Use of telehealth platforms for delivering supportive care to adults with primary brain tumors and their family caregivers: A systematic review

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Abstract

Objective: Telehealth platforms have potential utility for providing remote access to supportive care to people with brain tumour. This systematic review aimed to evaluate the feasibility, acceptability and efficacy of delivering supportive care via telehealth platforms to adults with primary brain tumour and family caregivers.

Methods: A systematic search of PsycINFO, MEDLINE, CINAHL, Embase, Scopus and Cochrane Library was conducted from 1980 to 1st June 2020 to identify eligible studies. Methodological quality was assessed by two independent reviewers.

Results: Seventeen articles, reporting on 16 studies, evaluated telephone-based support (5 studies), videoconferencing (3 studies), web-based programs and resources (7 studies) or combined use of videoconferencing and web-based modules (1 study) to deliver supportive care remotely. Caregivers were involved in 31% of interventions. Mean rates of accrual (68%) and adherence (74%) were moderate, whereas acceptability or satisfaction for those completing the interventions was typically high (M satisfied or very satisfied = 81%). Adherence rates were generally higher and clinical gains were more evident for interventions involving real-time interaction as opposed to self-guided interventions.

Conclusions: Telehealth delivery of supportive care is feasible and acceptable to a high proportion of individuals with primary brain tumour and their caregivers. It is recommended that future research focuses on implementation outcomes, including factors influencing the uptake and sustainability of telehealth platforms in practice.

Keywords
cancer, brain tumour, oncology, psycho-oncology, supportive care, telehealth
Primary brain tumours comprise gliomas and benign intracranial pathologies. It is relatively rare, with approximately 3,300,000 new diagnoses of malignant brain cancer worldwide each year.\(^4\) However, the burden of disease and impacts on quality of life (QoL) are substantial. Brain tumours are associated with significant functional impairments which can reduce individuals’ independence, social and work functioning.\(^2\) Treatment can be prolonged and multifaceted depending on the nature of the condition and may include active surveillance, surgery, chemotherapy and radiotherapy used in isolation or together. High rates (40%–50%) of depression and anxiety have been reported in people with benign or malignant brain tumors\(^3\) and in family caregiver samples.\(^4,5\) Such distress can persist long-term as they face ongoing threat regarding recurrence, progression and functional decline.\(^5,6\)

Due to relatively brief hospital stays and the greater emphasis on outpatient care, family members typically assume the primary role of supporting individuals to cope with the functional and emotional effects of the illness.\(^7\) Increased awareness of the diverse physical, cognitive and behavioural effects of brain tumours and their associated treatments develops after hospital discharge\(^6\); hence, the early post-treatment phase is a period of heightened risk for psychological distress.

International clinical practice guidelines\(^9\) emphasise the need to routinely screen people with cancer for distress and provide appropriate supportive care. In this context, supportive care refers to interventions, approaches and services for managing symptoms and improving QoL and care for people living with or impacted by the illness.\(^10\) This may relate to information, emotional, spiritual, social or physical needs during diagnosis, treatment, rehabilitation or follow-up care, with a view to enhancing health promotion/prevention, quality of survivorship, palliative care and adjustment to bereavement.\(^10\) The timing and flexibility of access to supportive care is critical as individuals and family members impacted by a brain tumour can have varied preferences for information, and readiness for support can change over time as the disease progresses.\(^2\)

Previous reviews on supportive care for people with brain tumours have largely identified low or insufficient evidence of efficacy.\(^11–13\) For example, international palliative care guidelines for glioma\(^11\) identified a lack of evidence for supportive care interventions addressing fatigue, mood and behaviour, caregiver needs and advanced care planning. In a review of controlled trials evaluating health-related QoL outcomes, Pan-Weisz and colleagues\(^12\) found that only two interventions (i.e., acupuncture and a home-based psychological support program) had positive effects relative to control conditions. Reviews on cognitive rehabilitation have yielded more promising findings in terms of improvements in cognitive function,\(^14,15\) although such interventions have not shown benefits for mental health or QoL.

Notably, these reviews highlight that most supportive care interventions have been evaluated in a hospital or clinic setting, in clinician’s presence. Yet, people with brain tumours face many potential barriers to accessing clinic-based care, including geographical distance, debilitating symptoms (e.g., seizures and vestibular dysfunction), inability to drive, lack of alternative transport and financial hardship.\(^16\) Despite the demonstrated efficacy of in-person home-based psychological support,\(^17\) such interventions are typically not feasible to implement broadly in practice. In view of these considerations, telehealth platforms have potential to improve access to professional support.

