Hemsley, Bronwyn; Palmer, Stuart; Balandin, Susan “Tweet reach: a research protocol for using Twitter to increase information exchange in people with communication disabilities”. Originally published in Developmental Neurorehabilitation Vol. 17, Issue 2, p. 84-89 (2014) ©Informa Healthcare

Available from: http://dx.doi.org/10.3109/17518423.2013.861529

This is an Accepted Manuscript of an article published by Taylor & Francis in Developmental Neurorehabilitation in 31/12/2013, available at:


Accessed from: http://hdl.handle.net/1959.13/1041908
Tweet reach: a research protocol for using Twitter to increase information exchange in people with communication disabilities

Bronwyn Hemsley, Stuart Palmer, Susan Balandin

Revised version re-submitted 28th October 2013 to Developmental Neurorehabilitation

Now published in Developmental Neurorehabilitation, Special Issue Communication Rehabilitation, Vol 17 no. 2. pp 84-89

http://informahealthcare.com/journal/pdr
Abstract

Objective: To (a) outline the background to research evaluating Twitter use by people with severe physical and communication disabilities participating actively in online communication forums for increasing information exchange, and (b) illustrate a range of potential methods that might be applied in furthering research on the use of social media by people with developmental and acquired communication disabilities.

Methods: The literature on communication disabilities, augmentative and alternative communication, and social media research informed the rationale for and design of three studies investigating the use of Twitter by people with communication disabilities.

Results: To date, there is little information in the literature about how people with a range of communication disabilities might use Twitter to increase their access to information and help them to feel knowledgeable and in control of their own lives. In this paper, three studies are proposed to investigate the use of Twitter by people with communication disabilities.
Tweet reach: a research protocol for using Twitter to increase information exchange in people with communication disabilities

The information-sharing network Twitter boasts 220 million users worldwide with approximately 2.2 million in Australia [1]. Twitter is claimed to benefit the public by increasing access to information [2,3], consequently there is a growing body of research pertaining to the use of Twitter for learning in the general population [3,4,5]. Yet little is known about how people with a range of communication disabilities utilise Twitter despite recognition that they experience difficulty in accessing information that would help them to feel knowledgeable and in control of their own lives [6,7,8].

People with physical disabilities and communication impairments make up a sizeable minority (~7% [9]) of the population but report being disenfranchised from communities through not having access to information [6,7,8] about their own health condition and care, and being excluded from employment and educational opportunities as a result of having problems communicating by speech [6,8]. Difficulties with accessing information include: (a) People with cerebral palsy relying on a small circle of family and direct support workers, who are for the most part untrained, to access the information that they need in everyday life [6]; (b) Adults with communication difficulty after a stroke lacking information about this, and wanting more information about their condition and treatment options after hospital discharge [8]; and (c) Adults with progressive deteriorating disease (e.g., motor neurone disease) facing a future of dwindling social networks, related to the gradual loss of communication, mobility, eating, drinking, and self-care skills [10]. Timely access to information about their condition and how to improve and maintain the quality of their lives is particularly important for those with progressive deteriorating disease.

Additionally, people with physical and communication disabilities have noted that they are not listened to or considered experts in their own conditions or needs [6]. Young people with physical and communication disabilities use social media including Facebook [11,12] and virtual
worlds [13,14] but nevertheless, are under-represented in social media communities [2] and the extent and benefit of their use of Twitter is unknown. Twitter is a powerful medium for information and education [3] and can potentially be used to connect a person with severe communication disabilities “to the world”, [10, p.31]. The opportunity for a wide network of social media connections may increase quality of life for people with chronic conditions [4] who are often isolated and lonelier than their nondisabled peers [15]. The Twitter network offers people with physical and communication disabilities opportunities not only to exchange information but also to have a voice in a growing global online community [2]. People with physical and communication disabilities could increase their participation in discussion and information sharing forums [2] and benefit by exchanging information and contributing to knowledge creation by using Twitter. This in turn could increase their participation in both the online disability community and the broader community.

