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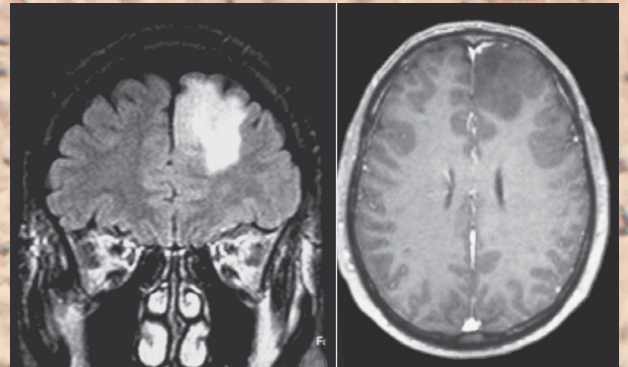
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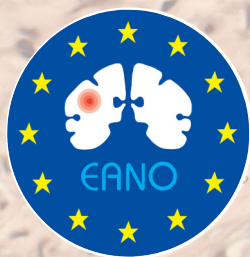
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Austrian Patients with Glioblastoma Multiforme and Their Families: Socioeconomic Aspects

Birgit Flechl, Christine Marosi

Abstract: Patients with glioblastoma multiforme (GBM) are still confronted with an incurable cancer disease affecting not only their body but also their personality and cognition. We present recent Austrian studies performed at the Medical University of Vienna on GBM patients dealing with socio-economic outcomes.

By analyzing quality of life (QOL), performance status, living and working situations, muscular strength of subsets of GBM patients, as well as satisfaction with the care and the end-of-life (EOL) situation of GBM patients of their primary caregivers, we tried to assess the impact of glioblastoma on patients and their families. We found that GBM long-term survivors (LTS) were mainly independent in their activities of daily living and mostly also in instrumental activities of

daily living, but showed some moderate cognitive deficits and suffered from financial difficulties. Only a minority of GBM LTS was able to stay in their respective jobs. Even with adolescent and young adult (AYA) patients diagnosed with GBM before 40 years only 1/3 succeeded in staying employed after the diagnosis of GBM. Near half of the AYA patients returned to the household of their parents, which reflects their loss of independence. Moreover, we found that patients with GBM present a significant loss of strength in the proximal musculature of the legs, impairing their ability of climbing stairs and walking very early in the disease course. The complex patterns of physical, neurological, and cognitive impairments in GBM cause their needs for support starting very early in the disease. Family

members become caregivers and are confronted with challenging life-changing situations. Thus, it is not surprising that family caregivers feel overstrained. We found that families with lower incomes and lower education levels showed higher distress levels as well as less satisfaction with the care of the patient, EOL care, and a worse bereavement adjustment. As a conclusion, in studies focusing on QOL and socio-economic impact of GBM we found an unmet need for support and information of patients and their caregivers. **Eur Assoc NeuroOncol Mag 2013; 3 (2): 46–8.**

Key words: glioblastoma, caregiver burden, socioeconomic aspects, financial difficulties, end-of-life phase, working situation

■ Introduction

As glioblastoma multiforme (GBM) is to date not curable despite resection, concomitant radio/chemotherapy, and adjuvant chemotherapy, patients are confronted with the scary outlook of a short remaining life span, aggravated by probable cognitive decline and loss of independence. The group of patients living ≥ 3 years after diagnosis is indeed small, but increases since the concomitant and adjuvant therapies with temozolomide have become standard of care and will hopefully further increase due to upcoming – probably personalized – therapeutic options.

■ GBM Long-Term Survivors

We recently published results of 17 GBM long-term survivors (LTS) treated at the Medical University of Vienna [1]. We investigated their cognition, sociodemographic characteristics, and quality of life. Their age ranged from 24–71 years with a median of 51 years. Seven GBM long-term survivors > 60 years were already retired at the time of diagnosis. The remaining 10 men and women had been employed in full-time jobs at the time of diagnosis. Noticeably, only 4 LTS were able to keep their jobs and thus maintain their income after diagnosis and therapy. They worked as actress, office clerks, and self-employed custodial worker. The remaining 6 pa-

tients, who were employed before being diagnosed with GBM, received disability benefits due to inability to continue working because of their disease.

Neurocognitive deficits in brain tumour patients have been shown to be associated with negative outcomes in a previous study and are unfortunately common [2]. We used the computer software NeuroCog FX for neurocognitive testing, a tool developed in Germany for patients with neurological deficits [3]. Analysis showed “conspicuous” results in 23 % of the patients, “borderline” results in 18 %, and “normal” summary values in 59 % of the patients. All patients who were still employed showed normal cognition. Interestingly, we measured a trend in cognitive functions, favouring the GBM patients with > 5 years survival after diagnosis. This is in contrast to older studies in which late toxicities of brain radiotherapy have been described [4] and supports the findings in the review of Armstrong et al [5] who reported that the late-delayed effects of radiation in cases of partial brain radiotherapy appear to be limited.

