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Brunner, Melissa; Hemsley, Bronwyn; Dann, Stephen; Togher, Leanne & Palmer, Stuart. "Hashtag #TBI: a content and network data analysis of tweets about traumatic brain injury" Published in Brain Injury, Vol. 32, Issue 1, Pages 49-63, (2018)

Available from: <https://doi.org/10.1080/02699052.2017.1403047>

This is an Accepted Manuscript of an article published by Taylor & Francis in Brain Injury on 08/12/2017, available online:

<https://www.tandfonline.com/doi/full/10.1080/02699052.2017.1403047>.

**Accessed from:** <http://hdl.handle.net/1959.13/1383862>

**Title:**

#Hashtag TBI: A Content and Network Data Analysis of Traumatic Brain Injury-related Tweets

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**Running head:** #TBI: Analysis of TBI-related tweets

**Keywords:** Twitter; Social networks; Traumatic Brain Injury; Communication Disorder; Cognitive Disorder; Rehabilitation

**Hashtag #TBI: A content and network data analysis of Traumatic Brain Injury-related tweets**

**Abstract**

**Objective.** The aims of this study were to: (a) determine how Twitter is used by people with Traumatic Brain Injury (TBI) and TBI organisations, (b) analyse the Twitter networks and content of tweets tagged with TBI-related hashtags, and (c) identify any challenges people with TBI encounter in using Twitter.

**Research Design.** Mixed methods in a Twitter hashtag study.

**Methods and Procedures.** Tweets tagged with TBI-related hashtags were harvested from the Twitter website over a one-month period in 2016 and analysed qualitatively and quantitatively.

**Results.** The sample of 29 199 tweets included tweets sent by 893 @users, 219 of whom had a brain injury. Twitter was used to: (a) discuss health issues, (b) raise awareness of TBI, (c) talk about life after TBI, (d) talk about sport and concussion, and (e) communicate inspirational messages.

**Conclusions.** Twitter is an important platform for research and knowledge translation on TBI, and for hearing the voices of people with TBI as they express their personal views and stories of living with TBI and become more visible and influential in Twitter communities. TBI clinicians could use these narratives of people with TBI in Twitter to develop more effective and personally meaningful rehabilitation goals.

## **Hashtag #TBI: A content and network data analysis of Traumatic Brain Injury-related tweets**

In recent years, there has been a steady growth in the body of literature concerned with the use of social media by adults with communication disability [1,2]. With expanding use of digital technologies in society and for everyday communication, there is an increasing need for online communication skills to be incorporated into rehabilitation goals [2]. To date, the majority of social media research in the field of communication disability has focused on experiences of individuals with lifelong communication disability [3-8] and people who use Augmentative and Alternative Communication (AAC) [1,4,9,10]. However, people with acquired communication disability also use social media to facilitate connections with friends, family, and with health professionals [2,9,11]. And yet, research in this area is limited in scope. Brunner [11] reviewed the use of social media by people with traumatic brain injury (TBI), and concluded that most research had focused on Facebook, with a greater emphasis on the risks of social media than on its benefits.

TBI is an important cause of preventable morbidity and mortality, with an estimated annual incidence of 295 people per 100 000 of the population experiencing a TBI worldwide [12]. In Australia, more than 1 000 000 people have an acquired brain injury (ABI) with over half living with disability [13] and TBI accounting for over 60 percent of the country's non-fatal injury burden [14]. Cognitive-communication disability following TBI can be diverse and long-lasting [15,16], and social isolation with loss of friendships after TBI is common [17]. The impairments people have after their TBI can restrict their ability to live independently, return to work or education, participate socially, and maintain existing or build new interpersonal relationships [18]. Adolescents and adults with cognitive-communication impairments associated with TBI, face challenges in accessing information independently and engaging effectively in social networks [18]. Currently, little is known

about how people with TBI use social media safely to access information, communicate, and participate socially [11].

Thus far, very little social media research in the field of communication disability examines the use of Twitter [1]. Twitter has potential as being an important platform for people with acquired communication disability, because of its short message length reducing demands on written literacy [9]. As yet, few researchers have made use of publicly available social media data to examine how people with acquired communication disability are using the platform [19,20] and there are no studies examining the use of Twitter by adults with communication disability following a TBI. Their communication needs and online skills are likely to differ from people with lifelong disability, owing to their (a) cognitive-communication impairments, (b) stable or improving communication skills through recovery and rehabilitation, and (c) complex sequelae of TBI. This group might struggle to use Twitter, which is often reported to be confusing [21,22] and hard to learn [23]. Nonetheless, using social media platforms including Twitter may empower people with TBI by providing a valuable means of expression online. Given the use of social media platforms as a form of social marketing [24,25], Twitter may also have the potential to raise awareness of the general community participating in discussions or awareness campaigns about TBI. Therefore, it is important to obtain a deeper understanding and appreciation of how people with TBI might use Twitter to engage in public discourse, to exchange information, and to build public networks online.

### **Twitter for communication research**

Twitter (<http://www.twitter.com>), is a microblogging social networking site (SNS) used globally by millions of users [26]. Microblogging involves writing short messages on the Internet designed to communicate what the user is doing, thinking, or feeling [27].

Twitter is an information network that allows users to post short messages frequently (up to

140 characters) called ‘tweets’ [28] and is accessed via the Internet using a range of software applications [29]. The platform is considered a universal method of communicating digital content quickly [26]. Each user on Twitter establishes an account with a username preceded by ‘@’. Twitter @users can include images, videos, or links to other online material to be seen by their ‘followers’ who follow their Twitter account [28], and also non-followers who might see their tweets by clicking on a hashtag (e.g. #TBI), or viewing the @user’s profile. To pass along content to their followers, Twitter @users can re-tweet or quote a tweet, and @reply to other user accounts in conversational tweets [28].

As approximately 90% of Twitter accounts are publicly available (i.e. not protected) [30], Twitter is also a rich source of data yielding insights into peoples’ lives, and also the way they are using the platform to communicate content. There is a growing body of literature relating to the collection and analysis of Twitter data and networks [31]. Twitter hashtag research specifically involves searching Twitter for tagged tweets, collecting these tweets, and using a range of analytic methods to make sense of and display the data [32].

### **Twitter and cognitive-communication research**

Social media may offer people with TBI a useful way to connect with family, friends, and the broader community online [11]. However, using social media including Twitter might also pose several challenges, particularly in relation to the operation of communication technology and the social pragmatics associated with TBI [2]. Therefore, the aim of this research was to: (a) understand how Twitter is being used by TBI communities, including people who self-identify as having had a TBI, and organisations involved in advocacy, support, and fundraising for people with TBI; (b) gather and determine tweet content and Twitter networks evident in tweets tagged with TBI related hashtags; and (c) identify any challenges people with TBI face in using Twitter, considering tweets as an artefact of their attempts. The results of the study could inform the development of: (a) training or supports

for adults with TBI to use Twitter; (b) guidance for the general public to obtain information about TBI using Twitter; (c) strategies for TBI organisations to support people with TBI in their effective use of Twitter to connect with a range of audiences; and (d) a future research agenda exploring the use of Twitter in the field of TBI and cognitive-communication rehabilitation [1,2,11,33].

### **Method**

This Twitter hashtag study was conducted with ethical approval of the University of Newcastle. It involved harvesting relevant tweets (including original tweets and retweets) from Twitter for a mixed methods analysis using established computational and hand-coding methods [34-36]. A systematic Twitter search process [4,19,20,32,34-36] used the most commonly occurring TBI-related hashtags, previously determined through repeated scans of Twitter, as follows: #ABI, #brainawareness, #braininjury, #braininjuryawareness, #braininjuryawarenessmonth, #brainweek, #concussion, #concussionawareness, #concussionmovie, #headinjury, #hopeafterheadinjury, #ibia2016, #mtbi, #notaloneinbraininjury, #TBI, #traumaticbraininjury, #tbiaffectedme, #tbiawareness, and #tbisurvivor. One month in 2016 (March) was randomly selected from three national TBI awareness months in 2016 for data collection. Tweets captured through a search in Twitter are typically limited in quantity and time frame [36]. Therefore, to capture the most tweets possible using the Twitter search bar, tweets were collected on a daily basis from 1<sup>st</sup> to 31<sup>st</sup> March 2016. Tweets were captured using NCapture [37], and imported into NVivo [38] before being exported to Microsoft Excel [39] for further analysis. Tweets outside the date-range of data collection and duplicate tweets were removed so that only original tweets and retweets sent in March 2016 were retained. Tweets were then examined to exclude: irrelevant tweets and those not related to TBI (e.g. if hashtag #TBI referred to ‘Team Bring It’); tweets written in a language other than English; tweets that contained no text; spam (e.g.

bulk advertising); and advertisements (e.g. for competitions). This was done to increase the relevance of the tweet content to meet the aims of the research.

