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Review of the Literature on the Use of Social Media by People with Traumatic Brain Injury (TBI)

Abstract

Purpose: To review the literature relating to use of social media by people with a traumatic brain injury (TBI), specifically its use for social engagement, information exchange, or rehabilitation.

Method: A systematic review with a qualitative meta-synthesis of content themes was conducted. In June 2014, 10 databases were searched for relevant, peer-reviewed research studies in English that related to both TBI and social media.

Results: Sixteen studies met the inclusion criteria, with Facebook™ and Twitter™ being the most common social media represented in the included studies. Content analysis identified three major categories of meaning in relation to social media and TBI: 1) risks and benefits; 2) barriers and facilitators; and 3) purposes of use of social media. A greater emphasis was evident regarding potential risks and apparent barriers to social media use, with little focus on facilitators of successful use by people with TBI.

Conclusions: Research to date reveals a range of benefits to the use of social media by people with TBI however there is little empirical research investigating its use. Further research focusing on ways to remove the barriers and increase facilitators for the use of social media by people with TBI is needed.

A Review of the Literature on the Use of Social Media by People with Traumatic Brain Injury (TBI)

Social media use has rapidly become a usual part of everyday life and communication for many people, including teenagers, young adults [1-4] and older people [4,5]. Indeed, connecting online in social media is now considered an integral part of society regardless of a person's age, gender, education, or socio-economic status [1,2,6,7]. Increasingly, both synchronous and asynchronous conversations are taking place in the online environment using Web 2.0 platforms [1-3,8,9] such as Facebook™ and Twitter™. Reflecting its multipurpose design, social media is used for finding and exchanging information, engaging socially, and connecting with a wide range of people in a global context [1,8,9]. In 2010, Kaplan and Haenlein [10] classified the diverse range of social media according to the following categories: blogs (e.g. WordPress™); collaborative projects (e.g. Wikipedia™); social networking sites (e.g. Facebook™ and Twitter™); content communities (e.g. YouTube™); virtual social worlds (e.g. Second Life™); and virtual game worlds (e.g. World of Warcraft™). This classification scheme [10] provides a broad framework of reference to encapsulate the range of social media available in online communities. Participating in online forums afforded by social media (e.g., Twitter™ chats; Google™ hangouts; Facebook™ groups) is also a form of self-expression and identity [7,9,10]. Furthermore, social media is increasingly being used by governments to promote health information for consumers [11]. Consequently, people who have acquired communication disabilities related to traumatic brain injury (TBI) and who used social media before their injury may need or desire the ability to maintain their current social media use, or to recover these functions if impaired following the TBI [7,12].

People with TBI often experience significant changes in communication after injury [13]. Communication disabilities after TBI can be related to receptive and expressive aphasia,

changes in attention and concentration, social communication disorders, as well as difficulties with timing, processing, and higher level language skills (cognitive-communication) [13-18]. Although TBI is generally more common in the very young or elderly, serious brain injuries have a higher incidence in males aged 15-24 years [13]. Concussion (a subset of mild TBI) is often associated with nausea, headaches, dizziness, slowed information processing, and loss of memory, all of which generally resolve [13,19,20]. In contrast, those who sustain a severe TBI often have ongoing physical and neuropsychological impairments that persist long term [13,21] and function may deteriorate over time [22]. In terms of functional outcomes, people with a significant (moderate-severe) TBI generally achieve independence for activities of daily life [13]. However, loss of communication skills for those with a significant TBI is common due to cognitive-communicative deficits, which can have wide-ranging consequences socially [13-15,18,23]. It is common for people with TBI to lose friends within the first year after injury and there are often notable difficulties after TBI in maintaining and building social networks [13,23-25], including changing relationships and communication with family members [26-28]. Their ability to socialise and to build or maintain relationships is often greatly impaired [13,15,18]. This frequently leads to feelings of social disconnection and loss of self-identity [13,15,18,23-25,29]. There has been considerable investigation into rehabilitation of social communication disorders after TBI [13,23,24,30-37], including the benefit of training communication partners of people with a TBI [27,38-40] and it is generally agreed in the literature that it can be very challenging for people with a TBI to reintegrate into society and to communicate effectively in the many social domains of life after brain injury.

With a rise in the use of social media in everyday communications, it is possible that social media may play a part in the rehabilitation of communication skills and building or maintaining social networks after TBI. Social media can allow people time, without

prejudice, to comprehend and respond in a way that face to face conversations might not always afford [41-43]. In addition, social networking sites (e.g., Twitter™) that make use of shorter messages with less focus on correct spelling and grammar [44,45], might reduce demands upon literacy and increase opportunities for online interactions in people who have impaired literacy.

There is a small body of research examining the experiences of young people with communication disabilities (teenagers and young adults with cerebral palsy, physical disability, and acquired brain injury) using social media [46-49]. Young people with communication disabilities have expressed an interest and desire to participate in online forums [46-49], with one participant in the Hynan et al. [48] study stating: ‘the internet and social media are an important part of my life. I cannot imagine life without that’ (p.179). Positive outcomes have been reported for participants in both performance and satisfaction when socialising online (using games, Skype™, Chat, Facebook™, Twitter™, videos, email, Livewire™, and blogging) [46,47,50,51]. Currently, Hemsley et al. [52] are investigating the use of Twitter™ for people with lifelong, acquired, and progressive physical and communication disabilities (i.e., people with: cerebral palsy; stroke; motor neurone disease) to increase information exchange and active online participation [52]. The results of this research are expected to provide further insights into the potential of providing social media training for people with complex communication needs.

