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End-of-life caregivers' perception of medical and psychological support during the final weeks of glioma patients: a questionnaire-based survey

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Abstract: Background : The prognosis for glioma remains dismal, and little is known about the final disease phase. To obtain information about this period, we surveyed caregivers of patients who were registered in the German Glioma Network and who died from the disease. Methods A questionnaire with 15 items, focusing on medical, logistic, and mental health support and symptom control during the final 4 weeks, was sent to caregivers. For some of the questions, a scale from 1 (inadequate) to 10 (excellent) was used. Results Of 1655 questionnaires, 605 were returned (36.6%) and evaluated. We found that 67.9% of the patients were taken care of at home for the last 4 weeks; 47.7% died at home, 22.6% died in hospitals, and 19.3% died in hospice facilities. Medical support was provided by general practitioners in 72.3% of cases, by physicians affiliated with a nursing home or hospice in 29.9%, and by general oncologists in 17%. Specialized neuro-oncologists were involved in 6%. The caregivers ranked the medical support with a mean of 7.2 (using a 10-point scale), nursing service with 8.1, and mental health support with 5.5. In 22.9% of cases, no support for the caregivers themselves was offered by medical institutions. Conclusions Although these data reflect the caregivers' subjective views, they are useful in understanding and improving current patterns of care. While patients and their caregivers are supported mainly by neuro-oncologists for most of the disease phase, the end-of-life phase is managed predominantly by general practitioners and specialists in palliative care. Close cooperation between these specialties is necessary to meet the specific needs of glioma patients.

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End of life – caregivers’ perception of medical and psychological support during the final weeks of glioma patients: a questionnaire-based survey

Oliver Heese, Eva Vogeler, Tobias Martens, Oliver Schnell, Jörg-Christian Tonn, Matthias Simon, Johannes Schramm, Dietmar Krex, Gabriele Schackert, Thomas Reithmeier, Guido Nikkhah, Michael Sabel, Hans-Jakob Steiger, Uwe Schlegel, Markus Löffler, Michael Weller, Manfred Westphal, for the German Glioma Network

Department of Neurological Surgery, University Medical Center Hamburg-Eppendorf, Martinistr. 52, 20246 Hamburg, Germany (O.H., E.V., T.M., M.W.); Department of Neurosurgery, University of Munich LMU, Marchioninstr. 15, 81377 Munich, Germany (O.S., J.C.T.); Department of Neurosurgery, University of Bonn Medical Center, Sigmund-Freud-Str. 25, 53105 Bonn, Germany (M.S., J.S.); Department of Neurosurgery, Technical University Dresden, Fetscherstr. 74, 01307 Dresden, Germany (D.K., G.S.); Department of Stereotactic Neurosurgery, University of Freiburg, Breisacher Str. 64, 79106 Breisach, Germany (T.R., G.N.); Department of Neurosurgery, Medical Faculty, Heinrich-Heine University Düsseldorf, Moorenstr. 5, 40225 Düsseldorf, Germany (M.S., H.J.S.); Department of Neurology, Ruhr-University Bochum, In der Schornau 23-25, 44892 Bochum, Germany (U.S.); Institute of Medicinal Informatics, Statistics and Epidemiology, University of Leipzig, Härtelstr. 16-18, 04107 Leipzig, Germany (M.L.); Department of Neurology, University Hospital Zurich, Frauenklinikstr. 26, CH-8091 Zurich, Switzerland (M.W.)

Running Title: End of life in glioma patients

Corresponding Author: Oliver Heese, M.D., MBA, Department of Neurosurgery, HELIOS Medical Center Schwerin, Wismarsche Str. 393-397, 19049 Schwerin, Germany, Email: oliver.heese@helios-kliniken.de, Phone: +49-385-520-2750, Fax: +49-385-520-2755

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Abstract:

Background: The prognosis for glioma remains dismal, and little is known about the final disease phase. To obtain information about this period, we surveyed caregivers of patients who were registered in the German Glioma Network (GGN) and died from the disease.

Methods: A questionnaire with 15 questions, focusing on medical, logistic and mental health support and symptom control during the final four weeks, was sent to caregivers. For some of the questions, a scale from 1 (inadequate) to 10 (excellent) was used.

