

# Trust and Transparency in the Communication about Stem Cells for Spinal Cord Injury: Striking a “Cord” with Patients

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NEUROETHICS



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THE UNIVERSITY OF BRITISH COLUMBIA



Stem Cell Network  
Réseau de cellules souches



# Outline

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- Spinal cord injury (SCI) and stem cells
- Conversations about stem cells and SCI
  - Research goal
  - Methods
  - Results
- Moving forward

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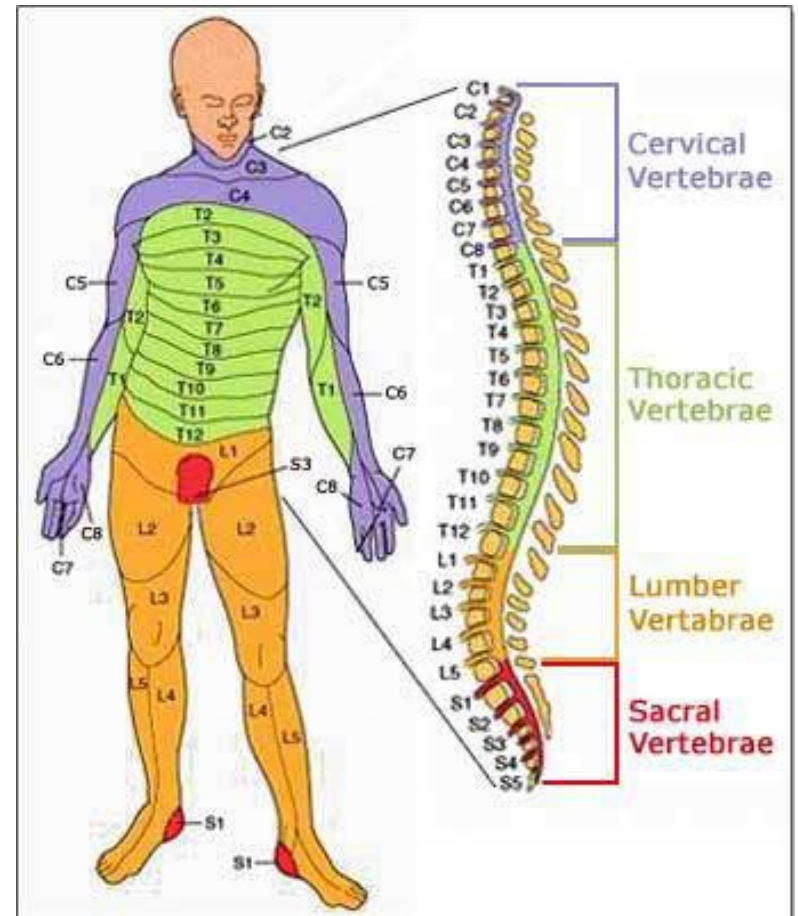


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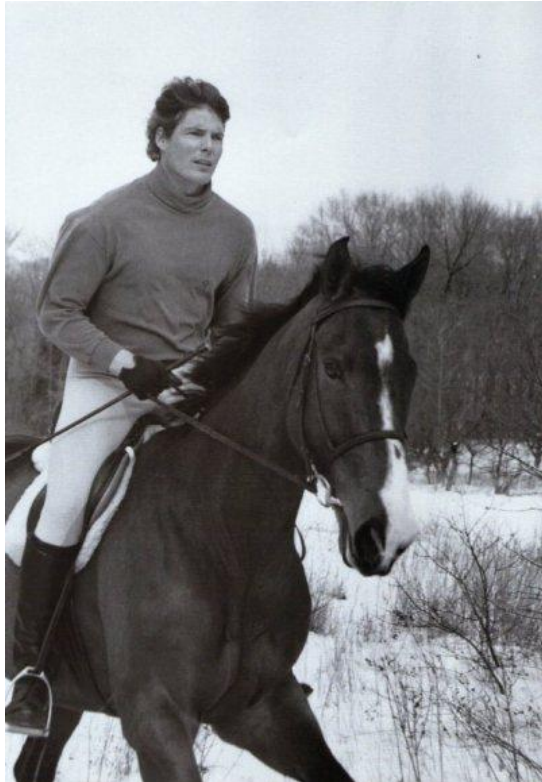
# Spinal Cord Injury (SCI)



- Caused by traumatic injury or disease affecting the vertebral column or spinal cord
- Long term complications include: Paralysis, pain, sexual dysfunction, bladder and bowel dysfunction
- Level and severity of injury determines loss of function



