

Use of Social Media in Stroke: A Systematic Review

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Abstract

Background: Stroke is a leading cause of death and disability globally. Over the last decade, digital health and related technology has emerged as a useful adjunct in the management of persons with stroke, particularly with the development of a large number of mobile phone applications dedicated to various aspects of stroke. However, whether social media can provide similar key support in stroke is an intriguing question. In this systematic review, we aimed to the scope and limits of social media platforms in care and research pertinent to persons with stroke. **Methods:** PubMed database was searched using Medical Subject Headings terms and exploded keywords. The search retrieved 556 abstracts, which were screened by two reviewers. Of these, 14 studies met the review inclusion criteria. Given the small number of studies and heterogeneity of outcomes, quantitative analysis was not possible. The review was registered on PROSPERO (CRD42022324384). **Results:** The social media platforms employed by the included studies comprised YouTube (n = 5), Twitter (n = 5), Facebook (n = 2), both Twitter and Facebook (n = 1), and WhatsApp (n = 1). Four assessed quality and accuracy of videos on YouTube available for stroke patients and caregivers. Three used social media to research link between role of gender and stroke descriptors on social media platforms, and one studied Twitter-derived racial/ethnic perceptual construction on the occurrence of cardiovascular disease. Three studies described use of social media by stroke survivors, in post-stroke care and engagement. 11 studies were assessed to be of “fair” quality and three were assessed to be of “poor” quality. **Conclusions:** Limited preliminary data of low quality indicates that social media is used by persons with stroke and their caregivers, and may be harnessed as a tool of education and research. Future studies must address the current lack of high-quality evidence for the use of social media in stroke care.

Keywords: Altmetrics, social media, stroke, Twitter, YouTube

INTRODUCTION

Social network or social media platforms, which provide the ability and the means to create, publish and disseminate information via the Internet, are ubiquitous. By definition, these platforms enable users to generate content, provide high-level interaction with other users, and permit convenient integration with other sites for wider outreach. Some popular platforms include Twitter, YouTube, Facebook, Instagram, and WhatsApp messenger. The contemporaneous and advancing importance of social media platforms in healthcare is far-reaching.^[1] This is also evidenced by the fact that the American Academy of Neurology has engendered a position statement on the ethical use of social media in healthcare.^[2]

Stroke is a leading cause of death and disability globally.^[3] New paradigms continue to be sought for optimizing stroke-related healthcare. The characteristics of omnipresence and high popularity, along with an interactive format, enable social media platforms to potentially serve as powerful tools for awareness, engagement, education, and recruitment of persons with stroke and their caregivers, as well as stroke healthcare professionals and trainees.^[4] Over the last decade, digital health and related technology has emerged as a useful adjunct in the management of persons with stroke, particularly with the development of a large number of mobile phone applications dedicated to detection of atrial fibrillation, drug adherence, management of hypertension, and stroke rehabilitation.^[5-7]

However, whether social media platforms can provide similar key support in stroke, both in terms of stroke care and stroke research, remains an intriguing question.

In this systematic review, we aimed to assess the scope and limits of social media platforms in care and research pertinent to persons with stroke.

METHODS

We conducted a systematic review to assess how social media platforms have been used in various aspects of care for persons with stroke. Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) guidelines were used for this review. The review was registered on PROSPERO (CRD42022324384).

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Search strategy

PubMed database was searched on April 9, 2022, using Medical Subject Headings terms and keywords. The search strategy is outlined in Table 1.

Inclusion and exclusion criteria

Titles and abstracts of articles retrieved using the above search strategy were screened. Articles published in English language alone were included. Studies were included if they (1) described the use of social media platforms, defined as “platforms that provide the ability and the tools to create and publish information accessed via the INTERNET” and (2) were focused on stroke-related information, persons with stroke or caregivers of persons with stroke. We excluded studies which were not in English, dealt with other medical disorders, and described the use of mobile applications, rather than social media platforms.

