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Utilization of social media communities for caregiver information support in stroke recovery: An analysis of content and interactions

Elton H. Lobo1,2*, Tara Johnson2,3, Anne Frølich2,4, Finn Kensing5, Lene J. Rasmussen6,7, Sarah M. Hosking3, Amy T. Page6,8, Patricia M. Livingston9, Sheikh Mohammed Shariful Islam10, John Grundy11, Mohamed Abdelrazek1

1 School of Information Technology, Deakin University, Geelong, VIC, Australia, 2 Department of Public Health, University of Copenhagen, Copenhagen, Denmark, 3 Faculty of Health, Deakin University, Geelong, VIC, Australia, 4 Innovation and Research Centre for Multimorbidity, Slagelse Hospital, Slagelse, Region Zealand, Denmark, 5 Department of Computer Science, University of Copenhagen, Copenhagen, Denmark, 6 Department of Cellular and Molecular Medicine, University of Copenhagen, Copenhagen, Denmark, 7 Center for Healthy Aging, University of Copenhagen, Copenhagen, Denmark, 8 Pharmacy Department, Alfred Health, Melbourne, VIC, Australia, 9 Centre for Medicine Use and Safety, Monash University, Melbourne, VIC, Australia, 10 Institute for Physical Activity and Nutrition (IPAN), Deakin University, Geelong, Australia, 11 Faculty of Information Technology, Monash University, Melbourne, VIC, Australia

* elobo@deakin.edu.au

Abstract

Background
Caregivers often use the internet to access information related to stroke care to improve preparedness, thereby reducing uncertainty and enhancing the quality of care.

Method
Social media communities used by caregivers of people affected by stroke were identified using popular keywords searched for using Google. Communities were filtered based on their ability to provide support to caregivers. Data from the included communities were extracted and analysed to determine the content and level of interaction.

Results
There was a significant rise in the use of social media by caregivers of people affected by stroke. The most popular social media communities were charitable and governmental organizations with the highest user interaction—this was for topics related to stroke prevention, signs and symptoms, and caregiver self-care delivered through video-based resources.

Conclusion
Findings show the ability of social media to support stroke caregiver needs and practices that should be considered to increase their interaction and support.
Introduction

Stroke is the leading cause of dependency and disability worldwide [1], resulting in family caregivers providing substantial care to people with stroke [2]. Family caregivers, generally known as informal caregivers [3] are responsible for assisting with daily activities, including mobilization, toileting, bathing, transportation, and navigating the healthcare system [4]. Despite their key role in care, many caregivers feel unprepared [5], leading to psychological, social, physical, and financial strains [6].

Family (or informal) caregivers have varying needs for education and support during the stroke care trajectory [7]. Yet, to date, standard clinical practice guidelines have not considered programs to ensure caregiver education and support [8]. The most common form of information received by caregivers at the hospital included booklets and pamphlets, which caregivers have reported to be very basic or out of date [9]. Caregivers may attempt to source alternate information sources to improve preparedness to reduce uncertainty and enhance recovery [10].

In the past, caregivers have predominately used the internet (or online) sources to access information related to stroke care [11–13]. The internet is changing how health information is accessed [14], thereby influencing individuals’ knowledge, attitudes, and beliefs towards a specific health behaviour [15]. As a result, the trend towards internet use for health information purposes has been significantly rising [16]. A cross-sectional study by Naqvi, Montiel [17] reported over 96.8% of caregivers having access to the internet to generally browse web pages (84.6%) and access their emails (89.4%).

Today, in the era of Web 2.0, social media such as Facebook and Twitter has changed the landscape in healthcare information delivery [16, 18]. Social media can empower people to adopt a healthy lifestyle and help improve health management and decision-making processes [19]. Furthermore, social media creates an unprecedented opportunity to enhance the quality of care by mobilizing many social media users and enabling the users to generate a large amount of content [19]. The content generated is in the form of user health care knowledge, experiences, symptoms, health care products, doctors, and medicines in easily accessible formats, such as images, text, and videos [18].

Social media use has provided organizations and individuals with an openly accessible platform to engage actively and participate in healthcare [20]. However, very little is known about its potential benefit to caregiving and its ability to interact with the caregiver actively. This study presents three key aims. This study aims to:

1. Investigate frequency of searches for stroke-related terms over time using Google Insights and Google Trends.
2. Identify the information content available to caregivers on popular information-support-based social media platforms (i.e., Facebook and Twitter) to support their needs and activities.
3. Understand the levels of interaction for the different social media posts identified through the likes, comments, and shares by content types (i.e., image, video, link, or text).

Method

Study design

Our study consisted of a mixed-method approach to answer identified research aims. The mixed methods approach is a type of research where a researcher or group of researchers combine elements of quantitative and qualitative methods (e.g. use of quantitative and qualitative
viewpoints for data collection, analysis and inference techniques) to provide a broad understanding of the research problem [21]. For example, to investigate the frequency of stroke terms, a quantitative analysis was conducted to determine the online activity of people interested in stroke recovery and care using tools such as Google Trends and Google Insights. Google Trends and Google Insights provide a platform for individuals to investigate its users’ search behaviour throughout time based on a relative cumulative search volume score from 0–100, which is the ratio of single search term volume to all possible searches. A qualitative analysis was used to analyse the information content using a thematic synthesis approach. Finally, the levels of interaction were identified through a quantitative statistical analysis of likes, comments, and shares based on the different content types.

Identifying relevant communities

The identification of relevant social media communities (or groups) in stroke recovery involved multiple steps. Initially, we identified the relevant search keywords used based on discussions with topic experts and electronic database searches. We tested the keywords on Google Insights and Google Trends to determine their relevance to individuals around the world in stroke recovery and care based on their searching behaviour. Finally, we performed individual searches on two popular social media platforms (i.e., Facebook and Twitter).

A search of social media platforms (i.e., Facebook and Twitter) was conducted from December 2020 to January 2021 and was limited to those available in the English language. Moreover, the search included only communities made public by the administrator (or did not require permissions to be accessed by the user).

Community selection

Initially, the researchers used a custom-built web form to manually extract information from all social media communities, including community names, descriptions, links, number of followers (or likes), and several posts, and store the data in a MySQL database. The communities identified were then filtered based on the inclusion and exclusion criteria described in Table 1.

