

**Optimising communication function in primary brain tumour: A randomised controlled trial of
CanCommunicate**

Running head: CanCommunicate

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Abstract

Purpose: To evaluate the efficacy of CanCommunicate for improving perceived communication disability and quality of life in people with brain tumour, compared to usual care.

Materials & Methods: A randomised trial with a waitlist control was used. Participants were randomised to CanCommunicate (immediate intervention) or a wait list (control). CanCommunicate involved a 7-week communication intervention guided by Goal Attainment Scaling with group and individualised sessions. Participants completed the Comprehensive Aphasia Test Disability Questionnaire (CAT DQ), Functional Assessment of Cancer Therapy - General (FACT-G), La Trobe Communication questionnaire (LCQ) and semi-structured interviews at baseline and post-intervention.

Results: 39 people participated (Immediate intervention n=24, waitlist n=15). There was a significant between-group difference on the CAT DQ over time ($p = 0.04$) in favour of the intervention group, but not for the LCQ ($p = 0.58$) or FACT-G ($p = 0.80$). When data were combined for all participants who completed CanCommunicate (n=23), ratings were significantly improved on the CAT-DQ ($p < 0.001$) and LCQ ($p = 0.04$) at 6-week follow-up. Participants perceived CanCommunicate favourably and made suggestions for further optimisation.

Conclusion: The current study supports the benefits of communication intervention for people with brain tumour and reinforces the need for tailored, goal-based interventions.

Keywords: glioma; brain tumour; communication; quality of life; goal attainment scaling

Introduction

Over two thirds of people with a brain tumour experience some form of communication change (Brownsett et al., 2019). These communication changes can originate from the tumour itself or treatment(s), with changes observed both pre- and post-resection (Davie et al., 2009). These changes can span multiple elements of communication, including impaired word finding (Brownsett et al., 2019; Davie et al., 2009), reading comprehension and written expression (Brownsett et al., 2019), motor speech difficulties (Åke et al., 2023; Palmisciano et al., 2022), and increased effort for communication in general (Åke et al., 2023). Such difficulties can persist, with Åke and colleagues (2023) finding that people with a brain tumour reported enduring communication changes 3-5 years after surgery. Given the negative impact of communication difficulties on social participation and Quality of Life (QoL) (Rimmer et al., 2023), it is critical that communication changes in the context of brain tumour are identified and managed with support also provided to the family and caregivers.

Speech pathologists play a crucial role in supporting communication skills in people with a range of neurological conditions. Despite the increasing knowledge of communication changes associated with a brain tumour (Åke et al., 2023; Brownsett et al., 2019), there is limited evidence for speech pathology interventions for this patient population, either within remediation or compensatory approaches. Thus far, the limited communication treatments designed specifically for people with a brain tumour have been investigated largely by single case studies and case series designs. Existing research in this field has focused on aphasia (e.g., Jacobs, 2001; Milman et al., 2020; van Rij et al., 2021), high level language impairment (e.g., Lo Buono et al., 2016), dysarthria (e.g., Sherman et al., 2005), and social communication difficulties (e.g., Hassler et al., 2010; Rao & Bieliauskas, 1983; Whiting et al., 2012), typically at the pilot, feasibility phase without outcomes for efficacy. Only three studies have used more methodologically rigorous approaches such as Single Case Experimental Design (SCED) (Hassler et al., 2010; Milman et al., 2020; Whiting et al., 2012). Due

to the predominantly case-level focus of existing research, it is unknown whether these communication interventions are applicable to the wider brain tumour population.

A small additional body of literature has included a communication training element as a component of a multidisciplinary intervention, such as Sherer et al. (1997) and Shahpar et al. (2018), who provided speech pathology intervention as part of a multidisciplinary outpatient rehabilitation program. However, the evaluation of communication outcomes in these studies is typically hindered by the use of global indices of functioning or multidisciplinary measures (such as productivity and independence in Sherer et al., (1997)) to evaluate the effects of the intervention, rather than communication-related measures.

Recent research suggests that not only is there a lack of evidence-based communication interventions for people with brain tumour, but access to speech pathology services is poor due to lack of routine referral pathways, transport and geographical distance issues. Halkett et al. (2022) found that only 28% of people diagnosed with a high grade brain tumour living in Australia received routine referral to a speech pathologist. Given the limited evidence base to guide the management of people with communication difficulties arising from brain tumour, and the lack of access to services, there is an urgent need to develop a comprehensive and feasible to access communication intervention for people with a brain tumour and their families. Our research team has previously developed and piloted a novel intervention (“CanCommunicate”) for people with communication difficulties following brain tumour (Finch et al., under review).

The development of CanCommunicate was guided by the Medical Research Council’s (MRC; UK) best practice approach for developing complex healthcare interventions (Craig et al., 2008). The content and structure of CanCommunicate was informed by existing clinical guidelines for other neurological populations (INCOG 2.0 Cognitive Communication and Social Cognition disorders, (Togher et al., 2023); Clinical Guidelines for Stroke Management (Stroke Foundation, 2020)); a chart audit of communication management for people with a brain tumour; interviews of people with a

brain tumour and their significant others about communication difficulties experienced, services received, and their ideal communication service; and a consumer advisory group comprising two spouses and one person with a brain tumour (Finch et al., under review). The draft intervention was also reviewed by four clinical speech pathologists (stakeholders). The intervention was designed to be person-centred, goal-based and accessible through either in-person or through telehealth delivery (with the delivery mode designed to be dependent on participant preference given the need for flexibility in light of participants' medical diagnosis and management). The feasibility of CanCommunicate as a 7-week intervention involving group education and individual sessions was supported by pilot research (Finch et al., under review) which explored the acceptability, demand, implementation, practicality and initial efficiency (based on self-report measures and an interview). Over the 2.5 month recruitment period (shortened due to COVID-19 pandemic impacts), 17 participants were referred to the pilot study, with four people consenting and two participating in the intervention. The current project represented the third phase in intervention development (assessing efficacy).

Primary aims:

This randomised controlled trial with waitlist control had two primary aims and corresponding outcome measures:

- 1) To evaluate the efficacy of CanCommunicate plus usual care in improving perceived communication disability¹ (i.e., the everyday functional impacts of communication changes) in

¹ Disability was defined using the World Health Organisation definition of "an umbrella term for impairments, activity limitations and participation restrictions" World Health Organisation. (2002). *Towards a Common Language for Functioning, Disability and Health (ICF)*. WHO/EIP/GPE/CAS/01.3. https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4&download=true

people with a brain tumour, compared to usual care only, immediately post intervention and at 6-week follow-up.

2) To evaluate the efficacy of CanCommunicate in improving QoL in people with a brain tumour compared to usual care at post-intervention and 6-week follow-up.

Secondary aims:

1) To determine whether CanCommunicate reduces perceived communication difficulties (i.e., actual changes in communication) in people with brain tumour compared to usual care at post-intervention and 6-week follow-up.

2) To explore the perceptions of people with brain tumour about CanCommunicate.

Hypotheses

CanCommunicate will result in reduced perceived communication disability and difficulty, and improved self-rated health-related QoL compared to usual care.

