will lead, earlier or later, to conflicts and ambiguities as described in this paragraph; conflicts that can only be clarified by understanding the existence of pre-existing moral doctrines.

Problems of character

These drugs may undermine the sense of "individual identity ". We will discuss this later. As can be deduced from the above, the use of systems for the "improvement" of brain functions is a highly controversial subject. Simply, if we start from the concept of improving, the following should be asked: "if healthy adults come in a wide spectrum of normality, what does improving mean?". The problem lies in the fact that transhumanistic ideas verge on the pathologization of normal brain capability, which entails the risk of stigma and discrimination.

There are people who see their personal qualities of being forgetful, serious, lively, etc. as part of their own identity. These people could be victims of coercion or discrimination by feeling forced to alter their personalities. People who reject cognitive improvement could be taken as guilty of going against the norms accepted by the community [15], with the ultimate risk of mitigating diversity within a population.

Procedures and drugs that erase unpleasant memories from the memory may prevent the formation of a strong and consistent personality. In addition, without being aware of what we live, do or suffer, there might not be a place for justice or even for forgiveness. All that caused suffering would simply be forgotten [5]. As Echarte formulated in what he called the *fallacy of normality*, *reality would not be as important to Man as the fictions in which he would wish to live* [33].

Attempting to suppress the emotions and memories that the transhumanist considers negative does nothing but represent the substitution of the natural way in which the human being relates to their environment for a sentimental way, assuming a radical shift towards non-human ways of manifesting Being [34]. Thus, in the case of drugs for one to become "happier or to not suffer", the main moral criterion, i.e., judgments about the good and bad of a thing, would depend only on the feelings that they evoke in the user [33]. If sadness is evoked it is bad, and if the opposite is evoked it is good.

In the case of drugs that increase concentration and decrease the need for sleep, this could lead to a partnership with overwork, 24 hours a day/7 days a week, where people might be exploited to their own detriment and to the well-being of their family [33]. In addition, persons could be victims of commercial exploitation by seeing themselves forced to buy them. Conversely, physicians could face increased pressures to prescribe these "improvements" to the population. Such pressure could be augmented by pharmaceutical companies, who would stand to benefit from the expansion of the

spectrum of use and recommendations of their already approved products [26].

Another aspect to consider is that cognitive "improvement" can be considered a "cheat", in reference to one having an unfair advantage over others, in particular in situations of competition or taking of tests (taking into account that transhumanism justifies, for example, doping in athletes); entailing that virtues like hard work and motivation will become outdated, as being due to irrational effort, through considering these values as ends in themselves and not as means to attain an end [17]. All this can undermine our ability to confront with responsibility and dignity the imperfections and limits of our lives and those of others [6].

Some problems of ethical and philosophical anthropology in the transhumanist theory

Aside from the medical, social and economic problems presented above, we believe that the core of the problem focuses on an inadequate vision of the concept of the human person. To put it another way, before any discussion on the ethical dimension of the "improvements", it should be asked whether manipulation of the person is ethical in itself.

The transhumanist conception shows a malleable view of personal identity, taking the human body and the human being as merely instrumental. They do not assume that human nature can direct itself to an end [35]. To the transhumanists, Man is in himself embodied technology [36], and as such, it makes no sense to assert that technological modification of his body negatively affects his identity.

From the above it follows that transhumanism uses a reductionist concept of human nature, where it is reduced to pure matter (materialistic) and the human being is limited to their neural connections (neurobiological reductionism) [35]. Man is something that can be perceived and molded, without intrinsic purpose and without the possibility of transcendence to the immaterial. This absence of intrinsic finality precludes, in its turn, an ethic where the human being is the ultimate end. On the contrary, for transhumanism the ultimate end is the simple volition of the subject.

While seeking to understand and control the operation of the brain, the transhumanists seek to control human beings. This is to say that by knowing how the brain works, it would be known how the whole man functions: "the man is his brain". This reductionism forgets, however, that the brain is infinitely more complex than simple neural connections since it has capacity for reasoning, logical and illogical, expected and unexpected, chaotic or ordered, creative or not.

The decisions that Man takes and runs are not only based in reason and objectivity, but in his personal reality, his context, his culture, and his idiosyncrasies. Everything that defines his personal identity and human nature. In other words, the attribution of mental phenomena is responsible for the individual's background of reasons, beliefs, and intentions. It is not possible to reduce a psychic description that arises and makes sense in the mental context to reductionist theories about neuronal interactions, or images in a scanner; it not being clear that mind and brain are the same [35].

Regarding the concept of the person, transhumanists believe such to be those beings who have the capacity to reason. This would justify, for example, the exclusion of this concept (and hence the possibility of manipulation) from beings incapable of doing so as they are embryos, fetuses, children, insane, etc. With this it may be appreciated that the transhumanist moral posture does not impose any limitation on action [31].

This concept of the person would moreover bestow personhood on advanced machines, extraterrestrials, or, as they have come to affirm, higher apes. This form of rationalistic reductionism (person = reason), forgets that the individual is not a person because their rational capacity occurs, but rather that this last is able to manifest itself because the individual is a person in themselves. As a result of this rationalistic concept of the person is derived a similar concept of dignity: *a quality, a kind of excellence admitting of degrees and applicable to entities both within and without the human realm* [37].

For Bostrom, for example, dignity would be a quality in human functioning like a virtue or an ideal which can be cultivated, encouraged, admired or promoted, without realizing that this reduces it to a mere quality control. But it is then worth questioning: who would then establish that parameter of quality? Or in other words, who will then establish the standards of quality that human life ought to have? If some few are elected for this task on the basis of liberal and utilitarian criteria, there is an inevitable fall into technocratic nepotism, eugenics, and social justice issues.

In addition, Bostrom makes statements that conflict with traditional moral values: Other enhancements might reduce our Dignity as a Quality.

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For instance, a greatly increased capacity for empathy and compassion might (given the state of this world) diminish our composure and our self-contained serenity, leading to a reduction of our Dignity as a Quality. In the face of the preceding it is fitting for us to ask: are we less worthy for having more compassion?

Bostrom responds by establishing that dignity is also a virtue, but it is not the only one. *Thus, some loss of Dignity as a Quality could be compensated for by a gain in other virtues* [38]. Insisting that dignity "in the modern sense" consists of what we are and what we have the potential to be, not in our pedigree or our causal origin [37].

This concept of dignity takes brings him to speak of lives more worthy and therefore more valuable than others: ... *Additionally, we may favor future people being posthuman rather than human, if the posthumans would lead lives more worthwhile than the alternative humans would* [39].

Contrary to what they advocate, we believe that the dignity of the person does not reside in a mere internal or external assessment. The dignity of the person is in fact a matter of innate dignity. It is a fundamental intuition, an intrinsic value, which transcends social and cultural barriers and is present throughout the peculiar ontological range of the human person [40], beyond any other personal reality or assessment (for example, reasoning or not).

While the transhumanists are clamoring for the defense of human rights [37], for practical purposes, we can see that the transhumanistic concept of dignity contradicts three fundamental principles of the *Universal Declaration of Human Rights* [41]: 1) human dignity is universal, something that all individuals possess only by the fact of being human; (2) human dignity is inherent in human nature and is not dependent on their achievements or their particular "excellencies"; and (3) human dignity applies equally to all persons, not allowing different degrees of it.

Again, if the idea of dignity is equated to that of autonomy or quality as defended by the transhumanists, they could justify any instrumental practice in humans. Transhumanism forgets, however, that the imperfection of the human being and his dissatisfaction with reality allows for having aspirations, for progress, for thinking, for winning or even for being wrong... but allows him, above all, to live and to transcend; in other words, to be human.

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Participation of the authors

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The right and duty of secrecy, as a patient protection

Maria Elisa Villas-Bôas

Abstract

The text reflects on the duty of professional secrecy about the information received from patients during medical assistance in order to respect the right and protection of the patient. In spite of being one of the most traditional moral concepts in health care, secrecy is still one of the less respected principles. This is particularly worrying considering our times of intense exposition of privacy. The guarantee of confidentiality, besides stimulating the link between patient and health professional, could favour the assent to a treatment and more independent decision making as the guarantee ensures the patient that aspects of his or her personal life that could cause judgement will not be exposed. The secrecy, in this context, works as a mechanism of protection for the patient in regard to the patient's values and personal experiences, supporting the necessary confidence in the doctor - patient relationship.

Keywords: Confidentiality. Privacy. Physician-patient relations.

Resumo

O direito-dever de sigilo na proteção ao paciente

O texto reflete sobre o dever de sigilo profissional em saúde quanto às informações recebidas do paciente durante a assistência médica como cumprimento de um direito desse paciente, bem como de sua proteção. Embora tido como um dos mais tradicionais preceitos morais da assistência em saúde, o sigilo ainda é um dos princípios menos respeitados, fato particularmente preocupante em épocas de intensa exposição da intimidade como os tempos atuais. De outro lado, a garantia da confidencialidade, além de estimular o vínculo profissional-paciente, pode favorecer a adesão ao tratamento e a tomada de decisões mais autônomas, ao assegurar ao paciente a não exposição de circunstâncias de sua vida pessoal que possam ensejar julgamentos que ele deseja evitar, mesmo aos entes mais próximos. O sigilo, nesse contexto, funciona como mecanismo de proteção ao paciente no tocante a seus valores e vivências pessoais, lastreando a necessária confiança na relação médico-paciente.

Palavras-chave: Confidencialidade. Privacidade. Relações médico-paciente.

Resumen

El derecho-deber de sigilo en la protección al paciente

El texto reflexiona acerca del deber de confidencialidad profesional en salud en relación a las informaciones recibidas de parte del paciente durante la asistencia médica, como cumplimiento de un derecho de este paciente, así como para su protección. Aunque se trate de uno de los más tradicionales preceptos morales de la asistencia en salud, la confidencialidad sigue siendo uno de los principios menos respetados, hecho particularmente preocupante en épocas de intensa exposición de la intimidad como lo son los tiempos actuales. Por otro lado, la garantía de la confidencialidad, además de estimular el vínculo profesional-paciente, puede favorecer la adhesión al tratamiento y la toma de decisiones más autónomas, al asegurar al paciente la no exposición de circunstancias de su vida personal que puedan dar lugar a juicios que él desea evitar, incluso con entes muy próximos. La confidencialidad, en este contexto, funciona como un mecanismo de protección al paciente en lo relacionado a sus valores y vivencias personales, posibilitando la confianza necesaria en la relación médico-paciente.

Palabras-clave: Confidencialidad. Privacidad. Relaciones médico-paciente.

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Declara não haver conflito de interesse.

Don't open yourself to your friend
because he has another friend
And the friend of your friend
has friends too ...
Mario Quintana [1]

Confidentiality and respect for privacy are traditional moral precepts of health professions and are indicative of the duty of secrecy of professionals, regarding data about a third party, obtained through the exercise of his or her work. The professional/patient relationship must be guided by the trust based on the duty of professional secrecy.

Some refer to secrecy as the duty to keep a secret, and the secret as the object of secrecy. There will be no such distinction here inasmuch as the distinction is irrelevant to this study. In any case, professional secrecy has been, nowadays, associated with the bioethical principle of autonomy considering that personal data belong to the patient, who is the only one who can decide, a priori, to whom he or she wants to give information. The doctor, nurse, psychologist, as recipients of those data, by virtue of their profession, should not disclose the information except by permission of the patient or in exceptional circumstances, outlined by the law and ethics, such as cases of compulsory notification provided by law and regulations, wherein the professional must breach the secrecy because of epidemiological criteria from the public health system.

However, even before the recognition of bioethical principles and fundamental human rights, the duty of professional confidentiality was already required from health professionals, particularly doctors. The Hippocratic Oath preached that "*Into whatever houses I enter… Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret. (Translation from Greek by Francis Adams – 1849)*" [2,3].

Regardless of being such an old precept in healthcare, the duty of secrecy is, still to this day, one of the ethical commitments most disrespected in the day-to-day of hospitals and health facilities. See, for example, how widespread are conversations in corridors and elevators about illnesses of patients or even how often medical records, with names of patients and their diagnostics, are placed in public areas. Even the physical disposition of stretchers and medical beds allow unnecessary exposure of patients. Somehow, the information technology has reduced this risk, but it is still difficult to determine who should have access to the data and how to protect them from external interferences.

Maintaining secrecy is a measure that allows individuals to protect their peculiarities, idiosyncrasies and the privacy of their way of life, allowing them to choose what to reveal to the judgment of the outside world or even the judgment of people who are close to them. It is reasonable to claim that the proper respect for secrecy in health care not only would avoid many controversies, but it would also ensure greater freedom to patients and to the decision making concerning health care, which would allow the effective exercise of those patients' individuality. That's because even privacy has concentric spheres, among which the privacy of medical records is one of the most inward and significant.

A brief comment is made in this paper about professional secrecy as a right of the patient, duty of the professional and protection mechanism for the patient, in his or her autonomy. We also indicate some of the main aspects in which professional secrecy should be observed in daily practice, as well as some of its ethical and legal implications.

Who owns the secret: respect for the modesty and privacy of the patient

As we've seen, the secrecy is simultaneously a right of the patient and a duty of the professional. For Diego Gracia [4], it is even more a duty than a right, as it is based on a commitment of protection that can outrank the applicant's request. Secrecy is expected from all those who have access to the patient's personal data because of their professional activity.

So doctors, nurses, technical assistants, psychologists, social workers - who received information directly from the patient - as well as other professionals such as such as archivists and auditors, who had access to the patient's medical records, are required to keep secret about all that they know because of their work [2,3,5-7].

In this area, it is necessary to recommend particular care with medical records, which should not be accessible to any person, and to refrain from indiscreet hallway conversations [8], even with professional colleagues, which would enable the identification of the patient, avoiding passing on information that only concerns the patient, in order to preserve his or her privacy. Indeed, even the discussion of cases among professionals, supported by similar duty of secrecy, or in teaching, must preserve as much as possible, the identity of the patient.

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It should be remembered that patients who expose their secrets and privacy to a professional don't do so by choice but, above all, by necessity. Having chosen or needing to resort to a professional in particular, patients, at that moment, intend to reveal their data to that professional alone.

Questioning on the other hand from whom one should keep secret, it is to be observed that secrecy is extensive to all those who do not have strict necessity to have access to the mentioned data, observing the specific benefit of the patient, who is responsible to authorise any other case. Even companions should be informed, as a rule, if and when the patient consents, except in cases of incapacitated patients, when the legal guardian will be responsible to authorise or not information to others.

This care does not exempt nor allow even other health professionals to receive information, if they do not act in the care of the patient and were not authorised by him or her. If health professionals act in the care of a patient, their level of information should also be limited - besides what they were told by the patient - to the elements which are essential to their adequate professional performance. In both situations and also if they happen to be aware of other data, the professional should maintain secrecy about the information.

On the other hand, the patient should not confuse the duty of secrecy with the right to the information necessary to his or her decision-making, whilst knowing that, being private, his or her data will only be exposed in exceptional cases. The full and adequate exercise of autonomy requires, as it is known, the effective clarification and the free consent about the procedures to which the patient will be submitted. In this context, what is possible is called the right of not to know, if this is the patient's desire - although, in most cases, what happens is in fact a desire not to be reminded of his or her disease... [9] What we want to emphasise is that the duty of secrecy exists in the face of others, and should not be held against the patient, to whom the personal data are related.

The object of the protection of the professional secrecy is associated with privacy in its more inward sphere. The right to privacy, according to Costa Junior [10], originated from the recognition of the Anglo-Saxon law in the 19th century to the right to be alone. This right consists of concentric spheres of protection, embracing more internally the protection of privacy and of the so-called circle of secrecy, to which only individuals selected by the interested person can have access. Secrecy serves, therefore, the protection of the privacy of the patient, his or her personal information, choices or life events, test results, modesty, physical and moral images.

Professional secrecy, research, teaching and right to non exposure of the image

Regarding the protection of the physical image, for example, a particular zeal is necessary in the clinical examination of the patient, even if a child. Although the conditions of care and examination, especially in emergency units and collective wards, are not always ideal, it is recommended to respect and as much as possible, to protect the natural modesty of the individual, sparing him or her from unnecessary exposure, which would consist of one more aggression towards someone who is already weakened. It is advisable, therefore, to use curtains of separation between beds during tests and procedures in order to avoid attracting the curiosity of other patients and companions.

The prior information and clarification about the procedure to be performed, besides being an important element in the establishment of the professional-patient relationship and in the obtainment of consent, is also an indicative of respect for the privacy of the patient - even in the case of children and incapable patients in general (according to the limits of their cognition) - helping to overcome natural modesty and to allow for a quieter examination or procedure.

The same is true regarding the use of the patient's image, even for teaching purposes. The use of images must be preceded by informed consent. This is valid for photographic images of external body parts, for example, or images originated from diagnostic methods which involve unidentifiable images, that is, internal organs, such as radiologic images. All those kinds of images refer to body parts of an individual who, therefore, is responsible for allowing or not their divulgation.

Indeed, secrecy should be observed in teaching activities, so that usual visits of students to the bedside should be preceded by information to the patient and his or her consent. Moreover, we must be careful to avoid comments on diagnosis, prognosis or other personal data in front of other patients or companions.

Students should be taught from the beginning that patients are not mere "interesting cases", but human beings deserving of respect, especially con-

sidering their particular vulnerability . One should treat others as one would like to be treated, without forgetting that this does not make the professional a judge of what should or should not be secret, because even information that to others may appear personally banal and for whom its disclosure would be irrelevant, could be considered extremely sensitive to the patient, given her or his scale of values. Therefore, the rule has to be to maintain secrecy about all data relating to the patient, prohibiting unnecessary comments. The secret belongs to the patient and only the patient decides what can be revealed and to whom, the professional being simply a faithful custodian.

Also the researcher and collaborators, when they access data from medical records or patient information, should commit themselves to secrecy about what was found due to the survey, as required by the regulation on the matter present in theResolution 466/2012 of the Conselho Nacional de Saude (Health National Council) [11].

Still with regard to research, even because of regulatory requirement, it is always important to make clear, in the presentation of the project, the researcher's confidentiality commitment to the obtained data. This requirement extends to studies conducted with medical records, in which, no longer being possible to obtain the patient's consent , must contain an explicit commitment on the part of all who have access to documents that the research subjects will not be identified and their personal data will not be exposed. In addition, information that enables identification will not be shared5 [12].

Duty of confidentiality and protection of autonomy

The duty of professional secrecy is also a patient's right from the point of view of the effective exercise of the patient's autonomy through the protection of the existential privacy and its influence in decision-making. The duty of secrecy as protection of autonomy includes the patient's right to decide freely, solely according to the law and to the patient's own way of thinking. Therefore, this commitment is part of the framework of respect and recognition of the role of patients in health decisions regarding their own health.

The decision making process in this context takes into account not only the technical information provided by professionals about the clinical condition of a patient but it also considers the social, mental, emotional and cultural aspects involved as well as the impact that the decision will have in future. Human beings, as the social creatures that they are, live in interaction. However, despite the era of harsh exposure (consented or not) that we now live in, the fact is that certain personal aspects should have their social exposure modulated and determined solely by the principal involved, who will suffer the most direct consequences of the spread of such information.

This concern motivated the 1988 constituent assembly and the infra-constitutional legislation to provide for the possibility of punitive damages and other penalties in cases of not consented exposure, be the exposure in relation to physical image or in relation to information that could negatively change the social image, in his or her environment, of the person affected. In the case of decisions in the health area, they will only be taken in the sphere of effective autonomy, ensuring that they will not receive interference, as a determining factor, from the fear of the social impact of a virtual knowledge of data that should only be revealed by the patient to whom he or she decides and at the moment and extension that suits the patient. Secrecy will allow, in this case, to fully exercise the right to individuality, diversity and the constitutional liberties through the guarantee of secretive consent or refusal.

This situation has arisen, as a frequent example in the case of Jehovah's Witnesses, when the capacitated patient is consulted on the permission or not to receive blood. That patient's conscious refusal of such treatment - possibility that we advocate - should be observed by guaranteeing full confidentiality, including with respect to data access and possible authorisation entered on medical records, in order to ensure the most reliable possible answer, as the patient is accountable only to his or her conscience in regards to the decision making. Indeed, perhaps because of the guarantee of full confidentiality about their decision, patients would be willing to authorise procedures that they are not comfortable with in public when they are subjected, before the dictates of their own conscience, to exterior judgment even if only from their loved ones.

The same weighting refers to situations involving abortion (even being lawful), reproductive capacity, sexually transmitted diseases treatment (which interest only the partners, as it will be mentioned ahead), drug use, and even cancer (which remains, in many social environments, to this day, as "the disease that should not be named"). It should be remembered, in fact, that the patient goes to the

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doctor to be treated, not to be judged or to have her or his privacy exposed. Therefore, the patient is the sole responsible for ethical decisions on procedures that he or she legally accepts to submit to and it is the patient who should weigh up whether the social burden of the decision does not outweigh his or her private consciousness.

Assuring secrecy guarantees the right of individuals to their idiosyncrasies , the personal management of their relations, the autonomy over decisions concerning their health, respect for the diversity of thought and the particular circumstances that affect it, as well as the safeguarding, as much as possible, of the freedom of decisions about health when facing external judgment pressures.

Confidentiality and teenager care

Admittedly, when it comes to an adult patient, lucid and capacitated, only the patient can decide who will have access to his or her data. Therefore, the information should be preceded by authorisation of the patient even if requested by his or her companions.

As for the child or legally incompetent adult, the legal guardians are in charge of he patient's personal information - although it would be positive to get the participation of those patients in the decision making, whenever possible, through information compatible with their level of understanding, encouraging their commitment to their own health and stimulating their participation in treatments.

A doubt arises, however, particularly regarding adolescents or, more precisely, the legally incompetent but who, because of some degree of autonomy and maturity, can manifest the desire against the communication of certain information about him or her to the legal responsible.

Notice that the breach of confidentiality in these situations can pose a serious breach of trust, when the teenager is driven to move away from the professional and fails to recur to the professional in order to clear doubts. It could also cause those teenagers to omit information relevant to their care. In this context, there are many authors who defend the concept of mature minor, presented by the Society for Adolescent Health and Medicine, in the 1970s, as a proposal for a moderate exercise of self-management, which values the privacy, confidentiality and the relative autonomy of adolescents [13-19]. The mentioned Society supports the concept that individuals can exercise their rights, provided that they have the maturity to understand them [20].

Such provision specifies that both invasive procedures involving risks as well as the circumstances under which treatment is indispensable should also be reported to patients who are minor, from whom it is necessary to obtain consent, as much as possible, whilst recognising that the legal authorisation depends on the legal responsible , since they are not legally autonomous individuals. In case of conflict between the autonomy of parents as surrogate decision-makers and the beneficence of the minor, the pro beneficence understanding will prevail because this is, in fact, a situation of heteronomy.

One should, however, communicate and clarify minors on the need for medical intervention, answering their questions and promoting their participation in the decision-making, assuring, as much as possible, the maximum confidentiality on information about the minors. In regard to the theory of mature minors it is advocated that, if a refusal with supposedly harmful effects comes from the adolescents themselves, and not from their representatives, the refusal should be accepted as far as possible, as long as the maturity of the adolescent to deal with the matter is recognised and possibilities of false autonomy, such as the one due to external pressures or failure to understand the consequences of the decision, are discarded.

This thesis, though not expressly adopted in Brazil, can be seen in national and international normative precepts, such as the appreciation of what minors have to say and their gradual autonomy, provided by the articles, related to fundamental rights, of the Brazilian Child and Adolescent Statute (abbreviated as ECA in Brazil , for Estatuto da Crianca e do Adolescente), from 1990, and the Declaration of Ottawa on Child Health, from 1998. In this regard, the Brazilian Code of Medical Ethics from 2010 (abbreviated as CEM in Brazil, for Codigo de Etica Medica) also establishes in its article 74 that : [It is prohibited to the doctor] to reveal professional secrecy related to minors, including parents or legal representatives, as long as the minor has discernment capacity, unless the non-disclosure may cause harm to the patient [21].

Based on this article from the CEM, individual consultations with teenagers are recognised and even recommended. It is an occasion when more accurate information about a teenager's health and lifestyle habits might be obtained. This information, a priori, should be kept confidential even from the legal responsible if the patient has, in the words of

Article 103 of the Brazilian Code of Medical Ethics from 1988, which preceded the current one , *competence to evaluate his or her problem and act by his or her own means to solve it* [22] - That said, the difficulty of evaluating these aspects in an emergency consultation is also considered.

But when the situation involves risks to the patient such as, for example, pregnancy (with the consequent risk of miscarriage), drug use, suicidal ideas - then the communication of the professional to the legal representatives becomes compulsory, but not before encouraging adolescents to do it themselves. The parents, if applicable, should be referred to the specialised support of a psychologist, social worker etc. It is a situation where the patient must not be lost from sight, since he or she is at risk [3,23,24].

Legal and deontological duty to keep a secret

The duty of secrecy is not only ethical, but legal. Internationally, the Universal Declaration of Human Rights, from 1948, provides in its Article XII: *No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks* [25]. Still at the international level, the International Code of Medical Ethics adopted by the World Medical Association (WMA) in 1949, states that *a physician shall respect a patient's right to confidentiality* [26].

The Brazilian Constitution of 1988 provides, in the title about the fundamental principles: *Article 5 X – the privacy, private life, honour and image of persons are inviolable, and the right to compensation for property or moral damages resulting from their violation is ensured;* [27]. And the Penal Code qualifies the violation of professional secrecy as a crime, in the following terms: *Art 154 - if someone reveals without cause a secret which is known because of function, ministry, trade or profession, and whose revelation can produce damage to others. Penalty - detention of three months to one year or a fine* [28]. It is understood, from a jurisprudential point of view, that this legal disposition includes the conduct of the doctor who attends patients with abortion history and who is not required to notify the offence [5].

The Brazilian Code of Criminal Procedure, in turn, in its article 207, prohibits the testimony of people who, because of function, ministry, trade or profession, are required to keep a secret unless they are given permission by the interested party and want to give their testimony [29]. Once summoned they should go to court but only to inform their impossibility to testimony, considering the ethical and legal duty of secrecy. Similar provisions are contained in the Brazilian Civil Code in its Article 229: *No one may be compelled to testify about facts: I - about which, by status or profession, should keep secret* [30]; and the Code of Civil Procedure, in its Article 347, says that: *The party is not required to give evidence of facts: (...) II - about which, by status or profession, should maintain confidentiality* [31].

As a result, the medical record, where there is sensitive data about the patient , can not be displayed even to the judiciary without permission of the patient to whom the data belongs: the patient, whilst the health unit acts only as a faithful custodian. These provisions are consistent with the provisions of codes of ethics for health professionals, highlighting, in the 2010 CEM, the principle XI: *Doctors will keep secrecy about information they hold knowledge because of the performance of their duties, with the exception of cases provided by law* [22]. The chapter IX, which is specifically about medical confidentiality, should also be highlighted. The medical reports may only be disclosed with permission of the patient or the responsible, in the case of incompetent patients.

In the same vein, the Nursing Professionals Ethics Code expressed similar concern in its Article 29, when it establishes, among the duties of those professionals, to maintain secrecy on confidential fact that they *have knowledge by reason of their professional activity, except in cases provided by law*. The Article 54 also adds, among the prohibitions: *To publish works with elements that identify the patient without his or her consent* [32].

Other ethics codes in healthcare reiterate that concern, as can be seen in the Code of Professional Ethics of Physiotherapy and Occupational Therapy (Article 7 VIII: *Keep secret about sensitive data brought to attention because of their professional activities and require the same behaviour from staff under your direction* [33]) and the Code of Ethics of the Social Worker, where secrecy is presented simultaneously as right (Article 15: *It is a right of the Social Worker to maintain professional secrecy*) and as a professional duty (Article 17: *The social worker is forbidden to reveal confidential information* [34]).

Article 20 of the last code mentioned prohibits social workers to *give evidence, as witnesses, about the user on secretive situations that they have knowledge of due to their professional practice,*

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even when authorised to do so [34]. This requirement calls attention because it is more restrictive than the procedural and civil law of the country, which provide the option to the professional, when the patient authorises, to reveal secrets obtained this way. But the professional, in this case, will not be punished if he or she, even being authorised, does not want to reveal confidential information.

Article 9 of the Universal Declaration on Bioethics and Human Rights acts in the same direction when it defines, quite accurately, the following directive: *The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law* [35].

Breach of confidentiality causes

The imperative of secrecy, however, involves exceptions. The discussion on the possible need for secrecy flexibility gained ethical and legal space in the event that became known as Case Tarasoff 36, occurred in 1969. This is the case of a student at the University of California, Prosenjit Poddar, who killed the student Tatiana Tarasoff, having previously reported to doctor Lawrence Moore, who attended him professionally, his intention of killing the young woman. He even informed the time when he would attempt the murder.

The professional consulted with his supervisor whether or not he should breach confidentiality in this case, warning Ms. Tarasoff about the threat to her life. They decided not to warn Tatiana Tarasoff, considering the respect for professional confidentiality. Tatiana Tarasoff, alone in her home, was first shot and then stabbed to death by Poddar. The parents of the victim filed a lawsuit against the university, obtaining favourable ruling.

From then on it was, in general, determined that situations involving risk of life for oneself or others should be reported to the appropriate authorities and legal guardians. This includes proven or suspicious situations (only if based on reasonable grounds) of children and adolescents maltreatment as well as episodes of notifiable diseases. This provision is clear, *exempli gratia*, in the article 18 of the Brazilian Code of Ethics of the Social Worker: *A breach of confidentiality shall be admissible only in situations which seriousness can, whether or not involving criminal fact, bring harm to the user, third parties and the community. Sole Paragraph - The revelation will be made within the limits necessary, whether on the subject revealed or the extent and number of people that should be informed* [34].

With respect to risk situations, one example that creates doubts is the knowledge of a diagnosis of HIV seropositivity, a circumstance that usually generates great anxiety among health professionals, who understand that this information should be automatically communicated not only to sexual partners but also to other colleagues, laboratory personnel etc. in order to prevent the risk of contamination of these professionals. Note , however, that in this case the breach of confidentiality is unfounded, considering that adequate health care measures should be universal and should not depend, therefore, on information on HIV seropositivity to be applied. In addition, AIDS is not the only bloodborne serious infection, not to mention the many patients who have AIDS but whose diagnosis is not known during health care. In this sense, it is important to note that the fact that a notifiable disease is a legal reason for breach of confidentiality does not, however, imply an undiscriminated disclosure of the information, even among team members, except if necessary for the treatment. The staff of the public authority which received the communication is expected to act with discretion,in a way that the care and necessary epidemiological conduct which cause the inclusion of the illness among the notifiable diseases, do not cause unnecessary exposure and source of discrimination and embarrassment to the patient.

Somehow, this understanding led to the alteration of the CFM (Conselho Federal de Medicina- Federal Medical Council) Resolution 1,359 / 1992, which provided the express communication to sexual partners and sharers of syringes [38], for the CFM Resolution 1,665 / 2003, seen as more in line with the Declaration of Madrid, adopted by the WMA in 1987 37. In this regard, the resolution provides for the immediate and direct information only to health workers for which this data is of unequivocal importance in the care and treatment of the patient. This way, the respect for the confidentiality of the data is also kept in this circumstance [39].

According to this list of documents, the direct interest of the patient (in the scope of the health team) or, in the case of third parties, the right of those to whom the information implies immediate or prior risk requires perhaps swift intervention in order to prevent further damage, as it is in the

case of individuals known to be at risk of contamination by unprotected sex. Even so, the ideal is to encourage patients to take the initiative to inform their partners, avoiding thereby the disclosure of secrecy. This disclosure will only be made without the patient's consent if it is established that with his or her conduct and resistance, the patient is endangering another person's integrity, which is a criminally punishable conduct, considering the wilful intention to contaminate other people or the gross negligence of the act .

Other legal situations that exempt professionals from the duty of confidentiality concerns children and adolescents maltreatment, an increasingly diagnosed condition, to which health professionals' attention and action are essential in order to prevent the minor's return to the cycle of violence, which often occurs in his or her own residence. To prevent such events, the Child and Adolescent Statute (abbreviated ECA in Brazil - Estatuto da Crianca e Adolescente) determines, in its article 13: *The cases of suspected or confirmed abuse against children or adolescents will obligatorily be notified to the local Tutelary Counci , without prejudice to other legal provisions*. And further, in Article 245, the statute characterises as administrative infractions, among other situations: *the doctor, teacher or responsible for health care establishment, primary education school, preschool or kindergarten, who refrain to communicate to the competent authority, cases of suspected or confirmed children or adolescent maltreatment. Penalty - fine of three to twenty reference wages and double that amount in case of repetition* [40].

Similar measure was also included in the the Elderly Statute, intended to curb abuse against this group, also of particular vulnerability. In order to identify such cases, a cautious investigation, by thorough examination and anamnesis. Despite the possibility of harm caused by frivolous accusations, the legal provision supports the communication of based suspicions, in order to avoid any crime of slander. Once the evidence is verified then those patients should not be lost from sight, considering that they are at risk where they are. It may even be necessary to maintain the patient in the health unit for social preventive issues pending action of the Tutelary Council or prosecutor. In places where the tutelar council doesn't exist, the communication of suspected maltreatment related to the minor patient should be made to the Justiça da Infância e da Juventude (Justice of Childhood and Youth) or to the State prosecutor [41-44], accounting for just cause for breach of confidentiality.

In turn, the notifiable diseases, another hypothesis of legal breach of confidentiality, are contained in the Ordinance 1,271 / 2014, of the Ministry of Health [45]. It is a criminal offence to not communicate those diseases to the competent public institutions, in accordance with Article 269 of the Brazilian Criminal Code: *If the doctor fails to report notifiable diseases to the public authority : Penalty - detention of six (6) months to two (2) years and a fine* [28]. The compulsory character, in this case, represents an exceptional restriction of the interest of the individual in favour of public health and security, since it aims at the possible need for action in the area of public health policies.

Other hypothesis of breach of confidentiality admitted by the jurisprudence are the judicial request of medical records and the need to defend the professional, within the limits of what is essential to these purposes, according to the CFM Resolution 1,605 / 2000 [46].

Post mortem secrecy

Finally, we must point out that the duty of secrecy does not cease with the death of the patient - which would open space for debate on the ethical appropriateness of the current regulatory requirement to record the cause of death on the death certificate provided by notaries, despite the undeniable importance of such registration to public health - or because it is public knowledge (Article 73 of the CEM, from 2010 [21]).

As access to medical records after the patient's death, the aforementioned article 77 of the CEM (Abbreviation of Codigo de Etica Medica in Brazil - Code of Medical Ethics) was changed by the CFM Resolution 1,997 / 2012, with the intention of including in its latest redaction the following prohibition: *To provide information to insurance companies on the circumstances of the death of the patient in your care, besides those contained in death certificates* [47]. The previous text was more flexible in terms of family authorisation when it prohibited the provision of *information to insurance companies about the circumstances of death of the patient in your care, besides those contained in death certificates, except by express consent of the patient's legal representative* [21]. As seen, it is not unreasonable to consider that the very mention of the cause of death on the public certificate already is a disclosure of data that maybe the patient - who owns the secrecy and is favoured by it - did not want to see disclosed.

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In this context, however, it is essential to highlight the recent CFM Recommendation 3/2014, which, under the strength of the preliminary injunction in the minutes of public civil action 26.798-86.2012.4.01.3500, filed by federal prosecutors of Goiás (a Brazilian federative state), with interposition of an interlocutory appeal, complied with the provisions below: *Recommend to medical professionals and medical, clinical, ambulatory or hospital treatment institutions in order to: a) provide, when requested by the surviving spouse / partner of the dead patient, and subsequently by the next in line legitimate successors of the patient, or relatives up to the fourth degree, the medical records of the deceased patient: Provided that the family bond has documentary proof and observed the order of heredity; b) inform patients about the need for an explicit statement of objection to the disclosure of their medical records* [48].

It must be recognised that, in most cases, patients have no reason to hide their medical records from their friends and family, and that access to such a documentation has legal repercussions when there are doubts, for example, about the adequacy of the medical care of the patient, so the absolute secrecy would in this case be paradoxically contrary to the interests of the patient. However, given that medical confidentiality is a strictly personal right of the patient [49], the rule should be the post mortem preservation, always preceded by questioning the patient, at the time of his or her internment , on whether or not to allow the family to have access to medical records. Considering the way that item b was formulated, it appears that secrecy about the medical record of a dead patient is an exception, which in itself would raise a doubt, with psychological repercussions, for the family of the patient as they wouldn't be sure if they were acting according to the patient's wishes or not. Perhaps the patient had wished to avoid this uncertainty. Thus, it is more relevant to affirm the secrecy of medical records and their very personal character as a rule, except for a previous consultation with the patient about who would be allowed to authorise access to the patient's medical records, in case of loss of consciousness or post mortem.

Final considerations

Secrecy is a patient's right and a duty of the professional, especially when it comes to interpersonal relations in healthcare. The guarantee of confidentiality allows for a more autonomous exercise of diversity and individuality, by protecting against external pressures which could eventually be coercive, aiming at equalisation of the majority or even the minority which are representative of the social environment. Only with effective respect to medical confidentiality will it be possible, in many cases, to have a consent that is in fact free, after due explanation, leaving solely to the patient the judgement of his or her own circumstances without fear of the repercussion that their personal health decisions may have on their environment.

Everybody who has access to personal data about patients should keep the information confidential. This applies both to the professional environment and to the research and teaching universe. Secrecy must be kept, inclusive of and as far as possible - that is, safeguarding the cases of risk to life or of serious risk to the integrity - in the case of a patient who is a minor but who has the competence to conduct herself or himself according to their own initiative.

This is because secrecy, in the legal framework, is associated with the constitutional rights of privacy, recognised as fundamental in Brazilian law, following the example of human rights at international level and with influence on the infra-constitutional legislation, including the deontological codes. Exceptions to the duty of secrecy are specific, consisting, according to ethical and legal provisions, of the risk of death to oneself or others as well as legally stipulated cases, such as notifiable diseases and suspicions of abuse against incompetent or particularly vulnerable individuals.

It should be remembered also that the medical record belongs to the patient, and the health unit works only as a custodian of the record. Thus, the access to those records should not be franchised to insurance companies or other health professionals unrelated to the treatment, nor the family, unless the patient, when able, authorises it. This decision is up to their legal guardians in the case of incompetent patients. Finally, the professional duty of secrecy does not end with the death of the patient or because it is a public fact or regards a public person, although one can discuss the easing of access, when expressly authorised by the patient or in the case of suspicion of poor professional practice which intervened in the cause of death.

From all the above, it is concluded that, with respect to the patient, the guarantee of secrecy works not only as a factor to stimulate participation in medical treatment, due to the patient's trust in

the professionals, but also as a space for the most reliable manifestation of autonomy, representing a protective mechanism for the very exercise of freedom. This is because patients, confident that their medical data will not be disclosed except by their permission, feel freer to express their peculiarities and their particular ways of thinking, making their decisions on health matters without fear of judgment or the external repression about the most private aspects of their personality.

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The morality of surgery for aesthetic purposes in accordance with principlist bioethics

Giselle Crosara Lettieri Gracindo

Abstract

The cult of beauty emerged in the West with the goddess Aphrodite, and reigns today in social media, driven by the worship of celebrities' images. The "fever" of selfies fuels the desire to change. In 2013, Brazil led the world ranking of plastic surgery, overtaking the United States, according to the International Society of Aesthetic Plastic Surgery report. This excessive practice concerns the organizations responsible for medical practice, such as the Brazilian Federal Council of Medicine and the Brazilian Society of Plastic Surgery. As they have a huge impact on patients' lives, aesthetic surgeries should preferably be carried out by specialized doctors. Patients have the right to have these surgeries and to choose their doctors; nevertheless, their autonomy is not absolute. The professional has the duty to inform the patient about the risks and contraindications of the procedure, and has the right to refuse to perform surgery if it is considered potentially harmful or hazardous to the patient's health.

Keywords: Bioethics. Plastic surgery. Aesthetics. Photo-body image. Malpractice-personal autonomy.

Resumo

A moralidade das intervenções cirúrgicas com fins estéticos de acordo com a bioética principialista

O culto à beleza surgiu no Ocidente com o mito da deusa Afrodite, e hoje impera nas mídias sociais, impulsionado pela adoração da imagem de celebridades. A "febre" dos *selfies* incita o desejo de transformações. Em 2013, o Brasil liderou o *ranking* mundial de cirurgia plástica, ultrapassando os Estados Unidos, segundo relatório da International Society of Aesthetic Plastic Surgery. Essa prática excessiva preocupa os órgãos responsáveis pela atuação médica, como o Conselho Federal de Medicina e a Sociedade Brasileira de Cirurgia Plástica. Por terem enorme interferência na vida do paciente, cirurgias com fins estéticos devem ser realizadas, preferencialmente, por médicos especialistas. O paciente tem o direito de fazê-las e de escolher seu médico, mas sua autonomia não é absoluta. O profissional tem o dever de informar sobre riscos e contraindicações do procedimento bem como o direito de recusar as cirurgias que considerar potencialmente lesivas ou arriscadas à saúde do paciente.

Palavras-chave: Bioética. Cirurgia plástica. Estética. Fotografia-imagem corporal. Imperícia-autonomia pessoal.

Resumen

La moralidad de la cirugía con fines estéticos de acuerdo con la bioética principialista

El culto a la belleza surgió en Occidente con la diosa Afrodita, reina hoy en los medios sociales, y es impulsado por el culto a la imagen de las celebridades. La "fiebre" de las *selfies* incita el deseo de cambiar. En 2013 Brasil lideró el *ranking* mundial de cirugías plásticas, superando a los Estados Unidos, según el informe de la Sociedad Internacional de Cirugía Plástica Estética. Esta práctica excesiva preocupa a las organizaciones responsables por la acción médica, como el Consejo Federal de Medicina de Brasil o la Sociedad Brasileña de Cirugía Plástica. Debido a que tienen gran interferencia en la vida del paciente, las cirugías con fines estéticos deben ser realizadas, preferentemente, por médicos especialistas. El paciente tiene el derecho de hacerse estas cirugías y de elegir a su médico; sin embargo, su autonomía no es absoluta. El profesional tiene el deber de informar acerca de los riesgos y contraindicaciones del procedimiento, así como el derecho de negarse a hacer cirugías por considerarlas potencialmente dañinas o peligrosas para la salud del paciente.

Palabras-clave: Bioética. Cirugía plástica. Estética. Fotografía-imagen corporal. Mala praxis-autonomía personal.

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Declara não haver conflito de interesse.

In Greco-Roman mythology, beauty arouses admiration. According to the myth, the Greek goddess Aphrodite, like Venus, her Roman counterpart, caused an uproar wherever she went, because of her unparalleled beauty. In Western culture, the heir of Greco-Roman values, women are admired for their beauty, which is considered the most valuable female attribute. Adorned and encouraged to always remain beautiful, every woman learns from childhood the importance of appearances to keep and enhance her position in society. Beauty makes her powerful and desired.

Even in childhood, and especially in adolescence, young women feel very uncomfortable with certain parts of their bodies, which (real or perceived) seems to them to not fit the expected standards. The scrutiny intensifies if the person has deformities that are congenital or resulting from trauma, injuries or cancer. Amongst youth, the nose and breasts are prime targets of this quest; however, other parts of the body and face, such as the belly, buttocks and cheekbones, do not escape harsh criticism.

As years go by, the sense of discomfort with their own imperfections tends to increase, and signs of aging, maternity marks, or "extra pounds" reinforce women's dissatisfaction with their own image, given that the ideal standard promoted by the media focuses on youth and slender bodies. These parameters instigate the quest to change aspects of one's body, feeding the vanity and the desire of women to be well accepted by society. Awakening the desire for change, in relation to what is considered disproportionate or ugly, initiates a search to alter one's form.

This is the crux of the current Brazilian culture, with respect to the image of women and the expected feminine attributes. There are probably, to a greater or lesser degree, regional variations in the characteristics of what is considered beautiful or imperfect. The cult of beauty also occurs in other societies that share the same cultural roots, especially those in which the female figure is objectified and where a woman's social value is measured primarily by her appearance.

Social media, celebrities and the increase in plastic surgery

A mirror reflects our image, which is why it is has been used for centuries. It is even a key feature in fairy tales. There are those who stay for hours in front of a mirror admiring themselves, discovering details not only regarding their bodies, but primarily their face, as the face is considered the defining element of our identity. However, with current technology, the mirror is no longer the only object that reflects the body's image.

Photography came to prominence when it took part of the function that, for centuries, had been attributed to mirrors, as a result of increasingly modern devices, with cameras attached to computers and embedded in mobile phones. Together with internet access, these devices have made it possible, at any time and place, to take self-portraits and post them on social networks in real time, as in the case of selfies.

Technological advances and the globalized world enable the swift transmission of information. The internet reaches an incalculable number of users in various parts of the world in near real time. Such ease of communication contributes to virtual contact between individuals through social networks and dating websites, with diverse objectives.

Some say that appearance is "a person's business card", since "first impressions are the most lasting". On social networks like Google+, Facebook and Instagram, it is common to post personal photos, especially self-portraits. Those who publish photos on these social platforms expect to present a good image and to be recognized with a "like", a "comment" and sometimes even a "share". Wikipedia defines *selfie* as a kind of *self-portrait photography, usually taken with a handheld camera or a phone with a camera [and] was considered the international word of the year in 2013 by the Oxford English Dictionary* [1]. The purpose of the *selfie* is to show the best angle of one's personal image for disclosure in social networks. It is the fad of the moment! A mirror of a person's self-esteem.

However, initially one might not get a good photo, entailing many attempts to get the effect one wants to project. Close-up shots, like selfies, almost always reveal deformities and imperfections, even if you use the selfie stick (monopod) to distance the camera. Due to the short distance, inadequate lighting, low resolution camera and mobile lenses, the picture usually does not match the real (or ideal) image of the person [2].

Those who wish to look like celebrities often get frustrated, failing to pay attention to the fact that the images of the "famous" published in the media do not always correspond to reality. Before being sent to social networks, photos can undergo changes and special effects. When these effects are removed, the result is normal, not exceptional.

According to a statement from Stephen S Park., president of the American Academy of Facial Plastic and Reconstructive Surgery (AAFPRS), which was published in an article on the entity's website in 2015, *some people are attracted to the power, fame and attention that being a celebrity brings (...). It is important to remember that simply changing your appearance will not give you the same level of recognition. Celebrity photos are so often re-touched that their images are distorted, which can result in unrealistic expectations that propel consumers to seek excessive or extreme surgeries* [3].

The desire for recognition, fame and power intensifies the pursuit of internet users to improve their appearance, making this pursuit virtually inevitable. This gives strength to the beauty industry and consequently stimulates the growth of aesthetic plastic surgery.

Unsurprisingly there is a realization that beauty has great value in society. Vitor Ferreira, quoting Ernest Fischer says that *man has always been preoccupied with the form of an object, in order to facilitate its handling, functionality and also to become visually pleasing* [4]. And it is misleading to think that plastic surgery is a new technique to achieve this objective. It is one of the oldest medical specialties [5].

