Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers

Nordentoft, Sara; Dieperink, Karin B.; Johansson, Susan D.; Jarden, Mary; Piil, Karin

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Title page

Title: Evaluation of a multimodal rehabilitative palliative care program for patients with high-grade glioma and their family caregivers

Corresponding author:
Sara Nordentoft, RN, MHSc Copenhagen University Hospital, Department of Neurosurgery
Inge Lehmanns Vej 8, 2100, Copenhagen Ø, Denmark.
Telephone: +45 29866734. E-mail: sara.marie.juel.nordentoft@regionh.dk

Author block:

S. Nordentoft¹,²,⁷, RN, MHSc
ORCID ID: 0000-0001-5600-2644

K. B. Dieperink³,⁴,⁹, RN. Ph.D, Associate Professor
ORCID ID: 0000-0003-4766-3242

S. D. Johansson⁴, Physiotherapist, Project manager

M. Jarden⁵,⁶, MScN, Ph.D, Professor

K. Piil⁷,⁸, MHScN, Ph.D, Associate Professor
ORCID ID: 0000-0001-7972-4674

¹Copenhagen University Hospital, Rigshospitalet. Research Unit, Center for Cancer and Organ Disease, Tagensvej 22, 2100, Copenhagen, Denmark.

²Copenhagen University Hospital, Rigshospitalet, Department of Neurosurgery, Inge Lehmanns Vej 8, 2100 Copenhagen, Denmark.

³Odense University Hospital, Department of Oncology, Odense, Denmark

⁴REHPA, Danish Center for Rehabilitation and Palliative Care, Nyborg, Denmark

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Key words: High-grade glioma, rehabilitation, palliative care, neuro-oncology, family, caregiver, evaluation, supportive care.

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Evaluation of a multimodal rehabilitative palliative care program for patients with high-grade glioma and their family caregivers

Abstract

Background: Patients diagnosed with high-grade glioma and their family caregivers often experience intense disease and treatment trajectories. Fluctuations in patient’s symptoms lead to enormous burdens for caregivers and the risk of developing symptoms of stress, anxiety, and depression.

Aim: The study aim is to explore patient and caregiver experiences and evaluate the relevance of and satisfaction with a multimodal rehabilitative palliative care program for patients diagnosed with an HGG and their family caregivers.

Methods: In a longitudinal multi-methods study, adult patients with high-grade glioma (n=17) and their family caregivers (n=16) completed a four-day residential program and a two-day follow-up program three months later. Participants completed questionnaires after each program, scoring relevance and satisfaction on a 5-point Likert scale. Qualitative data were collected during four evaluation group interviews with patients and caregivers.

Results: The mean overall satisfaction score was 4.80 (standard deviation [SD], 0.55) for the initial four-day program and 4.28 (SD, 0.83) for the follow-up program. Three themes emerged in the evaluation group interviews: 1) meeting peers strengthens social well-being, 2) the value of information and focusing on individual needs, and 3) accepting life as an unpredictable passage.

Conclusion: Participants found completing the REHPA-HGG program feasible and rated all sessions highly for relevance and satisfaction. Qualitative findings confirm the value of individualised information, acceptance, and peer interactions.

Implication for practice: A multimodal rehabilitative palliative care program addressed unmet patient and caregiver needs. Peer-to-peer interventions for family caregivers may address individual support needs. Similar programs may maximize benefit by avoiding planned behavior changes and enhancing palliative approaches.


Key words: High-grade glioma, rehabilitation, palliative care, neuro-oncology, family, caregiver, evaluation, supportive care.
Introduction

The most common primary brain tumor is high-grade glioma (HGG), with an incidence of 7.03 per 100,000 in Denmark (1, 2). The most prevalent subtype of HGG is glioblastoma; 600 newly diagnosed patients in Denmark per year reflecting an incidence of 45.6% (3, 4). HGG is associated with a poor prognosis, and the five-year survival rate for glioblastomas is 5% (5).

Standard treatment for HGG is initiated with a surgical procedure followed by the Stupp regimen consisting of concomitant chemoradiotherapy followed by adjuvant maintenance chemotherapy with temozolomide (6). The symptom burden varies over time (7) and worsens as the disease progresses (8).

