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### RESEARCH REPORT

# 'It gives you encouragement because you're not alone': A pilot study of a multi-component social media skills intervention for people with acquired brain injury

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### Abstract

Background: People with an acquired brain injury (ABI) find it challenging to use social media due to changes in their cognition and communication skills. Using social media can provide opportunities for positive connection, but there is a lack of interventions specifically designed to support safe and successful social media use after ABI.

Aims: To investigate the outcomes of completing a social media skills intervention and identify barriers and facilitators for future implementation.

Methods & Procedures: The study used a mixed-methods, pre-postintervention design. A total of 17 adults with an ABI were recruited. Participants completed an intervention that included a short self-guided course about social media skills (social-ABI-lity course), and then participated in a private, moderated Facebook group over a 12-week period (social-ABI-lity Facebook group). Data were collected over this period through observation of group activity and weekly surveys. They were also collected on social media use and quality of life at pre-intervention, post-intervention and after 3 months. Participants provided feedback on the experience of participating in the programme via a post-intervention interview.

Outcomes & Results: At post-intervention, there were significant improvements in confidence in using Facebook (p = 0.002) and enjoyment of using Facebook to connect with others (p = 0.013). There was no significant change in reported quality of life, although participants described the multiple benefits of connection they perceived from involvement in the group. Observational data and feedback interviews were informative about the feasibility and acceptability of the intervention.

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Therapists.

**Conclusions & Implications:** This pilot study provided preliminary evidence that an intervention comprising a short, self-guided training course and a private, moderated Facebook group improved outcomes for people with ABI. Key recommendations for future implementation include embedding active peer moderators within groups and taking an individualized approach to delivery of the intervention.

### KEYWORDS

brain injury, rehabilitation, social communication, social media

### WHAT THIS PAPER ADDS

What is already known on the subject

Research has documented the challenges that people with ABI experience in using social media, and the difficulty for rehabilitation clinicians in providing appropriate support in this field.

### What this paper adds to existing knowledge

This pilot study reports the outcomes of people with ABI completing a short, self-guided social media skills course and participating in a private, moderated Facebook group. After the intervention, participants reported significantly increased confidence and enjoyment in using Facebook, described the benefits of connection found in the groups, and suggested potential improvements for future implementation.

### What are the potential or actual clinical implications of this work?

With the growing use of social media for connection and participation, there is a professional obligation to address social media communication skills in cognitive–communication rehabilitation for people with ABI. The findings of this study will inform interventions and future research to assist people with ABI to build their social media skills for communication, social support and a sense of connection.

### INTRODUCTION

A common challenge for people with an acquired brain injury (ABI) is social isolation (Northcott & Hilari, 2011; Salas et al., 2018) and loneliness (Lowe et al., 2020). Social media can offer a positive and low-cost way for people with ABI to connect with others in the same situation (Brunner et al., 2021a). Globally, we have observed an increase in communications via online platforms in the past 2 years, with social media use increasing at a rate of more than 1 million new users every day (Datareportal et al., 2021). One of the most important types of support for people with mild ABI has been reported to be connecting with others through social media (Eghdam et al., 2016). Indeed, a 2021 study indicated that 90% of people with moderate-to-severe traumatic brain injury (TBI) have used at least one social media platform, with Facebook and Facebook Messenger being the most popular platforms (Morrow et al., 2021). This high rate of social media use is consistent with that of the general population (We Are Social & Hootsuite, 2022), and notably with that of the age groups of people most at risk of ABI (Roozenbeek et al., 2013), with adolescents and young adults using digital communications from a young age (Ciccia & Threats, 2015). People with TBI have also reported they used multiple social media platforms for a range of purposes, and all had the desire to use social media to connect with people or the broader community (Brunner, 2020). Indeed, reviews in the field have highlighted the benefits of social media use after ABI for social connection, with untapped potential for reducing social isolation and improving quality of life (Brunner et al., 2015, 2021a).

Alongside the positive opportunities and benefits that online interactions can provide, people with ABI have been observed to be vulnerable to risks associated with reduced cognition and social judgment (Gould et al., 2021). They have also reported challenges using social media such as cognitive fatigue, feeling overwhelmed, difficulty understanding the navigation and procedures of different social media platforms, and experiences or perpetration of cyberbullying (Brunner, 2020). Due to the cognitivecommunication difficulties which commonly occur after an ABI (MacDonald, 2017), tailored interventions are needed to assist people with ABI to safely access mainstream social media platforms, such as Facebook, Twitter, Instagram and TikTok. However, people with TBI have reported receiving little professional support to use social media (Brunner et al., 2019) and rehabilitation professionals have described being inadequately prepared to support them in its use (Brunner et al., 2021b). A recent scoping review identified that, to date, there have been few interventions reported in the literature specifically addressing this area for people with ABI (Brunner et al., 2022b). There was limited evidence regarding the effectiveness of social media training, with Brunner et al. identifying that social media training for people with ABI should be developed through user-centred design and evaluation (Brunner et al., 2022b). Many of the included social media skills training interventions and information sources incorporated or recommended training in aspects of cybersafety, opportunities for real-life practice and supports tailored to individual needs (Brunner et al., 2022b).

In response to this absence of such interventions, new resources with a focus on online communication after ABI have recently become available. The CyberABIlity training programme (Monash University, 2022) provides free online training for people with ABI to learn specifically about cybersafety, including identifying and navigating cyberscams. The self-directed online course, 'social-ABI-lity', focuses on successful use of social media after ABI (Brunner et al., 2022a). This course was developed through a collaborative design process with participants with ABI, family members and clinicians, and tested through a proof-of-concept study with four participants with ABI.

Findings from this proof-of-concept study (Brunner et al., 2022a) indicated that the social-ABI-lity course was acceptable and engaging for the participants, and that some aspects of social media communication skills for people with an ABI could be trained through an online, self-directed course. However, its efficacy as a standalone treatment is yet to be determined. Moreover, it is likely that this course would be most beneficial as one element within a multi-component approach to improving social media communication skills, with participants in the proof-ofconcept study identifying the need for additional support to assist safe and meaningful access and participation in social media (Brunner et al., 2022a). Additionally, role-play and group contexts in safe settings have previously been demonstrated as successful in supporting practice of new behaviours in meaningful activities before generalizing skills in more natural or less structured settings (Meulenbroek et al., 2019). Therefore, building positive and safe networks in easily accessible, secure and familiar social media platforms to provide a context for practising social media communication skills may be another beneficial support to people with an ABI.

Following the initial proof-of-concept study for the social-ABI-lity course (Brunner et al., 2022a), the current project evaluated a multi-component intervention focused on developing skills for using social media after ABI. The aims of the study were to investigate whether completing the social-ABI-lity course and then participating in a private, moderated social-ABI-lity Facebook group resulted in improved skills in interacting online or improved quality of life for people with ABI. We also aimed to determine the feasibility and acceptability of private, moderated Facebook groups for providing support to people with ABI.

