

Social Responsibility in Stem Cell Research - Is the News All Bad?

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Abstract Transparent public discourse about translational stem cell research promotes informed hope about scientific progress and the sustainable development of biotechnologies. Using an a priori coding scheme, we surveyed articles from leading news media about stem cell interventions for neurodegenerative diseases (1991–2014) from United States ($n = 83$), Canada ($n = 29$), and United Kingdom ($n = 65$). While, this analysis of translational contexts in the news demonstrates a lingering tendency to celebrate the benefits of research with little context of its caveats even for chronic neurologic diseases, in a departure from many previous studies, the data also reveal conscientious reporting about stem cell tourism and timeframe estimates for the development of relevant therapeutics.

Keywords Stem cells · Neurodegeneration · Science communication · Social responsibility · Clinical translation

Frontline Communication About Biotechnology

The media have come under enormous scrutiny over the past years for the way that they cover the translation of biotechnology, and stem cell interventions in particular. Whether the focus is print or online news, study after study has provided data about hyperbolic reporting of the benefits of

biotechnology with little context of its risks, limitations or timeframes for application [1–4].

It would seem from past research that the problem is ubiquitous and indiscriminate to technology type and phase of research and development. We sought to understand this reporting phenomenon in the particularly acute case of neurodegenerative diseases that not only rob affected individuals of their mobility and cognitive function, but for which the success for novel therapeutics becomes more urgent due to disease progression.

Is the news all bad? We find that the answer is no. Through an analysis of representations of discrete stages in the stem cell research process, regulatory checkpoints and hurdles in clinical translation, and timeframe projections for the clinical application of stem cell biotechnologies in news articles, we find evidence of socially responsible journalism in the stem cell arena for neurological diseases that has been seldom reported (Table 1). Why should stem cell scientists care? Online and print media provide the most accessible information about health and science to the public. Science reporting about research and medicine both shapes and reflects public discourse while promoting public understanding of science and participation in science policy. Simply stated, the integrity and sustainability of public and industry support for stem cell research and development, therefore, hinges on transparent and conscientious representations of translational medicine in the media that celebrate the promise of scientific discovery and ground hopes for health innovation in scientific realities.

Surveying News Articles

Clinical translation of stem cell research has raised much hope for the treatment of a myriad of currently incurable diseases. While the strong translational ethos in the stem cell arena has

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contributed to the rise of registered clinical trials, the majority remains in early phases aimed at establishing indexes of safety [5]. The earliest year of media coverage about stem cell interventions for neurological diseases was 1991. Using customized search algorithms to create a sample, we mined media databases Factiva (US, UK) and Canadian Newsstand (CA) from that year through 2014, and retrieved 177 unique news articles (US $n=83$; CA $n=29$; UK $n=65$) relevant to the analysis of interest. We examined the pool both as a whole, and as two independent sets: a set of 94 articles broadly focused on stem cell interventions for non-neurodegenerative diseases that still discussed neurodegenerative diseases in a substantial way; and, a set of 83 articles primarily focused on human stem cell interventions for neurodegenerative diseases.

Using an a priori coding scheme informed by other studies of health biotechnologies [6, 7], we investigated timeframe projections, tone of projections, spokespersons who made projections, and public health claims in all the articles. We then coded the set of articles that primarily focused on human stem cell interventions for neurodegenerative diseases for additional constructs: dominant themes, descriptions of clinical trial phases and sample sizes, checkpoints and hurdles for translation, and descriptions of availability of stem cell interventions abroad (Table 2). Cohen's kappa tests on a random 14 % of the articles yielded k scores in the range of 0.64–1.00 with a mean score of 0.84, indicating substantial inter-coder reliability [8]. Finally, we carried out a cross comparison of projected quantitative media timeframes for the implementation of stem cell research with outcomes published in ClinicalTrials.gov.

Celebrating Progress

Sixty percent of the articles celebrate progress in stem cell research, and depict its potential for neurodegenerative diseases. Articles discuss such progress most prominently in the contexts of Parkinson disease, multiple sclerosis, amyotrophic lateral sclerosis, and Batten disease. For example:

“To date, adult cells have produced 72 treatments of human diseases, ranging from cancer and diabetes to

lupus and multiple sclerosis, with new findings every week” [9].

