Title

"If I knew what I was doing on Twitter then I would use it more": Twitter experiences and networks of people with traumatic brain injury (TBI).

Running Head

Twitter experiences & networks of people with TBI.

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Abstract

The aim of this study was to examine the Twitter experiences and networks of six adults with cognitive-communication disability after a traumatic brain injury (TBI). Using mixed methods, the study integrated: (a) quantitative analysis of Twitter networks using computational and manual coding of tweets; and (b) narrative analysis of in-depth interviews. Diverse experiences were evident, with two experienced and four novice users of the platform. However, all reported feeling connected and included, and identified both positive and negative experiences in their use of Twitter. Developing a supportive network facilitated higher frequency of tweets and increased feelings of enjoyment and connectedness. All expressed a desire to continue using or learning to use Twitter but novices lacked support from rehabilitation professionals or experienced Twitter users, and relied instead on a 'trial and error' approach. Proactive integration of Twitter use during rehabilitation after TBI is warranted to support safe, enjoyable, and meaningful use.

"If I knew what I was doing on Twitter then I would use it more": Twitter experiences and networks of people with traumatic brain injury (TBI)

The use of Twitter by adults with Traumatic Brain Injury (TBI) is of high relevance in the field of TBI rehabilitation, considering the high prevalence of TBI in young adults (Nguyen et al., 2016), the extensive use of Twitter by young adults in general for communication (Omnicore, 2019), and the devastating impacts of TBI on social communication (Elbourn, Togher, Kenny, & Power, 2017). TBI is most frequently associated with external trauma to the head from traffic and sporting accidents, trauma-related violence, and falls (Johnson & Griswold, 2017). The injury to the brain is complex, and typically affects the person's frontal and temporal lobes, often resulting in diffuse white matter changes (McDonald, Dalton, Rushby, & Landin-Romero, 2018). When considering how young adults with TBI might engage with social media, it is important to recognise the several physical and cognitive impacts of TBI on their potential engagement in online communication (Brunner, Hemsley, Togher, & Palmer, 2017).

It is estimated that cognitive-communication disability affects as many as 80 to 100 percent of people with a TBI (MacDonald & Wiseman-Hakes, 2010). Cognitive-communication disability refers to changes in communication that reflect the underlying changes in cognitive function after a TBI which can include impairments in attention and information processing, working memory, and executive function (College of Audiologists and Speech-Language Pathologists of Ontario, 2015). Family, friends, and the general public may not recognise or understand changes in cognition and behaviours (Schellinger, 2015) resulting in uncomfortable social interactions, leading to the injured person developing a negative self-image and withdrawing socially (Douglas, 2017). Consequences of cognitive-communication disability contribute to long-term difficulties in inter-personal relationships, returning to work, and social participation within the community (Elbourn et al., 2017). Some

people with cognitive-communication disability following TBI present as overtalkative and tangential in their conversations, having an 'excessive' communication style, while others have difficulty engaging in conversations and are limited in their expressive language output, having an 'impoverished' communication style (Tate, 1999). For both groups, the use of social media might be affected considering the nature of their injuries and cognitive-communication disability.

There is a growing body of research examining how a person's cognitive-communication disability after TBI influences their inclusion and participation in online communities (Brunner, Hemsley, Dann, Togher, & Palmer, 2018; Brunner, Hemsley, Palmer, Dann, & Togher, 2015; Brunner, Palmer, Togher, & Hemsley, 2019). Overall, people with TBI use social media platforms in similar patterns and for similar purposes, as the general public (Baker-Sparr et al., 2018; Brunner et al., 2015) to form and maintain connections with other people, to observe others, share information, and voice their opinions (Brunner, Hemsley, et al., 2018; Brunner, Palmer, Togher, & Hemsley, 2019). Twitter is also well-known for being a platform to give voice to advocacy movements (Trevisan, 2017). Considering their need for social connectedness (Douglas, 2017), potential benefits and risks of social media (Brunner et al., 2015; Paterson, 2017), and the relatively high cognitive-communication demands of social media platforms (Brunner, Palmer, Togher, & Hemsley, 2019), there is a strong rationale for examining the use of Twitter by people with TBI. For example, Twitter is commonly described as being confusing for novice users, who report taking a long time to understand the operational and strategic uses of the platform (Yadron, 2016).

Although people with TBI use a diverse range of social media (Baker-Sparr et al., 2018; Brunner, Palmer, Togher, & Hemsley, 2019), the cognitive-communication changes they experience can make navigating the various platforms difficult (Brunner, Palmer,

Togher, & Hemsley, 2019). Managing an abundance of information and adjusting to frequent changes and updates on social media platforms increases cognitive demands for people with a TBI (Baker-Sparr et al., 2018; Brunner, Hemsley, et al., 2018). This can lead to cognitive fatigue and a feeling of being overwhelmed (Brunner, Palmer, Togher, & Hemsley, 2019). Presently, little is known about either the barriers or facilitators to adults with TBI using Twitter (Brunner, Hemsley, et al., 2018). Understanding more about their Twitter experiences might not only help guide rehabilitation professionals in supporting people with TBI in the use of the platform to meet social communication goals. It might also enable their access to benefits reported by other populations with communication disability, namely interaction with both familiar and unfamiliar people, a way to reach a wider audience, and a means to access their communication and consumer rights (Hemsley, Palmer, Dann, & Balandin, 2018).

The operational aspects of Twitter might also pose a barrier or a facilitator to its use by people with TBI. Twitter differs significantly from other types of social media as a microblog format where social relationships need not be reciprocated as users may follow any other user with a public profile (Bruns & Moe, 2014). Due to the shorter length of posts, tweets have the potential to facilitate communication from people with both reduced and verbose communicative output (Brunner, Hemsley, et al., 2018; Paterson, 2017). Additionally, there is reduced need for correct spelling and grammar, and for immediate responses (Hemsley, Palmer, Goonan, & Dann, 2017), which may enable users to employ metacognitive strategies, such as a ‘stop-think-do’ approach, often used in cognitive-communication rehabilitation after TBI (Ylvisaker, 2006). It is not yet known whether Twitter, allowing only short messages of 280 characters of text, would enable excessive communicators to positively limit their expressions (or in contrast negatively emphasise this

style of communication); or provide impoverished communicators with a way to harness their brevity (or indeed further limit their expression).

