Reflections on human embryo research: the debate in Portuguese ethics organizations

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Abstract

This article analyzes the arguments used by Portuguese ethics organizations on to the regulation of human embryo research. Documents produced between 2006 and 2010 were collected and, based on thematic content analysis, the discursive strategies were studied from a semantic approach to data. The debate focused the status of abstract embryos (human being/person or biological artifact/laboratory neostructure) and the criteria that should guide best practices and balance expectations and risks on embryo research, in which heterogeneous arguments coexist based on principialist, secular and interventional bioethics. The perspectives of those who must decide the fate of real embryos should be incorporated into the discussion.

Keywords: human embryo research; research ethics; social responsibility; Portugal.

Until 2006, the year in which a law regulating medically assisted reproduction in Portugal was enacted, namely Law No. 32 of July 26, 2006 (Curado, 2008, p.257-271), there was no specific regulation in Portugal on human embryo research. Since then, cryopreserved embryos may be used for scientific research, though the production of embryos in vitro may only occur as part of infertility treatments or to prevent the transmission of serious disease, being prohibited their deliberate creation for research purposes. Experiments using these embryos may only be authorized by the Conselho Nacional de Procriação Medicamente Assistida (National Council of Medically Assisted Reproduction)[1] if they result in present or future benefits for humanity. These principles reflect the latest international trends in regulation of embryonic stem cell research, particularly on the following aspects: authorization of research projects using cryopreserved embryos remaining in fertility centers; banning of the sale of embryos and their production solely for research; requirement of evaluation of human embryo research projects prior to implementation by specific organizations, performed by regulatory authorities and ethics committees; and the need to obtain informed consent from the woman and the man that their embryos can be used in scientific studies (Diniz, Avelino, 2009). Several issues are involved in regulating the conditions under which human embryo research can be performed and their applications, being the objective of this paper to analyze the arguments used by Portuguese ethics organizations in this domain.

In October 2011, the Court of Justice of the European Union banned the registration of patents resulting from research on embryonic stem cells obtained from human embryos in the blastocyst stage, justifying such decision with two main arguments: the dignity of human beings is affected in this process; the granting of patents implies, in principle, the possibility of industrial and commercial exploitation. However, it admitted the possibility of patentability if the research results in therapeutic or diagnostic applications useful to embryos, such as the correction of malformations. This decision was commented on in the principal Portuguese newspapers, based mainly on the opinions of the presidents of national ethics organizations, according to whom the resolution would prevent the search for therapeutic solutions for many patients and undermine the public good, contributing to halting the progress of biomedical research and limiting competitiveness within Europe by promoting a ‘brain drain’ to the United States and Asian countries (Borja-Santos, 2011; Tribunal..., 2011).

Several patient organizations and public figures such as actor Michael J. Fox (Parkinson’s sufferer), actor Christopher Reeve (quadriplegic after falling from a horse) or former U.S. first lady Nancy Reagan (supporter of research for the cause of Alzheimer’s disease, which her husband, Ronald Reagan, suffered from), publicly declared their support for research using embryonic stem cells (Santa-Maria, 2007, p.276). Patient organizations and medical and scientific communities are the strongest supporters of human embryo research, engaging in a variety of strategies to show its benefits, such as forums, mobilizing activists and communicating to the public (Downey, Geransar, 2008, p.76). Such militancy can be perceived as an illustration of what Moratalla (2005) called a lobby for embryonic stem cells, which promotes a double imperative in order to reduce human suffering – a moral imperative (Holm, 2002, p.506) and a research imperative (Callahan, 2003). In line with this view, the movements supporting human embryo research are creating new models of ‘collective consciousness' (Durkheim, 1912), based on optimistic visions of medicine and technology, and generating new patterns of solidarity (Prainsack, Buyx, 2011).

The expectations of medicine are nowadays based on values such as the promotion of individual welfare and the common good (Chapman, Frankel, Garfinkel, 1999) and revolve around imagined promising futures (Borup et al., 2006), and around the images of what humankind want the world to be (Nunes, 2001). Within this framework, solidary expectations have emerged, that is the expectations people have of the diagnosis, treatment, prognosis and prevention of diseases affecting others. In the biomedical mode of reproduction[2], these expectations are focused on stem cells and human embryos as elements constituting the foundation of a new chain of values that connects the present and future of the biology (Thompson, 2005).

According to McKay (2000) interest in human embryonic stem cells is due to two main reasons: the fact that they can be used to investigate specific features of human embryonic development; and because they generate types of somatic cells (non-reproductive cells in the human body) whose study allows us to obtain knowledge about the cell replacement process. From this perspective, human embryonic stem cells embody potential and opportunities that contribute to converting knowledge into hope. According to Mieth (2000, p.4) the term stem cell acts as a kind of magical password that will allow access to a world in which clinicians will be able to definitively cure all diseases. Burns (2009) also argues that stem cells represent – for the natural science community – a new superhero, promising salvation, since they not only propose to eliminate disease (like antibiotics), but also (and moreover) to regenerate.

Nightingale and Martin (2004) show how public expectations of the future results of human embryo research tend to be overestimated, and can influence public investment decisions and changes in the hierarchy of priorities in scientific research, resulting in the neglect of existing knowledge about disease prevention. This view is shared by Brown (2007, p.586), who highlights the fact that one can forget the promises of research in other areas of medicine and that the potential of alternative sources of stem cells may not be exploited properly, resulting in social and financial costs.

