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The construction of meaning by experts and would-be parents in assisted reproductive technology

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Abstract This article explores the construction of meaning regarding assisted reproductive technology by legal framers, medical practitioners and would-be parents, through the concept of ecology of knowledge. It is argued that these inter-relationships between experts and lay people can be understood in terms of the formation of a social structure of ecology of knowledge, which depends on local and emotional knowledge co-produced by medical doctors, jurists and lay people in dynamic ways without compromising the autonomy of medical, legal and lay knowledge and skills. The assessment of the benefits and risks of assisted reproductive technology partially represents negotiations of knowledge between these social and professional groups, aiming to reproduce existing relations and practices, particularly the social power of medicine and technology, the dominant perceptions about women's and men's bodies and the geneticisation of genealogy. These negotiations of knowledge generate new rights, new social actors, new scientific fields and new ways of thinking and talking about individual and institutional responsibilities. Ecology of knowledge comes imbued with hope, trust, power, credibility of institutions and moralisation whereby some citizens' rights may be weakened.

Keywords: ecology of knowledge, public understanding of assisted reproductive technology, citizenship

Introduction

Contemporary medical and legal discourse on the subject of assisted reproductive technology (ART) has been concerned with quality, safety, reliability, effectiveness and efficiency (Dancet *et al.* 2010). This is a general trend both worldwide (Vayena *et al.* 2002), in Europe (Soini *et al.* 2006) and in Portugal (Silva and Machado 2009a). During the last five years, several initiatives have been taken by the Portuguese Government in the field of ART, such as the publication of the first legislation on ART in July 2006, standardisation of quality procedures in 2008 and expansion of the access to and the affordability of treatments in 2009. However, the assessment of benefits and risks of ART is still controversial. In the country, the public sector's management of ART may be characterised as follows: absence of private insurance coverage; predominance of infertility centres in the private sector and in larger

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urban centres; inadequacy of human resources and constraints of physical spaces in the public sector; doctors working both in the public and the private sectors; and restriction of potential users to heterosexual couples married and/or stable[1] with a medical diagnosis of infertility or certain genetic diseases.

This article attempts to explore the construction of meaning in ART by legal framers, medical practitioners and would-be parents in Portugal, through the concept of ecology of knowledge (Star 1995, Akera 2007, Santos 2007). The concept of ecology of knowledge recognises the plurality and heterogeneity of knowledge that interact in a sustainable and dynamic way without questioning its partial autonomy. Three main sources of heterogeneous knowledge in the field of ART in Portugal are recognised as being modern law, medical science and citizens undergoing IVF treatments. The focus of this article is on discussing a new approach for studying the associations between knowledge, actions, objects and social contexts from a sociological perspective. This specific representation of the circulation of meanings analyses the co-production of knowledge at seven dimensions, corresponding to historical events, social institutions, occupations and disciplines, organisations, skilled practices, artifacts, and human actors. As Akera states:

> I hope to shift the conversation away from a language of causality towards an emphasis on the reproduction of existing relations and practices, and the incremental transformations of them that generate new knowledge and its supporting institutions. (Akera 2007: 415)

As the following sections will show, the discourse of legal framers, medical professionals and would-be parents on ART in Portugal have tended to reproduce existing relations and practices, particularly the social power of medicine and technology, dominant perceptions about women's and men's bodies and geneticisation of genealogy. However, these narratives also generate a new repertoire of perceptions, understandings and meanings concerning the institutional and individual management of expectations, risks and responsibilities imbued with hope and trust, whereby some citizens' rights may be weakened; for example: new rights based on genetic information press for both a healthier society (Ettorre 2008), and changes in the social definition of identity, affiliation and citizenship (Wallbank 2004, Donovan 2006, Freeman and Richards 2006); new individual and institutional responsibilities based on co-production of medicine, law and social order have guaranteed the success and acceptability of ART (Thompson 2005); and new social actors and new scientific fields have been created to regulate ART (Jackson 2001), such as biolaw, bioethics, The National Council of Medically Assisted Reproduction and The Portuguese Association of Fertility.

