

Transnational Stem Cell Tourism: An Ethical Analysis

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Keywords: stem cells, medical tourism, transnational ethics, global health ethics

Transnational medical tourism is a growing sector of modern global health care, facilitated by globalism and connecting platforms like the Internet, which provides opportunities for health care to those who can afford it. Patients who can afford the steep price (and, very often, those who can't) partake in organ tourism as alternative means of seeking a needed organ, reproductive tourism as a method to treat infertility, in the form of egg donation and surrogacy, as well as stem cell tourism. During the past decade, stem cell research has skyrocketed spurring increased scientific excitement about what the future of stem cell research could hold for regenerative medicine and treatment of untreatable diseases. However, a developing market commercializing in an international setting without regulation and restriction has led to expensive pseudo medical treatments, for which there is no scientific rationale or evidence of efficacy or safety, that threaten the health of patients. Several highly publicized cases including the death of a child in the German¹ stem-cell clinic XCell Center, as well as the highly publicized paralysis and cancer-like growth of American patient Jim Gass in stem-cell clinics in Mexico, China, and Argentina have prompted global outcry and a call for increased regulation and implantation of safety standards.^{2,3} The prevalence of stem-cell clinics that provide untested and potentially lethal medical interventions threatens the global health and financial security of patients.

Stem cell tourism, a growing industry largely advertised online, involves privately owned stem cell clinics, often managed by physicians, fraudulently advertising pseudoscientific stem-cell cures for a variety of untreatable conditions directly to health consumers. Patients looking for stem-cell treatments travel from a diverse range of locations in North America, Europe, the Middle East and Asia.⁴ The clinics they travel to are located around the world, the most popular ones in countries at the forefront of medical stem-cell innovation and in nations with lax stem-cell clinic laws. Companies are located in United States, Mexico, Russia, Germany, India, and China, among several other countries.⁵ They all rely on weak and subjective claims of improvement, selective anecdotes and testimonials, favorable media reports, untested scientific jargon, and links to unrelated studies to appeal to health consumers.⁶ A further study on the data collected from clinics illustrates a therapeutic effect likely due only to a placebo effect.⁷ No clinical data or procedures have been released from these clinics, having the most dangerous implications. No data or procedures released means that efficacy cannot be measured, so hurtful experiences are not counted and actual therapeutically valuable data cannot be used or tested for efficacy against other studies of accepted treatment.^{8,9} These clinics cannot be held to clinical standards of safety or effectiveness and are not held responsible for futile treatment. This shoddy science threatens the future beneficiaries of such innovative clinical science and weakens proof that stem-cell clinics are anything but a farce.

These clinics prey on the hopes and fears of their clients by appealing to a broad array of degenerative, chronic, and fatal diseases.¹⁰ Unknown risks were withheld from patients, threatening not just their autonomy to make an informed decision about their own health but also violates the primary principle of medicine: to do no harm. Embryonic and other stem cells have tumorigenic potential and have been proposed as a source of common origin for cancer.¹¹ These clinics exist as an alternative to patients not eligible for clinical trials or otherwise averse to such trials in the US.¹² Patients go abroad in search of treatments unavailable at home, searching for a source of hope. Patients suffering from serious or debilitating conditions, like Alzheimer's and multiple sclerosis, can't be cured with modern medical treatments. Their only treatment options include

palliative care, symptom management or drugs that temporarily slow the progress of the disease.¹³ These situations create similar circumstances of rashness that drive organ tourism and foment human rights violations.¹⁴

Stem-cell companies provided misleading medical information to their consumers, projecting medical authority and expertise in order to frame their stem-cell therapies as new and innovative rather than unproven.¹⁵ Doing so is intentionally maleficent and puts patients in harm's way. Stem cell tourism brings unique intricate ethical concerns where generalized medical knowledge is at odds with patients' immediate desire to survive, pushing patients to risky treatment many would not consider. This is not simply another case of buyer beware. The potential for serious harm to vulnerable patients is at stake.¹⁶

The stem cell tourism industry is a complex, extensive industry with multiple interlaced causes and contributions. One pronounced contributor is the patient frustration with the lack of treatment in their native country and their immediate healthcare needs. The overselling of stem cell treatments before they have been sufficiently validated and tested for safety has been attributed to the sensationalized attention given to stem cell research in popular media. Stem cell research is portrayed as the next new big thing in medicine, in which the promising research potential is seen as rapidly translatable to cures. With some theatricals, stem cell clinics can extend the applicability of accepted clinical treatments to swindle customers.¹⁷ The perpetrators of the crime are the medical entrepreneurs and brokers who advertise and provide the treatments, but emphasis on communicating openly with patients to understand why patients go abroad for treatment rather than on persecuting brokers and dishonest clinicians carrying out procedures, may be a more effective way of battling unsafe stem cell tourism from the root.