Methods

Study design

A randomised controlled trial with a waitlist and a 1:1 allocation ratio was used to evaluate CanCommunicate compared to usual care. A waitlist control was used so that the control group still received the intervention (albeit delayed) as the intervention had been piloted and presumed to be beneficial, and therefore it was considered unethical for the control group to miss out on the intervention. Manuscript reporting was guided by the updated 2025 Consolidated Standards of

Reporting Trials (CONSORT) (Hopewell et al., 2025) and Template for Intervention Description and Replication (TIDiER) (Hoffmann et al., 2014) guidelines. The trial was prospectively registered with the Australian New Zealand Clinical Trials Registry (ANZCTR) (Trial registration number: ACTRN12623000039684; date registered: 13 January 2023).

Setting

The study was initially commenced at a single quaternary, metropolitan hospital in South-East Queensland, Australia (Recruitment occurred November, 2023 – June, 2024). Due to COVID-19 pandemic associated impacts on recruitment (resulting in a delayed trial start), recruitment was expanded mid-trial (March, 2024) to include a second quaternary, metropolitan hospital in South-East Queensland, Australia to maximise the recruitment rate.

Participants

The inclusion criteria were: aged 18 years or older; a diagnosis of primary brain tumour (including benign, lower-grade glioma and higher-grade glioma); being post-initial tumour treatment; perceived or objective communication difficulties as per the treating speech pathologist or doctor who referred them to CanCommunicate; and were able to participate in assessment and intervention sessions (with communication support as required). All participants had functional English (i.e., language function sufficient to engage in therapy sessions and answer questions via interviews or questionnaires) guided by the referring clinicians, given the outcome measures and intervention content. Our inclusion criteria were deliberately broad to reflect the diverse types of brain tumour seen in clinical practice at the recruiting hospitals and to enhance the generalisability of the findings to the wider brain tumour population. Exclusion criteria were: comorbid substance abuse or

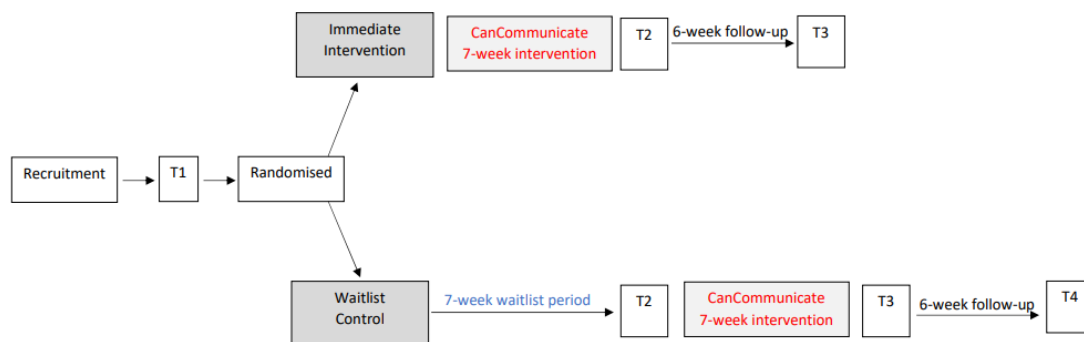
psychiatric disorder not effectively managed; or experiencing rapid deterioration in health which would limit engagement in the intervention.

Based on an anticipated minimum mean difference of 6.8 on the Comprehensive Aphasia Test (CAT) Disability Questionnaire (DQ) (Swinburn et al., 2004), a sample size of at least 70 (35 per group) would have adequate power (0.80) to detect a statistically significant result (alpha set at 0.05). To allow for 20% dropout, the target sample size was 84 participants.

Procedure

Ethical approval was obtained from the Metro South Human Research Ethics Committee (HREC/2023/QMS/92333). All potential participants were screened for eligibility, recruited, consented and assessed by a blinded research assistant, and randomised to the intervention or waitlist control. Randomisation was conducted at an individual level in blocks of 10 participants by a researcher who was not involved in the baseline and outcome assessment or intervention delivery using a computerised random number generator, with 1:1 concealed allocation to CanCommunicate or usual care. Participants then commenced CanCommunicate (immediate intervention condition) or were placed on a wait list (control condition). Intervention participants received a 7-week block of weekly, one hour, goal-based communication intervention combining group and individualised sessions. The wait list control group received usual care during the 7-week waitlist period and were then offered the intervention after the post-assessment. Participants completed the study measures in-person or via videoconferencing with a blinded assessor at initial entry into study (T1: baseline assessment, both groups), at the end of the wait list period (wait list group only), at the end of the intervention (both groups), and 6 weeks follow-up after the intervention (both groups; See Figure 1). The trial was ceased due to the completion of the funding period.

Figure 1. Flow diagram depicting the study timeline



Note. T1 = Assessment time point 1; T2 = Assessment time point 2; T3 = Assessment time point 3; T4 = Assessment time point 4

Intervention condition (CanCommunicate)

CanCommunicate had two key elements: whole-group education sessions and individual therapy sessions, which were distributed over 7 x weekly one-hour sessions. Both elements were delivered by a qualified speech pathologist. Based on interviews from pilot study and feedback from the consumer advisory group, the intervention was designed to be delivered via telehealth or face-to-face format dependent on individual participant preferences. In the current trial, all group sessions were delivered via telehealth using Microsoft Teams with visual information shared using Microsoft Powerpoint. The individual sessions were a mix of face-to-face, telehealth via Microsoft Teams or via phone; based on participant preference (with access the main reason for participants choosing to attend via telehealth). Participants who preferred to attend via telehealth but who were not independent with or did not have access to the necessary technological equipment were encouraged to seek assistance from family/friends and/or travel to their local hospital (non-metropolitan participants) to use their telehealth services. Informal technical support was provided by the treating speech pathologist (a qualified speech pathologist experienced in telehealth therapy delivery). If technical issues arose that could not be resolved, the telehealth session was converted to a phone call. The communication supports used during the sessions included using familiar items in the

participant's environment (for example, their own photo book for aphasia therapy to increase engagement), Microsoft word and/or screen sharing to provide written/pictorial cues, support from neighbours/ family, and posting hard copies of therapy materials prior to sessions or asking the participant to print intervention tasks in preparation for virtual sessions.

The structure of CanCommunicate is presented in Figure 2.

- The first two **group education sessions** explored the concepts of language and communication, common language changes with a brain tumour, and effective communication strategies, targeting both the needs of family/friends and the person with the brain tumour to support and optimize their communication.
- The four **individual sessions** were driven by each participant's individual goals and were conducted after the first two group sessions – this timing was selected so that participants had some general knowledge about communication, communication changes with a brain tumour, and general communication strategies prior to starting the individual, goal-based sessions. Goal Attainment Scaling- Light (GAS-Light) as described by Turner-Stokes (2009) was used to identify and specify goals that were person-centred and meaningful to participants prior to their therapy, and to make the goals specific to enable review of and reflection on progress by participants over time, in keeping with goal setting practice in rehabilitation. Consequently, due to the person-centred, goal-directed focus, the intervention components were tailored to/applied to the person's goals during individual sessions. Supplementary online material 1 provides a summary of areas covered during the individual sessions. Activities included a combination of functional tasks involving strategy training and practice (such as work-specific tasks, organising a holiday, planning a meal), impairment-based tasks (such as word finding activities and deduction puzzles), formal and informal assessment (to provide a detailed measure and feedback of the participant's communication function), and education (such as communication partner training, education

about word finding difficulties). Homework tasks were frequently provided. Each session lasted for approximately one hour and occurred either via telehealth or face-to-face at an allied health research centre near the hospital campus (depending on the participant's preference).

