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ORIGINAL ARTICLE

Patients and carers' perspectives of participating in a pilot tailored exercise program during chemoradiotherapy for high grade glioma: A qualitative study

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Abstract

Objective: To describe glioblastoma patients' and carers' perspectives of participating in a tailored exercise intervention during chemoradiotherapy.

Methods: A pilot study was conducted to evaluate if exercise was a feasible and safe therapy in patients with glioblastoma undergoing chemoradiotherapy. Patients received a supervised exercise intervention involving an individualised prescription of moderate-intensity aerobic and resistance exercise twice weekly, performed at the hospital when they attended for treatment. Semi-structured interviews were conducted with participants and their carers. Recordings were analysed using thematic analysis.

Results: 19 patients and 15 carers participated. Benefits and challenges of participating in the exercise intervention were described. Benefits included an individually tailored exercise program, improvements in health, regaining a sense of control, interacting with people, keeping active and benefits for carers. Challenges included managing symptoms associated with diagnosis and treatment, juggling treatment and exercise, and difficulties engaging in the program.

Conclusion: Patients and carers expressed positive perceptions and experiences of participating in exercise during chemoradiotherapy; however, some challenges were experienced. These results support the quantitative pilot study which demonstrated that supervised exercise is feasible, safe and well tolerated by patients receiving chemoradiotherapy for glioblastoma. Randomised controlled trials now need to be conducted with this population.

KEYWORDS
carers, exercise, glioblastoma, patients, semi-structured interviews

1 | INTRODUCTION

Recent systematic reviews have concluded that exercise is a safe and effective therapy for cancer survivors (Ballard-Barbash et al., 2012; Cormie et al., 2017; Courneya & Friedenreich, 2011; Craft et al., 2012; Mishra et al., 2012). Furthermore, major health organisations internationally and in Australia recommend exercise be encouraged for this population to counteract the adverse effects of cancer and its treatment (Cormie et al., 2018; COSA Exercise & Cancer Group, 2020; Hayes et al., 2019; Schmitz et al., 2019). In

many cancers, appropriate exercise prescription has been shown to improve quality of life across multiple domains, reduce cancer-related fatigue alleviate psychological distress (Craft et al., 2012) and improve physical function (Schmitz et al., 2019). However, limited research has evaluated the potential safety, efficacy and impact of exercise for people with glioblastoma (grade IV glioma) (Cormie et al., 2015).

Glioblastomas are terminal progressive brain cancers, with a median survival of 15 months even with optimal treatment strategies (Stupp et al., 2005). Glioblastoma affects young people as well as the elderly and has a large impact on every aspect of a patient's life. Patients experience neurological and functional deficits, cognitive decline and behavioural and personality changes. They may lose function and independence early, resulting in a high social burden and financial cost to both individuals and the healthcare system.

Optimal care for glioblastoma includes maximal resection followed by chemoradiotherapy [60 Gray (Gy) in 30 fractions conformal radiotherapy concurrent with daily oral temozolomide (TMZ)], then 6 months adjuvant TMZ (Stupp et al., 2009). Shorter courses of 45 Gy in 15 fractions may be used for elderly patients (Perry et al., 2017). Chemoradiotherapy usually commences between 4 and 6 weeks following surgical resection and is delivered over 7 weeks (for 60 Gy treatment regimen). During this time, many patients are on corticosteroids such as dexamethasone, with potential toxicities including weight gain, insomnia, proximal myopathy and mood disturbance. Anticonvulsant medications may promote fatigue and somnolence. Combined chemoradiotherapy also results in significant fatigue. There are no proven pharmacological strategies which may ameliorate these common and debilitating toxicities of treatment and supportive care medications.

The potential of exercise as an intervention to aid in the management of glioblastoma is promising, especially given the corticosteroid use and functional deterioration experienced by these patients (Cormie et al., 2015). However, patients with glioblastoma can suffer considerable ill-health and a general physical activity recommendation may be inappropriate requiring more targeted exercise prescription in a supervised environment.

Preclinical research (in mice) has demonstrated voluntary exercise slows progression of high grade glioma and preserves motor function (Tantillo et al., 2020). To date, three case studies have been published demonstrating the potential and feasibility of introducing high-intensity exercise in the management of adult patients diagnosed with glioblastoma to improve physical function and mental health (Hansen et al., 2019; Levin et al., 2016; Troschel et al., 2019). Preliminary trials with adult patients (n = 23) suggest potential for improving cardiorespiratory fitness and BMI (Gehring et al., 2018) and improved cognitive function (Gehring et al., 2020). Furthermore, numerous high-quality trials have demonstrated functional and structural benefits for patients with other advanced cancers undergoing chemoradiotherapy (Samuel et al., 2019). It is important to evaluate tailored exercise medicine in patients with HGG to gather further evidence to inform patient best-practice management and understand patients' perspectives of participating in exercise during active treatment.

