Health Biosciences, Biotechnologies, Intercultural Dialogue and Gender:
The Case of Stem Cell Research

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1. Introduction

Since the early 80s a series of new developments in the Health Sciences and Biotechnologies have been substantively transforming the health systems, where radical changes are foreseen in the short to middle term. These changes include the increasing use of: new reproductive technologies, such as in-vitro fertilization (Acero, 2004; 2006); molecular-based genetic testing and vaccines, for cancer, tuberculosis and other communicable and non-communicable diseases; human and animal stem cell research and therapy; biosynthetic biology applied to health, transgenic products and therapies, like xeno-transplants, health nanotechnologies and human and animal cloning techniques.

This paper focuses on human stem cell research and therapy (SCR) as a privileged setting to highlight trends towards, and the need for, a rapprochement of cultures within Science & policy-making at different levels. Inter-sector dialogues do or should involve relevant stakeholders, as well as, the general public in different cultures. But they often either neglect gender-sensibility or are bluntly gender-blind.

Stem cell research (SCR) is increasingly becoming a global activity (Harvey & Mc Meekin, 2007), with initiatives located in industrialized and major developing countries (ICs and DCs) promising important socio-economic contributions (Greenwood, et.al. 2006), as part of contemporary developments in regenerative medicine (implants, transplants, cell regeneration and organ development), that will become of utmost significance within the public health sectors in the near future. These contributions involve the design of new therapies for non-communicable diseases, such as, heart failure, neuronal, blood, muscular and bone disease and cancer, which are on the rise among rapidly aging populations (Thomas, 2003) in both the developed and the developing world, and for other less severe conditions (e.g. burns, eye and muscle injuries), as well as, cosmetic medicine.

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3 We refer to middle-income level countries in different regions, such as: Brazil, Argentina and Mexico; India; China, South Korea and Singapore.
The increasing use of human embryonic stem cell lines (hESCR) for research and therapy testing, as an innovation pathway, has given rise to international controversies concerning the procurement, use and disposal of the embryos (Herold, 2006). These controversies are also pertinent to issues of sustainability of experimental, high-risk research and health biotechnology choices/niches in developing countries (Leach, 2007), and also to the need to develop alternative pathways to unproven therapeutic solutions. Science breakthroughs in SCR among emerging economies involve both the use of adult (ASC) and embryonic stem cells (ESC), and present and future challenges include, quality control of these lines and the building of adequate banks and infrastructures for translational research into therapy.

Many of the therapies that may be marketed in industrialised countries are being tested in developing countries in conditions that would be unacceptable in developed economies. Future technological and regulatory regimes will intersect and influence each other. Different concerned stakeholders are to be strengthened in order to allow an informed, participatory and democratic engagement process towards gender-equity.

While the UK, Canada, lately the US and other developed countries, have had a liberal approach to hESCR, based upon long-standing regulation and specific governance frameworks, a number of complex issues are still under public discussion (Parry, 2006; Isasi and Knopper, 2006). In contrast, in many DCs, the regulation of hESRC is still a new challenge, involving either severe restrictions, nonexistent or unspecific frameworks (Harmon, 2006; 2007).

Unresolved moral and policy conflicts between key social players have intervened in the pursuit of hESCR, influencing the direction of research and the design of governance frameworks (Maio, 2004). In most DCs, the views and opinions of key social actors, - most specially of women and the women´s movement-, have been either largely excluded from debates or used for political ends (Sleeboom-Faulkner, 2008 a.; Acero, 2011). In some cases, this extends to poorer research subjects and potential end-consumers, who constitute a significant democratically-relevant group for public engagement with adult and hESCR (Bharadwaj, 2006; 2008; Sleeboom-Faulkner, 2008 b). Exclusion of alternative voices can curtail social awareness of SCR, hinder appropriate governance and undermine trust in Science and in the new therapies, that might be used in the near future within the public health sector.
2. Stem Cell Research

Stem cells (SC) are the foundation of our body; they have the capacity to differentiate into specialized cells that, in turn, form the basis of different body-tissues. They can also self-renew and be used for tissue-regeneration. There are various types and sources of SCs, among them: adult stem cells as found, for example, in bone marrow and umbilical cord blood; embryonic stem cells, isolated from very early embryos created through in-vitro fertilization; induced stem cells (iPS), reprogrammed into early cells from adult tissue, like the skin, and fetal stem cells.