- The final (third) group session focused on **skill generalisation and maintenance** of skills in daily life. Each group session, conducted via telehealth, lasted approximately one hour, including information provision and discussion/questions.

More information about the intervention is provided in supplementary online material 4. The CanCommunicate intervention manual is available here: osf.io/sqx59

Figure 2. Overarching structure of the CanCommunicate sessions

Group sessions (2 x 1 hour)	Individual sessions (4 x 1 hour)	Final session (1 x 1 hour)
• 1: What is communication + changes with a brain tumour • 2: Communication strategies	• 3: Goal setting • 4-6: Individual therapy	• 7: (Group or individual) generalisation, consolidation and planning for maintenance

Usual Care Waitlist control condition

Participants on the waitlist received the usual medical and speech pathology care provided to people with brain tumour at the recruiting hospitals. At the first hospital, in terms of speech pathology management, people with a brain tumour may receive a brief communication screen on a single occasion with a speech pathologist while in hospital following their acute surgical management or as an outpatient while receiving radiation therapy, with typically no or limited subsequent therapy or referral to other services if impairments are detected. A limited number of individuals with identified

communication difficulties receive a block of inpatient or outpatient rehabilitation as part of a multidisciplinary management program. At the second hospital, people with a brain tumour received an inpatient speech pathology assessment to determine their communication functioning to guide discharge planning and referral to other/community services. Patient and family education would also be provided regarding current communication, strategies to support/optimize functioning, with no outpatient rehabilitation service model.

Research outcome measures

Due to the typically progressive nature of brain tumour, the research team decided to focus on activity/participation and QoL measures for the primary outcomes, given the likelihood of deterioration on impairment-based measures due to tumour progression during the course of the research. All outcome measures were administered via telehealth (Microsoft Teams or phone), or in person, dependent on participant preference, by a blinded assessor not involved in delivering CanCommunicate. The blinded assessor was a speech pathologist with extensive clinical experience managing people with a brain tumour and previous clinical research experience. The total assessment session time was approximately one hour. If needed, based on participant availability and fatigue levels, each assessment session was split into two shorter sessions.

Primary outcome measure:

1. *Comprehensive Aphasia Test (CAT) Disability Questionnaire (DQ)*: A measure of communication disability (i.e., the everyday impacts of communication changes). The DQ explored the impact of individuals' communication difficulties on their everyday life, self-image and consequences of aphasia (Howard et al., 2010). The DQ has demonstrated sound inter-rater reliability ($r = 0.99$) and test-retest reliability ($r = 0.98$) (Swinburn et al., 2004). Higher scores denote that the participant

perceives more communication disability. CAT raw scores can be converted to T scores with a mean of 50 and a standard deviation of 10.

Secondary measures:

1. *Functional Assessment of Cancer Therapy - General (FACT-G)*: A 27 item health related QOL questionnaire developed to measure physical, social, emotional, and functional well-being in people with cancer (FACIT.org, 2007). The FACT-G has excellent reliability ($r = 0.82 - 0.92$) and sensitivity to change ($p = 0.002$) (Cella et al., 1993). Higher scores on the FACT-G denote better QoL.

2. *La Trobe Communication Questionnaire (LCQ)*: A measure of perceived communication difficulties used to explore perceptions of everyday interactions and the perspectives of the person with brain tumour. The LCQ was designed for people with acquired brain injury, reflecting the most common and distressing communication difficulties. The 30-item questionnaire explores perceived communication difficulties using a scale of 1 (never/rarely) to 4 (usually/always). The LCQ has high internal consistency and stability of ratings over time, and normative data for younger adults (Douglas et al., 2000). Higher scores denote more self-perceived communication difficulties.

3. *Qualitative Semi-Structured Interview*: Conducted with the blinded assessor to explore perceptions of the intervention (Note. The blinded assessor was unblinded at the end of the post-intervention assessment session (after the other study measures had been completed) as this determined whether they proceeded to the interview to explore perceptions towards CanCommunicate). Each interview, completed at baseline and post intervention, lasted approximately 30 minutes and explored current communication function, communication changes noticed, and perceptions of CanCommunicate (post-intervention only). The interview guide is provided in supplementary online material 2. The interviews were conducted online using Microsoft Teams or in person. Interviews were recorded via Microsoft Teams to allow automated transcription.

4. *Demographic information*: Obtained from the patient's medical chart and self-report and included age, gender, tumour location and grade, and treatment.

Data analysis

Quantitative analyses were conducted by members of the research team blinded to group allocation and not involved in delivering the intervention. The data were initially screened for missing values on the CAT DQ, FACT-G and LCQ. Baseline values were compared between participants with and without missing outcome values, and no differences were found between the groups. To manage participant attrition, the intention-to-treat principle was applied, and analyses were conducted according to participants' initial group allocation. Missing data were handled by the available case analysis approach described by Pigott (2001) (i.e., missing data were not substituted).

Three sets of statistical analyses were conducted. First, the demographic and baseline characteristics of the immediate intervention and waitlist control groups were compared using paired samples t-tests with frequencies (counts, percentages) and means (standard deviations, SD), as appropriate. Second, mixed-effects regression models were used to estimate the effect of the intervention on the outcomes. These models were chosen because they account for repeated outcome measures in the pre-intervention and post-intervention periods. Each model (one for each outcome) controlled for the same covariates, including tumour grade and receipt of radiation therapy, which were not balanced between the early intervention and waitlist control groups after randomisation. Third, paired t-tests were conducted for each of the three outcomes. The Shapiro-Wilk normality test was used to determine the suitability of the parametric paired t-tests. The t-tests compared outcomes in the pre-intervention period and the 6-week follow-up after the intervention for all individuals who received the intervention, regardless of their group. Hedges' g was used to estimate effect sizes. For all the quantitative data analyses, a p -value of <0.05 was considered

statistically significant. All statistical analyses were performed in R software (version 4.2.2, R Foundation for Statistical Computing, Vienna, Austria).

In terms of the qualitative data, interview transcripts were analysed using inductive thematic analysis (Braun & Clarke, 2006) to identify key themes within the data related to participants' perceptions of the intervention. The analysis process involved one member of the research team (EF) repeatedly reviewing the transcripts and generating codes (with each code representing a group of words with a shared meaning of interest). Codes were then grouped together to form themes and subthemes. Themes and subthemes were iteratively reviewed in relation to the transcripts and modified as needed to better reflect the transcripts. To ensure rigour, the themes and subthemes were checked by a second member of the research team (EK). Field notes were taken during the interviews by EK, and an audit trail was kept during the analysis process. A content analysis of GAS-Light goal statements was conducted to describe and categorise goal areas using the qualitative content analysis process described by Graneheim and Lundman (2004). This process involved one member of the research team (EF) identifying the key focus of each goal statement (i.e., identifying meaning units) and then labelling each meaning unit with a code. Related codes were then grouped together to form categories and subcategories. Microsoft Excel was used for the qualitative analysis process.