BOX 1 Patient Interview questions

1. Could you please tell me about your experience with the exercise program?
   a. Did you have any fears about doing the program?
   b. Were there any symptoms that limited your involvement in the exercise?
   c. What did the program involve for you?
   d. What form of exercise did you do before joining the program? How often?
2. Do you feel that your involvement in the exercise program affected your wellbeing? How?
   a. Do you feel it changed how you manage your illness physically and/or mentally? If so, how?
3. Did you feel that you were capable of participating in the program and completing all the elements within the program?
   a. What was difficult for you within the program?
   b. What aspects of the program did you enjoy?
4. Were there any aspects of the program that you feel could have been improved? How?
5. Do you plan to continue exercising? Why/why not?
6. Our purpose today was to find out more about your experience of the exercise program, particularly in relation to helping you tolerate chemoradiotherapy. Have we missed anything you'd like to discuss?
7. Before we finish, I would like to summarise what you have discussed and check that you agree with what I have understood from our discussions. The main things I have gathered from the interview today are… Do you agree with what I have said? Do you have any questions or comments?

A pilot study was conducted by our team to evaluate if exercise was a feasible and safe therapy in patients with glioblastoma undergoing chemoradiotherapy in an Australian setting (manuscript in preparation, 2021). The current study explores glioblastoma patients' and carers' perspectives of participating in a tailored exercise intervention during chemoradiotherapy.

2 | METHODS

A mixed-method design was used for the overall study. This qualitative phase used an exploratory qualitative research design drawing upon a social constructionist interpretive framework. This framework places an emphasis on understanding participants' views and

experiences. The researchers' intent was to make sense of the meanings the participants constructed (O'Connor, 2015).

Human research ethics committee approval was gained from the participating hospitals and universities. Participants and carers provided written informed consent.

2.1 | Recruitment

Patients who were 18 years or older and scheduled to receive chemoradiotherapy for glioblastoma were recruited to participate in the exercise program by their attending specialist. Carers of eligible participants were also invited to participate. Exclusion criteria included: (a) ECOG performance status >1; (b) neurological deficits precluding full participation in the program or assessments (expressive dysphasia, receptive dysphasia, and cognitive impairment); (c) acute illness or any musculoskeletal, cardiovascular or neurological disorder that could inhibit or put participants at risk from exercising; and (d) inability to read and understand English. Potential participant details were provided to independent research assistants who conducted the interviews. Recruitment to participate in the interviews occurred after patients had completed their radiotherapy and exercise sessions at the hospital.

2.2 | Procedure

2.2.1 | Exercise intervention

Patients received a supervised and individually tailored exercise intervention at the hospital when they attended for treatment. The intervention was designed in accordance with international guidelines for cancer patients undergoing treatment (Hayes et al., 2019). It involved a combination of aerobic and resistance exercise performed during three, 1-hour sessions per week for the 7-week duration of chemoradiotherapy. Sessions were conducted in groups of up to five participants with the option of carers also participating. Exercise sessions were supervised by accredited exercise physiologists and delivered at the exercise clinic within participating hospitals. The aerobic exercise component included 20–30 min of moderate to vigorous-intensity cardiovascular exercise (~60%–85% of estimated maximum heart rate) using a variety of modes such as walking on a treadmill or cycling on a stationary ergometer and incorporating both moderate continuous and high-intensity interval modes. The resistance exercise component involved 6–8 exercises that targeted the major upper and lower body muscle groups using loads that permitted 6–12 repetitions per set for 1–3 sets. Exercise prescriptions were progressive and modified according to individual response. Participants were also encouraged to undertake additional home-based aerobic exercise with the goal of progressing towards a total of 150 min of moderate-intensity aerobic exercise weekly. The exercise sessions were delivered to small groups of 1–3 patients ensuring personalised care, support and tailoring. At each session, patients were asked about their level of fatigue, pain and whether their health or medical treatment had changed. Based on this discussion, the volume and intensity of the exercises for the session were adjusted accordingly.

2.2.2 | Semi-structured interviews

Semi-structured interviews were conducted by independent research assistants via telephone with participants and their carers' to gain an understanding of their perspectives of participating in a tailored exercise intervention during chemoradiotherapy. An interview guide (Box 1) and prompts were used to elicit examples and enable participants to elaborate on their answers. Similar questions were asked of both patients and carers. All interviews were conducted between June 2014 and February 2016.

2.3 | Data analysis

Interviews were transcribed verbatim and analysed using thematic analysis. Braun and Clarke's (2006) six phases for thematic analysis were used to derive themes. These steps included familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final manuscript.

