Original Article

Patient perception of spinal cord injury through social media: An analysis of 703 Instagram and 117 Twitter posts

ABSTRACT

Introduction: Social media has developed exponentially over the last decade as a means for individuals and patients to connect to others and has provided a unique opportunity for physicians to provide broader information to the general public to attempt to positively modify health behavior. The purpose of this study was to assess the patient's perception of spinal cord injury (SCI) on social media.

Methods: Instagram and Twitter social media platforms were analyzed to determine posts written by patients with SCI. The initial search for Instagram posts tagged with "#spinalcordinjury" yielded over 270,000 posts in April 2021. Posts pertaining to the patient's experience were retrospectively collected from January 2020 to April 2021. Twitter posts that included "#spinalcordinjury," "@spinalcordinjury," and "spinal cord injury" were retrospectively collected in April 2021. One hundred seventeen tweets were found that were directly from a patient with SCI. Themes associated with patients' experiences living with SCI were coded.

Results: The most common theme on Instagram was spreading positivity and on Twitter was the appearance of the wheelchair (75.8% and 37.3%, respectively). Other common themes on Instagram were the appearance of a wheelchair (71.8%), recovery or rehabilitation (29.9%), and life satisfaction (29.0%). Prevalent themes on Twitter included spreading positivity (23.2%) and recovery or rehabilitation (21.3%).

Conclusion: The prevalence of themes of positivity and awareness may indicate the utilization of social media as a support mechanism for patients living with SCI. Identification of prevalent themes is important for the holistic treatment of SCI survivors.

Keywords: Instagram, patient experience, social media, spinal cord injury, Twitter

Avi A. Gajjar[1,2], Anthony Huy Dinh Le[3], Rachel Jacobs[2], James H. Mooney[4], Raj Swaroop Lavadi[2], Rohit Prem Kumar[2], Michael D. White[5], Galal A. Elsayed[6], Nitin Agarwal[2,7]

[1]Department of Neurosurgery, Albany Medical College, Albany, NY, USA, [2]Department of Neurological Surgery, University of Pittsburgh School of Medicine, [3]Department of Neurosurgery, University of Missouri–Kansas City School of Medicine, Kansas City, Missouri, [4]Department of Neurosurgery, University of Alabama at Birmingham, Birmingham, AL, [5]Department of Neurological Surgery, Barrow Neurologic Institute, Phoenix, Arizona, [6]Department of Neurosurgery, Weill Cornell Medical College, New York, NY, [7]Department of Neurological Surgery, University of Pittsburgh Medical Center, Pittsburgh, PA, USA

Address for correspondence: Dr. Nitin Agarwal, Department of Neurological Surgery, University of Pittsburgh Medical Center, University of Pittsburgh School of Medicine, 200 Lothrop Street, Suite B-400, Pittsburgh 15213, PA, USA. E-mail: nitin.agarwal@upmc.edu

INTRODUCTION

Most Americans have access to the Internet and turn to it as a first-line health resource.[1,2] In particular, social media communications in health care are becoming increasingly studied, although the evaluation of social media in medicine is still in the early stages of research.[3] Social media usage has grown over the last decade as a means for patients to connect to others.[4,5] This growth has provided a unique opportunity for physicians to disseminate information broadly to the general public with the potential to positively modify health behaviors through health education promotion, sleep deprivation reduction, management of drug and substance abuse, and the modification of other risk factors.[4,6-8]

How to cite this article: Gajjar AA, Le AH, Jacobs R, Mooney JH, Lavadi RS, Kumar RP, et al. Patient perception of spinal cord injury through social media: An analysis of 703 Instagram and 117 Twitter posts. J Craniovert Jun Spine 2023;14:288-91.

