Towards improving health-related quality of life in glioma patients and their informal caregivers
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Brain tumors

Primary malignant brain tumors originate from the brain tissue itself. The most common primary malignant brain tumors are gliomas, with an incidence of 5.9 per 100,000 individuals. This means that in the Netherlands, approximately 1000 individuals are confronted with this diagnosis annually.

Treatment decisions and prognosis are primarily based on the malignancy grade of the tumor. Patients diagnosed with a World Health Organization (WHO) grade I glioma may be cured after surgical intervention. WHO grade II gliomas are generally slow-growing and have infiltrative properties. These tumors almost always recur after treatment and can eventually evolve into a higher grade glioma. Anaplastic gliomas (WHO grade III) and glioblastomas (WHO grade IV) are generally rapidly progressive tumors and are typically associated with a poor prognosis. Despite efforts in improving the treatment of gliomas, the median survival of patients suffering from a low-grade glioma is 5-15 years, while patients with a grade III tumor have a median survival of 2-3 years. For patients with grade IV tumors, the median survival does not exceed 12-14 months.

The treatment usually consists of a combination of surgery, radiotherapy and chemotherapy. In making treatment decisions, any benefit from these treatment modalities should be weighed against the expected HRQOL and symptom burden of patients.

Symptoms and problems

As a result of the diagnosis and prognosis, glioma patients can experience psychological distress. In addition, gliomas often give rise to a variety of neurological and cognitive symptoms. Depending on the location of the tumor and the side-effects of treatment, patients can have function loss as a result of paresis or paralysis, other motor dysfunction, problems with speech, sensory loss, and visual-perceptual deficits. Cognitive deficits such as problems with memory or concentration are present in a large number of glioma patients, but more specific (focal) cognitive disturbances may also occur. In addition, fatigue, depression and changes in personality and behavior are frequently reported. These symptoms can affect the lives of both patients and their significant others to a great extent, influencing the quality of both their lives.

Informal caregivers

Throughout the disease trajectory, the symptoms and problems described above may cause patients to rely more on their immediate environment for care and support. Consequently, spouses, family members or close friends often have to take on a new role as the primary informal caregiver, providing daily emotional and/or physical support. This caregiving role may invoke positive sentiments, such as a feeling of privilege or satisfaction, but it can also cause substantial burden and stress. In the literature, the nomenclature used to describe these caregivers varies from ‘caregiver’, to ‘informal caregiver’, ‘family caregiver’ or ‘neuro-oncology caregiver’. In this dissertation, we will use ‘informal caregiver’ to clearly distinguish between professional caregivers (e.g. treating physicians, nurses) and those performing their role informally. 

FREQUENTLY USED CONCEPTS IN THIS DISSERTATION

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Frequently used concepts in this dissertation

1.2

caregiving activities without financial compensation. In addition, if we did not explicitly select participating spouses, family members or close friends based on their caregiving activities, the term ‘significant others’ will be used to describe the patients’ loved ones.

Health-related quality of life

Quality of life is a multi-dimensional concept that is by definition self-reported, and therefore subjective in nature. In fact, its very definition is subject of discussion, although the WHO has made efforts to provide a fairly univocal description. The WHO defines quality of life as ‘a person’s perception of their physical, cognitive, and affective state, as well as their perception of their interpersonal relationships and social roles’. Here, a distinction has to be made between quality of life and health-related quality of life (HRQOL), the latter being related to the impact of health or illness specifically. However, these concepts are often used interchangeably in the literature, which can complicate interpretation. Throughout this dissertation, we will refer to HRQOL consistently as we use instruments designed to measure HRQOL. Instruments assessing HRQOL can be divided into generic or disease-specific instruments. The generic instruments are highly useful to compare HRQOL across different study populations, whereas disease-specific instruments include items assessing symptoms and concerns that are characteristic of certain diagnostic groups. For the brain tumor patient population, valid and reliable instruments assessing HRQOL are readily available. In clinical trials aimed at improving survival of glioma patients, there is a growing trend towards the measurement and preservation of HRQOL as an important outcome, with the benefits of any form of tumor directed treatment being weighed against the possible harm to patients’ wellbeing.