### **Data analysis**

**Twitter @user profile data.** Tweets in the dataset were analysed both qualitatively and quantitatively using a variety of methods. The quantitative analysis determined the overall number of tweets and the number of unique contributors (@users) [32]. The bio statements of unique @user profiles were classified as @users who: (a) have a TBI or were a family member of a person with TBI; (b) were in a field related to TBI (e.g. a TBI organisation); or (c) were the general public or other. This information provided context to the qualitative analysis of the data.

**Computational analysis: Gephi and KH Coder visualisations.** The computational analysis of the tweets involved using two free software programs, Gephi [40] and KH Coder [41], to analyse the Twitter networks and text content respectively [36]. Using Gephi, an open source network visualisation tool, the Twitter network data was displayed graphically to visualise the connections between @users as they interacted [36]. A Fruchterman-Reingold layout from Gephi was used as its properties lend itself to production of the best visual clarity of large network datasets [42]. In the graphic, communication paths are referred to as an ‘edge’ and are presented as curved lines, with the direction of communication being clockwise along the edges, with the thickness of an edge being proportional to the amount of tweets sent between the two nodes in that direction [36]. Thus, Gephi visualisations display the paths that tweets travel either to ‘the world’ (undirected to another @user) or to other @users (directed) [36].

The visualisation software KH Coder [41] conceptualised the content of the tweets according to an algorithm relying on co-occurring frequency and distance of words in the tweets (i.e. a co-occurring network). The multidimensional scaling (MDS) plot computes



‘similarity’ between words in the tweets [43] and was derived using the Jaccard distance measure [44] and the Kruskal distance scaling method for dimensional reduction [45]. The co-occurrence network (CON) computes text that frequently co-occur in the tweets [43], terms appear as circles in a network based on the Fruchterman and Reingold (1991) layout algorithm, and connecting lines indicate the relative strength of the association between terms by the thickness of the line. As the software builds the graphics according to an algorithm affected by word frequency in the texts, the arrangement of the word or word fragment concepts in the graphic is independent of researcher’s interpretation of concepts appearing in the data [20]. Colour coding schemas are also applied to emphasise different term clusters within the network, though they are only indicative.

**Content classification of tweets.** Tweet content was coded using Microsoft Excel [39] data sorting and filtering processes according to Dann’s content classification [35], as follows: (i) Conversational tweets, in which the user communicates directly with another Twitter user (i.e. the tweet includes an @user); (ii) News tweets, containing identifiable news content (i.e. journalism and reporting on real-time events such as conferences); (iii) Pass-Along tweets, to share information between users (e.g. retweets, curation of and sharing links to other Internet content); (iv) Social presence tweets, showing connected presence with other Twitter users as if they are in the room (e.g. ‘hi everyone’ or ‘thank you!’); or (v) Status Broadcast tweets, expressing the user’s thoughts, feelings, and experiences [35]. The first author coded the tweets and a research assistant provided consensus coding, with any discrepancies resolved by the second author.

**Qualitative content analysis.** The conversational and status broadcast tweets were further coded inductively in Excel [39] according to their qualitative content themes [20,34]. Tweets were read and re-read by the first author and the second author. In an iterative process, coding of the tweets proceeded until the first two authors agreed on both the overall

framework of the tweet coding categories and on the individual codes applied to each tweet. Connecting themes across the categories were also identified for comparison with the computational analyses visualised using Gephi and KH Coder. This was done as a means of confirming and triangulating the qualitative analysis [20,34].

**Linguistic analysis.** Following the qualitative analysis, tweets identified as being written by people with a TBI were further analysed by their linguistic content [46]. A brief psycholinguistic and sociolinguistic screening of tweet content was conducted by the first author to observe communicative function for any difficulties previously observed in people after TBI [18,47]. Tweets were examined for spelling or grammatical errors [48], and for cohesive adequacy and completeness [49] (i.e. whether the tweet made sense). Additionally, tweets were examined to detect whether @users followed the recommended social etiquette of using no more than two hashtags per tweet to avoid the appearance of being spam [50,51].

## Results

The hashtag search yielded 508 NCapture files, containing 65 084 tweets dated from the 21<sup>st</sup> of February 2016 to the 31<sup>st</sup> of March 2016. Duplicate tweets and tweets outside the date-range of 1<sup>st</sup> to 31<sup>st</sup> March 2016 were removed ( $n = 12\ 503$ ), leaving a total of 52 581 tweets in the sample. Applying the exclusion criteria removed a further 23 382 tweets, leaving 29 199 tweets remaining in the dataset for analysis. The multi-stage data collection process is shown in Figure 1.

Insert Figure 1 about here

Twitter profile data was examined and coded as follows: (a) 131 of the 893 unique Twitter @users were coded as having a TBI ( $n = 53$ ), working in TBI-related areas ( $n = 76$ ), or being a family member of a person with TBI ( $n = 2$ ); (b) 422 @users were coded as ‘other’ as the bio provided no insight into their interest in TBI; and (c) 343 @users were coded as ‘unknown’ as the bio provided no insight into their identity (e.g. their @user profile

contained no information or was written in a language other than English). On reading of the tweets, it was apparent that a further 166 Twitter @users had written tweets disclosing their TBI, resulting in a total of 219 @users being coded as having a brain injury. Figure 2 presents the information gathered about Twitter @users with TBI and their supporters.

Insert Figure 2 about here

### **Content classification**

The content classification analysis is presented graphically in Figure 3. The vast majority of tweets were in the pass-along category ( $n = 23\,077$ ), reflecting the primary use of the platform being to share content on TBI through almost effortless retweets ( $n = 15\,289$ , or 52%) or by composing tweets that included links for passing along to other Twitter @users ( $n = 7\,788$ , 27%). The sample also included conversational tweets ( $n = 4\,000$ , or 14%) and status broadcast tweets ( $n = 1\,419$ , or 5%), with a relatively small number of news tweets ( $n = 406$ , 1%) and a very small proportion of social presence tweets ( $n = 297$ , 1%).

Insert Figure 3 about here

### **Computational analysis**

**Network visualisation of results.** The Gephi visualisation, presented in Figure 4, revealed a complex network of multiple communities engaging in a large amount of communication about TBI. The Gephi visualisation reflects: (a) straightforward sharing and retweeting of undirected tweets by @users in the network; (b) complex connections and/or interactions between @users; (c) a collection of ‘plumes’ in the visualisation each representing relatively large volumes of retweeting of a single user at the centre of each plume (i.e. an individual acted as a hub sending information out to others not connected to the larger community); and d) small groups of two or more users sharing TBI-related tweets, with no connection to the main TBI Twitter network. The high proportion of retweets and links help to explain the ‘busy’ nature of the Gephi visualisation.

Insert Figure 4 about here

**Content concept visualisation of results.** The KH Coder visualisations, presented in Figure 5, show largely complementary themes present in the text data or content of the tweets. One notable feature present in both the MDS and CON representations is relatively large circles for the terms ‘rt’ (i.e. retweet), and ‘concussion’. The MDS (Figure 5a) and CON (Figure 5b) visualisations revealed seven separately coloured clusters of concepts in the tweets, as follows: (i) retweets and links showing Twitter being used to disseminate information across all of the content categories, (ii) tweets raising awareness of TBI and related conditions, (iii) tweets discussing sport and TBI, with discussion on concussion being prominent, (iv) tweets describing everyday life with a brain injury, (v) tweets discussing mood and TBI, (vi) tweets describing rehabilitation and recovery after TBI, and (vii) tweets sending messages of hope and encouragement.

Insert Figure 5 about here

### **Qualitative content analysis**

Considering the very high volume of retweets, the inductive content analysis was restricted to the conversational tweets (i.e. those directed at another @user) and status broadcast tweets (i.e. undirected tweets sent out to no particular @user or ‘the world’ of their followers and people clicking TBI-related hashtags). In this smaller sub-set of tweets ( $n = 5419$ ), the content analysis reflected that Twitter was used for a variety of purposes, namely to: (i) discuss and share TBI-related health information; (ii) raise awareness of TBI-related issues including causes, symptoms, and associated disability; (iii) provide personal narratives of life experiences through having a TBI, including sharing poetic descriptions of TBI as an ‘invisible injury’; (iv) have conversations about recovery and rehabilitation after TBI; (v) discuss and share information on popular and/or controversial issues (e.g. sport and TBI, causal factors for TBI in sport, policy, litigation, conspiracy, and the ‘Concussion’ movie

which featured these topics); (vi) share positive, inspirational, and encouraging words to people with TBI and their families; and (vii) network and connect with others within Twitter TBI communities. These major categories of use align with those evident in the KH Coder MDS and CON plots (Figure 5). The conversational tweets conveyed social commentary ( $n = 479$ ), provision of information ( $n = 236$ ), promotion of events ( $n = 200$ ), small talk [52] ( $n = 149$ ), asking for ( $n = 11$ ) or providing support ( $n = 48$ ), and asking ( $n = 15$ ) or presenting an opinion ( $n = 27$ ). These purposes of the conversational tweets are displayed in graphic form in Figure 6.

