Inequalities in access to neuro-oncology supportive care and rehabilitation: a survey of healthcare professionals' perspectives

on behalf of the Nurse and Allied Health Professionals Committee and the Disparity and Inclusion Committee of EANO

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Abstract

Background

Neuro-oncology patients and caregivers should have equitable access to rehabilitation, supportive-, and palliative care. To investigate existing issues and potential solutions, we surveyed neuro-oncology professionals to explore current barriers and facilitators to screening patients' needs and referral to services.

Methods

Members of the European Association of Neuro-Oncology (EANO) and the European Organisation for Research and Treatment of Cancer Brain Tumor Group (EORTC-BTG) were invited to complete a 39-item online questionnaire covering availability of services, screening and referral practice. Responses were analyzed descriptively; associations between sociodemographic/clinical variables and screening/referral practice were explored.

Results

In total, 103 participants completed the survey (67% women; 57% medical doctors). Fifteen professions from 23 countries were represented. Various rehabilitation, supportive- and palliative care services were available yet rated 'inadequate' by 21-37% of participants. Most respondents with a clinical role (n=94) declare to screen (78%) and to refer (83%) their patients routinely for physical/cognitive/emotional issues. Survey completers (n=103) indicated the main reasons for not screening/referring were 1) lack of suitable referral options (50%); 2) shortage of healthcare professionals (48%); 3) long waiting lists (42%). To improve service provision, respondents suggested there is a need for education about neuro-oncology specific issues (75%), improving availability of services (65%) and staff (64%), developing international guidelines (64%), and strengthening the existing evidence-base for rehabilitation (60%).

Conclusion

Detecting and managing neuro-oncology patients' and caregivers' rehabilitation, supportive- and palliative care needs can be improved. Better international collaboration can help address healthcare disparities.

Key words: Inequalities, disparity, rehabilitation, supportive/palliative care, brain tumor

Introduction

People diagnosed with a brain tumor often experience a high disease burden. Diagnosis is usually sudden and unexpected, symptoms can be debilitating, and the often-aggressive treatment regimens can lead to substantial side-effects both in the short and long term[1]. Patients and their family caregivers consistently report high unmet needs related to daily living, psychological, physical, health system, and information domains throughout the disease trajectory[2-4].

While supportive care and rehabilitation may greatly enhance patient outcomes and health-related quality of life[5-7], equitable access to these services is not evident. There are noticeable differences in the availability and organization of services across various European countries, regions, and centers. These variations can be attributed to a range of factors, including differences in healthcare systems, resource allocations, government policies, socio-economic conditions, and cultural norms. Long waiting lists, potential inadequacy of available oncology services in addressing neuro-oncology specific issues, and potential lack of awareness of referral options may also play a role[8-10]. At an individual patient or caregiver level, costs, accessibility (distance, transport options, travel time), communication barriers (related to neurological impairment), cognitive impairments, cultural barriers, and personal help-seeking preferences as well as impaired medical decision-making capacity can reduce uptake of available services[11-13].

To provide more equitable access to services and to minimize health disparities, it is of importance to gain more insight into the current issues. This involves understanding the extent of these disparities and identifying the factors that contribute to them, taking into account each factor's modifiability. Internationally, new initiatives have been reported which seek to address current practice in provision of services. These can offer valuable insights into the challenges, successes, and potential best practices for achieving equitable and comprehensive neuro-oncological healthcare. In Australia, a recent healthcare professional survey (*n*=42) addressed availability of supportive care services for patients with high-grade glioma and their caregivers, highlighting significant disparities in referral options from regional/rural centers compared to metropolitan centers[14]. Another Australian study highlighted system-level barriers hindering access to psychological support for individuals with brain tumors, encompassing challenges such as constrained resources and funding, inadequate staff time, extended waitlists and associated costs, suboptimal service coordination, and a shortage of personnel with specialized training in brain tumor care[15]. In a qualitative study, healthcare professionals have acknowledged the imperative for enhanced access to care coordination and multidisciplinary psychosocial care that is specifically tailored to address the diverse needs of individuals with brain tumors and their families[16].The Society for Neuro-Oncology (SNO) organized a survey on identifying needs of neuro-oncology providers in community settings, identifying avenues to strengthen relationships with tertiary/academic institutions (results not published yet). In parallel recognition of these initiatives, the European Association of Neuro-Oncology (EANO) has designed a survey to distribute among its membership, the outcomes of which are covered in this article. The membership of EANO represents many different countries and cultures, comprising a multitude of healthcare systems with varying levels of resources for supportive and rehabilitative services, offering a unique opportunity to gather valuable data on disparities in access to these healthcare services. This could complement the other efforts described above, opening up a global dialogue and inspiring greater international cooperation in tackling healthcare disparities, both within and across continents. Addressing inequalities in access to neuro-oncology supportive care and rehabilitation aligns with healthcare professionals' values, ethics, and commitment to patient and caregiver wellbeing. It is a necessary step towards building more inclusive and equitable healthcare systems that provide optimal care for all individuals affected by neuro-oncological conditions. Therefore, the aim of the current study is to identify barriers and facilitators in relation to disparities in access to rehabilitation and support services among neuro-oncology patients and their caregivers. By doing so, the study seeks to identify actionable strategies that can be employed to improve access and elevate the provision of supportive/palliative care and rehabilitation for all individuals affected by a brain tumor.

