

Rehabilitation Professionals' Views on Social Media Use in Traumatic Brain Injury Rehabilitation: Gatekeepers to Participation

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Acknowledgements. The authors would like to acknowledge and thank the participants for their time and for sharing their experiences, and University A [de-identified] and University B [de-identified] for administration of funding and support in the conduction of this study. This research was funded through an Australian Government Research Training Program scholarship (first author) and a Discovery Early Career Research Award from the Australian Research Council (last author).

Declaration of interest. The authors have no conflicts of interest to disclose.

Keywords: traumatic brain injury; social media; rehabilitation; health professionals

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Purpose: Rehabilitation professionals support people with traumatic brain injury to return to meaningful participation in life and society – which now includes the use of social media. However, the role of health professionals in supporting the use of social media by adults with traumatic brain injury is not yet known. This study aimed to investigate the experiences and views of rehabilitation professionals on the use of social media by people with traumatic brain injury during rehabilitation. Method: Two focus groups were conducted and analysed qualitatively for content themes. Results: Eleven rehabilitation professionals, including allied health, recreational therapy, and service management, took part in this study. Participants identified potential benefits to people with traumatic brain injury using social media, including reduced social isolation. However, they expressed concerns about social media risks relating to the vulnerability, exploitation, and reputation management for people with traumatic brain injury. Rehabilitation professionals viewed their role as being to protect people from these increased risks of harm, either through imposing restrictions on social media use or responding to problems after these occurred. Conclusion: A knowledge translation approach might help guide and support rehabilitation professionals in enabling adults with traumatic brain injury to safely access and experience the benefits of meaningful engagement in social media during rehabilitation.

Introduction

Rehabilitation services aim to assist individuals with traumatic brain injury (TBI) to return to meaningful participation in life and society [1], with the treating team providing interventions and supports to help people to regain their skills and autonomy [2]. Interventions targeting social communication need to take the individual's communicative environments into account and consider how they participate in them. For example, it is recommended that the person's communication partners and the contexts in which they communicate should be incorporated into treatment [3]. Furthermore, rehabilitation goals should also address the individual's inclusion in and use of online communication [4], including the use of mobile phones for texting, email, internet video calls, and social media (e.g., Facebook, Twitter, Instagram, SnapChat).

A TBI often occurs as a result of falls, motor vehicle accident, or violent assault, and is a major cause of disability and death globally [5]. Following a TBI, the individual's life is disrupted, and returning to everyday activities can be difficult [6]. For people with cognitive-communication impairments following their TBI, loss of pre-injury friendships and vocational endeavours, alongside changed family dynamics and difficulties in navigating relationships, can be devastating [7]. The injury sustained to the brain is complex, with marked changes in cognition and executive function [3]; including an initial transient period of post-traumatic amnesia. During post-traumatic amnesia, memory is disrupted and people with a TBI are often confused, and this may last for several weeks after a severe injury [8]. Cognitive-communication disability occurs as a result of these changes in cognition and executive function [3,9], affecting how a person is able to comprehend and respond across a broad range of communicative contexts [7], often with long-term negative effects on relationships, work or study, and social participation within the community [6]. Changes in behaviour and communication are often misunderstood by family and friends [10], leading to

people with TBI feeling isolated and alone, unsure of their new post-injury identity or of how they fit into society [7].

Although there is emerging evidence that people with TBI value and use social media for a variety of purposes [4, 11-14], to date there is little information about how individuals with TBI are supported to use social media during rehabilitation. Knowledge developed through systematic reviews of the literature on the use of social media by adults with TBI [11], examining the tweets sent by individuals with TBI [13], the content of tweets about TBI [12], and interviews with adults with TBI about their social media [4] and Twitter experiences [14] has helped to formulate evidence-based models on ways that adults with TBI might be supported to use social media during rehabilitation [15]. Based on a review of the literature on the use of information and communication technologies (ICT) in TBI rehabilitation, Brunner et al. [16] identified several influences on the successful use of ICT in communication rehabilitation following TBI, demonstrating the need for holistic, personally meaningful rehabilitation goals addressing social participation and inclusion.

Knowledge of the risks and benefits of people with communication disability using social media is also emerging, with studies investigating the efficacy and outcomes of providing social media training for individuals with communication disability [17-21]. Cyber-victimisation (e.g., cyberbullying or online scams), cognitive fatigue, emotional reactivity, and cyber-resilience have all been identified as risks and challenges of social media use by people with TBI [4,14,22]. However, social media platforms also support communication, affording people with cognitive-communication difficulties sufficient time to understand and generate responses in their own time [4]. Using social media could help people with TBI to find information about TBI and to connect with other people who have a TBI, enabling them to share information about their lives and receive messages of hope and support [12,13]. Whilst there is growing evidence of the benefits and risks people with a TBI

may encounter when using social media, research on the best way interventions support their safety in using social media remains scarce, and there is no information on the views of rehabilitation professionals on the use of social media by adults with TBI during their rehabilitation.

Although some adults with TBI report experiencing negative online interactions (e.g., scams, trolling), they also expressed a willingness to continue to use social media platforms for connection and information exchange [4,13,14]. Nonetheless, research to date suggests that social media platforms are being under-utilised to interact in conversations, particularly with rehabilitation professionals; or to express experiences of recovery or rehabilitation [4,12,13]. In order for people with a TBI to take advantage of the benefits that using social media affords, it is important to identify ways to overcome barriers they might encounter when using social media, particularly if its use is personally meaningful and enables them to tell their story and connect in online environments.

