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In the Know and in the News: How Science and the Media Communicate About Stem Cells, Autism and Cerebral Palsy

Kimberly Sharpe[1] · **Nina Di Pietro**[1] · **Judy Illes**[1,2]

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Abstract Stem cell research has generated considerable attention for its potential to remediate many disorders of the central nervous system including neurodevelopmental disorders such as autism spectrum disorder (ASD) and cerebral palsy (CP) that place a high burden on individual children, families and society. Here we characterized messaging about the use of stem cells for ASD and CP in news media articles and concurrent dissemination of discoveries through conventional science discourse. We searched LexisNexis and Canadian Newsstand for news articles from the US, UK, Canada and Australia in the period between 2000 and 2014, and PubMed for peer reviewed articles for the same 10 years. Using in-depth content analysis methods, we found less cautionary messaging about stem cells for ASD and CP in the resulting sample of 73 media articles than in the sample of 87 science papers, and a privileging of benefits over risk. News media also present stem cells as ready for clinical application to treat these neurodevelopmental disorders, even while the science literature calls for further research. Investigative news reports that explicitly quote researchers, however, provide the most accurate information to actual science news. The hope, hype, and promise of stem cell interventions for neurodevelopmental disorders, combined with the extreme vulnerability of these children and their families, creates a perfect storm in which journalists and stem cell scientists must commit to a continued, if not even more robust, partnership to promote balanced and accurate messaging.

Keywords Stem cells · Cerebral palsy · Autism spectrum disorder · Media · Newspaper reporting

✉ Judy Illes
jilles@mail.ubc.ca; http://www.neuroethicscanada.ca

[1] National Core for Neuroethics, Division of Neurology, Department of Medicine, University of British Columbia, 2211 Wesbrook Mall, Koerner S124, Vancouver, BC V6T 2B5, Canada

[2] Djavad Mowafaghian Centre for Brain Health, Vancouver Coastal Health Research Institute, Vancouver, Canada

Introduction

Stem cell research has generated considerable attention for its potential to remediate many disorders of the central nervous system including neurodevelopmental disorders such as autism spectrum disorder (ASD) and cerebral palsy (CP) that place a high burden on individual children, families and society. ASD affects approximately 1 in 166 children and manifests in repetitive behaviour and impaired social skills and speech. CP is a chronic non-progressive disorder that affects approximately 1 in every 500 children and compromises motor control, speech and, in some cases, cognitive functioning. The news media is a major source of health and science information [1], and plays an important role in introducing the public to the risks and benefits of health research [2]; not surprisingly, the media is an important source of information about stem cell research for neurodevelopmental disorders, as well as for stem cell tourism [3–6].

Past research has shown that news coverage of stem cells in general tends to be overwhelmingly positive [7–10] and, for the case of neurological disorders, often drifts from clinical realities [11]. Besides conveying optimism, news media can also influence its readers through agenda setting and framing. The degree of attention placed on issues in the media adds salience to the issues and influences the priorities afforded them by the public. Powerfully framed discussions around an issue highlight certain points of view and marginalize

others [12]. Thus, while the media cannot dictate to the public what to think, it can influence what the public thinks about [13]. Given the extreme vulnerability of children with neurodevelopmental disorders and their families to communication about hope and promise [6, 14, 15], we sought to examine news coverage alongside science messaging about stem cell progress for ASD and CP as case studies specifically.

Materials and Methods

Data Collection

We searched for ["stem cell"] AND ["autis*" OR "cerebral palsy"] in the LexisNexis and Canadian Newsstand databases. Our inclusion criteria limited articles in news media to English speaking countries (Canada, USA, Australia, and United Kingdom) dated between January 2000 and June 2014. To identify the relevant science literature for the matching time period, we searched for English language science articles in PubMed using the terms ["stem cell" OR "progenitor cell"] AND ["cerebral palsy" OR "autis*"]. Duplicates and articles irrelevant to stem cells in relation to CP or ASD were eliminated manually.