Dominant narratives on ART are thus remaking the terms on which people come to be incorporated within the social whole and construct their cultural belonging to the nation-state. The ways in which the construction of meaning by experts and would-be parents in ART shape abilities and capacities for people to participate in civic life and political arenas are drawing several implications which can be analysed from a perspective which links the concept of ecology of knowledge to the study of citizenship. First, citizenship configured by ART contributes to the dilution of the State's responsibilities and to the weakening of patient rights. Second, the idea that social values and moral principles have biological grounds is a mediator of citizenship. Third, the performance of agency in relation to the State in the field of ART in Portugal is characterised by reinforcing individual rights, accessing several sources of information and medical services at a national and international level, highlighting the routine practices, embodiment and emotions and negotiating the design of medical treatments. Finally, it is argued that the inter-relationship between experts and lay people can

be understood in terms of an interaction between citizenship and formation of a social structure of ecology of knowledge, which depends on local and emotional knowledge, skills and meanings co-produced by medical practitioners, legal framers and would-be parents, in sustained and dynamic ways and without compromising the autonomy of medical, legal and lay knowledge.

A qualitative and interpretative multidimensional perspective was used, based on the following sources of information: interviews conducted with medical practitioners and legal framers who had professional experience with ART, and with women and men who had tried to conceive by ART in Portugal; the portfolio of risks presented in the Portuguese law on medically-assisted reproduction and in consent forms that must be signed by the beneficiaries of these techniques; and legal articles published in the only Portuguese scholarly journal devoted to health law. After presentation of the research methodology used in this study, an analysis of definitions of ART in Portugal follows, in which it is argued that these definitions have promoted a local and parascientific reconfiguration of the acceptable uses of ART. Autonomous, sustained and dynamic interconnections between narratives of legal framers, medical practitioners and would-be parents will be explored in the final sections of this article.

Methodology

This qualitative study was conducted in Portugal, where the first legislation on ART was published on 26 July 2006 (Law no 32/2006). A nonprobabilistic, purposive sampling approach was used. This means that new data was added to the analysis when it was of theoretical interest and its size was determined by data saturation. That is to say, recruitment continued until no new themes emerged from the interview data and medical and legal documentation (Guest *et al.* 2006).

In October 2005, 19 letters were sent by post to all medical doctors responsible for IVF clinics in Portugal. Thirteen letters were also sent to jurists who published academic works dedicated to the understanding of the regulation of ART. IVF patients were recruited through newsletters, which the first author sent via e-mail to colleagues and friends who forwarded the mail to their network, through a snowball strategy. Thirty-three semistructured interviews were conducted with: nine jurists with academic works published in the field of the regulation of ART, between January and March 2007; nine medical doctors, who were responsible for IVF clinics, between November 2005 and February 2006; and nine women, one man and five heterosexual couples who tried to conceive through ART in Portugal, between July 2005 and February 2006.

The twenty women and men who tried to conceive through ART that participated in this study were all Portuguese and, as dictated by law in Portugal as a requirement for access to these technologies, heterosexual and married or in stable partnerships. Their ages ranged from 30 to 43 years. In terms of educational attainment, four interviewees had nine years of education, two had twelve years of education and 14 had a university degree.

Interviews took place at the homes or at the work places of the participants who volunteered to take part in this study. All interviews were tape recorded and transcribed verbatim by the first author. Transcripts of the interviews were checked for transcription accuracy. The data were then systematically coded and thematically analysed. The findings are reported below with verbatim quotes from interview transcripts translated by the author.

A meaningful definition of ART

According to the classification of The European Society of Human Genetics and The European Society of Human Reproduction and Embryology (Soini *et al*. 2006: 644), which is consistent with the glossary of the International Committee for Monitoring ART–World Health Organisation, ART has been defined as:

> All treatments or procedures that include the *in vitro* handling of human oocytes and sperm or embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, *in vitro* fertilisation and transcervical embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation and gestational surrogacy. ART does not include assisted insemination (artificial insemination) using sperm from either a woman's partner or sperm donor (Vayena *et al*. 2002: xix).

According to this definition, assisted/artificial insemination is not considered an ART, but a technique of 'conception brought about by noncoital conjunction of the gametes' (Vayena *et al*. 2002: xx), giving rise to another concept – medically-assisted conception. However, reports have been produced by The European IVF Monitoring Programme including data on intrauterine inseminations (e.g. Andersen *et al*. 2008).

For the purposes of this article, ART was defined as all treatments or procedures including medically-assisted conception which is consistent with the Portuguese legal framework (Article 2 of Law no 32/2006), where ART is described as a therapeutic answer to medical and biogenetic problems that must be the object of medical diagnosis, particularly: infertility; 'serious' illnesses; and risk of transmitting genetic, infectious or other diseases (Article 4 of Law no 32/2006). Besides the legal requirement of diagnosis for accessing ART in Portugal, bio-genetic essentialism (Freeman and Richards 2006) tends to be disseminated through three other main juridical domains: criteria to access gamete donation; legal definition of identity; and geneticisation of genealogy. First, in gamete donation Portuguese law requires a guarantee of gamete quality and certification of the impossibility of achieving a pregnancy using the couple's own gametes. Second, the Portuguese juridical framework highlights the importance of genetic truth for individual identity. Third, it promotes the idea that pregnancy and 'social' paternity are biological consequences of genetic elements.

