Content and network analysis of tweets tagged with #aphasia: an emergent community of practice

Lucy Bryant , Melissa Brunner , Emma Power & Bronwyn Hemsley

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Lucy Bryant [ID][a], Melissa Brunner [ID][a,b], Emma Power [ID][a] and Bronwyn Hemsley [ID][a]

[a]Graduate School of Health Speech Pathology, University of Technology Sydney, Chippendale, Australia; [b]Speech Pathology, Faculty of Medicine and Health, Sydney School of Health Sciences, The University of Sydney, Sydney, Australia

ABSTRACT

Background: A reduced quality of life for people with aphasia is in part associated with their loss of friendships and social networks. Twitter offers people with communication disability a way to exchange information, develop and maintain their social networks and connections, and participate in society online. However, little is known about how Twitter is used to exchange information about aphasia or to build communities online that might support people with aphasia in their communication goals.

Aims: To examine the network data and content of tweets tagged with #aphasia to understand more about how Twitter is used by people with aphasia, aphasia organisations, aphasiologists, clinicians, and the public.

Method: A Twitter hashtag study was conducted to locate tweets highly relevant to aphasia. A daily tweet capture using the Twitter search bar was conducted for one month, November 2018, searching for publicly available tweets tagged with aphasia-related hashtags. The tweets collected were analysed using both qualitative and quantitative methods.

Results: A sample of 2,519 tweets were included in the analysis. The sample comprised 865 original tweets and 1,654 retweets which included "quote tweets", sent by 839 unique Twitter @Users. Tweet content reflected users discussing aphasia research, exchanging health information, advice and inspiration, providing personal stories, raising awareness about aphasia, and an emergent aphasia community online.

Conclusion: The aphasia community in Twitter is relatively small compared to other communities focused on communication disability and is emergent in terms of its size and the strength of connections. The majority of people or organisations tweeting about aphasia, and hence influencing the network, were health professionals working in the field of aphasia. There was minimal conversational interaction evident. These results demonstrate that Twitter is underutilised as a platform for interaction and engagement in relation to aphasia, and further research is needed.

Background

One of the world's most popular social media platforms is Twitter, used by an estimated 330 million people (as at May 2019; Omnicore Agency, 2019). Recent research on the use

CONTACT Lucy Bryant ✉ lucy.bryant@uts.edu.au ▣ Graduate School of Health, Speech Pathology, University of Technology Sydney, 15 Broadway, Chippendale, NSW 2008 Australia

of Twitter by people with communication disability, and associated health conditions, has highlighted its potential to be used to improve community connections and to raise awareness (Hemsley, Dann, Palmer, Allan & Balandin, 2015). Twitter can be used by people with communication disability to forge connections online, increase feelings of belonging, and improve their access to information (Hemsley & Palmer, 2016; Hemsley et al., 2018, 2017). Previous investigations have examined the use of publicly available Twitter data created by people with communication disability, including people with cerebral palsy (Hemsley et al., 2018), traumatic brain injury (TBI) (Brunner et al., 2018), and motor neurone disease (MND) (Hemsley & Palmer, 2016; Hemsley et al., 2017). In a single case multiple baseline design study, Hemsley et al. (2018) taught people with communication disability to use Twitter, finding that the training increased the size and reduced the density of the users' Twitter networks by increasing the number of interactions they had with other users on the platform. Participants, who all had cerebral palsy and used augmentative and alternative communication systems, reported a range of real-world impacts including improved access to communication and consumer rights, information, and social interaction.

The growing evidence base on the usefulness of Twitter in the field of communication disability (Brunner et al., 2015; Eghdam et al., 2018; Hemsley et al., 2014, 2018) highlights the utility of its publicly available data for understanding more about how people are using the platform to discuss various aspects of life with a communication disability. Much of this research uses the content of tweets and examination of the Twitter networks created by users to gain a better understanding of how people with communication disability use social media to communicate, and how they may be supported in their use of social media platforms given their communication difficulties (Brunner et al., 2019; Hemsley et al., 2018). Twitter is one social media platform that may be of particular importance in the field of communication disability due to the limited demands on written communication created by the short message length (Hemsley et al., 2014; Paterson, 2017). However, despite the increased research attention to the use of Twitter by people with communication disability, there is little information available as to its use by people with aphasia, an acquired communication disability caused by injury to the areas of the brain responsible for comprehension and expression of language. This represents a significant gap in the research, considering that: (a) an estimated one-third of all individuals who experience a stroke present with aphasia (Kauhanen et al., 2000); and (b) approximately 15 million strokes occur worldwide annually (Worrall, 2014) with up to 5 million new individuals diagnosed with aphasia every year. The use of social media by people with aphasia may be challenging, owing to the nature of their language difficulties and use of the Internet following stroke. Menger et al. (2019) reported that reduced use of the Internet by people with aphasia may impact heavily on their social media engagement (e.g., using email and instant messaging) and that internet-based communication was a primary area of digital exclusion for people with aphasia. To date, there is no research examining how having aphasia might affect an individual's use of Twitter.

Lack of attention to the use of social media by people with aphasia leaves unexplored the potential benefits for those who experience significant negative impacts on their quality of life (Lam & Wodchis, 2010), particularly in relation to social isolation and reduced engagement in leisure activities (Hilari, 2011; Simmons-Mackie & Kagan, 2007). While goals relating to improving social life and participation are common amongst

people with aphasia, these may be under-recognised and under-explored by rehabilitation professionals (Worrall et al., 2011). Worrall et al. (2017) examined the factors that contributed to a person living well with aphasia in the first 12 months following stroke; that is, how well the person adapted to life with aphasia for improved quality of life. With regards to participation in life activities, the size of the person's social network was a key factor in achieving success. The authors suggested that maximising the size of the person's social networks should be a key focus for individuals with a primary aphasia rehabilitation goal of life participation (Worrall et al., 2017). It is now well recognised that people with communication disability can expand their social networks for a range of purposes by engaging in social media (Brunner et al., 2018; Caron & Light, 2015; Raghavendra et al., 2015).

