

The Aftercare Survey: Assessment and intervention practices after brain tumor surgery in Europe

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Abstract

Background. People with gliomas need specialized neurosurgical, neuro-oncological, psycho-oncological, and neuropsychological care. The role of language and cognitive recovery and rehabilitation in patients' well-being and resumption of work is crucial, but there are no clear guidelines for the ideal timing and character of assessments and interventions. The goal of the present work was to describe representative (neuro) psychological practices implemented after brain surgery in Europe.

Methods. An online survey was addressed to professionals working with individuals after brain surgery. We inquired about the assessments and interventions and the involvement of caregivers. Additionally, we asked about recommendations for an ideal assessment and intervention plan.

Results. Thirty-eight European centers completed the survey. Thirty of them offered at least one postsurgical (neuro)psychological assessment, mainly for language and cognition, especially during the early recovery stage and at long term. Twenty-eight of the participating centers offered postsurgical therapies. Patients who stand the highest chances of being included in evaluation and therapy postsurgically are those who underwent awake brain surgery, harbored a low-grade glioma, or showed poor recovery. Nearly half of the respondents offer support programs to caregivers, and all teams recommend them. Treatments differed between those offered to individuals with low-grade glioma vs those with high-grade glioma. The figure of caregiver is not yet fully recognized in the recovery phase.

Conclusion. We stress the need for more complete rehabilitation plans, including the emotional and health-related aspects of recovery. In respondents' opinions, assessment and rehabilitation plans should also be individually tailored and goal-directed (eg, professional reinsertion).

Keywords

caregivers | glioma aftercare | postsurgical outcomes | quality of life | survey

Brain tumors require complex medical procedures and a follow-through plan. They are associated with a triple burden on patients: (i) a potentially fatal disease, (ii) the need for invasive treatment, and (iii) the risk of subsequent iatrogenic impairments (ie, motor, language, cognitive). Patients with brain tumors neurosurgical, neuro-oncological, psycho-oncological, and neuropsychological care.

Although the role of language/cognitive recovery in patients' well-being and resumption of work is crucial, only scarce evidence is available regarding the outcomes of these patients.^{1,2} Moreover, the results reported are inconsistent. Most do not consider psychological distress factors, treatments (ongoing or completed), and/or baseline scores on neuropsychological and language assessments (for a review, see Refs.^{3,4}). Notably, a review by Ford and colleagues⁵ indicated that 48% of people with brain tumors experience high depression and anxiety rates. Most importantly, the (neuro)psychological assessment protocols and general aftercare programs (considering patients' well-being at medical, cognitive, and psychological levels) are not yet well defined.

In one of the latest surveys by the European Low Grade Glioma Network (ELGGN), 37% of respondent centers were aware of the observed rate of work resumption after glioma surgery at their institution, and only 31% evaluated the quality of life (QoL) of their patients.⁶ Also, according to the literature, a scarce number of systematic language/cognitive rehabilitation programs are offered in brain surgery aftercare.^{7,8} Concurrently, there have been reports that have

highlighted the positive effects of such interventions on individuals with brain tumors.^{9,10} With regard to the perioperative care protocols, prior ELGGN surveys have provided substantial information about commonly used preoperative neuropsychological assessments,^{6,11} neuroradiological planning¹², and adjuvant treatments.¹³ These surveys have collected information on preoperative, intraoperative, and early postsurgical assessment, monitoring, and treatment protocols, but not on (long-term) aftercare.

The main aim of the present survey was to characterize the postsurgical aftercare practices in patients with brain tumors in Europe. This main objective was accomplished by examining the representative (neuro)psychological assessments and intervention practices during the first year after brain surgery and long term (after 1 year). Additionally, the survey results opened an avenue for a direct clinical application, as the respondents' opinions created an optimal model of postoperative care for patients and their caregivers.

Methods

Survey Construction and Platform

The survey was created using an online *LimeSurvey* platform (An Open-Source survey tool/LimeSurvey GmbH, Hamburg, Germany, <http://www.limesurvey.org>). It was addressed to professionals working with individuals

requiring brain tumor surgery aftercare (ie, neurosurgeons, neuro-oncologists, (neuro)psychologists, therapists, and other healthcare professionals).

The survey consisted of three blocks: (i) general information, (ii) assessment, and (iii) intervention. The *general information block* gathered information on participating institutions (eg, number of glioma surgeries performed per year, if awake brain mapping is conducted). Firstly, respondents were asked which kind of institution/service they represent and in which city and country. Subsequently, they were instructed to provide information about how many surgeries for brain tumor removal (in adults, any location) are performed at their institution per year. Then, respondents specified how many of these surgeries were for high-grade gliomas (HGG-WHO III and IV) and low-grade gliomas (LGG-WHO I and II). Finally, they were asked if brain mapping protocols have been provided at their center at least once, and, if so, to specify which kind.

