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Participants' perspectives of feasibility of a novel group treatment for people  
with cognitive communication difficulties following acquired brain injury

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## **Abstract**

### **Purpose**

To determine whether treatment was acceptable to participants and perceived as beneficial by exploring the experiences of people with cognitive communication difficulties following acquired brain injury who participated in a novel, group, communication, project-based treatment. The purpose of the treatment was to improve participants' communication skills and quality of life, by focusing group activity towards the production of a project and by incorporating individualised communication goals into group sessions.

### **Methods**

Twenty-one people with acquired brain injury recruited from community settings participated in project-based treatment, which comprised one individual and nine group sessions (of 2-3 people) over six weeks. Structured interviews were conducted post-treatment as part of a broader assessment battery. Interviews were transcribed verbatim and analysed using content analysis to identify codes, categories and themes.

### **Results**

Themes identified from the analysis centred around the treatment experience (general experience; group experience; project experience; working on goals) and benefit of treatment (communicative benefit; other benefits; emotional effects; meeting others; something to do). These themes were consistent with the treatment being perceived as acceptable and having initial efficacy for the participant group.

### **Conclusion**

The qualitative data presented here provide positive feasibility findings (acceptability and initial efficacy) of project-based treatment for people with acquired brain injury. The results

highlight the value of incorporating participants' views in assessing feasibility in developing novel interventions.

### **Key words**

Cognitive-communication; feasibility; brain injury; qualitative research; group; acceptability

### **Implications for Rehabilitation**

- Inviting people (with cognitive communication difficulties following acquired brain injury) to feedback on their treatment experience provides valuable information that can confirm treatment choice and content or inform adjustments to future treatment.
- Group treatment with a meaningful and motivating focus, and individualised communication goals, seem to promote positive change in communication, emotional state, cognition, self-awareness, and social interaction.
- This study highlights the value of individuals' perspectives in evaluating feasibility of a novel intervention.

## Introduction

The term ‘cognitive-communication difficulties’ is used to describe the range of communication problems that can occur after acquired brain injury (ABI) and that primarily result from cognitive deficits [1]. The incidence of cognitive-communication difficulties for people with ABI has been reported to be typically greater than 75% [2]. The clinical presentation of a person with cognitive-communication difficulties is complex and highly heterogeneous [3] varying with respect to injury type, severity, cognitive and communication profiles [2, 4]. People may present as verbose, tangential, impolite or rude, frequently interrupt others, have perseverative or confabulatory responses, poor eye contact, problems with topic management, struggle to contribute to the conversation, poor social awareness and problems adapting their skills to their communication partner or context [2, 4, 5, 6, 7]. These communication problems can negatively affect a person’s quality of life (QOL) [7], particularly in areas of social functioning, social integration into the community, and return to work [8, 9, 10]. Communication problems may also lead to the feelings of loneliness, social isolation and low self-esteem, which people often experience after ABI [11, 12]. As a result, the broader impact of the treatment should be considered beyond communication skills alone [13, 14].

Project-based treatment is a broad treatment approach that could have a positive impact on both communication skills *and* QOL for people with ABI. Projects involving a tangible end-product designed by the activities of a group have been commonly used in educational settings to engage students in exploring real-life problems [15, 16]. In such settings, the approach requires a meaningful driving question that organises the activities of a group that then results in a final project to address the driving question [15]. The project can produce roles for people where they are recognised as an expert or helper and provide an opportunity to use skills in planning and organisation [17]. This treatment has been used

therapeutically to improve communication skills, self-esteem and sense of competence in people with ABI [17, 18] and older people in residential care settings [19, 20]. In these contexts additional benefits for mood [21] and personal goal achievement [22] have been noted. Earlier work on the treatment for adults with ABI provided an operational definition that minimally described the treatment as 10 guiding principles [17, 18], making it difficult to replicate. Thus, the aim of the current research study was to systematically apply those guiding principles in a trial of project-based treatment to examine both communication and QOL outcomes. People with ABI worked collaboratively as a group to participate in a range of meaningful activities whereby they aim to achieve a product or *project*. Two core features of this treatment involve the project to be designed to help others (e.g. an educational video about brain injury experiences) and chosen by people with ABI themselves in order to be intrinsically motivating, emotionally satisfying and consistent with a person's pre-injury sense of self [18]. An environment is created by the group and project focus where people can learn and practise a range of communication, cognitive, behavioural and emotional skills. A group-based treatment was chosen as the evidence is greatest and strongest for such delivery methods in working with people with ABI [13, 14]. Groups enable people with ABI to be supported and given the opportunity to socialise with others, give and receive feedback, plan and organise, solve functional problems, deal with oppositional and egocentric attitudes and problems with disinhibited behaviour and low self-esteem. To increase the focus on communication, inclusion of an individualised communication goal was incorporated into the treatment. Addressing patient-identified goals is a key recommendation developed by an international panel of expert researchers and clinicians in cognitive rehabilitation (known as INCOG) [13] and further endorsed in a recent systematic review for people with communication impairments after ABI [14].