The growing importance of embryos and embryonic stem cells in the dissemination and implementation of scientific and technological innovations in healthcare raises other additional issues, among which the most prominent are: the social and moral acceptability of human embryo research (Perry, 2000; Critchley, 2008; Downey, Geransar, 2008; Langstrup, 2011; Frias, 2012); the instrumentalization and commercialization of human tissues and human embryonic stem cells (Resnik, 2002; Serrão, 2003; Nogueira-Filho, 2009); the use of women and men as sources of embryos (Haimes, Luce, 2006; Scully, Rehmann-Sutter, 2006); intellectual property and patenting of research using embryonic stem cells (Porter et al., 2006; Taymor, Scott, Greely, 2006); scientific tourism and possible jurisdiction competition involving the movement of scientists, embryos and funding to regions of the world with less restrictive jurisdictions (Zarzeczny, Caulfield, 2009, p.100); differential access to therapies resulting from research on embryonic stem cells (Zarzeczny, Caulfield, 2009, p.100); regulation of the information conveyed by the media and the lack of public involvement in decision-making regarding funding for embryonic stem cell research (Árnason et al., 2007; Vicsek, 2011).

The arguments used in the debate on issues related to the permissibility of human embryo research and possible restrictions are taken into account in policy-making processes (Frias, 2012, p.14). In the regulation of scientific progress in the fields of biology, medicine or health and life sciences, democracy has demanded that the legislative, judicial and executive branches be assisted by independent national agencies in the analysis and evaluation of ethical issues raised by these developments, with a view to determining what position the country and/or humanity should take. In Portugal, the national entities that produce studies and advise on ethical issues related to human embryos research are the Conselho Nacional de Procriação Medicamente Assistida (CNPMA, National Council of Medically Assisted Reproduction), the Conselho Nacional de Ética para as Ciências da Vida (CNECV, National Ethics Council for the Life Sciences) and the Associação Portuguesa de Bioética (APB, Portuguese Bioethics Association).[3] The objective of this article is to reflect on the regulation of human embryo research based on the mapping and analysis of the arguments used in this field in documents published by these organizations between 2006 and 2010.

Methods

The documents produced on human embryo research by Portuguese ethics organizations were identified through a search of all the reports available in the websites of CNPMA, CNECV and APB, using the keyword embryo or its plural. Documents published between January 2006 (the year the first law regulating medically assisted reproduction in Portugal, allowing human embryos research, was enacted) and December 2010 (the year the master's thesis on which this article is based was begun) were scrutinized. All documents discussing issues related to human embryo research were included, while those that just described requirements and operating parameters for fertility centers and decisions on applications for licenses and authorization were excluded.

Twelve documents were selected for analysis, six published by CNPMA (27 fev. 2009, 16 out. 2009, 30 abr. 2010, 21 maio 2010, 16 jul. 2010, 12 nov. 2010), five published by CNECV (abr. 2006, abr. 2007, jul. 2007, dez. 2007, fev. 2008) and one published by APB (5 maio 2006). In line with their competencies, CNECV and APB issued opinions, while CNPMA published four decisions and two recommendations. Thematic content analysis was conducted by two independent researchers, and the following themes emerged: classification of the status of the human embryo; and criteria that should guide good practices in human embryo research. The discursive strategies were studied from a semantic approach to data, and findings are reported below by including selected relevant quotations for illustrating the main arguments used by the Portuguese ethics organizations with respect to the regulation of human embryo research.

The status of the human embryo

One of the topics under discussion within the documents produced by Portuguese ethics organizations with respect to the regulation of human embryo research relates to the status of the embryo (Table 1). Overall, the views of the users of assisted reproductive techniques on the affective and moral value of cryopreserved embryos (Haimes et al., 2008; Silva, Machado, 2009), as well as approaches that identify the embryo as a *tertium genius*, that is as neither a 'person'/'human being' nor a 'thing' (Raposo, 2009), were not discussed.

Table 1: Classification of the status of the human embryo

Laboratory artifact	• "If [the product of somatic cell nuclear transfer] is considered an embryo, it cannot be used because this would constitute a violation of its intrinsic dignity... if it is considered a laboratory artifact, it can be used in biomedical research"[4] (CNECV, abr. 2006, p.3).
Biological neostructure	• "Research in cell reprogramming ... may permit the continuation of ongoing research with stem cells without the production of any new biological structure likely to be identified as a human embryo" (CNECV, abr. 2006, p.4).
Human being	• "All 'human beings' deserve to exist and require respect for their life even if embryonic" (CNECV, abr. 2007, p.1, statement by Michel Renaud). • "In this case [human cloning], the same principle prohibiting destructive research on embryos will be applied ... because experimentation on humans unable to consent is permissible only for their direct therapeutic benefit" (CNECV, abr. 2006, p.4, statement by Ramos Ascensão). • "Any legal document to be enacted should define the juridical status of the human embryo... any legislative solution on the matter will have to include a coherent, complete set of rules that thoroughly ensure human embryos the protection that the legislature deems necessary" (APB, 5 maio 2006, p.4).
Person	• "There is no single concept of a person in Portuguese society, but rather multiple concepts, some valuing belonging to the human species, others the ability to feel pain, yet others rationality... depending on the status of that person assumed at the philosophical level, different legal solutions for the status of the embryo in vitro will be proposed. ... Either you choose to assign personhood to the embryo and will not, as a rule, allow it to be lawfully destroyed, or you choose not to give it this status and its destruction may be considered perfectly lawful" (APB, 5 maio 2006, p.8-9).