It is not yet known whether Twitter is used for discussions related to aphasia, and this knowledge might be useful considering that the general lack of public awareness of aphasia. Such limited public awareness is problematic as it may contribute to poor recognition of the condition and its impacts, and act as a barrier to advocacy that might support people with aphasia to participate in community activities and access rehabilitation (Flynn et al., 2009; Guinan & Carroll, 2019; McCann et al., 2013; Simmons-Mackie et al., 2002). An international survey of 978 people in England, Australia, and the USA identified that only 13.6% of participants had heard of aphasia. However, only 5.4% had basic knowledge of what "aphasia" actually meant (Simmons-Mackie et al., 2002). Additional research since suggested that awareness had not changed in the decade following this study (McCann et al., 2013). This public awareness acts as a barrier to the engagement of people with aphasia in community activities (Le Dorze et al., 2014).

Therefore, this research aims to determine (a) the content of tweets tagged with aphasia-related hashtags; and (b) how Twitter is currently being used by people with aphasia and their families, professionals, organisations, and others in the online community. This information would provide insights into who is using Twitter to communicate and exchange information about aphasia, how the platform is being used (e.g., for conversation, or to disseminate information) and the nature of the content being shared. This information could improve knowledge about how individuals and organisations could use the platform more effectively to improve awareness of aphasia online. An understanding of whether and how people with aphasia are using Twitter to support their communication and establish social connections may also guide future strategies to support social and communicative rehabilitation for people with aphasia and interventions to improve their use of social media.

Method

This research was reviewed and approved by the Human Research Ethics Committee of the University of Technology Sydney (ETH18-2722).

The design of this study was based on established methods for hashtag research including studies on topics related to communication disorders (Brunner et al., 2018; Hemsley et al., 2015; Hemsley & Palmer, 2016) with this study having a focus on aphasia. In Twitter, users can add hashtags to their tweets to deliberately direct their thoughts and comments to an intended audience interested in that hashtag (Bruns & Moe, 2014;

Dann, 2010) and this can include an audience of Twitter users who are not following the user.

Identifying relevant hashtags for the research

In order to first determine the most appropriate hashtags to search in relation to the topic of aphasia, the first author used the Twitter search bar to identify the most commonly used aphasia-related hashtags. These were #aphasia, #dysphasia, #AphasiaChoir, #LivingWithAphasia, #AphasiaAwareness, #AphasiaAwarenessMonth, #TalkAboutAphasia, #AphasiaResearchWednesdys, #AphasiaStrong, #AphasiaCafe, and #AphasiaFriendly. Other aphasia-related hashtags that appeared rarely in the sample were not included in the subsequent search strategy. To illustrate, the hashtag #para-phasia appeared only five times in four years of tweets captured in the scoping search, and #WordFindingDifficuly appeared seven times in the past eight years, with only one clearly relevant to aphasia.

Informing tweeters of the research

Prior to collecting the tweets from the platform using the Twitter search bar, the first author sent out a tweet to followers (i.e., people likely to be tweeting with hashtags related to aphasia) to: (a) inform them of the data being collected using aphasia-related hashtags, and (b) give them the option of contacting the first author to remove their publicly available Twitter data from the study. This tweet was repeated weekly throughout the study period. No @Users requested removal of their Twitter data from the study.

Collecting tweet data from Twitter

The hashtags were used to search Twitter each day for one month (November 1, 2018 to November 30, 2018) to capture as many tweets as possible related to aphasia, as the Twitter search process limits the number of results returned by time and quantity (Palmer, 2014). Tweets and Twitter data associated with users posting the tweets (i.e., biographical information) were harvested using the NCapture (QSR International, 2011) add-on to the Google Chrome internet browser, and imported as .csv files into NVivo (QSR International, 2018). Using these methods, tweets retrieved using the search bar include only those posted by users with a public Twitter account (Twitter Inc, 2018).

Exporting data for analysis and applying inclusion and exclusion criteria

At the end of the collection period, all tweets were exported and collated in a Microsoft Excel file for analysis. To be included in the study, tweets had to be: (i) original tweets or retweets written in English; (ii) sent during the month of November 2018; and (iii) related to the communication disability aphasia or sent by people with aphasia or their families. Tweets were excluded if they were: (i) duplicates or not written in English; (ii) sent outside the target date range of this study; (iii) were not relevant to the communication disability "aphasia" (e.g., related to a heavy metal band called Aphasia); or (iv) contained no content.

Quantitative and qualitative data analysis

Twitter @user profile and #hashtag data

Descriptive research techniques were used to identify: (a) the number and frequency of tweets sent using the study hashtags, and (b) the profile of unique @Users who tweeted about aphasia. First, the hashtags within each tweet were counted and analysed using descriptive statistics. Descriptive content analysis was used to identify the co-occurrence of hashtags on tweets, and whether the tweet related to: (i) a conference or seminar; (ii) a health condition impacting communication or language (e.g., stroke or Parkinson's disease); and (iii) communication or language. Second, the biographical statements of @Users were examined to categorise users as belonging to specific groups, according to their self-report: (i) a person with aphasia; (ii) family or friends of people with aphasia; (iii) health professionals working with people with aphasia; (iv) aphasiologists or researchers interested in aphasia; (v) organisations with a focus on or interest in aphasia; (vi) the general public or other; and (vii) other unknown. Descriptive statistics were used to determine the frequencies and percentages of users in each of these categories, providing important context to the qualitative analysis of the content of the tweets in the sample.

