

University of Groningen

## THE AFTERCARE SURVEY

Sierpowska, Joanna; Rofes, Adrià; Dahlslätt, Kristoffer; Mandonnet, Emmanuel; ter Laan, Mark; Połczynska, Monika; De Witt Hamer, Philip; Halaj, Matej; Spena, Giannantonio; Meling, Torstein

*Published in:*  
Neuro-oncology practice

*DOI:*  
[10.1093/nop/npac029](https://doi.org/10.1093/nop/npac029)

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Final author's version (accepted by publisher, after peer review)

*Publication date:*  
2022

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Sierpowska, J., Rofes, A., Dahlslätt, K., Mandonnet, E., ter Laan, M., Połczynska, M., De Witt Hamer, P., Halaj, M., Spena, G., Meling, T., Motomura, K., Reyes, A. F., Rainha Campos, A., Robe, P. A., Zigiotta, L., Sarubbo, S., Freyschlag, C. F., Broen, M. P. G., Stranjalis, G., ... Piai, V. (Accepted/In press). THE AFTERCARE SURVEY: Assessment and intervention practices after brain tumour surgery in Europe . *Neuro-oncology practice*, [npac029]. <https://doi.org/10.1093/nop/npac029>

### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

# THE AFTERCARE SURVEY: Assessment and intervention practices after brain tumour surgery in Europe

Joanna Sierpowska (1,2), Adrià Rofes (3), Kristoffer Dahlslett (\*), Emmanuel Mandonnet (4), Mark ter Laan (5), Monika Polczyńska (6), Philip De Witt Hamer (7), Matej Halaj (8), Giannantonio Spina (9), Torstein R. Meling (10), Kazuya Motomura (11), Andrés Felipe Reyes (12,13), Alexandre Rainha Campos (14), Pierre A Robe (15), Luca Zigiotta (16, 17), Silvio Sarubbo (16, 17), Christian F. Freyschlag (18), Martijn P. G. Broen (19), George Stranjalis (20), Konstantinos Papadopoulos (20), Evangelia Liouta (20), Geert-Jan Rutten (21), Catarina Pessanha Viegas (22), Ana Silvestre (22), Federico Perrote (23), Natacha Brochero (23), Cynthia Cáceres (24), Agata Zdun-Ryżewska (25), Wojciech Kloc (26, 27), Djaina Satoer (28), Olga Dragoy (29), Marc PH Hendriks (1, 30, 31), Juan C. Alvarez-Carriles (32, 33, 34), Vitória Piai (1,2)

(1) Radboud University, Donders Institute for Brain, Cognition and Behaviour, Nijmegen, The Netherlands

(2) Radboud University Medical Center, Donders Institute for Brain Cognition and Behaviour, Department of Medical Psychology, Nijmegen, The Netherlands

(3) Department of Neurolinguistics, University of Groningen, Groningen, The Netherlands

(4) Neurosurgery Department, Hôpital Lariboisière, Paris, France

(5) Radboud University Medical Center, Radboud Institute of Health Science, Department of Neurosurgery, Nijmegen, The Netherlands

(6) Department of Psychiatry and Biobehavioral Sciences, University of California, Los Angeles, USA

(7) Amsterdam University Medical Department, Amsterdam, The Netherlands

(8) Department of Neurosurgery, University Hospital Olomouc, Czech Republic

(9) Neurosurgery Department, Alessandro Manzoni Hospital, Lecco, Italy

(10) Department of Neurosurgery, Geneva University Hospital, Geneva, Switzerland

(11) Department of Neurosurgery, Nagoya University School of Medicine, Nagoya, Japan

(12) Experimental Psychology Lab, Faculty of Psychology, Universidad El Bosque, Bogotá, Colombia

(13) Graduate School for the Humanities (GSH), University of Groningen, The Netherlands

(14) Department of Neurosurgery, Hospital de Santa Maria, Centro Hospitalar Universitário Lisboa Norte, Lisbon, Portugal

(15) Department of Neurology and Neurosurgery, University Medical Center of Utrecht, Utrecht, The Netherlands

(16) Department of Neurosurgery, "S. Chiara" Hospital, Azienda Provinciale per i Servizi Sanitari, Trento, Italy

(17) Structural and Functional Connectivity Lab Project, "S. Chiara" Hospital, Azienda Provinciale per i Servizi Sanitari, Trento, Italy

(18) Department of Neurosurgery, Medical University of Innsbruck, Innsbruck, Austria

(19) Department of Neurology, GROW School for Oncology and Developmental Biology, Maastricht University Medical Center, Maastricht, The Netherlands

(20) Department of Neurosurgery, National and Kapodistrian University of Athens, Evangelismos Hospital, Athens, Greece

© The Author(s) 2022. Published by Oxford University Press on behalf of the Society for Neuro-Oncology and the European Association of Neuro-Oncology.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact [journals.permissions@oup.com](mailto:journals.permissions@oup.com)

