



## **ESMO Palliative Care Fellowship** (Jan 2016 – Mar 2016)

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### **FINAL REPORT**

Home Institute: Medical Oncology University Hospital Basel

Host Institute: Dr. Senckenbergisches Institut für Neuroonkologie

#### **Introduction**

Glioblastoma (GBM) is the most common and aggressive malignant brain tumor in adults [1]. In contrast to other malignant diseases, patients and partners are not only confronted with drastically shortened life expectancy but also intellectual and emotional changes as well as rapid physical decline [2-4]. This imposes profound chronic distress on patients and their social networks [5-7]. However, the impact of bio-behavioral stress on GBM prognosis is unknown. Furthermore, the role of stress-modulating factors, such as physical activity and stress-flow within patient-partner dyads, have never been systematically and longitudinally assessed [8,9]. Therefore, we initiated a clinical trial focusing on the analysis of stress and stress-modulating factors in patients suffering from GBM and in a close partner, entitled „Stress, exercise behavior and survival in patients with newly diagnosed glioblastoma and in a close partner (TOGETHER-study):a prospective multicenter cohort study." The study results will help to define targets for future multi professional palliative care interventions in both patients and partners suffering from one of the most aggressive malignant diseases. The trial is currently running in 4 centers in Switzerland (study registrationclinicaltrial.gov and kofam.ch: NCT02129335). Recruitment of patients and partners in this investigator-initiated study with is challenging and requires qualified and motivated study teams that are following enrollment and patient/partner supervision. We therefore planned to connect with a dedicated Centre in Germany to first, open the TOGETHER study there, to improve study recruitment and second, to exchange centre-based strategies to improved individual and patient-centered cared palliative care in GBM patients. For this purpose, the Dr. Senckenbergisches Institute of Neurooncology, Frankfurt/Germany was chosen the host institute for my fellowship.

#### **Goals or aims**

**Aims of the TOGETHER study** The general aim of this prospective, multicenter observational cohort study is to determine the impact of baseline bio-behavioral stress (Aim I) on cancer progression and survival in patients with newly diagnosed GBM undergoing standard radio chemotherapy. The role of baseline physical activity and baseline partner's distress as stress-modulating factors will be assessed in an



exploratory analysis. A secondary aim is the longitudinal assessment of self-reported psychological distress in this homogenous patient cohort and in their partners (Aim II). In a translational subproject, we aim at determining the role of serum copeptin as a biomarker for distress (Aim III). Aims of the ESMO palliative care research fellowship were- to establish the TOGETHER study at the "Dr. Senckenberg Institute für Neuroonkologie" at the University Hospital Frankfurt, Germany to increase patient and partner recruitment and study power- to build up a collaborative network between host and home institutions that will support future research focus on patient-centered outcome questions in neurooncology- to help establish and improve complex palliative care for neurooncology patients in the home clinic that strengthen the gateway Palliative Care/Medical Oncology

### **Description of the time spent at host institute**

My fellowship was planned for three months and started in January 2016 at the Dr. Senckenbergisches Institute for Neurooncology in Frankfurt/Main, Germany. I was warmly welcomed and immediately integrated in the clinic and team around Prof. Joachim Steinbach. I had the chance to attend the outpatient clinic, where I saw patients that came for planning, treatment and follow up of various brain tumors. Patients came from Frankfurt and the surrounding area but also from far distances and I learned about the different strategies in planning specialized palliative and patient-centered care depending on regional differences of available resources. I observed and discussed different examination and communication strategies. Additionally, I had the chance to visit the in-patient clinic, where I attended the communication of the physicians with patients and relatives at admission or after diagnostic procedures. Furthermore, I attended the neurooncology tumor board and discussed standard operating procedures for glioma patients with Prof. Steinbach and his team. This was a very good experience for me, as there are no standard treatment recommendations for second line treatment strategies for GBM. Moreover, no standardized palliative care strategy for GBM patients does exist. I also visited the palliative care unit, headed by Dr. Christiane Gog of the University Hospital Frankfurt. There, the majority of hospitalized patients suffer from cancer. Patients were mainly hospitalized together with family members and the relationship of interaction was a mix of patient- and relative-centered information with information of a multidisciplinary team (mainly involved were nurses, psych oncologists, physicians, spiritual caregivers and social workers). This was a great learning experience. I already experienced complex family communications, but I never attended multidisciplinary communication settings. I spent one day with Dr. Nina Ransburg for psych oncology councils and attended complex conversations about fears and illness-related sadness. As I never had the chance to follow on these specialized dialogues, I was impressed and surprised mainly on the improvements patients and relatives can feel during a guided opening on their concerns and emotions. I am very grateful, that I was allowed to attend these sensitive and private openings. In the second block of my fellowship, I worked on implementing the TOGETHER study at the site Frankfurt. I prepared the ethics package, study kits and instructed the responsible physician-investigator Dr. Martin Voss and study nurse Clarissa Schaumburg-Bähr in TOGETHER study aims and procedures. Both helped me with a tremendous engagement in the study set up and we managed to open the trial for accrual by the end of the fellowship. Inclusion criteria for patients are: age  $\geq 18$  years; a Karnofsky Performance Score  $\geq 50$  %; a histologically confirmed, previously untreated GBM, planned radio chemotherapy according to Stupp; no cardiovascular or neurological



contraindications for 6-Minute-Walking-Test. Inclusion criteria for partners are: age  $\geq$  18 years; spouse or partner living in the same home as the patient or closest contact as named by the patient (1-2h 5 days a week). Exclusion criteria for patients are any other disease or chronic treatment that interferes with the

adequate measurement of the stress axis, severe, medically treated psychiatric disorder prior to the diagnosis of glioblastoma, participation in a study with investigational drugs except for patients receiving the standard treatment (control group) who are eligible, severe asthma or known allergy against tetracosacid (Synacthen®), pregnancy or breast feeding, unable to follow the procedures of the study, e.g. due to language problems, psychological disorders, neurologic deficits that interfere with the planned walking tests, dementia or confused state. Exclusion criteria for partners are any individuals who have any disease, either metabolic or psychological, that interferes with the adequate measurement of the stress axis, pregnancy or breast feeding and the inability to follow the procedures of the study, e.g. due to language problems, psychological disorders, dementia or confused state.

## Conclusion

The ESMO palliative care fellowship was one of the most exciting experiences in my working practice. First, I improved my knowledge in neurooncology, palliative care and psych oncology in general. Secondly, I follow up on the TOGETHER study, to professionalize study procedures and set up the study at a center with high quality to further improve recruitment rate and study outcome.

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