Different type of therapies are being developed based on these cells, for tissue and organ reconstruction and regeneration. They are applied mainly in cases of non-infectious disease, such as: neuromuscular, blood, neuronal diseases and severe skin burns. Some of these therapies are already quite well-established, like bone marrow and umbilical blood cord transplants; and others are under experimentation, such as those involving embryonic stem cells, at present being tested in initial clinical trials.

SCR has been developing in the world since the mid 60s and early 70s, though mainly with adult cells, isolated preferably from the spinal cord and used in bone marrow transplants. Since then, wide experimentation on animal and human stem cells has systematically continued globally and new therapies have been developed, especially for blood disorders (See, for example, Hinxton Group stem cell maps by world region, www.hinxtongroup.org). But it was James Thomson´s isolation of human embryonic stem cells and the derivation of the first human stem cell lines in the US, in 1998, that led both, to wider public visibility of this research, as well as, to international controversies (Thomson et.al., 1998).

At present, it is estimated that overall, stem cells are being used in approximately more than seventy different types of applications and/or diseases⁴. And their sources of biological materials, have expanded to include a large variety of human tissues (International Society for Stem Cell Research, 2006; 2008a; 2008b).

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⁴ Stem cells are also used in laboratory models to design and test new drugs and medicines.
3. Culturally-Specific Gender Contexts for SCR

Culturally-specific gender contexts influence the development of SCR, in numerous ways, including the definition of: specific research trajectories, more restrictive or permissive regulatory policies and ethical guidelines, monitoring and oversight of research and therapy (Walters, 2004; Knowles, 2010). For example, ethical and regulatory frameworks on embryonic stem cell research based on religious, moral and cultural/gender values are shaped by a multiplicity of socially-embedded approaches, that co-exist, converge and diverge, in the globalizing world of Science, Medicine and Health.

Four selected cultural and gender factors, as they shape stem cell research and therapy, will be discussed in this section: a) the interaction between genetic diversity and ethnic discrimination; b) bioethical differences as embedded in social and gender beliefs; c) the role of women as donors of their body tissues and ‘products’ and, d) civil society’s and women organizations’ participation, in policy and decision-making in the new field of health biosciences and biotechnologies.

Genetic diversity impacts directly the type of stem cell (SC) therapies derived. On the one hand, the genetic variations in a population influence the degree of compatibility of tissues for transplants and implants derived from SCR (See, for example, World Marrow Donor Association- www.worldmarrow.org ). If research is carried out in limited and/or selected social groups and it is focused preferentially upon one sex, inevitably research results and eventual therapies will discriminate against the under-researched populations, particularly ethnic minorities by gender. On the other hand, therapy-development in this area has been focusing on diseases prevalent in: developed and/or emerging countries, aging populations, men and higher income groups. Until now globally, diseases prevalent among ethnic minorities and poorer sectors, as well as, some of female-specific reproductive conditions, have been substantively under-researched (WHO, 2002; UNESCO, 2006).

Social and gender-based ethical and moral/religious beliefs on the beginnings of human life, as well as, on the rights of embryos (and therefore, the role of abortion), have influenced the development of embryonic stem cell research and given rise to important national and international controversies. SCR has become the locus of specific intersections in the co-production between Science and Society.
A new trend has arisen in many developed countries, towards regarding the stem cell as the initial source of life or life itself. But, in the rest of the world, perspectives on the beginnings of life vary and the subject remains an unresolved issue, giving rise to contradictory narratives and policies. Many times, this research has been curtailed by this fact, or else, social negotiations about research paths have been largely unfruitful or have reached only temporary compromises (Acero, 2011, in press).

In some countries, such as Brazil, a distinction has been made between the research use of non-viable surplus embryos from in-vitro fertilization and that of viable human embryos derived from those techniques; or else, between viable frozen and fresh embryos (Diniz and Avelino, 2009). The use of viable in-vitro embryos has become the most usual practice within the developed countries, based on the definition of a ‘pre-embryo’\(^5\), an international standard to support embryo research (Franklin, 2009). But the distinction between embryos and pre-embryos has not been adopted by many developing countries.