There is a paucity of information regarding the role of rehabilitation professionals in supporting people to use social media at any stage of the rehabilitation journey. Without knowledge of the views of rehabilitation professionals, it is not possible to identify whether creating social media goals during rehabilitation would be feasible. People with TBI and rehabilitation professionals may differ in terms of their personalities and their concept of meaningful activities, creating a ‘potential mismatch’ that impedes rehabilitation [23]. The mismatch between people with TBI and their rehabilitation professionals can result in people with TBI having reduced access to services, particularly as their personality changes, defiant behaviour, and reduced participation in therapy activities may be perceived as non-compliance in more traditional models of rehabilitation [1,23]. In order to counteract the effects of any such mismatch, it is important for collaborative goal setting to occur for people with TBI to build their social networks and participate through meaningful goals successfully

[1]. An understanding of the views of rehabilitation professionals is needed to identify their views on barriers relating to the use of social media in rehabilitation, and facilitators for creating collaborative social media goals with adults with TBI. Thus, the aim of this study was to investigate the experiences and views of rehabilitation professionals on the use of social media by adults with TBI during their rehabilitation. This research, when considered in combination with the views and experiences of people with TBI [4,13,14], may inform how rehabilitation professionals consider forming collaborative person-centred social media rehabilitation goals with individuals with TBI who need support to use social media safely and meaningfully.

Method

This study protocol was approved by the Human Research Ethics Committees at University A [de-identified] and University B [de-identified], and by the Executive Board and Ethics Committee of the participating rehabilitation organisation (de-identified for confidentiality of the participants). Written informed consent was obtained from all participants, who understood that participation was voluntary, and that all information would be treated confidentially. A detailed audit trail was maintained throughout the project in order to increase study rigour and confidence in the findings [24].

Recruitment

A purposive sample of TBI rehabilitation professionals working in diverse roles across inpatient, outpatient, and community settings was sought. Potential participants were at a large metropolitan rehabilitation organisation (known for its program and staff expertise in TBI rehabilitation) were invited to take part in the study via email invitations sent from a rehabilitation team member to all members of the TBI rehabilitation staff. In total, 11 participants responded to the invitation and gave informed consent to participate in one of two focus groups arranged for the time and date most convenient to participants.

Participants

In total, four male and seven female TBI rehabilitation professionals (N=11) participated in the two focus groups, with a median age range of 30-40 years. All of the participants were employed at the rehabilitation organisation in a full time capacity, with roles represented across speech pathology (participants P2, P3, P4, P7, and P8), occupational therapy (participants P6 and P9), rehabilitation case management (participant P5 and P6; rehabilitation case managers with clinical backgrounds in social work and occupational therapy respectively), nursing (participant P10), recreational therapy (participant P1; a recreational therapist that designs and facilitate leisure and recreation experiences and programmes with the client and the rehabilitation team), and service management (participant P11; an outpatient rehabilitation service coordinator). One participant worked in two roles (P6) and only two participants (P1 and P4) disclosed information regarding the length of their employment in their current role (>10 years and 1-5 years respectively). The characteristics of the participants and focus groups are presented in table 1.

[Insert table 1 about here]

Data collection

The focus groups, each lasting one hour, were conducted in a meeting room at the participants' rehabilitation organisation, in February and March 2018. Following informed consent, demographic details were collected at the beginning of the focus groups with the participants filling in their own details onto a group form (i.e., name, email contact details, age range, role, and number of years in their current role). The first author, a speech pathologist experienced in qualitative research methods and in conducting focus groups, moderated the focus groups using a topic guide (see Appendix A) to focus discussions which was based on findings from previous research in the field of social media after TBI [4,11,16].

The moderator took care not to provide their own views on the use of social media in TBI

rehabilitation nor to influence the progression of the discussion in relation to either positive or negative views on the way it could be used. Focus group methodology enabled researchers to gather diverse experiences and insights from participants, capitalise on group interaction effects for discussion to generate new ideas, and develop consensus across the groups [25]. Each focus group was digitally audio-recorded, transcribed verbatim, and de-identified for analysis of content themes.

Data Analysis

During and immediately after each focus group, the first author made detailed field notes, documenting interpretations and reflections for future discussion with the research team [24]. The first author read and re-read the transcripts, and developed a four-page draft interpretive summary [26] for discussion with co-authors to reach consensus agreement on their interpretations of the categories of meaning and content themes in each focus group. Each focus group's transcript and summary was emailed to its participants for verification of the content, confirmation of the researchers' interpretations, and to identify any details to add, remove, or change prior to further data analysis. In total, only three of the 11 participants (across both groups) responded to verify that the transcripts and summaries reflected their discussions and no changes were requested.

Using an inductive and iterative approach to the analysis independent of theoretical approaches [27], the first author drafted and periodically returned to a 'mind map' of the concepts identified in the data [26]. These concepts were repeatedly discussed with co-authors [24] to identify narrative themes within and across the focus groups that best represented the participants' experiences and views [27]. Credibility of the results was further supported by a thorough period of analysis and conceptualisation of the findings and interpretations to identify the overarching theme and its relationship to the content themes and component categories of meaning [24].

