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The end-of-life phase of high-grade glioma patients

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6.1 Summary

Patients with high-grade glioma (HGG), the most frequently occurring and most malignant primary brain tumour, have a poor prognosis. Despite intensive treatment with surgery, radiotherapy and chemotherapy, patients cannot be cured. Hence, throughout the disease process, the goal of treatment shifts from primarily life-prolongation to primarily quality of life. For all patients inevitably the moment will come when the disease progresses and life-prolonging tumour treatment is no longer an option. At this moment, the end-of-life (EOL) phase begins. At the start of this research project, little was known about this EOL phase in HGG. In the studies described in this thesis, we explored what happens to HGG patients after ending tumour treatment.

In Chapter 1.2 we present a systematic overview of current (until April 2012) knowledge on the EOL phase of HGG patients with respect to symptoms and signs, quality of life and quality of dying, caregiver burden, organization and location of palliative care, supportive treatment and EOL decision-making. In the past few years, the EOL phase of HGG patients is receiving increasing attention. Nevertheless, nearly all studies concerning the EOL phase of HGG patients were observational and there is a lack of high-quality intervention studies. Furthermore, an important conclusion that can be drawn from our overview is that the EOL phase of HGG patients is different from other cancerpatients.

In the following chapters, we largely report on original data collected in two types of studies. First, a *chart review* in which we examined the files of 55 HGG patients who maintained contact on a regular basis with the clinical nurse specialist in neuro-oncology after ending tumour-directed treatment. The clinical nurse specialist used a checklist, systematically asking for specific symptoms and signs. Second, a *retrospective cohort study* in which we identified a cohort of HGG patients diagnosed with HGG in 2005 and 2006 in three Dutch tertiary referral centres for neuro-oncology. In 2009, we approached physicians and relatives of deceased patients from this cohort and invited them to fill in a questionnaire about the EOL phase of the specific patient.

Chapter 2 focuses on symptoms and signs of patients in the EOL phase. In chapter 2.1 we report on the above mentioned chart review. Common symptoms after ending tumour-directed treatment were progressive neurological deficit, incontinence, progressive cognitive deficit, and headache. Loss of consciousness and difficulty with swallowing occurred in particular in the week before death. Nearly half of the patients in the EOL phase, and one third of the patients in the week before dying, had seizures. Given the high prevalence of seizures found in this pilot study, we further report on seizure prevalence in chapter 2.2, using data collected in our cohort study (physician data). Next to providing descriptive statistics on seizure prevalence, we aimed to identify predictors for the development of seizures in the last week of life. We report on 92 patients, of whom 29% had seizures in the last week before death. A history of status epilepticus was the only significant predictor we

identified. AEDs were reported to be frequently tapered before death. We conclude that AED treatment throughout the EOL phase warrants improvement.

Chapter 3 focuses on the quality of life in HGG patients. In chapter 3.1, we review the current knowledge on the quality of life in HGG patients. In particular, we focus on the concept of health-related quality of life (HRQoL) and available instruments to measure this outcome. Since all available instruments to measure HRQoL in HGG patients are patient-reported outcomes to be used in prospective studies, we developed a proxy-reported questionnaire to measure HRQoL of HGG patients in the EOL phase in retrospect. In chapter 3.2 we describe the development and first validation of this questionnaire. The content validity was found to be adequate and the internal consistency of the multi-item scales varied from reasonable to good. Furthermore, we report on the patient's HRQoL in the EOL phase, which was poor and deteriorated over time. While the symptom burden increased towards death, a concomitant decrease was observed for cognitive, physical, social and psychological functioning.

In chapter 4, we describe the EOL decision-making process in HGG patients from both the physician's and relatives' perspective. We found that more than half of the patients became incompetent to make decisions relatively early, due to delirium, cognitive deficits and / or decreasing consciousness. Nearly all patients were prepared to discuss EOL decision-making, which is in contrast to the fact that the patients' preferences towards EOL treatment and decisions were frequently unknown to the physician. We suggest that given the high occurrence of incompetent patients close before death, patients' preferences regarding the EOL should be discussed timely..

Chapter 5 focuses on dying with dignity, a relatively new outcome measure emerging as an overarching goal of palliative care. The majority of HGG patients in our cohort died with dignity (75%) according to their relatives. Multivariate analysis identified satisfaction with the physician, the ability to communicate, and the absence of transitions between health care settings as most predictive for a dignified death. Since communication deficits increase towards death, we recommend physicians caring for HGG patients to explain possible treatment options and preferences in an early stage. If at all possible, patients should die at their preferred place of death, and undesirable transitions between health care settings at the EOL should be avoided.