

## The caregivers' perspective on the end-of-life phase of glioblastoma patients

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**Abstract** Glioblastoma multiforme (GBM) still harbors a fatal prognosis. The involvement of the neurocognition and psyche poses unique challenges for care provision by relatives. We lack data about the caregivers' perspective on the end-of-life (EOL) phase of GBM patients to improve counseling and support. In this study we investigated the experiences of 52 caregivers of deceased GBM patients treated in Austria. We used a questionnaire developed by the University Medical Centre of Amsterdam for exploration of the EOL-phase in glioma patients. The caregivers (17 men, 34 women) completed the questionnaire in median three years after the patients' death. 29 % of caregivers reported that they felt incompletely prepared for their tasks, however, those with higher education levels felt

significantly better informed. 29 % suffered from financial difficulties, which was associated with burnout (60 %) and reduced quality of life (QOL). The patients' most common symptoms reported by caregivers were fatigue (87 %), reduced consciousness (81 %) and aphasia (77 %). 22 % of patients were bedbound during their last three months increasing to 80 % in the last week of life. The reported QOL of caregivers was very low and did not differ between caregivers of patients, who died at home (40 %) and caregivers of patients, who died in hospital (46 %). The caregiver reported that their QOL was only slightly better than the QOL they attributed to the patients. Furthermore, the high frequency of financial difficulties, burnout symptoms and feelings of insufficient information emphasize the urgent need for support and training dedicated to caregivers.

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## Introduction

Limited duration of survival, changes in cognition, in personality and in behavior as well as side effects of treatments cause unique challenges for providing care to patients with glioblastoma multiforme (GBM) [1, 2]. Moreover, GBM patients are treated in day clinics as most therapy regimens consist in oral or in short-course intravenous drugs, in this way greatly increasing the caregivers' role. It is indeed not surprising that caregivers described their task as mentally overwhelming and physically exhausting [1, 3, 4]. Thus the care-team is required to consider the patients' living circumstances in order to facilitate caregiving by primary caregivers. It is well accepted, that the caregivers' burden can be reduced by educational and support programs [1, 4–17]. Therefore end-of-life (EOL) preferences should be discussed timely [18] at least before they become urgent. There is yet no consensus on when the EOL-phase in glioma patients begins. However, as the symptom burden often increases at tumor recurrence and the goals of care shift to supportive treatment [19], it appears plausible to consider symptomatic recurrence as start for the EOL-phase. There are limited data on the caregivers' situation in the EOL-phase of glioma patients [4, 7, 18, 20]. Oberndorfer et al. [21] evaluated the EOL-phase of hospitalized glioma patients as a symptom- and drug-intensive period and mandated further research to develop evidence-based guidelines. Pace et al. [6] support these findings in their survey on 324 glioma patients followed at home until death by a neuro-oncological home care palliative team. They explored symptoms and EOL-issues and concluded that palliative management of terminally ill brain tumor patients requires a multidisciplinary approach, as their EOL-phase involves more dimensions than in general cancer patients [22].

Recently Sizoo et al. [23] published a Dutch study on EOL decision-making in brain tumor patients. They included 101 high-grade-glioma patients, diagnosed in 2005–2006. Data were recorded with a questionnaire filled by the involved primary-care physicians. Sizoo et al. reported that EOL-preferences and even EOL-practices are common in the Netherlands but frequently unknown to the treating physicians. They therefore recommend early advanced care planning and timely discussion with patients and families. We were invited by the Dutch team to investigate the same topics in Austria. Our aim was to assess the Austrian caregivers' perspective on the last three months of patients with GBM.

## Methods

Patients' baseline and treatment data were taken from the medical files. The questionnaire for this study (see supplement document) was developed and validated in the Netherlands by the working group of Taphoorn et al. [23] and translated by two independent graduated translators. All questions regarding euthanasia were deleted as Austria has clear laws against physician-assisted death or physician-assisted suicide.

The questionnaire consists of two parts. The first part explores the caregiver's view of the patients' terminal phase (38 questions). Part 2 includes questions about the experiences and emotions of the caregiver during the last three months of the patients' life (26 questions). Biographical characteristics of the caregiver include age, education and living situation, health-related problems, job restrictions, quality of life (QOL), quality of care (QOC), satisfaction with information, EOL-preferences and places of death (POD).