The *assessment block* was devoted to four aspects of patient care: (1) speech and language, (2) cognitive abilities (other than language), (3) emotional well-being, and (4) health-related psychological distress. For each topic, five time points were specified: (1), bedside = 1-10 days after surgery, (2) acute stage of recovery = 11-60 days, (3) early recovery = 2-5 months, (4) late recovery = 5-12 months, and (5) long term = 1 year after surgery (timeline specified according to the previous literature^{3,4} and determined after a pilot study). According to the European practice, the bedside period could also be considered as “inpatient,” whereas the rest of the time points can be classified as “outpatient.” At the end of this block, participants indicated which kinds of assessments they recommended to be implemented at their institution. We indicated that these recommendations were valid even if they would concern only selected patients. We used a 5-point Likert scale (1—representing “I would not recommend at all,” 2— “neither recommend nor discourage,” 3— “I would recommend under certain conditions,” 4— “I do recommend,” and 5— “I think it is essential”). The participating centers could specify if a particular type of assessment was more suitable for any specific time point.

The *intervention block* contained queries about speech therapy, general neuropsychological rehabilitation, individual psychotherapy, support groups, occupational therapy, music therapy, physiotherapy, and professional reinsertion programs. For each intervention type, frequency (specified weekly) and length (in minutes) were gathered. Here, participants indicated which therapies they would recommend for their institution (using a Likert scale, responses not assigned to any time points), even if only selected patients would benefit from them. Both *assessment* and *intervention* blocks contained free-text sections with unconstrained opinions and recommendations. The remaining questions concerned support and educational programs for caregivers.

The survey was disseminated using social media, conferences, and personal contact lists. A copy of the questions is available upon request. The study was covered by the approval of the Ethics Committee Social Sciences (ECSS 2017-3001-455), Radboud University Nijmegen (Netherlands). All participants were made explicitly aware of the study purpose and implementation and accepted the survey conditions by their online participation. Survey

data are safely stored at the Radboud University server and participants' contact information was not available to third parties. Any identifiable information (eg, Institution name or initials) was erased from the shared database.

Statistical Analyses

Descriptive statistics were used to summarize and interpret the data. Software used for these analyses included R embedded in RStudio, and the following packages: *tidyverse*,¹⁴ *here*,¹⁵ *magrittr*,¹⁶ *summarytools*,¹⁷ *glue*,¹⁸ *fs*,¹⁹ *patchwork*,²⁰ and *ggforce*.²¹ Data and code are published online under Open Science Framework (osf.io/7nqwz). Individual figures were obtained by manually adapting the code until the intended result was obtained.

Results

General Information

A total of 38 European institutions completed the survey to the full extent (Figure 1a). Additionally, seven non-European countries also completed the survey and their qualitative “free-text” opinions were considered. However, the quantitative data from these countries were not taken into account to ensure that the survey only represents Europe.

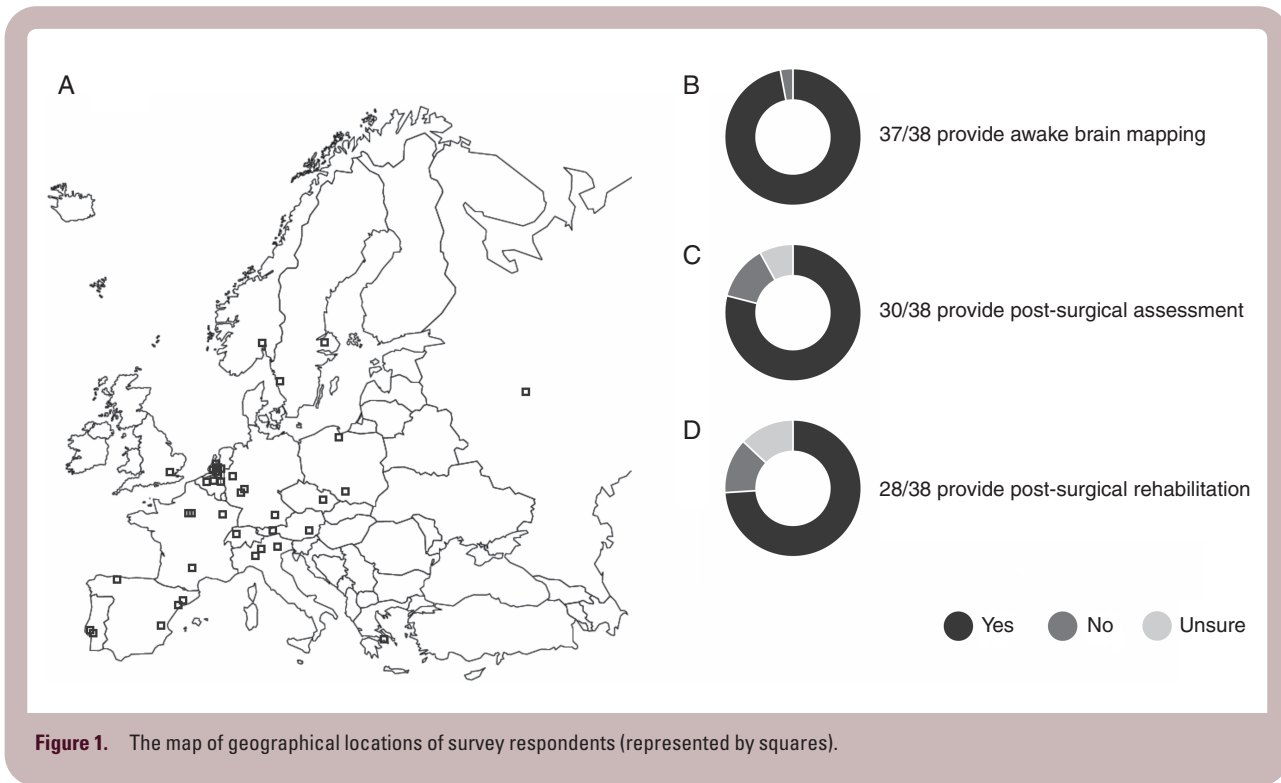
The respondents primarily represented neurosurgery (30/38) and neuropsychology units (10/38). A smaller proportion included neuro-oncologists (5/38), speech therapists (3/38), and (neuro)psychologists/psychotherapists (2/38). Note that the final number of respondents exceeded 38 since some institutions were represented by more than one professional. The remaining respondents represented: neurology, neurophysiology or psychiatry departments, an epilepsy clinic, and a University research center. 27/38 responding institutions were members of the ELGGN.