Results

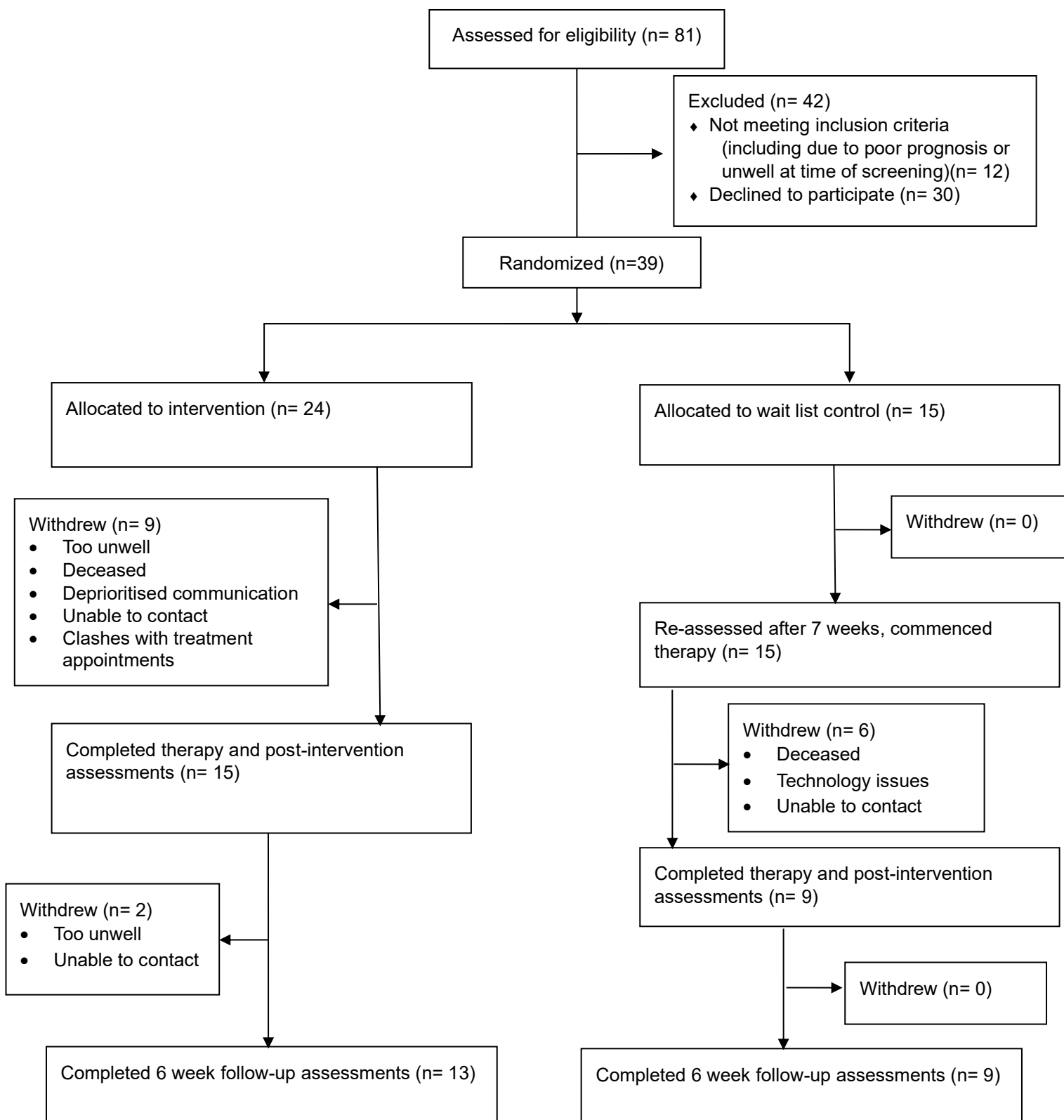
Participant flow

The participant recruitment flow is presented in Figure 3. Eighty-one participants were referred to the study, with 42 excluded (including declining to participate or not meeting the inclusion criteria, including experiencing brain metastases and poor prognosis at the time of screening). Frequent reasons for declining study participation included having no self-perceived communication difficulties (contrary to health professional identification of communication difficulties and referral to the study) and experiencing rapid functional decline due to the tumour. Differential attrition led to thirty-nine

participants randomised to either the immediate intervention (n = 24) or the wait list control (n =15) group. Frequent reasons for study withdrawal included health decline due to tumour progression, death, and being unable to be contacted.

Figure 3. Participant recruitment flow diagram

Participant Flow Diagram



In total, 39 people with a primary brain tumour participated in CanCommunicate. Overall, the mean age was 55.10 years (standard deviation = 13.77), with 21 females and 18 males. In terms of medical management, 38 had undergone surgical resection, 29 had received radiation therapy, and 26 had received chemotherapy. Over half of participants (62%) had been diagnosed with a high-grade glioma. Following randomisation, 24 participants were allocated to the immediate intervention group and 15 were allocated to the waitlist control group. Table 1 compares the demographic and baseline characteristics of the two groups. There were no statistically significant differences between the two groups according to age, gender, tumour side, tumour location, or surgical or chemotherapy management (all $p > .05$). However, there was a statistically significant difference between the two groups according to the tumour grade and use of radiation therapy. Approximately 79 of participants in the immediate intervention group had higher tumour grades (WHO Grades 3 & 4), compared to 33.4% in the waitlist control group. Additionally, 87.5% of participants in the immediate intervention group received radiation therapy, compared to 53.3% in the waitlist control group (see Table 1). In terms of other speech pathology services, one participant in the immediate intervention group (BT12) received radiation oncology speech pathology services (focusing on dysphagia and radiation therapy side effects) while attending group sessions with their carer and then withdrew from the study. In the waitlist control group BT19 received speech pathology services from another organisation but was discharged prior to starting CanCommunicate, and one participant (BT29) withdrew from another speech pathology service due to fatigue prior to CanCommunicate; demonstrating a low frequency of intervention in this population.

Table 1. Baseline characteristics by intervention group

Characteristic	Waitlist control (n = 15)	Immediate intervention (n = 24)	P-value
Age (mean (SD))	53.87 (14.71)	55.88 (13.42)	0.664
Age group (%)			
25 – 44	5 (33.3)	4 (16.7)	0.362
45 – 64	5 (33.3)	13 (54.2)	
65+	5 (33.3)	7 (29.2)	
Sex (%)			
Female	11 (73.3)	10 (41.7)	0.110
Male	4 (26.7)	14 (58.3)	
Tumour side (%)			
Left	11 (73.3)	15 (62.5)	0.262
Right	3 (20.0)	9 (37.5)	
Missing	1 (6.7)	0 (0.0)	
Location (%)			
Frontal	6 (40.0)	11 (45.8)	0.360
Frontoparietal	0 (0.0)	2 (8.3)	
Frontotemporal	2 (13.3)	1 (4.2)	
Occipital	1 (6.7)	1 (4.2)	
Parasagittal	1 (6.7)	0 (0.0)	
Parietal	0 (0.0)	1 (4.2)	
Temporal	3 (20.0)	7 (29.2)	
Temporoparietal	0 (0.0)	1 (4.2)	
Missing	2 (13.3)	0 (0.0)	
Tumour grade (%) [#]			
WHO Grade 1	1 (6.7)	0 (0.0)	0.048
WHO Grade 2	6 (40.0)	2 (8.3)	
WHO Grade 3	1 (6.7)	4 (16.7)	
WHO Grade 4	4 (26.7)	15 (62.5)	
Missing	3 (20.0)	3 (12.5)	
Surgery (%)			
N	0 (0.0)	1 (4.2)	1.000
Y	15 (100.0)	23 (95.8)	
Radiation therapy (%)			
N	7 (46.7)	3 (12.5)	0.045
Y	8 (53.3)	21 (87.5)	
Chemotherapy (%)			
N	8 (53.3)	5 (20.8)	0.081
Y	7 (46.7)	19 (79.2)	

Note. WHO = World Health Organisation; Y = Yes; N = No; # = With benign tumours encompassing

schwannomas and meningiomas WHO Grade 1; lower-grade gliomas encompassing all WHO Grade 2

tumours and IDH (isocitrate dehydrogenase) mutant WHO Grade 3 tumours; and higher-grade gliomas encompassing IDH wild type WHO Grade 3 tumours and all WHO Grade 4 tumours.