We analyzed differences in evaluation considering baseline characteristics of the patients and of the caregivers and the preference POD by the patients. We tried to identify factors for caregivers' burnout and QOL during patient's EOL and the caregivers' satisfaction with information. Furthermore, the results were compared to the data from the Dutch study.

### Study population and procedure

The study was done at the Medical University Hospital of Vienna and at the Kaiser Franz Josef Hospital, Vienna, Austria. The protocol has been reviewed and approved by the local Ethics Committees.

The caregiver was defined as the person stated in the medical files as next of kin and mostly lived in the same household. We tried to reach all caregivers of adult (>18 years) patients with GBM diagnosed and treated in the centers from 2005–2006. If a telephone number was known, the caregivers were contacted by phone and invited to participate. In case of agreement, the informed consent forms and questionnaires were sent with the option of further contact by phone or meeting face-to-face on request. We encountered more difficulties than anticipated, due to the fact that mobile phone numbers of patients are indeed useless after their death. When no telephone number was available, the questionnaire was sent to the last known patient address. When letters came back undeliverable or when no contact to the primary caregiver was achievable, we regarded the caregivers as "not traceable". We identified 119 patients diagnosed 2005–2006. 31 patients were not eligible, 7 because of insufficient German skills, 5 had no recorded primary caregiver and 19 caregivers unknown

new addresses. A total of 81 eligible caregivers were identified and 33 of them agreed to participate.

The majority of those caregivers, who declined participation did not give any reasons (40/48), however, Six caregivers did not want to spend time on this study, two declined because they felt emotionally overwhelmed.

Furthermore, as we offer the possibility of schedules for family members in the outpatients, even after the death of patient. 19 caregivers of deceased GBM patients visited us during data collection for this study and we asked them for participation. Considering inclusion of “self-comers” as possible bias, we started analyzing this group apart. In total 52 caregivers were included in the study, see Fig. 1.

Statistical analysis

SPSS software 20.0 was used for statistical analysis. The patients’ and the caregivers’ data were described using descriptive statistics. Group comparisons were done with the students *t* test, Spearman correlation factor, the Chi square test with continuity correction, the Wilcoxon rank sum test and ANOVA. The significance level was set with  $\leq 0.05$ .

Results

Baseline characteristics

The baseline characteristics are shown in Table 1.

The majority of patients were male (63 %) with a median age of 63 years (35–83 years). The median age of the caregivers was equal to patients’ age with 62 years, (28–85 years). Two-thirds of the caregivers were female, most of them were the partners of the patients (88 %). One father and one mother cared for their daughter; one man

cared for his mother, one woman for her father, one woman for her sister and one woman for her female friend. The education levels of the patients and their respective caregivers were similar. The median time of caring (time period from diagnosis to death) was 11 months (1–63 months), the median time elapsed from the patients’ death to the date of study was three years (Table 1).

Symptoms and mobility

The caregivers were asked to recall and quote the patients’ symptoms for two time ‘points: the last three months and the last week of the patients’ life (Fig. 2). The highest prevalence of 87 % was recorded for fatigue during the last three months which decreased slightly in the last week to 83 %. The next frequently reported symptom was reduced consciousness and the third aphasia.

The patients’ mobility was generally reduced (see supplement Fig. 1). Just 20 % were fully independent in mobility during their last three months, 6 % still in the last week of life. 27 % of the patients needed walking aids, 31 % used a wheelchair. 22 % were bedbound during their last three months and this number increased to 80 % in the last week of life.

Seizures were observed in 52 % of patients during their last three months, decreasing to 38 % during the last week.

Caregivers’ symptoms and restrictions

Supplement Table 1 summarizes the caregivers’ own symptoms during the EOL-phase.

Sadness was the most often mentioned symptom (90 %) during the last three patients’ months, followed by fear (69 %), burnout (60 %), less interest in others (54 %) and irritation (42 %). Furthermore, 15 caregivers (29 %) indicated financial difficulties due to the patients’ disease.