Due to complex symptom burdens, patients gradually become dependent on their informal caregivers (9). Physical, cognitive, and psychological disease-related factors affect relationships and reduce social participation, representing barriers to social integration (10). Informal caregivers struggle to adjust to the change in family roles (11, 12), and late-stage caregiving is a challenging experience after an already burdensome treatment trajectory (13). Despite aggressive oncological treatments, tumor recurrence is inevitable, often leaving little time for patients and family caregivers to accommodate to a life-threatening situation (12). Compared with caregivers of patients with other types of brain tumors, caregivers of patients diagnosed with HGG have lower quality of life (QoL) (14). The caregiver burden is multidimensional, and caregivers often neglect their physical, emotional, and social needs (12, 15, 16). Symptoms among caregivers arise due to disturbed sleep (17), stress, anxiety (18), and social isolation (12). In a Danish population, the prevalence of moderate-to-severe depressive symptoms was five times higher...
among patients with glioma compared with cancer-free individuals (19). Jansson et al. also found that partners of patients diagnosed with glioma have a four-fold higher risk of a first prescription for psychotropic medications within the first year of diagnosis (20). Caregivers describe healthcare professionals as rarely or never inviting them to discuss their caregiving role; hence, they have limited opportunities to talk about challenges in everyday life (21). However, identifying the appropriate type and timing of supportive care interventions is challenging, and interventions do not necessarily meet caregiver preferences or fulfil intended outcomes (22).

When a family member is diagnosed with high-grade glioma it not only affects the patient, but the entire family (23). Patients and caregivers alike need support and to be approached together as a family unit (23). Studies of supportive care programs show interesting and beneficial outcomes among families affected by a brain tumor. Examples include the Milton Marks Family Camp (24), a telehealth program targeting patients with a primary brain tumor (25, 26), and a family care intervention (27). Recently, Cubis and colleagues called for interventions focusing on ways to maintain social participation and supportive relationships (28). A systematic review of rehabilitative and supportive interventions for patients with HGG and their caregivers found that there was a need for additional supportive interventions targeting caregivers (29). Another recent systematic review on supportive-care interventions for adults with brain tumors found only a few randomised controlled trials demonstrating improvements in health-related QoL and concluded that a paucity of research exists to inform clinical decisions and evidence-based practice (30). Thus, additional research of supportive care interventions for this particular group of patients with HGG and their caregivers is required.

The aim of this study was to explore patient and caregiver experiences and evaluate the relevance of and satisfaction with a multimodal rehabilitative palliative care program (REHPA-HGG) for patients diagnosed with HGG and their family caregivers.
Materials and methods

Study design
A longitudinal multi-methods approach used concurrently collected qualitative interview data and quantitative survey data to evaluate the program offered to patients and family caregivers. Triangulating qualitative and quantitative data can increase the reliability of findings (31, 32).

Participants and procedures
Using a convenience sampling strategy, dyads consisting of patients diagnosed with HGG and their family caregivers were recruited from neurology and neuro-oncology departments in Denmark. Providers in these locations referred patients and their closest caregivers to the rehabilitative palliative care program.

Inclusion criteria were: 1) patients aged $\geq 18$ years diagnosed with HGG, 2) family caregivers identified by patients as providing informal care, 3) ability to speak and understand Danish and 4) no professional assistance needed during the program. Family caregivers were excluded from the follow-up program if the patient died. Excluded caregivers received a telephone consultation with the program coordinator in lieu of participation.

The REHPA HGG program
In 2016, the Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) held a national workshop to develop a rehabilitative palliative program for patients diagnosed with HGG and their family caregivers. Workshop participants comprised a multidisciplinary cross-sectoral team of clinical specialists (physicians, clinical specialist nurses, physiotherapists, occupational therapists, neuropsychologists, social workers), researchers, and a consultant from the Center for Brain Injury. The team represented most specialties within the HGG disease and treatment trajectory. The team offered the most important elements that should be included in a rehabilitative program e.g. physical activity (33), personal coping strategies, end-of-life support, peer-support (16), and psychosocial support/education and massage therapy (29).

REHPA-HGG was designed to provide patients and family caregivers with information and facilitate discussions among peers about daily life and family interactions. An additional aim was
to provide patients and family caregivers with tools and strategies to manage the substantial changes to their life situations.

REHPA-HGG components were based on the biopsychosocial approach from the International Classification of Functioning, Disability, and Health (33) and the total pain model developed by Dame Cicely Saunders (34). REHPA-HGG offers patients and caregivers:

- Information and instruction based on evidence and international literature
- Consultative conversations with healthcare professionals
- Physical training and mindfulness by physiotherapists
- Interaction with peers for both patients and family caregivers

REHPA-HGG was a four-day residential program tailored to the target population (Table 1) with a two-day follow-up program 12 weeks later (Table 2). The program, which included lodging and food, was provided at no charge to participants.

**Initial REHPA-HGG program**

Upon arrival, all participants joined an introductory session. The course coordinator introduced the coaches responsible for program sessions and presented a detailed program and practical information. Multidisciplinary coaches included neuropsychologists, physicians, nurses, social workers, physiotherapists, occupational therapists, and massage therapists. Participants received verbal and written information about REHPA-HGG, including the evaluation questionnaire and scheduled evaluation group interviews. The course coordinator then facilitated a round of participant self-introductions that included name, place of residence, duration of diagnosis, and expectations about the program. The initial program included 16 sessions guided by health care professionals and two optional sessions. Each day started with a group song, an overview of the day’s schedule including comments from the previous day.