Other articles focus on economic development (13 %) that hail the potential for capital gains through investment in stem cell enterprises, and human interest stories (13 %) that highlight the importance of stem cell research by featuring the voices of advocates of stem cell technologies including hopeful patients, families and clinicians.

We also observe celebrations of progress in 58 % percent of all the articles that make explicit public health claims, and assert that stem cell biotechnologies will produce therapeutic solutions for a diversity of ailments:

“Stem cell therapy is already regarded by scientists as having huge potential for treating a range of diseases and disabilities including Alzheimer's and heart problems” [10].

Descriptions of clinical trial stages provide some context about the progress of clinical research that aims to produce such public health benefits (Fig. 1). The sample sizes of human subjects in clinical trials are mentioned in 40 % of articles about clinical research. Overall, the prominent celebration of progress in the stem cell sphere is consistent with previous studies that indicate an over-emphasis of the benefits of developing biotechnologies [1, 3]. It presents a continuing opportunity for future reporting that focuses on contextual details in translation, including descriptions of clinical trial phases, their goals, and the numbers of research participants in human studies.

Never Say Never

The prominent celebration of progress in the stem cell arena calls for commensurate context about when the benefits of this research trajectory might be realized. As such, socially responsible communications about the promise of stem cell research ought to be followed by details about timeframes for translation, be it the discrete steps such as the commencement of clinical trials or end-goals like clinical implementation. The

Table 1 Summary of socially responsible representations and opportunities to promote social responsibility in news articles about stem cell research

Socially responsible representations of translational contexts	Opportunities for socially responsible representations
<ul style="list-style-type: none"> • Qualitative timeframes with accurate estimates for clinical implementation • Condemnation of unregulated stem cell interventions 	<ul style="list-style-type: none"> • Mention of sample sizes in clinical research • Portrayal of clinical trial phases and their goals • Representations of hurdles and checkpoints to clinical implementation • Descriptions of timeframes to clinical implementation

Table 2 Summary of main coding categories

Coding categories	News articles with secondary focus on neurodegeneration	News articles with primary focus on neurodegeneration	Total news articles analyzed
Tone of future projections			
Positive	(46) 49 %	(42) 51 %	(88) 50 %
Neutral	(18) 19 %	(11) 13 %	(29) 16 %
Negative	(7) 7 %	(2) 2 %	(9) 5 %
Not mentioned	(23) 24 %	(28) 34 %	(51) 29 %
Timeframe projections			
Yes	(29) 31 %	(45) 54 %	(74) 42 %
No	(65) 69 %	(38) 46 %	(103) 58 %
Spokespeople making timeframe projection			
Media reporter	(19) 20 %	(36) 43 %	(55) 31 %
Public sector researcher	(8) 9 %	(3) 4 %	(11) 6 %
Biotechnology company representative	(1) 1 %	(1) 1 %	(2) 1 %
Clinician	(0) 0 %	(2) 2 %	(2) 1 %
Other	(1) 1 %	(3) 4 %	(4) 2 %
Not applicable	(65) 69 %	(45) 46 %	(103) 58 %
Public health claims			
Yes	(63) 67 %	(40) 48 %	(103) 58 %
No	(31) 33 %	(43) 52 %	(74) 42 %
Dominant themes			
	N/A		
Celebration of progress		(50) 60 %	(50) 60 %
Economic development		(11) 13 %	(11) 13 %
Human interest stories		(11) 13 %	(11) 13 %
Other		(11) 13 %	(11) 13 %
Description of clinical trial phases/ goals^a			
	N/A		
Not mentioned		(21) 25 %	(21) 25 %
Safety		(15) 18 %	(15) 18 %
Phase I		(8) 10 %	(8) 10 %
Safety and efficacy		(8) 10 %	(8) 10 %
Phase I/II		(1) 1 %	(1) 1 %
Efficacy		(24) 29 %	(24) 29 %
Phase II		(3) 4 %	(3) 4 %
Not applicable		(15) 18 %	(15) 18 %
Sample sizes			
	N/A		
Yes		(33) 40 %	(33) 40 %
No		(38) 46 %	(38) 46 %
Not applicable		(12) 14 %	(12) 14 %
Hurdles and checkpoints for translation			
	N/A		
Yes		(37) 45 %	(37) 45 %
No		(46) 55 %	(46) 55 %
Availability of stem cell interventions abroad			
	N/A		
Yes		(26) 31 %	(26) 31 %
No		(57) 69 %	(57) 69 %