Analysis the findings

The analysis process involved a multi-stage data extraction and management process using a custom-built python scraper consisting of all the community page links and outputs findings to a MySQL database. The data was then extracted as a Microsoft Excel file and coded independently using QSR NVivo 12 by two researchers based on a three-stage thematic synthesis approach, involving: ‘line by line’ coding of text, development of descriptive themes, and generation of analytical themes [22]. All posts unrelated to the caregiver and/or posts that did not provide information support (e.g., advertisements, event photos, news articles, research studies, etc.) were excluded from the study. Additionally, descriptive characteristics data from the communities (such as community name, origin, published date, and basic information) and interaction data (such as likes and comments) were charted by one researcher to answer the specific research aims.

Table 1. Inclusion and exclusion criteria used to filter social media communities.

| Inclusion Criteria | Exclusion Criteria |
|--------------------|--------------------|
| • Considers Caregivers of Stroke described through its description or content | • Does not include Caregivers of Stroke |
| • Provides Information regarding Stroke | • Blocks Users from Replying to Posts |
| • Supports User Interaction on Posts | |

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Collating and summarizing

Both qualitative and quantitative findings were collated and summarized to answer the research questions resulting in the descriptive numerical summary and thematic analysis. The predefined descriptive classification applied to the initial coding of the communities include:

a. **Community Demographics**
   - *Year Published*—to understand the growth in online communities over the past few decades.
   - *Community location*—to understand the target population
   - *Community affiliation*—to know if the content created is by people working in the stroke domain

b. **Community Purpose**—to understand the purpose of the community through the community description

c. **Information Support**—to understand the type of information provided to the caregiver in the post (i.e., disease, patient care management, self-care, etc.) and the method of delivery (i.e., text, image, video, or link) using a thematic analysis technique

d. **Community Interaction**
   - *Post purpose*—to understand the information type required by the user
   - *Likes, followers, reactions, and comments*—to understand user interaction based on the post purpose

Results

**Digital interest regarding stroke**

Overall, 94 keywords were identified from discussions with topic experts and electronic database searches. Of these 94 keywords, 15 keywords were based on stroke disease and its definitions, 25 keywords were related to the signs & symptoms of stroke, 37 keywords included different medications used in stroke and 17 keywords focused on aspects related to recovery & care.

Findings from the Google Trends and Google Insights searches demonstrated an apparent increase in the cumulative search volumes for the terms identified through discussions with topic experts and electronic database searches over the past ten years (Fig 1). The rise in the cumulative search volume was 12.4 between January 2011 and December 2020 identified by:

\[
a_{ij} = \frac{\sum_{i=1}^{10} k_i}{N_{ij}}
\]

Where \(a_{ij}\) is the average cumulative search volume for each topic \((j)\) each year \((i)\), \(k\) is the cumulative search volume acquired from Google Trends and Insights for all the keywords associated with the topic for year \(i\), \(N\) is the total number of keywords in the topic \((j)\) for year \(i\), \(i\) is the year ranging from 1 to 10 and \(j\) is the topic ranging from 1 to 4.

\[
Y_i = \frac{\sum_{j=1}^{4} a_{ij}}{4}
\]
where $y_i$ is the average cumulative search volume for all topics ($a_{ij}$) in year $i$ ranging from 1 to 10

$$A = Y_{10} - Y_1$$

where $A$ is the rise in the cumulative search volume between the Tenth ($Y_{10}$) and First ($Y_1$) Years (i.e. January 2011 and December 2020).

Topics including ‘stroke definition’ and ‘stroke recovery’ were the most commonly searched during the ten years. Issues such as ‘signs & symptoms of stroke’, and stroke medication have had a significant rise in searches during the past four years.

**Identification of relevant keywords.** Table 2 presents the ten most commonly searched terms identified by the online search (or usage) activity as extracted from Google Trends and Google Insights. The ten most frequently used keywords were selected based on their cumulative search volume over the past year.

**Table 2. Ten most commonly used keywords in stroke identified through Google Trends.**

| Keyword                                      | Cumulative Search Volume |
|----------------------------------------------|--------------------------|
| Stroke                                       | 85.3                     |
| Stroke Care                                   | 81.6                     |
| Stroke Recovery                               | 76.8                     |
| Apoplexy                                     | 76.3                     |
| Cerebrovascular Accident                      | 75.6                     |
| Stroke Unit                                  | 75.1                     |
| Traumatic Brain Injury                        | 74.5                     |
| Lacunar Infarct                              | 74.2                     |
| Stroke Medication                            | 73.6                     |
| Aphasia                                      | 73.1                     |

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Social media communities

The combined search strategies identified 352 social media communities using the keywords identified in Table 2, which were then screened for eligibility using the inclusion and exclusion criteria demonstrated in Table 1. Out of the 352 social media communities, 111 were excluded as they were not related to stroke patient caregivers, 23 were not accessible to the public, 17 were not associated with stroke, and 3 were not available in English. Overall, 198 social media communities were included in the study, as shown in Table 3.

Descriptive characteristics. Out of the 198 social media communities, 141 (71.2%) were available on Facebook and 57 (28.8%) were available on Twitter. These communities were created by individuals (n = 64; 32.3%), charitable or non-profit organizations (n = 61; 30.8%), community centres (n = 24; 12.1%), educational organizations (n = 20; 10.1%), medical centres (n = 13; 9.1%), small and medium sized organizations (n = 8; 4.0%) and governmental organizations (n = 3; 1.5%) identified based on administrator affiliations and community descriptions as illustrated in Fig 2. The most popular groups, identified by the number of followers, were charitable organizations and governmental organizations (Fig 3).

Across all social media platforms, Twitter was seen to have the highest average number of followers and posts (7093.6 followers and 4828.7 posts), followed by Facebook (4202.8 followers and 579.6 posts) as shown in Fig 4. The earliest identified pages were published in 2009 on both Twitter (n = 10; 5.1%) and Facebook (n = 5; 2.5%). Since 2009, both social media platforms have witnessed a variation in the number of new stroke communities for caregivers (Fig 5).