**Table 1 Initial program for REHPA-HGG**

**Follow-up program at 12 weeks**
Upon arrival, all participants joined an introduction session where they received the evaluation questionnaire for the follow-up program. After check-in and registration, the course coordinator introduced the coaches, who included a psychologist, nurse, social worker, physiotherapist, and priest. Participants had the opportunity to share experiences from the last three months, especially in light of their individual action plans. The introduction session also emphasized participants’ expectations for and concerns about the two-day program.

Table 2 Follow-up program for REHPA-HGG

Data collection

Procedure
Upon arrival at each REHPA-HGG program, patients and family caregivers received a packet containing anonymous evaluation questionnaires and were asked to complete individual questionnaires after each program session. Participants returned all completed questionnaires on the final day of each program in a sealed envelope. Furthermore, a total of two evaluation group interviews were planned for each completed REHPA-HGG program. One group interview took place upon arrival to the follow program and on the last day at follow-up.

The evaluation group interviews
Two group interviews were planned for each completed program. Interviews took place when participants arrived at and on the last day of the follow-up program and were based on a single research question: What do you think of the REHPA-HGG program? Participants discussed their experiences, satisfaction with and perceived relevance of the program. All group interviews took place at REHPA and were audio-recorded and transcribed verbatim.

The evaluation questionnaire
The initial program evaluation questionnaire consisted of 20 items, in addition to sociodemographics: 14 about the sessions, 5 about lodging and meals (not reported), and a single item about overall satisfaction. The evaluation questionnaire for the follow-up program consisted of ten items about the sessions and one item rating overall satisfaction. Participants scored each session for relevance and satisfaction on a 5-point Likert scale (0, not relevant/satisfied; 5, very...
relevant/highly satisfied). Patients’ medical data (i.e., diagnosis and time since diagnosis) were obtained from physicians’ referral documents to the REHPA-HGG program.

**Data analyses and interpretation**

**Thematic analysis**

Interview transcriptions were analysed using NVivo 11 (12) to systemize and facilitate the thematic analysis, following Braun and Clarke (35). Thematic analysis comprised six phases: familiarization with the data based on repeated readings, generating initial codes, searching for themes, reviewing themes, defining identified themes, and producing the report. To ensure trustworthiness and research integrity, two authors (SN, KP) conducted the analysis and discussed it with the entire research team. All researchers were experienced in the field of neuro-oncology.

**Statistical analysis**

Data for patients and family caregivers were pooled to preserve anonymity. Data on sociodemographics and program satisfaction and relevance were analysed descriptively as means and standard deviations (SD) for continuous variables and frequencies for categorical variables. Data for the session related to working life were excluded from the analysis because only a single participant attended that session. All analyses were performed with SPSS.

**Ethical considerations**

All participants received written and verbal information and provided written consent for participation. The study was carried out according to the Declaration of Helsinki, (36) and approved by the Danish Data Protection Agency (file no. 2008-58-0035).

**Results**

**Participants**

In December 2017 to February 2018, 17 patients were recruited from a general practitioner (n=7) and physicians from Danish departments of neurology (n=1) and neuro-oncology (n=9), using an informational pamphlet. The REHPA-HGG program was provided twice in 2018. Participants
enrolled in the program represented dyads of patients (n=17) and family caregivers (n=16). Despite the inclusion criteria, one patient was allowed to join without a caregiver.

Participants were aged 25-73 years (median, 60). Nine (27%) patients were male and 8 (25%) patients were female; 5 (15%) family caregivers were male and 11 (33%) were female. Family caregivers comprised 13 spouses, two siblings, and one parent. Ten patients were diagnosed with a World Health Organization (WHO) grade IV glioblastoma and seven patients were diagnosed with a WHO grade III HGG. Time since diagnosis varied from a few months to more than three years (Table 3).

Seventeen patients and 16 family caregivers participated in the initial REHPA-HGG program. Seven dyads of patients and family caregivers who participated in the initial program did not participate in the follow-up program at 12 weeks. Reasons for non-participation were disease progression (n=1), patient death (n=2), too distressed by the absence of peers (n=2), patient resigned (n=1), and lost to follow-up (n=1).

Several patients used scheduled program breaks to rest in their rooms. Only one patient had difficulty participating in the full program due to cognitive and psychological deficits. The course coordinator talked with the patient daily to guide and prioritize program activities, and the patient participated in 50% of sessions. Additionally, some family caregivers stated that they had had to help their sick relative complete the evaluation questionnaire.