The origin of plastic surgery dates back centuries before Christ, driven by the need for techniques to restore human deformities caused by trauma, physical punishments and penalties. According to historical records, these procedures started in India, where they practiced nose amputation as punishment. In modern times, the First World War represented a major milestone for plastic surgery, given the large-scale physical mutilation caused by weapons used in the fighting. In this context, Sir Harold Delf Gillies stands out in the repairing of war injuries, having been appointed as the main medical doctor who dedicated himself to the development and improvement of techniques in the reconstruction of the faces, noses and jaws of affected soldiers [6].

Unlike the pioneering plastic surgery of the First World War, from World War II, studies and research aimed at the general population were developed, resulting in an increase in the number of reconstructive surgeries and expansion of the types of surgery, such as the ones performed in cases of fracture repairs, burns, peripheral nerves, orthopaedic corrections, etcetera [7].

Currently, seventy years after the end of the last World War, the profile of most people who seek the procedure has changed again. Now elective surgery, focused on the improvement of physical characteristics that can be considered "normal", has taken the stage.

According to an article published in 2014 on the AAFPRS website, a survey conducted by the organization in 2013 showed an increase of requests for cosmetic procedures (especially among individuals under 30 years of age) as a consequence of the publication of selfies. The self-portrait influenced the desire for facial changes, given the perceived imperfections that respondents attributed to specific parts of their bodies. According to the survey that year there was a growth of 10% in nose plastic surgery, 7% in hair implants and 6% in eyelid surgery [8].

In the aforementioned report, published on its website in 2015, the AAFPRS presented other research (undertaken in 2014) showing that in addition to selfies, videos also motivate the use of plastic surgery, since they reproduce moving images, thereby exposing more facial imperfections [3].

In addition, this study, conducted with a group of 2,500 respondents who were members of the institution, found that the demand for cosmetic surgery is also motivated by the desire of people to emulate current celebrities. The survey found that 13% of facial plastic surgeons testified to an increase in requests for procedures to simulate the appearance of celebrities. In 2014, this level was well above the 3% of requests in 2013 and 7% in 2012. The most popular surgeries in 2014 were: 1) Angelina Jolie's lips and cheekbones; 2) Beyoncé's facial structure; 3) Kim Kardashian's eyes and chin; 4) Brad Pitt's nose; and 5) Natalie Portman's nose [3]. Although the study has given more emphasis to the female audience, it is worth remembering that men are gaining more and more ground in the world of beauty and plastic surgery.

What woman has not dreamed of being proposed to and presented with a diamond ring?! But, on the day, some "worry lines" have been making brides distressed! Would their hands match the beauty of the ring when the time comes to make that perfect *selfie*? The Brazilian Society of Plastic Surgery (SBCP) commented on a New York Times report, which warned that there was another trend in 2014 in the area of plastic surgery: the selfie of the perfect hand with the engagement ring. The SBPC informs that, according to the New York newspaper article, the finding of some surgeons is that there is, in fact, a demand from brides for wrinkle fillers, the treatment of sun marks, as well as the elimina-

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tion of protruding veins, and the bony appearance of hands - all to get the perfect picture of their hand with the ring posted on social networks [9]. This confirms, therefore, the notorious influence of social networks in the cult of beauty, not to mention the impact of television and print media, especially through programs and magazines that are dedicated to disclosing the lives of the famous.

The websites of plastic surgery societies from various countries provide warnings and recommendations to the public about the harmful effects of failed interventions, seeking to prevent those who are thinking of using the procedure, inducing them to consider the risks and also informing them that the surgeries are not recommended to everyone, indiscriminately.

In general, the goal of those who resort to cosmetic surgery goes beyond the physical benefits, and relates to self-esteem, which is the reason for such warnings. Therefore, the professionals advise that people consider, as a criterion to identify the right time to look for a doctor, the moment their dissatisfaction and discomfort with their own appearance negatively influences their behaviour. In turn, these organizations consider the pursuit of resembling celebrities as a mistake, since every aspect of individual characteristics is to be respected.

Brazil has a high number of plastic surgeries. It is among the countries that most practice this type of procedure. According to SBCP, the 2013 report from the International Society of Aesthetic Plastic Surgery (ISAPS), mentions Brazil as foremost in performing cosmetic surgery, overtaking the United States [10]. The desire to achieve ideal beauty through the tip of a scalpel is increasingly common in the country, including individuals of various ages and socioeconomic groups. Because of its high cost and because it is not considered an essential service guaranteed by the Brazilian Public Health System (except for remedial interventions in specific cases), surgery for purely aesthetic purposes ends up being one of the targets in the commercialization of medicine.

In the case of plastic surgery and other similar cosmetic procedures, this commercialization has spread in Brazilian society, to the point where these services are offered through leaflets, billboards, newspapers, magazines and electronic media, with the marketing of beauty treatment "plans", that is predefined sales with certain values, even before the assessment of the patient by a doctor. This state of affairs led the *Procon-SP* Foundation, an agency of the Department of Defense and Citizenship of the State of São Paulo, to request a ruling from the SBPC [11]. In response, the organization decided to stimulate discussion in the medical field, resulting in the issue of Resolution 1,836/2008 of the CFM in order to discipline *the financing plans or rotating savings and credit associations (ROSCA) for medical procedures*, including those for aesthetic purposes [11]. According to an article published in CFM's website '*Portal Médico*' , a survey of the Brazilian Association of ROSCA Administrators (ABAC) held in 2012 showed that in the first half of that year, interest in ROSCA that focus on services had an increase of over 25% and that the specialty "health and beauty" led the ranking amongst these ROSCA, with nearly 16% of the letters of credit. Also according to the article, SBCP considered these figures with concern [12].

Teenagers also turn to doctors' offices in search of aesthetic results. According to a post from Diego Cordeiro published on the official SBCP blog, the discussion about the real needs of these adolescents to undergo cosmetic surgery is growing in line with the growth of demand for these surgeries. Although many professionals consider that people of this age group should not submit themselves to such procedures, the number of plastic surgeries for adolescents and young people grew 141% between 2008 and 2012. Cordeiro said that about 60% of plastic surgery undergone by teenagers are aesthetic, and, among them, liposuction stands out as one of the most sought after procedures [13]. In other words, the desire to change appearance is not only among the older generations.

According to SBCP, the ISAPS report confirms this high demand for liposuction [10]. The CFM, through Resolution 1711/2003, stipulates that this type of surgery should not be indicated for weight loss purposes (article 2), restricting the use of these procedure to the correction of body contours in relation to the distribution of subcutaneous adipose tissue (article 1). The doctor who executes the procedure must have specific training, and a prior qualification in general surgery is mandatory (article 3) [14]. Therefore, to perform a liposuction, rhinoplasty, mammoplasty, blepharoplasty or any other surgery, appropriate medical training is essential, in order to provide security for the patient and society.

In addition to these technical, procedural and structural aspects, it is important that the patient be alerted about the need to be in harmony with their inner and outer beauty, to have a better understanding of their physical characteristics and to

reflect on their real wants and needs. It is essential to know one's own body, its limits, and maintain self-esteem. The doctor has a duty to their patients to clarify these matters, as well as to inform them about the diagnostic and therapeutic procedures to be adopted.

Doctor-patient relationship and bioethics

The aesthetic plastic surgeon handles a wide range of concepts and standards of beauty, imposed daily by the media, by celebrities, etcetera, which incite the desire of the patient to achieve the "perfect" image. This fact has turned into a new challenge for the physician, whatever their speciality, that is, to understand the perception that the patients have of themselves, how they see their body and face, as well as the psychological effects of this projection. Such understanding is essential, since the patient is looking for results that meet not only the real goal, but also one that is pictured in their own mind - the intangible.

In this sense, the knowledge of the standard or reference of beauty defined by society can work as a guideline for professionals in their attempt to understand the patient and their motivations. Proof of this is the increasing desire of people to replicate, in themselves, the facial features of artists and media icons. However, the physician must be aware of the fact that the face of each person is unique, and that there is no way to impose the same ideal of beauty on everyone, for this singular appearance is a trace of individuality and, therefore, changes from person to person. However, as we live in an increasingly 'mass appeal' society, people end up taking on these standards as examples to be pursued in order to respond to the hegemonic concept of beauty.

The medical practice of plastic surgeons alters the physical characteristics of their patients, so it requires the relationship between them to be profound and humane. As the impact of changes in appearance goes beyond the physical level, the physician must be sensitive to understand the expectations and limits of their patients. What might be perfect for some, can represent great dissatisfaction for others. Consequently, practitioners have to commit to acquiring technical expertise and pursuing scientific innovations without neglecting respect for the patient and other intersubjective aspects that guide good relationships; only in this way can they play their role with humility and for the greater good [5].

Among the propositions defended by principialist bioethics, the principle of autonomy, also known as the principle of respect for the individual, stands out [15]. This provision relates to the need to inform the patient - clearly and precisely - about all the procedures to which they will be subjected, as well as ensuring the absence of any pressure in order to obtain the patient's acceptance or rejection of the proposed treatment. According to the principialist theory Tom Beauchamp and James Childress explained in "Biomedical Ethics Principles" [16], it is essential to maintain these parameters, so that the person can express their consent (or not) to submit to any medical act. One can consider this principle as a moral rule, supported by many deontological professional codes, which allow very few exceptions to the principle of autonomy, especially in cases of imminent risk of death.

In accordance with Articles 22 and 31 of the Code of Medical Ethics (CEM) [17], the informed consent form is a document containing the necessary clarifications about the objectives and rationale of the procedures to which they will be subjected. It informs patients of the discomforts, potential risks and expected benefits, alternative methods of diagnosis or treatment, side effects and specific complications. Such a document *is mandatory and the form is written clearly to detail accountability of predictable failures and should apply irrespective of the magnitude of intervention* [18]. The informed consent document is the right means for the patient to express their will and to become aware of what can and will happen during a procedure or surgery.

To be valid, the document must have the free and spontaneous consent of the patient. The patient must fill and sign the form, in order to certify their competence and ability to understand and consent to its contents. Moreover, it has to be backed up by verbal information that is sufficient, clear and appropriate, so that the patient can understand the information in its entirety [18]. According to Teresa Ancona Lopez*, the duty to inform is one of the duties attached to objective good faith. Thus, the general rule of good faith must be present at all times in the doctor-client relationship from both sides* [19].

The doctor-patient relationship is relevant to the development of a successful medical practice, especially when it comes to surgery for aesthetic purposes, in which the patient is seeking to improve their appearance, and all possible risks must be brought to their attention. The existence of physical harm, or results that differ from what was expected, can cause numerous consequences to the patient's

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life, including those of a psychological nature. Therefore, to achieve the desired result, it is extremely important that the doctor-patient relationship be based on trust and transparency.

A healthy person who undergoes cosmetic surgery has a specific goal: to improve their appearance. Due to this circumstance, the responsibility of the physician to the patient increases, and the patient must be informed - preferably personally and explicitly - of all the risks and rewards inherent in the procedure. In this case, the duty to inform is more imperative than in the case of surgery without aesthetic purposes, especially because, if the doctor does not inform the patient properly, the doctor will answer for an obligation of results[20].

However, it should be noted that, both in this and in other cases, the physician has full autonomy to refuse to perform the procedures. Doctors should not perform surgeries when they are convinced that such intervention can bring more harm than good to the patient. Therefore, the patient's autonomy and their right to choose are limited by the autonomy and responsibility of the professional. Whenever, in the physician's understanding, the patient's wishes pose a risk to their own physical and mental health, the doctor should refuse to treat them, even if such conduct is infringing the patient's autonomy. This refusal is provided for in the principialist theory, which takes into account the *prima facie* principle [21].

Plastic surgery, legislation and CFM resolutions

Certainly, there is nothing wrong with wanting to improve one's appearance and seeking the desired results. And aesthetic plastic surgery is a means to achieve that purpose, resulting in benefits to the patient's physical health, and psychological and social wellbeing. According to Article 1 of the CFM Resolution 1,621/2001*, plastic surgery is a unique, indivisible specialty and as such should be performed by qualified doctors, using standard and scientifically recognized techniques* [22].

However, it is necessary to avoid excesses and negative complications during surgery or procedures. Therefore, it is important that the patient knows the professional to whom they entrust their body, health and life. The training and experience of these professionals are critical to achieving a positive surgical outcome.

According to article 17 of Law 3,268/1957 in force in the country [23], a doctor with a diploma registered with the Brazilian Regional Council of Medicine (CRM) can work in any field, even without a specialist title. As a result, CFM could not create a resolution making it compulsory for plastic surgeries to be conducted only by physicians specialised in such practice. However, this situation can change with the regulation of the legislative powers of CFM, as prescribed in Article 7 of Law 12,842/2013, also called the Medical Act Law [24].

In the US, for example, qualifying as a plastic surgeon can occur in two ways. The first, by a combined program, in which the candidate undertakes a single selective test, having just completed training in medicine. A resident doctor will then do three years of general surgery and two or three years of plastic surgery. The professional may still need one more additional year of research between their residency in general surgery and plastic surgery. Another means of training future US plastic surgeons comes from the traditional program, for which it is necessary to pass two selective tests, one for admission to the general surgery program, lasting five years, and another to enter the plastic surgery program, which lasts two to three years [25].

As mentioned before, in Brazil, there is no legal requirement for a specialist qualification in plastic surgery to perform the procedure. Article 20 of the current legislation [23] provides only that, to promote operations in any medical field or specialty, the professional must be registered with the CRM. Regarding the plastic surgery speciality, the resolutions of CFM recommend that, to perform the procedure, the physician should have specific training, including a mandatory prior qualification in general surgery, among other recommendations and determinations defined in related resolutions.

However, what was mentioned earlier must be emphasized: that Article 7 of Law 12,842/2013 was introduced to enforce the supervisory powers of the CRM and CFM, covering the inspection and control of procedures of an experimental nature when these do not meet certain requirements under this same law [24]. In this context, the CFM is expressly authorized to issue regulations on medical procedures, and may even consent to these procedures by requiring that the physician have a certain degree of technical knowledge, or prohibit professionals who do not possess a specialist title from practicing these medical procedures. It is noteworthy that the recent Decree 8,516/2015, regulates the formation of the National Specialist Register, with a view to assisting

the ministries of Health and Education as a source of information for the regulation of public health and health education [26].

The register will have official information regarding the medical speciality of each medical professional contained in the databases of the National Medical Residency Commission (CNRM), the CFM, the Brazilian Medical Association (AMA), and the associations of different specialties related to these organizations. Decree 8516/2015 also establishes a Specialties Joint Committee under the CFM, giving it the power to define, by consensus, the medical specialities of the country, while the CNRM determines the competence matrix for the training of specialists in their field of medical residency [26].

Despite the practice of plastic surgery being made available to all professionals registered at the CRM, in 2001, CFM considered such a procedure as a medical speciality. Since then, the practice has come to be regulated by the organisation, and the professional is recognized once they register a specialist degree, which must have been obtained on completion of a medical residency accredited by the CNRM, or upon passing a specific test applied by SBCP. To enable professionals to declare themselves plastic surgeons, CFM defines a number of prerequisites as well as technical and scientific knowledge acquired during college or postgraduate studies (medical residency and/or specialisation) [22]. We reiterate that, in accordance with Article 4 of Resolution 1634 CFM/2002, *the doctor may only declare links with a speciality or field of expertise when possessing a corresponding degree or certificate, duly registered with the Brazilian Regional Council of Medicine*[27].

As stated in this same resolution, the three entities - CFM, AMB and CNRM - signed an agreement that assumed common behaviours in the adoption of new medical specialties in Brazil. The agreement states that three years of training are necessary for professionals to register themselves with the CNRM and AMB as specialists in plastic surgery, provided they have passed, as has been mentioned before, a medical residency program in plastic surgery or an exam conducted by SBCP [27]. Normally, the title of specialist in plastic surgery is preceded by a residency in general surgery, with an average duration of two years, which follows the six years of graduation. It is clear that, adding up all this time, the qualification of a plastic surgeon is the result of at least 11 years of study.

With support of Article 17 of Law 3268/1957 [23], doctors without proper expertise have also been performing plastic surgery for aesthetic purposes. Many of these surgical procedures are extremely complex and, when the results are negative, often catastrophic, and can lead to the death of the patient. Another reason for the CFM and SBCP insisting on plastic surgeons having academic qualifications, is both for the protection of patients and for the protection of the medical profession itself.

As a regulatory body of professional practice, CFM adopted the "Manual of administrative procedures" to guide the supervision of doctors' registration numbers with CRM and to establish criteria for the operating permit of medical services of any nature [28]. This manual also stipulated the minimum criteria for the operation of establishments in which plastic surgery can be performed, and prohibits those that do not meet these requirements, based on the manual for medical auditing and inspection in Brazil [29,30]. It is noted, therefore, that the rules of CFM are not limited to the medical act, because they also apply to medical environments and services, thereby ensuring adequate conditions for their practice.

These guides are intended to ensure safe medical care for the population. Based on this imperative, CFM considered three basic conditions for carrying out such procedures: 1) adequate physical environment and building; 2) equipment and supplies for the workup, therapeutic application and rehabilitation procedures, as well as investigative diagnostic methods; 3) infrastructure to treat complications of interventions, if applicable [29].

The CFM determinations are of paramount importance in light of the significant increase in aesthetic plastic surgery in the country. According to CFM, medicine cannot be practiced for the purpose of commerce, advertising with images and patient outcomes cannot infringe ethical principles, and the responsibility of the doctor during care of patients is integral, unique and non-transferable, both in the diagnosis of disease and deformities, and in the indication and undertaking of treatment.

Taking into account the responsibility of the physician, CFM, through Resolution 1836/2008, stated it was necessary to prohibit *the medical care of patients referred by companies that advertise and / or market financing plans or ROSCA for medical procedures* [11]. According to the regulation, it is up to the professional to set values and the method to charge their fees, by referring to the CEM.

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Doctor's responsibility

Hippocrates, quoted by Beauchamp and Childress, advocated that the doctor should have at least two objectives: *help or, at least, do no harm* [31]. Such teaching corresponds to the principle of non-maleficence (do no harm to the patient), present in the medical code of ethics worldwide and reproduced in the principialist theory. In addition to this, there is another Hippocratic precept that guides both medical practice and principlism: the principle of beneficence, which is to do good for the patient, *I will apply all measures for the benefit of the sick according to my power and understanding, never to cause damage or to harm someone (...) In every house, I will come for the benefit of patients, keeping myself far from all voluntary damage* [32].

In medical practice, however, it is humanly impossible not to have errors, failures that cause harm to patients, and can in some cases be attributed to physicians and, in other cases, to the technical problems of hospitals, not to mention other plausible hypotheses. In the medical field, generally, one does not work with guaranteed results, because the doctor has the obligation of means, not of results. However, in the case of plastic surgery for aesthetic purposes, it is assumed that the obligation is of results, as ruled by the Brazilian Supreme Court in 2013 [33], although the doctor's responsibility, even in case of purely cosmetic surgery, remains subjective and is established upon proof of guilt.

The obligation of the doctor to repair the damage caused to the patient is dependent upon such evidence, since the sole paragraph of Article 1, Chapter III, of the CEM states that *medical responsibility is always personal and cannot be presumed* [17]. Therefore, patients who complain of malpractice must prove such a claim; otherwise, the doctor cannot be held responsible. This is because, the Brazilian legal system, does not adopt the premise of professional risk [34].

The application of consumerist responsibility to the doctor-patient relationship suffers from contradictions. However, one must keep in mind that this relationship is far from being a mere product, especially because it is founded on the essential care of the patients' health. There is no need to ignore its application when it comes to health facilities, which hold strict liability. Notwithstanding the provisions of paragraph 4 of Article 14 of the Brazilian Consumer Protection Code, according to which the *personal responsibility of independent professionals shall be determined upon verification of guilt* [35], the doctor develops a very personal involvement, which has a contractual nature, even if it is verbal or tacit.

According to the Civil Code, the offender will be required to indemnify the victim or the victim's family in the case of murder (article 948), by injury or other harm to health (article 949), including if this injury or defect prevents the victim from working, exercising their profession, their trade, or decreases their ability to do so (article 950). The offender must also bear all the costs of lost earnings and treatment, compensating for any pecuniary loss that the victim might incur as a result of licit action taken by the offender, when this, by negligence, recklessness or professional malpractice, *causes the death of patients, aggravates their illness, causes them injury, or makes them unable to work* (article 951) [36].

In addition to being subject to the ethical (CEM) and civil (Civil Code) responsibilities, doctors are also criminally liable if they practice any conduct specified in the Penal Code, such as illegally practicing medicine (article 282), issuing false certificates (article 302), omitting to give notification of reportable diseases (article 269), and violating professional confidentiality (article 154), etcetera. [37].

CRM and CFM seek to curb the practice of an offense, investigating complaints in order to determine the responsibility of the physician at fault and applying the appropriate penalties when guilt is proven [23]. The medical error occurs when the professional - acts with incompetence, recklessness or negligence in the practice of medicine - performs conduct in violation of procedures, or of the rules and legislation aimed at regulating their actions and preventing such a mistake, resulting in damage to the life or health of the patient. In addition to safeguarding the profession, working ethically and respecting the life and dignity of human beings, doctors must do everything in their power (diagnosis and treatment) for the benefit of patients, without harming them.

Research conducted in the CFM Ethical-Professional Process System [38], on the 23th March 2015, showed that, among the specialties that most infringed Article 1 of the CEM, which prohibits doctors from causing harm to patients, by act or omission [17], plastic surgery was ranked third. It is noteworthy that the statistics do not necessarily correspond to mistakes made by experts from the fields indicated, but to the specialities with more ethical infringements, whether the physician was an expert or not. Aesthetic damage occurs as a result of an unwanted and vex-

ations change in the patient's body [39], affecting the patient both physically and mentally, besides exposing them to embarrassment and humiliation in the social sphere.

Statistics of medical areas with more notes for infringement of Article 1 of the Code of Medical Ethics - 2010-2014

Speciality	Total
Gynaecology and obstetrics	160
Clinical medicine	91
Plastic Surgery	63
Paediatrics	60
General surgery	41
Orthopaedics and traumatology	29
Paediatric surgery	3
Neurosurgery	2
Cardiovascular Surgery	1
Hand surgery	1
Head and neck surgery	1
Sports medicine	1
Forensic medicine	1
Sexology	1

Source: CFM: data obtained from the CFM Ethical-Professional Process System (SIEM / SAS) 23th March 2015.

**** This statistic is compiled based on professionals reported, since an infringement process can have more than one professional reported. Survey of the penalty for infringement of letters "a", "b", "c" and "e" of Article 22 of Law 3,268/1957.***

These statistics corroborate the need to impose limits on the exercise of medical practice in general. Such an imposition is not intended to suppress good people, but to indicate ways to prevent errors and promote patient safety.

Final considerations

The promising market that plastic surgery has become, mainly for aesthetic purposes, does not preclude physicians' ethical duty to treat medicine as an essential activity for human life. To exercise it, the professional as well as being conscientious, competent and qualified, must ensure, for the greater good, the life and well-being of their patients.

The mechanisms that influence the growing demand for cosmetic surgeries revolve around the exacerbated spread of unequivocal standards of beauty, based on slimness and a youthful body and face. Electronic media, through selfies and postings on social networks, as well as news stories published by other means, lead fans and celebrity admirers to seek these, sometimes unrealistic, standards of beauty. Physicians should make their patients aware as to whether or not these procedures should be applied.

Clinical bioethics, especially its principialist aspect, cherishes the best doctor-patient relationship. In medical practice, therefore, the principles of beneficence, non-maleficence, autonomy and justice propounded by principialist bioethics should be practiced daily, so that neither the patient nor the doctor are subjected to unethical and harmful situations. The doctor has a duty to do good for each patient, without harming them; the doctor's conduct should be guided by ethics, be appropriate and fair, resulting in providing correct, accurate and instructive information to their patients in order to ensure they enjoy their freedom and autonomy to make decisions. By contrast, doctors have their rights, including the right to refuse medical or surgical procedures that go against their values, knowledge and experience; that is, the right to refuse to perform interventions that they consider unethical and that can be more harmful than beneficial for the patient.

One of the main functions of organisations that regulate, inspect and control the practice of medicine - CFM, CRM, AMB, SBCP - is to safeguard the technical and legal performance of medicine, by demanding more specialized training, defining ethical and procedural criteria, avoiding harmful acts, and investigating and punishing possible and potential medical errors. In view of this statute, it is of paramount importance that these institutions devote themselves to the fullest, to impose limits on cosmetic surgery whenever there is a hazardous situation for the patient, which will inevitably impact on the medical field itself.

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Overdiagnosis and its implications in Clinical Engineering

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Abstract

The objective of this study was to analyze the indiscriminate use of medical technologies could cause damage. The methodology involved a literature review of the use of technologies that can precociously detect diseases, generating premature diagnoses, unnecessary actions and burden health systems. Resulting in guidelines that seek the rational use of medical technologies to ensure access to those who really will benefit and protect those who do not need to be exposed to risk. The objective of Clinical Engineering is to help and even intervene in the health sector aiming for wellbeing, safety, cost reduction and quality in health services. Health care costs have been increasing drastically and are a global concern. Financial resources are finite compared to the numerous technological resources. Ethical and bioethical issues that should support the policies and practices of health professionals were considered in the end.

Keywords: Biomedical engineering. Health systems. Bioethics and biomedical technology.

Resumo

Sobrediagnóstico e suas implicações na engenharia clínica

Pretendeu-se analisar em que medida o uso indiscriminado de tecnologias médicas pode causar prejuízos. A metodologia envolveu a revisão da literatura acerca do emprego de tecnologias capazes de detectar doenças de maneira bastante precoce, gerando diagnósticos prematuros, ações desnecessárias e oneração dos sistemas de saúde, o que resultou em orientações centradas no uso racional das tecnologias médicas, para garantir o acesso aos que realmente terão benefícios, bem como a proteção dos que não precisam ser expostos a risco. A engenharia clínica destina-se a auxiliar, e mesmo interferir, na área da saúde em função de bem-estar, segurança, redução de custos e qualidade nos serviços de saúde. Os custos com a saúde têm aumentado drasticamente, e é uma preocupação mundial. Os aportes financeiros são finitos diante de inúmeros recursos tecnológicos disponíveis. As questões éticas e bioéticas que devem fundamentar as políticas e as práticas dos profissionais de saúde foram consideradas ao final.

Palavras-chave: Engenharia biomédica. Sistemas de saúde. Bioética e tecnologia biomédica.

Resumen

El sobrediagnóstico y sus implicaciones en la Ingeniería Clínica

El objetivo de este estudio fue analizar que el uso indiscriminado de tecnologías médicas podría ocasionar perjuicios. La metodología incluyó una revisión de la literatura sobre el uso de tecnologías que pueden detectar muy anticipadamente enfermedades, generar diagnósticos prematuros, acciones innecesarias y resultar onerosos para los sistemas de salud. Resultando en directrices que buscan el uso racional de las tecnologías médicas para garantizar el acceso a aquellos que realmente se beneficiarán y protegiendo a aquellos que no deben ser expuestos al riesgo. La Ingeniería Clínica tiene como objetivo ayudar e incluso interferir en el cuidado de la salud buscando el bienestar, la seguridad, la reducción de costos y la calidad de los servicios de salud. Los costos de atención de la salud han aumentado drásticamente y es una preocupación mundial. Los recursos financieros son finitos frente a los inúmeros recursos tecnológicos. Las cuestiones éticas y bioéticas que deben fundamentar las políticas y prácticas de los profesionales de salud fueron consideradas al final.

Palabras-clave: Ingeniería biomédica. Sistemas de salud. Bioética y tecnología biomédica.

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Declaram não haver conflito de interesse.

Among the precepts of medicine is the *primum non nocere* principle (above all, do no harm). All medical technologies bear some inherent risk and thus should be used when benefits outweigh the potential harm. The use of medical technologies in face of insufficient benefits maximizes the risk and ends up resulting in potential loss.

The indiscriminate use of these technologies may compromise the efficiency of health services, given that the promotion of service quality must pursue the best clinical outcomes, greater benefits and fewer risks to patients, at an appropriate cost.

The so-called hard medical technologies include medical-care equipment, whose life cycle is characterized by the following phases: innovation, dissemination, incorporation and abandonment [1]. High complexity equipment has a high cost of acquisition. To have an idea of such costs, the Management and Information System for Equipment and Materials funded by the National Health System (Sigem) [2] makes available the updated values of some devices used in diagnostics, as shown in Table 1.

Table 1. Cost of medical care equipment used in highly complex diagnostics - Brazil, 2015

Equipment	Cost (BRL)
Positron emission tomography (PET-CT)	5,000,000
Nuclear magnetic resonance 1,5 T	3,800,00
Computerized tomography (64 channels)	1,900,000
Scintigraphic camera (Gamma Camera)	1,100,000
X-ray machine with remote-controlled fluoroscopy	650,000
Digital mammography device	600,000
Fixed digital radiology unit (DR)	330,000

Source: FNS/Sigem, 2015 [2].

In diagnostics, the use of these technologies may allow the detection of diseases at a very early stage. Numerous technological varieties compete for the establishment of early diagnoses. However, when isolated and with inadequate evaluation, such diagnoses may lead to premature treatment and unnecessary actions, in addition of burdening health systems. Thus, the rational use of these technologies is an indispensable measure to avoid exposure and the unnecessary treatment of healthy individuals.

Technological innovations are constant and accompanied by the proliferation of sophisticated diagnostic tests, which are the result of biomedical discoveries that heavily pressure the market and the health industrial complex. Such innovations must be assessed so that they can be incorporated into the safest and most effective technologies when it comes to cost.

This study analyzes the impact of overdiagnosis in the clinical area, considering aspects related to the management and financing as well as ethical and bioethical conflicts, which have been constant in that context. The work methodology involves bibliographical and documentary review.

Overdiagnosis

Diagnosis can be defined as the classification provided by a physician to a disease or physiological state, based on medical history assessment as well as on the observation of symptoms and various tests. Overdiagnosis occurs when symptomless individuals are diagnosed by means of a simple image or laboratory finding, which, at first, would not result in symptoms or damage.

Therefore, the challenge is to best distinguish benign abnormalities from those which will progress and lead to damage. Issues regarding overdiagnosis may be discussed based on two perspectives: the first one relates to the patient on an individual level and refers to the unnecessary exposure of patients to the risks inherent in medical technologies; the second one has a collective dimension and concerns the rationalization of resources used.

The rational use of medical technologies must focus on ensuring access to those whose will truly benefit, as well as on protecting those who do not need to be exposed to the risks arising from the use of such technologies. In summary, resources must be offered to those who will truly benefit and the access to such resources must be guaranteed. Avoiding excesses will allow access to potential users. Therefore, access and excess must be balanced.

In a study made for the Institute of Supplementary Health Studies (IESS), Reis and Mansini claim that the US health care system wastes between US $ 543 billion and $ 815 billion annually. *The amount represents 20% to 30% of the total invested in the sector or 3.6% to 4.5% of the American Gross Domestic Product (GDP)*[3]. In a statement published on the IESS website in April 2015, the institute's executive superintendent, Luiz Augusto Carneiro, points out: *We are aware that health cost variation above inflation is a global phenomenon. Nevertheless, this causes a lot of concern in Brazil, as the increase in*

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costs has remained at a very high level [4]. The burden resulting from overdiagnosis significantly threatens collective health systems.

Complementary tests are important, provided they are made based on the appropriate criteria. The responsibility of overdiagnosis lies in several factors: lack of adequate medical training, resulting in lack of assurance in the diagnosis; marketing issues pressing for the increased number of patients assisted and decreased consultation time; inefficient government policies, such as disease screening in healthy individuals; commercial interests and marketing strategies used by medical technology suppliers; defensive medicine, supported by legal mechanisms which fight underdiagnosis, but do not punish overdiagnosis; the popular culture of "the more, the better"; patient's preference and insistence when it comes to requesting diagnostic tests, which is driven by the belief that the mere request made by physicians represents a parameter to assess the quality of care provided by them.

A few decades ago, physicians could examine a patient in 50 minutes and ask for a few tests to confirm the diagnosis. Medical history and a physical exam were the basis of clinical diagnosis and guided the request for further tests. When performed under appropriate conditions and by qualified physicians, a medical history assessment can account for up to 90% of correct diagnostic hypotheses, thus having great value in the diagnosis procedure. Nowadays, however, this situation is reversed: tests precede the diagnosis, and the doctor-patient relationship has come to be mediated, if not monopolized, by the use of hard medical technologies.

A series of negative events may result from excessive and uncontrolled use of medical technologies. In addition to unnecessary therapies and to the fact that the financial resources allotted could promote more benefits if used in the treatment and care of real pathologies, other factors must be considered: anxiety, adverse effects and absenteeism on the part of patients; expansion of the limits of pathology characterization and lower thresholds for treatment in medical practice [5].

Health strategies aimed at preventive care led to increased disease screening of apparently healthy individuals. While screening is conducted broadly, its benefits are neither universally defined nor accepted [5].

A study by Welch and Black involving several types of cancers describes the large repertoire of subclinical findings in autopsy analysis of several individuals who died from causes other than cancer itself [6]. In the same study, the authors emphasize that the main factor responsible for accidental cancer detection is the increased use of diagnostic imaging, not necessarily resulting from a larger number of tests performed, but rather due to the increased sensitivity of the tests.

The practice of medicine based on clinical evidence tends to replace general exams for more cost-effective health actions, such as the selective periodic health exam, targeting specific characteristics of individuals [5].

When the benefits of screening strategies are analyzed, it is necessary to consider ways to identify those "initial abnormalities" which, although found in the tests, will never progress, and consider their possible impact on budget constraints as well as on morbidity and mortality rates. Harm analysis must consider aspects such as the assessment of the damage caused by exposure to these technologies; the false-positive result rate; overtreatment due to indolent-behavior malignant lesions treated regardless of the certainty about their evolution. In addition to false-negative results, false-positive ones lead to significant clinical, social and psychological impacts: about one-third to one-fifth of the cancers identified in screening are considered to be overdiagnosis; that is, if it were not for screening, the disease would not have been diagnosed and would not have caused harm to patients [7].

Besides the ability to make the diagnosis, physicians must have capacity to distinguish the findings which will develop into a disease, thus becoming a health problem, from those present in tests of individuals who have the disease but showed no symptoms or health problems related to this diagnosis. Daniel Guimarães Tiezzi, physician and professor of mastology and gynecological oncology at the Ribeirão Preto Medical School (FMRP), University of São Paulo (USP), reports that, *through mammography we can diagnose lesions that may or may not develop into a more aggressive cancer, as well as highly invasive lesions which would never progress, or would progress so slowly they would have no effect on patients' current or future quality of life*[8].

A study undertaken by Santiago et. al. to assess the prevalence and factors associated with screening tests for prostate cancer in elderly individuals in the city of Juiz de Fora/MG, concluded that *the benefits and risks of screening for this type of cancer have been widely discussed in medical literature and there is no consensus on the guidelines for its use at population level, in addition, it continues to*

have significant implications for public health, such as overdiagnosis and overtreatment [9].

According to the National Cancer Institute (Inca), we must *carefully weigh a number of factors before requesting additional tests, as conducting multiple tests does not necessarily mean a more accurate diagnosis. There is often an excessive request for tests, which leads to increased health care costs. It should also be noted that, contrary to current opinion, the fact that a service relies on sophisticated equipment does not necessarily mean that the standard of care is superior* [10].

In their study, Marsaro and Lima report the following in regard to hypertension overdiagnosis during medical appointments (HC): *It has been known for a long time that BP (Blood Pressure) may increase in the presence of physicians, however, the advent of ambulatory blood pressure monitoring (Map) allowed the exaggerated increase in BP, related to consultations, to be recognized and referred to as the white-coat effect. This persistent pressure increase in the medical environment may reach levels which are typical of HA (Hypertension) and be associated with normal ambulatory BP on other occasions.* According to the authors, the white-coat effect *causes an overestimation of BP and overdiagnosis of hypertension, both qualitatively and quantitatively, and is responsible for the improper use of antihypertensive medication in some patients* [11]. To correct this effect, it is recommended that blood pressure be measured after the establishment of a doctor-patient interaction.

Clinical engineering and overdiagnosis

In the 1960s, in the United States, in response to concerns about patient safety and the intense proliferation of clinical equipment, engineers were encouraged to enter hospital service [12]. Clinical engineering is defined as the branch of engineering dedicated to assist and, even interfere in, health, to achieve well-being, safety, cost reduction and quality of services available to patients and the hospital's multidisciplinary team, which occurs through the application of managerial and engineering knowledge to health care technology. Overdiagnosis significantly impacts clinical engineering, as it is often related to the excessive reliance on hospital equipment used to detect diseases and establish diagnoses.

It can even be said that this impact is felt in all fields of activity in clinical engineering: medical and hospital technology management; research, development and innovation; evaluation of health care technologies; regulatory agencies; insurers and the commercial area. In addition, overdiagnosis clearly interferes in services and routines, making it difficult to maximize available resources and reduce the risks of exposure to health care technologies.

As new methods and technologies become available in hospitals, the dimensions of actions and the knowledge domain regarding clinical engineering are multiplied. Such actions consist in assessing the needs for improvement when it comes to patient care, as well as in checking their compliance with effectiveness and safety requirements [12].

Health care costs have increased dramatically, and this is a global concern. Financial resources are finite in face of the countless technological resources available. Therefore, clinical engineers must strive to rationalize resource distribution, seeking to maximize health care benefits, ensuring access to safe and effective technologies.

In addition to substantially fostering the economy and expertise, medical technologies actively contribute to the field of innovations. Clinical engineering professionals are pressed by advances in science and engineering, and are responsible for evaluating technologies in terms of their functionality, efficiency and effectiveness, cost-effectiveness, results and outcomes, safety, actual level of innovation (incremental or radical) and dissemination phase so that the decision on whether such technologies will be adopted can be made. In summary, they must technically assess these innovations so as to distinguish marketing strategies disguised as technological advance.

Gadelha emphasizes the role of the medical equipment industry *permanently encourages the debate on the tension between industrial and sanitary logic*[13]*, which happens both due to this industry's innovation potential – it strongly incorporates the advances associated with the microelectronic paradigm – and due to the impact it has on services – as it represents a constant source of changes in health care practices* [13].

The uncontrolled adoption of medical technologies affects health care services, overloads the hospital technological park and contributes to the waste of resources. In general, aggregate new technologies are cumulative and characterized by the complementation of existing methods, rather than by their replacement, *which actually presses the cost of health care services* [14].

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Based on considerations made by Panerai and Peña-Mohr, the Ministry of Health comments on technological innovation and the obsolescence of medical equipment: *the technological innovation rate since World War II was not accompanied by a similar rate of abandonment of older technologies, resulting in a continuous increase in the inventory of health care technologies available. It took some technologies which have proven ineffective or obsolete long to be definitely abandoned* [15].

For the Ministry of Health, *unlike technologies that resist abandonment, a considerable number of other technologies are forced out of the market due to the so-called "artificial obsolescence". This strategy is used by many industries to increase their sales. Artificial obsolescence often involves small innovations rather than radical ones, adding little value for patients or physicians* [15].

Gadelha says that the dissemination of technological innovations linked to the medical equipment industry happens extremely fast in health care services. For the author, *more relevant than the effort for productive efficiency is the permanent pressure to add new procedures, such as the use of magnetic resonance imaging, computed tomography, ultrasound and X-rays, often in the same units providing diagnostic imaging services* [14].

In summary, the contribution made by clinical engineering must focus on the evaluation of health care technologies, so as to ensure the safety and quality of services with cost control, avoiding excessive consumption of hard medical technologies, the use of ineffective equipment and unnecessary exposure to risk.

Bioethics and overdiagnosis

In the field of bioethics, overdiagnosis has clear implications on the principles of justice, beneficence and nonmaleficence. Health care systems have an ethical obligation to extend benefits as much as possible and reduce damage or loss to the most minimum level. Their actions must be based on justice, equality of opportunity, the rule of efficiency, the provision of quality services as well as on increasing the number of accesses and the degree of service coverage [16].

The Code of Medical Ethics and other regulations provided by the Federal Council of Medicine establish that, in the relationship with patients, physicians are forbidden *to exaggerate diagnosis or prognosis severity, complicate therapy or exceed in the number of consultations, visits or any other medical procedures* [17].

Correa and Mejía state that, in the management of the public health care system, distributive justice occurs through the identification of the needs and the establishment of priorities so that resources are properly distributed. However, for the authors, without scientific basis, such resources may be allocated to non-beneficial services, instead of being put to better use in other needs [18].

In the management of health services, ethics must consider that resources are insufficient to meet all needs and that, therefore, efficiency becomes *sine qua non* for the establishment of fairness as well as of an ethical imperative at the administrative level [19]. Health care professionals and public health managers are ethically obliged to optimize resources to contemplate more access to the system, with the best quality and at the lowest possible cost [19]. At all levels, health technology management must consider the ethical implications of its actions.

According to the National Policy on Health Care Technology Management, provided by Ministry of Health, the evaluation of health care technologies *is the ongoing process of analysis and synthesis of health care benefits, as well as of economic and social consequences related to the use of such technologies, considering the following aspects: safety, accuracy, efficacy, effectiveness, cost, cost-effectiveness and fairness, in addition to ethical, cultural and environmental impacts involved in their use* [20].

The adoption high-cost complex technologies – often prematurely abandoned due to lack of inputs and spare parts – contributes to the formation of actual equipment graveyards in hospitals [21]. It is estimated that up to 40% of medical equipment in the public sector is underutilized or inoperative, resulting from misuse, improper acquisition, maintenance and infrastructure issues [22].

Underutilized, or even inoperative, medical technologies lead to losses to health care services, compromising access to the system and the offer of health care actions. The indiscriminate use of complex technology, with high added value and broad commercial appeal - marketed as indispensable and which are often prematurely abandoned – not only negatively impacts the rationalization of resources, but also generates issues related to the disposal of such equipment, because, apart from the housing, many of these pieces of equipment contain elements whose recycling or disposal processes are costly and laborious, such as pipes and

X-ray generators, electronic elements, chemicals, among others.

When it comes to the use of these medical technologies, excess must consider the entire life cycle of the equipment, from the innovation phase to abandonment. In addition to creating opportunities of access and quality services, both the risk-benefit and cost-effectiveness ratios must be taken into account.

Final Considerations

Rationalizing the use of technology and promoting its proper assessment are extremely important measures to support the decision-making process within health care systems. Therefore, it is necessary to ensure that health care professionals would be willing to give up the unjustified use, without clinical evidence, of the most sophisticated technological innovations in favor of more effective technologies which are accessible to most of the population. To that effect, the focus of health care must be reconsidered taking promotion and prevention into account, with no unnecessary resource imbalances and risks, so as to protect healthy individuals and assist those who truly need health care services.

The idea, which is widespread among the general population, that to maintain health it is essential to carry out numerous tests must be reconsidered. It is the culture of the more, the better. Such perspective is based on the concept that modern technologies are necessarily superior to conventional ones. However, we must think of health care as a set of factors that include health, quality of life, healthy habits, rather than as the unnecessary conduction of numerous tests to identify alleged infirmities which are unlikely to bring any harm to patients.

We must verify whether the increased number of tests has actually contributed to reduce morbidity and mortality, whereas considering the impact of false-positive results in the early detection of pathologies which are unlikely to cause harm. Medical technologies must be adopted based on scientific evidence, rather than on the basis of market logic. Adherence to technologies must be based on benefits which overweigh potential risks and justify related costs.

Advances and technological innovations, along with the importance of prevention, increasingly drive the demand for additional tests. Thus, it is necessary not only to balance and optimize resources based on the sustainability of health care systems, but also to avoid the excessive use of these technologies, which, in addition to burdening the system, may lead to damage to the health of individuals. Such initiatives are made possible by strengthening the sustainable management of hospital technology parks, encouraging moderate consumption as well as actions to avoid underutilization and early abandonment of hard medical technologies.

Rationalization and effectiveness of resources in diagnostic services not only represent a challenge for clinical engineering, but require the commitment of the medical profession, society and decision makers in the scope of health systems. When contemplating the bioethical debate, such instances must start from the central question, which is that these actions must prioritize the welfare and safety of human beings as well as of the community.

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Fotini Santos Toscas conceived and wrote the paper. Fernanda Toscas made the critical review.

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What shout is this? Sounds of women – an argument for recognition

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Abstract

This article intends to address the weaknesses surrounding the existence of women for the simple fact that biologically they are female. The arguments used for exploring this theme are anchored in Amartya Sen's dialogues with other thinkers from different fields. It is worth noting that this essay uses distinct scenarios as its basis, from social movements, to situations exploited by the media, among others. It is also suggested that this field of discussion of gender relations is carried by positions of power, tensions, confrontations, accommodations and evictions that need to be problematized in relation to women, whether in contexts of education, health, social inclusion, work and housing.

Keywords: Women. Gender identity. Social movements.

Resumo

Que grito é esse? Sonoridades de mulheres: uma discussão por reconhecimento

Este artigo pretende discutir as fragilidades que circundam a existência das mulheres pelo simples fato biológico de serem fêmeas. Os argumentos utilizados para explorar essa temática estão ancorados na fala de Amartya Sen, em diálogo com outros pensadores de diferentes áreas. Cabe frisar que este ensaio trabalha com distintos cenários como alicerce, desde movimentos sociais até casos explorados pela mídia, entre outros. Sugere, também, que esse campo de discussão das relações de gênero está carregado de espaços de poder, tensões, enfrentamentos, acomodações e desalojamentos, que devem ser problematizados no tocante às mulheres, no contexto da educação, saúde, inserção social, do trabalho, da habitação.

Palavras-chave: Mulheres. Identidade de gênero. Movimentos sociais.

Resumen

¿Qué grito es ese? Sonoridades de mujeres: una discusión por el reconocimiento

Este artículo pretende abordar las fragilidades que rodean la existencia de las mujeres por el simple hecho biológico de ser hembras. Los argumentos utilizados para explorar esta temática se anclan en el discurso de Amartya Sen, en diálogo con otros pensadores de distintas áreas. Vale subrayar que este ensayo trabaja con diferentes escenarios para su exposición, desde movimientos sociales hasta situaciones ya muy discutidas por los medios de comunicación, entre otros. Sugiere, también, que el campo de discusión de las relaciones de género está cargado de espacios de poder, tensiones, enfrentamientos, resignaciones y desalojos, que deben ser problematizados con respeto a las mujeres, en el contexto de la educación, la salud, la inclusión social, el trabajo y la vivienda.

Palabras-clave: Mujeres. Identidad de género. Movimientos sociales.

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Declaram não haver conflito de interesse.

On that day of open skies, the unique blue of Brasília once again witnessed a cry, a march, single voice: revindicating, soliciting, laying bare the paradigms facing the feminine and the masculine. Certainly, on the 18th of June of 2011, the 2,000 people (men and women) who traveled to the central zone of the Federal Capital demonstrated their indignation at the speech and asymmetric opinions, coming from every social class, which diminished women.

Almost a year later, on the 26th of May of 2012, again, close to 3,000 people met together under the same blue sky of Brasília. The hot afternoon of that day witnessed the voice of thousands of demonstrators who stood up against the oppression, expressed by asymmetrical axes interposed in the trajectory of women and backed by patriarchal norms which permeate the social context. The two demonstrations referred to were the Slut Walk.