The quality-of-life analysis of GBM LTS showed no reduction in global health score compared to the reference values, but reduced scores in social and cognitive functioning. Unexpectedly, the highest difference between GBM LTS and the reference population was measured in the item “financial difficulties”. Seven patients (41 %) stated financial problems due to their cancer disease. Moreover, financial difficulties correlated significantly with uncertainty about the future.

■ Financial Aspects

After diagnosis of a malignant disease, when a person is unable to work for a prolonged time, the health care systems in Western Europe usually provide sick pay consisting of a high percentage of the last salary, but – at least in Austria – it is lim-

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ited to the duration of one year. So patients with jobs where tips or provisions are regular parts of their monthly income suffer greater losses in their incomes than other professions. Moreover, after the respective maximal duration of sick leave, patients either have to return to work or apply for disability benefit. In many European countries including Austria, disability benefit is calculated according to an algorithm based on the last income and the number of working years, therefore lower for younger patients. Opportunities for support from social authorities are mostly available but application procedures may be troubling and humiliating for GBM patients and often beyond their cognitive and emotional capacities. Mainly GBM patients dependent on disability pensions complained about disease-related financial problems.

Finally, in “unprotected” working situations, it is unfortunately not surprising that most GBM patients lose their jobs. Frequent sick leaves during the first weeks of treatment, followed by fatigue and eventual neurocognitive deficits developing later in the disease course, as well as prejudices against patients with brain diseases by employers and workmates preclude their ability of remaining in their original employments. People with brain tumours are at risk of seizures and thus not allowed to drive professionally, to handle big machinery, or doing shift-work. Moreover, their need for breaks is also perceived as debilitating and thus not tolerable in many real-life working situations. In general, employers will prefer “healthy” applicants and patients with GBM get *a priori* the short end of the stick.

■ Adult Young and Adolescent Patients with GBM

Leibetseder et al recently published a study about 47 adolescent and young adult GBM patients aged < 40 years [6]. Of note, about half of these young patients with malignant brain cancer were not able to manage and support their routine daily life independently in their own home. They returned to the households of their parents, mostly into their old nurseries. This alarming number illustrates the high rate of loss of independence in this group of patients. 57 % of AYA patients with GBM lost their jobs within the first 2 months after diagnosis. Only self-employed people or persons working in family businesses or in large enterprises in administrative jobs or on computers were able to stay employed. Patients from other occupational groups, mainly craftsmen like butchers, car mechanics, photographers, shoemakers, clerks, fitters and, noticeably, all health care workers, including physicians and midwives, and all teachers lost their jobs due to their disease a few weeks after diagnosis. None of the patients surviving in good performance status for several years were able to return to employment after GBM diagnosis.

■ Loss of Muscular Strength

It is well-known that glioblastoma leads to a decrease in muscular strength due to neuromuscular dysfunction caused by the tumour itself and due to corticoid treatment which is required to decrease intracranial pressure. Although steroids are generally tapered off as soon as possible after neurosurgical intervention, Keilani et al [7] recently described significant

deficits in muscular strength and general physical performance in Austrian GBM patients. The loss of strength of the proximal muscles of the legs needed for walking was measured before the start of radio/chemotherapy and did not improve after 3 months.

Another adverse feature of brain tumours is that the resection scar and hair-loss resulting from radiotherapy are plainly visible. In addition, many patients gain weight and develop Cushingoid signs, which change their appearance – this might also unsettle persons in their working environment. It can be assumed that such cosmetic aspects are further disadvantages for patients with brain tumours looking for a job.

■ Family Caregivers

To compensate for the loss of income experienced by GBM patients, partners or other family members are forced to keep their jobs and incomes. As if this were not challenging enough, they experience a changing role. They become caregivers. This begins very early in the course of the disease. After a recovery phase *post* surgery, the logistic demands for daily transports to radio- and/or chemotherapy visits have to be organized. Kumthekar et al recently showed that the financial burden of families of GBM patients was much higher than in families with breast cancer or lymphoma patients [8]. Moreover, the patients’ work shares in household, garden, in the family as well as financial aspects have to be considered and managed. Family members are forced during this hard time not only to cope with the disease of their loved ones but also to keep their lives going. This is already hard in early stages of the patients’ disease but probably more challenging later, when patients develop dependencies due to neurological and neurocognitive deficits and require permanent assistance.