Data extraction

After screening articles and obtaining those studies which met the eligibility criteria outlined above, we extracted the following information: First author, year of publication, title of the study, journal of publication, DOI, study design, study location, single/multiple centers, number of participants, type of participants (persons with stroke/caregivers/lay population), age of participants, objectives, results, and limitations.

Quality assessment

Quality assessment was conducted using the National Heart, Lung and Blood Institute Assessment tool.^[8] Quality assessment was conducted individually by two reviewers (DG, AA). Any conflicts were resolved in concert with the third reviewer (VVY).

RESULTS

Figure 1 illustrates the PRISMA flow diagram of screening and inclusion of studies.

The initial search retrieved 556 results, which were screened by title and abstracts by two reviewers (DG, AA). After removal

of duplicates, the full-text of 24 studies was accessed. Of these, 14 studies met the review eligibility criteria. Any conflict between reviewers was resolved in concert with the third reviewer (VVY). The reported agreement after first pass between the two reviewers (DG, AA) was 97%. The kappa value was 0.71. 13 studies required advice from the third reviewer (VVY).

The key characteristics of these studies are presented in Table 2. Given the small number of studies and heterogeneity of outcomes, quantitative analysis was not possible. The social media platforms employed by the included studies comprised YouTube (n = 5), Twitter (n = 5), Facebook (n = 2), both Twitter and Facebook (n = 1), and WhatsApp (n = 1).

YouTube content

As YouTube is predominantly a video content based platform, four studies assessed the accuracy and content of videos available on YouTube on stroke information, information for caregivers of persons with stroke, and the utility of repetitive transcranial magnetic stimulation for stroke. A total of 349 videos were analyzed in these four studies.^[9,16,19,21]

In two of these studies, rating instruments were used for analysis of quality of video content, including DISCERN, Journal of American Medical Association (JAMA) Benchmark criteria, and Global Quality score.^[19,21] Based on these instruments, most videos were considered to be of intermediate quality, and with suboptimal content.

One study assessed the content of 246 stroke vlogs on YouTube made by 15 stroke survivors.^[12] Various uses of stroke vlogging were described in the vlogger’s own words in the study, and included self-tracking of progress, as a journal, and enabled connection with other users online.

Twitter content

Twitter was used for diverse purposes. A total of 44,29,704 tweets were analyzed among six studies. One study broadly analyzed the use of the “#stroke” hashtag on Twitter, using Symplur Signals which is a platform to conduct social media content analysis. An increase in the usage of the

Table 1: Search strategy (PubMed) used for the review

Search number	Query	Sort by	Filters	Search Details	Results
9	#6 AND #8			(“Stroke”[MeSH Terms] OR “Stroke”[Text Word] OR “cerebrovascular acciden*”[Text Word]) AND (“Social Media”[MeSH Terms] OR “Mobile Applications”[MeSH Terms] OR “Social Media”[Text Word] OR “Twitter”[Text Word] OR “Facebook”[Text Word] OR “Instagram”[Text Word] OR “Whatsapp”[Text Word] OR “mobile application*”[Text Word] OR “mobile app*”[Text Word] OR “mobile technolog*”[Text Word] OR “smartphone”[Text Word])	556
8	“Social Media”[Mesh] OR “Mobile Applications” [Mesh] OR “social media”[tw] OR Twitter[tw] OR Facebook[tw] OR Instagram[tw] OR Whatsapp[tw] OR “mobile application*”[tw] OR “mobile app*” [tw] OR “mobile technolog*”[tw] OR smartphone [tw]			“Social Media”[MeSH Terms] OR “Mobile Applications”[MeSH Terms] OR “Social Media”[Text Word] OR “Twitter”[Text Word] OR “Facebook”[Text Word] OR “Instagram”[Text Word] OR “Whatsapp”[Text Word] OR “mobile application*”[Text Word] OR “mobile app*”[Text Word] OR “mobile technolog*”[Text Word] OR “smartphone”[Text Word]	56,423
6	“Stroke”[Mesh] OR stroke[tw] OR “cerebrovascular acciden*” [tw]			“Stroke”[MeSH Terms] OR “Stroke”[Text Word] OR “cerebrovascular acciden*”[Text Word]	3,65,927