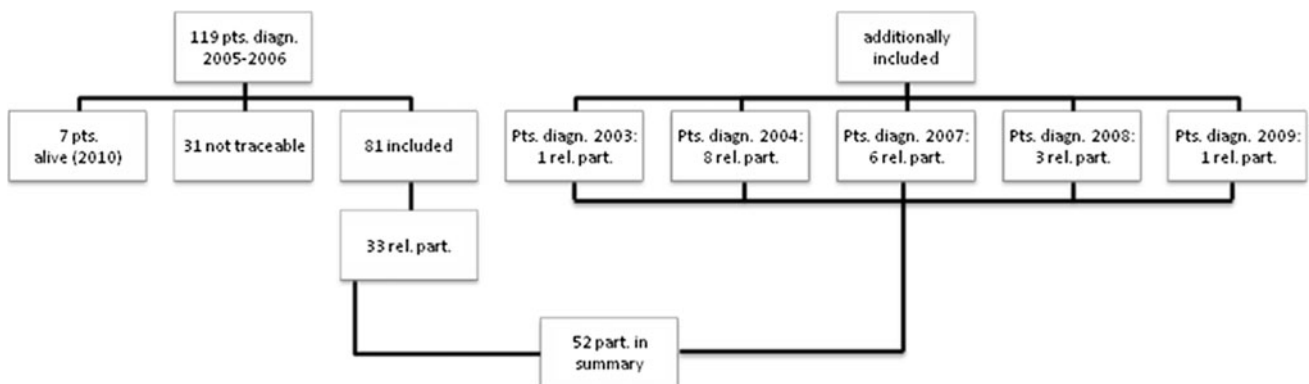


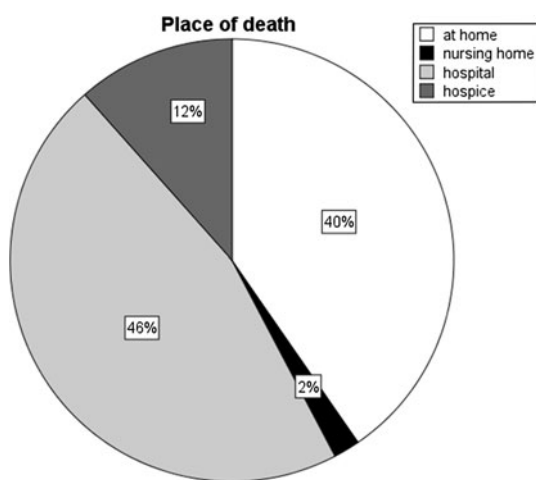
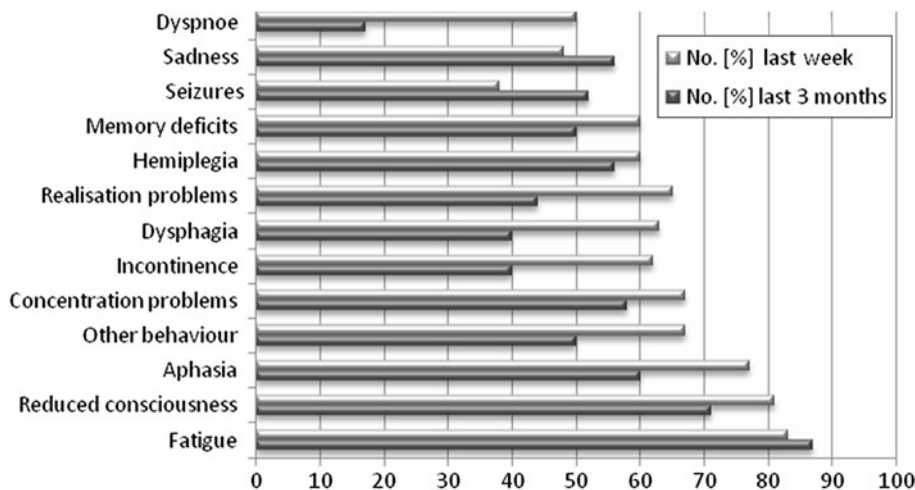
Fig. 1 Left side of numbers in the boxes show the patients who were identified and finally participated, right side of numbers in the boxes show the additional included patients with their years of diagnosis. Pts patients, rel relative(s), part participated, diagn diagnosed

