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QUALITY IMPROVEMENT

Retrospective Characterization of Specialized Palliative Care in Patients With Gliomas

SISSE JOSEPHINE RUDKJØBING,[1,3], MD, KATRINE RAHBEK SCHØNNEMANN,[1,2,3] MD, PhD, JESPER RAHR LAURITSEN,[1] MD, BO HALLE,[3,4] MD, PhD, and RIKKE HEDEGAARD DAHLROT,[1,3] MD, PhD

From [1]Department of Oncology, Odense University Hospital, Denmark; [2]Palliative Team Funen, Region of Southern Denmark, Denmark; [3]Institute of Clinical Research, University of Southern Denmark, Denmark; [4]Department of Neurosurgery, Odense University Hospital, Denmark

Authors' disclosures of conflicts of interest are found at the end of this article.

Correspondence to: Rikke H. Dahlrot, Odense University Hospital, J. B. Winsløws Vej 4, 5000 Odense, Denmark

E-mail: rikke.dahlrot@rsyd.dk

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Abstract

Background: Patients with gliomas face significant challenges in daily life due to rapidly progressing neurological and cognitive symptoms. In recent years, there has been increased awareness of the importance of timely referral to specialized palliative care (SPC) for patients with gliomas. This study evaluated referral processes and interdisciplinary services used by patients with gliomas and their caregivers. **Methods:** Patients with gliomas (World Health Organization [WHO] grade 2–4) treated at Odense University Hospital in Denmark from 2016 to 2020 were retrospectively identified. Data on demographics, treatment, and SPC referrals were collected from medical records and the Danish Palliative Care Database. Descriptive statistics and survival analysis were performed using STATA 17. **Results:** Among 443 patients, 185 initiated SPC, generally 7 months after the primary diagnosis. Patients with WHO grade 4 gliomas received SPC for a median of 2.5 months before death. All SPC patients had contact with both a palliative care physician and a designated contact nurse; in addition, 63% utilized the services of at least one other multidisciplinary professional, most commonly a physiotherapist. Use of the services of two or more multidisciplinary professionals was most frequent in patients under 50 years old (67%), compared with 39% of patients aged 50 to 70 years and 16% of patients over 70 years. **Conclusion:** Patients with gliomas are often referred to SPC but typically late in their disease trajectory. The involvement of various SPC professionals underscores a significant demand for interdisciplinary support, which may be underestimated in this study. Younger patients made greater use of SPC services than older patients, indicating an age-dependent need for support from different professionals within the SPC team. Further investigation is needed, particularly in older patients.

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Living with a glioma (graded 2–4 by the World Health Organization [WHO]) significantly affects daily life and quality of life (QOL) for both patients and caregivers (Sterckx et al., 2013). Survival is often short, especially for patients with WHO grade 4 gliomas (Stupp et al., 2009). Additionally, patients may experience rapidly progressing, life-altering symptoms such as neurological deficits, neurocognitive symptoms, and unpredictable personality changes, which can result in a loss of autonomy (Golla et al., 2014; Ostgathe et al., 2010; Sterckx et al., 2013). These symptoms are caused by the glioma itself, but extensive treatment with surgery, chemotherapy, and radiotherapy also affects patients' overall condition (Schubart et al., 2008), leading to difficulties in maintaining hope and good QOL (Boele et al., 2022; Renovanz et al., 2018; Seekatz et al., 2017).

According to the WHO, specialized palliative care (SPC) is defined as "an approach that improves the quality of life of patients and their families facing...life-threatening illness, through the prevention and relief of suffering..." (WHO, 2020). Previous randomized controlled trials in patients with advanced cancer have shown that early integration of palliative care can reduce symptom burden and improve QOL (Bakitas et al., 2015; Dionne-Odom et al., 2015; Temel et al., 2017). Notably, patients with gliomas were not included in these studies.

In recent years, palliative outpatient clinics have been integrated in oncology departments (Gill et al., 2023; Kaasa, 2013), increasing awareness of the need for earlier referral to SPC. A key challenge in SPC referral is accurately identifying the right patients at the right time to ensure timely access to SPC services. Previous retrospective studies investigating SPC in patients with glioblastoma (WHO grade 4) have reported that palliative care is often initiated late in the disease trajectory. Patients with late SPC initiation are more frequently hospitalized and are less likely to die at home (Hemminger et al., 2017; Kuchinad et al., 2017). To our knowledge, no studies have investigated the referral of patients with gliomas WHO grade 2 to 3 to SPC.

