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# A Regulatory Void? Reprogenetics in Portugal

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## Introduction

The issues related to the manipulation of human life, in particular those connected to health and reproduction, set the stage for this case study. The focus is on the current debates on embryo research and its links to the regulation of Medically Assisted Procreation (MAP) in Portugal. This case, which, at the time of writing, is still an "open" case, is particularly interesting from three points of view. First, the case offers a privileged entry point into one of the most controversial issues in "policy for science"; secondly, it provides a particularly interesting example of the interaction [?]of "policy for science" and "science for policy" and of the actors and dynamics involved in it; thirdly, the explicit links of this debate to European and global attempts at defining common frameworks for the governance of the manipulation of life – and of human life in particular – makes it an interesting instance of the articulation of scales (national, European, global) in the governance of science and technology. The case allows a fuller characterization of the organization of research in the Portuguese context, and of its links to health and medicine, to ethical debates, to the legal field and to policy-making.

## 1. Background: the rise of reprogenetics[1]

The 25-year period since the birth, in Britain, of Louise Brown, the first “test-tube baby”, has witnessed the remarkable development of a range of techniques associated with the manipulation of reproductive processes and an improvement in the effectiveness of methods of medically assisted procreation in humans. These techniques now include in vitro fertilization, embryo transfer, gamete intrafallopian transfer (GIFT), intracytoplasmic sperm injection (ICSI), the cryopreservation of embryos and sperm, and, more recently, of ovocytes, preimplantation diagnosis and somatic cell nuclear transfer; they have made possible practices such as sperm or egg donation, surrogate motherhood and the selection of embryos before implantation through Pre-Implantation Diagnosis. These techniques and practices correspond to unprecedented articulations of genetic knowledge and practices of cell and tissue manipulation that allow women or men diagnosed with different forms of sterility to conceive children. In

[1] This section draws extensively on Nunes, 2003a.

addition, they carry promises of a growing capacity of early detection of potentially fatal or severely impairing conditions in embryos, thus allowing a selection of viable embryos among those generated by some of the above mentioned techniques. More recently, the newly christened field of "reprogenetics" – the coupling of "genetic, nuclear transfer and stem cell technologies" which "will potentially provide powerful tools for preimplantation genetic profiling, h(uman) E(mbryonic) S(tem) cell alteration, and germ line therapy" (McLean, 2001: 205, note 1) – has been hailed by some as promising future inroads into a medicine that would become not merely curative or predictive, but regenerative, and denounced by others as bringing with it a dangerous potential for all kinds of ethical abuses in the manipulation of human life and for new forms of eugenics.[2]

A significant consequence of the developments in this field (as a technical requirement of all the techniques involving in vitro fertilization and embryo transfer) is the production of human embryos in excess of those which are implanted in women who desire a pregnancy. These “excess” embryos are cryopreserved and either implanted at a later stage in the same women for further attempts at a pregnancy, donated or stored up to five years, after which they would no longer be viable and would somehow have to be disposed of. Proposals arose for a number of the latter embryos to be used, under certain conditions, and subject to strict ethical and legal standards, for research on the embryo itself and on its development, on the reproductive process in order to improve medically assisted procreation, or for research related with severe diseases. The growing number of scientific studies pointing towards the role of embryonic stem cells in understanding both cell differentiation and proliferation and possible conditions for the regeneration of damaged tissues or organs turned these excess embryos into a scarce and coveted resource for biomedical and biological research. It is hardly surprising, then, that the debate on how to regulate MAP often ended up confronting head on the issue of the status and potential uses of the human embryos which were one of the outcomes of MAP techniques. And it should be added that this debate encouraged the

[2] For useful accounts of these developments and debates, see Holland, Lebacqz and Zoloth, 2001; McGee, 2000; Maienschein, 2003. Techniques of medically assisted reproduction and their social and ethical implications are discussed in detail in Testart, 2003. For social scientific studies of MAP and of its implications for the experience of women and for conceptions of parenthood, kinship and identity, see Strathern, 1992a, b; Franklin, 1997; Cussins, 1998a, b, Steinberg, 1997. On surrogate motherhood, see Ragoné, 1994. For discussions of the ways in which the new possibilities of manipulating life are shaping

search for ways of producing human stem cells for research and therapy that would not involve the creation of entities with the potential to become human beings – for instance, through the harvest and culture of adult stem cells, of cells from umbilical cord blood, or through the creation of "quasi-embryos" using somatic cell nuclear transfer.

The debates and controversies on the threats and benefits associated with developments in this field, and, in particular, the ethical and legal issues raised by them, mobilized a number of actors in countries where the capacity for developing this area and the will to do so was present. This was the case of most European countries and of the United States and Canada, among others. The issues were also brought to international fora, such as the United Nations and their organizations (such as UNESCO), the Council of Europe or the European Parliament. These institutions produced several documents which aimed at providing a common framework for the regulation of practices involving the manipulation of human life, such as the Universal Declaration on the Human Genome and the Rights of the Human Person (proposed by UNESCO in 1996) or the Convention for the Protection of Human Rights and Dignity of Human Being with Regard to the Application of Biology and Medicine (Council of Europe, 1996), subscribed to by 21 countries in Oviedo, Spain, in 1997.

