Introduction
The promises of stem cell research have provided hope to those who suffer from a variety of diseases and conditions, but to date, there are very few proven therapies that involve stem cells. However, a growing number of clinics around the globe have begun offering stem cell treatments for a wide range of conditions. While it is difficult to know exact numbers, previous studies have suggested that possibly thousands of people travel abroad every year to receive stem cell therapy for a vast array of conditions, and all at a hefty cost.

This growing phenomenon has been dubbed “stem cell tourism”, equating it with other forms of medical tourism that marry facelifts and beach vacations. This terminology has been criticized for ignoring the often serious and desperate conditions in which many stem cell therapy patients find themselves. Whatever the name, these unproven stem cell therapies have provided hope for many and drawn criticism from the scientific community as well as many others.4

Much of the criticism is based on the lack of evidence gathered through clinical trials regarding the safety and efficacy of these treatments.5 Also, a lack of transparency in treatment protocols at the clinics and no apparent post-treatment follow-up has raised concerns about the adverse effects and risks of the treatment.6 Other issues have been raised including the lack of true informed consent7 and vulnerable people (including children) being taken advantage of or put at risk,8 to name a few.

Due to this lack of transparency on the part of these clinics it is also difficult to assess how many people are pursuing treatment, where they are going, why they are going, and what their experiences are during treatment and recovery. Personal blogs, written by patients or their caregivers, provide a unique method for gaining an understanding into the motivations for pursuing treatment and the actual experiences of preparing for and undergoing stem cell therapies abroad.

Methods
In order to gain more insight into patients and/or their caregivers who choose to pursue unproven stem cell therapies in overseas clinics, we conducted a thematic analysis of publicly available blogs written either by patients or their caregivers who plan on, are in the midst of, or have received stem cell therapy at an overseas clinic. Personal blogs were collected using the Google Blog Search engine with the following search terms: stem cell treatment or stem cell therapy, as well as travel, overseas, abroad, tourism, or variations of these terms (e.g., travel or traveling). No date restrictions were used and the search was restricted to English-language blogs only.

Some of the stem cell clinics host patient blogs on the clinic website to help promote the success of their therapies; however, we excluded these blogs from our sample so as to limit the chances of bias presented in the data. In total, we collected a sample of 30 blogs, which included the experiences of 32 patients.
Two researchers conducted an initial analysis of a random sample of 10 blogs. Each researcher analyzed 5 blogs independently by collecting patient demographic information, writing notes about patients’ reasons for pursuing treatment, experiences at the clinic and during recovery, as well as any other information relevant to the patient experience with stem cell therapy. From these notes, the researchers developed a list of common themes from across the blogs. The researchers’ lists of themes were then compared, and a list of 7 themes based on both of the analyses was compiled. One of the researchers then analyzed the remaining 20 blogs, adding to the list of themes for a total of 10 themes.

**Findings**

**Demographics**

The purpose of this study was not to construct a complete picture of the range of patients that pursue stem cell therapy abroad. However, the demographics of the patients presented in the blogs bears some consideration. As previously mentioned, there were 32 patients aged 7 months to 65 years old when the last blog entry was analyzed. There were 17 adults (53%) and 15 minors (47%). Patients were from five different countries: US (24), Canada (4), Australia (2), UK (1), and Brazil (1). Patients were pursuing treatment for 13 different diseases with the majority of patients having Multiple Sclerosis (MS) (6) or a brain injury or damage (5). Other diseases included Multiple System Atrophy (MSA) (3), Cerebral Palsy (3), Batten Disease (3), Amyotrophic Lateral Sclerosis (ALS) (3), Spino-Cerebellar Ataxia (2), Optic Nerve Hypoplasia (1), Muscular Dystrophy (1), Cancer (1), Glut-1 Deficiency (1), and Arterio-Venous Malformation (AVM) (1). Two patients also had undiagnosed diseases, possibly Lyme disease and autism.

Patients had either traveled to, were currently in, or planning on pursuing treatment in 8 different countries. One patient was only in the planning stages and had not yet chosen a clinic for treatment. As is consistent with previous studies the most popular destination was China (17), followed by Costa Rica (4), Germany (3), India (2), Israel (2), Dominican Republic (1), South Korea (1), and Mexico (1).

The cost of the treatment was mentioned in only 10 of the blogs, which ranged from $10,000US to $150,000US (this being the total for 3 trips over 1 year). The average cost was approximately $48,000US. Patients or caregivers that mentioned cost either did extensive fundraising or secured bank loans. Donation information was provided in 19 of the blogs.