Results

In this report, results are presented as the overarching theme and four content themes, to reflect the patterns of meaning identified across the data sets. The overarching theme and content themes are supported by illustrative quotes and excerpts from the text to increase the plausibility and credibility of the findings, and enable the reader to explore the relationships between the thematic categories. Within each sub-theme, there are associated categories of meaning providing detail in relation to participants' discussions.

Overarching Theme: Rehabilitation professionals as 'Gatekeepers' to the use of social media by people with a TBI

The overarching theme, connecting the sub-themes and categories of meaning in the results, was that of TBI rehabilitation professionals seeing their role as being 'gatekeepers' who attempt, not always successfully, to be the arbiters of social media use for adults with TBI during rehabilitation. In the majority of the scenarios put forward by participants, there was a strong focus on their duty of care to prevent harm to people with TBI and this related most to the potential harms of social media use. The content themes informing this overarching theme were: (a) the clinical context of being risk averse; (b) the challenge of feeling 'lost in a sea' of social media; (c) the consequence of restriction and reactivity; and (d) the counter-theme of being supporters of social media use during rehabilitation after TBI. Each of these themes are explored in detail, and the relationship of the overarching theme to the content themes is presented in table 2, supported with illustrative participant quotes.

[Insert table 2 about here]

The clinical context of being risk averse

The participants' discussion revealed their sense of responsibility for a person's vulnerability and risk in being exploited online after a TBI. They wanted to minimise the person's exposure to both immediate and future harmful consequences of negative social media

incidents. Inherent to their role in TBI rehabilitation, the participants considered it their responsibility to safeguard people with TBI from harm in general, and this extended into online interactions in social media, as P5 reflected: “If he was taken advantage of and I was aware of that situation ... how do we protect them?”. As such, participants identified several potential risks and barriers in using social media that require navigation during TBI rehabilitation and these are outlined in this section.

The risks of people with a TBI using social media. Participants reported the potential for social media use to be detrimental during rehabilitation after TBI, through reduced engagement in therapy due to social media fixation, cognitive fatigue, negative mental health effects, or withdrawal from in-person interactions. In particular, they were concerned about reputation management for people using social media after a TBI and the negative effects posting in social media may have on their loved ones, friends, and the broader community. Participants perceived people with TBI were likely to post or respond to social media posts in ways that were very different to their pre-injury self. This was particularly of concern when a person with TBI was in post-traumatic amnesia. For example, participants agreed that people with TBI who use social media too early during their rehabilitation may come to regret what they have posted, risking their reputation at a later date: “if it's too premature they can shoot themselves in the foot” (P2). It was reported that they had commonly observed “clients post inappropriate photos and write inappropriate messages to people” (P8), which had affected some of their relationships “by saying something that’s not received well” (P3). Disinhibition and impulsivity after their injury was also perceived to be a social media risk in terms of managing their finances and security, with participants concerned about people with TBI being exploited or “taken advantage of” (P2) online. One participant described an incident where a previous client was put at risk when they had accepted friend requests from “people in Africa ... they were trying to befriend her and ask for money and things like that” (P8).

Other participants reported having privacy concerns, where people with TBI “might post things that they're not supposed to post on social media” (P11), as this may compromise privacy or security for themselves and others. As such, these risks meant that the timing of social media access and use required careful consideration during rehabilitation, as “social media is forever, and they can do more than harm than good in this, so it's about the right time” (P10).

Participants also agreed that the inherent characteristics of certain social media platforms that draw the user in, such as “those incentives and the rewards that you get” (P7), provided the potential for social media use to “take over from other activities” (P7). One participant recalled working with a client who was “obsessed with just checking her devices” (P8) and regarded this as being compounded by their brain injury: “I think when you've got a brain injury on top of that, it's almost like times a hundred” (P8). Cognitive fatigue was also observed to be an issue, with another participant remarking, “you check their device and they've been up, like, 'til like five in the morning and not notice” (P9). This was exacerbated by executive function difficulties, where “you know their sleep's already been disrupted 'cause of their TBI and they can't self-monitor” (P9). Some participants noted that people with TBI may ruminate on who they used to be, as reflected in past social media posts, which could “really impact on acceptance, um, of what has happened and what the journey is ahead” (P7). Similarly, observing their friends’ posts may negatively affect a person’s mood or motivation during rehabilitation after their injury, as “they see all their mates like, going to a party or going out or doing the things that they used to do and they’re stuck in this rehab centre” (P9). As such, the participants’ experiences to date had led to their perception that social media may negatively affect a person’s emotions, take over other activities, or add to their cognitive fatigue: “It can be a massive time suck” (P6).