Material and Methods

Study design

A cross-sectional study comprising a web-based survey was conducted following review by and approval from the EANO Board, the Nurse and Allied Health Professionals Committee and the Disparity and Inclusion Committee. Its aim was to gain insights into the present supportive and rehabilitative services from the perspectives of healthcare professionals working in neuro-oncology. All members of EANO and/or the European Organisation for Research and Treatment of Cancer (EORTC) Brain Tumor Group were eligible to participate in the survey, irrespective of their occupation or specialty.

Outcome measure

The questionnaire was designed to align with EANO's vision of improving practice and rehabilitation/supportive care for brain tumor patients. Survey items were inspired by similar literature.[16 17] The web-based survey was drafted by KP, finalized together with members of the EANO Nurses and Allied Health Care Professional committee (FB, LR, SN, SM, EN, IR, AW, MDK, AC, MP), Disparity and Inclusion committee (SS, KP, FB, NG, GM, RR, MT, ELR, BK, JF, LD), and the president of EANO (SS). The web-based survey (using FindMind) was written in English, comprised 29 questions, and was designed with user-friendly drop-down menus and multiple-choice options to ensure simplicity and clarity for participants. Participants were asked to provide sociodemographic information (ten questions), such as their profession, experience and qualifications, the type of institution they work at, and which patient groups they work with. The survey included seven questions on participants' screening practice, six questions on participants' referral practice, nine questions on the availability of rehabilitation and supportive care services at the participants' center. Six questions explored the specific examination tools applied when identifying symptom prevalence and severity e.g., for cognitive deficits, fatigue, functional and neurological status, distress/mood and health-related quality of life (HRQoL) (not reported on in current paper). A final open-ended question allowed for comments, questions, or concerns. Estimated time to complete the web-based survey was eight to ten minutes. The complete survey can be found in Supplemental File 1.

Procedure

Recruitment of participants took place through EANO and the EORTC Brain Tumor Group, using their respective email lists. The survey was open from 01-06-2023 until 29-09-2023. The invitation email was sent to potential participants with a link to the anonymous survey and a brief explanation of the study aims. Two reminders were sent out (after 5 weeks and 7 weeks) to the EANO membership to increase response rates. Furthermore, the survey was promoted during the 2023 EANO conference.

Analysis

De-identified answers were exported from FindMind and entered into SPSS software (IBM version 29.0) for analysis. Sociodemographics (sex, age, highest degree obtained) of participants who completed the full survey were compared to those who did not, using Chi-square and independent samples T-tests. Descriptive statistics were used to report the sociodemographic characteristics of respondents, and item responses. Free text responses were categorized along item response options or otherwise grouped together based on content. Descriptive statistics were employed to summarize the key findings, such as frequencies, percentages, and mean scores. Only those respondents who indicated that they had a clinical role (*n*=94) were included in analyses of responses related to screening or referral practices. Chi-square tests were used to explore whether screening and referral practices (yes/no variables) were related to participants' age (<45 or ≥45 years), sex (male/female/not disclosed), profession (medical doctor/nurse/allied health professional (AHP) including psychologist), and highest degree obtained (bachelor/master/doctorate), and diagnostic group(s) seen (only glioma/a mix of primary brain tumors/both primary and secondary brain tumors). A p-value less than 0.05 was considered statistically significant, we did not correct for multiple testing due to the explorative nature of the study.