Table 3 Demographic Characteristics of Study Participants

Participants perspective and experiences of the REHPA-HGG
The interview was conducted as joint interviews with dyads and was moderated by the course coordinator and an experienced clinical specialized oncology nurse. The four group interviews lasted approximately 60 minutes. Three themes emerged: 1) meeting peers strengthens social well-being, 2) the value of information and focusing on individual needs, and 3) accepting life as an unpredictable passage.

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Meeting peers strengthens social well-being

Participants valued spending time with other patients and family caregivers who knew the struggles they experienced in daily life. Discussing common experiences facilitated reflections and provided participants with new perspectives on how to tackle challenges.

Several participants expressed difficulties with a doctor’s words indicating a poor prognosis. The prognosis was expressed so definitively that participants nearly lost all hope. These patients and family caregivers felt relieved to meet others with the same diagnosis who had defied statistics. They expressed that meeting peers gave them hope in the most difficult situation. Some participants had never met peers diagnosed with HGG.

“The greatest joy and biggest help were to meet peers going through the same trajectory”
(patient)

Participants appreciated the time at REHPA-HGG and enjoyed spending time with others in similar situations who were also going through difficult times. They expressed being able to relax more in the company of other participants because of their shared understanding. Furthermore, they valued the ability to laugh and have fun despite their situations.

All participants reported that they had missed being social and were surprised to discover all the opportunities that were possible during REHPA-HGG. Exercising and doing other activities together presented a whole new perspective for them. Socializing with others strengthened their emotional well-being and provided them with energy.

“The social aspect of it, surprised me the most. I didn’t know how much I needed it and it felt so good” (patient)

Family caregivers particularly emphasized the importance of meeting peers. They described how they benefited from meeting with peers and sharing experiences that were deemed as valuable. They recognized that they could speak more openly with other family caregivers and were surprised to acknowledge that they could share personal issues more easily with peers than with

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their own family. Furthermore, they emphasized the need to meet with peers without patients being present.

**The value of information and focusing on individual needs**

Participants described being affected by the patient’s constantly changing symptoms during the disease and treatment trajectory. They described this as exhausting and frustrating, especially for family caregivers who felt inadequately prepared for their new caregiver role. Participants highly valued being provided with information targeting their individual needs and situations. They described using an enormous amount of energy to learn about the disease and the elements of the standard trajectory and emphasized the knowledge and overview they received at the program.

During interviews, participants highlighted the opportunity to meet with a multidisciplinary clinical specialist team providing information and identifying appropriate supportive tools to support daily life. Participants described the coaches as inspiring and empathic. The knowledge they received gave participants courage to talk about the disease and contributed to better understanding their situations. More knowledge, such as strategies for talking about the disease and its future consequences, also guided and motivated them to handle difficult conversations. To the same degree, they highlighted the usefulness of inspiration for integrating relaxation and mindfulness into daily life, helping them avoid a constant focus on the disease. However, some participants would have liked to have had the information and knowledge within the first year after the patient’s diagnosis.

“I suddenly became aware of the value of joy in my life and more importantly, how I could motivate it myself” (patient)

Patients and family caregivers both valued information about conserving energy and understood the need to save energy in order to gain a better day. On the basis of new information, participants expressed a new understanding of the disease and new perspectives on their situations. They became aware of their ability to change focus, received tools to integrate this practice into everyday life, and were able to embrace more hope and appreciate the small things in life.
“I left REHPA-HCG with greater motivation and willingness to fight, I will not allow this disease to win over me” (patient)

Participants positively evaluated the two-part nature of the program, which provided the opportunity to hear the same information more than once. They viewed group therapy as beneficial and contributing to a positive dynamic among participants; it also provided opportunities to share experiences and knowledge. However, a few participants requested that the follow-up program include a more existential session and less recurring content.

Accepting life as an unpredictable passage
Participants felt that the future was unpredictable, which led to emotional distress and vulnerability. Some participants described how they had accepted the conditions of their disease, including an unpredictable life passage.

“This disease will never just go by the book. Everyday life itself is enough to knock you down” (patient)

Participants described keeping track of the action plan, in addition to maintaining control and managing the challenges of daily life, as impossible. Maintaining an overview of the patient’s treatment plan was crucial to participants; combining that task with difficulty navigating the health care system and dealing with daily life challenges, they already had more than enough to handle. Several participants agreed that the action plan created on the last day of the initial program was challenging to integrate into their unpredictable daily lives. The action plan was stressful, not the intended contribution of structure and help, and some participants described experiencing a sense of defeat at being unable to follow their action plans.

Participants who were living apart from patients also described difficulty implementing action plans. They pointed out that the program focused primarily on patients and daily life as a dyad. When family caregivers did not share daily life, the action plan was less useful and more difficult to engage in. Moreover, constant changes in patients’ conditions, such as disease progression or
new treatment side effects, made it even more problematic for family caregivers to maintain an understanding of patients’ current states and needs. They requested guidance about supporting patients from a distance in the context of unpredictable daily life.