Thus, with the theme of rape as a motto, this march raises questions linked to the issue of gender, more specifically, feminine vulnerability in the face of legitimization and naturalization of roles established by the dominant system. As reported in the Red Portal:

The Slut Walk was created in the year 2011, as a response to a lecture on rape prevention, held at the University of Toronto, in Canada. The policeman who administered the lecture asked women to "avoid dressing like sluts, in order to not be victims (of rape)." The college women, outraged by the comment, organized the first Slut Walk. The fight soon spread around the world, after all it is not only in Canada that women are blamed for the violence that they suffer [1].

The movement, recognizing the limited space reserved for women in the social imagination, quickly took possession of the derogatory terms directed at them, who are the main victims of rape: "women who are easy"; "women who dress provocatively"; "women who appear to be available". Obviously, the name of the movement – Slut Walk – was astonishing to many people. The women were not few who, feeling themselves insulted, condemned this designation due to not knowing the group's history. However, receptivity was also verified, especially by the youngest and best informed women, who understood how the police observations that led to the march went against the human rights of women.

Faced with such disparate reactions, it became necessary to justify the name of the movement: *Every woman already was or will be called a slut one day. For this, it is enough that she has a more assertive attitude in the face of oppressive behavior. Because of this, we will not constrain ourselves in facing up to this term. We will appropriate it* [1], one of the organizers of the march in Brasília stated, in a report about the movement. This response carries an underlying provocative tone, marked by gender issues that pervade the societal relations of the dominant hegemonic movement, which separates what is allowed from what is prohibited for men and women [2-4].

Surely, the differentiated rules for each gender produce favoritism and subalternities and, as a a result of these dissimilarities, regarded as legitimate, there are applied *rules and from both distinct attitudes are demaded* [5]. Thus, to better understand the issue, "gender" is taken, in this article, as a social condition which identifies its subjects as men and women in the varied dimensions of masculinity and femininity [6].

From this line of reasoning, which refers to the arguments of disadvantage, inequality and, in consequence, the inability produced by the external environment, which sometimes brings the woman to remain totally or partially unable to obtain or achieve freedom, it is that this article emerges and dialogues with the concerns of the Indian economist and philosopher Amartya Sen [7]. For the author, who works with the theme globally, these social conjunctures have been a constant subject of reflection. In discussing the problem, treating development as freedom and freedom as development, the thinker stresses the need to promote egalitarian opportunities for women and men, in the context of individual and social achievements.

Thinking of the asymmetries

Sen, in his work, *Development as Freedom* [7], states that economic growth is not the only factor in the development of a nation, but there should also be consideration of the entire context which involves people's lives. The author stresses that *development has to be related, above all, to the improvement of the lives we lead and the freedoms we enjoy* [8]. To expound his thinking more clearly, Sen uses the concept of "substantive freedoms", whose absence results in the impossibility of access to several benefits: (...) *in global opulence, the contemporary world, denies elementary freedoms to vast numbers of people* (...). *The lack of substantive free-*

doms directly relates to economic poverty, which robs people of the freedom to satisfy hunger; or to achieve sufficient nutrition, or to obtain remedies for treatable diseases, the opportunityto be adequately clothed or sheltered, or to enjoy clean water or sanitary facilities(…). [There is] *a lack of public services and social assistance* (...), *effective institutions for the maintenance of peace and order* (...). *The violation of freedom results directly from denial of political and civil liberties* (...) *and from imposed restrictions on the freedom to participate in the social, political and economic life of the community* [9].

In emphasizing the problem of freedoms, the thinker highlights the issue of access and choice. In fact, he questions how it is possible that an individual can be free if he does not have access to health, education, quality housing, or sanitation; if he does not even have the right to physical integrity, as is the case with many women in the world and in Brazil.

Aimed at achieving access to political and civil liberties, the March of the Daisies (a movement formed by field, forest and water workers) took place on the 12th of August of 2015, in Brasília/DF. The motto of the movement this year was: Sustainable Development with Democracy, Justice, Autonomy, Equality and Freedom. Among the demands of the Daisies, delivered to the Federal Government, were the clamor for public policies for refuge for rural women, for providing tools to combat violence, for the end of rural femicide. According to the Minister of the Secretariat of Policies for Women of the Presidency of the Republic, Eleonora Menicucci, the demands *represent the resistance of those who are facing the obstacles of life and,* (...) *of those who are working on the land. Women who resist machismo and all of its predjuiced actsdaily* [10]. Surely, these women, by engaging themselves in the march using speech and pacifism seek, irrefutably, to overcome the vulnerabilities that surround them.

Continuing the theme of freedom, Sen points out that *expanding the freedoms that we have reason to value not only makes our lives richer and more unfettered, but allows us to befuller social persons, exercising our own volitions, and interacting with – and influencing - the world in which we live* [9].

In the economist's view, the deprivation of liberty is manifested in various ways, whether by the hunger spectrum, the malnutrition of the vulnerable, the numerous human beings deprived of access to substantive freedoms, or even by the asymmetry between women and men. As for this last aspect, Sen declares that *the inequality between men and women afflicts – and sometimes prematurely ends – the lives of millions of women and, in different ways, severely restricts the substantive freedoms that women enjoy* [9]. The question of asymmetry thus exposes evidence of the existential reality for many women in the world, who, despite globalization, still manage to exhibit this problem as a priority for the planet.

Certainly, there are countries which treat this issue distinctly by promoting actions to minimize or extinguish oppressive processes. Still, it is worth noting that these measures are still timid before the reality of gender issues. In Brazil, President Dilma Rousseff gave a speech in September of 2011, during the High Level Colloquium on the Political Participation of Women, (Colóquio de Alto Nível sobre a Participação Política de Mulheres), a dialogue promoted by UN Women, in which it endorsed the importance of the issue. In her speech, published in the issue of Carta Capital magazine, the president asserted that, *despite some noteworthy advances, inequality remains in the XXI century. It is women who suffer most from extreme poverty, illiteracy, health system failures, conflicts and sexual violence. In general, women receive lower wages for the same occupation and have limited presence in key decision-making bodies* [11].

It should be noted that speeches (made by State representatives or by intellectuals) should be viewed with some reserve. According to Segundo Spivak [12], it is imperative to question the place from which they come, since the words are spoken by those who are dominant, and are not at all neutral. They carry within themselves the gene pool of the prestigious spaces in which they speak. In the preface to Spivak's work, "Can the subaltern speak?' ("Pode o subalterno falar?"), Almeida stresses that the author *acknowledges her complicity in the process, but makes of this recognition a productive space that allows her to question the very place from where she theorizes* [13]. According to Almeida, the Spivak critque is in the sense that the whole body is or has been institutionalized, *hence the it is impossible to articulate a discourse of resistance that is soutside of the hegemonic discourses* [14].

Spivak's contribution is crucial and, at the same time, painful for the intellectuals who work with the subject, insofar as it removes them from their comfort zone, launching them into the desolation of trying to produce, according to Almeida, alternatives for questioning *the subaltern subjects' forms of repression* [14], assessing his own position. Thus, it is fitting for intellectuals or representatives

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of these categories to examine the spaces where they met while speaking.

A study on violence against women, presented in 2011 by the UN's Special Rapporteur, Rashida Manjoo, to the UN General Assembly Committee for Social, Humanitarian and Cultural Affairs, and cited in an article published on the UN website in Brazil, identified that *aggressions such as rape, sexual assault, traffic, forced prostitution, violence against migrant women, pornography, among other similar acts, practiced in the domestic and community sphereswithin the scope of governments and in the international arena.* (...) *certain groups of women presented an increased risk of violence. In the United States, for example, African-Americans suffered 35% more violence from their partners than white women.* (...) *Poor women and those with little education, widowed or separated were more vulnerable due to the lack of family or community support.* According to the Brazilian jurist Sílvia Pimentel, who was mentioned in the samearticle, *the United Nations Population Fund (UNFPA) records approximately 5,000 women murdered by family members, who claimed to have had their honor tainted* [15].

Making use of Sen's line of reasoning as a vehicle for discussion of the state of asymmetry experienced by many women, it can be affirmed that the individuals only managed to positively meet their personal requirements and those of their social environment through *economic opportunities, political liberties, social powers, and by enabling conditions such as health, basic education and incentivization and improvement of the initiatives that are offered* [16].

Paraphrasing Sen [7], the question that arises is: how do women placed in a context of disadvantage find a way out in order to change such processes if they do not have access to the so-called "substantive liberties"? Even the women who, in some way, possess them still suffer from some degree of vulnerability by the simple fact of being women. The naturalization of roles, as much the feminine (subalternity) as the masculine (superiority), in the social imagination ensures that the oppressed person does not recognize her own oppression, whether through the process of socialization to which she was submitted, or through the process of scarcity that surrounds her.

This assertion is consistent with Cardoso's speech, quoted by Machado, by warning about the relationship between insult and pain: (…) *when the act of physical aggression is not culturally understood as an insult, it does not imply in (sic) violence* [17]. This affirmation allows us to conclude that these naturalizations are legitimized and adopted into everyday life, since *women* themselves*, in the name of their gender, are perceived and perceive themselves as placed in a situation of inferior hierarchical value and subjected to power and physical and symbolic violence* [18].

It should be noted that it is not only men who commit violence against women; many times, they themselves assume the mastery of violence, symbolic or not, against other women. In this case, they end up naturalizing the disciplining of their own body, by virtue of their socialization.

This reflection can be analyzed on the basis of the perspective of Bourdieu and Wacquant [19], for whom, depending on the way in which it is exercised upon a social agent, violence ends up depending, not infrequently, on the complicity of the agent itself. The repressive vector does not recognize this manifestation of connivance, and the person who is under the state of oppression may never have had access to different forms of freedom. Corroborating these affirmations, Sen states that the *political and civil freedoms are constitutive elements of human freedoms, their denial is a handicap in itself*[20].

Therefore, while running through social, political and economic denials, in what refers to decisions about their own bodies, these women face difficulties in being recognized as spokespersons in the decision-making process. Among examples of this condition, are the choice to continue or not continue with a pregnancy; the obtainment of economic income equivalent to a man who occupies a similar position; the practice of sex willingly, and not for mere convenience of the partner; the rejection of the imposition of any physical or psychological violence related to the gender issue.

A woman can go through a process of deprivation of her ego when the right to choose is taken away. At this conjuncture, there is an obstacle created to the *person having valuable results* [21] for herself. This approach is recognized by Sen, in underlining that *the vision of freedom adopted here involves as much the processes which permit the freedom of actions and decisions as the real opportunities that people have, given their personal and social circumstances. The deprivation of freedom may arise* (...) *from inadequate opportunities which some people have to carry out the minimum of what they would like to do* [21].

In this sense, when a woman finds herself locked out of the growth process or facing an asym-

metrical offer (as in the case of a wage differentiated by the criterion of gender), the subalternity of the woman is reinforced, becoming even more cemented. Even in this condition, the woman is not exempt from social burdens and existential demands, such as the payment of electricity, water, taxes, housing, health, and subsistence expenses. In this case, however, she would be embedded in a network of unjust social relations, full of asymmetrical meanings.

For Sen, this situation would fit into the issue of *deprivation of freedom,* arising from *inadequate processes* or *inadequate opportunities* [20]. In other words, there would exist in this woman a type of failure caused by the dominant system, which offers men opportunities that are denied, limited or made difficult for women throughouttheir entire life trajectory. In the analysis of this issue and considering that the expansion of the "capabilities" of people leads to a "two-way relationship" between development and freedom, it is opportune to revisit Sen's ideas: *Attention is thus paid particularly to the expansion of the "capabilities" of persons to lead the kind of lives they value - and have reason to value. These capabilities can be enhanced by public policy, but also, on the other side, the direction of public policy can be influenced by the effective use of participatory capabilities by the public.* [22].

Based on Sen's work [7], the importance may be seen of the capacity to access or real advancement that the other exercises on the formation of their own opinions, self-empowerment, ability to manage their choices and to take ownership of these [23]. According to Gonçalves:

[empowerment would be the] *individual's ability* [to] *make choices free from political, economic and social constraints, that is, for the subject to make use of her freedom, without coercion mechanisms; in order for this to occur reliably, she should be "educated" for this purpose. To work the institutions (church, family, the State…), and not the person individually. To empower the subject to recognize her vulnerability, reinforcing self-awareness, self-knowledge and self-esteem, in the sense of seeking the best conditions for the expansion of her real needs, which include: education, housing, decision-making power, access to health care, social services, freedom of expression* [24].

The individual, upon reaching the stage of empowerment, would gain freedom, and it is only through this condition that she would be able to put herself in the position of freedom, understood as an extremely complex and comprehensive skill. Surely, the Gonçalves study [23] as well as his work in collaboration with other authors [25], is in agreement with Sen's thought [7] on the essentiality of substantive individual freedoms.

The authors agree with the thought that a society would only be considered successful if the individuals living in it were endowed with the capability of reaching full choices. For Sen [7], the one who can choose is in possession of the moral tool of choice: positive freedom. Whereas the person who cannot choose, because of some obstacle, has negative liberty. Applying this theory to the status of the woman in the world, it can be considered that today she still remains within the compass of injustice, especially with regard to the economic, social and political spheres and in access to basic goods, such as education and health.

This mapping of asymmetries shows the weaknesses which surround the existence of the woman, among which is the impossibility of achieving formal education to empower herself. Even when qualified, she is faced with the patriarchal structure of the companies and organizations that offer lower wages than that of men. Positioning themselves in the labor market with wages equivalent to men and climbing to the top of the career ladder are nearly unattainable goals for women, faced by the sexist design woven into employment structures. In a sweet and subtle way, these structures deny the existence of their structural perversity.

On this issue, Spivak's speech, cited by Almeida, is perfectly adapted to women, since they make up *the bottom layers of society constituted by specific modes of exclusion from markets, political-legal representation, and the possibility of full membership in dominant social strata* [26].

In this line of reasoning, it can be pointed out that the woman finds herself put into a position of negative freedom, as Sen would say, and that this condition is often responsible for her lack of appropriate social rights, as well as for her belief, deduced from her own speeches, in the oppression forced on her body, impeding her from reaching a place of prestige. For Arendt [27], she lacks the ability to recognize her citizenship status; that is, in her view residing, also, in the understanding, already embedded in society, of not seeing herself with "the right to have rights".

Eleonora Menicucci, Chief Minister of the Special Secretariat of Policies for Women of the Presidency of the Republic, while participating in

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the Rio+20 Conference, signaled this problem and, subsequently, wrote an article for the *Jornal do Dia newspaper*, in which she manifests her concern: *Simultaneously, we cannot think of a sustainable world that accepts violence against women, and the sexual exploitation of children, adolescents and women, nor human trafficking. We cannot think of a sustainable world that accepts a discriminatory, sexist and racist education. Nor of a green economy which coexists with the existing wage gap between women and men* [28].

To underpin such considerations, the theoretical framework of bioethics may be used, which concentrates its view on different moral tools in an attempt to find solutions able to minimize, or even extinguish the conditions that generate inequality and destitution of any order. In this sense the discipline relies on the moral instrument of equity – understood here as a tool productive of equal opportunity –, having seen that in this field, individual differences are permitted, and, in consequence, the specific needs of each person. Such a problem is debated by Diniz and Guilhem, for whom the difference cannot be translated nor confused with oppression and/or inequality: *[there should not be] confusion of vulnerability, oppression and inequality with difference. Difference is a moral value of modernity that deserves to be and should be preserved.* (...) *The presupposition of difference is, therefore, one of the components of the philosophical project of moral pluralism;* (...)*mutual co-existence in difference is possible.Thus, it is important to differentiate vulnerability from difference, even inequality from difference. And what makes inequality and difference two separate categories is the access to and the enjoyment of social power given to each person* [29].

In an analogy to Sen's thought [7], it is possible to sustain that a woman, in this specific case, in which her right to substantive liberties is denied, neither will nor can feel herself included in the social picture, whose opportunities are distributed by different access channels. For the author, there is an urgent necessity to opt for the right to speak of those who find themselves in a state of destitution: (...) *it is necessary to keep in mind* (...) *that if we want a stronger voice in the world, whether be of poor countries, of women, of men, or of the poorest segment of the population in a country* [22].

Based on this reasoning, several questions arise, among these the question of the subalternity in which women of different levels are found, in the social, economic, political, educational, and health fields, among others. Thus, it is fitting to question: to what extent can a woman suffering from poverty have her voice, her outcry heard? Wouldshe be in the group of those who could be heard? What is the level of autonomy for her to gain mastery of the decision-making process of her own life trajectory?

Observing from a different angle, even the woman who has education, work and access to health care should not be taken as someone exercising full freedom on her journey, since she cannot decide on practices such as abortion, for example – in which, to terminate the pregnancy, she has to undergo evaluation. Although the profile of this work does not focus on the issue of abortion, this argument is used with the objective of anchoring to the reasoning which follows.

Based on what is shown, a question is fitting: if the situation were presented ininverse form, in which the man, for example, abandons a woman pregnant with his child, the moral judgment – considering the context of the social representations – would it be the same? Certainly not. Men are not morally judged in this circumstance. Only the woman is penalized, while the man remains free from any participation in the process. Thus, it can be affirmed that men and women are disciplined for different ends: the woman, to achieve the domestic sphere; and a man, to extend himself to the public sphere [3].

With the funds received by being awarded with the Nobel Prize in Economics in 1998, Sen appointed two funds, one in India and another in Bangladesh, for the fight against illiteracy, against asymmetries between the sexes, as well as for the promotion of access to basic medical care. Withthis, the scholar intended to address one of his greatest concerns, manifested in a Brazilian TV interview: *One of the greatest concerns is the inequality between sexes and, therefore the issue of girls in schools is a central aspect* [30].

It is known that education is a great differential in the lives of women. Promoting it should be a universal concern. It is necessary to recognize that a considerable number of women remain impoverished and without access to formal education. They are often prevented from making choices in situations involving their own bodies, their sexuality, their sexual behavior, their pregnancy process. This is perhaps one of the greatest challenges posed to humanity, because, in the face of the longing for a more just, more egalitarian world, the moral tool of acceptance is invoked. This path will require a stripping away of moral certainties which are closely linked to the organizational system of society, re-

sponsible for the production and maintenance of the patriarchal structure. Thus, it is believed that the human advancement of women can remove them from their subordinate condition and from exploitation of their bodies.

Women condemned to extreme poverty, to lacking formal education, to the sphere of submission and even to submission by the socialization process tend to find it difficult to produce their own moral grammar. They occupy, thus, the space of the unheard, as believed by Gonçalves [3] and Gonçalves and Varandas [4] – this thought is confluent with Spivak's line of reasoning, for whom, according to Almeida, *the subaltern, in this particular case, the woman as subaltern, cannot speak and when she tries to, she does not find the means by which she can make herself heard* [31].

Thus, women surrounded by situations of greater vulnerability are subjected to the place of the invisible and inaudible. Almeida stresses that, for the Indian theory, *it is not possible to speak for the subaltern, but it is possible to work "against" subalternity, creating spaces in which the subaltern can articulate themselves and, as a consequence, can also be heard* [32]. Empowering them and prompting them to draw up a new moral grammar, which removes them from the position of subalternity that they occupy –often unconsciously – could be one possible path, as shown by Gonçalves [23].

In agreement with Almeida, Spivak believes that, *if the speech of the subaltern is obliterated, the subalternwoman finds herself in an even more peripheral position due to the problems underlying gender* [32]. In the words of the author, cited by Almeida, if*, in the context of colonial production, the subaltern has no history and cannot speak, the subaltern as female is even deeper in shadow* [31].

To change this situation, Spivak [12] suggests to intellectuals or the representatives of these categories – and even to the intellectual woman who questions the position from which she is speaking – that they do not reproduce a discourse invested in the dominant structure. This fear is also manifested by Sen [33], when he states that, in order to awaken the "potential" of an individual, it is necessary to create a network of cooperation, subsistence and subsidy and survey of individual needs, thus avoiding possible mismatches. In another work [34], he stresses that this measure would enable the development of a fundamental characteristic of the human being: the capability to not be indifferent to the pain of others.

Spivak [12], in turn, calls on the intellectual woman to be responsible for this process in a more compelling way, according to the words of Almeida: (...) *it is up to her to create spaces and conditions for self-representation and for questioning representational limits, as well as her own place of enunciation and her participation in intellectual work* [31].

Sen and Spivak equally direct their concern to the field of individual spans, bearing in mind those who are found placed in a position of vulnerability and, at the same time, those who wish to extend the right to speak to those who still do not possess it.

From delivered speech

Whether it is in the social movements, or in the speech of women, there is an effort for the sound of the word to mean more than the word. In this sense, echoing the feminist movement, Rangel proposes that *the solution for the problem (would be) in a broad political reform, capable of reaching and altering discrimination factors* [35]. Thus, it is believed that there is a need for incessant vigilance, in order to ensure that the sound of the word emitted is neither lost nor becomes a dialect that few or very few are capable of articulating. The sound cannot remain restricted to small groups.

A confrontation is proposed so that an increasing number of people can understand and empower themselves in the struggle against violence and the countless complexities in which this subject is submerged. There is also proposed an objective in which the social actor (weakened or not, intellectualized or not) would not be a distant participant but a multiplying agent of the expression delivered: no to violence! Paraphrasing Spivak [12], it can be said that the confrontation fought has been continued, so that the subaltern subject is not a mere repeater of the dominant discourse, but, indeed, someone capable of inventing and (re)inventing their own moral grammar, as Gonçalves would say [3].

The decision of the women's movement to appropriate the term "sluts": represented, above all, a form of boldness, without taking into consideration the moral judgment of those who were outside of the protest situation. The purpose of the march was not only to request gender equality, but also to call for women's freedom of choice to be respected, as much in relation to their partners, as to the right to exercise their sexuality as they prefer and to dress the way that is most comfortable for them, among others. According to material published by the Agên-

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cia Brasil newspaper in May of 2012, the goal of the Slut Walk was also *to call society's attention to the fact that violence and sexual abuse is not the fault of the victim. "It is of the abuser and of the rapist", Daniela* [Daniela Montper, organizer of the event] *stresses. "When society is judging the victim, looking for any reason to say that she deserved (the violence), it is taking the fault, from the rapist, from the abuser, and heaping it on the victim", she added* [36].

Another flag raised by the movement, according to the article, was the challenge of "Medida Provisória" (Provisional Measure) 557, written in December 2011, *which established the National System for Registry, Surveillance and Monitoring of Pregnant and Postpartum Women (woman who recently gave birth) for the Prevention of Maternal Mortality within the scope of the SUS (Sistema Único de Saúde). The organizers of the Slut Walk consider that the MP 557 is discriminatory and offensive and has the character of criminalizing women who choose not to continue with the pregnancy, besides controlling these women* [36].

In other words, the MP 557/2011 [37] had been been drafted containing a veiled precaution to prevent the possible eventuality of a pregnant woman to opting for the termination of pregnancy. It is also worth noting that in no part of the text, is mention made of the maternal deaths caused by abortion. In this sense, the MP would be disrespecting the privacy and reproductive autonomy of women. This problem is addressed by the march, since another goal of the movement is to draw attention to the need for women to assume the control of their own lives.

In this way, the movement also seeks to embrace the issue of decriminalizing abortion and, at the same time, to emphasize topics related to groups taken as "minorities", whether women or girls. The march also advocates acceptance of sexual diversity, rejecting all discrimination relative to the sexual orientation or identity of any individual [36]. The intent is to give voices to those who live in a state of silence, whether due to individual or group vulnerability.

Through calling attention to the ethical aspects embedded in the cause, it also intends that this struggle should be plural, independent of segments. From this perspective, the slogans of the movement, taken from the manifesto letter "Why do we march? and cited in the Slut Walk blog, plead for everyone's understanding: *The right to a life free from violence is one of the most basic rights of every woman, and it is by the guarantee of this fundamental right that we march today and we will march until we are all free* [38].

This struggle is considered arduous and requires courage and determination, above all to be made known, as noted by Sen [7] and Spivak [12]. A significant example of this fearlessness was epitomized by television presenter Xuxa Meneghel, who publically exposed her weakness in being a woman, reporting that she had been a victim of sexual abuse during adolescence, according to an article in *Veja* magazine from May 2012 [39]. To make this matter explicit is too painful, since the abused person feels dirty, impure and even promiscuous. Such a feeling arises from the social imagination in which the abused subjectparticipates [3]. Until recently, social belief took as a guiding path the assumption that the person who was raped had provoked her own rape, either by her dress, gestures, behavior, or even way of looking. This misconception exempted the abuser from any responsibility.

To touch upon this issue, besides being something that bothers people, since in any civilization there will always be someone forbidden to someone, means *breaking a cultural barrier, which preached that what went on inside the house was only of interest to those involved* [40]. Thus, it legitimized silence around the issue, demonstrating the pseudo-idea of freedom and respect for another's body.

In Brazil, images broadcast by television and print media show the discrepancy between the apparent sexual liberty instituted and exhibited in the Carnival and the actual behavioral situation experienced by society. Respect for the naked body or the few garments of the people who "sell" the image of Brazilian Carnival are merely a deceptive social arrangement. Culturally, it tries to pass off the idea of a normality that does not reflect the harsh reality lived by women and children in the country. Dalka Ferrari, coordinator at the Reference Center for the Victims of Violence of the Sedes Sapientiae Institute, and data from the Forensic Psychiatry and Psychology Program at the University of São Paulo, published in the same issue of *Veja* magazine, noted that *97% of the perpetrators are known to the family, 38% the own father, 29% the stepfather, and those remaining, the brother, grandfather, uncle, cousin, teacher or family friend* [41].

Based on the elements explained above, it can be affirmed that sexual abuse is often committed by those who should protect women and children. In this sense, any move to bring the issue of abuse to the agenda of discussions is beneficial to the advancement of women.

Final Considerations

It is believed that the role of the academic intellectual is to scrutinize the situation presented here. To smooth over such an issue neither can nor should be understood as a minimalist proposal in the current situation, or as an elaboration of thoughts turned to their "own navel", but rather as the route to be travelled in order to achieve social justice between women and men.

Not to be raped is a woman's right, as it is the State's duty to promote tools capable of supporting them in the maintenance of their physical and moral integrity. A secure path to follow is the systematic adoption of deconstruction of the discourses which, in themselves, contain gender asymmetries. The inclusion of all these issues in the primary school curriculum is a possible alternative for the development of a youth less violent and more caring in relation to women.

Certainly, such measures have reduced the number of rapes and physical and moral aggressions that have been committed against women. Thus, human rights and citizenship would be guaranteed to women, independent of race, social class, religion and education. Decisions are necessary, therefore, from the public power, civil society, legislators and from the intellectuals themselves as much on the discussion about the subalternity of women – especially concerning their rights – as on the combat against this malady. The question is urged: what shout is this? We should take this cry of loneliness from one segment and make it audible throughout society.

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Participation of the authors

Erli Helena Gonçalves is responsible for the intellectual production and research for this article and Adriano Bastos Gentil is responsible for the intellectual production and for formatting the text.

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Medical students in the perception of patients

Jaqueline Berwanger [1], *Gabriele Denti de Geroni* [2], *Elcio Luiz Bonamigo* [3]

Abstract

The objective of this research was to identify the perceptions of patients when treated with student participation. The descriptive and crosscut research was carried out through a questionnaire applied to 200 patients of two Strategies for Family Health units and two outpatient medical specialties. As a result, 98% of patients reported satisfaction to be contributing to medical education, 90% reported receiving more explanations about their disease, 95% received polite, attentive and respectful treatment from students and 97.5% said that students introduced themselves and requested previous consent. It was concluded that most patients are pleased to contribute with teaching and receive further explanation in the presence of students. However, a small percentage reported inadequate approach and dissatisfaction, particularly in the specialties of gynecology and urology, implying the need for the supply of specific guidelines and greater emphasis in the teaching of disciplines concerning the relationship with patients, particularly of Bioethics, by the course coordination and health services.
Keywords: Patient satisfaction. Students, Medical. Outpatients. Patient care. Medical care.

Resumo

Estudantes de medicina na percepção dos pacientes

O objetivo deste estudo foi identificar a percepção de pacientes quando atendidos na presença de estudantes de medicina. Realizou-se pesquisa descritiva e transversal por meio de questionário aplicado a 200 pacientes de duas unidades da Estratégia de Saúde da Família (ESF) e de duas especialidades ambulatoriais. Como resultado, 98% dos pacientes declararam satisfação em contribuir para o ensino médico, 90% informaram receber mais explicações sobre sua doença, 95% receberam tratamento educado, atencioso e respeitoso e 97,5% afirmaram que os estudantes apresentaram-se e solicitaram consentimento prévio. Concluiu-se que a maioria dos pacientes está satisfeita em colaborar para o ensino e recebe mais explicações quando os estudantes estão presentes. Entretanto, pequena parcela informou abordagem inadequada e insatisfação, sobretudo nas especialidades de ginecologia e urologia, inferindo-se a necessidade de fornecer, por parte da coordenação do curso e dos serviços de saúde, orientações específicas e de dar maior ênfase ao ensino de disciplinas que tratam da relação com os pacientes, sobretudo a bioética.
Palavras-chave: Satisfação do paciente. Estudantes de medicina. Pacientes ambulatoriais. Assistência ao paciente. Atendimento médico.

Resumen

Estudiantes de medicina en la percepción de pacientes

El objetivo de esta investigación fue identificar la percepción de pacientes tratados con la participación de estudiantes de medicina. Se realizó un estudio descriptivo y transversal mediante un cuestionario aplicado a 200 pacientes de dos unidades de la Estrategia de Salud de la Familia (ESF) y de dos especialidades ambulatorias. Como resultado, el 98% de los pacientes manifestó satisfacción en contribuir con la educación médica, un 90% informó recibir más explicaciones acerca de su enfermedad, el 95% recibió un trato educado, atento y respetuoso y el 97,5% dijo que los estudiantes se presentaron y pidieron consentimiento previo. Se concluyó que la mayoría de los pacientes están dispuestos a contribuir a la enseñanza y reciben más explicaciones cuando los estudiantes están presentes. No obstante, una pequeña proporción reportó un abordaje inadecuado e insatisfacción, sobre todo en las especialidades de ginecología y urología, infiriéndose la necesidad de proveer, por parte de la coordinación de la carrera y de los servicios de salud, orientaciones específicas y de poner un mayor énfasis en la enseñanza de disciplinas que tratan sobre la relación con pacientes, particularmente de bioética.
Palabras-clave: Satisfacción del paciente. Estudiantes de medicina. Pacientes ambulatorios. Atención al paciente. Atención médica.

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Conflito de interesses: Jaqueline Berwanger e Gabriele Denti de Geroni declaram que, quando da elaboração deste trabalho, eram estudantes do curso de medicina pesquisado. Elcio Luiz Bonamigo declara não haver conflito de interesse.

Research article

Patients have contributed to medical teaching since the beginning of medicine. Great masters have transmitted their knowledge around the diseased or in outpatient clinics. The observation of the behavior of teachers during appointments and the direct contact with patients provides students essential opportunities for their scientific and humanistic development.

In their majority, patients usually take the presence of medical students naturally during their consultations. However, would there be a difference of perception between the service given by the physician alone and that with the participation of medical students? Moreover, in th perspective of patients, would the behavior of students be appropriate in these cases?

It is estimated that the presence of students during the consultation tends to reduce the privacy of the patient, possibly causing discomfort and embarrassment in the disclosure of information. On the other hand, the participation of students could mean the delivery of more detailed information to the patient, bringing additional benefits to the understanding of their disease and better orientation on the treatment.

Studies on this theme are not frequent in the literature. The present study sought to assess the perception of patients on the presence of medical students in ambulatory care of a medical school and of two units of the Estratégia de Saúde da Família (Family Health Strategy - ESF), as well as to identify occasional problems and to propose solutions.

Methods

This is a descriptive and crosscut study, performed during the course of Trabalho de Conclusão de Curso (TCC I, TCC II and TCC III, Graduation Project I, II and II), taught in the 8th , 9th and 10th semesters of the medical school course of the Universidade do Oeste de Santa Catarina (University of West Santa Catarina - Unoesc), in which 200 patients were randomly selected, being 50 of each of two units of ESF in the municipalities of Joaçaba and Herval d'Oeste, both located in in the State of Santa Catarina, Brazil, and 50 in each of the ambulatory care centers for gynecology and urology of the Ambulatório Médico Universitário (University Medical Ambulatory Clinic, AMU) of Joaçaba.

The selected ESF in both municipalities were the ones that regularly had medical students in heath care and both provide general, not specialized care. A inclusion of the AMU, which has specialized ambulatory clinics was due to the need to consider patients of two specialties that deal with the most private parts of the body, gynecology and urology, with the aim to investigate if their perceptions on the presence of students during medical care would show differences. The patients of the AMU had been forwarded by several institutions, including the ESF included in this study.

The survey was performed using a questionnaire with 3 social-demographic questions and 11 specific questions, structured and in the Likert scale. It was carried out between the months of February and August 2012. The perception variables indicated as answers to the questions were: "*Definitely yes*", "*Probably yes*", "*Probably not*" and "*Definitely not*"; or "*Totally agree*", "*Agree*", "Disagree", and "*Totally disagree*". For the reference of quantity the alternatives used were: "*Usually*", "*Sometimes*", "*Rarely*" and "*Never*". The topics of the questions were chosen with basis on the problems most frequently found in literature reviews. The structure of the questions for each type of perception was based on the guidelines presented in the book "How to design questionnaires" [1].

The questionnaire was applied randomly by two of authors to patients in the research places, during routine ambulatory care, after explaining the objectives of the research, agreement to participate and signing of the term of free informed consent. The average time to answer the questionnaire was of approximately 12 minutes.

Answers were analyzed after the first week of data collection and, there being no problem as to the understanding of the questionnaire by the participants, the survey was carried out as planned. Data were stored in Microsoft Office Excel 2007. The test of analysis of variance (ANOVA), Tukey test and G test were performed through the software package BioEstat [5].

Results

As to the age, 40 patients (20%) were between 18 and 30 years old; 38 of them (19%) were between 31 and 40 years old; 41 interviewees (20.5%) were between 41 and 50 years old; 40 (20%) were between 51 and 60 years old; and 41 (20.5%) were 61 years old or older. Concerning gender, 128 participants (64%) were women and 72 (36%) were men.

Concerning schooling, 9 patients (4.5%) were illiterate; 88 (44%) had not completed elementary

school; 29 (14.5%) had finished elementary school; 21 (10.5%) had not completed high school; 35 (17.5%) had finished high school; 10 (5%) had incomplete college studies; 5 (2.5%) had completed college, and 3 (1.5%) had some type of post-college study. Through the analysis of variance and, later, by the application of the Tukey test, it was observed that the predominant schooling among surveyed patients was basic education with a history of incomplete elementary studies ($p < 0.05$).

As to marital status, 114 (57%) participants were married; 32 (16%) were single; 29 (14.5%) were in stable relationships; 11 (5.5%) were divorced, and 14 (7%) were widows or widowers.

Of the total participants, 196 (98%) stated they were pleased to contribute to the learning of medical students, of which 148 (74%) answered "*Definitely pleased*" and 48 (24%), "*Probably*". However, 4 (2%) stated they were not pleased, 3 of which (1.5% of the total) answered "*Probably*" e 1 (0.5%), "*Definitely not pleased*".

It was found that 86 participants from the ESF (86%) answered they they received more explanations about their condition with the presence of students during the appointment, while 14 (14%) disagreed with the statement. In the AMU, 94 participants (94%) agreed and 6 (6%) disagreed. In total 180 (90%) agreed and 20 (10%) disagreed (Table 1).

Table 1. Perception of patients as to receiving more explanations about their condition with the participation of medical students during the appointment

Answers of participants	ESF n (%)	AMU n (%)	All n (%)
Totally agree	45 (45)	56 (56)	101 (50,5)
Agree	41 (41)	38 (38)	79 (39,5)
Disagree	13 (13)	5 (5)	18 (9)
Totally disagree	1 (1)	1 (1)	2 (1)
Total	**100 (100)**	**100 (100)**	**200 (100)**

Facing the statement on the polite, thoughtful and respectful attitude demonstrated by medical students during the appointment, 95 patients of the ESF (95%) and 100% of the patients of the AMU agreed. In total, 195 patients (97.5%) agreed and 5 (2.5%) disagreed (Table 2).

Table 2. Perception of patients as to the politeness, thoughtfulness and respect of medical students during the appointment

Responses from participants	ESF n (%)	AMU n (%)	All n (%)
Totally agree	67 (67)	79 (79)	146 (73)
Agree	28 (28)	21 (21)	49 (24,5)
Disagree	0 (0)	0 (0)	0 (0)
Totally disagree	5 (5)	0 (0)	5 (2,5)
Total	**100 (100)**	**100 (100)**	**200 (100)**

About feeling uncomfortable or embarrassed with the presence of medical students during appointments to the point of not communicating a symptom about their own disease, 135 participants (66.5%) answered "*Never*"; 26 (13%) "*Rarely*"; 33 (16.5%) "*Sometimes*", and 6 (3%), "Usually" (Table 3). There was statistical correlation for the Joaçaba ESF ($p < 0.05$) and in the gynecology specialty in the AMU ($p < 0.05$). There was no statistical correlation in the ESF of Herval d'Oeste ($p > 0.05$) or in the specialty or urology in the AMU ($p > 0.05$).

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Table 3. Discomfort, embarrassment and the lack of communication of symptoms due to the presence of medical students during appointment

Frequency	ESF Joaçaba*	ESF Herval d'Oeste**	AMU Gynecology*	AMU Urology**	All
	n (%)	n (%)	n (%)	n (%)	n (%)
Usually	1 (2)	3 (6)	1 (2)	1 (2)	6 (3)
Sometimes	9 (18)	13 (26)	7 (14)	4 (8)	33 (16,5)
Rarely	6 (12)	9 (18)	6 (12)	5 (10)	26 (13)
Never	34 (68)	25 (50)	36 (72)	40 (80)	135 (66,5)
Total	**50 (100)**	**50 (100)**	**50 (100)**	**50 (100)**	**200 (100)**

*p < 0,05. **p > 0,05.

When asked if there was any episode of disrespect or impoliteness by students present in the appointment, 7 patients of the ESF (7%) and 4 of the AMU (4%) answered affirmatively, but the results did not show statistical difference in relation to the different health care units (p > 0.05).

In case the reason for the appointment were gynecological, urological or any other related to private parts of the body, half of the patients of the ESF units and 29 specialties of the AMU (29%) agreed that they would feel troubled by the presence of students. In total, 79 (39.5%) agreed that the presence of students can inhibit them, of which 24 (12%) answered "*Definitely*" and 50 (25%) answered "*Probably*"; however, 121 (60.5%) disagreed, of which 51 (25.5%) answered "*Probably*" and 70 (35%) answered "*Definitely*".

About the concern to disclose some private problem due to the possibility of secrecy breach by the students, 41 patients (20.5%) agreed and 158 (79.5%) disagreed. Of the total, 173 (86.5%) agreed that the medical students introduced themselves and asked for previous consent to perform the proceeding; however, 27 (13.5%) disagreed.

When asked about the possibility they would feel more at ease during the consultation without the presence of students, ate the Joaçaba ESF, 27 patients (54%) agreed and 23 (46%) disagreed; at the Herval d'Oeste ESF unit, 26 (52%) agreed e 24 (48%) disagreed. At the AMU, 19 patients of the gynecology ambulatory clinic (38%) agreed and 31 (62%) disagreed, and 17 patients of the urology ambulatory clinic (34%) agreed and 33 (66%) disagreed. The differences in answers were not statistically significant in relation to the places: ate the Joaçaba ESF unit, we obtained p > 0.05; in Herval d'Oeste, p > 0.05. The same happened in the specialties of gynecology (p > 0.05) and urology (p > 0.05) of the AMU.

About the delay in the appointment when medical students are present, 92 patients (46%) answered that they are never bothered and 108 (54%) answered that they are bothered. Of the latter, 14 (7%) answered to be bothered "*Usually*"; 57 (28.5%), "*Sometimes*", and 37 (18.5%), "*Rarely*".

The feelings caused by the presence of students during appointments were also surveyed and the results were that 38 patients (19%) felt at ease; 103 (51%) felt tranquil, and 29 (14%) considered the appointment an opportunity to talk about personal problems. On the other hand, 17 participants (9%) felt not at ease; 4 (2%) felt untranquil; 6 (3%) felt embarrassed, and 1 (0.5%) felt troubled. Only 2 (1%) spontaneously reported another feeling during the consultation, one being contentment and the other was discomfort (in this for being a gynecological consultation). Statistically, there was no significant difference among the answers in relation to the health care units of the appointments (p > 0.05).

Discussion

The happiness of patients to contribute to the learning of medical students was almost unanimous (98%). This result is in accordance with what was found in other studies [2,3], in which patients also felt

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at ease in the presence of students and showed personal commitment with their training.

The interaction between students and patients is essential for medical training, and students must also be aware of the value of this relationship. According to a study [4] performed with 25 students in the 12th semester of a medical school in the south of Brazil, 68% of them agreed that the practical learning takes place during appointments, extra-curricular internships and during the internship period, which shows the the recognition by the surveyed of the value of the patient for medical teaching. In the same study, 84% of the students declared that learning also takes place through observation of teachers, residents and classmates seen as role models. The technical learning obtained since the first years of medical school, with the inclusion of the patient in teaching, contributes effectively to the integration of the different disciplines, as well as to a better understanding of students concerning their studies [5].

Most patients agreed that they get more information about their condition when there are students in the consultation. In the general context, the good interaction between students and patients make possible a more thoughtful assistance, providing more ease in identifying complaints, better adhesion to medical orientation, fewer complaints against the physician and higher satisfaction with the service [4]. It is inferred, thus, that this improvement in the quality of assistance to patients results in the following factors: higher availability of time for the examination; more thorough explanations during the discussion about the disease between the teacher and the students; the possibility for the patient to solve doubts and to get additional information from students about his/her disease.

Another factor that influences the acceptance of students by the patient during the consultation is the small number of appointments in the teaching environment, allowing for a longer time for examination. A study performed in the United States in 2003 [3] found that only 28.9% of the patients reported not receiving more attention with the presence of medical students. In comparison, in the present study, this number was lower, ranging from 6% in the AMU to 15% in the ESF units, which evidences that, for the majority, this form of assistance is more thorough and thoughtful. This aspect shows the importance of improving information and attention to patients during routine appointments performed by physicians also without the presence of students.

Few patients of the AMU reported episodes of unthoughtfulness, disrespect or impoliteness by students; however, when asked about being troubled or embarrassed due to their presence during the consultation, 36% of the participants answered "*Usually*" or "*Sometimes*". This shows the need to provide specific orientation to students on the obligation to respect the patient's will and the need to obtain their consent at the beginning of the appointment, in order to fulfill the bioethical principles of autonomy and non-maleficence. Privacy, psychic-emotional well-being and comfort of the patient are rights stated in the *Carta dos Direitos dos Usuários da Saúde ("Bill of rights of the users of health services)* [6] in Brazil, calling for a reflexion on the convenience of limiting the presence of students during certain clinical proceedings.

The acceptance of medical students during the appointment vary according to the patient's age, social class and ethnic group [7]. Young, well-informed patients with few comorbidities tend to feel less embarrassed. On the other hand, the elder population, with less schooling and several comorbidities tends to be less receptive to consultations with the presence of students. The groups with the larger number of participants were above 50 years of age and incomplete elementary studies, and this aspect may have contributed for a relatively important fraction of these referred trouble or embarrassment. However, it is estimated that a respectful attitude along with prior clarification on the part of students from the start of their activities would fulfill the bioethical principles of autonomy and non-maleficence, as well as would contribute to the increase of confidence of patients.

Nearly all patients reported that the attitude of the students was appropriate, with 5% of the students of the ESF units and none at the AMU disagreeing with this. As to the behavior, 7% of the patients of the ESF units and 4% of the AMU reported disrespect, unthoughtfulness or impoliteness by students. Although the undesirable behavior happens in small number, as it is reported for a minority of students, an effort is necessary in order to totally eliminate it.

As to the possibility of the patient not communicating some complaint for fear of breach of secrecy by the student, 20% answered that this concern occurs "usually" or sometimes, with no statistically significant difference between the places studied. This lack of confidence must be solved through prior clarification which clearly assure the respect to the privacy of the patient. About this, a study of 2003 [3] on the perception of patients of the dermatological clinic about the participation of medical students in

consultations found a little lower values of lack of confidence, as 90% of the patients declared not to be troubled by disclosing personal information in the presence of students. This difference in results may arise from the place of the disease in the body of the patient, which is usually less private in dermatology, as well as from a more or less clarifying and respectful stance by students, especially in relation to the guarantee of secrecy. Such conjecture is corroborated by a recent study performed in Pará, in which only 37.4% of the students declare they received guidance on medical secrecy [8].

When asked if the presence of students during the appointment would trouble them in the case of an urological or gynecological consultation, half of the patients of the ESF units answered affirmatively while in the AMU, which treats cases of gynecology and urology, these answers corresponded to 29%. This result, although apparently paradoxical for the lower discomfort shown by AMU patients, may be explained by the previous knowledge of patients about the nature of the service provided in that place, that is, specialized care with the participation of medical students. Since most ESF units do not have the participation of students and do not usually have the necessary infrastructure and gynecology and urology specialists, it is presumed that the introduction of students in these health care units may generate annoyance or discomfort.

In the Joaçaba ESF Unit and in the gynecology specialty of the AMU, there was significant statistical correlation ($p < 0,05$) showing that in these places the discomfort is more intense. To illustrate this result, a patient spontaneously referred her discomfort in having a gynecological consultation with the presence of students. In the cases when the patient has shown his/her discomfort, the responsible physician must consider the rights of this patient and the possibility of dismissing students during the appointment. This is because, even in a place also dedicated to teaching, the benefit to the patient is a fundamental ethical principle of the medical practice.

For 86.5% of the participants in this study, students presented themselves previously and asked for consent to perform the proceedings. However, 13.5% disagreed, meaning that there was no previous identification or request of consent by the students. A study performed at the hospital of the Universidade Federal da Paraíba (Federal University of Paraiba) [9] found a much less favorable result, as 50% of the interviewees answered they were not requested consent. By taking this politeness and truthful stance in the beginning of the appointment, the student earns more easily the confidence of the patient. It is emphasized – repeatedly – that previous orientation to students on this aspect is indispensable by the ones responsible for teaching.

When asked about the possibility of having the appointment without th presence of students and if this would make the patient more at ease, 44.5% agreed with the statement, but the result did not show statistical significance among the places studied ($p>0.05$). According to a study performed at the "Hospital das Clínicas da Universidade Federal de Minas Gerais" (Clinical Hospital of the Federal University of Minas Gerais, HC-UFMG) [10] with 131 patients, 69.5% did not mind being treated by students and 49.2% considered their own participation in the learning of future physicians important, in consonance with the findings pf the present study. The study with dermatology patients mentioned above [3] found even more favorable results, as 94.2% of the patients valued the interaction with students and 99% did not demand exclusive service by the physician. In general, patients feel at ease to discuss their personal problems with medical students and are aware of the benefit of their personal contribution to the training of future physicians [11].