Results

Participants

A total of 140 colleagues opened the survey, with 103 completing the full survey and thus providing the data taken forward in analysis. Completers did not differ from non-completers in sex, age, or highest degree obtained ($p>0.05$). Sixty-seven percent (*n*=69) of participants were female, most had a doctorate degree (*n*=56; 54%), and while 15 different professions responded, most were medical doctors (*n*=59; 57%). Participants came from 23 countries, including 19 European nations and 4 from outside Europe: the United States (*n*=4; 4%), Japan (*n*=1; 1%), Argentina (*n*=1; 1%), and Israel *n*=1; 1%). The best represented countries were: The Netherlands (*n*=18; 18%), United Kingdom (*n*=17;17%), Italy (*n*=13;13%), Sweden and Denmark (both *n*=9; 9%) and Germany and Austria (both *n*=7; 7%). Most participants reported having neuro-oncology patient contact at least weekly or daily (*n*=85; 83%), many seeing multiple patient subgroups (high-grade glioma *n*=100 (97%), low-grade glioma *n*=97 (94%), meningioma *n*=76 (74%), brain metastases *n*=70 (68%). The majority (*n*=93; 90%) cared for adult populations, with 10 respondents (10%) caring for patients of all ages or pediatric groups. See Table 1 for further sociodemographic characteristics.

Available services

All participants (*n*=103) were asked which professions, resources and services are available at their centers (Table 2, Figures 1 and 2). On a 4-point scale (good; adequate; inadequate; don’t know), the quality of rehabilitation services was rated adequate or good by *n*=68 (66%) of participants, while *n*=32 (31%) rated these as inadequate. Similarly, supportive care services were deemed adequate or good by *n*=79 (77%), with 22 (21%) finding these inadequate. Services for caregivers were found adequate or good by *n*=56 (54%), and inadequate by *n*=38 (37%).

Screening and referral practice

Among those with a clinical role (*n*=94), over three quarters indicated that they screen their patients routinely for physical, cognitive, or emotional issues (*n*=73; 78%), while 19 said they did not (20%; 9 medical doctors, 4 nurses, 6 AHPs) and two answered ‘not applicable’ (2%; 1 nurse and 1 AHP). Table 3 details which issues are screened for by those clinical professionals who screen their patients, and how regularly. To screen for any of these issues, most (*n*=70; 96%) relied on their own clinical assessment and dialogue with the patient, but many also referred to relying on a team of nurses and allied healthcare professions (*n*=41; 56%), family caregivers (*n*=39; 53%), or a validated (*n*=26; 36%) or self-developed (*n*=8; 11%) patient-reported tool.

Most participants with a clinical role (*n*=78; 83%) indicated to refer patients to rehabilitation, supportive care and/or palliative care services. See Table 3 for details on the services referred to.

Factors associated with screening and referral

In analyses to explore associations between screening for physical, cognitive, or emotional issues (yes/no) and participant characteristics, we found that the diagnostic group(s) participants see (only glioma, a mix of primary brain tumors, or both primary and secondary brain tumors) was associated with screening practice (X^2=19.071, p<0.001). Those who focus on primary brain tumors all screen (*n*=14, 100%), but those who see both primary and secondary brain tumor patients (*n*=65) do not always screen (80%). Those who see only glioma patients (*n*=15) are least likely to screen (47%). Of note, those who only see glioma patients are more commonly nurses (*n*=6, 40%) and AHPs (*n*=7, 47%) and less often medical doctors (*n*=2, 13%). Participants' age (<45 or ≥45 years), sex, profession (medical doctor, nurse, allied health professional (AHP) including psychologist, or researcher only), and highest degree obtained were not directly associated with screening practice.

For referring practice (yes/no), we similarly found an association with diagnostic group(s), X^2=16.871, p<0.001). Those who see either a mix of primary (*n*=14) or both primary and secondary brain tumors (*n*=65) generally refer their patients (86% and 91%, respectively), while only 47% of those who only see glioma populations (*n*=15) refers. Moreover, older participants (≥45 years) were more likely to refer patients (X^2=3.728, p=0.05). Of those over ≥45 (*n*=50), 90% refer patients whereas only 75% of those under 45 (*n*=44) refer.

Participants' profession was also associated with referring practice (X^2=11.949, p=0.003). Medical doctors (*n*=59) were most likely to refer (93%), with nurses (*n*=13) and AHPs (*n*=22) less likely to refer (69% and 64%, respectively). Participant sex and highest degree obtained were not related to referring practice.