Anecdotally we know that young people with physical and communication disabilities rarely use Twitter despite the potential benefits of this medium. The reasons for this are not clear but given that people with physical and communication disabilities access social media such as Facebook [16,17], disability alone may not account for the lack of use. Therefore, in order to facilitate people with physical and communication disabilities to have equal access to a range of social media including Twitter, it may be important to develop and test an online training module to facilitate the use of Twitter by this group. Training eases the use of communication technologies [10,18], and provides trainees with the support and confidence to use technology independently. Twitter is a social media with its own syntax (e.g., MT, RT, # hashtags, @) and, like other communication technologies, effective use relies upon the user developing operational and linguistic competence for the specific medium [10,18]. Users need to be competent with the operational aspects of a technology before they can develop strategic competence, or use the technology to fulfil a strategic purpose [18]. To date, there is no research investigating (a) how best to train young people with physical and communication disabilities to use Twitter [2], or (b) if
Twitter is an effective medium for increasing this population’s access to information and participation in online community discourse. Consequently, research to evaluate the effectiveness of a Twitter online training module and the impact of Twitter on information exchange and active online participation for people with severe physical and communication disabilities is lacking.

**Significance of the research problem: lack of access to information and social networks**

According to ABS [9] 14.4% of Australians have a disability that results in core activity (mobility, communication, self-care) impairment. Furthermore, for approximately 7% of Australians the restriction is moderate, severe, or profound [9]. The incidence of severe communication impairments is high in some groups, with up to 25% of all people with physical disabilities associated with lifelong conditions (e.g., cerebral palsy [19]), acquired conditions (e.g., aphasia following stroke [20]) and the majority of people with progressive deteriorating conditions (e.g., motor neurone disease) also having severe or profound communication impairments [10]. Even if they have no cognitive impairment, people in this population cannot rely upon natural speech to communicate with others, and need to use augmentative and alternative communication (AAC) systems, including a range of communication technologies (e.g., mobile devices, computers, speech generating devices, eye gaze technologies) to get their message across. 10 Young people and adults with physical and communication disabilities suffer (a) social exclusion, isolation, and loneliness [11,15]; and (b) significant health inequalities along with problem in accessing reliable health information [6,7]. While governments and businesses increasingly embrace social media to convey information to the public [21], people with communication disabilities lag behind the general population in their use online information technologies [2, 21]. For all people with communication disabilities, whether lifelong or acquired, the advent of interactive online forums such as Twitter in everyday society offers a way to connect and communicate with many more people than might occur in the immediate social, home, health, or educational environments [7].

**The feasibility of Twitter as a potential solution**
Twitter is a well-recognised form of micro-blogging involving publication of short messages on the Twitter website [3,5,23]. Twitter offers a short text-based form of communication with the ultimate purpose of information sharing [23]. Tweets are a maximum of 140 characters and can include shortened links to other websites, and hashtags (i.e., #). Twitter affords users the opportunity for synchronous ‘chatting’ on topics when those chatting add the same hashtag to their Tweets (e.g., #qanda). The use of Twitter on small portable mobile devices such as smart phones has (a) led to a tolerance of and preference for short messages, (b) reduced the importance of correct spelling and (c) increased tolerance of poor grammar 10. There is growing evidence that Twitter is effective for giving and receiving information by distributing information to communities and following information shared by communities [3,5,21].

As Tweets are short, Twitter is useful for people with limited literacy, including those with developmental disabilities who have had fewer opportunities for developing literacy and those with aphasia whose prior intact literacy may have been disrupted by stroke [10]. Short messages mean fewer keystrokes for communication and this is also useful for those with poor motor control or progressive disorders who fatigue easily such as people with cerebral palsy [19] or ALS [10]. Recent research has shown that people with severe communication disabilities prefer the use of short instant message text communication over other forms of online communication [22]. Twitter bypasses speech impairments as it uses only short segments of text. Thus Twitter use would potentially give people who cannot rely on natural speech a means to engage actively in community debates and information exchange. The use of social media by people with physical and communication impairments is under-researched [12, 22], with early findings indicating that this group’s use of social media is likely to be affected by a range of factors including lack of training, lack of access to the technology, and lack of policies supporting its use [2].

