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Empower GBM: A pilot study of a patient–caregiver supportive intervention for patients with glioblastoma

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Abstract

Objectives. The aim of this article is to develop and pilot test a new supportive care intervention, Empower GBM, designed for patients with glioblastoma and their family caregivers to reduce psychological distress and improve quality of life.

Methods. Qualitative interviews were conducted with patients diagnosed with glioblastoma and their caregivers to obtain information about their experiences and needs in coping with glioblastoma. We also gathered their feedback about the supportive care intervention we were proposing (Phase I). Following Phase I, we conducted a single-arm pilot to evaluate the feasibility and acceptability of the 6-session intervention (Phase II).

Results. During interviews ($N = 14$), patients and caregivers reported having the most difficulty and distress surrounding disease progression and management, maintaining dignity and autonomy, negotiation of roles and responsibilities, and maintaining connection with one another. Participants endorsed that an intervention like Empower GBM with skills focused on managing symptoms to increase independence, increasing caregiving efficacy and support, and coping with dyadic challenges would be of potential benefit. Preliminary results from the pilot study ($N = 11$) suggested the intervention is both feasible (e.g., 82% completed all 6 sessions and post-treatment surveys) and acceptable (88.9% reported a mean satisfaction score of 3 or higher; mean score of 3.57/4.0). Improvements in psychological outcomes, functional well-being, and caregiving efficacy from pre- to post-treatment survey results suggested the potential benefits of the intervention.

Significance of results. We developed a novel supportive care intervention informed by the dyadic illness model that is designed to meet the individual and interpersonal needs of patients with glioblastoma and their caregivers. Unique features include its flexibility to be delivered to patients and/or their family caregivers individually or jointly, while providing skills and strategies to meet the needs of both individuals and the dyad as the unit of care in coping with glioblastoma.

Introduction

Glioblastoma is a highly aggressive brain tumor (Ostrom et al. 2018) with a median survival of 13.5 months post-diagnosis and a cumulative 5-year survival of 5.8% (Marenco-Hillembrand et al. 2020). Due to the rapid progression of GBM, psychological distress (e.g., symptoms of anxiety and depression) is common for patients as their quality of life becomes significantly impaired due to reductions in functional independence, cognitive difficulties (e.g., executive dysfunction, memory and motor deficits), and aphasia (Mugge et al. 2020; Renovanz et al. 2020).

The psychological sequelae of glioblastoma also profoundly affect family caregivers. Family caregivers of glioblastoma patients are often responsible for providing support and coordinating patients' healthcare needs and communication, learning and navigating the healthcare system, and coping with changes in roles and responsibilities within their family system. These role changes may result in a loss of equality within the patient and caregiver relationship, leaving caregivers with fewer opportunities for self-care and at an increased risk for psychological distress (Giammalva et al. 2018; O'Keeffe et al. 2021). Additionally, caregivers experiencing high caregiver burden are more likely to report lower levels of resiliency, less likely to be informed and engaged in self-care, and less likely to have coping mechanisms to manage their loved one's glioblastoma diagnosis (Wu et al. 2022).

Given the negative impacts of this disease on both patients and family members, there is emerging research on interventions designed to support patients, caregivers, and the patient–caregiver dyad. For example, one study provided patients with a 6-session intervention focused

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on symptom management, healthcare communication, meaning, and future planning (Loughan et al. 2022). Another study offered caregivers cognitive-behavioral, coping, and acceptance-based strategies to reduce their distress and improve self-efficacy (Forst et al. 2024). There have also been patient-focused interventions that encourage but do not require caregiver participation (e.g., Loughan et al. 2022; Ownsworth et al. 2023), yet outcomes have been primarily focused on the patients or found no positive benefits for the caregiver, perhaps because their participation was optional. Dyadic studies have included a single-session intervention in which dyads engaged in a brief discussion of personal and/or healthcare goals (Ketcher et al. 2020) and a dyadic yoga intervention to enhance quality of life and reduce caregiver burden (Milbury et al. 2019). Thus, while there have been a number of interventions that show promise in improving outcomes for patients with glioblastoma and their caregivers, there have been very few interventions focused specifically on patient–caregiver communication or other interpersonal processes.