With respect to TBI, there has been increased attention in the literature on the accumulative effects of concussion in sport on the player’s brain and several studies have investigated the reporting of concussion in social media [53-60]. There is also emerging interest in the use of email [61-64], telehealth [32,65], the Internet [66-70], Internet chat rooms [30], and social media [12,30,41-43,53,54,56,58-60,71-80] in TBI rehabilitation. These studies show that participants are satisfied and interested in using social media

[12,30,41-43,54,66,68,69,71-73]. Furthermore when social media is used to connect with friends and family, social isolation that is common following TBI is reduced [12,30,72]. People with TBI have also reported that social media enabled them to access back into the social world and life itself [41,43], as one Twitter™ user with TBI reported: ‘I have developed friendships there that are as meaningful as real life ones and in many ways, more supportive’ [41](p.22). Another adult with TBI described the benefit of other people in social media not being aware of the individual’s TBI and ‘for this reason, Social Media has become very important to me. Social Media is my new, virtual, happy place! I no longer have a brain injury. I am whole. I am a free and unencumbered spirit’ [43](p.16).

Studies to date are descriptive in nature and do not directly investigate impacts of using social media on communication skills following TBI [81-89]. It is not known how social media is used by people with TBI or how it might be used in rehabilitation following TBI. Furthermore, commentary papers and clinical guidelines for evidence-based practice in TBI rehabilitation have made no reference to the use of social media by people with TBI [34,37,90-92]. They do however emphasise the need for rehabilitation to be person-centred and to facilitate function and participation in daily life contexts [37,91,92], and this could now include online interactions occurring in social media. Therefore, the aim of this study was to review and synthesise the findings of original research on the use of social media by people with TBI. The results of the review could be used to inform clinical practice in the provision of rehabilitation for people with TBI, policies supporting the inclusion of people with TBI in social media forums, training for people with TBI and their families on social media use, and further research on ways to introduce or rehabilitate patients’ use of social media after TBI.

Method

Inclusion Criteria

We sought studies relating to both social media and TBI. Social media was defined as Internet based applications that allow the creation and exchange of information between its users [10]. TBI was defined as brain injury caused by an external force [93] and inclusive of all levels of severity (from concussion and mild TBI through to severe TBI). Owing to limitations in language of the authors, only reports published in English were included in the review. No limitations were placed on the search in relation to year of publication, study type (e.g., literature review, original research) or design (e.g., controlled trials or qualitative reports) or age of participants in the studies (e.g., adults or children). To find any potentially relevant information to guide practice, all levels of TBI severity, all types of resulting disability (i.e., not restricted to communication disability), all forms of social media, and all peer-reviewed publications (i.e., including journal articles, theses/dissertations, peer-reviewed conference proceedings) were considered for inclusion in the review.

Exclusion Criteria

Reports of research were excluded if they were not in English, not peer reviewed, did not relate to TBI *and* social media, or primarily related to online forums for higher/professional education; professional networking; marketing; or professional issues (e.g., Internet privacy, medico-legal concerns, or job recruitment). Studies were excluded that did not relate to TBI but related to other acquired brain injuries (e.g., stroke), or related only to the Internet, applications, mobile or e-health technologies, or if there was no component of user generated content in a publicly accessible Internet domain.

Search Strategy

Ten electronic databases were searched in June 2014: CINAHL, EMBASE, Medline, Proquest, PsycBITE, PsycINFO, PubMed, speechBITE, Web of Science, and Google Scholar. Multiple search terms related to “TBI” [traumatic brain injury OR TBI OR brain injury OR concussion], “health” [health OR disability] and “social media” [social media OR

social networking sites OR micro-blog OR Twitter OR Facebook]. The search results were extended by searching for forward and backward citations of relevant studies found; conducting related records searches; and using search alerts of new publications until December 2014.

Study Selection

The search yielded 11673 potentially relevant titles that were imported into Endnote X7. The first author screened titles and abstracts of studies for eligibility and retrieved the potentially relevant studies as full text ($n = 33$). On reading of full text, the first and second authors then applied the selection criteria as needed to decide on inclusion or exclusion of the study from the review.

Data Extraction and Quality Assessment

Data were extracted from each included study and entered into a Microsoft Excel file by the first author, with accuracy and completeness checked by the second author. Data included bibliographic information, study type, population characteristics, focus of the study, aims, methods, description of social media tool/s used, findings, authors' conclusions, and directions for future research. Where relevant, the level of evidence of each of the included studies as per the guidelines of the National Health and Medical Research Council of Australia (NHMRC) [94] was noted.

Data Synthesis and Analysis

A qualitative meta-analysis of findings across the included studies involved identifying individual categories in the results of each study and then creating a code-set of categories to encapsulate the themes across the studies. The authors discussed the findings in the context of TBI rehabilitation and also the use of social media for other people with communication disabilities. Results are displayed in evidence tables and quotes or excerpts from the findings used to illustrate key aspects of the qualitative meta-synthesis.