Qualitative content analysis of tweets

The content of all tweets was analysed in two stages. First, Dann's Content Classification of tweets (Dann, 2015) was used to deductively code the purpose and intent of tweets. Each tweet was examined and coded as a: (i) Pass Along tweet, sharing external content and content from third parties, including retweets, annotated media such as photos, and links to external websites or other Twitter content; (ii) Conversational tweet, representing interaction between two or more @Users (including conversational replies, referrals to pass content to specific @Users, and rhetorical presence tweets giving an illusion of togetherness); (iii) Status Broadcast tweet, expressing the @User's experiences (including actions, reflections, experiences, and broadcast statements expressing observations of life); (iv) News tweet, informing others of noteworthy events and current affairs (including real-time event tweets reporting facts and describing current events, and press releases of forthcoming events); and (v) Social Presence tweet, communicating a connected presence between @Users (including ceremonial greetings, expressions of thanks, tweets to address the audience, and self-referential commentaries). Tweets were coded by the first author and reviewed by the second author, with any differences of opinion being resolved by consensus coding. A third coder was consulted where agreement could not be reached and based on a majority decision. Dann's framework was adapted slightly to account for the differences in tweeting that have been implemented since the development of the coding structure. Specifically, some tweets that commenced with @User profile names did not always represent conversational tweets and instead reported news-like content of real-time events. In this study, unless clearly a conversational reply, the @User name at the start of the tweet was interpreted as being added to highlight the subject of the tweet. In these cases, the tweet was coded as News/Real-Time Event. Additionally, it is now possible to pass along authored content and comment on it (i.e., retweets are now able to be sent with or without added commentary). In this study, retweets with commentary were considered to be Pass Along tweets.

In the second stage of analysis, the information content of all original tweets (i.e., excluding retweets that did not include additional comment) was analysed inductively to determine the categories and sub-categories of topics being discussed in Twitter related to aphasia. Each tweet was coded in Microsoft Excel. Tweets were read and re-read by the first author, who made notes about the key content ideas evident in the tweets. The coding structure was checked by the second author. These initial content codes were discussed with the third and fourth authors to verify and confirm the first author's interpretation of the categories and sub-categories of topics and connecting content themes. An iterative coding process was implemented to group content codes together into themes through discussion with all authors coming to consensus on the qualitative analysis.

Although ethical approval was gained to conduct a linguistic analysis of the tweets of people with aphasia, this was not conducted owing to the small number of tweets originating from people with aphasia captured in the sample.

Results

In total, 3,591 tweets were captured in 203 NCapture files over the data collection period. The hashtag #aphasia yielded the most tweets in the sample (n = 3,487, 97.10%) and other hashtags identified no more than 25 tweets each. This demonstrates that #aphasia is the most relevant hashtag for locating aphasia-related content on Twitter. The search and exclusion process is illustrated in Figure 1. In total, 2,519 tweets met the inclusion criteria and were retained for further analysis. The analysed sample included 865 original tweets (i.e., written by the @User) and 1,654 retweets (i.e., distributing content created by others). These tweets were
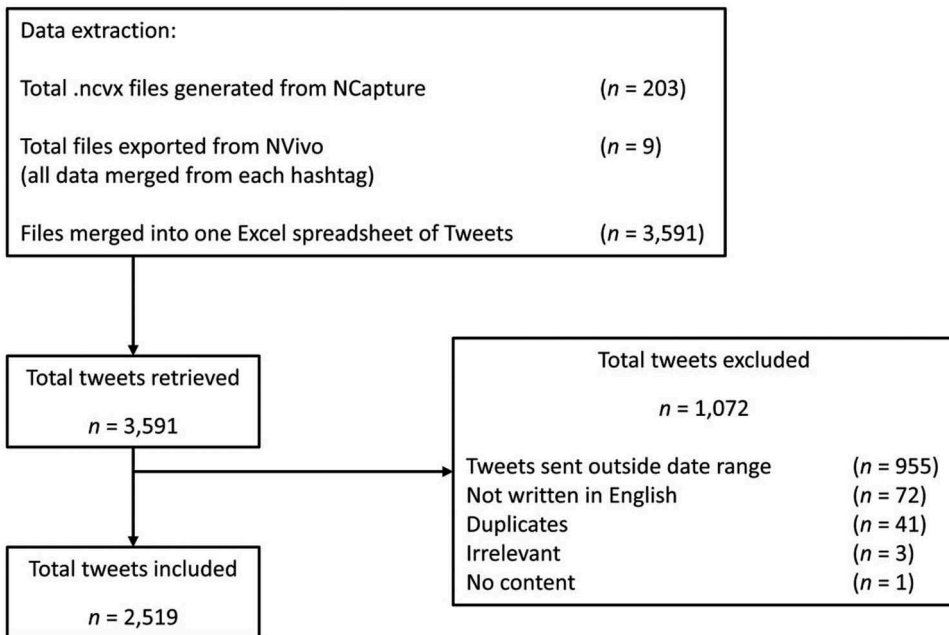

Figure 1. Twitter search and data sorting.

sent by 839 unique @Users, of whom 270 (32.18%) authored original tweets, and 569 (67.82%) retweeted (thus did not make original contributions to the aphasia-related tweets).

Analysis of Twitter @Users' biographical statements

The biographical statements of @Users were coded according to their primary, self-reported role or identity, shown in Table 1.

Further analysis of the Twitter profiles of the 29 people who identified as having aphasia (or a health condition associated with communication or language disorders) revealed that they had language difficulties including aphasia (n = 4), developmental language disorder (n = 1), or a health condition including stroke (n = 14), brain injury (n = 3) or other (e.g., Parkinson's disease, a brain tumour, locked-in syndrome, or an unspecified communication disorder; n = 7). The eight family members in the sample all identified having a close relative with aphasia. Together, these 37 @Users sent 70 (2.78%) of the 2,519 tweets in the dataset, including 37 retweets (27 by people with aphasia), and 33 tweets with original authored content (16 by people with aphasia).

The 413 @User profiles of professionals who worked with people with aphasia or related conditions in a variety of disciplines included academics, clinicians, and students and made up almost half of those tweeting about aphasia (49.23%). This group contributed 50.83% of tweets to the dataset (n = 1,281) including 335 original tweets and 946 retweets. Their @User profiles were further analysed to determine their specific disciplines of work or study, and the frequency of their tweets about aphasia. This data is presented in Table 2. Overall, speech-language pathologists made up the largest sub-group of professionals and were the most prolific contributors to sample of tweets relating to

Table 1. Self-reported @User groups engaging in the network.