### 1.1 Use of telehealth interventions in supportive care

Technology is increasingly used to provide supportive care remotely to people with cancer,\(^18\) brain injury\(^19\) and other chronic conditions including stroke\(^20\) and multiple sclerosis.\(^21\) Telehealth platforms can involve communication in real-time (i.e., synchronous) such as telephone and videoconferencing, or delayed exchange of information (i.e., asynchronous), and self-guided online platforms.\(^18–21\) Telehealth services and interventions can address broad support needs relating to information and education, symptom monitoring and review, counselling, physical therapy, cognitive rehabilitation, care coordination and caregiver support.\(^18–21\) Such platforms may reduce the need for travel, improve access to specialist services, enable greater flexibility with appointment scheduling and allow extended follow-up support. In the stroke literature, there is some evidence that functional gains after telehealth interventions are comparable to conventional (in-person) delivery\(^20\) and that remote delivery has cost benefits.\(^22\)
Supportive care delivered via telehealth platforms can have many benefits for people with cancer, including reduced disruption to their lives, personalised care away from the hospital setting and providing a ‘safety net’ through continued connection to health professionals. Despite these benefits, there is potential for burden related to technological challenges, perceived disconnection, and concerns regarding equitable access for people with low computer literacy and resources. People with neurological disorders often face additional challenges related to sensory, motor and cognitive-linguistic impairments.

Several studies have evaluated the use of telehealth platforms for symptom monitoring, education and rehabilitation of people with brain tumours in a supervised clinic-based setting. For example, in a mixed brain tumour sample, Erharter and colleagues evaluated the implementation of computer-based symptom monitoring in the waiting room to alert physicians to changes in health. Most patients found the tablets easy to use and that administration time was acceptable, although nearly one third (30%) were unable to independently use the tablets due to functional impairment. Furthermore, El-Jawahri et al. found that video-based education was acceptable for facilitating end-of-life discussions of people with malignant glioma and influenced their preference for comfort care over potentially life-prolonging interventions. Numerous studies involving mixed brain tumour samples have evaluated the efficacy of computer-based cognitive retraining and virtual reality programs within clinic settings and reported high levels of adherence and completion rates (>80%), with drop-out mainly due to disease progression.

Although these studies support the use of telehealth platforms in a supervised setting, there are potential barriers to their remote application, including technology problems and cognitive-linguistic impairments. Health professionals’ perspectives on these issues are informative and can guide implementation in practice. However, remote delivery of supportive care ultimately needs to be perceived as feasible and beneficial for people with brain tumours and family caregivers. People’s capacity and willingness to use technology can be enhanced by engaging end-users in the initial development and refinement stages. Co-design or collaboration between clinicians, researchers and people with lived experience has been used effectively to develop technological solutions to problems for people with cognitive and communication impairments due to other causes.

2 | METHOD

This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and the protocol was registered with the International Prospective Register of Systematic Reviews (registration no: CRD42020181574).

2.1 | Search strategy

Relevant articles were identified through electronic searches of Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Scopus, PsycINFO, Embase and Cochrane Library from 1980 to 1st June, 2020. In accordance with the patient, problem or population, intervention, comparison, control or comparator, outcome(s) framework. Population refers to adults with primary brain tumours (gliomas or other intracranial pathologies including benign disease) and Intervention refers to supportive care delivered remotely using telehealth technology. Comparison relates to any alternative intervention or condition (e.g., usual care), if relevant to the study design. Outcome refers to data concerning feasibility, acceptability, efficacy and/or implementation as defined in Table S1. The three sets of key words and example search terms were:

- Population: brain cancer; brain tumo*; neoplasm; CNS tumo*; glioma; AND
- Technology: Tele*; video*; computer; online; internet; digital health; techno*; AND
- Supportive care: intervention; program*; rehabilitation; therapy; support*; education

The search strategy was tailored for each database, according to search limit options. The full search strategy for CINAHL is included in Table S2. Forward and backward citation searching was conducted for all eligible articles and reference lists of relevant reviews were searched to identify other potentially eligible articles.

