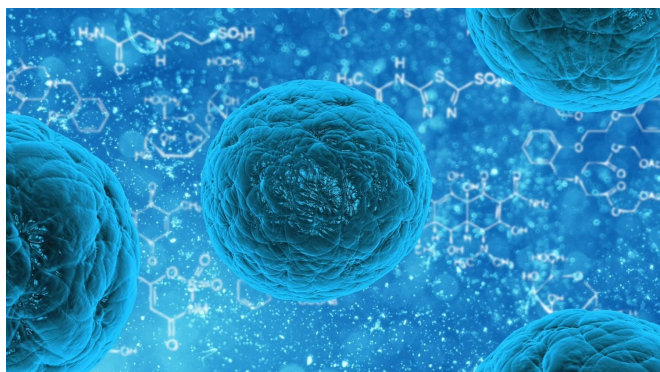


Stem cell 'therapy' injuries more widespread than we knew

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Grotesque side effects from unproven 'stem cell' therapies are more common than we realized, reports a team of researchers led by UConn Health in *Annals of Neurology* on July 29. And despite the dangers, many neurologists feel ill-equipped to warn and educate their patients.

People who have suffered debilitating brain or spinal cord damage, or have been diagnosed with [progressive neurological disease](#), are often frustrated by the lack of treatments available to help them. That frustration can make them easy targets for clinics that inject [patients](#) with "stem cells". But most of these clinics are operating outside of the Food and Drug Administration's jurisdiction, and the treatments they offer are unproven. And pricey.

"It's an unethical industry. They use fancy websites promising cures left and right, but which are nothing of the sort. They steal your money but give nothing in return," says Jaime Imitola, senior author of the paper and director of the Comprehensive Multiple Sclerosis Center at UConn Health.

Patients often pay \$25,000 to \$50,000 in cash for procedures that claim to cure everything from multiple sclerosis to paralysis, but have no evidence to back them up. The clinics, which can operate in the US but are more commonly found in Mexico, China, Russia and other countries with looser health regulations, entice patients to fly out for a week or two of spa-like treatment, [physical therapy](#) and injections of stem cells supposedly designed to cure multiple sclerosis, ALS, paralysis, or whatever other neurological impairment the person suffers from. The physical therapy often makes the patient feel better for a week or two. But sadly, there are no treatments that can reliably improve most of these diseases, and definitely none using stem cells. And anecdotal stories have begun popping up of patients who have had these stem cell procedures and then developed horrifying side effects, from hepatitis to nerve pain to bizarre spinal cord tumors.

In an effort to better understand the impact of this stem cell tourism, as the field calls it, a team of researchers lead by UConn Health conducted a nationwide survey of academic neurologists' experiences in stem cell tourism complications. The survey also investigated the level of physician preparation to counsel and educate patients.

Imitola led the study with colleagues from the Ohio State's Neuroscience Research Institute. The researchers know as well as anyone how far medicine is from any kind of stem cell treatment for these neurological diseases. And they have had patients come to them asking for permission—the clinics call it 'clearance'—to get the stem cell injection treatments.

The results of the survey show that bad outcomes from stem cell tourism are much more common than anyone had realized. Of the neurologists who responded to the survey, one in four had had a patient with complications related to stem cell therapy. Patients who had suffered infections,

strokes, spinal tumors, seizures, and even deaths were all reported. And 73% of neurologists responding to the survey said they felt that having more educational tools to discuss the issue with patients would be helpful.

"Stem cells hold the promise for patients, not just the desperate ones with terminal illnesses but also those who are looking for a 'natural solution' where modern medicine has failed them. Anecdotally, I have spent many hours talking to patients about powerful new immunotherapies to prevent relapses of multiple sclerosis or neuromyelitis optica; but, when they ask if these therapies will help them walk or see again, I have to admit they won't," says Michael Levy, research director for the division of neuroimmunology and neuroinfectious disease at Massachusetts General Hospital, Harvard Medical School, who was not involved in the study.

Levy says the paper by Imitola and his colleagues found that many neurologists are faced with these questions but most have no experience with stem cell therapies.

"Patients as well as physicians are constantly looking for ways to maintain hope. So if a patient asks about it, the doctor may say 'I encourage them to look into it,'" says Dr. Alfredo Quinones-Hinojosa, the William J. and Charles H. Mayo Professor and chair of Neurologic Surgery at the Mayo Clinic, who was also not involved in the study. "We need to be careful how we as physicians find a balance between giving patients hope and maintaining scientific accuracy to the highest standards."

"It is really shocking that only 28% of board-certified neurologists feel completely prepared to discuss this important issue with their patients," Imitola says. The International Society of Stem Cell Research has information available on their website, but Imitola and his colleagues say there is a need for regular educational sessions on stem cell tourism to be held at international and national neurology meetings as well.

"The ultimate goal of this research is to be able to determine the extent of the complications and the readiness of neurologists to counsel patients. All of us are interested in bringing real stem [cells](#) to the

clinic, but this process is arduous and requires a great level of rigor and reproducibility," Imitola said.

The team also plans on starting a national patient registry, where physicians can report complications from stem cell tourism procedures so that the medical world and regulators can get a better sense of the extent of the problem, and have more data with which to educate patients. These findings are more pressing now, when some stem cell clinics are even promoting cures for COVID19 with [stem cells](#).

Provided by University of Connecticut

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