Access this article online	
Website: www.jcvjs.com	**Quick Response Code**
DOI: 10.4103/jcvjs.jcvjs_87_23	

With recent advancements in technology, social media allows for larger numbers of people to rapidly share information on specific and pertinent topics, improving patient knowledge, and connectedness with the potential to positively influence patient behavior.[9] Widespread Internet accessibility in recent years has maximized the reach and influence of social media. Social media has already impacted the habits and lifestyles of patients with other common medical conditions such as heart disease and stroke.[3,10,11] Multiple prior studies have also investigated the usage of social media on a variety of neurosurgical diseases, such as hydrocephalus, scoliosis, and more.[12-16] Barriers to the study of social media trends on a large scale include the absence of standardized data metrics and limiting the ability to develop automated computer analyses.[17] In particular, Kim *et al.* and Neethu and Rajasree suggest that subjective analysis of Twitter posts can be superior to an automated analysis conducted by a computer.[18,19]

For patients with spinal cord injury (SCI), social media may serve as another potential avenue to facilitate rehabilitation. The authors hypothesize that patients with SCI may utilize social media as a virtual support group. This study aims to evaluate this hypothesis using thematic analysis of the patient experience with SCI.

METHODS

Hashtags were selected pertaining to SCI. The search was limited to posts under the tag "#spinalcordinjury" on Instagram and "#spinalcordinjury," "@spinalcordinjury," and "spinal cord injury" on Twitter. Only posts written in English were included in the study.

Two hundred and seventy-five thousand posts were found by an initial search for Instagram posts tagged with "#spinalcordinjury." Posts that were excluded from the study included those that were not made by the patient or included the patient's own experience with SCI or posts by health-care institutions. Seven hundred and three Instagram posts that were made from January 2020 to April 2021 were analyzed after the elimination of posts that were not pertinent to the study. Posts that were from institutions, health-care organizations, and did not refer to the patient's own experience (e.g., family member, politician, or celebrity) were eliminated.

The Twitter platform was then searched for "tweets" with the hashtags and tags "#spinalcordinjury," "@spinalcordinjury," and "spinal cord injury." This resulted in 1,301 results. One

thousand, one hundred and eighty-four tweets were not included based on the same elimination criteria as stated above, resulting in 117 tweets made from January 2020 to April 2021.

Both Instagram and Twitter posts were qualitatively reviewed to generate a preliminary list of themes. Posts were coded by an individual investigator as relating to none, one, or multiple themes. A second investigator verified the thematic analysis for all relevant Instagram and Twitter posts. Any discrepancy in themes was verbally discussed by both investigators until a unanimous decision was made. The frequency of major themes regarding the experiences of patients with SCI is shown in Table 1.

RESULTS

Of the 703 Instagram posts, 50.2% were made by females (49.4% were from males and 0.4% unknown sex). From the 92 tweets, 52.2% were made by females and 47.8% were made by males. The frequency of themes pertaining to the experience of living with SCI is presented in Table 1. The most common themes throughout the Instagram and Twitter posts were the appearance of a wheelchair (71.8% and 37.3%), spreading positivity (75.8% and 23.2%), and mentions of recovery or rehabilitation (29.9% and 21.3%), respectively. The least common themes on Instagram were survival (3.8%), COVID-19 (2.3%), and an explanation of injury (2.1%) [Table 1]. The least mentioned themes on Twitter were life satisfaction (1.9%), religious connotations (1.9%), and offering/reaching out for online support (0.9%).

Table 1: Compared frequency of themes within patient Instagram and Twitter posts regarding spinal cord injury

Themes	Instagram post frequency, *n* (%)	Twitter post frequency, *n* (%)
Spreading positivity	533 (75.8)	25 (23.2)
Appearance of a wheelchair	505 (71.8)	41 (37.3)
Recovery or rehabilitation	210 (29.9)	25 (21.3)
Life satisfaction	204 (29.0)	2 (1.9)
Raising awareness of environmental hazards (such as motorcycle accidents)	135 (19.2)	5 (4.6)
Resiliency	102 (14.5)	5 (4.6)
Recounting complications to followers	60 (8.5)	3 (2.8)
Religious connotations	53 (7.5)	2 (1.9)
Offering/reaching out for online support	52 (7.4)	1 (0.9)
Most difficult part of the experience	48 (6.8)	3 (2.8)
Physical and mental pain	42 (6.0)	6 (5.0)
Survival	27 (3.8)	6 (5.0)
COVID-19	16 (2.3)	7 (5.8)
Explanation of injury	15 (2.1)	5 (4.6)

