

Fueling Hope: Stem Cells in Social Media

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Abstract Social media is broadening opportunities to engage in discussions about biomedical advances such as stem cell research. However, little is known about how information pertaining to stem cells is disseminated on platforms such as Twitter. To fill this gap, we conducted a content analysis of tweets containing (i) a stem cell keyword, and (ii) a keyword related to either spinal cord injury (SCI) or Parkinson disease (PD). We found that the discussion about stem cells and SCI or PD revolves around different aspects of the research process. We also found that the tone of most tweets about stem cells is either positive or neutral. The findings contribute new knowledge about Twitter as a connecting platform for many voices and as a key tool for the dissemination of information about stem cells and disorders of the central nervous system.

Keywords Stem cells · Twitter · Social media · Parkinson disease · Spinal cord injury · Neuroethics

Introduction

Since the discovery of stem cells in the 1960s, significant and rapid progress has been made in characterizing their properties and potential clinical applications. While early efforts focused on cell therapies for recovering organ function [1], more recent research has explored therapeutic applications of stem cells to a wide variety of conditions such as spinal cord injury (SCI) [2] and age-associated conditions such as Alzheimer's disease [3] and Parkinson's disease (PD) [4, 5]. New findings routinely garner the attention of news media [6, 7], and fuel hope for the treatment of these target diseases and even others still out of scope [3, 8, 9].

Trends in news coverage emphasize the translational applications of stem cell research [10–12]. In one study conducted in Canada, Caulfield and Rachul (2011) reported that news representations of novel stem cell methods are generally supportive of stem cell research, and focus mainly on the positive ethical implications for stem cell treatment. In another study by the same group that examined athletes' publicized use of stem cell therapies, media articles generally promoted the efficacy of unproven treatments, aiding in the legitimization of these procedures in the public eye [10]. In addition to traditional media, new forms of social media are encouraging conversations about innovations in health research [13–16], and the opportunity for online interaction and communication flow represents a shift that has wider implications for public discussion [17]. Some research has revealed risks of anonymity and personalized information with online health information and tools [18], as well as variability in accuracy of information [18, 19]. Qualitative analyses of online, direct-to-

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consumer advertisements for stem cell treatments show that this type of online content capitalizes on the high optimism surrounding new technologies to contribute to the “political economy of hope” [20]. Nonetheless, numerous benefits have been linked to online health platforms including the possibility for greater interactions between health care professionals and patients, more accessible and tailored information, and lower costs for health surveillance and communication [17, 19]. Qualitative studies of the role of social media in relation to stem cell research and therapy specifically also point to use that extends beyond information exchange, and includes journaling and fundraising [21]. Overall, online platforms are providing new forums for fostering important discussions regarding health, disease and research [18, 22].

Among social media networks, Twitter is the most popular microblogging platform and one of the most popular social networking sites (EBizMBA, 2014). Twitter allows users to post or read short messages limited to 140 characters, and provides accessibility to a range of content, varying from emergency news updates to personalized health information. Information shared on Twitter has been shown to have an impact on health behaviour, health behaviour tracking and public engagement with health information [23, 24]. To date, however, little attention has been paid to who participates on Twitter and the information that is shared about stem cells. Specifically, there is a lack of research examining how Twitter is used to disseminate information and engage discussions on specific and different health issues within the context of stem cell research.

The goal of the present study is to fill this knowledge gap through a rigorous empirical content analysis of Twitter posts. We examined tweets containing keywords for stem cells and one of two conditions: SCI or PD. SCI was chosen as a sample condition based on previous work showing that SCI patients and their families turn to the Internet for health resources [25]. PD was chosen as a sample condition to match SCI as a movement disorder for which stem cell treatments are currently being investigated in clinical trials. We sought to examine who is sharing what information about stem cells in samples centered around SCI, and PD, and specifically i) characterize the participants of each sample; ii) explore the sources of information shared; and iii) identify the content of the discussion.