Results

A search of 10 electronic databases identified 11673 potentially relevant articles that were imported into Endnote X7 for further consideration. After removing duplicates and studies with no author details, titles and abstracts were screened according to the inclusion criteria. In total, 7480 articles were excluded on title and abstract, and full text articles for 33 studies were retrieved from library holdings as being potentially relevant studies. On reading of the full texts, a further 17 articles were excluded on focus and/or type of publication, leaving 16 articles included for critical appraisal and analysis [12,30,53,54,56,58-60,71-78]. Figure 1 summarises the search results and application of the inclusion/exclusion criteria to potentially relevant studies (PRISMA flow diagram [95]).

Insert figure 1 about here

Type and Level of Evidence

The 16 studies identified included in total: one systematic review, one case series study, three qualitative studies, two qualitative descriptive studies, one thesis, one narrative literature review, and seven conference abstracts/proceedings. The majority of the studies ($n = 14$) used qualitative methods and were exploratory or descriptive in nature. The remaining studies included one level I systematic review of the use of Internet chatrooms by teenagers with TBI, and the other as a level IV case series using a social networking site as a concussion management intervention [94]. The NHMRC quality assessment was not conducted on qualitative studies due to both the nature and limited methodological detail provided in the published reports on the studies.

Focus of Included Studies

The focus of the included studies varied, with just over two thirds ($n = 12$) investigating the use of social media for people with TBI [12,30,53,54,58,71-74,76-78] and

the remainder ($n = 5$) analysing the content of information about TBI available on social media [54,56,59,60,75]. The characteristics of the included studies are presented in table 1.

Insert table 1 about here

Participants in Included Studies

The included studies used a variety of research methods with participant populations of TBI ($n = 7$) [12,71-73,76-78] or concussion ($n = 7$) [53,54,56,58-60,74], and two of these studies including reference to both TBI and concussion [30,75].

The number of participants in the included studies was reported in only 9 of the 16 studies reviewed [12,30,54,56,58-60,75,78]. Reported participant numbers ranged from 8 to 155,101 participants. The sources of data included in studies about social media and TBI or concussion included surveys, interviews, websites, and social networking posts (written, image and video posts). Studies reporting participant ages ($n = 4$) ranged from 16-70 years of age.

Social Media Sites in Included Studies

The social media used or referenced in the articles were the social networking sites Facebook™ ($n = 12$) [12,53,54,56,58,72-78], Twitter™ ($n = 8$) [59,71,73-78], and the video content community YouTube™ ($n = 5$) [60,72,75,77,78]. Other social media mentioned in the studies included MySpace™, LinkedIn™, Ustream™, Skype™, blogs, forums, Internet chatrooms, and social media in general [30,72-78]. This diversity in social media platforms is consistent with literature regarding the use of social media in populations with other health conditions [81,83,85-88].

Thematic Content Analysis of Included Studies

A meta-synthesis and analysis of qualitative findings in the included studies identified three main categories in the content themes: 1) benefits and risks of use of social media in TBI; 2) barriers and facilitators to use of social media in TBI; and 3) purposes of use of social

media in TBI (encompassing health communication; communication and social participation; and rehabilitation). A summary of the content themes of the included studies is presented in table 2.

Insert table 2 about here

Benefits and Risks of Use of Social Media in TBI

Benefits of use of social media in TBI. The benefits of the use of social media by people with TBI was raised in all but one of the included papers ($n = 15$) [12,30,53,54,56,58-60,71-74,76-78]. The potential for social media to support individuals socially was documented in 11 studies ($n = 11$) [12,30,53,54,56,58,71,72,74,77,78], with one author [72] concluding that ‘the potential benefits appear endless’ (p.E15). Across the studies, the use of social media as a source of information by consumers ($n = 9$) [12,53,54,56,58-60,74,77], for interactive communication ($n = 9$) [12,30,53,54,59,60,72,74,76], to improve social connection ($n = 7$) [12,30,71-73,77,78], and for disseminating health information by healthcare professionals ($n = 7$) [53,54,58-60,74,77] were also outlined. Following a systematic review of the literature which included social networking, Kilov et al. [30] postulated that ‘online conversations with peers may assist them [teenagers with a TBI] to develop communication and social skills that enable them to be more proficient and potentially more socially accepted in everyday interactions’ (p.1169).

The convenience of social media for people with TBI was highlighted in eight studies [12,30,56,59,60,71,72,76]. Convenience was noted in regards to its low cost ($n = 3$) [12,72,76], easy access and international reach ($n = 6$) [12,59,60,72,74,76], reduction in travel particularly for people in rural and remote areas ($n = 5$) [12,56,71,72,76] and lack of time pressure for use ($n = 2$) [12,76]. Other benefits noted in the use of social media use by people with TBI included: the ability to communicate in a different mode ($n = 6$) [12,30,59,60,72,76], the potential to provide intervention ($n = 4$) [53,54,58,71], and the

opportunity to communicate in an environment with reduced stigma associated with TBI ($n = 2$) [30,76]. Smith [76] noted that ‘social media provides a venue that levels the playing field for some’ (slide 18) and Youcha [77] proposed that social media may be of benefit to not only those with TBI but also ‘those who care for them’ (p.391).