Results: From 1655 questionnaires, 605 were returned (36.6%) and evaluated. We found that 67.9% of the patients were taken care of at home for the last 4 weeks. While 47.7% patients died at home, 22.6% died in hospitals and 19.3% in a hospice facility. Medical support was provided by general practitioners in 72.3%, physicians affiliated with a nursing home or hospice in 29.9% and general oncologists in 17%. Specialized neuro-oncologists were involved in 6%. The caregivers ranked the medical support with a mean of 7.2 (using a 10-point scale), nursing service with 8.1 and mental health support with a 5.5. No support for the caregivers themselves was offered by medical institutions in 22.9%.

Conclusions: Although these data reflect the subjective caregivers' views, they are useful in understanding and improving current patterns of care. While patients and their caregivers are mainly supported by neuro-oncologists for most of the disease phase, the end-of-life phase is predominantly managed by general practitioners and specialists in palliative care. Close cooperation between these specialties is necessary to meet the specific needs of glioma patients.

Key words: glioma, palliative care, supportive therapy

Introduction:

The disease course of glioma is highly variable, but with its devastating long-term prognosis, it is an immense challenge to patients and their social environment.¹ As opposed to most other types of cancer, by affecting neurological integrity, gliomas may influence physical abilities, cognitive function, mood, and personality.²⁻⁴ At the final stage of the disease, caregivers are often unprepared and inadequately supported to address a patient suffering from impaired cognition, disorientation, impairment of consciousness, seizures, incontinence and other complex neurological deficits.⁵⁻⁸ Therapy and support provided by specialized neurooncologists

is given mostly in the phase of active treatment against glial tumors. However, in the final stage, when neuro-oncologists become less involved, little is known about the symptoms and particular needs of glioma patients, and even less is known of their caregivers'. There is presumably a "neuro-oncological gap" of adequate support, with many patients not receiving optimal palliative care, such that the burden of care often falls on patients' families and caregivers, assisted by professionals with no specialized neuro-oncological expertise.⁹ Thus, to improve the clinical care of glioma patients in the end stage of the disease, a thorough evaluation of the current situation is necessary. The survey undertaken here was designed to not only assess patterns of care but also to identify shortcomings in care with respect to the patients' distress and that of their caregivers and social environment.

Understanding these patterns of care in the context of the physical decline experienced by patients with glioma may enable the provision of adequate supportive care and appropriate communication, when patients and caregivers need it most.¹⁰⁻¹¹

In this context, the large, well-documented database of the German Glioma Network (GGN), a clinical research network sponsored by the German Cancer Aid (Deutsche Krebshilfe), provides a unique opportunity to identify the following trends in the end-of-life care for glioma patients: the individuals providing care for the patients, the location of the patient during the final phase and subsequent death, and the support available to caregivers.

Patients and Methods:

Patients who died from a brain tumor at least 3 months before inclusion in this study and their caregivers were selected from the database of seven clinical centers of the GGN (i.e., Bochum, Bonn, Düsseldorf, Dresden, Freiburg, Hamburg, Munich) (www.gliomnetzwerk.de).

Informed consent was obtained from all patients prior to their inclusion in the GGN. Data collection procedures received approval from the local ethical committees of the participating centers. An additional ethics approval for the process of collecting data from the caregivers of the patients, which was not integrated in the initial ethical approval, was obtained. Selection criteria for this study were a glial cerebral tumor, as diagnosed by the local neuropathologist and confirmed by the German Brain Tumor Reference Center, and death with at least 3 months prior to inclusion in the study. The questionnaires were sent to the patient's last address documented in the GGN database with a letter explaining the study purpose and design and a return envelope, with the assumption that using the patients' address would ensure that the most important caregiver was contacted. Due to the sensitivity of the matter of the survey, "reminder letters" or phone calls to the caregivers to increase the return rate were not used.

Each questionnaire consisted of 15 questions and a space to give an individual comment. The questions focused on the last 4 weeks before the death of the patients. In 6 questions, a 10-point scale numbered between 1 (inadequate) and 10 (excellent) was used (Table 1).

Statistical analyses were performed using SPSS software for chi-square and Mann-Whitney-U tests.

