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Two Studies on Twitter Networks and Tweet Content in Relation to Amyotrophic Lateral Sclerosis (ALS): Conversation, Information, and ‘Diary of a Daily Life’

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Abstract. To date, there is no research examining how adults with Amyotrophic Lateral Sclerosis (ALS) or Motor Neurone Disease (MND) and severe communication disability use Twitter, nor the use of Twitter in relation to ALS/MND beyond its use for fundraising and raising awareness. In this paper we (a) outline a rationale for the use of Twitter as a method of communication and information exchange for adults with ALS/MND, (b) detail multiple qualitative and quantitative methods used to analyse Twitter networks and tweet content in the our studies, and (c) present the results of two studies designed to provide insights on the use of Twitter by an adult with ALS/MND and by \#ALS and \#MND hashtag communities in Twitter. We will also discuss findings across the studies, implications for health service providers in Twitter, and directions for future Twitter research in relation to ALS/MND.

Keywords. Twitter, tweet content, Amyotrophic Lateral Sclerosis, Motor Neurone Disease, severe communication disability, Twitter research

Introduction

Twitter is as an important platform for information exchange in relation to health conditions \cite{1} and, in bypassing speech and supporting short messages, a valued method of text-based communication for people with severe communication disability who cannot rely on natural speech to communicate \cite{2, 3}. However, there are no studies reporting on the use of Twitter as a rapid source of high quality health information on Amyotrophic Lateral Sclerosis (ALS) and Motor Neurone Disease (MND) a method of communication for adults with ALS/MND, or as an instrument of social participation improving quality of life in adults with ALS/MND. Therefore, little is known about how Twitter is used by people with ALS/MND who have severe

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communication disability, either as a timely source of high quality health information, a method of communication, or as a form of interaction and engagement online.\textsuperscript{2}

In this study we aimed to test the feasibility and utility of (i) gathering Twitter data from the Twitter profile of an adult with ALS/MND and from Twitter searches for relevant tweets tagged with #ALS or #MND and minor related tags, and (ii) using qualitative and quantitative analyses, including manual and computational coding of tweet content, to identify patterns in the use of Twitter in the data. The methods and findings of two small-scale studies using different types of Twitter data related to ALS will be presented. Implications for healthcare providers using Twitter to communicate information to adults with ALS/MND and their families will be discussed, along with directions for future Twitter research in ALS/MND.

1. Methods

1.1. Data Collection and Analysis Methods

1.1.1. Study 1: Tweet Data Collected from a Single Twitter Profile of an Adult with ALS

In 2015 we obtained ethical approval from The University of Newcastle, Australia, to harvest the tweets of adults with severe communication disability, with recruitment via Twitter. In this paper we report on data obtained from one Twitter user (pseudonym ‘Hab’) a middle-aged adult who had ALS/MND for over ten years (i.e., prior to the start of Twitter in 1996) who was not able to use natural speech and used a speech generating device to communicate. At the time of data collection, Hab had used Twitter for at least five years, and had between 5-10,000 followers. Informed consent was obtained to harvest tweets from Hab’s Twitter profile using NCapture \textsuperscript{[4]}, yielding 4625 tweets in continuous weeks over 2-year period. Informed consent was also obtained for an online interview to verify researcher interpretations, but this was abandoned owing to Hab’s time constraints and to reduce the impact of the research on Hab.

1.1.2. Study 2: Twitter Hashtag Study Using #ALS and #MND and Related Tags

In 2016 we obtained ethical approval from The University of Newcastle to harvest tweets including #ALS, #MND and related hashtags previously identified as highly relevant in a scoping study to seek ethical approval for use of a list. In this study we did not differentiate ALS tweets from MND tweets, as it was apparent that many tweeters were using the tags synonymously. From 22,687 tweets harvested we created a purposive sample, by excluding (a) duplicate tweets, (b) fundraising tweets originating from one suspended account, (c) tweets with identical content sent out at different time intervals from many accounts, and (d) tweets tagged with #ALSIceBucketChallenge or #StrikeOutALS. This process resulted in 18,062 tweets being deleted and N = 4625 tweets being included in the sample.