Some researchers contribute the growth of stem cell tourism to American scientists and clinicians. They argue that scientists and clinicians underestimate the relevance of hope to patients making the decisions to travel abroad for dubious treatment, proposing that, even unfounded hope is better than no hope at all in the patient's mind.¹⁸ It is imperative for discussion to reflect on why so little hope is found at home rather than just importance of allowing hope to flourish offshore.¹⁹

The paternalistic dismissive attitude of American physicians in the face of patients considering dangerous or futile stem-cell treatment in the hope of some improvement has been argued to push patients away from established medical professionals to dubious stem-cell clinics. The lack of health care at home has also been identified as a contributing factor. Salter and colleagues insist that the matter at hand isn't toning down the hype but rather domestically available health care supply.²⁰ Patients in need don't care about expanding medical knowledge or the benefit of future suffering patients, they care about is getting better and surviving. Demonizing stem cell tourism will never squelch this vital instinct.²¹ Acceptable channels must be made available to seriously ill patients. Constraints such as the proximity of death as well as the specific burdens of a particular disease condition contribute to the stress of the limits of local treatment to impress an immediacy pointing to external care.²² Recognizing the role of health consumer choices in this emerging global market will be essential to discouraging risky and exploitative healthcare decisions.

¹ Mendick, R. and Hall, A. (2011) Europe's largest stem cell clinic shut down after death of baby, The Telegraph, 8 May. Available at www.telegraph.co.uk/news/worldnews/europe/germany/8500233/Europes-largest-stem-cell-clinic-shut-down-after-death-of-baby.html (accessed 1 May 2017)

² Berkowitz, Aaron L., Miller, Micheal B., Mir Saad A., Daniel Cagney Daniel, Chavakula Vamsidhar, Guleria Indira, Aizer Ayal, Ligon Keith L., Chi John H., N Engl J Med 2016; 375:196-198

³ Kolata Gina, (2016) A Cautionary Tale of 'Stem Cell Tourism'. The New York Times, 22 June (Accessed May 1, 2017)

⁴ Lau D, Ogbogu U, Taylor B, Stafinski T, Menon D, Caulfield T. Stem cell clinics online: the direct-to-consumer portrayal of stem cell medicine. Cell Stem Cell 2008; 3(6): 591–594. China Stem Cell News. <http://www.stemcellschina.com>

⁵ ALSUntangled Group. ALSUntangled update 4: investigating the XCell-Center. Amyotroph Lateral Scler 2010; 11(3): 337–338

⁶ Sipp, Douglas. The unregulated commercialization of stem cell treatments: a global perspective. Front. Med. 2011, 5(4): 348–355

⁷ See *supra* note 4.

- ⁸ Sipp, Douglas. The unregulated commercialization of stem cell treatments: a global perspective. *Front. Med.* 2011, 5(4): 348–355
- ⁹ Devereaux, Mary and Loring, Jeanne F. (2010) Growth of an Industry: How U.S. Scientists and Clinicians Have Enabled Stem Cell Tourism, *The American Journal of Bioethics*, 10:5, 45-46
- ¹⁰ Ibid
- ¹¹ See *supra* note 2.
- ¹² Hyun, Insoo (2013) *Bioethics and the Future of Stem Cell Research*, Print Cambridge University Press, pg.186-204
- ¹³ See *supra* note 8.
- ¹⁴ Shalev, Carmel (2010) Stem Cell Tourism—A Challenge for Trans-National Governance, *The American Journal of Bioethics*, 10:5, 40-42
- ¹⁵ R. Alta Charo, Alta R. On the Road (to a Cure?) — Stem-Cell Tourism and Lessons for Gene Editing, *N Engl J Med* 2016; 374:901-903
- ¹⁶ Murdoch, C.E. and Scott, C.T. (2010) Stem cell tourism and the power of hope, *American Journal of Bioethics*, 10, 5, 16–23.
- ¹⁷ See *supra* note 15.
- ¹⁸ Cohen, C.B. and Cohen, P.J. (2010) International stem cell tourism and the need for effective regulation. Part 2, Developing sound oversight measures and effective patients support, *Kennedy Institute of Ethics Journal*, 20, 3, 207–30.
- ¹⁹ Patra PK, Sleeboom-Faulkner M. Bionetworking: Between Guidelines and Practice in Stem Cell Therapy Enterprise in India. (2010) 7:2 *SCRIPTed* 295, <http://www.law.ed.ac.uk/ahrc/script-ed/vol7-2/patra.asp>
- ²⁰ See *supra* note 12.
- ²¹ International Society for Stem Cell Research. 2008. Guidelines for clinical translation of SCs. Available at: http://www.isscr.org/clinical_trans/pdfs/ISSCRGLClinicalTrans.pdf
- ²² Olle Lindvall and Insoo Hyun, Medical Innovation Versus Stem Cell Tourism, *Science* 324, 1664 (2009)