In Denmark, data on all patients referred to SPC are systematically collected in a national database (Groenvold et al., 2016), but there has been no comprehensive overview conducted of patients with gliomas. In this study, we evaluated patients with gliomas treated at our institution and referred to SPC. As a novel aspect, we assessed which interdisciplinary services patients and their caregivers utilized within the SPC setting. Furthermore, since it has been reported that the need for SPC in elderly patients is often underassessed and possibly undertreated (Lloyd et al., 2015; Davies & Higginson, 2004), the needs of elderly patients were also assessed.

METHODS

Newly diagnosed patients with gliomas (WHO grade 2–4) or patients with progression referred to the Department of Oncology at Odense University Hospital between January 1, 2016, and December 31, 2020, were identified (Figure 1). Patient characteristics, including sex, age at diagnosis, presenting symptoms, Eastern Cooperative Oncology Group (ECOG) performance status (PS), tumor pathology, tumor location, and treatment, were obtained from medical records.

For patients referred to SPC, additional information, including marital status, parental status (having children, living with or without children at home), work situation, referring department, and place of death, was obtained from the Danish Palliative Care Database (DPCD), a national quality-of-care database with high completeness (Groenvold et al., 2016). Quality of life data were obtained using the EORTC QLQ-C15-PAL questionnaire (Groenvold et al., 2006), a standardized and validated 15-item instrument with a 7-point scale, ranging from 1 "very poor" to 7 "excellent".

Information on interdisciplinary SPC services (social worker, psychologist, physiotherapist, priest, and volunteer efforts) was extracted from patients' medical records. For analysis, patients were categorized based on histology (glioblastoma [GBM, WHO grade 4] vs. non-GBM [WHO grade 2–3]) and age group (younger patients [< 50 years], middle-aged patients [50–70 years], and older patients [> 70 years]). Descriptive statistics were used to summarize patient characteristics. Overall survival (OS) was defined as the time from initial surgery until death or censoring (November 1, 2023). All analyses were performed using STATA 17.