Group of @User	Number of @Users	Proportion of Total @Users
Clinicians or health professionals working with people with aphasia	215	25.63
Organisations working in field of aphasia or associated health conditions	194	23.12
University academics working with aphasia	167	19.9
Could not classify using provided biographical information	107	12.75
No Biographical information provided	54	6.44
Employees of organisations working in field of aphasia or associated health conditions	44	5.24
University students studying a related health field	31	3.69
People with aphasia or associated health condition	29	3.46
General public	25	2.98
Family members of friends of people with aphasia	8	0.95

Table 2. Professional @User groups and their tweets, retweets, and total tweets about aphasia.

	Tweets		Retweets		Total	
Discipline	@Users	Tweets	@Users RT only (all)	Tweets	@Users	Tweets
Speech pathology	100	317	157 (216)	763	257	1,080
Medical	4	4	70 (70)	70	74	74
Allied health	6	6	32 (34)	39	38	45
Other	0	0	19 (19)	26	19	26
Unclassifiable	6	8	19 (21)	48	25	56
All professionals	116	335	297 (360)	946	413	1,281

aphasia, authoring or retweeting 84.31% of the tweets sent by professionals, and 42.87% of the total tweets in the dataset.

Twitter accounts held by organisations and their employees were the next largest subgroup of @Users in the dataset, making up 30.51% ($n = 256$) of accounts tweeting about aphasia. Many of these organisations ($n = 111/256$; 43.36%) worked in supporting individuals with specific health conditions, including aphasia, stroke, brain injury, and dementia. Organisations were associated with a range of health professionals, including speech pathologists ($n = 48$), medical providers ($n = 43$), and other allied health ($n = 7$). Organisations also served a range of purposes, including: (a) professional associations representing service providers and professional bodies ($n = 69$); (b) teaching and research organisations including higher education institutions, conferences, research publications, and projects ($n = 68$); (c) consumer organisations including community groups, charities, and those focused on raising awareness ($n = 67$); and (d) commercial bodies including companies and media outlets ($n = 41$). Among these organisations, those associated with health professionals, particularly academic conferences, provided the most tweets (see Figure 2). While most organisations sent more retweets than original tweets, consumer organisations used the platform differently, sending more original tweets conveying their own messages than retweets to amplify content authored by other @Users.

The #aphasia network

Tweets mentioning @Users to alert them to or engage them with the content of the tweet showed interaction and conversation within the aphasia Twitter network. Of 865 original tweets, 53.76% ($n = 496$) mentioned other @Users, and a total of 417 @Users were mentioned 1081 times. On average, only one other @User was mentioned in these tweets (range 1 to 13). Of the 417 @Users mentioned, 42.93% ($n = 179$) also contributed tweets to the collected sample. Most of the tweets including @User mentions were sent by
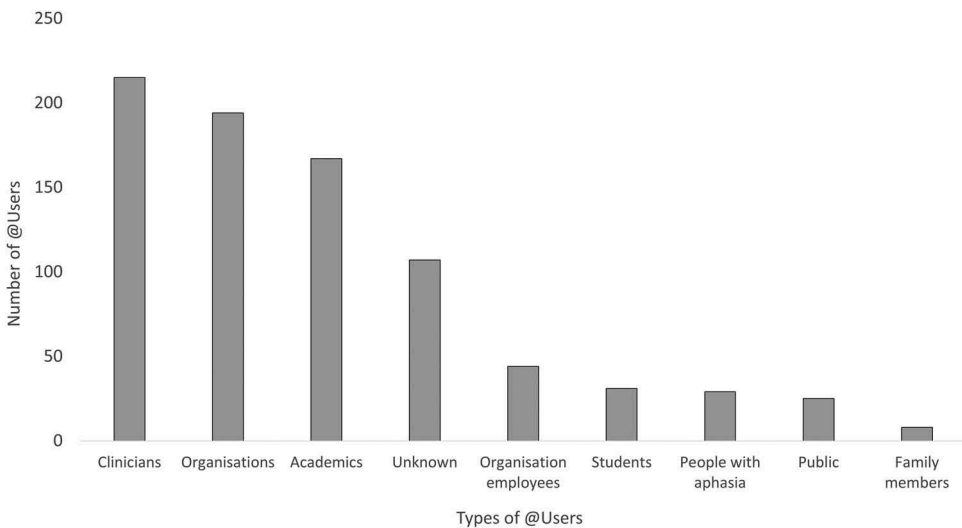

Figure 2. Tweets and retweets by type of organisation @User.

professionals (*n* = 244/496; 49.19%), particularly speech-language pathologists (*n* = 211); and organisations (*n* = 217); however, people with aphasia and their family members (*n* = 13), and the general public (*n* = 6) also used this technique in writing original tweets to increase engagement.

Dissemination and connection of information within Twitter was also established through the use of #hashtags. While all tweets within the dataset contained at least one hashtag related to aphasia, 72.25% of original tweets (*n* = 625) also contained other hashtags linking information to other networks, topics, or events. These hashtags were related to (a) professional conferences (*n* = 333) including #ASA2018 and #ASAQLD2018 for the Aphasiology Symposium of Australia (*n* = 160), #BAS2018 for the British Aphasiology Symposium (*n* = 80), #ASHA18 for the American Speech-language and Hearing Association annual convention (*n* = 43), and #AAA2018 for the Australian Aphasia Association conference (*n* = 20); (b) content tagged with discipline-related hashtags for speech-language pathology (*n* = 14) (e.g., #SLT, #SLPeeps, #wespeechies, and #slp2b); (c) health conditions associated with aphasia (*n* = 132) (e.g., #stroke, #BrainInjury, #Parkinsons, and #dementia); and (d) communication and language in general (*n* = 33) (e.g., #communication, #language, #discourse, #speech).