Coding and Analysis

Coding and content analysis were managed using NVivo 10 qualitative research software (QSR International). An initial coding scheme was developed based on *a priori frames* from previous media analyses on biotechnology messaging [2, 6] and refined iteratively through in-depth analysis of the articles in the analysis pool. Disagreements in the application of the coding scheme were resolved by discussion between two independent coders (K.S. and N.D.), and a final coding guide was then applied.

Attribute Codes We assigned attribute codes to each news and science article for year of publication, name of journal/newspaper, scope of newspaper, country of origin, type of research or news format/frame (Table 1). We also coded for sources of information (i.e., quotes from patients,

Table 1 List of attribute codes

Attribute of publication	Definitions and examples
Year	Year of publication
Name	Name of journal (e.g., Stem Cell Reviews and Reports) or news publisher (e.g., Vancouver Sun)
Scope of distribution	Limited circulation news media: Smaller circulation size with distribution limited to one area such as a small city or township
	Large circulation news media: Largest circulation size with wide distribution at the state/provincial or national level or major metropolitan area
Country	Country in which the research article or newspaper was published (i.e., Canada, Australia, United States, United Kingdom).
News format/frame	Narrative techniques used to portray an issue in the news:
	−Latest news: Short pieces reporting on noteworthy information, especially about current or important events
	−Profile/human interest story: A feature story discussing a person or people in an emotional way
	−Investigative: In-depth coverage of a single topic of interest, possibly including multiple sources of information
	−Journalistic interview: Report based on questions and answers with one or more individuals.
Sources of information	Sources of information directly cited in the news:
	−Patient, parents, other family
	−Medical or allied health practitioner
	−Researcher
	−Science article or research study
	−Clinic spokesperson
	−Author only (default attribute when no other voice is used)

doctors, researchers) of news articles. Attribute codes were mutually exclusive, such that only one could be applied to each publication; multiple codes could be applied to each news publication for sources of information.

Themes The thematic analysis focused on statements, references, and rhetorical strategies about stem cells in the context of ASD and CP. Claims about risks or benefits mentioned were further categorized and coded by type. Statements about

Table 2 Characteristics of news articles (n=73) and science articles (n=87) from January 2000 to June 2014

	Number of articles	Percentage of articles
Media		
Country of origin		
Australia	22	30
Canada	19	26
USA	17	23
UK	15	21
Year of publication		
2000–2004	0	0
2005–2009	31	42
2010–2014*	42	58
Scope of newspaper		
Major	44	60
Local	29	40
News frame		
Human interest	41	56
Latest news	17	23
Investigative	14	19
Interview	1	1
Sources of information		
Family members	53	73
Researchers	26	36
Clinic spokesperson	8	11
Stem cell clinic	7	10
Science		
Country of origin (top 5)		
USA	38	44
Canada	8	9
China	7	8
South Korea	5	6
India	5	6
Year of publication		
2000–2004	2	2
2005–2009	8	9
2010–2014*	77	89
Name of Journal (top 5)		
PLoS One	6	7
Cell Transplantation	5	6
Journal of Translational Medicine	3	3
Case Reports in Translation	3	3
Human Molecular Genetics	3	3

Top five refers to the five categories with the highest frequency count

*Up to September 2014

risks or benefits were then cross-analyzed with attribute data to determine the source of risk/benefit information and the news frame associated with the risk/benefit claims. Using a rich coding strategy, multiple codes were applied as appropriate. Coding was carried out by KS and a trained research assistant. Cohen's Kappa was used to assess inter-coder reliability.

Results

A total of 73 newspaper articles and 87 science articles were retrieved for analysis. Cohen's Kappa was .915 for coder agreement.

Attribute Data

News articles: Media articles were retrieved from all four countries sampled. The first media article appeared in 2005, two years after the first science article was published by Bartley and Carroll (2003) in the USA. The highest number of articles originated from Australia (30 %; n=22) (Table 2). Over half of the articles were human interest pieces focusing on individuals and their families (56 %; n=41). Family members were the most frequently cited sources of information in the media (73; n=53) and the sole cited source of information in 42 % (n=31) of articles . Published research results were referenced in only 4 % (n=3) of media articles.