All participants (*n*=103) were asked for possible reasons why patients with symptoms and unmet needs are not referred to healthcare services (multiple choice question with free text space if 'other' was ticked). The top three reasons were 1) lack of referral options for patients with malignant brain tumors (*n*=51, 50%), 2) shortage of healthcare professionals (*n*=49, 48%), and 3) long waiting times (*n*=43, 42%), see Table 4 for full list of reasons. Other reasons provided in free text responses included under-recognition of patient symptoms and needs (*n*=4, 4%), and the perceived lack of benefit from support services (*n*=2, 2%). Several options were identified as potential ways to improve supportive/palliative care services and rehabilitation (Table 4). In another multiple-choice question, the top 5 most frequently selected suggestions to improve services were: 1) improving healthcare professionals' education on neuro-oncology specific supportive care and rehabilitation (n=77, 75%), 2) improving availability of specific healthcare services (*n*=67, 65%) or 3) healthcare professionals per se (*n*=66, 64%), 4) developing international guidelines on supportive care and rehabilitation (*n*=66, 64%), and 5) strengthening the evidence-base for rehabilitation (*n*=62, 60%).

Discussion

The right to equitable and timely access to high-quality healthcare is a fundamental principle that underpins modern healthcare systems[18]. However, disparities in access to healthcare services, in the context of rehabilitation and supportive care for individuals diagnosed with brain tumors, appears to persist across the 19 European and 4 non-European countries represented in this survey. With this survey we aimed to assess and understand the extent of potential inequalities seen from the healthcare providers' perspectives, key challenges, and potential solutions. Issues seem to be driven by 1) lack of specialized services able to meet the needs of neuro-oncology populations; 2) limited availability of nurses and allied health care professionals providing supportive care and rehabilitation, and; 3) long waiting lists.

It is well-known that people suffering from a brain tumor have profound supportive care and rehabilitation needs[19]. This applies to not only the patients who can benefit from cognitive rehabilitation[6 20], physical exercise[21 22 7], supportive and palliative care[5 23 24], but also to their families who can benefit from support[25-28]. These needs are evident throughout the disease trajectory, into long-term survivorship. In addition, the importance of various allied health care services e.g., speech and language therapy, is emphasized by both our survey respondents and in existing literature[29]. Our results indicate that those who see only glioma patients, rather than a mix of primary, or primary and secondary brain tumor groups, are less likely to screen. While no direct association with profession was found, it does appear that those who only see glioma patients are more often nurses and AHPs – implying that patients may have been referred to them, making screening less necessary. Similarly, referral practice was associated with diagnostic groups seen, but we also observed that older individuals (over 45) and medical doctors are more likely to refer their patients to supportive and palliative care services. These associations are logical, considering the different roles of medical doctors, nurses, and AHPs in the clinical care pathway, but also imply that those with greater (life) experience are more likely to refer their patients. Indeed, improving healthcare providers' knowledge on suitable supportive care and rehabilitation options was highlighted as important in improving patient care by nearly three quarters of participants. We acknowledge that the survey was not solely targeted at specialists directly engaged in patient care, which may have introduced some bias. However, based on our findings we recommend that healthcare providers working in neuro-oncology – especially those with a role in screening and referral – receive enhanced clinical education and training. This can be achieved by offering education and exchange programs designed to foster cross-cultural collaboration, knowledge sharing, and the exchange of best practices via rotation and travel awards[30]. In addition, a lack of evidence from supportive and rehabilitation healthcare services was identified as a barrier to referral by 15%, with 60% and 52% of respondents highlighting the need to strengthen the evidence-base for supportive care for patients and their caregivers, respectively. This underscores the pressing need to invest in research. Considering disparities in research priorities and funding opportunities for neuro-oncology research and working closely with patient advocacy groups to jointly raise awareness and advocate for the importance of supportive and rehabilitation services is important[18].

Other barriers to patient referrals identified included shortages in healthcare professionals (48%), healthcare services in general (28%), and especially in remote, sparsely populated areas (24%), along with lack of public resources allocated to healthcare (20%) as significant obstacles. We contend that a key problem in supportive care and rehabilitation is the inadequate allocation of funding for specialized allied healthcare positions. While our data did not allow for between-country comparisons, the specific healthcare system and funding structure per country is likely to play a role. Regardless, our survey highlighted that 55% seldom or never refer their patients to address social or financial issues, although this has been identified as an unmet need [31 32] and is an important aspect of providing patient-centred, holistic cancer care[33]. Moreover, for caregivers, support may only be reimbursed if referred through primary care. Our survey also exposed that 18% and 17% of respondents see lack of services targeting vulnerable groups and young patients as a barrier to referral, respectively. More than a quarter of respondents believe that targeting services to specific subgroups, but also monitoring access to healthcare and making efforts to extend the coverage of voluntary health insurance, could lead to improved services.