^a Coding categories are not mutually exclusive

majority (58 %) of articles do not make timeframe projections about the research and development of stem cell interventions for neurodegenerative diseases, and none of the articles discuss the possibility that stem cell therapies may never be

realized. These findings highlight an opportunity to promote social responsibility in media communications through additional context about timeframes and through the stipulation of statistics that emphasize the high attrition rate in clinical

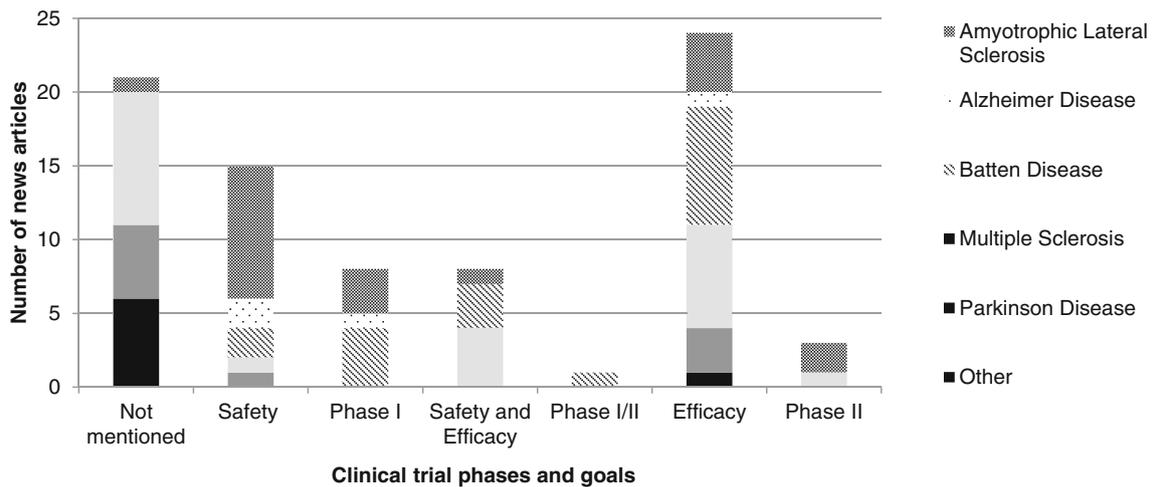


Fig. 1 Clinical trial phases and goals in news articles about stem cell clinical trials stratified by disease

research [11]. Most of the timeframe projections are qualitative in nature (71 %), and are vague estimates for the implementation of stem cell research (Fig. 2). The majority of estimates are modest claims and suggest that clinical implementation of stem cell research will be realized in the distant future. For example:

“...the practical application of this theory has been less than spectacular and any cures are in the *distant future*” [12].

Eight percent of the articles make explicit quantitative projections (Table 3). Thirty-three percent of these were actualized within the estimated timeframes and

40 % were not. The accuracy of the remaining estimates cannot be determined because their projected timeframes have not yet been reached.

News reporters make 74 % of the timeframe projections in the sample; experts such as researchers and clinicians make the minority (18 %) of these estimations. Other stakeholders such as representatives of biotechnology companies and affected individuals accounted for the remainder. This finding deviates from previous reporting trends that showcase expert opinions of trusted clinicians and researchers [1, 2, 13]. We cannot speculate, however, whether reporters are paraphrasing the timeframe estimates of experts or making *de novo* timeframe projections.