**Themes**

Themes fall into three main categories: (A) characterizations of the patient and their reasons for pursuing and documenting their treatment (Table 1); (B) characterizations of their experience at the clinic and during recovery (Table 2); (C) skeptical accounts of stem cell treatment (Table 3).

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**A. Patient Motivations for Pursuing Stem Cell Therapy**

i. Patients feel this is the only option left or the only option at all

The one theme that ran through all of the blogs was one of desperation and the sense that patients had nothing to lose. For some, there are no known treatments or cures for their disease or condition in their country of residence. For yet others, they have tried every other option available to them in their native countries but nothing has worked and their diseases continue to progress, and still others were unsatisfied with the treatments available to them and they did not want to wait for further research while their health continued to worsen.

ii. Patients perceive themselves as well-informed

Many of the patients and/or their caregivers believed that they were well-informed about the experimental...
nature of stem cell therapy and what to expect at the clinic. Before making decisions, they reported that they conducted extensive research through a variety of sources including brochures and websites from overseas clinics, testimonials from other people that have undergone stem cell therapy, and some even tried to access published, peer-reviewed journal articles. For some patients the evidence needed to make the decision to pursue treatment was anecdotal, for others it was the information available to them regarding treatment protocol and number of patients treated successfully at a clinic, among other factors.

iii. Patients have hope and belief in the power of the treatment
Patients and/or their caregivers had a lot of faith that stem cell treatment would help improve, if not cure, their conditions and make their lives easier and more enjoyable. Even when little or no improvement was seen, and in some cases patients’ conditions became worse, there was often an unwavering belief and hope that stem cells are still the answer, if not now, then in the future.

iv. Patients are critical of health care and research in home country
Many patients made comparisons between the treatment they received in overseas stem cell clinics and the treatment they have received in their native countries. Patients were often critical of the healthcare and research progress in their home countries. Some patients reported difficulties in finding doctors that would take the stem cell therapy seriously after they returned home, and in some cases, patients became ineligible or were kicked out of clinical studies due to the stem cell therapy.

v. Patients believe they are medical pioneers that are adding to scientific knowledge
Many of the blogs were written for the purposes of providing information about a particular disease and about stem cell treatment at a particular clinic or in general. In many cases, patients believed that by undergoing treatment and writing about it, they were adding to a body of scientific evidence that supports the efficacy of stem cell treatment, sometimes with the hope of encouraging governments or policy-makers at home to de-regulate research and allow stem cell therapy. Many of the blogs contained links to media articles and scientific reports about stem cell therapy as well.

B. Details of Treatment and Experience at Clinics

i. Patient care and living in a clinic
Reports of clinic experiences varied between patients. The majority of blog authors reported good patient care, especially when compared to the care they have received at home in their respective countries, but some patients disliked the hospital setting and living arrangements. Many of the clinics had facilities where the patients and their caregivers were able to stay together during the treatment process, especially when the treatment was over a period of several weeks. In other clinics, patients and their caregivers stayed in nearby hotels during the course of their treatment. Experiences while at the clinic varied considerably, but there seemed to be a common respect for the attitudes toward sickness and wellness in these clinics when compared to their home countries.

ii. “One size fits all” treatment and making treatment choices
Many patients reported consulting with the doctors at the overseas clinic regarding the number of treatments they received and being able to choose the methods for injections that they “felt” were appropriate for them based on pain tolerance and other factors. Also, while there seemed to be considerable differences in the treatment protocol between different clinics and especially in different countries, treatments did not appear to vary between patients and disease-types within specific clinics. Clinics seemed to use the same types of stem cells, similar lengths of treatment and similar procedures and concurrent therapies with every patient, no matter the condition.

iii. Stem cell treatment was combined with other therapies
Stem cell treatments, as reported in the blogs, appeared to usually be combined with other therapies (e.g., intense physiotherapy, occupational therapy, massage, herbs, acupuncture, electro-stimulation, etc.) which were often continued when the patient returned home. In some cases, the patients were not engaging in these activities previous to the stem cell treatment. Some patients also reported that they received either concurrent gene therapy or that their stem cell injections were mixed with Nerve Growth Factor (NGF).

iv. Looking for signs of improvement, but very little significant improvement reported
Both during treatment and once patients returned home, there was a continual dialogue present in the
blogs about any changes, positive or negative, big or small, that patients were experiencing. Patients became very self-aware and even the slightest difference became cause for excitement or disappointment. For the blogs that record patients’ progress after they returned to their respective countries, and especially for those patients who updated their progress for more than a year post-treatment, there was very little significant improvement reported in their condition. In some cases, there was no improvement at all, and even deterioration.