Techniques of medically assisted procreation have been, from very early on, at the centre of a number of ethical and legal controversies. Even after the legitimacy of intervening to "correct nature" in situations of infertility became consensual, questions remained concerning the legitimate scope of these interventions and their implications for current definitions of parenthood, kinship and personal identity. Issues such as sperm donor insemination, "distributed" motherhood (one woman providing the egg, another one carrying the pregnancy to term) or surrogate motherhood were prominent topics of controversy. The definition of the conditions under which techniques of medically assisted procreation could be accessed was a matter of debate as well. Should MAP techniques be seen as a subsidiary resource, to be drawn upon when "natural" conception could not take place? Is MAP a therapeutic intervention meant to be used only in cases of clinically diagnosed infertility (male or female)? Or should it be offered to single women and to lesbian couples as well as a means of access to parenthood in

understandings of kinship and reproduction, see, besides the works by Strathern, Franklin and Ragoné,

the absence of a heterosexual union? Should donor insemination or surrogate motherhood be allowed? And if yes, can it be subject to payment? How to define who the "real" mother and father are in situations of "distributed" conception, pregnancy and delivery? Should pre-implantation diagnosis of embryos produced through in vitro fertilization be allowed as a means of selecting "healthy" embryos? And if yes, with which kinds of anomalies? Should the costs of the use of MAP by infertile couples be covered by the public health sector and by health insurance? How and by whom should this field be regulated?

As if these issues were not complex enough, further developments in the field of reprogenetics and, in particular, new horizons for research on human reproduction and human genetics generated heated debates and controversies over the promises and uses of genetics and biotechnology, bringing to the fore a range of broader social and moral questions:

- Are the new lines of research morally acceptable to those who are funding them and who will have to live with both the beneficial and harmful consequences of this research?

- Should public funds be awarded for research that is controversial and likely to be morally questionable for a considerable part of the population?

- Should private entities be allowed to carry out this kind of research - or, in other words, is the public/private divide relevant when these issues are at stake?

- Do the research orientations under discussion correspond to collectively defined priorities in the allocation of intellectual and material resources according to criteria of justice and equity?

- Who is entitled to discuss these matters and make decisions on them?

These questions frame a discussion that is exemplary of the intermingling of the scientific, the political, the social, the economic, the cultural, the legal and the ethical which is a defining feature of the objects and practices of the life sciences as we know them today.

1998.

The recent development of stem cell research and cloning and, more generally, of what is now described as reprogenetics and regenerative medicine raise specific problems with considerable ethical implications, such as:

- The status of the embryo as a moral entity;
- The totipotency of the embryo *versus* the pluripotency of embryonic stem-cells and the implications of the acceptance of this difference for the acceptability of research using human embryos;
- The issue of deriving *versus* creating fetal tissues for research;
- The relationships between the sources of embryo tissues (abortion, IVF, somatic cell nuclear transfer) and research;
- The legitimacy of creating hybrids of human/non-human cell lines;
- The public/private distinction in funding and regulation;
- The acceptability of public funding of human embryonic stem-cell research.

To these one may add questions on the very definition of the need, desirability or priority of these directions of research when placed alongside pressing needs for health care, reproductive rights of women, reproductive rights and access to reproductive technologies by LGBTs (lesbians, gays, bisexuals and transsexuals), public health campaigns, particularly for the poor, marginalized and excluded and disabled people and for populations of the Southern hemisphere. The problems of the distribution of benefits and hazards associated with the new technologies and the new forms of inequality that may arise from them in terms of access or new forms of discrimination based on biological "fitness" require as well that issues of justice be brought into the discussion. Besides the question of who is to be admitted to the definition of the issues at stake and to debate and deliberation (and who is to decide on criteria of participation), there have been criticisms of the focus on the moral status of the embryo, for instance, and the relative neglect of discussing them in relation to the status of women, It is important to follow the rhetorical shaping of these debates, namely the extent to which it is possible for participants to agree on the *topoi*, the commonplaces that provide some shared ground for agreeing and disagreeing, as well as the arguments brought forward

by different participants, to state their points of disagreement. It should be noticed, however, that whereas some of these problems are likely to be the object of debate and deliberation, others seem to be rooted in ethical stances that appear as incommensurable. Different countries have taken different approaches to deal with these controversies, and many have created legal frameworks, advisory boards and public fora for debate and deliberation. Others, like Portugal, have been living for almost two decades in a peculiar situation where a legal void coexists with an extensive use of a range of available techniques for medically assisted procreation and, as a consequence, with the production of excess embryos.

## 2. Portugal: reprogenetics in a legal void

### 2.1. From bioethics to biopolitics: a winding path

In the mid-1980s, in Portugal, interest arose among legal scholars in the new technologies for assisted procreation and their legal and ethical implications. The French experiences in this field were followed with particular attention. In fact, the French *Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé* was a central source of inspiration for attempts at creating a similar advisory body.[3] The legal field was, in fact, the stage of the first attempts at outlining a regulatory framework for MAP. In May 1986, the Portuguese Ministry of Justice created a committee in charge of the drafting of proposals for a legislative framework on MAP. In July 1987, the committee delivered to the Government drafts of laws on the use of techniques of medically assisted procreation, centres for assisted procreation and the creation of a National Council for Bioethics. The results of this work were published, but no legislative initiatives were taken after it (Comissão para o Enquadramento Legislativo das Novas Tecnologias, 1990).

Only in 1989 did the Portuguese Parliament vote on the law that created the National Council for Ethics in the Life Sciences (CNECV), defining its objectives, its composition and the modes of nomination of its members. The Council was granted independence from Government and Parliament, its role being that of producing advice

on matters related to the fields of the life and biomedical sciences involving ethical issues, at the request of entities which included the Government, the Parliament, professional bodies or citizens.

The first proposal for the creation of the Council came form the Parliamentary Group of the Socialist Party, then in opposition. All parliamentary parties welcomed the proposal, which was meant to be, according to its proponents, a crucial step in dealing with "the moral problems raised by scientific progress in the fields of biology, medicine or health in general" (Melo in Archer et al, 1996: 287).