Another aspect studied was the longer duration of appointments wit the participation of students, considering the time past from their arrival at the health care unit to their final release. Over half of the patients answered that the longer duration of the appointment troubles them. A study at the "Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo" (Clinical Hospital of theUniversity of São Paulo Medical School, HC-FMUSP) in 2001 [12] estimated that the total time for the medical appointment in a service with the presence of medical students lasted, on average, 123 minutes, being a cause of complaints by the patients, in opposition of the positive aspects of the service. Such fact point to the need to adopt measures in order to rationalize the waiting time in services that count with students, mainly with the scheduling the arrival of the patient closer to the time of the appointment, greater agility in the consultation and the release right after the end of the procedures.

In order to expand this study, patients were asked about other feelings in relation to the presence of students in the appointments. The majority reported positive feelings of tranquility, comfort and the opportunity to talk. A portion, however, mentioned discomfort, untranquilness and embarrassment, showing the need of the course coordination and the responsible physician and/or preceptor to help

improve the posture of students and, thus, reduce the negative feelings of patients.

Students get involved in embarrassing situations, either caused by the teacher or by the patients [13]. In the first case, the inadequate conduct of the physician responsible in post-abortion care, recriminating the patient, constitutes a negative example for the student. As to the second case, occasionally, the student, sensitive to the suffering of the patient, tries to solve problems beyond his competency or gets involved only because family members called his/her attention – examples that give a measure of the complexity of this interaction. As pointed by the literature [14], the psycho-analytic theory of Balint may contribute to the development of emotional intelligence of the student and of competencies that favor the good student-patient relationship in medical school.

The way the teachers relate to the students, trying to treat them by their names is similar to the relationship they keep with their patients, which influences positively in the construction of the good student-patient interaction. The learning of medicine through observation and practice was already adopted by the lad Greek masters, as personally reported by the philosopher Plato [15]. However, the recent change in medical teaching, with the introduction of patient care from the beginning of the course has increased the need for teachers to be constructive examples for the scientific and humanistic training of students.

The practice performed by students in the health system as well as the incentive to th contact with patients and the inclusion of communicational abilities in the teaching of medicine converge to the improvement of the relationship with patients [16]. A fundamental aspect for the humanistic training of students was the insertion of bioethics in medical teaching. The good relationship with patients depends not only on the personal traits of students but also on the development of communication activities and the acquisition of knowledge about the rights of patients offered in the context of bioethics. Moreover, the consciousness of having a social role in the appointment leads students to identify with the community and contributes to the development of the very sense sense of citizenship [17].

In this context, the recent appreciation of patient autonomy has encouraged shared decision making, which assumes a teaching focused on the needs of patients [18]. In turn, the acquisition of communicational abilities during medical school is increasing in medical training,with the introduction of new strategies [19]. Communication is fundamental in human relationships so that, in order to fulfill the curricular guidelines established by Resolution 4/2001 of the CNE/CES (Conselho Nacional de Educação, Câmara de Educação Superior – "National Council of Education, Higher Education Chamber") [20], medical schools included subjects with the aim to develop and foster this ability in the student in their curricula. This way, it is estimated that the measure, besides contributing to the improvement of the communicative ability during medical school, will also improve the quality of the student-patient relationship.

Besides, students must be sensitized for the humanization of patient care, avoiding the fascination with technology [21]. Movies enshrined by the public, such as "The Doctor" [22] and "Wit" [23], dramatized scenes that made some not recommended conducts of medical students during patient care in teaching environments widely known, signaling to the need of greater awareness of the ones responsible to the introduction of measures to prevent such behaviors. In the present study, the presence of flaws of conduct in students was evident. These, although rare, implied some difficulties in the student-patient-relationship, indicating the urgent need for orientation by the course coordination and/or by preceptor physicians. In this context, the convenience of preventive measures, through a broad approach of the theme in disciplines dealing with the relationship with patients in preparatory stages to ambulatory clinical practice – especially during the teaching of bioethics –, so that these conducts are not repeated with the future patients of the institution. In consonance with the recommendations of the present study, the AMU has recently approved a norm [24] with orientation to students about the need of attention and "extreme" respect in dealing with patients.

Final Considerations

Most patients reported to have received more information about their disease when medical students were present in the appointment and were pleased to contribute to medical teaching.

According to participants, most students behaved in a polite, respectful and thoughtful manner during appointments, and a small portion reported episodes of disrespect and impoliteness, as well as discomfort, untranquilness, embarrassment and and

being troubled, which contributed to the omission of information on private matters in the presence of students. Moreover, part of the patients reported lack of prior identification and/or of request for consent by students during the approach.

We conclude that the perception of most patients relative to the behavior of students during health care service was broadly positive. However, the identification of some problems suggests the need to provide specific guidance on the patient-student relationship by the ones responsible for teaching and for the health services, and that of emphasizing this aspect in the teaching of related subjects, especially bioethics.

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Participation of the authors

Elcio Luiz Bonamigo is responsible for the conception, design, supervision, elaboration and review of the article. Gabriele Denti de Geroni and Jaqueline Berwanger participated in the conception of the project, the collection of data, and in the elaboration and review of the article.

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Annex

Questionnaire for data collection

1. What is your age?
( ) From 18 to 30 years
( ) From 31 to 40 years
( ) From 41 to 50 years
( ) From 51 to 60 years
( ) Over 61 years

2. Schooling:
( ) Illiterate
( ) Incomplete Elementary School
( ) Complete Elementary School
( ) Incomplete High School
( ) Complete High School
( ) Incomplete College
( ) Complete College
( ) Post-College

3. Marital status:
( ) Single
( ) Stable relationship
( ) Married
( ) Divorced
( ) Widow/Widower

4. Are you being cared:
( ) at the University Medical Ambulatory Clinic (Ambulatório Médico Universitário - AMU)
( ) at the Family Health Strategy Unit (Estratégia de Saúde da Família - ESF) of Joaçaba
( ) at the Family Health Strategy Unit (Estratégia de Saúde da Família - ESF) of Herval d'Oeste (ESF)

5. Are you pleased to be contributing to the learning of medical students?
( ) Definitely yes
( ) Probably yes
( ) Probably not
( ) Definitely not

6. During the medical consultation, do you feel troubled or embarrassed wit the presence of medical students in the office, not communicating symptom(s) about your condition?
( ) Usually
( ) Sometimes
( ) Rarely
( ) Never

7. When medical students are present at the consultation, you get more explanations about your condition.
( ) Totally agree
( ) Agree
( ) Disagree
( ) Totally disagree

8. During the consultation with the medical student, he/she was always polite, thoughtful and respectful to you.
( ) Totally agree
( ) Agree
( ) Disagree
( ) Totally disagree

9. Was there any occasion in which the student present to the consultation showed disrespect or impoliteness to you?
( ) Usually
( ) Sometimes
( ) Rarely
( ) Never

10. If your problem were gynecological, urological or of another type located in a private part of your body, would you feel more troubled with the presence of medical student(s) during the consultation?
( ) Definitely yes
( ) Probably yes
( ) Probably not
( ) Definitely not

11. You are afraid of revealing a private problem during a consultation with the presence of students because they can tell other people.
( ) Totally agree
( ) Agree
( ) Disagree
( ) Totally disagree

12. Medical students who participated in your consultation introduced themselves as medical students and asked for your consent to perform the examination.
( ) Totally agree
( ) Agree
( ) Disagree
( ) Totally disagree

13. If you could chose to be cared for without the participation of students would you feel more at ease during the consultation?
( ) Definitely yes
( ) Probably yes
( ) Probably not
( ) Definitely not

14. Which word or phrase best defines your feeling during the consultation in a medical office when there are medical students present?
( ) Comfortable
( ) Tranquil
( ) An opportunity to talk about my problems
( ) Uncomfortable
( ) Untranquil
( ) Embarrassed
( ) Troubled
( ) I have other feeling(s). Which?.....

The following questions (15 and 16) are directed towards AMU patients.

15. Service at the University Medical Ambulatory Clinic (Ambulatório Médico Universitário - AMU) is better than at the Family Health Strategy Unit (Estratégia de Saúde da Família - ESF) in my neighborhood.
( ) Totally agree
( ) Agree
( ) Disagree
( ) Totally disagree
( ) I am not being cared for at the AMU

16. In case you agreed with the statement of the previous question, to what reason do you attribute the better service of the University Medical Ambulatory Clinic (Ambulatório Médico Universitário – AMU) in relation to the Family Health Strategy Unit (Estratégia de Saúde da Família - ESF) in your neighborhood? (You may mark more than one answer).
( ) Larger number of students present at the consultations at the AMU
( ) I receive more information about my condition ate the AMU
( ) The presence of specialist physician at the AMU
( ) I haven't had the opportunity to consult in both places
( ) Another reason. Which?.....
( ) I am not being cared for at the AMU

Knowledge of medical students regarding living wills

José Antonio Cordero da Silva [1], Luis Eduardo Almeida de Souza [2], Jorge Logan Furtado Costa [3], Henrique da Costa Miranda [4]

Abstract

The end of a person's life raises many ethical dilemmas. Recently, the Brazil's Federal Council of Medicine approved and regulated the concept of "living will"; as a result, it is of considerable importance that doctors understand the issues that surround this matter. The aim of the present study was to evaluate the knowledge of medical students from the Pará State University, Brazil, of "living wills" and decisions involving the end of life. A cross-sectional study was performed with 238 students who answered a questionnaire of 10 questions. Only 8% of students demonstrated a clear understanding of the term "living will". Nevertheless, when the definition of "living will" was explained to the participants of the study by the researchers, 92% of students declared that they would respect its provisions. Therefore it appears that while most respondents had a low level of understanding of the concept of "living will", the vast majority positioned themselves in favor of accepting such a document.

Keywords: Knowledge. Living wills. Patient rights-Right to die. Advance directives. Advance directive adherence. Students, Medical. Education.

Resumo

Conhecimento de estudantes de medicina sobre o testamento vital

A terminalidade da vida levanta cada vez mais dilemas éticos. Dada a importância do tema e a recente regulamentação do testamento vital pelo Conselho Federal de Medicina, é de grande valor o conhecimento dessa problemática por parte dos futuros médicos. Assim, buscou-se aferir a compreensão dos estudantes de medicina da Universidade do Estado do Pará acerca do testamento vital e das decisões envolvendo o final da vida. O estudo qualiquantitativo descritivo e transversal entrevistou 238 estudantes por meio de questionário com 10 questões. Apenas 8% dos estudantes demonstraram ter uma noção clara sobre o significado do termo "testamento vital". Apesar disso, após ouvirem a definição das diretivas antecipadas de vontade fornecida pelos pesquisadores, 92% deles declararam que respeitariam o previsto no testamento vital. Portanto, conclui-se que, embora boa parte dos entrevistados tenha pouco entendimento sobre o tema "testamento vital", a grande maioria posicionou-se a favor de sua aceitação.

Palavras-chave: Conhecimento. Testamentos quanto à vida. Direitos do paciente-direito a morrer. Diretivas antecipadas. Adesão a diretivas antecipadas. Estudantes de medicina. Educação.

Resumen

El conocimiento de los estudiantes de medicina sobre testamento vital

La terminalidad de la vida levanta cada vez más dilemas éticos. Dada la importancia del tema y la reciente regulación del testamento vital por el Consejo Federal de Medicina del Brasil, es de gran valor el conocimiento de los futuros médicos acerca de este problema. Por lo tanto, tratamos de evaluar el conocimiento de los estudiantes de medicina de la Universidad del Estado del Pará, en Brasil, acerca del testamento vital y de las decisiones que involucran el final de la vida. La muestra del estudio cualitativo y cuantitativo descriptivo y transversal entrevistó 238 estudiantes y utilizó cuestionario con 10 preguntas. Sólo el 8% de los estudiantes han demostrado una clara comprensión sobre el término "testamento en vida". Sin embargo, después de escuchar la definición de directrices anticipadas de voluntad proporcionada por los investigadores, el 92% del total declaró que respetarían las disposiciones del testamento vital. Por lo tanto, parece que la mayoría de los encuestados tienen un bajo nivel de comprensión del tema del "Testamento Vital", pero la gran mayoría se ha posicionado a favor de la aceptación.

Palabras-chave: Conocimiento. Voluntad en vida. Derechos del paciente-derecho a morir. Directivas anticipadas. Adhesión a las directivas anticipadas. Estudiantes de medicina. Educación.

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Declaram não haver conflito de interesse.

Research article

The terminal phase of a disease raises a growing number of ethical dilemmas, generating conflicts among health professionals, patients and family members [1]. When an illness becomes terminal, therapeutic measures can no longer increase the patient's chances of survival, and instead merely prolong the process of dying [2].

In order to alleviate the pain inherent in the terminal phase of an illness, three approaches are usually defined: euthanasia, orthothanasia and dysthanasia. Euthanasia, or the "good death", is a practice designed to prevent the suffering of the patient from extending to the end of his or her life [3]. Dysthanasia is a form of therapeutic obstinacy, aimed at delaying an inevitable death. Orthothanasia, meanwhile, treats death as a natural process, in which patients receive treatment only to eliminate or lessen their pain and suffering [4,5].

However, until recently, people with terminal illnesses who found themselves in a vulnerable situation, with a loss of cognitive, mental and relationship capacity, could not decide what kind of medical treatment they would receive. In such cases, any decision regarding treatment was up to the legal representative of the patient. In order to preserve patient autonomy, a significant number of countries (Mexico, Argentina, Colombia, Bolivia and several states of the United States) have incorporated into legislation the concept of "advance healthcare directives", previously called a "living will". This is a document written by a person in full possession of their mental faculties, the purpose of which is to specify the care, treatment and procedures which they want, or do not want, to receive when affected by serious illness and are unable to freely express their will [6].

The living will was first proposed in 1967 by the then American Society of Euthanasia as a document relating to anticipated care. In this document, an individual could express in writing his or her desire to suspend medical procedures aimed at the maintenance of life. But it was only in 1991 that a legal provision on the subject was approved: the Patient Self Determination Act (PSDA), the first US federal law to recognize the right to the self-determination of the patient [7].

In Europe, the first country to legalize advance healthcare directives was Spain in 2002. In Portugal, official debate on the subject only began in 2006, based on the proposal of the *Associação Portuguesa de Bioética* (Portuguese Bioethics Association), which was submitted to the Comissão de Saúde da Assembleia da República (Health Commission of the Portuguese Parliament). According to Nunes [8], a bill on informed consent was presented in 2009. While this bill originally proposed the legalization of advance healthcare directives, this topic has since been removed. It was only in July 2012 that the Portuguese Parliament enacted Law 25, which *governs advance healthcare directives such as living wills and the appointment of a health care proxy and creates the Registro Nacional do Testamento Vital (National Living Will Registry)* [9]. In Argentina, where discussion of the topic remains on the political agenda, the first legislation on advance healthcare directives was Law 4263, in the province of Río Negro, enacted on December 19, 2007 [10].

In Brazil, no individual is prevented from notarizing their will in relation to the medical care desired in case of incurable disease. However, with respect to the bioethical principle of autonomy, which expresses the individual's free will, there is no legislation that requires medical practitioners to comply with the patient's wishes in a terminal situation. As a result, this right is little known and observed by society. However, on August 31, 2012, the *Conselho Federal de Medicina* (CFM - Federal Council of Medicine) published Resolution 1995, which governs advance healthcare directives (living wills) [11,12]. From this moment onwards, doctors have been obliged to respect the wishes of terminally ill patients, unless those desires (or the desires of their legal representatives) are in conflict with the precepts of the Código de Ética Médica (CEM - Code of Medical Ethics) [13]. According to this resolution, the advance healthcare directives of patients prevail over any other non-medical opinion, including the wishes of relatives [11].

Medicine is currently undergoing a period in which a sensible balance in the doctor-patient relationship is sought. Traditional medical ethics were marked by a strong paternalistic instinct, where the patient would simply comply with the medical decisions made for him or her. Thus, until the first half of the twentieth century, any medical act was judged by taking into account only the morality of the agent, without considering the values and beliefs of patients. It was only in the 1960s that professional codes of ethics came to recognize the patient as an autonomous agent [14].

Whether because of the significance of the decisions of the patient regarding the healing process and diagnostic and therapeutic actions, particularly with regard to future medical conduct, or by the

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regulating of this issue by the CFM [11,15], knowledge of advance healthcare directives and their consequences for the patient is now of vital importance to medical students,. The issue is therefore of great relevance to both professionals and patients, manifesting itself both as a concern for the autonomy of patients and part of any consideration of the future of the medical profession and its relationship with the attitudes and aspirations of society. The aim of this study was therefore to determine the level of knowledge of medical students regarding the subject of living wills.

Method

The present work took the form of a descriptive qualitative and quantitative cross-sectional study. A total of 238 medical students from the *Universidade do Estado do Pará* (UEPA - Pará State University), in the 1st to the 8th semester of study, were surveyed during the month of September 2013. All medical students in this group were included in this study, subject to the exclusion criteria, which were: (1) students under 18; (2) students who refused to participate in the interview or to sign the "termo de consentimento livre e esclarecido" (TCLE - free and informed consent form), which described in detail the objectives of the study.

The research instrument was a questionnaire designed specifically for the study (Appendix 1). This consisted of ten questions, four to classify the respondents into groups (age, gender, current semester of course, religion), an objective question on behavior when treating a terminally ill patient (dysthanasia, euthanasia or orthothanasia) and an open question in which the interviewee talked about what he or she understood by the term "living will". After this question the interviewees were given a definition of "living will" before answering the 7th question, which was whether they would or would not accept the living will of a patient in the final phase of life. The three last questions asked about: whether the student had come into contact with the term "living will" during his or her university course (8th); knowledge of the existence of Resolution 1.995 (9th), and the source of this knowledge (10th).

The question in which the student discussed the living will was analyzed using the "discurso do sujeito coletivo" (discourse of the collective subject - DSC), which sought to ascertain whether the respondent had a clear or partial notion of, or was not aware of, the theme. When applying the questionnaires to the students, the researchers provided instructions collectively, in the classroom, explaining the objectives and the form of the participation of individuals in the study. At this time, the TCLE was provided and the optional nature of participation in the study was stressed, together with a reminder that the questionnaire should be filled out individually and without consulting external bibliographic references.

All the subjects in the study were treated in accordance with the precepts of the *Declaration of Helsinki* [16] and the *Nuremburg Code* [17], and the guidelines and directives governing research involving humans expressed in Resolution 466/2012 of the Federal Council of Medicine were respected [18]. The study was approved by the *Núcleo de Pesquisa e Extensão de Medicina* (NUPEM - Center for Medical Research and Extension Studies) and the research supervisor of the work.

The Excel 2007 software program was used to process the quantitative data, and from a qualitative perspective, the table from the study by Piccini et al [19] (Appendix 2) was used to analyze the DSC. The Word 2007 software program was used to prepare the text. Descriptive statistical analysis was performed, based on the absolute and percentage values studied.

Results

Of the 238 students interviewed, 108 were men (45.3%) and 130 were women (54.7%). Of these, 45 (19%) were in the first two semesters of their course; 63 (26%), in the 3th or 4th semester; 68 (29%), in the 5th or 6th semester, and 62 (26%), in the 7th or 8th semester.

The age of the students varied between 17 and 28 years. In the first two semesters, the majority (82%) were between 17 and 20 years. In the 3rd and 4th semesters, 57% were aged between 17 and 20 years. In the 5th and 6th, the age groups 17 to 20 years (48%) and 21 to 24 years (44%) were almost equal. In the last two semesters, the majority of respondents (79%) were aged between 21 and 24 years.

In terms of understanding of the term "living will", only 6% of respondents demonstrated a clear notion, while 33.1% of respondents had a partial notion, 11% were unaware of the theme and the great majority (50%) refrained from answering the question (Table 1).

Table 1. Understanding of UEPA medicine students in the 1st to the 8th semester of study, in September 2013, of the term "living will"

Understanding/ Semester	1st-2nd n (%)	3rd-4th n (%)	5th-6th n (%)	7th-8thn (%)
Clear	5 (11)	5 (8)	2 (3)	7 (11)
Partial	14 (31)	16 (23)	20 (29)	18 (29)
Unaware	10 (22)	11 (17)	3 (4)	2 (3)
"Nothing to declare"	16 (36)	31 (52)	43 (64)	35 (57)
Total	**45 (100)**	**63 (100)**	**68 (100)**	**62 (100)**

When asked about the possibility of treating a terminally ill patient with a living will, 43 of students (95%) from the 1st and the 2nd semesters, 62 (98%) from the 3rd and 4th, 64 (94%) from the 5th and the 6th and 60 (97%) from the 7th and 8th semesters, stated that they would respect the wishes of the patient (Table 2).

Table 2. Position of UEPA medicine students in the 1st to the 8th semester of study, in September 2013, regarding the possibility of treating a terminally ill patient with a living will

Position/ Semester	1st-2nd n (%)	3rd-4th n (%)	5th-6th n (%)	7th-8thn (%)
Would respect	43 (95)	62 (98)	64 (94)	60 (97)
Would not respect	2 (5)	1 (2)	4 (6)	2 (3)
Total	**45 (100)**	**63 (100)**	**68 (100)**	**62 (100)**

In terms of the knowledge of the respondents about CFM Resolution 1.995/2012, the great majority (29%) said that they were unaware of such resolution. Only six (15%) students from the 1st and the 2nd semesters, 21 (33%) from the 3rd and 4th semesters, 24 (35%) from the 5th and 6th and 20 (32%) from the 7th and 8th semesters possessed some knowledge of the subject. All those who declared they knew about the resolution said in the questionnaire that they had obtained their information from the university itself.

Only a small number (18%) of students from the first two semesters said they had had the opportunity to discuss the theme of "living will" during their course. This percentage varied in subsequent semesters, with 66% of students in the 3rd and 4th semesters, 53% from the 5th and 6th and 45% from the 7th and 8th having had such a discussion (Table 3).

Table 3. Distribution of students in the 1st to the 8th semester of the UEPA medicine course, in September 2013, who had had the opportunity to discuss the subject of the "living will" as part of their degree

Opportunity/ Semester	1st-2nd n (%)	3rd-4th n (%)	5th-6th n (%)	7th-8thn (%)
Discussed	8 (18)	42 (66)	36 (53)	28 (45)
Had not discussed	37 (82)	21 (34)	32 (47)	34 (55)
Total	**45 (100)**	**63 (100)**	**68 (100)**	**62 (100)**

Discussion

In the medicine course at UEPA, the first (and only) curricular contact of students with themes of bioethics occurs in the 3rd or 4th semester, in the discipline of Medical Ethics and Human Rights. Despite the fact that issues relating to bioethics are an essential part of medical practice, it can be seen that this area is largely absent from the training of future medical professionals.

When questioned, only 8% of students demonstrated a clear notion of the meaning of the term "living will". Of these, 74% were in at least their 3rd semester. In contrast, 64% of those interviewed from the 3rd to the 8th semester chose the option "Nothing to declare" or revealed that they were not aware of the term. As Hossne and Hossne have observed, medicine courses, in general, deal with the subject of bioethics before students have experienced clinical situations, meaning that they are unable to recognize the importance of the theme [20]. Moreover, the authors point out that, in most cases, the approach to these topics is considered only from an ethical angle, from the perspective of the Código de Ética Médica (CEM - Code of Medical Ethics). There is therefore the sense of a need for a greater stimulus for discussion of these issues in order to enable the construction of ideas among students and improve their personal training.

In a similar study, conducted with students in their final year of medical school, Piccini et al [19] also found a low level of knowledge regarding living

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wills, with only 29% of respondents demonstrating a clear understanding of the subject. In this study, both professionals and students of medicine and law were analyzed, and a critical panorama of a lack of knowledge of a subject of importance to both disciplines was revealed. Such results may be partly explained however, by the fact that CFM Resolution 1.995/2012, which led to the subject of living wills being more widely discussed, was published only in the year after the study [21].

Despite the large number of students who were unfamiliar with the topic, after a brief explanation of the subject, performed by researchers at time of interview, 92% said they would respect the wishes previously recorded in the living will of a patient at the end of life, against 8% who said they would make the medical decisions they deemed to be best for the patient, even if they contradicted those expressed in the document.

Such a position follows CFM Resolution 1.995/2012, which governs the subject in relation the practice of medicine in Brazil. Article 2 of the Resolution states: *In decisions about the care and treatment of patients who are unable to communicate their will or to express their desires freely and independently, the doctor shall consider the advance healthcare directives* [living will] [11]. And, as stated by Gusmão [6], the *CFM Resolutions, while not legally binding, are considered to be mandatory for doctors. To disobey them can be interpreted as a breach of the Code of Medical Ethics, which can cause serious problems and even revocation of the permission to practice medicine*. It is therefore imperative that medical students from this and future generations are aware of this professional duty, as well as the serious implications of non-compliance with the advance healthcare directives of terminal patients [22,23].

Due to the importance given to themes of the terminal phases of illness, various religious institutions have reflected on and debated the subject. According to the *Confederação Nacional dos Bispos do Brasil* (CNBB - National Confederation of Bishops of Brazil), a doctor should accept his or her patient's desire to receive only palliative care [24]. In Portugal, while the Catholic Church was not initially in favor of accepting the living will, after several debates, it now supports the legalization of this device [25].

Final considerations

It can be seen that, despite the publicity given to the theme of the terminal phase of illness by the media, many of the students interviewed were unaware of the basic concepts of the subject. Given its relevance for future doctors and for patient autonomy, the need to intensify this discussion during medical training is therefore apparent.

Most respondents had only a partial notion of the meaning of the term "living will". When asked whether they would or would not accept the patient's choice, most said they would accept. It was not verified whether this decision was influenced by religious or family issues. Other studies, which could, for example, expand the survey to other environments such as private universities or specific age groups, are required in order to answer the questions posed by this work.

The data of the present study can contribute to the ethical education of medical students and thus improve patient care, which involves the promotion of psychosocial care and support when hospitalized, conduct that also extends to the family members of a terminally ill patient. Medical schools should develop teaching and learning strategies based on the humanities, including issues of bioethics and medical ethics, in order to train doctors with a critical, ethical and reflexive vision.

The information gathered by this study may contribute to improving health services, providing guidance to healthcare managers and teams as they try to improve the care offered in terminal phase of a disease, especially with regard to the urgent need to promote discussions about the theme during training and training courses.

Finally, there is an urgent requirement to extend the discussion of the topic to wider society, informing people about the meaning and scope of advance healthcare directives, as well as making them aware of the understanding that the patient's decision should be discussed in all its complexity, and respected by health professionals.

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Participation of the authors

All the authors participated equally in the preparation and revision of the article. Luis Eduardo Almeida de Souza, Jorge Logan Furtado Costa and Henrique da Costa Miranda carried out data collection and wrote the original text. José Antonio Cordero da Silva coordinated the research and the preparation of the original text, and carried out a critical review.

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Research article

Appendix 1
Questionnaire

1. Age: _____ years.

2. Gender ( ) M ( ) F

3. Year of medical course:_____

4. Religion
( ) Catholic
( ) Protestant
( ) Spiritualist
( ) Other: _____

5. When treating a patient in the final phase of life, are you in favor of:
( ) prolonging the life of a terminally ill patient through the intensive use of drugs and equipment, even while knowing that this approach could prolong and increase the patient's suffering (dysthanasia).
( ) hastening the end, adopting an active or passive approach to interrupting life (euthanasia).
( ) promoting palliative care, with the purpose of reducing suffering during the patient's final moments, without investing in treatments that aim to conserve life beyond its natural limits when there is no possibility of improvement (orthothanasia).

6. How would you define the term "living will" or what do you understand by such an expression? (Answer without consulting any external bibliographical references, or in other words, provide your own opinion).

(At this stage, the researcher should explain the meaning of the term "living will" to the respondent).

7. In the event that the patient in the final phase of life has or is the owner of a "living will," would you respect the provisions of this document, subject to your own conscientious objections?
( ) Yes, I would respect the will of the patient in relation to the medical treatment that he or she wishes to receive, provided it does not conflict with the Code of Medical Ethics.
( ) No, I would take the medical decisions that I believed to be best for my patient, even if they did not coincide with his or her wishes as expressed in the living will.

8. During your course, have you had the opportunity to discuss the theme of a "living will"?
( ) Yes ( ) No

9. Are you aware of Federal Medical Council Resolution No. 1.995, dated 9 August 2012, which defined "advance healthcare directives", also known as a "living will"?
( ) Yes ( ) No

10. If you are aware of this resolution, how did you learn about it?

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Appendix 2

Analytical framework of discourse of the collective subject (DSC)

Clear notion of living will Central idea – A living will is the advance expression of my will and guarantees my autonomy	
Key expressions: [1] When patients, in a lucid state, decide that they wish or do not wish to be treated in a more invasive and persistent manner in the end of life phase; [2] Documentation of the will of a patient, who while of sound mental and cognitive health, described the kind of care he or she wished to receive when in a terminal condition; [3] A document where the patient, in a condition of full autonomy, chooses policies to be followed if he or she finds himself or herself in the end of life phase and can no longer exercise such directives.	DSC: A living will is the prior expression of the will of a person by means of a written document (prepared when in full possession of said person's mental and cognitive abilities) expressing his or her desires regarding the medical procedures to be adopted should he or she find himself or herself in the end of life phase and can no longer express his or her wishes.
Partial notion of living will Central idea – A living will is a statement in which the patient defines the medical approach with which he is to be treated in the event of certain diseases	
Key-expressions: [1] A statement which defines the care a person is to receive in the event of suffering from a degenerative disease of the central nervous system; [2] A document in which the patient sets out his or her final requests, including with respect to how to maintain (extend) life; [3] The autonomy of the patient regarding his pathology, conduct, follow-up care; [4] The desires of a person regarding how he or she is to be treated in the terminal phase, whether treatment should continue or if the machines should be switched off.	DSC: O testamento vital é um documento no qual a pessoa relata sua vontade diante de um quadro clínico de final de vida, quando acometida por determinadas doenças: se deve ser mantida por aparelhos ou deseja que os mesmos sejam desligados.
Unaware of "living will" Central idea – Did not have sufficient knowledge to define the term	
Key-expressions: [1] I am unaware of the term; [2] I understand it to be a written request for life to be interrupted in the event of terminal illness; [3] Current bioethics speaks a great deal about consent and information. Information is vital for the patient's decision, which should be respected; [4] I do not recognize the expression.	DSC: I am unaware of the term "living will", despite current bioethics discussing at length the need to inform the patient and obtain consent, respecting his or her decisions. However I understand that the term is a written request from the patient requesting his or her life to be interrupted in the event of suffering from a terminal illness.

Living will: What do healthcare professionals think about it?

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Abstract

The living will is a document in which the patients specify their wishes regarding what treatments should be carried out if they are in terminal condition. As it is a new subject, it has been generating doubts in relation to its diffusion, social acceptance and ethical principles. Our study is aimed at verifying the knowledge of healthcare professionals about this document, and analyzing different aspects related to its legal regulation and applicability. A cross-sectional, descriptive and quantitative study was performed in a sample of 351 healthcare professionals, through the application of a survey containing 29 multiple-choice questions, 9 about the sociodemographic profile and 20 about the opinion of the interviewees regarding the document. Among the respondents, 7.98% declared they knew how to write the document, 73.79% felt safer with its regulation, and 61.82% would do it for themselves ($p < 0.05$). Despite not previously knowing what a living will was, the majority of the sample stated they were in favour of the document and its regulation. This result suggests a need for further discussion and disclosure on the subject in the health sector.

Keywords: Advance directives. Bioethics. Critical illness. Professional practice.

Resumo

Testamento vital: o que pensam profissionais de saúde?

O testamento vital é um documento em que os pacientes expõem suas vontades acerca de quais tratamentos serão realizados caso se encontrem em estado terminal. Por ser tema recente, tem gerado dúvidas em relação à sua difusão, aceitação social e princípios éticos. Nosso objetivo foi verificar o grau de conhecimento dos profissionais de saúde a respeito desse documento e analisar aspectos de sua regulamentação legal e aplicabilidade. Tratou-se de pesquisa transversal, descritiva e quantitativa, com 351 profissionais de saúde, mediante entrevista composta de 29 questões de múltipla escolha, 9 abrangendo o perfil sociodemográfico da amostra e 20, a opinião sobre o testamento vital. Entre os entrevistados, 7,98% declararam saber redigi-lo, 73,79% se sentiriam mais seguros com sua regulamentação e 61,82% o fariam para si próprios ($p < 0,05$). A maioria amostral declarou-se favorável ao documento e à sua regulamentação, apesar de desconhecê-lo previamente, o que sugere a necessidade de maior discussão e divulgação sobre o tema na área de saúde.

Palavras-chave: Bioética. Diretivas antecipadas. Estado terminal. Prática profissional.

Resumen

Testamento vital: ¿lo que piensan profesionales de la salud?

El testamento vital es un documento en el cual los pacientes exponen sus deseos acerca de qué tratamientos se realizarán si se encuentran en estado terminal. Por ser un tema reciente, ha generado dudas sobre su difusión, aceptación social y principios éticos. Nuestro objetivo consiste en verificar el grado de conocimiento de los profesionales de la salud sobre este documento y analizar aspectos de su regulación legal y aplicabilidad. Se trata de una investigación transversal, descriptiva y cuantitativa, con 351 profesionales de la salud, a través de una entrevista que consta de 29 preguntas de opción múltiple, 9 relativas al perfil sociodemográfico de la muestra y 20 a la opinión sobre el testamento vital. Un 7,98% afirmaron saber redactarlo. Un 73,79% demostraron más seguridad con respecto a su regulación y un 61,82% lo harían para ellos mismos ($p < 0,05$). La mayoría de la muestra resultó favorable al documento y a su regulación, aunque lo desconocía anteriormente, lo que sugiere la necesidad de continuar el debate y la divulgación sobre el tema en el área de la salud.

Palabras-clave: Bioética. Directivas anticipadas. Enfermedad crítica. Práctica profesional.

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Research article

The advance directives of a living will can be defined as written instructions in which the person, in a free and informed way, expresses their directives and preferences, in order to guide future decisions about their health. Living wills take effect from the time when there is medical proof that the patient is unable to make decisions and can be written by all adults, regardless of their current state of health. There are two types of advance directives: the power of attorney and the living will. The power of attorney corresponds to the appointment by the person of someone they trust to make decisions about the care of their health, if they ever become incapacitated. The living will is a legal authorisation, in which the patient defines what kind of treatment and medical procedure they want to undergo when a reversal of their clinical condition is no longer possible and they are not able to make decisions [1-4]. Considering that this study focuses on the perspective of the health team, who are directly responsible for patient care, we chose to focus on the living will.

Lately, patients are taking a more active participatory and influential role in matters involving their own health, even in the most critical and conflicting matters - as in the case of terminal diseases[5] - which contributes to increase the complexity of the patient's relationship with the health team. This behavioral change has arisen due to greater dissemination of technical and legal knowledge by the media, such as print, radio and television networks, as well as the internet. Health professionals have also adopted a new attitude in recent years, influenced by changes in the curriculum of medical schools, which seek to make more room for patient participation in decisions about treatment, stimulated largely by bioethics [6,7].

Some situations present conflicts arising from the change in the doctor-patient relationship. An example of this is a matter related to the right to life, where there is no certainty as to the cost-benefit of prolonging life if the application of technologies means only prolonging the patient's suffering. Another aspect likely to lead to conflict concerns the autonomy of the patient, is when the patient's views on key decisions to be made regarding their treatment differs from the opinion of relatives or attending professionals. Faced with such circumstances, the living will provides an option that is able to protect the patient's rights and endorse the attitudes of professionals in special situations [8].

Some authors believe that the regulation of living wills would be a way to encourage euthanasia. In contrast, other scholars argue that its adoption does not mean advocating the abbreviation of life nor the suspension of ordinary and palliative treatments, but the suspension of those extraordinary and futile procedures that fail to bring any obvious benefits to the patient [4,9]. By following the determinations of the living will, the doctor would be respecting the bioethical principle of respect for autonomy, given that the document asserts the patient's right to consciously decide about the treatments to which they want to undergo or not, even if their choice goes against the opinion of the physician [5,10,11]. To respect autonomy implies recognizing that the individual must decide and take action according to their own life plan, beliefs, aspirations and values, even when contrary to those prevailing in society [12].

Such questions have been raised recently with the publication of Resolution 1995/2012 by the Conselho Federal de Medicina (Brazilian Federal Council of Medicine - CFM), which recognizes the validity of advance directives of a living will and which protects the doctor to follow its provisions [7]. Although this decision has normative force, which means that the failure of planned actions goes against the Code of Medical Ethics (CEM), the resolution is not yet regulated in the Civil Code[13]. The absence of a definitive positioning in the legislative field can increase the insecurity of professionals to follow the decisions of a patient [14,15]. Research that attempted to identify the attitude of professionals regarding the living showed that only 60.77% of respondents said they followed the decisions of patients [16].

Another ethical question related to the living will is regarding the authenticity and impermanence of the decision of the patient, since the preparation of the document is based on an imaginary construction of how their life would be in some future situation never before experienced, and that, from the moment when they really experience such a condition, their point of view could change. Also, another conflicting factor is the ambiguity of the term "terminal patient", which is often linked to living wills, and currently the target of criticism. In this case, the word "terminal", which can cover different situations, is rather vague, which is the reason why it could interfere with the understanding and precision of those who produce the document [17].

Given the importance of discussing the topic in Brazil, as about 40% of the country's hospital beds are occupied by terminal patients, there is little published research that assesses the level of knowledge about the living will (its definition and applicability) among patients and health professionals [18]. Investigations into the different positions and

views of those involved will always ensure a better understanding of the impacts of this document and will eventually assist in the decision-making by the authorities regarding its promotion and regulation.

Our study deals with an important issue regarding the Brazilian bioethical context, in which health professionals' understanding of the matter represents the possibility of knowing the underlying ethical challenges for professional practices in light of the living will. Thus, the research focused on the evaluation of multidisciplinary health teams, which are in constant contact with hospital patients. We aim, therefore, to verify the degree of knowledge these professionals have regarding the document, according to the different variables analyzed, and to identify aspects related both to its regulation, in the form of laws and resolutions, and to its application in the hospital.

Method

The research was cross-sectional, diligent, original, descriptive and quantitative, in which factor and outcomes were measured concurrently, with an estimate of the prevalence of the outcome variable, in this case, *the opinion of health professionals in the city of Juiz de Fora, Brazil, regarding the living will* [19].

Participants were interviewed in their workplace, such as offices and clinics, across the whole city center, and randomly incorporated into the study. When the researcher did not find a qualified person in the sector to conduct an interview, new appointments were scheduled at different times. Juiz de Fora is characterized by a heavy centralization of health care facilities while the homes of the professionals are located in different regions (central, north, south, east, west) and city neighborhoods.

Inclusion criteria were: to be a health care professional in the fields of medicine, nursing, nutrition, psychology and physiotherapy; working in a hospital environment, because these professionals are more likely to deal with patients in severe and delicate clinical situations. As a sample loss, we defined the questionnaires interrupted for any reason, or with incomplete data, and failure to return the "termo de consentimento livre e esclarecido" (TCLE - informed consent form) signed.

The sample size calculated to research this health outcome was 351 individuals. This sample spectrum strictly meets the criteria and statistical requirements and it took into account a sampling error of 4.5% (plus or minus). The data collection instrument consisted of a questionnaire composed of 29 questions, of which 9 were multiple choice on the socio-demographic profile of the sample, and 20 related to knowledge and opinion about the studied context (see Appendix).

The contextual variables of respondents were divided into groups and presented as follows: profession (medical doctor and other health professionals); stratified age (up to 35 years or over 35 years); sex (male or female); color (white or non-white); income (up to double the minimum wage or more than double the minimum wage); religious beliefs; training (technical course or degree); marital status (single or otherwise); living arrangements (living alone or other arrangement); place of residence. The study considered the following settings for methodological refinement:

- *Terminal patient*: one whose condition is irreversible, whether treated or not, and that is highly likely to die in a relatively short period of time [20];
- Unidade de Tratamento Intensivo (*Intensive Care Unit* - UTI): Hospital sector which provides intensive, continuous care to patients in critical condition;
- *Euthanasia*: precipitation of the death of an incurable patient, who is usually terminal and in great pain, motivated by compassion for the patient [21];
- *Dysthanasia*: postponement of the dying process by obdurate therapy and the overuse of drugs and devices [21];
- *Orthothanasia*: encouragement of the use of palliative care to relieve the patient's suffering, giving up mechanisms that are meant to prolong the process of dying, in an artificial and disproportionate manner, and accepting, therefore, the condition of human death [21].

The professionals were addressed in a standardized manner by a trained researcher, who gave them detailed knowledge of the study, after which respondents were invited to participate in the study, voluntarily indicating their acceptance by signing the informed consent form. Training for the fieldwork was done through a pilot study with 12 subjects, and focused on identifying problems in understanding the questions, in order to ensure the quality of data collection and to get more cooperation from interviewees.

The research does not present immediate benefits to its participants; however, it allows the

identification of the perceptions and expectations of the sample related to living wills. The data collected can be a source of information regarding the subject, which will assist in the regulation of the document, by including the perspective of health professionals. Furthermore, it will enable discussion of possible criticism and questions, considering the complexity and differences of opinion surrounding the issue. Therefore, by undertaking such a debate, the whole of society will benefit indirectly.

Participation in the survey implied minimal risk to participants, that is, there was no interference from the researcher in any aspect of the respondents' physical, psychological and social well-being, as well as their privacy, as established by Resolution 466/2012 of the National Council of Health/Ministry of Health [22], which regulates research involving human subjects. The interviews were conducted individually, and the participants' identities were kept confidential with no identification in any publication. The respondents incurred no cost nor received any financial benefit, and any questions they had, regarding any aspect of the study, were clarified. The respondents were free to participate or refuse to do so, given that they could provide or withdraw their consent or discontinue participation at any time. Therefore, their participation was voluntary, and the survey results remain at their disposal.

Statistical analysis

The variables analyzed were divided into two groups: 1) continuous quantitative (only for age), and 2) dichotomous qualitative. A descriptive and exploratory data analysis used absolute frequencies (n), relative frequencies (%), measures of central tendency (average), dispersion measurements (standard deviation) and a median, which was used as the cutoff point for age.

For the comparative analysis of the proportions of dichotomous variables (association between these variables), we applied the chi-squared test of independence (uncorrected). The significance level for this test was 5% ($p \leq 0.05$) for a 95% confidence interval.

For a dependent variable that takes only two values, as in our research, crosstabs was the analytical strategy chosen to estimate the risk of failure associated with several variables being considered. As is usual in such cases, we presented the results based on the estimation of the relative risk (RR) by the odds ratio (OR) calculation, thereby indicating how the probability of an event changes when it moves between different categories of the same variable. For the statistical processing and assembly of the database, the statistical software SPSS version 15.0, 2010 was used.

Results

With regard to the variable "profession", 41.9% of the sample consisted of medical doctors, and 58.1% of other health professionals. The average age was 36.6 ± 11.6 years and the median 35 years. The percentage of female respondents was 63.5% and males 36.5%. In the category "color", the self-declared "white" sample was the majority, with 78.9%, across all the areas surveyed, relative to 21.1% non-white (mixed-race, black, yellow and indigenous).

The social status of respondents was based on their income. The cutoff was equivalent to double the Brazilian minimum wage, and the results showed that 15.1% earn up to double the minimum wage and 84.9% earn more than double the minimum wage.

Regarding the location of the respondents' homes, it was found that 39.9% of them reside in the central area of the city, while 60.1% have their homes distributed throughout the northern, southern, eastern and western regions, and the rural areas.

With regard to the training of these professionals, the results revealed that 20.2% have technical qualifications and 79.8% have degrees.

Among the religious beliefs of the participants, Catholicism stood out, with 62.1%, while the Spiritualists totaled 16.8%, followed by evangelicals with 11.4%, and other beliefs (atheists and others) with 9.9%. The cutoff point was established between Catholics and non-Catholics: with 62.1% and 37.9%, respectively.

In the professional environment, 64.6% of medical doctors surveyed reported working in UTIs; while, among other health professionals this value was 50%, demonstrating that the majority of the sample works in this sector (OR = 182%).

With regard to the health professional's obligation to inform the patient about the living will, 79.6% of medical doctors and 68.1% of other health professionals agreed with this statement, showing that the majority is in favor of providing this type of information (OR = 182%). When asked whether pa-

tients often express opinions relating to therapeutic treatment that they will be submitted to, 81% of doctors and 70.1% of other health professionals said yes (OR = 181%).

Analyzing the frequency with which respondents deal with critically ill patients, 25.9% of doctors reported that they seldom deal with this type of patient. In the group of other health professionals the figure is 35.8% (OR = 62%).

When asked about the concept of euthanasia, most medical doctors (74.8%) claimed to know about it, as did 55.9% of other professionals, (OR = 234%).

Most respondents said they knew about the concept of orthothanasia, among them, 96.3% of doctors and only 40.7% of other health professionals (OR = 341%). The research reveal that 58.9% of the professionals who work in the UTI and 45.5% of those who do not work in this environment said they knew the term "orthothanasia" (OR = 172%).

Regarding the concept of dysthanasia, 58.5% of the doctors knew it, whereas, among other health professionals, this percentage was 37.2% (OR = 237%). Regarding the fact whether professionals feel at ease or do not feel at ease following the provisions contained in a living will, most participants indicated not being comfortable. When considering professional groups, 47.6% of medical doctors and 27.9% of other health professionals said that they felt free to follow the provisions (OR = 234%). As for the division of the groups in relation to the workplace, 41.6% of those who work in the UTI and 29.2% of those not working in this environment declared they felt at ease with such conduct (OR = 172%).

When asked about the creation of a law to regulate the living will, most claimed to be in favor. Among occupational groups, 89.1% of medical doctors and 77.9% of other health professionals supported this proposal (OR = 238%). As for feeling safe with the regulations of this document, a large portion of the sample (73.8%) answered in the affirmative. Regarding the groups, 83% of doctors and 67.1% of other health professionals reported that they would feel more secure if there were regulations (OR = 238%).

When asked if they would make a living will for themselves, the majority of respondents said yes. In professional groups, 70.8% of medical doctors and 55.4% of other health professionals shared this opinion (OR = 195%). Meanwhile, when it comes to working in UTI, 67.5% of those who work and 54.6% of those who do not work in this environment said they would (OR = 173%). Regarding knowledge of CFM Resolution 1995/2012, 82.1% of the sample responded negatively. Those who said they know it represent 21.8% of those working in UTI and only 13% of those who do not work in UTI (OR = 187%). Although we have not observed statistically significant differences between groups in this respect, knowledge of the sample regarding the definition of the living will was generally low, with only 37.89% having said they knew it.