As this treatment is relatively new and its effect not evaluated for improving communication skills *and* QOL, feasibility should first be established. As a general rule, feasibility studies are recommended to employ a combination of quantitative and qualitative methods [23]. The addition of qualitative data complements and helps to explain the quantitative results as well as extending the results by exploring the participant experience of a treatment. Two key aspects feasibility proposed by Bowen and colleagues [24] which have the potential to be addressed by qualitative data alone are acceptability and initial efficacy. Acceptability refers to how targeted individuals react to the treatment, and initial efficacy refers to whether the treatment shows promise of being successful with the intended population. Collecting qualitative data within a broader quantitative assessment battery can be a challenge due to participant burden however, other studies in brain injury have used structured surveys and questionnaires to collect this information [25, 26]. A disadvantage of this method is that it restricts the amount of qualitative information obtained due to lack of probing. However, the information can still provide details about aspects of a treatment considered more or less helpful or the perceived benefits of the treatment. For example, Kreutzer et al. [25] used qualitative data from a structured survey to identify that sessions on solving problems, setting goals, asking for help and encouraging a positive focus were perceived more strongly than other training sessions; and as such, should influence future training for people with ABI and their caregivers. Anson and Ponsford [26] used a structured questionnaire to people with TBI to identify some of the self-perceived benefits from a coping skills group and future changes that could be made with respect to session length and intensity, and scheduling of sessions.

Qualitative data is important for exploratory studies testing the feasibility of a treatment and can help to identify which aspects of the treatment were most important to participants, which aspects facilitated and/or hindered their learning, and what improvements

or changes they would make to the treatment. For example, in a training programme for people with aphasia after stroke, Simmons-Mackie et al., [27] found that participants and their caregivers reported the group format to be helpful in enabling them to learn skills about a range of topics (e.g. solving problems effectively, better at managing stress, and how to be more patient). Information such as this could not be obtained from quantitative data alone. In another study focused on communication training for people with brain injury, qualitative data was used to identify valuable components of the programme which included providing specific feedback about conversations, role-plays, a combination of individual and group sessions and the social component of training [28]. Participants in that study also identified challenges and the need for improvements that included more real-life examples, more interesting course content, and involvement of other family members. A challenge in the current study is achieving qualitative interviews within a substantial test battery as there is a trade-off between depth of exploration of the participant experience with assessment burden of participating in research and completing quantitative measures.

## **Aims**

This study was part of a feasibility study exploring the benefits of project-based treatment on improving communication skills and quality of life in people with ABI. This involved a waitlist, quasi-randomised design, comparing communication and QOL outcomes between participants allocated to an immediate treatment group (n=11) versus a waitlist control group (n=10) [29]. Change for all participants involved in the treatment was also examined. Outcomes were collected on a range of measures at three time points; pre and post treatment, and at 6-8 weeks follow-up. Communication outcomes involved measures of conversation, perceived communicative ability and goal achievement. QOL outcomes involved measures of health-related QOL and subjective well-being. Here we report the

qualitative data that was collected through semi-structured interviews conducted 1-2 weeks post-treatment. This data is used to explore the participant experience of project-based treatment and addresses two key areas of feasibility:

1. How do participants react to the treatment, and what components of the treatment did they react to most positively (i.e. acceptability)?
2. In what way was the treatment considered successful to participants (i.e. initial efficacy)?

## **Method**

The consolidated criteria for reporting qualitative research (COREQ) checklist was used to report important aspects of the study (see Supplementary Table S1).

## **Participants**

People with ABI were recruited from charitable brain injury organisations and local support groups from across England. All participants had been discharged from residential rehabilitation services and were living in the community. Consultant psychologists and/or speech and language therapists identified potential participants from brain injury organisations, and day-service co-ordinators identified potential participants from local support groups. Potential participants were contacted and visited by the first author to conduct a formal capacity assessment that determined his or her ability to consent to inclusion into the study. As part of this assessment, the study information sheet was shown and discussed. If a person had capacity, and met the following inclusion and exclusion criteria, informed written consent to participate was obtained. Inclusion criteria for people with ABI were: (i) diagnosis of ABI at least one year earlier, where for participants who sustained a TBI, they sustained a moderate-to-severe injury based on period of post-traumatic

amnesia (PTA), Glasgow Coma Scale score at time of injury, and/or clinical presentation; (ii) discharged from residential rehabilitation services; (iii) presence of significant cognitive-communication difficulties as diagnosed by a speech and language therapist; (iv) able to identify a communication partner with whom they interact with regularly (to attend assessment sessions and contribute to goal setting, and receive weekly texted communication goals to facilitate carryover into everyday life); (v) able to attend assessment and treatment sessions; (vi) a mobile phone that can receive text messages; (vii) capacity to consent in the study; and (viii) sufficient English to participate. Exclusion criteria for participants with ABI included: (i) severe dysarthria which made speech unintelligible; (ii) severe aphasia, as the linguistic support needed would be different to what was needed for this target population; (iii) people receiving on-going speech therapy; (iv) active psychosis; and (v) significant behavioural problems.

Twenty-one participants were recruited and agreed to participate in the study. There were 12 males and 9 females. Participants ranged in age from 24 to 67 years (mean = 45.8 years) and years' post-ABI from 2 to 47 years (mean = 11.95 years). Injury severity was noted for thirteen participants who had sustained a TBI (severe = 12; moderate = 1). Diagnoses of the remaining 8 participants included meningioma, hypoxic injury, atrial venous malformation and stroke. For living arrangements, 5 people lived alone independently, 11 lived independently with a family member or spouse, 4 lived independently with carer support, and 1 lived in a care home. The majority of people were not employed (n=18), with 1 person in full-time paid work, 1 person in part-time paid work, and 1 person in part-time voluntary work.