Institutions reported to perform from 10 to 800 surgeries per year (mean = 256, SD = 194). Of these, between 4 and 300 were for HGG (mean = 91, SD = 66), and 2 and 350 for LGG (mean = 44, SD = 60). Almost all institutions offered awake brain mapping (37/38, Figure 1b) for at least one of the following domains: motor, sensory, language, visual perception, executive functions, and music. Individual institutions mapped/monitored memory, arithmetic, reading, writing, social cognition, spatial attention, proprioception, body image, and praxis.

Assessment

30/38 institutions offered at least one (neuro)psychological and/or language assessment after surgery (Figure 1c). All of these 30 centers assessed speech/language, whereas other types of assessments were proposed less frequently (Figure 2a).

Institutions mainly administered (neuro)psychological and/or language assessments at bedside (inpatient) and in acute and early stages of recovery (for more details, see Supplementary Table 1). Only some centers (12/30) included all patients in their (neuro)psychological



and language assessments, whereas 18/30 applied specific criteria for inclusion. The most frequent reasons for an assessment included: prior awake brain surgery, low-grade glioma, and/or patient's or caregiver's demand. Fewer institutions offered follow-up assessments based on general outcomes from postoperative recovery (either good or poor) or lesion location. Patients with HGG and/or those who underwent adjuvant chemo-, radio-, or chemoradiation were rarely referred for assessments (Figure 2b).

The professionals' responses differ as to when it is best to provide a specific kind of assessment. At bedside and during early recovery, they most often provided speech/language assessments. At the remaining time points, speech and language assessments were conducted as often as the other evaluations (see Figure 3 and Supplementary Table 1).

The professionals recommended speech/language and cognitive assessments as the most important (Figure 4 and Supplementary Table 2). The respondents agreed that assessing patients during early recovery was the most recommendable and that long-term evaluations should be covered more extensively (see Figure 4). At bedside, around half of the respondents recommended assessing speech/language, cognition, and emotional well-being, but inquiring about health-related psychological distress was discouraged at this point (Figure 4 and Supplementary Table 2).

When asked for unconstrained comments, one respondent highlighted the importance of individually tailored interventions and their preference for paper-and-pencil methods over computerized approaches. The participants highlighted that the course of postoperative

recovery can differ substantially, depending on tumor grade; for example, it is easier to diagnose aphasia type in patients with HGG. By contrast, existing approaches are limited in assessing language impairments in individuals with LGG. One team stated that neurosurgical patients "tend to get worse just after the surgery," but "recover with regard to motor, language and neurocognitive function within 9-12 weeks after surgery." Another team said that effective neuro-oncological care involves a preoperative neurocognitive examination of 75-90 minutes, at 3- to 4-month post-surgery and also in "parallel to neuroimaging surveillance." Yet another team stressed the importance of "more long-term assessments of the language network, as well as its neighbouring regions." Finally, several respondents indicated that postoperative assessments should be functional rather than impairment-based.

Interventions

28/38 surveyed institutions offered at least one (neuro)rehabilitation intervention after brain surgery, five were uncertain, and five did not offer any rehabilitation (Figure 1d).