### **Research hypotheses**

- Participating in the social-ABI-lity course and Facebook group programme will improve skills in interacting online and improve quality of life for people with ABI.
- It will be feasible and acceptable to participants to interact in a private, moderated Facebook group.

### METHOD

This pilot study builds on the previous proof-of-concept study (Brunner et al., 2022a) and focuses on evaluating this multi-component social media skills intervention using a mixed-methods pre-post-design. Ethical approval to conduct this study was sought and received from the University of Sydney Human Research Ethics Committee (2021/019). Guidelines for reporting qualitative research (Tong et al., 2007) and pilot studies (Thabane et al., 2010) were followed in the reporting of this study, and the intervention was described using the TIDieR guidelines (Hoffmann et al., 2014).

## Recruitment

Recruitment of participants occurred via posts sent on social media (Twitter and Facebook), the University of Sydney ABI Communication Lab's website, and through speech-language pathology and brain injury rehabilitation email networks of the researchers. All potential participants with ABI who expressed an interest in the study met with either authors M.B. or R.R. via Zoom (Zoom Video Communications Inc., 2021) to discuss the study and ask questions, and then completed an 'Assessment of Capacity to Consent' form (Jeste et al., 2007) adapted to include information specific to this study to enable consistent screening of potential participants. Following the Zoom call, all potential participants agreed to participate and all provided written consent. Each participant was offered an AUD\$100 shopping voucher after the initial assessment as reimbursement for their time.

# Inclusion criteria

All participants were required to be over 18 years and located in Australia. Participants were eligible to participate if they:

- had a self-reported ABI at least 6 months previously, which required hospitalization;
- were discharged or partially discharged from hospital, and able to spend time at home on a regular basis;
- had self-identified goals relating to using social media;
- had adequate English proficiency for completing assessment tasks without the aid of an interpreter.

Exclusion criteria were:

- Severe amnesia which would prevent participants from providing informed consent.
- Active psychosis.
- Self-reported co-occurring degenerative neurological disorder, more than one episode of moderate-severe ABI or premorbid intellectual disability.

# Sample size

This research was exploratory and therefore no formal sample size calculations were conducted. The aims of the research were to test feasibility and gather initial acceptability feedback and therefore the planned sample size was two Facebook groups, each with 5–10 participants. Outcomes of this pilot study may be used to inform sample size calculations for a future clinical trial.

# Procedures

# Process

Each participant attended an initial assessment via Zoom with authors MB or RR to complete demographic questionnaires, an assessment of their functional and communication skills, and a questionnaire about social media use. Researchers conducting data collection sessions were familiar with working with people with ABI and modified sessions as needed, including adapting information delivery or offering breaks.

Following their assessment, each participant was provided with printed log-in details and guidance to access the prototype social-ABI-lity course hosted on the Thinkific platform (Thinkific Labs Inc., 2021) which provided information on how to use social media safely and successfully (Brunner et al., 2022a). An updated version of the course is now available at https://abi-communication-lab.sydney. edu.au/courses/social-abi-lity/. The course included four modules on the following topics: (1) What is social media?; (2) Staying safe in social media; (3) How do I use social media?; and (4) Who can I connect with in social media? Module content included short educational videos and interactive quizzes. Participants were asked to work through the course over a 1-month period, before being invited to join one of the two private social-ABI-lity Facebook groups. The participants worked through the course independently at their own pace, and were able to have a family member or friend assist them. If participants had not completed the course after 1 month, they received a reminder via email or telephone call.

A private social-ABI-lity Facebook group (Facebook, 2022) was launched once there was a cohort of at least five participants ready to commence. The social media platform Facebook was chosen due to its popularity and private group function, which meant that participants were interacting in a naturalistic and familiar environment that also provided privacy and safety. The group function enabled participants to enjoy the benefits of social interaction and skill development within a positive and supported environment. The purpose of the group was to encourage participants to 'participate, engage and connect' through providing opportunities to practice social media communication skills in a safe and supported group. A 12-week programme of topics to discuss in the Facebook groups was developed to facilitate and support this, and included a combination of conversation starters (e.g., 'share a picture of something you did on the weekend' or 'what's your favourite type of food?'), discussion topics (e.g., 'what do you want to get out of this group?'), tip sharing (e.g., 'how do you keep safe online?'), polls (e.g., 'what types of technology do you use?') and reminders (e.g., 'our next Zoom catch up is this morning at 9 am, here's the link ...'). At least one post per week in the 12-week programme was focused on a social media function or safety related topic.

Moderators (K.Su., R.R. and M.B.) delivered the 12-week programme, facilitated regular discussions within the two private social-ABI-lity Facebook groups, and developed a moderator's guide to support consistent delivery of the intervention (available on request from the study authors). The moderators were the social media community liaison officer from Brain Injury Australia and two speechlanguage pathologists and researchers from the University of Sydney. All were experienced in working with people who have an ABI and supporting communication in online environments. Moderation of the groups included providing orientation to group rules and procedures, starting discussions, sharing resources, commenting on and encouraging others' posts, and following up on participants' responses or member queries. Safety guidelines were also readily accessible on the group page. Participants with ABI were asked to check the group at least twice a week and post or add a comment. If a participant had not been added to the group in a week, a moderator made contact via the participant's preferred mode of contact (email or phone) to discuss and provide support if needed. Moderators hosted optional half-hour morning teas on Zoom every 2-3 weeks and facilitated a social group conversation between members who attended. Group participants were emailed weekly with a short online survey about their social media use over the previous week. All participants accessed both the social-ABI-lity course and the social-ABI-lity Facebook group from home using their own computer, tablet or phone. One participant was loaned an iPad with Internet access for the duration of the intervention.

After 12 weeks of participation in the private social-ABI-lity Facebook group, participants completed a postassessment over Zoom of up to 1 h duration with author R.R. At a further 3 months after the post-assessment, participants completed a follow-up assessment of up to 1 h duration over Zoom with author R.R.

### Data collection

Data were gathered from the following sources:

- Demographic information form: post-traumatic amnesia duration at time of injury (if available), months post-injury, cause of injury, gender, age, years of education, description of any vision impairment, description of any hearing impairment, frequency of internet usage.
- Assessment of functional and communication skills of participants with ABI:
- OGlasgow Outcome Scale Extended (GOSE) (Teasdale et al., 1998).
- OCare and Needs Scale (CANS) (Tate, 2004).
- OFunctional Assessment of Verbal Reasoning and Executive Strategies (FAVRES) (MacDonald, 2005) (Task 4 only). This was administered via Zoom with permission via a letter of no objection from CCD Publishing.

• ORepeatable Battery for the Assessment of Neuropsychological Status (RBANS) (Randolph, 2012). This assessment was administered via Zoom with permission via a letter of no objection from Pearson Clinical Assessment.