Previous Twitter research on TBI-related tweets has determined the presence and large size of networks and communities interested in TBI (Brunner, Hemsley, et al., 2018; Sullivan et al., 2012; Workewych et al., 2017), but it is not yet known how people with TBI use and perceive Twitter. However, hashtag research focuses on the tweets of a group adding the relevant hashtags to tweets, and not on the individuals contributing to those networks. Subsequently, Brunner et al. (2019) examined the tweets of individuals with TBI and reported that content related to finding support and connection, and emotional expressions about life after TBI (Brunner, Palmer, Togher, Dann, & Hemsley, 2019). However, research to date has not explored the views of people with TBI on their use of Twitter to understand the nature of their experiences and their perceived challenges or benefits arising from its use. Therefore, the aim of this study was to examine (a) the experiences and views of adults with TBI on their use of Twitter, in the context of their Twitter data and networks; and (b) any barriers to and facilitators or enablers to successful use of Twitter after TBI. The results of the study could inform design of rehabilitation programs for people with TBI in terms of the use of Twitter and other social media platforms with similar cognitive-communication demands and operational features.

Method

This research was ethically approved by [de-identified: the universities involved to be inserted following peer review]. Employing a mixed methods approach (Murthy, 2017), this socio-technical Twitter research used both qualitative and quantitative data (Bruns & Stieglitz, 2013; Dann, 2015; Hemsley, Dann, Palmer, Allan, & Balandin, 2015) to provide greater insight into the experiences of people with TBI who use Twitter. To date, most

research on the use of social media by people with communication disability apart from TBI (e.g., cerebral palsy, motor neurone disease) has involved interviews with participants about their experiences and views of using social media, without also analysing the content of their social media posts (Hemsley, Balandin, Palmer, & Dann, 2017). Relying only on people's perceptions of social media use may miss important insights that can be gained by combining interviews with an analysis of their social media data as an important context to the experiences (Hemsley et al., 2015). An interpretivist approach was taken to build initial understanding of the context (Tracy, 2013). Based on the findings of previous research, the authors acknowledged that people with TBI who use Twitter appreciate the benefits of the platform. Nonetheless, it was also recognised that underlying cognitive impairments and cognitive-communication disability could result in people with TBI experiencing difficulties in using Twitter. As such, researchers sought to understand the views of people with TBI as one part of this complex issue, so as to inform stages of the TBI rehabilitation pathway, involving recovery and rebuilding of social communication skills. Therefore, this study used realist methods drawing upon multiple data sources, namely interviews and social media data analysis, to enable triangulation and verification of the analysis from each source, enabling a deeper exploration of the issue (McPhail & Lourie, 2017) and to increase rigour in the research (Patton, 2015). To protect participants' identity, pseudonyms are used to replace their names.

Participants

All participants were aged over 18 years and were able to give their own informed consent, self-identified as having cognitive-communication difficulties arising from a TBI, and used Twitter. Participants were recruited as part of a larger study investigating the use of social media by people with TBI (Brunner, Palmer, Togher, & Hemsley, 2019). Over a 13 month period, and using several recruitment methods (including calling for participants

through a research registry, social media promotion, and professional networks) a purposeful sample (Patton, 2015) was selected to locate six participants who had a TBI and who used Twitter agreed to participate in the study. While small, this group of participants provided in-depth interviews and triangulating data in the collection of tweets, enabling a rich and detailed exploration of their diverse experiences of a platform known for both its potential benefits and challenges for people with communication disability. People with TBI can be difficult to reach and recruit to research (Bell et al., 2008), owing to their cognitive impairments. In this study, a small sample provided meaningful data, since the aim was at generating insight into the experience of using Twitter without attempting to determine the most frequent or common experiences (Patton, 2015).

In total, two males (Lee and Sam) and four females (Pat, Kris, Alex, and Jo) took part in the study, ranging in age from 26 to 72 years. Three participants were employed or students and three were either unemployed or worked as a volunteer. On average, mean age of injury was 22 years of age (range 13-31 years). Three participants sustained their injury in a motor vehicle accident, and three in different types of sporting accidents. One participant used multimodal communication in the form of an alphabet board, a speech generating device, and mobile communication device during the interview. This participant presented with an impoverished communication style (i.e., characterised by short phrases and difficulty with elaboration); and five participants presented with an excessive communication style (i.e., characterised by lengthy, tangential monologues with restricted content). Information about the participants is presented in Table A.

Data Collection

Twitter data. To enable a full appreciation of the ways that participants were using Twitter, participants' tweets were harvested from the Twitter platform using NCapture. The

tweet data was imported into NVivo11 then exported to Microsoft Excel software for analysis using the data sorting and filtering processes. Computational analysis of tweet data was also conducted for use during participant interviews as follows: NVivo11 software was used to generate chart visualisations of participant tweet activity; and Gephi software (The Gephi Consortium, 2012) was used to generate visualisations of participant Twitter networks (Palmer, 2014).

Interview data. All participants were interviewed by the first author, one in-person, one via telephone, and four using Skype. Interviews used a conversational style following a pre-determined topic guide designed to elicit stories of participants' experiences (Brunner, Palmer, Togher, & Hemsley, 2019) and their interpretations of their own tweet activity and networks (Hemsley et al., 2015). The interview guide is available on request from the first author. Before their interview, participants were sent their tweet data and invited to remove any tweets they did not wish to be included in the analysis. No participants requested removal of any of the tweets from the data. Participants were then sent a copy of the visualisations of their tweet activity and Twitter networks for reflection during the interview. Interviews ranged from 38 to 145 minutes in length, were audio-recorded, transcribed verbatim, and analysed. Demographic details were collected at the beginning of the interviews including the participant's recollections of their injury (i.e., self-reported details and perceptions of their TBI). On the basis of their interview data, the first author (a speech pathologist experienced in TBI rehabilitation) classified the participants' communication styles as being either impoverished or excessive (Tate, 1999).

Analysis

Twitter network analysis. Analysis of tweet data addressed (a) user metrics: number of tweets sent, type of tweet (original or retweet), number of followers, number of @users

followed, and number of other @users mentioned in tweets; and (b) temporal metrics: time since joining Twitter, and number of tweets sent over time (Bruns & Stieglitz, 2013).