Table 1 - Medical doctors vs. Other health professionals

Questions	Doctors		Non-doctors		Sig.	OR	IC 95%
	n	%	n	%			
Works in UTI	95	64,6	102	50	0,006	1,82↑	1,18-2,82
Does not work in UTI	52	35,4	102	50			
The health professional should inform the patient about the living will	117	79,6	139	68,1	0,017	1,82↑	1,10-3,00
The health professional should not inform the patient about the living will	30	20,4	65	31,9			
Patients usually express their opinion	119	81	143	70,1	0,021	1,81↑	1,09-3,01
Patients usually do not express their opinion	28	19	61	29,9			
Seldom deal with severely ill patients	38	25,9	73	35,8	0,048	0,62↑	0,39-0,99
Often deal with severely ill patients	109	74,1	131	64,2			
Feel at ease following the determinations of a living will	70	47,6	57	27,9	0,000	2,34↑	1,50-3,66
Do not feel at ease following the determinations of a living will	77	52,4	147	72,1			

(continua)

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(conclusão)

Questions	Doctors		Non-doctors		Sig.	OR	IC 95%
	n	%	n	%			
In favor of the creation of regulatory law regarding living wills	131	89,1	159	77,9	0,006	2,31↑	1,25-4,28
Not in favor of the creation of regulatory law regarding living wills	16	10,9	45	22,1			
Would feel safer with the regulation of living wills	122	83	137	67,1	0,001	2,38↑	1,41-4,01
Would not feel safer with the regulation of living wills	25	17	67	32,9			
Would make a living will	104	70,8	113	55,4	0,003	1,95↑	1,24-3,05
Would not make a living will	43	29,2	91	44,6			

Note 1. The figures in the columns represent the total sample (100%) in each category. Note 2. OR (odds ratio): values different from (1) were converted into percentage. If ↑, it is a risk factor; if ↓, it is a protective factor. Note 3. Sig. (statistical significance of differences): Pearson X^2 test.

Table 2 - Professionals working in UTI vs. Professionals who do not work in UTI

Questions	Works in UTI		Does not work in UTI		Sig.	OR	IC 95%
	n	%	n	%			
Seldom deal with severely ill patients	38	19,3	73	47,4	0,000	0,26↑	0,16-0,42
Often deal with severely ill patients	159	80,7	81	52,6			
Has acquaintances with terminal disease	45	22,8	13	8,4	0,000	3,21↑	1,66-6,20
Does not have acquaintances with terminal disease	152	77,2	141	91,6			
Feel at ease following the determinations of a living will	82	41,6	45	29,2	0,016	1,72↑	1,10-2,70
Do not feel at ease following the determinations of a living will	115	58,4	109	70,8			
Knows the Resolution CFM 1.995/2012	43	21,8	20	13	0,032	1,87↑	1,04-3,33
Does not know the Resolution CFM 1.995/2012	154	78,2	134	87			
Would make a living will	133	67,5	84	54,6	0,013	1,73↑	1,12-2,67
Would not make a living will	64	32,5	70	45,4			

Note 1. The figures in the columns represent the total sample (100%) in each category. Note 2. OR (odds ratio): values different from (1) were converted into percentage. If ↑, it is a risk factor; if ↓, it is a protective factor. Note 3. Sig. (statistical significance of differences): Pearson X^2 test.

Discussion

Studies regarding the living will in Brazil are still very recent and scarce, especially when the focus is on the practice of health professionals. Therefore, it is expected that these professionals have scant knowledge of living wills, as shown in this study - where only 37.89% of respondents stated that they knew about the document - as well as in the specific literature [16]. This probably occurs because of the topicality of the subject, and the fact that the assessments of living wills are still basic and often restricted to the academic environment. Such questions highlight the need to broaden the debate and research on the topic, especially considering the changing panorama of the relationship between health staff and terminally ill patients [23].

Nowadays, patients bring ethical questions about the real value of therapies that seek to stave off death without, however, promoting quality of

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life. Professionals who have more experience of patients' suffering and have sensitized themselves to the wishes expressed by their patients, are opposed to such unnecessary treatment. In our study, those who work in UTI and deal constantly with seriously ill patients were more inclined to follow the advance directives than those who work outside of this environment (Table 2). This fact is corroborated by the literature, which shows that the perception of health professionals regarding the situation of patients varies according to their work environment [8,24,25]. Another significant aspect that reaffirms this finding, in the present study, is that the UTI professionals are also more inclined to draw up a living will for themselves (Table 2).

When it comes to team communication with the patient, the question arises whether to inform the patient or not about the living will. As evidenced by Antolín et al. [26], whose study examined whether the patients felt well informed or not, the vast majority of them reported not being sufficiently informed by the professionals. However, when we look at the other side of the relationship, most of our sample (Table 1) considered it their duty to inform the patient of the existence of the living will after becoming aware of it. This difference in perspective reinforces the need to improve the doctor-patient relationship and the dissemination of information regarding the topic.

Another relevant issue is the participation of patients in decisions about the therapeutic procedure that they will be submitted to. Until recently, this dialogue was not common; today, however, we can see a change in this outlook, reflected in patients' greater interest in their own treatment. In our research, most professionals said patients often express their opinion (Table 1). It is necessary, however, that the health team is also willing to discuss and try to adapt their approach in order to create greater trust and provide more effective palliative care. According to Jones et al. [27], patients over the age of 65, who require palliative care or are hospitalized in long-term institutions, tend to participate in decisions about their treatment, precisely because of their closer contact with the team that provides them care.

Although we have identified increased attention from the multidisciplinary team regarding the preferences of patients, there is still some concern regarding advance directives. In this study, most of the sample declared themselves uncomfortable following the determinations of a living will (Tables 1 and 2). This possibly happened because discussions are still rudimentary and unable to answer questions regarding the approach to be adopted when the family does not agree with the determinations of the patient and regarding the ethical and legal implications that can affect the health care professional. In the research from Piccini et al [16], the majority of medical doctors in favor of the living will consider it useful, but limited. Probably this fact is associated with motives similar to those verified by our research.

The document is already part of the legal framework in several countries [28-33]; but in Brazil, professionals are guided solely by CFM Resolution 1995/2012, which recognizes the patient's wishes expressed in living wills and have normative force, by ensuring that the doctor is administratively linked to the patient's directives, and must therefore follow the patient's determinations. The CFM Resolution itself can and must have legal backing, since, with the advent of neo-constitutionalism, everything regarding fundamental rights dispenses with legal regulations to be effective[14]. Despite this, our study demonstrated that most professionals are unaware of such a resolution (Table 2), and, apparently, its applicability in patients' daily lives is low.

Despite the lack of mandatory inclusion of advance directives of will in the current legal framework, the presence of a specific law in the national legal framework would be important to enhance the existing efficiency, since such a law would supposedly give more security to doctors, patients and families regarding this delicate subject [14]. This fact is confirmed by our research, which finds that the majority of respondents reported that they would feel more secure with the regulation of living wills (Table 1).

Final considerations

The majority of health professionals interviewed were unaware of the living will and CFM Resolution 1995/2012. However, they support the creation of a specific law, since the regulation would facilitate the applicability of the document, providing more comfort and security to patients. Professionals working in the UTI, or who have extensive experience in dealing with serious illnesses, are more inclined to follow the determinations of the living will as well as prepare it for themselves.

Finally, although it is a widely accepted document among health professionals, the living will faces a major obstacle in its application: the fact that it is little known by the professionals themselves.

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The data found in this study, combined with the large number of ethical issues involved, calls attention to the importance of broadening the discussion about this subject among health professionals. This would contribute not only to the further spread of knowledge about CFM Resolution 1995/2012 but also to the formation of a more uniform approach for the needs of the terminally ill.

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Participation of the authors

Alvaro Henrique de Almeida Delgado, Caio Gomes Tabet, Guilherme Gomide Almeida, Isadora Figueiredo Vieira and Natalia Cristina Simão da Silva participated in the design of the research project, literature review, data collection and writing of the article. José Antonio Chehuen Neto supervised and reviewed the project and participated in the formatting and editing of the text. Renato Erothildes Ferreira participated in the research design, statistical analysis and its interpretation.

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Appendix

Data collection instrument:

Socio-demographic profile of the sample		
1	**Age in years:**	( )
2	**Sex:**	(1) Female (2) Male
3	**Color:**	(1) White (2) Mixed-race (3) Black (4) Yellow (5) Indigenous
4	**Income of interviewee:**	(1) Up to double the minimum wage (2) More than double the minimum wages
5	**Religious belief:**	(1) Atheist (2) Catholic (3) Evangelic (4) Spiritualist (5) Others
6	**Education:**	(1) Technical course (2) Bachelor degree or equivalent (3) Post-graduation course (specialization) (4) Master degree (5) PhD
7	**Marital status:**	(1) Single (2) Married (3) Widower (4) Divorced (5) Other
8	**Living arrangements :**	(1) Live alone (2) Live with their parents (3) Live with a partner (4) Live in a retirement home (5) Others
9	**Where do you live?**	(1) City center (2) South (3) East (4) West (5) North (6) Rural areas

Opinion regarding living will (LW)		
1	**What is your profession?**	(1) Medical Doctor (2) Nurse (3) Nutritionist (4) Psychologist (5) Physiotherapist
2	**Do you work in an intensive care unit?**	(1) Yes (2) No
3	**How often do you deal with critically ill patients?**	(1) Seldom (2) Often
4	**Do patients often express opinions regarding procedures to which they will be submitted?**	(1) Yes (2) No
5	**Do you consider that the professionals are concerned about informing the patient of his/her health condition?**	(1) Yes (2) No
6	**Do you believe that the terminal patients tend to be properly informed about their condition?**	(1) Yes (2) No
7	**Do you know the concepts:** **Euthanasia?** **Orthothanasia?** **Dysthanasia**	 (1) Yes (2) No (1) Yes (2) No (1) Yes (2) No
8	**Do you have close relatives or acquaintances with a terminal disease?**	(1) Yes (2) No
9	**If you answered "yes", what disease?**	(1) COPD (2) Heart Failure (3) Cirrhosis of the liver (4) Cancer (5) Others
10	**Do you know the CFM Resolution 1995/2012?**	(1) Yes (2) No
11	**Do you know the definition of a living will (LW)? ***	(1) Yes (2) No
12	**Do you consider it a duty of health professionals to inform patients about LW?**	(1) Yes (2) No
13	**Do you know how to write a LW?**	(1) Yes (2) No
14	**Have you ever attended to any patient who had or who required a LW?**	(1) Yes (2) No
15	**Would you feel comfortable in following the determinations of a LW?**	(1) Yes (2) No
16	**Are you in favor of the creation of a regulatory law regarding living wills in Brazil?**	(1) Yes (2) No
17	**Would you feel safer with the regulation of LWs?**	(1) Yes (2) No
18	**In your opinion, is it important to discuss this issue among health professionals?**	(1) Yes (2) No
19	**Do you consider important the dissemination of information about LWs in the media?**	(1) Yes (2) No
20	**Would you make a living will for yourself?**	(1) Yes (2) No

* Question 11: If the respondent answers “no”, the interviewer should briefly explain the living will, enabling the interviewee to have the knowledge to answer questions 12 to 20.

Moral deliberation in palliative sedation focusing on an oncology palliative care team

Melisse Eich [1], *Marta Inez Machado Verdi* [2], *Pedro Paulo Scremin Martins* [3]

Abstract

The aim of this study was to understand how a palliative care team seeks solutions for ethical conflicts related to deep palliative sedation in everyday care and whether the discussions and the decisions that are made within the multidisciplinary team involve the sick person and his family. This is a descriptive exploratory qualitative study, based on dialectical hermeneutics. The research subjects were ten professionals on the health team of a hospital's Oncology Palliative Care department. The results indicate that a humanistic attitude assumes, among many things, the prudent use of palliative sedation as an available resource to minimize suffering during the process of dying. The practice of palliative sedation requires a thorough analysis of the clinical facts, ethical reflection by the multidisciplinary team, as well as respect for the values of the sick person and their family and their participation, which would result in a process of moral deliberation.

Keywords: Deep sedation. Palliative care. Bioethics. Decision making.

Resumo

Deliberação moral em sedação paliativa para uma equipe de cuidados paliativos oncológicos

O objetivo deste estudo foi compreender como uma equipe de cuidados paliativos busca soluções para os conflitos éticos relacionados à sedação paliativa, no cotidiano assistencial, e se as discussões e decisões são feitas e deliberadas em equipe multiprofissional, envolvendo também o sujeito doente e sua família. Trata-se de pesquisa exploratório-descritiva de abordagem qualitativa, com base analítica na hermenêutica dialética. Os participantes da pesquisa foram 10 profissionais que integram a equipe de saúde de um setor hospitalar de cuidados paliativos oncológicos. Os resultados indicam que uma assistência humanizada pressupõe, entre tantos aspectos, o uso prudente da sedação paliativa como recurso disponível para a minimização do sofrimento no processo de morrer. A prática da sedação paliativa requer análise minuciosa dos fatos clínicos, reflexão ética em equipe multiprofissional, assim como participação e respeito aos valores da pessoa doente e seus familiares, o que propiciaria um processo de deliberação moral.

Palavras-chave: Sedação profunda. Cuidados paliativos. Bioética. Tomada de decisões.

Resumen

Deliberación moral en sedación paliativa destinada a un equipo de cuidados paliativos oncológicos

El objetivo de este estudio fue comprender cómo un equipo de cuidados paliativos busca soluciones en la cotidianeidad de la asistencia para los conflictos éticos relacionados a la sedación paliativa y si las discusiones y decisiones son tomadas y deliberadas en el ámbito del equipo multiprofesional, englobando al sujeto enfermo y a su familia. Se trata de una investigación exploratoria-descriptiva de abordaje cualitativo, con base analítica en la hermenéutica dialéctica. Los sujetos de investigación fueron diez profesionales que integran el equipo de salud de un sector hospitalario de cuidados paliativos oncológicos. Los resultados indican que una asistencia humanizada presupone, entre muchos otros aspectos, el uso prudente de la sedación paliativa, como un recurso disponible para la minimización del sufrimiento en el proceso de morir. La práctica de la sedación paliativa requiere de un análisis minucioso de los factores clínicos, la reflexión ética en equipo multiprofesional, así como también de la participación y el respeto a los valores de la persona enferma y los de sus familiares; lo cual daría lugar a un proceso de deliberación moral.

Palabras-clave: Sedación profunda. Cuidados paliativos. Bioética. Toma de decisiones.

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Declaram não haver conflito de interesse.

Research article

The practice of *palliative sedation* to assist people in advanced stages of oncological disease and terminal stages of life, the essence of which is responsible care, should start from the assumption that the process of dying and death itself comprises the most *undeniable reality of humankind.* So, *to die with dignity, properly assisted, is as important as receiving the necessary care to maintain health and continue the always finite and temporary journey* [1]. In fact, palliative care is defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [2].

The need to seek solutions to cacothanasia, and thereby prevent many diseases that lead *to the premature conclusion of the life cycle by nursing conditions, affectivity, and mental states that can inevitably cause a painful death and extreme anguish* [3], requires due consideration by contemporary society. Furthermore, in the face of the difficulty in controlling the progress of diseases such as cancer, it is essential to transform the conditions of health assistance for people at the end of their lives, in order to minimize suffering before death. This assumes not only more equitable and universal palliative care as a human right, but also the development of a way of providing individualized care, based on ethical considerations that are able to raise the ethical and moral conscience of those who work in terminal care.

In addition to ethical reflection, it is necessary to see dialogue as a highly effective tool in the practice of palliative care when proposing palliative sedation as a resource available to the sick person, given its ability to integrate an act of caring intended for the whole community. Apropos, Camargo-Borges, Mishima and McNamee [4] understand that we are relational beings and that we should invest in this human condition, establishing interventions that are more sensitive to relational aspects, by emphasizing the similarities and interactions in a sensitization process geared towards more collaborative, contextual and responsible communication, thereby producing less polarized and hierarchical relationships.

Although palliative sedation is not an unusual procedure in this type of care, its use depends on several factors, which is why its prevalence varies widely. Several authors, such as Maltoni et al. [5] and Chiu et al. [6], argue that palliative sedation, including continuous sedation until the time of death, does not aim to shorten or prolong life, but to alleviate suffering. It consists of conduct that leads *to a reduction of consciousness, from mild to profound, temporary or permanent, but not deliberately causing the death of subjects affected by disease at an advanced stage, in the final phase of life and with specific refractory symptoms*[7], palliative sedation is highly recommended in the practice of palliative care provided by multidisciplinary teams.

However, the use of palliative sedation generates ethical and interpersonal conflicts in the day-to-day life of the palliative care team, so that confronting these issues implies the need to make decisions based not only on ethics but also on the axiology, namely, the values of the people involved. This is what Diego Gracia proposed when drawing up his methodology for "moral deliberation"[8]. We believe that this method is very important in the practice of palliative sedation because, when the sick person's death is imminent and suffering becomes more acute in all its dimensions, it also intensifies the anguish experienced by family members and other related persons, including members of the care team.

In this context, prudent and reasonable decision-making requires clarification and consideration of the values of the people involved in the process. That is because several factors, including poor communication or lack thereof, may create tensions and ethical conflicts. This results in a situation in which the sick person and their family are not sufficiently informed about the physical and psychological distress inherent in the final stage of life, as well as the resources that can be offered to minimize them, including palliative sedation. In the face of suffering and distress, it is necessary to take a responsible and committed decision regarding the process of dying with dignity. Effectively, we need to decide! In this sense, Diego Gracia says:

Problems need to be tackled through a process of deliberation. And the intended objective is not to take decisions that are definitive or exclusive, but merely prudent. Different people can make different decisions based on the same facts and also be prudent (...). This is perhaps the great challenge ahead of us that will gain more and more importance in the coming years: the need to assume a kind of rationality that allows the participation of all those involved in the deliberation process regarding the practical problems - in our case, the moral problems. (...) Only then can we contribute to the great challenge for ethics and bioethics: the promotion of "responsibility" [9].

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Therefore, moral deliberation is the method to find a solution to a problem, by seeking to overcome the ethical conflict with due care and responsibility, and considering the decision making as part of this process. This is a dynamic methodology, which needs, first of all, to take into account the socio-cultural and historical context of the person with advanced disease and without possibility of a cure, this also implies an understanding of the family context as a prerequisite to identify the ethical conflicts and values in question.

Elma Zoboli, referring to the method of moral deliberation in the work of Diego Gracia, sums up the deliberation process as an itinerary that includes: deliberation based on facts (presentation of the case and clarification of the facts); deliberation regarding the values (identification of the moral issues of the case, indication of the fundamental moral problem, and identification of conflicting values); deliberation regarding the duties (identification of extreme, intermediate and optimal courses of action); and deliberation regarding the responsibilities (submission of the optimal course of action to prove consistency regarding time, promotion and legality) [10].

In light of this problem, this study sought to understand how health professionals deal with ethical conflicts related to palliative sedation, as well as to investigate whether the discussions and decisions are carried out and resolved within the multidisciplinary team and include the subject patient and their family, circumstances that favors the moral deliberation process, according to Gracia [8].

Method

To reflect on the deliberation process, namely, the discussions and decisions regarding the practice of palliative sedation within an oncology palliative care team, a descriptive exploratory qualitative study was developed based on the dialectic hermeneutical method. The research field was the palliative care unit of a hospital in southern Brazil.

Participants in the study were professionals within the health team: nurses, doctors, nursing technicians, social workers, psychologists, pharmacists, physiotherapists, and nutritionists, totalling 10 participants. The survey methodology took place through interviews with a team of health professionals with extensive experience in palliative care.

A semi-structured interview was used as the data collection instrument and adopted the content of the information presented by the research participants as saturation criterion. That is, the repetition of information from one interview constituted an occurring parameter of saturation

In the process of analysis, the researchers employed a software program (Atlas.ti® 7.1.5) to organize and analyse qualitative data, by following these steps: 1) initial categorization; 2) reorganization of the data and a final analysis, as proposed by Minayo [11]. The analytical process of the reports of the experiences of the survey participants, which was done based on the guidelines for semi-structured interviews revealed the primary topic that is the subject of discussion in this article: the decision-making process.

The ethical aspects of this research – because it involves human beings - was treated according to the rules and guidelines of Resolution 466/2012 of the Brazilian National Health Council (Conselho Nacional de Saúde), which requires the submission of a project evaluation by an ethics committee on any research involving human subjects [12].

Participants were informed about the purpose and procedures of the research, as well as the possibility to refuse participation at any time, and were then asked to confirm their consent by signing the free and informed consent form (ICF).

Results and discussion

The interpretation of the topic, which emerged from the interview data analysis process, was divided into sub-categories or sub-themes related to the practice of palliative sedation, namely: understanding of ethical conflicts, process planning, and solutions to ethical conflicts. The sub-themes are discussed in the light of Diego Gracia's [8,9] contributions to bioethics applied in medical practice and of other scholars of the subject [10], as well as of researchers whose works focus on the practice of palliative sedation in palliative care [5-7].

To maintain the anonymity of respondents, the quotes that summarised responses to the problem have been referred to by code names: Daisy, Violet, Sunflower, Gardenia, Tulip, Hydrangea, Lily, Rosemary.

Understanding ethical conflicts and values

In this analytical subcategory, it became clear that the decision-making process related to palliative sedation is considered complex, with tense moments and situations within the team and in its

relationship with the sick persons and their families, as can be seen in the following account of ethical conflicts experienced by one of these professionals: *"The main conflicts were experienced when the family did not accept sedation when there was a clear indication, for example, a refractory dyspnoea. There was also a family that wanted the patient to be sedated, and the patient did not want to be sedated. And there were cases in which the team did not reach consensus"* (Daisy).

For the healthcare professionals, when refractory symptoms are present, it indicates the sedation of the person in distress in the face of imminent death. This is where the issue of involving the family and the patient emerges, as highlighted in the testimony of another participant: *"When the symptoms are intolerable for patients, after we have made every possible effort to provide palliative care and we do not have satisfactory results controlling the patient's suffering, the possibility of palliative sedation is addressed by the staff and then discussed with family members. We consider the family's acceptance and, where possible, the patient's. It sometimes happens that the patient wanted to be sedated and the family did not want to allow this; we have had situations like this"* (Violet).

In the meantime, conflicts of values between the sick person and the family also start to emerge. Furthermore, it is necessary to understand the "facts", bearing in mind that the "values" of the professionals also interfere in the process. Between the healthcare team and the patients and their relatives, the main conflicts reported are associated with *"values, beliefs and culture": "We acknowledge the values, beliefs and culture of the patient and the family. Certainly, one cannot help but notice that each patient reacts differently. Sometimes very differently from what I think, and in a way that clashes with my own values and the team values"* (Sunflower).

Indeed, between "facts" and "values", there is fertile ground for the exercise of decision-making that takes into account the resolution of ethical conflicts and the values involved. In other words, it is an opportune field for the exercise of moral deliberation, which, according to Gracia [9], seeks to analyze the problems in all their complexity. This means assessing the implied principles and values, as well as the circumstances and consequences of the case, allowing the identification of all, or at least most, potential courses of action, that is, the feasible decisions.

From this perspective, as reported by one respondent, *"the rationale is as follows: there is a discussion amongst the multidisciplinary team. Afterwards, we have a conversation with the family and the patient, within the same timeframe. However, we will respect the wishes of the patient, because the patient is our primary concern. It is not uncommon that sometimes the family asks for the comfort that palliative sedation provides, and we really respect the autonomy of the patient when they can decide for themselves"* (Gardenia).

Planning of the decision-making process

In this subcategory, the focus is on the planning of the deliberative process and decision-making, with the objective of considering how the actions are planned and carried out.

It was identified that the multidisciplinary team has been creating two occasions to discuss the palliative sedation cases: a weekly staff meeting, in which they seek to develop multidisciplinary work, and a family meeting, which is held in line with the needs of the patient and their family. According to a report from an interviewee, the professionals participating in the team meeting include: *"the doctor, nurse, psychologist, nutritionist, pharmacist, social worker, occupational therapist, nursing technicians from the ward and outpatients care (when their duties allow them to be available) and physiotherapist. Everyone involved in the care of the patient attend the meeting, and it is an important commitment"* (Tulip).

This statement also follows that the multidisciplinary meeting is considered an indispensable requirement for the development of multidisciplinary work that reflects the importance of the discussion process among the team members. The multidisciplinary meeting constitutes a legitimate forum to exercise bioethical reflection, since it is in these meetings that the team identifies and discusses the values involved in the practice of palliative sedation, whether they come from the inner circle of support (patient and family) or from the multidisciplinary team. This is because, according to Zoboli, *intuitive values may be clear to each of us individually, but we need to share them with others, as these values may differ between individuals* [13].

To plan and make prudent and responsible decisions, respondents understand that it is necessary to identify the ethical and value conflicts, including those within the team: *"We try to resolve these in the team meeting. Of course, we have to remember that everyone who works here also have their beliefs, their own ethics and their own morals; based*

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on their home and social environment and their own upbringing" (Daisy). The importance of the values of the professionals involved stands out in this report: *"We all have our beliefs, and the multidisciplinary team is important to guide this decision. The team provides a foundation for this decision, this attitude. Without a doubt, my values (my ghosts, my beliefs, my knowledge) are imprinted there."* (Violet).

Resorting to moral deliberation as a method to reach a reasonable and prudent solution to the problem, with a focus on the conflicts to be solved, means to align the parties involved to the idea that the decision to be taken is just part of a dynamic process. In this process, it is also necessary to analyze the experiences of people who are in the advanced stages of an illness with no possibility of healing, together with the experiences of their families. Only from this perspective, can health professionals consider their values and discern them from those of the sick person and their friends and family.

From the reports of the participants, it became clear that the deliberation process is still under construction, given that, in addition to knowledge and skills, *deliberation implies attitudes, such as mutual respect, humility or intellectual modesty, and a desire to enrich understanding of the facts by listening to others* [14]. Without doubt, the planning of actions to be taken involves team discussions and decisions, as confirmed in the following statement: *"I cannot take a complex decision like this by myself. It (team deliberation) is a very precious resource and so specific to a single moment, a unique experience"* (Violet). In fact, when considering the importance of this practice for all those involved in the decision-making process regarding palliative sedation, it is evident how important shared understanding is, particularly for the professionals, as can be seen in the words of one respondent:

"I do not know if it is because, every time something is not being done in the best way, I question it. Then, if we question, think about it, and talk to reach a particular conclusion, I think it is being done in the best possible way. I believe that it would not have been done in the best possible way, if I had left a doubt without questioning, without answering, without asking why. Therefore, every time I have doubts regarding the sedation, I try to listen to the opinion of the doctor and other professionals, because discussion is necessary. After all, I will be dealing closely with the family, and then they will bring these questions to me and I need to respond calmly" (Hydrangea).

By analyzing the reports, it was found that the planning of the deliberative process and the professional conduct conducive to making prudent decisions are both factors associated not with only the professional experience, but also with the experiences related to the practice of palliative sedation:

"I believe there was a great evolution over the time I experienced this. Even me, as a professional, wow, I changed a lot! It is a paradigm shift. It changes your life, the way you confront life. Then, I think there was a shift in improving the discussion of palliative sedation, because now people have more experience. They have experienced many cases and many situations, so they have a more holistic perspective than when we started this process. At first, it was very difficult, there was no consensus. Sometimes the decisions were very one-sided; it was more the doctor's decision. With time, the decisions were more well-grounded. I think it is difficult for us to look at ourselves and appreciate this growth, but it happened. Because it is a very difficult issue for everyone, it is a difficult subject to broach. Therefore, I think we grew over time and I think we always have room for improvement" (Lily).

There is a consensus, among the professionals, regarding the high relevance of discussing cases in teams, as well as the priority of identifying the values that are imbued in the family and the patient. Therefore, *"the service will adapt to the increasing professional care surrounding patients"* (Lily) – which means looking beyond the available facts: *"Clinical facts are important, but, in palliative care, the person who will say what is important is the individual who is undergoing the experience and their family. Listening makes a difference because it guides the care towards their lives"* (Violet).

Respondents believe that it is qualified listening that reveals the values of clinical facts. Thus, the understanding of this aspect by the multidisciplinary team allows an enriching dialogue that results in more reasonable and prudent decision making, which can be assimilated by all or most of the team members, in order to ensure the success of the endeavour. In this sense, the family meeting - seen as a time when the multi-professional team joins the family to talk about the healthcare needs of the patient - is extremely important for the correct understanding of the values, which, in turn, will be important in decision making, because, as stated by Zoboli, *clinical ethics begins with the clinical data, but the inclusion of values in decision-making increases the quality of care* [15].

In addition to professionals, the family meeting is a time for interaction among a representative group of the multidisciplinary team, as shown in the two accompanying reports: *"We asked the social worker to contact all family members via phone for a meeting at the institution's premises. One of the team doctors, the social worker, the nurse and the psychologist participated in the meeting."* (Daisy) *"This meeting is attended by the doctor, the psychologist, the social worker, the nurse, and, sometimes, by the nutritionist and the occupational therapist, depending on the moment"* (Violet).

According to the needs of each family, the composition of the team that participates in these meetings can vary, and some take part with less or more frequency, depending on the concerns raised by the families: *"Each professional will demystify the situation regarding their expertise, but families ask questions. One of the families' areas of concerns is food. Their worry is the fact that the patient has not been eating and, when necessary, a family meeting is called to discuss the issue, as well as the benefits and risks of eating at this stage of the patient's life. The meeting includes: the nutritionist, the doctor, the nurse, the social worker and the psychologist"* (Hydrangea).

It was found, as can be seen in the following report, that the patient does not participate in the family meeting: *"Our family meeting includes the multidisciplinary team and the family, but the patient does not participate" (Gardenia).* The communication with the patient is held at a different time from the conversation with the family; so *"the patient does not participate in these meetings, only the family"* (Hydrangea).

Most likely, the reason for this procedure is due to the daily contact of the sick person with the health team, and the need to shield the patient from the discussions with family, or to the fact that the decision-making has often been delegated to the family. Generally, this occurs when the sick person presents evidence of refractory symptoms, when it is common to find the patient confused and disoriented due to the progression of the disease. In other words, although it is believed that palliative sedation should be proposed to the subject during the course of the progression of their disease, while they are still able to make decisions, this is not always possible.

In this case, as the patient cannot express their wishes regarding the process of dying, the sick person is dependent on the perceptions of family members and of the professionals in charge of their everyday care regarding the "signs" of the patient's wishes. This becomes clear in the following statement: *"We, in our work, because we apply multidisciplinary care, make joint decisions. The team observes signs of distress and seeks to re-establish the patient's autonomy, or their possible autonomy. When the patient's autonomy is not present, we seek the family's opinion. We also try to recover anything through which the patient might have given a sign, any clue they might have given before they became unconscious".* (Gardenia).

One of the reasons for the family meeting is to apprise the maximum number of family members about palliative sedation, in order to share the responsibility in making decisions: *"We call on everyone to acknowledge their responsibility, (...) and the psychologist (...) tactfully makes the family members realise their responsibilities. So that everyone has an understanding of the process and of their responsibilities to ensure everything goes smoothly."* (Tulip).

In addition, there is a concern regarding adequate preparation for grief. This measure is justified, since without a clear division of responsibilities in the decision-making process, grieving could end up causing additional suffering for the family. Therefore, according to Gracia, *it is irresponsible to make a decision while considering only the principles. Our responsibility always extends to the future and therefore it is necessary to consider the consequences as an integral part of moral judgment* [16]. It is in this sense that professionals assert the importance of the family meeting: *"We hold a meeting where we ask for more family members to be involved. It is not only the family member that is accompanying [the patient} who decides. We ask that the family be called, including those closest to the patient, so that we can sit, talk, and explain the disease from the diagnosis to the prognosis and everything else; to discuss expectations, to explain what sedation entails, and only then, a consensus is reached"* (Sunflower).

Therefore, an analysis of the interviews showed that for the patient, good communication based on a clear understanding of the information provided by the health team is essential for the family, to fulfill their responsibilities: *"If the family does not deal well with the question of sedation, it will be a family that will have problems in mourning. And they will begin to wonder: 'Why did I allow it? Why did I not stay? If I had not allowed it, would he/she not have survived more days?' While the family does not understand the whole question of sedation, they are not ready to*

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accept sedation. So, we work things out. Sometimes it is necessary to talk with each family member separately, to understand why they do not want sedation, and it is very personal" (Hydrangea).

Close examination of the data showed that the work that is being developed by a multidisciplinary team is concerned with analyzing each situation to find a consensual solution, in other words, a group of professionals committed to finding the best solution for *every difficult case, in order to improve the decision-making process and ensure, where possible, that these solutions are reasonable and prudent* [17]. For the professionals, the team discussion, as well as the family involvement, is essential: *"The decision to sedate is never simple. It is never a simple thing, but it must be taken, so we do everything to facilitate it"* (Rosemary).

As seen, other problems arise as a result of the process of dying and the decision regarding palliative sedation.

Sought solutions to ethical and values conflicts

By the analysis of the third sub-category, *solutions to conflicts*, it was found that the solutions to the problems were not present from the start, but - instead – they were sought by team debates. This search is exemplified by the decision to give enteral feeding to a patient, when the option was for an "intermediate" solution, seeking respect for the beliefs and values of the family and the principle of non-maleficence: *"Not feeding is one of the issues that we face. Because, to the family, not eating, means the death of the patient. For the family, it is very sad to see their loved one unable to eat. So, often the enteral nutrition is left to a minimum, only to reduce the family anxiety, to make the family at ease. In the explanations about palliative sedation it is explained that the medications will be stopped, as they will no longer be necessary, with the reduction of nourishment, as patients remain with reduced feeding" (*Hydrangea).

To make deliberations like this, in a consensual way and without accentuating conflicts between family members, it is necessary to identify what their values are in relation to food: *"We try to show respect and try to talk, explaining the procedure, what will be best for the patient, while respecting the opinion of the family and the patient. For example, if we explain that the food could be removed and the family says no, we leave it. And I seek, within my expertise, to do everything that can make things easier, that can help to make the patient more relaxed and that can bring relief without causing harm. We value the knowledge of everyone, respecting their opinions and beliefs, and seek to understand "*(Tulip).

In order to achieve prudent decision making and to respect the choice of the sick person and their family, the team relies on interpersonal dialogue in times of discussion, especially in cases where, for some reason, the family and / or the patient do not accept the use of palliative sedation. This dialogue is crucial in the deliberation process, given that *the ultimate goal of a moral life is making prudent decisions. And these do not consist merely of the application of the principles, but in the intention to conform to the basic tenets of human decency* [18].

For the professionals, when the patient does not accept sedation, "the team remains very anxious (...) *cannot handle the suffering; becomes very distressed and, once again, we have to talk, as it is not our decision,* (...) *if this suffering is distressing for us, it is even more so for the family, it is much greater. If it is difficult for me, it is much more difficult for the patient, and [I] respect them above all." (Hydrangea) Other respondents corroborated this point of view:*

"We talked a lot, the team engages in dialogue to share experiences" (Sunflower);

"It's difficult and complicated to work with the decision of not applying palliative sedation when the patient has a refractory symptom. In general, the policy that we have among the professionals is that, when the family does not accept it, sedation is not applied. The autonomy of the patient and the family is respected as a justification for not performing the palliative sedation."(Daisy);

"We work with the team, recollecting our principles and remembering our respect for autonomy. Then the autonomy should be what the patient decides, rather than what the patient says that sounds like what we would do." (Gardenia)

It was possible to identify that mutual respect permeates the decision-making process in the multidisciplinary team. To Zoboli, *moral deliberation in clinical practice requires a dialogue that enables the exchange of facts, emotions, feelings, beliefs, values, and not only information about signs, symptoms and test results. Recognising bonds and affections, and respecting differences and diversity, in an atmosphere of mutual respect, are essential to listening* [14].

However, one must consider that each professional is able to decide according to their expertise and their professional competence, so that, in the decision-making process, there is no guarantee that the solution reached by consensus shall be taken to effect, because we must not confuse the deliberative process with the ability to decide [10]. Therefore, in teamwork, one must take into account the specific competencies of the professions related to the act of caring: *"Most of the time, it is the attending physician or attending medical team [who decide]. And this is usually a decision taken after examination of the case, discussion of the case, and it is a decision that, obviously, must be shared."* (Daisy).

The analysis of the reports led to the conclusion that the professionals consider fundamental the idea that, in order for the decision-making to be, effectively, made by the team, it needs to be based on the "arguments" of knowledge of the case, and not on the *"authority"* to argue. *"Sure, everyone can [argue]. But the decision will also have to be agreed by all, that's what happens."* (Lily)

The moral deliberation proposed by Gracia [8] is a method that can lead to a major improvement in the "way of thinking" in teams, particularly when it comes to the multidisciplinary palliative care team, in which health professionals, according to their expertise, can directly affect, positively and / or negatively, the patient's quality of life and hence the quality of the patient's death. Effects that depend on, among other factors, not only the theoretical basis and technical capability to provide care, but, above all, the moral justification of ethical systems that serve as ethical support for the work of these professionals. This means, that this refers to knowing whether they consider or not, or even, to what extent they reflect about the facts, duties and values involved in the whole process.

Each professional of the team has a good understanding of the clinical and personal history, that is, the "facts" and "values", of the patient and their family. However, to facilitate decision-making, this knowledge should be shared with the team, as reported below by one interviewee:

"You know this patient intimately, the whole family structure, in most cases, the profession of each of them, the inter-personal relationships. The problems experienced by the family are brought by the social service, the psychologist and also by us, through the daily contact that we share with them. And this becomes very easy for us to deal with, in the sense that we get to know the family structure and hierarchy. Consequently, the decisions become less difficult with this perspective. When you make the decision simply based on isolated facts or specific symptoms, without the whole story to support it, it becomes more complicated." (Lily)

Besides favoring the deliberation process for prudent and responsible decision-making, sharing information helps to promote ethical reflection as a team. That is why the ethical deliberation regarding health is also a *permanent educational tool for professionals, through the mutual exchange of experiences and the dialogue on values, beliefs and principles* [19].

Therefore, when it is stated that, in the field of research in question, you can create a process of moral deliberation, there is a conviction that this construction could be improved based on Gracia's proposal [8]. This proposal suggests that, *a collective deliberation about common goals, with the exposure of different views and their rationale* can be, according to the author, *the appropriate method for the remoralization of the professions and the resurgence of professional ethics* [17]. Certainly, the same suggestion could be well received by any other palliative care service that has not yet created a deliberative and decision-making methodology, with the necessary bioethical foundation. Even for services that already have an established method it pays to become acquainted with the "moral deliberation" of Diego Gracia [8].

Final considerations

This study sought to investigate, through reflection and dialogue with health professionals involved in palliative care, in order to understand the deliberation process regarding some ethical conflicts related to palliative sedation. It was possible to identify that the reflections regarding this practice are done in multi-professional teams, demonstrating multidisciplinary work, and that the discussions held with family members regarding ethical problems and conflicts occur at different times and separately from those carried out with the patient. Even so, the research shows that the deliberation process still under construction, regardless of the team decision-making that is made based on the will and values of the patient, remains an unconsolidated procedure. However, the healthcare team understands and seeks solutions to ethical and value conflicts related to the practice of palliative sedation, even though, sometimes none of the solutions are entirely satisfactory.

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Certain peculiar characteristics were verified not only regarding the professional culture but also regarding the culture of the users of palliative care (patients and family members) - cultures that are actually the source of the moral values of all involved.

According to the analytical framework used, for moral deliberation and its respective decision-making process regarding the practice of palliative sedation, a deep knowledge of the clinical facts (the physical and psycho-existential refractory symptoms), of the duties and of the values was identified as a necessity for the multidisciplinary team. In other words, to reach a prudent and responsible decision, it is necessary that the facts be clarified, that potential ethical conflicts are weighed within the multidisciplinary team, and that the values of the patient and their family are known and respected, as they are responsible for the final decision. This is the tripod of moral deliberation for the use (or not) of palliative sedation for sick people at the end of their lives.

It is in this sense that bioethics has become one of the conductors of the practices of health professionals, particularly in the context of palliative care, which, by its nature, routinely addresses the issues and problems concerning the boundaries between life and death, while always seeking to respect the sick patient and family values.

Therefore, the decision to use (or not) palliative sedation requires extensive team discussions , in which the role of the patient and of their families in decision making is respected above all - a condition considered essential for the characterization of this practice. It should also be noted that, in order to guarantee the right to information and respect for the autonomy of the patient, the use of palliative sedation should be proposed in advance, that is, during the progression of the disease, while the subject's capacity to make decisions has not yet been compromised.

Thus, the promotion of access to palliative sedation is of paramount importance in comprehensive care at end of life, given its ability to minimize suffering inherent in the process of dying from cancer, and to promote death with dignity. However, concurrent with the dissemination of this practice, it is recommended that palliative care professionals improve their ethical knowledge and axiology and that the grasping of such knowledge by them is encouraged, once the decision-making process is contextualised with the clinical facts, it requires the entire team to apply extensive ethical consideration and respect for the values involved.

In short, only in the context of the team's working relationship, is it possible to redirect the path to be followed in the practice of palliative sedation – a route taken with the consensus of all involved, with the objective of prudent and reasonable decision-making, that is, a moral decision.

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Participation of the authors

Melisse Eich is responsible for the conception, bibliographic research, data collection, transcription of the interviews, analysis and interpretation of the results and writing of the article, under the academic supervision and revision of Marta Inex Machado Verdi. Pedro Paulo Scremin Martins collaborated in the bibliographic research, writing and formatting of the original text.

Research article

Palliative care and primary health care: scoping review

Danielle Yuri Takauti Saito [1], *Elma Lourdes Campos Pavone Zoboli* [2]

Abstract

The ageing population has increased the incidence of chronic health conditions, requiring the inclusion of different levels of palliative care (PC) in different parts of the health system, including the Primary Health Care (PHC). This new reality might interfere with the ethical issues of PHC. This research aimed to identify, from the point of view of health professionals, the ethical problems which arise from the palliative care in PHC. We carried out a systematic review in PubMed, EMBASE, LILACS, CINAHL, using the descriptors 'ethics', 'bioethic's, 'Primary Health Care' and 'Palliative Care'. We found 3,915 articles of which 16 remained after analyses. The ethical problems found were: lack of resources; lack of knowledge about palliative care; lack of communication skills; difficulty in establishing limits in clinical relationship; work overload; lack of support from referral services. These problems, in general are similar to those experienced in the PHC but with differences in specific situations. The incorporation of palliative care to the Primary Health Care specific guidelines and training as well as the custom of shared and co-responsible care.

Keywords: Palliative Care. Chronic Disease. Primary Health Care. End-of-life. Bioethics. Ethics.

Resumo

Cuidados paliativos e a atenção primária à saúde: *scoping review*

O envelhecimento da população aumentou a incidência de doenças crônicas, demandando a inserção dos cuidados paliativos (CP) em diferentes níveis da rede, incluindo a atenção primária à saúde (APS). Isso poderá interferir nas questões éticas da APS. A presente pesquisa teve como objetivo identificar, na visão dos profissionais de saúde, os problemas éticos decorrentes da prática dos CP na APS. Fez-se revisão sistemática nas bases PubMed, Embase, Lilacs, CINAHL, com os descritores "ética", "bioética", "atenção primária à saúde" e "cuidados paliativos". Localizaram-se 3.915 artigos, restando 16, após a análise. Os problemas éticos detectados foram: escassez de recursos; desconhecimento sobre CP; falta de habilidades comunicacionais; dificuldade de estabelecer limites na relação clínica; sobrecarga de trabalho; falta de apoio dos serviços de referência. Na abrangência, esses problemas assemelham-se aos vividos na APS, com diferenças nas situações específicas. Para incorporar os CP na APS, são necessárias normatizações e formação específicas, além da cultura do cuidado compartilhado e corresponsável.

Palavras-chave: Cuidados paliativos. Doença crônica. Atenção primária à saúde. Terminalidade de vida. Bioética. Ética.

Resumen

Los cuidados paliativos y la atención primaria de salud: *scoping review*

El envejecimiento poblacional aumentó las enfermedades crónicas, planteando la inclusión de diferentes niveles de cuidados paliativos (CP) en la red sanitaria, incluyendo la Atención Primaria de Salud (APS). Esto puede interferir con la ética de la APS. Nuestra investigación objetivó identificar, según los profesionales, cuales son los problemas éticos de los CP en la APS. La revisión sistemática en PubMed, EMBASE, LILACS, CINAHL, con descriptores "ética", "bioética", "Atención Primaria de Salud" y "Cuidados Paliativos", identificó 3.915 artículos, restando 16, después del análisis. Los problemas éticos fueron: falta de recursos; desconocimiento en CP; falta de habilidades comunicacionales; dificultad con los límites de la relación clínica; sobrecarga de trabajo; insuficiente soporte de servicios de referencia. En general, los problemas se asemejan a los experimentados en la APS, con las peculiaridades de situaciones más específicas. La incorporación del CP en la APS requiere: directrices y formación específicas; cultura de la atención compartida y corresponsabilidad.

Palabras-clave: Cuidados Paliativos. Enfermedad Crónica. Atención Primaria de Salud. Fin de la vida. Bioética. Ética.

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Declaram não haver conflito de interesse.

Research article

The demographic and epidemiological transition has changed the morbidity and mortality profile of the Brazilian population. Infectious diseases were the most frequent causes of death until the first half of the twentieth century but, currently, noncommunicable chronic diseases are epidemic, in particular cardiovascular diseases, cancer and type 2 diabetes. The highest morbidity and mortality rates, due to these diseases, grow each year and account for about 70% of the health spending in the country [1].

Chronic health conditions, because of their progressive and degenerative evolution, demand continuous and ongoing assistance - which includes palliative care- in various parts of the health care system (Rede de Atencao a Saude -RAS). The continued assistance in chronic health conditions involves attention to the latent moments of the disease when it evolves without perception of the person who will suffer the deterioration of quality of life [2].

It is a challenge for the Unified Health System (Abbreviated as SUS in Brazil - Sistema Unico de Saude) and the Primary Health Care (PHC) to reorganise themselves in order to meet the current health needs and demands of an ageing population with chronic diseases. Historically, the health systems were organised and focused on responding to acute conditions or episodes of worsening of chronic conditions [2].

Palliative care has the objective of promoting a better quality of life, through therapeutic projects planned by a multidisciplinary team, for people with chronic degenerative diseases or are in a terminal state. The care is not restricted to specific contexts and institutions and must be performed at every level of the health system. Specialised Palliative Care is an assignment attributed to specialists in hospices, while primary health care provides the overall palliative care. All health workers should be trained for the palliative care approach, since this kind of attention needs to be established early, from the moment of the diagnosis of chronic health conditions, and aimed at a good quality of life [3].

The main challenge for the palliative care at an international level is to go beyond the care of terminally ill patients with cancer. It is proposed that palliative cases should be: introduced as soon as possible in caring for diseases, not only during terminal stages; go beyond the physical dimensions of care and cover the social, psychological and existential aspects; span from hospices and specialised services to the general services in hospitals and in the community, disseminating in the community in order to support caregivers and patient's relatives [3].

The best results in providing palliative care depend on the integrated operation of services as well as the alliance between specialists, generalists and home caregivers [4]. Given the demographic and epidemiological transition, the demand for palliative care in the Primary Health Care became a reality, so much so that both teams of the Family Health Strategy (abbreviated as ESF in Brazi) face situations of attention linked to the death process [5].

However, this demand for palliative care at a local level is not properly evaluated or estimated. Nevertheless, it is possible to foresee the "impact" that it would bring to ethical issues experienced in the primary health care. But what would this impact be?

Method

This is a systematic review based on the scoping study or scoping literature reviews. The strategy called scoping review (SR) consists of a systematic review, exploratory, aimed at mapping scientific production and relevant studies in a given area. The scoping review has a comprehensive approach, as the search question is extensive and the evaluation of studies' quality is less strict [6] .