Source: Compiled by the authors

In some documents, the embryo was framed into biological or technical categories, translated into its naming as 'biological neostructure' or 'laboratory artifact,' respectively. In consonance with the genetic and developmental theory (Pussi, Pussi, 2005, p.69), the embryo was equated with human generative material or tissue (Johnson, 2006), identical to other cells in the human body at least in the early days of its existence (Leite, 1996, p.126), with its use in scientific research considered lawful. The non-attribution of a moral status to embryos was sustained in arguments from the personalistic theory and the theory of interests, whereby embryos lack the physiological basis for interests, self-awareness and rationality (Frias, 2012). Absent from the debate were some of the arguments used by the gradualist approach to support the possibility of research using human embryos (Ormerod, 2003; Pussi, Pussi, 2005), in particular the identification and explanation of biological milestones to define the moment at which the embryo acquires the status of a person, such as, for example, implantation in the uterus (fifth/sixth day); formation of the primitive streak[5] (14th day), closing of the neural tube and formation of the beginnings of the brain (around the 28th day); or the moment of birth.

Other documents referred to the embryo in vitro as a 'human being' or 'person,' with dignity and the right to protection and respect, sometimes citing the need for justifications for their use in research (e.g., the existence of direct therapeutic benefits), sometimes stating that embryo research is unacceptable because it destroys them. In the first case, the foundation used was inspired by arguments derived from the utilitarians and/or consequentialists, which advocate the use of human embryos for research purposes for higher ends, such as the treatment of severe diseases (Serrão, 2003, p.42), and thus it can be considered morally acceptable if it benefits the majority of people or a large number of patients[6] (Gomes, 2007, p.79). The biolegitimacy (Caselas, 2009, p.88) underlying this approach is often used by patients' associations to sustain support for human embryo research (Abellán, 2004; Cortina Orts, 2004; Cesarino, 2007) – the sufferer invokes recognition of her/his suffering in a society increasingly focused on quantifying health gains. The justification for the unacceptability of human embryo research is based on the conceptionist theory, in the sense that embryos are classified as human beings that have a unique genetic heritage and whose human life begins at fertilization (Gallian, 2005; Pussi, Pussi, 2005). Therefore, any action that disrupts cell division and prevents embryo development is considered an attack against human life and dignity (Diniz, Avelino, 2009).

Arguments like individuality and future value, of belonging to the human species, that we all started as an embryo, and the potential of becoming a person were deconstructed by Frias (2012), and refuted as reasons that could sustain a ban on the use of human embryos in scientific research. The author concluded that the acquisition of the right to life begins sometime after 14 days, since it is only then that cell differentiation allows us to affirm that there is an individual; however, he showed that the symbolic and moral value of embryos legitimizes the existence of restrictions on their use in scientific research and requires that such use be properly justified. This perspective aligns with some of the general principles enshrined in the Convention on Human Rights and Biomedicine (Curado, 2008, p.53-95), since it attributes to human embryos a special status that justifies, among other things, the impossibility of their creation for the purpose of scientific research and the establishment of criteria and guidelines on social responsibility and ethics in research.

Criteria for regulating research on human embryos

The debate on the criteria to use to regulate human embryo research was an 'instructive story' (Nunes, 2001), as it combined genetic, biological, cultural, social and economic elements in arguments and guidelines whose objective was to draw attention to expectations and risks, and to ensure good practices in this scientific field. In the limbo between trust and fear (Mulkay, 1993), Portuguese ethics organizations tried to predict and control the proliferation of undesirable effects (Andrews, Elster, 2000), namely the domino effect or 'slippery slope' and the intentional creation of embryos for research purposes, while warning of the lack of scientific and social consensus regarding the use of embryonic stem cells and the importance of carefully prioritizing resource allocation in health care (Table 2).

The "slippery slope" argument was based on the "ethically dubious" speculative purposes allegation; indeed, these will mainly depend on the social uses of human embryo research and not on biotechnology itself, and it therefore appears to be a "fallacy" (Frias, 2012, p.161). But the argument of intentionality was welcomed by the Portuguese legal system, as it prohibits the deliberate creation of human embryos for research purposes. The demand for broader consensus and social justice in healthcare resulted in the proposal of alternative methods for obtaining stem cells, such as the "less expensive harvesting" of non-embryonic stem cells, and the restriction of accessibility to assisted reproductive techniques in the public sector "only within the existing limits of human, material and technological resources." Attempts to obtain embryonic stem cells without destroying the embryo in vitro illustrate one of the current trends in consultation between the scientific and ethics agenda (Carvalho, 2010, p.47). They include the following possibilities: (1) parthenogenesis (Hao et al., 2009), or the stimulation of an oocyte so that it develops as if it had been fertilized; (2) the use of defective embryos from which 'normal' stem cells can be obtained (Alikani, Munné, 2005); (3) obtaining embryonic stem cells after embryonic death (which seems to occur after prolonged interruption of cell division); (4) the blastocyst transfer method, which leads to embryonic biopsy in the blastocyst stage to obtain pluripotent stem cells (Taei et al., 2010); and (5) the genetic reprogramming of adult stem cells so that they acquire characteristics of embryonic stem cells, resulting in what is known as induced pluripotent stem cells (Carvalho, 2010, p.49).