Ethical approval was gained from City, University of London, School of Health Sciences Ethics Committee, and the Brain Injury Rehabilitation Trust's Research Ethics Committee. Each participant provided written consent to be involved in the study.

## **Procedure**

### **Intervention**

Intervention was conducted in groups of 2 or 3 participants. The group needed to offer peer and social support while offering opportunities for peer feedback and sufficient time for each participants goal to be focused upon within the group. Given the range of cognitive problems people can present with after a brain injury, it is widely accepted that groups can have as few as 2 participants [30, 31]. Each participant attended the treatment, which involved an individualised session between themselves, the speech and language therapist and their communication partner, followed by nine 2-hour group sessions (with a 15-minute break) conducted over a 6-week period. The individual session focused on the identification of a specific communication goal to be targeted throughout the group sessions. To help remind participants, their goal was texted to them on a daily basis and to their communication partner on a weekly basis. Group sessions included group interaction, expression of ideas and opinions and peer feedback, in order to achieve individual communication goals, while completing a project. The project was a tangible end-product (e.g. pamphlet, educational video, artwork) that was identified and designed by the group and created during the group sessions. The role of the treating speech and language therapist was to facilitate this process by using strategies to compensate for participants' cognitive impairments. These included the use of structure and routine, visual scaffolds for planning and using frameworks to facilitate problem-solving processes. The content of the treatment has been comprehensively described elsewhere using the TIDieR framework [32] and manualised to facilitate fidelity.

### **Data collection**

Individual interviews were conducted post-treatment with each participant to explore their experiences of being involved in the treatment. Each interview was structured and was audio- and video-taped. An interview topic guide was utilised to ensure consistency across the interviews (see Supplementary Table S2). Verbal prompts were given for people with brain injury to explain, clarify, and give examples of comments they made during the interview. These prompts ensured that the information given was as accurate and unambiguous as possible without unnecessarily influencing their opinions. Final checks were conducted at the end of each interview to summarise and clarify responses to ensure the information provided was as accurate as possible. Interviews lasted an average of 17 minutes (range 10-25 minutes) and were conducted in a quiet room, either in the treatment setting or within a participant's own home. Participants were interviewed by the first author (speech and language therapist with over 15 years of clinical experience in brain injury, with a research master's degree including previous experience of conducting post-treatment qualitative interviews), who was also responsible for delivering the treatment. Whilst it would be preferable for the researcher not to be the interviewer in the study, limited resources meant that this was not possible. Interviews were conducted without preconceptions and participants were encouraged to share any negative thoughts of the treatment. Careful consideration of the findings with steps to reduce bias were incorporated during the analysis stages of the study as the interviewer had a positive view and interpretation of the treatment which may influence relationships and outcomes.

### **Data analysis**

The interviews were transcribed verbatim with all identifying information removed. Each participant was then provided with a copy of his or her interview transcript between post-treatment and follow-up visits. At the follow-up visit participants were supported to

check and verify that the information provided in the transcript reflected a complete and accurate recount of their experience of the treatment. This form of member checking was done as one form of data validation [33]. Analysis of the data began after all transcripts had been collected and checked by the participants. Transcripts were entered into NVivo version 12.0, which was used to manage the data and reflect on codes, categories and themes.

All of the data was analysed by the first author using content analysis [34] where the content of the transcripts were analysed and themes identified. Given that there was limited probing during the interviews there was no attempt at explanatory analysis but mainly a descriptive analysis where both a cluster of ideas and frequencies of those ideas contributed to the identification of key findings. These transcripts were read and re-read to become familiarised with the data. Key units of data were underlined and coded in the text margins with labels used by the participants or determined by the researchers. To reduce bias, five randomly chosen transcripts were coded separately by the first and last author and then discussed to identify discrepancies, as was the final formation of themes and sub-themes, and member checking of each interview. In addition, the remaining authors, who were not involved in the treatment also reviewed the formation of themes and sub-themes. These steps to validate the analysis were critical as the first author was the interviewer, therapist, and person responsible for the entire analysis [33], and aimed to reduce potential bias that may arise during the process of analysis. The remaining 16 transcripts were then read and re-read to become familiarised with the data, with units of data coded and labelled accordingly. Any key points were checked to ensure accurate coding had been completed.

The data from each of the transcripts were then organised into a series of main themes subdivided with sub-themes and categories [35], with use of constant comparative analysis where areas of commonality, differences and relationships across and within transcripts were identified [36]. As this process evolved, some of the data was re-coded into a different

category, sub-theme or theme. The final list of themes, sub-themes, and categories was then tabulated and described. The coded and categorised data, and tabulated descriptions were then reviewed and further validated by the second researcher. Discrepancies in the allocation of some data was discussed and re-allocated through consensus between the researchers. The final list of tabulated data was organised according to the most prominent themes, sub-themes and categories. Key participant quotations were used to illustrate each of these. Finally, the researchers reflected on the data with reference to the outcomes of the treatment and future design considerations.