Results:

Of the 1655 questionnaires sent out, a total of 605 were available for evaluation, representing an overall return rate of 36.6%. Because 443 questionnaires (27%) were returned to sender due to incorrect addresses (relatives / caregivers no longer living at the documented address), the actual return rate (questionnaire received and the respondents willing to answer) was 50.1%. The median age of patients in the study was 58.8 years (min 17.6 years, max 86.7 years), with a gender distribution of 63.6% male and 36.4% female. The overall survival across all histological subtypes (OAS) was 2.3 years, and the progression-free survival (PFS) was 1.1 years. The distribution of histological subtypes was as follows: 13.3% were diagnosed with a WHO grade II tumor, 15.4% with a WHO grade III tumor and 71.3% with a WHO grade IV tumor (according to the German Brain Tumor Reference Center). Compared to the whole study population of the GGN (> 4000 patients) some differences were seen in regard to age (older patients in the study group), gender (more male patients in the study group), and histology (higher rate of malignant glioma in study group) (Table 3). These differences are in part expected since we analyzed deceased patients and therefore it is expected that the rate of high grade gliomas and the median age is higher than in the overall

cohort. Regarding the gender differences we can only speculate that female caregivers may be more motivated to return the questionnaire in a sense of being a caregiver beyond the patients death and therefore more motivated to return the questionnaire.

In the cases in the study, 68% of the patients received care at home during the final four weeks of the disease; 49.8% of these had the support of a nursing service and 18.2% did not. In 28.4% of all cases in the study, patients spent at least some time during their final four weeks in hospitals (equally distributed between hospitals affiliated with the GGN and those not affiliated). Almost one-third of the patients received 24-h professional care outside of hospitals (20.2% in hospices and 9% in nursing homes) (Figure 1). Although 68% of all patients stayed at home in their final disease period, many were moved to a 24-h care institution in the final days, so only 47.7% of all patients died in their home environment (31% of these with the support of a nursing service and 16.7% without). Of the patients who did not die at home, 22.7% died in hospitals (13.6% not affiliated with the GGN and 9.1% affiliated with the GGN), 19.3% died in a hospice facility and 7.3% in a nursing home (Figure 2). In summary, only a small portion of patients who, during the active therapy of their disease, were tightly bound to neuro-oncological specialists in the GGN were supported by these centers during the final phase of the disease. Accordingly, the neuro-oncologists of the GGN were not the primary providers of professional advice and care during the final phase of the disease; they were only involved in 6.1% of the cases, with 72.3% of the patients receiving care from general practitioners. Only 29.9% of all cases involved physicians from hospitals that did not belong to the GGN, and 21.3% of patients received care from physicians who specialized in palliative medicine or served as consultants to nursing homes or hospice facilities (Figure 3). In 47.2% caregivers mentioned one primary physician, in 34.8% two and in 18% three or more. In the cohort of two physicians the combination of general practitioner plus oncologist was seen in 37.9%, the combination of general practitioner and neurologist in 29.1% and general practitioner plus physician associated to the GGN (either neurologist or neurosurgeon) in 12.1%. Various other combination were seen in less than 10%. The results in regard to the quality of care felt by caregivers did not differ between these groups. Using a 10-point scale (1: inadequate to 10: excellent) to judge the quality of medical and mental health and nursing service support during the end-of-life phase, the highest score was given to nursing services (median 8, SD 2), followed by support from physicians (median 7, SD 2). Mental health support was only rated with a median score of 5 (SD 2) (Figure 4). In addition to the caregivers' perception of support received by patients, they were asked about the support available to themselves in the stressful end-of-life situation. Most of the

support came from non-professional sources, such as family (79.2%) and friends (38.6%). Professional support was offered by general practitioners (51%) and social services (48.3%). Many caregivers (23%) reported that they received no support during the final phase of caring for their family member (Figure 5).

When asked whether alternative / complementary therapies were used by caregivers to relieve the patients' symptoms during the final phase, 11.1% answered positively. A considerable number 17.8% of caregivers stated that they experienced financial difficulties during the end of life phase. Caregivers were also asked whether they were satisfied with the support of their primary physician with regard to common symptoms occurring during the final disease phase (Table 1); approximately 54.4% of the respondents were generally satisfied. Dysphagia (72.9%), incontinence (70.8%) and epilepsy (63.8%) were treated well, according to the caregivers, whereas nausea (49.4%), nutritive issues (36.2%) and cognitive deficits (26.3%) were the symptoms reported to be treated least effectively.

To detect any possible influences of patients' individual parameters, the answers were stratified for age, histology, gender and overall survival (Table 3); however, no statistically significant differences were observed. The only detectable trend was observed in the subgroup of younger patients (< 20y to 40y) with WHO grade II and long OAS. This cohort received medical support from neurologists in 30.1% of the cases compared to only 14.3% of cases receiving such support in the overall study population, and only a small proportion of patients in this cohort spent their final four weeks in a nursing home (2.3% vs. 9% in the overall study population). In addition, the younger cohort sought more information about the end-of-life phase than the overall study population.