In this context, new rights arise; for example: the right to genetic identity; the right to genetic inheritance; the right to know one's genetic history; and the right not to inherit genetic problems that can be scientifically detected and eliminated (e.g. Wallbank 2004, Donovan 2006). The biogenetic relationship has also been used with the purpose of defining the contours of the 'good' mothering in contrast to egg donation programmes (Silva and Machado 2009a). In fact, some Portuguese doctrine urges legal prohibition of egg donation programmes (but not semen donation), due to risks involved in ovarian stimulation protocols (Loureiro 2006). These risks are similar in all IVF programmes performed with eggs collected in stimulated cycles, but there is a tendency to consider that women should submit to risks only when a genetic relationship between mother and child exists. Consequently, this legal discourse may reinforce the cultural assumption according to which every woman should accept risks associated to 'genetic' maternity (Becker 2000).

Focusing on modern law as a social institution, ecology of knowledge allows us to map local definitions of ART at different representational scales, corresponding to historical events (e.g. female acceptance of risks for purposes of maternity and geneticisation of

genealogy), disciplines (e.g. medicine, genetics and law), technical knowledge (e.g. gamete quality and identification of genetic problems), skilled practices (e.g. medical diagnosis), material artifacts (e.g. gamete), and human actors (e.g. legal framers, medical practitioners, women, men and children) (cf. Akera 2007: 418–20). The establishment of a legal framework on ART in Portugal was framed within a social and cultural context where infertility was seen as a disease and maternity as the desire of women (Machado and Remoaldo 2009). To classify a certain condition as disease – as happens with infertility – has been a significant factor used by social institutions aiming to discipline bodies and reinforce hegemonic definitions of gender and sexuality (Ussher 1997). Indeed, although there is a widespread variation in legal and regulatory frameworks in the field of ART worldwide (Langdridge and Blyth 2001, Vayena *et al.* 2002), in general they tend to reinforce the social, cultural and political hegemonic order emphasising both the child's interests and welfare (Jackson 2002) and the importance of healthy bio-genetic links (Ettorre 2008).

Accordingly, several local definitions of ART were produced in Portugal with two main aims: reproduction of 'normal' social behaviour in the domain of maternity and paternity; and definition of social institutions and actors with legitimacy to frame that 'normality' (cf. Throsby 2004); for example, the Portuguese Society of Reproductive Medicine has defined ART as 'methods treating diseases', differing from 'asexual procreation' which is why these technologies 'should only be used when reproductive physiology of heterosexual couples with a stable relationship fails', contributing to assure a 'traditional' bi-parental affiliation (Portuguese Society of Reproductive Medicine 2003). A similar way of thinking may be found in juridical discourse. The following quotation from a legal book devoted to affiliation law reinforces the perception of ART as an 'undesirable' method of conception. Furthermore, this social image can be linked with the idea that blood ties spontaneously justify parents' feelings for their own child:

> The transmission of human life cannot be disentailed from a personal, free, conscious and natural act of a man and woman. As a rule and desirably, through sexual intercourse ... Human nature and interest testify in this sense. I do not know why parents love children, but I know that this love causes, and makes sense of, procreation (Campos 2006: 1031 [authors' translation]).

One additional example that clearly illustrates the 'inadequacy' of ART was the reason for change of the name of the Portuguese Association of Infertility, established in May 2006, to the Portuguese Association of Fertility in November 2007. The main reason invoked by this Association at the time to justify the shift from infertility to fertility was the following: to be closer to Portuguese society through emphasising what is usually positive and normal concerning maternity and paternity.

> The shift from INFERTILITY to FERTILITY is truly paradigmatic, constituting a new world and a more positive understanding of ourselves as project and people … From now on FERTILITY defines us because it highlights what is positive and common to other people; it brings us closer to society and to the desire to have children (http://www.apfertilidade.org/phpBB2/viewtopic.php?t=10565&sid=d022c401a49be3ef5e81f723575df3fe, date last consulted 7 October 2009).