2.2 | Selection criteria

Peer-reviewed articles published in English with abstracts were selected for review. Titles and abstracts of potentially eligible articles were initially reviewed by one author according to the following criteria:

- Sample of adults (Mean age ≥18 years) with primary brain tumours (i.e., benign, malignant and mixed tumour types) and/or family caregivers. In samples including people with brain metastases, at least 60% had primary brain tumours
- Study evaluated a supportive care intervention involving technology for remote use (i.e., not clinic-based). Supportive care includes interventions, approaches and services for monitoring and managing symptoms and improving QoL. Platforms could include
but were not limited to telephone, videoconferencing, web-based resources and computerised training
• Study reported on feasibility and/or acceptability from the perspectives of people with brain tumours or family caregivers, or data concerning efficacy and/or implementation outcomes (see Table S1)

No limitations were applied to sample size or study design. However, studies were excluded if platforms were used purely for data collection, such as an online survey of QoL or computerised neurocognitive assessment, without a supportive care intervention. Furthermore, studies reporting only on the perspectives of health professionals, or future development of technology were excluded.

2.3 | Data extraction and quality appraisal

Following initial screening of titles and abstracts, two authors (Tamara Ownsworth & Stephanie Jones) independently reviewed full texts of potentially eligible articles. Level of agreement regarding eligibility was established and any disagreements were discussed to reach consensus. Due to the diverse research designs employed, quality of methodology was assessed according to select criteria previously used to appraise research on telerehabilitation after brain injury19 (note: criteria most relevant to randomized controlled trials [RCTs] were excluded) and the Joanna Briggs Critical Appraisal Checklist for Case Series.37 In recognition of the increased emphasis on engagement of end-users in the design on technology-based interventions,31,32 we developed an additional criterion related to co-design or collaborative development and/or refinement of the telehealth platform people with brain tumours and/or caregivers.

As detailed in Table S3, the quality criteria included: (1) evidence of a co-design process prior to evaluating the telehealth platform; (2) representative sampling (e.g., consecutive or multi-site); (3) eligibility criteria and screening outcomes specified; (4) adequate description of the telehealth platform and intervention characteristics; (5) sample characteristics reported with minimum requirements of age, sex and tumour type; (6) outcomes documented for all participants using the telehealth platform; (7) rates of decline and/or drop-out and reasons reported and (8) conducted a follow-up of ≥ 1 month of post-intervention outcomes, platform use or other service-level outcomes. Although randomisation was not included as a quality criterion due to the primary aim of evaluating feasibility and acceptability, for studies evaluating the efficacy of telehealth platforms, RCTs were considered methodologically stronger than non-randomised, single-arm and case series designs. Level of agreement between two independent raters was examined using Kappa, with discrepancies discussed to reach consensus on final decisions.

2.4 | Data synthesis

A narrative synthesis was conducted, with study characteristics and data on feasibility, acceptability, efficacy and implementation outcomes summarised in a table and the text. The data that support the findings are available in the supplementary material of this article (Table S4).

3 | RESULTS

3.1 | Search outcomes

As shown in Figure 1, a total of 8412 articles were identified across six databases and five additional articles were identified from other sources (total = 8417). Of these, 2,693 duplicate articles were removed. A further 5657 were excluded based on title and/or abstract, leaving 67 full-text articles to be screened for eligibility. There was 93% agreement between the two authors regarding inclusion or exclusion of these full-text articles. This process identified 17 eligible articles, reporting on 16 studies. Two articles38,39 on the same study reported separately on feasibility and acceptability38 and efficacy39 outcomes. Most studies were conducted in the United States (31%), The Netherlands (25%) or Australia (19%). Table S4 outlines the sample characteristics, design, intervention characteristics and key findings of the 16 studies.

3.2 | Methodological quality

 Interrater agreement regarding ratings for the eight methodological quality criteria was substantial (κ = 0.72, p < 0.001). As shown in Table S3, one study met three criteria, two met four criteria, three met five criteria, eight met six criteria and one met seven criteria. Most studies (>75%) outlined the eligibility and screening process, sample characteristics, intervention characteristics and outcomes and rates of decline or drop-out. Half of the studies conducted a post-intervention follow-up of at least 1 month. Only two studies by Moscato et al.38 and Halkett et al.40 developed the interventions through a co-design process.