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- Social Media Questionnaire (designed for the current project and available on request from the study authors) administered at initial assessment, post-assessment and follow-up): Size of individual's network, frequency of use, ratings of confidence (five-point Likert scale rating from not at all confident to extremely confident), ratings of enjoyment (five-point Likert scale rating from not at all enjoyable to extremely enjoyable) and social media knowledge questions in response to two case studies (knowledge of potential markers of a romance cyberscam and ability to generate relevant advice, knowledge of hashtag use and ability to generate a hashtag example)
- Quality of Life After Brain Injury (QOLIBRI) scale (von Steinbuchel et al., 2010) (administered at initial assessment, post-assessment and follow-up).
- Weekly optional email survey hosted on REDCap (Vanderbilt University, 2022): Questions on social media usage outside the group.
- Frequency and type of engagement within the social-ABI-lity Facebook group: De-identified posts, comments and reactions within the group.

Additionally, a post-intervention interview using a semistructured interview guide developed for this study (see Appendix A) was conducted on Zoom by author R.R., a female speech-language pathologist with a PhD and experience interviewing people with ABI. Before the interview, R.R. had interacted with participants as a moderator of the Facebook group. The participants were aware that R.R. was interviewing them on behalf of the research team to learn about their experiences of the intervention, to support future improvements. Given R.R.'s role in moderating the group, it is acknowledged there may have been a bias towards the discussion of positive outcomes. R.R. was conscious of explicitly inviting participants to discuss negative experiences and recommendations for improvements. Most participants were alone for the interview; one participant had a family member present. The interviews were video-recorded for all but one participant, who did not wish to be recorded. R.R. also wrote field notes during the interviews. Interviews ranged from 15 to 36 min. All participants completed their interviews at home, in a single sitting. Interviews were transcribed, but transcripts were not provided to participants. Following the completion of all individual interviews, a de-identified summary of key feedback was shared with participants via the Facebook group page, but no further feedback was received. Given

this was a small pilot study, interviews were conducted with all participants rather than following the principles of data saturation.

### Outcomes

The outcome measures obtained through the social media questionnaire were (1) frequency of Facebook use, (2) confidence in using Facebook, (3) enjoyment in using Facebook to communicate and (4) knowledge of cyberscams and hashtag use. The overall QOLIBRI score was also an outcome measure. Given this was a pilot study, the analysis of study outcomes was exploratory with no predetermined primary outcome measure. Acceptability and feasibility outcomes were evaluated through the synthesis of the weekly email survey, observations of engagement within the Facebook group and data from the post-training interviews. Feasibility was evaluated based on the number of engaged participants and feedback from surveys and interviews.

## Data analysis

To describe participant characteristics, analysis of data involved descriptive summaries of the demographic variables and assessment scores of participants. Ratings of usefulness, likelihood of recommending the programme to others and accuracy of responses to questions regarding cyberscams and hashtag use were also analysed descriptively. Engagement within the group was analysed quantitatively (e.g., number of reactions, replies and posts by each participant), with each participant categorized by the level of their engagement, that is, passive, intermittent or active contributor (Brandtzaeg & Heim, 2011). On entry to the study, participants were asked to 'use the group actively for 3 months. This means adding a post or comment to the group at least twice each week'. As such, participants were classified as passive contributors in the Facebook group if they predominantly lurked and observed group activity. Those who contributed at least two responses per week (e.g., liking or replying to a post) were classified as intermittent contributors, and participants who contributed at least two responses per week and more than 12 independent posts throughout the 12-week period (i.e., an average of one post per week) were classified as active contributors.

IBM SPSS Statistics (IBM Corp, 2022) was used for statistical analyses. Data for the QOLIBRI and reported ratings of frequency, confidence and enjoyability of Facebook use were inspected for normality. As QOLIBRI data were normally distributed, paired sample *t*-tests were used to compare pre-intervention with post-intervention data to evaluate outcomes of the programme, and postintervention with follow-up data to evaluate maintenance of any treatment effects. Ratings of Facebook users were not normally distributed, and so related-samples Wilcoxon signed-rank tests were used to compare pre-intervention with post-intervention ratings, and post-intervention with follow-up ratings.

Transcripts of post-intervention interviews providing qualitative feedback were analysed using conventional content analysis (Hsieh & Shannon, 2005). This involved deriving codes from reading and re-reading interview transcripts and then organizing related codes into categories. Example quotes relevant to each category were identified from the transcripts. This process was completed by K.So., R.R. and M.B., who are certified practising speechlanguage pathologists, and M.B. and R.R. are researchers with experience in qualitative analysis. Coding and interpretation was supported using NVivo (QSR International, 2022) and Miro (Miro, 2022) software. Trustworthiness of the analysis was aided through discussion between the researchers, acknowledging their own clinical knowledge and experiences (K.So., R.R. and M.B.), and involvement in creating and delivering the multi-component intervention (R.R. and M.B.), as influencing factors throughout the process, and checking that interpretations were representative of the data as a whole.

# RESULTS

# Participants

All participants who completed the initial Zoom call to complete the assessment of capacity to consent were eligible to participate. Recruitment commenced in April 2021, with seven participants recruited to group 1 between April and July 2021, and ten participants recruited to group 2 between August and September 2021 (N = 17). There were no deviations from the study protocol. Group 1 included two females and five males between the ages of 20 and 59 years (median = 38). Group 2 included two females and eight males between the ages of 20 and 57 years (median = 24.5). There were no significant differences identified between groups 1 and 2 in age, gender identity, years of education and time post-injury (p > 0.05). Appendix B provides details of participant demographic information and scores on their psychosocial and cognitive assessments. A total of 16 participants completed the initial assessment, engaged in the social-ABI-lity course, participated in the 12-week social-ABI-lity Facebook group and completed the immediate and 3-month follow-up assessments. One participant (P17) completed some initial assessment tasks and then withdrew from the study due to not having enough



**FIGURE 1** Four content categories identified in the content analysis [Colour figure can be viewed at wileyonlinelibrary.com]

time to participate. One participant (P13) was unable to be contacted for the follow-up assessment.

One participant (P9) had never used the Internet or Facebook before taking part in the study. All other participants (n = 15) had a Facebook account, with the majority accessing Facebook every day (n = 12). The size of their Facebook friend networks at pre-test were varied, ranging from zero friends to 1141 friends, and their frequency of posting ranged from none to 30 posts in the past month (see Appendix B). One participant (P6) used two Facebook accounts: one for personal use and another specifically for interacting with brain injury-related contacts.

### **Participant outcomes**

Participant outcomes are reported for each of the two hypotheses below. Across the two hypotheses, four content categories are described that were identified in the content analysis (Figure 1).

Hypothesis 1: Improved online interaction skills and quality of life.

### Skills in interacting online

The social media questionnaire and observations of engagement in the Facebook group yielded relevant data for the hypothesis related to improved skills in interacting online.

### Facebook use

Table 1 provides information about participant Facebook use at pre-test, post-test and 3-month follow-up. At posttest, reported frequency of participant Facebook activity had not changed significantly (Z = 0.65, p = 0.52). Statistically significant increases in both confidence in using Facebook (Z = 3.07, p = 0.002) and enjoyment from using Facebook to communicate (Z = 2.48, p = 0.013) were observed across both groups from pre- to post-intervention. There were no significant changes between post-test and 3-month follow-up (p > 0.05), suggesting improvements were maintained.