Table 2: Expectations and risks associated with human embryo research

'Slippery slope'	• "Allowing selecting of embryos for the benefit of others creates... a precedent that I consider irreversible and easily portable to different situations with ethically dubious purposes" (CNECV, abr. 2007, p.2 of Peter Fevereiro's statement).
Prioritization	• "Non-embryonic stem cells... in addition to not offering major ethical problems, are the only type for which therapeutic applications already exist, and their harvesting is less expensive, so here too we face the issue of justice in the allocation of resources for health" (CNECV, abr. 2006, p.4 of Ramos Ascensão's statement). • "There are other, clearly more important diagnosis and treatment modes, including cancer treatment or mandatory vaccination programs. Thus, we are of the opinion that these techniques should be included in the provision of public health only within the existing limits of human, material and technological resources" (APB, 5 maio 2006, p.15). • "The ethical value of the embryo [is] clearly superior to that of a gamete" (CNPMA, 16 jul. 2010, p.1).
Intentionality	• "If we allow research using surplus, in vitro, thawed embryos which are neither implanted nor implantable... why would it not be legitimate to use clones produced via somatic-cell nuclear transfer for research? The only difference here may lie in the intent and purpose for which the embryos are created: while surplus embryos from in vitro fertilization or intracytoplasmic sperm injection are not, a priori, intentionally made for research purposes, in the case of somatic-cell nuclear transfer this is the case" (CNECV, abr. 2006, p.2 of Miguel Oliveira da Silva's statement). • "As long as cryopreserved embryos are available, it is not ethically acceptable to create new embryos" (CNPMA, 12 nov. 2010, p.1).
General consensus	• "There is still not a broad consensus in the scientific community and society in general on the use of embryonic stem cells in research or medical treatments" (CNECV, dez. 2007, p.5).

Source: Compiled by the authors

According to the documents analyzed in this study, social responsibility in human embryo research should still include a guarantee of high standards of quality and safety in technical and laboratory procedures and in the scientific and organizational requirements which were laid down in a set of ethical principles (Table 3). Firstly, the prevention against commercialization and instrumentalization of embryos. Such principles enshrined in the guidelines for donation of human biological material, emphasizing gratuitousness, altruism and solidarity. Secondly, taking into account the precautionary principle when assessing the best interests of the embryos and the uses that will result in the 'lesser evil,' in reference to the principles of proportionality and subsidiarity, particularly regarding the use of research methods deemed necessary for the intended purpose, as long as there are no more acceptable alternatives (such as the use of embryos in reproductive projects), or less invasive and harmful alternatives. Finally, the reference to the consent of the couples allowing their embryos to be used in scientific research projects approved by CNPMA stressed the importance of individual autonomy and respect for the privacy of those using assisted reproductive techniques, while taking into account the principle of justice and beneficence for improving and safeguarding health by suggesting that approval of research projects is dependent on the present or future benefits for humanity.

In sum, arguments based on principialism, on the one hand, and on consequentialism, on the other, co-existed in the reflections of Portuguese ethics organizations on the criteria to use in regulating human embryo research, stimulating, according to Carvalho (2010, p.46), a search for both scientific and morally progressive solutions.

Table 3: Ethical principles in the regulation of human embryo research

Prevention against commercialization	• "[One of the] ethical problems ... inherent in the use of human biological material... [is] that it must not be sold" (CNECV, abr. 2006, p.3). • "The CNPMA ... recommends: not paying any compensation in cases of embryo donation" (CNPMA, 21 maio 2010, p.4).
Prevention against instrumentalization	• "The intentional production of embryos ... in order to select them to treat an illness in a family member corresponds to the instrumentalization of embryonic human life for the sake of the survival of another human, more-developed life" (CNECV, abr. 2007, p.2 of Maria do Céu Patrão Neves' statement). • "Can this selection [of embryos for immunological compatibility with a sick sibling] be considered instrumentalization of the unborn child ...? It seems not, since the fact of its birth being 'helpful' to the health and life of his or her sibling does not mean that the child is not also desired for itself" (APB, 5 maio 2006, p.10).
Lesser evil	• "And it is a lesser evil ... that [the embryo] is part of a reproductive project rather than being annihilated" (CNECV, abr. 2007, p.3 of José de Oliveira Ascensão's statement). • "In cases in which ... embryos can be thawed and disposed of, the Council sees no reason why these embryos cannot, during the elimination process, be used in assisted reproductive techniques and procedures" (CNPMA, 30 abr. 2010, p.1).
The embryo's best interest	• "The best interest of the embryo is ensured ... [by providing] the possibility of subsequent uterine implantation. Other procedures do not ensure its best interests: for example, allowing its use for often destructive research purposes" (APB, 5 maio 2006, p.14).
Precaution	• "In ... the event of a lack of scientific and philosophical unanimity ... about the nature of the product of somatic cell nuclear transfer, one must apply the ethical precautionary principle" (CNECV, abr. 2006, p.3). • "I disagree in particular with the use of the ethical principle of precaution to try to discourage experimentation, in this case somatic cell nuclear transfer" (CNECV, abr. 2006, p.2 of Pedro Fevereiro's statement).
Consent	• "Only surplus cryopreserved embryos may be used for scientific research, those for which there is no parental plan, with the prior, express, informed consent of the couples for whom the embryos were intended and when such use is part of a research project approved by the Council" (CNPMA, 30 abr. 2010, p.1).

Source: Compiled by the authors

Final considerations

This study evidenced the heterogeneous positions and the ambiguity in the arguments used in the debate on the regulation of human embryo research sponsored by Portuguese ethics organizations. The management of the boundaries between expectations and limitations, benefits and risks or hopes and threats related to human embryo research uncovered struggle and tension reflected in the ethical and argumentative debate. Such a variety of positions was observed both between organizations and between elements within a single organization, a phenomenon especially noticeable in the number of individual statements included in the opinions examined in this study. However, the exclusive participation of experts in specific fields of knowledge, mostly men and academics from the health sciences, biological sciences and law, may have restricted the possible virtues of a pluralistic debate on the issue. In fact, the topics under discussion were similar, and the ethical arguments were restricted to four major trends: (1) the classification of the status of the embryo and its impact on the level of legitimacy and acceptability of human embryo research; (2) avoidance of potential instrumentalization of embryos, especially when they can be created for specific purposes, such as for scientific research; (3) warning of the importance of achieving consensual decisions, both in scientific and social terms, on the use of embryos in scientific research, in a context in which the relative scarcity of empirical evidence of the results promised by embryonic stem cell research should be combined with investment in the study and application of medical solutions using alternative sources, resources and technologies; (4) and the need to safeguard ethical principles in the regulation of human embryo research.