In this review, we used the PICo strategy for the formulation of the question, "P" being for population , "I" for phenomenum of interest , "Co" for context . Adjusting the object of study to the PICO strategy, the guiding question is: What are the ethical issues, for health professionals, in palliative care in the primary health care ? In order to ensure a coverage adequate to a Scoping review, the gathering of information used two search strategies. The first was held in the databases Lilacs, Embase, CINAHL and PubMed, using the descriptors "ethics," "bioethics" and "primary health care".

The second search used the descriptors "ethics," "bioethics" and "palliative care". The data bases were the same as those from the first search, with the exception of Embase, due to the the University of São Paulo (Universidade de Sao Paulo-USP) having discontinued its subscription to that data base. Both searches were limited to the scientific production in the period from December 31, 2002 to January 1, 2013. We included articles in Portuguese, Spanish and English. When the articles contained empirical studies, the subjects of interest were healthcare professionals of the Primary Health Care. The inclusion criteria were articles related to ethical

and operational conflicts as well as the relationships of the professionals with the users of the health system. Studies that did not meet these criteria were excluded from the review.

When the articles were not fully available in the databases, we tried to obtain them through the Portal of Magazines of the USP's libraries, the Portal of periodicals of the Coordination for the Improvement of Higher Education Personnel (abbreviated as Capes in Brazil -Coordenação de Aperfeiçoamento de Pessoal de Nível Superior) or direct contact with the author by e-mail or through Research Gate. The articles were not considered in the survey if, after these attempts, we couldn't have access to the text in its whole.

We introduced, in addition to the search in those databases and in accordance with the inclusion criteria, articles from the private collection of one of the authors, who specialises in the bioethics area in the Primary Health Care and already had works collected in previous searches.

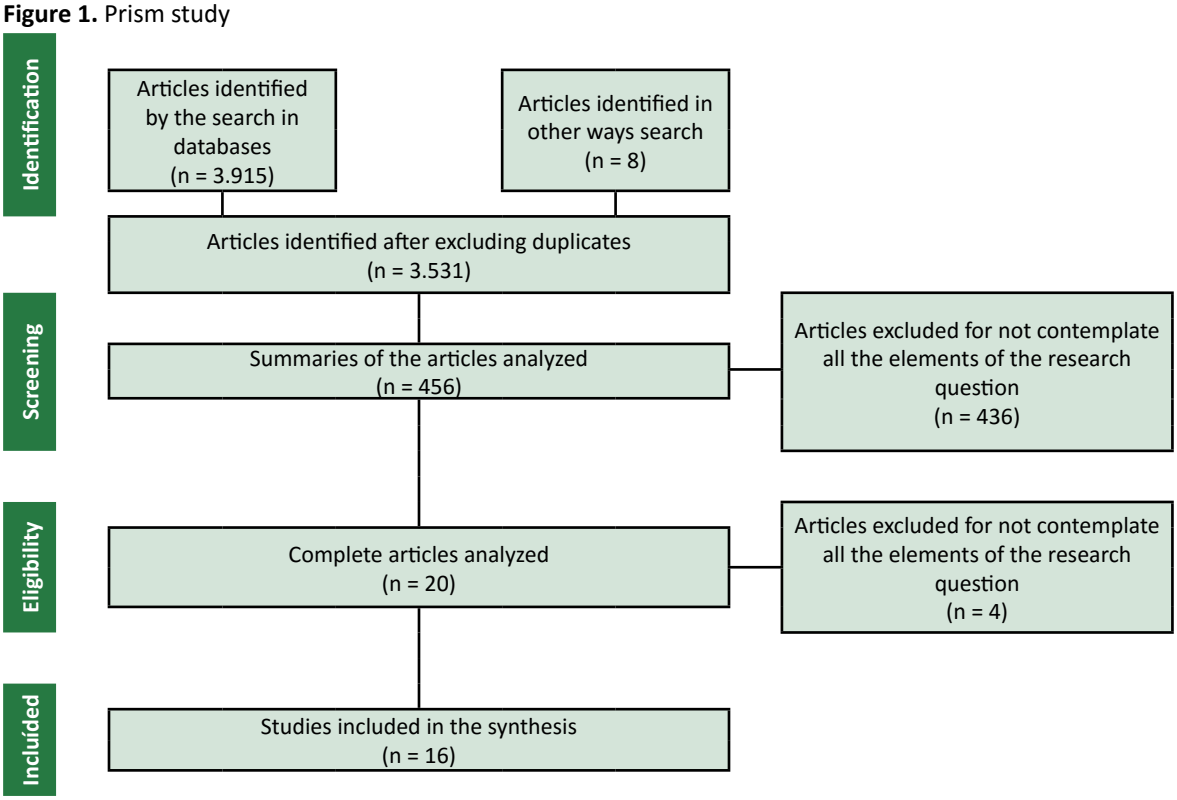
We evaluated, for the systematisation of data, the following: periodical (title, volume, number and year); title of the article; authorship; origin of the article (thesis, dissertation or monograph); existence of funding for the research; location of the study (institution, country, state and city); goals (article or research); method (type of research, sample, participants, setting, data analysis); results; reference to ethical problems concerning palliative care the in primary health care.

The articles were identified with letters and numbers, according to the database used and the sequence in which they were found. One example: P1 is the first study taken from the PubMed database, and so forth.

Results

The first search strategy identified 2,366 studies; the second search identified 1,549 studies, besides 8 articles taken from the private collection of one of the authors. The Prisma (preferred reporting items for systematic reviews and meta-analyses) is in Figure 1. The screening covered the analysis steps according to their titles and abstracts. Based on the title, 3,075 articles were excluded, remaining then 456 for analysis of the abstracts. The 16 articles included in the review refer to 15 studies, since the A11 and A12 have results which are different aspects of the same research.

Figure 1. Prism study



Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) [7].

The table 1, annexed to the end of this paper, shows the included articles and their respective authors as well as original locations of the study. The Table 2, also presented as an annex, exposes the ethical problems found in each article included in the review.

Different scenarios in which palliative care are provided affect significantly, the manifestation and the kind of ethical question, being necessary to emphasise that such problems are inextricably linked to the peculiarities of each service. Article E1, the aim of which was to analyse ethical problems experienced by paediatricians whilst associating them to their workplace, found that the 16 UBS doctors (UBS stands for Unidade Basica de Saude - Health system Basic Unit) had no ethical problems relating to end-of-life care 8. Despite these peculiarities, the ethical issues are focused on decision making, the futility of therapy, the patient's autonomy and nursing work [9].

The non-resuscitation orders and the choice made by patients not to be treated, with consideration of their quality of life, stand out in the decision making . The usefulness of treatments is determined by the expectation of benefits. Decisions to prolong life are avoided. As for the autonomy, patients must be well informed about their situation because many euthanasia requests result from the loss of control about the care. In their work, the nurses feel responsible for defending the rights of patients and stand firm in their defence, to the point of even confronting the medical team. Nevertheless, these professionals complain about "difficult patients" who are never satisfied with the nursing work. In these situations, they need to make an effort to feel sympathy for those patients, besides remaining motivated to watch them and talk to them about death [9].

Primary health care professionals feel the duty to accompany patients in their last days of life [10]. Doctors justify such an obligation as a way to compensate for the powerlessness they feel because of the impossibility to provide to patients in palliative care a treatment as effective as the one for patients with normal life expectancy. Therefore they devote more time and attention to patients in the palliative care [11].

When it comes to terminally ill patients with cardio-respiratory diseases, the feeling of impotence of physicians increases. Because they were insufficiently trained to offer palliative care in the terminal stage of this class of diseases, doctors recognise that their help is lower in these cases than in the final stages of cancer. Therefore, in these situations, professionals no longer inform patients that they are in the final stage of their illness [12]. If a doctor from the Primary Health Care did not follow the curative treatment phase, then the communication about the transfer to palliative care is more complicated [11]. Physicians find it difficult to determine whether the person is terminally ill in the absence of a diagnosis of underlying malignant disease [12].

Doctors believe that to discuss palliative care is time consuming and therefore it is unlikely that they will have this kind of conversation with patients. They consider that this discussion is not beneficial to the patient, as it is exhausting and uncomfortable [13]. In turn, nurses recognise the importance of talking about death with patients who have no chance of a cure, although they only have this kind of conversation when they are willing to or when there is an opportunity [14]. The lack of truthfulness whilst talking to patients and their families about their actual health situation is another ethical problem identified in the relationship and communication of primary health care professionals working in palliative care [15]. Besides the lack of information, professionals report breach of confidentiality in the treatment and prognosis of patients [16].

This deficiency in the communication and relationship between professionals and patients as well as their families may explain why most of Primary Health Care doctors were unaware of the final wishes of their patients, even when they had already expressed those wishes in anticipated directives in another health service. Another example of the consequence of ineffective communication happens when patients say that they had not expressed any anticipated directive whilst doctors claim otherwise. Although the review leaves unclear the reason of this disagreement, at least it is indicative of communication problems [17]. Nurses attribute the inadequate communication with patients and families to their poor training in this requirement [15]. In the United States, anticipated directives are legal documents, not clinical documents; that is, they are a particular initiative of the patient or anyone else, regardless of their health status [17].

Communication also fails between doctors and nurses, among members of the Primary Health care team [18,19] and teams of different services [12,16,20.] Primary Health Care doctors complain that the specialists do not share information [20]. In cases of cardiorespiratory diseases, Primary Health Care physicians feel frustrated for failing to take full care of the patients as, during the worsening crisis of underlying diseases, the specialists of the hospital are the ones who manage the palliative care.

Primary health care doctors say that medical specialists fail in the transmission of information, since they do not inform the decisions taken at the hospital about the patients' treatment regimens who are under their care. As a result, they lose confidence in the hospital which, in addition to failing to communicate about treatments and interventions, often gets in to conflict with the prescriptions already given by primary health care doctors . Conflicts arising from inadequate communication between services are worse in cases of cancer patients who participate in clinical trials because the team of researchers prohibits that the primary health care and the hospital modify or introduce any conduct without their consent [12].

Nurses from the primary health care see in doctors a reluctance to accept new initiatives and to respond to the needs of patients and requests from the nurses. Nurses get an idea about the "good" or "bad" doctor based on the willingness of that professional to receive and respond to requests from patients or the nursing staff and also on the respect with which doctors treat other professionals. Thus, in the assessing of the nurses, technical expertise and medical knowledge are less important than interpersonal relationships [21.22].

For nurses, the quality of interpersonal relationships and the perception that each professional has about the performance of other professionals are factors that influence teamwork and the referral of users to another services. The team cohesion depends more on the relationships among its members than in the care to be provided to the user. For doctors, the negotiating issues and interpersonal relationships count less on the assessment made of the professionals. This could be due to the difference of authority between doctors and nurses. The question of the leadership of doctors became clear in the focus groups of articles: nurses did not give their opinions, and the groups were to be represented, formally or informally, by a doctor, who chooses the day of the meeting and would eventually lead it, directing the discussion [21.22].

The excessive importance attached to interprofessional relationships is evident when Primary health care professionals assess the benefits of introducing a program to improve the quality of care solely on the basis of those relations, without taking into account the interactions with patients and the impact on the direct care. When professionals from the primary health care need to refer the patient to specialists, and make that decision considering only the relationship with these professionals, it is possible that they will be successful. In such cases, it would indicate the possibility of obtaining facilities now and in the future, which ultimately influence the judgment that the primary health care team makes of the professionals from the specialised services [21,22].

Nurses don't have availability for palliative care interventions [15]. Insecurity, lack of access to emergency drugs, the lack of interpreters to attend the aboriginal population, the high cost of overtime and the limited cell phone coverage are aspects that justify the non-availability of these professionals to work at night. They claim that an amendment of the legislation in order to allow nurses to make the assessment of death could increase the participation of these professionals in the palliative care, especially in shifts after opening hours of the primary health care [18].

Doctors of primary health care, in turn, also mention some obstacles to their involvement with palliative care: lack of time; home visits; personal or family commitments; lack of interest; unavailability for work after hours; lack of knowledge of palliative care; emotional reasons, and lack of support of specialists [20]. The nurses agree that the limited availability of doctors to work after hours is one of the limiting factors for palliative care in the primary health care system. In turn, doctors claim that the unavailability of nurses for work after hours is also a limiting factor [18].

Doctors and nurses have proposed some strategies for improvement of work in home-based palliative care: regular multidisciplinary meetings; easiness of referral to specialised services of palliative care; more nurses for home visits; nursing training in telephone service after the opening hours of the primary health care and, especially, the development and adoption of standardised protocols for the plan of treatment concerning each patient [18].

Professionals in the primary health care involved in palliative care wish to continue in the program, but the scarcity of resources, lack of organisation and management of services cause overload [10,16]. The lack of resources and referral services, the work overload and lack of space to discuss the experiences in the care of dying patients are factors that make nurses more prone to psychological illnesses, besides creating frustration among them, because they can not provide care of good quality[23]. The difficulty of access to referral services, mainly the ones specialised in palliative care, is higher for patients with cardiorespiratory disease and lower for patients with cancer, as reported by nurses and doctors in one of the studies [12].

Nurses and doctors find it difficult to set limits to the relationship with terminally ill patients and their families [15,23]. The close proximity of professionals to users of the primary health care creates intense bonds, which causes distress to nurses [11,23.] Primary health care professionals go to the point of giving the number of their personal phones to family members of patients in palliative care so they can get in touch if necessary. Those professionals also do voluntary home visits after working hours [10]. This attachment is also present when families and caregivers require actions outside the scope of the competence of the primary health care when the family requests, for example, constant visits to the patient [23].

The proximity between primary health care professionals and patients in palliative care interferes with communication of the truth about the patient's health condition. Some PHC doctors do not report poor prognosis to patients for fear that if they do, patients and/or family will nurture resentment towards them, leaving this task to the specialists who will have to watch the patients until the end [9].

Doctors report that fatalistic thoughts, insecurity and helplessness of caregivers tend to compromise the autonomy of patients, making them dependent and susceptible to emotional suffering [11]. Therefore, while recognising the importance of family support, nurses believe that such support sometimes hinders the care [14]. They also mention suspicion of physical, psychological and economical abuse practiced by the patient's family towards the patient. [16]. When faced with abuse, carelessness and neglect by family members, nurses change their behaviour in the attention to the patient , restricting their care to an exclusively technical scope.

As for the family members who mistreat patients, nurses do not assess that they also need care [23]. Doctors feel lack of support for dealing with ethical issues related to palliative care [11] and assurance of the continuity of home care to patients, especially after the opening hours of the primary health care services [18,19]. They suggest courses on standards and ethical values, including how to discuss and confront problematic situations from an ethical point of view in the sphere of operation of the primary health care staff [11].

Doctors' lack of information about available services and resources in the community and in the primary health care after opening hours contributes to the discontinuity of care for patients in palliative care at home [18]. Another factor is the poor cooperation between teams and between professionals [19], such as the absence of reports from nurses about interventions in multidisciplinary teams [15].

Doctors report that informal caregivers are the main collaborators in the provision of palliative care at home [19]. The relationship between professionals of the PHC and the family and informal caregivers is of poor quality, according to those professionals [16]. The nurses claim lack of conditions, time and preparation to accompany the mourning family and informal caregivers [15], while recognising their emotional suffering [11].

The PHC professionals consider that the lack of their knowledge about palliative care limits their activities [11], especially in the management of symptoms [9,11,15,20] and complex clinical situations [10,20]. In such cases, they base themselves on their accumulated clinical experience through professional practice, but do not feel safe on the best approach to be adopted [10]. Doctors mention the lack of time to devote to studies as an obstacle to their continued training in palliative care [18.]

Doctors think that the most important aspect of palliative care is more in the somatic domain than in psychosocial and spiritual grounds, which is why they rarely cooperate with religious ministers or discuss spiritual issues with patients [19]. Nurses also feel unprepared to address spiritual or religious matters with patients, although they recognise the importance of these talks at the final stage of life [14].

When dying patients in home care ask PHC professionals about issues related to the search for the meaning of life, the professionals, though unprepared, feel the duty to talk about it with patients and their family. Due to the prolonged coexistence of PHC professionals with the people in their care, many of them visit homes of friends and relatives of hospital's patients. It is a peculiarity of the palliative care in the PHC that is not as common in other areas of the Health System [9].

Doctors do not accept that ethical issues such as euthanasia can be solved by just good provision of palliative care [11]. In Sweden for example, even if rarely and despite counting with an excellent palliative care service, doctors feel obliged to offer euthanasia as a last resort due to unfavourable social conditions of some patients [9]. This finding drew attention of the authors of this article, as it is difficult to guess what would be the unfavourable social conditions in Sweden, when we live in a country much poorer and socially uneven; however, the article included in the review does not specify those situations.

Discussion

Attitudes and skills necessary to provide high quality palliative care overlap with those needed for optimal PHC: communication skills; understanding of reality and the peculiarities of the way of life of the patient; commitment to comprehensive and integrated care of the patient and family; attention to the psychosocial and spiritual issues; emphasis on quality of life and independence of the patient; respect for the values, objectives and priorities of patients in managing their own health condition; provision of care in the community, depending on its cultural diversity; collaboration with other professionals, including specialists. This way, it appears that the palliative care and the PHC can, and should, be strengthened and also strengthen each other [24].

With regard to collaboration among professionals, we need to face several challenges: conflict, ambiguity and overlapping of the roles of the professionals; inadequate communication, and leadership problems. The introduction of multidisciplinary teams is a necessity for the provision of health services in order to increase the efficiency of care, especially the palliative care. The team represents a workspace focused on creative problem solving, especially when the contribution of all its professionals is based on respect and when there is a sense of responsibility towards the patient's well-being [25].

This review found out that the type of ethical problem faced by professionals is closely related to the place where the palliative care is provided, which reinforces the fact that such conflicts are inextricably linked to the peculiarities of each health service. Ethics in health care implies the acting of moral subjects in situations of life and in the process of health-disease [26]. As the situations and processes are peculiar to each subject, ethical issues deriving from them will also be specific. Problems arise with their own characteristics in the various spheres of social life. Therefore, it is necessary to grasp, in each one of these contexts, the logic and modulation of ethical principles which are peculiar to them [27].

At the prospect of introducing palliative care in the PHC, especially through the ESF (Abbreviation, in Portuguese, of Estrategia Saude da Familia - Family Health Strategy) , two aspects are fundamental: that the informal caregiver can rely on the provision of educational activities aimed at the comprehensive care of the patient [5] and the presence of a professional in the team [28].

In the professional practice of palliative care at home, the informal caregivers consider important the knowledge, behaviour, communication skills and relationship quality of the professionals with their patients and their family members [28]. In general, the ethical problems found by this review are close to the ethical issues experienced by PHC professionals and identified in other studies [26]:

- Closer and more intense bond of PHC professionals with patients and families, which ends up creating difficulties for the maintenance of impartiality in clinical relations
- Request of unnecessary or improper procedures, which in the case of the palliative care, are considered extraordinary or outside the scope or the potential of the PHC
- Lack of collaboration between teams, creating difficulties in interprofessional work
- Lack of interprofessional respect, bad relationship between members of the multidisciplinary team
- Lack of institutional support for the management of ethical problems
- Work overload
- Disregard, by the reference and specialised services, of medical prescriptions made by PHC doctors
- Lack of resources to carry out home visits

Considering the axes on which the ethical problems of PHC are placed, the ethical issues of the palliative care, according to this review, focus on the practice of the teams and their professional profile. The first aspect presents ethical problems arising from the fragmentation of the work of teams and difficulties in interdisciplinary practice. The professional profile covers the ethical issues related to the behaviour of the PHC Professionals [26].

These two axes are focused on ethical problems related to the following aspects: bad relationship between the teams and difficult interprofessional communication, which interferes negatively with the quality of the care provided; training and preparation insufficient to act in the PHC and palliative care ; lack of communication skills of professionals for conversations in the scope of the clinical relationship, the interprofessional relationship and other points of attention of the RAS (Abbreviation of 'Redes de Atencao a Saude" in Brazil - Health System Network) ; lack of shared information.

Apparently, the introduction of the palliative care in the PHC will not interfere in the axes of ethi-

cal problems in this area of care, even if the specifics and peculiarities of palliative care reveal themselves in new situations.

In their practice, the ESF teams face the demand for palliative care at the end of life stage and, earlier, in the diagnosis of chronic degenerative diseases [5]. As a result, the systematisation of guidelines for palliative care actions in the PHC is essential, considering especially those aimed at addressing the ethical issues involved in this type of care.

Dying with dignity is a result of living with dignity; before the right to a dignified death, there is a right to a dignified life, with conditions to blossom fully - that means right to health [29]. Thus, ethical palliative care are the result of an ethical PHC.

Final considerations

This research aimed to discuss the ethical dilemmas relating to palliative care in the PHC. For this, we developed a systematic literature review to identify, from the point of view of health professionals, what are the ethical issues that arise from the practice of the services. The review also served to detect the difficulties in the professional profile, in the practice of the teams, management of services and health care systems in different parts of the world that offer palliative care in the PHC. Such difficulties are indicative that the lack of organisation of services and the lack of specific qualifications of professionals to deal with demands and needs of chronic health conditions is present also in countries which have had an ageing population for longer than Brazil.

There is a shortage of knowledge from professionals about palliative care, which contributes to the emergence of ethical problems in situations more traditionally associated with this kind of care such as the accompaniment of the death and grieving process, the communication of bad news, management of complex symptoms and clinical conditions. In the SUS (abbreviation of "Sistema Unico de Saude" in Brazil - Unified Health System), one must take into account that the ESF (abbreviation of "Estrategias Saude da Family" in Brazil- Family Health Strategies) teams already face the demands of terminal patients and users with chronic health conditions. And in this aspect, perhaps the biggest ethical challenge for incorporation of palliative care in the PHC is: to change the view of the professionals about the palliative care in order to introduce them earlier in the services, starting from the diagnosis of chronic health conditions.

Palliative care is not only suitable for people with cancer or people who are close to death. It is an extremely beneficial care and its early intervention, well before the final stage of the disease, may become essential to the excellence of the PHC before the demographic- epidemiological transition and its impact on the population's morbidity and mortality profiles. The palliative care must be offered according to the health needs of the population, so that the Primary Health Care and the RAS (Abbreviation of 'Redes de Atencao a Saude" in Brazil - Health System Network) can realize their social function.

Communication difficulties also affect the internal work of the team and of the team with the RAS. Political definitions and guidelines for the effectiveness of the health care network in the SUS are not enough; It is necessary to invest in interpersonal and inter professional communication as well as between the different levels of services, creating a collaborative culture based on the co-responsibility for the health of the population.

The survey results highlighted the work overload of the PHC teams, which is an obstacle to the implementation of palliative care. The ESF teams, in addition to caring for the health of the population in their area of work, have to contribute for the UBS to be able to deal with the many spontaneous demands that are required from them. Moreover, chronic health conditions require constant monitoring, including periods when the disease is latent, because this condition implies the need for early palliative care, that is, general palliative care aimed at maintaining good quality of life in the present and during the disease progression. For the introduction of palliative care under the SUS's Primary Health Care, it is essential to review the number of ascribed families in the ESF teams and reorganise the work process and the primary health care services.

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Participation of the authors

Danielle Yuri Saito Takauti developed the master's study in which this article is based, participated as the first reviewer in the scoping review and drafted the original article. Elma Lourdes Campos Pavone Zoboli directed the master's study from which this article has been originated. She also participated as secondary reviewer of the scoping review and revised the original article.

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Annex

Table 1. List of Studies included in the revision

Artigo	Título	Autores	Local
E1 [8]	Ethical problems in paediatrics: What does the setting of care and education show us?	Guedert JM, Grosseman S	Brasil
E2 [17]	The personal and social context of planning for end-of-life care	Kahana B, Dan A, Kahana E, Kercher K	EUA
E3 [13]	Primary care physician knowledge, utilization, and attitude regarding advance care planning, hospice, and palliative care: Much work remains	Snyder S, Allen K, Hezelett S, Raswany S	EUA
P4 [10]	Understanding the provision of palliative care in the context of primary health care: Qualitative research findings from a pilot study in a community setting in Chile	Cameron BL, Santos Sala A	Canadá
C5 [11]	Education needs of general practitioners in palliative care: Outcome of a focus group study	Meijler WJ, Van Heest F, Ottor R, Sleijfer DTH	EUA
P6 [14]	Identifying care actions to conserve dignity in end-of-life care	Brown H, Johnston B, Ostlund U	Reino Unido
A7 [15]	Os cuidados paliativos no âmbito dos cuidados de saúde primários: as intervenções dos enfermeiros	Carvalho SCC, Botelho MAR	Portugal
A8 [16]	Identificación de los conflictos éticos en la atención sociosanitaria. Un estudio exploratorio	Ribas S, Aguado H, Tella M, Márquez I, Viñas P, Himénez J, Asens G	Espanha
A9 [20]	Attitudes and barriers to involvement in palliative care by Australian urban general practitioners	Rhee JJO, Zwar N, Vagholkar S, Dennis S, Broadbent AM, Mitchell G	Austrália
A10 [18]	GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved: A mixed methods study	Tan HM, O'Connor MM, Miles G, Klein B, Schattner P	Austrália
A11 [21]	Judgements about fellow professional and the management of patients receiving palliative care in primary care: A qualitative study	Walshe C, Todd C, Caress AL, Chew-Graham C	Inglaterra
A12 [22]	Implementation and impact of the Gold Standards Framework in community palliative care: A qualitative study of three primary care trusts	Walshe C, Todd C, Caress AL, Chew-Graham C	Inglaterra
A13 [23]	Estudo fenomenológico sobre a visita domiciliária do enfermeiro à família no processo de terminalidade	Valente SH, Teixeira MB	Brasil
A14 [19]	Interdisciplinary cooperation of GPs in palliative care at home: A nationwide survey in the Netherlands	Borgsteede SD, Deliens L, van der Wal G, Francke AL, Stalman WAB, van Eijk JTM	Holanda
A15 [12]	Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients, lay-carers and health care professional	Exley C, Field D, Jones L, Stokes T	Reino Unido
P16 [9]	Moral problems in palliative care practice: A qualitative study	Hermsen MA, ten Have HA	Holanda

Table 2. Ethical problems concerning palliative care in the primary health care

Article	Ethical issues
E1 [8]	• None of the 16 doctors from the UBS (UBS stands for Unidade Basica de Saude - Health system Basic Unit) had a problem with end-of-life care
E2 [17]	• 75% of PHC doctors were unaware of their patients final wishes of life, even if these patients had already stated them in anticipated directives (AD) in another service • 11% of doctors did the anticipated directives without the patient's consent
E3 [13]	• Most doctors believe that to discuss palliative care is time consuming, so it is unlikely that they will have that discussion with patients • To discuss palliative care with the patient is stressful and uncomfortable for most doctors • Most doctors do not believe that this discussion is beneficial to the patient
P4 [10]	•Primary health care staff professionals feel obliged to accompany patients in their last days of life; therefore, they give their personal phone numbers so they can be contacted by the family of the patient. They even visit the patient's home after working hours • The professionals involved in palliative care show enthusiasm to stay in the program, but the scarcity of resources causes overload • The biggest concern of the professionals was related to the inadequacy of their expertise in palliative care. They see this as a limitation when faced with complex clinical situations because, although they work based on clinical work learned through practice, many times they have doubts about the best course of action
C5 [11]	Doctors feel powerless in the palliative care as to what they can do for terminally ill patients, compared to what they can do for those patients whose life expectancy is normal. To compensate for this impotence, they feel compelled to pay more attention to patients in palliative care, staying next to them for a longer time. • Doctors report emotional distress of patients, families and professionals • Doctors mention that fatalistic thoughts, insecurity and helplessness of informal caregivers tend to compromise the autonomy of patients, creating dependency and suffering • One doctor reports a crisis of confidence between the patient and the doctor of the PHC who was not involved in curative care because the specialist was in charge of it. • According to doctors of the PHC, the poor quality of communication in the moving of a patient from the second to the first level of attention disturbs the application of the palliative care at home. • Doctors feel lack of support for dealing with ethical issues in palliative care and suggest the need for a course on the subject, including notions of norms and values, as well as ways to discuss and share these problems within the work team • Doctors report a lack of knowledge and training of professionals in the management of symptoms (pain, nausea, dysphagia, delirium, depression etc.) of patients in palliative care • Doctors refuse to accept that ethical issues such as euthanasia can be solved only with the good performance of palliative care
P6 [14]	• Nurses recognise the importance of talking about death with patients; however, they only do so when they are willing to or when the opportunity arises • Nurses report that they do not feel prepared to talk to users about spirituality or religiosity, even knowing that this subject is essential in the final stage of life • Nurses recognise the importance of family support, but they say that sometimes that support hinders care
A7 [15]	• Nurses don't have availability for interventions in palliative care • Three nurses mention the lack of veracity whilst talking to the patient and the family about the patient's actual health situation • Nurses recognise that they lack knowledge in the management of symptoms of patients in palliative care • The communication with patients, according to nurses, is not appropriate because of the deficient training of the professionals • Nurses report lack of conditions, time and training to accompany the mourning • None of the nurses reported interventions in multidisciplinary teams

Article	Ethical issues
A8 [16]	• Professionals mention the lack of information and breach of confidentiality about the treatment and the prognosis • Professionals report suspicion that patients suffer physical, psychological, economic or other types of abuse by family members • Professionals report poor relationship with the team and of the team with the different levels of the health care network • Professionals report poor relationship with family members of patients and / or informal caregivers • Professionals mention the lack of social and financial resources of the services
A9 [20]	• Between 20% and 30% of 269 PHC doctors who provide palliative care report that the specialists do not share information with them • 25.2% of 269 doctors from the PHC mention, as obstacles for their involvement with palliative care: lack of time; home visits; personal and family commitments; lack of interest; unavailability for work after hours; lack of knowledge; emotional reasons and a lack of support of specialists • 25.2% of 269 doctors of the PHC do not feel safe to deal with issues related to palliative care, such as terminal restlessness, psychosocial aspects, agitation and neuropathic pain
A10 [18]	• 82% of 114 doctors and 85% of 52 nurses report that the communication between professionals is flawed • 59% of 114 doctors and 62% of 52 nurses mention that patients are reluctant to call in the professionals who are available after work hours • 58% of 114 doctors and 87% of 52 nurses claim that the amendment of legislation to allow the nurse to review the death could increase the offer of after hours palliative care services. • The professionals report a lack of continuity in the care for people receiving palliative care at home, after the closing time of Primary Health care services • 54% of 114 doctors and 67% of 52 nurses mention the high cost of overtime on the provision of palliative care • 41% of 114 doctors and 63% of 52 nurses claim that the insecurity in services leads them to give up night shifts • 40% of 114 doctors and 44% of 52 nurses reported that the limited coverage of mobile telephony has a negative impact on the provision of palliative care • 76% of 114 doctors and 90% of 52 nurses consider that the limited availability of doctors to work after hours is a limiting factor of palliative care in the PHC • 79% of 114 doctors and 83% of 52 nurses estimate that the limited availability of nurses to work after hours is a limiting factor of palliative care in the Primary Health Care • 49% of 114 doctors and 54% of 52 nurses report the lack of interpreters, after opening hours, to attend the needs of aboriginal populations • 69% of 114 doctors and 71% of 52 nurses mention that the access to emergency medications is limited after hours • Doctors reported lack of training to provide palliative care as they don't have time to devote to a continuous training in this specialty • Doctors are unaware of which services and resources, available in the community and in the primary health care (PHC), are able to ensure continuity of care after hours or are adequate to plan the support to attend the needs of patients in palliative care
A11 [21]/A12 [22]	• 14 nurses from PHC consider that doctors are resistant to new initiatives and are reluctant to meet the needs of patients and the requests of the nursing staff • The concepts of "good" or "bad" doctor, in the view of nurses, do not necessarily relate to technical expertise or knowledge, but to the availability of the professional to receive and respond to requests, be them from the nurse or the patient • Nurses recognise that interpersonal relationships and perceptions of each other about their respective performances influence the work of the staff and the referrals of users to other services. The team cohesion stems more from interpersonal relationships than from the patient care • Doctors enjoy friendly working relationships with nurses; however, trading issues and interpersonal relationships do not weigh much on the assessment made of these professionals, probably by the difference in authority between the two categories • Professionals describe the positive impact of the introduction of a program to improve the quality of care in the PHC based only on the professional relationship, ignoring interactions with patients and the influence on their care

Article	Ethical issues
A13 [23]	• Nurses claim that the work overload and the lack of space in everyday life to discuss the feelings experienced in the care of dying patients, causes the professionals to be more susceptible to emotional distress • Nurses feel frustrated because they can not provide quality care because of the lack of resources in the PHC and reference services as well • Nurses can not establish limits for their relationship with terminally ill patients and their families • Nurses create intense links with terminal patients in their care, which leads to suffering at work • Nurses, given their close proximity to users, go beyond technical limitations in their work in the ESF (abbreviation of "Estrategias Saude da Family" in Brazil- Family Health Strategies) staff. • When faced with abuse, lack of care and neglect of the patient by the family, nurses change their behaviour: they start to offer merely technical care to the patient, and do not consider the possibility of family members also being part of the care • Nurses report that families and informal caregivers request care or actions that are beyond the means of Primary Health Care, such as constant visits to the patient
A14 [19]	• Doctors consider the somatic domain as the most important in palliative care, followed by psychosocial and spiritual care • 63% of doctors report that informal caregivers are the main collaborators in palliative care • Few doctors cooperate with religious ministers, which may indicate that they alone deal with such problems, or that few patients have spiritual problems, or that few doctors recognise the spiritual problems • In 71% of cases, doctors describe that cooperation with colleagues was present. This number could be considered low and provoke questions about the quality of communication and continuity of care, considering that an efficient exchange of information about patients is expected so 24 hours healthcare services can provide proper care after the end of working hours in the primary health care
A15 [12]	• In cases of patients with cardiorespiratory disease, PHC doctors report frustration because they can not take full care, as specialists from hospitals are the ones who manage these patients palliative care when the underlying disease gets worse. • According to doctors from the PHC, hospitals' specialists fail to give them information, not making them aware of decisions taken in the hospital about the treatment regimen of patients under their care • PHC doctors lose confidence in the hospital because communication about treatments and interventions is flawed, and conflict with the requirements of PHC, especially in cases of cancer patients enrolled in clinical trials prohibiting the PHC and the hospital to change or introduce treatment without the consent of the research team • Doctors and nurses from the PHC say it is easier to get specialised services for palliative care patients with cancer than for those in the final stage of cardiorespiratory diseases • PHC doctors recognise that they provide less help when it comes to patients with end-stage cardiorespiratory diseases, than in the case of cancer patients at the same stage as they were not sufficiently trained to deal with the first situation • For doctors of PHC, it is more difficult to reach the conclusion that the person is dying when the person does not have a malignancy. This makes professionals less willing to communicate to these people that they are in a state of terminal illness

Article	Ethical issues
P16 [9]	• PHC professionals face moral problems when, in respect for the principle of the patient autonomy, must decide on the resuscitation or not, or the performance or nonperformance of futile medical actions for the patient who has no chance of cure • PHC Professionals face moral problems when the treatment chosen by the patient is considered futile by doctors but improves their quality of life • PHC professionals struggle to create a bond and motivate themselves to look and talk about death when the patient is considered "difficult," such as the one who is never satisfied with the work of nursing. This compromises the quality of care • PHC doctors offer the option of euthanasia to the patient when there is no possible treatment to relieve their symptoms, although this procedure is not carried out under the PHC and even terminal patients in home care raise questions regarding the search for the meaning of life, often appealing to the PHC professionals. These, unprepared, try to answer the patient and family members, who are also their patients • PHC Doctors prefer that the specialist inform the patient about the poor prognosis because they believe that if they do, it can generate conflict in their relationship with the patient and the family, and they fear it may interfere with keeping a care of quality • The PHC professionals face moral problems in the management of symptoms such as terminal sedation, principle of the double effect and use of opioids

Terminally child life: perceptions and feelings of nurses

Gisele Elise Menin [1], *Marinez Koller Pettenon* [2]

Abstract

Objective: To understand the perceptions and feelings of professional nurses towards death and the dying process of children. Methodology: qualitative and exploratory, based on thematic categories. The participants were seven nurses of the Neonatal and Pediatric Intensive Care Unit of a general hospital in the Northwest region of the Rio Grande do Sul (One of the Brazilian States). Data were collected through open questions in the period from February to March 2013 and were submitted to analysis by rating, sorting and final data analysis. Results: There has been difficulty for nurses to accept, confront and assimilate the finiteness of child life. It was also observed that nurse care is fundamental in those moments of end-of-life. Conclusion: The results show the lack of emotional preparedness of nurses and the lack of assistance, be it in the academic training or in continued education, as well as the lack of therapeutical support to deal with the situation in health care institutions.

Keywords: Death. Child. Family. Nursing. The intensive care unit.

Resumo

Terminalidade da vida infantil: percepções e sentimentos de enfermeiros

Objetivo: compreender as percepções e sentimentos do profissional enfermeiro diante do processo de morte e morrer infantil. Metodologia: qualitativa e exploratória, pautada por categorias temáticas. Participaram da pesquisa sete enfermeiros da unidade de terapia intensiva mista neonatal e pediátrica de um hospital geral da região noroeste do Rio Grande do Sul. Dados coletados por meio de pergunta aberta, no período de fevereiro a março de 2013, e submetidos a análise por classificação, ordenação e análise final. Resultados: além da difícil aceitação, enfrentamento e assimilação da finitude da vida infantil por parte dos enfermeiros, observou-se que o cuidado de enfermagem é fundamental nesse momento. Conclusão: os resultados evidenciam o despreparo emocional dos enfermeiros e a insuficiência de subsídio, seja em sua formação acadêmica, seja em sua educação continuada, bem como a falta de suporte terapêutico nas instituições de saúde para lidar com a situação.

Palavras-chave: Morte. Criança. Família. Enfermagem. Unidade de terapia intensiva.

Resumen

Terminalidad de la vida infantil: percepciones y sentimientos de los enfermeros

Objetivo: Comprender las percepciones y sentimientos del profesional enfermero ante el proceso de muerte y morir infantil. Metodología: cualitativa y exploratoria, basada en categorías temáticas. Participaron de la investigación siete enfermeros de la unidad de terapia intensiva mixta neonatal y pediátrica de un hospital general de la región noroeste de Rio Grande do Sul. Los datos fueron recogidos a través de preguntas abiertas en el período de febrero a marzo de 2013 y fueron sometidos a análisis por clasificación, ordenamiento y análisis final. Resultados: además de la difícil aceptación, afrontamiento y asimilación de la finitud de la vida infantil por parte de los enfermeros, se observó que el cuidado que proporciona la enfermería es fundamental en este momento. Conclusión: los resultados evidencian la falta de preparación emocional de los enfermeros y la insuficiencia de herramientas, tanto en su formación académica y en su formación continua, así como también la falta de apoyo terapéutico en las instituciones de salud para hacer frente a esta situación.

Palabras-clave: Muerte. Niño. Familia. Enfermería. La unidad de cuidados intensivos.

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Declaram não haver conflito de interesse.

Research article

The Intensive Care Units (ICU) are environments of differentiated care, due to the concentration of technology and meticulous routine of patient care in face of conditions of urgency and the need to sustain life[1]. The universe of infant hospitalisation encompasses the child, the professional who provides assistance and the family, in a coexistence that can last from days to months [2].

Terminality of life in childhood in a neonatal intensive care unit (NICU) and / or paediatric intensive care unit (PICU) is considered more complex than the terminality of life of adults, since a child's death has - inevitably - a tragic connotation, before which survival is the first objective of the assistance team, given the high capacity of recuperation of paediatric patients [3].

During the care given to the child, healthcare professionals create bonds of affection [4], which establish a security base in the exercise of their work. However, when this sense of harmony is broken by the presence of death, professionals are thrown into suffering and sense of loss, which characterises mourning. An expected response in the face of the separation that the finitude causes [5].

Continuous exposure to death and the dying process reveals the need to reflect and deal with fears and insecurities that create an obstacle to the performance of nursing professionals in face of the finitude of life. Technical and scientific knowledge, thanks to that need, are essential to the profession. The experience of an infant death with all the doubts, insecurities and uncertainties that permeate it causes nurses to review their concepts and feelings about the loss, which leads to the adoption of their own coping strategies, as well as to rethink their role as professionals in the intensive care unit [6].

This study, through the use of field reports, seeks to bring assistance to nurses, in order that they can work through their feelings and understand the importance of integral and humanised care during the process of finitude of a child's life. By revealing the perceptions and coping mechanisms used by nurses working in NICU (Neonatal Intensive Care Unit) and or PICU (Paediatric Intensive Care Unit) , facing the death and dying of a newborn or a child, this study contributes to nursing professionals, leading them to understand that they are not alone in their feelings and everybody needs support to live and overcome this sort of situation.

Method

It is a qualitative, exploratory study, based on thematic categories and conducted with nurses from the Neonatal/Paediatric ICU of a general hospital in the northwestern region of Rio Grande do Sul (One of Brazil's federated states). Data collection occurred from February 2013 to March 2013, and the inclusion criteria was to be a nurse, to accept to take part in the survey and to be linked to the service as a collaborator of the institution for at least six months .

The initial population of the study consisted of 11 nurses, but the final sample comprised seven professionals, six of them female and one male. Of the remaining four, two did not deliver the questionnaire, one entered on maternity leave during the survey period and the other left the workforce during the data collection phase.

The survey was realised through a guiding question which required a written response: "What are the perceptions and coping mechanisms used by nurses who work in neonatal intensive care unit and / or paediatric intensive care unit before the death and the dying process of a newborn or a child?". March 11, 2013, was stipulated as the date to return the questionnaires so the participants of the survey had 20 days to fill out the questionnaire.

After the return of the questionnaires , we proceeded to the reading and rereading of the survey instrument as well as the organisation of the responses. At this stage, the data were subjected to methodological treatment, which consisted of ordering, classification and final analysis [7].

Ethical principles were respected in their entirety: An informed consent (IC) form was used and the research was approved by the Ethics Committee of the Regional University of the Northwest of Rio Grande do Sul (abbreviated CEP Unijuí in Brazil), under the substantiated judgement number 182102 / 2013. The anonymity of the participants was assured through the use of the general name "Nurse", added by numbers 1 to 7.

Results and discussion

The experience of nurses when facing the death and the dying process of newborns and infant

patients, revealed the perceptions of those professionals on the subject. Three analytical categories emerged from the study: 1) being a nurse who faces the death of children; 2) nurses in the care of the family during the process of finitude of a child life; 3) the need for professional qualifications and knowledge on the subject.

Being a nurse who faces the death and the dying process of a child

The hospitalisation of children is perceived as a disturbing moment for anyone [8], especially for those who maintain emotional bonds with the children. And when the possibility of death is evident, the role of the nurse is not limited to patient care as the care is also extended to the family [9]. Thus, in view of the finiteness of a child's life, nurses need to elaborate a care that provides less painful experiences to parents and other family members, trying to make the nearness of death less distressing [10]:

"The nursing care, in a neonatal and/or paediatric intensive care unit . facing the death and the dying process of a newborn or a child consists of alleviating and helping to minimise the pain." (Nurse 4)

For me, at this moment, what we have to do is to try to give the maximum comfort to the parents ... to offer water, a hug, a shoulder to cry on and, if it is available at the institution, psychological support." (Nurse 6)

Because of their training focused on the care and well-being of the patient, it is notoriously difficult for nurses to accept death and often even to provide adequate assistance when they verify the terminality of life [9]. Although common sense has as its premise the idea that health professionals are cold about a patient's death, many of them feel compelled to try to "save" the life; this way, if they assume a dispassionate air, it is above all to mask and deny the feelings of sadness and disturbing emotions when they witness the death process[10]:

"Nurses must draw from within themselves enormous strength and they need, in these moments, to adopt a sense of coldness that often does not belong to them. To suppress the crying, to swallow a tear. It is not always possible to control emotions, but quite often it becomes essential!" (Nurse 5)

"It is important that all nurses know how to control their emotions in order not to impair or diminish their professional performance." (Nurse 4)

Another aspect also due to the education of nurses is that they see in the terminality of life the opportunity to project onto the patient their desire to heal. For these professionals, the patient always has a chance of recovery, regardless of their clinical status. But when they can not prevent or delay the death, the nurses realise their limitations as human beings and professionals, which can cause feelings of powerlessness in the face of the finitude of life [11]:

"There are moments of frustration when we don't achieve the desired success and the baby ends up dying; We ask ourselves: where did we go wrong? What we did not do to improve the health of this newborn [abbreviated as RN , in Brazil, for recem nascido]*?"* (Nurse 1)

"The professional nurse is trained to work in the care of life, prevention of diseases and, undoubtedly, in the rehabilitation of individuals (...). *Death, especially the death of newborns or children, triggers a sense of frustration, worthlessness and impotence in professionals committed to promote life."* (Nurse 2)

The feeling of helplessness expressed by nurses in the face of terminality of life reflects their unpreparedness to accompany this moment [12]. Daily, the nursing staff of the ICU face situations of assistance to patients who are in the process of dying. To answer these conditions effectively without causing undue suffering to the professional, a solid preparation of the intensive care unit nurse is essential. This preparation is essential not only for the nurse to act effectively in the technical, management and assistance care activities provided to patients but, above all, to ensure the physical and psychosocial health of those nurses [13] who, without it, could end up failing as professionals.

Death is still seen as taboo in our society. It is considered "morbid" to talk about it, even in the therapeutic areas in which it occurs with relative frequency, as in the ICU of hospitals. Such prohibition is explained by the psychological approach, according to which man seeks to defend itself in various ways of the increasing fear of death and the inability to foresee and prevent it [14], as seen in the words of one of the nurses:

"[Death] *generates tension in the whole team, differentiated behaviours, ways of acting, thinking, expressing, insecurity, anger and fears before this undesirable situation,* (...) *that quite often we are not prepared to deal with* (...) *and we must be prepared to lead the team, for the work to continue. To*

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demand staff efficiency, professional ethics and the respect for children, religions and attitudes of each family." (Nurse 3)

Dealing with a social taboo is no easy task and it becomes even harder to deal with it when the taboo is directly related to the death of children and babies, who, according to our perception, would normally have a lifetime ahead of them. Besides all the pressure inherent in such circumstances it is important for nurses to provide motivation to their team, making the team harmonious and committed to improving the service provided, even if such assistance is directed only to provide relief to the little patient who dies [15]. Thus, the nursing professional should emphasise humanised care and the perception of the patient as a whole, in order to reduce the agressivity of the treatment and to maintain the dignity and respect for the rights of the patients and their families [16].

Acceptance of an infant death is difficult for nurses. In order to be able to maintain their role at times when they feel that they are beginning to falter, the nursing professional must keep in mind that the care given to the newborn or child, as well as the family, is essential to the welfare of these people, and the care should be based on comprehensiveness of the assistance provided, ensuring respect, ethics and human dignity.