The composition of the council was a lively theme of debate in Parliament. Some advocated a composition along the lines of British and American advisory bodies, restricting membership to biologists and physicians. Arguments in favour of this position stressed the need to avoid obstacles to the reduction of the lag between scientific advances and the production of legal and regulatory frameworks, which, according to the proponents of this view, would inevitably arise from the presence of a disparate set of approaches and concerns. Others favoured an orientation inspired by the "French" model, towards a more inclusive body, with the presence of legal scholars, philosophers, ethicists and spokespersons for different religious orientations.

Concerns with the lack of regulation of areas such as transplants and organ donation, practices associated with assisted reproduction, definitions of death and the prevention, diagnosis and therapy of hereditary diseases were voiced by all the participants in the debate. Socialists in particular were careful to point out that regulatory interventions were urgently needed, but that they should not be turned into obstacles to scientific research. New forms of regulation were needed, however, particularly in some areas of medicine, where established forms of professional regulation were likely to prove inadequate. But the most precise and concise statement of the new conditions requiring new regulatory approaches was to come from a communist MP:

> "(…) in this world of ours, admirable but terrible as well, you may be born in vitro and die as a consequence of having your last breath determined by switching off a machine; it is possible to procreate without sexuality, to conceive without generation, to generate without

[3] This influence is clear in one of the first publications by a Portuguese author – the current chair of the

> having conceived, to have not one but two mothers – the mother who provided the egg and the mother who offered her uterus -, to be the son of a donor father who is part of a specific [sperm] bank (…). Nowadays, the humblest candidate to motherhood may have well-founded expectations to conceive a son of the Nobel Peace Prize laureate or of the persecuted author of the *Satanic Verses* or, more domestically, of Prime Minister Cavaco Silva (why not?)". The same MP criticized the Government for its failure to respond to the urgency of legislating on these issues, thus putting Portugal at risk of becoming a "genetic haven", like some "genetic Monaco, a simile of Silicon Valley, right here, on the edge of Europe, where everything can be done, that is, on the one hand, garbage, on the other hand the most sordid trade in embryos, unruly experiments, not allowed in the F(ederal) R(epublic of) G(ermany), in France, in Italy and in Spain, but tolerated in Portugal, because the Government does not know, there is no council, or because nobody cares" (José Magalhães, MP, Communist Party, in Assembleia da República, 1990).

At this stage, the actors involved in this process were basically in agreement on the need to regulate the field of research and medical uses of the life sciences, addressing ethical concerns without raising hurdles to scientific research and the development of new diagnostic and therapeutic resources. Ethical concern, political responsibility and support for scientific progress were shared premises of any further steps towards creating adequate legal and regulatory tools and institutions, and as shared commonplaces or *topoi* of subsequent debates. The creation of an advisory council or committee in charge of addressing ethical issues was a matter of consensus as well, although disagreements were apparent on the composition of such a body. These disagreements were related to the relative weight given to the concern with regulation and with the definition of the conditions and constraints of research and medical practice and to the priority given to the promotion of scientific research and the use of emerging technologies. Whereas the first orientation seemed to point towards a more precautionary approach to what Michel Foucault (Foucault, 1976) called biopolitics and a more heterogeneous and inclusive composition of the council, in order to balance different interests and concerns, the latter favoured a council of experts in the life and

CNECV) – on the legal aspects of MAP (Silva, 1986).

biomedical sciences, allegedly less prone to let themselves get entangled in discussions of matters seen as potential hurdles to the development and use of fast-developing technologies. Mistrust of the capacity of law to respond in a timely and adequate way to regulatory needs in an area undergoing rapid change was a common way of expressing the concerns underlying this position. As we shall see, in the wake of the creation of the Council and of the first documents produced by it, both the space of argument and the alignments of actors within that space underwent some significant changes.

The Council was finally created as an interdisciplinary body, including members with a background in biology, medicine, law and ethics. It included five personalities appointed by the President of the Republic, "taking into account the main ethical and religious currents" (Assembleia da República, 1990). The Parliament appointed five members as well, the Government three and, finally, each University involved in teaching the biomedical sciences was entitled to nominate one member, with experience in teaching and research in the area, chosen by its scientific board. The President also chose one of the members of the Council to be its chair.

The Council started its activity in 1990, chaired by Luís Archer, a pioneer of molecular biology in Portugal and a Jesuit priest. A distinctive feature of the Council from its inception was the strong presence of Catholic physicians, generally with a conservative orientation.[4] The first document issued by the Council (1991) was a statement on transplants of tissues and organs.

Some legal instruments regulating medical acts or the conditions under which the harvesting of organs in human beings were to be allowed did mention the need to draft specific laws regulating MAP techniques and practices such as the donation of eggs and sperm, and the transfer and manipulation of human embryos. But only in 1993 did CNECV publish the first of a series of documents on MAP and related issues, an advisory report on the ethical principles to be followed in MAP. Another report, in 1995, insisted on the need for specific legislation on the human embryo, and advised that the production of human embryos for the purpose of research should be forbidden. These were followed by reports on the legal protection of biotechnological inventions,

[4] For exemplary statements of catholic members of the Council, see Archer, 2000; Archer et al, 1996; Osswald, 1999; Silva, 1997). The documents produced by the Council are published (Conselho Nacional

on cloning and on medical approaches to in vitro diagnosis (all in 1997), on the therapeutic use of biological products (1998) and, in 2000, on the human genome. All had some bearing on issues related to MAP and the status of the human embryo in relation to research. As we shall see, however, a failure to move from bioethical advice to the production and enforcement of legislative and regulatory frameworks on matters such as MAP and research with human embryos – has emerged as a conspicuous feature of the landscape of biopolitics in Portugal.

