



Stem Cell Hype and the Dangers of Stem Cell “Tourism”

By Lori P. Knowles

Significant scientific discoveries and innovations quite naturally lead to great enthusiasm about the benefits that may flow from them. One danger, however, is that enthusiasm may lead to hype, defined as exaggerated publicity or extravagant claims. Hype can lead to unrealistic expectations of both the benefits that will flow to the public and how quickly they will be achieved. A problem with excessive hype is that it may mask the fact that a therapy is still in experimental or research phases, which makes it difficult to properly communicate the risks of clinical trials. For example, gene therapy was the subject of hype: it was claimed that researchers would find cures for all kinds of diseases with a genetic origin. Genetic diseases, however, turned out to be much more complex than first imagined, and therapies were few and far between and often had serious side effects.¹ Gene therapy failed to live up to its hype. The failure lies not in the science itself, which will almost certainly yield benefits, but in the hype that surrounded it and the unrealistic expectations that were engendered for swift, effective genetic “cure-all’s.”

Stem cell researchers and advocates have reason to be concerned that the story of stem cell therapy does not replay those same mistakes. When expectations for hyped benefits are not realized, the public and funding agencies may abandon a field of scientific endeavor that may yet have benefits to yield. In addition, where the hype concerns medical benefits, untested clinical applications touting these benefits often lure patients into expensive and even harmful research. There are stories of this happening in some instances with stem cell therapies.

Since the isolation of human embryonic stem cells (hES), news of stem cell developments and policy discussions have been accompanied by stories of the promise of stem cell therapy. Initially, the dominant story was that stem cells would be used to create replacement tissue and organs using a patient’s own DNA. Such autologous transplantation could avoid the common occurrence of immunological rejection of organs and tissues that have been transplanted from other individuals. It would also avoid the need to suppress a transplant recipient’s immune system with expensive anti-rejection drugs, something that is necessary to allow the transplanted tissue to be accepted by the body, but that leaves the patient open to infections at a time when they are most vulnerable. This will be a tremendous advance in the field of regenerative medicine, but communications about stem cells need to be clear that the science is not there just yet, so it remains a hope for the future.

Stem cell researchers have walked a fine line between enthusiastically describing the long-term potential of stem cell therapies which helps get support for their work and in cautioning that science and research take time and sustained support. Part of the tension for researchers lies in the need to work slowly and carefully, and yet also to attract industry funding based on the potential commercial and clinical applications from their work. Increasingly, universities and government funders are looking at commercial applications and numbers of patent applications as a measure of commercial potential and ultimate success of research. Finally, scientists, like most people, crave opportunities to advance at their universities and most are genuinely enthusiastic about their work and its promise. This enthusiasm may lead researchers to

¹ Kaiser, J., “Panel urges limits on X-SCID trials.” *Science* 11 March 2005:Vol. 307, no. 5715, pp. 1544 - 1545.

overstate the time to realization or scope of the benefits from stem cell research. This is dangerous in that it sets up the research for failure if it does not deliver these benefits or does not deliver them quickly.

The media in turn, plays a part in the hype around new genetic and medical technologies, including stem cell therapies. As the public's attention gets shorter, science journalism is pushed further to tell complicated, nuanced stories in fewer lines. This means less room can be devoted to possible complications or stumbling blocks on the road to clinical success. The usual drive to tell a clear, compelling story militates against including this type of detail. Add to this the fact that journalists depend on high profile science journals for their understanding of the science, and the editorial boards of these journals become the keepers of the true scientific story, as the public ultimately hears it. Biomedical journals also have commercial bottom lines to be met and tend to emphasize positive results (success stories) over negative results.

All the hype around each new scientific development in the stem cell story has led to stem cell quackery and stem cell tourism. Stem cell quackery is similar to other types of medical quackery that follow an area of medical or biotechnological research promising real medical benefits. In particular, where there is such promise of benefits coupled with funding or regulatory restrictions such as in the United States and Canada respectively, waiting for stem cell therapies can seem interminable for people in need.