Insert Figure 6 about here

There were seven categories of content topic in the status broadcast and conversational tweets, and these are presented graphically in Figure 7. Topic categories included: (i) TBI awareness ( $n = 916$ ), (ii) film and media on TBI ( $n = 530$ ), (iii) living with TBI ( $n = 423$ ), (iv) TBI services ( $n = 86$ ), (v) inspirational or motivational content ( $n = 42$ ), (vi) humour ( $n = 48$ ), and (vii) the impact of TBI on families and communities ( $n = 30$ ). The frequency of status broadcast and conversational tweets across these topic categories is presented graphically in Figure 7.

Insert Figure 7 about here

As shown in Figure 5 and Figure 7, tweets sent with the purpose of raising awareness of TBI were the most common, reflecting the awareness campaigns in the sampling period, particularly those led by TBI-related organisations such as Brain Injury Associations (US), Headway (UK), and Brain Injury Australia. Tweets discussing film, media, and life experiences of people with TBI were also prominent.

**Personal narratives of people with TBI.** All of the tweets coded as being about the life experiences of people with TBI were authored by people who identified as having TBI (either in their @user profiles or tweets). These tweets formed several topic sub-categories

(see Figure 8): (i) their feelings after TBI ( $n = 130$ ), (ii) their strategies for living successfully with TBI or overcoming difficulties ( $n = 72$ ), (iii) changes in cognition after TBI ( $n = 68$ ), (iv) changes in physical ability after TBI ( $n = 47$ ), (v) events relating to their TBI ( $n = 37$ ), (vi) rehabilitation after TBI ( $n = 43$ ), (vii) changes in activity and participation after TBI ( $n = 24$ ), and (viii) thoughts on TBI research ( $n = 1$ ). Tweets about their emotions or feelings, and cognitive changes after TBI appeared alongside tweets about the strategies used to help improve functioning. The status broadcast tweets contained little information on experiences of rehabilitation or changes in their activity and participation, and this information appeared primarily in conversational tweets ( $n = 41$ ). This suggests that people with TBI might be more likely to discuss their rehabilitation experience with individual @users (i.e. through conversational @reply tweets) than with followers as a group (i.e. using status broadcast tweets).

Emotional themes appeared across the tweet content categories, in expressions of: frustration, vulnerability, trauma related to TBI, acceptance of TBI, and emotional or other support of others which was coded as ‘generosity’ (see Figure 9). Frustration appeared in relation to experiencing ongoing, persistent problems, and impatience to improve more rapidly, to paraphrase: ‘just want to get better’. Vulnerability was also evident in emotive tweets that reflected the trauma of TBI in becoming exhausted or overloaded cognitively, and feeling ‘lost’, ‘disoriented’, ‘helpless’, anxious, or depressed, and the sentiment that TBI brings such sadness and tears ‘daily’. Physical pain after TBI and its impact on everyday life also featured in several tweets ( $n = 33$ ). However, there were also positive expressions of acceptance of TBI and dealing with its challenges in terms of living with a disability and accepting their new self, as in: ‘still learning how to understand the new me’. Many tweets reflected people with TBI and their family members generously sharing strategies that they had found ‘helped’ in recovery after TBI. Similar to adults with motor neurone disease [20],

they also sent inspirational messages of support to ‘keep going’, often contextualised with poetic hashtags (e.g. #hopeafterheadinjury and #notaloneinbraininjury).

Insert Figure 8 about here

Insert Figure 9 about here

**Film and media tweets on TBI.** Status broadcast tweets in the topic category ‘film and media’ related to the Concussion movie based on a novel of the same name [53]. The story was based on Doctor Bennet Omalu, a forensic pathologist and his work on Chronic Traumatic Encephalopathy (CTE) in professional football players and his dispute with the US National Football League (NFL). Omalu’s work in CTE and concussion research has raised the profile of the long term effects of repetitive trauma to the brain in footballers [54-56], as well as in other athletes and military veterans [57-60]. In the film, the US actor Will Smith played the part of Omalu [61]. Status broadcast tweets expressed opinions on the Concussion movie ( $n = 59$ ) in terms of its storyline or content ( $n = 108$ ), and on Will Smith’s acting ( $n = 98$ ), particularly his accent in the film, and controversy surrounding him not being nominated for an Academy Award [62]. Conversational tweets contained comments on the Concussion movie ( $n = 74$ ), commentary on the controversy of concussion in impact sports ( $n = 60$ ), and on other documentaries ( $n = 14$ ), e.g. Louis Theroux [63] on people living with brain injury [64]. Thus, Twitter served to amplify the public discourse about concussion in impact sports, through the ‘back-channel chat’ [65,66] from movie-goers and people watching the Academy Awards and documentaries about TBI.

**TBI awareness and TBI services.** As noted previously, TBI awareness-raising tweets appeared frequently, primarily in relation to concussion in sport ( $n = 423$ ). Tweeters discussed the controversy of CTE in sport and expressed their concerns for players’ well-being. To a lesser degree, TBI awareness tweets encouraged community education on TBI in general and asked for support for people with TBI ( $n = 140$ ). Tweets also passed along

information on symptoms, causes, and increasing incidence of TBI ( $n = 162$ ), and the associated increased financial costs to society ( $n = 44$ ). Advocacy tweets were also prominent ( $n = 187$ ), raising awareness of issues such as homelessness for people with TBI in conversations about politics, and encouraging training to support people with TBI. Tweeters also used the platform to discuss TBI research ( $n = 102$ ), providing their opinions on conflicts of interest in concussion research funded by the US NFL, and commenting on research priorities. For example, they identified a need for CTE research now and not waiting for the death of sporting celebrities who have elected to donate their brains for research after death.

TBI awareness tweets also contained information about recovery and disability following TBI ( $n = 85$ ), highlighting the increased energy required for rehabilitation efforts, the need for rest during recovery, the effects of cognitive fatigue, and the impact of early intervention on recovery. Many tweeters expressed the importance of accurate diagnosis and early intervention with qualified health professionals using evidence-based rehabilitation techniques. TBI awareness-raising tweets focused on popular culture and the media, including sports concussion ( $n = 423$ ), and the symptoms, incidence, and diagnosis of TBI ( $n = 141$ ). Reflecting use of the platform as a support network, there were more tweets about specific strategies from people with a TBI ( $n = 69$ ) than from health professionals and organisations ( $n = 13$ ). Relatively few tweets related to support networks ( $n = 24$ ), provided links to resources ( $n = 32$ ), or reflected information exchange with health professionals ( $n = 3$ ). For example, tweets about TBI services ( $n = 86$ ) reflected organisations ( $n = 28$ ) and health professionals ( $n = 10$ ) tweeting about the services that they provide for people with TBI. Health professionals also discussed their professional lives ( $n = 7$ ), including enjoyment in working in TBI rehabilitation, using technology for work, and using Twitter for discussing health matters. Some TBI service tweets promoted products ( $n = 16$ ) (e.g. first aid courses, apps for concussion diagnosis, massage therapy, exercise, yoga, cannabis, and dietary



supplements) reflecting use of the platform for the purposes of marketing health products and materials [67].

**Inspirational messages and humour about TBI.** Inspirational tweets - also referred to colloquially and in Twitter as #inspo tweets [68,69] - were small in number ( $n = 42$ ) but highly relevant to resilience and recovery in TBI [70-72]. Tweets contained statements of persistence ( $n = 13$ ), motivation ( $n = 11$ ), and hope ( $n = 11$ ). Tweeters encouraged people with TBI to ‘fight’, adapt, and learn from their mistakes in order to ‘win’ against adversity in the form of impairments, disability, or life in general after TBI. They wrote of brighter futures and offered motivational messages for people with TBI to take recovery one step at a time, and reminding them that every individual follows a different journey after TBI, requiring individual goal setting and persistence. Conversational tweets were sent to support one another in knowing that they are ‘not alone’ ( $n = 9$ ), but only two tweets reflected a sense of achievement as a survivor of TBI [73].

