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From abortion to embryonic stem cell research:

Biossociality and the constitution of subjects in the debate over human rights

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Resumo

O artigo analisa a presença do discurso dos direitos humanos nos debates sobre o aborto e sobre a pesquisa com células-tronco embrionárias como integrante do processo de biossocialidade. Tais questões emergem no campo da saúde reprodutiva e chegam à esfera do Direito em vista de problemas éticos. O discurso para constituir fetos e embriões em sujeitos de direitos será examinado em eventos do Supremo Tribunal Federal: a ADI 3510 contra o artigo 5 da Lei de Biossegurança que autorizou o uso de embriões excedentes de reprodução assistida para obter células-tronco, e a ADPF 54 que propõe incluir a antecipação de parto de anencéfalo na interpretação dos permissivos para o aborto legal.
Palavras-chave: direitos humanos, biossocialidade, aborto de anencéfalo, células-tronco embrionárias, ADI 3510, ADPF 54.

Abstract

The article analyzes human rights discourses in debates regarding abortion and human embryonic stem cell research as a part of the process of biosociality. These questions arise in the health and reproductive field and move into the realm of the law because of ethical issues. The text examines discourses regarding the transformation of embryos and fetuses into subjects of rights in the context of the Supreme Court: the legal move for unconstitutionality against Biossecurity Law that authorized stem cell extraction from supernumerary embryos created through assisted reproduction (ADI 3510), and the

legal case that proposes to include in legal abortion anticipated parturition of anencephalous fetuses (ADPF 54).
Keywords: human rights, biosociality, abortion of anencephalous, human embryonic stem cells, ADI 3510, ADPF 54.

From abortion to embryonic stem cell research:

Biossociality and the constitution of subjects in the debate over human rights[1]

Naara Luna

The present article analyzes how human rights discourse is inserted in legal struggles in Brazil in the context of the debate regarding research utilizing stem cells extracted from human embryos created during the *in vitro* fertilization process (IVF). We take as our principal material for analysis two cases in front of the Brazilian Federal Supreme Court. These questions emerge from the field of reproductive health and end up in the legal realm due to the ethical problems that arise in several distinct contexts.

The article follows Rabinow's strategy for research, concentrating life practices as the most potent space for the development of new powers and forms of knowledge (1999, p. 137), widening the scope of this strategy to take in juridical structures. Rabinow believes that, in the future, the new genetics will cease to be a biological metaphor for modern society, becoming instead a network in which identity terms and restricted spaces circulate and through which a new form of self-production – biosociality – will emerge. (Rabinow, 1999: 143). With biosociality, nature will be molded around culture, understood and reworked through practical techniques. Nature will become artificial exactly as culture has become natural. With regards to the topic of the present article, biosociality will see human rights discourse appropriating beings who were earlier strictly defined by biology. New subjects will be constructed along this interface between biology and the law.

1 This article was constructed based on the presentation, "Do aborto à pesquisa com células-tronco embrionárias: o estatuto de embriões e de fetos e o debate sobre direitos humanos" given at the 8th Meeting of MERCOSUL Anthropology, workgoup #20, "Implementação de Direitos e Gestão da Vida" (The Creation of Life and the Implementation of Rights). Iit is part of the"Do aborto à pesquisa com células-tronco embrionárias: o estatuto de embriões e fetos e o debate sobre direitos humanos no Brasil" Project (From Abortion to Research with Embryonic Stem Cells: the status of fetuses and the debate over human rights in Brazil), which has received APQ1 funding from FAPERJ.

Associated with the concept of biosociality is that of biological citizenship, a term invented by Petryna (2004), which means "a demand for, but limited access to, a form of social welfare based on medical, scientific, and legal criteria that recognize injury and compensate for it" (Petryna, 2004, p. 261). The concept was created based upon the situation following the Chernobyl disaster, when people who had been affected by the reactor's radioactive fallout demanded that the Ukrainian government provide them with social assistance and compensation based on medical, scientific and legal criteria. Rose and Novas (2005) argue that a new kind of biological citizenship is taking form in this era of rapid biological and genomic discoveries and biotechnological fabrication and biomedicine. New subjectivities, new policies and new ethical standards are forming the biological citizens of today. Rose and Novas claim that biological citizenship has both individualizing and collectivizing trends. It is individualizing to the degree that individuals reform their relationship with themselves in terms of understanding their somatic individuality. It becomes collective when the new forms of biosociality and ethical technologies are grouped around categories of bodily vulnerability, somatic suffering and genetic risk and susceptibility (Rose and Novas, 2005). Fassin believes that biolegitimacy creates the foundation of biocitizenship. Biolegitimacy is the "power of life as such" and is linked to the sense and worth given to life or to concrete lives, referring in this sense to the sacred character of life. The concept of biolegitimacy reflects upon how contemporary societies treat their members, to the value attributed to life in general and the worth attributed to lives in particular. Connecting the three concepts, the circulation of identity markers that is characteristic of biosociality is related to the revindications that emerge from a biological citizenship that is, in turn, founded upon biolegitimacy. These processes can be perceived throughout material analyzed below.

The present article thus seeks to debate the formation of new subjects and identities, looking in particular at those moments when new modes of recognition and legitimacy emerge from biomedical technologies as they are understood and absorbed by juridical technologies, particularly those technologies dealing with embryo production, anencephalic fetuses and stem cells and which recreate these beings in public spaces. In Rabinow's concept of biosociality, nature is recreated as culture. This is the very problem exposed by the public debates regarding research with stem cells

extracted from human embryos and the abortion of anencephalic fetuses. By discussing the recognition of these new beings, these fetuses and embryos, juridical thought must ask itself if they are subjects of rights (Dworkin, 2003) to whom the law owes protection. Biological characteristics are emphasized in order to deny or attribute to these beings the status of personhood. This process illustrates the individualizing aspects of biocitizenship, but here we can plainly see that the constitution of subjects through biosociality is not restricted to biomedicinal discourse, but is also dependent upon juridical technologies. Boltanski's concept of the technofetus can help clarify our thoughts on these matters (2004). The technofetus emerges from the new medical technologies of conception *(in vitro* fertilization) and imaging (fetal visualization) and from the juridical technologies that regulate these beings. The technofetus has a central place in both the abortion debates and in the discussions regarding anencephalic fetuses, touched upon below. It also is central to the debates regarding the status of extra-corporal embryos, which in turn involves assisted reproduction and research with embryo stem cells.

The background to these controversies is the individualist configuration of values that is characteristic of modern Western cosmology and which, for the purposes of this article, we understand according to the works of Dumont. In modern individualist societies, the human being is the atomic, indivisible element, represented as a biological, thinking subject. Each human being is incarnate and humanity as a whole is the measure of all things. Society is the means and each individual life is the ends. Equality and liberty are central ideas to modern life and presuppose, in principle, the existence of the human individual. Each individual carries the essence of humanity. The individual is almost sacred and his/her rights are limited by the identical rights of other individuals (Dumont, 1997). The individual is a moral being, independent and autonomous. Essentially asocial, he is the vessel and vehicle of the supreme values (equality and liberty) and occupies pride of place in the modern ideology of humanity and society (Dumont, 1992). One cannot speak of biological citizenship or in biosexuality if there is no prior concept of the modern subject as an individual.

In the controversies regarding abortion or research with extracorporal embryos, the inherent rights of subjects are juxtaposed. On the one hand, we have women's prerogative to control their own body; on the other, rights attributed to fetuses and embryos, independent of the context in which they

are found. Fetuses and embryos become represented as autonomous subjects, as if they could dispense with a uterus and continue developing and existing.

Discourses situating fetuses and embryos in a lab as autonomous, rights-bearing subjects appear in the Federal Supreme Court Cases we will analyze below. The first of these is *Ação de Inconstitucionalidade* (Movement to Declare as Unconstitutional, ADI)[2] 3510 against Article 5 of Brazil's *Lei de Biossegurança* (Biosecurity Law), which authorizes the use of left-over embryos from assisted reproduction therapy for the production of embryonic stem cells. The second case analyzed here is Arguição de Descumprimento de Preceito Fundamental 54 (Accusation of Non-Compliance with a Fundamental Precept ADPF 54),[3] which proposes to include the premature birth of anencephalic fetuses as a legal form of abortion.