The question of when individual life begins (Frias, 2012) underlies the debate about the status of the human embryo, and the answer depended not only on ontological issues, but also (and especially) on socio-cultural and utilitarian norms (Ruiz-Canela , 2002, p.23), with implications in the regulation of human embryo research (Mulkay, 1993; King, 1997). The existence of different classifications for cryopreserved embryos in the documents analyzed in this study – biological neostructure, laboratory artifact, human, person – reinforces the argument that embryos are not universal, fixed biological entities that share the same individual rights with each of us. Its classification can be reconfigured, with the embryo acquiring statuses (simultaneously moral and social) and different meanings (personal, family, legal and cultural) according to the historical and geographical contexts and social position of those who classified them (Haimes et al., 2008).

The possibility of using embryos in scientific research makes the definition of their status complex, since ‘new’ elements were introduced into the discussion. For example, new uses unrelated to reproduction and protagonists who see the human embryo as a particularly precious resource that symbolizes confidence in the ability of science, technology and medicine to eliminate disease and human suffering, as long as their use in research is governed by ethical principles and accompanied by reflections on the expected results, reconciling principialist bioethics (Schramm, Palácios, Rego, 2008) with the secular and interventional bioethics (Garrafa, 2005, p.126). The belief in the therapeutic potential of embryonic stem cells has generated anchors of reservation and hope in the regeneration and healthy prolongation of life (Mauron, Jaconi, 2007, p.332). They have supported the view that human embryo research is a therapeutic imperative of collective mobilization (Mieth, 2000), since it represents a qualitative spiral in health research by increasing knowledge about the causes of diseases, enabling the realization of more specific diagnoses and aiding the development of more effective therapies (Corrêa, 2002, p.278).

In the debate sponsored by Portuguese ethical organizations it is important to introduce reflections which go beyond discussing the moral status of abstract embryos in a "no man's land" (Novaes, Salem, 1995, p.88) and the proposals for regulating human embryo research based on ethical principles or on their consequences. It is urgent that this discussion include the thoughts and experiences of those who must decide what to do with real embryos, together with the views of experts and politicians, contributing to the democratization of governance and regulatory processes, especially in a context in which the expectations of these social actors with respect to the results expected of human embryo research play an important role in the development, financing and support of scientific research projects in the health sciences (Alves, Silva, 2012).

Taking into account that the discussion on human embryo research and embryonic stem cells has gone beyond the boundaries of ethics organizations and academia (Luna, 2007, p.588) to increased media visibility, with repercussions on its political and legal regulation, one of the limitations of this study is related to the fact that the analysis focuses solely on the reflections published by Portuguese ethics organizations, excluding debates occurring in the media. However, despite science and health news tending to focus on what is new, unprecedented and extraordinary, especially if the findings promise to save or prolong lives (Bertolli Filho, 2007), the media debate on human embryo research was scarce and led, mainly, by specialists involved with the ethics organizations included in this study (Tribunal..., 2011).

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NOTES

[1] The Conselho Nacional de Procriação Medicamente Assistida is composed of nine members (five individuals appointed by the National Assembly and four nominated by the Ministry of Health) and its function is to supervise, monitor and evaluate research and practices in assisted reproductive technologies.

[2] Thompson (2005) uses the concept of mode of reproduction in association with the Marxist notion of mode of production, referring to the articulation between productive forces and production relationships capable of reproduction, constituting the economic and social infrastructure. The author aims to show how biomedicine and biotechnology are a fundamental part of the global economy.

[3] In 2010, these organizations consisted of 33 permanent members, distributed as follows: 18 in CNECV, ten in CNPMA, and five in APB. With a majority of men (21 men and 12 women), the members are professionals and/or researchers in medicine (16) and law (five), philosophy (three), psychology (two), pharmaceutical sciences (two), sociology (one), biology (one), microbiology (one), physics (one) and business management

(one). The representatives from the health sciences and biological sciences constituted 54.5% of total members (18 individuals).

[4] In this and other citations of text from Portuguese, a free translations has been provided.

[5] This criterion was used by the Warnock Committee, responsible for the production of the first official UK report on human embryo research in 1984, which proposed the concept of pre-embryo to represent the set of human cells up to 14 days of development, paving the way for the country to be the first to authorize embryonic stem cell research and therapeutic cloning in 2001 (Diniz, Avelino, 2009, p.544).

[6] The results obtained from the European biotechnology barometer show that most citizens of the European Union support the development of biotechnologies able to treat human diseases (Fagot-Largeault, 2004, p.234-235). This fact has been used to strengthen the legitimacy and social and ethical recognition of human embryo research in various countries, such as the UK, Sweden and Belgium (Diniz, Avelino, 2009, p.543).

REFERENCES

ABELLÁN, Eduardo Ruiz.
Entre el cientificismo y el mito de la 'eterna juventud'. *Cuadernos de Bioética*, Madrid, v.15, n.54, p.179-192. 2004.

ALIKANI, Mina; MUNNÉ, Santiago.
Nonviable human pre-implantation embryos as a source of stem cells for research and potential therapy. *Stem Cell Reviews and Reports*, s.l., v.1, n.4, p.337-343. 2005.