- (21) Department of Neurosurgery, Elisabeth-Tweesteden Hospital, Tilburg, the Netherlands
- (22) Department of Neurosurgery, Hospital Garcia de Orta, Lisbon, Portugal
- (23) Department of Neurosurgery and Neurology, Private University Hospital of Córdoba, Argentina
- (24) Department of Neurosciences, Hospital Universitari Germans Trias i Pujol, Barcelona, Spain
- (25) Department of Quality-of-Life Research, Medical University of Gdansk, Gdansk, Poland
- (26) Department of Psychology and Sociology of Health and Public Health School of Public Health Collegium Medicum, University of Warmia - Mazury in Olsztyn, Poland
- (27) Department of Neurosurgery, Copernicus PL, Gdansk, Poland
- (28) Department of Neurosurgery, Erasmus MC - University Medical Center Rotterdam, the Netherlands
- (29) Center for Language and Brain, HSE University, Moscow, Russia
- (30) Academic Centre for Epileptology, Kempenhaeghe, Heeze, The Netherlands
- (31) Maastricht University Medical Centre (MUMC+), dept. of Neurosurgery, Maastricht, the Netherlands
- (32) Clinical Neuropsychology Unit, Liaison Mental Health Service, Hospital Universitario Central de Asturias, Oviedo, Spain
- (33) Department of Psychology, University of Oviedo, Spain
- (34) ISPA, Health Research Institute of Principado de Asturias, Oviedo, Spain
- (\*) independent researcher

\*Corresponding author:

Joanna Sierpowska, PhD

Radboud University, Donders Centre for Cognition

Radboudumc, Department of Medical Psychology

Thomas van Aquinostraat 4, Maria Montessori Building, 03.318, 6525 GD Nijmegen, NL

Telephone (+31) (0) 24-3655935; Email: joanna.sierpowska@donders.ru.nl

Accepted Manuscript

## ABSTRACT

**Introduction:** 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 centres completed the survey. Thirty of them offered at least one post-surgical (neuro)psychological assessment, mainly for language and cognition, especially during the early recovery stage and at long-term. Twenty-eight of the participating centres offered post-surgical therapies. Patients who stand the highest chances of being included in evaluation and therapy post-surgically are those who underwent awake brain surgery, harboured 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 versus 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 (e.g., professional reinsertion).

Accepted Manuscript

## FUNDING

Funding – Funded by the Netherlands Organization for Scientific Research (grant no. 024.001.006 to Language in Interaction consortium) and partially funded by the National Institute on Deafness and Other Communication Disorders, USA (grant no. K01DC016904) and by the Center for Language and Brain NRU Higher School of Economics, RF Government Grant (ag. No. 14.641.31.0004).

## CONFLICT OF INTEREST

Conflicts of interest/Competing interests - none.

Accepted Manuscript

## INTRODUCTION

Brain tumours 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 (i.e., motor, language, cognitive). Patients with brain tumours need multidisciplinary care from 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<sup>1,2</sup>. 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<sup>3,4</sup>). Notably, a review by Ford and colleagues<sup>5</sup> indicated that 48% of people with brain tumours 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 centres 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<sup>6</sup>. Also, according to the literature, a scarce number of systematic language/cognitive rehabilitation programs are offered in brain surgery aftercare<sup>7,8</sup>. Concurrently, there have been reports that have highlighted the positive effects of such interventions on individuals with brain tumours<sup>9,10</sup>. With regard to the perioperative care protocols, prior ELGGN surveys have provided substantial information about commonly used preoperative neuropsychological assessments<sup>6,11</sup>, neuroradiological planning, and adjuvant treatments<sup>13,14</sup>. 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 post-surgical aftercare practices in patients with brain tumours 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 one 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 tumour surgery aftercare (i.e., 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 (e.g., 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 tumour 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, II). Finally, they were asked if brain mapping protocols have been provided at their centre 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<sup>3,4</sup> 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 centres 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, conference 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 is safely stored at the Radboud University server and participants' contact information was not available to third parties. Any identifiable information (e.g., Institution name or initials) was erased from the shared database.

## Statistical analyses

Descriptive statistics were used to summarise and interpret the data. Software used for these analyses included R embedded in R-Studio, and the following packages: *tidyverse*<sup>15</sup>, *here*<sup>16</sup>, *magrittr*<sup>17</sup>, *summarytools*<sup>18</sup>, *glue*<sup>19</sup>, *fs*<sup>20</sup>, *patchwork*<sup>21</sup>, and *ggforce*<sup>22</sup>. Data and code are published online under Open Science Framework ([osf.io/7nqwz](https://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 (Fig. 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 the Europe.