In the first case, the rights of patients who are the potential beneficiaries of stem cell research are set against the rights of the frozen embryos. Here, we will examine the petition for and judgment of ADI 3510 and the public hearings regarding these processes. In defense of the right to life, we find such actors as the Catholic Church and other religious segments, pro-life movements, associated scientists and jurists. Questioning this right, we find feminist movements, liberal jurists, scientists in favor of embryonic stem cell research and (in the religious field) the non-governmental organization (NGO) Catholics for Choice. After presenting all the stages of the ADI 3510 debate, the article will then analyze the public hearings surrounding ADPF 54. We will then compare and contrast both lines of argumentation in our

2 According to the Federal Supreme Court's juridical glossary, an *Ação Direta de Inconstitucionalidade* (ADI) is an "act that has as its goal the declaration that a law or part of a law is unconstitutional; in other words, against the Federal Constitution. The ADI is one of those instruments jurists call 'a concentrated control of the constitutionality of the laws'. In other words, in theory, it is the direct contestation of legal norms". The entities and people who can propose this act include: the President of the Republic, the Chair of the Federal Senate, the Chair of the Chamber of Deputies. The chair of a legislative assembly or of the Federal District's legislative chamber, any state governor or the governor of the federal district, the Attorney General of the Republic, the federal council of the Brazilian Bar Association (Ordem dos Advogados do Brasil), anyn political party with representatives in the National Congress, any national-level labor organization. Available at: *http://www.stf.jus.br/portal/glossario/verVerbete.asp?letra=A&id=481* Acessed on 12/29/2014.

3 According to the Federal Supreme Court's juridical glossary, an *Arguição de Descumprimento de Preceito Fundamental* (ADPF) is "a type of action, exclusively judged by the Federal Supreme Court, which has as its goal the avoidance or repair of damage to a fundamental precept, resulting from the act of some public power. In this case, it is said that the ADPF is an autonomous action. However, this type of action can also be equivalent in nature to the ADIs, given that it can question the constituionality of a norm using the Federal Constitution (in this case the pre-1988 constitution). ADPFs are regulated by Federal Law #9.882/99. The same powers that might enact an ADI can enact an ADPF. Available at: http://www.stf.jus.br/portal/glossario/verVerbete.asp?letra=A&id=481 . Acessed on 12/29/2014.

conclusion. Values regarding autonomy, human dignity, and the right to life are central to this debate.

1. ADI 3510

Article 5 of Brazil's biosecurity law authorizes the extraction of stem cells from human embryos created for assisted reproduction, which are not viable, or which had been frozen for three or more years at the time the law was passed, with the "genitors'" (sic) permission. Congress passed the law in March 2005 and then-President Luiz Ignácio "Lula" da Silva[4] signed it into effect in October of that year. Before this, however, in May 2005, then Attorney General of the Republic, Claúdio Fonteles, authorized a Move to Declare as Unconstitutional (ADI). ADI 3510 questioned the constitutionality of Article 5 of the biosecurity law, arguing that this negatively affected the right to life and human dignity, the foundation stones of democratic rule of law. The press accused Fonteles of Catholic religious motivations. The Catholic Church entered into the case as an interested party, from the beginning.

1.1 The Initial Petition

Fonteles' petition questioned Article 5 based on constitutional arguments. The petion's central thesis affirms that "human life begins upon fertilization" (p.2). This affirmation was based upon testimony, scientific articles and a book published by the Brazilian National Bishops' Conference (CNBB), *Life: The first right of citizenship* (*Vida: o primeiro direito da cidadania*), in which scientists defend the thesis that life begins at fertilization. The petition emphasizes the advances of research undertaken with adult stem cells and the laws protecting embryos in other countries. After arguing against the constitutionality of Article 5, the petition proposes that public hearings be conducted in the Federal Supreme Court and suggests as speakers nine scientists, six of whom were cited in the petition.

The petition concludes:

4 Luiz Inácio Lula da Silva, Brazilian President for the Workers' Party (PT), during two mandates, from 2003 to 2010.

- human life begins at fertilization: the zygote is generated by the meeting of 23 masculine and 23 feminine chromosomes;
- it begins at fertilization, and because human life is continuous, it develops;
- it continues to develop because the zygote, made up of a single cell, immediately produces human proteins and enzymes and is totipotent, meaning that it gives the embryonic human being the ability to form all of the human body's tissues, which differentiate and renew themselves, becoming a unique and unrepeatable human being.
- beginning with fertilization, the mother takes in the zygote and, from that point on, provides the environment for its development, an environment which is, in its final stage, the uterus. It is not, however, the uterus which becomes pregnant but the entire woman, at the moment of fertilization. (p. 10-11)

These arguments are employed to establish that an embryo is a human being and that Article 5 of the biosecurity law thus violates the right to life and breaks the foundation upon which the democratic rule of law resides: the preservation of human dignity.

The petition and its justification are grounded in biological data in order to demonstrate the status of the human embryo as a person and as a human life. This is the "individual" described by Dumont (1992) as an asocial and autonomous being, the atomic reference of value in modern western culture. Uniqueness and autonomy characterize this zygote as an individual.

The hearing with the scientists

Attending to the petition's proposal, the case's relator in front of the Federal Supreme Court, Justice Carlos Ayres Britto, convoked the first public hearing for the benefit of the Court on the 20th of April, 2007. 22 invited specialists attended, almost all professionals, researchers and professors in the biomedical sphere, the sole exception being an anthropologist with a post-doctoral degree in bioethics. The testimony was divided into two blocks: one including those chosen to testify by the Attorney General of the Republic and the CNBB and the other suggested by those "accused by the Movement to Declare as Unconstitutional": "the National Congress, the President of the Republic and friends of the Court". According to the case's sponsor, the hearing's goal was to seek "a jurisdictional concept for the word 'life'" and for the expression "human dignity".

Examining the trajectories of both groups of specialists, we can see that the greater part of those against the use of embryonic stem cells in research were involved with the institutions of the Catholic Church. This is not surprising, given that the CNBB helped to choose the invited specialists who were to testify.[5]

The synthesis presented below focuses on the arguments regarding the condition of the embryo in the laboratory, principally with regards to questions about whether or not it is a life or a person. Here, we will pay special attention to the underlying ideologies informing these arguments.[6] The discourses allow us to understand how these bioentities or somatic identities actually emerge.[7]The values of modern Western individualist ideology could be identified in both groups of expert speakers. The life of an embryo was understood to be sacred as are the rights of individuals in Western ideology (cf. Dumont, 1997). The block opposed to the use of embryos in research surrounded itself with biological arguments and refuted other biology-based arguments offered up by the block that favored research. Both groups understood nature to be the foundation stone of reality (Laqueur, 1992)[8]. The group that questioned the biosecurity law made great use of bioethical discourses. Those in favor of it adopted a relativistic discourse, preoccupied with the dynamics and consequences of research while their opponents' strongest argument had to do with the sacredness of life and the rejection of relativism in the face of sacred realities. However, this group also based their definition of the statute on biological markers.

5 We analyzed the Lattes CV (the official CV all Brazilian scientists maintain with the Federal Government) of all the people invited to give testimony. Where this CV did not existed, we searched for similar data via the internet. With regards to scientific production and participation in research with stem cells, it was discovered that the group in favor of research using embryonic stem cells was composed (except for the anthropologist) of researchers engaged in stem cell studies, many with quite impressive scientific credentials. In the group that was against the researchers, there were few who had participated in stem cell research. The arguments of these individuals thus centered on the positive results obtained with therapies conducted using adult stem cells – research in large part undertaken by members of the first group. The scientific production of the second group was much less in comparison with that of the first group and many of the second group's members were engaged in issues of bioethics.

6 This hearing is described in Luna (2010b).

7 Bioentities are somatic entities constituted through emphasizing procedures involving bodily, medical, esthetic and hygienic care (Ortega, 2003).

8 Laqueur identifies the emergence of a new episteme in illuminism whereby nature is understood as the bedrock foundation of reality. "Biology – the stable, ahistoric and sexed body – is understood to be the epistemological foundation of prescriptions for social order" (1992, p. 6).

The group which opposed the research attempted to fuse the concepts of life and personhood, creating a base for their arguments. They considered the human embryo to be a living being in an initial stage of life, based on the fact that certain vital biological processes. These were understood to represent true human existence and thus establish the embryo as a human person with all due legal rights. The concept of life itself is taken from biography (cf. Waldby, 2002)[9] and is sacralized. The anti-research group wanted to establish fertilization as the natural beginning of human life, in contrast to other biological referents which might be used but which were accused of being arbitrary.