2.3.1 | Quality and rigour

Several methods of quality and rigour such as credibility, dependability and transferability were engaged (Rice & Ezzy, 1999). Data coding was completed by two researchers to identify themes and different meanings that were derived. These themes were then verified by the other investigators who reviewed them and were then involved in manuscript writing. An audit trail of all study steps and decisions was kept. To ensure transferability, we present demographic information in Table 1. The Standards for Reporting Qualitative Research (SRQR) were used to inform reporting of this study (O'Brien et al., 2014).

3 | RESULTS

Nineteen patients and 15 carers were interviewed. 14 patient carer dyads were included, 5 patients were interviewed without carers and one carer participated without the patients' participation in an interview. All patients were receiving chemoradiotherapy for glioblastoma. Patient characteristics are presented in Table 1 (n = 20). Patient (p) and Carer (c) perspectives are presented.

3.1 | Themes

The two overarching themes were benefits and challenges of participating in the tailored exercise intervention during

TABLE 1 Patient demographics

n (%)	*N* = 20
Age Mean (SD)	53.4 (11.76)
Min.-Max.	25.7–68.6
Marital status	
Single	1 (5.0)
Married/De facto	19 (95.0)
Highest level of education	
Secondary school	5 (25.0)
Trade	2 (10.0)
Certificate/diploma	7 (35.0)
Bachelor degree	3 (15.0)
Higher degree	3 (15.0)
Currently employed	
Yes	7 (35.0)
No	13 (65.0)
Months since diagnosis to initiating the exercise intervention[a]	
1 month	7 (36.8)
2 months	7 (36.8)
≥3 months	5 (26.3)
Time from surgery to initiating the exercise intervention (months)[a]	
≤1 month	5 (26.3)
>1–2 months	11 (57.9)
>2–3 months	2 (10.5)
>3 months[b]	1 (5.3)
Taking dexamethasone	
Yes	8 (40.0)
No	12 (60.0)
Prior seizure	
Yes	11 (55.0)
Seizure type[a]	
Generalised seizure	6 (54.5)
Focal motor seizure	2 (18.2)
Other partial seizure	2 (18.2)
No	9 (45.0)
On anticonvulsant when last had a seizure	
Yes	6 (54.5)
No	5 (45.5)
Comorbid conditions	
Yes	11 (55.0)
No	9 (45.0)
BMI[a]	
Healthy weight (18.5–24.9)	4 (21.1)
Overweight (25.0–29.9)	14 (73.7)
Obese (≥30.0)	1 (5.3)

[a]Contains missing data.

[b]Patient received surgery, then was treated with chemoradiotherapy in the context of radiological transformation to high grade glioma.

chemoradiotherapy. Subthemes were grouped in relation to the benefits and challenges of participating in the intervention (Table 2). Benefits included having an individually tailored exercise program designed by an exercise specialist, improvements in health, regaining a sense of control, interacting with people, keeping active and benefits for carers. Challenges included managing symptoms associated with diagnosis and treatment while participating in the program, juggling treatment and exercise and difficulties engaging in the program.

3.1.1 | Benefits

Individualised program

Both patients (P) and carers (C) reported benefits of participating. The exercise physiologists' efforts to personalise activities according to patients' physical ability was recognised by patients and carers:

> *They actually designed a program around what he could do so that was very good.*
>
> (C18)

> *It was all tailored and the trainer was monitoring me. When she could see that I was taxed she eased off a little.*
>
> (P17)

Participants valued the adjustments made by the staff to accommodate fluctuating abilities, symptoms and side effects:

> *Some days he couldn't complete all elements of the program and they wouldn't push him. They'd let him do as much as he could.*
>
> *(C6)*

Improvements in health

Many improvements in health and wellbeing were reported by patients and carers. Improvements in health were further categorised as improvements in physical or psychological health.

Improvements in physical health

Several patients reported improvements in overall fitness:

> *I think it helps with your fitness because otherwise it would drop off with the drugs and things.*
>
> (P14)

> *I'm feeling so much better through the gym work and even my wife has been amazed about how very fit I've become.*
>
> (P22)

TABLE 2 Perspectives of exercise during chemoradiotherapy for HGG

Themes	Subthemes
Benefits	• Having an individually tailored exercise program designed by an exercise specialist • Improvements in health Improvements in physical health Improvements in psychological health • Regaining a sense of control • Interacting with people • Keeping active • Benefits for carers
Challenges	• Managing symptoms while participating in program • Juggling treatment and exercise • Difficulties engaging with the program

Others reported more specific improvements:

> *I wanted to make sure that [with] my arms and my legs, that I maintain the strength of them as long as I can, so I really thought it was beneficial from that aspect.*
>
> (P15)

Several participants reported the benefits of exercise in counteracting the adverse effects of corticosteroids on muscle wasting and functional capacity:

> *She hasn't lost as much muscle mass as she probably could have if she didn't do the exercises.*
>
> (C21)

> *Even my wife has noticed how strong my legs are because when I came out of hospital I was completely withered. I was on… a bucket load of steroids.*
>
> (P22)

Beneficial changes in weight were noted by several patients and their carers:

> *He has been able to drop a lot of weight, which has been good for him because he was overweight.*
>
> (C22)

This patient also described improved blood glucose levels:

> *With all the weights and isometrics and everything else … it has aided me in keeping my sugar levels down.*
>
> (P22)

Exercise was seen by some as a way of alleviating adverse effects of treatment:

> *Radiation and chemotherapy made me very tired, but I felt the exercise made me feel a little bit better.*
>
> *(P2)*

> *The exercise has been absolutely essential … [it] insulated me for the first four weeks from any adverse effects from radiotherapy.*
>
> *(P22)*

Improvements in psychological well-being

Participants also experienced improvements in psychological well-being. This carer noted enhanced self-image and confidence:

> *It gave him self-esteem. I noticed that he was taking a bit more care how he dressed.*
>
> (C4)

Patients noted that exercise reduced stress and improved mood:

> *It gave me a focus and it relaxed me even though I was very weary at the end of it.... If I hadn't had it I would have continued in deep depression.*
>
> (P17)

Carers perceived exercise as an important aid to improving mood during the demanding treatment regimens:

> *[Treatment] is a fairly gruelling process for them so I certainly think it was great helping stave off any depression. I think it did actually help him just cope with the day not just the treatment, but the whole thing of getting up there and back again.*
>
> (C12)

Carers also discussed the benefits of exercise as a distraction and positive alternative focus:

> *It was good and I know that he is not going to sit around and feel sorry for himself.*
>
> *(C18)*

Regaining a sense of control

Regaining control was an important benefit experienced with patients feeling empowered through involvement in exercise:

It has made me feel I'm playing my part, it's not just the medication and the radiotherapy … and that I'm doing something for myself, with the diet, the meditation and the exercise…

(P22)

You feel like you can actually be useful towards getting through it. Whereas everything else makes you feel pretty useless.

(P1)

Patients also felt feelings of accomplishment:

It gave me a sense of completion, of achievement, doing something.

(P13)

Regaining a sense of control was also a theme emerging from the carers:

He'd lost a lot of control of his own life and having this exercise program was putting some control back into his life.

(C4)

Interacting with people

Benefits of social interaction were discussed by both patients and carers. Patients reflected on the enjoyment of socialising with other participants:

I enjoyed the social side of just meeting people, the same people each time.

(P14)

The importance of peer relationships in support through the cancer experience, which the program facilitated, was expressed as follows:

You were doing it with other people. It was good …that 10-15 minutes while you were doing your exercises chatting to them about kind of their situation, your situation and knowing that other people are in the same kind of boat as you.

(P11)

Keeping active

Keeping active referred to the benefits of exercise as a distraction and relief from adverse effects. Several patients reported the benefits of doing physical activity rather than sitting at home:

It made things slightly better because it got me off the couch.

(P13)

It was a great idea because you've got to do it and it kept me going [and]… I knew that my body needed something.

(P6)

Patients also reported more specific benefits:

With chemo and radiation you generally just want to sleep and sit around and do nothing, whereas with the program you've got to actually get up and do something.

(P10)

Keeping active was an important way of providing a positive focus:

He likes doing the exercise…it gave him something positive to focus on

(C12);

I found myself getting annoyed or angry just not having anything to do…doing the exercise gave me something to do and … took my mind off things.

(P11)

A planned exercise intervention scheduled into the treatment program facilitated these benefits:

The nice thing about set times is that you don't make excuses especially if there are two of you to egg [encourage] each other on.

(C8)

The value of having a supervised exercise program was highlighted:

At least when you're there you're committed to doing the exercises rather at home where you may or may not do them fully.

(C21)

Both patients and carers report that keeping active through the scheduled program led to additional self-initiated activity:

She has done a lot more exercise on her own as a result of doing the program

(C8);

Even on the days when I haven't been able to get down to the gym… I've still worked out at home or gone for a run.

(P22)

For several participants, exercise became enjoyable again and the benefits of physical activity also encouraged them to continue exercise beyond the study:

I found it a very enjoyable activity, something that I looked forward to every day on the three days a week that I did it.

(P9)

Enjoyment influenced motivations for longer-term persistence with exercise:

I'm going to continue going to the gym with the exercise physiologist.

(P2)

The system is there and the opportunity there to use the facility I will [use it in the long term].

(P1)

Carers also expressed their support for patients continuing to exercise:

We'll try to get her to keep going and she will [continue to] benefit.