The barriers to people with a TBI using social media. Participants agreed that both physical and cognitive impairments formed barriers for people with TBI using social media in rehabilitation (e.g., a person's vision, hand mobility, fine motor control, or being able to get out of bed to get to their device independently). However, it was reduced executive function and cognitive-communication impairments that were viewed as key barriers to the use of social media. For example, changes in cognitive-communication skills may make it challenging for people to generate language and understand what is written; with some misinterpreting what other users have posted due to difficulties "reading between the lines" (P7). Participants also viewed changes in apathy, initiation, behaviour regulation, and self-monitoring ability as potentially influencing what people with TBI might post online: "that impulsivity, being able to kind of self-monitor what's appropriate and what's not appropriate, that's definitely a barrier" (P8). This may also influence their ability to problem solve when faced with misunderstandings of what has been posted: "the way that you would interpret that information is quite different to pre-injury" (P7). Additionally, it was noted that memory difficulties may alter a person's ability to remember passwords to access social media and follow procedures for accessing information would influence navigation of different platforms. Participants also questioned the extent to which these impairments affected a person's capacity to understand the terms of agreement and provide informed consent to use of social media platforms.

The challenge of feeling 'lost in a sea' of social media

Discussions revealed that staff knowledge of social media, or lack thereof, was a barrier to supporting people with TBI in using social media after their injury, as P10 said: "it's like we need another skill set". Most of the participants did not actively engage with social media, and if they did, it was limited to only a few platforms, such as Facebook, LinkedIn, and Instagram. As such, they considered themselves as lacking the knowledge and experience in

ways to incorporate social media into rehabilitation. They reported that they felt ‘lost in the sea’ of social media platforms that constantly changed and evolved. As a result, they were unsure of how to stay up-to-date in such a rapidly changing environment on top of their already busy workload: “I don't have time outside of work to keep up with everything” (P2). Participants were hesitant in knowing how or when to introduce social media in rehabilitation, and how this should be managed once a person with TBI has left inpatient rehabilitation and is living in the community. Participants were also uncertain about their medico-legal responsibilities and reported feeling a lack of control or knowledge of the boundaries of being the gatekeeper to using social media, (i.e., whether they should restrict or allow people with TBI to use social media).

Perceptions of social media value and safety. Social media use outside rehabilitation sessions was mostly viewed as a leisure activity, rather than an opportunity to practice what is being learnt in rehabilitation sessions. Some perceived social media as more of a frivolous activity, with “people getting really distracted by things like candy crush and things like that” (P7). Participants were aware of some of the strategies available in the public domain for increasing the safety of people using social media. They also acknowledged that their own limitations and preferences determined their use of social media in therapy and influenced their attitude that social media was of limited use for anything other than connecting with current friends. One participant described working with a “high level client” (P3), helping him to create a story of his experiences. However, they were dubious as to where to direct the client in terms of social media platform for publication: “I don't know where he'll post it or what we'll do with it. But it's having then an audience for that too, so that someone else can benefit from his experience” (P3).

They want guidance and rules to follow. Participants across both groups expressed a desire for specific direction regarding how to address social media during TBI rehabilitation.

In particular, they wanted guidance on their role, such as when it was appropriate to ‘let go’ of their control of the person’s use of social media, when to introduce the use of social media, and when to encourage greater social media engagement of people with TBI. Considering their views on the potential risks that people with a TBI face in using social media, participants considered that simulated online environments may enable better social media risk management. However, they viewed that research guiding practice in this area “would be key” (P10), particularly if it created access to evidence-based training, in-services, resources, or support people who are highly skilled with using social media. Both groups agreed that policy and guidelines to enable a more structured approach to education, support, and training in social media use after TBI are needed. Focus group two agreed with P9 who said that having access to guidelines would be “amazing! To have a decision tree?”. Participants considered that having a decision aid about the introduction and use of social media during TBI rehabilitation would strengthen their clinical practice knowledge and confidence. They also wanted guidance regarding the legal issues surrounding social media use and the roles and responsibilities of rehabilitation professionals, particularly clarifying their duty of care to the person with TBI in the social media space.

The consequence of restriction and reactivity

As a result of their uncertainty, in clinical practice rehabilitation professionals were predominantly reactive to people with TBI using social media and use was initially restricted. Once access to social media was allowed participants responded to problems as they arose, and were protective regarding reputation management, for example teaching people with TBI how to be ‘appropriate’ in social media platforms.

Restricting access or use. Participants noted that restrictions were barriers put in place during rehabilitation after TBI due to safety concerns, for example encouraging or enabling families to keep devices at home, limiting internet connectivity, or managing privacy settings

to ‘allow’ lurking but not posting in social media platforms. It was also reported that family members or partners would check or monitor social media use which may generate further barriers to use. It was considered that some platforms may create more difficulties than others, for example Facebook has no limits on how much or how often you post content, whereas Twitter has character limits on posts, and Instagram monitored for inappropriate graphics being posted. As one participant observed, “I feel like some social medias are safer than others ... like I feel like Facebook’s probably the worst” (P8), and due to the unlimited length of posts, people with TBI may post “every thought that pops up” (P9). It was concerns over this high frequency, tangential, or inappropriate posting that often prompted risk management strategies, and participants identified that in these instances private networks or groups could be safer online environment for people with TBI to engage in.

Reactivity once problems arise. Current clinical practice did not routinely include looking at pre-injury social media posts, for example to determine previous styles of use, common topics discussed, or language skills and styles displayed. Despite their aforementioned concerns, Facebook was the most prevalent social media platform used and addressed in therapy during rehabilitation. Instagram, SnapChat, Twitter, and LinkedIn were all identified as popular and relevant social media platforms and that these could and should be addressed during rehabilitation. Participants observed that social media use was often only addressed in rehabilitation once it was identified as problematic, with a team approach used to manage issues as they arise. None of the participants mentioned use of evidence based models to address social media use specifically in clinical practice. It was also acknowledged that it was difficult to find the correct balance between protection and restriction, and how to match that with the person's ability which also changes over time. Other participants reported that they had provided feedback on social media posts if they were perceived or reported as being inappropriate, and discussed the risks or consequences of posting inappropriate content.