# Prognosis of SCI



Injury



Affected individuals must adjust to a new life reality

# Emerging Biotechnology for SCI: Stem Cells



- Both researchers and individuals with SCI (ISCIs) are hopeful for potential of stem cell treatments

## Human neu locomotor

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CA 92697; <sup>†</sup>StemCells, Inc., 3155  
La Jolla, CA 92037

Communicated by Irving L. Weiss

We report that prospectively  
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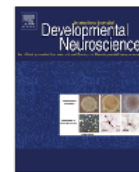


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Review

## Review of transplantation of neural stem/progenitor cells for spinal cord injury

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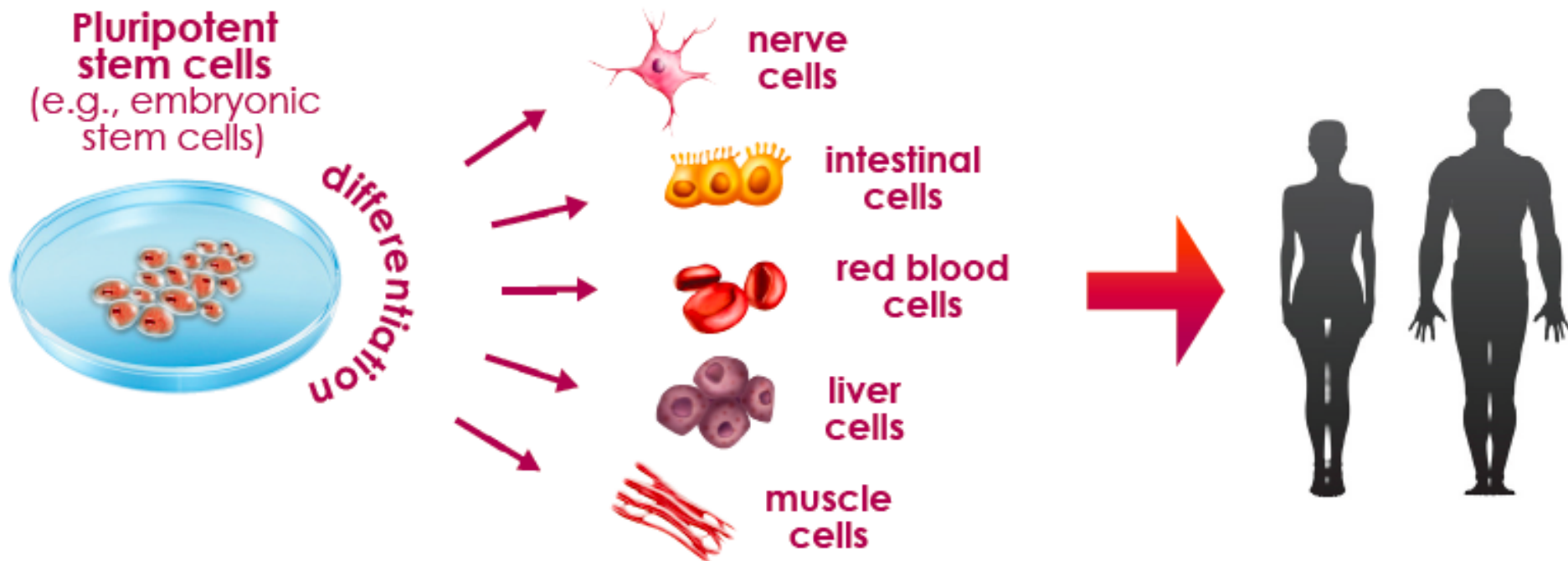
### ABSTRACT

Spinal cord injury (SCI) is a debilitating condition often resulting in paralysis, yet currently there is no effective treatment. Stem cell transplantation is a promising therapeutic strategy for promoting tissue repair after SCI. Stem cells offer a renewable source of cells with inherent plasticity for tissue regeneration. Neural stem/progenitor cells (NSPCs) are multipotent cells that self-renew and are committed to the neural lineage, and thus, they are especially suited to SCI repair. NSPCs may differentiate into neural cells after transplantation into the injured spinal cord, replacing lost or damaged cells, providing trophic support, restoring connectivity, and facilitating regeneration. Here, we review experimental studies and considerations for clinical translation of NSPC transplantation for SCI.