There are always individuals and companies who will take advantage of the necessary lag between research and clinical applications to hold forth the promise of contemporary cures and therapies. Researchers at the University of Alberta have shown that if you google "stem cell therapy" there are a number of companies offering a panoply of treatments for a "dazzling array of ailments, including heart disease, Parkinson's, chronic fatigue," autism, eye disorders, and aging.² These internet sites generally do not supply raw data but rely on testimonials. There is nothing inherently wrong with testimonials, but the need for peer-reviewed data is clear – without it we cannot know whether a treatment is truly beneficial (is something else conferring the benefit?), ineffectual or even harmful.

The review of internet sites offering stem cell therapies concluded that in general "indications for therapy are indeterminate or over-broad, benefits are overstated, risks are understated, and certainty of knowledge in the field is inflated." Knowing the risks associated with a stem cell therapy is crucial. While stem cells appear to be marvelously malleable researchers have not yet discovered how predictably to "direct" the growth of these cells into the tissue type we desire. The very malleability that gives stem cells their potential also makes them dangerous – they have a striking ability to grow into tumours. Turning off their tumour-causing properties is central to controlling the risks associated with stem cell therapy. In order for a patient to give informed consent to any stem cell therapy or research trials the risks need to be discussed and understood.

In response to the finding by the University of Alberta, the International Society for Stem Cell Research (ISSCR), a leading professional group, has issued a guide for patients and their families advising them to approach stem-cell therapy with extreme caution. The report examines the translation of stem cell research into clinical therapies and provides some context for treatments that are being offered today.

Canadians and Americans have somewhat restrictive stem cell research environments due to regulatory and funding restrictions. Other countries such as Britain, Israel, Singapore and China have less restrictive regimes. While some countries, like Britain and Israel couple their liberal research laws with comprehensive medical oversight, others like China, Mexico and Costa Rica simply have less oversight of both stem cell research and therapies. Such places are becoming havens for stem cell tourism. Stem cell tourism involves traveling, often very far away, to pay for stem cell therapies that are not available in one's own country. Examples of stem cell tourism abound in the news. Journalists are aware that there is a story to be told about desperate people flying across the world for a chance, however remote, to save a child or improve the quality of a loved one's life. Parents fly to Costa Rica to help an autistic child through injections of adult stem cells

2 Lau, D., Ogbogu, U., Taylor, B., Stafinski, T., Menon, D., and Caulfield, T. Stem cell clinics online: the direct-to-consumer portrayal of stem cell medicine. *Cell Stem Cell* 3, 591-594 (2008).

from umbilical cord blood at a cost of over 15 thousand dollars.³ Little girls previously blind receive injections of umbilical cord blood in China and are reported to be able to see light. These treatments can cost tens of thousands of dollars.

Nothing is inherently wrong with stem cell tourism, except there is a reason that these therapies are not available in Canada, the United States and many other nations. They have not been tested to national standards to prove safety and efficacy and some of them raise serious concerns. Blogs discussing this stem cell tourism evidence the ambivalence about these interventions. Some commentators think that the people willing to take the chance that these treatments don't work or

may harm them or their children are medical pioneers. Others think our high standards for scientific validity and tight regulatory approval are barriers to medical innovation, "while we wait for them to kill some rabbits the rest of the world seems to be moving ahead. There are too many studies mid-stream finding this stuff works to keep our heads stuck in the sand. For all our sakes let's hope China doesn't tie themselves up in the same knots we've got over here. Medical progress takes science and guts. Literally."⁴ Still others argue that these treatments are expensive quackery of the worst kind. All that can definitely be concluded is that without knowing the real risks and benefits it is impossible to give informed consent to these treatments, and that all those searching for a stem cell cure today need to be wary.

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The International Society for Stem Cell Research, Guidelines for the Clinical Translation of Stem Cells, http://www.isscr.org/clinical_trans/pdfs/ISSCRGLClinicalTrans.pdf

Appendix 1: *Patient Handbook on Stem Cell Therapies* http://www.isscr.org/clinical_trans/pdfs/ISSCRPatientHandbook.pdf

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3 Chew, K., "Stem Cell Therapy/Tourism" <http://www.autismvox.com/stem-cell-therapytourism> (accessed March 28, 2008).

4 <http://bayblab.blogspot.com/2008/03/stem-cell-tourism-in-china.html> (accessed July 16, 2008).