Ahmed et al. reported that social media appeals to a younger demographic, an important point with TBI being more prevalent in young people [58], and that ‘Facebook has a relatively untapped potential in the field of health’ [53] (p.41). Young people are also more likely to seek information regarding health via the Internet and social media ($n = 4$) than through face-to-face consultations, particularly with regard to concussion [56,58,59,74].

Risks of social media use in TBI. Risks relating to social media by people with TBI were highlighted in 12 of the included studies [12,30,53,54,58-60,71,72,74,76,77]. The risks identified focused on Internet safety ($n = 9$) [12,30,53,54,58,60,71,72,77] (e.g., the possibility of cyber-bullying, challenging online relationships - particularly between patients or peers with TBI [12,30,53,54,58,60,71,72,77]), and the potential for those with TBIs to be more vulnerable to online miscommunications and online scams [72]. In a survey of 98 people with TBI, Tsaousides et al. [12] identified that ‘the most commonly endorsed barrier’ to use of social networking sites was security concerns (p.1159). Conway et al. [72] concurred and noted that people with disabilities after TBI ‘are faced with additional hazards with possibility of exposure to scam artists and required assistance to maintain safety in our ever-changing virtual social world’ (p.E15). However, people with TBI may not share these concerns, as one participant in Ahmed’s study [54] stated ‘I’m not too worried about privacy as there was not very sensitive information discussed’ (p.259).

Other risks raised in relation to social media use by people with TBI included (a) risks related to them posting inappropriate content ($n = 5$) [53,54,58,71,76], (b) risks to confidentiality and privacy of information ($n = 6$) [12,53,54,58,76,77], and (c) concerns about

the quality and accuracy of information about TBI being posted ($n = 5$) [53,54,59,60,74]. Other risks identified included concerns regarding the need for adequate cognitive rest (i.e., rest from activities that involve cognitive function such as reading) for those with a TBI ($n = 2$) [53,54], with social media presumed to add to the cognitive demands as a result of using social media for extended periods of time [53], and the potential legal and ethical issues arising from ‘friend’ relationships developing between patients and health professionals online as a result of social media use [71]. There were no adverse events resulting from use of social media by people with TBIs reported in the included studies.

Barriers and Facilitators to the Use of Social Media by People with TBI

Barriers to social media use in TBI. The barriers to the use of social media encountered by people with TBI were outlined in 10 of the included studies [12,30,53,54,58,71-74,76]. Most of the barriers noted related to the previously described risks, and included either cognitive disability ($n = 5$) [12,30,71,73,76] or behavioural disability, including social and communicative disability ($n = 4$) [12,30,71,76], as well as the need for people with TBI to have cognitive rest ($n = 3$) [53,54,58], particularly in the early stages of recovery. Specific reference was made in several papers about the potential for incorrect information on TBI being posted and shared ($n = 4$) [53,54,58,74]. Provvienza et al. [74] concluded that moderation and evaluation of online content is essential to ‘to ensure proper information is communicated’ (p.336).

Other barriers to the use of social media by people with TBI related to poor accessibility of social media sites [12,30,71-73]. These accessibility issues included: problems accessing electronic devices/internet ($n = 3$) [12,71,72], the technical complexity of social media sites ($n = 2$) [12,73], the constant development and re-development or update of social media sites ($n = 2$) [12,71], and poor accessibility for people with visual deficits ($n = 2$) [12,30]. Mason [73] suggested that the use of social networking is likely to be lower for those

with more significant or severe TBIs ‘due to the technical complexity’ of social networking sites (p.135). Tsaousides et al. [12] identified that perceived barriers by the participants were often attributed to challenges in access, with ‘forgetting passwords’ considered a significant barrier to social media use (p.1158) and one participant stating ‘Facebook does not recognize ‘talk and type’ software, on which disabled people often depend’ (p.1159). Only one study noted that the age of a person ($n = 1$) [72] might be a barrier, with an increase in age resulting in reduction of access to social media observed. The immediacy and informal style of social media was noted in one study as a barrier [71].

Facilitators for social media use in TBI. The facilitators to social media use in this population were discussed in half of the included studies ($n = 8$) [12,30,53,54,58,74,76,77]. The most common facilitator for social media use in TBI was education and training in social media use for people with TBI and their communication partners ($n = 8$) [12,30,53,54,58,74,76,77]. Indeed, Kilov et al. [30] proposed that training be developed and provided ‘for a broader spectrum of people involved in the care of teenagers with TBI (e.g. case worker, teacher, parent)’ in order to facilitate social media use ‘to improve daily communication and social skills’ (p.1169). Tsaousides et al. [12] suggested barriers to use of social networking sites ‘could potentially be addressed through hands-on training’ (p.1160). Collectively, the authors of the studies recommended that training include clear instructions ($n = 6$) [12,30,53,54,58,76], provide information on privacy settings ($n = 4$) [12,53,54,58], and suggest a code of conduct or guide to social media ‘etiquette’ ($n = 2$) [54,76]. Smith [76] reported that ‘presenting yourself to the world’ via the Internet is ‘a lot like “real world” etiquette’ (Slide 35). The iCon Facebook™ intervention study by Ahmed included a code of conduct to facilitate appropriate social media behaviours [54]. Ways to improve the accessibility of social media use in TBI was addressed in one paper ($n = 1$) [12], with specific reference to assisting people with TBI manage their screen brightness, colour contrast, font

size, Internet access, and the use of appropriate AAC software as needed to overcome technology-based accessibility barriers.

