The Review

Safeguarding patients against stem cell tourism

The globalisation of health care¹ has exposed patients to novel treatments they may never have previously encountered, such as stem cell therapy. The practice is for the most part illegal in the UK, but the proliferation of stem cell clinics in countries such as India, China, Mexico, and Germany, and their subsequent marketing efforts has attracted 'stem cell tourists' — patients in search of a cure for their illness. The lack of clinical evidence to support stem cell therapy puts patients at risk of receiving at best ineffective,² and at worst unsafe or even harmful treatments,³ raising calls for a campaign to raise awareness and educate patients about these dangers. This issue has recently become urgent. Media frenzy surrounding the case of Dr Trossel and his dismissal following his controversial advice, and offer of unregulated stem cell treatment to a multiple sclerosis patient,⁴ led the General Medical Council (GMC) to conclude he had breached medical practice by 'exploiting vulnerable patients'. It has been reported that nine patients were involved in the case, and that Dr Trossel allegedly injected a substance containing stem cells into at least five of them in his Rotterdam clinic. Large sums of money, of at least £10 000 per patient, had been forwarded to him in advance of the treatment. Following some investigation, it is doubted whether the substance used contained any form of stem cells at all. The GMC's stance is that this was a gross abuse of a position of trust, and Dr Trossel was intentionally misleading vulnerable patients, making exaggerated claims, and using illegitimate, unscientific treatments.

A Google™ search reveals a plethora of similar clinics offering false hope of curing the incurable. Clinics in countries as close to the UK as Germany list on their websites an A–Z of conditions that they claim to be able to treat, from Alzheimer's disease and autism, through to stroke-related disability. These treatments come at a considerable price, with an average cost of \$21 400 (approximately £15 000) for a course of treatment.⁵ Although the exact number of stem cell tourists from the UK using these 'services' is unknown, it is estimated to be in the hundreds with an increasing number asking medical experts for advice on the practice.⁶

One of the most pressing concerns is that of safety. A lack of associated preclinical data or meticulously produced evidence of safety or efficacy, limited follow-up of patients, and reporting of adverse events raises great concern. Such concern is potentiated by the negative and harmful side effects which have been noted as a result of some of the therapies. The majority of the papers on the topic recall the case regarding a 13-year old Israeli boy who, following treatment with fetal neuronal stem cells at a hospital in Russia, developed abnormal growths in his brain and spinal cord, that were later determined to be of non-host origin, and most likely derived from the transplanted cells.⁷ A link was also established between a particular case of stem cell implants in China for spinal cord injuries, and meningitis contracted after the operation.⁸

In December 2008, the International Society for Stem Cell Research (ISSCR) released a *Patient Handbook on Stem Cell Therapies*,⁹ a compilation of 14 'frequently asked questions' regarding stem cell treatment, including 'What should I be cautious about if I am considering stem cell therapy?' and 'How do I know if an approved stem cell therapy is safe?' Following the release of the ISSCR handbook, the Department of Health¹⁰ issued a 'warning on unproven stem cell treatments', a message that was reinforced in press releases by respected and trusted charities, such as the Multiple Sclerosis Society.¹¹ These reiterated the importance of tackling stem cell tourism.

As a group of UK student doctors we decided to further examine this issue. Using our literature review and internet search, we identified members of the public in the UK with conditions commonly targeted by overseas stem cell clinics, such as multiple sclerosis, spinal cord injury, diabetes, motor neurone disease, Parkinson's disease, and autism. We then sent these potential

participants questionnaires via internet forums, social networking sites, and support groups. Follow-up telephone interviews were then conducted to further elucidate educational needs. The results were conclusive; 80% of the sample of 183 favoured the need for greater education regarding stem cell tourism. Doctors, particularly GPs, significantly outweighed other options as the preferred source of education. Despite this patients did not see their local GP as always accessible or knowledgeable enough on the subject, highlighting recommendations for change.

Patients felt that despite a healthy relationship with their doctor there is sometimes a lack of support with regard to stem cell therapy. GPs are: 'a crucial part of the process because they are the professionals monitoring their patients overall health in the short and long term',¹² but they tended to shy away from the topic, sometimes treating it with a certain degree of scepticism, which stems from a lack of knowledge on the topic and inadequate education in the professional context. Alongside recommending an education campaign for patients, we advocate a need for education from both sides of the doctor–patient relationship, therefore also focusing on the doctors' educational deficit. The foundations for effective education have already been laid in that an established and trusted relationship between doctor and patient exists.