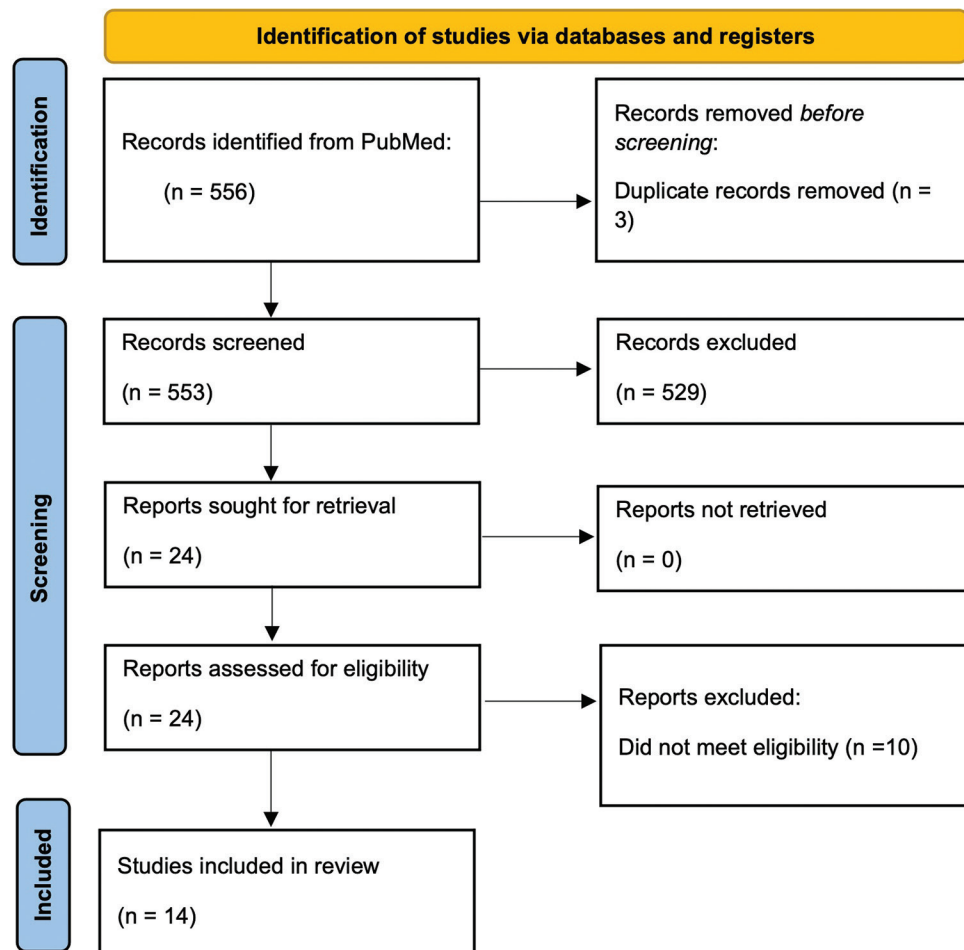


Figure 1: PRISMA flow diagram of studies included in review

hashtag was observed from 2012 to 2018, and the hashtag was attached to tweets dealing with stroke prevention, cardiovascular health, atrial fibrillation, etc.^[11] The top used hashtags related to stroke on Twitter included “#stroke,” “#WorldStrokeDay,” “#StrokeMonth,” “StrokeRecovery,” and “SignsAgainstStroke.”