Considering that GBM affects patients, caregivers, and their relationships, our goal was to develop a supportive care intervention that meets both individual and interpersonal needs (e.g., communication skills training) and equally supports both the patient and their family caregiver as the unit of care. In addition, our intervention is designed to be delivered flexibly to the dyad, patient, or caregiver.

The intervention we propose, Empower GBM, is informed by the theory of dyadic illness management (Lyons and Lee 2018), which theorizes that appraisal and management of illness is dyadic in nature and that it is imperative to optimize the health of each dyad member and the dyad itself. In developing the intervention content, we drew on evidence-based treatments including Cognitive Behavioral Therapy (thoughts, behaviors, feelings), Acceptance and Commitment Therapy (values, mindfulness), and Cognitive Behavioral Couple Therapy (relationship as context, communication). Overall, Empower GBM provides patients and caregivers with information, skills, and strategies to improve distress, manage symptoms, improve communication, and enhance their individual and relational well-being.

In Phase I of the project, we conducted interviews with patients and caregivers to understand their unmet needs, as well as to obtain feedback and suggestions to further develop and refine the intervention protocol. In Phase II of the project, we conducted a single-arm pilot test to evaluate the feasibility and acceptability of the intervention and included assessments that focused on both patient and caregiver outcomes.

Phase I: Refinement of the Empower GBM intervention

Phase I: Methods

The study utilized the following eligibility criteria for Phases I and II of the study. Inclusion criteria for patients and their family caregivers included (1) self-referral to the study through the Glioblastoma Foundation (https://glioblastomafoundation.org), (2) age 18 years or older, and (3) English speaking. Exclusion criteria for patients and their family caregivers included (1) being unable to provide consent/assent, (2) having visual or hearing impairments that precluded participation, or (3) being too sick to participate.

All study procedures were approved by the Duke University Health System Institutional Review Board (Pro00110738). The study is registered through ClinicalTrials.gov (NCT#06038604).

Table 1. Coping skills and strategies presented in interviews

Skill	Description and presentation
Strategies to manage common patient symptoms	Discuss strategies to manage and cope with common patient symptoms such as changes in cognition, mood, and personality and behavior with caregivers.
Brief relaxation	Guide patients and caregivers as they learn and practice a brief relaxation exercise. Interviewer provides rationale for relaxation as a tool to manage stress and worry.
Strategies to manage cognitive changes/declines	Offer caregivers tools and ideas to adapt and enhance cognitive management changes in patients. Offer communication and organizational tips that allow for patient independence and help manage caregiver burden.
Self-care	Offer psychoeducation regarding the importance and benefits of self-care.
Pleasant activity scheduling	Discuss the importance of pleasant activity scheduling. Guide patients and caregivers in selecting enjoyable and meaningful activities for self-care and for completing together.

Participants and their family caregivers received a study advertisement from the Glioblastoma Foundation detailing the aims and scope of our study, and the foundation provided the research team with contact information of interested individuals. The study staff then contacted interested individuals to provide more information about the study, assessed the participants' eligibility criteria (e.g., do you have any visual or hearing impairments?), and answered any study-related questions. Informed consent was obtained from all participants for Phases I and II.

Interview procedures

For Phase I, using a standardized interview guide developed by our study team, we collected participants' demographic information and conducted a 60-minute interview. During the interview, we asked participants about their experience with a glioblastoma diagnosis (e.g., past and current treatments, symptoms and side effects of treatment, and emotional reactions), relationship type and length, and caregiving challenges experienced. We then presented the goals of the study and obtained feedback regarding the format of the intervention, including (1) completing specific sessions individually or as a dyad, (2) frequency of sessions (e.g., weekly and biweekly), and (3) delivery of sessions using a video-conference format. Additionally, we described anticipated session topics (e.g., relaxation, self-care, and pleasant activity scheduling; see Table 1 for session descriptions) and elicited participants' feedback about each session. Patients and family caregivers each received $20 for completing the interview. All interviews were audio-recorded and transcribed.