Several papers identified that the use of a facilitator to monitor and moderate posts was appropriate to ensure that accurate information was shared ($n = 4$) [53,54,58,74], as well as to refer people with TBI to seek appropriate help when indicated ($n = 3$) [53,54,58], or encourage adequate cognitive rest ($n = 2$) [53,54]. In a survey exploring the opinions of eight general practitioners, Ahmed et al. [53] concluded that moderation of information is ‘essential to assist users to contextualise information and to provide appropriate responses to inaccurate postings’ (p.41). Only one study in this review evaluated the impact of implementation of facilitators for social media on its use [54] including health professionals moderating a Facebook™ page and support for a small group of people who had experienced a concussion. Outcomes from the Ahmed study [54] were positive, showing Facebook™ has the potential to be used ‘as an adjunct to traditional management strategies for concussion’ (p.IV).

Purposes of Use of Social Media in TBI

Social media use for communication of health information. Almost two thirds of the included studies ($n = 10$) noted the use of social media for accessing health information and communicating health related issues [53,54,56,58-60,74,75,77,78] including the use of social media to disseminate information about TBI and concussion ($n = 9$) [53,54,56,58-60,74,75,78]. Indeed, using social media to seek and find information ($n = 7$) [54,56,58-60,74,75], as well as sharing personal stories and symptoms ($n = 5$) [54,56,59,60,74], was common across the studies. In discussing results of their studies, Williams et al. [60] noted that YouTube™ ‘has quickly become the medium of choice for the sharing of videos’ and that its ‘simplicity and power’ enable users to share videos rapidly (p.110); and Sullivan et al. [59] identified the potential of Twitter™ ‘to connect with the busy ‘now’ generation’ and the

ability to assist in healthcare knowledge transfer to feed the ever-growing ‘information-hungry audience’ (p.262). In addition, the use of social media for health promotion and increasing the awareness of TBI and concussion was highlighted in six studies [54,58-60,74,75] even if the social network sites were used primarily for reading or ‘lurking’ (reading without actively contributing) [54,59]. Social networking sites, such as Twitter™, allow consumers to share and spread information to a wide and diverse audience ‘whether they are followers, lurkers or persons simply exploring this medium’ [59] (p.262).

Social media use for communication and social participation. Using social media for communication and social participation was documented in 12 of the included studies [12,30,54,56,58,59,71-74,77,78]. The most common reason found for using social media was for social interaction ($n = 8$) [12,30,54,56,59,72,77,78] between peers ($n = 5$) [30,54,56,72,77] and families ($n = 5$) [30,54,56,71,72], for both social support ($n = 11$) [12,30,54,56,58,71-74,77,78] and to share experiences ($n = 5$) [12,54,56,59,74]. Tsaousides et al. [12] also suggested that social media was a way to reduce the social isolation that is common after TBI, as it may allow people with TBI ‘to engage in social interactions on their own terms’ (p.1160). Peer-to-peer interactions were valued by the participants in the iCon Facebook™ intervention study by Ahmed [54], with participants stating ‘everyone was contributing and so it was great’ and ‘more interaction between people in group would have been good’ (p.260).

Four of the included studies reported on the potential for social media use to help people with a TBI to maintain and form new relationships ($n = 4$) [12,30,72,73]. Indeed, social media was reported as being beneficial for communication and social participation of people with communication disabilities [30,54,56,72] even when used for ‘lurking’ or passive participation only [54]. There was agreement across the studies that social media use in people with TBI had the potential to improve outcomes in relation to social connection,

support, and relationships, not just for the individual themselves but also for their families and friends. Conway et al. [72] noted positive, meaningful outcomes of social media use in relationships where previously family members of the person with a TBI were unsure of how to communicate with them, now were able to do so.

Social media use in rehabilitation. A majority of included studies ($n = 11$) mentioned the use of social media for some aspect of rehabilitation in TBI [12,30,53,54,56,58,59,71-73,77]. Ten studies documented the use of social media to deliver intervention or rehabilitation [12,30,53,54,56,58,59,71,72,77] and five considered the use of social media as a functional goal for rehabilitation after TBI ($n = 5$) [12,30,71-73] to stay connected, build on social opportunities, and facilitate progression of skills with training and education. Becker [71] recommended that in the development of an individuals' rehabilitation goals, clinicians should 'consider their patients' use of new media and its impact on the rehabilitation process' (p.659). Specific reference to rehabilitation of *communication disability* following TBI was found in only two studies [30,72]. Conway et al. [72] observed that social media provided people with communication disabilities after a TBI with 'a portal for maintaining personal and family contact' (p.E15) and use of different communication modes facilitated more opportunities for interaction, for example using 'Skype was a visual way for someone with a TBI to communicate' (p.E15). Furthermore, Kilov et al. [30] noted that use of social media by people with TBIs 'could also provide a natural context for generalization of therapy skills and high level communication skills outside clinical contexts' (p.1169).