The nurse in the care of the family during the process of finitude of child life

In the process of death, the family needs assistance to understand and better experience the mourning [17]. By knowing things such as the story of life of the children, their relatives and the reason for the hospital admission, among others, the nurse ends up getting emotionally involved in the case. Often such involvement occurs simply because the patients are children. And, given the impossibility of healing , the professional suffers because of the child's loss, the pain of the parents or the nurses reflection on their own finitude [18]:

"Death is hard to be accepted by most people who lose a family member or loved one, and also for nurses working with children because most of the time we end up creating a strong relationship of empathy with parents and children because of the time they remain hospitalised and because of the the good relationship that is created with patient's families." (Nurse 6)

To sympathise and understand the whole situation and the experience of parents during the hospitalisation of their child in an ICU, the nurse seeks to establish with them a clearer and more effective form of communication, which also extends to other family members. The professional understands that , even with the impossibility of cure, parents continue to believe that the child will survive. At such times, it is necessary that the professionals perceive the limitation of parents and relatives to deal with this circumstance, and thereby assist them to accept the finitude of life of their babies [19]. To carry out, effectively, this arduous task, the nurse must consider that each family interprets and experiences the death and dying process in different ways, according to their historical and sociocultural context [20]:

"From the time to talk with the mother and father, the emotional aspect of the situation is so evident (...) *This confrontation is always difficult* (...) *each moment is different, it is a special experience; families always react in different ways* (...) *The mother, when she enters the unit and finds her child among "thousands" of pipes, appliances, portholes, until she puts her hand on her baby, [keeps] the look of astonishment, the search for a gesture, a word of comfort that says: 'Soon everything will be better, even in cases so complicated'"* (Nurse 1).

"Let them go through this time reacting in their own way, because it's all part of the mourning, they need to get through this. There are parents who scream, cry, pray that the child will "come back', and we should leave them to react that way as it is a hopeless suffering, and each one has his or her own ways of going through this phase." (Nurse 6)

"(...) *But no professional can accept, especially when asked by parents or family members who only wish the clinical improvement* [of the patient]*."* (Nurse 2)

It matters to nurses to realize the need of the child and the respective family to stay close as long as possible after exhausting all possibilities of healing. This proximity provides the relaxing of the strict rules of segregation in an ICU and values the presence of parents and family throughout the process, helping them to face death and at the same time allowing them to make it more dignified to the little ones [21]:

"*When I realise that the newborn or child might die, I usually try to provide the visit of the parents, I try to see which one of the parents is more likely to hear me talk a little about how their lives will be without their*

baby or child (...) *I provide time to allow parents to be alone with the child* (...) *When the child dies, we try to offer parents the chance to pick up the child in their arms* (...) *if they have a camera, I suggest the possibility of taking a picture to remember their child."* (Nurse 7)

"(...) *Offering relief, asking if they want to stay with the child, after the child's death, for a while."* (Nurse 6)

Being a nurse faced with the impossibility of healing of a child, when trying to offer a dignified process of dying, means looking beyond these little patients, means to perceive the family as part of the care, as targets worthy of attention, understanding, respect and support for the experience of those moments that make the family so fragile.

Needs of professional training and knowledge on the subject

The training of professionals in the health area provides them with technical and scientific knowledge aimed primarily to save lives and prevent death. Consequently, their unpreparedness to deal with terminality of life is clear [22]:

"The lack of professional preparation to deal with death is well known (...) *This confrontation is always difficult because they really are not prepared* (...) *although death is an event present every day or with frequency."* (Nurse 1)

Silva et al [23] warn of the need to include this theme in continuing education programs for health institutions. Thus, according to the authors, it is possible to improve the quality of assistance offered and minimise the feelings generated on the team by the patients' loss:

"It would be very important for the institutions to work these matters concerning the support to teams, specific preparations, courses and debates." (Nurse 1)

"I believe that a multidisciplinary team that works with the theme of feelings and attitudes of professionals, would alleviate sorrows, fears and would also give better emotional support to face or try to understand death (...) *And, this way, we would be able to lead the team through these changes which would improve the spiritual, physical and emotional aspects of the nurses' work . And we would also be better prepared to work with the family."* (Nurse 3)

Feelings of fear and insecurity generated in nurses by death and the process of dying reveal possible gaps in undergraduate education, including the ineffectiveness of educational and psychological support to future professionals, in order that they can coexist with the suffering of patients and their families [24]:

"It is important to note that this theme should be addressed over the course of graduation, as so often nursing professionals reveal an overlapping of professional feelings with personal feelings. Therefore, a suggestion to this work could be the development of teaching strategies in order to develop assistance for professionals to better cope, emotionally and professionally, with the idea of death." (Nurse 2)

"Death of children or newborns often disturbs the peace in a hospital; however, it is known that this subject is little explained / clarified in the curricula of nursing courses." (Nurse 4)

It is recommended, as an important measure, to reformulate the academic curricula of nursing, by inserting disciplines and reflection spaces that focus on loss and grief, so that future professionals will be able to experience the reality of the finiteness of life and provide a participatory relationship, providing adequate and skilled attendance at such times [25]. Death completes the cycle of life; However, professionals are emotionally unprepared to face and to deal with the feelings aroused by death. They also face difficulty in the care to a patient who, slowly or gradually, is going to die [24].

It is essential to create a different look for the assistance and the care given to the child who has no healing possibilities. Therefore, it is essential to offer assistance to nursing professionals who deal with these patients in order to guarantee to these patients a better quality of life through the comprehensiveness and humanisation of the care given, regardless of the time still left to those patients.

Final considerations

The work of a nurse is permeated by a broader look, aimed at ensuring a humane and comprehensive care. But when the assistance needs to focus on the death and dying process of a child at any age, disturbing feelings emerge. They are difficult to accept by those responsible for the care of the child, especially the nurses. It is important that these

professionals understand that the care provided to patients at end-of-life stage delivers some quality to the life that remains and provides a dignified death, which implies redefinition of their role as nursing professionals.

The presence of parents and family during the hospitalisation period, be it of a newborn or a child in end-of-life stage, is essential for the parents in order to experience the most they can in the last moments of their child's life. Thus, the attention given by the nursing team should provide for the social, psychological and emotional aspects that are part of every family context, offering help and support, so that parents can face the loss of their child. To this end, it is recommended that nurses receive the necessary training to provide quality care in order to provide comfort and emotional support, facilitating the interaction between patients and their families.

The lack of academic training of nursing professionals in facing end-of-life illnesses and the process surrounding it is clear. Such failure implies the need for hospitals to offer psychological support and continuing education on this subject, considering that the death of an infant, seen socially as complex and of specially difficult acceptance, requires an adequately trained professional. Thus, professional training will enable nurses to face their own taboos about the terminality of life without suffering too much or becoming ill whilst they try to exercise their professional tasks.

By revealing the perceptions of nurses that attend to children in newborn intensive care units and/or paediatric intensive care units, this study aims to contribute to the awareness of health institutions about the urgent need to improve the continuing education of professionals, especially regarding the issue of finiteness of a child's life. This measure will help nurses to better understand and experience their feelings and thereby will make them more qualified to provide adequate care for these young patients and their families.

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Participation of the authors

Gisele Elise Menin participated in the conception and design of the study, literature review, completion of the field work, data analysis, article writing. Marinez Koller Pettenon participated in the conception and design of the study, data analysis, article writing and critical review.

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Research article

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Religion in the treatment of chronic kidney disease: a comparison between doctors and patients

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Abstract

Chronic kidney disease is a disease with high morbidity and mortality. The daily life of affected patients includes negative feelings, fear of prognosis, disability, and economic dependence, as well as challenges related to changes in self-image. Religion and spirituality can be important resources in dealing with these difficulties. To test this hypothesis a qualitative, descriptive study was undertaken at the Hospital das Clínicas Samuel Libânio, Pouso Alegre/MG, in order to verify from the point of view of both doctors and patients if they believe that religion influences the treatment of the disease. For doctors, religion represents a strength and a comfort when facing any disease. Patients, however, identify religion with the hope that they will get better. While the significance of religion in their lives was different between the groups, both agreed that it represents a beneficial factor in the life of patients, providing relief, support and optimism.

Keywords: Religion. Renal insufficiency, chronic. Qualitative research. Quality of life. Bioethics.

Resumo

Religião no tratamento da doença renal crônica: comparação entre médicos e pacientes

A insuficiência renal crônica é uma doença de elevada morbimortalidade. O cotidiano dos pacientes acometidos reveste-se de sentimentos negativos, medo do prognóstico, incapacidade, dependência econômica, além daqueles relacionados à alteração da autoimagem. A religião e a espiritualidade podem ser recursos importantes para lidar com essas dificuldades. Para verificar essa hipótese, realizou-se no Hospital das Clínicas Samuel Libânio de Pouso Alegre/MG estudo qualitativo descritivo, objetivando avaliar, do ponto de vista do médico e do paciente, em que medida a religião influi no tratamento da doença. Para os médicos, a religião representa força e conforto no enfrentamento de qualquer doença. Já os pacientes, todavia, depositam na religião a esperança de que irão melhorar. O significado da religião em suas vidas foi distinto entre os dois grupos analisados; entretanto, ambos concordam que a religião configura um fator benéfico na vida do paciente, propiciando alívio, suporte e otimismo.

Palavras-chave: Religião. Insuficiência renal crônica. Pesquisa qualitativa. Qualidade de vida. Bioética.

Resumen

Religión en el tratamiento de la enfermedad renal crónica: una comparación entre médicos y pacientes

La insuficiencia renal crónica es una enfermedad con una elevada morbilidad y mortalidad. La vida diaria de los pacientes afectados es de sentimientos negativos, el miedo ante el pronóstico, la incapacidad, la dependencia económica, además de aquello relacionado con el cambio de imagen de sí mismo. La religión y la espiritualidad pueden ser recursos importantes para hacer frente a estas dificultades. Para comprobar esta hipótesis, se llevó a cabo en el Hospital das Clínicas Samuel Libânio, de Pouso Alegre/MG un estudio cualitativo, descriptivo, con el fin de verificar, desde el punto de vista del médico y del paciente en qué medida la religión influye en el tratamiento de la enfermedad. Para los médicos, la religión representa fuerza y bienestar para hacer frente a cualquier enfermedad. Los pacientes, por su parte, depositan en la religión la esperanza de que van a mejorar. El significado de la religión en sus vidas fue diferente en los dos grupos analizados, sin embargo, ambos coinciden en que ésta configura un factor beneficioso en la vida del paciente, proporcionando apoyo, alivio y optimismo.

Palabras-clave: Religión. Insuficiencia renal crónica. Investigación cualitativa. Calidad de vida. Bioética.

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Research article

Chronic kidney failure is a disease with high morbidity and mortality rates. It is characterized by a progressive decline in renal function and by its chronicity, which leads to physical, social and emotional limitations, which significantly affect the quality of life of patients. In "The epidemiology and prevention of chronic kidney disease in Brazil," Sesso [1] warns that the incidence and prevalence of advanced stages of the disease have increased both in Brazil and worldwide.

The available treatment options for the disease achieve only partial replacement of renal function, relieving symptoms and preserving life, although none are curative [2]. In addition, the therapeutic process is difficult and painful, which, although essential for maintaining the life of the chronic kidney disease sufferer, makes his or her daily routine and eating habits extremely challenging, as well as causing changes in physical and emotional integrity, among other aspects of life.

Such experiences involve significant changes in social and family life, and can end up triggering dependency on social care and a loss of autonomy [3]. In general, patients report increasing physical limitations, provoked by fatigue and constant pain which prevents them from performing certain tasks [4]. Daily contact with these patients can reveal the expression of negative feelings, such as anxiety, insecurity, panic, depression, discouragement, a feeling of being attached to the dialysis machine, fear related to the limitations resulting from their situation, the effects of the disease and the changes in how they live and how they are as people, with possible changes in quality of life [5].

A study conducted by the Universidade Federal do Rio Grande do Sul (UFRGS) in 2011, entitled "Perceptions and changes in the quality of life of patients undergoing hemodialysis" [6] found changes in the quality of life of those suffering from this disease, as can be seen in the words of one of the participants of the study: "*I had a very intense, physically active life; I was a physical education teacher. So it was a very complicated experience, I was going to the gym, going to dance class, it was my life, it was my greatest achievement* (...) *now I find myself kind of useless, sometimes I'm at home, I have too much free time and at the same time, I cannot find anything that occupies me and makes me feel happy* (...) *for me, it was very complicated, all of a sudden you feel weak because of the anemia, and you're not able to do lots of things you used to do, you're trapped in a machine to survive*" [6].

Patients with chronic kidney disease must adapt not only to the disease and its treatment, but also to numerous physiological, psychosocial and spiritual problems arising from the condition. In this difficult environment, many cling to faith and religion as a source of support and relief from their suffering. Religion and spirituality are becoming more and more important in health care, as they are commonly perceived as a way to give meaning to life and provide hope and a way to find peace in the midst of serious events such as chronic illness [7].

Today, an association between greater religiosity or spirituality of patients and greater general well-being has been found in cases of mental illness [8]; lower prevalence of depression [9], drug abuse and suicide [11 10]; a better quality of life [12-14]; a more appropriate way to deal with a disease (coping) [15]; lower mortality [16,17]; less time spent in hospital [18]; and better immune system functioning [19]. With so many benefits, it is important to evaluate the relationship with religion and spirituality in dialysis patients.

State of the art

The September 2007 edition of the European journal Nephrology Dialysis Transplantation took as its central theme the relationship between spirituality, quality of life and dialysis patients. The editorial states that the *relationship between spirituality and various quality of life domains is certainly worth exploring in more detail…since it has been difficult to positively impact on the quality of life of ESRD patients.* The editorial finishes by asking: *Would it not seem reasonable then to further explore the role of spirituality in helping to support, guide and coordinate the care of these patients?* [20] Another study demonstrated that in patients with end-stage renal disease, perception of the importance of religious faith was associated with adapting to changes caused by the disease, and was directly linked to behavior and inversely related to alienation or spiritual suffering [21].

Religion has brought comfort to relatives, as well as being a form of support, as the religious community encourages involvement among its members by facilitating the sharing of experiences. Religion also promotes social interaction and support between the family and other members of society [22]. It can therefore be seen that in addition to the patient, religious association and spirituality is also beneficial to family members living with the disease carrier.

Another important aspect to be considered is the importance given by doctors and health profes-

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sionals to the knowledge and encouragement of the spiritual practice of the patient in order to improve their quality of life. In 2006, a study conducted in the United States [23] warned that patients expect healthcare professionals (doctors, nurses) to ask them about their spirituality, and utilize spiritual resources in their care. When the subject of spirituality was raised by a chaplain with dialysis unit patients under his pastoral care, there was an overall improvement in team performance and in responses to the spiritual concerns of patients.

It is necessary, therefore, that health professionals, especially doctors and nurses who are treating a patient, understand not only the meaning of spirituality and religion for that patient, but also the extent to which significant events such as chronic kidney disease may influence how they deal with this experience, so that, in clinical practice, concerns about aspects of spirituality can genuinely form part of holistic care [24].

Everyone has their own life story. The relationship between health professionals and a sick individual is, above all, interpersonal by nature. In the contact between the two, stories intersect, connect, and overlap. At times, professionals and patients build a new, living history together. It is in this context that the spirituality that is constructed makes a difference [25].

Religion and spirituality are undeniably of significant relevance in the treatment of chronic kidney disease, whether it is for patients or to family and friends who live with the chronic pain caused by the disease. It is for health professionals in general, and the doctors and nurses who closely follow these patients in particular, to value this relationship and stimulate their patients' reflection on the subject.

The aim of this study was to understand the importance that doctors at the Hospital das Clinicas Samuel Libânio, in Pouso Alegre, Minas Gerais, and their patients attribute to religion and spirituality, as well as identifying how they relate the same to the treatment of chronic kidney disease in this specific context.

Method

Considering the nature of this study, a qualitative exploratory research approach was chosen, adopting as a methodological reference social representation theory (SRT). SRT is extremely useful for health studies as it brings together subjective aspects from an area and synthesizes them into common ideas. In order to discover and describe the importance of religion in treating chronic kidney disease, under the framework of social representation, the discourse of the collective subject method (DCS) was used, as it allows the study of this phenomenon.

An exploratory survey is conducted in an area in which the subject is relatively unexplored, and there is therefore little accumulated and systematized knowledge. It is, in fact, the first stage in a wider investigation. As it represents a survey, it does not involve assumptions which, however, may arise during or at the end of the study [26].

Individual interviews with two semi-structured questions were carried out, preceded by the signing a free and informed consent form (FICF), as required by Resolution 466/2012 of the National Health Council, which addresses research involving human subjects. In addition, this regulation also guided the ethical issues of the study, which were presented by the investigators to the research subjects [27].

The survey, conducted from December 1 2013 to October 1 2014, involved ten doctors and ten patients with chronic kidney disease at the Hospital das Clinicas Samuel Libânio. The interviews sought to identify the meaning and importance of religion in the treatment of chronic kidney disease. Each interview was recorded and then transcribed for analysis.

The results, based on DSC (written in the first person singular), revealed key expressions (KEP) with the same central ideas (CI) and the same anchor (AC), strictly obeying the order of the following steps:

1st) Literal transcription of answers, after repeated listening to the recordings and a clear understanding of the general idea and discourse contained within.

2nd) Overall Reading of the responses of each of the respondents, followed by a separate reading of all the answers to the question being analyzed.

3rd) Transcribing of the answers to Question 1, with the KEP being marked in italics and underlined to indicate the CI, representing a description, and not an interpretation of the KEP. Same procedure performed for all other questions.

4th) individual transcribing of each central idea and their respective KEP.

5th) Extraction of the theme of each of the questions, collating their respective CIs of the subjects (represented by the number of respondents) and frequencies of ideas into tables.

6th) Finally, the separate construction from the DSC of each central idea with its respective KEP.

Results

In terms of the religious profile of the ten interviewed chronic kidney disease patients on dialysis at the Hospital das Clínicas Samuel Libânio, 80% said they were Catholic and 20% said they were Protestant. The average time since being diagnosed with the disease among the interviewed patients was 6.7 years, while the average dialysis treatment time was 3.9 years.

Table 1. Religious profile of chronic kidney disease patients, time since diagnosis and treatment time – Hospital das Clínicas Samuel Libânio (Pouso Alegre/MG)

Patient	Religion	Time since diagnosis (years)	Time of dialysis treatment (years)
1	Catholic	3	3
2	Catholic	6	1
3	Catholic	2	2
4	Catholic	17	15
5	Catholic	1	1
6	Catholic	20	6
7	Protestant	2	1
8	Protestant	5	5
9	Catholic	10	4
10	Catholic	1	1

All the health professionals were medical doctors who had graduated between one and 30 years ago, and three had ten or more years of education. As for religious belief, 50% said they were Catholic; 20%, agnostic; 20% Spiritualist; and 10%, Protestant.

When doctors were asked "*What does religion mean to you in your life*?" 50% of the answers contained the following central idea: *Faith, not religion, is what matters*. The prevalent keywords in the CSD were *"faith," "God," "ritual", "dogmas", "churches", "spirituality", "strength", "soul", "belief"*, as can be seen in the following extract from DSC 1:

"Faith, not the name of a religion, is what elevates us to God. I believe in God's mercy toward humans, independent of rituals, dogmas and churches. (...) *In my life, spirituality has a greater magnitude than religion, and it is on that which I base my actions and which forms my character.* (...) *Religion in my life means to have faith, to believe that there is a higher power guiding us, blessing, illuminating each decision we take, protecting us from evil in everyday life.* (...) *Religion is not important, because only God changes your soul and saves you.* (...) *Religion is one way of exercising faith, one way of expressing belief".*

The second central idea, identified by another 50% of respondents, was that *Religion is an essential factor in life*. The set of keywords related this were *"essential", "important", "protection", "fundamental", "spiritual", "strength"*. This idea relates to the following section of DSC 2:

"I believe that religion is an essential factor in preserving mental health. When we belong to a group, whatever it is, it releases a sense of importance and protection of our subconscious. (...) *Religion is a fundamental part of my life, because it helps me to develop my spiritual side.* (...) *Something that gives us strength to tackle the difficulties we face.* (...) *A strength to support us.* (...) *It's something more, a place where patients can leave their pain and sufferings".*

When patients were asked the same question - "*What does religion mean to you in your life*?" the central idea in 30% of answers was: *Faith in God*. The keywords associated with this were *"faith", "basis", "God", "nothing"*. DSC 3 illustrates this choice of terms:

"Faith in God. (...) *Without faith, we can achieve nothing, right? Faith is the basis of everything, it goes beyond the doctors and everything else.* (...) *We have to have a lot of faith in God, right? Because without faith in God, nothing can be done".*

Another central idea that appeared often in the discourse of the participating patients was *Means everything*, which corresponded to 70% of the answers, as noted by the keywords identified, *"everything," "I became," "nothing," "religious," "content", "happy".* The following DSC 4 explains such terms:

"It's everything, without religion we are nothing, I believe strongly in religion. (...) *I was born and raised in a religious environment, my father was Catholic, that's where I got it from, right? And I became religious.* (...) *It means everything. A person who isn't religious is nothing. Thank God.* (...) *God is very good for us, you know. I've been religious for 20 years, I am very content and happy.* (...) *Religion, to me, means everything, because without God we are nothing".*

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Among the doctors evaluated, it was observed that 50% valued faith in God, placing it above religion. For them, religion is just different forms of exercising faith. The other half considered religion to be the primary factor in people's lives. There was agreement between these results in relation to patients, as 30% of the latter believed that the meaning of religion is faith in God, while 70% reported that religion meant everything in their lives. It can be seen, therefore, that this group of respondents, both doctors and patients, valued belief in God, considering it important in their lives.

In answer to the question "*If someone asked you about the importance of religion in treating chronic kidney disease, what would you say*," the answers of 60% of doctors contained the following central idea: *It represents strength and comfort*. The set of keywords was made up of *"bearable", "comfort", "acceptance", "positive", "comfort", "optimistic", "strength"*, as is shown in DSC 5:

"Faith makes a burden more bearable for the suffering. (...) *Through religion, I believe that these patients find great comfort and a sense of transcendentalism, which gives them a new perspective on the disease itself, leading to greater acceptance and a positive impact on their own survival.* (...) *I would say that religion can serve as a comfort to these patients, capable of making them optimistic.* (...) *One more strength. Faith helps a lot".*

Another central idea, identified in the discourse of 40% of doctors, was *Help in any disease*. This corresponded to the keywords *"any," "bearable", "treatment", "similar"*, reproduced in DSC 6 below:

"Faith helps cure any disease. (...) *In chronic kidney disease, as with any disease, faith makes the burden more bearable for the sufferer.* (...) *Religion is of great importance in medical treatment, once patients find religion (and do not just say they do) they tend to be more optimistic, accept treatment and follow it correctly.* (...) *Religion, in my opinion, has a similar importance for all diseases. Of course you notice a heavier reliance on religion in more stigmatizing diseases such as cancer, degenerative diseases etc..."*

When patients were asked the same question, " *If someone asked you about the importance of religion in treating chronic kidney disease, what would you say*?", the following key words and expressions were identified: *"cure", "get better", "grace", "above", "I'll get improve", "get out of here", "courage"*. These terms are summarized in the central idea of 90% of speeches, *Hope that I will get better*, as can be seen in DSC 7 below:

"I think it's very important for the cure for my illness. (...) *I still have faith I'll get better.* (...) *I pray a lot, and thanks to God it looks like I'll find grace.* (...) *I have faith, I believe that God is above the doctors. I'll improve. I'm going to get out of here. I do not want to stay because I have my family to look after. Think positive, have faith.* (...) *It gives us more courage, more enthusiasm to face each day.* (...)

In terms of difficulty, one patient interviewed (10%) said they "didn't know how to answer" the questions from the researchers, a response representing the *corpus* of DSC 8: "I don't know how to answer you." It is important to remember, however, that this statement may mean that the patient does not know the answer to the question, but may also indicate that he considers his future a mystery.

In assessing the relevance of religion in treating chronic kidney disease, it was found that both groups, doctors and patients, consider it very important in the evolution and prognosis of the disease. Among doctors, it became clear that they attach to religious belief a capacity to strengthen patients in the daily fight against the disease, and provide more comfort regarding the negative effects it has on quality of life. However, 40% of doctors highlighted the extent of the value of religion, which included, favorably and equally, the course of all diseases, and was not exclusive to chronic kidney disease. Among the patients, 90% saw religion as a healing factor and hoped for a positive outcome to their disease. They believed that God was greater than their illnesses and that, when putting their trust in him, there was a greater prospect of a cure.

Discussion

It was observed that for doctors, the meaning of the word health goes beyond the physical state of the patient, and also includes psychological factors such as religion, which was considered to be highly relevant. Some extracts from the interviews explain this fact: *"Our stability is based on three elements: the emotional the spiritual and the physical. If one of these is in poor condition, it reflects on the others, and destabilizes us emotionally, which is significant for chronic kidney disease*." This feeling is consistent with the trend found in recent studies [28,29] which emphasizes the importance of considering cultural and psychosocial characteristics as determinants of indi-

vidual and group behavior in the medical clinic, which can facilitate coping with the disease, adherence to treatment and the search for a better quality of life [30].

The idea of accepting and stimulating religion as a way to encourage the patient to cope with their illness and its everyday consequences and to safeguard a dimension of their human rights, is also compatible with the perspective of health adopted by the World Health Organization (WHO), which includes not only the absence of disease, but a more complete state of physical, mental and social well-being[31].

The terms "faith", "religion" and "spirituality" are often used interchangeably, but their meanings are not the same [32]. In this study an awareness of this distinction among the doctors interviewed was noted, as half said that faith is important, but not religion. Spirituality and religion can strengthen families by contributing to the formation of their beliefs and values, encourage healthy behavior and practices, stimulate social interaction, promote recreation and help in coping with crises and transitions of life [22]. It was found that both groups of participants, doctors and patients, agreed with this idea, expressing their confidence in the potential of religion and spirituality to help people, by providing them and their families with ways of dealing with the disease on a daily basis . For patients, believing that they can rely on spiritual forces brings feelings of comfort.

As a result, incentivizing of religion and spirituality has been one of the strategies adopted by health professionals in coping with terminal illnesses [33]. In this study, there was clear recognition of its potential by 60% of responding doctors, who said that religion represents strength and comfort for patients, facilitating the acceptance of the disease and the limitations it imposes. For hemodialysis patients, research shows that the followers of a religious belief have a higher quality of life, survival rates, satisfaction with life and medical care, adherence to treatment, ability to work and to deal with the symptoms of kidney disease, than non-religious patients [34]. Among respondents, 70% reported that religion means "everything" in their lives, as shown in this passage: "*God is very good for us, you know. I have been religious for 20 years, I am very happy and content*" (Patient 7)).

In 2006, a systematic review of literature was carried out, which included articles on the spiritual perspective of adult patients with terminal illnesses. The study covered a 40 year period, and began in 1966 [35]. Based on a sample of 11 articles, collectively representing the data of 217 adults, it found that feelings of alienation were an important aspect of spiritual suffering. A "sense of spiritual emptiness" is described as a secondary defining characteristic [36]. Among the patients interviewed in this study, there was no such sense of spiritual emptiness, except for one patient who could not answer. On the contrary, most were emphatic when explaining how religion is significant in their lives.

As previously described by Borges, the initiation of hemodialysis is a critical time for most patients facing the irreversibility of the disease and, in some ways, the impossibility of a cure by traditional medicine [37]. Accordingly, Loyola states that an illness that a doctor cannot cure can be interpreted as a disease with a spiritual background, and can therefore be treated in this as the cause, by exceeding medical expertise, must lie in the field of religion [38]. The same idea was expressed by 90% of patients in this study, who, when asked about the importance of religion in treating chronic kidney disease, answered: "*I hope that I will get better*." This clearly demonstrates the relevance of spirituality and religion in the course of this disease, as they are accumulators of hope, and make the life of each patient more dignified and comfortable.

Final considerations

The individual significance of religion was divergent among both physicians and patients, as some saw it as essential in their lives, while others considered only faith in God to be important. Both groups generally agreed, however, on the relevance of religion in treating chronic kidney disease. The study indicated that among the group studied, it was indeed considered – both by doctors and by patients – as a significant and important element of the evolution of chronic kidney disease, given its ability to bring comfort, support, strength and hope of improvement to the lives of patients.

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Participation of the authors

Eli Ávila Souza Júnior and Diego Da Silva Vanoni Trombini participated in the planning of the study, its development and the preparation of the text; Augusto Castelli Von participated as an orienter of these stages and Adriana Rodrigues dos Anjos Mendonça participated as a coordinator.

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Research article

Swear words among homosexuals: transgression of heteronormativity or replication of gender values?

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Abstract

Swearing words are powerful weapons of social control. In the act of swearing, gender values are not only represented but perpetuated. Based on previous research showing that there are binary and sexist values in swear words, the present study aimed to survey and compare the swear words considered as worst by self-declared homosexual groups in order to verify if the same kind of gender values are present or if they are subverted. A total of 303 questionnaires were applied, divided in 150 men (75 homosexuals and 75 heterosexuals) and 153 women (74 homosexuals and 79 heterosexuals). The answers underwent semantic and pragmatic analysis and were subsequently classified in analytical categories. After this stage, a quantitative and qualitative comparison between groups was conducted. It was observed that the worst swear words elected by homosexual categories were similar to those elected by the heterosexuals, pointing to the replication of heteronormative values in the choice of insults.
Keywords: Sexism. Social discrimination. Homosexuality.

Resumo

Xingamentos entre homossexuais: transgressão da heteronormatividade ou replicação dos valores de gênero?

Os xingamentos são poderosas armas de controle social. Neles, os valores de gênero são não apenas representados, mas também perpetuados. A partir dos resultados de pesquisas anteriores, que demonstraram a existência de valores binários e sexistas nos xingamentos, o presente estudo teve como escopo fazer um levantamento e comparação de xingamentos considerados piores pelos grupos autodeclarados homossexuais, para verificar se os mesmos valores de gênero se fazem presentes ou são diferentes. Foram aplicados 303 questionários, divididos em 150 homens (75 homossexuais e 75 heterossexuais) e 153 mulheres (74 homossexuais e 79 heterossexuais). As respostas passaram por análise semântica e pragmática e, posteriormente, foram classificados em categorias analíticas. Após essa etapa, realizou-se comparação quantitativa e qualitativa entre os grupos. Notou-se que os piores xingamentos eleitos pelos grupos homossexuais foram semelhantes aos dos heterossexuais, o que sugere a validade da hipótese da replicação de valores heteronormativos na escolha das ofensas.
Palavras-chaves: Sexismo. Discriminação social. Homossexualidade.

Resumen

Los insultos entre homosexuales: ¿la transgresión de la heteronormatividad o la duplicación de valores de género?

Los insultos son poderosas armas de control social. En ellos, los valores de género no sólo están representados, sino que también se perpetúan. A partir de los resultados de investigaciones hechas previamente, con las cuales se demostró que existen valores binarios y sexistas en los insultos, el presente estudio tuvo como objetivo recopilar y comparar los insultos considerados como los peores por parte de los grupos auto-declarados homosexuales, para determinar si los mismos valores de género se hacen presentes o son diferentes. Fueron aplicados 303 cuestionarios, divididos entre 150 hombres (75 homosexuales y 75 heterosexuales) y 153 mujeres (74 homosexuales y 79 heterosexuales). Las respuestas pasaron por un análisis semántico y pragmático, y fueron posteriormente clasificadas en categorías analíticas. Después de esta etapa se llevó a cabo una comparación cuantitativa y cualitativa entre los grupos. Se observó que los peores insultos seleccionados por los grupos homosexuales fueron similares a los escogidos por los heterosexuales, lo cual sugiere la validez de la hipótesis de duplicación de valores heteronormativos en la elección de las ofensas.
Palabras-clave: Sexismo. Discriminación social. Homosexualidad.

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Research article

Homosexuality, understood contemporaneously as the sexual and affective relationship between people of the same sex, presupposes several cultural and historical "pre-conceptions" (representations), among them the notion of sexual identity [1-3]. The representation of this relationship may be very different in an indigenous community, for example, in which the notion of person is not based on the idea of a constant identity [4]. Besides, in the past, several societies and even ours, western, interacted differently wit the practice of homosexuality [5]. This way, to equalize the relationship of a Greek youngster with his mentor in ancient Greece to the union between two men in the present would be a mistake, considering the distinct look on the phenomenon that both periods present.

Social acceptance of the sexual relation between people of the same sex is in accordance with the ideological apparatus established in a certain moment. According to historiography, from the rise of Christianity to the XVIIIth century, this behavior was seen as circumstantial, subject to prohibition and penalties for its sinful character [6]. From the advance of the medical knowledge during the XIXth century, with the broad elaboration of the classification of pathologies in the form known today, the sexual affective relationship between people of the same sex was linked to identity definitions, materialized in the creation of the social representation of the homosexual subject form the term homosexuality, conceived in the end of the 1860s decade [7-8].

When the figure of the "homosexual" individual is disseminated, heterosexuality is grounded as a naturalized way to express pleasure. That is, the maintenance of sexuality as identity made possible the establishment of an essentialist binarity in which homosexuality was perceived as the difference and the abnormality while heterosexuality would be conceived as the authentic way of affective and sexual relationship, biologically manifested in human beings [1-2]. For the decades following the creation of the term homosexuality, homosexual women and men lived with the stigma of having their sexuality marked by medical diagnoses, besides the aggressive and, in many cases, invasive healing techniques [6-9].

During the period in which it was submitted to the verdict of medicine, homosexuality was also object of study of psychology and psychoanalysis. From the Freudian theory [10], which focused on human psyche and its relation with sexuality, the psychoanalytic knowledge started contributing to the enhancement of the concept of sexual deviation in psycho-diagnosis, which was soon incorporated into the psychiatric semiotics [11]. However, in the middle of the XXth century, social movements started questioning the permanence of the definition of homosexuality as a disease. Faced with the discrimination based on the abnormality tag, groups were formed of subjects identified as homosexuals who, for seeing themselves as a marginalized category, ended up creating identity ties [12]. With the strengthening of a political-identity link, the gay militancy in the U.S. demanded that the American Psychiatric Association withdrew homosexuality form the classification of mental diseases, what happened in 1973 [13].

In Brazil, the first movements of homosexuals arouse in the 1970s in the context of the military ruling, a period in which several militant groups were ere created, questioning the authoritarianism in force. [9]. As occurred in the U.S. these organizations, initially, sought to discuss the social and individual implications of their sexual orientation, besides questioning discrimination and intolerance. As different forms of oppression were questioned in homosexual movements, the negative impact of male chauvinism was also debated.

It was mainly the group of lesbians who sought to denounce and contest the reproduction of male chauvinist behaviors within the militancy itself. With this, a gap was crated between the groups formed by homosexual men and women, as they opted to approach the feminist movements which, having great organization and studies in the area, could, in a certain way, respond with more understanding and affinity to the demands of the lesbian groups [4].

Feminist gender studies arose in the 1960s-70s, with the purpose of deconstructing the idea of a feminine essence, a concept that contributes to the permanence of women in underprivileged social positions [14]. Progressively, this ancient reductionist conception of woman was substituted by a more plural comprehension, composed for example, of the different attributes that may be incorporated by women, such as age, ethnicity and economy. Besides, such studies came to emphasize the need to regard gender considering its relational character, in such a way that men were also included in this perspective [15]. This condition is based on the complementarity and in the superposition of several categories related to gender roles, which belong to the same mode of social functioning [16].

The understanding of the relational character of gender, on the other hand, should not highlight the idea of differentiation between men and wom-

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en based on biological determinism, implicit in the usual concepts of "sex" and "sexual difference". The third wave of feminism, in the 1980s, broke up wit his logics of understanding by suggesting that the very understanding of sex is a gender construction. This new feminism also proposed the deconstruction of the concept of identity, heir, according to Judith Butler [1], of a western metaphysical tradition marked by the idea of substance.

For Butler, gender is not, in any way, stable, nor would it be an operating locus from which different act would proceed; it is, rather, an identity feebly constructed over time, an *identity instituted by a stylized repetition of acts* [17]. In this sense, gender is a performance that gradually crystallizes as a consequence of stylized repetition of acts, producing the (misguided) idea of substance. Such repetition does not occur freely: as stated by the thinker, there is a "*survival strategy*" that suggests a situation of clearly punitive social coercion, in which this performance takes place. This was, becoming a man or becoming a woman in our binary society would consist in *obligating the body to conform to a historical idea* [18] of "*woman*" or "*man*".

Thus, the dualistic regulation of sexuality is seen by Butler [1] as a way to erase the multiplicity of a subversive sexuality, which would break the heterosexual hegemony, whose construction counted on great theological-medical-juridical support. According to the thinker – who stresses the social pressure present in the compulsory linearity between sex, gender and sexuality –, *heterosexualization of desire requires and institutes the production of discriminates and asymmetric oppositions between "feminine" and "masculine", in wich these are understood as attributes of "male" and "female"* [19]. That is, like the thought of Witting [2], Butler understands human sexuality as a paradigmatic materialization of the incorporation of the values of gender in society.

Teresa de Lauretis [20] denominated *gender technologies* the social processes that involve discourses and epistemologies, beyond the institutional practices and everyday life that will influence the social representation of "masculine" and "feminine" along history. According to the author, gender would consist in a technology produced and reproduced through the most diverse social techniques, institutionalized practices and actions of everyday life whose function is to transform concrete individuals in men and women, promoting the engagement in socially acceptable subjectivity models. Among the gender technologies are the media in general and the use of insults.

Despite the theoretical advance in the field of gender studies, male chauvinist values related to the image of women subsist in our culture. Among these are the ideal of suppression of sexual desires in favor of a demure and pure image [21-22]; the ideal of zeal, expressed in an allegedly caring essence, marked by renunciation [23-24]; the made up volition for conjugality and maternity [25-26]; the control of the bodies, keeping the woman from deciding on the continuity of her pregnancy or encourages her to constantly seek an ideal of beauty that would make her stand out in the affective market [27]; the violence [28-29], and the exclusion form benefits that guarantee autonomy and liberty to enjoy the same opportunities assured to men.

Concerning masculinities, it is evident the imperative character of "*being man*". According to Badinter, *being a man is said more in the imperative than in the indicative form* [30]. Being man is, in this sense, the interposition of not being a "*little girl*", of which he will be demanded to show proof all his life, in living and belonging in the house of men [31]. Two pillar-values are highlighted: the sexual and productive working virility. The former is aligned with the idea of a "*comedor sexual ativo* (active sexual fucker)" [32-34]. The latter affirms the idea of productivity, of which the proof of success is the accumulation of wealth. As this model does not include every man, the concept of hegemonic masculinities was formulated, in which the groups that do not adapt to the normative standards would be dominant, while the subordinates would be the ones that do not fulfill social expectations, such as homosexual men, for example [35].

As seen, gender consists in a performance assured or evoked by social practices, among which gender technologies era highlighted. As a performance, insulting may be understood as one of the manifestations of these technologies, since, as it is uttered, it indicates to the interlocutor interdicted places and social values [36]. According to Houaiss and Villar, "xingar (to insult)" is a verb that expresses the action of *agredir por meio de palavras isultosas, injuriosas; ofender, descompor, destratar, afrontar (*attacking through insulting, injurious words; to offend, decompile, mistreat, reproach) [37].

Considering the characteristic of the action indicated by the verb "xingar", the choice of vocabulary to be used is never random, but it takes place mainly as a function of gender values. This choice comprehends not only the semantic aspect of the word but also its mode of use when attributed to people perceived as of different sexes in diverse

contexts, that is, the sense of its use, its pragmatic aspect [38]. With the aim to list gender values in insults, Zanello and Gomes [39] performed a study with a sample of 376 adults in Brasilia. Through questionnaires, participants were asked to point the worst insults attributable to a woman and a man, besides indicating the situation in which the insult would take place.

In the result of the study, it was observed that the insults considered as the worst by women, when attributed to themselves were the ones that denoted active sexual behavior (66.2%), such as "*puta (whore)*", "*piranha (slut)*" and "*vagabunda (tramp)*". In second place, came the ones with a relational character (10.94%), such as "*interesseira* (self-interested)" and "*falsa* (false)". In third place were insults related to aesthetic ideals, such as "*gorda (fat)*" for example. This way, the three forms of insult that were considered the worst were exactly those that our society keeps in relation to women: sexual restraint and abstinence; availability and dedication to others; and beauty.

In relation to men, the worst insults attributable to themselves were related to passive sexual behavior (46.6%), such as "*veado (fag)*", "*bichinha (*little faggot)" and "*boiola* (queer)". In second place came the ones with a self-investment character trait (37.8%), among which "*vagabundo* (bum)" and "*fracassado* (loser)". Thus, it can be noticed that the insults intended to affront sexual and productive working virility, identity base of the constitution of a "true" man in our culture.

In the study, the division of the participants by sex showed that both men and women shared male chauvinist social values and used insults as a reassurance of gender standards. Besides, in certain occasions, the same term took different senses according to their use (pragmatic aspect), when used towards a man or a woman. An example of that was the term "*vagabundo* (bum)", which, when used to insult a man, got the meaning of "man who does not work", "lazy", while when used to insult a woman got the sense of "woman with an active sexual behavior". However, even in the case of women, there were answers in which this insult got the meaning "woman who does not not work" [38].

The analysis of these results, however, indicated that it would be interesting to ask about the sexuality of participants in order to find if there would be a distinction between insults made by homosexual and heterosexual groups or if the heteronormative values also permeate the discourse of homosexual individuals, so that an equivalence is found between them.

Based on this reflection, the following questions were asked: would homophobia be present in the insults by groups of self-declared homosexual men? Among insults by homosexual women would there be values of sexual restraint in detriment of the references to homosexuality? And, if the answer is affirmative for both questions, would male chauvinistic and misogynous values prevail even among such groups? Do these groups insult homosexual and heterosexual man and women differently?

Thus, facing these questions, the present study sought to continue the study on insults performed previously, Now having as study target the groups of lesbians and gay men. Considering the specificity of the language adopted by these groups, the present study had, as a general objective, to survey the insults considered as the worst when directed both toward heterosexual women and men and to homosexual women and men, in a self-declared homosexual group. Besides, a comparison was sought between the forms of insult when the offense is attributed to people in general, homosexual or not, and to confront these data with the results obtained in a group self-declares heterosexual.

Methods

This research project was approved by the Comitê de Ética do Instituto de Ciências Humanas da Universidade de Brasília (Ethics Committee, Institute of Human Sciences, University of Brasilia, CEP/ICH-UnB). After acceptance by the CEP, questionnaires were applied to groups of goers to different events of lesbians, gays, bisexuals and transgender (LGBT) in the different administrative regions of the Federal District, as well as places with higher frequency of the target public of the research, during the second semester of 2012 and the beginning of the year of 2013.

Questionnaires consisted in four questions (each including a complementary question, in order to clarify the use of these insults): *1) What are the worst insults attributed to a heterosexual woman? In what situation?*; *2) What are the worst insults attributed to a heterosexual man? In what situation?*; *3) What are the worst insults attributed to a homosexual woman? In what situation?*; *4) What are the*

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worst insults attributed to a homosexual man? In what situation?

Questionnaires were applied in the University of Brasilia, in bars and restaurants frequented by the LGBT public and in the gay pride parade of Brasilia. At the end of the survey, data of 303 questionnaires were used, being 150 men (75 homosexual and 75 heterosexual) and 153 women (79 heterosexual and 74 homosexual). 73 questionnaires were excluded for not being properly answered, either due to the absence of the self-declaration of sexual orientation or because more than half of the four items were blank. We believe that the high occurrence of incomplete answers was due to the fact that the application of questionnaires occurred mainly in moments of leisure of the interviewees. These places were chosen due to the ease of access to the target public. The transcription of data was performed though the transfer of all social-demographic and answers to electronic indices, in order to facilitate data analysis.

In the group of homosexual women, the age of participants ranged between 16 and 62 years (average 28.27 years), with 43% of high school level education and 57% college level. Among heterosexual women, age ranged form 17 to 65 years (average 27.80 years), with 2.6% of elementary school education; 57.1% of high school, and 40.3% college-level. In the group of homosexual men, the age of participants ranged from 16 to 47 years (average 24.68 years), with 1.5% of elementary school level education; 51.5% high school and 47% college level. Among heterosexual men, age varied from 17 to 59 years (average 27.73), with 57.2% of high school education and 42.8% college level education.

Data were submitted both to content analysis [40] and to pragmatic analysis [41-42], seeking to evaluate the semantic content of the term and, at the same time, the sense of its use (pragmatic aspect) [38]. In this stage, data were worked in a way to permit the selection and grouping of answers in categories representative of their contents, as well as facilitate their understanding. Along the process, the answers and categories were tabulated.

From the thematic-semantic axes obtained in the groups, it was possible to perform a comparison of groups concerning: 1) contents that arose; 2) gender values present. In order to organize the information collected, results were distributed in four large blocks, according to the analyzed divisions of sex (men and women) and self-appointed sexual orientation (homosexual e heterosexual).

Discussion and results

Concerning insults mentioned by homosexual men, when asked about the worst offenses attributed to their own group, the main results found were associated to sexual behavior (68%) and exclusion and rejection (12%). Besides the significant difference perceived between the first and second places in occurrence, within the category of sexual behavior, the largest number of insults was observed in the "passive sexual behavior" subcategory (90%). That is, according to the answers, the worst insults that homosexual men consider for themselves are those denoting passivity or behaviors that bring them closer to traits considered as feminine. Among the most frequent examples found, are "*viado (fag)*", "*viadinho* (little fag)" and "*bicha (faggot*)". In the "exclusion and rejection" category, examples obtained were, "aberration") and "sick".

The other categories present were: relational character traits (4%), in offenses like "*sem-vergonha (*shameless)" and "bad company"; self-investment character traits (1%), such as "*vagabundo (bum)*" , "*sem future* (no future)" and "*incompetent*"; sexuality as insult (1%), which, in this case, would be to offend a homosexual man by calling him "*heterosexual*"; physical attributes (1%), such as "*feio* (ugly)" and "*fora de forma* (out of shape)"; intellectual attributes (1%), such as "*burro* (stupid)", and, lastly, the category "others" (2%), in which offenses do not fit in the remaining categories, like "*da moda* (trendy)" and "*xiboca* (too cheerful)".

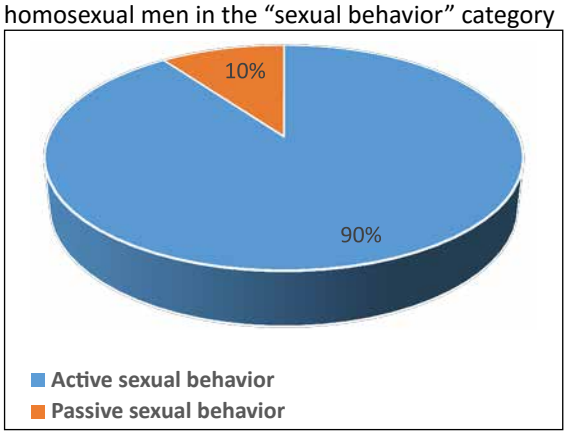
Insults referring to relational character traits are those that contradict dignity and honesty, while insults associated to the self-investment character traits are the ones that contest productivity, that is, the professional role and the ability to generate income. Besides the categories mentioned, there were questionnaires (10%) in which the participant either used expressions or terms that would not be insults if compared to the standards previously established by the research or left blank answers.