Another source of controversy has arisen during the design of policies on the use of cloned embryos in research, usually forbidden in Latin American countries. Also, policies for discarding research embryos have been only scarcely defined or debated. While some countries, like the UK, have authorized the creation of admixed (animal/human) research embryos, but social consensus on their use has proved unstable. Some studies have shown that different social groups still strongly oppose this policy decision, based on a heartfelt rejection towards trespassing interspecies’ boundaries (Brown, 2009; Parry, 2010). Bioethics, as a profession, has now become a new powerful actor that mediates the definition of new epistemological and institutional boundaries in relation to new biotechnologies, as well as, collaborates in the shaping of epistemic scientific communities and specific innovation trajectories (Salter, 2005; Gottweiss, 2005; 2007).

Hegemonic social attributes based on gender relations dominate social perspectives on ova/embryo research donors. Women’s social role as mothers are privileged in countries where stem cell is forbidden, and where usually abortion is illegal. In many countries that allow SCR, women are asked to supply ‘gift’ research donations, that will

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\(^5\) The very first stage of embryo development, till its fourteenth day, as it was initially defined in the U.K. Warnock Report (1990), whose conclusions pioneered the research field internationally.
support ‘the common good’. That is, women facilitate through their tissue donations, the development of therapies that will eventually cure the severely ill, but which are not designed with a focus on gender equity and whose access is engendered (Acero, 2009). Those gender attributes are interwoven into a referential framework often developed almost exclusively by the scientific and medical establishment (Parry, 2009), defended as a superior, or the ‘only discourse with authority’ (Jordan, 1997). These narratives are privileged above other forms of knowing, including the experiential knowledge of the subjects directly involved: the genitors of potential research embryos from in-vitro fertilization. Infertility is becoming then a valuable source of biological research materials and it is repositioned within culturally hegemonic social perspectives (Parry, 2006).

Other products of women’s bodies, like umbilical cord blood, are also advertised and often privately commercialized for research with adult stem cells. More recent developments in this field involve, for example, research carried out on stem cells isolated from the blood of the menstrual period (See, for example, www.cryopraxis.com.br), and on fetuses’ stem cells. A whole section of regenerative medicine uses, as their main source of biological materials, female body tissues.

There is some evidence on ongoing international trends in the shaping of chains of exploitation and trafficking of research female ova/eggs, facilitated by international gender inequities. Practices of cross border in-vitro fertilization between Western and Eastern Europe have been documented, whereby poorer Eastern women are taken to the West, generally through coercion or minimum monetary benefits, for in-vitro fertilization, for the extraction of research ova and/or to generate research embryos (Dickenson, 2007; Waldby, 2008). Poor women, unemployed females or female students are being recruited to supply research eggs for a fee, at considerable health costs (for example, in the USA, Canada and Brazil; See, www.sermulher.com.br; www.handsoffourovaries.com). Medical tourism is promoted to some Third World countries among terminal, severely or chronically-ill patients for treatment with untested SC therapies (e.g. to China, South Korea, Barbados, Singapore and other)6.

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6 A number of journal articles have been documenting these practices. And, for example, the firm Beike Biotech, founded in 2006, connects patients internationally with hospitals in China for cellular experimental therapies with stem cells, offering also patient recruitment services within the US for this medical tourism.
To contain or counteract existing or potentially negative trends towards the abuse of ‘free choices’ in SCR, international collaborations have been established for: a) the design of global ethical guidelines and patient orientation handbooks (e.g. International Bioethics Committee-IBC/ UNESCO; UK Stem Cell Bank; International Society for Stem Cell Research (ISSCR); BIONET, 2007; 2008; CIOMS, 2000; 2003); b) the definition of research and therapy protocols and the standardization of research procedures (e.g. the International Stem Cell Initiative (ISCI) of the International Stem Cell Forum (ISCF)\(^7\); c) the design of clinical trials and registries (e.g., WHO, World Stem Cell Summit, 2010). Most of these initiatives are oriented towards the establishment of general ethical and practical principles, which can be flexible enough, to attend to cultural diversity. But not many have a active concern on gender equity.

