

# In Delicate Balance: Stem Cells and Spinal Cord Injury Advocacy

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**Abstract** Spinal cord injury (SCI) is a major focus for stem cell therapy (SCT). However, the science of SCT has not been well matched with an understanding of perspectives of persons with SCI. The online advocacy community is a key source of health information for primary stakeholders and their caregivers. In this study, we sought to characterize the content of SCI advocacy websites with respect to their discussion of SCT and stem cell tourism. We performed a comprehensive analysis of SCI advocacy websites identified through a web search and verified by expert opinion. Two independent researchers coded the information for major themes (e.g., scientific & clinical facts, research & funding, policy, ethics) and valence (positive, negative, balanced, neutral). Of the 40 SCI advocacy websites that met inclusion criteria, 50% ( $N=20$ ) contained information about SCT. Less than 18% ( $N=7$ ) contained information on stem cell tourism. There were more than ten times as many statements about SCT with a positive valence ( $N=67$ ) as with a negative valence ( $N=6$ ). Ethics-related SCT information comprised 20% ( $N=37$ ) of the total content; the largest proportion of ethics-related content was devoted to stem cell tourism (80%,  $N=30$  statements). Of those, the

majority focused on the risks of stem cell tourism ( $N=16$ ). Given the still-developing science behind SCT, the presence of cautionary information about stem cell tourism at advocacy sites is ethically appropriate. The absence of stem cell tourism information at the majority of advocacy sites represents a lost educational opportunity.

## Introduction

Advances in stem cell research are giving way to clinical studies evaluating the therapeutic potential of stem cell therapy (SCT) in humans [1]. One major focus for SCT has been traumatic spinal cord injury (SCI), which results in paralysis of over 130,000 new people around the world each year [2]. Alongside basic research for SCI [3] is the steadily increasing presence of clinical interventions with SCT. For example, one US-based Phase 1 multi-center study is designed to test the effectiveness of hES-derived cells with nerve-growth stimulating and remyelinating potential [4, 5]. A Portuguese intervention uses olfactory mucosal autographs (OMAs) to treat persons with chronic, traumatic SCI [6]. The latter recently reported results from 20 subjects with chronic SCI in a prospective but uncontrolled study [7]. Other interventions are available for purchase at clinical sites around the world [8, 9].

Progress in SCT for SCI, however, has not been well matched with an understanding of the perspectives of persons with SCI, to whom we will refer as primary stakeholders, on quality of life and priorities for regaining function [10–12]. In fact, some studies have noted a conspicuous absence of perspectives from the SCI community on the motivators, barriers and readiness to engage in translational stem cell studies [13–15]. In particular, Estores (2003) advocated for the use of qualitative methods such as focus groups, in addition to quantitative methods, to assess

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the preferences of primary stakeholders with regard to priorities in translational research. Downey and Geransar (2008) examined the contribution of different stakeholder groups to the discussion of stem cell research and noted that there is little in the literature describing individual patient perspectives on SCT. Most recently, Reimer, Borgelt and Illes (2010) commented that early post-injury vulnerability places newly injured patients at risk for consenting to procedures without sufficient time or resources for fully informed decision-making. Their early findings also suggest an incongruity between primary stakeholder perspectives and current target recruitment times for SCT clinical trials.

The views of individuals sharing a common interest can also be captured through advocacy groups that, beyond their task to promote awareness and lobby for research and support, represent the voices of a community. Access to online SCI advocacy resources has become readily available, and almost half of Internet users, including those with SCI, search the web for health information on a regular basis [16, 17].

In this study, we sought to characterize the content of SCI advocacy websites with respect to their discussion of SCT. We specifically identify scientific information, research and funding information, as well as ethics and policy information, including discussion of the source of stem cells [18] and stem cell tourism. In contrast to peer reviewed basic and translational SCT research and controlled human SCT trials, stem cell tourism refers to medical interventions that lack scientific rationale and offer no preclinical evidence of efficacy or safety [19].

## Methods

### Identification of Relevant Websites

We conducted a systematic search for SCI advocacy group websites using the Google search engine and the search term ‘spinal cord injury’. The Google search returned SCI umbrella organizations and a site called “SCI info pages” that contained a list of individual SCI advocacy organization websites. We manually inspected each site for relevance and accepted for analysis sites meeting the following inclusion criteria: (a) an official organization with a tax code or a registered charity, (b) written in English, and (c) current (revised on or after January 2008). The final list was verified by two experts in SCI.