ALVES, Bruno Rodrigues; SILVA, Susana.
Questões científicas nos projetos de investigação em embriões realizados em Portugal. *Configurações*, Braga, n.8, p.57-71. 2012.

ANDREWS, Lori; ELSTER, Nanette.
Regulating reproductive technologies. *The Journal of Legal Medicine*, Chicago, n.21, p.35-65. 2000.

ÁRNASON, Vilhjálmur et al.
Debate and communication. In: Nordic Comittee on Bioethics. *Stem cell research in the Nordic countries*: science, ethics, public debate and law. Oslo: NordForsk. p.41-45. 2007. Disponível em: http://www.nordforsk.org/en/publikasjoner/policy-brief-2 Acesso em: 12 mar. 2012. 2007.

APB
Associação Portuguesa de Bioética. Parecer n.P/04/APB/06 sobre diagnóstico genético pré-implantação e intervenções na linha germinativa. 5 maio 2006. Disponível em: http://www.sbem-fmup.org/fotos/gca/12802559281147874067diag_pre_implantacao_parecer_04.pdf. Acesso em: 12 mar. 2012. 5 maio 2006.

BERTOLLI FILHO, Claudio.
Mídia e conhecimento público: as notícias sobre as células tronco. *Estudos de Sociologia*, Araraquara, v.12, n.22, p.63-90. 2007.

BORJA-SANTOS, Romana.
UE proíbe patentes derivadas de pesquisas com células estaminais embrionárias. *Público*, Lisboa, 19 out. 2011. Disponível em: http://publico.newspaperdirect.com/epaper/viewer.aspx. Acesso em 1 ago. 2013. 19 out. 2011.

BORUP, Mads et al.
The sociology of expectations in science and technology. *Technology Analysis and Strategic Management*, Manchester, v.18, n.3-4, p.285-298. 2006.

BROWN, Mark T.
The potential of the human embryo. *Journal of Medicine and Philosophy*, Oxford, v.32, n.6, p. 585-618. 2007

BURNS, Lawrence.
"You are our only hope": trading metaphorical "magic bullets" for stem cell "superheroes". *Theoretical Medicine and Bioethics*, Dordrecht, v.30, n.6, p. 427-442. 2009.

CALLAHAN, Daniel.
What price better health? Hazards of the research imperative. Berkeley: University of California Press. 2003.

CARVALHO, Ana Sofia.
Boa ética e boa ciência: o percurso da investigação em células estaminais. *Revista Interdisciplinar sobre o Desenvolvimento Humano*, Vila Nova de Gaia, n.1, p.45-51. 2010.

CASELAS, José.
Figuras contemporâneas do biopoder. *Saberes*, Natal, v.1, n.2, p. 81-92. 2009.

CESARINO, Letícia da Nóbrega.
Nas fronteiras do "humano": os debates britânico e brasileiro sobre a pesquisa com embriões. *Mana*, Rio de Janeiro, v.13, n.2, p. 347-380. 2007.

CHAPMAN, Audrey R., FRANKEL, Mark S., GARFINKEL, Michele S.
Stem cell research and applications: monitoring the frontiers of biomedical research. Disponível em http://shr.aaas.org/projects/bioethics/reports/stem.pdf. Acesso em: 12 mar. 2012. 1999.

CNECV
Conselho Nacional de Ética para as Ciências da Vida. Parecer n.55/CNECV/08 sobre a proposta de lei relativa ao regime jurídico da qualidade e segurança relativa à dádiva, colheita, análise, processamento, preservação, armazenamento, distribuição e aplicação de tecidos e células de origem humana. Disponível em: http://www.cnecv.pt/admin/files/data/docs/1273053986_P055TecidosCelulas.pdfAcesso em: 12 mar. 2012. fev. 2008.

CNECV
Conselho Nacional de Ética para as Ciências da Vida. Parecer n.54/CNECV/07 sobre o regime jurídico da qualidade e segurança relativa à dádiva, colheita, análise, processamento, preservação, armazenamento, distribuição e aplicação de tecidos e células de origem humana. Disponível em: http://www.cnecv.pt/admin/files/data/docs/1273054047_P054_tecidoscelulasorigemhumana.pdf. Acesso em: 12 mar. 2012. dez. 2007.

CNECV
Conselho Nacional de Ética para as Ciências da Vida. Parecer n.53/CNECV/07 sobre os projectos de lei n.126/X (Estabelece os princípios da investigação científica em células estaminais e a utilização de embriões), e n. 376/X (Estabelece o regime jurídico de utilização de células estaminais, para efeitos de investigação e respectivas aplicações terapêuticas). Disponível em: http://www.cnecv.pt/admin/files/data/docs/1273054065_53CNECV2007_celulas_estaminais.pdf. Acesso em: 12 mar. 2012. jul. 2007.

CNECV
Conselho Nacional de Ética para as Ciências da Vida. Parecer n.51/CNECV/07 sobre diagnóstico genético pré-implantação. Disponível em: http://www.cnecv.pt/admin/files/data/docs/1273054175_P051_ParecerDGPI.pdf. Acesso em: 12 mar. 2012. abr. 2007.