3.3 | Sample characteristics

A total of 569 participants were recruited across 16 studies, with sample sizes ranging from 3 to 162 (M = 38). The mean age of participants across the 16 studies was 49 years, and the range for mean age spanned 18–64 years. Five studies included high-grade glioma (HGG) patients, two included patients with low-grade glioma (LGG) or benign tumour, whereas seven included mixed gliomas or tumour subtypes, including one study involving adolescent and young adult survivors of paediatric brain tumours (M age: 18 years). One study included individuals with primary (63%) and metastatic brain tumours41 and another did not specify tumour type.42 At time of recruitment, participants in 50% of the studies were receiving initial treatment or post-treatment follow-up (≤3 months), whereas remaining studies involved participants at varying disease stages and time since diagnosis.
3.4 | Evaluation of telehealth platforms for delivering supportive care interventions

The studies evaluated telehealth interventions addressing five aspects of supportive care, including symptom review and post-treatment follow-up, information and educational support, physical exercise, cognitive rehabilitation, and psychological support. Telehealth platforms included telephone-based support, videoconferencing, web-based programs and resources, or combined use of videoconferencing and self-guided web-based modules. Caregivers were involved in 31% of interventions, including three supporting both patients and caregivers and a carer-specific information and support program. In terms of the nature of communication, eight interventions (50%) involved synchronous communication, or interaction in real-time with professionals, whereas four (25%) involved a combination of interaction in real-time and self-guided online programs and resources and four (25%) were mainly self-guided with asynchronous communication such as delayed email feedback. The following sections summarise the key findings according to the focus of supportive care.

3.5 | Symptom review and post-treatment follow-up

Sardell and colleagues evaluated a nurse-led telephone clinic as an alternative to conventional (in-person) clinic follow-up for individuals with HGG after primary therapy. Forty-five participants received monthly telephone calls instead of 2 monthly conventional clinic follow-up. Participants were engaged in the clinic for a median of 6 months, with rates decreasing (80% at 4 months; 34% at 1 year) due to disease progression. A subsample of 22 patients who attended for ≥4 months expressed high levels of satisfaction (Mdn = 90%). Although the 12-month follow-up was a strength, the eligibility criteria were not specified, and satisfaction ratings were only obtained from a subsample (65%). Patil et al. evaluated feasibility and safety of video clinic reviews for 65 adults with glioma (II-IV) who had completed ≥2 cycles of adjuvant temozolomide. All received conventional (in-person) follow-up initially and then video follow-up. Drop-out and connectivity issues were encountered during video calls for 51%, thus requiring multiple calls or reconnections to complete the interview. Yet, the majority (>70%) were satisfied with the quality of video and
audio features. Overall satisfaction was comparable between video follow-up (80% 'extremely satisfied') and conventional follow-up (86% 'extremely satisfied'). The median cost for video follow-up was lower (US$58.2) than for conventional clinic (US$131.2) due to patients or healthcare providers not needing to fund travel and accommodation. Study limitations include the non-consecutive recruitment and lack of data on rate of decline and reasons.

3.6 Information and educational support

Piil and colleagues\(^45\) prospectively evaluated the feasibility of an interactive brain tumour website (BTW), designed to provide information to people recently diagnosed with HGG and caregivers. Available nationwide in Denmark, BTW was accessed by 637 users over 6 months, with most visiting the 'ask a specialist' and 'share experiences' pages. Twenty-one participants were consecutively recruited post-surgery (81% accrual) and given information about accessing BTW. Nine patients and 8 caregivers were interviewed at 3-month follow-up; of these, only five (29%) had accessed BTW. Qualitative analysis revealed several challenges and barriers, including technology and technical difficulties and concerns about anonymity and becoming distressed by content. The lack of co-design process for website development is a key limitation.

Cahill et al.\(^46\) surveyed 162 patients with a glioma who had electronic access to personal health records (PHR). Through a website, patients could access personalised information regarding treatment, test results, appointments and a portal to communicate with their doctors. Over the 6-month period preceding the study, 40% were non-users (0 log-ins), 29% were low users (1–13 log-ins) and 31% were high users (>13 log-ins). Greater log-ins was significantly associated with higher education, lower performance status, residency in Texas (vs. out-of-state), middle income earners (vs. high and low income) and being on active treatment (vs. post-treatment and newly diagnosed). Increased PHR use was related to lower illness uncertainty; however, individual reasons for use and non-use were not obtained from patients or family members. The lack of co-design process and non-consecutive recruitment are other limitations.

Stuart et al.\(^47\) evaluated educational strategies for improving patients' knowledge and understanding of their diagnosis and treatment. Thirty participants with mixed brain tumour subtypes who were receiving chemotherapy were non-randomly allocated to: (1) standard care involving generic paper-based information, (2) tailored information in a paper-based binder or (3) standard care plus technology enhanced active learning (TEAL). TEAL entailed teaching patients how to use 'Cancergraph', an online tool allowing self-tracking of symptoms and side effects on an iPhone or tablet. Information was provided in-person within the hospital during a 20-min (groups 1 & 2) or 30-min (group 3) consultation. Patients completed a survey at baseline and 2-week follow-up to compare pre- and post-intervention treatment knowledge. Overall, there were no significant pre-post differences in treatment knowledge or contact with healthcare team professionals. Limitations include the lack of co-design process, non-randomised assignment, and insufficient data on patient accrual and adherence (i.e., remote use of Cancergraph).