Lack of patient and caregiver information regarding healthcare rights and available services, coupled with poor health literacy, can contribute even more to unmet healthcare needs. Indeed, previous literature shows that in addition to socioeconomic factors, individual patient characteristics can hinder accessibility to healthcare[34]. Issues such as low literacy, language barriers, cultural differences, and social isolation can impede effective access to supportive and rehabilitation services[34-36]. These studies, like our survey, show that geographical mobility can also pose challenges for patients seeking care. Traditionally, telehealth solutions are thought of as a way to overcome this barrier. Indeed, telehealth solutions have been found both feasible and effective in delivering support to neuro-oncology patients and caregivers[37 38]. Yet, less than a third of survey participants advocate for improving telehealth services. This highlights a limitation of our current work, in that the largely quantitative nature of data collected limits exploration of reasoning behind the proposed solutions. Presumably, the common misperception that telehealth solutions may be provided *instead of*, rather than *in addition to*, existing support services plays a role. If used appropriately, we note that telehealth approaches can be efficient and effective tools for improving health care access and outcomes[39]. Regardless of the strategy chosen, the issues described above underscore the need for an inclusive approach to reduce disparities and ensure that every neuro-oncology patient can receive the rehabilitation and supportive care they require, regardless of where they live, what they can afford to pay out of pocket, or their level of education or health literacy.

In light of the critical need to address health disparities and inequities, we draw inspiration from leading organizations such as the American Society of Clinical Oncology[30 40], the European Cancer Organisation's Essential Requirements for Quality Cancer Care[36] and the recommendations from the NCI-CONNECT Survivorship Care in NeuroOncology[41]. We propose an action plan to advocate for an EANO strategy which includes increased research on health disparities and inequity, which also encourages and supports incorporating diversity and inclusion policies within healthcare institutions' practices. This includes actively recruiting and retaining a diverse healthcare workforce and fostering an inclusive culture that values all individuals. By taking these steps, we can make a progress in the fight against neuro-oncological healthcare disparities and inequities.

Limitations

Limitations of this survey include a relatively small sample size, which precluded some subgroup analyses such as comparing responses per profession or country. We have not solely targeted specialists with regular patient care responsibilities. Some countries were better represented than others which may introduce some potential for bias. The distribution of services in nations with nationalized health systems may vary significantly from those without such services. These regional disparities should be considered when developing guidelines and plans for the improvement of service delivery, ensuring a nuanced and contextually relevant approach. Particularly, we have less representation from nations exhibiting performance levels below the European Union average concerning both healthcare access and disparities[35]. Hence, it is essential to recognize that countries with constrained budgets may have limited capabilities to provide a diverse range of healthcare services, and this aspect deserves consideration. The survey also does not address inequalities in socio-economic determinants external to the healthcare system, such as education and cultural traditions, which can significantly influence inequalities. These determinants were beyond the scope of this paper – however, clearly important aspects to consider in providing information and support to patients and families. The quantitative nature of the survey precluded us from investigating why respondents provided the answers they did. The survey was distributed in English which may have introduced bias in participation and interpretation of questionnaire items. The responses represent the views of individual respondents rather than the current practice within a site or center. Lastly, while this survey primarily focused on an insiders' perspective within the healthcare system, it is advisable to complement the monitoring of inequalities in access to healthcare with a patient and caregiver indicator based on self-reported unmet needs for rehabilitation and supportive care. Future research efforts should strive to improve on these limitations.

Conclusions and Clinical Implications

Based on responses from 103 professionals from 19 European and 4 non-European countries, we examined disparities in access to neuro-oncological rehabilitation and supportive care. The main takeaway message from our survey is that there is room for improvement in the current practice of detecting and managing neuro-oncology patients' and caregivers' rehabilitation, supportive and palliative care needs. Better international collaboration can help address healthcare disparities. The Nurse and Allied Health Care Professionals' committee and The Disparity and Inclusion committee of EANO envision a concerted effort to advance rehabilitation/supportive services for individuals affected by brain tumors. Our intention is to facilitate the sharing of experiences and best practices within the neuro-oncology community, with a particular emphasis on how to promote equitable access to healthcare. This can be achieved by implementing policies and strategies that address any imbalances in availability of healthcare facilities and professionals, reduce waiting times, and enhance the overall evidence of quality of care – whilst taking into account that access to rehabilitation and supportive and palliative care services should be dictated by healthcare needs and evidence.