Few institutions (5/28) provided postoperative interventions for all people with brain tumors, but the majority (23/28) required meeting specific criteria, for example, poor postoperative recovery, prior awake brain surgery, or a low grade of the tumor. Fewer institutions considered a low tumor grade and good postoperative recovery as reasons for inclusion, in addition to the patient's own choice. A high tumor grade was barely ever a reason for inclusion, and no patients were included based on undergoing adjuvant chemotherapy, radiotherapy, or chemoradiation only (Figure 5a). In unconstrained recommendations, a few respondents highlighted that participation

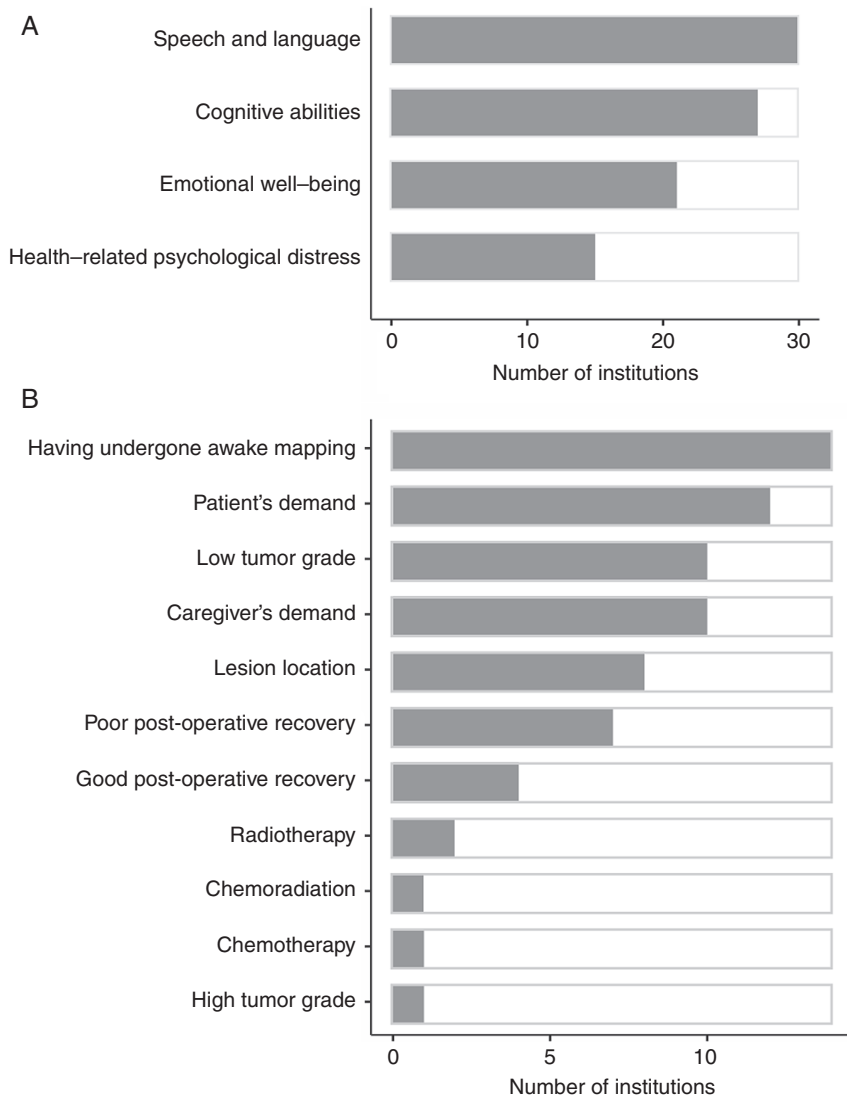


Figure 2. (a) Number of institutions and type of postoperative assessments. (b) Number of institutions per criterion for inclusion for postoperative assessments. Note that questions were not mutually exclusive, which means that the same institution could offer more than one type of assessment or inclusion criterion.