(C21)

Additionally, the following carer saw the benefit of continued engagement in an exercise program for both of them:

[Patient's name] will continue doing the exercise because she recognises that doing some exercise is potentially a good thing… and if she can do it with me then that's a bonus.

(C15)

Benefits for carers

In addition to patient benefits, there were several benefits specific to carers. These included having a break from caring and sharing positive experiences. Having time to themselves while their family member was involved in the exercise was an important benefit for some:

I actually took those times to go for a walk … I knew that [name] was safe and he was there so I took the time to get some timeout to be honest.

(C1)

Sharing time together doing exercise was also seen as an enjoyable activity and a break from routine:

It was a beautiful opportunity for me to be able to actually still get out there and do something and not have to worry … he was in an environment that is safe for him.

(C21)

The following carer had a similar experience:

It was really lovely because it put us both on equal footing… we were just two people in a gym doing an exercise routine and for me it was really good to be able to see [Name] doing something that was independent and normal. It reminded me that even though he may have this disease he is not… incapable…It gave us both something else to talk about other than the cancer.

(C12)

3.1.2 | Challenges

In addition to the benefits, several challenges were identified including; managing symptoms, adverse effects of treatment and difficulties engaging in the program.

Managing symptoms

Managing symptoms were a significant challenge for some patients. Symptoms impacting on patients' participation included fatigue, imbalance, headache, nausea, weakness and dizziness. Dizziness and fatigue made it difficult for patients to exercise:

I couldn't complete the whole routine because of dizziness.

(P2)

I think it was just probably because of fatigue…"

(P1)

Difficulties in managing symptoms and toxicities of treatment impacted on patients' experiences of exercising with several reporting medication side effects:

They changed them [my steroids] and there were quite a few times when I had severe headaches and nausea and there was probably three times that I didn't do sessions.

(P3)

Other treatments also produced side effects affecting participation:

The treatment and illness did make her very tired and so doing the exercise program did tend to tire her out quite a bit.

(C15)

He was having a lot of problems with the radiotherapy, the [cerebral] oedema and there would be quite a few days where he'd say, 'Oh, I just feel awful'.

(C22)

When he was in the middle of his treatment he found it very exhausting, but he still went.

(C5)

Juggling treatment and exercise

Some patients and carers highlighted the challenge of combining a treatment regime and an exercise program. Some viewed the exercise program as another appointment to endure:

So the exercise program was on top of all the therapy that I was having.

(P15)

At times treatments and procedures conflicted with program appointments:

At the beginning we were doing more exercises, but then because of having to take bloods and all the other things, it just got too difficult, so we went for two days a week instead of three.

(C21)

Carers were frequently juggling other commitments, which made transporting family members to the program difficult:

The timing for me was a bit hard because I was picking up my little granddaughter… but that's just our life, that's not the program's fault.

(C19)

Fitting the exercise around other treatments was frequently seen a challenge:

Sometimes the appointments, even though you sort of schedule it, they go maybe an hour overdue and it made it hard to get to the exercise.

(C21)

Some participants had long travel distances, which also presented difficulties:

I'd have my treatment [and] I'd do the program then I had to travel an hour and a half to get home by public transport.

(P3)

Difficulties engaging in the program

In addition to managing symptoms and juggling treatments, several difficulties engaging with the program were identified. Some participants expressed initial concerns about what the program would entail and whether they would be able to cope with the demands:

I was just wary about the whole thing.

(P19)

I wasn't sure if she was going to be up for it because with the treatment it can make you feel quite awful.

(C8)

Some patients had difficulty with the program due to the diverse patient groups they were exercising with:

I didn't meet any people with brain tumours. They were all older men with prostate cancer so it wasn't like what I had envisaged.

(P21)

4 | DISCUSSION

Overall, this qualitative study demonstrated that the tailored exercise program was enjoyed by patients and participating helped them feel actively involved in managing their cancer, and physically stronger, providing them with a sense of control. This pilot study also demonstrated that the supervised exercise intervention was safe and feasible in this population (manuscript in preparation, 2021). Although patients participating in the pilot study experienced significant symptoms and side effects of their treatment, they identified during interviews that they were able to continue the exercise program because it was tailored to how they were feeling each session. Carers were supportive of the program, highlighting that participation improved patient physical and psychological well-being, and provided carers with a break from caring. This pilot research builds on recent preliminary research introducing exercise interventions to glioma patients which suggest trends in improvements to cardiorespiratory fitness and reduced BMI (Gehring et al., 2018), and the potential to maintain and/or improve functional performance, mental health and quality of life (Hansen et al., 2019; Levin et al., 2016; Troschel et al., 2019).