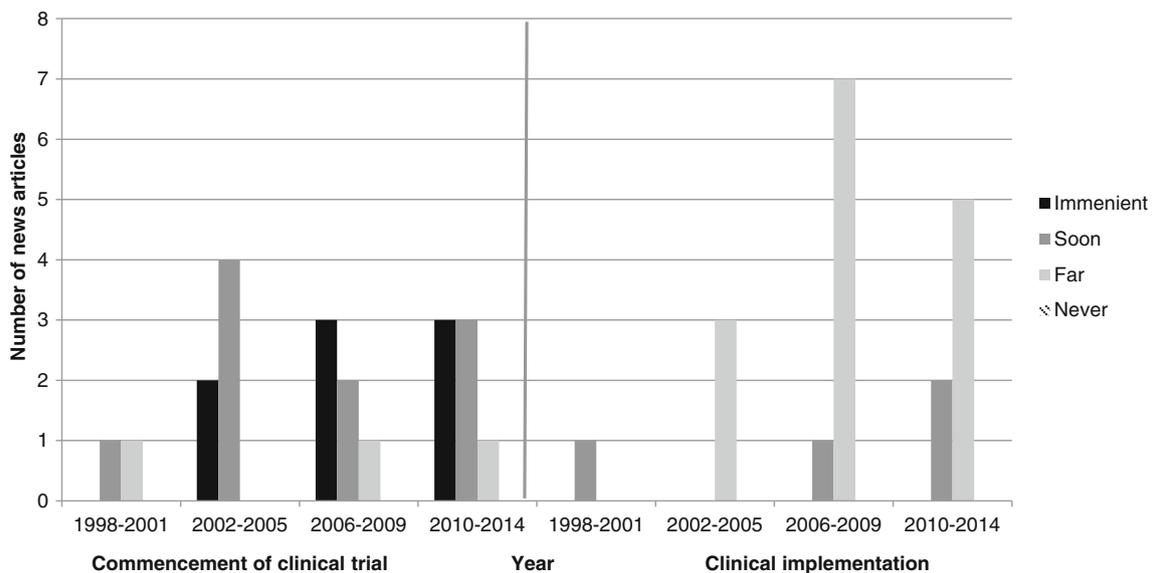


Fig. 2 Qualitative timeframe projections for the commencement of stem cell clinical trials for neurodegeneration (n = 21; left), and clinical implementation of stem cell interventions for neurodegeneration (n = 19; right)

Table 3 Examples of comparison between newspaper timeframe projections and outcomes about stem cell clinical interventions for neurodegeneration

Media timeframe projection	Projected outcome in context	Outcome	Projection met in estimated timeframe?
“The U.S. Food and Drug Administration approved Phase II of the clinical trial, which is overseen by U-M neurologist Dr. Eva Feldman... Surgeries could begin by the end of the summer” [18].	Phase II trial for amyotrophic lateral sclerosis will commence by the end of summer 2013.	Phase II neural stem cell trial for amyotrophic lateral sclerosis began in May 2013 (NCT01730716).	Yes
“Cutting-edge stem cell treatment to repair the damage caused by multiple sclerosis is to...start in February with people who have long standing MS... it’ll be the first phase two trial of any repair therapy in MS” [19].	Phase II mesenchymal stem cell trial for multiple sclerosis will commence in 2012.	Phase I/II mesenchymal stem cell trial for MS began in 2013 (NCT01606215).	No
“Repair to MS-related nerve damage using stem-cell therapy is I think, five to 10 years away” [20].	Stem cell therapies will become standard of care for MS by 2019.	To be determined	To be determined

Checkpoints and Hurdles

The regulatory and political milieu in which stem cell research is positioned may impact the pace of therapeutic development. Indeed, the political environment that historically followed stem cell research has focused as much on its social controversies as on its scientific potential, and has been addressed through heightened oversight that promotes social accountability [14]. Forty-five percent of the articles mention such checkpoints and hurdles (Fig. 3), and these are prominently explored in the political context of embryonic stem cell research, e.g.,:

“The California initiative was largely an effort to side-step restrictions on federal financing of human

embryonic stem cell research imposed by the Bush administration, which objects to the destruction of human embryos that is necessary in harvesting the stem cells” [15].

A minority of articles discusses other checkpoints and hurdles to the translation of stem cell research, such as government health regulations, ethics board review, and barriers to benefit-sharing including patents and intellectual property. Additional details about regulatory hurdles and checkpoints may serve to clarify the position of stem cell research endeavors along the translational continuum and contextualize the prominent celebration of progress we describe above.