----- Fig. 1. Placeholder -----

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 exceeds 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 centre. 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 to 350 for LGG (mean=44, SD=60). Almost all institutions offered awake brain mapping (37/38, Fig. 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 (Fig. 1c). All of these 30 centres assess speech/language, whereas other types of assessments are proposed less frequently (Fig. 2a).

----- Fig. 2. Placeholder -----

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 centres (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 of 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 (Fig. 2b).

----- Fig. 3. Placeholder -----

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 provide speech/language assessments. At the remaining time points, speech and language assessments were conducted as often as the other evaluations (see Fig. 3 and supplementary Table 1).

The professionals recommended speech/language and cognitive assessments as the most important (Fig. 4 and supplementary Table 2). The respondents agreed that assessing patients during early recovery is the most recommendable and that long-term evaluations should be covered more extensively (see Fig. 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 (Fig. 4 and supplementary Table 2).

----- Fig. 4. Placeholder -----

When asked for unconstrained comments, one respondent highlighted the importance of individually tailored interventions and their preference for paper-and-pencil methods over computerised approaches. The participants highlighted that the course of postoperative recovery can differ substantially, depending on tumour grade; e.g., 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 exam of 75-90 min., at 3-4 months 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 (Fig. 1 d).

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

----- Fig. 5. Placeholder -----

The most commonly used treatments were speech therapy, general neuropsychological rehabilitation, and physiotherapy. One team offered music therapy (Fig. 5b and 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 (Fig. 6a). In general, interventions were administered a few weeks after surgery. Neuropsychological rehabilitation and speech therapy are offered even up to 60 times (Fig. 6a and supplementary Table 3).

----- Fig. 6. Placeholder -----

Speech therapy and neuropsychological rehabilitation were recommended the most frequently, followed by physiotherapy (Fig. 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 grey in Fig. 3). The participants were also indicating that professional reinsertion programs were essential (Fig. 6b).

Using free text, the professionals pointed out the importance of the reintegration of the affected individual into their pre-existing 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 (e.g., language, cognition or motor). Psychological aspects, e.g., patients' well-being and quality of life, 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 centres (16/38) provided support programs for caregivers (18/38 do not, and 4/38 uncertain). 29/38 centres indicated that they find such programs useful (2/38 centres stated they are not useful, 7/38 centres were uncertain). The professionals admitted that they were aware of caregivers' burden. They emphasised 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 centre 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 do 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 post-surgical changes in the patient (emotional, behavioural, 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 emphasised 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, behavioural, 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 centres for continued rehabilitation (e.g., between neurosurgery and neuro-rehabilitation or neuro-oncology centres). For language, two teams emphasised 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 ELGGN,

www.brain tumours.eu). The institutions varied in the number of glioma surgeries per year and in their approaches to surgical aftercare.

The centres 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 (e.g., emotional well-being) throughout the entire first year after surgery. However, not all centres referred their patients to post-surgical assessments. The qualitative responses of professionals indicated that aftercare plans were and should be individually tailored. Quantitatively, this means that patients who stand the highest chances of being assessed post-surgically are those who underwent awake brain surgery, harboured a LGG or showed poor postoperative recovery. Being diagnosed with a HGG and undergoing chemo-, and/or radio- or chemoradiation are 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 tumours (also in young people<sup>23</sup>) and the additional burden of adjuvant oncological therapies on cognition<sup>24,25</sup>, the lack of post-surgical (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 radio-therapy.

Medical teams primarily provided therapies for language/speech and cognition and, again, these were offered mainly to patients who underwent awake brain surgery and harboured a LGG. However, individuals who are particularly suitable for interventions are people with a HGG, as they are vulnerable to postoperative iatrogenic damage<sup>26,27</sup>. 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 caution, as the inclusion criteria we provided are often intertwined, e.g., 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 post-surgical aftercare (e.g., including caregivers and people with HGG), and exploring discrepancies among centres 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 minimises indirect surgical costs<sup>28,29</sup>. 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 (e.g., in a gradual manner), professional occupation could help maintain healthy habits and adequate amounts of cognitive challenge, which are beneficial in recovery<sup>30,1</sup>. Moreover, an adequately implemented return to work can safeguard patients from resigning from professional activity due to overload or ill-designed schedules<sup>31</sup>. This topic is important for future developments in collaborations between psychologists and social employees working in post-surgical aftercare.

Notably, almost all teams recommend programs for caregivers' education and support implemented at their institutions, even though not all the centres 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<sup>32-34</sup>. Caregivers suffer from distress, especially around diagnosis and initial stages of treatment<sup>35,36</sup>, they report being unable to adequately support their affected family member, and feel overwhelmed<sup>36</sup>.