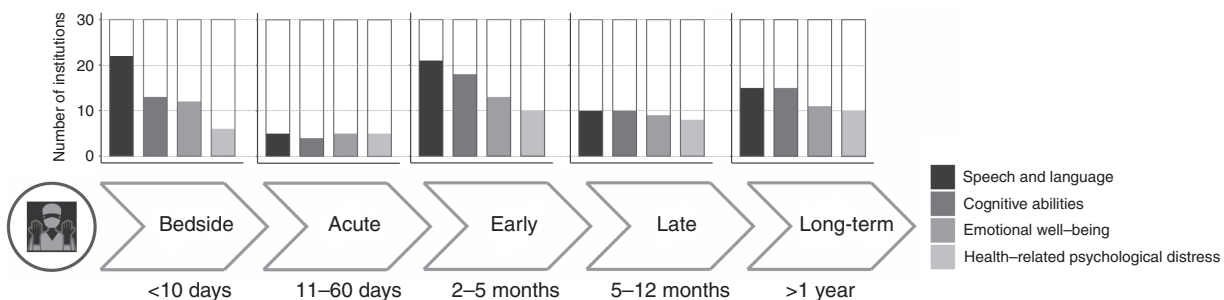
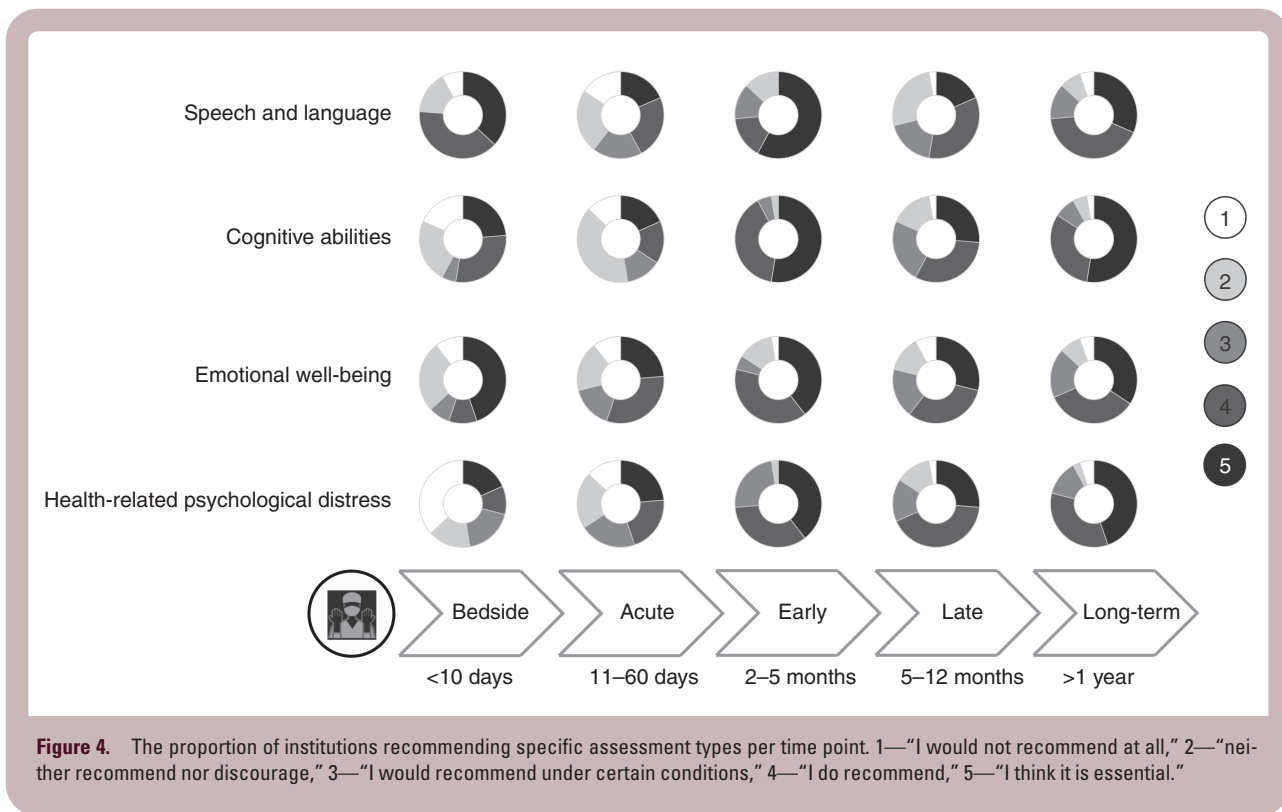


Figure 3. The proportion of institutions offering assessments at five given time points. Each bar indicates the type of assessment offered. Note that the questions were not mutually exclusive, which means that the same institution could provide more than one type of assessment.



in (neuro)rehabilitation programs at their institution is "not the choice of the patients," and/or that it depends on "cognitive complaints and deficits." Similarly, other professionals consider "neurological" deficits as the basis for (neuro)rehabilitation. One team takes into account the difficulties of the person to "integrate in the normal, socio-professional life," and their "cognitive problems" and "willingness" to undertake neuro-rehabilitation. Finally, one team reports that the decision of whether patients get enrolled in intervention programs is made solely by their rehabilitation units, which "may or may not include patients to their programs."

The most commonly used treatments were speech therapy, general neuropsychological rehabilitation, and physiotherapy. One team offered music therapy (Figure 5b and Supplementary Table 4), and another offered memory training (commented in a free-text section, not shown in the figure). Therapies differed in their starting time point, and the number and duration of sessions (Figure 6a). In general, interventions were administered a few weeks after surgery. Neuropsychological rehabilitation and speech therapy were offered even up to 60 times (Figure 6a and Supplementary Table 3).

Speech therapy and neuropsychological rehabilitation were recommended the most frequently, followed by physiotherapy (Figure 6b). Individual psychotherapy, support groups, and occupational therapy were recommended for patients who meet specific criteria (see the frequency of responses "3," indicated with dark gray in Figure 3). The participants were also indicating that professional reinsertion programs were essential (Figure 6b).

Using free text, the professionals pointed out the importance of the reintegration of the affected individual into their preexisting social surroundings. The respondents highlighted that

patients need to be able to return to their vocational/academic settings and daily activities. Teams stressed the benefits of a multidisciplinary approach in postsurgical care programs, and the consideration of individual patient needs. In their opinion, programs should be based on the character of postoperative impairments (eg, language, cognition, or motor). Psychological aspects, for example, patients' well-being and QoL, should also be taken into account. Notably, one group acknowledged the value of continuity in the transition from the hospital to the home setting and the relevance of easy access to nurses and relevant information.