Interview analyses

The interview transcripts were systematically evaluated, with the study team (K.R., L.S.P., and K.L.) reviewing and analyzing each transcript using thematic coding (Braun and Clarke 2006; Hsieh and Shannon 2005). Following 14 interviews, the study team determined that thematic saturation had been reached. To examine participant responses and reactions to the proposed intervention content, delivery, and format, 2 coders (K.L. and K.R.) independently rated each participant's responses to the skills presented as positive, neutral, or negative. A total of 94% (98/104) of response

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ratings were consistent across coders, and the remaining discrepant ratings (i.e., 6%) were resolved through discussion with a third coder (L.S.P.).

Phase I: Results

Of the 19 dyads approached, 14 caregivers and 4 patients participated in the interviews. Four patient–caregiver dyads completed the interview together, and 10 caregivers completed the interview individually. Patients' mean age was 53.5 (SD = 6.4), and all patients identified as male. Caregivers' mean age was 54.6 (SD = 14.3); 13 caregivers identified as female, and 1 caregiver identified as male. Twelve caregivers were spouses, 1 was a daughter, and 1 was a sister of the patient. Time since diagnosis as reported by patients and/or caregivers was approximately between 3 and 49 months (mean of 15.9 months). In describing their experiences with glioblastoma, several themes emerged for patients and caregivers. For patients, the most salient themes were fears around disease progression and distress around maintaining dignity and independence. For caregivers, themes included (1) emotional distress from having to adapt to the emotional and physical demands of the glioblastoma diagnosis; (2) difficulty with changes in roles and responsibilities, specifically taking on the primary role and major responsibilities in various settings and contexts; (3) feeling unsure of how to cope with the uncertainty of disease progression; and (4) balancing patients' dignity and autonomy with their declining function and need for assistance. As dyads, participants reported concerns around care planning, negotiation of roles within the relationship, and maintaining activities and connection with each other.

Regarding the format and delivery of the program, 71% of patients and caregivers responded positively to the proposed length (6 sessions), 93% responded positively to the frequency of sessions (weekly or every other week), and 86% responded positively to the videoconference format. Specifically, patients and caregivers reported that they appreciated the flexibility to attend sessions alone as caregivers or to be able to attend sessions together as a dyad (caregiver–patient), given the fluctuating nature of glioblastoma symptoms and progression of the disease. Caregivers also noted that attending sessions individually would provide them with much-needed support, focus, and time to learn how to manage and cope with glioblastoma. In terms of session frequency, patients and caregivers reported that 6 sessions conducted weekly, or every other week, would be feasible. Patients and caregivers liked that the videoconference format would allow for "face-to-face" interactions while simultaneously allowing for increased flexibility, access, and reach.

Regarding the intervention content, a total of 79% of patients and caregivers responded positively to strategies to manage cognitive changes and declines, and 79% responded positively to strategies to manage other common patient symptoms. Patients and caregivers reported that these strategies would be helpful and that they would have benefited from learning these strategies earlier following the diagnosis.

Most patients and caregivers (93%) responded positively to the brief relaxation exercise demonstrated during the interview. They expressed that the relaxation exercise would help with managing and reducing negative emotions such as stress and anxiety, especially when feeling overwhelmed (e.g., increasing patience and facilitating time to think of solutions). Patients and caregivers also responded positively to self-care; 79% of caregivers and patients expressed the importance and benefits of engaging in self-care and self-compassion and found it difficult to incorporate and implement in their daily lives. For example, caregivers described barriers to self-care, including lack of time and not having/knowing ways to implement self-care coping skills. One caregiver who reported frustration at the concept of self-care explained that while others may view self-care as a simple and easy task to engage in, self-care can be complex and difficult to implement as a caregiver due to limited time and competing responsibilities involved with caregiving. Finally, 93% of patients and caregivers responded positively to pleasant activity scheduling. They highlighted the importance of having time alone to engage in activities and hobbies, as well as the importance of quality time spent together and sharing experiences as a dyad. Ratings of responses and illustrative quotes regarding skills presented during the interviews are found in Table 2.

