Twitter networks and tweet content in relation to Amyotrophic Lateral Sclerosis (ALS): Conversation, information, and ‘diary of a daily life’.

How Twitter looks to a speech pathologist and an engineer

Bronwyn Hemsley and Stuart Palmer

@bronwynhemsley @s_palm

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dedication
Simon Greenway
@SimonGreenway

wishing all those affected by #mnd #als worldwide the highest quality of life possible in 2013 - world disease that needs a world solution

7:03 AM - 1 Jan 2013
Simon Greenway
@SimonGreenway

sorry for lack of tweets - back soon

1 RETWEET 2 LIKES

1:33 AM - 11 Feb 2013

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Aims

(a) use of Twitter as a method of communication and information exchange for adults with ALS/MND, 
(b) multiple qualitative and quantitative methods used to analyse Twitter networks and tweet content in the our studies, and 
(c) 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. 
(d) findings across the studies, implications for health service providers in Twitter, and directions for future Twitter research in relation to ALS/MND. 

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Methods

Twitter networks and tweet data

(a) Twitter data collection (single case + hashtag study)
(b) Structural layers of Twitter (Bruns & Moe, 2014)
(c) Content classification of tweets (Dann, 2015)
(d) Computational coding: qualitative and quantitative (Gephi; KH Coder)

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Data collection

• Identify relevant tags (scoping study re ALS/MND)
• Ethical approval for both studies
• Single case: Ncapture retrieval of tweets from profile of Twitter user with ALS/MND (keep all tweets)
• Hashtag study: collection of relevant tagged tweets using Twitter search function and Ncapture, Nvivo, and Excel (exclude spam and advertising/fundraising tweets/tweets not in English)
Structural layers of Twitter

Twitter is used for many communicative purposes – for conversations between friends and strangers, discussions in hashtag communities, and statements to follower networks.

Bruns and Moe (2014) conceptualised Twitter as having ‘structural layers’.
MICRO: Tweets starting with an @user are directed to a specific tweeter, and form the ‘micro’ layer of Twitter.

MESO: Tweets without the @user at the front are intended to appear in followers’ timelines, and form the ‘meso’ layer of Twitter.

MACRO: Tweets with a hashtag are intended for followers and non-followers alike, in the ‘macro’ layer of Twitter.
Content classification of tweets

(i) Conversational (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),
(v) Status broadcast, reflecting Twitter’s use as a ‘soapbox’ where users communicate their thoughts, feelings, experiences, and ‘diary of a daily life’ content.
Stuart Palmer @s_palm · 7m
@BronwynHemsley Good to have some demo tweets that you can use/show freely.

Bronwyn Hemsley @BronwynHemsley
@s_palm this is a Conversational Reply tweet, to Stuart.
10:05 AM · 22 Jul 2016

Bronwyn Hemsley @BronwynHemsley · now
Expressing my thoughts, experiences views, in a Status Broadcast tweet here: I am looking forward to visiting @DeakinSEBE again next week!

Bronwyn Hemsley @BronwynHemsley · now
A Live Conference #HIC16 tweet would be classified as a 'news' tweet (according to coding content categories we used, by @stephendann)

Bronwyn Hemsley @BronwynHemsley · 8s
Note to self - remember to download the @HISA_HIC conference app!

HIC 2016 @HISA_HIC · Jul 21
You Retweeted
Looks like this could be the strongest competition yet for the #HIC16 #selfie comp

Louise Schaper @louise_schaper
Who will win the best #HIC16 #selfie competition?
Gephi visualisations

**Figure 1.** Twitter network visualisation schema used in this paper.
KH Coder visualisations

Co-occurrence network: refers to the presence of two (or more) terms in the same text unit of analysis.
Study 1: tweet data collected from a single Twitter profile of “Hab” an adult with ALS*

*Pseudonym
Middle aged adult with ALS/MND >10yrs
Used Twitter > 5 yrs
Informed consent to harvest tweets
4625 tweets harvested
All approved for analysis
No quoting in reporting
Consented to interview
Interview not possible
Hab's tweets: Content classification

- Conversational
- News or Social Presence
- Pass Along
- Status Broadcast
Figure 5. The **Gephi** visualisation of tweet data in study 1
Figure 6. The KH Coder Co-Occurrence Network (CON) visualisation of Hab’s tweets Study 1
Study 2: Twitter hashtag study using #ALS and #MND and related tags

The terms ‘MND’ and ‘ALS’ in tweets were treated together, reflecting interchangeable use of the terms by hashtag communities.

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.
Status Broadcast tweets conveyed ‘diary of a daily life’ by people with ALS/MND (e.g., #ALSsucks, #KissMyALS, #KeepHopeing #NeverGiveUp #IveGrownAccustomedtoALS).
Figure 8. The Gephi visualisation of tweet data in study 2
Figure 9. The KH Coder Co-Occurrence Network (CON) visualisation of tweet data in Study 2
Multiple methods help

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 synthesized 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.

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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-utilized 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].
Directions for Future Research

• methods are (more) feasible, yield rich data and incur no additional time or effort for participants.
• use these methods with larger groups
• explore the lived experiences of people with ALS/MND and their family members.
• use Twitter to ***listen*** to the symptoms, progression, and end of life care of adults with ALS/MND
• use Twitter as a public health intervention for people with symptoms of ALS/MND (what messages?)
• use Twitter as a social care intervention for supports to participation and quality of life of people with ALS/MND
• what discussions could be useful?

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References


References