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### Social media skills

At post-test, nine participants showed an increase in their knowledge of potential markers of a romance cyberscam, and 11 participants gave more specific advice about the cyberscam at post-test. Five participants demonstrated an increase in their knowledge of hashtags at post-test and seven participants generated more hashtag suggestions. At 3-month follow-up, 15 participants had maintained their knowledge of cyberscams and 13 had maintained their knowledge of hashtags. See Appendix B for detailed participant data on social media use, confidence, enjoyability and knowledge (pre-test, post-test and 3-month follow-up).

# Quality of life

The QOLIBRI questionnaire and content analysis yielded relevant data for the hypothesis related to improved quality of life.

### QOLIBRI

There was no significant difference in QOLIBRI total score between pre-test (M = 56.13, SD = 17.09) and post-test (M = 61.38, SD = 14.81); t(15) = -1.60, p = 0.13, or between post-test (M = 60.67, SD = 15.05) and 3-month follow-up (M = 61.27, SD = 15.45); t(14) = -0.26, p = 0.80. See Table 2 for participant QOLIBRI scores.

### Content analysis

One of the content categories identified in the participant feedback interviews was the benefits of connection. All participants spoke about the sense of connection that they gained from the groups, with one commenting that it gave 'them something to look forward to, because one of the things with the injury, you get lonely, but you get depressed when you don't have something to do' (P2). Many spoke about feeling positive in themselves because of their group interactions, with one participant commenting that 'getting to share about you in the group made you feel awesome' (P14). Several participants spoke about the joy and validation they received from sharing parts of themselves, their ABI, and their identity with their peers, with one commenting, 'I love my art, so when I had responses to my art, that was an ego boost. It makes me happy' (P5). Others gained a sense of hope from posting and interacting in the group, 'because, if I have an idea about something I want to achieve in the future and I can post about it, and people just comment, telling their stories ... making me think that one day I can get to that point and do what I want to do' (P2).

The benefits of connection with peers were also a common element reported by participants, 'it was just sort of

Frequenc	Frequency of use (days per wee	week)	Level of confide moder:	Level of confidence (range: not at all, slightly, moderately, very, extremely)	t all, slightly, nelv)	Level of enjoyn moder	Level of enjoyment (range: not at all, slightly, moderately, very, extremely)	all, slightly, elv)
		3-month			3-month			3-month
Pre-test	Post-test	follow-up	<b>Pre-test</b>	Post-test	follow-up	<b>Pre-test</b>	Post-test	follow-up
3-4 days	Every day	Every day	Very	Extremely	Extremely	Very	Extremely	Extremely
Every day	Every day	Every day	Extremely	Extremely	Extremely	Very	Moderately	Very
Every day	Every day	Every day	Very	Extremely	Very	Moderately	Moderately	Extremely
Every day	Every day	Every day	Very	Very	Very	Very	Extremely	Extremely
Every day	Every day	Every day	Moderately	Extremely	Extremely	Very	Extremely	Extremely
Every day	Every day.	Every day	Moderately	Very	Very	Moderately	Very	Moderately
) days	Every day	1–2 days	Not at all	Somewhat	Very	Not at all	Moderately	Not at all
3-4 days	Every day	5-6 days	Moderately	Moderately	Moderately	Somewhat	Moderately	Moderately
) days	3-4 days	0 days	Not at all	Moderately	Not at all	Not at all	Very	Not at all
Every day	3-4 days	3–4 days	Moderately	Extremely	Moderately	Moderately	Moderately	Moderately
Every day	1–2 days	5-6 days	Moderately	Moderately	Somewhat	Moderately	Very	Extremely
Every day	Every day	Every day	Moderately	Very	Very	Very	Very	Very
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Facebook frequency of use confidence and enjoyment TABLE 1

Note: DNA, did not attend appointment.

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### **TABLE 2**Participant QOLIBRI scores

Participant number	Pre-test	Post-test	3-month follow-up
P1	77	77	81
P2	57	41	55
P3	62	63	74
P4	74	85	78
P5	26	59	39
P6	51	54	60
P7	56	60	54
P8	25	49	45
Р9	75	66	70
P10	71	72	68
P11	39	48	43
P12	81	91	91
P13	49	72	DNA
P14	55	53	62
P15	44	48	45
P16	56	44	54

*Note*: QOLIBRI scores from 0 to 100 indicate good (score  $\geq$  60), moderate (scores 40–59) or unfavourable (score < 40) health-related quality of life. DNA, did not attend appointment.

nice to know that there are people just like you going through something' (P10). Indeed, feelings of loneliness even when with others in real life were reported, with one observing that 'I just get lonely. And if you'd seen the way I live my life, you would think that's nuts, because I'm with good people all day every day, but just inside, I just feel lonely' (P2). One participant remarked that connecting with others in similar situations provided 'encouragement because you're not alone' (P6). This sense of connection was a particular need due to the COVID-19 restrictions in place at the time of running the groups, such that interacting with their peers 'had a massive impact, being able to keep in contact makes the COVID isolation easier' (P5). Some participants enjoyed 'knowing other ABI people and hearing a bit of their journey' (P6), and this at times further strengthened the connection they felt with others in their group: 'I had that connection, and it was just something really with him, just from seeing what he was doing, to see he's obviously been developing and growing, and that gives me a buzz' (P6). Participants reflected on the positives of making new friends with others in a similar situation and that they had built their self-confidence through their interactions, acknowledging the group provided an 'understanding that people similar to me can still do more or not as much as me, but we're all just going at life kind of thing' (P12).

Meeting new peers and learning from one another was illuminating for some, 'it showed me to be a bit more patient with myself in reality ... if they can do it, then I can' (P13). The value in being able to help others and give something back to the brain injury community was also mentioned by several, with one participant reflecting that 'there are people out there just like what you're going through and you can link up and sort of get involved and be part of the solution' (P10). The inclusion of activities such as the optional Zoom morning teas reinforced connections between group members and confirmed their understanding of each other as 'real people', with one participant stating, 'I think it adds value to the Facebook group, it puts a real person there' (P12). One participant also felt that being involved in groups such as these had the potential to change a person's life through the connections they could access and build, 'It could be a mind-blowing thing for someone to do, but it could be a life-changing, awesome thing. It could be their doorway into a community that will change their life' (P4).

# Hypothesis 2: Feasibility and acceptability of Facebook groups.

The first category of the content analysis, 'the benefits of connection', provided core primary evidence supporting the acceptability of the Facebook group. The engagement data, weekly survey and content analysis also yielded relevant data for the hypothesis related to feasibility and acceptability of Facebook groups.

# Facebook social-ABI-lity group interactions and engagement

The number of post-responses and number of posts shared independently by each of the 16 participants across the 12-week period, and their typology of engagement are reported in Table 3. Posts from participants sharing information or photos from their lives received the most engagement, and posts discussing use of technology or social media received less engagement. No participant posted any content which was in breach of the group safety guidelines. Across the two groups, 50% passively engaged (N = 8; group 1 n = 3, group 2 n = 5), 37.5% were intermittently engaged (N = 6; group 1 n = 2, group 2 n = 4) and 12.5% were actively engaged (N = 2; group 1 n = 2, group 2 n = 0).