Based on these findings, we finalized the intervention protocol for the pilot study to consist of 6 sessions, with flexibility for caregivers and patients to take part in the intervention alone or as a dyad. Additionally, participants were given up to 12 weeks to complete all 6 sessions (either on a weekly or biweekly basis) to accommodate preference for having sessions every other week, illness, travel, and other scheduling issues. In terms of content, given the variability in circumstances presented during the interviews, we realized that it was important to assess the needs of patients and caregivers in the first session so that we could tailor the content appropriately. Second, given the caregivers' stated logistical and practical support needs, we added content around this topic in session 2. For example, if, during session 1, a caregiver reported high levels of caregiving burden and low support, in session 2, we would focus on identifying and utilizing external resources, as well as strategies around asking for help with the purpose of reducing caregiving burden. Third, when introducing self-care, we provided a definition of self-care and engaged patients and/or caregivers in a discussion about what this concept means to them (e.g., "What are your thoughts about self-care? What does this mean to you? What might be an example of you practicing self-care?"). We took this approach to highlight the individualized nature of self-care and to provide validation or address any frustrations regarding the term. In addition to discussing the benefits of self-care, we provided psychoeducation and introduced a variety of related skills and activities (e.g., self-compassion, pleasant activities, relaxation, and guided meditation). We addressed barriers to self-care implementation using a cognitive-behavioral lens (e.g., thoughts, emotions, and behaviors) and asked participants to practice 1–2 self-care activities in between sessions with check-ins in place to address and problem-solve barriers to implementation. Fourth, we initially combined communication skills and managing common glioblastoma symptoms in a single session. However, we decided to dedicate one session specifically to communication skills training to help caregivers and patients address the most salient themes that emerged from the interviews, including negotiating roles and responsibilities, maintaining patients' dignity and independence, and increasing their connection with one another.

Finally, given the flexible delivery of the intervention, the content was developed to be relevant to individual patients and caregivers, as well as dyads, and easily adjusted depending on the target of the intervention. For example, session 4 focuses on strategies to manage cognitive changes or decline such as staying organized (e.g., maintaining a routine), becoming flexible (e.g., how to adapt activities as needed, limiting choices to simplify decision making), and promoting independence. These skills can be

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Table 2. Ratings and illustrative quotes from phase I (patient–caregiver interviews)

	Illustrative quotes	Ratings
Format		
Format	"I like that the caregiver is given priority to learn some skills, because I worry more about how [name] is going to deal with what's going to happen in the future, and so I see a lot of help to the caregiver. What's going to happen to me is already defined, I can't do anything about it but giving her some tools that will help her." (Patient)	10 (positive), 2 (neutral), 1 (negative), and 1 (no answer)
Frequency	"Okay, that sounds great. I think weekly because we have to really work around our patients and their schedules and how they are feeling." (Caregiver)	13 (positive) and 1 (no answer)
Delivery	"I think that's awesome. Because I can't get out of the house as much as the next person might be able to. It's just him and I. Now, if we had somebody else living here, that would be a totally different story because then I could say, 'Okay, I can get up and leave,' but I have to schedule somebody to come." (Caregiver)	12 (positive), 1 (neutral), and 1 (no answer)
Skill		
Strategies to manage common patient symptoms	"One night, we were just arguing about he was just being as stubborn as could be and defiant and wouldn't cooperate, and I got in the car, and I drove down to the park down the street and sat in the car and cried. And I came home, and I said, 'Okay, we've got to figure out how do we fix this. I can't just leave you. This is not healthy for either one of us.' So, yeah, I think some of that early on. Like I said, a lot of what you're showing, I wish I would have that from the very beginning." (Caregiver)	10 (positive), 3 (neutral), and 1 (no answer)
Relaxation	"It reminds you that whatever stress you're thinking right now is not probably earth-shattering, and that's true. I'm not going to answer it. It's a good thing to remember, if something is really stressing you out, breathe in, breathe out, work on lowering the elevation, a little bit of it, and I think deep breathing exercises do that." (Caregiver)	13 (positive) and 1 (no answer)
Strategies to manage cognitive changes/declines	"I think these are all really good. Again, things that we've come to by trial and error a little bit. One of the things that I've done, some of your examples down there at the bottom, giving choices." (Caregiver)	12 (positive) and 2 (no answer)
Self-care	"Yeah, I mean, I think that that's really important. I'm not sure that she gets enough of an opportunity to do that because of the nature of her job. She's a social worker at an assisted care facility, so that's her job. That's what she does at work all day. And then she comes home and gets to continue doing it." (Patient)	11 (positive), 1 (neutral), 1 (negative), and 1 (no answer)
Pleasant activity scheduling	I think that that's important because as a caregiver, you don't tend to think about yourself. You tend to think more about your patient, your relative, than you do about yourself, and I think that's important. After she got off of the radiation, when she graduated from that she had six weeks, and she wanted to go to see her son in [State]. And I said, "[Name], anywhere you want to go, I will take you. Any bucket list, I will take you," because we could share those experiences. So that was nice. (Caregiver)	13 (positive) and 1 (no answer)