“Focus is on the patient and the close relative, not for the relatives living apart from the patient” (caregiver)

**Initial program relevance and satisfaction**

Thirty participants evaluated the initial program, reflecting a response rate of 91% (Table 4); three (9%) participants lacked sufficient energy to complete the questionnaire. The largest difference between reported satisfaction and relevance was observed for the final program session related to action planning; the mean satisfaction score was 0.6 points lower than the mean relevance score. During the session offering individual or dyad conversations, 19 (58%) participants chose individual conversations. Participants also found it difficult to identify areas of focus at a more general level, and conversations tended to concentrate on smaller concrete challenges in daily life.

<table>
<thead>
<tr>
<th>Table 4 Relevance and satisfaction scores for REHPA-HGG initial program</th>
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</thead>
</table>

**Follow-up program relevance and satisfaction**

A total of 18 participants completed the follow-up evaluation questionnaire, yielding a response rate of 95% (Table 5). Results are similar to the results for the initial program; the range of mean scores for relevance and satisfaction was 3.3-5.0. Participants scored the caregiver support session slightly higher for relevance than for satisfaction, while they scored the optional physical activity session the reverse direction, with higher mean satisfaction and lower mean relevance.

<table>
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<tr>
<th>Table 5 Relevance and satisfaction scores for REHPA-HGG follow-up program</th>
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**Overall satisfaction with the REHPA-HGG program**

Overall mean satisfaction scores for the initial and follow-up programs were 4.80 (SD, 0.55) and 4.28 (SD, 0.83).

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Discussion
The aim of this study was to explore patient and caregiver experiences and evaluate relevance of and satisfaction with a multimodal rehabilitative palliative care program for patients diagnosed with HGG and their family caregivers. We were able to recruit participants for a full program; most participating caregivers were women and spouses. This is consistent with a recent review reporting that most family research includes only spouses and not extended family, even though it may be beneficial to be more inclusive because cancer disease affects the entire family (23). As planned, the REHPA-HGG initial program took place over four days in sessions that were deemed to be of appropriate lengths. However, some patients found the program demanding and used scheduled breaks to rest in their private rooms as needed. A supportive care program provides an annual residential week-long program that focuses primarily on the entire family (24). Thus, a residential program for this population appears to be a preferable delivery mode. Fatigue is a common symptom (37) of HGG, and avoiding daily transportation for participants may increase adherence to supportive care programs.

In general, the program offered participants new knowledge, counseling, physical training, and peer interactions. Participants highly valued the multidisciplinary and cross-sectoral team of clinical specialists. In contrast, Spetz et al. (38) described an intervention with a specialist nurse as a resource for family caregivers; focusing on availability, continuity, and guidance in the healthcare system. The specialist nurse was evaluated positively because she could establish personal relationships with family caregivers and provide ongoing personalised support, in contrast to the more intense REHPA-HGG structure with specialists available. Online support is another way of achieving knowledge and counseling and is universally available. A telehealth psychological support intervention for patients with brain tumors and their family members demonstrated a significant potential to improve the quality and sustainability of psychosocial care for participants (25). Family caregivers may particularly benefit from online support because their inability to leave patients unattended may leave their support needs unmet (39). But the requirement for patients and family caregivers to initiate needed support, including gathering the energy to do so, can present a barrier. Another intervention targeting caregivers of patients with HGG comprised telephone consultation, a personal resource file, a nurse-led home
visit, and ongoing telephone support. Participants positively evaluated the interventions’ value and structure, but some participants would have preferred to receiving it before commencing chemoradiotherapy (27). Similarly, some of our interview participants preferred that information and knowledge come within the first year after the patient’s diagnosis. However, newly diagnosed patients and their family caregivers in our study also appreciated the fact that time since diagnosis varied among patient participants, giving them a reason for hope.

Several sessions were based on conversations and counselling for groups of mixed participants, patients or family caregivers separately, or dyads; all constellations were feasible and evaluated positively by participants. The program enabled peer support, and all participants remarked on the energy and joy they experienced from meeting peers. Peer support among patients diagnosed with cancer yields increased beneficial effects (40). Peer support benefits both the person being supported and the person providing support (41). A theme that emerged from interviews was the importance to both patients and family caregivers of meeting peers. This finding is also documented in reports of similar rehabilitation programs that highlight the ability of multimodal rehabilitative palliative programs to provide more in-depth psychosocial support, which is different from rehabilitation services offered in local districts (42, 43).