**Table 1** - Baseline characteristics

	Caregivers				Patients			
	All (n = 52)	Diagnosed 2005 and 2006 (n = 33)	Additionally included (n = 19)	p value	All (n = 52)	Diagnosed 2005 and 2006 (n = 33)	Additionally included (n = 19)	p value
Age at diagnosis	Mean [years]	60	61	0.909	60	58	64	0.102
	Median [years]	62	60		63	61	68	
	Range	28-85	28-75		35-83	35-83	39-68	
Sex	Male	17 (33 %)	7 (37 %)	0.636	33 (63 %)	23 (70 %)	10 (53 %)	0.226
	Female	34 (67 %)	12 (63 %)		19 (37 %)	10 (30 %)	9 (47 %)	
Education	Lower school levels or less	31 (61 %)	10 (52 %)	0.051	33 (64 %)	23 (70 %)	13 (69 %)	0.568
	Higher school levels	11 (22 %)	3 (16 %)		10 (19 %)	6 (18 %)	1 (5 %)	
	University degree	9 (17 %)	6 (32 %)		9 (17 %)	4 (12 %)	5 (26 %)	
Time from diagnosis to death	Median [months]	11	15	0.027*				
	Mean [months]	16	21					
	Range [months]	1-63	2-63					
	Standard deviation	14.2	17.8					
Time from death to evaluation	Median [months]	39	18	0.070				
	Mean [months]	38	29					
	Range [months]	6-73	6-73					
	Standard deviation	17.6	22.9					

\*Significant on the level of  $p \leq 0.05$

**Fig. 2** Filled columns show the symptoms reported during the last three months and empty columns during the last week of life



**Fig. 3** Black sector shows the percentage of deaths in nursing homes, dark grey in hospices, light grey in hospitals and empty sector shows the percentage of patients who died at home

Of note, more than 50 % of caregivers reported job restrictions.

Quality of life (QOL), quality of care (QOC), wishes for place of death (POD), given information

The patients’ QOL was quoted with a median of 2.0 which is slightly lower than the mean of the caregivers’ QOL of 3.0 on a scale of 1–7 (see supplement Fig. 3). The QOC was reported with in a median of 5.2 during the last three months and a mean of 6.0 in the last week of life.

In this study, 46 % of the GBM patients died in hospitals, 40 % at home, 12 % in hospices and one patient in a nursing home (Fig. 3). 30/52 patients had expressed preferences for their POD; 79 % wished to die at home and 68 % of them fulfilled this (see Fig. 4).

15 caregivers (29 %) said they felt insufficiently informed by the medical staff, 62 % received sufficient and

6 % received more information than they wished for. No patient had expressed a formal advanced care directive.

Group comparisons and correlations

*Patients diagnosed 2005–2006 versus self-comers*

The patients’ characteristics between these groups were similar except for a longer period from diagnosis to death ( $p = 0.027$ , Table 1). Moreover, there was a trend ( $p = 0.051$ ) regarding the caregivers’ education levels. The self-comers tended to have higher education levels as compared to the study group.

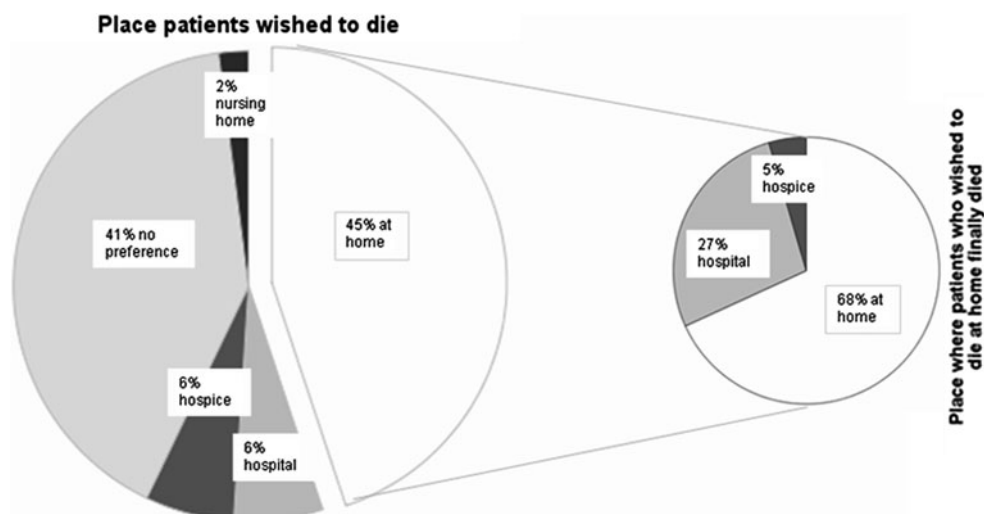
However, as the ANOVA test regarding the QOL during the last three months (QOL3 m), QOC during the last week of life (QOC1w), burnout, POD and satisfaction with information showed no differences between the self-comers and the study group. The following analyses were done with all participants.