The survey also included questions about caregivers. Nearly half of the centers (16/38) provided support programs for caregivers (18/38 did not, and 4/38 were uncertain). 29/38 centers indicated that they find such programs useful (2/38 centers stated they are not useful, 7/38 centers were uncertain). The professionals admitted that they were aware of caregivers' burden. They emphasized that caregivers can help recognize more cognitive complaints than patients themselves, and that they can play a key role in patients' recovery. The respondents stressed the importance of early detection of depression and anxiety in caregivers. One center suggested that "the best form of support would be a group meeting, an informative talk with nurses and, if necessary, a meeting with a psychologist."

Educational programs for caregivers were offered by 9/38 institutions (23/38 stated they did not, 6/38 were uncertain). The majority of the respondents (24/38) recommended such programs, 12/38 were uncertain about their usefulness, and 2/38 did not recommend them. In general, professionals recommended that caregivers learn about pre- and postsurgical changes in the patient (emotional,

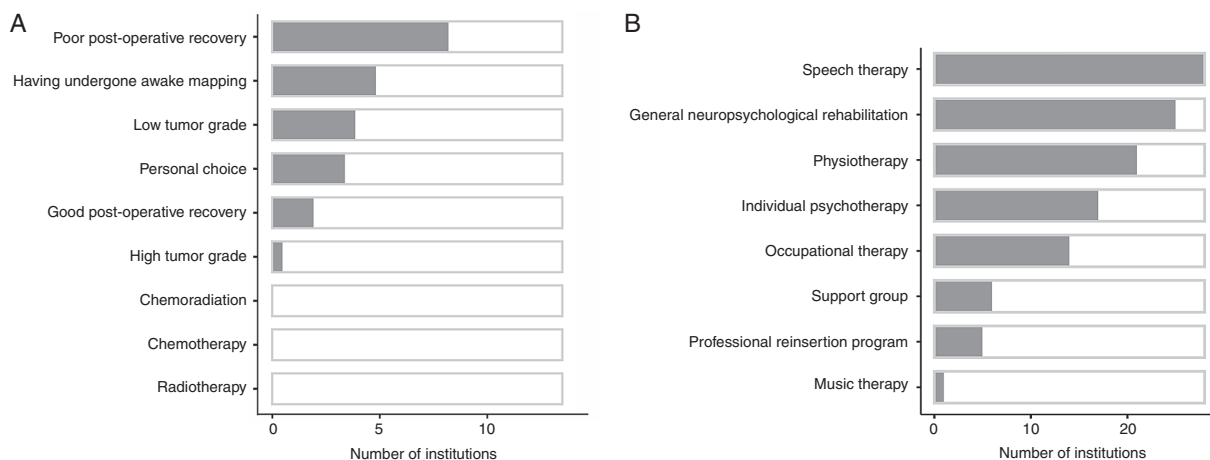


Figure 5. (a) Referrals for postoperative intervention plans based on outcomes and patient characteristics. (b) The number of institutions providing a specific kind of postsurgical therapy. Note that the questions were not mutually exclusive, which means that the same institutions can have more than one inclusion criterion or run more than one type of assessment.

behavioral, cognitive), and elementary techniques of home-based rehabilitation. They proposed taking caregivers “step by step through the treatment process, identify their obstacles, and give them emotional support.” The professionals emphasized that caregivers should be sufficiently informed about the entire trajectory of the disease, from the diagnosis to the latest developments in all aspects: surgical, medical, social, cognitive, emotional, behavioral, and overall well-being.

Using free text, the respondents stressed the importance of care individually tailored to patients’ needs and effective communication between different care centers for continued rehabilitation (eg, between neurosurgery and neuro-rehabilitation or neuro-oncology centers). For language, two teams emphasized there is a need for fine-grained language evaluation and rehabilitation protocols since the standard ones do not always detect language/cognitive deficits. The participants acknowledged that not all language impairments could be detected with the existing standard batteries, ranging from deficits of the core language aspects (such as grammar) to more subtle cognitive deficits, which—as they reported—are “often important in patients with LGG.”

Discussion

We surveyed the neurosurgical aftercare of people with gliomas in 38 institutions across 15 European countries. The survey was completed primarily by neurosurgeons, (likely thanks to the well-established network and previously accomplished similar projects by the ELGNN, www.brain tumours.eu). The institutions varied in the number of glioma surgeries per year and in their approaches to surgical aftercare.

The centers mainly offer speech/language and other cognitive assessments, especially during the early recovery stage and at long term. Some institutions also assess emotional well-being and health-related issues (with no specific time preference). The respondents recommend assessing non-cognitive aspects of patients’ outcome (eg, emotional well-being) throughout the entire first year after surgery. However, not all centers referred their patients to postsurgical assessments. The qualitative responses of professionals indicated that aftercare plans were and should be individually tailored. Quantitatively, this means that patients who stood the highest chances of being assessed postsurgically were those who underwent awake brain surgery, harbored a LGG or showed poor postoperative recovery. Being diagnosed with a HGG and undergoing chemo- and/or radio- or chemoradiation were rarely considered sufficient for inclusion in assessments. Some teams suggested considering patients’ request for being assessed as another important reason for inclusion. Given a higher prevalence of high-grade over low-grade tumors (also in young people²²) and the additional burden of adjuvant oncological therapies on cognition,^{23,24} the lack of postsurgical (neuro)psychological interventions is concerning and should be approached by institutions treating patients with gliomas in the future. However, one may argue that it would be beneficial to wait with cognitive rehabilitation until individuals with HGG complete their chemo- or radiotherapy.