### Preparation of Dataset

#### *Search Strategy*

We identified major subdivisions of each website homepage, usually well marked with tabs, and then documented each

occurrence of information relevant to stem cells for all subdivisions. Keywords for relevance were: cure, stem cell, adult stem cell, embryonic stem cell, fetal stem cell, iPS cell, cell transplant, research, funding, policy, news, blog, forum, ethics, source of cell, clinical trial, stem cell tourism, newsletter, magazine, annual report, lending library. We retained only textual content for analysis and documented links to public fora, including news links and blogs, as well as resources for download. All relevant content, access date, and the search sequence for each site division were also copied into a writable document for analysis. Tabs with no relevant content were excluded.

We transcribed the mission statement of each organization in a writable document and recorded eight website characteristics in a spreadsheet: (a) official name of advocacy organization and any abbreviations, (b) affiliation with an umbrella organization, (c) location of the organization, (d) web address of the site homepage, (e) date the site was last updated, (f) date of access and search, (g) presence or absence of stem cell content, (h) format of stem cell information (separate section, or dispersed throughout the site).

#### *Coding*

We developed a three-level coding scheme to analyze the stem cell content extracted from the SCI advocacy websites. The strategy was adopted from previous studies of online health information [16, 20]. Level 1 codes contained broad content categories; Level 2 and Level 3 codes sub-divided into categories that were more specific and nuanced. To control for redundancy and word count, each unique idea was coded as a discrete statement about stem cells.

We conducted an analysis of the 13 websites belonging to the International Campaign for Cures of Spinal Cord Injury Paralysis (ICCP), a major umbrella advocacy organization, to test the search strategy and generate a comprehensive coding scheme. The search was launched and completed in October 2009. We validated the method and applied it to the websites outside the ICCP cluster in January 2010.

#### *Inter-coder Reliability*

Two team members coded the dataset independently, compared the two unique datasets, and recorded each instance of initial agreement (A), and initial disagreement (D) on the categorization of discrete statements. Missing data in either coder’s dataset was classified as (D). The total number of discrete statements about stem cells were summed and recorded (N). The Cohen’s kappa index was then used to assess inter-coder reliability within each content and valence category.

## Data Reduction

### *Prevalence of Stem Cell Information*

We determined the overall prevalence of stem cell information on SCI advocacy websites by counting the number of websites that contained: (a) stem cell information, (b) a specific section devoted to stem cell information, (c) stem cell content dispersed throughout the site, (d) stem cell information but not public fora, news links, or resources for download, purchase or loan, and (e) no stem cell information or potential fora for stem cell information.

### *Content*

We determined the percentage of websites that contained relevant information for the major stem cell content categories. To classify each discrete statement by cell type (unspecified, embryonic, or adult/induced pluripotent [iPS]), we analyzed each statement independently and categorized it accordingly.

### *Valence*

We coded each discrete statement about stem cells for a valence of positive, negative, balanced or neutral. Statements coded as positive: (a) provided scientific and clinical facts about the benefits of stem cells, (b) indicated active support of SCT through stem cell research, and/or (c) supported the development of stem cell research and related policy.

We coded statements as negative if they were critical of stem cell research: (a) by presenting risks, (b) indicating a position against funding for stem cell research, and/or (c) criticizing policy that promotes development in stem cell research.

We coded statements as balanced if they met the criteria for both positive and negative valence. Neutral statements lacked valence altogether. They were, for example: (a) scientific or clinical facts, (b) information about grant funding, or (c) general information about policy.

### *Valence of Ethics Content*

In a separate analysis, we examined stem cell ethics content for three categories of interest: (a) stem cell tourism, (b) stem cell source, and (c) “other” ethics issues.

The valence of statements about stem cell tourism were coded as positive if, for example, they described successful outcomes from unproven cell-based therapies, explicitly promoted participation in stem cell tourism, or otherwise described the benefits of stem cell tourism. Statements were coded as negative if they described poor outcomes, explicitly warned against participation in stem cell tourism,

or otherwise described the risks of stem cell tourism. Balanced statements were those that considered both sides of an issue; neutral statements were valence-free.

We documented statements about stem cell source, cloning and animal research, but we did not code these for valence since they were outside the scope of the study.