## 2.2. How to govern Medically Assisted Reproduction?

From the mid-1980s onwards, the offer of MAP increased both in public and private clinics, thus making the definition of a regulatory framework a matter of urgency. At the time of writing, there are at least 6 public health units and 13 private clinics offering MAP techniques. In fact, the calls for establishing a legal framework for MAP were based on awareness of the growing demand for these services, on the one hand, and of the limits of professional self-regulation (with reference to the deontological code of the Medical Association), with some clinics defining their own ethical guidelines. Since 1985, when the first pregnancy was achieved through artificial insemination of a woman with her husband's sperm, a whole of techniques were introduced, including the cryoconservation of sperm in liquid nitrogen, donor insemination (both in 1985), in vitro fertilization (1986), GIFT (1987), ICTI (1994), pre-implantation diagnosis (1998), and the "washing" of sperm of HIV-positive men (1999). It is interesting to notice the use, since 1987, in a public clinic in Coimbra, of GIFT, a technique that does not require the production of embryos outside the woman's body. This option has been strongly supported by more conservative bioethicists as a way of preventing the problem of excess embryos, although it is not the most widespread technique and its use depends on the specificities of the diagnosis of the situation of infertility or inability to conceive.

The first legislative initiative in the field was drafted in July 1997, under the Socialist government. The project was endorsed by the CNECV and presented by the Government to Parliament, where it was voted favourably with some amendments, on

de Ética para as Ciências da Vida, 1992-1998) or can be accessed at the Council's website

June 17, 1999 (DL nr. 415/VII), with the abstention of PSD (the liberal party) and the opposition of the Communist and Green Parties.[5]

The decree defined who was entitled to access to MAP techniques, as well as who was legally authorized and qualified to deliver them. It specified as well the legitimate purposes of the use of MAP and those that were forbidden. Surrogate motherhood and the use of MAP techniques for human cloning or the deliberate creation of embryos for the purpose of scientific research were specifically ruled out, as were the use of PID for choice of certain characteristics of embryos, such as sex. Article 7 excluded the possibility of using embryos for scientific research or experiments, although the version voted in Parliament qualified this prohibition through the addition of the adjective "viable" to "embryos". Research on a given embryo would be allowed only if its results were to be beneficial to that embryo. The same article allowed PID only if the techniques used were of "recognized scientific value in terms of the benefits for the embryo arising from them. Matters such as the rights and duties of users of MAP, consent, confidentiality and the creation and keeping of records were defined in detail as well. Specific chapters focused on artificial insemination (Chapter III) and in vitro fertilization (Chapter IV), two techniques raising particularly thorny issues for the definition of motherhood and fatherhood.

Chapter IV was at the origin of the opposition of experts in MAP and of the Portuguese Society for Reproductive Medicine because of the restrictions it imposed on the number of embryos to be created through IVF. Article 20 stated that in "in vitro fertilization there should be no room for the deliberate creation of excess embryos" (the government's proposal was even more restrictive: it did not include the expression "deliberate"). Thus, the maximum number of eggs to be inseminated should not exceed the number the users had agreed upon as being transferred, but (and this was added by Parliament) up to a maximum of five. This article put severe constraints on the conditions for performing MAP. But Article 21 was even more strict: all embryos produced through in vitro fertilization "ought (*devem*) to be transferred to the uterus, and their destruction is not allowed". The following paragraphs did recognize the

(www.cnecv.gov.pt).

[5] For a detailed discussion of the legal aspects of the proposal, and of the differences between the document submitted by the government and the one that was voted by the majority of members of Parliament, see Duarte, 2003: 75-137.

possible existence of reasons for non-compliance, thus admitting the cryopreservation of non-implanted embryos. Users would commit themselves to using them for new transferences within a maximum of three years. After three years in case, again, of non-compliance, and if duly justified, these embryos could be used, following consent of the initial users, by another couple. The lack of consent or of agreement between parties would move the decision on what to do with the embryos into a court of law with competence in family matters. Interestingly, no changes were introduced to this article by Parliament. Article 22 was clear in criminalizing the production of excess embryos and Article 23 displaced the decision on modes of storage and conservation of embryos to subsequent legislation.[6] In fact, the need to avoid the production of excess embryos was a point repeatedly made by the supporters of the decree during the parliamentary debate. This position was in line with the dominant orientation within CNECV. As the chair of the Council himself, Luís Archer, stated, a failed pregnancy was seen as a "minor evil" in comparison with the problem of producing excess embryos. The centrality of this concern in debates on the regulation of MAP was linked to opposition to uses of human embryos for research. The latter concern, in fact, could jeopardize the viability of most techniques of MAP.

Another relevant feature of the document (added by Parliament) was the proposal for the creation of a Committee for Orientation and Monitoring of MAP, with the role of collecting information on the practice of MAP and its results in Portugal and to assess and discuss the "global medical-sanitary and psycho-sociological outcome" of that practice. The final paragraph does not define the "organization, composition and functioning" of the Committee, leaving that definition to the Government after consultation with the CNECV and the Medical Association (Article 29). The model for the regulation of MAP this paragraph suggests is one where regulation is basically ensured through the legal system, with room for discretionary action by Government and an advisory role of the bioethics committee and of a professional association (which, in Portugal, has considerable power in regulating access to the medical profession and sanctioning violations of medical ethics). There is no reference to broader, deliberative or advisory spaces and, in particular, no role is explicitly assigned to the users (or, in the language of the legal document, the "beneficiaries") of MAP. The

[6] The same postponing of a decision to future legislation applied to the definition of the eligibility to egg donation (Article 26).

latter appear in the document as identical with patients, protected by informed consent. As we shall see, this framing of the user of MAP as patients within an authoritarian understanding of doctor-patient relationships (which informed consent does not alter) has shown signs, over the last five years, of changes which may have some bearing on the way the regulation of the field is discussed in the current debate.