Our results provide an overview and a baseline for healthcare professionals and academics to improve neurosurgical aftercare of glioma patients. 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 is recommended during early recovery and at long-term (and not during the inpatient/bedside period). Concerning interventions, language/speech therapy, neuropsychological rehabilitation, and physiotherapy are considered the most substantial approaches to rehabilitation, although occupational therapy, professional reinsertion, and psychotherapy (individual or in a group) are also recommended. Therapies are 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), tumour size, location, and type, differentiating the aftercare plans for people with a LGG and HGG<sup>37</sup>. Although our survey examined assessment and intervention plans for all tumour 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 (e.g., reduced life expectancy<sup>37</sup>). People with a HGG, and their caregivers, require (often urgent) psychological support and educational programs to adjust to

a sudden change in their life<sup>36</sup>. In turn, people with a LGG could benefit more from professional reinsertion programs<sup>31</sup>. 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<sup>5</sup>. 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 in 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 favoured Occidental Europe. Future goals of our network should seek a better exchange of practices with centres from the Balkans, Central and Eastern Europe. Multilingual adaptations of perioperative tests set a promising avenue for this<sup>38,39</sup>. 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 neurooncological care could not be depicted to a sufficient extent. Future surveys, continuing this new line of research, should involve more professionals representing neurooncology, 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](https://uclahs.az1.qualtrics.com/jfe/form/SV_8DfC1nY465IUKZ7), which will be active for a time-limited period from submission date).

## ACKNOWLEDGMENTS

The authors thank all survey respondents, and Dr. Pieter van Groenestijn for assistance with LimeSurvey implementation, as well as Samiha Molla for an English read-through.

Accepted Manuscript

## BIBLIOGRAPHY

- [1] Ng, S., Herbet, G., Moritz-Gasser, S., & Duffau, H. Return to Work Following Surgery for Incidental Diffuse Low-Grade Glioma: A Prospective Series With 74 Patients. *Neurosurgery*.2020; 87(4), 720–729. <https://doi.org/10.1093/neuros/nyz513>
- [2] Rydén, I., Carstam, L., Gulati, S., et al. Return to work following diagnosis of low-grade glioma: A nationwide matched cohort study. *Neurology*. 2020; 95(7), e856–e866. <https://doi.org/10.1212/WNL.0000000000009982>
- [3] Campanella, F., Palese, A., Del Missier, F., et al. Long-Term Cognitive Functioning and Psychological Well-Being in Surgically Treated Patients with Low-Grade Glioma. *World Neurosurgery*, 2017; 103, 799-808.e9. <https://doi.org/10.1016/j.wneu.2017.04.006>
- [4] Satoer, D., Visch-Brink, E., Dirven, C., & Vincent, A. Glioma surgery in eloquent areas: Can we preserve cognition? *Acta Neurochir (Wien)*, 2016; 158(1), 35–50. <https://doi.org/10.1007/s00701-015-2601-7>
- [5] Ford, E., Catt, S., Chalmers, A., & Fallowfield, L. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro-Oncology*, 2012; 14(4), 392–404. <https://doi.org/10.1093/neuonc/nor229>
- [6] Mandonnet, E., Wager, M., Almairac, F., et al. Survey on current practice within the European Low-Grade Glioma Network: Where do we stand and what is the next step? *NEURO-ONCOLOGY PRACTICE*, 2017; 4(4), 241–247. <https://doi.org/10.1093/nop/npw031>
- [7] Nazemi, K. J., & Butler, R. W. Neuropsychological rehabilitation for survivors of childhood and adolescent brain tumors: A view of the past and a vision for a promising future. *Journal of Pediatric Rehabilitation Medicine*, 2011; 4(1), 37–46. <https://doi.org/10.3233/PRM-2011-0151>

- [8] Russell, B., Collins, A., Dally, M., et al. Living longer with adult high-grade glioma: setting a research agenda for patients and their caregivers. *Journal of Neuro-Oncology*, 2014; 120(1), 1–10. <https://doi.org/10.1007/s11060-014-1516-0>
- [9] Bartolo, M., Zucchella, C., Pace, A. Early rehabilitation after surgery improves functional outcome in inpatients with brain tumours. *Journal of Neuro-Oncology*, 2012; 107(3), 537–544. <https://doi.org/10.1007/s11060-011-0772-5>
- [10] van der Linden, S. D., Sitskoorn, M. M., Rutten, G.-J. M., & Gehring, K. Feasibility of the evidence-based cognitive telerehabilitation program Remind for patients with primary brain tumors. *Journal of Neuro-Oncology*, 2018; 137(3), 523–532. <https://doi.org/10.1007/s11060-017-2738-8>
- [11] Rofes, A., Mandonnet, E., Godden, J., et al. Survey on current cognitive practices within the European Low-Grade Glioma Network: Towards a European assessment protocol. *Acta Neurochir (Wien)*, 2017; 159(7), 1167–1178. <https://doi.org/10.1007/s00701-017-3192-2>
- [12] Freyschlag, C. F., Krieg, S. M., Kerschbaumer, J. Imaging practice in low-grade gliomas among European specialized centers and proposal for a minimum core of imaging. *J. Neurooncol.*, 2018; 139(3), 699–711. <https://doi.org/10.1007/s11060-018-2916-3>
- [13] Darlix, A., Griguolo, G., Thezenas, S. Hormone receptors status: A strong determinant of the kinetics of brain metastases occurrence compared with HER2 status in breast cancer. *Journal of Neuro-Oncology*, 2018; 138. <https://doi.org/10.1007/s11060-018-2805-9>
- [14] Straube, C., Scherb, H., Gempt, J. Adjuvant stereotactic fractionated radiotherapy to the resection cavity in recurrent glioblastoma – the GlioCave study (NOA 17 – ARO 2016/3 – DTK ROG trial). *BMC Cancer*, 2018; 18(1), 15. <https://doi.org/10.1186/s12885-017-3928-7>
- [15] Wickham, H., Averick, M., Bryan, J. Welcome to the Tidyverse. *Journal of Open Source Software*, 2019; 4(43), 1686. <https://doi.org/10.21105/joss.01686>