Among heterosexual men the worst insults attributable to homosexual men were also in the "sexual behavior" category (79%). In this, the passive sexual behavior, expressed in insults like "*viado* (fag)" and "*bichinha* (little faggot)", is also

predominant (93%). Other categories were also present, such as: traits of relational character (7%); self-investment character traits (3%); exclusion and rejection (2%); physical attributes (1%); intellectual attributes (1%); sexuality as insult (1%), and others (2%). In 4% of the questionnaires, either terms or expressions that would not be insults in comparison to the standards previously defined by the study or the item was no answered.

Analyzing the data obtained, one notices that the attribution of characteristics culturally associated to women, such as passivity, is considered the worst means of insulting the homosexual man. These evidences also arose in the groups of insults that homosexual and heterosexual women directed to homosexual men, in which the "passive sexual behavior" category predominated in the "sexual behavior" category (96% and 98%, respectively). Thus, it is possible to notice the misogyny predominant in the insults attributed to homosexual men, as the worst insults refer to the hatred to female traits [7]. The very group oh homosexual men, the largest target of this pattern of insult and possibly capable of subverting this situation, corroborated the reassurance of misogyny (Figure 1).

Figura 1. Insults from homosexual men attributed to homosexual men in the "sexual behavior" category



From Figure 1, one can infer the magnitude of the presence of sexually passive behavior in insults by homosexual men attributed to their own group. This datum denotes the presence of the homophobic discourse in homosexuality and the appropriation of virility values as representation of acceptable homosexuality. According to Badinter, *while practiced in its active form, homosexuality can be considered by men as a way to reaffirm its power;in its "passive" form, it is, on the contrary, a symbol of decadence* [43].

For heterosexual men, the main categories of the worst insults that they attribute to their own groups are sexual behavior (48%), relational character traits (27%) and self-investment character traits (12%). Four categories had 2% of occurrence; these are: exclusion and rejection; physical attributes; intellectual attributes, and others. The "politically correct" category had only 1%. In the sexual behavior category there was more spread among the subcategories, compared to the previous group.

Passive sexual behavior predominates with 57% and the passivity behavior by betrayal, expressed in insults such as "*corno* (cuckold)" and "*chifrudo* (also cuckold)" – denoting the inability of the man to keep control over the sexual behaviors of the partner in the relationship – is in second place (26%). Then, come sexually active behavior (10%), with insults like "*safado* (naughty)" and "*machão* (macho-man)", and the efficiency sexual behavior (7%), as "*brocha* (limpdick)" and "*ruim de cama* (bad in bed)". The "efficiency sexual behavior" category is the one that questions the effectiveness of the man during the sexual relation, manifested in expressions like "*pau mole* (floppy penis)" and "impotent". In 4% of the questionnaires, there was no answer to this question.

In the opinion of homosexual men, the categories with greater relevance as the worst insults directed at heterosexual men were sexual behavior (57%), self-investment character traits (19%) and relational character traits (15%). In the subcategories of of sexual behaviors, we had: passive sexual behavior in first place (74%); passivity by betrayal in second (15%); efficiency sexual behavior in third (6%); and, finally, active sexual behavior (5%). Beyond the main categories, in this group there were also: exclusions and rejection (4%), in insults like "disgraced"; physical attributes (2%), such as "fat" and "*pinto pequeno* (small penis); politically correct (1%), such as insulting a heterosexual man calling him "*machista* (chauvinist pig)" and others (1%), among which was the apparently unknown "*frakking*". Although this may correspond to the wrong spelling of the English slang "*freaking*", designating something or someone abnormal or strange, spelling mistakes were only considered as such when they were obvious, like in "*bixa*" instead of "*bicha* (faggot). In 1% of the questionnaires there was no answer to this question.

Homosexual women followed the pattern of homosexual men in the main categories of insults directed to heterosexual men. Sexual behavior was in first place (53%); self-investment character traits came in second (20%), and, in third place, the relational character traits (13%). Sexual behavior

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subcategories were: passive sexual behavior (64%); passivity by betrayal and efficiency sexual behavior, both with the same value (16%); as well as active sexual behavior (4%).

Other categories arose in this group: physical attributes (4%), with insults like "*bombado* (pumped up)" and "*careca* (bald)"; exclusion and rejection (3%), with insults like "*sujo* (filthy)" and "*lodo* (scum)"; intellectual attributes (2%), like "*burro* (stupid)" and "ignorant"; and, finally, politically correct (1%), in which again the term "*machista* (chauvinist pig)" arose as an insult. In 4% of the questionnaires, either expressions or terms were used which would either not constitute insults when compared with the standards previously established by the study, or the item was no answered.

In the distribution of the worst insults among homosexual women directed toward heterosexual men, sexual behavior was still predominant (51%), despite relational character traits having high occurrence (20%), followed by self-investment character traits (15%), intellectual attributes (5%), exclusion and rejection (4%) and physical attributes (2%). "Sexuality as insult" and others had only 1%.

In the subcategories of sexual behavior, passive sexual behavior still had the highest occurrence (60%), and passivity behavior by betrayal also had considerable occurrence (21%). Active sexual behavior and efficiency sexual behavior were less expressive (7% and 12%, respectively). In 1% of the questionnaires, there was no answer to this question.

Even the distribution of the categories and subcategories of sexual behavior being greater in the worst insults attributed to heterosexual men, it is evident that the sexual passive behavior is still prominent in the questionnaires. Joining this result to the one of the group of homosexual men, it is clear that, independently of the sex and the sexuality of those who answer the research, me are always called to answer for the ideal of virility required by the society, be that homosexual or heterosexual [7]. This result corroborates the theory by Daniel Welzer-Lang that men *must combat aspects that would make them associated to women* [44].

In relation to the questionnaires in which the worst insults were directed to women, as in the case of men, it is also possible to notice prevailing elements in the choice of the worst insults. When asked about the worst insults attributed to their own group, heterosexual women chose the active sexual behavior (74%), which was the only subcategory of sexual behavior that appeared in the results, with insults such as "*puta* (whore)", "*vadia* (tramp)" e "*piranha* (slut)".

Other less expressive categories were: intellectual attributes (6%), with "*burra* (stupid)", "*barbeira* (bad driver)" and "*dona Maria* (Miss Mary)"; relational character traits (6%), with "*pistoleira* (insensitive and moved only by self-interest)", "dishonest" and "*traíra* (traitor)"; physical attributes (5%), with "fat" and "*baranga* (very ugly and unattractive woman)"; exclusion and rejection (4%), with "*nojenta* (disgusting)" and "*porca* (female pig)"; self-investment character traits (3%), with the insults "*fracassada* (loser)" and "*incompetent*"; and others (2%), in which unknown terms, such as "*banda" and "rupiada*" were found.

In the worst offenses that homosexual women chose for heterosexual women is sexual behavior (76%), in which the subcategory "active sexual behavior" represents 89%, followed by inverted sexual behavior (8%) and frustration sexual behavior (3%) – this last one having as insults the expressions "*mal-amada* (badly loved)" and "*mal-comida* (badly fucked)". The other categories found were intellectual attributes (3%), relational character traits (3%), physical attributes (6%), exclusion and rejection (4%), self-investment character traits (3%) and others (1%).

In the "inverted sexual behavior" subcategory, predominant insults are "*sapata* (dyke), "*sapatona* (dyke)", "*caminhoneira* (truck driver)", which express, in the social imagination, the behavior of a woman who intends to approach to the behaviors socially attributed to men, i.e., an "inversion of roles". The choice of the term "inverted" is justified by the answer to the complementary question *In what situation?*, which suggested an idea of breaking the "necessary" relation (in the social imagination) between sex, gender and desire [1]. In 4% of the questionnaires there was no answer to this question.

Homosexual men elected, as the worst insults of heterosexual women, those related mainly to sexual behavior (80%), in which the subcategory "active sexual behavior" had 93%, followed by inverted sexual behavior (5%) and by passive behavior, with the insult "*pau no cu* (penis in the anus)", and the one of frustration, each with only 1%.

In this group other categories arose: relational character traits(6%); physical attributes (5%); intellectual attributes (2%); exclusion and rejection (2%); others (2%); besides self-investment character traits and biological sex as insult, each with 1%. In 1% of the questionnaires there was no answer to this

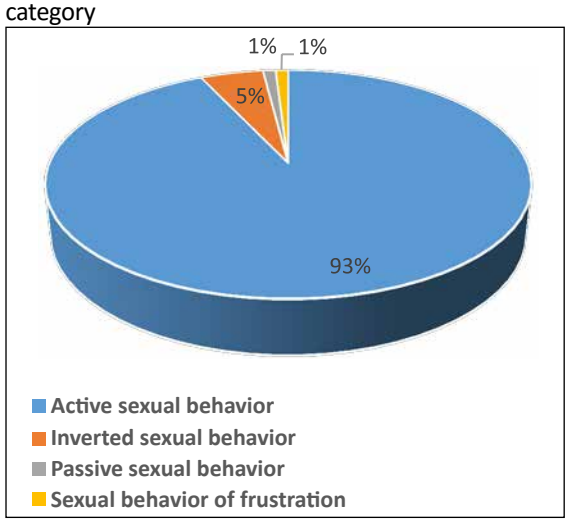
question. Insults associated with frustration sexual behavior such as "*mal-amada* (badly loved)" and "*encalhada* (stranded)", refer to the difficulty of the woman in being chosen as the object of love and/or desire of a man, which gets right at the "*love device*" [25], the privileged way, in or culture, of the subjective constitution of women [45].

In the group of the worst insults from heterosexual men toward heterosexual women, sexual behavior and physical attributes were the categories of higher occurrence: 70% and 13%, respectively. The other categories were less expressive: relational character traits (7%), exclusion and rejection (4%), intellectual attributes (3%), self-investment character traits (1%) and others (1%). In 1% of the questionnaires either there was no answers or expressions or terms were used which would not be insults if compared to the standards previously defined by the study. In the sexual behavior category, active sexual behavior was majority (97%). The other three subgroups were inverted, frustration and passive sexual behaviors, each with only 1% of occurrence.

Based on the results of the present study and in previous studies on insults [38-39-46], it is possible to notice that active sexual behavior, independent of the sexual orientation of the insulter, is the main tool of insult to heterosexual women. That is, there is a pattern in these insult mechanisms with the function of coercing to behaviors considered appropriate to women [26]. Since docility and femininity constitute attributes socially imposed to women, being a "*puta* (whore)" or "*vagabunda* (tramp)" is seen as something offensive, and, thus, are considered the worst insults. This phenomenon was quite evident in the insults of homosexual men directed to heterosexual women (Figure 2).

In the categories of the worst insults that heterosexual women attribute to homosexual women are: sexual behavior (63%); exclusion and rejection (17%), in which insults such as "sick" and "*nojenta* (disgusting)"; physical attributes (5%), such as "fat" and "*peluda* (hairy)"; intellectual attributes (2%), such as "*burra* (stupid)". In 10% of the questionnaires either the interviewee could not define any insult or mentioned expressions like "*você gosta de aranha* (carpet muncher)". The self-investment and relational character traits, as well as reference to celebrity had 1% of the occurrences each. This last category refers to the use of names of famous people as insults. In this group, the name chosen was that of the singer Justin Bieber. Among the subcategories of sexual behavior, inverted sexual behavior is predominant (72%), with "*sapatão* (dyke)" and "*mulher macho* (macho woman)", followed by active sexual behavior (25%), with "*vadia* (tramp)" and "*puta* (whore)", and frustration (3%), through insults like "*solteirona* (spinster) and "*mal-amada* (badly loved)".

Figura 2. Insults from homosexual men attributed to heterosexual women in the "sexual behavior" category



The sexual behavior category has expressive occurrence in the worst insults of heterosexual men directed to heterosexual women (77%). the remaining categories appeared as: relational character traits (7%), exclusion and rejection (5%), physical attributes (3%), followed by intellectual attributes, reference to the celebrity and others, each with 1%. In 5% of the questionnaires, the subject did not answer these questions. The sexual behavior categories were inverted sexual behavior (59%), active sexual behavior (33%), besides passive and frustration sexual behaviors, each with 4%.

If compared to the previous group, the list of categories that appeared in the worst insults of homosexual men to homosexual women: sexual behavior (71%), relational character traits (5%), exclusion and rejection (5%), physical attributes (4%), self-investment character traits (3%). Besides the categories "intellectual attributes" and "others", biological sex as as insult, when the words "*homem* (man)" or "*mulher* (woman)" were used as insults, each had 1%. As subcategories of sexual behavior there were: inverted sexual behavior, still ahead with 83%, followed by active sexual behavior (11%) and frustration and passive sexual behavior, each with 3%. This question was left blank in 9% of the questionnaires.

Sexual behavior remained as majority category in the worst insults chosen by homosexual women

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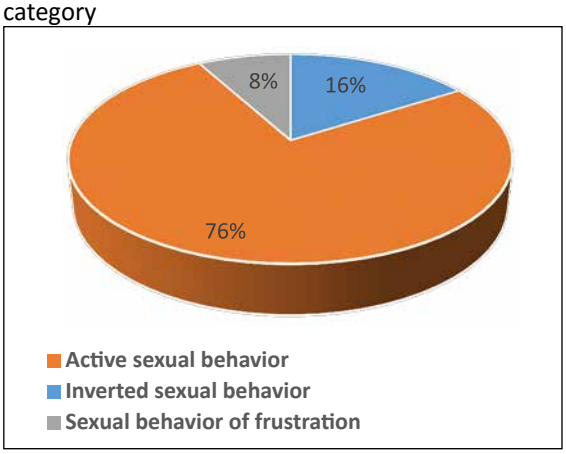
toward their own group (80%). Besides, the most frequent subgroup in this category was also inverted sexual behavior (76%), followed by active sexual behavior (16%), and the passive and frustration sexual behaviors, with 8% each. Other categories that appeared with less frequency were exclusion and rejection (5%), physical attributes (4%), relational character traits (3%), intellectual attributes (2%) and others (1%). There was no answer to this question in 5% of the questionnaires. One notices that homosexual women followed the same behaviors as the majority in the group of homosexual men, thus homogenizing the results. (Figure 3).

Figura 3. Insults from homosexual women attributed to homosexual women in the "sexual behavior" category



Final considerations

The aim of this study was to identify in which way self-declared homosexual subjects use insults and, mainly, to check if the values of gender remain in the maintenance of traditional social roles. With basis on the results, it was possible to define little distinction in the use of insults in the groups analyzed, which suggests the perpetuation of the male chauvinist and the values of gender in our society.

Among homosexual men, insults attributed to men, both homosexual and heterosexual, keep the category of passive sexual behavior as predominant insult, even if the insults are directed to the group itself. Therefore, although many times marginalized and oppressed due to their homosexuality, subjects resort to the same homophobic mechanisms against men in general. Besides, homosexual men consider the worst insults to heterosexual women those associated to active sexual behavior and, for homosexual women, those related to inverted sexual behavior, reassuring normative standards imposed on women.

Analogously to homosexual men, self-declared homosexual women also show the tendency to appropriate heteronormative values in the choice of the worst insults directed to different groups. Thus, they also attribute as the worst insults to men, be them homo sexual or heterosexual, those denoting passive sexual behavior. Moreover, they ratify the division found in the group of heterosexual women, in which the worst insults attributed to their group refer to the subcategory of active sexual behavior, while the worst insults directed to the very own group of homosexual women correspond to the subcategory of inverted sexual behavior.

In sum, from the data obtained, it can be inferred that homosexual men and women, although not included in the standards of oppositional homosexuality [1], reiterate social and traditional gender roles, which preach virility to men and sexual restrain to women. Besides, despite finding themselves at the margin of heteronormativity, they reproduce the behaviors of their heralds. Considering this situation , this study intends to highlight the importance of th reflexion about mechanisms that build subjectivity and guide moral judgments in social life, for it is understood that they are fundamental for the awareness on the behavioral patterns in force, which, by reproducing iniquitous, repressive moralities, even contrary to the basis of citizenship, go against the respect for individual autonomy.

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Participation of the authors
Felipe Baére participated of data collection and analysis, and in writing the article. Valeska Zanello was responsible for the conception of the study, besides participating in data collection and analysis, and in writing the article. Ana Carolina Romero participated in data collection and analysis.

Research article

The common morality theory in the work of Beauchamp and Childress

Letícia Erig Osório de Azambuja [1], *Volnei Garrafa* [2]

Abstract

"Principles of Biomedical Ethics" by Tom L. Beauchamp and James F. Childress, based on the concept of principlism, is the most studied book in the field of bioethics, and played a decisive role in the consolidation and global expansion of the discipline. Its four principles, however, were taken from different theories: the autonomy principle came from Kantian theory (Kant); beneficence, from utilitarian theory (Mill); justice, from the theory of justice (Rawls); and non-maleficence, from the common morality theory (Clouser and Gert). Since the 1990s several criticisms have arisen regarding the epistemological homogeneity of the work. As a result, changes, which are the subject of the present study, have been made to the text from the 4th edition onwards, especially concerning the common morality theory, incorporated in the book as the foundation of principlism. The aim of this study was to examine the inclusion of this theory into principlism, critically analyzing the contents of the last four editions of the book.

Keywords: Bioethics. Morals. Ethics, medical. Ethical theory.

Resumo

A teoria da moralidade comum na obra de Beauchamp e Childress

A obra "Principles of biomedical ethics", de Tom L. Beauchamp e James F. Childress, embasadora do principialismo, é o livro mais estudado no campo da bioética, tendo participado decisivamente do processo de consolidação e expansão mundial da disciplina. Seus quatro princípios, contudo, advêm de teorias diferentes: o princípio da autonomia foi retirado da teoria kantiana (Kant); a beneficência, da teoria utilitarista (Mill); a justiça, da teoria da justiça (Rawls); e a não maleficência, da teoria da moralidade comum (Clouser e Gert). A partir da década de 1990, diversas críticas surgiram quanto à homogeneidade epistemológica da proposta. Foram então introduzidas transformações na obra, que são objeto deste estudo, especialmente a teoria da moralidade comum, incorporada como fundamentação do principialismo, da 4ª edição em diante. O objetivo da pesquisa foi estudar a inclusão da referida teoria ao principialismo, analisando criticamente seu conteúdo a partir das quatro últimas edições do livro.

Palavras-chave: Bioética. Princípios morais. Ética médica. Teoria ética.

Resumen

La teoría de la moralidad común en el trabajo de Beauchamp y Childress

La obra "Principles of biomedical ethics", escrita por Tom L. Beauchamp y James F. Childress y que guía el principialismo, es el libro más estudiado en bioética, habiendo participado de forma decisiva en su proceso de consolidación y expansión global. Sus cuatro principios, sin embargo, proceden de diferentes teorías: el principio de la autonomía fue retomado de la teoría kantiana (Kant); el de beneficencia, de la teoría utilitarista (Mill); el de justicia, de la teoría de la justicia (Rawls); y el de no-maleficencia, de la teoría de la moralidad común (Clouser y Gert). Desde la década de los años '90 varias críticas han surgido con respecto a la homogeneidad epistemológica de la propuesta. Como resultado, se introdujeron cambios en el trabajo, que son objeto de este estudio, sobre todo con respecto a la teoría de la moralidad común, incorporada por los autores como fundamentación del principialismo desde la 4ª edición en adelante. El objetivo de la investigación fue estudiar la inclusión de dicha teoría al principialismo, analizando críticamente su contenido a partir de las últimas cuatro ediciones del libro.

Palabras-clave: Bioética. Principios morales. Ética médica. Teoría ética.

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Declaram não haver conflito de interesse.

Research article

Although Tom Beauchamp and James Childress (B&C) have not (even in the latest edition of the book "Principles of Biomedical Ethics" [1] – in which the idea is developed further than in previous editions) explicitly stated that common morality theory is one of the ethical doctrines that influenced principlism, it is clear that such a theory has come to be adopted by the authors as the main element of their theoretical argument. This, influence, which is evident from the 4th edition of the book onwards [2], is the motivation behind this study.

Common morality, while a historical product, comprises a basic set of moral standards, defined by the authors as a grouping of rules and moral principles which constitute a rational and socially stable set of rights and wrongs that are so widely accepted and spread that they form a true "social institution" [1]. Common morality theory, in turn, is an attempt to doctrinally explain this historical and pre-theoretical reference [3,4]. According to Karlesn and Solbakk [5], this theory can be applied to anyone, regardless of historical period or culture.

This theory, which is complex in its application, covers levels of rationale that go far beyond the choice between moral principles and rules. According to Gordon, Rauprich and Vollmann [6], this can basically be summed up as the concomitant use of one criterion and three groups: one of ten moral rules (the Decalogue), one of ten moral ideals, and one of ten-relevant moral achievements. The single criterion, at a maximum level of abstraction, used to determine when exceptions to the rules would be justified, especially in the event of a clash between them. It also includes, according to B&C [1], an analysis of universal character traits and moral positively (virtues), as well as character addictions.

Common morality theory and its relationship with principlism

Just like with other moralities, standards of common morality are learned over a lifetime. Over time, people also learn to separate these according to their membership of moral groups [1]. Despite this ability to identify and separate moral standards, certain understandings of determined basic demands that affect moral groups remain shared by all, such as that it is forbidden to kill, steal and lie [4,7].

The theory of common morality, or in other words the study of common morality as a theory, as proposed by Gert, Culver and Clouser, has its starting point in everyday moral experience. As this theory is based on common morality, something we all build and learn during everyday life, people generally know what it is instinctively, and even tend to apply it in daily life, even if they have never heard of it or studied it [3,4]. To belong to the institution of "common morality", moral norms should apply to anyone (as long as he or she is morally committed), regardless of historical time or place. This ability to permeate all cultures represents a true morally universal "meeting point" [8].

Common morality is based on human nature, and should be the same for everyone. However, this does not mean that a single global standard of morality should exist, nor that such a standard should resolve all moral questions, or be rationally endorsed by all [6]. According to this interpretation, incorporated by B&C in the text discussed in this study, common morality does not represent a particular form of morality (with non-universal guidelines, determined by cultural, religious and/or institutional issues) [3-5].

Impartiality and universality are its essential characteristics. Common morality comprises a single moral system, shared by all rational adults and capable of dealing with all moral questions. "Deal with," however, does not mean to solve, since, in many cases, it distinguishes only between morally acceptable and unacceptable solutions, separating the ethical from the non-ethical and indicating only the most morally appropriate solution [6,9].

For certain philosophers – such as Gordon, Rauprich and Vollmann; B&C (in principlism) and Gert and Clouser (in common morality theory) – there are several fundamentally suitable answers to the same moral conflict [6]. They believe that to solve a moral conflict does not mean seeking the only correct solution, but merely providing a well-justified moral solution. In this case, common morality does not lead to absolute truths. Justifying an act only because it is adopted by a group that shares the same morality does not mean that it represents the only truth, but merely the views of a certain moral group [8].

Obviously, the practice of bioethics also varies greatly from culture to culture, and from historical period to historical period. This is because bioethics is not static but is metaethically relative, and because there is historical pluralism within the context of each nation. This historic pluralism assumes that different observers can justifiably arrive at distinct moral conclusions about the same ethical dilemma, as they use different moral foundations, such as beliefs, values and the commitments of specific moral groups [10,11].

Universalism, also speaking metaethically, maintains that there exists a common morality shared by all rational people [8]. This universalism is not to be confused with common morality itself, although it may be one of its characteristics [5]. For these reasons, analysis of moral conflicts in different cultures needs to be contextualized. Imposing the moral vision of a culture or nation that is politically stronger than another is not contextualization, but mere uncritical importation of knowledge, otherwise known as moral imperialism [10].

In addition to the question of universalism, it should be remembered, according to Karlsen and Solbakk, that there is not one absolute theory of common morality, but rather several. For the authors, this, in itself, already compromises the claim of common morality theory to be universal [5]. Furthermore, none of the proposed theories regarding common morality can be complete and universal in isolation, given that they are based on the existence of different levels of common morality and their interrelationships and coextensions. This in turn creates another problem as one cannot speak about the existence of common morality at all logical levels, but only in the higher, more fundamental levels [4,5].

Another point is the nebulous question of whether common morality can vary according to the moral group to which it is inserted, as occurs with individual morals. Beauchamp argues that these changes can (and even should) occur, as long as they do so from time to time only and on an exceptional basis, and do not compromise the basic fundamental core of the theory [7]. For the author, the excess of instability in moral guidelines impedes arguments for a theory of common morality. On the other hand, however, excessive stability prevents the application of the same theory over time or in very different cultures. Ideally, he said, in a theory, there is instability in one or two guidelines, but the overall objectives should always remain stable.

According to Gordon, Rauprich and Vollmann, meanwhile, common morality, precisely because it is endowed with just enough universality and instability to make it dynamic, should be seen as true guiding principle, fundamentally more elevated than the others, which are in turn guided by this theory [6]. However, for Beauchamp himself, the framework of common morality seems to go further, functioning in the solution of moral conflicts not only as the super-principle organizer, but also as a collection of principles and rules (as occurs with principlism itself) [12].

As it is comprised of principles and rules (which are derived from principles) the theory of common morality inevitably results in a confrontation with asymmetric epistemological counter-positions [6]. In these conflicts, the most elevated and most generic standards (and there are no guidelines that are more elevated or more generic than super-principles) prevail at the expense of those that are shallower and more specific (such the rules) [6]. For Gordon, Rauprich and Vollmann, this form of practical application of common morality theory requires a review of more specific guidelines (rules), based on the more general (principles). Thus, rules are mandatorily reviewed in the light of principles, and principles in the light of super-principles. This gives greater consistency and teleological reliability to concrete applications [6].

Criticism of the use of common morality theory

Clouser and Gert claim that moral theories, when well-structured, are capable of reflecting the universality of morality and of the self-elimination of drift, and are never a set of principles and rules related in a more or less systematic form [13]. The authors criticize the claim of B&C that moral theories are at the top of the hierarchy of justification, followed by principles and finally rules. For them, such an argument is no more than an inadequate, minimalist and convenient way of explaining what a moral theory could be; this is because the ideal, according to B&C, is that a moral theory is based on what principlism can offer: a set of more or less related principles and rules.

Clouser and Gert point out, however, that in principlism, although theories are at the top of the hierarchy of justification, they do not play any part in practical moral reasoning; instead, they are the principles that assume the role of a final court of appeal [13]. According to these authors, there is nothing wrong with using principles in the analysis of specific cases in general; however, using them as mere substitutes for their ethical theories of origin seems more like an unconscious effort to cling to such theories.

Where did principles of principlism come from? Why were some chosen and not others? What is to be done when there is conflict between such principles? How or when to prioritize one principle above another? These are unanswered questions, as the principles of principlism not go beyond a historical

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summary of the theories of justice of John Rawls, the utilitarianism of John Stuart Mill, the autonomy of Immanuel Kant and the non-maleficence of Bernard Gert [3].

There is no denying that these theories are essential to morality; it is argued only whether or not they should form a coherent whole in principlism, which does not constitute a true theory itself [13]. It is important to point this out, as it is a requisite of a moral theory to offer considerations on the consequences of its implementation, including through the provision of rules on how to deal with situations of impartiality [3].

The greatest criticism of principlism, is not in fact to do with dispensing with the actual theory of principles itself. According to Clouser, even more serious is the fact that it is devoid of "any" theory capable of properly bringing together its principles (as they are derived from several theories) and functions as though it were autonomous [3].

Clouser and Gert go further, stating that principlism lacks systematic unity, thereby creating a practical and a theoretical problem. As there is no moral theory that adequately brings together its principles, there is also no unified guide to action that generates clear and consistent rules for such actions [13]. According to the authors, in principlism, the discussion is too eclectic, which is inevitable considering each principle is based on a different moral theory. Thus, for example, the principle of autonomy, recognizes that Kant was right to emphasize the importance of the individual; while the principle of non-maleficence recognizes that Gert was right to emphasize the importance of the duty to avoid harming others.

Following the same line of criticism as the authors studied here, it is clear that only with the use of a unified moral theory is it possible to deal with the full range of complex issues that bioethics currently covers. Only then, in a single, clear, consistent and comprehensive decision process, can true, morally valid answers be arrived at [13].

Garrafa and Porto have questioned the lack of a practical ethical intervention in principlism, especially when it comes to solving problems arising from the economic and social inequality that operates in peripheral countries. The authors defend, instead, the use of what they call bioethics of intervention, which is not bland or passive but is instead utilitarian, organically united, politically and concretely active [14].

Another advantage of having a valid moral theory is that all individuals who deal with the same moral conflict can communicate easily with each other. They would agree on the relevant aspects of the case, but not always arrive at the same decision, since consensus is not a necessary consequence of dialogue [4]. However, for these reasons, principlism finds it difficult to reconcile theory with practice, as its biggest problem lies not just in the contents of the principles, but in the form of their application. Philosophically, therefore, the starting point of several of the criticisms of the work of B&C is the systematization of their principles [4].

Some authors go as far as to say that the principles of principlism not operate as guides to action, so much so that they are inherently conflicting. These principles represent, according to these authors, mere names for a collection of superficial points, or *checklists*, as they simply list some moral obligations derived from different and unrelated moral theories. As such, they are limited to a grouping of summaries of moral values to be observed [13]. It seems, therefore, to constitute a reaction to the criticism of the lack of a theory to support principlism the fact that the theory of common morality was finally dealt with in the work of B&C.

The theory was introduced in the 4th edition of "Principles of Biomedical Ethics". However, it is only from the 5th edition, in which it comes to be used as a base theory for principlism [5,15,16], that greater visibility is given to the issue. In the 7th and latest edition, one of the most notable changes is precisely that the common morality theory is a constant presence throughout the work. According to B&C themselves, the theory was better "explained and justified" in this issue [1], in a clear attempt to respond to criticism.

However, although B&C have found a "solution" to the lack of a theoretical basis for principlism, the fact is that, in the view of Clouser and Gert, each principle remains merely a reminder of the existence of a moral value to be observed [3,13]. The biggest problem arises exactly when two or more principles may lead to different, or even opposed, commands, in what is commonly called ethical conflict. In principlism, principles do not obey any hierarchical arrangement, and are valid *prima facie*. In case of conflict, according to Patrão -Neves, it is only by proper concrete analysis, with all its nuances, can the decision be made that one principle should take precedence over another [17].

In such cases, as abstract principles must be described in terms of material principles, and confronted one against the other in order to establish which should guide the examination of the moral

conflict [4]. The result, according to Clouser, is that the chosen principles bear no resemblance to their parent theories, and that as many as four conflicting principles, or rather, up to four conflicting moral theories, can be evoked in the same case, reducing these principles to empty phrases [3].

It is worth mentioning that the principles placed in the context of their own theories are clear; it is within principlism that they become ambiguous. This is not about different interpretations, which is natural in the case of every principle, but how they behave without their own theory, given that, in a true theory, whether containing more than one principle or otherwise, the relationship between principles is clearly pre-established [13].

To Clouser and Gert [13], reading the chapters of principles in the work of B&C only reveals to the reader how these principles are interpreted by their own authors, since the four chapters do not outline any action guide for the resolving of moral conflicts; but offer only long discussions, full of examples of what their authors think of the principles [13]. Hence Clouser and Gert highlight two more of the serious problems of principlism: the first is that principles, as they are presented in principlism, are supposedly clearly structurally defined and justified, causing people to feel confident when applying them (or believing they are applying them). The second is that when using these principles, people are not aware of all the stages of their moral decisions, as these principles are not clear and mandatory guidelines, but only a collection of suggestions and observations of the authors who originally proposed them, which are, in many cases, conflicting.

Even more forcefully, Clouser and Gert [13] conclude their critique with the statement that while principlism acts as a moral tool, making possible the organization and discussion of the seemingly chaotic world of values in biomedical practice, it also brings, due to its instrumental ease of application, the risk of being repeated like a 'mantra', or in other words applied in an uncritical, decontextualized and generalized manner. At the same time, however, one should not overlook the fact that many of these criticisms are applicable to almost all moral theories, as, to date, none have managed to exempt themselves completely from objection. Principlism, perhaps due to not representing a theory in itself, also seems to have failed in this respect, like the original theories themselves.

The issue therefore is broad and controversial. To better understand the context in which B&C incorporate common morality theory in the book discussed in this article, it is necessary to study further the additions to the subject over the various editions of the article. The objective of this study was to perform a critical analysis of the inclusion of the theory of common morality as the theoretical support foundation for principlism, specifically from the 4th edition of the book "Principles of Biomedical Ethics." To this end, the content of this version of the work was compared with subsequent editions (5th, 6th and 7th).

Method

A qualitative research survey was carried out by analyzing the content of pre-selected literature [18]. The selected document sample consisted of the four most recent editions, in English, of the book "Principles of Biomedical Ethics", written by B&C.

In pre-analysis of the content of the foundations of principlism, performed through a floating reading, it was observed that the common morality theory was absent in the first three editions, and only appeared in the 4th edition. It was then present in the next three editions, although treated in a different manner in each of them. Thus, we sought the presence of the recording unit, "theory of common morality", and the context unit, "as the theoretical basis of principlism" from the 4th edition to the current (7th) edition (inclusive) by selecting the appropriate chapters, paragraphs and sub-paragraphs.

The English editions of the book were chosen not only to allow data to be extracted more faithfully, but also for reasons of parallelism between the texts, as only the 4th edition has been translated into Portuguese. This choice allowed for free translation and broad interpretation by researchers.

The exploration of the material phase consisted of the recording of the pre-selected passages. Using Word software program tables, each extract was transcribed and compared line by line, always being opposed, where appropriate, with its equivalent in the previous and subsequent editions (if any). Each line of the table corresponded to a transcribed paragraph, whereas the columns were divided into four: two of which oppose the contents of the different editions and the other two showing the respective page numbers.

During transcription, sections were positioned so as to facilitate the identification of corresponding (or non-corresponding) points. One-off changes were colored red, while more extensive changes, such as transposed sections were colored blue,

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with smaller changes within these passages also colored red.

With the changes highlighted, a new reading was performed in order to identify the content changes that responded to the objectives of the study. At this stage, the reference book "Qualitative Data Analysis" by Graham Gibbs [19] was used. Finally, free translations of the selected parts were performed.

Results and discussion

Theoretical and conceptual analysis of changes

The 4th edition was the first to deal with the theme of common morality and its theory [17], representing one of a number of responses that B&C attempt to provide, over the new editions of their book, to the numerous criticisms received, a fact noted by Childress himself in 1994 (the year in which the 4th edition was published), in an article he wrote alone: *Fiquei impressionado com o número e a força das críticas* (...) *as sucessivas edições de "Principles of Biomedical Ethics" refletem o impacto de inúmeras dessas críticas* (...) [20].

In the 4th edition, B&C separately define "moral", as a social convention about right and wrong human conduct that is so widely shared that it forms a stable community consensus, even if this is normally incomplete; and "ethics" as a general term that refers as much to morality as to ethical theory [2]. In the next issue, only moral is defined [21], it being understood that they had failed to clearly separate these two concepts.

The initial definition of morality presented in the 4th edition was a kind of compilation of guidelines of socially approved human conduct [2]. In the next edition, the concept became a set of guidelines shared by morally serious people [21]. In the 6th edition, B&C once again reformulate the same central idea of common morality, now redefined as a set of standards shared by all morally committed people, without modifying its connotation [22]. The 7th edition maintained this concept [1].

As can be seen, the change in the understanding of the authors of principlism about what was common morality was not for nothing. Reducing its scope of coverage to certain groups, firstly morally serious people, then the people committed to morality, made it easier to justify its alleged universality, since morality no longer need apply to all, without distinction, but as only to predetermined groups, chosen by the authors [23-25]. Thus, B&C were increasingly able to move their concept of common morality away from that initially proposed by Clouser and Gert, who defined it, according to Hester, as a set of universal moral standards endorsed by all rational moral agents [25].

This collective sense of morality does not identify with the origin of the word "moral". According to Donagan, morality comes from *mores* which refer to individual rules of behavior, and morality is nothing more than a system of *mores*. However, morality, for moral philosophers, eventually took on a different meaning, becoming something that is backed by virtue and that influences personal choices [26].

In the 7th edition, it is interesting to note that the word "moral", almost absent in the chapter titles of previous editions, is now constantly used. Other than in the general chapters that deal with the four principles and the chapter on the professional-patient relationship (which are, in any case, located in Part II, entitled "Moral principles"...), all the other chapters contain this word [1]. This is even more interesting because moral refers to the customs, and habits of a people and of a certain population [26].

As such the word "moral" must be related to issues concerning private aspects of morality, or even to moral pluralism itself, which recognizes the existence of a multitude of moral groups and their differences. In principlism, however, this word is closely linked to the universalism defended by its authors from the beginning of the theory principlism.

This is another strong contradiction in B&C's work, based on the misuse of a word that corresponds to the meaning that the authors try to give to it. This is because universalism and pluralism cannot be confused, as the former applies the same morality to the universality of subjects, while the latter is based on the theory of multiplicity in coexistence.

In an attempt to justify this universality, B&C eventually merge (perhaps on purpose) the types of universalism into ethics. It can be noted that they begin their defense of universality in the sense that everyone has the same common morality (an idea which they could not sustain) and moved to the defense of another idea, in which although all possess a common morality, each individual retains his own [26].

It is for this reason that, in the 5th edition, B&C clarify that they argued in the past for the existence of a single universal common morality [21]. In the same edition they also recognize the existence of more than one theory of common morality [27], as proposed by the authors Ross and Frankena. In this and subsequent editions (the 6th and 7th), both

make this clear when they say that some critical analysis of their work analyzes concluded that they, in building a self-justifying position that rotates in circles, initially defined common morality in terms of a certain moral commitment, before changing to the qualification that only morally committed individuals should accept its rules [1,21,22].

This is exactly the criticism of Herissone-Kelly: the manner in which the authors of principlism manipulate the theme of common morality. The author argues that, empirically, B&C are not able to present a single common universal morality, but instead a number of common morals which, furthermore, are only applicable to certain moral groups [23].

Curiously, on pages 4 and five of the same 5th edition, in recognizing the existence of a number of common morals and their many theories, B&C affirm, still hoping to justify the alleged universality of common morality in the context of principlism, that even in communities with their own customs, it is possible to identify a common morality in the most fundamental precepts [21]. From here they seek protection (even implicitly) in what Donagan describes as defined and not defined predicates – one being more primitive and therefore universal while the other is more specific, or in other words closer to practical applicability, but without universal scope [26]. So, B&C continue to try to justify that, at the most fundamental level (the undefined predicates), there still exists some much sought after universality.

In the same 5th edition, B&C sought to identify signs of convergence between the various theories of common morality [21], almost advocating a universal level of common morality within their own common moralities. This is further evidence that they cannot justify the universality of common morality as they initially attempted, and must now try to reduce it, both in its reasoning and its applicability.

Gordon, Rauprich and Vollmann, however, chose to support the creators of principlism. These authors explain that B&C are simply trying to empirically address the criticisms, arguing that common morality is a set of proven standards that are useful in achieving moral objectives [6,27]. What is noticeable, however, is that these authors do not assist in clarifying the truncated ideas proposed by B&C, nor explain their true intentions. Instead, they defend principlism for its usefulness, and not for its coherence or theoretical consistence.

Even B&C themselves, in the 4th edition, explain that not even a common morality would be complete, or without flaws [2]. This is another attempt to avoid criticism, as the key issue is not the practical applicability of principlism, but in the way it has been used. This search for universality was also performed by Kukla [28] – an innocuous strategy according to Strong, as common morality dispenses with universal acceptability, but not universal applicability [24]; in other words, it is not its nature that is important, but how it will be used in practice.

Both Holm [29] and Luna [16] claim that, despite the major change that the introduction of common morality in the 4th edition represents, it was in the next issue that the authors of principlism began to respond more strongly to the criticism they had suffered since the inaugural edition, which led to even greater changes in the content of the work. Perhaps this is because it was only in the 5th edition that B&C affirmed the intention of revealing their own version of common morality, and not attempt to present or justify a general ethical theory. Instead, they would concern themselves with the aspects of common morality that they had assumed, focused on questions of method and justification in biomedical ethics [21].

In fact, however, what we see is that from the 4th edition itself, and increasingly in following editions, B&C reinforced the idea of the unnecessariness of such a theory [2]. This is because Clouser and Gert, hoping to find in principlism a theory – or in other words, a doctrine endowed with unity and a systematic connection between rules, a clear model of justification and a practical decision making process – began to criticize the work from 1990 onwards, or in other words, between the publication of the 3rd and 4th edition of the study [13].

In the 4th edition, B&C make use of a quote by the philosopher Annette Baier, in which she reveals skepticism about the requirements of the theory advocated by Gert and Clouser advocate (great unity and a systematic connection between rules, a clear model of justification and a practical decision making process) [2]. From the 5th edition, the authors continued to mention this reference, although they exclude the name of the author, replacing it instead with "other philosophers" [21]. This quote, as well as the inclusion of the generic "other philosophers" where before there was a specific reference, shows the determination of B&C to show that they are not alone, or even little supported, in their defense of the exclusion of a theoretical body of moral justification.

In this context, in the 5th edition, B&C themselves referred to principlism as a moral philosophy, not as a theory [21]. However, it is not only their own work which they refer to in these terms, but also

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the theories of Frankena and Ross, perhaps as a way of removing the concept of theory and at the same time placing their work, which is not a theory, at the same level as two of the most renowned names in philosophy.

Continuing with their attempts to prove that a theory is not something dispensable, in the same 5th edition B&C include the statement that many authors suggest that only a theory can resolve moral conflicts, adding that, in fact, no theory can move from doctrine to practice in a direct and incontrovertible manner, even among those who adopt the such a theory [21].

In a contradictory manner, in the 6th edition, B & C once again defend the theory of common morality according to the conception of Clouser and Gert, as well as its use as a valid theory. They also as resume their support for the possibility of the existence of a universalism in common morality, in the same manner they initially advocated - namely a universalism in which all share the same morality [22].

A curious fact is that Gert provides a review of the book on the back cover of the 6th edition, in which he recognizes that B&C's work, more than any other, has helped to define the scope of biomedical ethics, as well as the edition in question surpassing the previous five in quality [22]. However, Gert provides a caveat, saying that he still has some misgivings about the idea of the "theory of principlism ", while stating that he has nothing but admiration for the thorough and comprehensive discussion of the moral problems which emerge from it. He concludes by stating his intention to make use of the 6th edition, as he did the previous editions, as one of the most key texts in his Philosophy of Medicine course.

By the 7th edition, meanwhile, Gert's citation on the back cover of the book has changed. Now, the author recognizes the importance of the 6th edition, but points out that B & C have reacted to the criticism they have received, including from Gert himself, and have altered their work accordingly. He ends once again by saying that he is not yet fully convinced of the idea of a "theory of principlism" while stressing his admiration for the work [1].

In the last two editions, B&C clarify that they accept moral pluralism (which is for them synonymous with relativism, another misconception) in private morals, but reject a historical moral pluralism in common morality, as common morality does not concern itself with persons or cultures, both of which it transcends [1,22]. In the 7th edition, B&C try to explain this again, now stating that in addition to having never appropriated the theory of common morality, they would never try to use its four principles as the essence of their argument [1].

The authors state that in order to formulate their principles of biomedical ethics, they resorted to common morality, even though they recognize that the rules of the same go beyond the principles on which they focused when conceiving principlism [1,30]. Only in the 5th edition have they admitted this, because, as they describe it, theories merely try to seize the moral point of view, with morality becoming the anchor of the theory, and not vice versa [21]. They even say that if an ethical theory rejects any of the four principles advocated in their work, they would have reason to doubt the theory, not the principles [21]. Thus, they demonstrate that they rely more on principles than on theory, perhaps because principlism itself cannot be a theory…

However, it is not only because of the accusation of the lack of a theory of principlism that Clouser and Gert are criticized by B&C. Other criticisms – included in the article "The Critique of Principlism" in 1990 - are included in the 4th edition. These include that principlism is no more than a "mantra of principles", suggesting there has been little reflection over the concept; that the principles are little more than checklists for important values, without substantial moral content or the ability to serve as a guide to action; and that its principles are *prima facie* and their justification ineffective in determining a decision making process [13]. Moreover, B&C highlight the criticism of Closer and Gert, also present in the article mentioned, over the lack of a clear procedure in principlism for resolving conflicts between principles. The authors rebut these arguments in the same 4th edition, arguing *a priori* that these are not, *in fact*, solvable issues and that no system of action guides could reasonably anticipate a complete list of conflicts [2]. In their view, it represents a virtue of principlism that it requires specification, or in other words, complementation, whereas it is a defect of the theory of Clouser and Gert to try and escape this, by drawing on rules [2,30].

It is certain that B&C, despite the alterations made to their work, cannot clearly explain what the methodology would be for applying the principles. Beauchamp, in an article published individually in 2014 [30], when trying to counteract the criticism of Kukla on the subject [28], again exhibits the brittleness of principlism, as he fails to present a method, but merely provides examples of situations in which the theory may be applied, such as in relationships of trust and in animal laboratory research [30].

In the 7th edition, B&C added the statement that no available ethical theories eliminate the importance of specification, balancing and reflective equilibrium (all these are types of supplementary principles) as aids to ethical practice [1].

In the 6th edition the authors rejected, the method of "working down", or in other words the application of theories or principles to specific cases [22], proposing, in the 7th edition in particular, the use of a "broad" reflective equilibrium [1]. This method, created by Rawls, consists of a set of moral judgments, moral principles and background theories to be "balanced", or in other words, they must be weighed against each other in the search for a balanced moral solution [24,31,32]. In principlism, this works as a way to control bias and the lack of objectivity in the choice of the judgements considered, using information about what is widely, or preferably universally, agreed to be correct [22].

For Strong, however, even this method does not serve the requirements of principlism. Taking a set of particular moral considerations, and then seeking the set of principles that best fit (which would be done to find the so-called "balanced solution"), does not mean that the method has been developed within (and for) principlism itself [24]. Reading between the lines, when B&C assume for themselves this part of the theory of justice of Rawls, not only do they rebut criticism of the lack of a proper theory of principlism but they also defend the criticism of the lack of a clear procedure for dealing with conflicts between principles. As such, the approach taken is similar to that adopted in relation to the theory of common morality of Clouser and Gert [31,32].

Final considerations

The 4th edition of "Principles of Biomedical Ethics" introduced the issue of common morality and its theory; on the other hand, it also began the construction of the idea of the disposability of the theory of principlism, describing it merely as a "moral philosophy." In this edition, the initial concept of common morality was a compilation of "*socially approved*" human conduct; while, in the 5th edition, it become a set of standards shared by "*morally serious people*", and in the 6th and 7th editions, a set of standards shared by all "*morally committed people* ".

Here B&C aimed to reduce the scope and reach of common morality, making it easy to justify the alleged universality of principlism, as it now applied only to predetermined groups. Thus, they abandoned the defense of a universalism in which all individuals have the same common morality (which could not be sustained) for the defense of another universalism in which all possess a common morality, even if each has his or her own, individual morality.

To avoid criticism, in the 5th edition the authors acknowledged that they would no longer defend the existence of a single common morality, nor of its theory, and even claimed to present their own version of common morality theory. In the 6th and 7th edition, however, B&C abandoned this position, defending instead their position in the 4th edition: the existence of a universal common morality and the applicability of the theory of common morality of Clouser and Gert.

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Participation of the authors
Volnei Garrafa oriented the first author, guiding the conception and design of the study as well as the preparation and review of the article. Leticia Erig Osório de Azambuja undertook the research and prepared the article, which is part of her doctoral thesis defended under the orientation of the author cited above.

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