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# Emerging Biotechnology for SCI: Stem Cells





# Stem Cell Tourism and SCI



- For-profit clinics are already offering stem cells to ISCI



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Brain Research



**Brain Research**

Yun-Hua Han,†

Human umbilical cord mesenchymal stem cell transplantation in rats after spinal cord injury

Krishna Kumar, Meena Gujral

**Research Report**

**A combination of taxol infusion and human umbilical cord mesenchymal stem cells transplantation for the treatment of rat spinal cord injury**

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<sup>c</sup> Department of Pathology

Zhou Zhilai<sup>a</sup>, Zhang Hui<sup>a</sup>, Jin Anmin<sup>a</sup>, Min Shaoxiong<sup>a</sup>, Yu Bo<sup>a</sup>, Chen Yin Hai<sup>b,\*</sup>

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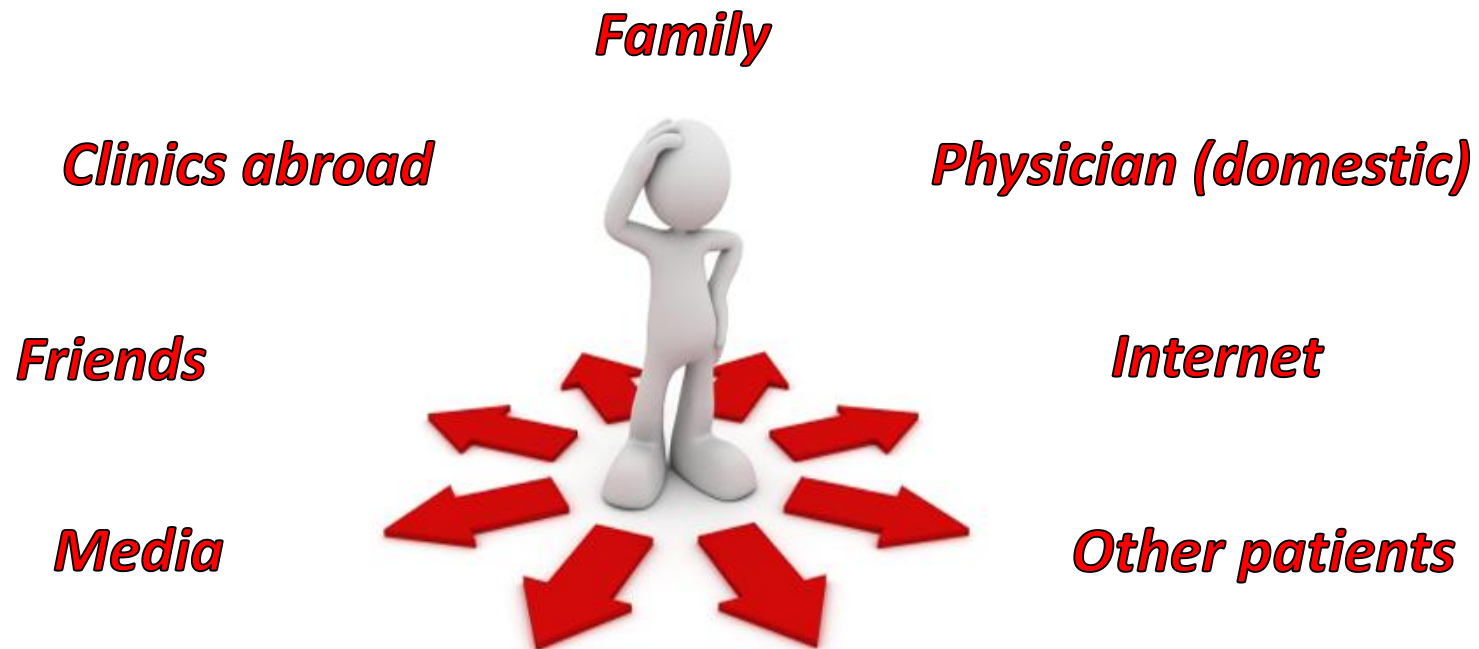
Seoul, South Korea  
Seoul, South Korea  
St. Paul, MN, USA



# Trust and Trusted Communication



- Where should affected individuals place their trust?



Trust and trusted effective communication is an essential part of a successful patient-physician relationship

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# Research Goals

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- To examine how trusting relationships between individuals with SCI and physicians are ***fostered and threatened*** in the context of the conversation about stem cell interventions for SCI.