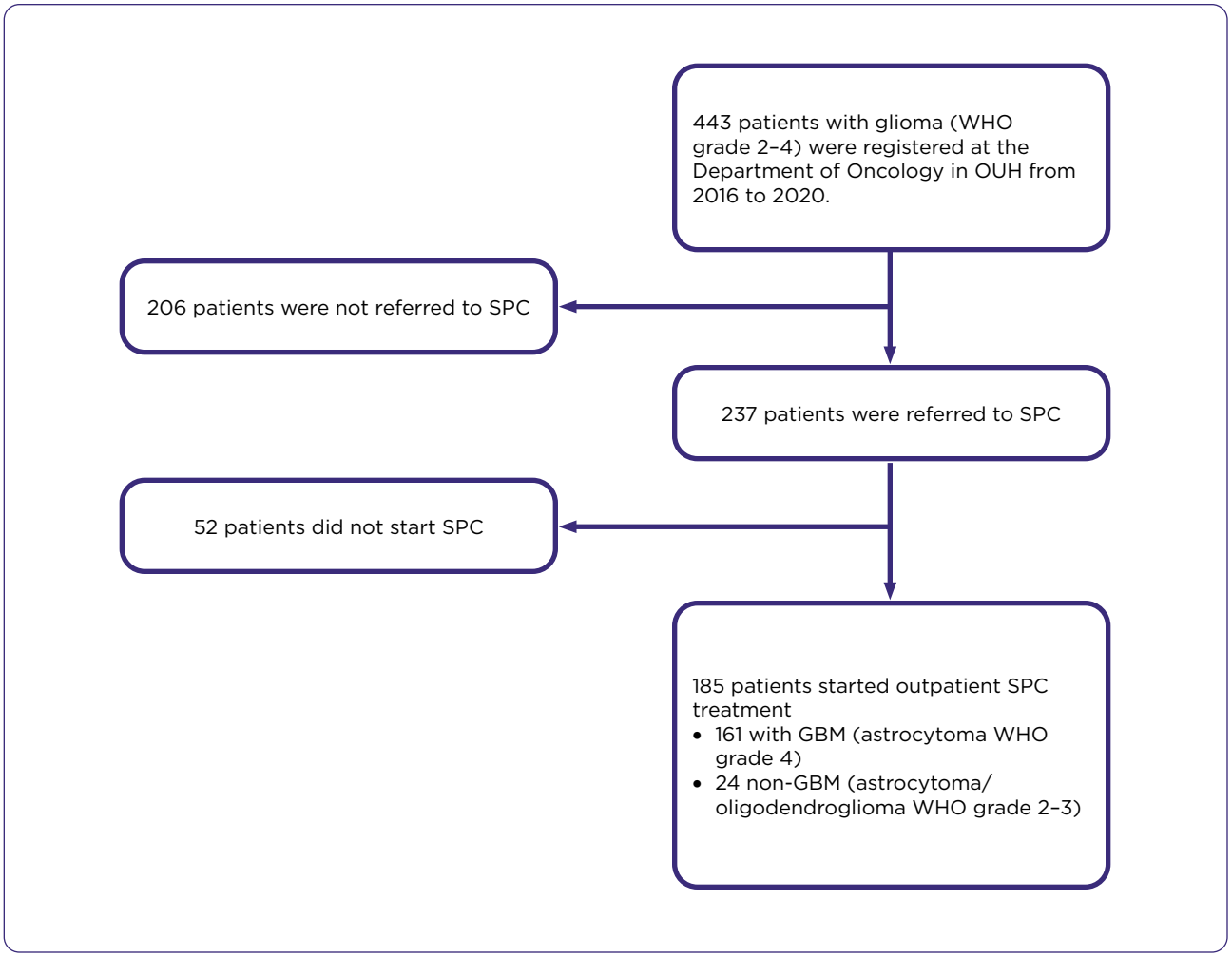

Figure 1. CONSORT diagram showing patients screened for the study and the number of patients receiving SPC. OUH = Odense University Hospital; SPC = specialized palliative care; GBM = glioblastoma; WHO = World Health Organization.

This study is a quality assurance study approved by the legal authority Odense University Hospital and the Region of Southern Denmark.

RESULTS

Characteristics of All Patients with Gliomas

In the 5-year period, a total of 443 patients were referred from other departments; 409 patients were newly diagnosed and 34 had progression. The median age at time of primary diagnosis was 65 years (range: 18–88; Table 1). The majority of patients had gliomas WHO grade 4 (n = 347), and most were male (60%). Most patients presented with one symptom at diagnosis, primarily neurological deficits. Generally, patients were ECOG PS 0 to 1 (n = 271). At the time of the analysis, 380 patients had died, and the median OS was 15 months (range: 0.3–334).

Characteristics of Patients With Gliomas Receiving SPC

A total of 237 patients were referred to SPC, of whom 185 (78%) patients started outpatient SPC treatment (161 GBM patients and 24 non-GBM patients).

On average, patients were referred to the SPC program 7 months (range: 0.3–295) after their primary diagnosis. The median time to referral was 8 months (range: 0.3–85 months) for GBM patients, compared with 27 months (range: 2.8–295 months) for non-GBM patients.

The median OS for all SPC patients was 15 months (range: 0.4–306). Patients with glioblastoma

Table 1. Characteristics of Patients Receiving Specialized Palliative Care

	All (*n* = 185)	GBM (*n* = 161)	Non-GBM (*n* = 24)
Sex			
Male	107 (58%)	93 (58%)	14 (58%)
Female	78 (42%)	68 (42%)	10 (42%)
Age at diagnoses	63 (19–88)	65 (19–88)	49 (25–73)
Age at referral	65 (29–88)	66 (36–88)	57 (29–75)
Age group at referral			
< 50	25 (14%)	16 (10%)	9 (37%)
50–70	93 (50%)	83 (52%)	10 (42%)
> 70	67 (36%)	62 (38%)	5 (21%)
Social status			
Living with someone	145 (78%)	125 (77%)	20 (83%)
Living alone	37 (20%)	33 (21%)	4 (17%)
Unknown	3 (2%)	3 (2%)	0 (0%)
Have children			
Yes	157 (85%)	138 (86%)	19 (80%)
No	20 (11%)	17 (11%)	3 (12%)
Unknown	8 (4%)	6 (3%)	2 (8%)
Children living at home			
Yes	34 (18%)	26 (16%)	8 (33%)
No	144 (78%)	128 (80%)	16 (67%)
Unknown	7 (4%)	7 (4%)	0 (0%)
Work situation			
Working[a]	68 (37%)	57 (35%)	11 (46%)
Retired	91 (49%)	82 (51%)	1 (4%)
Sick leave	8 (4%)	7 (4%)	9 (37%)
Unemployed	4 (2%)	4 (3%)	0 (0%)
Unknown	14 (8%)	11 (7%)	3 (13%)
QOL score			
1	16 (9%)	15 (9%)	1 (5%)
2	25 (13%)	23 (14%)	2 (8%)
3	13 (7%)	11 (7%)	2 (8%)
4	16 (9%)	15 (9%)	1 (5%)
5	11 (6%)	9 (5%)	2 (8%)
6	3 (2%)	3 (2%)	0 (0%)
7	5 (3%)	3 (2%)	2 (8%)
Missing	96 (51%)	82 (52%)	14 (58%)
Survival status			
Dead	180 (97%)	160 (99%)	20 (83%)
Alive	5 (3%)	1 (1%)	4 (17%)
Overall survival, mo	15 (0.4–306)	13 (0.4–104)	47 (6–306)
Survival after SPC, mo[b]	2.8 (0–99)	2.5 (0–99)	9.6 (0.5–56)