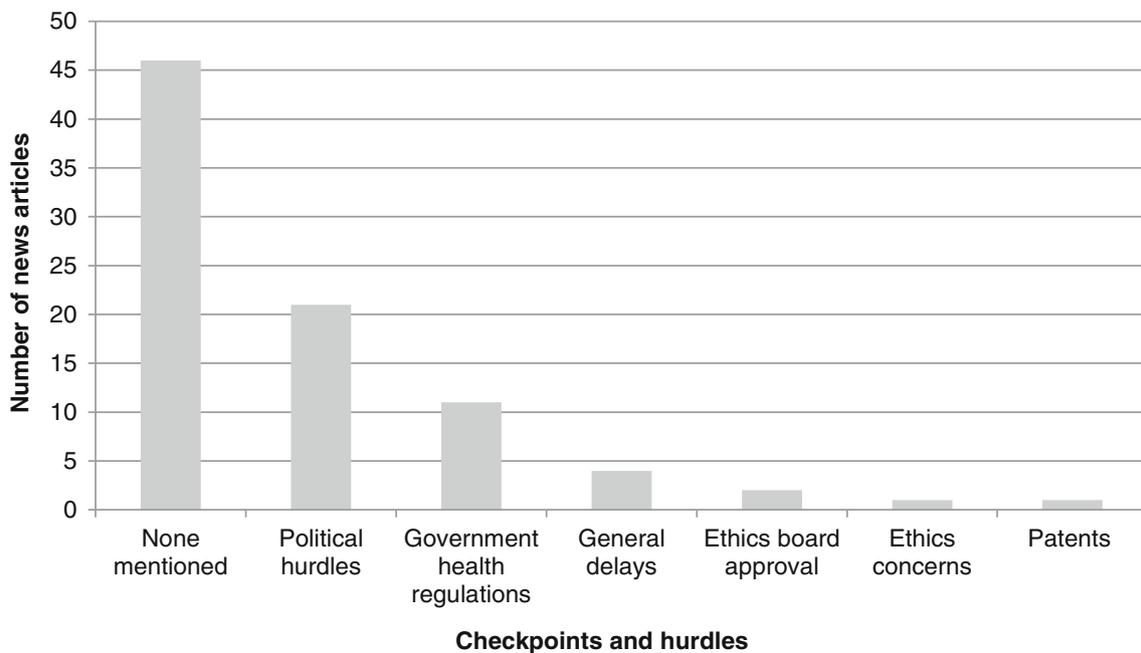


Fig. 3 Representations of regulatory checkpoints and hurdles to clinical implementation of stem cell research for neurodegeneration

Lured Away from Regulated Clinical Realities

With stem cell tourism on the rise, countless opportunities to access unapproved and unregulated stem cell interventions are available abroad, with purveyors most commonly targeting patients with neurological diseases [4]. Thirty one percent of the articles discuss stem cell interventions abroad. The tone of the articles about stem cell interventions abroad is largely negative (69 %) or neutral (23 %). Indeed, 73 % of relevant articles explicitly state that the interventions are unapproved and unregulated.

Transparency in Translation

In contrast to other literature that suggests that media representations of stem cell research are precocious or hyped [1, 16], we find scientifically and socially responsible examples of reporting. Indeed, distant qualitative timeframe estimations for the clinical availability of stem cell therapies (Fig. 2) are consistent with the 10–14 year timeframe for experimental products to move along the translational trajectory from novel target to market approval, and the additional time necessary to account for health technology assessment and integration into health care systems and insurance regimens [17]. Additionally, the condemnatory stance of the media about stem cell clinics that offer unregulated interventions has been previously hidden from view. Set against the financial and marketing forces of illegitimate stem cell clinics that detract attention from the scientific unknowns of stem cell biotechnologies and reframe the issue as an access problem, the media provide valuable interpretation in the context of neurological diseases. Diverse methods and procedural approaches, in addition to variability in contextual details (e.g., different biotechnologies, focus on different disorders), may contribute to the polarity of results here to those of the past.

Reporters as well as scientists and clinicians who communicate with the media have the individual and collective responsibility to highlight incremental advances in biotechnology and detail the steps necessary to achieve clinical implementation of research efforts. These are details such as number of research participants in clinical trials, phases of clinical research and their goals such as establishing safety or efficacy, and regulatory steps such as ethics approval, market approval, and health technology assessment. There may well be work to be done to achieve these goals with greater reproducibility, but there is also evidence to applaud the socially responsible media representations of stem cell interventions that are grounded in the context of incremental translational steps and

that promote informed hope about scientific progress and the sustainable development of biotechnologies.

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Compliance with Ethical Standards

Disclosures The authors indicate no potential conflicts of interest.

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