Supplementary material

Supplementary material is available online.

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Figure legends

Figure 1. Rehabilitation services

Figure 2. Supportive and palliative care services

Table 1. Sociodemographic characteristics

Respondent characteristics		Participants (*N*=103)
Sex		
	Female	69 (67%)
	Male	32 (31%)
	Do not wish to disclose	2 (2%)
Age, years		
	24-34	23 (22%)
	35-44	27 (26%)
	45-54	23 (22%)
	55-64	24 (23%)
	65-81	6 (6%)
Highest qualification		
	Bachelor	15 (15%)
	Master	32 (31%)
	Doctorate	56 (54%)
Country of residence, n (%)		
	The Netherlands	18 (18%)
	United Kingdom	17 (17%)
	Italy	13 (13%)
	Denmark	9 (9%)
	Sweden	9 (9%)
	Austria	7 (7%)
	Germany	7 (7%)
	Outside of Europe*	7 (7%)
	Belgium	3 (3%)
	France	2 (1%)
	Switzerland	2 (1%)
	Cyprus	1 (1%)
	Czech Republic	1 (1%)
	Greece	1 (1%)
	Macedonia	1 (1%)
	Norway	1 (1%)
	Romania	1 (1%)
	Slovakia	1 (1%)
	Spain	1 (1%)
	Turkey	1 (1%)
Profession (multiple options possible)		
	Medical doctor	59 (58%)
	Clinical, medical, or neuro-oncologist	17 (17%)
	Neurologist	18 (18%)
	Neurosurgeon	10 (10%)
	Neuropathologist	1 (1%)
	Palliative care physician	1 (1%)

Pediatric oncologist	2 (2%)
Radiation oncologist	13 (13%)
Researcher	24 (23%)
Nurse, clinical nurse specialist, nurse practitioner	14 (14%)
Psychologist, neuropsychologist	10 (10%)
Radiation therapist, radiographer	8 (8%)
Speech and language therapist, clinical linguist	4 (4%)
Physiotherapist	1 (1%)
Dietician	1 (1%)
Type of institution (multiple options possible)	
Hospital	66 (64%)
Municipal hospital	14 (14%)
Private hospital	2 (2%)
University hospital	54 (52%)
University	40 (39%)
Cancer center	35 (34%)
Private clinic	2 (2%)
Years' clinical experience with neuro-oncology populations	
0-1	6 (6%)
2-5	19 (19%)
6-20	55 (53%)
>20	23 (22%)
Frequency of neuro-oncology patient contact	
Once a year or less	5 (5%)
Few times a year	7 (7%)
At least once a month	6 (6%)
Weekly	27 (26%)
Daily	58 (56%)

*Outside of Europe responses were United States (n=4), Japan (n=1), Argentina (n=1), Israel (n=1)

Table 2. The available professions

Available nursing and allied healthcare professions	N (%)
Nursing	98 (95%)
Physiotherapy	93 (90%)
Dietetics	83 (81%)
Palliation	81 (79%)
Neuropsychology	75 (73%)
Psychology	75 (73%)
Speech and language therapy	75 (73%)
Social worker	66 (64%)
Occupational therapy	64 (62%)

Table 3. Screening and referral practice

	Never (0% of clients seen)	**Rarely (1-30% of clients seen)**	**Often (31-95% of clients seen)**	**Always (95-100% of clients seen)**
Screening practice among clinical professionals who screen patients (n=73)				
Neurological and physical issues	3 (4%)	4 (5%)	26 (36%)	40 (55%)
Cognitive issues	2 (3%)	12 (16%)	33 (45%)	26 (36%)
Psychological distress	4 (5%)	10 (14%)	30 (41%)	29 (40%)
Social or financial concerns	7 (10%)	21 (29%)	29 (40%)	16 (22%)
Referral practice among clinical professionals who refer patients (n=78)				
Physical rehabilitation	3 (4%)	26 (33%)	42 (54%)	7 (9%)
Cognitive rehabilitation	6 (8%)	41 (53%)	28 (36%)	3 (4%)
Psychological distress	2 (3%)	23 (29%)	46 (59%)	7 (9%)
Social or financial concerns	5 (6%)	38 (49%)	27 (35%)	8 (10%)
Palliative care	5 (6%)	23 (29%)	44 (56%)	6 (8%)