Discussion

The studies included in this review identified potential opportunities to enhance both activity and participation domains in the International Classification of Functioning, Disability and Health (ICF) [96] for people with TBI, by increasing communication,

interaction, and social connection. Therefore, the inclusion of social media goals in the rehabilitation of people with a TBI, particularly those with communication disabilities is supported by the literature. Improved social media use by people with TBI may enhance outcomes by assisting them to integrate into everyday online communities successfully and reduce social isolation and stigma that is often associated with TBI. Despite the several potential benefits of social media use, the studies included in this review report similar perceptions of risks associated with the use of social media (e.g., privacy and confidentiality) as previously reported for the general population [97-99], for children and adolescents [99-101], for students [102-106], and academics [88,107-112]. Furthermore, the barriers to social media use by people with TBI were related to these perceptions of risk and to an aversion to placing people with TBI, already considered a vulnerable population, at increased risk of harm. However, there were additional risks associated with social media use for people with TBI that were related to their cognitive impairments and need for cognitive rest. Environmental factors (e.g., low accessibility of social media sites) also featured strongly in access barriers to social media use by people with TBI. The limited use of social media by people with TBI (i.e., an activity limitation in the ICF) and resulting loss of social interaction opportunities (i.e., participation restriction in the ICF) might reflect that the perceived risks and environmental barriers to the use of social media by people with TBI are not yet addressed by training or support in the use of social media. Indeed, no studies were found to evaluate ways of reducing the risks associated with social media use by people with TBI so as to improve participation in social media and current evidence-based practice guidelines reflect this paucity of research.

The potential benefits of social media outlined in this review suggests that it is important that barriers to social media use are removed so that people with TBI may benefit from the improved social connection and participation afforded to other users of social media

[12,30,53,54,58,71-74,76]. Satisfaction in using online social media during rehabilitation and higher satisfaction for peer-to-peer interactions was noted in the intervention studies included in this review [54,56,73]. Such satisfaction in using social media is also reported in the literature on social media use by young people with physical disabilities and communication impairments [7,46-48,113]. Providing knowledge and experience in people with TBI using social media to access information and engage socially is potentially empowering not only for those with communication disabilities after TBI but also for the wider community via greater exposure and increasing knowledge of TBI. However, there is as yet limited research investigating the risks or interventions to assist people with TBI to use these social media tools more effectively or as part of their rehabilitation [30,54,56,72]. Education and hands-on training was frequently suggested to be facilitators for social media use [12,30,53,54,56,72,77,78] and the high level of interest in social media by people with TBI and willingness to undergo training to improve skills in social media [12] suggest that such training is feasible. Communicating via social media may allow the person with TBI more time to process information and respond at their own speed, in the comfort of a familiar environment [12,41-43]. The immediacy of social media was noted in one study as a barrier [71]. However this also has the potential to be seen as a benefit of social media use. Being able to access social media may give people with a TBI the sense of being connected right now, rather than feeling as if they are missing out.

The use of support people or facilitators in training or re-training people with TBI to use social media could also help guide skill development and reduce safety risk, such as cyber-bullying or posting of inappropriate content [12,53,54,58,74]. Despite several potential risks being raised as barriers to the use of social media, there were no reports of adverse events arising from its use in the included studies. This may suggest that people with TBI may face the same level of risk when using social media as any other individual. Attitudes

towards people with TBIs using social media may be too protective. Therefore, rehabilitation needs to address fears and minimise risks in order to aid access and successful social media use by people with a TBI. If training can incorporate information and assistance in increasing online personal safety (e.g., protection against fraud and scams) and compensatory strategies to assist communicative disabilities, the primary concerns outlined in the literature to date could be reduced to allow people with TBI the opportunity to enjoy the stated benefits of social media [12,53,54,58,76]. Concerns surrounding cognitive rest reported in the literature [53,54,58] related more to people in the acute TBI or concussion phase and the effects of social media use on cognitive fatigue should be explored further for people in the rehabilitation phases post TBI.

The wide ranging nature regarding purposes of use explored in the included literature reflects the variability and potential of social media to cater to a multitude of individual interests and needs within the TBI population. Whether an individual is seeking information, wanting to connect socially in an online environment or merely ‘lurk’ and learn by reading, social media can offer different opportunities to different individuals in their course of rehabilitation after TBI. The findings of this review align with the existing research into recovery after TBI in that reduction in social isolation by increasing social participation leads to higher satisfaction and greater communicative function and independence for people with a TBI [13,23,24,30-35]. The use of social media adds to other methods of communication such as face-to-face conversations, telephone calls, written letters or emails that might inform functional goals in rehabilitation for people with TBI. Social media affords an interactive method of online communication to assist more successful communication, interaction, and ultimately social participation [12,30,53,54,59,60,72,74,76].