tailored to individual patients and caregivers, or to dyads, and they require minimal adaptation for delivery in each of these contexts. Another example is the communication skills module. Here we discussed strategies such as stating one main point at a time, using clear and short sentences, acknowledging and reflecting what the other person is saying, and minimizing distractions and avoiding interruptions during discussions. Each of these skills is applicable to patients, caregivers, or dyads without the need for significant adjustments by the therapist.

Phase II: Pilot study

Phase II: Methods

We maintained the same eligibility criteria and overall recruitment procedures as in Phase I. For this pilot study, participants completed baseline surveys, participated in 6 sessions of the intervention, and completed post-treatment surveys. The surveys were completed electronically via REDCap, and each participant received an individual link via email to complete the surveys. Participants each received $40 total: $20 for completing the baseline surveys and $20 for completing the post-treatment surveys.

Measures

Feasibility. The intervention's feasibility was assessed based on participant completion of sessions and post-treatment surveys over a 4-month period (12 weeks to complete all 6 sessions, and 4 months to complete all study procedures including baseline and post-treatment surveys and sessions), with 70% completion serving as the benchmark.

Acceptability. Acceptability was assessed by participants' reports of their satisfaction with treatment using the Client Satisfaction Questionnaire (Larsen et al. 1979), which was tailored to the study intervention and administered post-treatment. A benchmark of 70% of participants reporting satisfaction with treatment (mean of 3.0 on a 1–4-point scale) was used as an indication of satisfaction.

Psychological distress. Depressive and anxiety symptoms were measured using the 14-item Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith 1983), with higher scores indicating higher levels of anxiety and depressive symptoms. In addition, general distress was measured using the National Comprehensive Cancer Network (NCCN) distress thermometer (Psychosocial Distress Practice Guidelines Panel 1999), a visual representation

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Table 3. The Empower GBM intervention content

Session	Skills training	Home practice
1	Introduction: Understanding glioblastoma and its impact, psychoeducation, relaxation, and assessing informational needs	– Practice brief relaxation exercise
2	Logistical and practical support during caregiving; introduction to self-care & guided meditation	– 1–3 strategies/access logistical and practical support – Aim to practice the guided meditation 1×/week
3	Care for self and each other; self-compassion; selection of pleasant activities	– Practice 1–3 self-care activities (whether it is using compassion script, guided meditation, or pleasant activities)
4	Managing cognitive changes and decline of a loved one	– Try out 1–3 cognitive strategies – Consider continuing with self-care and one pleasant activity
5	Caregiver- and dyad-focused communication strategies	– Keep communication strategies in mind when communicating with loved one – Continue with self-care and pleasant activities
6	Program overview; wrap up	N/A

of a thermometer that ranges from 0 (no distress) to 10 (extreme distress). A score of 3 or above on the distress thermometer is indicative of high levels of distress (Cutillo et al. 2017). Patients and caregivers completed both the HADS and the NCCN distress thermometer at baseline and post-treatment.

Functional well-being. Functional well-being was measured using the 7-item Functional Well-being Subscale of the Functional Assessment of Cancer Therapy – General (FACT-G; Cella et al. 1993). Scores range between 0 and 28, with higher scores indicating higher levels of functional well-being. Both patients and caregivers completed the survey at baseline and post-treatment.

Caregiver efficacy. Caregiver efficacy was measured using the Caregiver Inventory (CGI; Merluzzi et al. 2011; Serpentini et al. 2021). The CGI consists of 21 items to assess caregiving self-efficacy in domains including managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions. The items are measured on a 9-point Likert scale, with higher scores indicating higher levels of self-efficacy. Caregivers completed the CGI at baseline and post-treatment.