Materials & Methods

Design

We conducted a cross-sectional survey study using content analysis of posts on the online social media platform Twitter for a period of 6 months starting August 1st 2014 at 8:00 am. The methodology used for this study is based on previous

work by Robillard et al. [15] and on previous studies of social media content [15, 26–28].

Search Strategy and Data Mining

We created an automated program in the C++ programming language utilizing the Twitter API to search for English-language tweets containing the words “stem cells”. From this initial data set we used two additional sets of keywords to retrieve tweets related to SCI (“spine”, “spinal”) and Parkinson disease (“parkinson”). All tweets retrieved were included in the analysis. Data fields for users, freely contributed user information, date and time, and tweet content were parsed and stored. Twitter users were not contacted for this study and no attempts were made to access information that users set as private.

Coding and Inter-coder Reproducibility

An initial set of 10 % of the tweets for each data set (SCI, PD) was retrieved to conduct a pilot analysis and develop the coding scheme. Broad categories were established from the coding scheme using a priori themes from previous work [15] combined with an emergent coding strategy for themes specifically related to stem cells. Two researchers (JMR, EC) developed and refined the coding scheme into its final iteration. The unit of analysis consisted of each unique, complete tweet, and a rich coding strategy allowed for multiple categorizations of the units. The final coding scheme comprised the following major categories: 1) type of user (e.g., health care professional, organization); 2) content type of link (e.g., news site, social media site); 3) tweet content type (e.g., study, personal event); 4) tweet characteristics (e.g., tone); and 5) stem cell research (e.g., animal studies, clinical trials). Specific research studies uncovered in category 3, tweet content type, were further characterized according to their date and publication status. The geographic location of users was compiled when the information was volunteered freely on the users’ profiles. Retweets, or copies of tweets shared by different users were analyzed and the tweets most retweeted in each category were identified.

Following the creation of the full coding scheme, one researcher (EC) coded the entire sample. A second coder (JMR) analyzed 20 % of the final sample to test for reproducibility. Reproducibility was initially 94 % (SCI sample) and 96 % (PD sample), and consensus was achieved through discussion.

Statistical Analysis

Descriptive statistics were used to quantitatively characterize the composition of each sample as generated by the coding scheme. We conducted chi-square tests to compare the

distributions of categories within a theme between the SCI and the PD data sets.

Results

Sample

A total of $N=2226$ tweets were retrieved for analysis: 1168 tweets containing a SCI keyword and 1058 tweets containing a PD keyword. Unique tweets, that is, tweets that were not exact duplicates tweeted by different users or retweets, comprised 26 % ($n=303$) of the SCI sample and 23 % ($n=248$) of the PD sample. A total of 1493 unique users contributed to the sample of tweets, with 891 users identified in the SCI sample and 602 users identified in the PD sample. Users who shared information sufficient to evaluate traits about themselves or their organization constituted 81 % ($n=486$) of the PD sample and 74 % ($n=655$) of the SCI sample.

Characteristics of Users Tweeting About Stem Cells and SCI or PD

Publically available, user-volunteered data were evaluated for country of origin, interests, political views, mention of diseases, and user occupation or organization type (Fig. 1). A number of users disclosed their location: 65 % ($n=577$) in the SCI sample, and 62 % ($n=374$) in the PD sample. The distributions of user locations were significantly different between the SCI and PD communities ($\chi^2(8, N=951)=34.21, p<0.0001$). For both SCI and PD, the majority of users were located in the US (SCI: 54 %, PD: 66 %), but there was a higher frequency of Canadian users in the SCI sample (SCI: 11 %, PD: 3 %), and of users from the UK in the PD sample (SCI: 11 %, PD: 15 %).

The most common occupation among users with individual accounts who disclosed this information ($N_{SCI}=261, N_{PD}=165$) was research (SCI: 21 %, PD: 18 %; Fig. 2a). More users in the SCI sample identified as physicians (SCI: 12 %, PD: 7 %), and allied health (e.g., nurses, physiotherapists) (SCI: 13 %, PD: 8 %) than in the PD sample. By contrast, more users in the PD sample identified as business and marketing professionals (SCI: 7 %, PD: 11 %). Overall, the distributions of individual occupations between users for the two conditions were significantly different ($\chi^2(12, N=426)=34.37, p<0.001$).