Community purpose. The analysis of the social media community description identified six prominent themes (Fig 6) detailed below:

a. Support: Support-based social media communities were the most common community type (n = 81; 40.9%); these are intended to provide users with tools to support and share caregiving responsibilities. Moreover, these communities allowed users to join either virtual or local groups to promote emotional and psychological support.

b. Awareness: Communities in this theme (n = 59; 29.8%) intend to make the caregiver more aware of the tools and resources available locally to support the patient during care. It also allowed the caregiver to understand the risk factors and signs of a stroke to prepare them during a secondary stroke event.

c. Education: The education theme (n = 34; 17.2%) consisted of communities that share online books and resources intended to educate the caregiver on stroke-related topics, factors associated with its occurrence, secondary prevention techniques, management, support guidelines, medication resources, and similar issues. This was generally delivered in the form of text and video-based resources.

d. Advertising: These communities (n = 14; 7.1%) generally focused on advertising recovery products to support caregivers during care and ongoing research conducted at local universities to develop better care practices to support caregivers and their patients.

e. Motivation: Motivation (n = 8; 4.0%) oriented communities generally delivered this by caregivers and patients through personal stories and practices during recovery. Social media communities motivated their users through inspirational quotes and success stories.

f. Fundraising: The fundraising communities (n = 2; 1.0%) were either delivered by charitable organizations to support caregivers and their patients or by individual caregivers struggling to support patients due to financial constraints. The fundraising in charitable organizations involved links to fundraising campaigns and campaign invites to events conducted locally.
Table 3. Social media communities included in the review.

| Facebook (n = 169) |
|---------------------|
| • Association for the Rehabilitation of the Brain Injured |
| • Stroke Recovery Foundation |
| • United Stroke Alliance |
| • American Stroke Association |
| • Stroke Association |
| • Stroke Foundation |
| • National Aphasia Association |
| • Aphasia Recovery Connection |
| • American Stroke Foundation |
| • Stroke Association NJ |
| • Stroke Association South West |
| • Stroke Survivors Foundation |
| • Aphasia Ireland |
| • Stroke Association East of England |
| • Aphasia Network |
| • Aphasia Nova Scotia |
| • Stroke Association London |
| • Stroke Family Awareness |
| • Bright Spot Pediatric Stroke |
| • American Aphasia Society |
| • EAST Stroke Awareness |
| • World Stroke Day Kenya 2017 |
| • Stroke SA Inc |
| • Supporting Aphasia Fellowship and Education Fellowship and Education |
| • Brain Injury Recovery Foundation |
| • Australian Aphasia Association |
| • Stroke Foundation of NZ |
| • Think Ahead Stroke |
| • Stroke Fighters |
| • Stroke Survivors Empowering Each Other (SSEEO) |
| • Singapore National Stroke Association |
| • BINA Stroke & Brain Injury Assistance |
| • Stroke Rehabilitation & Healing, Inc. |
| • Calgary Aphasia Centre |
| • Stroke Support of Texas |
| • Stroke Help Network |
| • Aphasia NSW |
| • The Scott Cooppersmith Stroke Awareness Foundation |
| • Brain injury & Stroke Foundation KENYA |
| • Friends of Aphasia |
| • Retreat & Refresh Stroke Camp |
| • Adler Aphasia Center |
| • Aphasia Center of California |
| • Living with Aphasia |
| • Talkback Association for Aphasia Inc |
| • Stroke Information Support Group |
| • Alberta Aphasia Camp |
| • Aphasia Centre of Ottawa |
| • Aphasia vzw |
| • Stroke Rehabilitation Ireland |
| • Stroke Caregivers |
| • Stroke Ownership & Recovery |
| • Midwest Stroke support group for survivors and caregivers |
| • Stroke,tbi,and their, caregivers |
| • The Other Stroke Talk for survivors, caregivers and anyone who wants to be |
| • Support for Caregivers of Stroke Patients |
| • Malaysian Stroke Rehabilitation |
| • Stroke & Neuro Intervention |
| • Aphasia SG |
| • UCAN Stroke Rehabilitation in Merseyside and Cheshire |
| • Stroke Support India |
| • AphasiaAccess |
| • Minnesota Brain Injury Alliance/Minnesota Stroke Association |
| • Suncoast Aphasia Support Group |
| • Oceanside Stroke Recovery Society |
| • Orillia Stroke Survivor and Caregiver Support Group |
| • Delta Stroke Recovery Society• Pittsburgh Aphasia Community |
| • StrokeEd |
| • Aphasia Lab-USC |
| • BRAIN Lab: Brain Research for Aphasia and Intensive Neurorehabilitation Lab |
| • Aphasia CRE |
| • STROKE-The Road to Recovery |
| • World Stroke Campaign |
| • Stroke Special Interest Group |
| • University of Michigan Aphasia Program (UMAP) |
| • Stroke Rehabilitation Research |
| • Stroke and Cerebrovascular Accident Education |
| • Triangle Aphasia Project, Unlimited |
| • Aphasia Connections |
| • Priority Research Centre for Stroke and Brain Injury |
| • The Big Sky Aphasia Program |
| • Purdue University Aphasia Group |
| • Hazard & Surrounding Area Stroke Survivor & Caregiver Support Group |
| • Spot Stroke |
| • Kathi Naumann -Stroke Support & Survival Guide |
| • The Aphasia Cafe by Dr. Dawn McGuire |
| • Stroke Awareness |
| • Raising Stroke Awareness |
| • Stroke Awareness for Everyone |
| • Stroke Prevention |
| • Aphasia Awareness |
| • Stroke therapy tricks for stroke survivors |
| • Stroke Group |
| • Canadian Aphasia Association |
| • Aphasia Awareness |
| • Stroke |
| • Stroke Cure |
| • Stroke Rehabilitation Awareness |
| • Stroke Caregiver |
| • Rehabilitation for Stroke |
| • TBI Hope & Inspiration |
| • The Brain Fairy—Living with Brain Injury |
| • Aphasia Friendly Resources |
| • Stronger After Stroke Blog |
| • Stroke information |
| • Stroke Support |
| • Recovering from Brain Injury |
| • Stroke Recovery Tips |
| • Stroke Recovery: Stories from Patients, Doctors, Families and Caregivers |
| • Stroke |
| • GRASP—Geriatric Relearning After Stroke-Induced Paralysis |
| • Caregiving for Stroke Survivors |
| • Teamconnor fundraising and brain injury/stroke awareness |
| • Stroke Survivor Caregivers |
| • Surviving A Stroke |
| • Stroke Survivors |
| • Caregiving After Stroke |
| • Stroke Awareness |
| • Stroke Recovery KW |
| • Stroke Warriors |
| • Stroke Survivor |
| • Stroke Rehabilitation |
| • TBI & Stroke Victims |
| • Stroke Recovery Solutions |