Humorous tweets also appeared in the data ( $n = 41$ ). Only a small number of these tweets were posted by people with a TBI ( $n = 7$ ), with most written by people who had hit their head accidentally or were making light of TBI ( $n = 29$ ). Humorous tweets were usually self-deprecating, involving hyperbole and exaggeration of their injuries (e.g. ‘slapstick’ type descriptions of them hitting their head) or shortcomings ( $n = 20$ ). Others likened negative experiences to having a TBI ( $n = 5$ ) (e.g. the trauma of watching a bad movie or reality television celebrities) or contained humour arising out of everyday situations ( $n = 4$ ). While inspirational messages from people with TBI were plentiful and positive, humorous tweets predominantly displayed ‘dark humour’ tweeted by people who did not have a TBI. People with TBI are often vulnerable to stigma and discrimination [74], reflected in brief in the ‘humorous’ tweets sent by people without TBI. This may support previous findings that public perceptions of TBI are quite negative [74].

**Impact of TBI on families and communities.** Tweets also provided insights into the impact of TBI on families ( $n = 20$ ), on communities ( $n = 30$ ), and on relationships ( $n = 6$ ). Parents tweeted about their child's progress after TBI and the effect of TBI on their feelings and functions (e.g. mealtimes and sleeping patterns) or their return to school or work. Some tweets reflected that TBI awareness month provided people with TBI and their families with an opportunity to express daily struggles, including changes after TBI in the person's mood and levels of fatigue. Tweets about the impact of TBI on relationships also provided insights into how changes as a consequence of TBI had affected their own mental health. Four tweets also noted the impact of increased awareness of concussion on sporting communities leading to negative changes in the public's enjoyment of or participation in sports associated with concussion.

### **Linguistic analysis**

Of the conversational and status broadcast tweets, 366 were written by people with TBI about their life after injury. Analysis revealed small numbers of tweets containing spelling ( $n = 10$ , 3%) or grammatical errors ( $n = 1$ , 1%). A greater number of tweets were observed to have punctuation or typographical errors ( $n = 62$ , 17%), typically represented by a lack of spaces between words or between words and period markers. This did not appear to affect the cohesion of the tweet message communicated, with only two percent ( $n = 7$ ) judged as being 'incoherent or incomplete'. Incoherent or incomplete tweets were those where the message could not be determined, and occurred due to a combination of the content being written in all capitals (i.e. with ambiguity), being only hashtags, or missing key information. In a very small number of tweets people with TBI expressed their difficulties with cognitive-communication ( $n = 8$ , 2%), such as difficulties with reading comprehension, spelling, and grammar. In these tweets, people with TBI reported that their tweets 'don't make sense' or that they struggled to be succinct, which is 'harder with 140 character limit'. Over a third of

the tweets ( $n = 132$ , 36%) contained three or more hashtags, with a range of one to 17 hashtags being used per tweet. More than two hashtags is considered ‘overuse’ as tweets containing multiple hashtags can be likened to spam and is not recommended for engagement [51]. People tweeting with a high number of hashtags, particularly as many as 17, might not be aware of how to use hashtags effectively in their tweets for engagement in the TBI community.

### **Discussion**

Our purposive sample of tweets tagged with TBI-related tags represents a robust sample ( $n = 29,199$ ), as health-related hashtag studies have reported useful results on datasets of less than 3,000 tweets [75-79]. Reflecting use of the TBI-related tags to pass along information in the form of retweets (52% of tweets overall) and links (27% of tweets overall), the sample contained only 6,122 tweets in other content categories (21% of tweets overall) and 893 unique Twitter @users. This suggests that although TBI is of global importance with relatively high incidence [80-82], the Twitter network surrounding TBI is active but under-represents the population of people with TBI and those affected by TBI [13,14]. Furthermore, the network is reliant on a relatively small proportion of tweeters producing original tweet content. Considering that data collection occurred in a TBI awareness-raising month, this might reflect that Twitter is under-utilised as a platform for communicating about TBI and could be used more effectively for raising awareness.

### **Twitter TBI networks include the voices of people with TBI**

The results of this hashtag study, reflected in the network analysis Gephi visualisation, KH Coder Graphics, content classification results, and qualitative content themes, suggest that Twitter is an important source of connection and engagement for people with TBI and their families, organisations who support them, and the general public. The voices of people with TBI can be heard in tweets tagged with TBI-related hashtags.

Triangulation of the data increased confidence in the results of the inductive coding of tweets, as computerised KH Coder content analysis aligned well with hand-coding, to reveal the views of people with a TBI on their day-to-day experiences. The tweets reflected that @users with TBI faced some cognitive-communicative challenges using Twitter that are consistent with those in the literature for communication disability after TBI [18]. However, beyond exhibiting some lack of awareness on the utility of using hashtags effectively, their tweet content did not display overt communicative or linguistic dysfunction.

An important finding is that people with TBI might turn to Twitter not only to publish their ‘diary of a daily life’ [35], but also to produce and consume inspirational messages of hope. This process reflects their role as social media ‘prosumers’, that is, they both produce and consume information [25]. Stories of hope, support, and empowerment have appeared previously in the personal narratives of people with TBI [83-86]. Hope is fundamental to achieving positive outcomes in TBI recovery [70] and is an important feature of depression after TBI [87]. Indeed, a recent review identified that hope is a critical factor in rehabilitation and recovery after TBI [72] and rehabilitation professionals aim to foster hope and provide the person and their supporters with information and ways to garner emotional or practical support from peers [70]. The results of this study reflect people with TBI as being prosumers of inspirational messages of hope, and using the forum to engage in supporting their peers. However, very few tweets related to rehabilitation experiences, and it is not possible to ascertain whether its use for a wide range of purposes impacts on either rehabilitation or mood following TBI.

### **Tweeting personal narratives about TBI**

The delivery and analysis of personal narratives via social media has not previously been reported in either TBI rehabilitation or TBI research. By adding a TBI-related hashtag to their tweets, people with TBI in this study not only deliberately and thoughtfully added

meaningful context to their messages [88], they also intended that these messages capture the attention of a wider audience (i.e. non-followers) in the ‘macro’ structural layer of Twitter [89]. Thus, people with TBI using Twitter demonstrate being visible and potentially influential online [1]. Creating personal narratives about their experiences is an important part of the rehabilitation process for people after TBI [83,90,91] as it may aid the individual to accept changes in their abilities, re-define themselves after TBI, and recover from their injury [73,83,84,91,92]. In addition, engagement in meaningful activities such as writing personal narratives is important in re-establishing a sense of self and improving quality of life after TBI [91]. While the impact of publishing personal narratives on Twitter cannot be determined solely by a focus on tweet data, Twitter might form an important avenue for people with TBI to express their personal views and stories, and for clinicians in the audience to make use of these narratives in developing more effective and personally meaningful rehabilitation goals [83,85,92].

Exploring an individual’s personal experience of their injury and their context can educate and inform both researchers and clinicians [83], and is crucial in delivering evidence-based practice [93,94]. Health professionals and family members could support people with TBI to publish narratives about their lived experiences on Twitter and reflect on these to make meaning of the experience and develop goals for the future [73]. However, it is not yet known if an appreciation of the tweets of people with TBI will help health professionals to frame personalised, meaningful care that is mutually developed – previously recognised as being crucial for people to successfully recover from their injury [83,84,91,92]. Problematic use of Twitter by people with TBI [95] was not evident in this hashtag data, although the platform does appear to be under-utilised. Given the opportunities that Twitter has to offer in the field of TBI, further investigation is warranted on how to help overcome barriers that

people with TBI might face when using Twitter, particularly if it is personally meaningful for the individual to be able to tell their story and connect online.

### **Raising awareness of TBI via Twitter TBI networks**

The results of this study show that organisations and health professionals used Twitter in March 2016, a brain injury awareness month, to communicate about TBI-related information in similar ways to that reported in the literature for other health conditions [96]. However, apart from the news tweets of ‘back-channel chat’ [65,66] accompanying the Academy Awards and the Concussion Movie, there was no evidence of ‘hashtag chat’ activity [97] on TBI-related topics. This suggests that the TBI hashtag community, which includes support organisations, might strive to use Twitter for awareness-raising, but lack strategic direction in relation to facilitating hashtag discussions now evident in a range of other health fields (e.g. Speech Language Pathology #WeSpeechies, Physiotherapy #PhysioTalk, Nursing #WeNurses, Medicine #FOAMed and #WeDocs, Healthcare Communications and Social Media #hcsn) and other health conditions (e.g. diabetes with #diabetes and #OzDoc, multiple sclerosis with #ChatMS). This suggests that there is room for growth in developing hashtag chats around persistent TBI-related hashtags. Although TBI support organisations use Twitter extensively to disseminate information about TBI (i.e. raise awareness and funds) the affordance of hashtags for promoting synchronous and asynchronous discussion [98] appear to be underutilised.