Medical teams primarily provided therapies for language/speech and cognition and, again, these were offered mainly to patients who underwent awake brain surgery and harbored a LGG. However, individuals who are particularly suitable for interventions are people with a HGG, as they are vulnerable to postoperative iatrogenic damage.^{25,26} According to our respondents, being under chemo- and/or radiotherapy was not the (main) reason for inclusion in therapies either (these results should be interpreted with

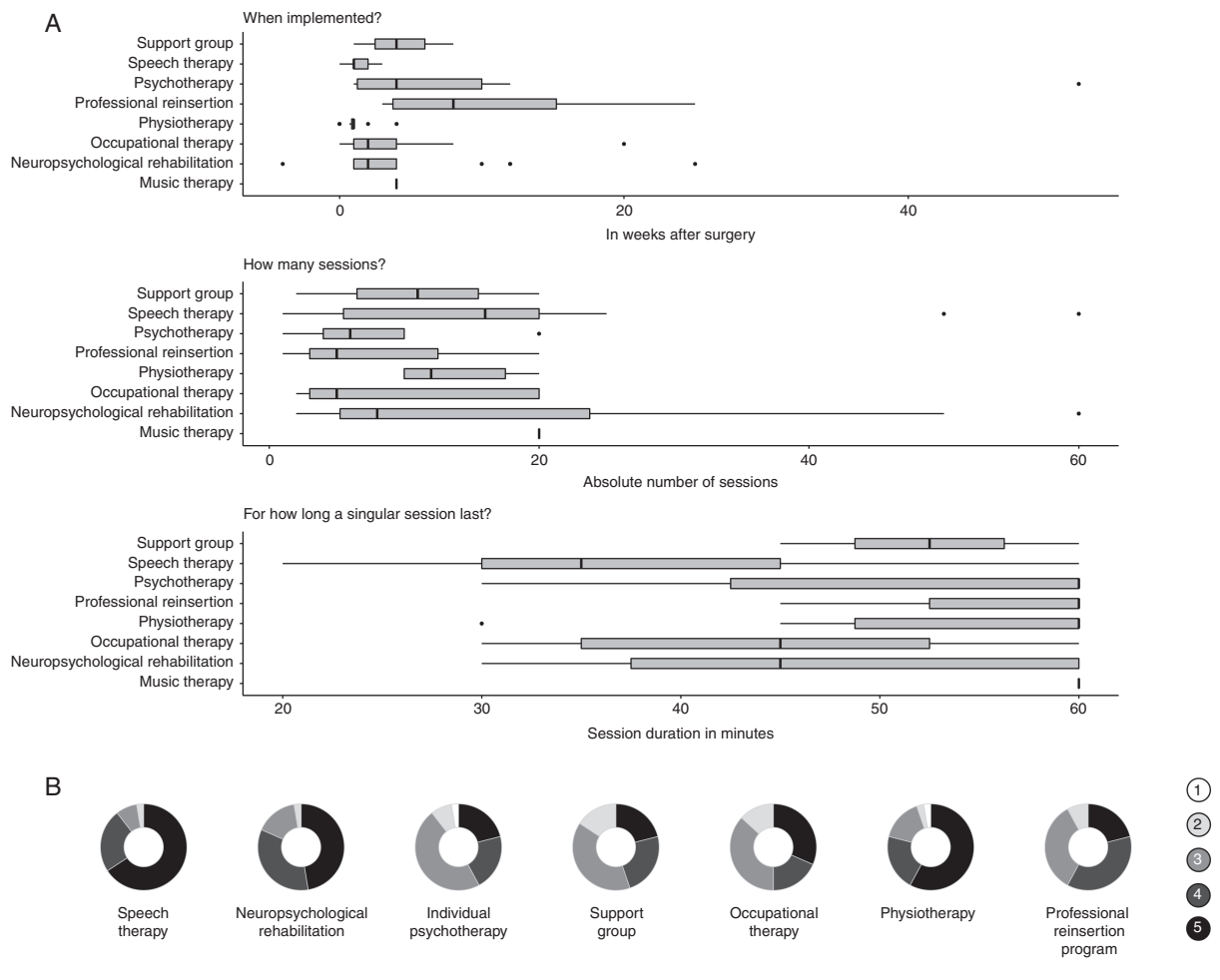


Figure 6. (a) Boxplots (showing median, first and third quartiles, and outliers) of eight therapies with their starting points (in weeks after surgery, negative numbers indicate that therapy began before the surgery), number of sessions, and session duration (in minutes). (b) The proportion of institutions recommending specific therapies after surgery (1—"I would not recommend at all," 2—"neither recommend nor discourage," 3—"I would recommend under certain conditions," 4—"I do recommend," 5—"I think it is essential").

caution, as the inclusion criteria we provided are often intertwined, eg, chemotherapy and a HGG). Given the low participation of neuro-oncologists in the survey, we cannot assess whether these results could be attributed to poor communication between neurosurgery and neuro-oncology units. Improving the communication between these specialties, and establishing novel, more inclusive plans of postsurgical aftercare (eg, including caregivers and people with HGG), and exploring discrepancies among centers should become a future priority.