Structural layers of Twitter analysis. Tweet data was analysed according to the three structural layers of Twitter communication (Bruns & Moe, 2014). Tweets were classified as being at the: (a) Micro level (i.e., tweets began with the @ symbol and were directed to an individual @user), (b) Meso level (i.e., tweets do not include a #hashtag and have a character before the @ symbol at the start, where they will generally capture the attention of Twitter users who follow the tweeter), or (c) Macro level (i.e., tweets use #hashtags thus creating the potential to reach a much wider audience where all Twitter users can view the tweet if they follow that #hashtag). Consensus coding was conducted, whereby a research assistant independently classified the tweets, achieving 99.27% inter-coder reliability, and all discrepancies resolved through discussion.

Content classification of tweets. Tweet content was manually coded according to Dann's content classification (Dann, 2015): (i) Conversational tweets used a @username to address another Twitter user; (ii) News tweets contained identifiable news content such as reporting on real-time events; (iii) Pass Along tweets shared information and links between users, (iv) Social Presence tweets showed a connected presence with other Twitter users as if they are in the room with them; and (v) Status Broadcast tweets expressed the user's thoughts and feelings (Dann, 2015). A research assistant independently conducted consensus coding, with 95.56% inter-coder reliability and all discrepancies resolved through discussion.

Narrative analysis of interviews. Detailed field notes were made during and after each interview, with a two to three page summary of each transcript developed and refined following discussion between first and final authors (Creswell, 2014). In order to verify the researchers' interpretations, each participant was sent a transcript of their interview and

summary to review and confirm it reflected their views. One participant requested the removal of some information from the summary, and two participants clarified and added information to their summary. Following incorporation of requested changes, all participants verified that the transcripts and summary interpretations of the researchers reflected their views. An iterative approach to the analysis was taken that was independent of theoretical approaches using an essentialist or realist method (Braun & Clarke, 2006). In order to provide a rich and detailed account of the phenomenon being explored, the analysis used an iterative approach and realist methods to understand the realities and insights of participants from their own perspective (Tracy, 2013). During this process, open codes were applied to the transcripts and summaries using NVivo11 software, with the list of open codes examined and discussed between the first and final author to identify categories of codes and component themes. In the analysis, the first author drafted and periodically returned to a mind map modelling the concepts identified in the data (Patton, 2015), all the while considering and carefully reading and re-reading the interview transcripts and interpretations (Rice & Ezzy, 1999). Regular discussions in the research team served to interrogate and confirm these concepts and an evolving model of categories in the data (Creswell, 2014) to identify themes within and across the interviews that best represented participants' experiences and views (Braun and Clarke, 2006). Overall, the results of both the Twitter data analysis and the interview narrative analysis were integrated for re-presentation in categories of meaning relating to the participants' views and experiences of their use of Twitter.

Rigour in the research. In order to increase rigour and confidence in the findings, a detailed audit trail was maintained throughout the project, inclusive of recruitment methods and outcomes, data collection, and all stages of the analysis. In-depth documentation of participant information enabled later rich descriptions to aid in consideration of the findings in relation to other adults with TBI with similar characteristics (Patton, 2015). Credibility of

the results was supported through member checking, reading and re-reading of the data, regular discussion between members of the research team, and a thorough period of analysis and conceptualisation of the findings and interpretations (Creswell, 2014). In this paper, the content themes are supported by quotes and excerpts from the data using participants' own words to increase the plausibility and credibility of the findings (Riessman, 2008) and to illustrate the relationships between the thematic categories (Patton, 2015). The design and reporting of the study were informed by the using the consolidated criteria for reporting qualitative research (COREQ) framework (Tong et al. 2007).

Results

Overall, participants' experiences of Twitter were diverse, with two experienced and four novice users of the platform. All reported feeling connected and included on the platform, and identified both positive and negative experiences in their use of Twitter. In terms of the content classification of tweets (Dann, 2015), Pass Along, Conversational, and Broadcast Status tweets featured most prominently; as is often the case in the typical Twitter user's profile (i.e., with limited use of News or Social Presence tweets). With diverse patterns of tweeting evident across participants, the development of supportive networks in Twitter facilitated higher frequency of tweets and increased feelings of enjoyment and connectedness. Moreover, novice and established users alike were keen to continue using Twitter and eager to learn more, but did not receive support to do so from either experienced Twitter users or rehabilitation professionals, relying instead on a 'trial and error' approach to continued engagement on the platform.

Tweet data

Tweet data collection commenced for the first participant on the 11th of September 2016 and ceased with collection of the final participant's tweets on the 4th of September

2017. In total, 6874 tweets with a date range from the 1st of June 2009 to the 13th of April 2017 were collected. The raw Twitter data is reported in Table A.

Insert Table A about here

The dataset of tweets reflected the available tweets retrieved from the search function of Twitter and the number returned was dependent on the capability of the Twitter API at the time of data collection (Twitter, 2018) and might not have reflected the total number of tweets sent by the participant.

User and temporal metrics. Three of the participants had been using Twitter for more than five years (Lee, Alex, and Jo), and three for approximately one year (Sam, Kris, and Pat). Years in Twitter and hence 'experience' in time was not associated with the number of tweets sent: Pat had tweeted more in a year than Alex had tweeted over six years; Lee had been using Twitter for seven years and sent a few hundred tweets; in five years of use Jo had sent less than 50 tweets; and relatively new to Twitter, Sam and Kris had both sent less than 60 tweets. Participants following less than 200 Twitter @users (Lee, Sam, Kris, and Jo) had approximately 10-20% of this number of followers, and this percentage rose substantially for participants following more than 400 tweeters (Pat and Alex) and even more so when they mentioned a larger number of other @users in their tweets (e.g., Pat).

Structural layers of Twitter. The frequency of tweets sent by individual participants to the three structural layers of Twitter (Bruns & Moe, 2014) is provided in Table B. The majority of tweets sent by all participants were at the Meso layer of Twitter (n = 2870, 42%) (i.e., tweets to all followers) with 32% of tweets sent at the Macro layer (n = 2185) (i.e., tweets to hashtag communities) and 26% at the Micro layer (n = 1819) (i.e., conversational tweets). Participants displayed different patterns of tweeting across the three structural layers of Twitter. Lee tweeted mostly at the Macro layer (83%), potentially reaching a much larger

audience. In contrast, Sam tweeted mostly to the Micro layer (78%) rarely including hashtags (6%), and hence communicating within a much smaller network of Twitter users. Alex and Jo tweeted mostly to their followers in the Meso layer of Twitter (74% and 58% respectively), whereas Kris tweeted mostly to the Macro layer (58%). However, Pat balanced tweets sent to the Macro (45%) and Micro (43%) layers of Twitter.