Due to the retrospective study design the interval from questionnaire submission to caregivers to patients death was between 3 month and 7 years. In order to evaluate whether differences were seen we compared 100 patients with the longest interval between death and questionnaire (6-7 years) with 100 patients with the shortest interval between death and questionnaire (1 year). Significant differences were identified in four parameters. Firstly it was seen that the rate of palliative-care physicians involved in patients care increased in the observed period from 13.5% to 30.9%, secondly non-GGN associated hospitals as place of death decreased from 17.7% to 6.3% and the internet as information source for care givers increased from 25.3% to 40.6%. Finally the rate of insufficient support for caregivers decreased from 33% to 15.3%. These informations demonstrate that retrospective surveys may differ in regard to results depending on the timepoint of evaluation which is in part inevitable in the retrospective context (Table 4).

54.3% of caregivers used the opportunity to express their thoughts on this topic in the free comment section. Besides positive comments regarding the end of life care (26% GGN, 65.6% outpatient) the caregivers complained about the lack of psychooncological support (63.4%), insufficient physician-caregiver communication (42.9%), insufficient logistic support in regard to technical support / devices for the home care of the dying glioma patient (22.1%) and problems in regard to transfers of patients to hospitals in cases of acute deterioration not manageable by caregivers themselves (19.1%).

Discussion:

In recent years, progress has been made in the medical management of glioma patients. Nevertheless, additional efforts are needed to improve supportive care and address end-of-life issues adequately. In general, the main goals of end-of-life care are to offer adequate symptom control, avoid inappropriately prolonging the dying process and provide psychological support to meet the emotional needs of patients and caregivers. Although the information obtained in this study on the terminal phase of glioma patients represents the caregivers' view on this topic and is therefore subjective, it may aid in understanding and improving current patterns of care.

An analysis of the location of palliative care during the final four weeks and subsequent death showed that approximately three-quarters of the patients were able to stay at home, and almost half of the patients died at home. A large portion of the remaining patients in the study spent this period in hospitals and died there, in some cases leading to unsatisfactory situations for patients and caregivers, as indicated in the supplemental comments given by the caregivers in the questionnaires. However, hospitals also represented an adequate alternative for caregivers when the patients' acute symptoms became impossible to manage at home. The inability to adequately handle symptoms of patients not enrolled in palliative home-care programs typically leads to re-hospitalization, increasing the burden on healthcare budgets, and more importantly, the worsening of patients' and caregivers' quality of life.¹² Although the GGN university hospitals are not primarily involved in end-of-life care, neuro-oncologists should be prepared to offer logistic advice and provide help in acute situations.

The opinions as to whether multidimensional care in the end-of-life phase of glioma patients should be within the scope of practice of general practitioners are mixed among these practitioners.^{10, 13} As shown in our survey, patients and their caregivers are supported mainly by neuro-oncology centers during the initial disease phase, while the end-of-life phase is predominantly supported by general practitioners. It is thus of paramount importance to

include specific neuro-oncological expertise (e.g., dosing and duration of steroids, management of headache or seizures) for all aspects of patient management.¹⁴ Due to the low incidence of glioma, general practitioners may be unfamiliar with the natural course of disease progression and may require education and strong communication with the neurooncology

specialist to offer the best medical and palliative care to patients and to reduce unnecessary hospitalization.¹⁵

Several studies indicate that taking care of a patient with a brain tumor can have an enormous impact on a caregiver's life.¹⁶ Financial problems and changes in relationships and responsibilities are among the burdens caregivers may carry.¹⁷ The extent to which this was experienced (17%) is still worrisome but indicates that within the German social system, the majority of affected families are sufficiently cared for. Moreover, brain tumor patients' symptoms, including cognitive deficits, anxiety and aggressive behavior, may cause subsequent distress to caregivers, negatively affecting their quality of life and thus their ability to cope with their new tasks. As determined from other studies, caregivers face the risk of becoming increasingly involved in patient care, subsequently isolated and eventually unable to continue with their daily lives. Patients and caregivers have reported anxiety and distress resulting from social isolation, stigmatization, feeling misunderstood and an inability to talk about their feelings or situations.¹⁸ Few studies evaluate the quality of life of untrained caregivers (e.g., partners or family members) of brain tumor patients. Janda et al reported that glioma patients and their caregivers had a clinically significant reduction in QOL compared with the general population.¹⁹ Understanding the necessities and gaps in specific education for the end-of-life phase of brain tumor patients and the provision of adequate support may greatly improve the negative impressions reported in such situations. Because caregivers described substantial deficits in mental health support for themselves, it is important to expand these services.²⁰⁻²¹