## Results

### Characteristics of the sample

Our search yielded 56 SCI advocacy organization websites. Forty met our inclusion criteria; 16 were excluded from analysis because they were not in English or were outdated. Of the 40 websites retained for analysis, three were associated with the International Spinal Cord Society (ISCOs), 24 were unaffiliated, and 13 were affiliated with the International Campaign for Spinal Cord Injury Paralysis (ICCP). Thirty-nine were from advocacy organizations in the US, Canada, UK, New Zealand, Australia, South Africa or Austria. One organization represented 18 affiliated Asian nations.

### Inter-coder Reliability

Across the 20 websites that contained stem cell content and thus were each coded twice, there were 183 discrete statements about stem cells. The overall percent agreement between the two coders was 90.2%.

We measured inter-coder reliability (ICR) measured using Cohen’s kappa. In general, values of Cohen’s kappa ( $k$ ) above 0.80 are considered good and values above 0.90 are considered excellent [21]. ICR was measured by content category, cell type, valence of stem cell content and valence specific to stem cell tourism content. The ICR by content category was 0.87 ( $N=183$  statements,  $k=0.868$ ,  $z=21.9$ ,  $p=0$ ). The ICR by cell type was 0.85 ( $N=117$  statements,  $k=0.852$ ,  $z=32.5$ ,  $p=0$ ). The ICR by valence of stem cell content was 0.85 ( $N=144$  statements,  $k=0.853$ ,  $z=25.5$ ,  $p=0$ ). The ICR by valence of stem cell tourism content was 0.81 ( $N=32$ ,  $k=0.811$ ,  $z=8.22$ ,  $p=2.22e-16$ ).

### Prevalence of Information about Stem Cells

50% ( $N=20$ ) of the SCI advocacy websites contained stem cell content. Of these, 80% ( $N=16$ ) contained content that was dispersed throughout the site. The other 20% ( $N=4$ ) had a specific section devoted to stem cell information. Although 183 total statements (scientific and clinical facts, research and funding, policy, and ethics) were coded, the analysis and results are only based on

**Table 1** Number and percentage of discrete statements coded by cell type, major content category and valence

Cell type	Discrete statements (N)	Percent of total (%)
Embryonic	51	28
Adult/iPS	29	16
Unspecified	102	56
Total	182	100
Major content category		
Scientific & clinical facts	74	41
Research & funding	48	26
Policy	23	13
Ethics	37	20
Total	182	100
Valence		
Neutral	59	41
Balanced	13	9
Positive	67	26
Negative	6	4
Total	145	100

182 statements. One statement was rejected by Coder 1 and therefore was excluded from analysis. We also coded 27 statements about public fora and resources for download, purchase or loan that were not specific to stem cells.

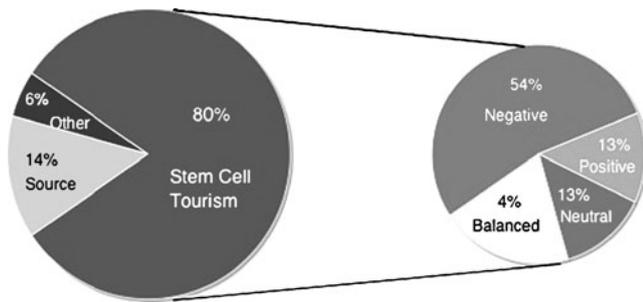
Of the websites with stem cell content, the Christopher and Dana Reeve Foundation provided the largest number of discrete statements about stem cells (28%;  $N=52$ ).

#### Content of Stem Cell Information

We classified discrete statements about stem cells by cell type (embryonic, adult, unspecified). We also classified stem cell content into four distinct categories: (a) scientific and clinical facts about stem cells, (b) research and funding, (c) stem cell policy, and (d) stem cell ethics.

**Table 2** Number and percentage of discrete statements coded by coded by sub-category and valence

Major content category	Sub-category	Discrete statements (N)	Percent of major content category (%)
Scientific & clinical facts	Neutral	35	48
	Balanced	9	12
	Benefits of SCT	24	32
	Risks of SCT	6	8
	Total	74	100
Research & funding	Neutral informational statements	20	48
	Research ownership, active grants or grant opportunities	28	42
	Total	48	100
Policy	Neutral descriptions	4	17
	Contact a public official	4	17
	Positive statements about SCT legislation	15	66
	Negative statements about SCT legislation	0	0
	Total	23	100
Ethics	Stem cell tourism	30	80
	Source debate	5	14
	Other	2	6
	Total	37	100



**Fig. 1** Left: content breakdown of stem cell ethics statements ( $N=37$  discrete instances); Right: valence breakdown of stem cell tourism information ( $N=30$  discrete instances)

*Cell Type* 28% ( $N=51$  discrete statements) discussed embryonic stem cells, and 16% ( $N=29$ ) adult or induced pluripotent stem cells (iPS cells). 56% ( $N=102$ ) did not specify type of cell (Table 1).