As is mandatory under the Portuguese Constitution, the decree was sent to the President of the Republic for ratification. The President vetoed the law and sent it again to Parliament, for rediscussion and, eventually, further amendments. The reasons for the veto are interesting. Researchers and practitioners in the field of MAP opposed the decree, and were active in expressing their views in the media. These positions were backed by a document sent to the President by the Portuguese Society of Reproductive Medicine. Among the main arguments were the critique of the inadequacy of the definition of the maximum number of embryos that could be generated in vitro as part of MAP. According to these experts, the restrictions of the decree would actually compromise the viability of techniques relying on embryo transfers. This would have consequences both in terms of increased physical and psychological stress and suffering for users and in terms of the costs involved. Other criticisms included concerns with the observance of the principle of the anonymity of the sperm donors and the de facto outlawing of PID.

In May 2001, a group of specialists in MAP linked to several scientific and professional societies, including the Portuguese Society for Reproductive Medicine (SPMR), the Portuguese Society for Andrology, the specialist Colleges of Obstetrics and Gynecology and Medical Genetics of the Medical Association (Ordem dos Médicos) and the Biologist's Association (Ordem dos Biólogos), in response to an initiative of the SPMR, created a group whose aim was to cooperate with Parliament in the drafting of an adequate legislative framework for MAP. Among the proposals of this group was that of the creation of a national Council for Medically Assisted Reproduction, with a multidisciplinary composition, and with the tasks of monitoring the practice of MAP in both the public and private sectors and to advise on matters such as research projects involving human embryos. This committee should include a (still non-existent) patient association (Moutinho, 2003: 130-131). The group drafted a document which was sent to Parliament, but with no result. In the meantime, the Socialist government fell, and the

electoral victory, in March 2002, of a conservative coalition had little effect on the process. In fact, the Socialist Party presented in 2002 a new proposed law, whose first proponent was a former socialist Minister of Health. The document still included some of the points that had been singled out as reasons for the presidential veto. This project was to undergo some changes at a later stage. In September 2003, SPMR, now under a new leadership, sent to Parliament a document on the subject, which proposed changes to the document vetoed by the President, restated its definition of MAP techniques as therapeutic means to treat infertility in couples and its opposition to the use of MAP for other purposes, reasserted the prohibition of deliberate production of excess embryos and limitations to research with embryos in order to protect its dignity and recommended that WHO guidelines that define infertility as a disease be adopted in Portugal.[7] Another parliamentary party, the Left Block, presented a proposal as well (on this, more later). Beyond their differences, a common feature of all proposals was the creation of a specific body to carry out the monitoring and advisory activity related to MAP, although there are differences in the designation, composition and functioning of this body. We shall come back to this later.

### 2.3. The embryo on the spot…

In the meantime, the CNECV saw its activity suspended for almost two years, due to a delay in appointing new members and a new chairperson after the mandate of the previous ones came to an end. A new chairperson, the lawyer Paula Martinho da Silva (author of one of the first publications on the regulation of MAP, in 1986), was appointed, but the Council was slow in resuming its activities. Due to the need for the Portuguese Government to have a position on research with human embryos in international fora, a group of 16 "sages" was nominated by the Ministry of Science to draft a White Paper on the subject (Ministério da Ciência e do Ensino Superior, 2003). Again, the composition of the group was criticized for leaving out most of the specialists in the area. The White Paper was made public in February 2003, and was drafted by Daniel Serrão, a former member of the CNCEV and a supporter of the more conservative and restrictive positions on the matter. The White Paper purported to

[7] http://www.spmr.pt/documento/lei_rmc.pdf.

present a balanced view of the state of the art in the field and of ongoing controversies, particularly those concerning the status of human embryos and its implications for research on stem cells.[8] In Council of Europe meetings, which he attended as the representative of Portugal, Serrão aligned his positions with the more conservative proposals put forward by Germany. It should be added that, in the meantime, the Portuguese Society for Reproductive Medicine, which had supported a more "liberal" framework for the use of MAP techniques (including Pre-implantation Diagnosis (PID) for embryo selection for certain fatal or impairing diseases) and for embryo research, after the election of a council dominated by (scientific and political) conservatives, made public statements in support of a restrictive legal framework and the banning of PID and embryo research.

In November 2003, the European Parliament discussed and voted on a proposal by the European Commission (on 19 November) on the funding of research on human embryonic stem cells. The approaching end date (December 31) for the moratorium decided on June 2002 on this matter and the need to decide on whether embryo stem cell research should be funded within the 6th Framework Program had led the Commission to present a proposal of guidelines which took up some of the points included in a report to the EP Committee on Industry by German Christian Democrat MEP Peter Liese. Liese's report advocated the following conditions for allowing the use of human embryos for stem-cell research:

- No funding for human embryonic stem cell research would be allowed in those EU member states where such research was forbidden;

- Research would be funded only for research carried out on human embryonic stem cells donated before 27 June 2002 and which would otherwise be destroyed;

- Informed consent by the donor would be required, and no financial gain from research was allowed;

- Research would be supported only in the absence of "adequate alternatives" [presumably meaning stem cells derived from adult cell lines or other sources than human embryos];

[8] Debates on embryo research in other European countries have been going on or almost two decades. On

- The creation of a European registry that would reduce the need for deriving stem cells and duplicating research activities.[9]

The EC guidelines followed Liese's proposal of restricting the use of cell lines to those created before 27 June 2002, the date of adoption of the 6th Framework Program. Portuguese representatives were divided in their vote of the Commission's guidelines. Socialist and communist MEPs were generally in favour, arguing that it would be "hypocritical" not to support research that might prove crucial for the search for the cure of severe or lethal diseases, when there were still many doubts concerning the potential of embryo *versus* adult stem cells. Their position resonated with that of European patient associations and of researchers. Liberals and conservatives (the parties supporting the government coalition), expressed several concerns with the implications of adopting the guidelines.