Content classification of tweets. The content classification analysis with individual participant data is presented in Table C. The majority of tweets were in the Pass Along category (n = 4840, 71%). The sample also included Conversational tweets (n = 1864, 27%) and Status Broadcast tweets (n = 139, 2%), as well as a small number of News (n = 15, 0.2%) and Social Presence (n = 16, 0.2%) tweets.

Insert Table B and C about here

Narrative Analysis: Experiences in Using Twitter

Participants' stories of experience in using Twitter suggested an evolving sense of social media mastery, and this affording them connectivity with others (Brunner, Palmer, Togher, & Hemsley, 2019). The major theme of 'mastery' in using Twitter contained four categories of meaning: getting started and drivers to use, navigation, manner of use, and an evolving sense of mastery. The second major theme 'connection' with others in Twitter, included the consideration that connections could be disrupted. This theme contained five categories of meaning: a sense of proximity, networks and community, making connections, being informed, and being included. Their reported sense of 'connection' or 'disconnection' influenced participants' use of the platform, and also shaped their evolving sense of Twitter mastery. There was some evidence of reciprocity in the relationship between the two major themes, in that participants' mastery in using Twitter shaped participants' connectivity in Twitter. Additionally, the sub-themes within connectivity were not mutually exclusive, with

each influencing others and shaping the participants' diverse experiences . Figure 1 provides a visual representation of the major themes, categories, and the relationship between the themes.

Insert Figure 1 about here

Mastery in using Twitter. Across participants, the diverse experiences of using Twitter narrated reflected an evolving sense of mastery in using the platform as reflected in four categories to this theme.

***Getting started and drivers to use*.** Four participants were actively encouraged by friends and family to use Twitter, as Sam said: "[a] bloke set me up with Twitter years ago". One participant (Kris) felt she started using it because other people were: "you hear about it, oh somebody's on it, and you open an account and then you just start". However, Pat started using Twitter for strategic reasons, in order to promote her blog, "I thought Twitter was one of the main ways how to get it out there really" (Pat). The participants used Twitter for a variety of reasons, often based on their personal interests. All reported that they used Twitter for connecting with others, with some accessing information (n = 3) or entertainment (n = 3): "I have been very involved in the monitoring of how the WWE Superstars are doing" (Lee). Others used Twitter to share information (n = 4) about their day-to-day lives and TBI, or as another way to communicate (n = 1). Twitter was also used for advocacy in a variety of ways (n = 3), such as through sharing of information about TBI and strategies for living with disability, sharing political information and opinions, connecting with politicians and political commentators, and asking for help for those in need.

***Navigation*.** Similar to their reports on using other types of social media (Brunner, Palmer, Togher, & Hemsley, 2019), the participants mostly learnt how to use Twitter through a "trial and error" (Sam) approach. Although friends had introduced them to Twitter and

helped them to set up their accounts, they had not received support in learning how to use the platform itself. One participant (Pat) reported using Google and watching other people to learn more about using Twitter. For most (*n* = 4), this lack of knowledge often led to limited use of the platform, as Jo reflected: "I don't actually use it that much but that's probably because I don't know how really". Some felt that "If I knew what I was doing on Twitter then I would use it more" (Sam). When given answers to their questions about Twitter use at the end of their interviews, participants displayed an eagerness to use the platform, with Sam noting he "will be able to explore the different tweets now".

Feelings of cognitive fatigue, confusion, and being overwhelmed were reported. One participant (Lee) reported that having not understood how to use Twitter, he had returned to a more familiar social media platform, "I go to Facebook because I know Facebook. I can understand Facebook". Some (*n* = 3) reported difficulty understanding what everything meant in Twitter and one mentioned trouble with layout as she found Twitter visually less appealing than other social media platforms. Emotional reactivity was a challenge for the participants (*n* = 4), with Kris noting: "It becomes overwhelming". Another (Alex) reported that she retweeted others' comments rather than tweet herself as it can be exhausting to find words to express her frustration with situations or events.

Sometimes difficulty in navigating Twitter created frustration: "if I don't like understand how to thread things very well it takes me a lot of like deleting and then redoing … I get frustrated so I'll just not do it" (Alex). Another felt Twitter was complicated at times, "it's not straightforward enough for me to use always, I don't like doing things that are hard" (Jo). Hashtags were one of the idiosyncrasies of Twitter that some found difficult (*n* = 3), "I don't understand them [hashtags] no, they're quite confusing. What do they mean?" (Lee). Although these participants did display knowledge of hashtags: "as far as I understand they just create a link and that can be sourced" (Jo), they were not confident in their use. Others

were more confident in using hashtags (*n* = 3), with one observing that she understood the concept from marketing (Kris). However, Alex reported caution in using hashtags, for example in tweets discussing political opinion. Refraining at times from using hashtags, Alex felt that this would limit negative comments directed at her: "I don't like getting responses from people if they're just going to use language that I'm, like, I don't need to hear". Most felt that if they were cyber-bullied they would ignore them (*n* = 5), with one who noted that cyber-bullying "happened to me today. Happens to me every day" (Kris). In response to these negative comments online, Kris often enjoyed responding with her "rapier wit" but "after that I sometimes feel bad and I go back and I'll delete like right afterwards" (Kris).

Manner of use. Four of the participants reported they used Twitter daily, whereas Kris and Jo used it only a few times a week. Most felt that they lurked (observed tweets without tweeting themselves) more than they actively tweeted, "every now and then I'll whip it out and have a look at what nice people are saying" (Jo). As Sam observed, he enjoyed reading about "a lot of different remarks about particular subjects" and another (Lee) sent auto-generated tweets from apps used in day-to-day life, e.g. a meditation app. Reflecting on their tweeting history, some participants noted they were "retweeting more than I'm tweeting" (Kris), whereas others "hardly ever retweet" (Lee). Infrequent tweeters observed that they tweeted "not often at all" (Lee), or that "I don't reply that much" (Alex). However, high-frequency tweeter Pat noted their activity with laughter, stating "it's a lot!". All of the participants (*n* = 6) felt that their use of Twitter had "definitely changed over the years" (Jo). A novice tweeter (Sam) reflected that he had started using Twitter by just watching and reading other people's tweets, and that it took years for him to send his first tweet. Even the most prolific tweeter remarked that their knowledge of the platform had "developed quite a lot over that time, it's been a steep learning curve" (Pat).