### Content Categories

#### (a) Scientific and Clinical Facts

We identified 74 discrete statements that provided scientific and clinical facts about stem cells. 80% were neutral statements or described the benefits of SCT (Table 2).

#### (b) Research and Funding

We found 48 discrete statements about SCT research and funding. 42% of the statements were informational and the others covered research ownership, active grants or grant opportunities (Table 2).

#### (c) Policy

Of 23 discrete statements about policy, we classified over 67% as in favor of SCT (i.e., supported the FDA approval of the Geron trial or Obama's lifting of the Bush restriction (Table 2)). Over 30% of statements were neutral descriptions or suggested that the reader should contact a public official for more information. None were negative.

#### (d) Ethics

Stem cell ethics information, found in 37 discrete statements, focused on stem cell tourism (80%,  $N=30$ ), the source of the stem cells (i.e., human embryonic tissue) (14%,  $N=5$ ), and "other" ethics issues (6%,  $N=2$ ) (Fig. 1). Of the 40 websites, 18% contained information on stem cell tourism ( $N=7$  websites), 10% included information on the source of the stem cells ( $N=4$ ), and 5% included information on other ethics issues including cloning and animal research ( $N=2$ ).

### Valence of Stem Cell Content

Of 145 discrete statements about scientific and clinical facts, research and funding, and stem cell policy, 46% ( $N=67$ ) were positive, 41% ( $N=59$ ) neutral, 9% ( $N=13$ ) balanced, and 4% ( $N=6$ ) negative (Table 2).

36% ( $N=24$ ) of the 67 positive statements were scientific and clinical facts about the benefits of stem cells, 42% ( $N=28$ ) were statements about the promise of SCT research and funding for SCT, and 22% ( $N=15$ ) were policy statements or statements in support of specific SCT legislation. Of the 6 negative statements, 100% were scientific and clinical facts describing the risks of SCT (Table 2).

### Valence of Ethics Content

Of the stem cell tourism content 53% ( $N=16$ ) had a negative valence, 13% ( $N=4$ ) had a positive valence, 13% ( $N=4$ ) were neutral, and 20% ( $N=6$ ) were balanced (Table 3; Fig. 1).

Of the five statements about stem cell source, one explicitly opposed the use of embryonic stem cells; another suggested a preference for use of adult stem cells, and two were neutral on the issue. One statement provided a link to external information on the source debate.

One statement about cloning supported stem cell research as long as it does not contribute to human reproductive cloning. We found one statement opposing stem cell experimentation on animals.

**Table 3** Valence of stem cell tourism content

Valence	Examples
Positive	"Nasal tissue that includes both olfactory ensheathing cells (OECs) and stem cells... is, at present, the most promising treatment for chronic (long-term) spinal cord injury internationally."—Spinal Cord Society of New Zealand
Negative	"It is far too soon to be experimenting with humans using these largely unproven and unstable therapies."—Center for Paralysis Research
Neutral	"Several studies of human fetal cell transplants have been carried out in Sweden and Russia...showing that transplanted fetal cells will engraft in human spinal cords."—Morton Cure Paralysis Fund
Balanced	"This is a new area of science and its enormous potential is well recognized by the public at large...What is less well understood are the potential risks and it is therefore of paramount importance that scientists, physicians and patients alike proceed with great care."—Christopher and Dana Reeve Foundation

## Discussion

Several studies of the dissemination of health information online have examined peer-to-peer communication and information exchange via blogs and online discussion fora [22–24]. To our knowledge, however, this is the first study to assess the content and valence of health information disseminated by advocacy groups online.

We found stem cell content at 50% of the SCI sites investigated. Among the other half, many provided hyperlinks to external sources such as blogs, news, and general resources for download. We predicted that basic science information, including details about research and funding, and scientific and clinical facts about stem cells would be the most prevalent categories of stem cell information, and this was the case. Discrete statements about scientific and clinical facts were relatively homogenous across the sample (i.e., many sites contained a basic definition of ‘stem cell’); statements about research and funding, policy and ethics issues were more heterogeneous, even among the 13 affiliated ICCP websites. The statements about research and funding were based on the research objectives and budget of each organization, while statements about policy and ethics issues were representative of the values and mission specific to each organization.