Twitter user accounts may represent organizations, and 271 SCI user accounts and 221 PD user accounts identified themselves as such (Fig. 2b). The distributions of the types of organizations differed significantly ($\chi^2(13, N=492)=61.87, p<0.0001$). Most users who represented organizations were news-based (SCI: 35 %, PD: 34 %). Organizations among SCI-based users were more frequently medical and

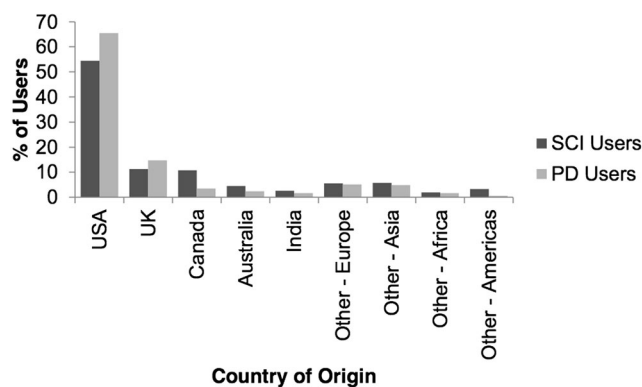


Fig. 1 Geographical location of Twitter user accounts from the SCI and the PD samples

technology companies (SCI: 12 %, PD: 9 %), medical organizations (SCI: 8 %, PD: 5 %) and clinics (SCI: 8 %: PD: 3 %). The PD sample contained more advocacy organizations (SCI: 10 %, PD: 14 %) and stock market companies (SCI: 0 %, PD: 10 %).

Among the political and moral views shared in profiles ($N_{SCI}=23, N_{PD}=55$), conservative (SCI: 35 %, PD: 44 %) and pro-life (SCI: 30 %, PD: 31 %) were the most frequent.

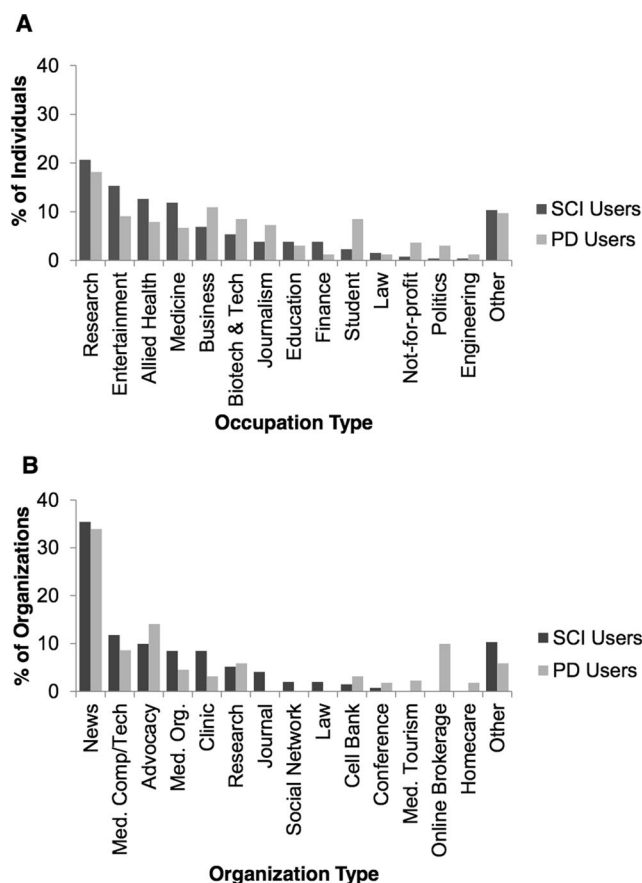


Fig. 2 Twitter user types for the SCI and PD samples. **a.** Self-declared occupation for user accounts belonging to individuals. **b.** Type of organization for user accounts belonging to organizations