Family caregivers participating in our study emphasized the importance of being able to meet with peers in family caregiver-only settings that allow them to share personal issues with peers in a safe space. Satisfaction and relevance of sessions for family caregivers in the initial program were also rated highly. Existing literature confirms family caregivers’ need for support in terms of opportunities to talk with peers and healthcare professionals (44). The Milton Marks Family Camp, offering support meetings for both patients and family caregivers, has similarly positive experiences with peer support (24). However, the camp generally focuses on allowing families to temporarily escape daily disease burdens, and REHPA-HGG focused more on the purpose of specific sessions. The session on life, disease, and hope, presented by a priest, invited participants to a conversation about how their families were affected by their disease. The high satisfaction and relevance scores for this particular session indicate the need to speak about existential aspects of life, yet still preserve hope. This finding confirms existing literature about the importance of hope shared by patients and family caregivers (7).
REHPA-HGG also provided several sessions about body and mind, including physical activity, massage, and mindfulness. Despite their varying physical and cognitive abilities, all participants were able to join in all sessions with differing degrees of energy and intensity. Several participants reported being positively surprised by their ability to participate in all the physical activities and the energy that resulted. The session on relaxation and couples massage received the highest score. It focused on creating a peaceful place and being in contact with one another through touch. A 2019 pilot study reported the potential effect of a dyad yoga intervention on symptoms and quality of life management (45). Moreover, dyadic interventions have a beneficial effect on multiple aspects of QOL for patients and family caregivers (46).

According to the International Classification of Functioning, Disability, and Health, rehabilitation is the development or maintenance of physical, mental, and social functioning, whereas the traditional goal of palliative care is to alleviate physical, mental, social, or existential suffering associated with a life-threatening disease (47). These approaches seemed to collide in the REHPA-HGG program. In the session on creating an action plan, healthcare professionals helped participants describe changes they wanted to implement in daily life and anchor the new habits. In rehabilitation, inherent in this approach is a philosophy of getting better (48, 49). However, we found patients that diagnosed with HGG and their family caregivers would have appreciated an enhanced focus on palliation. Interviews made it clear that integrating planned changes into already unpredictable daily lives was impossible. Furthermore, action plans induced stress for participants and even a sense of defeat. Ownsworth et al. (25) successfully included guidance related to goal setting in their telehealth program, but did so near the beginning of the program and with the opportunity of ongoing support.

REHPA-HGG comprised a four-day residential program and a two-day follow-up 12 weeks later. Participants positively evaluated the program’s two-part nature, but two dyads of participants did not participate in the follow-up program because they were distressed about the absence of peers whose disease had progressed or who had died or chose not to return for other reasons. Interventions reported by Halkett et al. (27) and Ownsworth et al. (25) offer ongoing support in the form of sessions provided over time; both interventions were evaluated positively.

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It is worth noting that both interventions relied on telephone and video conferences, limiting interaction with other participants and opportunities for peer support.

Controlled clinical studies must confirm our findings. We recommend further investigation of multimodal rehabilitative palliative care programs to meet the support needs of patients diagnosed with HGG and their family caregivers during the disease trajectory. That said, we tentatively endorse multidisciplinary residential programs for patients with HGG and their family caregivers that provide information and counselling tailored to individual needs and preferences and peer-to-peer interactions to meet the need for social activity and support.

**Study strengths and limitations**

Ours is one of very few programs targeting patients with HGG and their family caregivers. Using qualitative and quantitative methods, participants were consistent in assessing REHPA very positively. Although we included vulnerable participants, we can make no assertions about generalising our findings. We lack information about how healthcare professionals selected referred participants or how many patients did not accept referrals to REHPA. Evaluation questionnaires were returned anonymously, precluding separating data from patients and family caregivers and understanding whether and how their perspectives agreed and differed. REHPA-HGG may be characterized as a complex intervention consisting of several interacting components, and using a complex intervention evaluation framework would have strengthened our study design (50-52). Limitations of this study also include a small sample size in relation to the quantitative results, but also related to duration of diagnosis for the patients, therefore the results must be interpreted with caution and sustained by future research.

**Conclusion and clinical implications**

Our multimodal rehabilitative palliative program for patients diagnosed with HGG and their family caregivers addressed unmet patient and caregiver needs and may have the potential to enhance family health or coping mastery. The program was feasible and every session received high scores for satisfaction and relevance, as well as positive evaluations in the evaluation group interviews. Peer-to-peer interventions for family caregivers may address individual support needs. Multimodal rehabilitative palliative programs for this group of patients and their family
caregivers may maximize benefit by avoiding planned behavior changes and enhancing palliative approaches. Finally, future studies should explore strategies for supporting and guiding family caregivers who live apart from patients but are involved in their disease and treatment trajectories.

Conflict of Interest
The authors have no conflicts of interest to declare.