Interventions provided by the participating institutions include a whole range of therapies, and the professionals rarely considered them unnecessary. Interestingly, the respondents often recommended professional reinsertion programs. This recommendation is very promising as it meets not only the life interests of patients but also the economic interests of healthcare systems, as it potentially minimizes indirect surgical costs.^{27,28} We argue that difficulties with work resumption may be related to untreated cognitive and language impairments and lack of psychological

support for affected individuals. From this perspective, professional occupation could help maintain patients' social activity and personal development. If correctly administered (eg, in a gradual manner), professional occupation could help maintain healthy habits and adequate amounts of cognitive challenge, which can be beneficial in recovery.^{1,29} Moreover, an adequately implemented return to work can safeguard patients from resigning from professional activity due to overload or ill-designed schedules.³⁰ This topic is important for future developments in collaborations between psychologists and social employees working in postsurgical aftercare.

Notably, almost all teams recommend programs for caregivers' education and support implemented at their institutions, even though not all the centers offer them. The participating teams highlighted the fact that caregivers are crucial figures for rehabilitation. Available reports indicate that the topic of caregiver burden is extremely important but understudied.³¹⁻³³ Caregivers suffer from distress, especially around diagnosis and initial

stages of treatment,^{34,35} they report being unable to adequately support their affected family member and feeling overwhelmed.³⁵

Our results provide an overview and a baseline for healthcare professionals and academics to improve neurosurgical aftercare of patients with glioma. Based on our results, an ideal follow-up plan would include assessments of speech/language, cognition, and emotional well-being at three time points: bedside, during early recovery, and at long term. Evaluation of health-related psychological distress was recommended during early recovery and at long term (and not during the inpatient/bedside period). Concerning interventions, language/speech therapy, neuropsychological rehabilitation, and physiotherapy were considered the most substantial approaches to rehabilitation, although occupational therapy, professional reinsertion, and psychotherapy (individual or in a group) were also recommended. Therapies were provided a few weeks after surgery, with professional reinsertion being introduced last. The most common practice is to conduct 20 sessions, lasting 60 minutes, regardless of the type of the intervention.

The character of assessments and interventions should differ based on personal characteristics (age, lifestyle, profession), tumor size, location, and type differentiating the aftercare plans for people with a LGG and HGG.³⁶ Although our survey examined assessment and intervention plans for all tumor grades (I-IV) together, based on the prior literature, we argue that families affected by a HGG may require reinforced support. Indeed, they deal not only with cognitive and surgery-related issues but also with cancer-related issues (eg, reduced life expectancy³⁶). People with a HGG, and their caregivers, require (often urgent) psychological support and educational programs to adjust to a sudden change in their life.³⁵ In turn, people with a LGG could benefit more from professional reinsertion programs.³⁰ Additionally, the (neuro)psychological testing in patients after LGG resection could be more beneficial if implemented every year by default, whereas the timing of similar testing in people after HGG resection should be adapted more flexibly—taking into account the possible recurrence and limited survival. Compared to people affected by LGG, patients with HGG are most commonly older, hence with lower plasticity potentials.⁵ Consequently, supportive rehabilitation might require a longer period of time in this older population, a need which is somewhat antagonistic with the shorter progression-free survival for HGG. This paradox makes supportive care for HGG patients more challenging.

This survey has several limitations. First, there was a participation bias, as almost all respondents were ELGGN members, which means that this survey has not fully covered common European practices, and thus is mainly representative of the ELGGN. Concurrently, the respondents have decades of experience in neurosurgery, so their expertise in the field makes them excellently qualified to recommend certain practices. Secondly, despite our efforts, the geographical coverage we accomplished favored Occidental Europe. Future goals of our network should seek a better exchange of practices with centers from the Balkans, Central, and Eastern Europe. Multilingual adaptations of perioperative tests set a promising avenue for this.^{37,38} We also have an underrepresentation of professionals from neuro-oncology and therapy units, which

could skew the final results in the direction that represents mainly post-surgery interventions, whereas long-term neuro-oncological care could not be depicted to a sufficient extent. Future surveys, continuing this new line of research, should involve more professionals representing neuro-oncology, professional reinsertion, occupational therapy units, and memory clinics.

Future work related to this survey will cover a detailed description of specific (neuro)psychological questionnaires, tests, and batteries to provide an accessible set of practical recommendations for (neuro)psychologists. Additionally, work has started on more global coverage of postsurgical practice, which will allow even wider, intercontinental exchange of experience between professionals (an ongoing data acquisition in the Americas; contact the corresponding author for more information or access the North American Survey through this link: https://uclahs.az1.qualtrics.com/jfe/form/SV_8DfC1nY465IUKZ7, which will be active for a time-limited period from submission date).

Supplementary Material

Supplementary material is available at *Neuro-Oncology Practice* online.

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