## **Results**

Two main themes emerged from the data: treatment experience and benefit of treatment. Treatment experience was the largest theme in the data (in terms of the number of coded comments) and had four sub-themes: general experience, group experience, project experience, and working on goals. Each of these sub-themes is developed from categories. The second theme, benefit of treatment had five sub-themes: communicative benefits, other benefits, emotional effects, meeting others, and something to do. The themes, sub-themes and categories are shown in Table I.

Table I. *List of themes, sub-themes, and categories*

Themes	Sub-themes	Illustrative quote(s)	Categories
TREATMENT EXPERIENCE	General experience	I think it was really positive ( <i>P3, 67 years, 4 years post-injury</i> )	Emotional reaction, satisfaction with treatment, emerging value, other
	Group experience	I preferred it as a group ( <i>P20, 49 years, 10 years post-injury</i> ) A groups better because you're getting it from other people that have got brain injuries so it's all together ( <i>P13, 43 years, 2 years post-injury</i> )	Group dynamics/fit, emotional reaction, sharing, group size, other
	Project experience	I liked the video. I thought there were lots of things that were good ( <i>P18, 59 years, 4 years post-injury</i> ) I think the project start was a big thing. We didn't even know what the project is and suddenly one day I just had a, came up with the idea of 'better future', the other members agreed with that ( <i>P12, 36 years, 4 years post-injury</i> )	Project motivation, emotional reaction, project end product, sense of achievement, other
	Working on goals	I thought the setting of the goals was good thing to get some goals set out ( <i>P12, 36 years, 4 years post-injury</i> ) having the text reminders has made the idea of being in control of the conversation become more important to me so then I start think about different questions to ask them and stuff to keep the conversations going ( <i>P16, 27 years, 5 years post-injury</i> )	Texting, reminders (memory and goal), goal setting

BENEFIT OF TREATMENT	Communicative benefit	it helped me firstly to see where I still had areas of improvement in my conversational skills and expressing myself um... which I knew there were problems but I couldn't pinpoint them and no-one's ever been able to bring them up before um... and I think part of it would be able to see it for myself, that was the big thing ( <i>P6, 42 years, 11 years post-injury</i> )	Increased awareness, increased communication skills
	Other benefits	Concentration levels a bit better from the start. It's given me more positive outlook which helps me to concentrate. I can sit down and read something and get more out of it ( <i>P12, 36 years, 4 years post-injury</i> )	Awareness of self, awareness of cognition
	Emotional effects Meeting others	the whole of me feels more uplifted which is really really good. I just feel so much uplifted ( <i>P21, 39 years, 3 years post-injury</i> )	
	Something to do	Getting on the bus on my own and going into various shops that I wanted to go in ( <i>P11, 59 years, 38 years post-injury</i> )	

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## **Treatment experience**

*Treatment experience* comprised four sub-themes, and the first refers to the general experience of the treatment, with no specific reference to the group, project, or working on goals, which are discussed separately. Nearly every participant commented on the general treatment experience, and the majority of the responses were positive. A minority had less positive initial comments, which were specifically linked to their views of benefit from earlier sessions:

*I actually thought it was a bit childish to start with....and I couldn't see it going anywhere cause you said you wanted to put it on YouTube which probably to everyone else is a video but works of art, whose going to want to look at them. You're not going to get anything across on that (P10, 42 years, 8 years post-injury)*

A few participants suggested some minor changes for reasons of fatigue:

*I'd say the length of the sessions. Personally, it was a bit long, two hours (P12, 36 years, 4 years post-injury)*

Half the sample indicated that the value of treatment emerged over time, and evolved from negative to positive, mainly across sessions, and on occasion within sessions.

Participants spoke about being initially nervous and worried about what the treatment entailed and whom they would be working in the group. As the treatment progressed, their perceptions became more positive and they started to see the value of what they were doing. Change was also reported within sessions.

*When it was first talked about I thought is it going to be another one of this funny wonders but as the weeks progressed and I could feel that we were making progress and I thought it was all worthwhile (P17, 61 years, 34 years post-injury)*

*Because I turned up more or less every time, I felt I was really fed up but by the end of the session, I felt alright. So, that was important for me (P11, 59 years, 38 years post-injury)*

The second sub-theme in *treatment experience* was that of the group experience, and dynamics and fit of group members, which was most commonly reported. Participants reported that to work, a group needs the right mix of people:

*The right mixture of people. Without that you haven't got it so if there was one thing, it was the mixture of people, that was the thing that did it (P19, 57 years, 11 years post-injury)*

*[name of group member] is a nice guy and I like him but he is not the sort of person I would have chosen to socialise with (P17, 61 years, 34 years post-injury)*

The group did not need to be friends, but there needed to be trust, and equal understanding of each other's abilities to work. Groups were perceived to have worked well because people could openly discuss and share ideas, talk to each other, and bring a range of opinions and abilities together. Although some participants expressed frustration about others in the group:

*seeing how my gifts and abilities could be used as well as intermingle them with other people's cause we all have different ones so bring them together (P6, 42 years, 11 years post-injury)*

*His pace was very, he wanted to do things very slowly. What I think is slow. Um, so sometimes there were a couple of time where I thought Jesus (P18, 59 years, 4 years post-injury)*

Many participants particularly valued the group component of the intervention with a preference for group treatment however, some participants noted particular challenges in meeting others:

*Quite difficult. It was a challenge meeting the other group members and finding out what their strengths and weaknesses were (P12, 36 years, 4 years post-injury)*

The group gave many participants an opportunity to share their experiences, ideas, and problems within the group. Through doing this, participants would receive feedback from each other or the therapist that was accepted positively thus, contributing to feeling a sense of belonging. This meant participants felt equal to one another, safe, supported, and not judged by others, which enabled them to use the group context to communicate with each other, and practise, and rehearse the use of their individual communication goals.