*Age and gender*

Two-thirds of caregivers in this study were female. We investigated if there are any gender differences in outcomes related to the sex of patients or the sex of caregivers. We found no differences regarding the POD. The respective values in QOC1w and caregivers’ QOL3 m were similar. Nevertheless, male caregivers felt less insufficiently informed than female caregivers (12 % male, 39 % female,  $p = 0.09$ ).

We furthermore analyzed, if the caregivers’ symptoms, the satisfaction with information, the POD, the QOL and the QOC differs according to the age of the caregivers and the patients’ age. We found no significant differences, except for job restrictions as caregivers who were already retired mentioned no job restrictions.

**Fig. 4** Sectors of the *left circle* show the places where the patients wished to die; sectors in the *right circle* show the places of death from patients who wished to die at home



### Places of death

We compared QOC during the last week of patients' life, caregivers' burnout and fear as well as perceived information according to the POD (Table 2). Trends show better QOC for patients who died at home, but also more burnout for their caregivers, whereas fear was more prevalent for the patients who died in a hospital.

### Time spans

Time spans from death of the patient to evaluation ranged from 6–73 months. Our analysis showed no differences in the QOL3 m, QOC1w, burnout and percentage of insufficient information according to duration of care or to time elapsed since patient's death.

### Influencing factors for caregivers' quality of life, burnout and perception of information

Caregivers generally reported low QOL. We analyzed whether symptoms of the caregiver and of the patient influenced the caregivers' QOL significantly. Financial difficulties were identified to influence the caregivers' QOL

and burnout significantly with  $p = 0.029$  and  $p = 0.007$  but no patient symptom.

Moreover, lower education levels of the caregivers correlated significantly with the perception of insufficient information ( $p = 0.002$ ).

### Additional concerns noted by caregivers

20/52 caregivers used the option for additional concerns in the questionnaire. 11 caregivers added free text emphasizing the lack of information about their tasks of caregiving and about the patients' illness. Four participants mentioned logistic problems in providing necessary resources for caring. Three caregivers judged the therapy of their loved ones an unnecessary torture. Two participants complained about the QOC in the hospital; one even had obtained patient's discharge.

### Discussion

This is the first study investigating caregivers' perspective on the EOL-phase in brain tumor patients in Austria.

The low rate of participation (33/81) of caregivers requires discussion. Refusal might be due to the sensitive and potentially distressing nature of this topic. Moreover, as 19 bereaved caregivers came independently to the outpatient's clinic for discussing their experiences and clarifying last questions, these "self-comers" illustrate the need of caregivers for management during and after the period of caring for patients with GBM. Nevertheless, Guilbert et al. concluded in their study, that the non-response rate of surveys is insufficient judging on the quality of a survey [24]. Our findings show that a significant part of bereaved caregivers is emotionally able and motivated to talk about their experiences. This supports the

**Table 2** Evaluations sorted by places of death

Place of death	QOC last week	Fear	Burnout	Perceived insufficient information
	Range 1–7 (mean/median)	%	%	%
Hospital	4.9/6	75	58	33
At home	5.8/6	53	63	25
<i>p</i> values	0.110	0.198	0.748	0.546



findings of Lipsman et al. [25], who reported that patients with terminal brain cancer and their caregivers felt talking about these personal and distressing issues as helpful.

#### Comparisons to the Dutch study

The present study was based on the caregiver's view of patient's symptoms and their own burden. In contrast, the Dutch study by Sizoo et al. [22] reported the physician's perspective of glioma patients during the EOL-phase.

The baseline characteristics of both patient cohorts were similar according age of the patients with a mean age of 57 years by Sizoo et al. [22] and 60 years in this study. The majority of the participating caregivers were the partners of the patients (89 versus 82 % in Sizoo et al. [22]) and two-thirds of them were female. So it seems that women are more likely expressing their experiences in questionnaire-based studies.