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References


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## Table 1 Initial program for REHPA-HGG

<table>
<thead>
<tr>
<th>Day</th>
<th>Session</th>
<th>Health care professional</th>
<th>Description of session</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td>Changes and late effects of a brain tumor diagnosis (Maximum of 9 participants per session)</td>
<td>Neuropsychology</td>
<td>Informational session about how a brain tumor influences the brain and can be physically, emotionally, cognitively, and behaviourally expressed in daily life</td>
<td>To help participants recognize challenges and barriers from their own experiences and gain greater understanding</td>
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<td>60 min.</td>
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<tr>
<td>30 min.</td>
<td>Individual conversation regarding needs and goals</td>
<td>Physician, nurse, social worker, physiotherapist</td>
<td>A dialogue among patient, family caregiver, and a professional to help patients clarify individual needs and generate 2-3 focus areas for the program</td>
<td>To create a program overview and build a bridge to the last day, when participants are expected to establish a plan of action</td>
</tr>
<tr>
<td>60 min.</td>
<td>Music and entertainment</td>
<td>Conservatory-trained musicians</td>
<td>A pianist and a singer perform a musical journey involving participants in breathing exercises and singing together</td>
<td>To break the ice among participants and create a musical space where disease is secondary</td>
</tr>
<tr>
<td>Day 2</td>
<td>Energy management, strategies, and habits in everyday living (Maximum of 9 participants per session)</td>
<td>Occupational therapist</td>
<td>Group counselling regarding changes in everyday life (e.g., fatigue) and the need for an overview and strategies to address these challenges</td>
<td>To help participants obtain advice and guidance to manage energy and create a greater overview of everyday life</td>
</tr>
<tr>
<td>2 h., 30 min.</td>
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</tr>
<tr>
<td>60 min.</td>
<td>Body, movement, and relaxation (Maximum of 9 participants per session)</td>
<td>Physiotherapist</td>
<td>Based on participants’ physical capabilities, a gentle training session focusing on how movement and training strengthen the body and enhance energy and well-being in daily life</td>
<td>To experience the joy of moving the body and inspiration for integrating physical activities into daily life</td>
</tr>
<tr>
<td>1 h., 15 min.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2 h., 30 min.</td>
<td></td>
<td>Neurosurgical nurse and</td>
<td>Focus group interview focusing on caregivers’ preferences for support</td>
<td>To provide family caregivers with a space focused on their personal experiences and preferences</td>
</tr>
<tr>
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</tr>
<tr>
<td>Focus Group Interview</td>
<td>Consultant from the Centre for Brain Injury</td>
<td>During patients’ disease and treatment trajectories needs, guidance from professionals, and an opportunity to speak freely with peers</td>
<td></td>
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<td>-----------------------</td>
<td>---------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
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</tr>
<tr>
<td><strong>Day 3</strong></td>
<td><strong>Mental reactions</strong> and mindset session</td>
<td><strong>Neuropsychology</strong> Separate sessions for patients and caregivers focus on mental reactions associated with having a brain tumor and how a tumor can influence and change the mind, as well as reactions related to serious life-threatening disease. Sessions based on participants’ experiences.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2 h</strong></td>
<td><strong>Mental reactions and mindset session for patients</strong></td>
<td><strong>Physiotherapist</strong> A short relaxation session focusing on the body and senses To help participants focus on the moment, gather thoughts, and create grounding</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>30 min.</strong></td>
<td>Light physical activity and relaxation</td>
<td><strong>Professional sexologist</strong> Information and discussion about body and intimacy in the relationship To help participants learn how to support intimacy despite illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Optional session:</strong></td>
<td><strong>Intimacy and sexuality</strong></td>
<td><strong>Social worker</strong> Highlights the importance of a connection to working life To provide guidance about opportunities to maintain a job or options to leave the work force</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>90 min.</strong></td>
<td><strong>Working life</strong></td>
<td><strong>Course coordinator</strong> Informational session on motivation and making changes in daily life To help participants develop and sustain motivation for changes inspired by the program</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>60 min.</strong></td>
<td>Motivation and changes</td>
<td><strong>Psychologist, nurse, social worker, physiotherapist</strong> To discuss focus areas participants want to continue working with To support participants in gaining clarity about changes they want to make after returning home</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Day 4</strong></td>
<td>Individual (optional) or dyadic conversations</td>
<td><strong>Massage therapists</strong> Individual full body relaxing massage To promote participants’ experiences of their bodies and mental health</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>60 min.</strong></td>
<td>Plan of action</td>