Note. GBM = glioblastoma; QOL = quality of life.
[a]Working defined as working full-time, part-time, or being a student.
[b]Missing in 7 patients.

Table 2. Distribution of Professional Services Used by Patients and Relatives

	All (*n* = 185)	GBM (*n* = 161)	Non-GBM (*n* = 24)
Professional services used by patients			
Physiotherapist			
Yes	64 (34%)	57 (35%)	7 (29%)
No	118 (64%)	101 (63%)	17 (71%)
Unknown	3 (2%)	3 (2%)	0 (0%)
Social worker			
Yes	50 (27%)	42 (26%)	8 (33%)
No	133 (72%)	117 (73%)	16 (67%)
Unknown	2 (1%)	2 (1%)	0 (0%)
Psychologist			
Yes	36 (19%)	31 (19%)	5 (21%)
No	147 (80%)	128 (80%)	19 (89%)
Unknown	2 (1%)	2 (1%)	0 (0%)
Priest			
Yes	10 (5%)	8 (5%)	2 (8%)
No	173 (94%)	151 (94%)	22 (92%)
Unknown	2 (1%)	2 (1%)	0 (0%)
Volunteer			
Yes	14 (8%)	10 (6%)	4 (17%)
No	169 (91%)	149 (93%)	20 (83%)
Unknown	2 (1%)	2 (1%)	0 (0%)
Professional services used by caregivers			
Social worker			
Yes	57 (31%)	50 (31%)	7 (30%)
No	124 (67%)	107 (67%)	17 (70%)
Unknown	4 (2%)	4 (2%)	0 (0%)
Psychologist			
Yes	52 (28%)	47 (29%)	5 (21%)
No	129 (70%)	110 (68%)	19 (79%)
Unknown	4 (2%)	4 (3%)	0 (0%)
Priest			
Yes	2 (1%)	1 (< 1%)	1 (4%)
No	181 (98%)	158 (98%)	23 (96%)
Unknown	2 (1%)	2 (1%)	0 (0%)
Family team			
Yes	9 (5%)	8 (5%)	1 (4%)
No	173 (93%)	151 (94%)	22 (92%)
Unknown	3 (2%)	2 (1%)	1 (4%)

had a median OS of 13 months (range: 0.4–104), while non-GBM patients had a median OS of 47 months (range: 6–306). Median survival after SPC was 2.5 months (range: 0–99 months) for patients with GBM and 9.6 months (range: 0.5–56 months) for patients with non-GBM. Patients were referred to SPC from three main sources: the Department of Oncology (33%), other hospital departments (33%), and general practitioners (30%). Data were unavailable for five patients. There was no difference in the number of accepted referrals based on the referring physician's workplace.

The majority of patients starting SPC were male (n = 107) and aged 50 to 70 years (n = 93). Most were living with a partner (78%) and almost one fifth of patients had children living at home at the time of diagnosis. The proportion of patients living with children was higher in the non-GBM group (33%) compared with the GBM group (16%). Before their diagnosis, about one third of patients worked full-time in both the GBM group (32%) and the non-GBM group (38%). There was a higher proportion of retired patients in the GBM group (51%) compared to the non-GBM group (4%).

Upon meeting with the SPC team, each patient was assigned a dedicated physician and contact nurse from the team. Nurses affiliated with the SPC team have advanced training, enabling them to manage much of the necessary follow-up care. Accordingly, nurses are responsible for regular home visits or telephone consultations with the patient and their caregivers. Nurses are also able to make medication adjustments as needed and are available for discussions with either the patient or their caregivers, serving as facilitators in coordinating care with the homecare nurse or other interdisciplinary members of the SPC team. Additionally, all patients and their caregivers were offered multidisciplinary support from different SPC team professionals (Table 2). Sixty-three percent of patients utilized at least one of these services, most commonly a physiotherapist. Patients were often in contact with a physiotherapist (34%) or social worker (27%), whereas caregivers were most often in contact with a social worker (31%) or a psychologist (28%). Nine families with children living at home received support from the family team consisting of a social worker and a psychologist, focused on helping parents discuss life-threatening illnesses with their children.