The aims of this paper are to outline research methods that could be used to (a) determine the efficacy of an online training module for people with severe physical and communication disabilities to access and use Twitter; and (b) evaluate Twitter use by people with severe physical
and communication disabilities participating actively in online communication forums for increasing information exchange. The use of social media continues to burgeon and it is important that people with physical and communication disabilities are supported to have equal access to online communities.

Method

Conceptual framework: socio-technical research with research translation

Socio-technical research recognises that peoples’ use of technology inherently involves both social and technological aspects as both affect the interaction of people with one another when using technology [5]. Socio-technical research supports the use of both quantitative and qualitative research methods. The three component studies we put forward here together investigate the use, efficacy, and the impact of Twitter for increasing information exchange [23] by people with physical and communication disabilities. The research methods employed in the three studies over say a three year project are: (i) study one: expert consensus panel method [24] plus survey research [25] (informs Study 2); (ii) study two: multiple baselines single case study design [26,27], with Twitter Data Network Analysis [28]: evaluating the training module; and (iii) study three: narrative inquiry [29] with Tweet Data Analysis and a research translation phase. At the end of study three, the expert consensus panel will meet to discuss and finalise the published outputs of the research, being: (i) evidence-based training for adults with physical and communication disabilities that can be delivered online; (ii) an Evidence-based Framework showing barriers to and facilitators for successful use of Twitter for information exchange by this group; (iii) guidance in implementation of the training and use of the framework to guide policy and practice in supporting both adults with physical and communication disabilities and their direct support workers in the process of growing a Twitter network for increasing information exchange; and (iv) design of a mobile technology software application as a platform for disseminating results and promoting translation of the research findings into practice.

Study one: survey of adults with physical and communication disabilities.
Using a recent survey adapted from a survey on social media conducted with children with physical and communication disabilities [24] it is possible to determine the frequency of use of Twitter in the target population and the nature and extent of any problems experienced in learning to use Twitter. Results can inform development of the training module for adults in Study [2]. A face-to-face survey has been selected to avoid barriers to participation and rule out any unknown influence of carers in completing online surveys [22, 25], and to verify the primary communication method of each participant and any augmentative and alternative forms of communication used.

First, a face-to-face interview survey [25] of adults with physical and communication disabilities could be conducted. An expert consensus panel [24] comprising one adult with cerebral palsy, one adult with aphasia following stroke, one adult with motor neurone disease, one occupational therapist, one psychologist, and a researcher would meet to discuss and agree upon adaptations of the survey of children with physical and communication disabilities [11] for use with adults in this study. After piloting the survey with 10 adults and making any further revisions indicated, a survey of 400 adults with lifelong, acquired, and progressive physical and communication disabilities would be recruited through Disability Organisations (i.e., cerebral palsy associations; spina bifida associations; stroke associations, aphasia associations, motor neurone disease associations). Each sub-group of disability types (lifelong, acquired, progressive) would make up at least 25% of the sample for each data site.

Survey questions. Survey items could include categorical responses (Yes/No), Likert scale responses, with comments explaining responses. In order to ensure that all participants are encouraged to provide as much details as possible the final question should be open-ended inviting ‘any other comments’. Questions should seek information on each participant’s level of familiarity with and knowledge of Twitter, needs and preferences, expected barriers and facilitators to use of social media; and current rates of using social media for information or engagement.

Survey administration. The survey could be administered once for each participant in a face-to-face setting at a venue to suit the participant. The researcher administering the survey will verify
each participant’s level of communication impairment according to function (i.e., speech intelligibility in conversation) and note primary method of communication (i.e., speech, speech with a communication aid or device, speech with a speech interpreter). Face-to-face interviews for the survey are needed as participants might have poor literacy or difficulty entering responses on to a written survey owing to their physical disabilities.

**Data analysis.** Frequency counts and descriptive statistics will be calculated for categorical responses and content of the open-ended questions will be analysed to identify themes in reasons given for categorical responses [25]. The mean rating responses for the scale items will be presented. Differences in mean ratings for the scale items and the response proportions for the categorical survey items between the sub-groups in survey respondents will be examined for significance using appropriate statistical tests.