Park et al., (2016) found that Twitter followers are more likely to engage with content (i.e. to like and retweet tweets, or click on links) that is personal rather than organisational in nature [96]. As tweets in the sample reflected Twitter being used to engage with the broader community, organisations and health professionals could make more use of personal engagement tweets (e.g. conversational replies) to build up an active and engaged community conversing on TBI-related topics [96]. This study provides some evidence that Twitter is

useful in providing a platform for expression and amplifying commentary about popular media of films or TV about TBI. This may provide some limited insight into public perceptions of TBI [74,99,100].

The low number of research-related tweets in this study suggest that Twitter is not yet being used widely for research engagement or knowledge translation, even with the potential to reach and engage with a relatively large audience. TBI researchers in particular, and clinicians interested in contributing to knowledge translation in TBI, could more actively create and distribute TBI-related research findings [20]. Ensuring that research-related tweets are salient and are ‘heard’ in a high volume of tweets tagged with #TBI will be important if researchers are to also have a voice in TBI hashtag communities. Helping people with TBI to locate, sort, and evaluate the quality of information they find in Twitter using TBI-related hashtags might require greater engagement between @users with TBI, TBI organisations, and health professionals. With large amounts of information being in circulation on the TBI-related hashtags, it will not be sufficient merely to pass on TBI research-related news, as conversational tweets will grow in importance. Although this sample was not examined for quality of information distributed (i.e. information being accurate) researchers and health professionals could also use Twitter to counter misinformation about TBI and promote the sharing of high quality information [79].

In this study, tweets about the impact of TBI on families and communities resonates with earlier reports of TBI not only affecting the individual with TBI, but also being associated with trauma, recovery, and suffering in family members [101]. Researchers have shown that families and supporters of people with TBI considered they had received inadequate information and support from health professionals, particularly during transitions of rehabilitation or services [102]. Use of Twitter to communicate and share evidence-based TBI-related information may help to not only counter misinformation, but also make

evidence quickly accessible and personally relevant for a wider community of people living with TBI and their supporters [103,104]. There is complacency and arrogance in the belief that research publications can compete with the emotive messages of hope and miraculous cures that are shared via social media [104,105]. In order to be heard, healthcare professionals need to take ownership of marketing evidence-based research stories to make them more acceptable and so that they ‘stick’ in the minds of the community [106]. To do so, we need to actively engage within TBI networks online for knowledge translation and communication of scientific evidence [107-111]. As such, greater engagement with conversational @replies is required, providing balanced opinions and generating reasoned discussion, as simple retweets or brief comments may be misinterpreted and further perpetuate the spread of misinformation [103]. Given the complex sequelae and heterogeneity of individuals who live with cognitive-communicative disability after TBI [111], this will likely require frequent posting and engagement by multiple, experienced health professionals and researchers in the field of TBI to maintain currency and authenticity [103,104,106].

### **Limitations and future work**

As a hashtag study, the data examined only provides insight into the macro structural layer of Twitter. Furthermore, the sample collected was not intended to be either representative or a comprehensive set of all tweets sent about TBI in March 2016. Although the data collected also included tweets directed at other @users (i.e. conversational tweets) the results cannot be considered to reflect all topics of conversation appearing in Twitter for people with TBI. However, the conversations in this study are important, as they provide insights into the types of topics that people with TBI and their supporters intend for a larger audience. Returning to search Twitter for other tags which are clearly TBI-related yet less frequently used (e.g. #tbichat, #tbiresources, #tbisucks), following analysis of the content of the tweets, might have added further tweets to the sample. Furthermore, the dataset reflected



a sub-sample of each @users total tweets produced in that time period (i.e. only tweets tagged with TBI-related tags). While re-tweets and tweets with links were not subject to the level of scrutiny (i.e. inductive hand-coding) as the original conversational and status broadcast tweets, all tweets and retweets were included in the computational content analysis. It is possible that further hand-coding of the retweet data, and analysis of the links to online content in the tweets could have provided additional insights on the use of Twitter to communicate and share information about TBI.

People with TBI have similar patterns of social media use as the general public in their frequency of use and use of several different several different platforms [11, 95]. An in-depth understanding of how people with TBI experience using social media is therefore warranted, particularly as social media platforms are constantly evolving and changing [2,11,95]. Further research is needed to fully understand all of the ways that people with TBI and their supporters are using social media including Twitter. Interviews with tweeters who have a TBI could be used to further explore and identify their purposes of using the platform and any barriers to, or facilitators for those purposes being fulfilled [1,2,9,11]. Understanding more about this may help to strengthen a person with TBI's use of Twitter to connect with other people with TBI, engage with TBI support organisations, and interact with health professionals working in the field of TBI [1,2,11].

### **Conclusion**

The Twitter visualisations generated in this study reflected a large number of Twitter users, including several disclosing the presence of their own TBI or being a family member of a person with TBI. TBI communities, including people who identify as having a TBI, family members, TBI organisations and the public, use Twitter to discuss a diverse range of TBI-related topics. These topics range from personal narratives on living with TBI, to commentary on concussion in sport, and on popular film, media, and television about TBI.

The volume of tweets and retweets discussing TBI shows Twitter is an important platform for communication during a TBI awareness-raising month. The Twitter networks and tweet content reflect that while the number of tweets tagged with TBI-related hashtags is relatively large, there is underutilisation of the platform in terms of its strategic use for engagement and community-building, such as through the conduct of synchronous chats about topics that matter to people with TBI. TBI organisations included in the study's data used the platform to distribute information about TBI to the Twitter community. However, few tweets from either individuals with TBI or organisations supporting them provided any insight into rehabilitation following TBI.

The voices of people with TBI are particularly evident in conversational and status broadcast tweets using the hashtags #TBI, #braininjury, #concussion, #headinjury, #tbiawareness, #braininjuryawarenessmonth, #disability, #tbiaffectedme, #notalone, and #invisibleillness. It is apparent that people with TBI are using Twitter, through disclosure on their @user profile bio or in tweets tagged with TBI-related hashtags. While the study yielded some important insights into the ways people with TBI managed the functions of Twitter (e.g. tweeting, retweeting, inserting links, and using hashtags) and did not reveal patterns in errors in the tweets sent by people with TBI, it was not possible to determine whether the individuals involved experienced challenges in operating these functions. Nonetheless, the personal stories appearing in the data in this study suggest that using Twitter affords people with TBI the opportunity to express themselves publicly to outline their day-to-day challenges and strategies for managing their recovery.

Given the inclusion of people with TBI in the Twitter communities located in the data and the TBI-related information exchanged in Twitter networks, Twitter might be an important social media to consider further for use in TBI rehabilitation. Listening to the personal stories and inspirational tweets of people with TBI in Twitter could prove useful in:

(a) developing person-centred rehabilitation goals; or (b) stimulating further conversations with people with TBI about their views and experiences. Twitter could provide clinicians and researchers access to insights into the lived experiences of people with a TBI, as well as the opportunity to engage with a wide TBI community for research translation. Further research is needed to determine the experiences and views of people with TBI using Twitter, so that any supports necessary for them to engage in the Twitter community online can be identified and provided. By addressing barriers to and facilitators of using Twitter, people with TBI may be supported to develop their use of Twitter to become more visible and influential in Twitter communities. This might in turn provide benefit in terms of raising awareness of TBI, contributing vital voices to TBI awareness-raising months in Twitter.

#### **Acknowledgements and declaration of interest**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper. This research is funded through an Australian Government Research Training Program scholarship to the first author and a Discovery Early Career Research Award (Australian Research Council) to the second author.