However, registries of SC clinical trials are incipient or inexistent in many cultural contexts. Associated international registries and data bases, such as that proposed by WHO, are recent, non-binding and yet unknown or unexplored, by many developing countries (Isasi, 2010; Isasi and Nguyen, 2008). Oversight bodies in most Third World countries are new to SCR developments and lack specificity.

In Latin America, -vis-a-vis Europe and Canada-, civil society’s and the women’s movement participation in public debate and policy on SCR has been sporadic. Local ‘publics’ have been engaged mostly during specific events, for example, in stages previous to the approval of relevant laws. Often, public participation has been led by women or human rights’ NGOs. In those crucial moments and events, the use of TICs has been essential for the articulation between diverse civil society groups in order to feed SC public debates, and TICs they have been handled as educational and participatory tools, towards the fulfillment of a human right (Acero et. al., 2010).

But available national regulations on SCR in developing countries are usually not anchored on negotiation and consensus among cultural diversity and tend to be gender-blind. The meanings attached to this research by minority groups are largely excluded and the ‘publics’ tend to be ill-informed on recent trends in New Genetics and health biotechnologies. Public debates polarize radically between ‘pro-life’ and ‘pro-choice’

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\(^7\) This Forum was established in January 2003 and is formed at present by 19 members from: Europe, the US, China, Japan and Australia. It involves the participation of more than 30 laboratories worldwide, including the leaders at a global level. The Forum’s projects aim to establish standard criteria for the derivation, characterization and maintenance of embryonic stem cell lines.
groups and SCR tends to collude with unresolved abortion issues (Cesarino, 2007; Gottweis, 2009; Salter, 2008).

In summary, the social and gender factors briefly described above shape differential cultural specificities. Social perspectives and understandings, as a result of the uneven articulation of gender notions and gender attributes, as well as, the strength and visibility of local women’s movements condition the direction, pace and dynamics of scientific research and therapy development in unprecedented ways, most specially, in a field which relies heavily on the use of female tissues.

4. An Example: The Case of Brazilian Public Debates

In Brazil, social and community organizations articulated nationally and internationally through TICs, during the public debates of the Biosecurity National Law in 2005 and in 2007, at the Supreme Federal Court’s Public Hearing to rule on a legal case (ADI 3510). Through this case, embryonic SCR tried to be reversed, declaring the Law unconstitutional. The case was argued based upon the assumption that: “human life begins since and at the moment of fertilization”. Finally, the case was unsuccessful.

A number of organizations articulated successfully to defend SCR: patient groups, their families and associations related to specific diseases that could eventually benefit from stem cell therapies, as well as, law-oriented, anti-racial discrimination, bioethical and feminist NGOs and scientific organizations, and the most prominent media. These groups established permanent dialogue with local scientific organizations, such as, the Brazilian Society for Scientific Progress (SBPC) and the Brazilian Association of Cellular Therapies (ABTCEL), and also held inter-cultural dialogues with scientific and patient organizations and University research groups from other countries. They sought to clarify their positions and obtain international evidence and information on SCR, as documented in their respective websites (Acero, 2011, in press).

Many women’s voices were salient during this process, among them: the feminist NGOs: Católicas pelo Direito a Decidir, ANIS, Ser Mulher and Crioula. The patient organizations most actively participating were: MOVITAE (Movement in Favor of Life), Células-Tronco Esperança,- both, SCR-oriented patient and family organizations- and patient associations for specific diseases, such as, ABDIM (the Brazilian
Association for Muscular Dystrophy), ABRALE (the Brazilian Association for Lymphoma and Leukemia), NOVO SER (the organization of the disabled) and ABRELA (the Brazilian Association for Lateral Sclerosis). Women from these associations tended to lead social action in Congress, the media and in front of the Supreme Federal Court, as well as, organized public engagement of patients’ families and their support groups.