Two studies analyzed gender-related differences in stroke.^[10,14] One study assessed gender-based differences in emotional content of tweets by stroke survivors. “Positive” emotional content was higher in tweets posted by women stroke survivors, whereas “negative” emotional content was higher among men.^[14] In another study, tweets tagged with “#MoreMoments” were analyzed. The #MoreMoments campaign was a rebranding campaign by the Heart and Stroke Foundation of Canada.^[10] This study focused on gendered portrayal of stroke-related health specific to women, and discussed several problematic stereotyped discourses portraying women stroke survivors. Another study examined the association between sentiments toward racial and ethnic minorities and prevalence of cardiovascular diseases.^[17] Prevalence of positive and negative emotions were derived from Twitter and merged with cardiovascular diseases outcomes from the 2017 Behavioral Risk Factor

Surveillance System. Thirty million tweets were collected between 2015 and 2018. Persons who lived in states that expressed negative sentiments toward racial/ethnic minorities had 11% higher prevalence of hypertension, 15% higher prevalence of diabetes, 14% higher prevalence of obesity, 30% higher prevalence of stroke, 14% higher prevalence of myocardial infarction, 9% coronary heart disease, and 16% higher prevalence of any cardiovascular disease outcomes. Better outcomes were observed in states where individuals expressed positive emotions.

Bias toward tweeting more positive outcomes in stroke thrombectomy by neurointerventionalists was observed by a study, which compared the results as indicated on Twitter versus those observed in the HERMES trial.^[13] Tweeted cases had significantly higher rates of post-intervention modified Thrombolysis in Cerebral Infarction scale scores of 2c/3 (94% versus 71%, $P < 0.0001$) and National Institute of Health Stroke Scale (NIHSS) scores less than 3 (81% versus 21%, $P < 0.0001$) compared to HERMES. Tweeted cases had significantly lower complications, such as symptomatic intracranial hemorrhage (0% versus 4.4%, $P < 0.0001$), parenchymal hematoma (0% versus 5.1%, $P < 0.0001$), and mortality (0% versus 15.3%, $P < 0.0001$).