Content of Tweets About Stem Cells and SCI or PD

Most tweets in both SCI and PD samples contained links to webpages (SCI: 71 %, PD: 78 %). Links to news sites (SCI: 45 %, PD: 50 %) and social media sites (SCI: 28 %, PD: 26 %) were the most common. To a smaller degree, tweets contained links to websites for clinics (SCI: 8 %, PD: 2 %), businesses (SCI: 2 %, PD: 6 %), journals (SCI: 6 %, PD: 4 %) and advocacy groups (SCI: 7 %, PD: 6 %). The distributions of the types of websites to which there were links differed significantly between the SCI and PD samples ($\chi^2(6, N=418)=13.78, p<0.05$). The content of the tweets in both samples were largely news reports (SCI: 64 %, PD: 46 %; Fig. 3). The PD sample contained more tweets related to scientific studies than the SCI sample (SCI: 19 %; PD: 23 %), while more questions were posed among SCI users (SCI: 11 %, PD: 4 %). The types of questions were varied and included, for example, queries from patients and titles of news segments.

A portion of the tweets discussed the current therapeutic impact of stem cells for PD and SCI ($N_{PD}=26, N_{SCI}=86$). SCI tweets had a more diverse wording, including words such as “cure” (16 %), “repair” (15 %), “regenerate” (13 %), and “recovery” (12 %), while PD tweets almost only used “cure” (77 %). The tone for both PD and SCI tweets was similarly either neutral (SCI: 57 %, PD: 61 %) or positive (SCI: 41 %, PD: 36 %).

Some tweets expressed emotions (SCI, $N=65$; PD, $N=32$). Among the emotions that accounted for at least 10 % of the samples were hope and excitement (SCI: 49 %, PD: 56 %). Few tweets expressed reservation or pessimism (SCI: 5 %, PD: 9 %).

Stem Cell Research on Twitter for SCI or PD

Fifty percent ($N=151$) of SCI tweets and 46 % ($N=115$) of PD tweets mentioned research (Fig. 4). Tweets about research in the SCI sample included more discussion of human clinical trials (15 %) than in the PD sample (3 %). In the SCI sample, 9 % of tweets mentioned reviews of stem cell literature (SCI: 9 %); we found no mentions of reviews in the PD sample. By

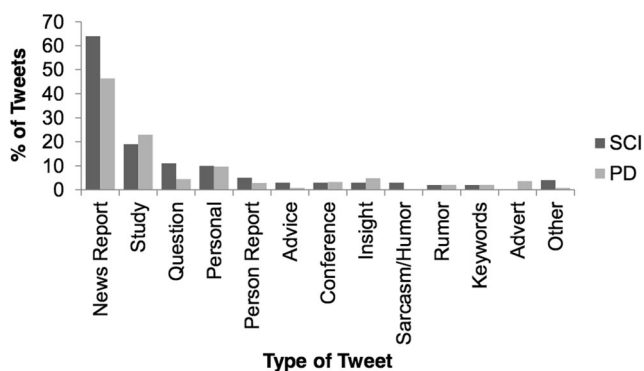


Fig. 3 Type of content for tweets in the SCI and the PD samples

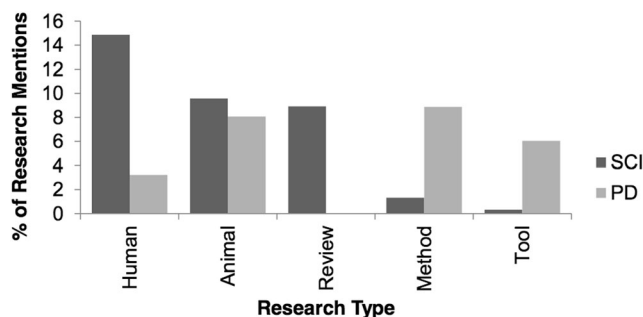


Fig. 4 Aspects of research discussed in tweets from the SCI and PD samples

contrast, tweets about research in the PD sample contained more mentions of methods and tools for conducting and applying stem cell research than in the SCI sample (SCI: 1 %, PD: 15 %). The differences between the distributions of mentions about research between the two samples were statistically significant ($\chi^2(5, N=551)=72.76, p<.0001$). Table 1 shows the scientific studies that were most discussed in this sample of tweets. The most frequently shared study for SCI was a meta-analysis examining the therapeutic benefits of stem cell transplants in animal models (41 % of tweets mentioning a scientific study); for PD, the most shared article (33 % of tweets mentioning a scientific study) examined immune response to transplantation of autologous cells in primate subjects (Table 1).