Lobbies for and against SCR tried to integrate the ‘publics’ as a resource,- patients and families among the defenders’ lobby; anti-abortion and religious groups within the opposition lobby-, through a ‘hype’ and ‘hope’ strategy, also frequent in other societies, like the U.K. (Martin, Brown and Kraft, 2008; Martin, Brown and Turner 2008). During this process, however, plural and diverse perspectives were included within the Brazilian public debate and a deep institutional learning and collaborative process towards gender equity took place.

Later on, the participating organizations tended to become silent. They had great difficulties in keeping alive their previous articulation and to maintain a stable active public engagement in the discussion of further initiatives in SCR. For example, in 2009, these organizations hardly engaged in the public consultations of the National Board for the Vigilance of Sanitary Conditions (ANVISA) about the establishment of a control system on embryo use, named SisEmbrio. Though these same organizations had previously struggled for the registry of potential reproductive and research embryos banked within in-vitro fertility clinics.

Regulation frameworks and monitoring strategies have to be often reviewed to accompany dynamic changes in this field. Participation flaws hinder institutional stability in public engagement for the democratic design of gender-equitable sustainable policies, which are particularly necessary in this highly innovative area.

5. Prospective Thoughts and Scenarios

As these therapies are increasingly entering public health systems, there is a need for: a greater visibility of existing women’s voices, analyses and action in this field; a wider representation of their diversity within SCR public policy and a focus on the gender dimension of research, therapy and policy, in order to pursue fruitful inter-cultural dialogues on Science, Medicine and Society.
The scientific community could be further motivated to publicize SRC results, through popular media and modalities, and engage more substantively with other stakeholders.

Inter-cultural dialogues have often been stifled by restrictive participation and lack of adequate representation. A number of intercultural dialogues are to be further promoted in this field, mainly: those between relevant local social sectors and/or stakeholders and the general public, as well as, sector-specific dialogues across cultures. Scientific and medical communities are fostering such dialogues frequently and fruitfully, between developed and developing countries (See, for example, World Stem Cell Summit, 2010). But South-South scientific dialogue initiatives have been more limited.

SCR policy-makers tend to lag behind in inter-cultural interaction, except those within international organizations. And the international development aid community has considered New Genetics’ developments less relevant for developing countries and largely postponed its discussion, except in the case of biotechnologies related to molecular-based genetic tests and vaccines (See, for example, Chataway, and Smith, 2006).

Though many patient organizations are transnational, active in international dialogue, and even provide financial support for this research (See, for example, Muscular Dystrophy Association USA www.mdausa.org), they tend to lack representation in many an emerging and/or developing economy. Internet means and a number of newer ITC tools could be an important resource for further interconnectivity. New communication technologies could also facilitate evidence-based public information campaigns on ongoing SCR practices targeted to ethnic minorities and to ‘publics’ in the Southern countries.

At least three potential prospective scenarios for stem cell research and therapy could emerge. These largely depend upon the promotion of national and international intercultural dialogue initiatives, as well as, on the degree of engagement of relevant stakeholders, -including women and their associations-, and on the inclusion of a gender-perspective in scientific research and therapy. Probably, these scenarios could also be relevant for other new scientific and health biotechnology developments with

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8 WHO, UNESCO, PAHO and OECD have been active regarding themes related to these new health biotechnologies, as well as, Foundations, Charities and Philanthropies, such as: The Welcome Trust, Bill Gates and the Heinrich Böll Stiftung Foundation.

9 In contrast to the relevance assigned to genetically modified food and crops, often presented as an important means for famine alleviation (Millstone, et.al. 2008).
similar impacts, such as: existing health nanotechnologies, often a support of with stem cell therapies, and molecular-based genetic testing and vaccines, as well as, eventual health-related biosynthetic technologies. The scenarios to be presented are modeled and reworked from findings on ethics in new emerging technologies and related scenario-building exercises on health biosciences and biotechnologies by other scholars (The Hinxton Group, 2006; OECD, 2009; Arundel, Sawaya and Valenau, 2009). These scenarios have been expanded to address relevant questions on Gender, Science and Society. They will be very briefly described.