Table 2: Characteristics of studies included in the review

First author	Year	Study design	Social media platform	Objectives	Results
Gupta <i>et al.</i> ^[9]	2014	Analytical	YouTube	To investigate “accuracy” and “adequacy” of information on stroke provided by YouTube videos	Total 201 videos analyzed, using search terms “Stroke,” “Cerebrovascular accident,” “Brain attack,” “Transient ischemic attack” and “stroke survival” 9% discussed possibility of administering IV-rtPA 31% discussed risk factors of stroke and preventive measures 88% discussed the symptoms and signs of stroke. Videos sourced from physicians more informative
Gonsalves <i>et al.</i> ^[10]	2017	Analytical	Facebook	To explore the meanings of women’s cardiovascular disease constructed within the Canadian Heart and Stroke Foundation Facebook page	Posts from Heart and Stroke Foundation and public user comments surrounding the launch of the Heart and Stroke Foundation re-branding were analyzed between November 2016 to March 2017. Constructions of women on Facebook of “typical” women at risk and risk reduction were inappropriate as women most at risk were excluded through the use of consumerist, medicalized identities.
Bundy <i>et al.</i> ^[11]	2018	Analytical	Twitter	To analyze tweets related to the “#stroke” hashtag	6,21,653 tweets analyzed from 20 March 2012 to 31 January 2018. Increase observed over six years in the number of users, impressions, and tweets containing the #Stroke hashtag. Frequently discussed themes included stroke prevention, diabetes, and atrial fibrillation Advocate organizations, patients, and non-healthcare individuals most frequently used the #Stroke hashtag on Twitter.
Chen <i>et al.</i> ^[12]	2018	Analytical	YouTube	Analysis of stroke vlogs on YouTube made by persons with stroke	246 vlogs made by 15 stroke patients were analyzed, using search terms, “stroke diary,” “stroke recovery,” “stroke rehabilitation.” Vlogging helped stroke patients to self-journal Vlogging was done via narration and/or demonstration Vloggers used it vlogs for self-tracking progress It enable connection with other people online.
Dmytriw <i>et al.</i> ^[13]	2019	Observational review	Twitter	To study publication bias among tweeted thrombectomy cases, by comparing Twitter-reported outcomes of mechanical thrombectomy with outcomes in the Highly Effective Reperfusion Evaluated in Multiple Endovascular Stroke (HERMES) trial	115 tweets from 35 tweeters were assessed. Tweeted cases had a bias towards showcasing better outcomes compared to the HERMES trial. Higher post-intervention rate of modified Thrombolysis In Cerebral Infarction scale score of 2c/3 (94% vs 71%,; $P<0.0001$) of tweeted cases and rate of NIHSS score ≤ 2 (81% vs 21%,; $P<0.0001$). Tweeted cases had significantly lower rates of complications, including symptomatic intracerebral hemorrhage (0% vs 4.4%,; $P<0.0001$), PH 2 (0% vs 5.1%,; $P<0.0001$), and mortality (0% vs 15.3%,; $P<0.0001$).
Garcia-Rudolph <i>et al.</i> ^[14]	2019	Analytical	Twitter	Aimed to compare posts by gender of the stroke survivor for: 8 basic emotions (anger, fear, anticipation, surprise, joy, sadness, trust and disgust); determine the proportion of each emotion in the collection of tweets; extract the main topics in the collection of tweets; and assign happiness scores to tweets and topics (using a tool)	800,424 tweets by stroke survivors analyzed. Positive emotions significantly higher in women, negative emotions significantly higher in men. Happiness scores higher in women.
Lemke <i>et al.</i> ^[15]	2020	Descriptive	Facebook	The aim of this study was to describe the experience of information and communication technology and explore the barriers/motivators to its use among stroke survivors	Six stroke survivors were identified. All used some form of communication technology on a daily basis. Out of six users, two used it to share rehabilitation experiences and maintain social connection. Barriers to use were related to disability due to stroke and challenge in using devices, such as smartphones.

Contd...

Table 2: Contd...

First author	Year	Study design	Social media platform	Objectives	Results
Denham <i>et al.</i> ^[16]	2020	Descriptive	YouTube	To assess quantity, quality and content of YouTube videos pertaining to caregivers of stroke survivors	Videos analyzed=26 291 unmet needs expressed by caregivers; an average of 11.2 unmet needs per video. Most common was impact on daily activities.
Huang <i>et al.</i> ^[17]	2020	Analytical	Twitter	To assess the impact of Twitter-derived sentiments towards racial/ethnic minorities on cardiovascular diseases assessed from the 2017 Behavioral Risk Factor Surveillance System	30 million race-related tweets analyzed. Individuals who resided in regions with higher negative sentiments towards racial/ethnic minorities had higher prevalence of hypertension, diabetes, obesity, myocardial infarction, coronary heart disease, stroke and any adverse cardiovascular outcome. Positive sentiment was associated with lower prevalence of adverse cardiovascular outcome.
Mansour <i>et al.</i> ^[18]	2020	Analytical	WhatsApp	To compare automated ASPECTS versus ASPECTS interpreted from CT images sent on WhatsApp to determine thrombolysis	Automated ASPECTS performed equal to expert readings by neuroradiologists, which was degraded on WhatsApp-delivered images
Szmuda <i>et al.</i> ^[19]	2020	Descriptive	YouTube	To assess quality and engagement of stroke-related videos on YouTube	101 videos analyzed. Most videos of fair quality, were uploaded by hospitals, mentioned stroke, had doctors speaking and contained diagrams
Gonsalves <i>et al.</i> ^[20]	2020	Analytical	Twitter	To assess impact of #MoreMoments campaign among Canadian Twitter users, in terms of women's health	Two primary discourses were identified by analyzing Twitter data between September 2017 and November 2012- tragedy and loss/life and health. Two identity positions were also identified- visionary leader and successful survivors
Askin <i>et al.</i> ^[21]	2022	Descriptive	YouTube	To assess the quality and accuracy of YouTube videos on the use of repetitive transcranial magnetic stimulation in patients with stroke	21 videos analyzed. Most videos were of intermediate quality and had partially sufficient data. High-quality videos had higher viewing, more dislikes, longer duration and scored better on accuracy
Lobo <i>et al.</i> ^[22]	2022	Descriptive	Facebook and Twitter	To determine level of content and interaction of caregivers of persons with stroke on social media communities	Rise in use of social media by caregivers of persons with stroke. Charitable and government based social communities were most popular.