- [16] Müller, K. here: A Simpler Way to Find Your Files. R package version 1.0.1., 2020; <https://CRAN.R-project.org/package=here>
- [17] Bache, S.M. and Wickham, H. magrittr: A Forward-Pipe Operator for R. R package version 1.5., 2014; <https://CRAN.R-project.org/package=magrittr>
- [18] Comtois, D. *summarytools: Tools to Quickly and Neatly Summarize Data* (0.9.9) [Computer software], 2021; <https://CRAN.R-project.org/package=summarytools>
- [19] Hester, J. *glue: Interpreted String Literals* (1.4.2) [Computer software]., 2020; <https://CRAN.R-project.org/package=glue>
- [20] Hester, J., Wickham, H. *fs: Cross-Platform File System Operations Based on 'libuv'* (1.5.2) [Computer software]., 2021; <https://CRAN.R-project.org/package=fs>
- [21] Pedersen, T. L. *patchwork: The Composer of Plots* (1.1.1) [Computer software]., 2020; <https://CRAN.R-project.org/package=patchwork>
- [22] Pedersen, T. L., & RStudio. *ggforce: Accelerating 'ggplot2'* (0.3.3) [Computer software]. , 2021; <https://CRAN.R-project.org/package=ggforce>
- [23] Ostrom, Q. T., Cioffi, G., Gittleman, H. CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2012-2016. *Neuro-Oncology*, 2019; 21(Suppl 5), v1–v100. <https://doi.org/10.1093/neuonc/noz150>
- [24] Simó, M., Root, J. C., Vaquero, L. Cognitive and Brain Structural Changes in a Lung Cancer Population. *Journal of Thoracic Oncology*, 2015; 10(1), 38–45. <https://doi.org/10.1097/JTO.0000000000000345>

- [25] Simó, M., Vaquero, L., Ripollés, P. Brain damage following prophylactic cranial irradiation in lung cancer survivors. *Brain Imaging and Behavior*, 2016; 10(1), 283–295. <https://doi.org/10.1007/s11682-015-9393-5>
- [26] Habets, E. J. J., Kloet, A., Walchenbach, R. Tumour and surgery effects on cognitive functioning in high-grade glioma patients. *Acta Neurochirurgica*, 2014; 156(8), 1451–1459. <https://doi.org/10.1007/s00701-014-2115-8>
- [27] Freyschlag, C. F., Kerschbaumer, J., Pinggera, D. Structured Evaluation of Glioma Patients by an Occupational Therapist-Is Our Clinical Examination Enough? *World Neurosurg*, 2017; 103, 493-500. doi:10.1016/j.wneu.2017.04.033
- [28] Gustavsson, A., Svensson, M., Jacobi, F. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol*, 2011; 21(10), 718–779. <https://doi.org/10.1016/j.euroneuro.2011.08.008>
- [29] Olesen, J., Gustavsson, A., Svensson, M. The economic cost of brain disorders in Europe. *Eur J Neurol*, 2012; 19(1), 155–162. <https://doi.org/10.1111/j.1468-1331.2011.03590.x>
- [30] Moritz-Gasser, S., Herbet, G., Maldonado, I. L., & Duffau, H. Lexical access speed is significantly correlated with the return to professional activities after awake surgery for low-grade gliomas. *Journal of Neuro-Oncology*, 2012; 107(3), 633–641. <https://doi.org/10.1007/s11060-011-0789-9>
- [31] Liasset, I. F., & Kvam, L. Experiences of returning to work after brain tumor treatment. *Work (Reading, Mass.)*, 2018; 60(4), 603–612. <https://doi.org/10.3233/WOR-182768>
- [32] Schubart, JR., Kinzie, MB., Farace E. Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro-Oncology*, 2018; 10(1), 61-72. <https://doi.org/10.1215/15228517-2007-040>
- [33] Reblin, M., Small, B., Jim, H. Mediating burden and stress over time: Caregivers of patients with primary brain tumor. *Psychooncology*, 2018; 27(2):607-612. doi: 10.1002/pon.4527.