(Continued)
### Table 3. (Continued)

| • Stroke Survivors | • Aphasia will not be silent / Stroke Survivor Coach |
|--------------------|--------------------------------------------------|
| • Certified Stroke Rehabilitation Specialist (CSRS) | • Stroke UK |
| • Greenhills Stroke Rehabilitation Center Ghana | • TBI TED—Brain Injury and CTE Support |
| • Stroke Rehabilitation | • Group Stroke |
| • Montgomery County Stroke Survivor, Caregiver, and Aphasia Support Group | • Stroke Therapy |
| • Stroke & Neuro Rehabilitation for Shropshire | • Stroke Rehab |
| • Stroke Rehabilitation Centre | • NXT Senior & Caregiver Resources Inc. |
| • UNT Aphasia Support Group | • Stroke Awareness |

### Twitter (n = 29)

| • American_Stroke | • CDC Division for Heart Disease & Stroke Prevention |
| • Stroke Association | • The Aphasia Center |
| • Sign Against Stroke | • Stroke Survivors Foundation |
| • heartandstroke | • Adler Aphasia Center |
| • Aphasia Hope | • Stroke Foundation NZ |
| • Stroke Foundation | • Caregiver’s Cargiver |
| • Croi- Heart & Stroke | • StrokeRehab Plymouth |
| • American Heart News | • Stroke Recovery |
| • Better Conversations | • Dyscover |
| • davida godett | • East Lancs Stroke Assistance & Support |
| • Million Hearts | • Heart & Stroke NL |
| • Tactus Therapy | • femanagh Stroke Support Group—SOSS |
| • ARC AphasiaRecovery | • Reclaiming Ourselves |
| • HeartFoundationSA | • StrokeSupport |
| • Northern Ireland Chest Heart & Stroke | • Stroke Recovery Association MB |
| • Stroke Association Yorkshire | • Stroke Support Group |
| • BAS | • act F.A.S.T |
| • INS | • Stroke Rehab |
| • Prasanna Tadi M.D TEDx Speaker, Stroke Doc, Blogge | • City Access—Resources for Aphasia |
| • Natl Aphasia Assoc | • Stroke Recovery Association NSW |
| • Heart&Stroke NB | • StrokeSmart Magazine |
| • Coeur+AVC NB | • IschemicStroke |
| • Aphasia Institute | • BIA-MA |
| • LivingWithAphasia | • Stroke Caregivers |
| • Heart & Stroke Science | • Signs Of Stroke |
| • Treat The Stroke | • Stroke Support |
| • Aphasia Nova Scotia | • BIAF |
| • Stroke Connection | • BrainLine.org |
| • Connect | |
| • BIAAZ | |

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**Community role in information support.** While community information extracted demonstrated a total of 356,960 posts, only 173,508 posts could be extracted using a python-based scraper tool. Of these 173,508 posts, the following posts were excluded: 6369 (related to motivating the individual), 16960 (focused on advertising local events, products, and research), 45726 (consisted of news articles regarding stroke), 25939 (included photos or videos of local community activities or events), 28089 (focused on creating awareness for the prevention of the disease), 4176 (looked to fundraise to support an individual or organization), 24672 (did not provide information support), and 14070 (did not offer general stroke information or focus on caregivers). The remaining 7507 posts provided the caregiver with information to support them during the care trajectory, and hence were further analysed and classified as summarized in Table 4.

**Analysis of interaction.** Table 5 summarizes user interaction based on the topics identified in Table 4 and content type (i.e., text, image, video, and link), identified through the average of likes, shares, and comments. The data presented showed that the individual’s interaction with the post varied based on the topic and the content type. For example, the
target user group generally interacted with video-based content (i.e., Likes– 13.41, Comments– 8.79 and Shares– 8.53) followed by image (i.e., Likes– 12.35, Comments– 4.46 and Shares– 6.69), link (i.e., Likes– 6.99, Comments– 1.59 and Shares– 3.06) and text (i.e., Likes– 4.03, Comments– 1.68 and Shares– 2.58) based content as shown in Fig 7. While the most interacted topics based on content type has been illustrated in Fig 8 identified through the data summarized on Table 5.

**Discussion**

This study aims to highlight the information-seeking behaviour of people affected by stroke and the interaction of content created for caregivers on popular social media platforms (i.e., Facebook and Twitter). This study is significant for content creators of social media communities to identify appropriate topics to support stroke caregiving needs and promote caregiver...
interaction within the community, thereby ensuring caregiver education and preparedness when supporting the survivor.

Findings from our Google Insights show an increase in search trends for stroke-related topics over the past ten years. The growth has been predominately for topics related to the signs and symptoms and medications, with stroke definition and recovery being the most popular searches over the past ten years. This concurs with Tan and Goonawardene [23], which suggests an increase in users seeking health information online to ensure education and preparedness for the disease, thereby allowing them to make better healthcare decisions during recovery.

The increase in user access to internet resources for stroke was not limited to Google searches but also within popular social media platforms. The findings from the study show an increase in social media communities for caregivers post-2009 created by individuals with different affiliations. A majority of which are individuals and charitable organizations. However,
the most accessed social media communities were found to be affiliated with governmental and charitable organizations. This could be due to the trust factor associated with information provided by federal agencies and community organizations, as highlighted in the study by Dutta-Bergman [24], suggesting that the information provided by these individuals is based on expert-based literature and credible sources.