### Survey feedback

Three participants did not contribute to the weekly survey. The 13 participants that did contribute submitted between one and 14 surveys over the 12-week period. Participants described their challenges in using Facebook, such as learning to navigate the platform and handling unwanted friend requests, as well as coping with targeted advertising and upsetting news stories, for example, 'seeing agitating news about Covid' (P8). One participant explained they

TABLE 3	Participant engagement in th	ne social-ABI-lity Facebook group	over the 12-week period
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Group/part	icipant	Number of post-responses (likes, replies, and sharing in response to others' posts)	Number of posts shared independently	Typology of engagement (passive, intermittent, or active contributor)
Group 1	P1	23	0	Passive
	P2	28	4	Intermittent
	P3	23	0	Passive
	P4	33	17	Active
	P5	22	14	Active
	P6	23	7	Intermittent
	P7	18	0	Passive
	Total	170	42	
	Range	22–33	0–17	
	Median	23	4	
Group 2	P8	44	5	Intermittent
	Р9	33	1	Intermittent
	P10	5	0	Passive
	P11	4	0	Passive
	P12	31	1	Intermittent
	P13	4	0	Passive
	P14	11	0	Passive
	P15	29	0	Intermittent
	P16	5	4	Passive
	Total	166	11	
	Range	4–44	0–5	
	Median	11	0	

sometimes had sent messages before they had fully understood what was being asked. Another participant described their anxiety over waiting for people to respond to their posts, 'as sender can cause anxiety that a message is sent yet a huge delay for response ... and then more messages might be sent based on feeling of anxiety that likely is maybe not necessary' (P4). Seven participants shared that they had enjoyed interacting with people (particularly during the pandemic) and making new friends, as P6 noted, the 'good stuff' about the Facebook group was: 'Seeing others. Learning about others. Having a good laugh' (P6). One participant found using Facebook was a method of stress relief and was also good for reminders, for example, birthdays of people in their friend network. Another participant reported that they enjoyed the groups' responses to their posts, 'I did share some information to a group and people liked it' (P12).

### Content analysis

Alongside the category 'benefits of connection' identified in the content analysis, a further three categories were identified that related to feasibility and acceptability of the Facebook groups: challenges encountered, ideas for improvement and advice for future participants.

### Challenges encountered

Despite the clear benefits of the connection they had observed, the participants recalled that they encountered several challenges. Some found it a challenge to remember to check the group page and others noted that they had to make a deliberate effort to go specifically into the group to post, 'I've got to get into the groups and then I've got to find the right group; it was more than just a simple thing' (P6). Being engaged throughout the 12 weeks was also noted as a challenge, as 'it's really hard to get new people on board, and those that are on board it's hard to even keep a lot of them interactive and consistent'. (P6). As such, finding those common points of interest in such a diverse group was observed to be complicated to navigate as 'we're all different, you can't say one size fits all' (P12).

Some participants reported that they were unsure of what they wanted, or needed, to learn by taking part in the group, 'I wanted to say what I wanted to learn but I couldn't put it into words' (P12). Awareness and acknowledging challenges were also noted to be difficult, as one participant acknowledged that they can be sensitive about their ABI and any resulting problems they encounter, 'we don't want to be different, we want to be normal' (P16). Some participants were unable to join the Zoom morning teas and reported that this 'makes you feel more isolated' (P15). As such, the absence of having 'met' one another via videoconferencing may have represented a barrier to meaningful engagement in the social-ABI-lity Facebook group. Another participant outlined the limited timeframe of the group as an inherent challenge for their preparedness to engage meaningfully, 'I tried to connect, but it wasn't a primary purpose to connect because I knew there was an expiry time' (P6). Additionally, online fatigue was mentioned as a challenge, with one participant noting the effect of the pandemic on their willingness to be on their devices: 'I think I'm sort of in some ways was steering away from being online as much' (P10).

### Ideas for improvement

The participants provided many practical recommendations for improving the group and addressing the challenges they had encountered, such as creating more activities which generate opportunities for participants to post or comment or providing more reminders to access the group, as 'even if the support is just reminders to actually do it, I think that could be really good' (P4). Other practical suggestions included having more Zoom morning teas and making these at a consistent time and day to reduce confusion, and having an in-person practical training component, as 'presenting a workshop would be 1,000 times better, and in that include actually helping them get online' (P6). Some participants felt that there should be more discussion of important things to be mindful of while you are using social media, as 'there is potential for misuse, mismanagement and mistakes essentially, and I think this could offer some support possibly' (P4). Others felt that 'there wasn't really a lot of talk about brain injuryrelated stuff' (P2), such as the issues they were dealing with or sharing advice on coping strategies. As such, participants suggested that sharing advice on living well after ABI could be fostered more, particularly around 'the issues that, I guess, we have to deal with on a daily basis' (P2).

Reinforcing the purpose of the group and explaining what is expected of group participants more regularly was encouraged, with one participant noting, 'it's ABI, so in situations my main thing is meeting these boundaries, and it's just really good to have them spelled out' (P4). Some suggested that a more structured programme with one or two goals for participants to work on would be of benefit, where moderators could clearly outline what to focus on, the step-by-step process of how to address the goals, and also provide support for participants to achieve those 14604984, 0, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/1460-4984.12806 by NHMRC National Cochrane Australia, Wiley Online Library on [29/11/2022]. See the Terms and Conditions (https://onlinelibrary.wiley.com/tems-and-conditions) on Wiley Online Library for rules of use; O A raticles are governed by the applicable Creative Commons License

goals: 'here is what we're going to get you to do ... that is what you'll be practicing in your social media posts in this group' (P4). Several participants recommended ways to encourage interactivity and engagement such as offering prizes or gamification where 'we can all verse each other and have like fun games' (P10), which might incentivise participants, 'I'm getting something and it's just fun' (P8). Another participant suggested shared experiences, 'like just cooking together' (P8), might be another option to build engagement in the group. Some participants felt that having a speech-language pathologist or rehabilitation clinician as moderators was beneficial for the group. However, all but one of the participants felt that having people with an ABI involved in moderating the group could be more beneficial as 'it gives them additional connection' (P6) through their shared experiences of living with ABI, 'but that's hard to instigate I guess' (P15). One participant also observed that having people with ABI moderating the group might also increase the longevity of the group as 'non-ABI moderators, only last for a certain period of time, and then you're back to your own self again, your own issue and your own problem. Whereas if it's run by an ABI person, it can then become ongoing and that group can continue on longer term' (P6).