Facebook content

Among the two studies that employed Facebook as a social media platform, one assessed the portrayal of women from the Heart and Stroke Foundation Facebook posts and public user comments surrounding the launch of the Heart and Stroke Foundation re-branding.^[20] The study deconstructed the portrayal of women surrounding this rebranding and found it restrictive and not inclusive of minorities, who are also at risk for stroke. The second study analyzed the posts of six stroke survivors who used Facebook,^[15] to identify barriers and motivators. Motivators identified from these posts included connection and reintegration with other users, rehabilitation, adoption of technology, and provision of safety. Barriers included physical aspects (sensory, motor, vision, and hearing impairment), and difficulty in using devices.

Another study used data from both Twitter and Facebook to analyze engagement of caregivers of persons with stroke with these platforms.^[22] An increasing engagement was noted, with most popular content being related to prevention of stroke, recognition of symptoms and signs of stroke, and caregiver self-care-related video content.

WhatsApp use

A single study used WhatsApp in stroke care in a reliability and cost-effectiveness analysis, to compare automated Alberta Stroke Programme Early CT Score (ASPECTS) versus ASPECTS determined over images sent on WhatsApp to determine eligibility for thrombolysis in 122 patients who had undergone successful intravenous thrombolysis.^[18] Automated ASPECTS by RAPID software performed equal to expert readings by neuroradiologists, which was degraded on WhatsApp-delivered images.

Quality assessment

In terms of quality assessment, 11 studies were assessed to be of "fair" quality and three were assessed to be of "poor" quality [Table 3].

DISCUSSION

This systematic review addressed the use of social media pertaining to stroke care across all social media platforms. Most studies included in the review were descriptive and of low to intermediate quality. High heterogeneity and lack of statistical information precluded statistical analysis.

Table 3: Quality assessment of studies included in the review using NIH Quality Assessment tool

First author	Quality Assessment
Gupta <i>et al.</i> ^[9]	Fair
Bundy <i>et al.</i> ^[11]	Fair
Chen <i>et al.</i> ^[12]	Poor
Dmytriw <i>et al.</i> ^[13]	Fair
Garcia-Rudolph <i>et al.</i> ^[14]	Fair
Gonsalves <i>et al.</i> 2017 ^[10]	Fair
Lemke <i>et al.</i> ^[15]	Poor
Denham <i>et al.</i> ^[16]	Poor
Huang <i>et al.</i> ^[17]	Fair
Mansour <i>et al.</i> ^[18]	Fair
Szmuda <i>et al.</i> ^[19]	Fair
Askin <i>et al.</i> ^[21]	Fair
Gonsalves <i>et al.</i> 2020 ^[20]	Fair
Lobo <i>et al.</i> ^[22]	Fair

Social media platforms have the potential to be harnessed for neurological conditions, by varying strata of stakeholders, including physicians, patients, caregivers, rehabilitation experts, support groups and advocacy programs, and researchers.^[23,24] Depending on the goal, the platform may be chosen. Where YouTube is dominantly video-based, Facebook offers diverse options for content sharing, and Twitter is chiefly a microblogging site with avenues for sharing short videos, images, and polls. We observed that platforms such as YouTube and Facebook were mainly used for longer, video-based content. Content mostly included informative videos pertaining to causes and pathophysiology of stroke, recognition of stroke, preventive measures, treatment including reperfusion therapies, and rehabilitation. Twitter was used in a multidimensional manner, including analysis of how the platform itself was used in stroke-related tweets, and analysis of gender and race-stratified stroke content. WhatsApp was essentially used for communication of radiological (CT-based) information in one study.