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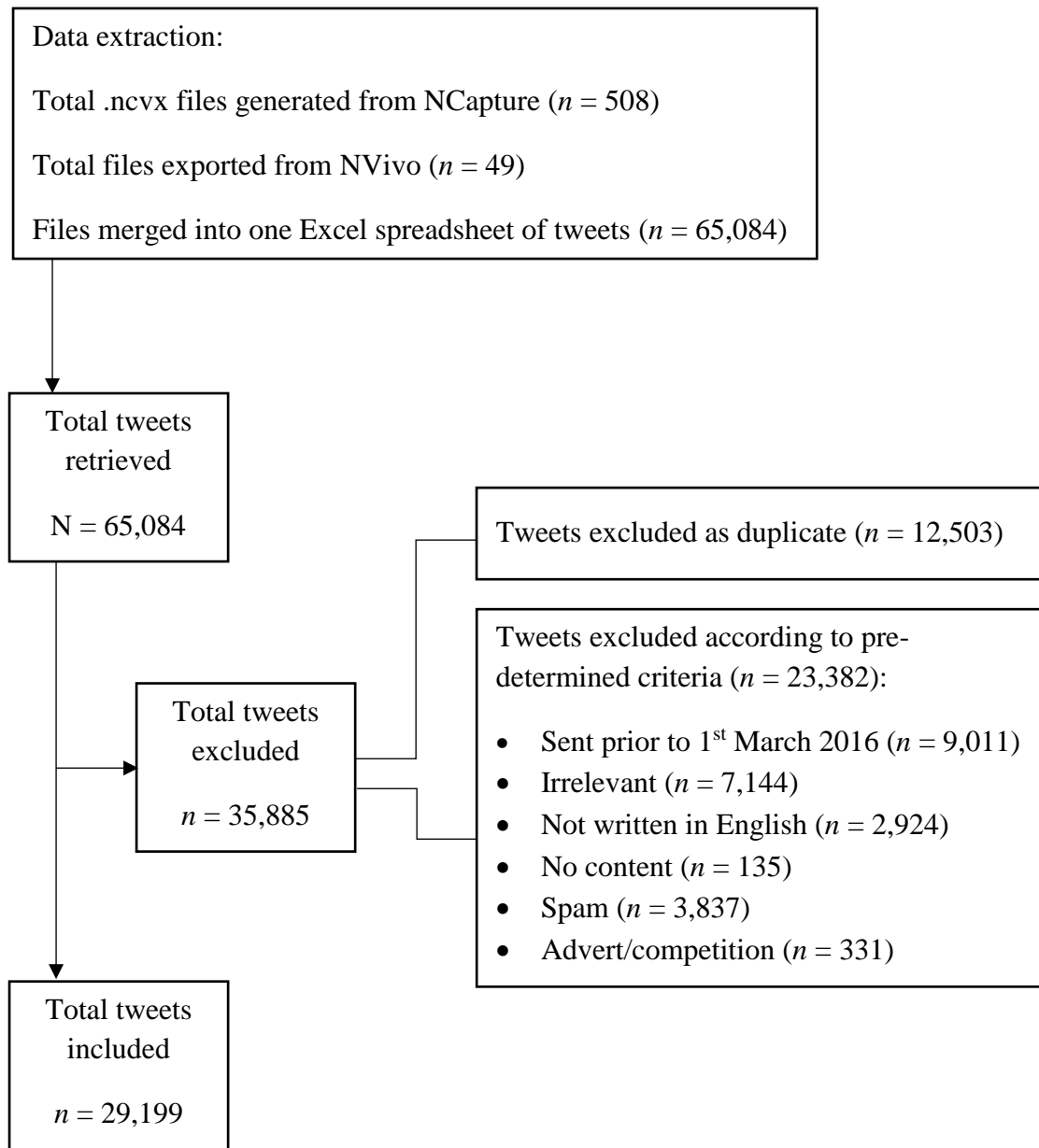
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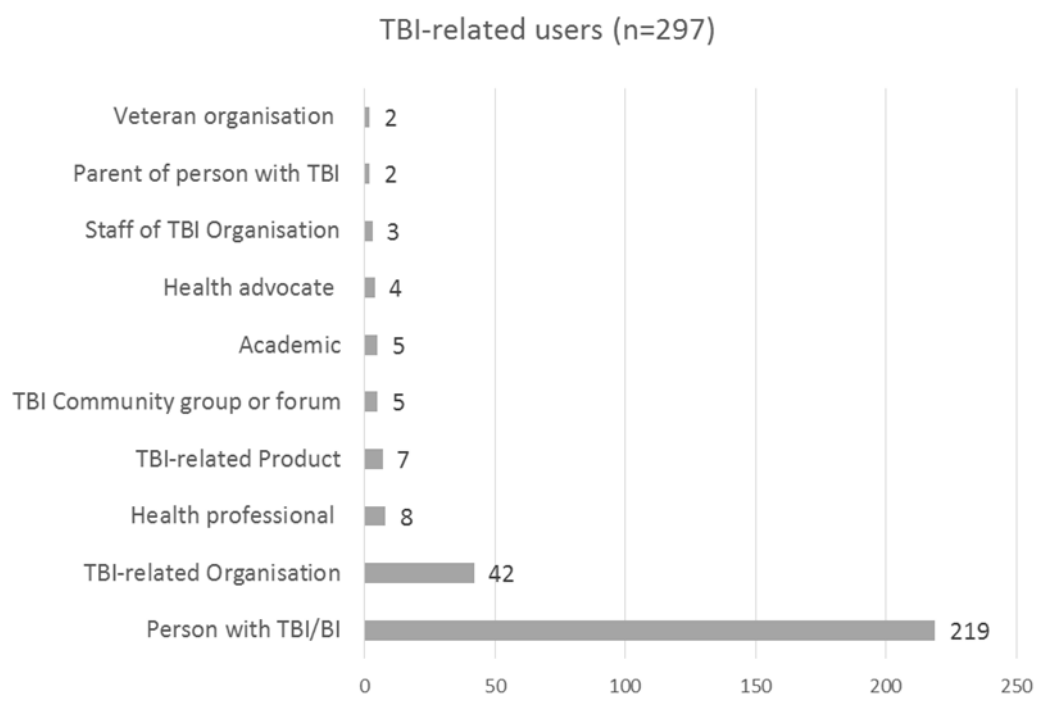


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**Figure 1. Systematic search results.**