Therapy addressing problematic use introduced the metacognitive ‘stop, think, post’ concept, tracking frequency and content of posts to reduce repetition and high-frequency of posting, and provision of template examples of ‘appropriate’ social media posts for people with brain injury to refer to when learning to compose posts. As one participant observed, this approach encouraged self-awareness regarding social media use, “so they're not doing the same message or posting the same message repetitively or posting every two seconds” (P2).

The counter-theme: Supporting social media use during rehabilitation after TBI

Participants acknowledged that their current role as gatekeeper was not their preferred approach, and they wanted to be more proactive and supportive in assisting people to use social media after their TBI. However, they also acknowledged that their perceptions of what was appropriate use of social media likely differed to the perceptions of people with TBI. Although they were unsure of how to address this in rehabilitation goals, enthusiastic discussion meant that several potential ideas for proactive support were considered. They wanted to capitalise on the potential of social media for the benefits it may afford people with a TBI, namely social participation and connection, education, rehabilitation opportunities, to share their stories of life after TBI, and to develop a positive sense of self-identity after their injury. While relating to the ‘lessening’ of the role of gatekeeper, this theme provides contrast and relief to the main theme and sub-themes as discussed above, in that rehabilitation professionals expressed a desire to move away from being gatekeepers to being supporters of social media use.

The benefits of people with a TBI using social media. Participants set aside discussion of the risks and identified several benefits of using social media after TBI, including the potential to reduce social isolation and increase connection to communities online: “that connection and ongoing development of friendships and relationships” (P2). As such, social media created opportunities for connection with a person’s community or social networks by

“reading through other peoples' messages and posts” (P3); and participants viewed that this could contribute to better mood and mental health for the person with a TBI. Using social media was identified as “something valuable and meaningful to engage with” (P1) which may provide a link to their “old self” (P9), and a way for people with a TBI who are participating in rehabilitation to show rehabilitation professionals their pre-injury identity, activities, and interests. In this manner, use of social media could be a way for people to resume part of their pre-injury life “so it’s just getting back to normal” (P6), to document or update family and friends about the person’s rehabilitation journey, and as an avenue for finding information. Additionally, participants noted that social media enabled people with a TBI to connect and engage with new people and communities, particularly if they wanted to link in with other people who have experienced a TBI, network and advertise their skills for study or employment, or to look for potential romantic or intimate partners. Through observing online commentaries about living with a TBI, people with a TBI who are experiencing rehabilitation may gain unique insights into how other people have navigated the challenges they face following their injury: “It’s real life ... Here’s someone saying ‘it’s not okay but this is what I’m now doing instead of what I used to do’.” (P1).

The changing landscape of communicative environments. Participants considered that in some ways social media was “probably just as important as face-to-face communication now” (P8). Social media was “not just about maintaining friendships anymore, it’s lots of different connections and roles that you have” (P9) in their communities, for example: “employers look at Facebook and things like that for employment” (P10). Participants noted that the person with a TBI’s likely purpose and use of social media was most certainly different to that of the rehabilitation professional: “in today, like today’s generation, it’s all about being visible socially and on social media and that” (P3). Participants recognised this, with one saying “sometimes I’m teaching someone, you know I’m giving them a template of

writing a post on Facebook, but that's how I would write it" (P8). Additionally, they identified the challenges in recommending partners or families monitor or moderate social media activity, "could you imagine your partner now having to check your Facebook? And check like what you're doing online?" (P9). They identified that this could negatively affect relationships that had already markedly changed following a person's injury, "especially if you're older as well, and you're very independent, and now your mum's checking your Facebook" (P9). However, familiarity with every social media platform by every therapist was "an unreal expectation" (P2). Therefore, using the knowledge and skills of person with TBI (or their friends or family) to assist the clinicians in knowing how to use the platform of interest was a possible future rehabilitation strategy. This was seen as a way to "to educate ourselves so that we can facilitate that [access]" (P2), as well as creating opportunities for "learning together" (P4) where the person with a TBI is an active participant in the rehabilitation team. As the recreational therapist observed "something new's out there, they teach us and it's a great learning curve for them to teach us" (P1), conceding "I can't do everyone's rec and leisure, I'm not an expert, so I constantly learn something new" (P1).

