



Stemming the scams

Clinics using stem cell research to defraud patients must be combatted, urges Professor Joel C Glover, Director of the Norwegian Center for Stem Cell Research...

Stem cell research and the field of regenerative medicine have become major enterprises in biomedical science. Impressive advances have been made in understanding how cells acquire pluripotency, how cell differentiation programmes are organised at the genetic and epigenetic levels, and how this knowledge can be harnessed to direct pluripotent cells to differentiate to any desired cell type and to drive differentiated cells back to pluripotency. Moreover, further advances have been made in understanding what sort of limitations the inherent cell biology places on using pluripotent and multipotent stem cells for treating disease.

The implications of stem cell research are so profound that most industrialised countries now have national or regional centres dedicated to such activity, as do many major universities. Although to a great extent still unrealised, the promise embodied by stem cell research to provide limitless supplies of personalised cells to replace tissues and organs stricken by injury or disease has fascinated both researchers and the public, and is frequently highlighted by the media.

As the Director of a national centre for stem cell research, I receive many inquiries from patients and families desperate to reap the benefits of the stem cell-based treatments that appear to be available now or just around

the corner. Many are requests for advice regarding a pending visit to a stem cell clinic in a foreign country that offers 'established' treatments for the patient's disease. As a consequence, I have spent some time investigating what these 'clinics' are and how they operate.

What is stem cell tourism?

Stem cell tourism has become a familiar concept in the public health sector. It refers to patients travelling to clinics, often far from home, to receive treatment using stem cells for a disease that can only be treated with difficulty or cannot altogether be treated through established medical procedures.

A growing number of clinics now offer 'stem cell treatments', and their portfolios for these clearly mirror the hype that has unfortunately accompanied the growth of stem cell research. Claims are often outrageous: the X-Cell Clinic in Germany that was finally forced to close down last year, for example, had a drop-down menu of treatable conditions taken straight from a medical lexicon –the first entry was 'agenesis of the corpus callosum'.

For researchers in the know, it is easy to disregard such offers as nonsense. However, for the layperson and, in particular, patients and their families who see no other option in a potentially life-and-death scenario, the situation is entirely

different. For them, it can rapidly become an economic and medical nightmare, creating a serious problem for both medical authorities and the stem cell field. Moreover, some bona fide stem cell treatments are being developed, and at some point it will be necessary to distinguish between the serious operators and the charlatans.

So, what can be done to address this problem? Defining and imposing international regulatory mechanisms is a long and tedious process, and enforcement can also be difficult. A critical element has to be educating patients so that they can avoid being duped by cynical opportunists.

Empowering patients and their families

Quality checks are easy to make

Few people would entrust the repair and servicing of a valuable item, such as a car, to novices. For this reason, it is common to check the credentials of mechanics and other tradesmen before soliciting their services. In some countries, this practice is also permitted and even encouraged when it comes to services provided by medical professionals.

However, this poses the question of how one runs a quality check on a completely unregulated industry, particularly in foreign countries that may not have agencies overseeing its activities. Specifically, how does one dig past the façade of a glossy website festooned with glowing, but impossible to corroborate, customer endorsements to check the credentials of a stem cell clinic?

There are two things patients can do to determine whether a stem cell clinic might be an operation based on well-founded science. Firstly, they should determine whether there is a scientific advisory board at all. If there is no sign of such a board in any of the clinic's marketing material, then it should be written off as unserious. Secondly, if an advisory board does exist, it should be evaluated for scientific merit. The easiest way to do this, at least to a first approximation, is to use the publicly available database PubMed to see if those listed as members of the board do in fact have any research background in stem cell biology.

Although this is not necessarily a trivial task for a layperson, with a little assistance from their doctor, it should be possible to determine if a given board member has published anything about stem cells at all, and how much they have published. A general rule of thumb would be that if a person has published less than two articles per year in recognised peer-reviewed science journals, then it is unlikely that they have sufficient expertise to serve as a scientific advisor to a clinic treating people.

PubMed is an excellent resource for investigating the research activity of scientists and doctors, and even if patients and families may not themselves be science literate, they should know that it exists and can be used in this way. Typically, they are already highly motivated and will take the necessary steps to find someone who can assist them in using this tool.

Know the classic modus operandi

Scams work because they are based on approaches that are known to fool people. There is in fact a typical stem cell clinic scam, and anything that resembles this modus

operandi should be met with extreme caution and scepticism. It goes like this. The patient and/or family first encounters a very professional website with a description of top-notch clinical facilities; a highly trained staff, including surgeons and other doctors; and any number of highly positive, but impossible to trace, endorsements from previous patients. The website provides contact details, and patients are invited to send in information about their condition, eventually winding up speaking to someone on the phone or even travelling to the clinic to meet someone there to discuss their case.

Often, this contact person is from their own country or area of the world, which provides a sense of validity and comfort for the potential customer. The contact person provides assurances that the treatments have been performed numerous times with no ill effects, but makes it clear that no medical procedure is perfect and that only about 80% of those treated actually respond to a first treatment, and that sometimes additional treatments are necessary. A contract is then drawn up, money is paid and the treatment is performed. The patient may in fact experience some improvement in their condition purely from the placebo effect, but as everyone knows, this eventually disappears and the patient is no better off. On contacting the clinic with this huge disappointment, the patient is met with sincere apologies and told that unfortunately they must be among the unlucky 20% who do not respond to first treatment. Then they are told that fortunately the odds of responding increase to 90% after a second treatment, so a new contract is drawn up, more money is paid, and a second treatment is administered.

Should the patient again experience no lasting improvement, they are met with the sad news that they must be among the 10% that don't respond to two treatments, but that three treatments give even higher odds, and moreover, a third treatment can be had for a substantial discount if they can provide the name of another potential patient. Sometimes the discount offer is made before the second treatment, to get the recruitment bit in before the patient realises either that this does not work or that they are being had, by which time substantial funds have already been lost by the patient and gained by the clinic.

The value of education

It is a sad fact that whenever science advances knowledge, there is someone who sees an opportunity to capitalise on this at someone else's expense. Education is the best weapon to avoid this. If patients know more about how to evaluate clinics that offer stem cell treatments, and know how the scams work, they are less likely to become a victim of stem cell tourism. Thus agencies trying to deal with this problem should actively disseminate this kind of information.



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