This study found that the tailored exercise program supervised by accredited exercise physiologists in a clinic setting resulted in considerable benefits for both patients and carers. Several studies in other groups of patients diagnosed with cancer have demonstrated that exercise can ameliorate treatment effects including fatigue, distress and functional decline (Cormie et al., 2015; Craft et al., 2012; Cramp & Byron-Daniel, 2012; Galvao et al., 2010; Liu & Latham, 2009; Mishra et al., 2012; Yang et al., 2012). Our study also highlights some of the challenges patients diagnosed with glioblastoma and their carers face when managing treatment-related appointments and juggling other commitments with scheduled exercise interventions. A key consideration when devising exercise interventions for this population is the importance of tailoring sessions to an individual's capacity on a daily basis. This clinical strategy is termed

'autoregulation' of exercise programming and is recommended in the current Australian guidelines for exercise medicine in cancer management (Hayes et al., 2019). Further, it is important, as much as is feasible, to group participants with a similar disease type, and provide allowance for flexible scheduling where possible.

The current study also explored the carers' perspectives, capturing an important insight into this group who are vital in supporting patients diagnosed with glioblastoma. Our previous work has demonstrated the impact that glioblastoma has on carers, the range of roles that they play, their unmet needs, and the high levels of distress they experience (Halkett et al., ,2017, 2018; Long et al., 2016). Carers valued the choice to concurrently participate in exercise or not. Those who exercised also reported benefits to their own well-being, which may assist in reducing distress. Those who chose not to exercise found time alone valuable. Including an element of choice for carer, participation may enhance carer well-being and potentially support patient compliance and participation.

Future larger studies should be conducted to demonstrate the role of exercise in people with glioblastoma. Cordier et al., (2019) recently published a protocol describing an RCT testing two types of exercise training with HGG patients. This initial research highlights the importance of providing patients with the opportunity to exercise and actively participate in their own treatment plan. Furthermore, this program was largely supported by carers who also found benefits for themselves through the patient's participation.

A limitation of this study was that it was not possible to interview those who chose not to participate in the program. However, this study demonstrates that for those who did participate, they enjoyed the program and found it beneficial in a range of ways. These results also support the quantitative pilot study which demonstrated that supervised exercise is feasible, safe and well tolerated by patients receiving chemoradiotherapy for glioblastoma (manuscript in preparation 2021).

5 | CONCLUSION

This study was the first to explore adult patients' and carers' perspectives of the benefits and challenges of a tailored exercise program while undergoing chemoradiotherapy for glioblastoma. The results provide important information from the patient and carer perspective and highlight the challenges experienced when juggling treatments, symptoms and a scheduled exercise program. These insights will be useful when designing future exercise programs for patients with cancer and provide opportunities to maximise the patient experience. Further research is warranted to demonstrate, using randomised controlled trials, any quality of life and survival benefits of exercise for patients diagnosed with glioblastoma.

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CONFLICT OF INTEREST

Nil to declare.

AUTHOR CONTRIBUTIONS

All authors made significant contributions to this project. PC, AN, GH, DG and RN obtained the funding for the overall project. GH led the qualitative phase of the project, thematic analysis and writing of the manuscript. SM and GH undertook the qualitative analyses. All authors involved in verification of themes. All authors contributed to manuscript writing, provided feedback and gave final approval for the article submitted.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES

Ballard-Barbash, R., Friedenreich, C. M., Courneya, K. S., Siddiqi, S. M., McTiernan, A., & Alfano, C. M. (2012). Physical activity, biomarkers, and disease outcomes in cancer survivors: A systematic review. *Journal of the National Cancer Institute*, *104*(11), 815–840. https://doi.org/10.1093/jnci/djs207

Braun, V., & Clarke, V. (2006). Using thematic analysis. *Qual Research in Psychol*, *3*(2), 77–101.

Cordier, D., Gerber, M., & Brand, S. (2019). Effects of two types of exercise training on psychological well-being, sleep, quality of life and physical fitness in patients with high-grade glioma (WHO III and IV): Study protocol for a randomized controlled trial. *Cancer Communications*, *39*(1), 46. https://doi.org/10.1186/s40880-019-0390-8

Cormie, P., Atkinson, M., Bucci, L., Cust, A., Eakin, E., Hayes, S., McCarthy, S., Murnane, A., Patchell, S., & Adams, D. (2018). Clinical Oncology Society of Australia position statement on exercise in cancer care. *Medical Journal of Australia*, *209*(4), 184–187. https://doi.org/10.5694/mja18.00199

Cormie, P., Galvão, D. A., Spry, N., Joseph, D., Chee, R., Taaffe, D. R., Chambers, S. K., & Newton, R. U. (2015). Can supervised exercise prevent treatment toxicity in prostate cancer patients initiating androgen deprivation therapy: A randomised controlled trial. *BJU International*, *115*(2), 256–66.