Being proactive rather than reactive. Acknowledging the growing importance of social media in society, participants expressed the desire to be more proactive in assisting people with TBI to reach their full potential after their injury. They perceived the use of social media as being integral for this purpose due to its potential for educational, vocational, community, and advocacy roles. Therefore, the participants considered there was a need to improve awareness of the risks and benefits in social media use, and to enable access with ongoing supports and provision of training in its use. One participant identified that it would be interesting to know whether people with TBI "felt like it [social media] was dealt with or even spoken about" (P9) during rehabilitation. As rehabilitation professionals, they wanted to 'open the gate' but were concerned about doing so due to the inherent risks. However, the

participants acknowledged this likely reduced the autonomy of the individual, undermining the key goal of social communication therapy and rehabilitation after TBI. As such, they voiced their opinion that “I don't think restriction is the answer” (P9) as it does not set people with a TBI up for ‘real life’. At present, “it's not prioritised” (P2), and participants reported they should be discussing social media use as a potential rehabilitation goal. As one participant suggested, incorporating the use of social media into rehabilitation after TBI “gives us a nice transition to see how their skills have generalised, so if you're working on turn taking and commenting and asking questions, then you can see that nice process, um, into social media to see whether if they're messaging someone, actually ask questions” (P4). In suggesting a more proactive approach, the participants sought to support people with TBI to use social media by addressing social media use during goal setting, and by providing education and feedback that was both positive and constructive. In this way, they hoped to liberate people with TBI to use social media successfully during rehabilitation and beyond.

Discussion

The participants in this study perceived one of their key roles as being to protect people with TBI from harm, often achieved via imposing restrictions on social media use or addressing problematic use as it occurred. Tension arose as participants wanted to be ‘supporters’ of social media use and increase social networking opportunities for adults with TBI, as was reflected in their aspirations to proactively work on social media in the future. They identified their other primary role was in supporting people with TBI to participate and be included socially, in online communities as well as in real life. Although their discussions revealed a desire to be supportive, the participants acknowledged they used an ad hoc approach, rather than setting people with TBI up for success in social media use from the outset. In acknowledging their preference in being more participation focused, they also identified a current lack of knowledge or support themselves to enable this approach and to move away

from merely being gatekeepers to social media use. As such, the participants observed their practice as being more risk averse due to their perceived duty of care (particularly in inpatient settings) and that to date, this had been difficult to change owing to lack of guidance in addressing social media during rehabilitation after TBI.

Finding balance – moving from paternalism to supporting autonomy

Traditionally, medicine and rehabilitation has been paternalistic, where rehabilitation professionals decide what is wrong and how to fix it [28]. The medical model views disability as an impairment in need of a cure [29], where rehabilitation professionals are ‘gatekeepers’ to resources [29, p.216] and people with disability, particularly people with TBI who are inpatients in hospital or rehabilitation settings, are under ‘continuous supervision and control’ [28, p.361]. The social model of disability moves beyond a medical focus to understand disability as being a construct of the environment (inclusive of social, political, and economic systems) and its ability or inability to accommodate people with impairments [30]. More recently, the biopsychosocial perspective has been embraced in health and healthcare with the development of the International Classification of Functioning, Disability and Health framework [2], recognises that it is the interaction of many factors in the individual and the environment, (e.g., including the use of tools and technology, and roles of communication partners) and the activities and participation of the person in society which form the person’s disability, and which form barriers or facilitators to inclusion. As such, the participants reported tendencies in being risk averse gatekeepers are likely rooted in traditional concepts of medical roles, but their willingness to address and support the active participation by people with TBI in online communities reflect the bio-psycho-social and person-centred models of disability, where formal structures and supports are still evolving. The results of this study suggest that in relation to the introduction of social media as a rehabilitation goal for people with TBI, health services need to consider functioning, disability, and health more

broadly to be inclusive of the biological, psychological, social, and environmental aspects involved in supporting a person with TBI to return to using social media following a TBI.

Concerns regarding a paternalistic approach in the field of TBI rehabilitation have previously been raised in terms of person-centred goal setting [31,32], as well as in controversial return-to-play guidelines for professional athletes following sports-related concussions [33]. More recently, commentary has emerged regarding the use of digital communications in brain injury rehabilitation units [34], primarily in response to safety concerns such as cognitive fatigue, interruption to rehabilitation, and potential adverse effects on reputation management. As yet, there has been little research investigating the beneficial or negative effects in use of mobile phones or social media during rehabilitation after TBI [11,16,35]. Therefore, in addressing the autonomy of adults with TBI in rehabilitation, clinicians need to balance both risk management and enabling access to participation in online communities, so as to avoid being overly authoritarian [28]. As such, in clinical practice rehabilitation professionals might need to question and change their enablement of restrictions to self-determination (e.g., enabling family members of people with TBI to remove access to personally owned digital communication devices) to finding ways to support the person's safe access. This is particularly pertinent given the recognised potential of social media platforms in supporting people with communication disability to access their human rights [17] and in creating diverse, inclusive digital communities [4,36,37].

Rehabilitation professionals or family members imposing restrictions or control over social media access is likely to have an oppositional reaction from the person with a TBI [38]. As reflected in the results of this study, rehabilitation professionals are unlikely to have similar perceptions of what is 'appropriate' behaviour or posts in social media. Therefore, therapy addressing social media use needs to target meaningful and motivating goals that are openly discussed in the context of successful social interactions and relationships.

Acknowledging differing attitudes and perceptions, and identifying that conformity is unlikely to facilitate long-term meaningful change for the person with a TBI, are not novel concepts in the field of TBI rehabilitation. Ylvisaker and Feeney [23] framed these concepts in social rehabilitation as being similar to rehabilitation professionals trying to “transform tough Dobermanns into passive and ‘socially appropriate’ poodles” [23, p.407]. This clearly illustrates the need for collaboration between rehabilitation professionals and people who have a TBI during rehabilitation when focusing on social media goals. That is, consideration of what people with TBI value or want should be the primary focus in social media rehabilitation goals, rather than on what they may be ‘allowed’ to do (or not) on social media. Addressing the autonomy of adults with TBI in rehabilitation needs to actively engage people with TBI in the development of person-centred social media goals, enabling greater understanding and respect as unique individuals [39].