Science literature: The frequency of publications has increased substantially since 2003 (Table 2). Science articles originated from 16 different countries. Publications from the USA (44 %; n=38) and Canada (9 %; n=8) account for more than one-half of the sample.

Types of Messaging

Positive messaging: Both news media and science articles contain more positive messaging about stem cells for CP and ASD than cautionary or negative messaging (Table 3). In the news media, hope for stem cell interventions 63 % (n=46) originated primarily with family members who spoke optimistically about the promise and hope for symptom improvement. Within this messaging, stem cell therapy was often portrayed uncritically as a viable treatment option. This messaging was especially prevalent in human interest stories and among family members who reported taking their children to stem cell clinics abroad. In the science literature, 75 % (n=65) of stem cell findings were described as promising with regard to potential interventions for CP and ASD, which have few treatment options, or, in the case of *in vitro* applications, as potential routes to learn more about the disorder or develop future therapeutics.

Cautious messaging: In 16 % (n=11) of news articles—largely investigative pieces in major newspapers – researchers emphasized that stem cell applications were in the early stages and not ready for implementation. Researchers also urged caution regarding stem cell tourism in 12 % (n=9) of these news reports, arguing that stem cell clinics operated in a regulatory grey zone often with little oversight and a lack of published data. One in five (21 %; n=16) news pieces contained messages of uncertainty where parents expressed their worries about the efficacy of stem cell clinics abroad as they prepared to travel to them.

In the science literature, we found cautionary content in 37 % (n=32) of articles that included acknowledgements that both *in vitro* and *in vivo* stem cell research for ASD and CP is still ongoing. None reported that stem cells are currently ready for clinical application.

Themes

Benefits: Both the print media and science literature mentioned benefits more frequently than risks (Fig. 1). Ninety percent of news articles (n=66) discussed benefits; 126 unique claims were coded. Eighty percent of the science articles (n=70) mentioned benefits related to stem cell research; 154 unique claims were coded. Health claims such as symptom improvements in language, cognition, walking abilities, or decreased rigidity were the most commonly cited benefits in both types of samples (Table 4).

Table 3 Types of messaging in media (n=73) and science articles (n=87)

Messaging for stem cells for ASD or CP	Number	Percent (%)
Positive		
Media		
Hope	46	63
Science		
Promise or potential	65	75
Cautious		
Media		
Uncertainty regarding efficacy	16	21
Further research required	11	16
Stem cell tourism warnings	9	12
Science		
Further research required	32	37
Negative		
Media		
No promise or potential	3	4
Science		
No promise or potential	2	2

Table 4 Benefits and risks in the news media (n=73) and science literature (n=87)

	Number	Percent (%)
Benefits		
Media (n= 73)		
Health	64	88
Improved understanding	6	8
Increased autonomy	2	3
Science (n= 87)		
Health	34	39
Improved understanding	32	37
Potential for new therapeutics	19	22
Risks		
Media (n= 73)		
Efficacy concerns	11	15
Health	11	15
Economic	6	8
Emotional	5	7
Science (n= 87)		
Health	22	25
Efficacy concerns	3	3
Emotional	2	2

Sources of Benefit Information in News Media Articles: Claims about benefits were most frequently made by news article authors (46 %; 58/126) and family members (40 %; 50/126). The latter largely discussed health benefits in terms of small but meaningful improvements, rather than cures.

Risks: Forty-nine individual risk statements were coded in 32 % (n=23) of news articles; 44 individual risk statements were coded in 29 % (n=25) of the science articles. Discussions of risks in the media were most often captured in the context of travel abroad for treatment (25 %; n=18) while concerns regarding the procedure itself appeared in only 7 % (n=5) of articles. Health risks, such as headache and nausea, were most prominently discussed in science articles (25 %; n=22). However, 33 % (n=29) of all articles reported that stem cells were generally safe or not harmful.

Sources of risk information in news media articles: Researchers and family members were the most frequent sources of individual risk statements (39 %; n=19/49; 28 %; n=14/49) in the media articles. Researchers discussed efficacy and health concerns, especially in regard to stem cell tourism, while family members were most concerned with the efficacy and cost of stem cell treatments abroad. Family members also mentioned health concerns but often qualified their concerns with statements that they felt reassured, after doing their own research, that the risks were minimal.