Cormie, P., Nowak, A. K., Chambers, S. K., Galvao, D. A., & Newton, R. U. (2015). The potential role of exercise in neuro-oncology. *Frontiers in Oncology*, *5*, 85. https://doi.org/10.3389/fonc.2015.00085

Cormie, P., Zopf, E. M., Zhang, X., & Schmitz, K. H. (2017). The impact of exercise on cancer mortality, recurrence, and treatment-related adverse effects. *Epidemiologic Reviews*, *39*(1), 71–92. https://doi.org/10.1093/epirev/mxx007

COSA Exercise and Cancer Group (2020). *COSA Position Statement on Exercise in Cancer Care (Version 3, December 2020)*. Retrieved from https://www.cosa.org.au/media/332757/cosa-position-statement-v3-dec2020-web-final.pdf

Courneya, K. S., & Friedenreich, C. M. (Eds.) (2011). *Physical activity and cancer*. Springer.

Craft, L. L., Vaniterson, E. H., Helenowski, I. B., Rademaker, A. W., & Courneya, K. S. (2012). Exercise effects on depressive symptoms in cancer survivors: A systematic review and meta-analysis. *Cancer Epidemiology, Biomarkers and Prevention*, *21*(1), 3–19. https://doi.org/10.1158/1055-9965.EPI-11-0634

Cramp, F., & Byron-Daniel, J. (2012). Exercise for the management of cancer-related fatigue in adults. *Cochrane Database Systematic Review*, *11*, CD006145. https://doi.org/10.1002/14651858.CD006145.pub3

Galvao, D. A., Taaffe, D. R., Spry, N., Joseph, D., & Newton, R. U. (2010). Combined resistance and aerobic exercise program reverses muscle loss in men undergoing androgen suppression therapy for prostate cancer without bone metastases: A randomized controlled trial. *Journal of Clinical Oncology*, *28*(2), 340–347.

Gehring, K., Kloek, C. J., Aaronson, N. K., Janssen, K. W., Jones, L. W., Sitskoorn, M. M., & Stuiver, M. M. (2018). Feasibility of a home-based exercise intervention with remote guidance for patients with stable grade II and III gliomas: A pilot randomized controlled trial. *Clinical Rehabilitation*, *32*(3), 352–366. https://doi.org/10.1177/0269215517728326

Gehring, K., Stuiver, M. M., Visser, E., Kloek, C., van den Bent, M., Hanse, M., Tijssen, C., Rutten, G. J., Taphoorn, M. J. B., Aaronson, N. K., & Sitskoorn, M. M. (2020). A pilot randomized controlled trial of exercise to improve cognitive performance in patients with stable glioma: A proof of concept. *Neuro-Oncology*, *22*(1), 103–115. https://doi.org/10.1093/neuonc/noz178

Halkett, G. K., Lobb, E. A., Shaw, T., Sinclair, M. M., Miller, L., Hovey, E., & Nowak, A. K. (2017). Distress and psychological morbidity do not reduce over time in carers of patients with high-grade glioma. *Supportive Care in Cancer*, *25*(3), 887–893. https://doi.org/10.1007/s00520-016-3478-6

Halkett, G., Lobb, E., Shaw, T., Sinclair, M., Miller, L., Hovey, E., & Nowak, A. (2018). Do carer's levels of unmet needs change over time when caring for patients diagnosed with high-grade glioma and how are these needs correlated with distress? *Supportive Care in Cancer*, *26*(1), 275–286.

Hansen, A., Sogaard, K., & Minet, L. R. (2019). Development of an exercise intervention as part of rehabilitation in a glioblastoma multiforme survivor during irradiation treatment: A case report. *Disability and Rehabilitation*, *41*(13), 1608–1614. https://doi.org/10.1080/09638288.2018.1432707

Hayes, S. C., Newton, R. U., Spence, R. R., & Galvao, D. A. (2019). The Exercise and Sports Science Australia position statement: Exercise medicine in cancer management. *Journal of Science and Medicine in Sport*, *22*(11), 1175–1199. https://doi.org/10.1016/j.jsams.2019.05.003

Levin, G. T., Greenwood, K. M., Singh, F., Tsoi, D., & Newton, R. U. (2016). Exercise improves physical function and mental health of brain cancer survivors: Two exploratory case studies. *Integrative Cancer Therapies*, *15*(2), 190–196. https://doi.org/10.1177/1534735415600068

Liu, C. J., & Latham, N. K. (2009). Progressive resistance strength training for improving physical function in older adults. *Cochrane Database of Systematic Reviews*, (3), 267. https://doi.org/10.1002/14651858.CD002759.pub2

Long, A., Halkett, G., Lobb, E., Shaw, T., Hovey, E., & Nowak, A. (2016). Carers of patients with high-grade glioma report high levels of distress, unmet needs, and psychological morbidity during patient chemoradiotherapy. *Neuro-Oncology Practice*, *3*(2), 105–112.