***An evolving sense of mastery*.** Similar levels of social media mastery were reported by participants for Twitter as for with social media in general (Brunner, Palmer, Togher, & Hemsley, 2019). Moreover, those who were identified as active or 'experienced' tweeters, were identified as having greater social media mastery than those who were identified as 'novice' social media users. This was evident in the number and type of tweets they sent, and the diversity of the Twitter @users that they connected with. 'Experienced' users (Pat and Alex) displayed enthusiasm and drive to use Twitter to achieve a purpose. Both were primarily interested in advocating for making life better for those living with the effects of having a TBI. However, they employed a different approach to doing this – one actively blogged and shared information and strategies (Pat), and the other actively campaigned politicians and political commentators to push for change (Alex). Pat actively sought information on how to use Twitter more effectively to disseminate her blog information and used hashtags consistently for this purpose, "mostly because I feel that #TBI, #ABI, and #braininjury are the ones that would help people find my work, if they haven't already" (Pat). In contrast, Alex felt that she mostly retweeting a lot of content and engaged in hashtag discussions of interest to her (e.g., political comedy or satire) or that she felt strongly about (e.g., healthcare policy).

Infrequent or 'novice' Twitter users felt they were mostly unsure about using the platform. Originally, Lee felt that he was just sharing "stuff" and not reading posts by other @users, but now appreciates what other people are saying and especially enjoyed being able "to celebrity stalk". Although he was a novice user, Lee displayed interest in connecting by tweeting using hashtags and indeed live-tweeted during his interview. Overall, Lee reported feelings of "indifference" for Twitter as compared with Facebook, predominantly due to the restricted length of posts: "In Twitter I believe you are limited to only a certain number of

characters in your tweet. Like a text message. It's horrible, it's horrible. In Facebook, there's no limit, it's lovely" (Lee).

Connectivity with others in Twitter. Five categories of meaning were identified in this theme, through an examination of both the interviews and Twitter data with regards to connection made or lost with others in Twitter: a sense of proximity, networks and community, making connections, being informed, and being included.

A sense of proximity. Participants described how, for them, Twitter provided a means of achieving proximity or nearness in space, time, or relationships. For some it overcame socio-geographical distance, enabling them to communicate directly with another user (*n* = 3). As Kris remarked, "He [politician] would have come into office and then it would have been, how do I tell this man what I think of him?" (Kris). Twitter also provided a means of staying informed about global events, such as meteorological conditions and environmental concerns: "We have hurricanes hitting right now and that's the best way to check the hurricanes is on Twitter" (Alex). Others commented on feelings of isolation in Twitter due to either having minimal followers or limited knowledge or confidence in who to follow themselves (*n* = 3). Jo felt that if she had more followers she may tweet more, otherwise tweeting seemed futile if she felt that there was no one listening. "I don't have any followers so I don't see the point" (Jo). Whereas Kris was unclear as to whom she could interact with: "I have all these friends and followers on Facebook, and then I get on Twitter where it's kind of, you know … who am I talking to?" (Kris).

Networks and community. All of the participants displayed surprise when seeing their Twitter networks presented graphically. Some reported mostly connecting with close friends and family (*n* = 4), others followed celebrities, politicians, or social commentators of interest to them (*n* = 5). Sam felt there were numerous people using Twitter that he could connect

with, although he also valued being able to connect with those close to him. Some participants reported being amazed with the size of their online networks: “I definitely interact with a lot of people … versus like how many I know in real life” (Alex). In contrast, Pat connected with many people all over the world, most of which she had never met in real life: “I’ve never met any of them in person. I think the majority of them … are probably American and Canadian”.

Making connections. Sam liked that there were so many people who use Twitter and felt it was a good way of connecting with other people. Others found that knowing usernames was helpful in identifying who to connect with or not (n = 2). Twitter was also viewed as a way of connecting with other people with similar views and overcoming feelings of isolation: “you get a sense of, ‘oh look, other people don’t like this either’. You know, I’m not alone in this… we can all join together… so there’s a, that belonging” (Kris). Additionally, being able to respond and interact with others in Twitter was important, as it enabled participants to build up a relationship with others. Pat noted the value in realising that behind a users’ avatar (an image that represents the user), there is a person: “You have to remember they’re really people. They’re not just names that turn up on your computer” (Pat). Being able to listen and engage with other people with similar opinions and ideals also helped Alex feel like she belonged, “I think it helps me on there to feel like I’m on the same wave, like I’m following the same stuff that other people are following ... so I guess it’s validating in that way” (Alex).

Being informed. Most participants reported that Twitter was a source of information and enabled them to stay informed about things of interest to them (n = 5), for example Jo noted: “I follow people for … their agenda”. Some used it for immediate, real-time news, “It definitely keeps me informed” (Alex). In particular, Alex found it a reliable means of accessing informed opinion, and valued it more than seeing uninformed posts – such that “I’d rather just read what experts say on something or like a really well thought out like op-ed

versus my friends Facebook statuses which sometimes can, like, just have things that aren't even true" (Alex). Even though, Alex often experienced cognitive fatigue, she felt that using Twitter for information was worth it: "There are days that exhaust me but knowledge to me is like, powerful, I'd rather just be informed. So I think it's empowered me" (Alex). In using the platform for knowledge, the participants also acknowledged the influence of their networks on how successful they were in accessing information.

Being included. In connecting with other users in Twitter, participants reported that they felt engaged and involved in a community. Some (n = 3) remembered wanting to be involved in what others were discussing, so they had "observed this round of this hashtag going around and I would have just wanted to be involved" (Jo) and then started to include the hashtag in tweets themselves. Twitter made Sam feel included as it gave him time to respond to people, which he often found difficult in face-to-face conversations. Others found Twitter as a means of sourcing information and commenting on it, "I'll hear something somebody said and I'll go on specifically to go say something to that person" (Kris). In fact, Alex often retweeted articles so that she could find it to read later, "if I forgot about what I read or if I like wanted to show it to somebody" (Alex). Alex also used Twitter to connect with local political representatives in order to advocate for change: "I do feel like I can at least try with the others to like call my local representatives and have them try and do something". Similarly, Kris felt that Twitter was a "way of getting out my frustration", emphatically stating, "I want my voice heard" (Kris).