A striking difference to the Dutch study is the lack of advance care directives in Austria: 42 % of the Dutch patients had advance directives, compared to zero in this series. This implies a difference in attitudes towards EOL conversations, which are not mandatory in Austria. This potential denial "turning a blind eye" to the inevitable outcome by the Austrian caregivers, physicians—and by the patients—might contribute to the reported feelings of insecurity and lack of information. However, it appears plausible that legalization of euthanasia in the Netherlands provokes the need for Dutch patients to plan an EOL-decision and might partly explain the national differences in advanced care directives.

Nearly half of Austrian patients died in hospitals, 40 % at home. These results are clearly different from the Dutch findings [22] where 66 % of patients died at home and only 17 % in hospitals. The most obvious explanation for the difference in POD is the different national health systems. Whereas both systems can be ranked to the best health-care systems worldwide, it seems that the availability of mobile palliative teams and of support programs for families needs to be improved in Austria, to reduce their burden and fear. This endeavor should be encouraged not only for socio-economic reasons, but most importantly to fulfill the wishes of the patients. Simon et al. [26] published recently that annually 47 % of deceased people in Germany die at home and that this proportion will increase.

#### Baseline characteristics, symptoms, associations

In concordance with the literature [27, 28, 29], fatigue was the most common symptom in patients with GBM during their EOL-phase, followed by impaired consciousness as reported by Oberndorfer et al. [21].

Of note only 20 % of patients stayed fully independent in their mobility reflecting the high need of care for GBM patients during the EOL-phase. More than half of the

patients suffered from hemiplegic symptoms, as previously reported that the most common activities of daily living, which require caregivers' assistance are walking inside the house and transportation, bathing, dressing, laundry and housework [7].

However, more than 50 % of caregivers were not able or willing to manage the care at home from a certain point of disease and 60 % of caregivers stated burnout problems. Of note, caregivers whose loved ones died at home quoted themselves as the best informed ones. Alarmingly, the caregivers' QOL during the EOL-phase was very low and almost as low as the QOL attributed to patients, as reported previously [25, 30, 31] whereas QOL was previously reported as one of the most appreciated values in terminal stage of brain cancer [25]. Interestingly, we identified significant correlations between the caregivers' financial difficulties and QOL and burnout ( $p = 0.007$  and  $p = 0.029$ ). We recently published our findings in GBM long-term survivors, who suffered from financial difficulties too [29]. Kumthekar et al. [32] presented recently that families of glioma patients are facing higher costs than families of patients with other tumors. These data warrant further investigative studies.

Interestingly, we found no differences or trends in any scale of this study related to the duration of patient's survival. Thus it seems that the experiences and perceptions of the EOL-phases in GBM patients are independent from the length of survival time.

The patients of the self-comer group survived significant longer their GBM, but were not different in other parameters, so we included these caregivers in the study.

Our study showed a trend to perceiving insufficient information in female caregivers. Surveys indicate that support groups are visited more often by female patients and caregivers assuming that women express more often the interest in disease related topics [33]. However, Schratte-Sehn et al. [34] reported that people participating in a Viennese support group for brain tumor patients and families were mainly male patients relying on female caregivers. This study shows that near one-third of caregivers (29 %) felt insufficiently informed about their tasks and about the patients' illness. Moreover caregivers complaining about insufficient information also reported significantly more financial difficulties ( $p = 0.002$ ). This implies that more attention has to be paid to information regarding the disease of the patient and to his/her psychosocial components including financial situation.

#### Limitations

Furthermore the reported responses of the caregivers are a reflection of experiences at the two participating hospitals in Vienna, a big city of Europe and may not be applicable to

caregivers of GBM patients in other smaller centers in Europe and in other parts of the world. Another limitation is that only German speaking caregivers were included, so potential cultural and ethnic differences remain undetected. Furthermore we still lack information about the EOL-phase in patients without a family member or friend who cared for them. Moreover, due to legal reasons of different national laws, we had to adapt the questionnaire for Austrian caregivers by deleting all questions regarding euthanasia.

## Conclusion

In this study, we showed that not only brain tumor patients but also their family caregivers suffer from various symptoms. They are moreover faced with financial difficulties and may feel insufficiently informed. Although the results of the present study are very helpful for discussing EOL-issues with GBM patients and their families in the outpatients', they show an urgent need for multidisciplinary support programs to face caregivers' problems and reduce their burden.

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