**Outcome.** This study will provide information on adults with physical and communication disabilities familiarity with and knowledge of Twitter, and their needs and preferences in relation to using Twitter for information and engagement. The results of the survey will also inform design of a Webinar series of online training modules in study two. In addition, the information gained in this study will guide the development of policies and practices that support adults with physical and communication disabilities to use Twitter for information and engagement.

**Study two: evaluating the efficacy of an online training module on Twitter for the target population.**

Training potentially involves a permanent change in the participant in regards to the outcome of interest. A non-concurrent multiple baselines single case study design is suitable as it (a) enables measure to be taken with participants with a range of disabilities acting as their own controls, and (b) can include randomisation to baselines of varying duration (i.e., three, four, five, six, seven, or eight weeks) thus controlling for extraneous variables so that the effects of the training can be determined4. In order to meet Clearinghouse standards, [26] a multiple baseline non-concurrent single case design, with three groups of six (CP, Aphasia, ALS), each individual randomly allocated
to different baseline lengths of three, four, five, six, seven or eight weeks [26] (i.e., at least three participants in the baseline and treatment phase with five data points per phase) is preferred.

Participants. Only people with computer and Internet access who are able to give their own consent to participate are suitable for inclusion in this study. 36 adults with: lifelong disabilities of cerebral palsy (n = 12); aphasia following stroke (n = 12); and acquired progressive conditions ALS (n = 12) who consider themselves to be novice in Twitter and want to increase their Twitter use for access to information are needed. The initial number of 36 allows for five participants from each group to drop out for a variety of reasons (e.g., loss of broadband, loss of computer, health issues, voluntarily withdrawing) and will result in seven in each group remaining. After giving consent to participate, participants will be given information from the resources publicly available in Twitter aimed at consumers [23]. Each participant will need to use the information on how to use Twitter to create their own profile handle and let the researcher know the name of their Twitter profile. The researcher will provide any necessary technical support and help resolve any difficulties encountered by participants as they develop their own profile.

Intervention elements (training). The pre-recorded webinar developed on the basis of the results of study one will be viewed by the participant in the presence of the researcher. The researcher will be on hand to answer any questions raised in the course of the training. Following the training, the participants will be instructed to use Twitter for accessing information. The participants will be advised that they can review the webinar at any time that in the future.

Variables. The independent variable is the online training module developed by the researchers. The dependent variables are (i) all automated quantitative frequencies taken of the Twitter network – numbers of Tweets, Retweets, and Tweet replies sent by each participant, each participant's number of Twitter followers, the number of Twitter profiles each participant is following in Twitter; and (ii) the use of Twitter for information exchange (as opposed to social closeness, etiquette, basic needs) judged by a content analysis of Tweets by two assessors and inter-assessor agreement on at least 20% of the data in each condition.
Repeated measure (weekly for 3 months – 12 measures): Twitter Data Network Analysis. All Tweets and related Twitter usage statistics will be captured using the Twitter data collection tool NCapture, an add-on for popular web browsers that connects with the data analysis software NVivo – both NCapture and NVivo are products of QSR International. The Tweets are imported into NVivo for tabulation and coding, and are exported as a Microsoft Excel spread sheet. Each outcome variable will be measured three times in baseline and at five time points after the training, then three monthly and six monthly follow up measures. The data collection process, via NCapture, captures the textual content of tweets automatically along with all the quantitative information gathered. NCapture calculates numerical measures from any Twitter profile, including number of followers, number of profiles being followed, frequency of Tweets, Tweets sent, Retweets, and replies to Tweets. The resultant Twitter communication network can be displayed as a visualisation (e.g., as a map or graph) using Gephi - an open source network visualisation tool. Results will be analysed visually for trends and statistically by Percentage All Non-overlapping Data [27] from baseline to training phase. To determine if Tweets sent are for information exchange, a content analysis by will identify which communication need is being met by the Tweet (i.e., basic needs communication; information exchange; communication for social closeness; etiquette) [10,18].