Discussion

This research, combining a quantitative Twitter data analysis and narrative analysis of interviews from six participants, reveals the Twitter experiences of six adults with TBI. Using multiple methods of analysis strengthened interpretations of results and enabled an in-depth

exploration of Twitter use by people with TBI (Murthy, 2017). Analysis of a sizeable sample of tweets combined with the reported experiences of the six participants provided unique insights into the Twitter networks and experiences of people with TBI. As such, the findings provide important considerations for TBI rehabilitation, which are discussed in this section.

Using Twitter to Connect with the World

The finding that people with TBI use Twitter for connecting with others and to escape feelings of isolation is important, as people with TBI have significant reduction in social relationships after their injury (Elbourn et al., 2017), and feelings of loneliness have been linked to negative changes in executive function, sleep, and psychological and physical well-being (Cacioppo & Cacioppo, 2014). Hence, their use of Twitter could be encouraged, given appropriate supports to use are provided. Indeed, the benefits of using Twitter for connection has been reported previously by other adults at risk of social isolation, including people with communication disability (Hemsley et al., 2015; Hemsley et al., 2018; Hemsley, Palmer, et al., 2017), and people with mental health conditions (Naslund, Aschbrenner, Marsch, & Bartels, 2016), who similarly report greater feelings of social connectedness, a sense of belonging, and value in sharing their personal stories and coping strategies. Understandably, participants in this study enjoyed Twitter use more when they had people to connect with consistently, and with whom they shared similar interests. This aligns with previous research in the general population revealing that online connectivity is motivated through shared interests and experiences (Malinen, 2015).

The results of this study provide unique insights into the ways that adults with TBI grew their Twitter networks and grow their mastery in using the platform. Some participants rapidly increased the size of their networks, while others were isolated, sending few tweets and having smaller networks. In this small group of participants with TBI, there was

alignment with Brandtzaeg and Heim's (2011) 50-30-20 proportion in typology (i.e., the types of users participating in online communities), in that around 50% percent of the participants could be considered 'passive participants' (Lee, Sam, Jo), 30% 'intermittent contributors' (Kris, Alex), and 20% 'heavy contributors' (Pat) (Brandtzaeg & Heim, 2011). Brandtzaeg and Heim's (2011) consideration of user typology of passive, intermittent, or heavy users might help identify the different modes and levels of participation in social media by people with TBI, particularly as change and mastery in using the platform is likely to occur over time (Brunner, Palmer, Togher, & Hemsley, 2019). As such, social media user typologies may need to be further considered when designing support or training interventions for people using social media after TBI.

Some participants in this study used Twitter for advocacy online and for their voice to be heard both in relation to their place in society and in support of others who have experienced TBI. Having a visible presence in online communities where stories of disability experience can be seen and heard, and connecting with people with similar experiences can contribute to a sense of belonging and empowerment (Ziebland & Wyke, 2012). The participants also reported that Twitter enabled them to voice their frustration and ask for action, particularly with regard to political, health, or disability issues (Trevisan, 2017). Therefore, Twitter and other social media platforms could be used more effectively for raising awareness and knowledge of TBI, as has been seen recently in conversations in Twitter about disability using hashtags such as #RepresentationMatters (Cassidy, 2018) and #CultureIsInclusion (PWD Australia [PWDAustralia], 2018, July 26). The findings of this study suggest that although many people with TBI might not yet be included in disability advocacy or activist movements in social media (Brunner, Palmer, Togher, & Hemsley, 2019; Trevisan, 2017), some people with TBI considered Twitter to be an important avenue for advocacy and empowerment. In contrast to the purposes of other social media platforms

expressed by people with TBI (Brunner, Palmer, Togher, & Hemsley, 2019), people with TBI in this study experienced Twitter as well suited for activism and providing a platform for those who 'want their voice heard'. This supports the findings of other research including adults with communication disability on their experiences and views of Twitter (Hemsley et al., 2015).

The Dark Side of Twitter for People with TBI

The participants in this study received no formal training or guidance in using Twitter aside from setting up their account. They generally felt unsure of the platform and that they had limited connections. As a result, people with TBI reported feelings of being 'lost at sea' encountering a large amount of fast-flowing information that seemed to appear random or meaningless. They found their way around Twitter through trial and error - via lurking, asking for help, engaging with known and new networks, and taking opportunities to practice communicating in the online environment. Having a defined purpose in using Twitter also enabled more strategic use of Twitter and drove active use and searching for answers.

In continuing to use Twitter despite their difficulties, adults with TBI in this study displayed cyber-resilience (Australian Securities and Investments Commission, 2015). While the results suggested participants considered they faced no greater risk or vulnerability on Twitter compared to other social media platforms, the more frequent tweeters in this study refrained from making divisive comments on topical issues. Twitter is a public platform and other users report avoiding some topics in their tweets as a way to stay safe and protect their reputations (Marwick & boyd, 2011). When connections were made, participants felt that they were personal and meaningful, an experience not always reported by other people with communication disability (Caron & Light, 2016; Hemsley et al., 2015). Participants acknowledged that Twitter had its own style (Hemsley, Palmer, & Balandin, 2014) and lack

of knowledge about this (e.g., knowing how and when to use hashtags) affected their ability to use the platform for communication. Indeed, being able to use Twitter effectively requires both operational and linguistic knowledge and competence in using the technology strategically (Hemsley et al., 2014), which can develop through repeated and consistent use (Brunner, Palmer, Togher, & Hemsley, 2019; Hemsley et al., 2015).