Tweet frequency

Tweets were analysed to determine and graphically visualise the frequency distribution across the month of data collection (see Figure 3). The distribution reflects a weekly pattern of fluctuation from less active tweeting at the start of each week, to more active periods of tweeting with weekly peaks occurring on Fridays and Saturdays. Tweeters using aphasia-related hashtags were understandably more active in tweeting "News" tweets during conferences. Indeed, the highest frequency of tweeting occurred between November 28 and 29, 2019 and coincided with the Aphasiology Symposium of Australia,
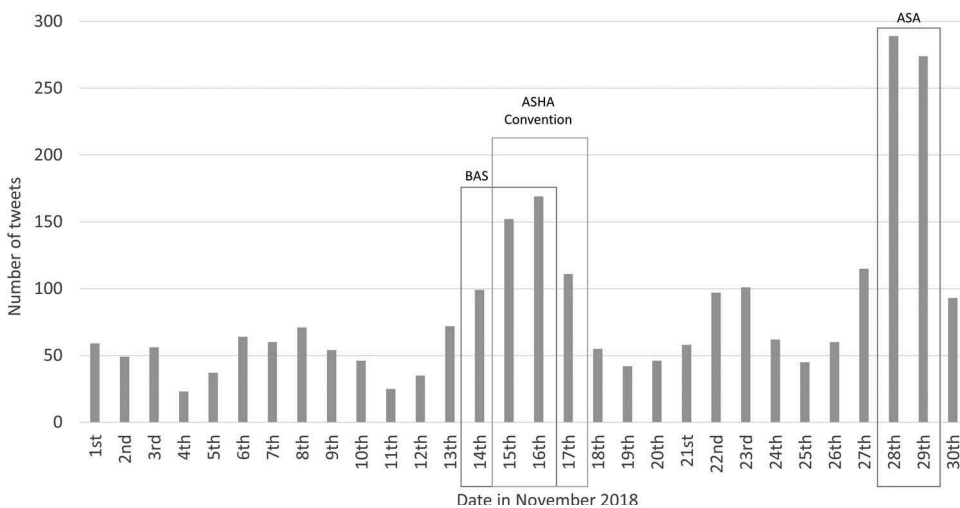

Figure 3. Frequency of tweets by time.

and the second highest peak from November 14 to 17, 2019 coincided with the British Aphasiology Symposium and the ASHA Convention.

Content classification

The content classification of tweets (Dann, 2015) is illustrated in Figure 4. The majority of tweets in the sample were Pass Along tweets ($n = 2233$; 88.65%), including retweets with or without added commentary ($n = 1789$), annotated media tweets that included videos or images ($n = 280$), and curated content providing a link to another website ($n = 227$). News tweets appeared relatively infrequently in the sample ($n = 143$; 5.68%) and all but two of the News tweets related to real-time events in the form of tweets sent during academic conferences.

Status Broadcast tweets ($n = 72$; 2.86%) provided @Users with the opportunity to: convey thoughts and feelings through broadcast statements ($n = 42$), reflect on their lives ($n = 14$), comment on experiences ($n = 11$), and express actions ($n = 5$). A relatively low proportion of Conversational tweets ($n = 62$; 2.46%) present in the sample included tweet replies to other users ($n = 40$), referrals of content to other users ($n = 18$), and expressions of rhetorical presence ($n = 4$). In keeping with prior Twitter research (Brunner et al., 2018; Hemsley et al., 2017), only 1% of the dataset represented tweets displaying Social Presence ($n = 9$) (e.g., saying "hello" or "thank you").
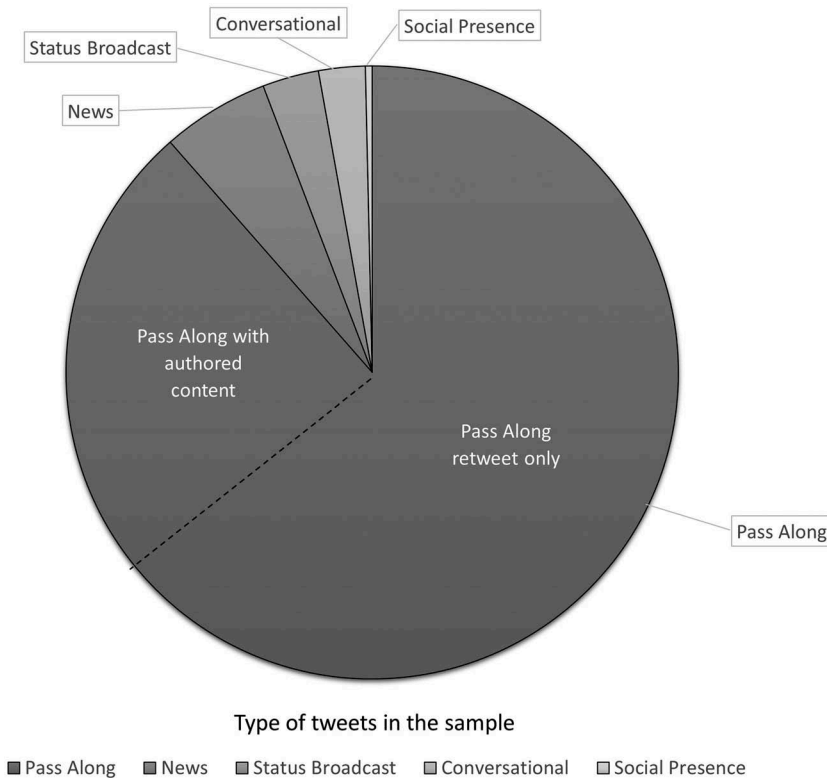

Figure 4. Frequency of content categories of tweets.