Nowadays, misinformation or lack of quality information is a growing problem [25]. Crocco, Villasis-Keever [26] in a systematic review highlighted the internet’s capacity to harm the health of the user to be equal to the good and useful information it provides in a relatively timely and inexpensive manner. For example, in one case the misinformation available on the internet contributed to emotional harm, while in another case lead to hepatorenal failure in an oncology patient who obtained misinformation regarding medication use over the internet [26]. To prevent healthcare issues and fears amongst the population, Cuan-Baltazar, Muñoz-Perez [25] suggests the need for governmental organizations to develop a strategy that teaches its residents to verify the quality of information they read. Moreover, Swire-Thompson and Lazer [27] describes the need for internet users to collaborate with physicians to ensure they are more actively involved in the decision-making processes, and they are aware of methods to separate health myths from facts that the internet provides.

While social media communities do not exclusively focus on the caregiver, it was possible to identify the relevant communities and posts through their content, which were classified in this study based on their relevance. The classification involved two categories; (i) General, i.e., posts that enabled the caregiver to understand the disease, causes, types, diagnosis methods, risk factors, prevention, consequences, and treatment, and (ii) Caregiver, i.e., information to enable the caregiver to communicate with relevant stakeholders, understand the impact of caregiving, understand the roles and decision making practices, understand means to support and care for the patient and to ensure self-care. Overall, findings from these comments highlight a positive interaction in terms of likes, shares, and comments, especially for video-based content and topics related to prevention, self-care, signs and symptoms, caregiver impact, and patient support and care.

Video-based education resources have numerous advantages to promote positive health decisions and lifestyle changes [28]. The benefits include: (i) cost-effectiveness, (ii) removal of
Table 4. Topics identified and their frequency of occurrence on the two social media platforms.

| Information Topics                      | Frequency | Percentage (%) |
|-----------------------------------------|-----------|----------------|
| GENERAL                                 | 4609      | 66.90          |
| What is Stroke?                         | 89        | 1.29           |
| Signs and Symptoms                      | 753       | 10.93          |
| Types of Stroke                         | 112       | 1.63           |
| Causes of Stroke                        | 54        | 0.78           |
| Diagnosis                               | 20        | 0.29           |
| Risk Factors                            | 1011      | 14.68          |
| Demographics                            | 122       | 1.77           |
| Heart and Vascular Health               | 714       | 10.36          |
| Mental Health                           | 46        | 0.67           |
| Women’s Health                          | 30        | 0.44           |
| Lifestyle                               | 312       | 4.53           |
| Medication                              | 66        | 0.96           |
| Other Medical Conditions                | 181       | 2.63           |
| Diabetes                                | 175       | 2.54           |
| Head Injury                             | 6         | 0.09           |
| Prevention                              | 1310      | 19.02          |
| Managing Lifestyle                      | 1236      | 17.94          |
| Managing Mental Health                  | 100       | 1.45           |
| Managing Medical Risks                  | 35        | 0.51           |
| Managing Sleep                          | 30        | 0.44           |
| Consequences                            | 758       | 11.00          |
| Cognitive                               | 613       | 8.90           |
| Emotional                               | 103       | 1.50           |
| Physical                                | 103       | 1.50           |
| Sleep                                   | 8         | 0.12           |
| Relationships                           | 2         | 0.03           |
| Quality of Life                         | 2         | 0.03           |
| Living and Independence                 | 5         | 0.07           |
| Treatment                               | 1234      | 17.91          |
| Treatment Practices                     | 103       | 1.50           |
| Importance of Early Treatment           | 83        | 1.20           |
| Rehabilitation                          | 820       | 11.90          |
| Guidelines                              | 454       | 6.59           |
| Importance                              | 28        | 0.41           |
| Cost                                    | 4         | 0.06           |
| At-Home Rehabilitation                  | 363       | 5.27           |
| Treatment of Risk Factors               | 305       | 4.43           |
| Monitoring                              | 136       | 1.97           |
| Surgery                                 | 13        | 0.19           |
| Medications                             | 204       | 2.96           |
| CAREGIVER                               | 2280      | 33.10          |
| Impact                                  | 184       | 2.67           |
| Communication Practices                 | 117       | 1.70           |
| Health Professional                     | 12        | 0.17           |
| Patient                                 | 105       | 1.52           |
| Roles and Decision Making               | 21        | 0.30           |

(Continued)
inconsistencies and presentation of information in a standardized format, (iii) creation of content that allows individuals with low health literacy to comprehend health information, and (iv) access through numerous different platforms or interventions [29]. However, Ferguson [28] highlights the importance of presenting the content concisely to avoid overwhelming the target audience with information, with a specific focus on the video length to ensure attentiveness of the target audience during the duration of the video.

While this study suggests caregivers in the stroke generally prefer video-based resources on social media communities, it is crucial to understand the influences of other media like text and images on health education. For instance, text-based resources allow individuals to access materials at their own pace and may be easier to access than video-based resources, particularly for individuals with low technical literacy [29]. On the other hand, images benefit individuals with low literacy skills [30] and have enhanced comprehension, satisfaction, and readability amongst the target audience [31].

Given that information type (i.e., video, image, and text) is a critical aspect for delivering information to specific individuals, it is also equally essential for one to consider individuals’ needs to maximize interaction. Despite the existing set of topics that researchers believe to be important to address specific health information needs, there are several differences in the actual individual’s needs [32]. For example, researchers are influenced by the disease type and researcher’s motivation [32], while in stroke caregiving, the caregiver’s needs differ based on the different stages of the survivors’ illness, the need to maintain care continuum, and to ensure self-care during recovery [7, 33]. The need to maintain a care continuum and ensure self-care was evident in this study, with maximum interaction identified in prevention, signs & symptoms, patient support & care, risk factors, caregiver impact, and self-care. However, greater emphasis would need to be considered to provide information at different stages of the survivors’ illness, which is currently not evident. In addition, it is important to understand the literacy and communication barriers that may impact the target audience and may limit their motivation to engage with the information, which can be restricted by co-designing information to limit these barriers [30].