Philip et al.\(^48\) evaluated the Information, Coordination, Preparation and Emotional support (I-CoPE) intervention delivered by cancer care coordinators over three phases: immediately post-diagnosis (Transition A), post-discharge prior to chemo/radiotherapy (Transition B) and post-radiotherapy (Transition C). Components included generic and individualised information on diagnosis, treatment and health professionals (A), distress screening and needs assessment (A, B & C) and a tailored information package with community links (C). Transition A was delivered face-to-face, whereas transition B was delivered via telephone. Transition C was delivered via either face-to-face or telephone. Thirty-two patients with a recently diagnosed HGG and 31 carers participated (86% accrual) and 88% of patients and 94% of carers completed the study. Acceptability was high with 81% of patients and 87% of carers rating care as 'very good' or 'excellent'. Patients and carers reported fewer information needs at post-intervention. Carers also reported fewer unmet supportive care needs and increased preparedness to care. There was no significant change in quality of life. I-CoPE was relatively inexpensive with a mean cost of Australian dollars $137 per patient-carer dyad. Limitations included the lack of co-design process and non-consecutive recruitment.

Halkett et al.\(^49\) piloted a multi-component supportive education intervention (CARE-IS) for carers of patients with HGG undergoing treatment (<2 months since diagnosis). Their focus was on scoping the feasibility of both the intervention and survey completion at baseline and post-intervention. Feedback received from two carer representatives helped to refine procedures prior to the study. The nurse-led intervention comprised an initial telephone assessment of unmet needs, personalised resource file, home visit and ongoing monthly telephone support for 6 months. Of the 12 carers approached, two declined (83% accrual) and 70% completed the intervention and survey measures. Carers generally found the information and support helpful, although they made suggestions regarding the timing of information and inclusion of additional topics. Use of a co-design process in developing the intervention was a major strength. The non-consecutive recruitment and lack of post-intervention follow-up are key limitations.

3.7 Physical exercise

Gehring et al.\(^50\) conducted a pilot RCT involving 34 patients with 'medically stable' grade II and III gliomas (M disease duration: 8 years) to evaluate the feasibility of a home-based aerobic intervention (n = 23) relative to wait list control (n = 11). The 6-month intervention entailed 3 weekly sessions of remotely guided exercise with participants encouraged to exercise at 60%–85% maximum heart rate. A physiotherapist developed an individualised exercise program and conducted an initial home visit. Participants wore a heart rate monitor connected to an online platform which was monitored weekly by a physiotherapist who provided email feedback. Accrual rate was 25% (34/136 eligible participants) with non-participation
mainly related to lack of motivation or time to exercise. Most had a seizure history (74%). Mean adherence was 79% and 70% completed ≥75% of sessions. Reasons for non-adherence included lack of time or motivation, tiredness and fear of seizures. The majority (70%) rated the program as good or excellent, and 74% intended to continue training. Mean increase in self-reported physical activity and aerobic fitness were significantly higher in the exercise group compared to control group, although differences in body mass index were not significant. Limitations included the lack of co-design process and post-intervention follow-up.

3.8 | Cognitive rehabilitation

Sacks-Zimmerman et al.\(^{51}\) presented data on a case series of three patients with LGG, selected from a broader intervention sample (\(n = 20\)). Over 5 weeks, they completed 25 training sessions (30–45 min) of Cogmed Working Memory Training\(^{®}\) on home computers. Participants showed modest and variable improvement on standardised tests of attention, working memory and verbal memory and mood measures between the pre-intervention and post-intervention and 3-month follow-up assessments. Practice effects were not accounted for and other limitations included the lack of co-design process and data concerning accrual, adherence and intervention outcomes of the broader sample.

van der Linden and colleagues\(^{50}\) piloted the feasibility of ReMind, an iPad-based cognitive rehabilitation program for patients with LGG or meningioma, 3 months after surgery. Adapted from a face-to-face program,\(^{24}\) the 10-week (3 h p/w) telerehabilitation program comprised six compensation training modules and four attention retraining modules. Patients were contacted via telephone every 2 weeks to monitor progress and could involve significant others for support. Accrual rate was 54%, and on average, participants completed 71% of strategy training and 76% of retraining modules. Adherence (completion of ≥80%) was achieved by 54% of participants. Despite modest rates of accrual and adherence, 85% were satisfied overall with ReMind and 100% indicated that they would recommend the program to other patients. The lack of co-design process and post-intervention follow-up were the main limitations.