The Empower GBM intervention

The Empower GBM intervention protocol consists of six 45–60-minute sessions conducted either jointly with patient–caregiver dyads or individually depending on their preference and given the variability and progression of patients' glioblastoma symptoms. The content of each session is described in Table 3. Briefly, sessions focused on assessing the impact of glioblastoma on both partners and the relationship, teaching skills for self-care including relaxation, self-compassion, and pleasant activities, teaching skills for managing cognitive changes and decline, and dyad-focused communication strategies.

Sessions were conducted by a clinical psychology intern (J.L.) and a clinical psychology postdoctoral fellow (K.L.) with experience working with couples in medical settings. Both therapists received training in the protocol and followed a detailed treatment manual when conducting sessions. Additionally, sessions were audio-recorded, and both therapists received individual supervision from the study's PIs (L.S.P. and K.R).

Phase II: Results

Feasibility and acceptability

Feasibility. A total of 11 participants consented to participate in the pilot study; 4 were patients, and 7 were caregivers. Three dyads decided to participate in the intervention together, 1 dyad chose to complete the sessions separately, and 3 caregivers participated on their own. Thus, we conducted sessions with 3 patient–caregiver dyads, 1 individual patient, and 4 individual caregivers. Patients' mean age was 60 years old (SD = 9.1); 3 patients identified as non-Hispanic Caucasian, and the fourth patient identified as Hispanic or Latino and 2 or more races. All patients identified as male. Caregivers' mean age was 59.7 years old (SD = 9.3); all caregivers identified as non-Hispanic Caucasian and female (see Table 4 for full demographic data). All caregivers were spouses of patients. Time since diagnosis ranged from 4 to 59 months (mean of 25.6 months). 82% of participants (i.e., 75% of patients, 86% of caregivers) completed post-treatment surveys and completed the 6 sessions of the intervention on schedule (6–9 weeks to complete all 6 sessions). One dyad (2 participants: 1 caregiver and 1 patient) completed the baseline surveys and 4 sessions before withdrawing from the study due to limited time and feeling overwhelmed.

Acceptability. 88.9% of participants who completed all sessions reported a treatment satisfaction score of 3.0 or higher (mean score of 3.57/4.00, SD = 0.46, range = 2.6–4.0). Six participants reported that the number of sessions was "about right," 1 noted that it was "too many," and 2 reported that it was "too few." Seven participants reported that session length (45–60 minutes) was "about right," one noted that it was "too short," and another noted that it was "too long." Four participants reported that it would have been more helpful to have this program closer to diagnoses, 4 reported that the timing was right, and 1 reported that they would have found this program more helpful in the future.

Patient and caregiver outcomes

From baseline to post-treatment, changes in outcome measures were in the expected direction. Specifically, patients and caregivers reported a decrease in symptoms of depression and anxiety (as measured by the HADS), and reductions in overall psychological distress (as captured from the NCCN distress thermometer) from baseline to post-treatment. Patients and caregivers reported slight improvements in functional well-being from baseline to

Table 4. Participants' demographic data for phase II (pilot study)

Variables	Patient ($N = 4$)	Caregiver ($N = 7$)
Age	60.0 (SD = 9.09)	59.7 (SD = 9.25)
Gender		
Male	4 (100%)	–
Female		7 (100%)
Race		
Caucasian/White	3 (75%)	7 (100%)
More than one race	1 (25%)	–
Ethnicity		
Non-Hispanic	3 (75%)	7 (100%)
Hispanic	1 (25%)	
Education		
4-Year college degree	3 (75%)	6 (85.7%)
Graduate degree	1 (25%)	1 (14.3%)
Income		
Less than $10,000	1 (25%)	–
$10,000–$19,999	–	1 (14.3%)
$20,000–$39,999	–	–
$40,000–$59,999	–	–
$60,000–$100,000	2 (50%)	2 (28.6%)
More than $100,000	1 (25%)	4 (57.1%)

post-treatment, and caregivers reported an increase in caregiving efficacy from baseline to post-treatment. See Table 5 for mean baseline, post-treatment, and change scores for patient and caregiver outcomes.