For conservative and liberal MEPs, the principle of subsidiarity was at stake in the Commission's proposal, since the latter would mean that the research under discussion would be funded by the money of taxpayers of all countries of the Union, but only in those countries which allowed that research. Another MEP justified his negative vote stating that "the embryo is a human being and the funding of research on it may have the perverse effect of creating more excess embryos" (Público, 20.11.03: 37). It is interesting to notice that this divide is more strongly aligned with a left-right political divide than in other countries (such as Germany or Spain), where party membership is not a reliable predictor of position towards stem cell research. The Commission's proposal was passed with 298 votes for, 214 against and 21 abstentions, and no time limit was set for the cell lines that could be used. According to some of the supporters of this position, lifting time restrictions on the cell lines that could be used for research would allow better conditions for research and would make it possible for countries like Denmark (where frozen embryos are discarded after 2 years) to have their own cell lines.

Three days later, the media announced that the Portuguese Government would vote against the Commission's proposal in the Council, advancing an alternative proposal,

the cases of the United Kingdom and the Netherlands, see Mulkay, 1997, and Kirejczyk, 1999.

[9] See http://www.europarl.eu.int/neetdocs/committees/itra/20031103/506271eu.pdf and http://europa.eu.int/eur-lex/eu/com/pdf/2003/com2003_0390eu01.pdf.

which would be presented on behalf of the Italian presidency of the Union. This proposal was supported by Germany, Austria and Italy. According to the document, EU funding would be allowed for cell lines created before 7 August 2001, the same date established by the US administration for allowing federal funding for research. Once more, the arguments were based on the defence of the subsidiarity principle and of ethical principles centered on the status of the human embryo and on the need to protect its integrity and dignity.

The response of Portuguese scientists involved in research and of most physicians working in the field of MAP was, as expected, negative. The two main problems they raised to the "alternative" proposal was, first, the lack of financial means to purchase cell lines created abroad and, secondly, the lack of a national legal framework authorizing research in this area. One of the leading researchers in the field, Mário Sousa, stressed the importance of national legislation, and he added: "If the Government is afraid that a permissive legislation may give rise to embryo trafficking, then they should allow only hospitals and schools of medicine to produce the cell lines and to grant free access to them, with a certificate of origin". He left open the possibility, in the event of a restrictive law, to move to Spain, where the (then conservative) Government had a more open stance towards research with embryos (*Público*, 26.11.03: 33).

In fact, neither of the proposals was adopted, and the decision on the funding of embryo stem cell research was postponed to 2004, to be decide under the Irish presidency of the Union.

### 2.4. …and back to MAP

At the national level, in 2003, new proposals of laws on MAP and research on human embryos were submitted to Parliament, by the Socialist Party (on MAP) and by a small party, the Left Block, which has been very active in bringing the issues related to genetics and the life sciences to parliamentary and public discussion. On MAP, the project advocated the coverage of MAP by the National Health Service and the preservation of the anonymity of donors. The project relaxed the constraints on the maximum number of embryos allowed to be produced, but still endorsed the prohibition of deliberate production of excess embryos for other purposes (such as research). The

two projects submitted by the Left Block are particularly interesting in so far as they were careful to incorporate the positions of researchers and practitioners, and, at the same time, tried to associate the users of MAP with the regulation of these practices. In fact, the project advocates the creation of specific regulatory bodies including experts and representatives of the citizens who use MAP techniques. The latter point is particularly interesting, in so far as this has become, more recently, a view strongly held by scientists and practitioners of MAP, who see in the mobilization of users a crucial force to put pressure on government and Parliament to be more sensitive to the experiences and expectations of infertile couples. Another interesting feature of these projects is their attempt at keeping the regulation of MAP and of research with human embryos separate, contrasting with some other approaches based on the concern with the regulation of MAP in order to reduce or avoid excess embryos regardless of its effects on the viability or effectiveness of available techniques that have been widely used. There have been criticisms of the project on MAP, however, coming from women's and LGBT movements (some of them politically close to the Left Block), for their tendentious endorsement of conventional, heterosexual couples as the main users of MAP. At the time of writing, the discussion is still on, but a convergence of their positions seems to be underway.

In March 2004, a preliminary draft of a document still being discussed within the CNECV was leaked to the media, and it generated a strong reaction by scientists and practitioners. They complained of not having been consulted in the drafting of an advisory document which would provide the baseline for new legislation, despite being the real experts with experience in the field. This battle for the recognition of who are the experts in the field is likely to become one of the fiercest public confrontations among scientists in Portuguese society. However, the dividing lines here tend to separate those who hold a more "liberal" view of the desirable regulatory framework from those who hold more restrictive views on what should be allowed both in research and MAP. This debate, however, does not simply replicate and extend the alignments of the late 1980s, between "scientists" and "ethicists" and those who advocated broader, interdisciplinary and heterogeneous advisory bodies and those who saw a body of experts as the guarantee of an adequate, science-friendly articulation of law, ethics and science. Scientists and practitioners who hold "liberal" views draw both on scientific-technical and ethical arguments, as do their more "conservative" opponents. But they do

it in different ways. The latter tend to advocate restrictions to MAP and to research with embryos in the name of the safeguard of the dignity of the embryo as a human entity, even if this means putting severe constraints on the conditions for the viability of most techniques of MAP. Limitations to the number of eggs that can be fertilized to produce embryos for implantation is advocated as a way of avoiding or, at least, reducing the number of "excess" embryos. Pre-Implantatory Diagnosis is denounced as an unacceptable form of eugenic selection. Sperm donation is generally refused. And constraints are put on access to MAP by HIV-carriers, allegedly due to the risk of thus giving birth to "premature orphans". The possibility of single women or gay or lesbian couples having access to these techniques is similarly ruled out, on the basis of a strong endorsement of normative heterosexuality and of stable heterosexual unions. Limitations to access to MAP are often justified by defining these techniques as therapeutic means for certain forms of infertility.