Building capacity through existing knowledge of rehabilitation after TBI

Knowing that motivation and engagement in rehabilitation can greatly influence outcomes, interventions are likely to fail where there is little meaningful participation and a lack of collaboration during goal setting in rehabilitation addressing the use of social media [40]. Therefore, an everyday functional rehabilitation approach [38] to social media re-training is likely to be beneficial, achieved through framing social media assessments and interventions in real life situations and contexts that the person with TBI finds meaningful. Rather than focusing on reducing impairment in order to improve activity or participation, success in building generalisation and adaptability within real life situations and contexts can assist people with TBI to develop a new sense of self-identity and feelings of self-worth [38]. This approach focuses on the provision of coaching and guidance from rehabilitation professionals, working along a hierarchy of supports, and adjusting these supports as skills are relearned or developed [38,41]. In this way, a guiding rather than authoritarian role could

be used to develop a culture of trust and accountability, giving people with TBI the opportunity and ability to learn from their social media mistakes. Employing such methods in clinical practice might provide interventions that are highly contextual, experiential, and collaborative, all of which are beneficial to improving everyday social participation and enjoyment for people with TBI [42].

Another consideration may be to adopt successful approaches applied in TBI rehabilitation in addressing other activities that place people with TBI, and their community, at risk. For example, in order for people with a TBI to return to driving after their injury, they participate in extra training with occupational therapists; adopt the use of any appropriate supports, strategies, or assistive devices; and are required to pass a comprehensive on-road driving tests [43]. Indeed, relearning driver skills includes goal-directed on-road training and may incorporate modifications, such as vehicle modifications, adaptive equipment, or driving restrictions (e.g., driving within a specified timeframe or geographical area) [43]. Given that the majority of people with TBI successfully pass on-road driving assessment despite having a moderate-severe TBI [44], it is not clear why are professionals might be so hesitant about supporting their use of social media, particularly when strategies known to be effective could be applied across different goals. For example, preventing cognitive fatigue associated with using social media might require use between specific timeframes or setting a timer to manage breaks.

Using behaviour change principles to drive knowledge translation in clinical practice

Using what is known in the field of TBI rehabilitation may assist in uptake of unfamiliar practice in social media rehabilitation. The categories in the International Classification of Functioning core sets for TBI [45], known social media activities of people with TBI [4,13,14,22], and factors affecting successful use of communication technologies [16] could be used to guide assessment of social media use following TBI and facilitate

collaborative goal setting for social media use during rehabilitation. However, theories of behaviour change and the results of this study suggest that TBI rehabilitation professionals will require guidance and structured support themselves to use social media in rehabilitation. Knowledge translation is the process of moving research evidence into clinical practice [46], with knowledge translation interventions designed to address known barriers to change [46]. In supporting this knowledge-to-action process, the Theoretical Domains Framework of behaviour change provides an evidence-based method for evaluating barriers and facilitators of change (namely factors of capability, opportunity, and motivation), including the adoption of new technologies [47,48].

Meeting the needs of TBI rehabilitation professionals is key to facilitating adoption of social media use as they are the gatekeepers and decision makers of rehabilitation intervention services. Furthermore, involving rehabilitation professionals in decision making and planning knowledge translation interventions is essential to determine how best to meet their needs to support people with TBI during rehabilitation. Using a systematic, comprehensive, and evidence-based framework such as the Theoretical Domains Framework gives researchers and rehabilitation professionals in the field of TBI an opportunity to be solution focused. Thus, it would also enable rehabilitation professionals to support low risk-taking in social media use during rehabilitation, respecting their need to be protective whilst moving away from a culture of restriction and moderation (i.e., paternalism). The findings of this study suggest there is a strong need for policy, education, resources, and ongoing knowledge translation supports to facilitate change in current clinical practice.

Overall, the results of this study suggest that rehabilitation professionals could (a) ask their clients about prior use of social media, and negotiate person-centred goals relating to returning to use for goals selected by the person with TBI; (b) learn more about social media platforms, using the ‘how to’ sections of the platform and practicing their own skills to

determine strategies for reducing risk; (c) make use of resources provided by social media platforms and governments relating to the safe use of social media; and (d) monitor outcomes of use including stories of experience for both benefits and any negative impacts of using social media. Discussion of social media in TBI groups might also provide the option for peer supports to be explored.

Limitations and future directions for research

Although strengthened by being conducted in a large rehabilitation organisation with services across the inpatient, outpatient and community pathway of TBI, and by the wide range of health professional disciplines and rehabilitation roles represented in the sample of participants, this was a small study in involving only 11 participants in two focus groups from a single organisation. Therefore, results should be interpreted with caution as they may not necessarily reflect the views of TBI rehabilitation professionals more generally. Additionally, information on the participants' years of experience in their respective roles was reliant on self-disclosure. As such, further research is needed to verify and expand upon the findings of this study with methods to involve a larger number of TBI rehabilitation professionals across sites, with varying levels of clinical experience.