Some of the specialists of the group that favored the use of embryos in research got around the definition of life by considering its conceptualization to be a "false problem" or an unanswerable question. A smaller number of specialists proposed the establishment of the nervous system as the beginning of life, looking to the already established medical definition of "brain death". The embryo's viability was also contextualized as life inside the mother. Some considered this relationship to be the beginning of human life. The non-viability of the embryos used in research was also repeatedly touched upon, and it was pointed out that this would eliminate their human character as established by the opposing group. The tiny size of the embryos was also employed as a rhetorical tactic to negate their status as people. Three distinct representations of the embryos could be found in the pro-research group. The first emphasized continued vital processes instead of individual biography or, in the words of Waldby, a "raw biological vitality" (Waldby, 2002)[10] The second focused on the embryo's relationship with the environment that allowed it to continue to exist (Fyfe, 1991)[11] : in other words, its relationship to the mother, which guaranteed its condition as a person

9 Those who opposed embryonic stem cell research understood an embryo's life as biographical: the beginning point of a human narrative which should be allowed to follow its social course (Waldby, 2002, p. 313)

10 For those who defended research with embryos, the embryo's life was a form of raw biological vitality. The embryo is not killed in this view of things. Rather, its vitality is re-channeled and reorganized (Waldby, 2002, p. 313).

11 In his analysis of abortion legislation in England between 1803 and 1967, Fyfe reveals a gradual separation of the fetus from its mother and the emergence of the concept of fetal viability (i.e. its capacity to be born alive). During this period, then, the fetus was redefined in the terms of medical knowledge as a limiting point for the classification of crimes.

(Salem, 1997)[12]. The third representation focused upon the emergence of the nervous system, both as the parameter for brain death (and thus, presumably, for birth) and as the first sign of rationality (Luna, 2010b) or sensibility (Salem, 1997).

The anti-research group based their testimony on the principle arguments to come out of the bioethical field regarding the status of embryos. Claudia Batista and Dalton Ramos repeated the formula used in Church documents regarding the embryo: "coordinated, continuous and gradual development" (Pontifícia Academia para a Vida, 2000). The emphasis here is on the beginning of individual human life. In the group who supported the bio-security law, anthropologist Débora Diniz shifted the discussion towards ethics in research. In this group, there were three positions. The first situated life as a continuous generative process, without answering the question of when it began. The second took into account the embryo's context, pointing out that it can only live if it is implanted in maternal womb (this might be labeled the relational perspective). The final position drew an analogy with brain death in order to invoke the establishment of the nervous system as the beginning of life. The pro-research group's principal strategy was to avoid the question of life and to concentrate on the origins of the embryos and their fate. To attribute dignity to this fate in the possibility of saving lives was also a way of appealing to religious values.

The anti-research group wanted to make the juridical, political and biological definitions of an embryo coincide with the concept of personhood, with this status being conceded to the embryo from the moment of fertilization. On the other side of the debate, Debora Diniz claimed that it was incorrect to believe that a biological phenomenon – in this case, fertilization – could be sufficient to decide moral questions such as how embryos are to be handled. Appeals to nature were present on both sides of the debate and I will explore these in more depth below. Right now, I want to argue that the use of biological references in order to define what is a person is related to the circulation of the identity terms that Rabinow (1999) explores, as well as the

12 Salem observes that an *in vitro* embryo does not have this relationship, which permits it to be considered on its own terms. In this view of things, implantation in a uterus would be the only criterion which creates the necessary relationship for life (1997, p. 85, 88). Also according to this author, embryos feel nothing before they generate a nervous system.

notion of biological citizenship: the sacredness of human life is emphasized at all times (Dworkin, 2003; Fassin, 2009). Subjects emerge through juridical and biomedical technological apparatuses in the cases studies here, exactly as these authors point out.

Judgment and the justiceial vote

The Federal Supreme Court began its first session on the 5th of March, 2008, when Justice Carlos Ayres Britto (the relator), Justice Ellen Gracie (then president of the court) and Justice Carlos Menezes Direito took to the bench. Justice Carlos Menezes Direito asked to examine the process. Judgment was forestalled and the case was taken up again in two sessions on the 28th and 29th of March, 2008. Six Justices voted in favor of the law's constitutionality and five partially questioned it. Of these five, three claimed that the use of embryos in research attacked the right to life. The other two restricted themselves to suggesting that organs should be created to oversee and supervise this research. The synthesis that we provide below shows what the voters thought with regards to the moment when life begins.

Rejection of the debate about when life begins

Four justices considered the debate regarding when human life begins to be of marginal interest. According to Justice Ellen Gracie, "There is no constitutional definition regarding when human life begins and it is not the role of the Supreme Court to establish concepts that are not specifically covered by the Federal Constitution. We are not an Academy of Science" (p. 2).[13] Gracie also dismissed the idea that the law violated the right to life.

Justice Carmen Lucia considered a juridical ruling on when life begins to be unnecessary in order to guarantee rights to embryos or fetuses (p.6). The principle of human dignity extends beyond the person and attaches to the entire species: all those who are a part of humanity – including embryos and the dead, who are not considered persons under the law – are contemplated by this value and are protected by the right to it (p.37).

13 All of the votes were collected as isolated documents and for this reason an independent pagination is used to reference the quotations.

Justice Joaquim Barbosa rejected the attempt to define the point at which life begins. A biological definition of this sort wouldn't solve the issue at hand (p.1). This original affirmation was an attempt to remove the debate from a purely biological sphere and, instead, shift it towards a verification of the legitimacy of creating an exception to the law's protection of the right to life (p.1). The right to life and the legal safeguards over it are two aspects of one single right which is not absolute (p.2). Barbosa claimed that there different degrees of legal controls over human life during different phases of the life cycle: fertilization, gestation, birth, development and death (p.2). He contrasted the rights of an embryo and the right to life of people who had incurable diseases (p.4).

Justice Gilmar Mendes thought it unnecessary to discuss the points where human life begins and ends for the purposes of legal protection (p.5). These points were not yet clear and there was no consensus about them in scientific, religious, philosophical, or vulgar thought. He concluded that in the debates regarding euthanasia, abortion and research with embryos, there were no morally correct, universally acceptable answers (p.6). Mendes also observed that it is not necessary for one to be a subject of rights in order for one's life to be protected by the law (p.6).

Relativization of the debate about when life begins

In the opinion of the relator, Justice Carlos Britto, the beginning of human life coincides with the instant of fertilization (p.35). However, this justice also observed that "the beginning of life is a reality that is set apart from those things that constitutes a physical or natural person... at least according to the Brazilian Juridical Code" (p.36). Britto cited the Brazilian Civil Code, which states that civil personhood begins at birth, but the justice also pointed out that the law protects the rights of the unborn from conception on (p.22). Personhood, in this view, is predicated on "who a person is in their biographical dimension and is thus more than simple biology" (p.22). Britto employed constitutionalist Richard Dworkin's concept of proportional juridical tutelage: "The law protects in different ways each step of the biological development of the human being" (p.28). Opposing the argument presented in the petition and by the scientists at the hearing, Britto

affirmed that embryos, fetuses and human people are distinct and separate realities. For this reason "an embryonic human person" doesn't exist, "but only embryos of human people" (p.34). The human person is understood here to be the result of this metamorphosis: she/he does not exist before it occurs (p.34). This concept of metamorphosis sets Carlos Britto's concept of humanity apart from the notion of "potentiality" implicit in the "life begins at fertilization" argument, which sees the realities of later stages of life as implicit or contained in the seed. Britto also differentiated between the use of embryos in a lab and the interruption of pregnancy: in the first case, there is no gestation underway and thus the laws criminalizing abortion do not apply. The embryo conceived in a laboratory and confined *in vitro* is not subject to reproductive progression (p.40). Britto likewise emphasized the importance of gestation to the continued life of a fetus (p.54) and he traces a parallel between the criteria for establishing brain death and the embryos referred to by the bio-security law: in the embryo's case, it does not have a nervous system, unlike a brain in gestation. Finally, this justice concluded that without a brain, there can be no human person, even potentially. In the context of the bio-security law, then, an embryo is "a vegetative life that comes before the development of the brain" (p.62s).