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1.2. Analysis of Tweet Data in Study 1 According to the Structural Layers of Twitter

Bruns and Moe [5] described three structural layers of Twitter corresponding with the positioning of the @ symbol, and the use of hashtags, on tweets. Tweets starting with the @ symbol are directed to a specific tweeter, and form the ‘micro’ layer of Twitter. Tweets without the @ symbol at the front are intended to appear in followers’ timelines, and form the ‘meso’ layer; and tweets with a hashtag added are intended for followers and non-followers alike, in the ‘macro’ layer. In this study, the first author and a research assistant separately coded tweets as ‘macro’ ‘meso’ or ‘micro’ layer tweets, with differences of opinion on coding resolved by consensus. All tweets in Study 2 are in the macro layer of Twitter so were not coded by this method of analysis.

1.3. Analysis of Data in Both Studies According to Twitter Content Classification

Dann [6] created a Twitter Content Classification system with five major categories for: (i) conversation (tweets mentioning another user), (ii) news (announcement and journalism), (iii) pass-along (sharing links to other Internet content), (iv) social presence (showing connection with other Twitter users), and (v) status broadcast, reflecting Twitter’s use as a ‘soapbox’ where users communicate their thoughts, feelings, experiences, and ‘diary of a daily life’ content. The first author and a research assistant separately coded tweets according to these content classifications with differences of opinion on codes resolved by consensus.

1.4. Analysis According to the Gephi Method for Study 2

The NCapture program [4] is able to capture all publicly available data (tweets and retweets) originating directly from a specific Twitter account, as well as data arising from a search for tweets that use a particular hashtag. The NVivo10 program [7] was used to convert the captured Twitter data into Microsoft Excel spreadsheets. The spreadsheet Twitter data were exported in comma separated values (CSV) format, and then imported into the Gephi program [8] to visualise the communication network embodied in the data. Gephi can be used to represent Twitter user accounts as ‘nodes’, and the communication path (representing one or more tweets) between two nodes as an ‘edge’ [see 9]. The Fruchterman-Reingold layout algorithm [10] was chosen to display the data in this study.

1.5. Analysis According to the KH Coder Method for Both Studies

The text analytics software package KH Coder [11] was used to analyse the text content of tweets collected. KH Coder supports a range of text data analysis and visualisation methods, and we used the co-occurrence network (CON) [12]. Co-occurrence refers to the presence of two (or more) terms in the same text unit of analysis. In this study, we were interested if the same term groups frequently co-occurred in individual tweets. KH Coder uses the Jaccard distance [13] (the dissimilarity between sample sets) as a measure of co-occurrence for term pairs. Based on specifying the minimum frequency of occurrence of a term for inclusion in the CON analysis and visualisation, terms appear as nodes in a network plot based on the Fruchterman and Reingold layout algorithm [9]. Frequently co-occurring terms in the visualisation are connected by lines/edges. The relative frequency of terms is shown by
the relative size of their node, and the relative frequency of co-occurrence of terms is shown by the relative thickness of the edge connecting their nodes. This method of analysis was used in both studies for comparison. Participants in both studies referred to both ‘ALS’ and MND, interchangeably. The KH Coder visualised ALS as ‘AL’, and MND as MND.

2. Results of Study 1 – An Adult with ALS and Severe Communication Disability

The analysis of Hab’s tweets in terms of the structural layer of Twitter used revealed that almost half (40%) of Hab’s tweets (N = 4625) were directed towards the micro layer of Twitter (n = 1864); 34% were directed to the meso layer (n = 1552), and only 26% (n = 1209) were directed towards the hashtag audience in the macro layer. Thus, the majority of Hab’s Twitter activity would potentially not be detected in a hashtag study. The content analysis revealed that the vast majority (~85%) of Hab’s tweets were conversational (n = 2089, or 45%) or for passing along Internet content (n = 1841 or 40%). Hab also used Twitter as a ‘soapbox’ with 664 (14%) being coded in the status broadcast category. News and social presence categories were minimally represented when combined (n = 31, ~1%). The KH Coder Co-Occurring Network visualisation on Hab’s tweets (see Figure 1) revealed a large cluster with many connected nodes, reflecting use of Twitter for: (i) a cluster relating to passing along Internet sites, in connection with an ALS/MND non-profit organisation, ‘stories of people with ALS/MND’; linked to (b) Internet sites, activities, products, sales; linked to (b) ‘use’ of assistive technologies. Six un-linked clusters revealed use of Twitter to communicate ‘new + happy + year’ (celebration); ‘today + go’ (daily activities), ‘great + meet’ (social engagement), ‘very + thanks’ (much gratitude), ‘feel + when’ (feelings in moments), and kisses ‘xxx’ connecting ‘hope’ and ‘love’ (love and support). It is important to note that emotion related concepts appeared in Hab’s sample (e.g., hope, love, feel, happy). In Figure 1, KH Coder converts ALS to ‘AL’ in its representation.