Qualitative content analysis

The inductive analysis of tweet content was restricted to original tweets and retweets containing originally authored content (i.e., "quote tweets", with added original text content provided by the retweeter) ($n = 865$). However, of these 865 tweets, 14 could not be analysed qualitatively as they contained insufficient text content. Analysis of the original tweets and quote tweets reflected that Twitter had been used to: (a) share and discuss aphasia research ($n = 510$); (b) exchange health-related information about aphasia, including resources and services ($n = 173$); (c) raise awareness about aphasia, what it is, its causes or prevalence, and the consequences of living with aphasia ($n = 112$); (d) share personal stories, advice, and inspiration about living with aphasia or working with people with aphasia ($n = 41$); and (e) network and connect with other people who use Twitter ($n = 15$). The contribution of each @User group to tweets within each of these identified themes relating to the purpose of the tweet is presented in Table 3.

Sharing and discussing research

All groups of tweeters in the sample posted at least one tweet about research, and most of these tweets were sent in relation to conferences and other research events ($n = 344$). These tweets frequently included a conference hashtag, with four major international conferences on aphasia occurring during the study period and appearing in the sample, as previously noted. Just over half of the research tweets were classified as Pass Along ($n = 180$), often in the form of annotated media tweets that included photographs of conference presenters, their presentations, or posters. @Users tweeted commentary on the conference talks, used annotated images to draw attention to particular researchers and their work, and highlighted research findings of interest.

Twitter @Users also shared research-related links to other webpages and content through Pass Along curation tweets ($n = 109$). These tweets illustrated how researchers could use Twitter to their research advantage, with tweets aimed at recruiting participants to studies by sharing study recruitment information, and links to participant information statements or online surveys. In these instances, tweet content often included a short statement of the research purpose, an indication of who was eligible to participate, and encouragement for readers to use the link to access more information. Research

Table 3. Frequency of tweets by each @User group for each theme in purpose of tweets.

Themes in purpose of tweets	People with Aphasia	Organisations	Professionals	Family Members	Public/ Other	Total
(a) share and discuss aphasia research	0	260	238	1	11	510
(b) exchange health-related information about aphasia, including resources and services	3	93	56	7	14	173
(c) raise awareness about aphasia, what it is, its causes or prevalence, and the consequences of living with aphasia	5	65	18	1	23	112
(d) share personal stories, advice and inspiration about living with aphasia, or working with people with aphasia	6	17	5	5	8	41
(e) network and connect with other people who use Twitter	1	2	11	0	1	15

publications and weblinks to publisher pages were also shared via Twitter (*n* = 22). Research tweets that were classified as News primarily provided commentary on real-time events including conferences.

Sharing health information, advice and inspiration

Health information, advice, and information about aphasia were frequently shared by consumer, provider, philanthropic, and commercial organisations. This information included resources for people with aphasia, their family members, and their speech pathologists to provide tips, tools, and information to support improved communication. Tweets sharing information on communication support tools appeared as advertisements or testimonials, providing scenarios and social interactions that could be difficult for people with aphasia and recommending a specific product (e.g., an "app" for a mobile device) as a solution in these situations. While people with aphasia appeared to be the target audience for some of this information, some tweets were directed towards service providers, particularly speech pathologists, who might recommend these products to their clients. Health-related tweets advertising support groups as a resource encouraged people with aphasia and their family members to seek and find a local support group. Some groups used Twitter to advertise their presence and their meetings, welcome new members, or comment on the groups' activities, including arts and crafts activities and singing; providing illustration of these through pictures and links to videos. Singing groups and aphasia choirs appeared in the sample, with many tweets purporting the benefits of singing for people with aphasia. These results demonstrate the use of Twitter for the social marketing of information about aphasia.

Tweets also contained "tips and advice", typically directed towards people with aphasia and their family members. Advice centred around things to do and strategies to use to enhance communication; for both people with aphasia when they needed to communicate and for family members to aid conversation with a loved one with aphasia. Only one tweet directed the same tips to health professionals, recognising that they may also need advice and strategies to assist them when communicating with clients or patients with aphasia. One other tweet provided health information about swallowing, adding the hashtag #dysphasia but not #dysphagia to identify the target audience for this information.

Raising awareness and personal stories

Tweets raising awareness or conveying personal stories of aphasia were primarily sent by organisations, although all @User groups tweeted this type of content. Indeed, half of all tweets by people with aphasia and their family members were coded in this category. Furthermore, many of the personal stories posted by third parties included direct quotes from people with aphasia.

Tweets to raise awareness provided facts about aphasia, to educate readers and increase their knowledge of aphasia. These tweets included facts around the number of people with aphasia, its causes, the chronic nature of aphasia, variation in symptom severity and types of symptoms, and risk factors for stroke and aphasia. Most of these tweets were classified as Pass Along and included links to other sources with more educational material to extend the information provided. Tweets placed a strong emphasis on aphasia as a language disorder, highlighting that people with aphasia do not have impaired intelligence. This was also reflected in the personal stories of people with aphasia, who often tweeted about negative interactions with people who "spoke down" to them. Almost all tweets of personal experiences detailed negative events and interactions

attributed to other people not understanding aphasia, communicating with the person with aphasia as if they had no language impairment, or speaking to them as if they had an intellectual impairment. Tweeters identified that aphasia cannot be seen and that people with aphasia often do not have a disability that is readily apparent to other people. Content reflected that the "invisible" nature of aphasia formed a major barrier to inclusion in community activities and access to services, particularly local businesses. Tweets called for businesses and individuals to make changes to become aphasia-friendly and promote inclusion and participation for people with aphasia. Tweeters were motivated to raise the level of awareness and "spread the word" about aphasia to promote inclusion and viewed sharing and retweeting awareness tweets was one way that this could be achieved.