Risk and benefit messaging as a function of news frame: The sources of information that were featured in an article affected the reporting of benefits and risks. This pattern was delineated along news frames. For instance, investigative pieces that cited researchers and medical professionals were the most balanced in their presentation of risks and benefits (Fig. 2). Researchers appeared most frequently in this news frame with cautious statements about the current state of research and the risks of stem cell tourism. By comparison, human interest stories largely cited family members as their primary or sole source of information and were more likely to present stem cells with unguarded optimism. Latest news articles were the least likely news frame to directly cite a source of information and to include risk information.

Stem cell tourism in the news media: 64 % of news articles (n=47) centered on stem cell tourism with interviews from

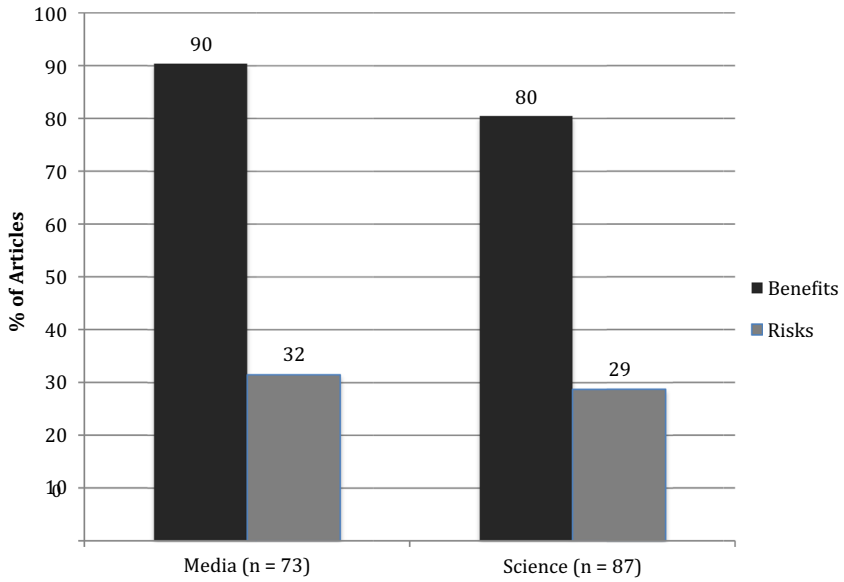

Fig. 1 Messages of benefits and risks

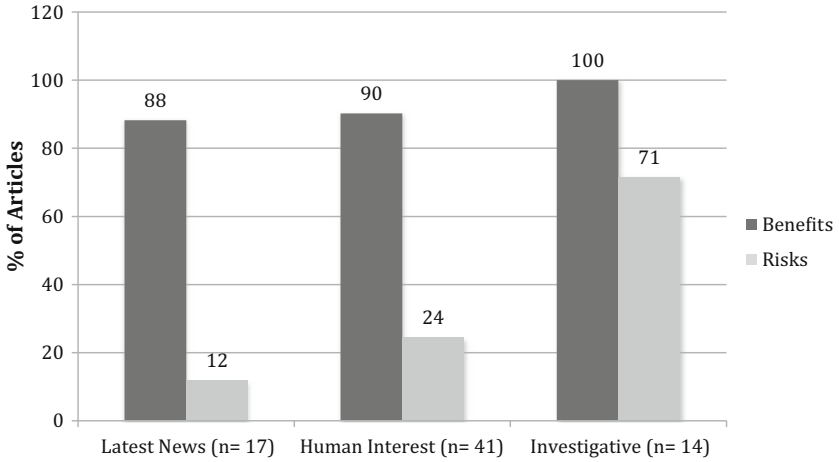

Fig. 2 Risks and benefits messaging by news frame (n=73)

families who traveled abroad, or wished to do so, in pursuit of advertised stem cell therapies for their child's ASD or CP. Within this subset, 72 % (n=32) were human interest stories narrating the plight of families (Table 5). These appeared most often in local (56 %; n=19) newspapers. Fundraising efforts to travel abroad to access stem cell clinics were documented in these articles and included details on how to donate to assist families with, for example, their out of pocket expenditures (which were reported to range from $7995 CAD per trip to $90,000 CAD overall) or recounted stories of a communities working together to help a sick child.