![Figure 1. The KH Coder Co-Occurrence Network (CON) visualisation of tweets in Study 1](image-url)
3. Results of Study 2 – A Twitter Hashtag Study on #ALS and #MND

The observable features of the Gephi layout (see Figure 2) which displays 3674 tweeter nodes, are: a near-centre ‘eye’ that is the focus of undirected tweets; a purple ‘whirlpool’ around the eye which is mainly users that have tweeted on one of the tags to no one in particular; a red area outside of the whirlpool which is mainly users who have mentioned other users in the tweets that included the tags; and an outer halo of users only using the tag(s) in micro tweets directed to other people. Also, the visualisation shows a more complex area of tweet interaction in the mid-top where the interconnections are more complex. This activity occurs around the nodes of non-profit organisation providing services and support to people with ALS/MND. It is important to note that Hab authored only 23 tweets in the data set, and is one of the nodes in the red area.

Figure 2. The Gephi visualisation of tweet data in study 2

The content classification analysis of tweets in the hashtag study (N = 8675) reflected the primary purpose of passing along Internet content (n = 7331 or ~85%). However, the conversational tweets (n = 696 or 8%) also added meaning to the set,
carrying sentiments of support, sympathy, concern, and encouragement; and the status broadcast tweets ($n = 551$ or ~6%) added meaning to the ‘fight’ concept by the use of poetic hashtags (e.g., #ALSsucks, #KissMyALS, #KeepHoping #NeverGiveUp #IveGrownAccustomedtoALS). Other content categories were few ($n = 97$/~1%).

The KH Coder Co-Occurring Network visualisation of the #ALS and #MND shows nine clusters of concepts (see Figure 3) being: (a) three connected clusters: (i) ALS/MND, activity of support associations, retweeting or passing along links related to fundraising, with the concepts of families, support and gratitude; (ii) raising awareness, quest for treatment and cure, awareness raising and help; and (iii) research translation, with co-occurring concepts of research, news, and stories, related to help and support; and (b) six separate clusters: (i) nutrition and other progressive conditions, (ii) ALS/MND guideline, (iii) challenge + video + life, (iv) ALS + job, (v) join + event (participation), and (vi) ‘fight + motor + neurone + disease’ (battle). It is interesting to note that the KH Coder graphic of this ‘macro’ layer of tweets does not feature the same emotional concepts as found in Study 1, reflecting that research including all structural layers of Twitter will be needed for a full appreciation content relating to ALS/MND.
4. Discussion and Conclusions

This Twitter research revealed differences between the personal story as observed and synthesised in the study of one adult with ALS/MND using Twitter, and the public story, as observed and synthesised via the #ALS or #MND hashtag study. Study 1 revealed more about the emotions communicated using Twitter than Study 2. The low frequency of Hab’s tweets in Study 2 reflect the importance of using both single case and large group designs in exploring how people with ALS/MND are using Twitter to communicate. The clusters of topics differed across studies and when combined could inform future social media research aiming to investigate ‘living with ALS/MND’. The findings suggest that Twitter is an important communication platform for people with ALS/MND and severe communication disability that is under-utilised as an instrument for facilitating discussion with this group. This supports the findings of research on the use of Twitter by local health organisations, who favoured its use for giving information [1]. The methods used in the studies outlined were feasible, yielding rich data but incurring little additional time or effort for participants. Directions for future research include using these methods with larger groups, and as an adjunct to traditional research methodologies, to explore both the use of Twitter by people with ALS/MND and communication disability, and the lived experiences of people with ALS/MND and their family members.

References