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# Methods



- Semi-structured interviews with individuals with spinal cord injury (ISCI) and physicians
- Applied a thematic analysis to the interview transcripts
- Data organized into themes and subthemes based on prominence



Interviews



Transcripts



Hierarchy of themes

# Outline

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# Interview Participants



## Individuals with Spinal Cord Injury (ISCI)

- Total n=18
- n=7 had conversations about stem cells with a physician
- n=1 had travelled abroad for stem cell interventions
- All resided in Western Canada (BC, AB, Yukon)

Gender	n
Male	15
Female	3
Age (years)	n
20-45	6
46-60	8
61+	4
Time from injury (years)	n
1-10	9
26-41	6
Unknown	3
Educational Level	n
Some high school	1
Trade school	1
High school degree	4
Post secondary degree	9
Doctoral degree	3



# Interview Participants



## Physicians

- Total n=12
- All had experience talking to ISCI about stem cells for SCI

Gender	n
Male	5
Female	7
Age (years)	n
30-50	9
51+	3
Clinical Practice or Research with SCI (years)	n
1-10	2
11+	10
Location of Practice	n
Canada	8
United States	4

# Key Findings



	Individuals with spinal cord injury ( <i>n</i> =18)	Physicians ( <i>n</i> =12)
Factors stressing trusted communication	<ul style="list-style-type: none"><li>◆ Hesitation to engage</li><li>◆ Lack of physician knowledge</li><li>◆ Difficulty with resources</li></ul>	<ul style="list-style-type: none"><li>◆ Communicating clinical realities</li><li>◆ Pressure from external information sources</li><li>◆ Patient misconception</li><li>◆ Challenges of resource content quality and accessibility</li></ul>
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# “I wouldn’t know anyone right now that I’d get more information from...”

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## ◆ Hesitation to engage

*“If doctors were **more open about... talking about [stem cells]**, that would be kind of cool...” (ISCI13)*

## ◆ Lack of physician knowledge

*“The ones that seemed kind of negative [about stem cells]...**maybe they don’t know or are not keeping current.**” (ISCI03)*



Perceived physician hesitation and lack of knowledge left some individuals unsure where to turn for advice about stem cells

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# “I don’t want to really discuss something that I can’t offer...”



## ◆ Communicating clinical realities

*“...when you’re...the bearer of bad news...you’re taking away hope...**it can affect the relationship...** it does put a bit of strain.” (P05)*



## ◆ Pressure from external sources

*“...you really want to be positive for your loved ones and...**you’re very selective at your interpretations and you interpret all the good things** but you don’t actually consider all the sort of cautionary points.” (P07)*

Difficulty communicating clinical realities and variable information from outside sources and are stressors for physicians

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# How Can Reluctance to Discuss Stem Cells Pose Challenges to Trust?



## ◆ Perceived patient misperception

*“...when it comes to the relationship with my patients, it...also set[s] up, the possibility of... perceptions that a **treatment is being withheld.**” (P08)*

*“...these patients may go away thinking , ‘Well, this surgeon never discussed anything about the stem cells, **he probably doesn’t know anything about it’...**” (P07)*



Physician avoidance of discussions may cause misperceptions amongst affected individuals that can damage trusted communication

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# Resources Challenges



*Both physicians and ISCIIs discussed were challenged by resources*

## ◆ Access to resources

*“What would be helpful is having **better access to up to date information** on what trials may be available.” (P09)*

## ◆ Quality of resources

*“...there’s a **lot of junk** out there that’s hard to filter through to find the real stuff.” (ISCI17)*



*“less reputable are widely available and the very reputable are highly regulated and there’s less access to them”*



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# Fostering Trusted Communication from the ISCI Perspective



## ◆ Physician Attitude

*“You can see it in their actions... they really care about their patients.” (ISCI08)*



## ◆ Physician Expertise

*“...the main reason to be trust in the doctor [sic] is if he gives you a background and if has **background and experience in that field.**” (ISCI18)*



Positive physician attitude and knowledge fosters trusted communication with affected individuals

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# Fostering Trusted Communication from a Physicians Perspective

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## ◆ Understanding the patient perspective

*“...Explore why a **patient is thinking about doing [stem cells]** and what their motivation is... you can help guide their decision making.” (P02)*



## ◆ Transparency

*“I think it **builds trust to admit that there’s gaps in my knowledge** and that there are things that I don’t know.” (P10)*

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# Improving Trusted Communication: Moving Forward



- Transparency should be privileged over silence
- Recommendation for tools that make dissemination of new findings easier
- Leverage new innovations in clinical interventions\*



\*Scott (2015) The case for stem cell counselors, *Stem Cell Reports*

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