The results of this review suggest that social media skills could be incorporated into rehabilitation for people with TBIs in order to increase their participation and reduce their

activity limitations as a result of their disabilities. Several potential benefits of social media use provide a strong rationale for future investigations exploring the use of social media in people with TBI, particularly in regard to ways to reduce barriers and increase facilitators to successful use. Most of the studies included in this review related to Facebook™, and to date there have not been any investigations into using Twitter™ as a medium to enhance communication and social participation for people with TBIs. We found no rigorous studies investigating interventions to improve communication via social media for people with communication disabilities after a TBI, nor evaluating the impact of training or support people to assist effective and successful social media use in people with TBI. Of the two studies that were found relating to communication disability following TBI and social media use, one study [72] was a conference abstract which provided minimal details regarding the methods used, participants included, or results of the study. The second study, a systematic review [30], focused on Internet chatroom use and found only 10 studies that addressed training of chatroom or Internet skills, however none of the studies provided details regarding the interventions. Therefore, there is as yet little direction in the literature on ways to incorporate social media goals into rehabilitation plans for people with TBI.

Limitations and Directions for Future Research

In this review, a wide range of search terms were used and databases were comprehensively searched which retrieved a large number of potentially relevant studies. However, only the first author excluded studies on title and the remainder were examined by the first two authors. Findings of the review should be interpreted with caution, as the quality of included studies in terms of identifying populations with TBI was relatively low and quite scattered, with seven of the 16 included sources being conference proceedings. As a result, readers are advised to refer to clinical guidelines as well as research to date when considering the use of social media in rehabilitation for people with TBI.

The search for literature and the subsequent review of relevant studies located reflects an emergent body of knowledge in relation to the use of social media by people with TBI. The main social networking sites featured in research to date on social media for people with TBI were Facebook™, Twitter™, and YouTube™. This might reflect the relatively low cost, high popularity, and global reach of these Web 2.0 platforms encouraging widespread use in the population of interest [1-3,7,9]. However, it might also reflect a narrow focus of research investigating social networking site use by people with TBI, which could miss important insights from this group's use of other sites such as Second Life™ (see Balandin & Stendal, this issue; Stendal & Balandin, this issue) or Instagram™. Rains and Brunner [114] reported that approximately 80% of social network site studies only examined Facebook™. Therefore, it is important that future research in the use of social media by people with TBI include a wider range of social networking sites. Future research could examine and address barriers of social media use particularly those due to communicative disabilities, including improving accessibility [12,30,53,54,58,74,76]; identifying facilitators and trialling the use of training to improve social media use [12,30,53,54,58,74,76]; and conducting larger scale trials of social media use in groups of people with TBI to determine change in outcomes for participants with greater certainty [54]. Given that the current literature contains only a small number of studies specifically investigating social media use in people with TBI, relating to concussion and Facebook™, the potential to explore the use of other social media platforms such as micro-blogging or Twitter™ is warranted. Further research is also needed on the role of support people and the impact of training people with TBI in the use of social media.

Conclusions

In English literature to date, there is minimal rigorous evaluation of social media use by people with TBI or in rehabilitation after TBI, and scant information regarding social

media use by people with communication disabilities after TBI. There is however emerging evidence and commentary regarding several benefits and risks, barriers and facilitators, and purposes of use of social media in people with TBI. The benefits of social media use by people with TBIs identified in the studies suggest that incorporating social media training and practice into TBI rehabilitation has the potential to increase social participation and support. The review identified risks of social media use relating to online safety and barriers as a result of cognitive and behavioural disabilities that need to be addressed in order to assist successful social media use by people with a TBI. The studies that have trialled social media use by people with a TBI have had small numbers of participants and none have rigorously investigated social media use by people with communication disabilities after a TBI. Research to date reflects the need for further investigation into the potential benefits and facilitators of social media use on communication, social participation, and social support with the aim of reducing social isolation of people with TBI.

Implications for Rehabilitation

- Communication disabilities following traumatic brain injury (TBI) can be wide-ranging in scope and social isolation with loss of friendships after TBI is common. For many people, social media is rapidly becoming a usual part of everyday communication and its use has the potential to increase communication and social participation for people with TBI.
- There is emerging evidence and commentary regarding the perceived benefits and risks, barriers and facilitators and purposes of use of social media within the TBI population.
- Risks associated with using social media, and low accessibility of social media sites, form barriers to its use. Facilitators for social media use in people with TBI include training the person with TBI and their communication partners in ways to enjoy and use social media safely.
- There is minimal rigorous evaluation of social media use by people with TBI and scant information regarding social media use by people with communication disabilities after TBI. Further investigation is needed into the potential benefits of social media use on communication, social participation, and social support with the aim of reducing social isolation in people with TBI.

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Declaration of Interest statement

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

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* Indicates included studies.

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Implications for Rehabilitation

- Communication disabilities following traumatic brain injury (TBI) can be wide-ranging in scope and social isolation with loss of friendships after TBI is common. For many people, social media is rapidly becoming a usual part of everyday communication and its use has the potential to increase communication and social participation for people with TBI.
- There is emerging evidence and commentary regarding the perceived benefits and risks, barriers and facilitators and purposes of use of social media within the TBI population.
- Risks associated with using social media, and low accessibility of social media sites, form barriers to its use. Facilitators for social media use in people with TBI include training the person with TBI and their communication partners in ways to enjoy and use social media safely.
- There is minimal rigorous evaluation of social media use by people with TBI and scant information regarding social media use by people with communication disabilities after TBI. Further investigation is needed into the potential benefits of social media use on communication, social participation, and social support with the aim of reducing social isolation in people with TBI.