We suggest the current UK Stem Cell Initiative¹³ is extended to incorporate this patient-facing unit, educating from both sides. As it stands, the only formal guidelines regarding this issue have been produced by the ISSCR. Their website offers easy access to both these guidelines and *The Patient Handbook on Stem Cell Therapies*. However, the only UK initiative comes in the form of the Department of Health warning, published in December 2008, referring patients to the ISSCR

"80% of the sample of 183 favoured the need for greater education regarding stem cell tourism. Doctors, particularly GPs, significantly outweighed other options as the preferred source of education."

"Perhaps if official guidelines as to how best to educate patients were produced by a formal body ... and incorporated into GP or physician training, this could lend more authority as to the educating of doctors."

website and advising them to e-mail the Department to determine whether specific treatments are regulated.

The Dr Trossel case has indicated that more needs to be done, particularly with the backing of official bodies such as the GMC. Perhaps if official guidelines as to how best to educate patients were produced by a formal body such as the GMC or Department of Health and incorporated into GP or physician training, this could lend more authority as to the educating of doctors. At the very least, the GMC should play a part in ensuring that doctors receive adequate support and guidance on patient education regarding stem cell therapy. Ultimately, patients will exercise their right to autonomy and make their own decisions, and so they should. But with such a case where there is significant potential risk, perhaps the most effective way to combat this issue is to empower patients with the right knowledge and education, so allowing them to make an informed decision, and prevent further such scenarios from taking place.

Ours was a small exploratory study, and there is scope for more definitive research. However, our results raise awareness of this issue and hopefully will promote more extensive research that directly helps vulnerable patients who seek out and access information on stem cell therapy in the future, via increased information provision and awareness of the growing interest in stem cell tourism.

Sarah Jawad,
Medical Student, Business School, Imperial College
London, London.

Aziza Al-Yassin,
Medical Student, Business School, Imperial College
London, London.

Daniel Herridge,
Medical Student, Business School, Imperial College
London, London.

Wai Kwan Lily Lai,
Medical Student, Business School, Imperial College
London, London.

Nigel Rozario,
Medical Student, Business School, Imperial College
London, London.

Jane Hendy,
Senior Lecturer in Healthcare Management &
Policy, University of Surrey, Guildford.

Provenance
Freely submitted; not externally peer reviewed.

DOI: 10.3399/bjgp12X641591

ADDRESS FOR CORRESPONDENCE

Sarah Jawad
Imperial College Business School, Imperial College
London, South Kensington, London, UK.
E-mail: sarah.jawad@kcl.ac.uk

REFERENCES

1. Walt G. Globalisation of international health. *Lancet* 1998; **351(9100)**: 434–437.
2. Lindvall O, Hyun I. Medical innovation versus stem cell tourism. *Science* 2009; **324(5935)**: 1664–1665.
3. BBC News. *Stem cell 'cure' boy gets tumour*. BBC (Online), 2009. <http://news.bbc.co.uk/1/hi/7894486.stm> [accessed 5 Apr 2012].
4. BBC News. *Stem cell doctor GMC hearing begins*. BBC (Online), 2010. <http://news.bbc.co.uk/1/hi/health/8448446.stm> [accessed 5 Apr 2012].
5. Lau D, Ogbogu U, Taylor B, et al. Stem cell clinics online: the direct-to-consumer portrayal of stem cell medicine. *Cell Stem Cell* 2008; **3(6)**: 591–594.
6. Moss L. *Warning over 'stem cell tourists'*. Edinburgh: The Scotsman, 18 February 2009. http://www.scotsman.com/news/warning_over_stem_cell_tourists_1_830072 [accessed 5 Apr 2012].
7. Amariglio N, Hirshberg A, Scheithauer BW, et al. Donor-derived brain tumor following neural stem cell transplantation in an ataxia telangiectasia patient. *PLoS Med* 2009; **6(2)**: e1000029.
8. Barclay E. Stem-cell experts raise concern about medical tourism. *Lancet* 2009; **373(9667)**: 883–884.
9. International Society of Stem Cell Research. *Patient handbook on stem cell therapies*. Deerfield, IL, US: ISSCR, 2008. http://www.isscr.org/clinical_trans/pdfs/ISSCRPatientHandbook.pdf [accessed 5 Apr 2012].
10. Department of Health. *What is stem cell therapy?* London: DoH, 2008. <http://www.dh.gov.uk/ab/GTAC/Stemcelltherapy/index.htm> [accessed 5 Apr 2012].
11. Multiple Sclerosis Society. http://www.mssociety.org.uk/news_events/news/press_releases/ibs_stem_cells.html [accessed 5 Apr 2012].
12. Crozier GK, Thomsen K. Stem cell tourism and the role of health professional organizations. *Am J Bioeth* 2010; **10(5)**: 36–38.
13. UK Stem Cell Initiative. *UK Stem Cell Initiative. Report and recommendations*. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4123849 [accessed 13 Apr 2012].