3.9 | Psychological support

Xiao and colleagues\(^{42}\) evaluated the effects of nurse-led continued psychological care (CPC) for people with brain tumours and caregivers. Using an asynchronous clinical control design, 162 patients (100% accrual) were allocated to CPC or the control intervention according to year of discharge. Controls received telephone-based reviews (1, 2 and 4 weeks & then monthly). CPC participants received telephone-based reviews plus home visits providing individualised psychological support and counselling. CPC participants reported significantly lower anxiety and depression at 2-week, 4-week and 3-month post-discharge and better treatment compliance (e.g., medication) at 12-month follow-up relative to controls. Key limitations were the non-randomised allocation and lack of detail on the components of CPC.

In a RCT, Boele et al.\(^{53}\) evaluated a 5-week online self-guided intervention for depression relative to a wait list. A nation-wide recruitment strategy was used, with 89 adults with glioma (79% accrual) recruited over 3.5 years. The intervention entailed five problem-solving modules with online feedback on completed exercises from a ‘coach’ (research psychologist or nurse) within 3 days. Adherence was high for the introduction (85%) and first module (77%); however, this decreased to 35% for the final module. Reasons for withdrawal included the program not meeting their needs, they no longer needed the program, they preferred a different treatment and cognitive or technical difficulties. No significant improvements were evident at post-intervention or 12-week follow-up for depression or health-related QoL. There was a trend for improved fatigue at post-intervention (\(p = .054\)). Satisfaction ratings (completed by 45%) indicated that most perceived benefits (73%), however, over 50% did not perceive changes in depression. Although the lack of co-design process was a limitation, methodological strengths included the RCT design, multi-site recruitment, detailed screening and drop-out data and lengthy follow-up.

Jones and colleagues\(^{53}\) used a multiple-baseline, across-subjects design to evaluate feasibility and efficacy of telephone-based individual psychotherapy intervention with four individuals with brain tumours. All four participants completed the 10-session program with only 13% of sessions (5/40) re-scheduled. High levels of therapeutic alliance (≥8/10) were reported and significant improvements in mental health were found at post-intervention and 6-week follow-up for two participants (50%). One participant reported auditory processing difficulties and stated a preference for face-to-face support. The lack of co-design process and non-consecutive recruitment were key limitations.

Two articles by Moscato et al.\(^{38}\) and Wade et al.\(^{39}\) reported on the feasibility, acceptability and preliminary efficacy of ‘A survivor’s journey’, a problem-solving intervention for adolescent and young adult survivors (AYAs) of paediatric brain tumour (13–25 years). Collaboratively developed with AYAs and parents,\(^{55}\) the 12–16-week intervention entailed self-guided review of four core and seven supplemental web-based modules followed by individual psychological support delivered via videoconferencing. Of the 19 participants (50% accrual), 95% completed at least the four core sessions, with an average of 8.3 sessions completed overall. Common technical problems included loss of content entered online and internet connection difficulties. The majority (>75%) were satisfied with the program and 100% would recommend it to others. Although the website was rated high in usability (M = 77/100), 29% rated the actual intervention below average on usability, with recommendations to customise content and better involve families.\(^{38}\) A within-subjects comparison showed significant improvements in self-rated global and physical QoL and parent-rated emotional QoL, but not self-rated emotional or social QoL or executive function. Greater gains in QoL were evident for AYAs diagnosed before age seven and for those with
average/above average IQ. Limitations included the non-consecutive recruitment and lack of post-intervention follow-up.

Ozier et al.\textsuperscript{44} piloted the feasibility and acceptability of a 10-session psychological support program delivered via videophone for individuals with HGG. Uniform modules on psychoeducation and cognitive and emotional functioning were delivered. Of 12 eligible participants, seven enrolled (58%) and five completed the intervention (71%). Feasibility, comfort with remote delivery and therapeutic rapport were rated high (87%–92%) despite occasional internet lagging. Satisfaction and perceived helpfulness were moderate (78%–79%). The lack of co-design process and post-intervention follow-up were main limitations.