In the group of younger patients, 67% used two or more multidisciplinary professions, most commonly a social worker (64%) and a psychologist (64%). In the middle-aged patients, 39% used two or more services, primarily a social worker (51%) and a physiotherapist (37%), whereas 16% of the oldest patients used two or more services, most commonly a physiotherapist (31%) or a psychologist (21%). Fourteen patients had contact with volunteers, with no significant variation between age groups. Ten patients spoke with the priest, with 7% of the middle-aged patients utilizing this service compared to 2% of younger and older patients (Figure 2).

DISCUSSION

In this retrospective study, we identified and described a cohort of patients diagnosed with a glioma referred to SPC. To provide a full overview, both GBM and non-GBM patients were included.

Nearly half of the patients in this population received SPC, similar to previous studies reporting that more than 50% of cancer patients are referred to an SPC team. However, patients with brain tumors are often underrepresented in clinical studies, as in the study by Boltezar et al. (2021). Only 1.8% of the included patients had a brain tumor, making it difficult to gain knowledge about their specific needs (Boltezar et al., 2021). Late referral to SPC has been mentioned several times as an important point of attention. In our study, patients with GBM in particular were referred to SPC late, often within months before death. This finding is consistent with previous studies, including a recent Danish study by Jøhnk et al. (2022), which reported that SPC referrals for cancer patients typically occur in the last months of life.

Furthermore, most patients receiving SPC lived with a partner. A Danish population-based, cross-sectional register study by Adsersen et al. (2019) investigated access to SPC in 599 cancer patients. It reported that married individuals were more likely to receive SPC than those living alone (55% vs. 44%). A similar tendency was observed by Addington-Hall et al. (2000).

Previous retrospective studies have found that patients with brain tumors often experience