"Liberals" endorse views which are at odds with these, although many of them share some of the views on the exclusion of certain uses of MAP. They advocate Pre-Implantatory Diagnosis as an available technique that all citizens with legitimate access to MAP should have the right to benefit from. The danger of a new eugenics arising from the use of PID would be checked by appropriate modes of regulation. Many of them advocate insemination by donor. They are against the discrimination of HIV-carriers in access to MAP, although, as hinted at above, many agree with the ban on non-heterosexual couples or single women having access to these techniques. There are nuances in this position, however. In a debate on television with the President of SPMR, the chair of CNECV and the journalist Sandra Moutinho (author of the first popular account of the experience of infertility and MAP in Portugal[10]), for instance, one of the leading specialists in MAP, Alberto Barros, explained that although he thought that every child that is born (including those born through MAP) should have a father and a mother, and thus, as a matter of conscience, would not accept lesbian couples or single women as patients or clients for MAP, he would advise them on where they could go (abroad) to have access to MAP (NTV, 3.04.04). "Liberals" are in favour as well of coverage of MAP by the National Health Service and by private health insurance.

[10] Besides being a very powerful account of the experience of MAP – the author, a journalist, was herself an user of MAP –, this book is an extremely useful introduction to the field and to the controversies within it in Portugal (Moutinho, 2003).

Specialists in MAP present themselves as spokespersons for infertile couples who seek help through MAP. But one of the most interesting features of their recent public statements is their explicit and active endorsement of the involvement of the public and of MAP users as participants in debate and regulation. This goes as far as proposing that instead of a restrictive and detailed legal framework regulation proceed through general and broadly defined normative principles and that the actual task of regulating difficult or controversial issues be delegated to a High Authority, where experts and citizens are represented and which would proceed on a case by case basis. This, in fact, is very similar to the solution proposed by the Left Block.

Another crucial issue in the debate is the way "conservatives" try to connect the regulation of MAP to the regulation of embryo research, whereas "liberals" resort to a rhetoric of separation, advocating the regulatory treatment of these two issues as different matters. The latter was the path followed by the Left Block in its legislative proposal as well.

## 3. Discussion

In the context of the debates, controversies and moves to create regulatory frameworks at the national, European and transnational levels, Portugal displays a number of singularities.

1. The country still lacks a legal and regulatory framework in areas such as the creation and use of and access to human genetic information for medical or other purposes, medically assisted reproduction, research on human embryos and genetically modified organisms. In fact, it is within the field of genetics and of the life sciences that the feature of not transposing, or delaying the transposition of, European directives and international conventions and declarations into domestic law seems to have been used as a resource to avoid the actual enactment of laws that could open up spaces for political controversy and mobilization of stakeholders, particularly in fields related to health.

2. The debate on the implications of MAP was characterized, since its beginning, by a strong presence of lawyers and legal scholars who focused on issues related to the

implications of MAP and derived areas (such as research on human embryos) for constitutional and civil law. Constitutional issues included the right to constitute a family, the right of access to MAP techniques, the right to personal identity and the right to life. The constitutional revision of 1997 raised additional issues, such as the right to genetic identity or the redefinition of the rights and duties of "conscious parenthood", as well as the duty of the state to regulate MAP. As far as civil law is concerned, matters related to the definition of motherhood and fatherhood were central. More recently, the legal status of the embryo was added to these concerns.[11]

The ethical debate seems to have taken off later, at least as far as its public visibility is concerned. Its main themes included issues such as the subsidiary character of MAP (as a surrogate for "traditional" procreation), the right of access to MAP, the legitimacy of the selection of characteristics of embryos through Pre-Implantation Diagnosis or through genetic manipulation, surrogate motherhood, gamete donation, post-mortem insemination, the status of the embryo and the acceptability of research on human embryos. The agenda of the ethical debate has been set by a predominantly Catholic and conservative group of biotethicists, most of them with little or no contact with actual practice of MAP and research in the area of reprogenetics. This means that bioethical discussion is often seen by experts and practitioners as an exercise in containing technological advances and research. Persistent features of conservative positions are the opposition to PID and to embryo research and the attempt at connecting the discussion of embryo research and its regulation with the need to prevent the use of "excess" embryos from MAP or the alleged encouragement of abortion that might follow from a growing demand of embryos by researchers. Opponents of the conservatives, in contrast, have tried to treat the regulation of MAP, of abortion and of research with human embryos separate. There remains, however, some overlap between "conservatives" and "liberals" in respect to the definition of MAP as a set of techniques for treating infertility, as well as in the endorsement of normative heterosexuality and conjugality as conditions for access to these techniques.

3. Although Portugal has had a National Council for Ethics in the Life Sciences, which is expected to act as an advisory body to Government and Parliament in its field of competence, since 1990, the capacity to turn advice into legislation has been almost

[11] On these matters, see Duarte, 2003.

non-existent. This may be related to the confrontational character of the relationship between most of the researchers and practitioners in the era and the Council. The former do not see their positions as being adequately represented within the latter, generally described as leaning heavily towards conservative positions, very close to the more conservative sectors of the Catholic Church. As Luigi Pellizzoni (2003) has argued, these councils and advisory boards are based on "excluding by composing". They define the range of those who are to be legitimate participants in debates and deliberations, excluding those who, either by virtue of their lack of qualifications or of their "extreme" positions, are allegedly unable to compromise in order to achieve consensus. In most existing cases, however, these councils, committees or boards display a feature which has led Susan Kelly to include them in the broader category of "boundary organizations". This is their inclusion as prominent participants of both spokespersons for science and expertise and spokespersons for ethics and politics. Thus, boundary organizations may appear as the ground on which the autonomy of science as well as its accountability to public concerns and to democratic decision-making are made compatible.