Justice Marco Aurelio also took a relativistic perspective with regards to the question of when life begins by suggesting that there is no escaping an opinionated perspective with regards to this question. He listed the various ways of marking this beginning: conception; implantation of the fetus in the uterus; formation of individual characteristics; quickening, or mother's first perception of the fetus' movements; viability; birth (p.4-5). His examples were all based on physical markers of development that are characteristic of the constitution of the person in modern western cosmology (cf. Conklin and Morgan, 1996).[14] Marco Aurelio also distinguished between stem cell research using embryos and abortion (p.6-7). Article 5 of the bio-security law specifies that viability is not an issue, because the embryos in question would never be implanted in a uterus and the only ones to be used will be those which have

14 Both sides of the abortion debate tend to seek fixed markers and structures in order to define when personhood begins. The irreversible nature of these criteria makes the question of whether or not a fetus is a person an "all or nothing" affair. If the fetus is even in the slightest considered to be a person, it has rights. The condition of personhood in this debate is, in any case, always established by recourse to biology (Conklin and Morgan, 1996, p. 660, 665)

been frozen for three years or are otherwise not viable (p.8). In this view of things, the beginning of life presumes not only fertilization, but viability, which does not exist without pregnancy (p.9). According to this justice, "it is controversial to claim that the constitution protects life in general, or even *in utero* life in any phase of existence" (p.9) and he brought up the example of abortions permitted to save the mother's life (p.9) or to end pregnancies that result from rape (p.10) as an example of this, as well as the case of *in vitro* embryos that do not necessarily end up implanted in a womb, let alone in births. The juridical person who has rights is thus dependent upon live birth (p.10). In *in vitro* fertilization, the people who furnish the eggs and sperm are not obliged to bring all resulting embryos to term (p.10), something which would turn women into mere "incubators", negating the family planning stipulations of the Brazilian constitution (p.11).

Justice Celso de Mello proposed judging this controversy from the perspective of human rights. He didn't question the "sacredness and inviolability of the right to life" (p.3) and emphasized "the postulate of the dignity of the human person" as the "true source of value" of the constitutional order (p.4). He defended the State's secular nature against the religious perspective with another principle of constitutional order (p.5). This justice did not see "an ontological parity, in the normative sphere, between an embryo... and a born person" (p.30). He affirmed that the right to life "can possibly be pondered by the State, in the face of situations that threaten this basic right". These circumstances, however, conflict (p.34) with the interests of people afflicted with incurable diseases who might gain relief from the fruits of research with embryonic stem cells (p. 35). Mello also reminded the court that the right to life from conception onward has not been established by the Brazilian constitution (p.35).

Justice Cezar Peluso took an different position from the others by defending the thesis that life does not exist in frozen human embryos. In his deposition, he defines as "theoretical subjects of the right to life" the following categories: frozen embryos, implanted embryos and the fetus and adult humans or human children who carry those attributes understood by the constitutional order to signify the quality of personhood (p.9). Peluso looked at whether there different degrees of constitutional protection for "people actually given life in all its plenitude" and embryos (p.9) and concluded that

the frozen embryo only participates to a very basic degree in the protections given to the human dignity of human adults (p.9). The object of the court's tutelary power with regards to life is only the life of a human person. The justice criticized the argument of the anti-research faction that life can be defined as the continuous development of the life cycle from the embryonic stage on: this did not apply to frozen embryos (p.27). According to Peluso, the life cycle perspective "does not consider or depreciates the biological function and the corresponding juridical-normative condition... of the female uterus" (p.25) which, to the justice's mind, was reduced by the petitioners to the status of "an adequate environment" and "source of necessary nutrients" for fetal development. "Intra-uterine life also has constitutional value" (p.26). The implantation of the fertilized egg in the uterus is a condition of its development and constitutes the criterion for the definition of the beginning of life.

The beginning of life at fertilization, understood as a fact

Three justices argued that life begins at fertilization and affirmed that life and personhood began at the same time. The three defended the thesis that obtaining stem cells by destroying embryos violated the right to life and attacked human dignity. Aside from questions regarding research regulation (which would affect assisted reproduction), these three justices would only allow proven non-viable embryos (those which had stopped dividing on their own for over 24 hours) to be destroyed for stem cell harvesting. With regards to frozen embryos, these justices would only allow techniques which would extract a cell without damaging the embryo, with further stem cells being cultivated from this cell.

Justice Menezes Direito wrote a technical opinion which referenced scientific literature regarding assisted reproduction and embryo cultivation. His particular original contribution was his analysis of the thesis defended by the group which favored embryo use in research: the philosophical discourse regarding the intermediate status of the embryo, which was supported by analogies referencing death (p.58). In this discourse, the embryo was understood as non-human life and the law cannot protect the right to life in this case because there was simply no person involved (although the protection of dignity could still be recognized). This intermediate status of the embryo

was associated with its incapacity for moral or rational thought. The justice insisted that the Supreme Court explain its position regarding the beginning of life. He criticized the metamorphosis model adopted by Carlos Britto and defended the concept of potentiality (p.47). Menezes Direito claimed that the embryo was already a potential being and would only not develop if prevented from doing so by outside circumstances (p.50). He also affirmed that life regulated the protection the embryo deserved and opposed the notion that life without personality was not human life. Personality was an attribute of life: not the other way around (p.59). Finally, Menezes Direito claimed that embryos were living based upon the characteristics of autonomous development, genetic patrimony and diversity (p.59).

Justice Ricardo Lewandowski's arguments were in many ways similar to those of Menezes Direito. With regards to human embryo stem cells, he believed that there were controversies because harvesting the material "required destroying a living organism that resulted from the fertilization of human gametes" (p.5), which some didn't consider to be "persons in the moral or juridical sense". This research represented a threat to the human species (p.6) and Lewandowski denounced what he considered to be the evil consequences of this scientific activity. He proposed ethical and juridical limits for science in order to avoid the transformation of people into things or objects (p.11). The justice also argued that, in the juridical sphere, life begins at conception according to the American Convention on Human Rights (or the Costa Rican Pact) of 1969, signed by Brazil in 2002.

Eros Grau wrote a synthesis opinion, claiming that the Brazilian Civil Code as stipulating that the civil person begins at live birth, "but the law protects the rights of the unborn from conception on" (p.4). Given this, the unborn are rights-bearing subjects under law and that they should logically thus be considered as people. Human dignity was understood by Grau to exist before birth (p.4) and "all beings capable of acquiring rights are people". The capacity to exercise the rights of legal personhood depends upon birth (p.5), but the unborn are indeed part of humanity. The constitution thus guarantees them protection of their dignity and the right to life (p.6).

The Supreme Court's ruling in the ADI 3510 case made the debate about the origins of life even clearer. Individual biography (identified as human life) as opposed to the simple biological process of cellular multiplication

were the two views of embryos present during the hearings and judgment of this case. By focusing on the circulation of terms of identity that is present in processes of biosociality, we will see in the discussions I present below that the focus on anencephalic fetuses during the ADPF 54 hearings moved in a very different direction from that seen regarding embryos in ADI 3510. The characteristics attributed to anencephalic fetuses in order to concede or deny them personhood were rooted in biology, but pointed to different aspects of humanity.

ADPF 54

In June 2004, the National Confederation of Health Workers (Confederação Nacional de Trabalhadores da Saúde) proposed ADPF 54 to the Federal Supreme Court in order to ensure that pregnant women carrying anencephalic fetuses would have the right to therapeutic early delivery and to ensure the right of doctors to perform this procedure, once this anomaly was detected, without requiring judicial authorization (Fernandes, 2007).

Anencephalic fetuses are known as brainless babies. Anencephaly is a congenital deformation characterized by total or partial absence of the brain and the skullcap (FEBRASGO, 2007). It originates in a failure during neural tube closure in embryonic development. The fetus does not develop brain hemispheres and its cephalic matter is exposed without bones or skin covering. An anencephalic fetus or baby is blind, deaf, unconscious and unable to feel pain. If not stillborn, the prognosis is death within hours or days after birth (National Institute of Neurological Disorders and Stroke, 2010). It is the most common lethal central nervous system abnormality. More than half of anencephalic fetuses are born dead (Fernández et al., 2005). A document published by FEBRASGO (the Brazilian Federation of Gynecology and Obstetrics Associations – Federação Brasileira das Associações de Ginecologia e Obstetrícia) claims that anencephaly is 100% lethal (2007). This biomedical discourse constructs anencephaly as incompatible with human life, but certain segments of the Brazilian public have questioned this definition.

During the four sessions of public hearings regarding ADPF 54, there was a clear-cut opposition between speakers who took the pro-choice line of reasoning adopted by ADPF 54 and those speakers who were pro-life. Both

sides made use of human rights discourse. As was the case with stem cell production using human embryos, the two groups organized around distinct identities in order to put forth their claims with regards to human right, in a process that neatly illustrates the dynamics of biosociality.

The ADPF 54 public hearings[15]

ADPF 54's relator, Justice Marco Aurelio Mello, granted a preliminary injunction recognizing the right of pregnant women carrying anencephalic fetuses to therapeutic anticipation of birth on July 1st, 2004. This injunction was repealed by a Supreme Court plenary October 20th of the same year (Fernandes, 2007)[16]. The relator's delay in convoking public hearings was understood to be due to his desire to wait for the final decision of the Supreme Court regarding ADI 3510.