Discussion

The aims of this study were to develop a supportive care intervention for patients and caregivers coping with glioblastoma and conduct a pilot test to assess its feasibility and acceptability. The results of the qualitative interviews yielded positive responses for the format, frequency, and delivery of the intervention via videoconference. Most patients and their caregivers responded positively to learning strategies and skills to manage symptoms of glioblastoma, including managing cognitive changes and decline. In addition, most patients and caregivers responded positively to the brief relaxation exercise, reporting that it could help them cope with and reduce negative emotions. Finally, most patients and caregivers noted the importance of self-care, self-compassion, and scheduling pleasant activities yet reported barriers to implementation (e.g., time and caregiving responsibilities).

The results of our pilot study suggest that the intervention was feasible and acceptable. 82% of participants completed the 6-session intervention and post-treatment survey within the allotted 4-month timeline; in fact, participants completed all 6 sessions within 6–9 weeks. 89% of participants reported high treatment satisfaction (score of 3.0 or higher). Additionally, most participants reported satisfaction with the number and length of sessions. Interestingly, there were more varied responses regarding the timing of the intervention; some participants reported that they would have found the program to be more helpful closer to the time of diagnosis, while an equal number reported that this was the right time to participate in the intervention. Upon closer examination of the data, participants who reported that the program would be more helpful closer to the time of diagnosis were about 19–44 months post-diagnosis, while those who reported that the program was helpful at this time were 13 months or less post-diagnosis. One exception to the latter was a caregiver whose spouse was diagnosed almost 5 years ago, which potentially highlights the unique needs of long-term caregiving with glioblastoma. Understanding the most effective timing for participants' involvement in the intervention is an important area for future research. Finally, most participants noted that the videoconference format of the sessions was convenient and helped facilitate participation. Finally, although most of the participants completed the surveys successfully, one caregiver reported having to read the survey questions to the patient as the patient could not read for long periods of time due to visual impairments as a symptom of disease progression. This feedback points to important considerations for ensuring accessibility when administering self-report surveys to this population (e.g., using large print, telephone, or voice-activated surveys).

The results of this pilot study suggest that the intervention showed promise in improving patient and caregiver adjustment. Specifically, from baseline to post-treatment, patients and caregivers reported decreases in depression and anxiety symptoms as measured by the HADS (Zigmond and Snaith 1983) and in psychological distress as assessed by the Distress Thermometer (Psychosocial Distress Practice Guidelines Panel 1999). Additionally, patients and caregivers reported increased functional well-being, and caregivers reported increased caregiving self-efficacy. While these results are encouraging, they should be interpreted with caution due to the single-arm nature of the study and the small sample size.

Our study demonstrated the feasibility and acceptability of a glioblastoma intervention that has the flexibility to be delivered to patients and caregivers individually or together. Specifically, we had 3 dyads who decided to participate in the intervention together, 1 dyad who chose to complete the sessions individually, and 3 caregivers who participated on their own, highlighting that the intervention is feasible and acceptable while accommodating intervention delivery preferences. An important area for future research is to better understand patients' and caregivers' preferences to engage in the intervention individually or as a dyad, and how that impacts the effects of the intervention. For example, Milbury et al. (2023) completed a 3-arm yoga pilot intervention for patients with a primary brain tumor and their caregivers. Results showed that although the dyadic yoga arm had higher attendance, caregivers in the individual yoga arm reported greater subjective benefits, improvements in quality of life, and reduced caregiver burden compared to caregivers in the dyadic yoga arm (Milbury et al. 2023). Additionally, the flexible delivery of the intervention may be a strength to help increase reach, utilization, and provide continuity of care (e.g., caregivers could continue to participate if patients are unable to), especially given the nature of the disease progression and the unique and fluctuating needs of patients and their caregivers. Another strength of our study is the comprehensive content of skills and strategies included in the intervention to (1) improve management of patients' symptoms to increase independence, (2) address the unique challenges faced by caregivers