Most Shared Content for Stem Cells and SCI or PD

Shown in Table 2 are the individual tweets for which duplicates (retweets) totaled 50 % of the total samples, calculated from the number of times a retweet appeared in the samples. These tweets were ranked based on the highest number of unique users sharing them, which was a measure of how broadly these popular tweets are disseminated. For both samples, the most retweeted tweets – representing the most popular content – were related to research findings.

Discussion

This analysis of posts relating to stem cells and SCI or PD shows that: (1) in both the SCI and the PD samples, a large variety of stakeholders are engaging in the discussion about stem cells, (2) research is at the forefront of the discussion, with the most retweeted content among both samples focused on publications, and (3) the tweets in both samples are mainly neutral or positive. The findings contribute new knowledge about Twitter as a connecting platform for many voices, and as a key tool for the dissemination of information about stem cells and disorders of the central nervous system (CNS).

Table 1 Most shared studies

Frequency (%)	Study type	Code	Study title	Publication
SCI ^a				
41	Meta-analysis: animal studies	transplant	Stem cell transplantation in traumatic spinal cord injury: a systematic review and meta-analysis of animal studies	PLOS Biology 2013
24	animal: animal stem cell transplanted into mice	scar	Resident neural stem cells restrict tissue damage and neuronal loss after spinal cord injury in mice	Science 2013
PD ^a				
33	animal: primate stem cells to primate	autologous	Parkinson's disease induced pluripotent stem cells with triplication of the α -synuclein locus	Nature Communications 2013
18	tool: human, rat, yeast stem cells to in vitro	synuclein	Identification and Rescue of α -Synuclein Toxicity in Parkinson Patient-Derived Neurons	Science 2013
9	method: animal and human in vitro	somatic	Deterministic direct reprogramming of somatic cells to pluripotency	Nature 2013
5	method: human stem cell to in vitro testing	progerin	Human iPSC-based modeling of late-onset disease via progerin-induced aging	Cell Stem Cell 2013

^a SCI spinal cord injury, PD Parkinson's disease

When examining freely-contributed profile information of users tweeting about stem cells, we found that geographic origins and occupations reveal differences in both the specific pool of users and their interests. These findings align with previous research on online health information usage. For example, a diversity of users was also found by Chou et al. (2009) who examined social media usage by individuals with different backgrounds, and correlations between health and sociodemographic data [17]. While some research has suggested that physicians remain hesitant about using online social media to interact with patients [29], the presence of doctors and allied health professionals in our samples coincides with findings that medical professionals, at least in the context of stem cells, SCI and PD, are indeed taking part in social media to seek out and contribute to medical and healthcare

knowledge [30, 31]. Similarly, the findings show that researchers are also taking part in the conversation about stem cells on Twitter, consistent with other examinations of social media conversations in this group [15, 32, 33]. The level of engagement on social media varies, however. Keller et al.'s findings, for example, suggest that despite the recognition of the benefits of social media, many researchers remain relatively reserved in their usage of social media and even more so, of Twitter [32].