Cognitive-communicative difficulties after TBI typically affect socio-pragmatic aspects of communication more so than linguistic aspects. Emerging research has suggested that people with TBI may miss subtle social cues written in text (Turkstra, Duff, Politis, & Mutlu, 2017). However, the participants in this study identified cognitive fatigue, emotional overload, and planning difficulties as more of a challenge for them than the writing of tweets. This makes sense, as cognitive fatigue affects between 32 and 73% of people after TBI, regardless of injury severity (Ponsford, 2017). However, it is possible that the additional cognitive fatigue experienced by adults with TBI using Twitter could worsen the effects of: (a) 'social media fatigue' limiting use of social media, in response to feeling overwhelmed with the amount of sites, content, users, and connections (Goasduff & Pettey, 2011); and (b) 'compassion fatigue' or emotional burnout, in response to social issues in an era of constant news updates (Gabbert, 2018). Thus, adults with TBI might need to learn strategies for managing social media, in taking regular breaks and learning ways to reduce exposure to information if it is overwhelming.

Most of the participants in this study expressed surprise at the size and breadth of their Twitter networks in terms of membership, and considered that a sense of community and purpose was needed for social media use to feel meaningful. Some of the participants were unaware of the number and diversity of Twitter users they had connected with during over time. Given that a sense of connection drove purpose and use of Twitter for the people in this study, people with TBI may need greater awareness of where social media may assist

them in practicing use of social communication skills. In turn, this may enable functional communicative practice in real-world contexts, with interactions and feedback from people in an environment where they can explore at their leisure and be included. Using strategies that have helped people with TBI to navigate use of Twitter, may form the building blocks of training in social media use during rehabilitation. In particular, any identified coping strategies to deal with cognitive fatigue and emotional overload should be explored to enable people with TBI to use Twitter, and other social media platforms, safely and enjoyably. As such, rehabilitation should incorporate greater awareness of social media use after TBI, including knowledge of familiar and unfamiliar social networks available to them.

Limitations and Directions for Future Research

While contributing important insights on the perspectives of adults with TBI, the findings of this study are based on a small sample and should be interpreted with caution in that they might not apply to other people with TBI. Nonetheless, people with TBI who have similar patterns of use in Twitter might have similar experiences. Additionally, this exploratory research relied on recruiting participants who self-identified as having a TBI, and the type or severity of their injury was not measured or confirmed through a review of medical records or clinical testing. A limitation relating to the Twitter data analysis was that the network density of the participants could not be calculated as the data only included tweets sent by participants, and not Twitter mentions data (i.e., tweets from others mentioning the participant). Additionally, Twitter data for Pat and Alex did not account for the entirety of their Twitter communication over time due to capability limitations of the Twitter API in returning a user's tweets when searching using the platform (Twitter, 2018). The structural layers of Twitter communication (Bruns & Moe, 2014) was an appropriate analysis method for the tweet data collected in this sample. However, it is important to note that this structure is now likely to evolve given changes to the platform, in that during 2017

the text character limits were changed from 140 to 280 within a tweet, and @usernames auto-populated at the start of replies and links attaching media content in tweets no longer count towards the text character limit within tweets (Twitter, 2017).

The views and experiences of adults with TBI should be considered in the design of TBI rehabilitation goals surrounding communication online. The findings support the notion that while Twitter affords greater connectivity and potential for online activism, it can be a more complex platform to learn than other social media. As such, training is likely to be required for people with TBI to use and enjoy the platform more effectively for their intended purposes. Training should be developed and trialled that addresses issues regarding: (a) use of the platform (i.e., what symbols are used and what they mean, how to reply, how to search, what hashtags are and how to use them); (b) connectivity (e.g., how to find people and access information, and strategies for engaging with communities of interest); (c) ongoing support (e.g., communication partners in social media platforms); (d) cognitive fatigue or overload (i.e., compensatory strategies); and (e) being safe online (i.e., cyberbullying and reputation management). However, further research is also needed to identify the views and experiences of rehabilitation professionals who potentially have important insights on how to incorporate and address social media goals into rehabilitation after TBI.

Clinical Implications for TBI Rehabilitation

The findings of this research suggest that targeted training might be useful for people with cognitive-communication disability after TBI who already use Twitter and want to enhance their strategic use of its functions to build safe and enjoyable networks with more people online. Encouraging Twitter use should be matched with appropriate supports for users with TBI to learn how to use Twitter and find their ‘communities’ or ‘interests’, rather than relying on a trial and error approach. Supporting individuals to recognise their

'typology', or preference for being a passive, intermittent, or heavy contributor to online forums (Brandtzaeg & Heim, 2011) might be useful, if the person's goal in using Twitter is to fulfil a broader purpose strategically (e.g., personal or political advocacy, making their voices heard). Rehabilitation professionals and adults with TBI alike need to be aware that changing typology in use might need to be accompanied by developing social media mastery and building cyber-resilience in response to challenges in using social media. Managing these challenges and any cognitive fatigue associated with social media use during rehabilitation is likely to require close collaboration between professionals and family members supporting adults with TBI.

Conclusion

The key drivers for the use and enjoyment of Twitter by people with TBI were connection with the world and engagement with others, and this influenced their mastery of the platform. Using Twitter enabled them to connect with their loved ones, make new relationships, and tell the world their stories and opinions. People with TBI reported both positive and negative experiences in using Twitter, feeling fatigued and overwhelmed at times. When able to develop a supportive network for engagement, they reported greater feelings of enjoyment and inclusion. Many 'lurked' in Twitter more than they tweeted and relied on a trial and error approach to developing their Twitter skills. As such, during rehabilitation people with TBI might benefit from tailored instruction, training, and ongoing support in using Twitter to reap the benefits reported by more active Twitter users in this study. Specific Twitter communication goals could include: identifying a strategic purpose for using Twitter, improving skills in using the platform, increasing frequency of tweets including conversational replies, growing a Twitter network through identifying supportive tweeters in the network, and finding more opportunities for engagement with others online.

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Conflict Of Interest

[Author A] has no conflicts of interest to disclose. [Author B] has no conflicts of interest to disclose. [Author C] has no conflicts of interest to disclose. [Author D] has no conflicts of interest to disclose. [Author E] has no conflicts of interest to disclose.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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Figure 1. Overarching themes and sub-themes identified within the participants' stories of experience in using Twitter.