C. Skepticism
While similar themes ran through most of the blogs, there were two blogs that provided a different perspective on stem cell treatments abroad. The first was co-written by a patient and his wife that tried stem cell therapy knowing that it was experimental. In the months and years following the treatment, both the patient and his wife began to report questionable behaviour by the clinic and they became increasingly critical of overseas clinics. Some of the clinic’s behaviour included requesting the patient to post his medical reports on his blog so that the clinic could use it to support their success, and also asking the patient to only visit the doctor when he is having a good day in order to avoid the appearance of negative results from stem cell therapy. After the patient began to write about these events on his blog and questioned the clinic’s motives, the link to the blog was removed from the clinic’s online list of patient blogs. The second blog was written by a patient’s wife who was skeptical of stem cell treatment, but agreed to accompany her husband in order to support him, not the treatment. The blog contained frequent references to the money-making, business aspects of the overseas clinics.

Conclusion
Previous research and commentary regarding the phenomenon of stem cell tourism has demonstrated the public’s growing interest in stem cell treatments, the risks of stem cell therapies, and the lack of evidence to demonstrate the safety and efficacy of these treatments.13 Due to the lack of transparency on the part of many clinics offering stem cell therapies, examining the first-hand accounts of patients who have chosen to pursue treatment abroad provide insight into who are going, why they are going, and their experiences at the clinic. Previous research also tends to highlight the risks of stem cell therapies and the scientific community’s perspective on stem cell tourism. When addressing healthcare issues it is also important to understand the perspective of those that are most affected, namely the patients who are receiving the healthcare.

This examination of personal blogs has highlighted characteristics of stem cell therapy patients, such as motivation to actively participate in their recovery and well-being and the desire to learn and understand what options are available to those suffering from a variety of diseases and conditions. While the patients represented in the sample of blogs included in this study may not be an unbiased and comprehensive representation of stem cell therapy patients, the study highlights a few key areas that may be helpful to scientists and policymakers in the field of stem cell research. First, many patients are not satisfied with traditional, or paternal, doctor-patient relationships. There needs to be more engagement with patients at all stages of research and clinical care. Second, people need and want to be more involved in their own healthcare decisions in order to feel that action is being taken in their recovery and well-being. Access to timely and relevant information about the risks, limitations, and state of stem cell research14 may be of great importance in balancing the needs and desires of patients with providing safe, effective treatments now and in the future.

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Endnotes
2 Darren Lau et al, “Stem Cell Clinics Online: The Direct-to-Consumer Portrayal of Stem Cell
Table 1. Sample quotations for themes about patient motivations for pursuing stem cell therapy

i. Patients feel this is the only option left or the only option at all

“I may die anyway, but at least I died fighting. This is an experiment. What did I have to lose?”

“While China is certainly not our first choice, it is our only choice for now. We will go anywhere and do anything to give our children a chance at life.”

ii. Patients perceive themselves as well-informed

“I have always understood of the fact that stem cell transplants are not yet a cure but a hopeful treatment alternative. The point behind this treatment is that it creates and maintains hope which is extremely important when the medical community offers nothing.”

“[Clinic is the company I decided on after months of research which included safety, percentage of positive results, number and type of stem cells used, price, length of stay, etc”

iii. Patients have hope and belief in the power of the treatment

“I can get the word out that there is hope! I have seen first hand the people that have waited too long to do anything or they just don’t know. I look at it this way, if I can reach one person and have them get the treatment I have received, then the story was well worth it.”

“I am so happy being here because I finally found my doctor “House” I’ve been looking for all this time.”

iv. Patients are critical of health care and research in home country

“We need therapies in our own cities and towns. It is deplorable and inhumane that we must put ourselves in harm’s way, pushing our already weakened bodies to the point of exhaustion, to seek stem cell therapy half way around the world.”