The hearing's four sessions were conducted on the 26th and 28th of August and on the 4th and 16th of September 2008. 27 speakers were heard, of which eleven were pro-life and sixteen pro-choice. Of the eleven pro-life speakers, three came as experts and the others represented for six entities and associations. Two religious organizations were present on the pro-life side: the CNBB, whose two representatives (the national adviser of the CNBB's Episcopal Commission for Life and Family – Comissão Episcopal para a Vida e a Família – and the president of the Union of Catholic Jurists of the Archdiocese of Rio de Janeiro – União de Juristas Católicos) shared their time and two representatives of the Brazilian Medical Spiritist Association (Associação Médico-Espírita do Brasil). Also speaking were representatives of the Pro-Life and Pro-Family Association (Associação Pró-Vida e Pró-Família), the National Citizens' Movement in Defense of Life: Brazil Without Abortion (Movimento Nacional da Cidadania em Defesa da Vida – Brasil Sem Aborto), the Association for the Development of the Family (Associação para o Desenvolvimento da Família) and a federal deputy who was then president of the Parliamentary Front for the Defense of Life (Frente Parlamentar em

15 I would like to thank Debora Diniz and the NGO Anis (Bioethics, Human Rights and Gender Institute) for facilitating my access to the hearing transcripts.

16 This hearing took place in April 2012, but will not be dealt with in the present article. We believe that looking at the groups present during the public hearings will contribute more to the debates regarding biosocialities and the constitution of social subjects through discourses regarding health and illness.

Defesa da Vida). Three experts were pro-life speakers: two in gynecology and obstetrics and a pediatrician who specialized in neurology.

Among the sixteen pro-choice speakers, two were public officials: Health justice Jose Gomes, and the justice of the Special Secretariat for Women's Policies and president of the National Council of Women's Rights (Conselho Nacional de Direitos da Mulher – CNDM), Nilcéa Freire, as well as a federal deputy who appeared as a specialist in gynecology and obstetrics. Also on the pro-choice side were five representatives from NGOs: Anis (Bioethics, Human Rights and Gender Institute – Instituto de Bioética, Direitos Humanos e Gênero), the People School: Communication Inclusion (Escola de Gente - Comunicação em Inclusão), the Feminist Health Network (Rede Feminista de Saúde), Citizenship, Study, Research, Information, Action (Cidadania, Estudo, Pesquisa, Informação, Ação – CEPIA), and Conectas Human Rights and the Human Rights Center (Conectas Direitos Humanos and the Centro de Direitos Humanos: one representative spoke for both NGOs). Representatives of scientific and professional associations councils also testified for the pro-choice side: Federal Council of Medicine (Conselho Federal de Medicina – CFM), the Brazilian Federation of Gynecology and Obstetrics (Federação Brasileira das Associações de Ginecologia e Obstetrícia – FEBRASGO), the Brazilian Society for Fetal Medicine (Sociedade Brasileira de Medicina Fetal), the Brazilian Society of Genetic Medicine (Sociedade Brasileira de Genética Médica), the Brazilian Society for the Progress of Science (Sociedade Brasileira para o Progresso da Ciência – SBPC) and the Brazilian Association of Psychiatry (Associação Brasileira de Psiquiatria). Finally, two religious groups participated on the pro-life side: a bishop from the Universal Church of the Kingdom of God (Igreja Universal do Reino de Deus) and the president of the NGO Catholics for Choice (Católicas pelo Direito de Decidir).

Medical doctors dominated in terms of profession, with 16 among the 27 speakers. The composition of the speakers contrasted with that of ADI 3510, which called in 22 experts (11 on each side), but no members of NGOs, social movements, or representatives of scientific or professional associations (Luna 2010b).

Below, I will outline core themes from the exhibitions. These reveal their origins in a common configuration of values, although their arguments are presented in symmetrical fashion. These themes are: life; the relationship between life, anencephaly and brain death; the human condition; dignity;

autonomy/choice; disability, eugenics, and degrees of anencephaly; technical descriptions of anencephaly; the right to life; the right of mothers/families; other rights; the contrast between abortion and therapeutic anticipation of delivery; maternal risk and suffering; the secular state. In general, questions revolved around whether or not anencephalic fetuses could be considered to be living human beings and whether they were thus due rights or not.

Luis Roberto Barroso, a lawyer who represented the National Confederation of Health Workers, presented seven theses in order to synthesize the case at the end of the hearings. Using these, one can identify the main axes that directed the debate:

1. The 100% certainty of the diagnosis of anencephaly and its irreversibility.
2. Anencephaly's 100% mortality rate. Barroso refrains from commenting on the case of "Marcela" considering it to be exceptional[17].
3. Gestation of anencephalic fetus is a risk to women's physical and mental health.
4. The absence in Brazil of any record of anencephalic fetuses organs being used in transplants. Such transplants are not feasible because the other organs of the fetus may carry defects.
5. Barroso proposes to treat the interruption of anencephalic pregnancy as the therapeutic anticipation of delivery and not as abortion, given that the fetuses are brain dead and the criterion for death under Brazilian law is brain death. Given that anencephalic fetuses are not really alive, they cannot be aborted and their removal is a therapeutic procedure.
6. The difference between anencephaly and physical deficiency, given that there are no anencephalic children or adults, and the lack of relationship with other humans in the case of anencephaly. Barroso classifies arguments relating to eugenics in this context "empty rhetoric"
7. In view of the testimony of the women who opted for therapeutic anticipation of delivery and of others refused, and given that both groups

17 This is the case of Marcela de Jesus, a girl diagnosed with anencephaly who survived for one year and eight months. Her mother decided to carry her pregnancy to term and is seen as an example by the Catholic Church , receiving support from this institution. Pro-life experts used this example to argue that there are degrees of anencephaly, corresponding to different prognoses for life and that these degrees are impossible to detect with ultrasound . Therefore, pregnancies involving anencephalic fetuses should not be terminated. Some pro-choice experts believed that Marcela was not anencephalic, however, but suffered from merocrania, a more rare anomaly which allows for longer survival and which is subject to intrauterine identification. This distinction was discussed by several speakers during the hearings.

> claim to be satisfied with their decisions, Barroso asks that Supreme Court to ensure these women's right to live in accordance with their choices, values and beliefs. "Each one should suffer as she wishes and not as the State imposes" (16th september, p. 38-39).[18]

Those who supported ADPF 54 sought to prove the absence of human life in anencephalic fetuses. If there was no life in these fetuses, early delivery or the termination of pregnancy would not be abortion. There are two cases in which abortion is exempt from punishment in the Brazilian Penal Code (both date from 1940): when the mother's life is at risk and in pregnancies resulting from rape. If the Supreme Court determined that anencephalic fetuses were not alive, then pregnant women and their doctors could decide to terminate these pregnancies without judicial authorization and without need for changing Brazil's laws (the prerogative of the legislative branch).

In defence of life

Those speakers opposed to early delivery of anencephalic fetuses argued that these possessed human **life** and that they thus needed to be defended and preserved. According to Father Luiz Antônio Bento, one of the CNBB representatives, individual life is "an unalienable personal good" but also "a social good that belongs to all". As such, it's society's obligation to "defend and promote these rights of the human person, of the fetus that has this anomaly" (26th of august, p. 4). Dr. Marlene Nobre from the Brazilian Medical Spiritist Association also defended the idea of life as a granted good. After describing scientific research that demonstrated that cells were designed by a higher intelligence[19], she then affirmed that "Life... is a granted good.... It is not religion that says this, but science" (26th of august, p.30). The view of life as a juridical good or blessing appears in law (cf. Fernandes, 2007), but the argumentation of the representative of the Brazilian Medical Spiritist Association is original in that it invokes the authority of science, and not that

18 The four sessions were transcribed as separate documents and, for this reason, I present the page numbers with the date of the session.

19 She cites the book *Darwin's Black Box*, which argues for intelligent planning (also known as intelligent design), according to which celular structure and functions follow an efficient plan. The book seeks to demonstrate that Darwin's theory of natural selection does not explain the origins of these structures and that the way in which these structures are arranged could only be part of a planned act (see a critical review of this book in Martins, 2001): this would be the superior intelligence that Doctor Marlene Nobre refers to.

of religion, in order to show that life is a blessing. Religious views consider life to be a gift from God (cf. Franklin, 1995):[20] Dr. Nobre's view mix science and religion. The anti-choice group wanted to show that fetuses are alive by moving away from the comparison with brain death. Cintia Macedo Specian, a pediatrician specializing in neurology, cited an article that showed that anencephalic babies can live for more than seven days while showing signs of cerebral activity. She concluded, based on this, that one cannot diagnose brain death from cerebral electric activity (4th of september). A member of the public at the hearings pointed to the presence of life and the human condition of the anencephalic fetus: "Can we consider this child to be stillborn even if it is crying and moving and giving all signs of life?" (Dóris Hipólito Pires of the National Association of Women for Life – Associação Nacional Mulheres pela Vida, on 16th of september, p. 36).