A RCT by Milbury et al.\textsuperscript{45} evaluated the feasibility, acceptability and preliminary efficacy of a couple-based meditation (CBM) program for individuals with primary (63%) or metastatic brain tumours and their partners. Thirty-seven dyads (62% accrual) were randomly allocated to CBM or usual care. Delivered over 4 weekly sessions via FaceTime, CBM incorporated mindfulness meditation and emotional sharing activities. Overall, couples completed a mean of 3.33 sessions, with 78% attending ≥3 sessions and 67% attending all four sessions. Attrition was mainly due to death and functional decline. All participants retained at the post-assessment the intervention reported it was beneficial or very beneficial and would recommend the program to other couples. CBM participants reported significantly fewer cognitive and disease symptoms and improved intimacy than those receiving usual care; however, partners of these individuals reported no significant improvements in well-being. The non-consecutive recruitment and heterogeneous sample characteristics (primary & secondary tumours, 1–270 weeks post-diagnosis) were key limitations.

3.10 Synthesis of findings

Overall, rates of accrual (percentage enrolled) across the 16 studies ranged from 25\%\textsuperscript{49} to 100%\textsuperscript{42} (M = 68\%), whereas adherence or completion rates varied from 29\%\textsuperscript{45} to 100%\textsuperscript{42} (M = 74\%). Derived from satisfaction data (i.e., ratings of satisfaction, benefits and usability), intervention acceptability ranged from 71\%\textsuperscript{38} to 100%\textsuperscript{41} (M = 81\%) for participants completing the intervention. For studies examining levels of adherence and efficacy outcomes, there was an overall pattern of higher adherence and/or more evidence of clinical gains for interventions involving synchronous communication\textsuperscript{41–43,48,53} as opposed to asynchronous or self-guided interventions.\textsuperscript{45,47,49,50,52}

4 DISCUSSION

To date, supportive care interventions for people with brain tumours have largely been evaluated in clinical settings.\textsuperscript{11–15} As highlighted by the COVID-19 pandemic,\textsuperscript{56} there is a pressing need for remote access to information and support following discharge. This review synthesised the findings of 16 studies evaluating the use of telephone-based support,\textsuperscript{40,42,43,48,53} videoconferencing,\textsuperscript{41,44,54} web-based programs or resources\textsuperscript{45–47,49–52} or the combined use of these platforms.\textsuperscript{38} The most common focus of supportive care interventions was psychological support (38\%), followed by provision of information and education (31\%).

In terms of feasibility, rates of accrual (M = 68\%) and adherence or completion (M = 74\%) in remotely delivered interventions were generally moderate, and lower than retention rates for tele-rehabilitation programs conducted in clinic settings (>80\%).\textsuperscript{26–29} Accrual rates were lowest for a study evaluating a 6-month remotely guided exercise intervention (25\%),\textsuperscript{49} with the key reasons cited as lack of motivation or time to exercise. Rates were highest (100\%) for a psychological support program involving routine telephone-based support and home visits, which had been integrated into standard care.\textsuperscript{42} Adherence and sustained use of the telehealth platforms was also variable, with only 29\% of participants of a selected sample accessing a BTW over 3 months.\textsuperscript{45} and 35\% completing a 5-week self-guided online intervention.\textsuperscript{52} For the study by Pill et al.,\textsuperscript{45} it would have been beneficial to survey the 637 broader users to gain a more representative perspective on the utility of the BTW. Interventions involving communication in real-time with professionals typically had higher rates of adherence or completion. For example, 80\%–100\% of patients remained engaged in telephone-based support over several months in four studies.\textsuperscript{42,43,48,53} Similarly, adherence or program completion was moderate to high (63\%–95\%) in videoconferencing interventions.\textsuperscript{38,41,54}

One possible explanation for the lower accrual and adherence rates for self-guided online interventions is that participants had greater familiarity with telephone and videoconferencing platforms, which enhanced their engagement with the technology. Another likely contributing factor is that communication was initiated and maintained by professionals, who were able to provide technical support and accommodate cognitive difficulties and other potential barriers to adherence (e.g., re-scheduling appointments due to illness\textsuperscript{55}). The barriers most commonly perceived for web-based interventions included lack of technical skills, poor internet connectivity, cognitive difficulties, being busy (having other priorities) and programs not meeting their needs.\textsuperscript{38,45,50,52} Individuals may have been less motivated to engage in self-guided web-based programs that were not tailored to their personal needs or goals.\textsuperscript{45,50,52} As an exception, in the Survivor’s Journey intervention,\textsuperscript{38} AYAs selected self-guided modules according to their needs and spent an average of 22 min on each, followed by a therapy session conducted via videoconferencing. Notably, this program was developed with AYAs and parents who provided feedback on survivor needs and challenges, intervention design and content.\textsuperscript{55} This co-design process is likely to have enhanced adherence (95\% completing core sessions) and satisfaction (>75\% satisfied; 100\% would recommend it to others) with the web-based platform.