*our little group we were all sharing and talking and supporting each other (P10, 42 years, 8 years post-injury)*

*I was hoping we would put more spirituality side of things into it but we didn't get to that...[we] tended to stray away from it as I knew [name of group member] wasn't too keen on getting into that side of things which is a shame as it may have helped her develop her views (P12, 36 years, 4 years post-injury)*

Half the sample commented upon group size, noted that a group of 2-3 people in the treatment was sufficient. A smaller number of participants suggested that the treatment could have worked with a slightly larger group, but no more than five people, acknowledging the

difficulties that could arise from larger groups. A few participants commented on the intensity of sessions (i.e. no more than twice a week), and structure (i.e. same venue, break in the middle) to also be sufficient.

*different opinions might be hard to get the goal done. People with different ideas...I think it were quite difficult when certain members kept trying to alter things part-way through. Like adding extra pictures or they didn't like the text and that was, could have resulted in slowing down the process (P12, 36 years, 4 years post-injury)*

The third sub-theme in *treatment experience* relates to participants experiences of engaging in the project treatment activities and included the project motivation, emotions experienced, the tangible end product and sense of achievement. Motivation behind the project featured here, and each group chose a different project to do, such as a pamphlet, educational video, podcast, and artwork. For each, there was a strong sense of helping others, whether that was to help people who had sustained a similar injury, or to increase awareness of brain injury to the general public. One participant explicitly engaged in the project, and the treatment, for the sole reason of *helping others* in the group. Over half of participants described feelings on project involvement many of which were positive but there were several participants who raised concerns:

*It was challenging (P9, 61 years, 15 years post-injury)*

One important aspect of the project experience included the creation of an end product, which was commented upon by a third of participants. The project idea and product needed a focus that united group members and was a tangible outcome.

*To start with I thought, “ohhhh, I can’t do this!” but actually it was really good to have something to get your teeth into and to actually see something at the end of it, the fruits of your work really (P6, 42 years, 11 years post-injury)*

A strong sense of satisfaction and achievement was gained from completing the project and seeing the end product and was commented upon by third of participants. Most reported being proud, surprised, happy, and rewarded with what they had accomplished. For one participant, his sense of achievement arose from witnessing the reactions of others, not involved in the project:

*Once we had them up on the wall and that old lady came in and just, “I had that”, tears flowing and I was just like gobsmacked. Driving home literally I was thinking we’ve created a monster. If this goes out there and we get reactions like that from people, it’s going to work. Brilliant. Over the moon. If I could have, I would have jumped for joy (P10, 42 years, 8 years post-injury)*

In addition, other categories to emerge related to the project experience included, doing project tasks and the need for structure. Tasks that needed to be done as part of the project included filming and editing the video, finding and printing pictures, or cutting and pasting pictures from the internet into the pamphlet. Some of these tasks were identified as enjoyable and motivating. Having a structure to the sessions was equally important for a few participants. Elements such as the traffic light system to help with problem solving, making a plan at the beginning of each session, creating a list of actions for the following session, and simply keeping a similar structure to each session, help participants anticipate, and feel comfortable with what would happen within sessions.

*The traffic light thing you had was good for us all in case we all went a step too far (P9, 61 years, 15 years post-injury)*

The fourth, and final sub-theme of *treatment experience* was working on goals, and included texting, reminders, and the goal setting process. Each participant received a daily text message to remind them of their communication goal, which were predominantly impairment-based. For example, “try and give more extended responses in conversation” and “make sure the topic you are talking about is interesting to the other person and makes sense”. Therefore, participant’s comments about text messaging (of goals) featured strongly, without any specific reference to their purpose, or content. Participants mainly used positive language (e.g. good, fine, pleased) to describe their experiences of the text-messages. Most comments were positive but one participant found the daily text messages annoying, and this was related to the high frequency of text messages, each day of the treatment.

Half of the group found the text messages to be useful reminders, without any specific reference to their goals or homework tasks. Interestingly, the way participants responded to the text was different; some would take the time to read the text on every occasion, while others could recall the text without reading it:

*It was very handy the texts that you kept sending me to the point that I was remembering them and I didn't have to go to the text to look and see what I have to do (P10, 42 years, 8 years post-injury)*

About a third of the group specifically commented on the text, as being a reminder of their individual communication goal. Participants described how the text had a significant impact on how they perceived and acted towards their own goal. Moreover, a few participants commented on how the texts were a useful reminder to their communication partner, who would then prompt the person with ABI about their goal.

*you might have done a good thing there cause even though you sent it to me each day you sent it to [name daughter] and [name second daughter]. I think every time and I think that got to me in a way, they're asking me, "did you get your message? What did it say sort of thing?", it's like reminding me (P2, 49 years, 5 years post-injury)*

A third of the group made positive comments about goal setting, and working on goals, separate to comments relating to text messaging. A few participants spoke about the role of videotaping to help build communicative awareness, which led to the identification of a communication goal. However, videotaping should be timed appropriately for the person with ABI, and not done too soon after the injury. Finally, a few participants talked about goals with reference to predicting their communication performance and evaluating their goal achievement each session.