In terms of CanCommunicate session attendance, for participants who participated in the intervention regardless of their allocated group, the following attendance data were recorded:

Attended the two initial group education sessions (2 sessions: $n = 17$, 1 group: $n = 7$, 0 groups: $n = 5$), attended the 4 individual sessions (4 sessions: $n = 10$, 3 sessions: $n = 7$, 2 sessions: $n = 5$, 1 session: $n = 4$), and the final session (group: $n = 12$, individual: $n = 8$). Reasons for lack of attendance included being medically unwell, work commitments, medical and other health professional appointments, the patient forgetting, and technological issues.

Quantitative data

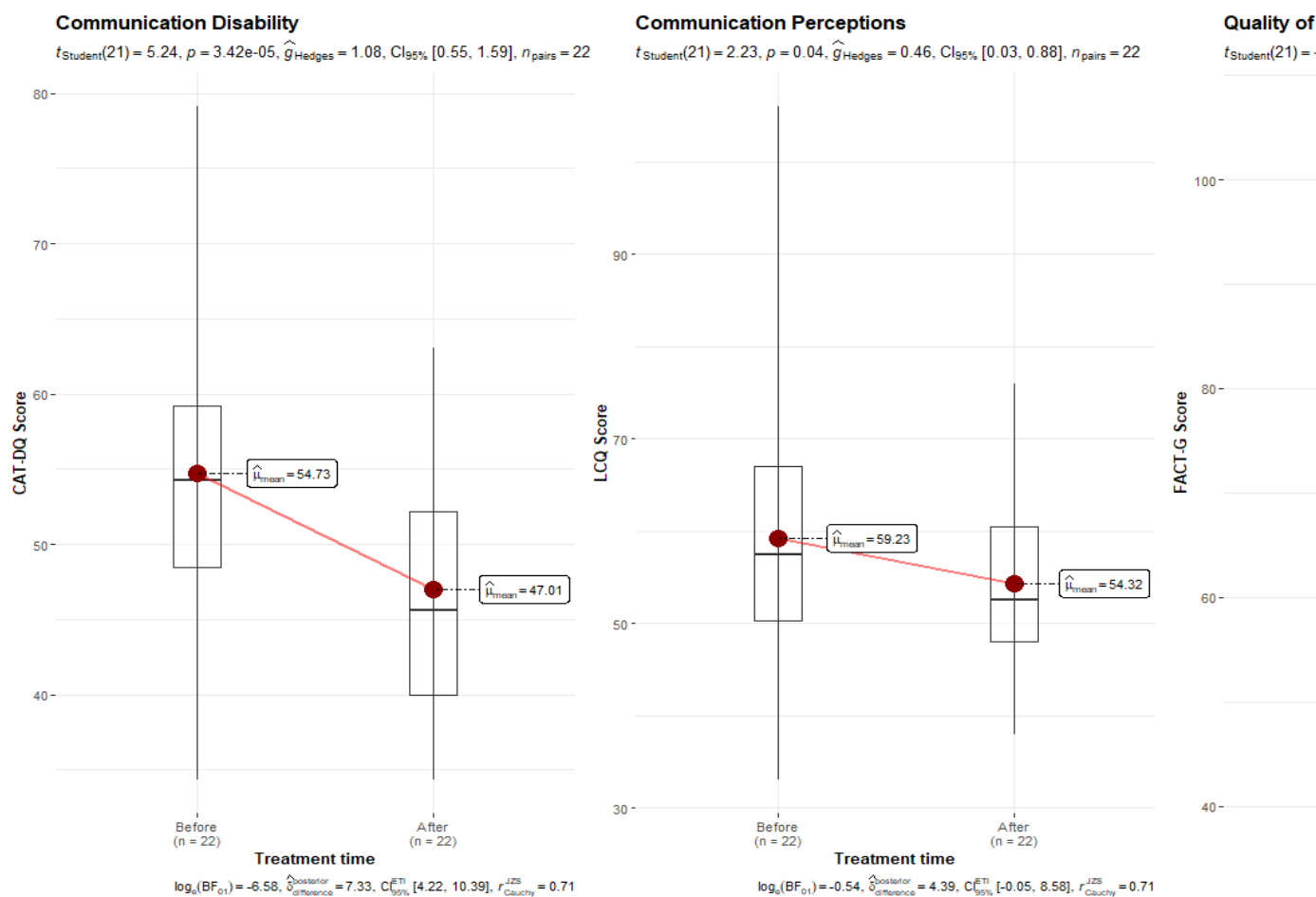
Table 2 presents the results of the mixed-effects regression models examining the between-group effects in the immediate intervention and waitlist control groups, controlling for baseline covariates of tumour grade and receipt of radiation therapy. The reported results include random intercept models, as more complex models (random intercept and random slope) did not provide a better fit to the data. The intraclass correlation coefficient (ICC) ranged from 0.53 to 0.80 across the three models (one for each outcome), indicating that mixed-effects models, which account for clustering, are expected to perform better than linear regression models that do not consider clustering.

The impact of the intervention is determined by the interaction term between the intervention group and time period. Given that lower CAT-DQ scores reflect better outcomes, the greater reduction in scores from pre to post in the immediate intervention group compared to the waitlist control group indicates a statistically significant beneficial effect of the intervention on the impacts of communication disability (intervention group $\times$ time period = post: -7.1 , $p = 0.04$) (Table 2). However, there were no statistically significant effects of the intervention on quality of life, as

measured by the FACT-G score, or on communication difficulties, as measured by the LCQ score (Table 2). No participant experienced any adverse events related to the intervention during the study, with withdrawals related to factors such as a decline in tumour-related health status, death, conflicts with medical management appointments, unable to be contacted, and technological issues (See Figure 3).

The paired t-test results are presented in Figure 4 for all participants who completed CanCommunicate. Compared to the pre-intervention period, individuals reported significantly lower communication disability at the 6-week follow-up, as measured by the CAT-DQ score (pre-intervention: $M = 54.73$, follow-up: $M = 47.01$, $t_{Student}(21) = 5.24$, $p < 0.001$), with a large effect size (Hedges' $g = 1.08$). Similarly, individuals reported significantly lower communication difficulties at the 6-week follow-up, as measured by the LCQ score (pre-intervention: $M = 59.23$, follow-up: $M = 54.32$, $t_{Student}(21) = 2.23$, $p = 0.04$), with a small effect size (Hedges' $g = 0.46$). However, there were no significant differences in QoL, as measured by the FACT-G score, between the pre-treatment and 6-week follow-up.

Figure 4. Results from the paired-samples t-tests between baseline and 6 week follow up.



Note. CAT DQ = Comprehensive Aphasia Test Disability Questionnaire; LCQ = La Trobe Communication Questionnaire; FACT-G = Functional Assessment of Cancer Therapy – General.