In terms of implementation outcomes, only one study examined factors influencing uptake or use of telehealth platforms.
Cahill and colleagues\textsuperscript{46} found that use of electronic personal health records was associated with higher education levels, lower performance status, being on active treatment and lower disease-related uncertainty. Timely access to information and the ability to communicate electronically with professionals may provide a greater sense of reassurance to people with brain tumours during treatment. In the broader cancer literature, Cox et al.\textsuperscript{18} similarly found that personalised care and sense of connection to health professionals were core themes underlying use of telehealth platforms.

Importantly, participants with high levels of adherence, or those completing the intervention typically reported high levels of acceptability or satisfaction (M = 81%) irrespective of the mode of communication.\textsuperscript{40,43,44,48–52} In the only study to compare mode of delivery, Patil et al.\textsuperscript{34} found that the level of satisfaction with video clinic follow-up (extremely satisfied = 80%) was comparable to conventional face-to-face follow-up (extremely satisfied = 86%). Furthermore, video follow-up was associated with less than half the costs of conventional follow-up, which is likely to be a key consideration for implementation in practice.\textsuperscript{57}

In the studies evaluating efficacy, there was mixed evidence from RCTs with non-significant findings reported by Boele and colleagues\textsuperscript{52}; yet, significant functional gains were associated with telehealth interventions in two RCTs.\textsuperscript{41,49} The evidence of efficacy was also mixed in non-randomised group,\textsuperscript{42,47} single-arm\textsuperscript{39,48} and case series designs.\textsuperscript{51,53} Irrespective of study design, functional gains were generally more evident for interventions involving tailored support and real-time interaction with professionals.\textsuperscript{39,41,48,49,53} as opposed to self-guided interventions or those providing general information or uniform modules.\textsuperscript{47,51,52} Only five interventions provided supportive care for caregivers, which included an interactive brain tumour website,\textsuperscript{45} couple-based yoga,\textsuperscript{41} psychological support\textsuperscript{42} and multi-component supportive education.\textsuperscript{40,48} Designed specifically for carers, the pilot findings of the CARE-IS program\textsuperscript{40} have informed intervention and assessment procedures for a large-scale RCT.\textsuperscript{58}

4.1 Study limitations

This review provides the first synthesis of telehealth literature specific to supportive care interventions for the adult brain tumour population. However, conclusions regarding the utility of these platforms are limited by the small number of studies meeting the inclusion criteria and heterogeneity with respect to design, intervention characteristics and telehealth platforms. Key gaps to address in future research relate to telehealth interventions focused on caregiver needs and factors influencing the adoption of platforms in practice. Only one study\textsuperscript{46} examined factors associated with platform use, which focused on individual user characteristics, but overlooked contextual factors which also influence uptake in practice.\textsuperscript{57}

4.2 Clinical implications

Previous reviews highlighted the feasibility and acceptability of clinic-based supportive care interventions for people with brain tumor.\textsuperscript{11–15} The current review findings indicate that delivery of supportive care interventions via telehealth platforms is feasible and acceptable to a high yet selected proportion of individuals with brain tumours and their caregivers. The studies reviewed reflect the advancing options and uses of technology to support health, with the earliest study in 2000 involving telephone follow-up,\textsuperscript{43} and more recent studies evaluating multi-modal systems such as interactive web-based platforms\textsuperscript{38,46} and wearable technologies.\textsuperscript{49} An interplay of factors influences uptake and sustained use of novel technologies in healthcare practice, including features of the innovation, individual adopters, social context (e.g., organisational readiness) and implementation and routinisation processes.\textsuperscript{57} Early involvement of people with brain tumours and caregivers in the design and development of telehealth platforms is essential to enhance the compatibility of the technology with their needs, resources and lifestyle. With a plethora of small studies examining efficacy of telehealth use in the literature, we propose a shift in the clinical research community to focus on real-world implementation or hybrid effectiveness/implementation studies examining the reach, effectiveness, adoption, implementation and maintenance (longer-term sustainability) of telehealth in people with brain tumours and their caregivers.

5 CONCLUSIONS

Delivery of supportive care via telehealth platforms was generally feasible and acceptable to people with brain tumours and family caregivers. Adherence was typically higher and functional gains were more evident for interventions involving tailored support and real-time interaction with professionals. Further research focused on remote delivery of supportive care for caregivers and implementation science including, but not limited to, understanding factors influencing the uptake of novel platforms in practice is recommended.

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