DISCUSSION

Social media can serve as a platform for patients with SCI to describe their experience with the disease. This study analyzed Twitter and Instagram usage by patients with SCI to identify major themes expressed by patients regarding their experience. The theme of spreading positivity was most prevalent among Instagram posts at 75.8%, and the appearance of a wheelchair was the most common theme for Twitter posts at 37.3%. patients who have undergone spine surgery with negative affect and depression typically have poorer outcomes than those without.[20] Therefore, spreading positivity may be a valuable way for patients with SCI to cope and connect with others. Some patients with SCI are also conscious of their self-image, as many of them previously did not require mobility assistance.[21] However, the high frequency of the appearance of a wheelchair on Twitter and Instagram indicates that many patients with SCI are not afraid to publicly display their life to others. Publicly sharing about one's experience with a disease can lead to other patients feeling more comfortable and can lead them to create informal support groups.[16,22]

This data may be useful for letting patients know that social media serves as an effective platform to gain additional support or advice from means other than their physicians, who likely have not undergone the procedure themselves.

Social media has the potential to serve as a support group network for patients with SCI. The patient's perspective of the rehabilitation process after their traumatic event can influence their perception of care and quality of life.[23] Patient collaboration through these posts may facilitate a better understanding of their injuries, procedures performed, and the future rehabilitation process, supplementing what they are told by their physicians. The real-time evaluation of thoughts and reactions through social media can provide a valuable alternative to formally requested feedback by the physician.

Despite these technological advancements, there have been adverse consequences with broadened social media access. For example, there has been a continuous rise in vaccine-related health misinformation by individuals who are not licensed medical professionals since 2012.[24] The rise of social media has facilitated the spread of misinformation regarding health-related issues such as procedures, conditions, diet, and public health interventions.[25] The ability of laymen to disseminate false health information can lead to negative health outcomes for unsuspecting patients. Therefore, it would be beneficial for health-care professionals to understand how to navigate the online environment pertaining to their specialty.[26]

Limitations
This was a retrospective study where all Twitter and Instagram posts were subjectively coded. The tweet limit of 280 characters on Twitter forces individuals to post more succinctly, providing a more concise and specific summary of their injury experiences. Instagram's caption limit is much larger at 2200 characters, allowing for users to be more descriptive about their experience. This difference in caption length may cause differences in content discussed by SCI on both platforms. Furthermore, due to the nature of social media, it is impossible to verify all information posted online by patients. Limited privacy settings on both platforms also limit the content available for analysis in both platforms. Furthermore, not all survivors of SCI are likely to post on social media. There is a selection bias present on the population willing to post about their SCI and their recovery process. Additional demographic data such as the age of the users on Instagram and Twitter were unknown, also limiting the scope of this study.

CONCLUSION

Thematic social media analysis provides enhanced insight into patient experiences with SCI. Patients most often shared images of their wheelchairs and spread positivity through Instagram and Twitter. Many patients also used social media to raise awareness of environmental hazards that can cause SCI. Social media platforms facilitate the spread of positivity and provide additional avenues of support for patients to share their experiences involving SCI. To this end, healthcare providers and educators may consider utilizing these outlets to provide patients with accurate and relevant information regarding SCI.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

REFERENCES

1. Agarwal N, Hansberry DR, Singh PL, Heary RF, Goldstein IM. Quality assessment of spinal cord injury patient education resources. Spine (Phila Pa 1976) 2014;39:E701-4.
2. Huang G, Fang CH, Agarwal N, Bhagat N, Eloy JA, Langer PD. Assessment of online patient education materials from major ophthalmologic associations. JAMA Ophthalmol 2015;133:449-54.