■ End-of-Life Phase

Sizoo et al [9] conducted a retrospective study in The Netherlands, evaluating a specially developed questionnaire for treating physicians and relatives of deceased high-grade glioma patients. They highlighted the importance of a timely discussion of end-of-life issues to reduce the patients’ and their caregivers’ burden.

Our study, performed at 2 centres in Vienna, supports this conclusion. We evaluated retrospectively the perspective of family caregivers of patients with GBM on the EOL phase defined as the last 3 months before death [10]. We used a questionnaire for the caregivers developed and validated by the working group of Taphoorn et al (Medical University of Amsterdam). Family caregivers of 52 patients with GBM, diagnosed from 2005–2009 and treated in Vienna, participated in this study. As assumed, caregivers indicated that the GBM patients suffered from fatigue, reduced consciousness, aphasia, and various neurological deficits during the EOL phase, which is different from the EOL phase of patients with other cancers. Moreover, partners or family members who cared for them went through a hard phase. Sadness, fear, and an alarmingly high percentage of overstraining were reported by the majority of caregivers, which reflects the excessive mental and physical demands on them. Moreover, family caregivers

also mentioned financial difficulties due to the patients' GBM. Caregivers who mentioned financial difficulties were also those who complained about insufficient information on the disease and about overstraining. However, Pace et al [11] showed in their impressive Italian study that a satisfying end-of-life period for both, patients and caregivers, is possible by supporting them at home with a mobile palliative team.

Gaiger recently presented a survey in 4000 cancer patients treated at the Medical University of Vienna [12]. Interestingly, patients with lower incomes showed significantly higher distress levels while patients with higher incomes more frequently underwent psychological counselling. Similar remarkable results were seen in their education levels. Patients with lower education levels showed higher distress levels but mentioned significantly less often the need for support.

Conclusion

Our results show that GBM patients and their caregivers have unmet needs regarding the socioeconomic impact of GBM on their lives. This starts with more practical information regarding the disease, different topics such as physical training, working situation, financial challenge, and social support possibilities. Particularly, GBM patients and families who are at risk of financial difficulties should be offered support to decrease their burden. Maybe early oncologic rehabilitation might help GBM patients to keep their jobs and lives running,

thereby maintaining the patients' and their family members' quality of life.

Conflict of Interest

Both authors declare that there is no conflict of interest.

References:

1. Flechl B, Ackerl M, Sax C, et al. Neuro-cognitive and sociodemographic functioning of glioblastoma long-term survivors. *J Neurooncol* 2012; 109: 331–9.
2. Taphoorn MJ, Klein M. Cognitive deficits in adult patients with brain tumours. *Lancet Neurol* 2004; 3: 159–68.
3. Hoppe C, Fließbach K, Schlegel U, et al. NeuroCog FX: computerized screening of cognitive functions in patients with epilepsy. *Epilepsy Behav* 2009; 16: 298–310.
4. Crossen JR, Garwood D, Glatstein E, et al. Neurobehavioral sequelae of cranial irradiation in adults: a review of radiation-induced encephalopathy. *J Clin Oncol* 1994; 12: 627–42.
5. Armstrong CL, Gyato K, Awadalla AW, et al. A critical review of the clinical effects of therapeutic irradiation damage to the brain: the roots of controversy. *Neuropsychol Rev* 2004; 14: 65–86.
6. Leibetseder A, Ackerl M, Flechl B, et al. Outcome and molecular characteristics of adolescent and young adult patients with newly diagnosed primary glioblastoma: a study of the Society of Austrian Neurooncology (SANO). *Neuro Oncol* 2013; 15: 112–21.
7. Keilani M, Krall C, Marosi C, et al. Strength of skeletal muscle and self-reported physical performance in Austrian glioblastoma-patients. *Wien Klin Wochenschr* 2012; 124: 377–83.
8. Kumthekar PU, Grimm S, Jacobs DI, et al. Financial burden experienced by patients undergoing treatment for malignant glioma: final data. Oral Presentation: 10th EANO Congress, Marseille, France, September 6–9, 2012.
9. Sizoo EM, Pasman HR, Buttollo J, et al. Decision-making in the end-of-life phase of high-grade glioma patients. *Eur J Cancer* 2012; 48: 226–32.
10. Flechl B, Ackerl M, Sax C, et al. The caregivers' perspective on the end-of-life phase of glioblastoma patients. Abstract: ESMO Congress 2012, Vienna, Austria.
11. Pace A, Lorenzo CD, Guariglia L, et al. End of life issues in brain tumour patients. *J Neurooncol* 2009; 91: 39–43.
12. Gaiger A, Acel A, Cenic O, et al. The Cancer Survival Index – a prognostic score integrating psychosocial and biological factors in patients diagnosed with cancer. *N Engl J Med* (submitted for publication).