CNECV
Conselho Nacional de Ética para as Ciências da Vida. Parecer n.48/CNECV/06 sobre clonagem humana. Disponível em: http://www.cnecv.pt/admin/files/data/docs/1273054340_P048_ParecerClonagemHumana.pdf. Acesso em: 12 mar. 2012. abr. 2006.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Recomendação para incluir a transferência de embriões criopreservados (TEC) na tabela de preços relativa aos actos praticados em PMA. Disponível em: http://www.cnpma.org.pt/Docs/PROFISSIONAIS_Recomendacao_TEC.pdf. Acesso em: 12 mar. 2012. 12 nov. 2010.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Deliberação n.4, de 16 de julho de 2010. Disponível em: http://www.cnpma.org.pt/Docs/PROFISSIONAIS_Deliberacao04_2010.pdf. Acesso em: 12 mar. 2012. 16 jul. 2010.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Recomendação sobre a atribuição aos dadores de células reprodutivas das compensações previstas no n.3 do art.22º da lei n.12/2009, de 26 de março. Disponível em: http://www.cnpma.org.pt/Docs/PROFISSIONAIS_Recomendacao_CompensacoesDadores.pdf. Acesso em: 12 mar. 2012. 21 maio 2010.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Deliberação n.3, de 30 de abril de 2010. Disponível em: http://www.cnpma.org.pt/Docs/PROFISSIONAIS_Deliberacao03-2010.pdf. Acesso em: 12 mar. 2012. 30 abr. 2010.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Deliberação n.4, de 16 de outubro de 2009. Disponível em http://www.cnpma.org.pt/cnpma_documentacao.aspx. Acesso em: 12 mar. 2012. 16 out. 2009.

CNPMA
Conselho Nacional de Procriação Medicamente Assistida. Deliberação n.3, de 27 de fevereiro de 2009. Disponível em: http://www.cnpma.org.pt/cnpma_documentacao.aspx. Acesso em: 12 mar. 2012. 27 fev. 2009.

CORRÊA, Marilena V.
O admirável projeto genoma humano. *Physis*, Rio de Janeiro, v.12, n.2, p.277-299. 2002.

CORTINA ORTS, Adela.
Principios éticos en la investigación sobre células troncales. *Monografias Humanitas*, Barcelona, v.4, p.71-82. 2004.

CRITCHLEY, Christine R.
Public opinion and trust in scientists: the role of the research context, and the perceived motivation of stem cell researchers. *Public Understanding of Science*, Bristol, v.17, n.3, p.309-327. 2008.

CURADO, Manuel.
Direito biomédico: colectânea de legislação e outros documentos. Lisboa: Quid Juris. 2008.

DINIZ, Debora; AVELINO, Daniel.
Cenário internacional da pesquisa em células-tronco embrionárias. *Revista de Saúde Pública*, São Paulo, v.43, n.3, p.541-547. 2009.

DOWNEY, Robin; GERANSAR, Rose.
Stem cell research, publics' and stakeholder views. *Health Law Review*, Edmonton, v.16, n.2, p.69-85. 2008.

DURKHEIM, Émile.
Les formes élémentaires de la vie religieuse. Paris: Alcan. 1912.

FAGOT-LARGEAULT, Anne.
Embriões, células-tronco e terapias celulares: questões filosóficas e antropológicas. *Estudos Avançados*, São Paulo, v.18, n.51, p.227-245. 2004.

FRIAS, Lincoln.
A ética do uso e da seleção de embriões. Florianópolis: EdUFSC. 2012.

GALLIAN, Dante Marcello Claramonte.
Por detrás do último ato da ciência-espetáculo: as células-tronco embrionárias. *Estudos Avançados*, São Paulo, v.19, n.55, p.253-260. 2005.

GARRAFA, Volnei.
Da bioética de princípios a uma bioética interventiva. *Revista Bioética*, Brasília, v.13, n.1, p.125-134. 2005.

GOMES, Delci.
Células-tronco embrionárias: implicações bioéticas e jurídicas. *Bioethikos*, São Paulo, v.1, n.2, p.78-87. 2007.

HAIMES, Erica; LUCE, Jacquelyne.
Studying potential donors' views on embryonic stem cell therapies and preimplantation genetic diagnosis. *Human Fertility*, Cambridge, v.9, n.2, p. 67-71. 2006.

HAIMES, Erica et al.
'So, what is an embryo?' A comparative study of the views of those asked to donate embryos for hESC research in the UK and Switzerland. *New Genetics and Society*, Basingstoke, v.27, n.2, p.113-126. 2008.

HAO, Jie et al.
Human parthenogenetic embryonic stem cells: one potential resource for cell therapy. *Science China Life Sciences*, Beijing, v.52, n.7, p.599-602. 2009.

HOLM, Soren.
Going to the roots of the stem cell controversy. *Bioethics*, Oxford, v.16, n.6, p.493-507. 2002.

JOHNSON, Martin H.
Escaping the tyranny of the embryo? A new approach to ART regulation based on UK and Australian experiences. *Human Reproduction*, Oxford, v.21, n.11, p.2756-2765. 2006.

KING, Patricia A.
Embryo research: the challenge for public policy. *Journal of Medicine and Philosophy*, Chicago, v.22, n.5, p.441-455. 1997.

LANGSTRUP, Henriette.
Interpellating patients as users: patient associations and the project-ness of stem cell research. *Science, Technology and Human Values*, New York, v.36, n.4, p.573-594. 2011.

LEITE, Eduardo de Oliveira.
O direito do embrião humano: mito ou realidade? *Revista da Faculdade de Direito da UFPR*, Curitiba, v.29, p.121-146. 1996.

LUNA, Naara.
Células-tronco: pesquisa básica em saúde, da ética à panaceia. *Interface*, Botucatu, v.11, n.23, p. 587-604. 2007.

MAURON, Alex; JACONI, Marisa E.
Stem cell science: current ethical and policy issues. *Clinical pharmacology and therapeutics*, Saint Louis, v.82, n.3, p.330-333. 2007.