- [34] Boele, FW., Rooney, AG., Bulbeck, H. Interventions to help support caregivers of people with a brain or spinal cord tumour. *Cochrane Database Systematic Review*, 2019; 2;7(7):CD012582. 10.1002/14651858.CD012582.pub2
- [35] Cavers, D., Hacking, B., Erridge, S. E. Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study. *Canadian Medical Association Journal*, 2012; 184(7), E373–E382. <https://doi.org/10.1503/cmaj.111622>
- [36] Sacher, M., Meixensberger, J., & Krupp, W. Interaction of quality of life, mood and depression of patients and their informal caregivers after surgical treatment of high-grade glioma: A prospective study. *Journal of Neuro-Oncology*, 2018; 140(2), 367–375. <https://doi.org/10.1007/s11060-018-2962-x>
- [37] McConigley, R., Halkett, G., Lobb, E., & Nowak, A. Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliative Medicine*, 2010; 24(5), 473–479. <https://doi.org/10.1177/0269216309360118>
- [38] Bastiaanse, R., Raaijmakers, S., Satoer, D., & Visch-Brink, E. The Multilingual Token Test. *Aphasiology*, 2016; 30(4), 508–508. <https://doi.org/10.1080/02687038.2015.1121710>
- [39] Alves, J., Cardoso, M., Morgado, M. Language assessment in awake brain surgery: The Portuguese adaptation of the Dutch linguistic intraoperative protocol (DuLIP). *Clinical Linguistics & Phonetics*, 2021; 0(0), 1–19. <https://doi.org/10.1080/02699206.2020.1868022>



## FIGURE LEGENDS

**Fig. 1.** The map of geographical locations of survey respondents (represented in squares).

**Fig. 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.

**Fig. 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.

**Fig. 4.** The proportion of institutions recommending specific assessment types per time points. 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".

**Fig. 5.** (a) Referrals for postoperative intervention plans based on outcomes and patient characteristics. (b) The number of institutions providing a specific kind of post-surgical 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.