Table 2. Results from mixed-effects models

<i>Predictors</i>	CAT DQ (Communication disability)		LCQ (Communication difficulties)		FACT-G (QoL)	
	<i>Estimates</i>	<i>CI</i>	<i>Estimates</i>	<i>CI</i>	<i>Estimates</i>	<i>CI</i>
(Intercept)	39.5 ***	18.8 – 60.3	38.0 *	1.2 – 74.7	81.9 ***	49.9 – 113.9
Group (Immediate)	1.9	-7.6 – 11.5	8.1	-8.6 – 24.8	-12.0	-27.4 – 3.4
Period (Post)	1.1	-3.7 – 5.8	-0.9	-8.2 – 6.4	6.8	-3.7 – 17.3
Tumour grade (WHO Grade 2)	9.0	-13.8 – 31.8	12.9	-27.4 – 53.3	-6.9	-42.0 – 28.1
Tumour grade (WHO Grade 3)	2.3	-22.3 – 26.9	4.4	-39.1 – 48.0	0.5	-37.3 – 38.3
Tumour grade (WHO Grade 4)	3.8	-19.7 – 27.3	7.1	-34.5 – 48.8	-3.8	-39.9 – 32.3
Radiation therapy (Yes)	8.1	-2.0 – 18.2	8.0	-9.9 – 25.8	0.5	-15.1 – 16.1
Intervention group (Immediate) × Period (Post)	-7.1 *	-13.7 – -0.5	-2.8	-12.8 – 7.3	1.8	-12.4 – 16.1
Random Effects						
σ^2	31.54		72.78		152.55	
τ_{00}	89.14 _{id}		293.12 _{id}		170.32 _{id}	
ICC	0.74		0.80		0.53	
N	33 _{id}		33 _{id}		33 _{id}	
Observations	56		56		56	
Marginal R ² / Conditional R ²	0.17 / 0.78		0.10 / 0.82		0.13 / 0.60	

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Note. CAT DQ = Comprehensive Aphasia Test Disability Questionnaire; LCQ = La Trobe Communication Questionnaire; FACT-G = Functional Assessment of Cancer Therapy – General; QoL = Quality of Life; WHO = World Health Organisation.

There was no significant change between the two baseline time points (T1 and T2) for the waitlist control group on the CAT DQ (paired samples t-test, 2 tailed, $p = 0.85$), the FACT-G (paired samples t-test, 2 tailed, $p = .054$ respectively) or the LCQ (paired samples t-test, 2 tailed, $p = 0.41$), suggesting baseline stability.

Qualitative data

Table 3 provides a summary of the GAS-Light goals across the participants. Detailed goals are provided in supplementary online material 3.

Table 3. Summary of participant goals using Goal Attainment Scaling- Light (GAS-Light, Turner-Stokes (2009) during the CanCommunicate intervention (immediate intervention and waitlist participant groups combined)

Category	Subcategory
Confidence and independence	Communication confidence (n = 4) Communication independence (n = 1)
Interactions with other people	Conversations with family members (n = 2) Group communication (n = 1) Interacting with familiar people (n = 2) Community re-engagement (n = 1)
Functional tasks	Plan a holiday (n = 1) Purchase lotto tickets (n = 1) Medication management (n = 1) Establish communication hobbies (n = 1) Return to work (n = 1) Public speaking (n = 1)

	Legacy work (n = 1) Problem solving (n = 1)
Specific communication domains and skills	Auditory comprehension (n = 4) Word finding (n = 13) Auditory recall (n = 2) Reading comprehension (n = 6) Verbal expression (n = 1) Written expression (n = 4) Complex language (n = 3) Vocal volume (n = 1) Smooth speech (n = 1) Articulation of consonants (n = 1) Understanding non-verbal communication (n = 1) Emotion expression (n = 1) Verbal explanation skills (n = 1) Prosody and facial expression (n = 1) Increased utterance length (n = 1)
Education and understanding	Increased understanding of own communication function (n = 1) Educate other people (n = 1) Communication partner training (n = 3) Establish baseline cognitive communication skills (n = 1)

Note. n = number of goals.

Thematic analysis of participant responses after participating in the intervention revealed three themes: (1) CanCommunicate met my needs; (2) Elements of CanCommunicate to change; and

(3) The impact of health factors on CanCommunicate. Each of these themes contained several subthemes. Table 4 provides a summary of the themes and subthemes.

Table 4. Themes and subthemes from the thematic analysis of participants' perceptions of CanCommunicate

Theme	Subtheme
CanCommunicate met my needs <i>This theme explored participants' perceptions that the intervention was well-structured and addressed their communication needs</i>	CanCommunicate was good overall The benefits of CanCommunicate The content of CanCommunicate met my needs The structure of CanCommunicate was optimal CanCommunicate complemented other services The project staff were supportive
Elements of CanCommunicate to change <i>This theme explored aspects of the intervention that participant thought needed be altered</i>	Changes to the structure of CanCommunicate The use of technology posed challenges The content of CanCommunicate needs to change No changes are needed
The impact of health factors on the intervention <i>This theme recognised the impact of health-related factors on participation in the intervention</i>	Influence of medical factors The impact of tumour progression

The first theme, CanCommunicate met my needs, focused on participants' favourable perceptions towards the intervention. Within this theme, participants commented that CanCommunicate was a positive experience overall. CanCommunicate was described as “good” [BT31], “great” [BT37] and “marvellous” [BT39]. Reasons for this included “*It has made my brain work better I think*” [BT31] and “*It has helped me*” [BT39]. Many participants expressed favourable opinions towards the content of CanCommunicate. A pivotal aspect of this centred upon learning strategies to facilitate communication. For example, BT15 commented:

“I think just those strategies were helpful, and just having access to every week, you know, to talk about anything that may have come up during that time.”

Other key areas of knowledge gained included learning how to manage communication changes and an understanding of participant's own level of communication function. Participants also expressed that the intervention led to improvements in psychological wellbeing, including increased confidence which led to resuming reading (BT20), a sense of hope and not feeling alone (BT35), and a perception of positivity (BT7). For example, BT35 described looking forward to the sessions, while BT 7 commented:

“Good. It's been really good. It makes me think about it all in a positive way. So that primarily, how, good overall, but I like to think out and beyond my own bleeding heart”

CanCommunicate was perceived to lead to direct changes in communication, such as improved word finding. CanCommunicate was viewed by some participants as filling a valuable service gap where they were unable to access other speech pathology services to meet their needs.

Participants expressed an appreciation for the structure of CanCommunicate. The predominantly telehealth delivery was seen as flexible and a way to reduce travel to appointments, especially in the context of being unable to drive and managing tumour-induced fatigue and illness:

"Yes [online was good] that reduced the amount of, like, the amount of appointment I gotta do. Oh, yes. So lots of travel for appointment. So anything online just makes it better when you're feeling exhausted and not well" [BT29]

BT15 reported that they usually preferred in-person appointments but highlighted that the telehealth delivery was ideal for their current circumstances:

"Yes, good not being able to travel because I don't, I can't drive at the moment, but I really like face to face, like with learning and appointments and things like that. I like face to face, but in this instance, it was perfect, but because I can't drive".