Many of the pro-life speakers justified their position based on the human condition of the anencephalic fetus. According to Luiz Antônio Bento of the CNBB: "the fetus carries the human genome, all of the genetic data is present in the life of this individual" (on 26th of august, p. 6). Genetic essentialism is the basis of this declaration (cf. Salem, 1995).[21] Others alleged that the anencephalic fetus is still conscious on some physical level. Doctor and adjunct professor Rodolfo Acatauassú Nunes (National Pro-Life and Pro-Family Association – Associação Nacional Pró-Vida e Pró-Família) believed that there is "a certain degree of primitive consciousness" and "the possibility that this nucleus of primitive consciousness is distributed between the diencephalitic, mesencephalitic and encephalitic trunk". Such structures are present in anencephalitic fetuses and, for this reason, their consciousness, demonstrated on the physical plane, indicates that they partake in the human condition. Doctor Irvênia Luiza de Santos Prada (Brazilian Medical Spiritist Association) also made a similar statement: "anencephalic fetuses have a neural substrate which carries out their vital functions and serves as a form of consciousness. For this reason, the abortion of these fetuses

20 Notions of life or vital force are frequently connected to belief in the supernatural, the divine and the sacred and these understandings are made more explicit in relation to death. These attributes characterize both the Judeo-Christian and classical understanding of life. According to the first of these traditions, life is interpreted and valued as a gift from God (Franklin, 1995, p. 1346).

21 According to Salem: "it is the gens which, substituting 'blood' or the biological, now appear embodying a reality that came before human designs, or an essential truth that imposes itself upon the superficial appearances of culture" (1995, p. 66).

is counter-indicated, as well as their use for organ transplants" (em 26th of august, p. 29). The physical presence of characteristics that were earlier understood to be part of the spirit or the mind, such as consciousness, refers to the concept of physicalism: "the belief that corporeality in itself is a self-explaining dimension of human being" (Duarte, 1999, p. 25). In these examples, consciousness demonstrated on the physical plane is a sign of humanity. The human identity of the anencephalic fetus is demonstrated through the biological substrate which proves the presence of human consciousness. Here we find a series of meanings that link immanent values to the presence of a rational human consciousness: rationality is understood as having a physical basis, recognized through biomedical techniques of fetal diagnosis.

More abstract dimensions of these values referencing the human condition are also invoked. Father Luiz Antonio Bento mentioned the value of human dignity with respect to the anencephalic fetus: this would be inherent as it is inherent to all individuals of the human species. (26th of august). The value of autonomy was also brought up by Father Bento: "a fetus with anencephaly is not relative to anything or anyone and does not depend on another or others for its dignity" (26th of august, p. 4). This autonomy granted to anencephalic fetuses was denied to pregnant women, however, by Doctor Ieda Therezinha do Nascimento Verreschi (Association for the Development of the Family – Associação para o Desenvolvimento da Família): "the fetal-placental unit – which is unique and has a sick component – must be respected" (4th of september, p. 26). The woman who is pregnant with an anencephalic fetus is thus understood to be part of a "fetal-placental unit", but it is the sick component of this unit – the fetus – which truly matters here. The right to life of an anencephalic fetus is here opposed to the mother's rights: "the life of an anencephalic fetus overrides any right of already formed people – in this case, the mother. Life is a fundamental good. Life is a blessing granted. It is science itself that tells us this" (Marlene Noble, Brazilian Medical Spiritist Association, 26/08, p. 31). Once again, scientific authority is here invoked in order to support transcendent truths. The rights of a pregnant woman are encompassed by the rights of the being she contains. Elizabeth Kipman Cerqueira, a specialist in Obstetrics and Gynecology, questions the liberation of anencephalic abortions: "Who is more important:

the fetus or the woman? The fetus – of this we are certain" (16th of september, p.1). From the pro-life group's perspective, a pregnant woman's presumed suffering does not justify the "sacrifice of her son's life," in the words of Father Bento (CNBB). Congressman Luiz Bassuma (of the Workers' Party – PT – at the time of the hearings), president of the Parliamentary Front for the Defense of Life and Against Abortion, was one of many who invoked the **inviolability of the right to life** as established by the Brazilian Constitution (28th of august). Several other speakers compared the condition of anencephalic fetus to that of the **physically disabled**: "the anencephalic fetus is deficient; he is not undead" said biologist Lenise Aparecida Martins Garcia (National Citizenship Movement in Defense of Life: Brazil Without Abortions, 28th of august, p. 49), arguing that anencephaly was a variable condition that allows for different lengths of survival after birth. To support her argument, she mobilized statistical data and the case of Marcela de Jesus. Garcia also remarked upon the inability to determine, with certainty, the degree of anencephaly in intrauterine examinations. Gynecology and obstetrics specialist Dernival da Silva Brandão rejected the euphemism "therapeutic anticipation of birth", claiming that the technical term, used in health care, was abortion: "the withdrawal of the child before it is viable" (4th of september, p.52).

The protection of the anencephalic fetuses supposedly demand on account of their biological characteristics illustrates the concept of biocitizenship (Petryna, 2004 Rose and Novas, 2005). The attribution of rights here occurs through legal devices that create a technofetus (Boltanski, 2004) and which are integrated into networks of circulation of identity in terms of biosociality.

Pro-choice

The same themes were repeated among the speakers in favor of ADPF 54, although with opposite approaches. The concept of **life** was symmetrically associated with **brain death**, the defining mark of death in Brazilian law. José Aristodemo Pinotti, a professor of obstetrics and gynecology and a federal Congressman (Democrats – Democratas; DEM) said: "An anencephalic fetus has no brain, no potential for life " (28th of august, p.42). Similarly, Rafael

Thomaz Gollop (SBPC, gynecologist and obstetrician) noted that: "The anencephalic fetus is a brain dead but has a heartbeat and is breathing.... It has no cortical activity... [and] has is only in a state of vegetative survival" (28th of august, pp.54s). The representation of the anencephalic fetus is that of an ambiguous figure: a dead body that is nevertheless breathing and demonstrating a heartbeat.[22] According to Lia Zanotta Machado (Feminist Health Network – Rede Feminista de Saúde – and senior anthropology professor), there would not "even be any **legal interests** to consider" because the expected child will not legally appear (4th september). Gollop quotes the CFM resolution on brain death, applying it to anencephalic fetuses: "Infraspinal signs of reactivity – ie., breathing and heartbeat – do not prevent a diagnosis of brain death" (28th of august, p. 54). Signs of vegetative life are not enough to avoid a diagnosis of brain death: the identity of a living human being depends upon the verification of cortical activity, thus invoking another sign produced by the biological body in support of a position regarding the status of anencephalic fetuses.

The **human condition** of this fetus is questioned: "this baby will not think and it will not be a human person the law protects" says Luiz Roberto D'Avila of the CFM (28th of august, p.4). In the words of Gollop (SBPC), "it has no skull or brain. Therefore, it cannot have any kind of feeling, because there is no station to process this" (28th of august, p. 56). The lack of the possibility of creating human relationships, represented by feeling and thinking, shifts the anencephalic fetus away from human personhood as protected by law. Claudia Werneck, representative of the School for People: Communication and Inclusion (an NGO that works towards the social inclusion of people with disabilities) established the crucial point for the defense of terminating anencephalic pregnancies. After stating that "humanity" is a "not subject to gradations" (4th of september, p.14), she rejected the classification of anencephalic fetuses as **disabled people**, citing the UN Convention on the Rights of Persons with Disabilities, which "assumes.... the presence of life even in the form of expected life" (p. 15). Lack of extra-uterine life expectancy excludes anencephaly from the category of disability. **Life** expectancy or **viability,**

22 In order to deal with this ambiguity Penna avoids using the term "biologically active organism" in an article that questions the criminalization of abortion of anencephalic fetuses. Penna compares the anomaly to brain death and thus avoids the contradiction between dead person / living organism (2005).

associated with the presence of **rationality** or **consciousness**, characterizes the **human person**. The overall lethality of anencephaly was affirmed in order to refute the claims that terminating these pregnancies was a denial of the right to life and discrimination due to disability. Rabinow points to the circulation of terms of identity and sites of restriction in the constitution of biosociality (1999, p. 143). In the case of anencephaly, we can see the restriction in terms of the denying anencephalic fetuses identity as living human beings due to their not being expected to live (not being viable) and also due to their lack of awareness and rationality. The pro-choice position questioned the biolegitimacy of anencephalic fetuses: if there is no viability, there is no value to life, nor could one speak of biological citizenship.