Of the 31 individuals and their families who were interviewed about travelling abroad to access stem cell interventions, 14 were in the planning stages and 17 had already travelled within the past year. In the retrospective stories, all but two families reported health improvements such as improved language abilities and limb control and decreased rigidity.

Discussion

In this analysis of news media and science literature related to stem cells for CP and ASD, we found that both types of communications contain more positive than negative messages and report more benefits than risks. The news media has a sustained focus on stem cell tourism, with reports of children, often under the age of five, and their families fundraising for treatment abroad or recounting their positive experiences. In contrast, the science literature contains more cautionary messages and emphasizes the need for further research. No science articles report that stem cells are currently ready for commercial clinical application.

The findings generally correspond with previous research on skewed reporting of benefits over risks of stem cell research [7, 8, 11, 16]. In a departure from past research, however, the results here show that the presentation of stem cells for CP and ASD is not homogenous across news formats . In particular, investigative pieces in major newspapers tend to contain the most varied sources of information and the most balanced messages. In contrast, human interest stories most often originate from local newspapers with relatively low circulation, and overwhelmingly highlight hope and benefits expressed by family members as sources of information. This type of soft, entertainment-oriented news emphasizes dramatic narratives [17], is episodic, and has been shown to capture the attention of readers to a greater extent than the thematic framing of hard news [18]. Indeed, previous studies have found that human interest stories are remembered vividly and readers find them most engaging [7, 19]. By reporting small but beneficial improvements rather than miracle cures, human interest stories may also convey that stem cell clinics abroad offer realistic treatment benefits for children with CP and ASD, and therefore offer a rational treatment option.

Table 5 Snapshot of stem cell tourism in news articles (n=47) about ASD or CP from January 2000 to June 2014

Age of child (in years)	Country of origin	Destination country (top 4)	Pre or post travel abroad	News frame	Fundraising reported
0–5 (74 %, n=35)	Canada (30 %, n=14)	China (28 %, n=13)	Pre- travel (64 %, n=30)	Human interest (72 %, n=34)	Yes (85 %, n=40)
6–12 (21 %, n=10)	UK (30 %, n=14)	USA (23 %, n=11)	Post- travel (36 %, n=17)	Latest news (9 %, n=4)	No (15 %, n=7)
13–19 (2 %, n=1)	Australia (21 %, n=10)	Germany (23 %,n=11)		Investigative (19 %, n=9)	
20+(2 %, n=1)	USA (19 %, n=9)	Mexico (15 %, n=7)			

Like Zarzeczny et al. [8], the findings here further demonstrate that when scientists engage directly science reporters, the information tends to be most accurate. The success of this partnership seems to trump the historical tendency for news hyping, hype to which science journals themselves are not immune, and even advertising to consumers that capitalize on messages of hope [20]. To this end, Nisbet and Scheufele's [21] call for researchers to look beyond elite audiences and engage media at different levels of readership could not be more apropos: ASD and CP do not discriminate by the socio-economic status of a child. Moreover, by carefully tailoring messages, researchers can sensitively and meaningfully convey realistic timeframes for the translation of novel biotechnologies into clinical interventions [22].

The exclusive focus on news media here and on ASD and CP in the absence of much greater analysis of online news, television and social media that are increasingly playing a role in disseminating health information [23–25] is no doubt a limitation of this study. We also did not study the impact of these communications on readers. We reserve these important trajectories for research for the future.

Direct researcher engagement with the media about stem cell research in the context of ASD and CP must be a priority—a priority for scientists, and a priority for reporters. The welfare of already vulnerable children is at stake, as is public trust. A commitment to informed hope [26] through a dedicated science reporting partnership is the key to help affected children and their families to navigate the increasingly complex landscape of stem cell research.

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Conflict of Interest The authors declare they have no conflicts of interest.

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