# Advice for future participants of the social-ABI-lity Facebook group

The participants were positive in their advice for others with an ABI to 'give it [the group] a go, 100 percent, give it a go' (P9), and recommending that they should 'give it a try and see how it goes' (P14). In group 1, four out of seven participants reported the group was very or extremely useful and five out of seven said they would be extremely likely (a rating of 10/10) to recommend the group to other people with an ABI. In group 2, four out of nine participants reported the group was very or extremely useful and two out of nine said they would be extremely likely to recommend the group to other people with an ABI, with one participant proposing that 'this group would benefit someone who is willing to understand not only themselves but other people and how they've dealt with these differences' (P13). Some participants suggested that people should have clear expectations of what they hope to gain from being involved, with one participant stating 'I think it's good to work out what you want from the course and say it. Tell the people running it and bring it up online' (P12) and another reinforcing the aim of the group be clear from the outset as 'it's not about getting them on social media, it's getting them more interactive on social media, I think, is the way this group was' (P6). However, another participant felt that people joining the group should 'just be open-minded and don't have an expectation of what exactly you're going to

get from it. Just be prepared to participate and hear other people's voice, as equally valid as your voice' (P16).

## DISCUSSION

The purpose of this study was to evaluate a multicomponent intervention focused on developing skills for using social media after ABI. We hypothesized that participating in the social-ABI-lity course and Facebook group would improve skills in interacting online and improve quality of life for people with ABI. Results from the pilot study suggest our hypotheses were partially supported as participants demonstrated significant improvements in their Facebook confidence and Facebook enjoyment, and participants reported that they found the intervention improved their sense of connection with others. Although there were no significant changes in quality of life observed on the QOLIBRI, all participants remarked on the benefits they gained from the connections encountered in their groups. Our second hypothesis was that the Facebook group would be feasible and acceptable to participants. Feasibility was partially supported, with half (50%) of participants across the two groups passively engaged and an eighth (12.5%) who were actively engaged. A number of challenges navigating to and participating in the group were identified. Acceptability was also partially supported, with a proportion of participants reporting a high likelihood to recommend to other people with ABI, describing the group as useful and providing positive qualitative feedback. Findings indicated that it may be feasible and acceptable to train some aspects of social media communication skills for people with an ABI using an online, self-directed course in combination with a private, moderated social media group to practice their skills.

The positive outcomes reported by participants from being involved in the Facebook group were similar to those observed in face-to-face ABI peer support groups, that is, obtaining friendship and support, expression of feelings, sharing of coping strategies and gaining information (Hughes et al., 2020). Sharing stories of living experiences of ABI has been shown to enable greater personal and emotional information sharing (D'Cruz et al., 2020), and the participants in this study wanted more opportunities to do so, as they reported feeling valued connections when others shared their experiences of brain injury in the group. Additionally, they reported positive changes in sense of self resulting from their group interactions, which has been linked to greater success in rehabilitation after brain injury (Ownsworth, 2014). However, one of the groups (group 1) was more engaged than the other, with individuals' patterns of use influencing the group dynamics. Although the participants in group 2 reported that they wanted

more interaction and activity in the group, the participants themselves did not actively contribute content, with most group members being sporadic contributors or lurkers. As such, another important consideration when facilitating group engagement is the typology of group members' engagement, that is, whether they be passive (sporadic and lurker profiles), intermittent (debater and socializer profiles) or active contributors (Brandtzaeg & Heim, 2011). Therefore, when fostering and building a social media support community, having a blend of these five contributor typologies amongst group members is likely to generate greater engagement and longevity.

Throughout the Facebook group pilot study, a draft moderators guide was developed by K.Su, with support from R.R. and M.B. The guide included basic information on determining the group's purpose and rules, planning the moderation of the group, creating boundaries for moderators and group members, navigating interactions when boundaries or group rules are broken, supporting and welcoming group members into the group, and practical tips on how to moderate the group and problem solve when issues arise. Whilst this resource did not have an exhaustive list of strategies to troubleshoot barriers, the challenges participants encountered in this study and their ideas for improvement provided valuable insights to help shape the guide further. Their suggestions included moderators that could provide incentives for people to stay engaged, encourage discussion about living with a brain injury, and offer tips on navigating the platform and integrating the group into their life (e.g., sending reminders and encouragement to post). Of importance to note was the need for an individualized approach, acknowledging that individuals, group members and moderators alike, engage in these groups differently. Participants in this study suggested that this intervention could be improved through tailoring supports to address people's individualized social media goals and providing regular reminders of the group's purpose. Several recommended that having peer moderators would strengthen the group and had the potential to increase its longevity. As such, the authors intend to continuously update the moderators' guide based on stakeholder input and feedback so as to provide greater guidance to address individual needs, including development of a peer moderators guide, and for these guides to be made freely available on the ABI Communication Lab website.

# **Clinical implications**

There is a professional obligation to address social media communication and safety skills in rehabilitation for people with ABI due to the growing use of social media This pilot study provided preliminary evidence that an intervention comprising a short, self-guided training course (the social-ABI-lity course) and a private, moderated Facebook group (the social-ABI-lity Facebook group) improved outcomes for people with ABI. Participants improved their confidence and enjoyment in using Facebook and built a sense of connection with others in the group. The results provided preliminary support that the multi-component intervention, which combined both education and contextualized opportunities to apply skills in social media, was feasible and acceptable. Navigating the platform, remembering to check the groups' posts, and catering to individual needs were some of the challenges identified by participants. Their key recommendations for future implementation of this programme included embedding active peer moderators within groups and taking a more individualized and structured approach to delivery of the intervention. Future research will integrate these recommendations as part of ongoing evaluation of the impact of the multi-component social-ABI-lity intervention on social media skills and quality of life after ABI.

CONCLUSIONS

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### **CONFLICT OF INTEREST**

The authors have no conflicts of interest to disclose.

### PATIENT CONSENT STATEMENT

All patients who participated in the study provided written consent.

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for connection and participation and the risks associated with its use. Clinicians now have preliminary evidence to support the incorporation of social media skills training into ABI rehabilitation services, as well as clinical resources to do so through the freely available social-ABIlity online course. Access to the social-ABI-lity course or guidance on establishing and moderating a social media peer support group themselves is also available via contacting the authors. The findings of this study will better inform future research and the development of additional interventions to support people with ABI in building their social media skills for communication, social inclusion and quality of life. For others who experience difficulties in social communication (e.g., young people with developmental language disabilities or adults with dementia), this research could also inform resources adapted for their needs.

# Limitations and future directions for research

There were several limitations to this study. Although the study was open to people with any type of ABI, the sample was comprised predominantly of people with TBI. Additionally, participants self-selected to participate and as such their motivation levels may have been higher than other people with ABI. Many participants were already frequent Internet and Facebook users, which may have made it easier for them to participate and gain benefit from the social-ABI-lity course and Facebook group. To make stronger conclusions about the efficacy of this multi-component intervention, future research should be conducted with larger groups of participants, with a focus on including people who do not already use Facebook, people with different types and severities of ABI, and adapting this intervention to trial with children and adolescents with ABI.