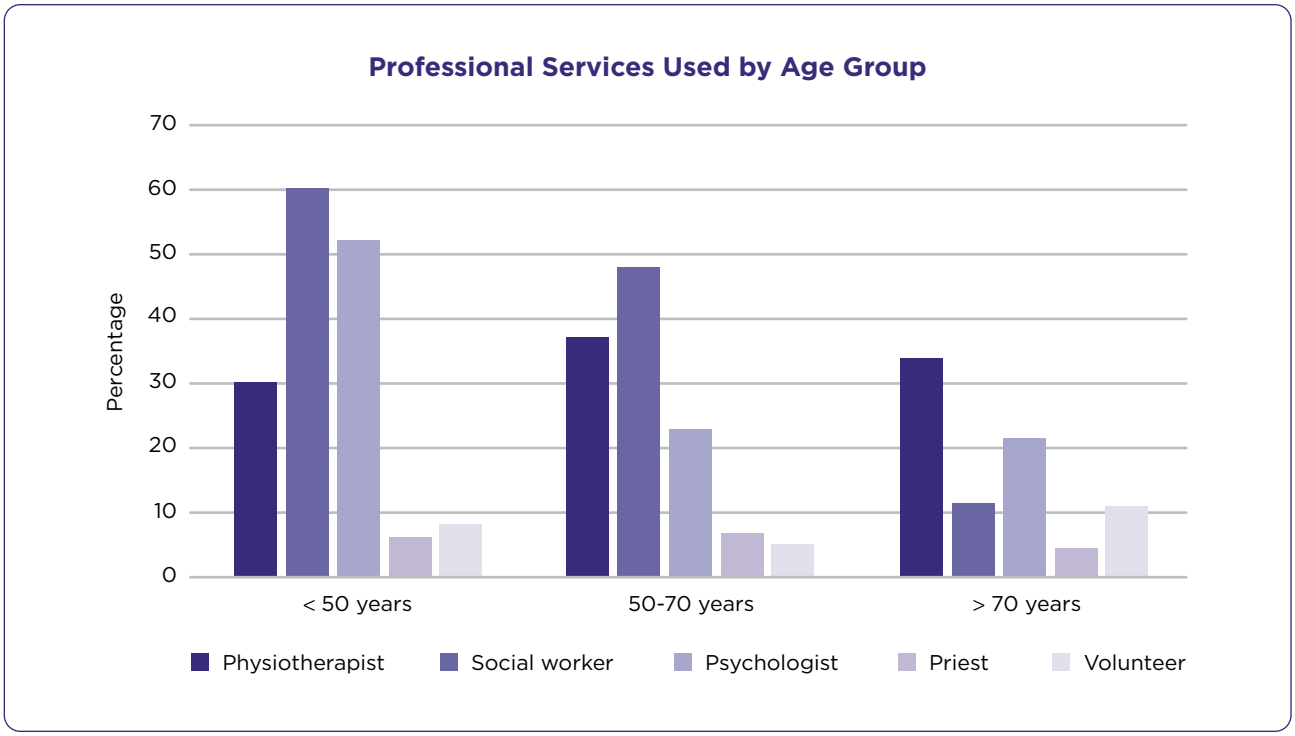

Figure 2. Diagram showing use of different professional services for both patients and caregivers divided into patient age groups.

cognitive symptoms, including delirium, at the end of life (Arber et al., 2010; Oberndorfer et al., 2008). In our study, nearly one third of patients had cognitive symptoms at the time of diagnosis. It is well known that patients with brain tumors often present with different symptoms than other cancer patients. This difference in symptom profile often mandates a different approach to the patient, with a greater focus on caregivers as an essential resource. Johnsen et al. (2009) investigated self-reported symptoms in patients with advanced cancer, including patients with brain tumors, and found that patients living alone reported lower QOL compared with those living with a partner. Notably, most of the patients living alone did not receive SPC. One possible explanation is that the support and resources provided by a spouse increase the likelihood of SPC referral, as caregivers can advocate for the patient's needs and seek assistance to reduce the caregiving burden. In our study, the median self-reported QOL score at the time of SPC referral was 3 (range: 1–7), highlighting the need for improvement. Unfortunately, it was only possible to attain QOL data in the SPC population, as systematic QOL screening is not routinely obtained in the oncology departments.

To our knowledge, this is the first study reporting the use of different multidisciplinary professions among patients with gliomas admitted to SPC. The findings indicate a high demand for multidisciplinary support, suggesting a complex symptom burden. This aligns with the study by Tagami et al. (2022), which retrospectively examined the perspectives of bereaved caregivers and found that many wished they had consulted the SPC team earlier.

We found that the use of multidisciplinary professions varied by age groups. Younger patients were more likely to receive support from two or more professionals, who offered support to both the patient and their caregivers. Older patients primarily used physiotherapists, who focus on patient-centered care. The reason older patients utilized fewer SPC services than younger patients is unclear. It may be that older patients have needs for services not routinely offered by current professionals on the SPC team. Another speculation is that older patients may be less inclined to express their needs, potentially resulting in insufficient

support. This speculation is in line with a report from Edinburgh (Lloyd et al., 2015) describing that older patients had more difficulties understanding and processing information about their prognosis, making them unable to express their needs.

Despite increasing awareness of physical, psychosocial, and existential symptoms in the daily oncology setting, there is still sparse knowledge about which patients will benefit from SPC and when referral should occur. Closer collaboration with SPC teams could facilitate earlier referrals, ultimately enabling more patients to receive timely palliative care. Further, the high utilization of multiple SPC professions indicates earlier referral could improve end-of-life QOL by reducing distress, as shown for other cancer diagnoses (Bakitas et al., 2015).

Several randomized trials investigating SPC in the end-of-life phase have focused on patients with solid tumors and excluded patients with cognitive impairments. This explains why patients with primary brain tumors are often not represented in trials (Bakitas et al., 2009; Temel et al., 2017). Due to the retrospective nature of this study, we could not evaluate if SPC increased OS in the cohort. However, we found that longer survival increased the likelihood of receiving SPC, suggesting that some patients died before their need for SPC was recognized. It is possible systematic screening for SPC eligibility would result in earlier referral. Few trials have investigated a screening in primary brain tumors, but no standard tool is available as of yet (Kim et al., 2020). Currently, a phase III trial is investigating the effect of early palliative care in GBM patients (Golla et al., 2020).

The majority of patients with gliomas in this study were referred to SPC, especially younger patients and those living with a partner. There was an age-dependent variation in the need for multidisciplinary SPC support, warranting further investigations, especially in older patients. Over the past decade, health-care teams have become increasingly aware of the importance of a palliative approach when managing patients with brain tumors. Development of a screening tool for determining the palliative needs of patients with gliomas would likely increase awareness and lead to further improvements in palliative care referral.

Disclosure

The authors have no conflicts of interest to disclose.

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