The present analysis is the first to describe the thematic content of tweets related to stem cells and health. Analyses of news media show trends in communication that are in line with our findings. As with coverage in traditional media, Twitter serves as a real-time feed of significant events, and the content of the tweets reflect these events. For the most shared

Table 2 Most retweeted posts

	Number of Retweets	Number of different users sharing
SCI ^a		
Stem Cell Scarring Aids Recovery from Spinal Cord Injury - [LINK] #stemcell	108	98
Start of stem-cell study offers hope to patients with spinal-cord injuries [LINK] via @CTVNews	70	66
Will Stem Cell Therapy Help Cure Spinal Cord Injury? [LINK]	67	60
Adult (Fetal) Stem Cell Trial for Spinal Cord Injury Presents New Ethical Questions - [LINK]	42	36
Spinal injuries and stem cell scarring - Medical News Today - [LINK]	33	31
PD ^a		
Stem cell therapy for Parkinson's proves safe in primates [LINK]	81	76
Adult Stem Cell Research Breakthrough Could Lead to Treatments for Parkinson's, Diabetes [LINK] via @[USER] #Auspol	79	71
New insights into treating Parkinson's from yeast, stem cell experiments [LINK]	42	36
Parkinson's stem cell project aims for 2014 approval [LINK] [from U-T San Diego]	25	22
ISCO Gaining New Recognition for Its Work with Parkinson's [LINK]	59	20

^a SCI spinal cord injury, PD Parkinson's disease

tweets, both disease groups refer to various events in their respective areas of interest, and these events shape discussion of the disease for that period. Similarly, previous research has shown that through media exposure, key events in stem cell research and stem cell policy shapes public discourse on an issue [8]. As such, we can hypothesize that differences in content may be explained by the status of clinical trials and media representations about them. In parallel with event coverage, the sharing of information about clinical trials in particular by the SCI community on Twitter may reflect openness to treatment. Themes of “readiness”, “informed hope” and acceptance have been identified among public discussion [25, 34]. For SCI specifically, research suggests that news coverage has shifted towards a focus on cures rather than rehabilitation [12], a finding that is consistent with the clinical trial mentions in this community. Overall, the difference in the discussions of research highlights both the unique information to which each sample is exposed, and the extent to which the stakeholders may anticipate therapeutic results from advances in research.

The frequent occurrence of tweets related to research is in line with previous findings on media and social media. Robillard, Johnson, Hennessey et al. (2013) reported that in a sample of tweets about dementia, research findings are a prominent component of the discussion [15]. Prior content analyses of media reporting on stem cell issues has also shown that stem cell research is often hyped [6, 11], and that social media contributes to that phenomenon [35]. Hyped representations of stem cell research in both traditional and social media, which have been described in the work of others [6, 11, 35], may well be a contributing factor to the extended discussion of this topic on Twitter observed in the present study.

The positive or neutral tone of tweets about stem cells, SCI and PD is consistent with other recent research showing, for example, favourable opinions of gene therapy on social media [14] and of stem cell research overall [34]. While tone tends to be more negative when users draw on core themes of opposition, such as the use of human embryonic stem cells in research [13], our observations show little negativity towards stem cell research.

In interpreting the data from the present study, we consider certain limitations. Twitter is the most popular microblogging platform, but other platforms exist in the social media sphere. Web forums, for example, allow for longer and more detailed discussions. As well, social media lends itself to sampling biases and it is difficult to generalize the findings from our samples to a general population. Further, given that there are currently several active clinical trials involving a stem cell-derived product for SCI, the key words “stem cell” may have inherently biased the sample towards SCI. While the overall demographics of Twitter users are available [36], the information shared cannot always be verified given the anonymity of

individual users. Incorporation of demographic variables specific to the samples into the analyses, therefore, is difficult. Finally, while the data were collected over a 6-month timeframe, the conversations that occur as research progresses and the foci of public discussion are constantly evolving. Despite these limitations, the data provide important findings regarding online discussions of stem cell research for SCI and PD, and Twitter, with over 280 million active users, remains a core platform for these discussions [19].

Overall the findings contribute new knowledge about social media as a dissemination tool for information about stem cells for SCI and PD. Twitter serves as a popular medium for patients with these CNS disorders, their families and members of the general public to share, discuss and promote scientific and medical information. Given the possibility for rapid and ongoing information exchange, Twitter offers a dynamic and multidimensional means of communication.

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Conflicts of Interest The authors declare that they have no conflict of interest.

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