One method that can be implemented when designing health information is Participatory Design (or PD) approach [34]. The PD approach has been drawn from several methods,

| Information Topics                      | Frequency | Percentage (%) |
|-----------------------------------------|-----------|----------------|
| Patient Support & Care                  | 1195      | 17.35          |
| Care Guidelines                         | 1077      | 15.63          |
| Supporting Activities of Daily Living   | 123       | 1.79           |
| Finance & Legal Support                 | 72        | 1.05           |
| Care Planning                           | 162       | 2.35           |
| Self-care                               | 864       | 12.54          |
| Need                                    | 81        | 1.18           |
| Strategies                              | 864       | 12.54          |
| Take a Break                            | 52        | 0.75           |
| Engage in Other Activities              | 105       | 1.52           |
| Manage Quality-of-Life                  | 131       | 1.90           |
| Manage Health & Well-being              | 677       | 9.83           |
| Manage Emotions                         | 46        | 0.67           |
| Manage Relationships                    | 48        | 0.70           |
| Sharing Care Responsibilities           | 55        | 0.80           |

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Table 5. Analysis of user interaction based on the averages of likes, shares and comments for different content types.

| Content             | Type | Likes | Shares | Comments |
|---------------------|------|-------|--------|----------|
| General             | Text | 4.12  | 1.83   | 2.07     |
|                     | Image| 13.36 | 4.35   | 6.5      |
|                     | Video| 14.73 | 9.44   | 9.03     |
|                     | Link | 7.39  | 1.73   | 3.49     |
| What is Stroke?     | Text | 0.33  | 1      | 0.33     |
|                     | Image| 12.62 | 3.73   | 10.87    |
|                     | Video| 1     | 0      | 0.67     |
|                     | Link | 9     | 0.41   | 2.54     |
| Signs and Symptoms  | Text | 17.87 | 3.1    | 2.57     |
|                     | Image| 13.29 | 3.6    | 11.61    |
|                     | Video| 19.42 | 7      | 13.02    |
|                     | Link | 9.77  | 3.96   | 8.11     |
| Types of Stroke     | Text | 7.75  | 1      | 6.5      |
|                     | Image| 8.04  | 0.96   | 4.81     |
|                     | Video| 2.71  | 0      | 1.71     |
|                     | Link | 10.57 | 1.25   | 4.35     |
| Causes of Stroke    | Text | 0.67  | 0.67   | 0.67     |
|                     | Image| 6     | 3      | 3.8      |
|                     | Video| 8     | 0      | 7.67     |
|                     | Link | 14.32 | 1.84   | 7.38     |
| Diagnosis           | Text | 2     | 0      | 0        |
|                     | Image| 6     | 0      | 0.5      |
|                     | Video| 0.5   | 0      | 0        |
|                     | Link | 11.67 | 0.67   | 5.67     |
| Risk Factors        | Text | 7.6   | 2.82   | 3.2      |
|                     | Image| 25.61 | 5.28   | 6.66     |
|                     | Video| 6.49  | 7.18   | 6.28     |
|                     | Link | 4.54  | 2.25   | 3.67     |
| Prevention          | Text | 8.45  | 3.21   | 3.69     |
|                     | Image| 18.21 | 4.13   | 5.92     |
|                     | Video| 21.51 | 8.07   | 12.1     |
|                     | Link | 3.54  | 1.86   | 2.56     |
| Consequences        | Text | 1.53  | 1.69   | 1.59     |
|                     | Image| 9.58  | 2.63   | 4.15     |
|                     | Video| 20.92 | 9.64   | 6.44     |
|                     | Link | 16.57 | 1.12   | 4.28     |
| Treatment           | Text | 2.17  | 1.2    | 1.29     |
|                     | Image| 11.39 | 6.39   | 7.72     |
|                     | Video| 10.8  | 12.82  | 6.38     |
|                     | Link | 5.46  | 0.76   | 1.99     |
| Caregiver           | Text | 2.73  | 1.96   | 2.3      |
|                     | Image| 15.68 | 3.95   | 5.38     |
|                     | Video| 19    | 8      | 1.18     |
|                     | Link | 5.94  | 1.5    | 2.43     |
| Impact              | Text | 2.67  | 0      | 0.67     |
|                     | Image| 6.19  | 3.3    | 3.11     |
|                     | Video| 14.25 | 11.13  | 13.75    |
|                     | Link | 15.1  | 2.15   | 4.1      |

(Continued)
theories, and evidence from multiple disciplines such as human factors, marketing, engineering, sociology, and health [35]. This approach aims to actively involve different stakeholders with the intention to understand their needs and barriers towards creating meaningful, actionable, and feasible knowledge [34, 36], thereby enhancing communication and enriching the health information designed [37]. Hence, making it an ideal methodology for co-designing information in stroke caregiving.

**Study limitations**

The study was focused on understanding the information-seeking behaviour, types of information available, and interaction of caregivers online through Google Insights and Content Analysis of popular social media platforms. During the analysis process, several limitations...
arose. First, the inability of the scraper tool developed to extract all the posts from the social media community due to the particular restrictions by the social media platforms that monitor programs accessing social media content and blocking its access. Further, several posts were excluded during the filtration process if they did not include the target audience, i.e., the caregiver. These limitations may have resulted in several excluded posts that may have supported the caregiver during their care process. Second, the user interaction analysis considered the likes, shares, and comments of all audiences within the community as it was impossible to segregate the users based on their role. If the posts were segregated based on the type of user, the outcomes might demonstrate a difference in caregiver information needs and their level of interaction on the popular social media platforms. Third, the search criterion was limited to only English, and we are unsure if the inclusion of non-English communities may impact the outcomes of the findings. Finally, the exclusion of communities that are not publicly accessible. We excluded these communities due to ethical considerations and privacy. As a result, we are unsure if the discussions within these communities would provide a comprehensive understanding of the health information needs of caregivers and their levels of interaction.

Conclusions

The study investigated the information-seeking behavior on Google and the content and user interaction on popular social media platforms. Findings suggest that there is a significant rise in online searches over the past ten years in stroke. The surge is indicated on both Google and social media communities. On analysis of comments designed explicitly for caregivers, topics related to the continuum of care and self-care were most engaging, especially in video-based formats. However, content creators need to understand the influences of information needs and delivery to maximize user interaction. This may be possible through co-design practices such as participatory design, which has in the past demonstrated efficient results in enhancing communication practices and enriching health information quality. Therefore, creating a deeper understanding of the caregiver and necessary information topics ensures they are prepared throughout the care process.
Supporting information

S1 File. Keywords searched in Google Trends and Insights. (XLSX)

S2 File. Included social media communities. (XLSX)

S3 File. Included community posts and user interactions. (XLSX)

Author Contributions

Conceptualization: Elton H. Lobo, Anne Frølich, Finn Kensing, Lene J. Rasmussen, Sarah M. Hosking, Amy T. Page, Patricia M. Livingston, Sheikh Mohammed Shariful Islam, John Grundy, Mohamed Abdelrazek.