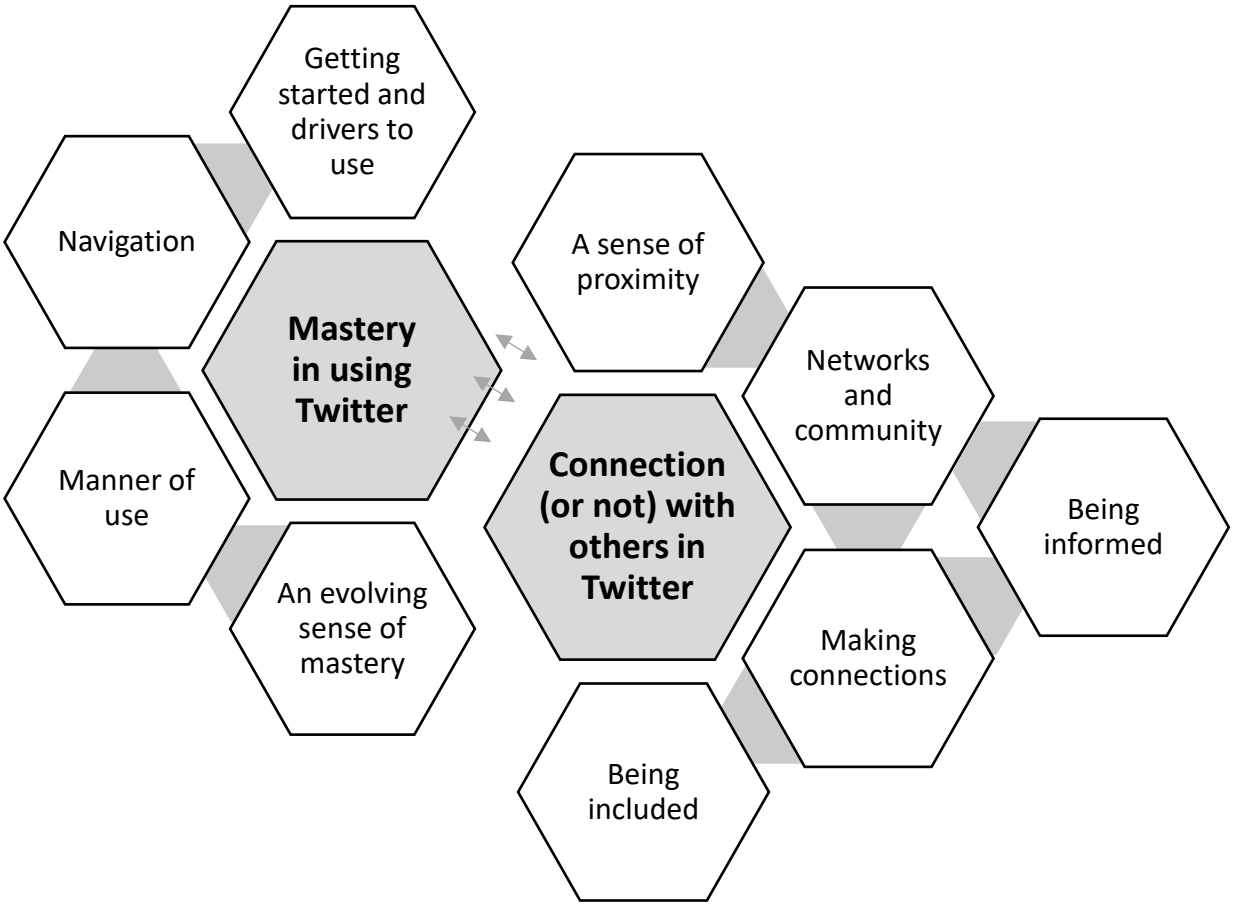

Table A. Participant characteristics and Twitter user metrics.

Participant	**Lee**	**Sam**	**Pat**	**Kris**	**Alex**	**Jo**
Age (years)	27	72	34	52	29	26
Gender (female / male)	Male	Male	Female	Female	Female	Female
Cause of injury	MVA	SA	MVA	MVA	SA	SA
Time since injury (years)	7	59	3	32	2	5
Mobility and ADLs	Indep	Assist	Indep	Indep	Indep	Indep
Employment	N	N	Vol	FT	PTSt	PT&St
Communication mode	Speech	AAC	Speech	Speech	Speech	Speech
Communication style	Exc	Imp	Exc	Exc	Exc	Exc
Time using Twitter (years)	7	1	1	1	6	5
Followers (n)	30	15	2313	20	172	21
@users followed (n)	158	149	2007	129	455	90
Tweets sent - all time (n)	323	51	10752	43	5477	40
Tweets sent - data sample (n)	319	47	2513	36	915	8
Retweets - data sample (n)	3	4	697	7	2293	32
Total tweets - data sample (n)	322	51	3210	43	3208	40
Time frame of data sample (days)	2573	395	80	210	402	1738
Time frame of data sample (years)	6	1	0.2	0.6	1	4.75

Tweets captured (% of all time)	99.7	100.0	29.9	100.0	58.6	100.0
@users mentioned in tweets (n)	12	42	755	6	216	2

Table Key: MVA = Motor Vehicle Accident; SA = Sporting Accident; ADLs = Activities of Daily Life; Indep = Independent; Assist = Requires assistance; N = Unemployed; FT = Full time paid employment; PT = Part time paid employment; Vol = Volunteer work; St = Student; AAC = Augmentative and Alternative Communication; Exc = Excessive communication style; Imp = Impoverished communication style.

Table B. Structural layers of tweets sent by participants: Micro, Meso, and Macro layers (Bruns & Moe, 2014).

Participant	Micro		Meso		Macro		Totals
Lee	4	1%	52	16%	266	83%	322
Sam	40	78%	8	16%	3	6%	51
Pat	1367	43%	393	12%	1450	45%	3210
Kris	12	28%	6	14%	25	58%	43
Alex	393	12%	2388	74%	427	13%	3208
Jo	3	7%	23	58%	14	35%	40
Totals		1819		2870		2185	6874

Table C. Content classification of tweets (Dann, 2015).

	Content Classification (%)				
Participant	Conversational	News	Pass Along	Social Presence	Status Broadcast
Lee	2.17	0.31	89.75	1.55	6.21
Sam	78.43	0	15.69	0	5.88
Pat	42.59	0	57.38	0.03	0
Kris	74.42	0	23.25	0	2.33
Alex	12.94	0.34	82.86	0.31	3.55
Jo	7.5	7.5	82.5	0	2.5
Average (%)	36.34	1.36	58.57	0.32	3.41