Thus, the circulation of knowledge between medical practitioners, legal framers and would-be parents is grounded on habituated structures of practice that sustain new medical knowledge (Akera 2007); in other words, the 'routine' conception of biological healthy

children by sexual intercourse is used to produce meanings concerning new ways of making parents. Moreover, ART is endorsed as a set of techniques that only help nature (Franklin 1997: 10) with the objective of significantly increasing the probability of achieving pregnancy (Silva 2008). The reinforcement of the desirability of 'natural' conception and healthy people has guaranteed the acceptability of ART. However, some citizens' reproductive rights may be restricted (e.g. no access to ART by non-heterosexual couples and/or single women in Portugal), while reconfiguring would-be parents' identity, emotions and social well-being.

Legal narratives

Like other European systems, the Portuguese legal system has been very receptive to scientific and technological progress (Machado 2008), usually illustrating co-production of social order and technoscience (Jasanoff 2004); for example, in Article 11 of the Portuguese Law on ART, the supremacy of medical criteria is reinforced by emphasis on the exclusive competence of medical doctors in proposing the most 'scientifically appropriate' technique to would-be parents:

> The medical doctor responsible is competent to propose to beneficiaries the medically-assisted reproduction technique that is likely to be scientifically more suitable when other treatments have not succeeded, do not offer perspective of success or are not fitting according to precepts of medical knowledge (No 1 of Article 11 of Law no 32/2006).

In this legal statement, the law may sustain the power of medical professionals by establishing linkages between medical knowledge and the most 'appropriate' technique to be proposed to would-be parents, thus usually contributing to restrict the public's opportunity to question the medical doctors' proposals. Moreover, a legal scholar has referred to the ways medical developments and the law mutually facilitate and implicate one another without compromising their autonomy, stating that biolaw (a new scientific field), has two interrelated symbolic meanings: biolaw provides a 'biologisation' or 'medicalisation' of law, submitting it to the objectivity of life sciences; at the same time, biolaw preserves law's specificity which means guaranteeing respect for human dignity and limiting scientific and technological development through a 'prudent' distinction between risks and benefits:

> There is a tendency for 'biologisation' or 'medicalisation' of law, because it is not possible to disentangle law from 'life sciences'. Therefore, the difficult task of bioethics and biolaw consists of sifting the wheat from the chaff, in order to collect the fruits produced by genetic engineering, embryology and molecular biology, and to determine with objective prudence where 'life sciences' can go without offending human dignity (Diniz 2005: 10 [authors' translation]).

According to jurists interviewed, confidence in medical institutions and in their professionals was founded on one main historical event: ART was used in Portugal for over twenty years (since 1986), without a legal framework and there was no 'abuse' by medical doctors during this time. In the following quotation, two professors of law congratulated medical doctors' code of ethics and guidelines, emphasising the 'humility' of Portuguese law on ART in the presence of the social power of medicine and technology. This submission of law to the 'wonderful' world of medical science (Jasanoff 2006), may contribute to the emergence of

unpredictable risks which can weaken citizens' rights, restricting opportunities of questioning medical practices by both juridical institutions and lay people.

> All medical doctors and other health professionals deserve applause, because they were successful with regard to self-regulation in such a sensitive domain during the absence of legislation [on ART] … It [Portuguese law on ART] demonstrates humility in the face of science … while also being intransigent on juridical principles (Raposo and Pereira 2006: 89–90 [authors' translation]).

The dynamic interconnections between medical knowledge and juridical knowledge did not compromise the autonomy of law in protecting the citizens' rights and social well-being. Indeed, the jurists interviewed restricted the law tasks to the following: the definition of who can use ART and under which criteria, in particular concerning kinship rules, anonymity of gamete donors, (in)admissibility of surrogate motherhood and post mortem insemination and the fate of human embryos; prohibition of the commercialisation of eggs, sperm and cryopreserved embryos; the guarantee of right to information; and the establishment of guidelines for research projects on human embryos. In order to accomplish these tasks, lawmakers had to use sanctity of human life and human dignity as basic principles, corresponding to historical events.

One jurist interviewed invoked these principles as arguments that justify his/her fears about ART: 'Jurists are a rather afraid of knowing how far it [ART] can go, because of life and human dignity'. Two categories of fears have emerged from the interview data: uncertainties concerning the future output of medical practices; and some disturbing social changes that may occur, such as autonomous maternity, issues arising out of eugenics and the loss of human individuality and uniqueness. Thus, some medical uses of ART were disapproved of by interviewees; for example: germline intervention for selection; human cloning; and preimplantation genetic diagnosis for sex selection. According to the jurists who participated in this study, gestational motherhood and post mortem insemination should only be admitted exceptionally under the supervision of the National Council of Medically Assisted Reproduction – a new social actor created by law for governing ART in Portugal. They also emphasised problems associated with gamete donation, such as lack of security when establishing maternity, paternity, affiliation and personal identity, and interference of a 'third' element into the couple's relationship.