There was no formal evaluation of intervention fidelity in this study. The development of a moderator's guide may support fidelity to be maintained in future implementation of this intervention. As suggested by the participants in this study, it would also be of benefit to examine the potential for the intervention to be conducted with peer moderators. Inclusion of people with ABI as co-researchers will also be valuable to incorporate in this future research. Finally, the study involved analyses of multiple self-reported measures of social media use, and the interviews and content analysis were conducted by researchers who were also involved in the design and delivery of the intervention. These factors mean that the study findings should be interpreted with caution. Emma Power https://orcid.org/0000-0002-2638-0406 Melissa Miao https://orcid.org/0000-0002-4113-0149 Leanne Togher https://orcid.org/0000-0002-4518-6748

### REFERENCES

- Brandtzaeg, P.B. & Heim, J. (2011) A typology of social networking sites users. *International Journal of Web Based Communities*, 7, 28–51.
- Brunner, M. (2020) #TwitterMind—Social Media Use by People with Communication Difficulties after Traumatic Brain Injury (TBI). [Doctoral dissertation, University of Technology Sydney]. OPUS. http://hdl.handle.net/10453/142209
- Brunner, M., Hemsley, B., Togher, L., Dann, S. & Palmer, S. (2021a) Social media and people with traumatic brain injury: a metasynthesis of research informing a framework for rehabilitation clinical practice, policy, and training. *American Journal of Speech–Language Pathology*, 30, 19–33.
- Brunner, M., Hemsley, B., Palmer, S., Dann, S. & Togher, L. (2015) Review of the Literature on the Use of Social Media by People with Traumatic Brain Injury (TBI). *Disability and Rehabilitation (Special Issue: Social Media and Communication)*, 37(17), 1511–1521.
- Brunner, M., Palmer, S., Togher, L. & Hemsley, B. (2019) 'I kind of figured it out': the views and experiences of people with traumatic brain injury (TBI) in using social media—Self-determination for participation and inclusion online. *International Journal of Language and Communication Disorders (Special Issue: The Use of Technology in Speech and Language Therapy)*, 54, 221–233.
- Brunner, M., Rietdijk, R., Avramovic, P., Power, E., Miao, M., Rushworth, N., et al. (2022a) Developing social-ABI-lity: an online course to support safe use of social media for connection after acquired brain injury. *American Journal of Speech–Language Pathology*, [accepted 09/09/2022].
- Brunner, M., Rietdijk, R. & Togher, L. (2022b) Training resources targeting social media skills: a scoping review to inform rehabilitation for people who have an acquired brain injury. *Journal of Medical Internet Research [Electronic Resource]*, 24(4), e35595.
- Brunner, M., Togher, L., Palmer, S., Dann, S. & Hemsley, B. (2021b) Rehabilitation professionals' views on social media use in traumatic brain injury rehabilitation: gatekeepers to participation. *Disability and Rehabilitation*, 43, 1955–1964.
- Ciccia, A. & Threats, T. (2015) Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: emerging concepts identified through modified narrative review. *International Journal of Language & Communication Disorders*, 50, 436–451.
- D'Cruz, K., Douglas, J. & Serry, T. (2020) Sharing stories of lived experience: a qualitative analysis of the intersection of experiences between storytellers with acquired brain injury and storytelling facilitators. *British Journal of Occupational Therapy*, 83, 576–584.
- Datareportal, we are Social & Hootsuite. (2021) *Digital* 2021 October Global Statshot Report [Online]. Available: https://datareportal.com/reports/digital-2021-october-globalstatshot [Accessed 2022].
- Eghdam, A., Bartfai, A., Oldenburg, C. & Koch, S. (2016) How do persons with mild acquired cognitive impairment use informa-

tion and communication technology and e-services? Results from a Swedish National Survey. *Plos One*, 11, e0159362.

- Facebook. (2022) *Facebook Groups* [Online]. Available: https://www.facebook.com/help/1629740080681586 [Accessed 2022].
- Gould, K.R., Carminati, J.-Y.J. & Ponsford, J.L. (2021) 'They just say how stupid I was for being conned'. Cyberscams and acquired brain injury: a qualitative exploration of the lived experience of survivors and close others. *Neuropsychological Rehabilitation*, 1–21. https://doi.org/10.1080/09602011.2021.2016447
- Hoffmann, T.C., Glasziou, P.P., Boutron, I., Milne, R., Perera, R., Moher, D., et al. (2014) Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ* : *British Medical Journal*, 348, g1687.
- Hsieh, H. & Shannon, S. (2005) Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277–1288.
- Hughes, R., Fleming, P. & Henshall, L. (2020) Peer support groups after acquired brain injury: a systematic review. *Brain Injury*, 34, 847–856.
- IBM CORP (2022) IBM SPSS statistics for windows, Version 28.0.1. Armonk, NY, IBM Corp.
- Jeste, D., Palmer, B., Appelbaum, P., Golshan, S., Glorioso, D., Dunn, L., et al. (2007) A new brief instrument for assessing decisional capacity for clinical research. *Archives of General Psychiatry*, 64, 966–974.
- Lowe, N., Crawley, L., Wilson, C. & Waldron, B. (2020) 'Lonely in my head': the experiences of loneliness in individuals with brain injury. *British Journal of Health Psychology*, 26, 444– 463.
- Macdonald, S. (2005) Functional assessment of verbal reasoning and executive strategies. Ontario, Canada, CCD Publishing.
- Macdonald, S. (2017) Introducing the model of cognitive– communication competence: a model to guide evidence-based communication interventions after brain injury. *Brain Injury*, 31, 1760–1780.
- Meulenbroek, P., Ness, B., Lemoncello, R., Byom, L., Macdonald, S., O'Neil-Pirozzi, T., et al. (2019) Social communication following traumatic brain injury part 2: identifying effective treatment ingredients. *International Journal of Speech–Language Pathology*, 21, 128–142.

MIRO (2022) Miro. https://miro.com/.

- Monash University. (2022) *CYBERABILITY* [Online]. Available: https://cyberability.org.au/ [Accessed 2022].
- Morrow, E.L., Zhao, F., Turkstra, L., Toma, C., Mutlu, B. & Duff, M.C. (2021) Computer-mediated communication in adults with and without moderate-to-severe traumatic brain injury: survey of social media use. *Rehabilitation and Assistive Technologies*, 8, e26586.
- Northcott, S. & Hilari, K. (2011) Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders*, 46, 524–534.
- Ownsworth, T. (2014) *Self-identity after brain injury*. New York, NY, Taylor & Francis Group.
- QSR International (2022) *NVivo Version 1.5.1 (940)*. Doncaster, QSR International.
- Randolph, C. (2012) *RBANS update: repeatable battery for the assessment of neuropsychological status.* Bloomington, MN, PsychCorp.
- Roozenbeek, B., Maas, A. & Menon, D. (2013) Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, 9, 231–236.