The weekly one-hour format of CanCommunicate was perceived as optimal, especially in the context of fatigue. For example, BT34 commented: *"Yeah, I get tired pretty much an hour. So yeah, yeah. Kind of perfect for me"*. Participants also viewed the seven-week duration of the intervention as ideal, with BT20 commenting *"I think seven weeks was good because I know myself, I had improved from week one to the final week. Yeah, I felt I didn't need to go on any longer."* The key benefits of the individual sessions were the opportunity to focus on individual goals and strategies, and the tailoring of the content to the individual participant and their interests. While participants perceived benefits of receiving individual sessions, the group sessions were viewed as a valuable opportunity to connect with other people going through the similar health experiences. Specific to the research project, some participants viewed the study assessments as highly relevant and an opportunity to quantify how they were going with their communication. For participants, such as BT28, the assessment feedback contributed to an increase in self-confidence through reflecting their communication abilities (Note. One of the individual session activities for this participant was a detailed assessment of their current communication with feedback):

"I like being able to know where I'm at. So, with the assessments, yep, it gave me that little bit more confidence being told actually you doing fine, after the test, yeah you know you're

not as bad as you think you are, and you know, to little bits and pieces to practice over the week, to continually increase my confidence in general, after having the surgeries.” [BT28]

CanCommunicate was viewed as complementary to other services, such as medical services (including radiation therapy appointments) and other speech pathology services. Only one participant received concurrent speech pathology therapy (which was from radiation oncology working on goals related to dysphagia and radiation side effects, which were outside of the communication focus of CanCommunicate). Additionally, this only occurred during the group education sessions. For the two participants who received speech pathology services prior to commencing CanCommunicate, the CanCommunicate intervention speech pathologist liaised with the previous speech pathology services. Participants also spoke favourably about the supportiveness of the project staff, especially the ability of staff to create a comfortable and relaxed environment. BT39 described this as:

“Good quality time that she spent there and you feel more relaxed when you[’re] coming out of the session”.

The second theme explored elements of CanCommunicate that participants thought should change. Interestingly, many of the suggested areas of change were aspects of the intervention that other participants described as good, highlighting the importance of individual sessions and tailoring the intervention to each participant’s needs and circumstances. Suggested changes to the structure of CanCommunicate encompassed: more individual sessions, longer sessions, sessions at a consistent time each week, condensing the two initial groups into a single group session, easier assessment questions, and splitting each assessment session into multiple sessions. For example, BT31 commented:

“With a lot of things, you need a good four to eight weeks to really start getting into the nitty gritty of things, the first week is quite general stuff”.

Three participants [BT6, BT18, BT28] offered thoughts about modifications to the content of CanCommunicate. These suggested changes included increased personalisation and relevancy, more impairment-focused therapy, and fewer activities out of their perceived “comfort zone”. Along these lines, BT18 commented:

“I think it doesn't even have to be overly individualized. I think just more a little closer to, a little bit closer to home than, than what we've spoken about”

While BT6 commented:

“Yeah, I felt something was missing.. some things were missing... like things we targeted... Uh... no the therapy was... somehow the therapy was missing...” [Interviewer: Yeah. Okay. Like would have you liked it to be a bit more targeting like impairments rather than?] *“Therapy missing somehow...”* [Interviewer: Yeah. Okay. So was it more that you would like it to target those impairments? More at that] *“Target more the impairment”*

In terms of feeling out of their comfort zone, BT28 commented:

“Pushing me to get out of, like, my comfort zone... to see if there was anything that I may need support in, because I haven't gone out and used my communication skills in like a large group or things like that. So I felt a little a bit uneasy about having to go and do things that I wasn't felt like I wasn't capable of...”

At times, the use of technology posed challenges, leading participants to suggest delivery of the sessions at home, or in-person delivery rather than via telehealth. BT20 commented *“No, the only issue I've had, like I said, was with the IT, no it [CanCommunicate] worked the quite well, yeah, yeah, I really enjoyed it”*. For BT13, difficulties mastering the intervention via virtually led to the participant attending sessions in person instead. Six participants commented that no changes were required to CanCommunicate [BT3, BT7, BT13, BT15, BT17, BT36].

The third, and final, theme explored the impact of health factors on participation in the intervention, including factors originating from the brain tumour itself or medical management of the tumour. These health-related factors involved fatigue, feeling unwell, memory difficulties and managing the effects of radiation. P38 commented:

“So it's been very easy to participate in. I think the hardest part is the ups and downs while doing the planning or the while doing the can study. Yeah, it's been harder, I think, to manage with what's going on. But in saying that it was what I wanted to do... but if I was otherwise, well at all times, well, well as you can be when you've got a tumour, I'd find it quite enjoyable.” [P35]

Typically, the impacts of health factors manifested as reduced session attendance:

“Oh look it's my fault, because I was always either sick or missed out a lot of them, yeah, but yeah, definitely do do more, yeah.” [BT13]

In some cases, tumour progression led to a worsening of communication function during the course of the study perceived by participants. Linked to this, some participants expressed that CanCommunicate should be started earlier in their brain tumour journey.

Fidelity

Some small adjustments for individuals were made during the course of the study due to participant availability and/or preference. For eight participants, the final group CanCommunicate session was provided as an individual session (following the same content as the group version). In some cases, participants needed more speech pathology guidance with GAS-Light goal development due to a sudden significant change in the participant's activities of daily living, work status and or overall functioning, such that in some cases participants did not know what they needed for communication support and were distressed regarding their medical diagnosis and likely prognosis.

Discussion

The aim of the present study was to evaluate the efficacy of a new intervention for improving perceived communication disability and QoL in people with a brain tumour. Despite not achieving the target sample size, overall, CanCommunicate led to statistically significant improvements in perceived communication disability compared to usual care, but not in QoL or perceived communication function. When data for all participants who completed CanCommunicate were combined (regardless of their allocated group), there was a statistically significant improvement in communication disability and communication difficulties following the intervention, but no change in QoL. Participants expressed favourable perceptions towards CanCommunicate; however, valuable suggestions to optimise the intervention were also made.

Communication difficulties are widespread and persistent for many people with brain tumours (Åke et al., 2023; Brownsett et al., 2019; Davie et al., 2009). Consistent with previous research (Åke et al., 2023; Brownsett et al., 2019; Davie et al., 2009; Palmisciano et al., 2022), the communication difficulties experienced by participants in the present study (based on patient perception, clinician notes and informal assessments during the study sessions) included impaired word finding, impaired reading comprehension and written expression, motor speech difficulties, and increased effort of communication. The current study, therefore, adds to the growing knowledge base about the need for people with a brain tumour to receive communication intervention. Based on the GAS-Light goals, it also highlights the breadth of communication priorities of people with a brain tumour and the need for communication interventions to be individualised and tailored to the individual's specific communication needs, as well as flexible to altering care aims given the dynamic diagnosis.

To date, research into the management of communication difficulties associated with a brain tumour has been largely dominated by single case studies and case series designs (e.g., Jacobs, 2001;

Milman et al., 2020; Sherman et al., 2005). The current study extends this body of research by using an RCT design with 39 participants. Another strength was the pragmatic design used with broad inclusion criteria to maximise external validity. An additional novel aspect of the current study was the multidimensional communication focus tailored to each individual's needs through the use of GAS to drive the intervention content within the individual sessions. Furthermore, this multidimensional communication focus may have contributed to the significant changes in perceived communication disability. The finding that the intervention was associated with significant reductions in perceived communication disability even after a seven week delay for waitlist control participants (as indicated by the pooled data analysis) suggests that individuals with a brain tumour can experience improvements in perceived communication function with a targeted intervention. This has important implications for the timing of communication-focused service provision to people with a brain tumour, which would benefit from further exploration in future research to determine the optimal timing for communication interventions in this patient population with complex medical and social needs.