The review also provided an insight into the type of users utilizing social media platforms for stroke-related content. Physicians engaged in creation and dissemination of content related to stroke information.^[9] However, advocate organizations, patients, caregivers of patients with stroke, and non-healthcare individuals also utilized these platforms. An interesting observation was the manner in which stroke survivors engaged with social media. Use of vlogging was associated with a form of a self-journaling process, marking progress in stroke recovery, and also promoted social interaction with the community. Caregivers of stroke patients also engaged with social media to express challenges and needs while caring for persons with stroke. Social media platforms may have the potential to be used as a support structure, enabling the patient and the caregiver to gradually re-engage with society. Previously, participation in a Twitter social media support group was demonstrated to increase breast cancer patients' perceived knowledge and decrease their anxiety.^[25]

Another interesting observation was the manner in which social media platforms were used for research. One category included assessment of accuracy and quality of content posted, using varied instruments for quality assessment. This is an important research format, as a plethora of inaccurate and suboptimal information may be available on these platforms. Importantly, the studies targeting quality assessment observed that most content was suboptimal and of low quality. This analysis underlines a need to improve social media content by concerned stakeholders, and also as a message to those seeking information from these platforms to seek a reliable source. This may further help in decreasing misinformation and non-scientific community practices. Another format was targeted at racial and gender paradigms in terms of stroke information available.

It is apparent that the research potential of social media platforms is substantial, and may be harnessed in a directed manner. Moreover, several stroke and health organizations actively engage in social media, especially during "World Stroke Day" campaigns and meetings. The impact of such activities has not been studied so far and constitutes an interesting area for potential future research. Another future prospect for research could be how rehabilitation-based content improved long-term outcomes among persons with stroke. Apart from research, social media platforms have also been used to enhance the citation scores of journals. There is some evidence that tweeted stroke articles may improve the citation rates of the article.^[26] This is an area of future research and deserves further exploration.

A concern with social media use, which may deter clinicians, are ethical concerns regarding privacy, breach of confidentiality etc.^[27] In this regard, it is useful to go by established guidelines on this theme, such as the position statement by the American Academy of Neurology, which recommend certain caveats while using social media in healthcare.^[2] Within such frames of reference, social media can be used ethically, and with a personal touch. This was evident during the COVID-19 pandemic, during which social media played a vital role in dissemination of healthcare information, patient support and advocacy, and stroke rehabilitation when in-person hospital visits were not feasible.

This is the first systematic review on the use of social media in stroke care. Despite heterogeneity of the studies included, it is obvious that social media platforms may be accruing a place in stroke care, especially education. This needs recognition and a paradigm shift, in order to incorporate its strengths in the care of stroke patients. Social media platforms may provide support to patients and their caregivers by enabling communication and connectivity with not just the stroke community, but the community at large.

A limitation of our systematic review was that we restricted our search to PubMed and to articles in English language, which may have decreased the search yield. Most of the studies included in the review were of intermediate to low quality,

indicating a need for more systematic studies on this topic. The included studies had a diverse range of objectives, ranging from content quality assessment to gender-stratified portrayal of at-risk persons. Most of the studies were descriptive.

CONCLUSIONS

In this systematic review, limited preliminary data of low quality indicates that social media is used by persons with stroke and their caregivers, and may be harnessed as a tool of education and research. Future studies must address the current lack of high-quality evidence for the use of social media in stroke care. There is potential that rigorous studies, especially mixed-methods ones, may demonstrate robust benefit of social media in stroke care.

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Conflicts of interest

There are no conflicts of interest.

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