Data curation: Elton H. Lobo, Tara Johnson, Patricia M. Livingston, Mohamed Abdelrazek.

Formal analysis: Elton H. Lobo, Tara Johnson, Anne Frølich, Sheikh Mohammed Shariful Islam, Mohamed Abdelrazek.

Investigation: Elton H. Lobo, Tara Johnson, Amy T. Page.

Methodology: Elton H. Lobo, Finn Kensing, Sheikh Mohammed Shariful Islam, Mohamed Abdelrazek.

Software: Elton H. Lobo.

Supervision: Anne Frølich, Finn Kensing, Lene J. Rasmussen, Patricia M. Livingston, Sheikh Mohammed Shariful Islam, John Grundy, Mohamed Abdelrazek.

Validation: Elton H. Lobo, Anne Frølich, Finn Kensing, Lene J. Rasmussen, Patricia M. Livingston, Sheikh Mohammed Shariful Islam, Mohamed Abdelrazek.

Writing – original draft: Elton H. Lobo, Tara Johnson.

Writing – review & editing: Elton H. Lobo, Anne Frølich, Finn Kensing, Lene J. Rasmussen, Sarah M. Hosking, Amy T. Page, Patricia M. Livingston, Sheikh Mohammed Shariful Islam, John Grundy, Mohamed Abdelrazek.

References

1. Deyhoul N, Vasli P, Rohani C, Shakeri N, Hosseini M. The effect of family-centered empowerment program on the family caregiver burden and the activities of daily living of Iranian patients with stroke: a randomized controlled trial study. Aging clinical and experimental research. 2020 Jul; 32(7):1343–52. https://doi.org/10.1007/s40520-019-01321-4 PMID: 31473982

2. Kumar R, Kaur S, Reddemma K. Family needs of caregivers of stroke survivors. Adv Practice Nurs. 2016; 1(120):2.

3. McCurley JL, Funes CJ, Zale EL, Lin A, Jacobo M, Jacobs JM, et al. Preventing Chronic Emotional Distress in Stroke Survivors and Their Informal Caregivers. Neurocritical Care. 2019 2019/06/01; 30 (3):581–9. https://doi.org/10.1007/s12028-018-0641-6 PMID: 30421266

4. Mores G, Whiteman RM, Ploeg J, Knobl P, Cahn M, Klaponski L., et al. An Evaluation of the Family Informal Caregiver Stroke Self-Management Program. The Canadian journal of neurological sciences Le journal canadien des sciences neurologiques. 2018 Nov; 45(6):660–8. https://doi.org/10.1017/cjn.2018.335 PMID: 30430966

5. Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, et al. Improving Stroke Caregiver Readiness for Transition From Inpatient Rehabilitation to Home. The Gerontologist. 2017 Oct 1; 57 (5):880–9. PMID: PMC5881730. https://doi.org/10.1093/geront/gnw135 PMID: 27816914
6. Lobo EH, Fratish A, Rasmussen LJ, Livingston PM, Grundy J, Abdelrazeq M, et al. Understanding the Methodological Issues and Solutions in the Research Design of Stroke Caregiving Technology. Frontiers in public health. 2021; 9:647249. PMID: PMC8085388. https://doi.org/10.3389/fpubh.2021.647249 PMID: 33937175

7. Tsai P-C, Yip P-K, Tai JJ, Lou M-F. Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. Patient Prefer Adherence. 2015; 9:449–57. https://doi.org/10.2147/PPA. S77713 PMID: 25834409

8. Tseung V, Jaglal SB, Salbach NM, Yoshida K, Cameron JI. Key informants’ perspectives on implementing caregiver programs in an organized system of stroke care. Disability and rehabilitation. 2021 Apr; 43(8):1145–52. https://doi.org/10.1080/09638288.2019.1652704 PMID: 31424961

9. Ang SY, Tin AS, Pavitar G, Ng WM, Lee KE, Lim LH, et al. A Qualitative Study into Stroke Caregivers’ Educational Needs—Perspectives of Caregivers and Healthcare Professionals. Proceedings of Singapore Healthcare. 2013 2013/09/01; 22(3):166–74. https://doi.org/10.1177/2010581302200303

10. Wu C-m. Learning to be a family caregiver for severely debilitated stroke survivors during the first year in Taiwan. Iowa City: University of Iowa; 2009.

11. Smith SD, Gignac MAM, Richardson D, Cameron JI. Differences in the experiences and support needs of family caregivers to stroke survivors: does age matter? Top Stroke Rehabil. 2008 Nov-Dec; 15(6):593–601. https://doi.org/10.1310/tsr1506-593 PMID: 19158067

12. Creasy KR, Lutz BJ, Young ME, Ford A, Martz C. The impact of interactions with providers on stroke caregivers’ needs. Rehabilitation nursing: the official journal of the Association of Rehabilitation Nurses. 2013 Mar-Apr; 38(2):88–98. PMID: PMC3742102. https://doi.org/10.1002/rnj.69 PMID: 23529947

13. Danzl MM, Harrison A, Hunter EG, Kuperstein J, Sylvia V, Maddy K, et al. “A Lot of Things Passed Me by”: Rural Stroke Survivors’ and Caregivers’ Experience of Receiving Education From Health Care Providers. The Journal of rural health: official journal of the American Rural Health Association and the National Rural Health Care Association. 2016 Winter; 32(1):13–24. https://doi.org/10.1111/jrh.12124 PMID: 26100171

14. Scantlebury A, Booth A, Hanley B. Experiences, practices and barriers to accessing health information: A qualitative study. International Journal of Medical Informatics. 2017 2017/07/01; 103:103–8. https://doi.org/10.1016/j.ijmedinf.2017.04.018 PMID: 28550995