Over half of the participants in the present study had a high grade glioma and were medically unwell with a poor prognosis. Anecdotally, this group is often not prioritised for speech pathology communication interventions, compared to patients with non-progressive diagnoses such as stroke and traumatic brain injury. However, in the case of people with a brain tumour, these communication difficulties can render communication with health professionals challenging at a time when effective communication is vital (Langbecker et al., 2013). The finding that CanCommunicate significantly improved self-perceived communication disability adds to the growing body of research that highlights that people with a brain tumour (including those with high grade gliomas) need and can benefit from tailored and flexible communication intervention despite experiencing a potentially life limiting medical condition. Interestingly, participants in the immediate intervention group were significantly more likely to have a high grade glioma and to have received radiation therapy as part of their medical management than participants in the waitlist control group (which reflects the current

medical standard of care, in that radiation therapy is part of standard care for people with a high grade glioma). It is possible, therefore, that people with high grade glioma were more likely participate in the intervention if it was available immediately, again highlighting that further research is needed to determine the optimal timing of communication services for people with a brain tumour and their families.

Brain tumours are known to detrimentally impact QoL (Rimmer et al., 2023; Ståhl et al., 2022). Some participants raised during the study interviews that health-related factors, including those originating from the brain tumour itself or medical management of the tumour, impacted on their participation in the intervention. Interestingly, in the present study there was a lack of significant change in QoL according to the FACT-G. While it is possible that this may have been impacted by the large proportion of participants who were diagnosed with a high grade glioma (given that people with a high grade glioma often experience reduced QoL than people with a lower grade glioma (Rimmer et al., 2023)), it is also possible that the FACT-G is not sufficiently sensitive to communicative QoL. Specifically, the FACT-G focuses on physical wellbeing (including energy, nausea and pain), social/family wellbeing (including emotional support from family and family's acceptance of the tumour), emotional wellbeing (including sadness and coping), and functional wellbeing (including work and sleep). This is particularly pertinent given that a psychosocial intervention (the Making Sense of Brain Tumours program) has been found to improve global QoL, particularly through improvements in emotional and functional well-being (Ownsworth et al., 2015; Ownsworth et al., 2023).

Overall, the majority of participants reported that CanCommunicate was beneficial. Interestingly some of the features of CanCommunicate that some participants liked, such as telehealth delivery, session length, and the group component, were the same features that other participants disliked. This contrast brings to the forefront the importance of individualisation and tailoring the intervention to each participant's individual needs and circumstances. This concept is

not unique, as research in people with aphasia and people with traumatic brain injury has highlighted the importance of individual tailoring of communication interventions (Borgen et al., 2023; Thiessen & Brown, 2021). However, the complex and progressive nature of communication difficulties associated with a brain tumour serves to amplify this need.

Interestingly, nine participants withdrew from the immediate intervention group, none withdrew from the waitlist control group initially, and then six participants from the waitlist control group withdrew when they commenced the intervention. These withdrawals related to factors such as a decline in tumour-related health status, death, conflicts with medical management appointments, unable to be contacted, and technological issues. In the case of tumour-related medical decline and death, it is possible that fewer withdrawals due to these reasons may have occurred if the intervention was undertaken earlier in the participant's tumour journey. In the case of other withdrawals, it is possible that participants were able to participate in the study assessment sessions (which were approximately one hour) but then the time commitment of CanCommunicate become challenging. Future research could explore considerations related to timing (including timing in the participant's tumour journey and the ideal intervention dose) in more detail.

Limitations

The current study was impacted by the COVID-19 global pandemic which led to a delayed start to recruitment and consequently a lower than anticipated number of participants. There was also a sizeable dropout rate, most often due to a decline in health status, which while not unexpected in this patient population, nonetheless is important to acknowledge as a limitation. When considered together, these issues affecting sample size meant that the study was underpowered for some analyses. Additionally, the maintenance of change was not explored as participants in the waitlist control condition received intervention after 7 weeks. While this occurred due to ethical considerations (i.e., limiting the delay in communication treatment commencement), it means that it

is unknown whether the improvements were durable. It is also worth acknowledging that the non-consecutive recruitment is likely to bias the sample, especially given that participants who lacked self-awareness of their communication difficulties (i.e., did not recognise communication difficulties) were less likely to participate, which may affect the representativeness of the sample and hence the generalizability of the findings to the broader population. Furthermore, the inclusion criterion of perceived or objective communication difficulties as per the treating speech pathologist or doctor who referred them to CanCommunicate meant that the findings are applicable primarily to individuals with clinically recognised communication needs, and may have led to potential selection bias. However, the current study still represents the largest controlled trial of a communication intervention to date with people with brain tumour.

The study findings may be further limited using self-report measures rather than objective indices of functioning. This was an intentional decision made by the research team during the initial study planning phase to focus on non-impairment based measures as the primary outcome measures, given the aim of the intervention, the likelihood of deterioration on impairment-based measures due to tumour progression during the study, and the importance of the lived experience of patients from their own perspective. This was also likely reflected in the functional language and legacy goals of some participants for the intervention. Another limitation of the study was that while information was extracted about tumour side, information was not available about which brain hemisphere was dominant for language or handedness for each participant. The research team also acknowledge that in some clinical trials 'usual care' for participants on a study can be elevated because both the healthcare team and patient are aware of the scrutiny on the study. This was accounted for by the research team recording communication interventions that participants may have received before and during study participation. We also acknowledge that our criterion of functional English skills was broad and included a wide range of ability from native-like proficiency through to minimal function in daily life. Finally, technology issues impacted multiple intervention

sessions. Future iterations of the intervention could incorporate technological support and participant training prior to each participant's first online session.

Conclusion

Despite impacts from the COVID-19 global pandemic resulting in a lower than anticipated number of participants, the present study found that CanCommunicate led to statistically significant improvements in perceived communication disability, but not in QoL or perceived communication function. The current study adds to the growing evidence on communication intervention for people with a brain tumour; however, it also highlights the breadth of communication difficulties they experience and the need for individualised communication interventions tailored to the individual's specific communication needs. Although research with this population is challenging due to the confounding effects of tumour progression and impact of symptoms on participation, further research is recommended to understand when and how interventions such as CanCommunicate can be adapted and flexibly delivered to meet individuals' needs.

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Trial registration

Prospectively registered with the Australian New Zealand Clinical Trials Registry (ANZCTR) (Trial registration number: ACTRN12623000039684)

Data availability

The data that support the findings of this study are available on request from the corresponding author, EF. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

Declaration of interest

The authors report no conflicts of interest

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Figure captions:

Figure 1. Flow diagram depicting the study timeline

Figure 2. Overarching structure of the CanCommunicate sessions

Figure 3. Participant recruitment flow diagram

Figure 4. Figure 4. Results from the paired-samples t-tests between baseline and 6 week follow up

Alt text for figures:

Figure 1. A flow diagram of the study procedure for the immediate intervention and waitlist control groups. The diagram depicts assessment and intervention components for each group.

Figure 2. A diagram of the structure of CanCommunicate. Group sessions, individual sessions and a final session are listed.

Figure 3. A flow diagram depicting participant numbers for the immediate intervention and waitlist control participants during the study.

Figure 4. A set of three box plots depicting the change in communication disability, communication difficulties, and quality of life between baseline and 6 weeks after the intervention