The absence of the potential for life justifies the avoidance of the use of the term "abortion": there would be no interruption of pregnancy if the fetus was already dead. Since the fetus was "stillborn" the procedure to remove it would be properly known as the "therapeutic anticipation of delivery in order to save the mother's life", or so concludes Talvane Marins de Moraes of the Brazilian Psychiatric Association (16th of september, p. 33). According to anthropologist Debora Diniz (professor of bioethics, Anis NGO), the therapeutic anticipation of delivery is an "anthropological portrait" of the experience of these women, who talk of anticipating the birth of a fetus which would not survive (28th of august). Speakers who presented a technical description of anencephaly emphasized the mortality of the syndrome, the confidence of diagnosing it in the first trimester of pregnancy via ultrasound (an exam available in the Brazilian public health system) and its high frequency of occurrence (one birth in a thousand: the main cause of congenital malformation in the first three months of pregnancy). These speakers also questioned the diagnosis of anencephaly in Marcela de Jesus, as did the representative of the Brazilian Society for Fetal Medicine, Heverton Neves Pettersen (28th of august). Contesting the view that folic acid was a means of preventing anencephaly, Salmo Raskin of the Brazilian Society of Genetic Medicine stated that adding it to pregnant women's diet would reduce the cases of anencephaly between 10 and 40%. This would not extinguish the problem, due to a number of factors. Raskin also noted that, depending on the percentage of defects (20-40%), anencephalic fetuses should not be used for organ donation purposes (28th of august).

The suffering of pregnant woman and their families was mentioned by the pro-life speakers, but the risks of anencephalic pregnancy were omitted or minimized, a point emphasized by pro-choice speakers when they talked about the medical perspectives and the women. Representatives of scientific and professional associations and councils Luiz Roberto D'Avila (CFM), Jorge Neto Andalaft (FEBRASGO) and Gollop (SBPC), as well as Federal Deputy Pinotti (a specialist on gynecology and obstetrics), talked about the increases in morbidity and risk during anecephalic pregnancies and childbirth. They pointed to complications such as polyhydramnios (excess amniotic fluid), toxemia, hypertension and diabetes, placental dislocation, fetal positions that make delivery difficult, premature birth, prolonged gestation, no uterine contraction (requiring hysterectomy), and emotional impacts. Talvane Marins de Moraes of the Brazilian Psychiatric Association likened compared forcing a woman to carry out a anencephalic pregnancy to torture and remarked that this could trigger a serious psychiatric condition (16th of september). The researchers presenting the point of view of the women emphasized the emotional impact, which they felt was analogous to the "experience of torture". They said torture would not so much be in the anencephalic pregnancy itself, "but in the duty to maintain the pregnancy solely in order to bury the child after birth" (Debora Diniz , 28th of august, p. 61).

Mentioned was made of the value of the pregnant women's **human dignity,** a "constitutional democratic principle" that would not be observed in those cases where women opted to end anencephalic pregnancies under the current law (Maria José Rosado Nunes Fontelas of the NGO Catholics for Choice 26th of august). **Autonomy** was the main value that guided this group, expressed as a choice., and this them was emphasized by many of the pro-choice speakers. Bishop Carlos Macedo de Oliveira of the Universal Church of the Kingdom of God founded the **right to choose** in theology: "God gives every human free will. We argue that in these cases, the will of the woman undergoing these circumstances should prevail" (26th of august, p. 12)[23]. Those speakers focusing on autonomy referred to the woman or the doctor who was caring for her, given that authorization to end an

23 Gomes (2009) describes the relationship between the pursuit of "life in abundance", as defended by the IURD, to family planning. This creates a more flexible position with regards to abortion, which is seen as being necessary under certain circumstances. On the other hand, the disposition of this churches' representative centered upon the autonomy of women, whose rights and health were under threat.

anencephalic pregnancy depended on a judicial decision made by an external body. Jacqueline Pitanguy (CNDM, CEPIA, Citizenship and Reproduction Committee) claimed that the **right to choose** was private ethical matter: it was not the State's right or responsibility to interfere in intimate decisions about risks to individual health. The State's proper role was to respect diversity and guarantee the fundamental principles of the Constitution (4th of september). To not give the right to choose to terminate a pregnancy of this kind would be to treat women as things, said Maria José Rosado Nunes Fontelas (26/08). Health justice Jose Gomes questioned whether the lack of the right to terminate an anencephalic pregnancy didn't constitute the "political control of women's bodies" (4th of september). Salmo Raskin of the Brazilian Society of Genetic Medicine said that the "couple" should undergo genetic counseling after verification of the anomaly, in order that they might make an informed decision (28th of august). Luiz Roberto D'Avila of the CFM commented on the current impossibility of properly orientating couples due to doctors' dependence of the judiciary: "we are absolutely hostages of judicial decisions" (p. 4). He emphasized the need for greater respect for autonomy (28th of august, p. 5). Eleonora Menicucci de Oliveira of the NGO Conectas Human Rights and the Human Rights Center denounced the "humiliating and embarrassing process... through which women decide to terminate pregnancies of anencephalic fetuses in Brazil." Such women need to ask permission from a public power (the judiciary) in order to have a "reproductive right" that should be "private in nature" – private for the couple and, ultimately, for the woman herself, given that it is in her body that pregnancies are generated and born to term (16th of september, p. 17). Lia Zanotta Machado pointed out that certain judges and prosecutors refuse to authorize the procedure (4th of september). Talvane Marins de Moraes put forward the position of the Brazilian Psychiatric Association: "in the name of women's mental health" he defended "the mother's right to choose therapeutic early delivery in cases of pregnancy with anencephalic fetuses" (16th of september, p. 33). Nilcéa Freire, justice of the Special Secretariat for Women's Policies, presented the view of the National Council of Women's Rights that women need top have the right to make an informed and untrammeled choice in order that "women be seen as subjects of rights" (16th of september) .

Dumont's analysis (1997) of the individualistic configuration that is characteristic of the values of modern Western culture can be very fruitfully

applied to discussion of **rights**.[24] Women are individual subjects of rights, and the rights of a higher social power such as the State or a religion cannot compromise these rights, given that this would damage autonomy/freedom, which is understood to be a supreme value in the modern West. On the other hand, this configuration values can also create conflict between the rights of two individuals. An example of this can be seen in Jacqueline Pitanguy (CNDM, CEPIA, CCR) charges that a woman's lack of legal permission to terminate pregnancy in the case of an anencephalic fetus is "serious disrespect of her rights". "Here we see a *conceptus*, an act of conception that precludes any possibility of life prevailing over the right of a fully capable citizen to make decisions about her life and deal with any resulting consequences" (4th of september, p. 62). Jorge Neto Andalaft (FEBRASGO), by contrast, focused on the rights of doctors. According to Andalaft, the interruption of an anencephalic pregnancy "is a right of citizenship" to be requested by a pregnant woman from, her gynecologist, who is "her partner, her confidant, her caregiver" (28th of august, p. 11). The pro-choice side of the debate also sought to permit a variety of women's decisions regarding anencephalic pregnancies, ensuring the right to opt for interruption as well as to continue the pregnancy. "The right to choose is what makes effective the rights of women to reproductive health and to physical and mental health in the event of a fetal anomaly incompatible with extra-uterine life," said Eleonora Menicucci de Oliveira (16th of september, p.16). The Brazilian Psychiatric Association argued that women in this situation are entitled to government health assistance, especially with regards to their mental health (Talvane Marins de Moraes, 16th of september). Finally, Jacqueline Pitanguy brought up two specific rights violated in this particular context:

> 1) The right to health, established by the Constitution as a universal right and a duty of the State, taking into consideration physical risks and emotional consequences;
> 2) Access to the progress of science, as included in the Universal Declaration of Human Rights, given that ultrasound can diagnose fetal anencephaly at 12 weeks after conception (4th september).

24 The cardinal points of the ideology of modern western society are equality and liberty and the presumption of the unifying principle of the human individual, with each individual representing the essence of humanity. The individual is "almost sacred, absolute; nothing exists beyond his legitimate exigencies; his rights are only limited by the identical rights of other individuals" (Dumont, 1997, p. 53). According to this view, society is nothing more than a collection of these monads.