The jurists' narratives concerning benefits and risks associated with ART were grounded on a social imaginary that opposed sacred to profane and natural to unnatural (Jackson 2001), an allocation also reminiscent from the Mediterranean Catholic preoccupation with sin (Silva and Machado 2010a). According to their perspectives, the law must establish its boundaries in relation to ART and, consequently, restrict the uses that are seen as profane and/or unnatural. This may be one process of biolegality (Lynch and McNally 2009), by which developments in technoscience have been attuned to requirements and constraints in medical practices, while legal institutions anticipate, enable and react to those developments. Legal framers reinforced the specificity of their knowledge and skills, enacting law as a discipline performing agency by defining the acceptable uses of ART.

Medical narratives

Medical participants in this study invoked weak civil and political mobilisation of the Portuguese would-be parents as an argument that is likely to justify election of medical

doctors as legitimate social actors who publicly represent patients' rights, contributing both to the weakening of citizenship and to the reinforcement of social power of medicine and technology. In spite of recognising the circulation of knowledge between medical practitioners and their patients, interviewees also emphasised the differences in language used by medical doctors and lay people, which is why there are problems in communication between them. Medical doctors argued that they used a particular language due to the specificities of their particular knowledge, thus usually reinforcing the social image of medicine as the best scientific field with competence to regulate ART. Juridical language was by and large described by interviewees as generalist conceptions and values that can be rather distant from views and experiences of would-be parents; for example, in debates on donor anonymity and the right to genetic identity. In the following interview transcript, a medical doctor referred to these two issues as legal problems, but not medical and/or social topics of concern:

> I think that donor anonymity is more a legal problem than a child's problem … Genetic identity is a contemporary fantasy … People talk about parents' identity, not genetic identity. There has always been adultery in the world, there have always been children born outside marriage … and the identity of each human being never suffered with that situation.

An implicit support of confidentiality in the field of egg, semen and embryo donation programmes may underlie the above excerpt from the discourse of a medical doctor. This environment of secrecy can protect donors, beneficiaries and children, but it has usually kept medical procedures from detailed public scrutiny (Haimes 1993), that have usually been promoted by people who have some doubts about ART, such as jurists.

By contrast, the Portuguese law on ART was described by medical doctors interviewed as a subject of medical concern. According to medical doctors who participated in this study, such a law should protect professionals and promote an image of a country that follows transnational trends in the field of ART regulation, and there is no reference to guarantee citizens' rights and duties. The medical discourses around transnationalisation invoked the universality of medical knowledge and technical procedures in the field of ART, which were assured by a formative period of time abroad, the transnational provision of technologies and the participation on international research programmes. In the following statement, a medical doctor interviewee privileged clinical judgement over legal regulation:

> It is not important to have a good law on treating people better, because whoever treats the patients well, does it within a specific legal framework or without it. But it is an issue of image, especially for the country and for professionals … Without a law, Portuguese citizens (and others) could think that this is the banana republic.[2]

In this quotation, an uncritical perspective of the rationality of medical science was combined with the disqualification of the rationality of legal and lay people, whereby the circulation of meaning constructs between medicine, law and citizens in the field of ART was recognised by medical doctors (Kirkpatrick *et al.* 2009), but always under the aegis of medical sciences. This strategy may be seen as a way of using medical knowledge and skills to defend professional autonomy against the intrusions of bureaucrats (Epstein 1998), and citizens in health care management.

According to the Portuguese law on ART, couples must sign a consent form when starting a treatment. In order to do so, couples must be 'adequately' informed about the benefits and

risks that can result from the application of ART, as well as their ethical, social and legal repercussions. Practices of informed consent in clinical contexts were established in October 2008 by the National Council of Medically Assisted Reproduction[3] and constitute an important area of inquiry, because they may reveal the legitimate medical strategies of management of risks, expectations and responsibilities in the context of ART. The research findings that have been summarised in Table 1 may illustrate the rhetorical device used by Portuguese medical doctors when communicating 'adequate' written information about benefits and risks of ART to their patients, namely: naturalisation of uncertainties; emphasis on the biological dimension of probable risks; perception of risks as exceptional results of medical intervention; promotion of ART as a provider of public good; and privatisation of

Table 1 *The explanation of expectations and risks in the Portuguese consent forms in the context of ART*

Naturalisation of uncertainties
- Gestations resulting from this technique are subject to complications like any other gestation.
- We recognise that this text cannot describe exhaustively all situations that may occur in the future.
- Up to now the use of cryopreserved human embryos has not revealed an increased risk of foetal anomalies, but it is not possible to guarantee that the technique is absolutely risk-free.
- None of these techniques guarantee a pregnancy and success rate varies greatly, in particular depending on the clinical situation of both members of the couple.