Although the number of patients evaluated in this study is large, some possible limitations should be addressed. All of the patients in our study had been included in the database of the German Glioma Network; they had thus been treated in university medical centers with a neuro-oncological focus. Therefore, conclusions drawn from our data may not apply to patients treated in less specialized centers or to those treated in other countries, due to differences in the structure of health care systems. Nevertheless, we obtained valuable information about the final disease stage of glioma patients and identified opportunities to improve care during this stage, helping both patients and caregivers and reducing the burden

on caregivers. Despite the limitations of the study (retrospective approach, low return rate of questionnaires) these data may lead to a broader discussion on the patterns of care of glioma patients and hopefully serve as a starting point for further prospective studies in other countries.

In summary, we show that, despite valuable research efforts to improve the treatment of brain tumors that focus on tumor biology and refinements to surgery, radiation and chemotherapy, there is also room to improve aspects of care in the end-of-life situation. An integrative approach for glioma patients, from diagnosis to death, could potentially reduce the burden felt by caregivers in the final period.

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Figures:

Figure 1:

Distribution of place of care during the final four weeks in % (NS: nursing service, GGN+/-: hospital affiliated to the German Glioma Network or not). The total is >100%, due to more than 1 place of care during the last four weeks

Figure 2:

Distribution of place of death in % (NS: nursing service, GGN+/-: hospital affiliated to the German Glioma Network or not)

Figure 3:

Distribution of primary physician care during the final four weeks in % (GGN+/-: hospital affiliated to the German Glioma Network or not). The total is > 100% due to the possibility of more than one answer

Figure 4:

Caregivers' perception with regard to overall support from various occupational groups, mean values +/- SD (1: inadequate, 5: fair, 10: excellent)

Figure 5:

Medical and non-medical support for caregivers in % (GGN+/-: hospital affiliated to the German Glioma Network or not). The total is > 100% due to the possibility of more than one Answer

Tables:

Table 1:

Questions, summary:

- Place of palliative care during the final four weeks and place of death (2 questions)
- Supporting physician during the last four weeks
- Medical support for end-of-life problems (intracranial pressure, epilepsy, nausea, nutrition, dysphagia, depression, palsy, incontinence, consciousness)
- Information source for caregivers (others than physician)
- Supporting / contact person for caregivers (2 questions)
- Financial problems due to caring for patient
- Non-medical support during the last four weeks
- Counseling by physician with regard to palliative care (2 questions)
- Caregivers' perception of patients' support during the last four weeks (by medical professionals, mental health professional, or nurses) (3 questions)
 - Use of alternative therapies during the last four weeks

Table 2:

Subgroups:

Age < 20y to 40y (n=75) 41y to 60y (n=167) 61y to 80+y (n=324)

Gender Male (n= 360) Female (n=219)

Histology WHO II 13.3% (n=74) WHO III 15.4% (n=86) WHO IV 71.3% (n=398)

Survival < 1 year 42.1% (n= 238) 1–3 years 40.6% (n=231)
3-5 years 7.6% (n=43) > 5 years 9.7% (n=56)**Table 3:**

EOL study population vs. whole GGN study population:

EOL group (n=605) **GGN group (n=4053)****Age** 58 (17-86) 52 (17-88)

Gender Male 63.6% Male 58.7% Female 36.4% Female 41.3%

Histology WHO I 0% WHO I 5.3%
WHO II 13.3% WHO II 26.4%
WHO III 15.4% WHO III 19.1%
WHO IV 71.3% WHO IV 49.2%

Table 4:

Time resolved analysis of questioned cohorts with respect to length of interval between receiving questionnaire and death of patient:

	Total	earliest 100 patients	recent 100 patients
Physician, pall.-medicine	21.3%	13.5%	30.9%
Place of death, Non-GGN hospital	13.6%	17.7%	6.3%
Information source, Internet	31.7%	25.3%	40.6%
Support of caregivers, None	23.0%	33.0%	15.3%