

## Setting straight perspectives on stem cell tourism

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Resituating Overseas Stem Cell Therapy

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In literature discussing unproven stem cell therapies and stem cell tourism there are a considerable number of generalisations made about the desperation of patients seeking treatments, the permissiveness of government policies in different regions, the location of stem cell clinics offering treatments and more. Discussions on the unproven stem cell market need to consider social and economic settings on an individual, regional and global level to better understand why the number of clinics offering unproven stem cell treatments and the amount of patients seeking them has continued to grow around the world.



### What questions & challenges are raised?

Many ethicists, social scientists and medical researchers have expressed strong condemnation of selling unproven stem cell therapies, with the primary concern often being the lack of scientific evidence that these treatments are safe or effective. Yet, despite this lack of evidence, a growing number of individuals are traveling overseas to get unproven treatments in what has become known as 'stem cell tourism'. Many of the calls for regulation and other forms of action make generalisations that overlook issues that should be considered to better understand and manage the stem cell tourism industry. In his recent commentary Dr Amit Prasad from the University of Missouri quotes numerous published discussions surrounding unproven stem cell therapies to highlight how individuals are making broad generalisations about the unproven stem cell market, stem cell tourism and the individuals seeking out unproven treatments. Dr Prasad focuses on two particular 'inherent dilemmas' that will continue to stand in the way of controlling the market for unproven therapies until they are acknowledged and addressed.

showed that individuals remained open to the idea of unproven stem cell treatments even after being given cautionary information about their risks. Other studies show that the public generally has a positive view of unproven stem cell therapies. Furthermore, it appears that most patients from Western countries actively research their illnesses and treatment options. Indeed, patients may understand the risks, but decide to try unproven treatments anyway. Dr Prasad notes that people's decisions are impacted by information as well as current social attitudes. For example, communities might promote individuals to fight to overcome illness, make their own choices, and disregard guidance from all forms of authority. Hype about stem cells in the media and advertisements by clinics also play a role. Above all of these, discussions with other individuals (in person or online) appear to be the most influential in decision-making. Dr Prasad remarks that patients should not be viewed as desperate or uninformed. Patients may be in vulnerable situations, but they should be treated as individuals, not as 'vulnerable human subjects'. They should be engaged with respectful dialogue that allows them to think and make decisions. Ethics discussions need to situate patient 'desperation' and 'vulnerability' in a larger perspective that includes social, cultural and political circumstances.

### What insight & direction does this give for research policies?

Dr Prasad notes that bioethicists and medical researchers often ignore or 'slide through the tensions' of stem cell tourism dilemmas, but discussions need to acknowledge and analyze perspectives and issues that are often generalised or ignored. Discussions on stem cell tourism should recognise that decisions of individual patients play a large role in the demand for unproven stem cell treatments and that patients inform themselves to make their decisions. Furthermore, Dr Prasad contends that addressing stem cell tourism will require more than new regulations in countries such as India and China. Addressing the management of unproven stem cell treatments requires discussing a span of individual-to-global issues and perspectives, spanning from the social context of individual patients to the regulatory jurisdiction of governments in an international biomedical market. In this respect, simplistic generalisations are hardly helpful.

Dr Prasad notes that a second dilemma is that many articles depict countries overseas as generally lawless, lacking regulations and without any bioethics. Yet, he notes that stem cell tourism is no longer just about clinics in other countries and it appears unproven treatments are difficult to regulate by law alone. There has been a large emergence of stem cell clinics in the US and other Western countries, and very recently a clinic in the US left three patients blind. Dr Prasad states that laws are needed, but also notes that governments' action or inaction should be considered in context of global social and economic situations, such as India's stance to not enact specific regulations for stem cell therapies. To illustrate this, Dr Prasad recounts a discussion he had with a retired government official of India. The official commented that specific legislation on stem cell therapies should be put in place, but that current laws already offer patients protection. However, he further commented that these laws only apply in their own country and need international cooperation to hold international companies accountable. The retired official described his frustration at attempting to contact an international company (of Western origin) about cases where patients were seriously harmed in drug trials in India. The company never responded, which showed double standards in how Western countries deal with medical misconduct. Dr Prasad notes that the official's frustration may also reflect a larger issue of tension between India and Western countries that resulted from an international treaty India agreed to in 1995. This treaty caused a large increase in drug prices and appeared to many to be "heavily tilted towards protecting the patent rights of multinational companies, ... rather than the human subjects who undergo these trials."

### What background and point are discussed?

Dr Prasad points out that an abundant amount of scientific and ethical publications oversimplify stem cell tourism, claiming that clinics overseas have sprung up to take advantage of patients that are desperate and have no other options. To discourage individuals seeking treatment, researchers and bioethicists often try to educate people considering unproven therapies by pointing out the many risks and health concerns. However, Dr Prasad points out an inherent dilemma to this approach. A study in Canada