Table 4. Reasons for non-referral

Reasons for non-referral	**N (%)**
Few referral options for patients with a malignant brain tumor	51 (50%)
Shortages of healthcare professionals	49 (48%)
Long waiting times for health care services	43 (42%)
Lack of knowledge of where to refer patients to	35 (34%)
Lack of access to health care services, in general	29 (28%)
Lack of access to health care services, in remote and sparsely populated areas	25 (24%)
Few referral options for elderly patients (e.g above 65 years)	24 (23%)
The model of health system funding	24 (23%)
Public resources spent on healthcare	21 (20%)
Lack of services targeting vulnerable groups (e.g ethnic minorities, young adolescents, homeless)	19 (18%)
Few referral options for patients with benign tumors	17 (17%)
Few referral options for young patients (e.g below 30 years)	17 (17%)
Lack of evidence from supportive & rehabilitation healthcare services	15 (15%)
Suggested ways to improve services	
Education on neuro-oncological supportive care and rehabilitation for healthcare professionals	77 (75%)
Improved availability of specific healthcare services	67 (65%)
Improved availability of healthcare professionals	66 (64%)
International guideline on neuro-oncological supportive care and rehabilitation	66 (64%)
Strengthen the evidence from rehabilitation for patients	62 (60%)
Increase the overall budget for the health system	55 (53%)
Strengthen the evidence from supportive care for patients	54 (60%)
Strengthen the evidence from supportive care for caregivers/relatives	53 (52%)
Regular patient-reported needs assessments	48 (47%)
Shorten the waiting lists	42 (41%)
Improve telehealth services	29 (28%)
Improve monitoring of access to healthcare	28 (27%)
Target service for specific groups e.g. ethnic minorities	26 (25%)
Extend the coverage of voluntary health insurance	26 (25%)

Figure 1. Rehabilitation services

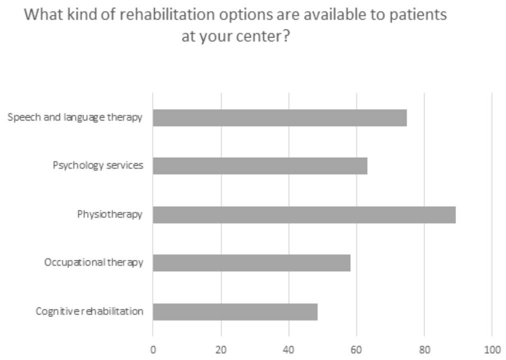
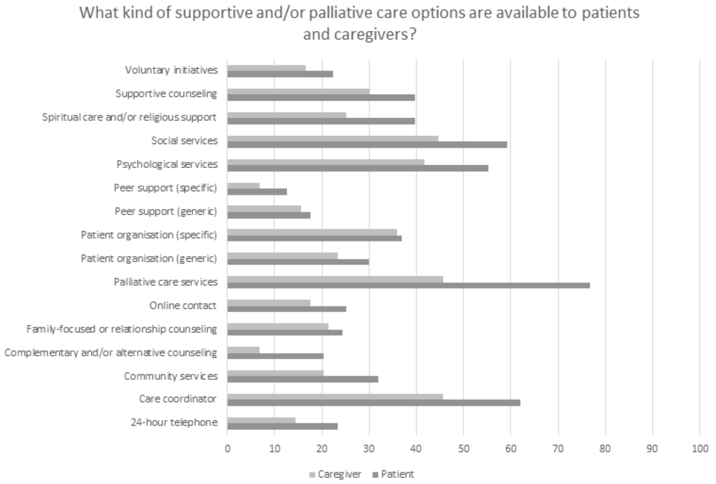


Figure 2

Figure 2. Supportive and palliative care services



Online contacts=virtual consultations, telehealth services, or digital communication channels

Boele, F. et al. (2024) Inequalities in access to neuro-oncology supportive care and rehabilitation: a survey of healthcare professionals' perspectives. *Neuro-Oncology Practice*, 11(4), pp. 484-493. (doi: 10.1093/nop/npae023