**Fig. 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").

Figure 1

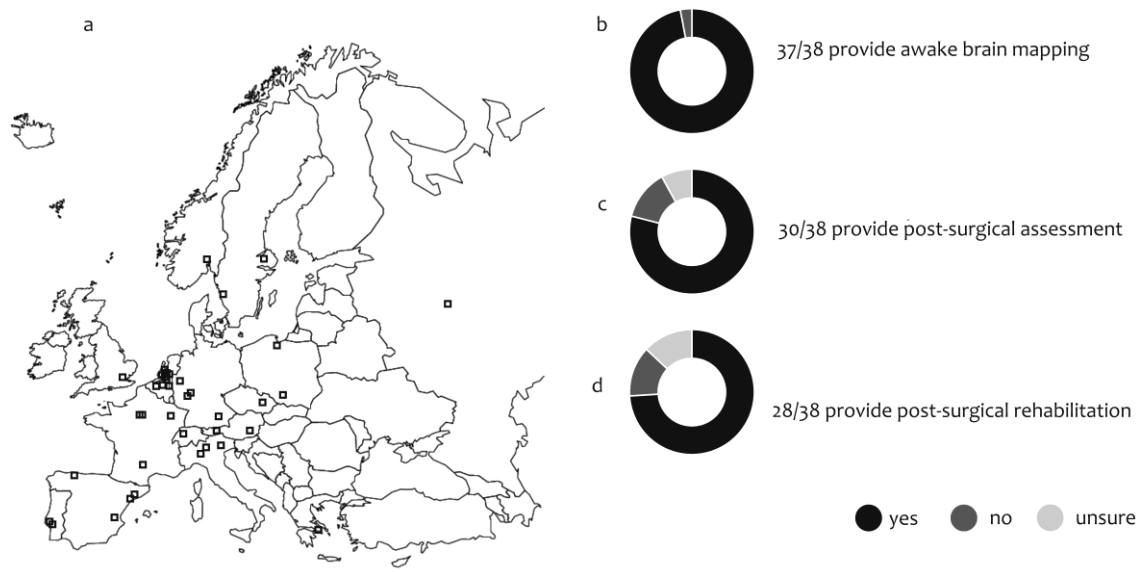
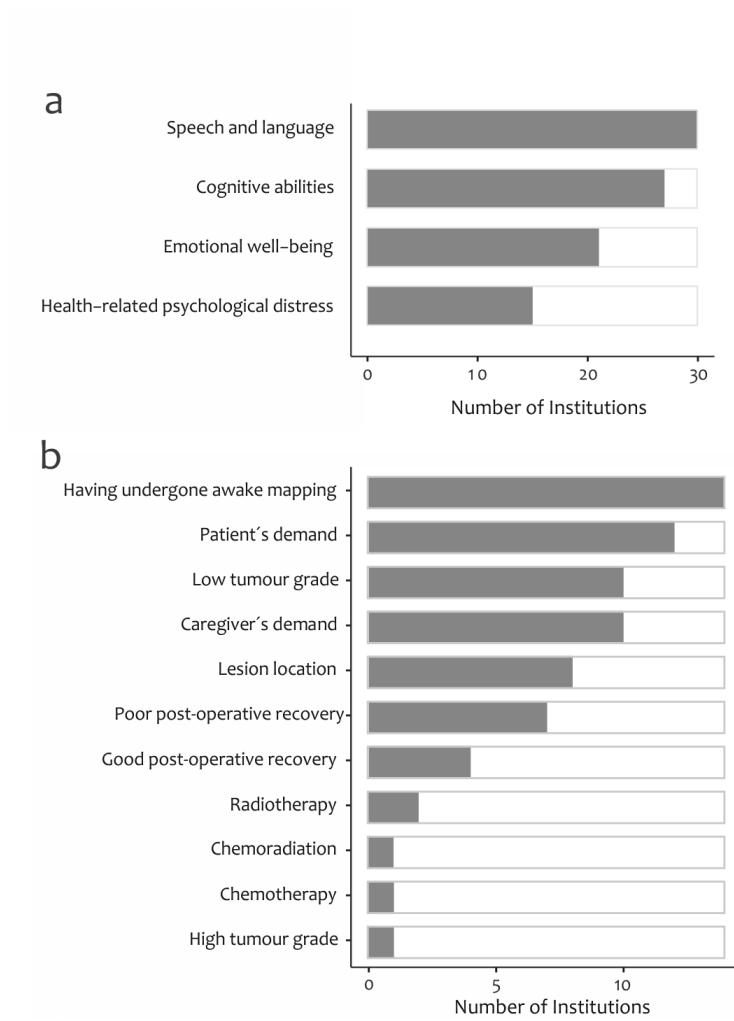
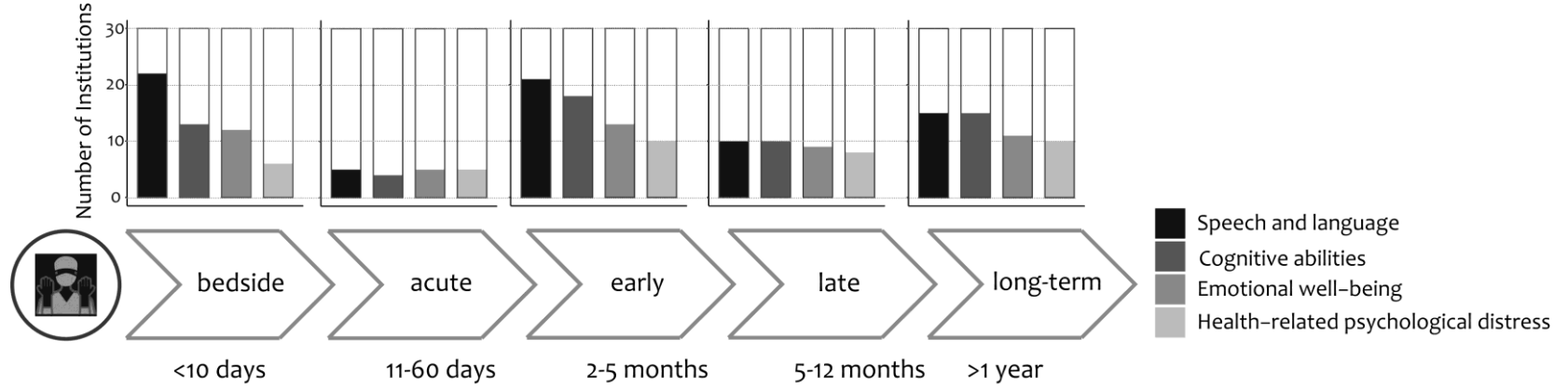