- Salas, C.E., Casassus, M., Rowlands, L., Pimm, S. & Flanagan, D.A.J. (2018) 'Relating through sameness': a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological Rehabilitation*, 28, 1161– 1178.
- Tate, R.L. (2004) Assessing support needs for people with traumatic brain injury: the care and needs scale (CANS). *Brain Injury*, 18, 445–460.
- Teasdale, G.M., Pettigrew, L.E.L., Wilson, J.T., Murray, G. & Jennett, B. (1998) Analyzing outcome of treatment of severe head injury: a review and update on advancing the use of the Glasgow Outcome Scale. *Journal of Neurotrauma*, 15, 587–597.
- Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L.P., et al. (2010) A tutorial on pilot studies: the what, why and how. BMC Medical Research Methodology, 10, 1.
- Thinkific Labs Inc. (2021) *Thinkific* [Online]. Available: https://www.thinkific.com/ [Accessed 2021].
- Tong, A., Sainsbury, P. & Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349–357.
- Vanderbilt University. (2022) *Research Electronic Data Capture (RED-Cap)* [Online]. Available: https://projectredcap.org/ [Accessed 2022].
- Von Steinbuchel, N., Wilson, L., Gibbons, H., Hawthorne, G., Hofer, S., Schmidt, S., et al. (2010) Quality of Life after Brain Injury (QOLIBRI): scale development and metric properties. *Journal of Neurotrauma*, 27, 1167–85.
- We are Social & Hootsuite. (2022) *Digital 2022 Global Overview Report* [Online]. Available: https://wearesocial.com/au/blog/ 2022/01/digital-2022-another-year-of-bumper-growth/ [Accessed 04/08/2022].
- Zoom Video Communications Inc. (2021) Zoom. https://zoom.us/

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# A | POST-INTERVENTION INTERVIEW GUIDE

What did you think about the social-ABI-lity course?

How did you go with the course activities? Any difficulties?

Did the course improve your skills? If so—what were the improvements?

How did you find participating in the social-ABI-lity Facebook group?

How could we improve how the groups are run in the future?

Has the group improved your life? If so—what were the improvements?

What impact has this change had on your life?

Think back to what you hoped you would learn from the course and the group. Did you learn what you were hoping to?

What advice would you give someone who was thinking about doing this program?

Would you like to share any other feedback?

				, Z								ť	•				
				Group 1								Gro	Group 2				
Participant number	Ρ1	P2	P3	P4	P5	P6	P7	P8	$\mathbf{P9}$	P10	PII	P12	P13	P14	P15	P16	P17
Age	32	20	45	38	22	59	50	23	53	26	22	51	23	22	57	45	20
Gender identity	M	ц	М	М	ц	M	M	Μ	Μ	М	М	ц	н	Μ	М	W	Μ
Years of education	15	14	15	18	13	23	18	12	15	16	13	21	13	13	14	13	13
English as second language	Yes	No	No	No	No	No	Yes	Yes	No	No	Yes	No	Yes	Yes	No	No	No
Vision impairment	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hearing impairment	No	No	No	Yes	No	No	No	No	No	No	No	Yes	Yes	No	Yes	No	No
Type of ABI	TBI	TBI	TBI	TBI	TBI	Stroke	TBI	TBI	TBI	TBI	Brain 7 tumour	TBI ur	TBI	TBI	TBI	TBI	TBI
PTA duration	Not know	Not know:	Not know	Not know:	Not know	n.a.	Not know.	32 days	Not know:	Not know	n.a.	Not know	Not know:	15 days	Not know:	Not know	Not known
Time post-injury	5 years	3 years	3 years	18	20	4 years	4 years	2 years	9 years	14	19	23	÷.	1 yr 6	28		11
		6 montl	6 8 yer months months 10 mo	hs 10 months	years	6 months	2 hs months	2 hs months	6 hs months	years 1S	years	years		months months years 8 montl	ns years 8 months	years	years
Frequency of internet use	Every day	Every day	Every day	Every day	Every day	Every day	Every day	Every day	Never	Every day	Every day	Every day	Every day	Every day	Every day	Every day	Every day
GOSE	LSD	LSD	UMD	LMD	LSD	LSD	LMD	LSD	USD	USD	LSD	LMD	LMD	LMD	LMD	LSD	UMD
CANS	9	7	1	4	6	5	3	4	5	4	4	1	3	3	2	9	4
FAVRES Accuracy	DNC	4	2	3	2	2	1	3	2	DNC	1	4	DNC	3	DNC	DNC	DNC
FAVRES Rationale	DNC	1	0	2	4	4	0	5	3	DNC	0	0	DNC	3	DNC	DNC	DNC
FAVRES Total Time	DNC	2 min 9 s	5 min 28 s	7 min 21 s	12 min 43 s	6 min 35 s	9 min 38 s	11 min	8 min 2 s	DNC	12 min 46 s	11 min 57 s	DNC	8 min 8 s	DNC	DNC	DNC
RBANS IS Immediate Memory	40	109	73	69	49	87	53	87	65	44	44	100	76	DNC	112	126	DNC
RBANS IS Visuospa- tial/Construction	69	60	105	72	62	96	81	87	100	53	64	100	69	DNC	96	60	DNC
RBANS IS Language	74	92	95	82	75	120	40	64	94	44	54	94	101	DNC	79	88	DNC
RBANS IS Attention	43	82	68	75	43	100	82	79	85	49	49	16	64	DNC	75	DNC	DNC
RBANS IS Delayed Memory	40	56	64	74	<i>LL</i>	108	77	56	68	40	80	97	97	DNC	67	94	DNC
RBANS IS Total	48	75	76	67	52	102	57	68	78	43	51	94	77	DNC	88	DNC	DNC
Notes: CANS scores of 0–7 indicate level of independence, with 0 indicating no support required and 7 needing support and assistance 24 h per day. All FAVRES scores are shown as raw scores (range = 0–5), with higher scores indicating more successful task completion. RBANS IS Total scores are shown as standard scores between 40 to 160 and are indicative of average/mild impairment ( $\geq$ 70), moderate impairment (55–69) and severe impairment (< 54).	tte level of i l task comp	ndepender detion. RB	ıce, with 0 ANS IS To	indicating i tal scores ar	no support e shown as	required a standard s	nd 7 needir cores betw	ng support een 40 to 1	and assista 60 and are	nce 24 h pe indicative c	r day. All F of average/1	AVRES sco nild impaiı	ores are sho rment (≥ 7	wn as raw 0), moderat	support required and 7 needing support and assistance 24 h per day. All FAVRES scores are shown as raw scores (range = 0−5), with higher shown as standard scores between 40 to 160 and are indicative of average/mild impairment (≥ 70), moderate impairment (55–69) and severe	ge = 0-5, w. int (55-69) a	ith higher nd severe

TABLE B1 Participant demographics and scores on psychosocial and cognitive assessments

ABI, acquired brain injury; CANS, Care and Needs Scale; DNC, did not complete; F, female; FAVRES, Functional Assessment of Verbal Reasoning and Executive Strategies; GOSE, Glasgow Outcome Scale Extended; IS, Index Score (index score of 100 is the mean for people without a brain injury); LMD, lower moderate disability; LSD, lower severe disability; M, male; RBANS, Repeatable Battery for the Assessment of Neuropsychological Status; TBI, traumatic brain injury; UMD, upper moderate disability; USD, spper severe disability. 14606984, 0, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.12806 by NHMRC National Cochrane Australia, Wiley Online Library on [29/11/2022]. See the Terms and Conditions

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