Table 5. Baseline and post-intervention mean scores

	Baseline, mean (SD, range)	Post-intervention, mean (SD, range)	Change score, mean (SD) [95% CI]	Effect size (Cohen's *d*)
Patient outcomes				
HADS total	18.8 (5.1, 14.0–26.0)	15.3(6.4, 8.0–20.0)	3.7 (4.0) [−6.37, 13.71]	0.58
HADS anxiety	10.5 (1.9, 9.0–13.0)	8.0 (2.6, 5.0–10.0)	3.0 (3.6) [−5.96–11.96]	1.28
HADS depression	8.3 (4.1, 3.0–13.0)	7.3 (4.0, 3.0–11.0)	0.7 (1.2) [−2.20, 3.53]	0.15
Distress	5.3 (2.2, 3.0–8.0)	4.0 (1.0, 3.0–5.0)	1.0 (1.7) [−3.30. 5.30]	0.50
Functional well-being	13.8 (7.0, 6.0–23.0)	15.0 (5.6, 10.0–21.0)	−0.7 (3.1) [−8.26, 6.92]	−0.09
Caregiver outcomes				
HADS total	18.4 (3.9, 14.0–26.0)	15.5 (2.0, 14.0–18.0)	3.3 (4.2) [−1.10, 7.77]	1.04
HADS anxiety	10.1 (2.3, 6.0–13.0)	8.5 (1.6, 6.0–11.0)	1.5 (3.9) [−2.58, 5.58]	0.72
HADS depression	8.3 (2.5, 5.0–13.0)	7.0 (2.6, 5.0–12.0)	1.8 (1.5) [0.29, 3.38]	0.76
Distress	5.7 (2.4, 2.0–8.0)	4.3 (1.6, 2.0–6.0)	1.3 (3.7) [−2.57. 5.24]	0.62
Functional well-being	16.5 (4.7, 8.0–23.3)	17.2 (4.4, 11.0–22.0)	−1.8 (4.5) [−6.44, 2.89]	−0.42
Caregiver efficacy	134.3 (26.6, 97.3–171.0)	157.3 (20.0, 138.6–187.0)	−26.2 (30.5) [−58.3, 5.83]	−1.09

Note: The negative effect sizes for functional well-being and caregiver efficacy indicate that there were improvements.

to increase caregiving efficacy and support (e.g., self-compassion), and (3) help caregivers and patients increase their connection and effectively cope with dyadic challenges such as negotiating roles and responsibilities.

Limitations

Despite our study's strengths, there were also some limitations. In addition to the small sample size, our sample lacked diversity. Most of the study participants identified as Caucasian, non-Hispanic, well-educated, and high SES. Additionally, most of our caregivers were homogenous in terms of gender (i.e., female) and their relationship to the patient (i.e., spouse) for phase II of the study. Additional limitations include a lack of a comparison group and long-term follow-up. For the latter, participants highlighted that they would appreciate a follow-up and/or a "refresher" as coping with glioblastoma evolves with time. Finally, we did not include measures related to dyadic outcomes such as relationship satisfaction or communication in the current study. These are areas to address and improve upon in a subsequent larger randomized controlled pilot study to increase the generalizability and efficacy of the results.

Implications

The results of the current study will be used to refine the Empower GBM intervention for a larger randomized controlled pilot study. For next steps, given the rapid progression of glioblastoma symptoms for patients, it is worth considering the primary recipients of the intervention based on time since diagnosis. For example, within the first 6 months of diagnosis, the intervention could be offered to both the patient and caregiver, an iteration of Empower GBM specifically for the newly diagnosed couple/dyad. For those with a longer period since diagnosis, the intervention can be targeted more at caregivers while encouraging patient participation as they are able, as we did in the current study.

Second, given that caregivers are likely to be the primary recipients of the Empower GBM intervention, the larger pilot study will focus on caregiver distress as the primary outcome and consider both caregiver and patient quality of life as secondary outcomes. It will also assess the patient–caregiver relationship, including relationship adjustment, mutuality, and attachment. This will allow us to have a clearer understanding of how relationship dynamics influence patient–caregiver coping in the context of glioblastoma. Finally, participants highlighted that coping with glioblastoma evolves with time, and previous research has shown that caregivers' reaction and distress are a function of the patient's clinical status (Au et al. 2022). Therefore, it would be important to assess caregivers' short- and long-term reactions to better understand their unique needs with time, which will help us to refine the intervention.

Conclusions

The study's initial data suggest that our supportive care intervention is feasible, acceptable, and shows promise in improving outcomes for patients and caregivers. The Empower GBM intervention for patients and caregivers coping with glioblastoma may be an effective approach to helping patients and caregivers cope effectively with the impact of a glioblastoma diagnosis.

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