*It was very powerful for me because if you'd have sat there and told me, I probably would have thought, well, where's he coming from this or... but to see it, it really sent it deep into me to know there's no hiding from it, I can see it (P6, 42 years, 11 years post-injury)*

*I guess it gave me a goal to aim for during the session I tried to better my score I set at the start (P12, 36 years, 4 years post-injury)*

### **Benefit of treatment**

Data in this theme reflects five sub-themes of communicative benefits, other benefits, emotional effects, meeting others, and something to do. Nearly every participant reported some benefit from the treatment. Many comments related to awareness and change in skills. A review of the data revealed a clear distinction between awareness and changes in

*communication*, and awareness and changes in *other areas* (i.e. self and cognition). In some cases, participants made comments that related only to communication, and not other areas. For that reason, the findings are presented as these two sub-themes.

Almost half of the group commented that they became more aware of how they communicated with others from involvement in the treatment and cited specific changes they could make to improve their own conversations with others. Participants provided examples where they had made changes to their communication. In all cases, the changes were directly linked to a participant's individualised communication goal and led to better conversations with others. Participants also reported that their family and friends had observed the positive changes.

*Like I said with one of my friends when we went for a drive, because I'd said to him "I'm supposed to be using natural fillers", I can't actually think of anything to use as a natural filler that I'm happy to use, we had the jokes tip of the tongue and all that but it didn't flow. But natural fillers did flow. So when I came up to the word natural fillers just literally fell in place. I just went "natural filler" and he said, "ah, ok", sat back, started doing whatever he was doing and left it while I was thinking of the word then we carried on the conversation. It worked really well. And it does with my family as well (P10, 42 years, 8 years post-injury)*

The second sub-theme referred to changes of awareness and skills in areas other than communication including self and cognition. Most changes related to participants being more reflective and learning new skills. Some participants reported an increased awareness of brain injury and that people can present differently following a brain injury. Other changes they had noticed were related to cognition and included changes to planning, taking time to do tasks, improved problem solving, and concentration.

These positive changes to awareness and skills helped people to reflect on the emotional impact the treatment had on them. Half of the participants described positive feelings. A few participants described how the treatment helped to relieve them of stress or manage negative emotions such as worry or concern.

*being confident with myself and not worry about things that I shouldn't be worrying about...I think I always used to make myself worry, just silly thoughts. But now I just try not to think about things that are likely not to happen (P4, 61 years, 6 years post-injury)*

Finally, over half of the sample commented on the opportunity to meet new people, and also having something to do, as comprising benefits of treatment. Participants enjoyed meeting the others in the group, which gave them the opportunity to socialise with others. This is further illustrated that post-treatment some participants referred to other group members as friends. Others commented on how the treatment gave them an opportunity to get out and about which sometimes led to further benefits including, other projects they may be able to do in the future.

## **Discussion**

The study used qualitative data to illustrate feasibility for a communication, group, project-based treatment for people with ABI. The qualitative data provided initial preliminary insights into the participant experience of the treatment. Participants expressed satisfaction with the treatment including the group delivery method, project focus and setting of individualised goals although they also identified some challenges. A small minority did not initially appreciate the value of treatment, indicated treatment could have been shorter and quicker, and had difficulty appreciating other participants' limitations in skills. These

findings provide useful information about the treatment methods that participants perceived most acceptable.

Participants were largely satisfied with the treatment but expressed initial reservation in meeting new people and participating in a treatment where the project idea had not been formulated. Groups were chosen as they are a common delivery model for treatments involving people with ABI [13]. The majority of participants were positive about the group setting and opportunity to share their thoughts and opinions. The small numbers in each group is likely to have afforded each participant the opportunity for close relationships to develop with other group members. However, some expressed problems in managing the different opinions and pace of working of group members. Managing conflict between other group members has similarly been reported in other group treatment studies [28]. Having a skilled therapist to manage these situations is likely to be important particularly, as some of the problems may arise from the different cognitive abilities of each group member. Despite concerns about group composition, the participants did seem to connect under the common focus of a tangible end-product and a sense of altruism.

Completion of personally meaningful projects considered important in helping others were key outcomes to participants described by Ylvisaker and colleagues [18]. For some, the personal value of the treatment was not apparent from the outset but emerged as the project unfolded and participants could see its relevance in helping others. The project has the potential to help fill the desire people with ABI have to give something back, interact with others, and be involved in an activity that is meaningful [37, 38]. Therefore, the therapist has a key role in engaging and motivating participants to find meaning in the project particularly, in earlier group sessions when they are most apprehensive. Moreover, the therapist needs to facilitate a project that can be completed as a sense of satisfaction and achievement by participants was most likely derived from the fact that they completed the project

independently. More practical challenges raised by participants related to the length of sessions being too long and pace too slow which is consistent with other treatment studies involving people with ABI where fatigue may be an issue [26, 28]. Sessions need to accommodate the range of cognitive abilities of participants so future considerations may include dividing the group to focus on different tasks that suit each of their abilities or providing individual sessions to support participants with more significant cognitive impairments.