Mishra, S. I., Scherer, R. W., Geigle, P. M., Berlanstein, D. R., Topaloglu, O., Gotay, C. C., & Snyder, C. (2012). Exercise interventions on health-related quality of life for cancer survivors. *Cochrane Database Systematic Review*, *8*, CD007566. https://doi.org/10.1002/14651858.CD007566.pub2

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

O'Connor, M. K. (2015). *Social work constructivist research* (Vol. *1134*). Routledge.

Perry, J. R., Laperriere, N., O'Callaghan, C. J., Brandes, A. A., Menten, J., Phillips, C., Fay, M., Nishikawa, R., Cairncross, J. G., Roa, W., Osoba, D., Rossiter, J. P., Sahgal, A., Hirte, H., Laigle-Donadey, F., Franceschi, E., Chinot, O., Golfinopoulos, V., Fariselli, L., … Trial, I. (2017). Short-course radiation plus temozolomide in elderly patients with glioblastoma. *New England Journal of Medicine*, *376*(11), 1027–1037. https://doi.org/10.1056/NEJMoa1611977

Rice, P., & Ezzy, D. (1999). *Qualitative research methods: A health focus*. Oxford University Press.

Samuel, S. R., Maiya, A. G., Fernandes, D. J., Guddattu, V., Saxena, P. U. P., Kurian, J. R., Lin, P. J., & Mustian, K. M. (2019). Effectiveness of exercise-based rehabilitation on functional capacity and quality of life in head and neck cancer patients receiving chemoradiotherapy. *Supportive Care in Cancer*, *27*(10), 3913–3920. https://doi.org/10.1007/s00520-019-04750-z

Schmitz, K. H., Campbell, A. M., Stuiver, M. M., Pinto, B. M., Schwartz, A. L., Morris, G. S., Ligibel, J. A., Cheville, A., Galvao, D. A., Alfano, C. M., Patel, A. V., Hue, T., Gerber, L. H., Sallis, R., Gusani, N. J., Stout, N. L., Chan, L., Flowers, F., Doyle, C., … Matthews, C. E. (2019). Exercise is medicine in oncology: Engaging clinicians to help patients move through cancer. *CA: A Cancer Journal for Clinicians*, *69*(6), 468–484. https://doi.org/10.3322/caac.21579

Stupp, R., Hegi, M. E., Mason, W. P., van den Bent, M. J., Taphoorn, M. J., Janzer, R. C., Ludwin, S. K., Allgeier, A., Fisher, B., Belanger, K., Hau, P., Brandes, A. A., Gijtenbeek, J., Marosi, C., Vecht, C. J., Mokhtari, K., Wesseling, P., Villa, S., Eisenhauer, E., … National Cancer Institute of Canada Clinical Trials, G. (2009). Effects of radiotherapy with concomitant and adjuvant temozolomide versus radiotherapy alone on survival in glioblastoma in a randomised phase III study: 5-year analysis of the EORTC-NCIC trial. *Lancet Oncology*, *10*(5), 459–466. https://doi.org/10.1016/S1470-2045(09)70025-7

Stupp, R., Mason, W. P., van den Bent, M. J., Weller, M., Fisher, B., Taphoorn, M. J. B., Belanger, K., Brandes, A. A., Marosi, C., Bogdahn, U., Curschmann, J., Janzer, R. C., Ludwin, S. K., Gorlia, T., Allgeier, A., Lacombe, D., Cairncross, J. G., Eisenhauer, E., & Mirimanoff, R. O. (2005). Radiotherapy plus concomitant and adjuvant temozolomide for glioblastoma. *New England Journal of Medicine*, *352*(10), 987–996.

Tantillo, E., Colistra, A., Baroncelli, L., Costa, M., Caleo, M., & Vannini, E. (2020). Voluntary physical exercise reduces motor dysfunction and hampers tumor cell proliferation in a mouse model of glioma. *International Journal of Environmental Research and Public Health*, *17*(16), 5667. https://doi.org/10.3390/ijerph17165667.

Troschel, F. M., Brandt, R., Wiewrodt, R., Stummer, W., & Wiewrodt, D. (2019). High-intensity physical exercise in a glioblastoma patient under multimodal treatment. *Medicine and Science in Sports and Exercise*, *51*(12), 2429–2433. https://doi.org/10.1249/MSS.0000000000002067

Yang, P. Y., Ho, K. H., Chen, H. C., & Chien, M. Y. (2012). Exercise training improves sleep quality in middle-aged and older adults with sleep problems: A systematic review. *Journal of Physiotherapy*, *58*(3), 157–163. https://doi.org/10.1016/S1836-9553(12)70106-6

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