15. Chu JTW, Wang MP, Shen C, Viswanath K, Lam TH, Chan SSC. How, When and Why People Seek Health Information Online: Qualitative Study in Hong Kong. Interact J Med Res. 2017 2017/12/12; 6(2):e24. https://doi.org/10.2196/ijmr.7000 PMID: 29233802

16. Zhao Y, Zhang J. Consumer health information seeking in social media: a literature review. Health information and libraries journal. 2017 Dec; 34(4):268–83. https://doi.org/10.1111/hir.12192 PMID: 29045011

17. Naqvi IA, Montiel TC, Bittar Y, Hunter N, Okpala M, Johnson C, et al. Internet Access and Usage Among Stroke Survivors and Their Informal Caregivers: Cross-sectional Study. JMIR Form Res. 2021 2021/3/8; 5(3):e25123. https://doi.org/10.2196/25123 PMID: 33683206

18. Li Y, Wang X, Lin X, Hajli M. Seeking and sharing health information on social media: A net valence model and cross-cultural comparison. Technological Forecasting and Social Change. 2018 2018/01/01/; 126:28–40. https://doi.org/10.1016/j.techfore.2016.07.021

19. Zhou L, Zhang D, Yang CC, Wang Y. Harnessing social media for health information management. Electronic Commerce Research and Applications. 2018 2018/01/01/; 27:139–51. https://doi.org/10.1016/j.elerap.2017.12.003 PMID: 30147638

20. Cabrera-Maqueda Jose M, Minhas Jatinder S. New Horizons for Stroke Medicine: Understanding the Value of Social Media. Stroke. 2018 2018/02/01; 49(2):e25–e7. https://doi.org/10.1161/STROKEAHA. 117.020068 PMID: 29301974

21. Schoonenboom J, Johnson RB. How to Construct a Mixed Methods Research Design. Kolner Z Soz Sozpsychol. 2017; 69(Suppl 2):107–31. https://doi.org/10.1007/s11577-017-0454-1 PMID: 28989188

22. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008 Jul 10; 8:45. PMID: PMC2478656. https://doi.org/10.1186/1471-2288-8-45 PMID: 18618818

23. Tan SS, Goonawardene N. Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review. Journal of medical Internet research. 2017 Jan 19; 19(1):e9. PMID: PMC5690294. https://doi.org/10.2196/jmir.5726 PMID: 28164579

24. Dutta-Bergman M. Trusted online sources of health information: differences in demographics, health beliefs, and health-information orientation. Journal of medical Internet research. 2003 Jul-Sep; 5(3): e21. PMID: PMC1550562. https://doi.org/10.2196/jmir.5.3.e21 PMID: 14517112
25. Cuan-Baltazar JY, Muñoz-Perez MJ, Robledo-Vega C, Pérez-Zepeda MF, Soto-Vega E. Misinformation of COVID-19 on the Internet: Infodemiology Study. JMIR public health and surveillance. 2020 Apr 9; 6(2):e18444. https://doi.org/10.2196/18444 PMID: 32250960

26. Crocco AG, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the internet. Jama. 2002 Jun 5; 287(21):2869–71. https://doi.org/10.1001/jama.287.21.2869 PMID: 12038937

27. Swire-Thompson B, Lazer D. Public Health and Online Misinformation: Challenges and Recommendations. Annual review of public health. 2020 Apr 2; 41:433–51. https://doi.org/10.1146/annurev-publhealth-040119-094127 PMID: 31874069

28. Ferguson LA. Implementing a Video Education Program to Improve Health Literacy. The Journal for Nurse Practitioners. 2012 2012/09/01/ ; 8(8):e17–e22. https://doi.org/10.1016/j.nurpra.2012.07.025

29. Tuong W, Larsen ER, Armstrong AW. Videos to influence: a systematic review of effectiveness of video-based education in modifying health behaviors. Journal of behavioral medicine. 2014 Apr; 37 (2):218–33. https://doi.org/10.1007/s10865-012-9480-7 PMID: 23188480

30. van Beusekom MM, Grootens-Wiegens P, Bos MJ, Guchelaar HJ, van den Broek JM. Low literacy and written drug information: information-seeking, leaflet evaluation and preferences, and roles for images. International journal of clinical pharmacy. 2016 Dec; 38(6):1372–9. PMID: PMC5124048. https://doi.org/10.1007/s11096-016-0376-4 PMID: 27655308

31. Lühnen J, Steckelberg A, Buhse S. Pictures in health information and their pitfalls: Focus group study and systematic review. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen. 2018 Nov; 137–138:77–89. https://doi.org/10.1016/j.zefq.2018.08.002 PMID: 30217737

32. Pian W, Song S, Zhang Y. Consumer health information needs: A systematic review of measures. Information Processing & Management. 2020 2020/03/01/ ; 57(2):102077. https://doi.org/10.1016/j.ipm.2019.102077

33. Pierce LL, Gordon M, Steiner V. Families dealing with stroke desire information about self-care needs. Rehabilitation nursing: the official journal of the Association of Rehabilitation Nurses. 2004 Jan-Feb; 29 (1):14–7. https://doi.org/10.1002/j.2048-7940.2004.tb00294.x PMID: 14727471

34. Smith F, Wallengren C, Ohlén J. Participatory design in education materials in a health care context. Action Research. 2016 2016/09/01/ ; 15(3):310–36. https://doi.org/10.1177/1476750316646832

35. Neuhauser L, Rothschild B, Graham C, Ivey SL, Konishi S. Participatory design of mass health communication in three languages for seniors and people with disabilities on Medicaid. American journal of public health. 2009 Dec; 99(12):2188–95. PMID: PMC2775764. https://doi.org/10.2105/AJPH.2008.155648 PMID: 19833990

36. Andersen TO, Bansier JP, Kensing F, Mølsted T, Nielsen KD, et al. Aligning Concerns in Telecare: Three Concepts to Guide the Design of Patient-Centred E-Health. Comput Supported Coop Work. 2019 2019/10/01/ ; 28(6):1039–72. https://doi.org/10.1007/s10606-018-9309-1

37. Paulovich B. Design to Improve the Health Education Experience: using participatory design methods in hospitals with clinicians and patients. Visible Language. 2015 04/; 49(1/2):144–59.