Participants discussed the aspect of goal setting and in particular text messaging, which prompted goal recall [39]. Some participants commented on the excessive text messages about goals, which were sent daily in the morning. Suggestions to manage texts would be to send them on alternate days and/or at random times during the day. The role of videotaping and watching conversations was reported by one participant as a potentially confronting experience particularly, in the early stages post-injury. However, this experience is likely to be related to a person's level of awareness, and would need to be managed accordingly [40]. Impaired self-awareness has previously been reported as a challenge in treatment studies [41] though videotaping has a role in improving self-awareness [42] as does a multi-faceted goal setting process which was employed in this study [43].

This study based the assessment of acceptability on how suitable and satisfying the treatment was to participants [24], derived solely from post-treatment interviews. Recently, Sekhon and colleagues [44] proposed a comprehensive framework for assessing acceptability of treatments that comprise seven components. This framework provides extensive information about the extent with which those receiving or delivering healthcare treatments consider a treatment to be acceptable, based on a range of cognitive and emotional responses from participants. The results of this paper retrospectively address four of these components (i.e. affective attitude, perceived effectiveness, burden and self-efficacy) to show

acceptability for the treatment. Other areas including ethicality, opportunity costs and intervention coherence were beyond the scope of this study, as was the ability to prospectively assess acceptability. Other indicators proposed such as enrolment rate, attrition or retention rate, uptake and adherence of treatment [45], have been addressed separately [29] as the focus of this paper was on qualitative data alone. Future feasibility and full-scale trials of this treatment would need to consider a broader range of acceptability constructs to help researchers make clearer decisions about the form, content and delivery of treatment components.

Participants described self-perceived effects that occurred from involvement in the treatment, adding to its feasibility. Most people reported improvements in their communicative ability, both in terms of awareness of how they communicated, and use of their new skills. Similar communication benefits have been reported in studies evaluating communication treatment for people with ABI, albeit of a different type of treatment [28]. Reports reflected individualised communication goals, showing that specific communication skills can be successfully targeted within a group treatment. The changes to awareness suggest that people with ABI were able to recognise and accept the implications of their difficulties and be motivated to engage in a treatment. The use of goals with involvement of communication partners has previously been described as a tool for helping to increase self-awareness [41]. Changes to self and cognition were a second benefit of the treatment. People with ABI were more reflective, developing their awareness of brain injury, and the different presentations people can have. The interviews do not reveal the mechanism that facilitated these changes, however people with ABI have previously identified that being able to compare their new and old self, and compare their recovery to others with a similar impairment, is important [46]. Potentially, the treatment facilitated this process, and contributed to a more positive sense of self, as people with ABI were emotionally influenced

by the treatment and could observe improvements in their cognitive skills. Changes to cognition most likely reflect the treatment strategies used to compensate for a person's cognitive impairments. These included, creating a things-to-do list at the beginning of each session, use of the traffic light system to solve problems, doing short structured tasks, and taking regular breaks. The comments do not indicate that the person with ABI learnt a range of strategies to help them into the future; rather, the strategies seem to have created an environment where the person with ABI was able to complete tasks and the project, as independently as possible, and this has most likely led to the perception of change. The treatment also had a positive emotional impact on people with ABI, which is likely to be connected to completing the treatment, and the sense of satisfaction, and achievement from completing the project. People with ABI were able to perceive the social benefit of being involved in the treatment, meeting others, and having something to do. These aspects are inextricably linked to the desire to socialise with others, and participate in meaningful activities, and are frequently identified as important by people with ABI in other qualitative research studies [38, 47, 48].

## **Limitations**

Findings are drawn from a small sample of participants who are a long-time post-injury, with the majority of people living independently either alone or with others (e.g. family, spouse, carer) and not receiving additional rehabilitation services. This profile limits the generalisability of the findings to people with more acute and early time post injury or to those who are more dependent on support and services. With respect to the qualitative analysis, a key limitation was the interviewer also being the assessor, and therapist. This dual role may have affected the interview as assumptions were made, which meant that there were limited opportunities for probing additional information, which would have added to our

understanding of the participant experience. Being in the role of therapist and interviewer may have led participants to respond in a socially desirable way and affect the degree of objectivity during the interview. This raises concerns about how candid participants are willing to be when providing their perceptions of the treatment including the discussion of challenging or negative issues. More positively, familiarity with the interviewer ensured that there was shared reference during interviews, which may have supported participants in detailing aspects of the treatment. We would also note that criticisms of the treatment were made, despite the risk of social compliance. Non-independent analysis of the interviews is a third limitation. To reduce bias, several interviews were coded separately by two people and then discussed, as was the final formation of themes and sub-themes, and member checking of each interview. Interviews were additionally limited in giving insights on possible initial efficacy and could have been supplemented through other data sources including feedback from communication partners. Finally, further work may benefit from inclusion of a framework such as the rehabilitation treatment specification system [49]. Such frameworks help to provide a clear description of the treatment methods needed for people with brain injury to achieve their goals [50].

## **Conclusions**

Structured interviews derived valuable information about the participant experience of the treatment, which adds to the acceptability and initial efficacy of a treatment. People with cognitive communication difficulties following ABI in this study considered the treatment, group context, project focus, and individualised texted goals acceptable. Furthermore, they reported improvements in their communication in conversation, cognitive functioning, self-awareness, emotional functioning, and social functioning (interaction and opportunities).