Awareness-raising tweets also communicated the impact of aphasia on the quality of life of people with aphasia and their family members. While such tweets included statements on the consequences of aphasia, it was the personal stories of people with aphasia and their family members living with aphasia which further highlighted these ideas. These tweets identified the ongoing stress experienced by those who provide ongoing care and support to people with aphasia, and of the difficulties of needing to provide support for activities previously done independently. Statements of fact from research and personal anecdotes also detailed what it is like to live with aphasia and the impact of loss of language, including the loss of friendships and social networks, jobs and income, and changes in social and familial roles. The impact of this loss on mental health, particularly in relation to depression, was also identified. Some tweets highlighted the daily struggle of living with aphasia, the ongoing pain and effort of trying to communicate with aphasia, and how exhausting this could be for people with aphasia and their families. Some @Users with aphasia tried to describe what it was like to have aphasia from their own perspective, in ways others might understand. They described the frustration of trying to communicate, maintain social connections and how difficult this could be. All but one of the stories attempted to articulate the struggles of aphasia; narrating the difficulties and frustrations of knowing what they wanted to say but being unable to say it. The one person with aphasia tweeting a positive story provided an account of how accessing services had helped in their recovery.

Networking and connecting through Twitter

Tweets where the primary purpose appeared to be networking with other Twitter @Users were sparse and were predominantly authored by academics. Networking tweets were largely conversational, directly mentioning the person with whom they were corresponding in the tweet. These tweets often thanked others for engaging in research or activities outside of social media, such as providing professional development, advice, or support for research or clinical activities. Some tweets also allowed users to engage with other @Users in order to share resources and ideas by passing along links to external sites, to organise in-person meetings and collaborations, and to encourage connectivity in Twitter by encouraging mutual acquaintances to follow one-another. Analysis of the sample revealed that the Twitter platform is not yet used for engagement in shared activities and discussion, with no tweets reflecting a "live discussion" taking place on any topic related to aphasia.

Discussion

Using purposive sampling to collect tweets tagged with #aphasia and related hashtags resulted in a small but useful dataset of 2,519 tweets. Perhaps reflecting the invisible nature of "aphasia" noted in the content of the tweets analysed, this sample is considerably smaller than appears in hashtag studies examining the content of tweets and network density for tweets sent about neurogenic conditions such as traumatic brain injury (TBI) (Brunner et al., 2018) and Motor Neurone Disease (MND)/Amyotrophic Lateral Sclerosis (ALS) (Hemsley et al., 2017). It must be noted, however, that such studies with considerably larger samples used computational forms of analysis, and this study used hand coding and reading and re-reading for an in-depth consideration of each tweet as a text. Furthermore, the number of tweets in this study exceeds the 2,000 tweets that have been postulated as the minimum requirement to derive a data-driven model of tweet content (O'Dea et al., 2015). Overall, the sample size in this study is comparable to other health-related hashtag studies (see Donelle & Booth, 2012; Krueger & Young, 2015) producing meaningful results on the analysis of 2,400 and 1,135 tweets, respectively.

The Twitter community interested in aphasia

The results of this study suggest that, at least during a month in which speech-language pathology and aphasia-related conferences occurred, Twitter discourse on aphasia is influenced heavily by professional users – academics, researchers, aphasiologists, clinicians, and related students. As in other hashtag studies related to communication disability (Brunner et al., 2018; Hemsley et al., 2017), tweets passing along information in the form of retweets were the most common types of tweets sent, and originally authored tweets were produced by a relatively small number of users in the sample. With the majority of original tweets and annotated retweets having a research focus (e.g., regarding conference presentations, research recruitment, or dissemination), the resulting dominance of the professional "voice" in the network differed to the consumer-focused voice observed in the TBI Twitter network, collected during a period that included TBI awareness month (Brunner et al., 2018); wherein the TBI Twitter network primarily contained messaged from people with TBI, with only a very small representation from health professionals. However, this relatively high representation of professional voices in Twitter communities using aphasia-related hashtags also raises the possibility that people with aphasia or their families do not typically add #aphasia or related hashtags, and that other Twitter data collection methods should be used to determine more about the ways people with aphasia and their families are using the platform (Hemsley et al., 2014). Reflecting the findings of previous research, health professionals aiming to reach people with aphasia in their audience might need to follow these individuals in Twitter so as to understand more about their lived experience with aphasia and determine other hashtags that could be used to unify the groups (Brunner et al., 2018; Hemsley et al., 2015).

   That speech-language pathologists were the most frequent professional contributors to the sample might reflect this discipline's key role in working with people with aphasia and using Twitter and social media (Hemsley & Bowen, 2014) to engage with the others professionally (Clement, 2019). This may reflect the lack of awareness of aphasia outside the discipline and the propensity for speech-language pathologists to treat colleagues as

their main audience for tweets conveying information about aphasia. This suggests a need for these professionals to expand their discussion through use of hashtags reaching out to other disciplines and including mentions in tweets to gain the attention of other groups and promote a wider dissemination of content with the general public. The appearance of a single tweet about swallowing disorders tagged with #dysphasia, but not #dysphagia, appeared to indicate that the tweeter had mistakenly used the tag #dysphasia instead of #dysphagia. Although only impacting one tweet, this is an important finding, as if user groups wish to use the platform to inform the public about aphasia, it is important that terms are defined clearly; the consistent use of "aphasia" rather than "dysphasia" could help to resolve errors in use of the term in general (Worrall et al., 2016).

Perhaps somewhat poetically reflecting their communication disability, people with aphasia and their family members were relatively quiet in this sample of tweets. While Twitter users might be tolerant of poor spelling or grammar, use of the platform requires some level of linguistic and operational competence in what is primarily a text-based form of communication. It is unlikely that the expansion of the Twitter text field from 140 to 280 characters has increased the text demands, but its high demands for both reading and writing function might reduce the number of people with aphasia who engage with Twitter for interaction and communication. Additionally, the minimised technological capabilities and engagement of people with aphasia (Menger et al., 2019) could also contribute to their limited use of Twitter. While language demands of social media no doubt contribute to reduced engagement with technology, co-occurring motor, visual and cognitive impairments also act barriers to technology access (Kearns et al., 2019). This might suggest that people with aphasia require greater support to engage with social media from their rehabilitation providers (Brunner et al., 2018).