Biological dimension of probable and exceptional risks
- Rarely, ovarian stimulation can provoke an excessive answer, originating the so-called 'ovarian hyperstimulation syndrome', that under certain circumstances can oblige a specific treatment with hospitalisation and, in truly exceptional circumstances, may be life threatening.
- Occasionally, oocyte retrieval gives rise to complications (for example, haemorrhage or infections).
- These [multiple] gestations constitute a major risk to the newborn, because of higher probability of pre-term delivery.
- Surplus embryos should be considered an undesirable effect and not an intentionally achieved objective.
- There is no reliable information about potential increased risk of foetal anomalies.

Reproductive medicine as a provider of public good
- ART … includes among its objectives a significantly increased probability of an infertile couple achieving the pregnancy they desire.
- ART … also includes among its objectives prophylaxis of the transmission of genetic diseases to descendents.

Privatisation of responsibility
- We understand and accept conditions, risks and limitations of these techniques.
- For various reasons, the treatment cycle may be cancelled before oocyte retrieval. The most frequent motive is deficient response of the ovaries to medication.
- It is not possible to exclude the possibility of decreasing the quality of [cryopreserved] spermatozoa … this predictable alteration usually reflects the quality of sperm at the moment of cryopreservation, and is is so much pronounced as worst spermatozoa characteristics in the moment of cryopreservation.
- The couple may choose to accept fecundation of as many oocytes as embryos that could be transferred to the uterus, according to good medical practice. However, this choice will probably result in a lower number (or even absence), of embryos to be transferred and thus in a lower pregnancy rate.

responsibility. Acceptance of the rationality of medicine might, in this case, imply agreement to enter into a process with uncertain results and whose end is always open, which can involve new risks that have been associated with success of reproductive technologies and not to their failures (Audétat 2001).

The data suggest that naturalisation, biologisation and socialisation of benefits and risks of ART come blended with mitigation or even suppression of some issues; for example: elective foetal reduction; amniocentesis; financial costs; women's physical suffering; the psychological burden; and the status of human embryos. Moreover, the success of ART frequently depends 'on clinical situation of both members of the couple' and on appropriate response of women's ovaries to medication, juggling insufficient standardisation of evaluation and classification of the quality of embryos and semen and omitting the occurrence of technical and/or laboratorial 'errors' and limitations. Actually, dominant medical discourses have been based on purification of knowledge and procedures (Van Der Ploeg 2001) and on privatisation of social responsibilities (Thompson 2005), supporting technomedicine as an instrument that benefits both humankind and infertile couples (e.g. Becker 2000). Some medical literature had been talking about patient-friendly ART (Pennings and Ombelet 2007), and/or patient-centred reproductive medicine (Dancet *et al*. 2010); technologies that are concerned with their own cost-effectiveness and with equity and minimisation of risks and uncertainties through four main strategies: reinforcement of quality assurance; precaution; emphasis on social and individual ethical responsibilities; and democratisation of decision-making and debate processes (Webster 2007).

Would-be parents' narratives

Narratives produced by would-be parents who participated in this study concerning the risks and benefits of ART were quite similar to previous western studies (e.g. Franklin 1997, Becker 2000, Throsby 2004, Thompson 2005), in the sense that they considered two main frameworks: first, the semantics of probability and naturalisation (namely of their discourse on achievement of pregnancy, multiple pregnancies and surplus embryos); second, acceptance of risks and individual responsibility for unsuccessful fertility treatments especially by the female interviewees (Silva and Machado 2010a). Medical and technical procedures which women on ART must undergo were described as 'common' and 'natural' practices and can be understood in terms of providing women with opportunities to reinforce their identity as potential 'good mothers'; for example, one female interviewee declared that she would 'easily forget' her present pain associated with IVF treatment when considering the expected 'compensation' – having a biological child. Thus, thinking about the potential expected outcome of ART may lead to minimisation of risks:

> Probably, any woman thinks about a second child, because the pain [associated with maternity] is easily forgotten, because there is compensation. The same happens in IVF treatments: when a woman achieves a biological child, she naturally thinks of this [physical and emotional pain] in a different manner! Obviously, there are uncomfortable things [in IVF treatment], there are things that hurt, of course they hurt!