Eleonora Menicucci de Oliveira recalled the norms of the UN Human Rights Committee: making it impossible for women to interrupt an anecephalic pregnancy is a violation of their human rights with regards to reproductive health and the right to be free from torture and inhuman or degrading treatment (16th of september). Here, Oliveira once again compares lack of choice with torture or degrading treatment. These denunciations may also take inspiration from the concept of biocitizenship.

Few speakers mentioned the problem of the **secular state**. Those who did were usually representatives of religious institutions. Most criticism was directed towards the Catholic Church. Representing a splinter group of the Church, Maria José Rosado Nunes Fontelas stated the need to "reaffirm" the secular nature of the Brazilian State, due to possible political pressure from the Catholic Church which had been "accustomed... for nearly four centuries, to believe that it represented the nation and the State" (26th of august, p. 22). Openly antagonizing Brazil's hegemonic religion, Carlos Macedo de Oliveira said that the Universal Church of the Kingdom of God, "understands the secularism of the State and respects and defends this, as well as the guarantee of freedom of worship, as determined by our Constitution" (26th of august, p 11)[25] The view generally expressed was that religion played a private role in modern secular society (cf. Berger, 1985): "To affirm the secular nature of the Brazilian State does not mean ignoring the importance of religion in people´s private lives and in the lives of our moral communities " (Debora Diniz, 28th of august, p. 62)[26].

ADI 3510 and ADPF 54: convergences in the debate

I would like to now trace some comparisons between the various stages of the ADI 3510 hearings and those of ADPF 54. First, let's look at the differences.

By proposing to legalize the therapeutic early deliver of anencephalitic fetuses, ADPF 54's stipulations related directly to the reproductive process. It dealt directly with the decision to carry pregnancies to term or not in a context where the parents are already anticipating the birth of a child, given

25 The Catholic Church played a large role in both of the debates I analyze here and I describe this in greater detail elsewhere (2010a). Machado's analysis of the theme of abortion (2000) reveals that the IURD has constructed an image public which contrasts with that of the Catholic Church.

26 With regards to religion in secularized contexts, "religion manifests itself in a typically modern form as a legitimating complex that is voluntarily adopted by a clientelle of their own free will. As such, it is localized in the private sphere of cotidian social life and is marked by characteristics that are typical of this sphere in modern society (Berger, 1985, p. 145).

that the diagnosis of anencephaly occurs around the third month of pregnancy. By contrast, the only reference to replication in ADI 3510 is indirect: surplus embryos from assisted reproductive that might serve as stem cell sources. The "genitors" who provided the germ material would not generally have reproductive use for it in this case, given that they had released their embryos to research after freezing them for three years.

The justification for the extraction of embryonic stem cells, (a procedure that involves embryo destruction) is that this might advance scientific knowledge and also allow for the creation of tissue replacement therapies. Political movements formed by patients are betting on these cells as a hope for a cure. Use of the embryos would thus benefit third parties. This argument is even used by those who oppose the use of embryos in research. Both the scientists at the ADI 3510 public hearing as well as the three justices who took part in it questioned this use of embryonic stem cells, on the grounds that this would transform embryos into a means while Kantian ethics clearly states that human beings are an end in and of themselves. The rationale for therapeutic early delivery of anencephalic fetuses, on the other hand, is that this would reduce the suffering of the mother and her family, given that they are aware of the lethal diagnosis.

In the public debates looked at here, we can identify three types of movements that attempt to constitute and support social subjects: the movement of patients who seek the right to health through biotechnological investment in such things as research into stem cells; the feminist movement, which defends women's autonomy in deciding about questions regarding reproduction; and finally there is the pro-life movement, which defends the right to life of embryos and fetuses and mobilizes against any form of abortion and manipulation of human embryos, whether in *in vitro* fertilization or in stem cell research. We can thus see, in the words of Rabinow, that we are dealing here with the "formation of new identities and individual and group practices that have emerged from these new identities" (1999, p. 147). We also see displayed the individualizing and collectivizing aspects of biocitizenship (Rose and Novas, 2005): collectivizing with regards to the formation of these movements that mobilize around the rights of fetuses or embryos, women and patients: individualizing with regards to the recognition of somatic identities, such as the unique genetic identity of an embryo in a laboratory or the identity of anencephalic fetuses as representative of human biodiversity. It is precisely this individuality that, in the pro-life perspective, make both fetuses and embryos the subjects of rights.

In the discussions surrounding ADPF 54, the figure of the mother repeatedly appeared as one of the principal protagonists of the case. Here, we saw a clash between two subjects of rights: the pregnant women and the anencephalic fetus. It was discussed whether or not early delivery was justifiable in these cases, which would mean ending of life process of the anencephalic fetus in order to reduce the mother's suffering. Pro-life arguments situated the fetus' right to life in relation to the mother's suffering in such a way that the prerogatives of the fetus encompassed the mother's right to well-being. Those who favored the pro-choice approach argued that there was no reason to protect a totally nonviable fetus that had next to zero life expectancy outside of the womb. The context of the ADI 3510 was different precisely because issues regarding pregnancy weren't involved. Scientists opposed to the use of embryos in research referred to the mother only in order to affirm the autonomy of the embryo in relation to her, accentuating the embryo's capacity to develop by itself in accordance with its genetic programing. Those who favored to the use of embryos in research attempted to shift the debate away from issues related to abortion in order to avoid issues of illegality: this was the position of Supreme Court justices and of the scientists. In this debate, the uterus appears only as a means of signifying the embryos' viability, given that only when said embryos are inserted in this environment are they able to develop as living beings.

If the contexts of ADI 3510 and ADPF 54 are different, what about the similarities of the arguments and ideas that were expressed in the two hearings? Four speakers were present at both public hearings. The definition of the statute of extra-corporeal embryos and anencephalic fetuses joined the principal points of the two debates. Are they alive? Are they people? With respect to the concept of life, the scientists at the ADI 3510 hearings who were against the use of human embryos in research highlighted the embryo as "living" *in vitro*, based on its active biological processes and its active genome. Those who favored the use of embryos in research tried to deconstruct this concept. They argued that life is a process in which the gametes that originated in the embryo are already living cells. The quality of "living" cannot thus be attached to an individualized embryo, which needs to be implanted in a uterus in order to develop into a life. Finally, the pro-research side emphasized relativistic positions, saying that beliefs vary from religion to religion and culture to culture. The pro-research side also compared the condition of the supposedly live embryo in the lab to that of the really, truly live patients

who were in dire need of the therapeutic techniques which stem cell research could develop. Why were the lives of these real human beings less important than the notional life of an embryo? In the debates surrounding ADPF 54, the efforts of the pro-life side were concentrated on showing that anencephalic fetuses were, in fact, alive while the pro-choice side refuted this alleging brain death. They claimed that in the absence of a juridical interest that needed to be protected (life), therapeutic early delivery could not in any way be considered abortion. In this flow of biological and legal meanings which establish social identities, we can clearly see examples of Rabinow's claim (1999) that nature is reshaped through culture and becomes artificial.

In the debates surrounding ADPF 54 as the ADI 3510, it is questioned whether or not the *in vitro* embryos and anencephalic fetuses are people, with all the rights and obligations attending to this status. The representation in both cases is that of the individual as described by Dumont (1992): an asocial, atomic being disconnected from any relationship. The frequent deletion of the mother from theses debates is due to the emphasis given to the fetus or embryo.

Here we find the value of life itself being debated: is human life sacred? The sacredness of life is a relevant question for lawyer and legal philosopher Ronald Dworkin, who distinguishes it from personhood, and also for anthropologist Didier Fassin, who points out that the value and the meaning of life and the concept of biolegitimacy are the foundations of biocitizenship both in the design of life in general and in the concept of lives are sacred. The relator of ADI 3150, Justice Carlos Britto, said: "What is sacred in religion corresponds to what is inviolable in law"[27] Human life is inviolable and therefore sacred. In these cases hangs the question of whether the life of an anencephalic fetus should be more sacred than the pregnant woman who carries it, or whether the lives of frozen embryos have more value than the individuals who would benefit from their destruction in research. The comparison of the two cases reveals the articulation of the pro-life movements, which brings together issues such as the use of embryos in research and permission for abortion. The concept of sacred human life unites the two debates: the mother's life is sacred, so she must have the right to choose; the life of anencephalic fetus is sacred and it should have the right to life. The

27 The debate produces new sacred biological beings: in the ADI 3510 hearings, three justices (Carlos Britto, Carmem Lúcia and Ricardo Lewandowski) refer to the UNESCO declaration on the human genome, which proposes a new intangible entity, "the genetic patrimony of humanity".

same equation holds for frozen embryos itself and those patients who are the potential beneficiaries of the research conducted with them.

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