The results of this study suggest that safety and legal responsibilities are common areas of concern for rehabilitation professionals in the field of TBI who might wish to embark on including social media in rehabilitation goals. As such, further research is needed to identify whether current social media safety guidelines apply to rehabilitation settings for people with TBI and whether additional guidance is needed for increased confidence in relation to safety. There is also a need to identify ways to assess the use of social media during rehabilitation so as to develop meaningful social media interventions to improve these online social communication skills and safety. Ideally, the development of any tools or resources for social media rehabilitation after TBI should be informed by: (a) the current

research evidence pertaining to cognitive-communication rehabilitation using technology [see: 11,16]; (b) existing knowledge in the field of TBI rehabilitation supporting return to activities that are considered high risk; and (c) the experiences and knowledge of people with TBI who use social media, rehabilitation professionals experienced in providing rehabilitation after TBI, and other people who may provide support in using social media, such as family members and peers. Further research is needed to determine (a) whether current recommendations for safe use of social media are helpful in the context of TBI rehabilitation, (b) the level of guidance and support needed by rehabilitation professionals to use social media in TBI rehabilitation, and (c) the impact on adults with TBI of rehabilitation professionals creating person-centred goals and taking a proactive approach to using social media in TBI rehabilitation, including both positive and negative impacts and ways to reduce the inherent risks of using social media for this population.

Conclusion

Rehabilitation professionals working in TBI rehabilitation view themselves as gatekeepers or arbiters of social media use, primarily due to safety concerns. In clinical practice they are reactive to problematic use and uncertain as to how to best support safe and meaningful use of social media. Counter to this authoritarian approach, rehabilitation professionals want to support people with TBI to use social media for social participation and inclusion.

Addressing social media goals in rehabilitation could be informed by many methods already successfully employed in TBI rehabilitation. However, in order for rehabilitation professionals to proactively address the social media goals of people with TBI, they need to feel adequately equipped to support them. A knowledge translation approach to the safe and effective use of social media for a range of purposes might help to facilitate rehabilitation professionals in their roles in enabling adults with TBI better access to social media during rehabilitation.

Acknowledgements. The authors would like to acknowledge and thank the participants for their time and for sharing their experiences, and University A [de-identified] and University B [de-identified] for administration of funding and support in the conduction of this study. This research was funded through an Australian Government Research Training Program scholarship (first author) and a Discovery Early Career Research Award from the Australian Research Council (last author).

Declaration of interest. The authors have no conflicts of interest to disclose.

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Table 1. Characteristics of participants and focus groups.

Rehabilitation professionals working in TBI rehabilitation (N=11)			
	Focus Group 1 (P1, P2, P3, P4)	Focus Group 2 (P5, P6, P7, P8, P9, P10, P11)	Combined
Gender			
Male	0	4	4
Female	4	3	7
Median age (range, in years)	30-40	30-40	30-40
Age range (years)	30-60	20-50	20-60
Role / Discipline*			
Speech Pathology	3	2	5
Occupational Therapy	0	2	2
Nursing	0	1	1
Rehabilitation Case Management	0	2	2
Recreational Therapy	1	0	1
Service Management	0	1	1
Years in current role (range, in years) ^	1 - >10	unknown	1 - >10

Key: P = Participant.

*One participant was employed in two different roles.

^ Only two participants (P1 and P4) self-disclosed information pertaining to the amount of time they had been in their current rehabilitation roles.

Table 2. The common theme and sub-themes; and its counter-theme.

Overarching Theme	Sub-Themes	Illustrative Quotes (Participant)
Rehabilitation professionals are ‘Gatekeepers’ to the use of social media by people with a TBI	The clinical context of being risk averse	“I think if it's too premature they can shoot themselves in the foot” (P2) “Don't give them their device, it's too risky” (P9)
	The challenge of feeling lost in a sea of social media	“There's so many platforms out there that you can't keep up” (P3) “We had a case recently and they were talking things that I wouldn't have a clue” (P10)
	The consequence of restriction and reactivity	“We come across a problem with the phone and apps themselves with one of our patients where you can restrict one but then it'll over-restrict another, ... so we had to completely stop one [social media app], to have appropriate access for another and then it just fell apart” (P6)
	Counter-Theme: Being supporters of social media use during rehabilitation after TBI	“It comes back to that client centredness and individual choice ... having it [social media] in our toolkit in terms of priorities when it comes to assessment, also when it comes to therapy, and also just supporting quality of life” (P3) “I don't think restriction is the answer” (P9)

Appendix A. Focus Group Topic Guide.

1. In relation to your clients with TBI,
 - What are the benefits of them using social media?
 - What are the risks?
 - What barriers in using social media do you see people with TBI facing?
 - What would facilitate their use of social media?
 2. What are your views and experiences on using social media with clients?
 3. What factors do you think influence the use of social media by people with TBI, or in TBI rehabilitation?
 4. What is or could be the future scope of our role in supporting people with TBI to use social media?
 5. If teaching people to use social media safety and strategically was a part of your role, what type of supports would you require? (e.g., training, guidance, equipment)
 6. Do you have any other comments or insights into the use of social media by people with TBI, or social media in TBI rehabilitation?
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