Tables with captions

Table 1. Characteristics of included studies.

Table 2. Summary of content themes regarding social media use by people with TBI in included studies.

Figures with captions

Figure 1. Search strategies and study selection (PRISMA flow diagram [95]).

Table 1. Characteristics of Included Studies.

Paper Author, Year and Reference Number	Publication type	Method	Social media	Population	Focus of study	Participants
Ahmed (2010) [56]	Original research	Content analysis	Facebook	Conc.	Identify the role and purpose of Facebook posts relating to conc.	145 Facebook posts (17 Facebook groups); persons with TBI (or a friend, relative or colleague); Under 16 years $n=15$, 16–25 years $n=44$, > 25 years $n=17$, Cannot determine age $n=68$
Ahmed (2013) [53]	Original research	Semi-structured interviews	Facebook	Conc.	Opinions of GPs re using Facebook for management	8 General Practitioners with 3 to 35 years clinical experience
Ahmed (2013) [54]	Thesis	Pilot study Content analysis; Semi-structured interviews;	Facebook	Conc.	Patient satisfaction in using Facebook for conc. Intervention	11 people with concussion aged 18-28 years
Ahmed (2013) [58]	Issues paper	Commentary	Facebook	Conc.	Ethical issues in using Facebook for conc. Intervention	N/A
Becker (2012) [71]	Conference	Literature review	New media Twitter	TBI	New media use for rehabilitation	Not stated
Conway (2012) [72]	Conference	Case series	Facebook Skype YouTube	TBI	Self-esteem and social connection	Not stated
Kilov (2010) [30]	Literature review	Systematic review	Internet chat rooms	TBI, Conc.	Chat room use of teenagers with and without TBI	112 sources and websites (Sample sizes identified in 21/46 literature sources. These ranged from one

						participant to 1210 participants); people with TBI; teenagers
Mason (2010) [73]	Conference	Survey	Facebook Twitter MySpace	TBI	Social media for rehabilitation	Not stated
Provvidenza (2013) [74]	Literature review	Narrative literature review	Social media Facebook Twitter	Conc.	Conc. knowledge transfer	Not stated
Scott (2013) [75]	Conference	Content analysis	Twitter Facebook YouTube blogs, forums	TBI, Conc.	Social media references to TBI	155,101 Facebook or Twitter or other posts; population group and age of participants not stated
Smith (2011) [76]	Conference	Commentary	Facebook LinkedIn Twitter	TBI	Social media use	N/A
Sullivan (2012) [59]	Original research	Content analysis	Twitter	Conc.	Conc. related tweets	1000 Tweets; participant ages not reported
Tsaousides (2011) [12]	Original research	Survey	Facebook	TBI	Prevalence of and barriers to Facebook use and interest in improving skills/use	96 people with TBI aged 23–70 years
Williams (2014) [60]	Original research	Content analysis	YouTube	Conc.	Content of online conc. related videos	98 YouTube videos; participant ages not reported
Youcha (2010) [77]	Conference	Commentary	Facebook LinkedIn Twitter YouTube	TBI	Social media use	N/A
Youcha (2011) [78]	Conference	Survey	Facebook LinkedIn	TBI	Social media use	50 people with TBI; ages not reported

			Twitter YouTube, Ustream			
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Abbreviations: BI – brain injury; Conc. – concussion; TBI – traumatic brain injury; N/A – not applicable.

Table 2. Content Themes in Included Studies.

Themes	Benefits and Risks		Barriers and Facilitators to Use		Purposes of Use		
	Benefits	Risks	Barriers	Facilitators	Health communication	Communication & social participation	Rehabilitation
Ahmed (2010) [56]	X	-	-	-	X	X	X
Ahmed (2013) [53]	X	X	X	X	X	X	X
Ahmed (2013) [54]	X	X	X	X	X	-	X
Ahmed (2013) [58]	X	X	X	X	X	X	X
Becker (2012) [71]	X	X	X	-	-	X	X
Conway (2012) [72]	X	X	X	-	-	X	X
Kilov (2010) [30]	X	X	X	X	-	X	X
Mason (2010) [73]	X	-	X	-	-	X	X
Provvidenza (2013) [74]	X	X	-	X	X	X	-
Scott (2013) [75]	-	-	X	-	X	-	-
Smith (2011) [76]	X	X	X	X	-	-	-
Sullivan (2012) [59]	X	X	-	-	X	X	X
Tsaousides (2011) [12]	X	X	X	X	-	X	X
Williams (2014) [60]	X	X	-	-	X	-	-
Youcha (2010) [77]	X	X	-	X	X	X	X
Youcha (2011) [78]	X	-	-	-	X	X	-

Note: An X indicates a theme is present in the included study.

Figure 1. Search strategies and study selection (PRISMA flow diagram [95]).