Figure 2



Accepte

Figure 3



Acc

Figure 4

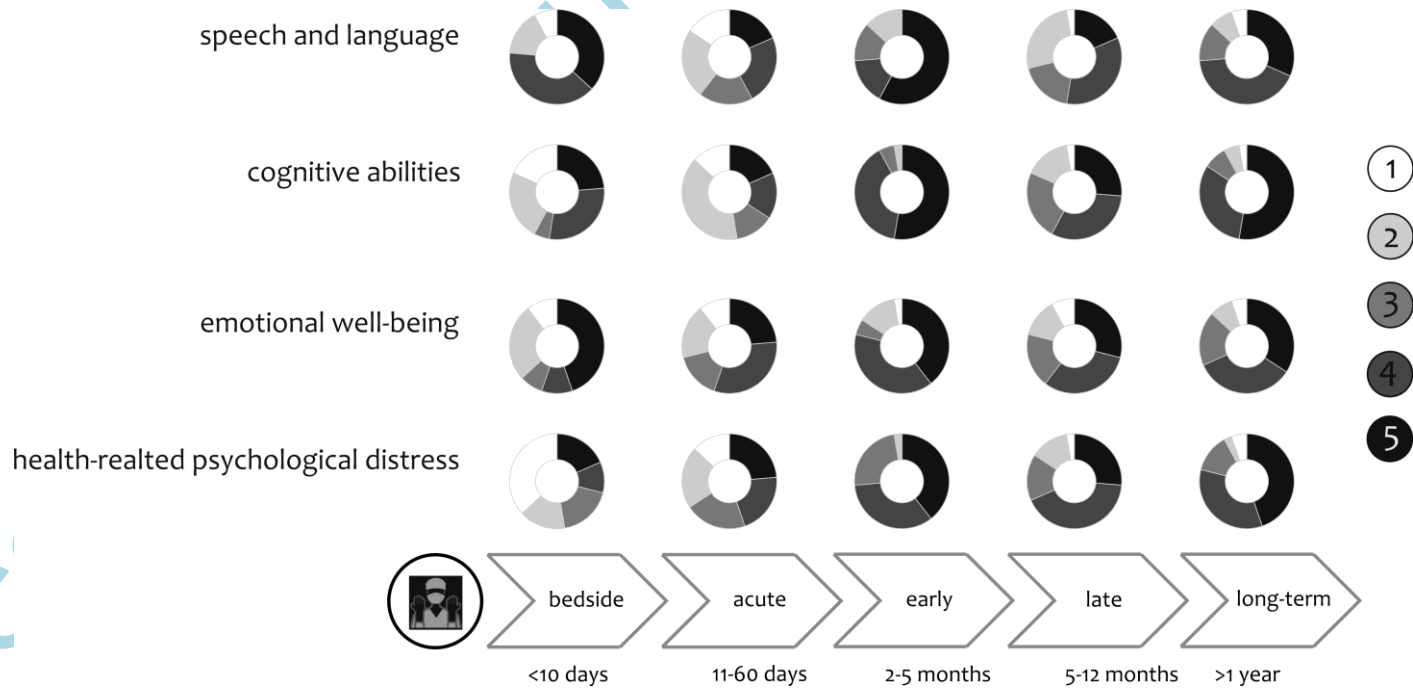


Figure 5

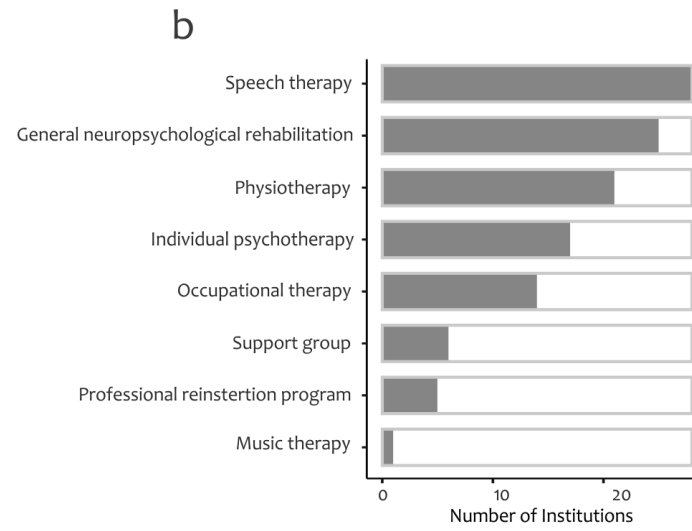
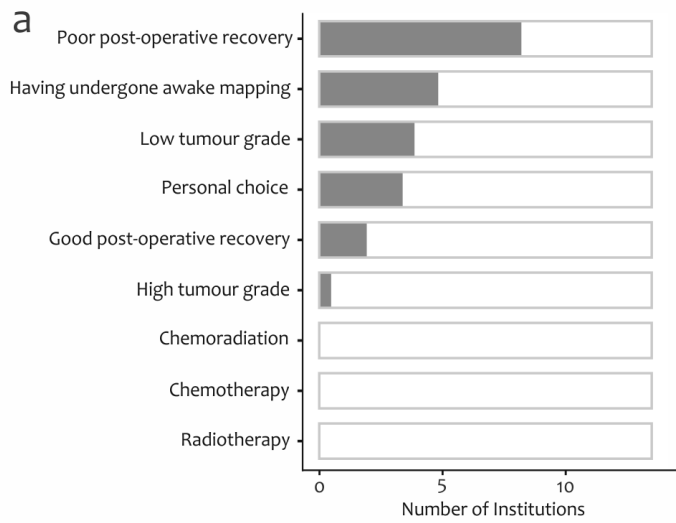


Figure 6