“AT LEAST CHINA IS DOING SOMETHING IN THE FIGHT AGAINST THIS AWFUL DISEASE. YA HEAR THAT USA-THEY ARE DOING, NOT SITTING ON THERE ASS HOPING! MAYBE YOU SHOULD TAKE A PAGE OUT OF THERE BOOK!”

v. Patients believe they are medical pioneers that are adding to scientific knowledge

“Stem cell treatment for MS is still experimental. There is no known percentage for improvement, repair, halt, or healing. It’s not known what the long term effects it will have in people with MS. Some people have called me a pioneer….honestly?… I feel I’m more of a lab rat, which is okay! Squeak”

“I am part of the first wave to benefit from the advance in stem cell medicine. Years from now it will be common. Basically this is the clinical trial on humans they won’t do in the west. We are pioneers. We have replaced the mouse model. (Your welcome, all you naysayer’s out there.)”
Table 2. Sample quotations for details of treatment and experience at clinics

i. Patient care and living in a clinic

“In Canada it seems the focus is more about acceptance of what you can or can’t do and trying to make things more comfortable or easier to cope with. I’m referring to a debilitating condition like MS or Ataxia and not an injury problem from an accident where rehabilitation is the goal. Here at the clinic it’s viewed that you can and will improve, a much more positive approach whereas in our society this wouldn’t really be viewed as realistic. I’m glad I came here!”

“Except for the counsellors and locked doors, this is starting to remind me of my early childhood trauma at a youth detention center.”

ii. “One size fits all” treatment and making treatment choices

“Since I’m now done with my original treatment and we still have eight days before we leave China, I have decided to go through another round of intramuscular site injections using two additional bags of stem cells. I feel there was a near immediate benefit from this treatment.”

“I have requested that my final treatment be a Lumbar Puncture instead of IV, and there seems to be no problems with that.”

iii. Stem cell treatment is combined with other therapies

“I imagine millions of stem cells sitting around in my cerebellum, waiting for their marching orders. I do believe that in order to get full benefit from the stem cell treatment, it is essential to train the brain through an exercise programme.”

“I have to say he started being more chatty once he started getting the physio and electric wave therapy, but it was also improved after the stem cell transplant. So, so far, I have noticed small improvements in his hands, hand-eye coordination and speech.”

iv. Looking for signs of improvement, but very little significant improvement reported

“She hasn’t been dribbling again today and I can only put that down to stem cells.”

“I went to the market again and when I got back she was all smiles and seemed to be responding very much. I think the stem cells are working maybe!!” (day after 1st injection)

“I haven’t had any immediate benefits from the treatment like the first one, but I am hopeful. I know stem cells will take some time to “get settled” so I’m waiting patiently.”


From blog co-written by patient and his wife:

“I can understand why there is so much skepticism about stem therapy in China. The burden of proof as to whether or not the treatment works has shifted to the patients and not the Chinese doctors or researchers...If the treatment works, then why not show the world solid empirical data instead of relying on soft anecdotal support? Patients can talk themselves blue in the face about how they think the treatment worked for them; unless the Chinese are willing to subject the trials to peer review, however, the treatment will never gain any legitimacy in the West.”

“I cannot shake the feeling that Big Brother is watching. Is [clinic representative] using our blog to monitor us? I’d like to believe that he is interested in [patient’s] health as a friend and not as a salesperson of stem cell treatment. However, some of his requests can be construed as too self-serving.”

From blog written by a patient’s wife:

“If I met three other patients in the two hours we were there, and they had already done 8 procedures...Holy Cow, we could pay off the government deficit in record time! I repeat again, selling hope is big business. (Sorry kids, but Daddy’s spending your ‘inheritance’!)”

“Those close to me know that I was completely against this trip. I have no confidence in stem cell therapy at this stage of it’s development...though it will be a miracle cure for many diseases one day, I’m sure. But, if I had refused to bring [patient] here and his condition worsened, he would always blame me for not allowing him the opportunity to find out if it would help his ALS. And I couldn’t live with that. So I sucked it up and got moving. Kind of like taking the trash to the curb or doing laundry... it’s not something I relish, but it needs to be done anyway.”


5 Lau et al, supra note 2.


9 To date, few scholars have studied patient-authored blogs. Ryan et al analyzed patient-authored blogs for patient demographics and treatment approaches at clinics, but did not collect data regarding patient motivations, experiences and recovery processes, supra note 2.

10 For a more in-depth blog analysis of patient demographics, see Ryan et al, supra note2.
11 Demographic information from this study of blogs was similar to results from previous studies, Ryan et al, supra note 2; Zarzeczny et al, supra note 2.
12 Treatment and location information was similar in both Ryan et al, supra note 2; Zarzeczny et al, supra note 2.
13 See generally, supra note 2.