Outcomes. This stage of the study will deliver systematic measures of Twitter usage before and after the online training module is delivered to show the effect of the training on use of Twitter for information exchange in the target population.

**Study three: evaluation of the training – views of participants and Tweet Data Analysis**

This study incorporates both quantitative and qualitative methods. Narrative inquiry is particularly suited to understanding the nature of the experience in a sequential time series, and any causal relationships that the participants themselves view impact upon their experiences [28] of using Twitter for information and engagement. Each participant’s follow-up Twitter Data Analysis will be produced immediately prior to his or her interview. The Tweet data ‘visualisations’ or graphic representations of the network [29] will be shown to the participant in their Narrative
Interview to prompt narratives around ‘what was happening’ for them at that point in time. This mixed qualitative and quantitative methods study will use narrative inquiry and Tweet data network analysis methods.

**Participants.** The same 36 participants recruited in study two will participate in study three. Participation is not dependent upon the participant’s level of Twitter use after training. This is a feasible sample for narrative inquiry design that provides rich information on the events and participants’ evaluation of outcomes of the experience of using Twitter.

**Data collection: Tweet data network analysis.** Follow-up measures will be taken at three and six months in year three. At these points, Tweets will be captured for using the Tweet data collection tool NCapture with import into NVivo. The data captured will be treated as in the analysis described in study two. Face-to-face in-depth narrative interviews will be conducted seeking participants’ views on their experience. Each participant will be shown their Tweet data analysis and visualisations through the study as a prompt to narrating their perspectives as the study proceeded.

**Analysis.** Interviews will be de-identified and analysed according to narrative inquiry, first locating the component story boundaries (abstract, setting, events, any trouble, evaluation, resolution) and re-ordering to chronological order [28]. A summary story will be written for each participant that encapsulates their experiences and views, and sent to him or her to verify or request any changes. Each participant’s story will contribute to an over-arching narrative across all participants to encapsulate the experiences, difficulties, and strategies used to exchange information.

**Outcomes.** The socio-technical approach recognises both the technological and social aspects of using Twitter, and the importance of including participants with little or no speech to inform social media research as experts in the consensus panel and as participants. The innovation in a project such as the one described here is in the delivery of an intervention that is sustainable, that draws upon the collective resources apparent in distributing information in Twitter, and that can be
delivered at low cost across many countries via National Broadband Networks. If training people who struggle to communicate by speech to access information using Twitter is effective, the training might be used in research where Twitter is the intervention agent (e.g., delivery of public health initiatives; management of chronic conditions; and open education programs).

**Implications for policy and practice**

Research such as we have proposed here will advance knowledge in the fields of (a) online teaching and learning policies and practices: training people with disabilities in use of Twitter for learning; (b) information communication technologies: using Twitter for information exchange; (c) equity, communication and information rights: inclusive practices to increase the representation of people with disability in social media initiatives by Governments and disability organisations; (d) socio-technical research: methods including participants who do not speak as new and improved technologies are developed in response to peoples’ needs; and (e) research into Twitter as a cost-effective intervention to address problems experienced by people with disability.

Introducing a social media tool that will increase information exchange for members of the community who, through their disabilities, are most vulnerable to being excluded from information, could have immediate and widespread benefit in two directions: (a) benefits to people with physical and communication disabilities not only accessing current information but being included in disseminating and generating information about disability; (b) benefits to all who participate in social media exchanges that include people with physical and communication disabilities, through greater awareness of disability, improved attitudes, and increased knowledge about disability and its impacts on people with disability and the wider community.
Declaration of interests

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.
References


[17] O’Gurek R. Living with a disability: owning my own business; being an entrepreneur, being a mentor to other AAC users. Proceedings of the Pittsburgh Employment Conference (p. 80) 2011. Pittsburgh, August 5-7


Declaration of interest

This research protocol formed the basis of an application by the first author to the Australian Research Council in 2013, for funding under the Discovery Early Career Researcher Scheme. The outcome of the application is not yet known.