In Portugal, the CNECV does rest upon "excluding by composing". But exclusion seems to have hit at least a significant part of the most prominent researchers and practitioners of the biomedical sciences who have a stake in the issues being deliberated upon by the Council. The consequence of this is a sort of constitutive weakness of the Council in gathering support for the legitimacy of their positions both among scientists and experts and upon policy-makers and elected officials. A conspicuous example of this was the veto of the President of the Republic, in 1999, on the first proposal of a law on MAP which was passed by the majority of MPs after a favourable advice by CNECV. The veto was justified by the PR on the basis of the technical objections of experts in the field, as was discussed above.

4. Public debate in Portugal has involved actors from fields such as law, bioethics, medicine and biology, but failed to include a broader public. Apart from a call for comments on the White Paper on embryo research made public in 2003, no other initiatives were taken to ensure that the issues raised by the paper would be the object of broader debate. The recent proposals of the Left Block submitted to Parliament does advocate, echoing similar proposals by the Portuguese Society for Reproductive

Medicine and opinions voiced by some experts, the creation of a Committee for the regulation of MAP including experts and representatives of the public. But the risk is high of turning the presence of the latter into a token one. The absence of an autonomous organization of MAP users makes it difficult for the latter and for other citizens who are not experts in any of the areas of knowledge involved to have their voices heard in debate and deliberation.

The production and disposal of human embryos, an issue raised in relation to MAP, generated a debate with some resonance in the media, paralleling similar debates in other countries, on the status of the human embryo and on the conditions under which excess embryos are to be stored and used for research purposes. Related problems, such as reproductive and therapeutic cloning, have come to be related to these discussions. But they have hardly reached beyond the confined space of experts and the media.

By the end of 2002, the Government nominated a committee of "sages" with the task of drafting a White Paper on embryo research, to serve as a basis for the position of the Portuguese Government in the Council of Europe. The document was issued online in February 2003, its rapporteur being one of the most visible spokespersons of the Council. A period of public discussion was opened, with an invitation for contributions and comments, via e-mail, to be sent to the Ministry of Science. No other initiatives for public debate were launched, and the impact of the document beyond the world of specialists is negligible. In spite of its effort to offer an even-handed presentation of all the positions in the debate, the White Book displays an orientation which tends to align itself, again, with the more conservative and restrictive positions. At the European level, the author of the White Book, acting as a representative of the Portuguese Government to the Work Group of the Council of Europe which drafted a regulatory instrument in this field, has backed the restrictive positions advanced by Germany.

5. Drawing on Rob Hagendijk and Egil Kallerud's typology of forms of scientific and technological governance, one might define the Portuguese situation, tentatively, as one where corporate or professional regulation of MAP coexists and interacts with market regulation, based on the demand for MAP by infertile women or couples. International declarations and conventions are often invoked to support or deny the legitimacy and acceptability of certain practices, but no legal framework exists that would allow the government, parliament or state agencies to regulate in a discretionary mode. The

deliberative mode is used in a very limited way (within the CNECV and by Parliament), excluding crucial actors in the process. Debate involving the public is virtually non-existent, although there has been some resonance in the media of the criticisms raised by scientists and experts of the 1999 decree, and the debate has resumed after the leak to the media of the draft of the advisory document currently being discussed by the CNECV. The international debate on embryo research is the object of regular coverage by the media as well, but there is very little active engagement of the actors linked to the field in Portugal with initiatives to promote public debate. It remains to be seen whether the recent calls for users to organize themselves in an association and to be represented in advisory or monitoring bodies will translate into an improved capacity to open up new spaces of public debate and deliberation.[12]

The recent creation, in Coimbra (with the support of the University), of *Crioestaminal*, a company which gathers and stores blood samples from umbilical chords to provide stem cells, as well as the plans for creating a public bank of the same kind proposed by one of the leading practitioners of MAP at the University of Oporto are developments which may well point towards a greater influence of consumer demand and of market regulation on the future directions of the field of reprogenetics.

6. The exclusion of infertility treatments from funding by the National Health Service and by private health insurance generates strong inequalities in access to MAP techniques, due to their cost. It does not come as a surprise, then, to see experts endorsing the definition of infertility, following WHO orientations, as a health problem whose costs should be covered by both public and private health insurance.

A more explicit form of exclusion, the proposal of preventing HIV-positive men from having access to MAP techniques - made safe for children to be born thanks to the "washing" of sperm -, which is being discussed by CNECV, has met the strong opposition of experts and of the Portuguese Society for Reproductive Medicine.

This defence by experts of broader access to MAP, however, has very definite limits. The definition of infertility as a disease and of MAP as a form of treatment means that

[12] On the obstacles to, and opportunities for public mobilization in Portuguese society over issues related to science, technology, health and environment, see Nunes, 2003b. The reduced capacity of autonomous mobilization by patients and patient associations – they tend to be tutored by physicians –, in particular, is

those who do not fit into the definition of the heterosexual "infertile couple" will be denied access to MAP. This is the case for single women, lesbians, women in lesbian unions and others who do not comply with normative heterosexuality and conjugality. It remains to be seen in how far the existence of an active LGBT movement with some public visibility will be a factor in moving towards a more open regime of access to MAP, as is the case in other countries.

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