<td><strong>Physiotherapist and course coordinator</strong> Participants plan and describe the changes they want to implement or maintain in everyday life To help participants anchor and maintain new habits until follow up at week 12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day</td>
<td>Session</td>
<td>Health care professional</td>
<td>Description of session</td>
<td>Purpose</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------</td>
<td>------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>Since we last saw each other</td>
<td>Physiotherapist and course coordinator</td>
<td>Based on action plans they created during the initial program, participants share experiences from the last three months, where they have been successful, challenges, and what areas they would like to focus on going forward.</td>
<td>To clarify what participants have successfully implemented in daily life and any needed adjustments to their individual action plans and allow participants to get a brief insight into each other’s daily lives</td>
</tr>
<tr>
<td>60 min.</td>
<td>Group conversation (patient session)</td>
<td>Course coordinator</td>
<td>Participants write down a topic they would like to discuss. The course coordinator categorizes the submitted topics, with the conversation based on the categories</td>
<td>To create a space where topics can be discussed with peers in a structured framework.</td>
</tr>
<tr>
<td>60 min.</td>
<td>Caregiver support – a focus group interview (caregiver session)</td>
<td>Neurosurgical nurse</td>
<td>Based on caregivers' needs for support identified in focus group interviews in the initial program, the group discussion is about specific supportive interventions caregivers would prioritize and think they could benefit the most from.</td>
<td>To discuss supportive interventions targeting caregivers of patients diagnosed with HGG</td>
</tr>
<tr>
<td>30 min.</td>
<td>Physical activity</td>
<td>Physiotherapist</td>
<td>Participants have the option to join a guided physical activity or go for a walk on their own.</td>
<td>To offer participants a mental breathing space where the focus is only on the body.</td>
</tr>
<tr>
<td>75 min.</td>
<td>Life, disease, and hope</td>
<td>Priest</td>
<td>A conversation about questions that arise when people are affected by HGG</td>
<td>To provide participants with the opportunity for an open conversation focused more on sharing thoughts and doubts, rather than finding answers</td>
</tr>
<tr>
<td>Day</td>
<td>Individual</td>
<td>Psychologist, nurse, Dyadic or individual</td>
<td></td>
<td>To help participants become</td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
<td>Facilitator</td>
<td>Description</td>
<td></td>
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<td>-------------</td>
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<td></td>
</tr>
<tr>
<td>2 h</td>
<td>conversations</td>
<td>social worker, physiotherapist</td>
<td>(optional) conversations about topics participants would like to discuss with a professional and continued development of action plans</td>
<td></td>
</tr>
<tr>
<td>30 min.</td>
<td></td>
<td></td>
<td>more clear about changes they want to make or maintain in everyday life</td>
<td></td>
</tr>
<tr>
<td>1 h</td>
<td>Optional session:</td>
<td>Physiotherapist</td>
<td>Practical instructions to give participants concrete tools</td>
<td></td>
</tr>
<tr>
<td>15 min.</td>
<td>Relaxation and couples massage</td>
<td></td>
<td>To help participants find a peaceful place and create contact with each other through touch</td>
<td></td>
</tr>
<tr>
<td>and</td>
<td>How do I use my energy in daily life?</td>
<td>Nurse</td>
<td>Based on participants’ concrete experiences, this session further develops the topic of energy management from the initial program</td>
<td></td>
</tr>
<tr>
<td>1 h. (follow-up)</td>
<td></td>
<td></td>
<td>To help participants become more aware of factors that contribute to weakening and strengthening energy through practical exercises</td>
<td></td>
</tr>
<tr>
<td>30 min.</td>
<td>Optional session:</td>
<td>Physiotherapist</td>
<td>Participants can join a guided physical activity or go for a walk on their own.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Light physical activity and relaxation</td>
<td></td>
<td>To offer participants a mental breathing space where the focus is only on the body</td>
<td></td>
</tr>
<tr>
<td>60 min.</td>
<td>Everyday life, habits, and action plans</td>
<td>Course coordinator</td>
<td>Participants adjust desired changes as needed and prepare to integrate them into their daily lives.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>To help participants anchor desired changes and ways to work toward them</td>
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</tbody>
</table>

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Table 3 Demographic Characteristics of Study Participants

<table>
<thead>
<tr>
<th></th>
<th>Patients (n=17)</th>
<th>Family caregivers (n=16)</th>
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<tbody>
<tr>
<td>Male/female</td>
<td>9/8</td>
<td>5/11</td>
</tr>
<tr>
<td>Age, median (range)</td>
<td>60 (32-73)</td>
<td>60 (25-73)</td>
</tr>
<tr>
<td>Patients’ diagnosis</td>
<td></td>
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<tr>
<td>HGG grade III</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>HGG grade IV</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-6 months</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>7-12 months</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>1-2 years</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>2-3 years</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>&gt;3 years</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Parent/sibling</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: HGG, high-grade glioma
Table 4 Relevance and satisfaction scores for REHPA-HGG initial program
Table 5 Relevance and satisfaction scores for REHPA-HGG follow-up program