MCKAY, Ron.
Stem cells: hype and hope. *Nature*, London, v.406, n.6794, p. 361-364. 2000.

MIETH, Dietmar.
Going to the roots of the stem cell debate: the ethical problems of using embryos for research. *EMBO Reports*, Oxford, v.1, n.1, p.4-6. 2000.

MORATALLA, Natalia López.
El lobby de las células embrionarias, telón de fondo del fraude de la clonación. *Cuadernos de Bioética*, Madrid, v.16, n.58, p.419-439. 2005.

MULKAY, Michael.
Rhetorics of hope and fear in the great embryo debate. *Social Studies of Science*, London, v.23, n.4, p.721-742. 1993.

NIGHTINGALE, Paul; MARTIN, Paul.
The myth of the biotech revolution. *Trends in Biotechnology*, Amsterdam, v.22, n.11, p.564-569. 2004.

NOGUEIRA-FILHO, Luiz Nódgi.
Estatuto ético do embrião humano. *Bioethikos*, São Paulo, v.3, n.2, p.225-234. 2009.

NOVAES, Simone; SALEM, Tania.
Recontextualizando o embrião. *Estudos Feministas*, Florianópolis, v.3, n.1, p.65-88. 1995.

NUNES, João Arriscado.
A síndrome do Parque Jurássico: história(s) edificante(s) da genética num mundo 'sem garantias'. *Revista Crítica de Ciências Sociais*, Coimbra, n.61, p.29-62. dez. 2001.

ORMEROD, Karen L.
Hope for a cure, or fear of a curse? Montreal: McGill University. 2003.

PERRY, Daniel.
Patients' voices: the powerful sound in the stem cell debate. *Science*, Washington, v.287, n.5457, 25 February, p.1423. 2000.

PORTER, Gerard et al.
The patentability of human embryonic stem cells in Europe. *Nature Biotechnology*, New York, v.24, n.6, p.653-655. 2006.

PRAINSACK, Barbara; BUYX, Alena.
Solidarity: reflections on an emerging concept in bioethics. London: Nuffield Council on Bioethics. 2011.

PUSSI, William Artur; PUSSI, Flávia Daniela.
Células tronco: o alfa e o ômega. *Arquivos do Conselho Regional de Medicina do Paraná*, Curitiba, v.22, n.86, p.57-75. 2005.

RAPOSO, Vera L.
Poder parental sobre os embriões excedentários. In: Silva, S.; Veloso, L. (Coord.). *Representações jurídicas das tecnologias reprodutivas*. Porto: Universidade do Porto Editorial. p.61-82. 2009.

RESNIK, David B.
The commercialization of human stem cells: ethical and policy issues. *Health Care Analysis*, Chichester, v.10, n.2, p.127-154. 2002.

RUIZ-CANELA, Miguel.
Embryonic stem cell research: the relevance of ethics in the progress of science. *Medical science monitor: international medical journal of experimental and clinical research*, Warsaw, v.8, n.5, p.SR21-26. 2002.

SANTA-MARIA, Philip.
Changing the direction of society through human enhancement and society's reactions. *Nebula*, s.l., v.4, n.2, p. 268-282. 2007.

SCHRAMM, Fermin Roland; PALÁCIOS, Marisa; REGO, Sergio.
O modelo bioético principialista para a análise da moralidade da pesquisa científica envolvendo seres humanos ainda é satisfatório? *Ciência e Saúde Coletiva*, Rio de Janeiro, v.13, n.2, p.361-370. 2008.

SCULLY, Jackie Leach; REHMANN-SUTTER, Christoph.
Creating donors: the 2005 Swiss law on donation of 'spare' embryos to hESC research. *Journal of Bioethical Inquiry*, Dunedin, v.3, n.1-2, p.81-93. 2006.

SERRÃO, Daniel.
Livro branco sobre o uso de embriões humanos em investigação científica. Lisboa: Ministério da Ciência e do Ensino Superior. 2003.

SILVA, Susana; MACHADO, Helena.
A compreensão jurídica, médica e 'leiga' do embrião em Portugal: um alinhamento com a biologia? *Interface: Comunicação, Saúde, Educação*, Botucatu, v.13, n.30, p.31-43. 2009.

TAEI, Adeleh et al.
Derivation of new human embryonic stem cell lines from preimplantation genetic screening and diagnosis-analyzed embryos. *In Vitro Cellular e Developmental Biology: Animal*, Columbia, v.46, n.3-4, p.395-402. 2010.

TAYMOR, K. S.; SCOTT, C. T.; GREELY, H. T.
The paths around stem cell intellectual property. *Nature Biotechnology*, New York, v.24, n.4, p.411-413. 2006.

THOMPSON, Charis.
Making parents: the ontological choreography of reproductive technologies. Cambridge: MIT Press. 2005.

TRIBUNAL...
Tribunal de Justiça da EU proíbe investigação com células estaminais que implique a destruição de embriões. *Ciência Hoje*. Disponível em http://www.cienciahoje.pt/index.php?oid=51478&op=all. Acesso em: 12 mar. 2012. 18 out. 2011.

VICSEK, Lilla.
Costs and benefits of stem cell research and treatment: media presentation and audience understanding in Hungary. *Science Communication*, s.l., v.33, n.3, p.309-340. 2011.

ZARZECZNY, Amy; CAULFIELD, Timothy.
Emerging ethical, legal and social issues associated with stem cell research and the current role of the moral status of the embryo. *Stem Cell Reviews and Reports*, s.l., v.5, n.2, p.96-101. 2009.

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