3. Shlobin NA, Hoffman SC, Clark JR, Hopkins BS, Kesavabhotla K, Dahdaleh NS. Social media in neurosurgery: A systematic review. World Neurosurg 2021;149:38-50.
4. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract 2013;14:15-23.
5. Agarwal N, Hansberry DR, Sabourin V, Tomei KL, Prestigiacomo CJ. A comparative analysis of the quality of patient education materials from medical specialties. JAMA Intern Med 2013;173:1257-9.
6. Elaheebocus SM, Weal M, Morrison L, Yardley L. Peer-based social media features in behavior change interventions: Systematic review. J Med Internet Res 2018;20:e20.
7. Royant-Parola S, Londe V, Tréhout S, Hartley S. The use of social media modifies teenagers' sleep-related behavior. Encephale 2018;44:321-8.
8. Prabhu AV, Gupta R, Kim C, Kashkoush A, Hansberry DR, Agarwal N, *et al.* Patient education materials in dermatology: Addressing the health literacy needs of patients. JAMA Dermatol 2016;152:946-7.
9. Wakefield MA, Loken B, Hornik RC. Use of mass media campaigns to change health behaviour. Lancet 2010;376:1261-71.
10. Widmer RJ, Arce MK, Aase LA, Timimi FK. Social media platforms and heart failure. J Card Fail 2017;23:809-12.
11. Cabrera-Maqueda JM, Minhas JS. New horizons for stroke medicine: Understanding the value of social media. Stroke 2018;49:e25-7.
12. Agarwal N, Rahman A, Jacobs R, Taylor T, Muthiah N, Alan N, *et al.* Patient perception of scoliosis correction surgery on instagram. Neurosurg Focus 2021;51:E6.
13. Gajjar AA, Jain A, Le AH, Salem MM, Jankowitz BT, Burkhardt JK. Cerebral Cavernous Malformations Patient Perception Analysis via Social Media [published online ahead of print, 2023 May 23]. J Neurol Surg A Cent Eur Neurosurg 2023;10.1055/a-1994-9435. doi:10.1055/a-1994-9435.
14. Gajjar AA, Salem MM, Hou NY, Davis RM, Le AH, Jankowitz BT, *et al.* What matters most to cerebral aneurysms patients: A digital analysis of 1127 social media posts [published online ahead of print, 2023 Apr 12]. Interv Neuroradiol. 2023;15910199231167914. doi:10.1177/15910199231167914.
15. Elkarim GA, Alotaibi NM, Samuel N, Wang S, Ibrahim GM, Fallah A, *et al.* Social media networking in pediatric hydrocephalus: A point-prevalence analysis of utilization. J Neurosurg Pediatr 2017;20:119-24.
16. Jacobs R, Prabhu AV, Monaco EA, Tonetti D, Agarwal N. Patient perception of gamma knife stereotactic radiosurgery through twitter and instagram. Interdiscip Neurosurg 2018;13:138-40.
17. Fernández-Luque L, Bau T. Health and social media: Perfect storm of information. Healthc Inform Res 2015;21:67-73.
18. Kim AE, Hansen HM, Murphy J, Richards AK, Duke J, Allen JA. Methodological considerations in analyzing twitter data. J Natl Cancer Inst Monogr 2013;2013:140-6.
19. Neethu MS, Rajasree R. Sentiment analysis in twitter using machine learning techniques. In: 2013 Fourth International Conference on Computing, Communications and Networking Technologies (ICCCNT); 2013. p. 1-5.
20. Seebach CL, Kirkhart M, Lating JM, Wegener ST, Song Y, Riley LH 3rd, *et al.* Examining the role of positive and negative affect in recovery from spine surgery. Pain 2012;153:518-25.
21. Lyford-Pike S, Nellis JC. Perceptions of patients with facial paralysis: Predicting social implications and setting goals. Facial Plast Surg Clin North Am 2021;29:369-74.
22. Fergie G, Hunt K, Hilton S. Social media as a space for support: Young adults' perspectives on producing and consuming user-generated content about diabetes and mental health. Soc Sci Med 2016;170:46-54.
23. Hammond FM, Barrett R, Dijkers MP, Zanca JM, Horn SD, Smout RJ, *et al.* Group therapy use and its impact on the outcomes of inpatient rehabilitation following traumatic brain injury: Data from TBI-PBE project. Arch Phys Med Rehabil 2015;96:S282-92.e5.
24. Wang Y, McKee M, Torbica A, Stuckler D. Systematic literature review on the spread of health-related misinformation on social media. Soc Sci Med 2019;240:112552.
25. Jenkins MC, Moreno MA. Vaccination discussion among parents on social media: A content analysis of comments on parenting blogs. J Health Commun 2020;25:232-42.
26. Wilson SL, Wiysonge C. Social media and vaccine hesitancy. BMJ Glob Health 2020;5:e004206.