The valence of the research content was primarily neutral, and contained descriptions of ongoing research studies. Within the category of scientific and clinical facts, the majority of discrete statements were neutral, but a significant portion also described the benefits of stem cell therapy.

The largest portion of the ethics information was devoted to stem cell tourism but appeared on only a limited number of sites overall. Although the stem cell source debate was not as prevalent or contentious as media hype would suggest [18], policy statements did support legislation that allowed human embryonic stem cell research. No policy statements rejected the Obama administration’s repeal of the Bush restrictions on human embryonic stem cell research, or supported anti-stem cell legislation.

Neutral and balanced statements accounted for half of the stem cell content overall. Neutral statements are significant because they provide basic information and background about stem cells; they also serve as a blank slate upon which positive valence or negative valence statements can shape a person’s perception of stem cells and stem cell therapy. With nearly half of the statements having a positive valence and less than 5% having a negative valence, users are left with a distinctly positive impression of stem cell therapy. This positive perception is also buttressed by the frequency of statements about the potential benefits versus risks of engaging in stem cell therapy. The prevalence of scientific and clinical facts about

potential benefits is four times the prevalence of facts about risks. Primary stakeholders in the chronic post-injury stage confirm these findings through reports that they feel well informed about the benefits of stem cell therapy, but have limited knowledge of the risks [25].

The limited quantity of information presented about risks does not necessarily reflect error or oversight on the part of the advocacy community. Offering specific risk information may be outside the scope of advocacy because the risks of stem cell research and translational studies are very context-specific, and are likely to vary significantly depending on cell type used, technique and extent of cell manipulation, route of administration (e.g., need for invasive procedures or immunosuppressant drugs), as well as a patient’s specific medical history. Risk information may also be less known and well characterized than benefit information because existing proof-of-principle studies primarily shed light on expected benefits. It is ethically appropriate, however, for advocacy to encourage and suggest guidelines for SCI community members to talk about risks with the physicians and researchers associated with specific SCT studies.

The optimistic outlook on stem cell research comes in sharp contrast to the SCI advocacy community’s view on stem cell tourism. The valence of stem cell tourism content is largely negative. However, cautionary stem cell tourism content may be too scarce and too scattered across the advocacy websites to balance the strong positive messages disseminated about stem cell therapy. By providing a positive representation of stem cell therapy in general, without explicitly differentiating between peer-reviewed stem cell trials and stem cell tourism, advocacy sites may unintentionally mislead stakeholders.

The possibility of participation in stem cell interventions can provide valuable hope for stakeholders [9, 26]. Explicit opposition to stem cell interventions, even those that are unproven, therefore, may be contrary to advocacy aims. In the absence of clinical trial data, however, even limited discussion of stem cell tourism may implicitly mitigate “false hopes for quick and unlikely fixes” [27]. We argue that SCI advocacy groups can foster hope by supporting medical innovation via peer-reviewed stem cell trials, while still cautioning against stem cell tourism. A one-stop clearinghouse of information that enables users to juxtapose and evaluate research trials, for example, in contrast to scientifically unproven services would be an invaluable health resource.

## Limitations

We did not code images and graphics. Our search was also time-locked so it is possible that some sites were missed or down at the time of data capture.

## Conclusions

We believe that the largely absent information about stem cell tourism on SCI advocacy sites represents a missed opportunity to address controversial information that is widely available through highly visible sources on the Internet, in the press, and on social and other media. Even with limited resources, this is a gap that can be closed. One solution is for SCI advocacy to partner with researchers and their trainees—generationally well-versed in online media—to help develop information pages, FAQs, and links that enable people to distinguish between SCT clinical trials and stem cell tourism. The FAQ model, for example, was used by Illes et al. [28] to disseminate information both in hard copy and online about new neuroimaging research on minimally conscious states. The FAQ model had significant uptake and distribution in professional neurology practices and clinics, and brain injury advocacy communities [29]. New kinds of advocacy-academy collaborations for online communication about SCI could provide mediated fora for discussion, keep hype at bay, and accurately and effectively inform and empower decision-making.

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