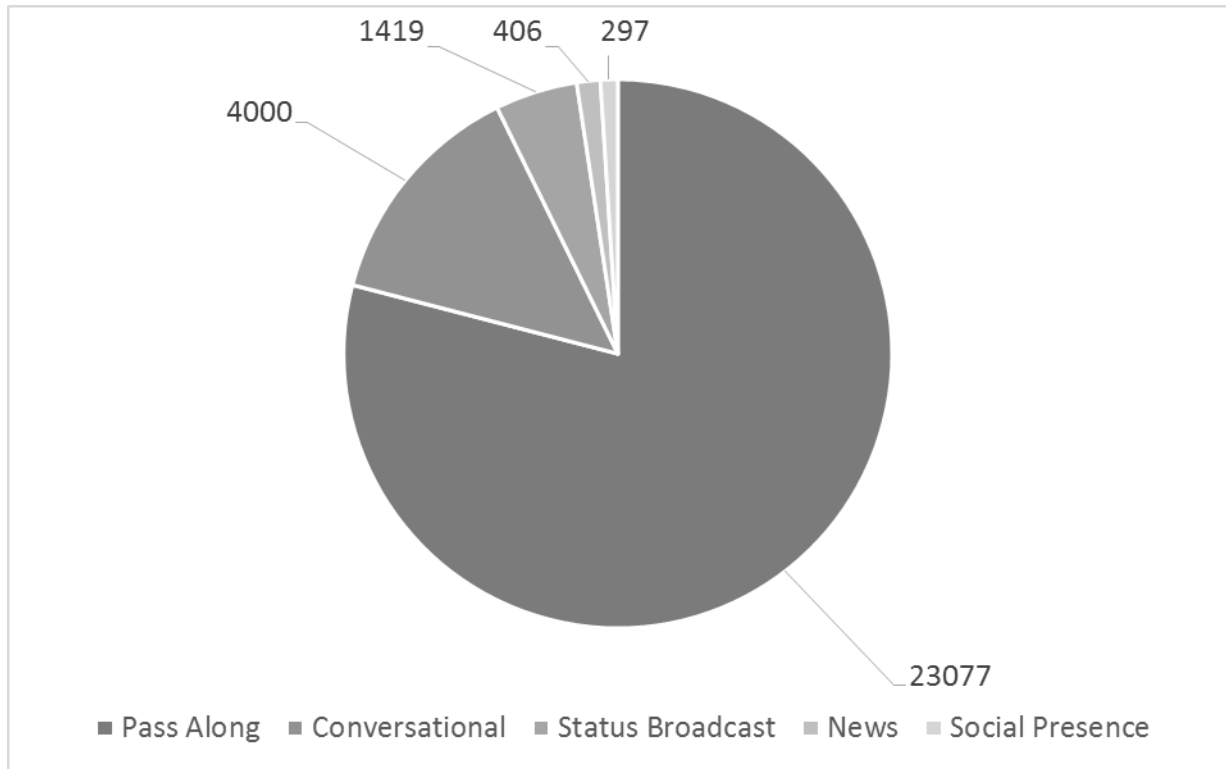


**Figure 2. Twitter @users with TBI and their supporters in the #TBI tweeting community.**

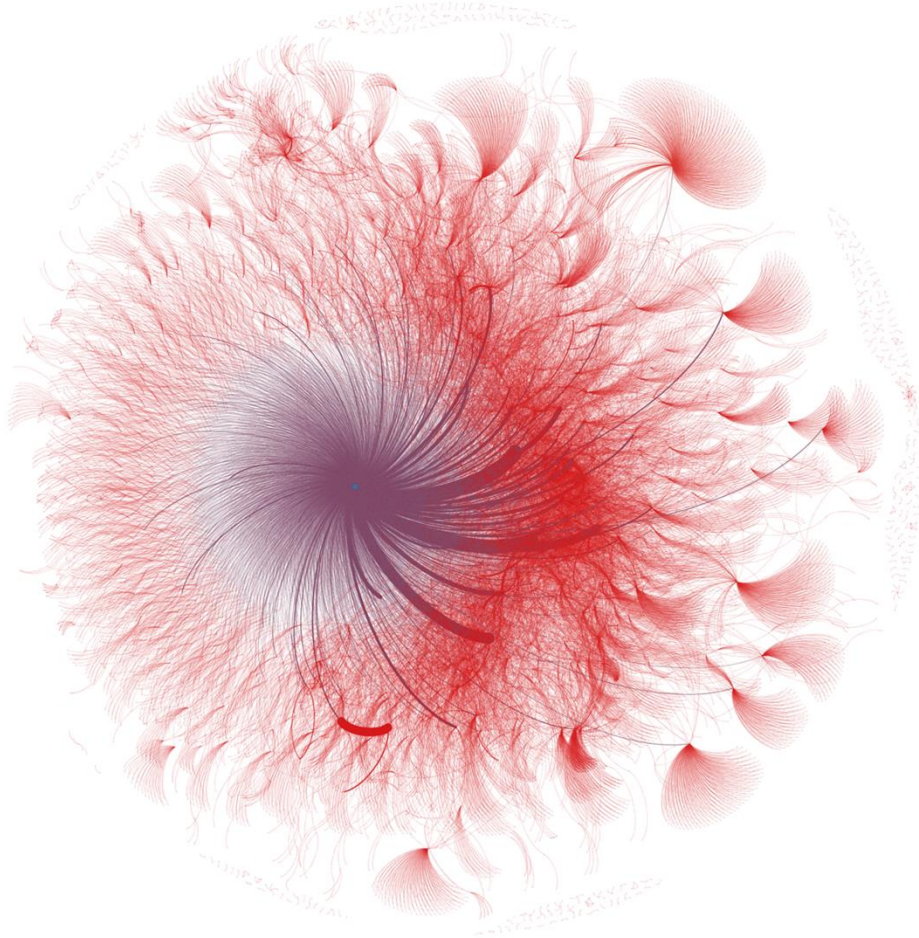


Acronyms: BI = brain injury; TBI = traumatic brain injury

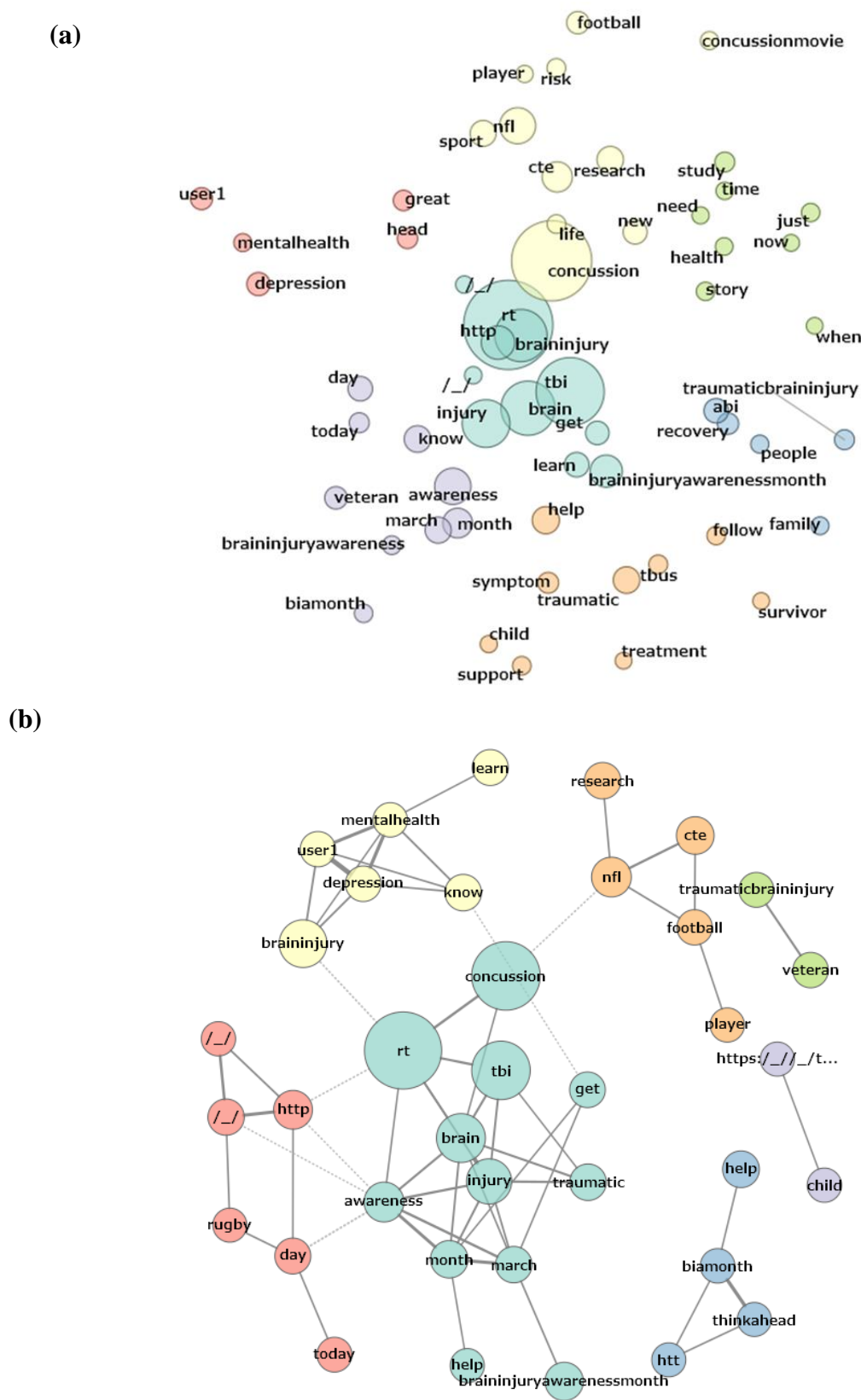
**Figure 3. Frequency of content categories of tweets.**



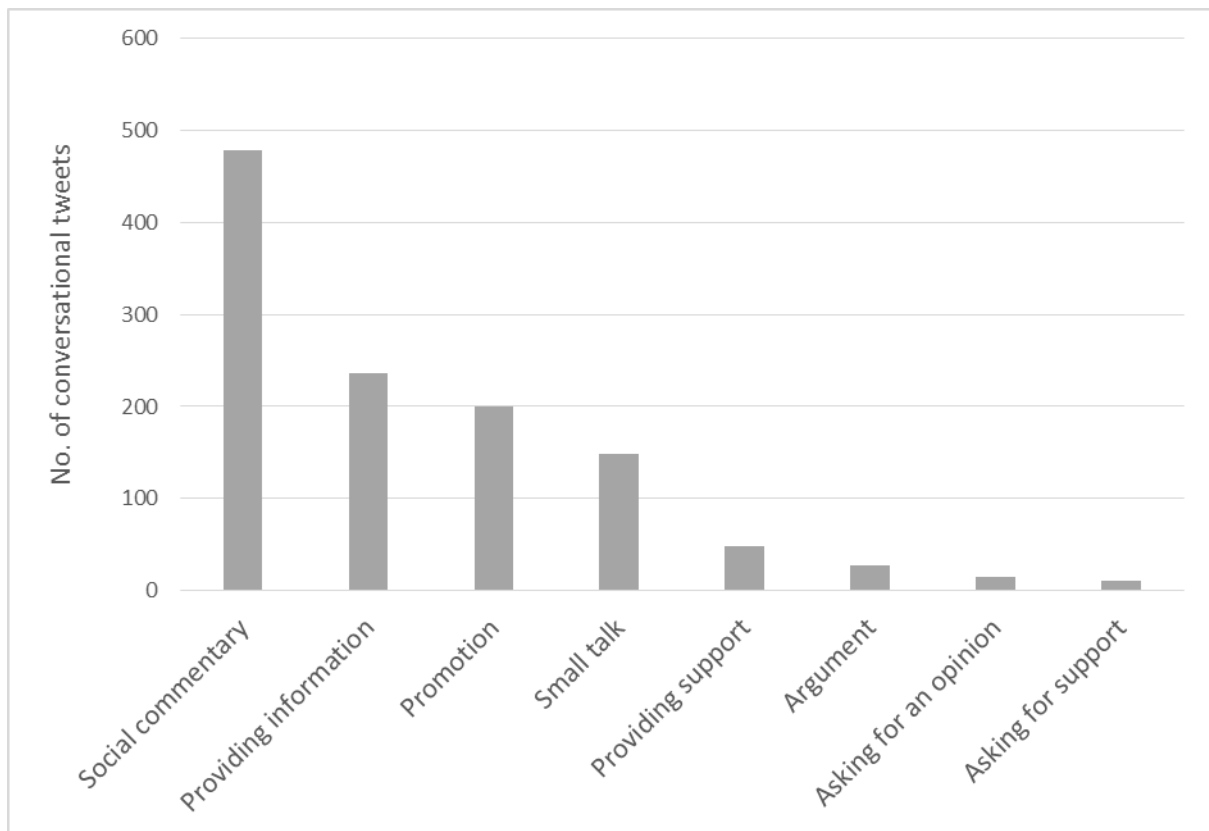
**Figure 4. Gephi network visualisation of the #TBI community.**