The interviewees' narratives concerning the possible occurrence of a multiple pregnancy were also put into the framework of achieving a biological child. So, this possibility might be described as a 'dispensable happiness' that can involve 'some risks' (Silva 2008). Moreover,

the participants in this study tended to underrate the possibility of multiple pregnancies. Indeed, they talked about multiple pregnancy as a remote hypothesis more than a real chance. Major concerns related with multiple pregnancies only appeared in the discourse of a female interviewee who had a twin pregnancy and of a couple with two-year-old twin daughters. These two interviews highlighted the dilemmas caused by amniocentesis, the financial burden, the physical and psychological tiredness and the need to reorganise the couple's everyday life as the main issues of worry and anxiety:

> To talk about having twins is one thing, but to know suddenly that they are two [embryos], we were a little [confused] … Does it really have to be like that? The doctor spoke about the risks [of multiple pregnancies] and we needed a lot of help [from family, friends and colleagues]. I know pregnancy is not an illness, but … Before, I had a normal pregnancy. Thank God everything is OK … One of our dilemmas was whether or not to have amniocentesis.

Wife: The ecography starts … and he [the doctor] says: 'you have twins' … I panicked, I was shocked … [When they were born] First, I had to employ a housekeeper to help me.

Husband: We lived in a small apartment. Suddenly, it seemed like a burrow … Sometimes when I returned home, when the girls were younger, I remember that I was deeply unhappy, but really deeply! … We did not want to go home … And a feeling hovered over me during the pregnancy and also in the post-birth – a fake positive feeling.

Wife: Their birth almost destroyed our relationship.

The interviewees described other situations that could be 'uncomfortable', namely: heterogeneity and intermittence of doctors; emphasis on economic criteria; poor cognitive medical skills; 'inadequate' or 'wrong' medical proposals; and 'insufficient' or 'incomplete' information about clinical situation and/or certain medical and technical procedures. When facing these situations, the interviewees declared that they would further evaluate experts' knowledge and practices with the objective of minimising limitations of ART; for example, interviewees looked for an expert considered more competent or an IVF clinic with a higher success rate; repetition of medical tests in reliable laboratories; and search for information about ART (Silva and Machado 2008, 2009b). Looking for information in several sources at national and international level was mainly described as a duty of the users of ART rather than assuming the right to be correctly informed by clinical practitioners; for example, one male interviewee stated that 'people cannot go to these treatments expecting all the information from the doctor; if someone has a specific doubt, they have to search [for information]'. A female interviewee declared that medical doctors give the 'minimum information' in an attempt to protect their patients, in order to avoid 'a lot of doubts' that might cause 'confusion'.

The interviewees' views on ovarian stimulation (Silva and Machado 2010b), and the existence of surplus embryos (Silva and Machado 2009b), also emphasised social, emotional, affective and moral dimensions in the would-be parents understanding of benefits and risks of ART. The majority of interviewees agreed with cryopreservation of human embryos in order to use them in the future. However, in two cases the interviewees suggested that surplus embryos should be avoided through different strategies: first, fecundation of only three oocytes, which was the number of embryos that could be

transferred to the uterus; second, performance of an IVF treatment without ovarian stimulation (thus, in 'natural' cycle).

These ways of enacting would-be parents' agency may lead to medical and technical procedures which were more suitable to patient's values, but they did not challenge the social dominance of the biomedical model on assessment of benefits and risks of ART. Although would-be parents' narratives emphasised emotions in perceptions of ART, they reproduced some features of medical discourse, namely: the semantics of probability and naturalisation; individualisation of responsibilities; promotion of reproductive medicine as a provider of public good; and the minimisation of women's bodily experiences by highlighting the couple and particularly the outcomes of ART – embryos, foetus and/or child (Van Der Ploeg 2001, Thompson 2005).

Conclusions

This article examines a case study in the field of construction of meaning in ART through an ecological view of knowledge, using the representation proposed by Akera (2007). The strength of this approach lies in its insights into how ways of circulating knowledge among different social and professional groups allows us to think linkages between historical events, institutions, occupations and disciplines, organisations, knowledge/skills, artifacts and actors. This article extends these insights by considering how the metaphor of ecology of knowledge can be articulated with the study of citizenship. The main issue to be discussed is how Akera's representation could/should be used in other sociological investigations to create opportunities for carry forward joint work of health and medical research and science and technology studies.