I. Continuity Scenario: The replication and reproduction of the most longstanding present trends at a global level; a scenario common to most emerging and developing countries involved in SCR, and to newcomers to this field of knowledge. This scenario is based on the main trends already described in this paper and it entails: the command of the design and implementation of SCR trajectories by selected groups within the scientific community, or epistemic closed groups. These mostly exclude medical associations, ethnic minorities and any reflection on gender issues for research and practice. The continuity scenario also entails a high participation of intermediaries, such as patent lawyers and brokers dealing with intellectual property rights (IPs); a late, liberal or neoliberal response to SRC developments from public policymaking, following private market practices; low or ‘top-down’ engagement of relevant stakeholders and/or the ‘publics’. In this scenario, two main paths on public engagement in SCR are followed. One where very little information is made public, or one that applies a ‘deficit-type’ engagement model approach, whereby, Governments, Universities and research centers design ‘one-way’, training programs and venues to educate and inform the general public (Wynne, 1995; Irwin, 1995).

II. Transitional Scenario: One where contradictions and ambiguities prevail. Trends and countretrends on SCR’s policies and regulations are either integrated into policy or conflict with each other, as is the case in many European countries and in Canada. This scenario also allows for space to set up public/private partnerships, adequate to specific research trajectories, therapies and technologies and for a limited inclusion of alternative voices into policy making, e.g. women and feminist organizations, human rights NGOs and patient organizations. Inter-cultural dialogues are either allowed or actively promoted, but their results are not necessarily incorporated into policy. Real engagement in public decision-making is restricted to selected social groups, merely the
stakeholders and associated organizations, and draws upon a gender perspective only regarding key controversial issues, and often as a result of public and/or Governmental pressure. Innovation trajectories are limited in range and choices. Major inconsistencies in the management of ‘top down’ and ‘bottom up’ public policy and action strategies are exposed (Irwin, 2006; Irwin and Michael, 2003; Wynne, 2006). Some of the more advanced emerging economies follow some of this scenario’s in-built assumptions, though mostly only for controversial themes and issues in SCR.

III. Reversal Scenario: A gender sensitive scenario; one to which it seems socially and ethically advisable to aim, given countertrends and seeds of change within the last global scenario. In this scenario the ‘publics’ control of SCR is promoted, as a human, and citizens’ right towards gender-equity. Participation is based on a more systematic and representative engagement of different social sectors in the design of research and therapy trajectories, as well as, on regular public consultation on the implementation of new developments. Gender perspectives are included at all levels of the SCR process: research design, methodologies, experimentation, banking of biological materials, clinical trials and access to new therapies, as well as, within targeted public consultations to include ethnic and racial minorities. Public engagement strategies are gender-sensitive, wider and varied, - e.g. through focus groups, public hearings and citizen forums-, and evolve towards a balance and articulation of ‘bottom up’ and ‘top down’ policies and action. International inter-cultural dialogues are actively promoted, their meanings debated widely, and their results made accountable and transparently available to the ‘publics’. These are also included in the design of national and international policies. International binding agreements on controversial issues in this field facilitate the sustainability of this policy-making process. During these inter-cultural dialogues, different associated sectors develop specific networks based on TICs, promoted and supported globally by Governments and international organizations.

These three future scenarios could coexist at a global level. But public actions of key national and international organizations, already actively involved in this area could guide transitions between scenarios. Globally, in the short to middle-term, - 5 to 10 years time-, probably the first scenario will prevail. While the second scenario continues to expand to some of the most advanced emerging economies. But the solution to an ethical, participatory and dialogical development and use of SCR inter-culturally,- as is the case of most New Genetics’ and biotechnology-based health
therapies-, lies in elements described for the last scenario, one to tend to in policy, action and advocacy in the longer-term.

**6. References**


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Stem cells and the emerging field of regenerative medicine are at the frontiers of modern medicine. These areas of scientific inquiry suggest that in the future, damaged tissue and organs might be repaired through personalized cell therapy as easily as the body repairs itself, revolutionizing the treatment of numerous diseases. Yet the use of stem cells is fraught with ethical and public policy dilemmas that challenge scientists, clinicians, the public health community, and people of good will everywhere. How shall we deal with these amazing biomedical advances, and how can we talk about poten...