Purposes of using Twitter in relation to aphasia

The primary purpose of tweets shared in the Twitter network using aphasia-related hashtags was to share information through Pass Along tweets; retweeting content written by other users. There were very few conversational tweets when compared to a similar study of TBI hashtags (Brunner et al., 2018). There were no Twitter hashtag chats in the sample, reflecting a paucity of interaction between Twitter @Users to engage about topics relating to aphasia and collaboratively build, extend, and share knowledge, particularly with a wider audience beyond speech-language pathology or professionals working in the field of aphasia. There were also considerably fewer Status Broadcast tweets about aphasia than in previous hashtag studies about communication disability (Brunner et al., 2018; Hemsley et al., 2015; Hemsley & Palmer, 2016).

In this study, tweets conveying personal stories of aphasia, advice for people with aphasia and their family members, and tweets raising awareness communicated several negative experiences, reflecting poor of interactions of people with aphasia with the public, retail or other businesses, and health or other service providers. People with aphasia highlighted barriers when they were spoken to in a way that did not support their aphasia or conversely in a way that treated them as if they had intellectual rather than communication disability. There is limited public awareness of aphasia amongst the general public (Flynn et al., 2009; Guinan & Carroll, 2019; McCann et al., 2013; Simmons-Mackie et al., 2002), and the results of this study suggest that some Twitter users attempted to address this by tweeting factual information about aphasia. However, with minimal public engagement evident in the aphasia hashtag community, it is not known whether these

awareness-raising tweets would be effective in removing barriers to communication for people with aphasia or in changing the attitudes of the public towards people with aphasia.

Limitations and directions for future research

As previously noted, although the sample size of tweets retrieved and included in this study is smaller than previous hashtag studies examining communication disability associated with MND or TBI using computational methods, it is comparable in size to other health-related hashtag studies yielding meaningful results (Donelle & Booth, 2012; Krueger & Young, 2015). Hashtag research using the Twitter search bar is inherently limited to locating public tweets and does not include tweets from @Users who have set their profile to "private". Therefore, the data sample cannot be considered as representative of all tweets about aphasia owing to these inherent limitations of public data collection. The prospective data collection techniques used in this study were designed to yield as many of the tweets sent as possible in the one-month period of sampling. Nonetheless, this date-range limitation meant that retrospective data drawn into the sample and appearing out of the date range, which might have yielded additional insights to the analysis, were excluded from the research.

This study informs several areas of future research. First, a larger sample of tweets tagged with all aphasia-related hashtags (i.e., collected prospectively over a 3–6 month period that includes an aphasia awareness month, as in Brunner et al., 2018) would likely yield a larger sample with which to verify and confirm the themes identified in this study. In addition, retrospective research including tweets from any date range appearing in the Twitter search could also provide additional insights into the use of Twitter in relation to aphasia by the various @User groups.

Second, people with aphasia and their family members who use Twitter (i.e., as identified in this or future hashtag studies) could be approached directly for permission to collect and analyse the publicly available tweets drawn from their individual Twitter profiles. This would be inclusive of tweets that are not tagged with aphasia-related hashtags, and that are conversational tweets or status broadcast tweets to followers (Dann, 2010). This could provide additional insights into how people with aphasia use Twitter, and enable further network analysis (i.e., showing more about the size and density of each @User's Twitter network), content analysis (e.g., of tweets relating to their lived experiences), and linguistic analysis (i.e., of text produced, and conversational discourse) to be performed.

Third, interviews could be conducted with people with aphasia and their families who use Twitter to understand their views and experiences on using Twitter to read tweets, engage and share information, connect with others, raise awareness of communication disability, or improve their communication skills. Interview research that includes analysis of social media data could show how people with aphasia integrate or align their use of Twitter with other social media platforms including Instagram, Facebook, or Tik Tok, which capitalise on the use of images, including photos and videos or other multimedia, more than text.

Finally, considering (a) the inherent risks of using social media relating to safety (e.g., privacy, trolling, cyberbullying) (Duggan et al., 2017; Katz et al., 2014), and (b) that people with communication disability are potentially at increased risk of harm owing to their difficulties communicating, future research should also gather the views of people with aphasia and their health professionals on any adverse events experienced in social media, and ways to support their safe and enjoyable use of social media, including Twitter, throughout the various stages of aphasia rehabilitation.

Conclusions

Aphasia-related hashtag communities in Twitter are emergent in terms and their size and the strength of their connections; comprising mostly health professionals and researchers interested in aphasia. Speech-language pathologists in particular are using Twitter to share information with their colleagues about aphasia but exhibit very little interaction or discussion in the network. Overall, Twitter is underutilised as a platform for building collective knowledge on aphasia or for collaboration. The predominant professional user-base is not necessarily obtaining the greatest impact in their existing Twitter use through the audience for their tweets being ostensibly professional colleagues. The theme of "aphasia" being invisible in society provided a strong impetus for tweeters in the network to use the platform to raise awareness about aphasia and its impacts. Tweets from or about people with aphasia designed to raise awareness reflect a limiting and disempowering reality for many individuals who encounter negative attitudes and stereotypes (e.g., of having low intelligence) in their communicative interactions with others in the real world.

However, as people with aphasia are not necessarily included in discussions between professionals about aphasia, their perspectives may be absent from online information that could improve public awareness of the challenges they face. Efforts of health professionals to engage people with aphasia in the Twitter discussions could improve the richness of Twitter content relating to aphasia, and lead to greater engagement between health professionals and the people they serve, and the general public using Twitter. Future research should examine the experiences and views of both people with aphasia, health professionals, and researchers or aphasiologists on ways to optimise the use of the platform, in particular how its affordances may be used to full capacity for the social marketing of information about aphasia, and to foster discussion and conversation about aphasia that connects this important online community.

Disclosure statement

The authors have no conflicts of interest to declare.

ORCID

Lucy Bryant 🔗 http://orcid.org/0000-0001-8497-7406
Melissa Brunner 🔗 http://orcid.org/0000-0001-6823-5189
Emma Power 🔗 http://orcid.org/0000-0002-2638-0406
Bronwyn Hemsley 🔗 http://orcid.org/0000-0002-6255-3140

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