The assessment of the benefits and risks of ART partially represents negotiations of knowledge between three main social and professional groups – legal framers, medical practitioners, and would-be parents, involving local and emotional processes often associated with issues of power, trust, hope and credibility of institutions. The formation of a social structure of ecology of knowledge has been grounded on the reproduction of the social power of medicine and technology, dominant perceptions about women's and men's bodies and geneticisation of genealogy, generating at the same time new knowledge, rights, responsibilities and their supporting institutions. Legal, medical and would-be parents' narratives concerning the benefits and risks of ART might be associated with molecular biopolitics and a new type of somatic ethics (Rose 2006), in the sense that they have revealed a way of governing human beings, individually and collectively, through new forms of genetic information and both old and new ways of thinking about expectations, risks and responsibilities open to medical management and modification, which implies obligations imbued with hope, trust and oriented to the future, yet demanding actions in the present.

The dynamic co-production of knowledge and social order by legal framers, medical practitioners and would-be parents does not question their autonomous knowledge and skills. Medical doctors with professional experience of ART in Portugal perceived medicine and technology as transnational products that must be used in accordance with local norms and values. These professional actors privileged clinical judgement over legal regulation, arguing that medical and technical procedures in the field of ART are instruments to promote human well-being and to help infertile couples and referring to professional identity of medical doctors as being grounded on their personal/clinical relationships with IVF patients. The jurists with professional experience in the legal regulation of ART in Portugal reinforced the supremacy of clinical judgement, but highlighted the importance of legal

norms in the definition of local acceptable uses of these technologies. By doing so, these professional actors reinforced the specificities of law: to guarantee respect for human life and dignity; to protect citizens' fundamental rights; and to define the limits of scientific and technological development in order to ensure present and future human well-being and public interest. By contrast, would-be parents with personal experiences of ART in Portugal emphasised their individual rights and responsibilities. These social actors viewed medicine and technology through the lens of trust, hope, emotions and everyday embodied experiences. Would-be parents demanded medical and technical procedures and social rules which were more appropriate to patients' values and knowledge, but they did not challenge the social dominance of the biomedical model when assessing the benefits and risks of ART.

References to the limitations of ART, as well as to lay people's voices and embodied experiences, particularly women's physical experiences, were usually absent from the competences of legal framers and medical practitioners. This mitigation permitted an institutional and individual management of benefits and risks of ART grounded on biologisation, naturalisation and privatisation, with some repercussions on would-be parents' narratives; for example, the use of the semantics of probability and uncertainty and the sense of individual responsibility of women for the unsuccessful (Throsby 2004, Silva and Machado 2010a). In general, the legal and medical narratives surrounding the benefits and risks of ART also concealed emotional and social factors involved in the uses of these technologies (Jackson 2001, Van Der Ploeg 2001), highlighting expected outcomes of ART – foetus, embryos and healthy newborns. Indeed, there is a tendency for the global expansion of the 'new' rights of the foetus and child (Thompson 2005: 73), such as the right to genetic identity and the right to not inherit genetic problems that can be scientifically detected and eliminated.

Experts' and would-be parents' meaning constructs of ART lead to new questions about intimate, scientific and biological citizenship (Svendsen 2007), in the sense that they may restrict the public's opportunity to question medical proposals and practices, as well as medical ethics. New forms of citizenship in the field of ART were reconfigured into intimate and apolitical forms of citizenship (Thompson 2005), thus contributing to the dilution of the State's social responsibilities and revealing unpredictable risks and uncertainties which can weaken patients' rights. This scenario is especially worrying if we take into account that configurations of citizenship in Portugal point to the fact that it continues to be conditioned and limited by the weakness of citizens' organisations and social movements. In particular, concerns about widely-held implicit assumptions should be explored which sustain views on the importance of the rights, duties and responsibilities of the family and of mothers, fathers and children, as well as perceptions about who should be reproduced, who should have the right to live and the main elements underlying the construction of identity and citizenship.

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Notes

1 According to the Portuguese law, a couple is stable if a woman and a man live at least two years under similar conditions to those of spouses.
2 Banana republic is a pejorative term for a country that is politically unstable, dependent on limited agriculture (e.g. bananas), and ruled by a small, self-elected, wealthy and corrupt government.
3 The National Council of Medically Assisted Reproduction approved 18 consent forms, one for each medical and technical procedure involved in ART in Portugal. Available at <http://www.cnpma.org.pt/profissionais_modelos.aspx>, date last consulted 7 October 2009.

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