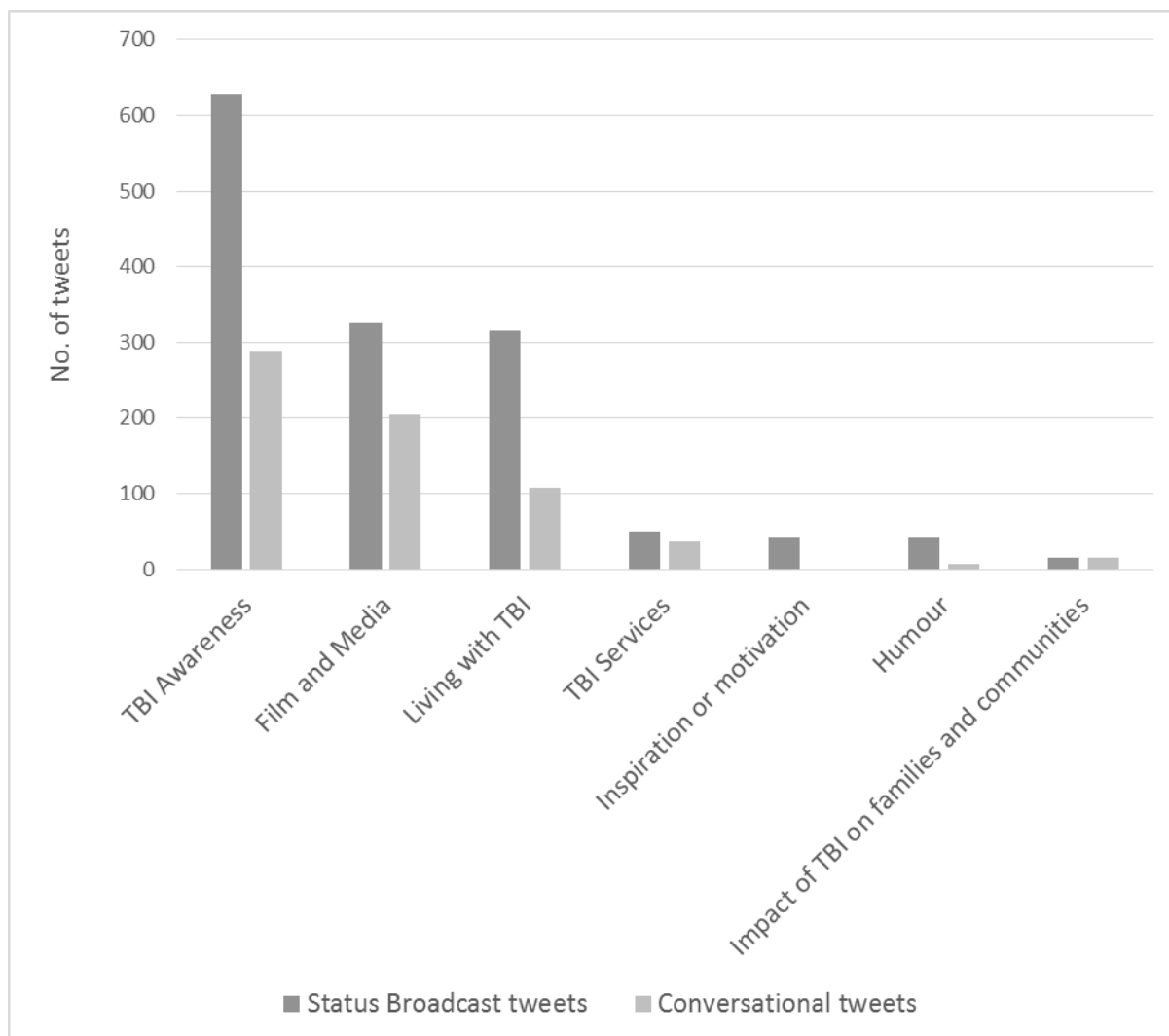
**Figure 5. KH Coder visualisation of tweet content concepts: (a) Multidimensional Scaling plot (MDS); and (b) Co-Occurrence Network (CON).**



**Figure 6. Features of conversational tweets.**

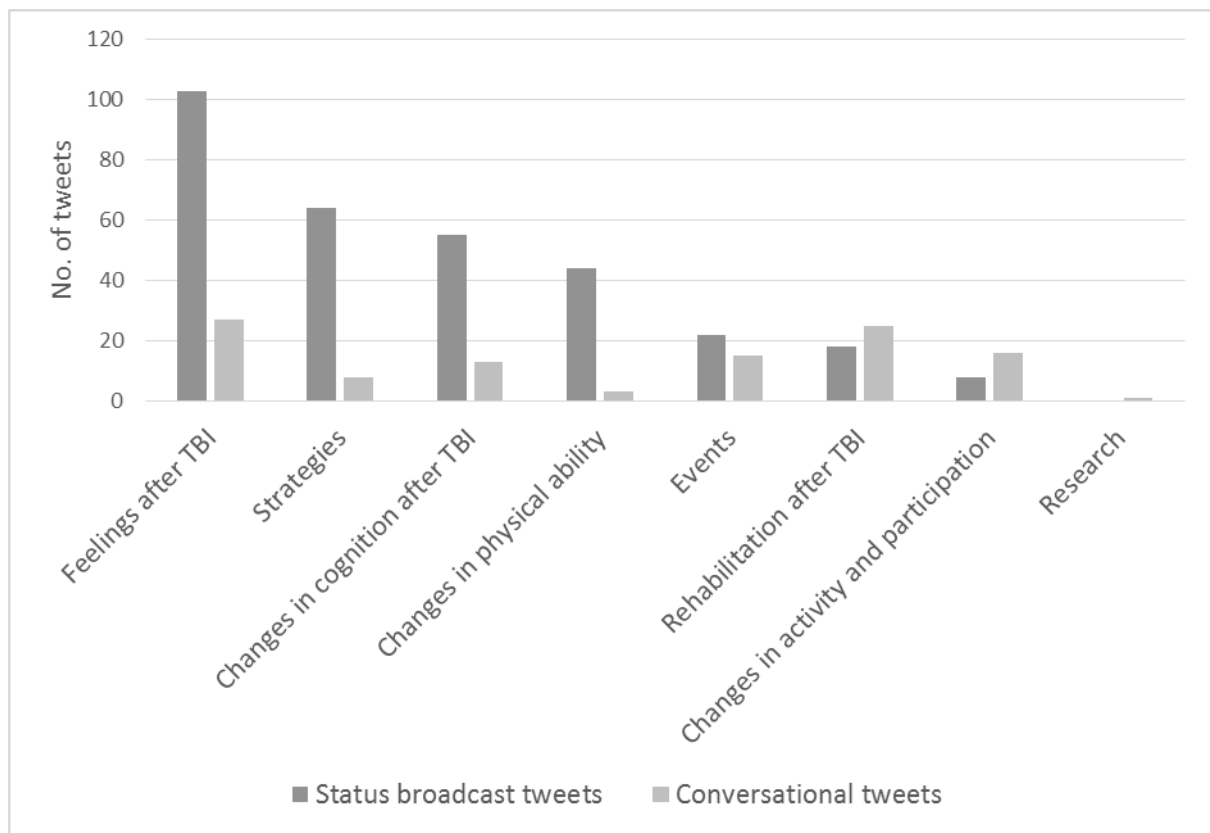


**Figure 7. Topic categories found in Status Broadcast and Conversational tweets.**





**Figure 8. Topic categories found in tweets containing personal narratives of people with TBI.**



**Figure 9. Emotional themes that connected tweets containing personal narratives of people with TBI.**