Three active ingredients can be extracted: negotiating a project to focus, unify and motivate;

individualised communication goals situated within group context; and daily texting of these goals as reminders promoting practice and generalisation. These findings provide positive support to complement the quantitative data of the controlled trial.

**The authors report no conflicts of interest.**

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**Supplementary Table S1.** Consolidated criteria for reporting qualitative research (COREQ)

Item No	Item	Description for current study
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal characteristics</i>		
1	<b>Interviewer/facilitator</b> Which author/s conducted the interview or focus group?	First author
2	<b>Credentials</b> What were the researcher's credentials? E.g. PhD, MD	Master's degree
3	<b>Occupation</b> What was their occupation at the time of the study?	Speech and Language Therapist
4	<b>Gender</b> Was the researcher male or female?	Male
5	<b>Experience and training</b> What experience or training did the researcher have?	Fifteen (15) years' experience in working with people with ABI. Had done a previous small-scale trial which involved qualitative interviews and had some training in qualitative research in methodology.
<i>Relationship with participants</i>		
6	<b>Relationship established</b> Was a relationship established prior to study commencement?	There was an existing relationship between interviewer and participant prior to collection of qualitative data.
7	<b>Participant knowledge of the Interviewer.</b> What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All participants knew the interviewer as the treating therapist.
8	<b>Interviewer characteristics</b> What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	The study was completed as part of the interviewers PhD research who had a belief in the benefit of project-based treatment for people with ABI
<b>Domain 2: Study design</b>		
<i>Theoretical framework</i>		
9	<b>Methodological orientation and Theory.</b> What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Content analysis
10	<b>Sampling</b> How were participants selected? e.g. purposive, convenience, consecutive, snowball	All participants involved in the treatment were interviewed. Recruitment methods to the feasibility trial are detailed in the main text.
11	<b>Method of approach</b> How were participants approached? e.g. face-to-face, telephone, mail, email	Face-to-face
12	<b>Sample size</b>	Twenty-one (21)

	How many participants were in the study?	
13	<b>Non-participation</b> How many people refused to participate or dropped out? Reasons?	No participants refused to participate or dropped out
<i>Setting</i>		
14	<b>Setting of data collection</b> Where was the data collected? e.g. home, clinic, workplace	In the persons own home or in the location of the treatment e.g. residential rehabilitation centre, day-service centre
15	<b>Presence of non-participants</b> Was anyone else present besides the participants and researchers?	No
16	<b>Description of sample</b> What are the important characteristics of the sample? e.g. demographic data, date	Presented in methods
<i>Data collection</i>		
17	<b>Interview guide</b> Were questions, prompts, guides provided by the authors? Was it pilot tested?	Structured topic guide. The guide was not pilot tested.
18	<b>Repeat interviews</b> Were repeat interviews carried out? If yes, how many?	No
19	<b>Audio/visual recording</b> Did the research use audio or visual recording to collect the data?	Video and audio-recorded
20	<b>Field notes</b> Were field notes made during and/or after the interview or focus group?	No
21	<b>Duration</b> What was the duration of the interviews or focus group?	Average of 17 minutes (range 10-25 minutes)
22	<b>Data saturation</b> Was data saturation discussed?	No
23	<b>Transcripts returned</b> Were transcripts returned to participants for comment and/or correction?	Yes they were posted to all participants and discussed face-to-face at a follow-up appointment 6-8 weeks after the collection of the data.
<b>Domain 3: Analysis and findings</b>		
<i>Data analysis</i>		
24	<b>Number of data coders</b> How many data coders coded the data?	One – first author
25	<b>Description of the coding tree</b> Did authors provide a description of the coding tree?	Yes, partially evident in Table 1
26	<b>Derivation of themes</b> Were themes identified in advance or derived from the data?	Themes were derived from the data
27	<b>Software</b> What software, if applicable, was used to manage the data?	NVivo, version 12.
28	<b>Participant checking</b> Did participants provide feedback on the findings?	No

<i>Reporting</i>		
29	<b>Quotations presented</b> Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes
30	<b>Data and findings consistent</b> Was there consistency between the data presented and the findings?	Yes
31	<b>Clarity of major themes</b> Were major themes clearly presented in the findings?	Yes
32	<b>Clarity of minor themes</b> Is there a description of diverse cases or discussion of minor themes?	Yes

## **Supplementary Table S2. Topic guide**

### **Opening probe question**

Your experiences with the treatment are important to us. We'd like to know more about your opinion on how it has been to participate in the treatment. We'll start with a very general question.... Tell me about your experiences with...

1. The treatment
2. Coming to the group
3. Doing the project (tasks)

### **Other topic probes if not covered (goals, texting, benefits of treatment)**

- What were your impressions of...?
- How do you feel about...?
- You've talked about X, tell me about...

### **To pull out change**

- Can you compare that to before the treatment/now?
- Can you provide some examples?

### **Clarifying/checking questions (only using yes/no questions)**

- So do you mean.....?
- Are you saying....
- It sounds like...

### **Improvements to program**

If we revised the program, what would you like to keep?

And what would you like to change?

### **Assessment process**

What are your thoughts about the assessments and questionnaires we did?

### **Probes**

- Which ones seemed to make most sense to you when you did them?
- Did it help explain what changed from the treatment?
- What was still a problem?

### **Finalise discussion**

Is there anything else you want to raise?

### **Check back**

So overall what you're saying is...am I understanding that correctly?