1.3 AIMS AND OUTLINE OF THIS DISSERTATION

The general aim of this dissertation is to work towards an improvement in HRQOL for both glioma patients and their informal caregivers. First, a review is presented to obtain an overview of the impact of symptoms of fatigue, cognitive deficits, depression and changes in personality and behavior on the everyday lives of patients and their significant others in chapter 1.4. Here, methods to improve supportive care provision in clinical practice are first introduced.

In the following chapters, the various aspects of HRQOL in patients (Section 2 – chapters 2.1 to 2.4) and their significant others (Section 3 – chapters 3.1 and 3.2) are illustrated and discussed.

Section 2: Towards improving health-related quality of life in glioma patients

The specific research questions addressed in this dissertation, focusing on patients are: 1) Are cognitive functioning and HRQOL associated?; 2) Is HRQOL compromised in patients with long-term stable disease?; 3) Can interventions reduce symptom burden and improve HRQOL?

Through observational and intervention studies, Section 2 focuses on tumor and treatment-related symptoms and HRQOL of glioma patients. After the diagnosis and initial treatment, most patients aim at participating in social and vocational activities to their best abilities. This effort may be hindered by the disease-specific symptoms that patients experience which can persist throughout periods of stable disease and may negatively affect their HRQOL.

The associations between cognitive functioning and HRQOL in low-grade glioma patients with stable disease are investigated (chapter 2.1), as well as the possible change in HRQOL in stable, long-term survivors of a low-grade glioma over time (chapter 2.2). In chapter 2.3, the effects of modafinil on brain tumor patients’ symptoms of fatigue, cognitive deficits, and mood, as investigated in a randomized placebo-controlled trial are described. Efforts in reducing symptom burden are still ongoing, and the design of a randomized controlled trial to reduce depressive symptoms and improve HRQOL in glioma patients through an online problem-solving therapy is described in chapter 2.4.

Section 3: Towards improving health-related quality of life in informal caregivers of glioma patients

The specific research questions addressed in this dissertation, focusing on significant others are: 1) Is there HRQOL compromise in significant others of glioma patients?; and 2) Can a psychological intervention be helpful in improving informal caregivers’ HRQOL?

Section 3 focuses on HRQOL issues in informal caregivers of glioma patients. As a result of the burden of caregiving, many informal caregivers experience psychological distress, which can contribute to a compromised HRQOL.

In a cross-sectional study, HRQOL of significant others of glioma patients is compared to HRQOL of significant others of patients with other malignancies that do not involve the central nervous system, but are comparable in terms of prognosis and the impact of the disease on daily life (non-small cell lung cancer and hematological malignancies; chapter 3.1).
Subsequently, in order to improve HRQOL and feelings of mastery (i.e. the combined effects of the informal caregiver’s self-perception and actual ability to successfully perform the activities of providing care), a psychological intervention was developed. The effectiveness of this intervention on feelings of mastery and HRQOL in informal caregivers of glioma patients is tested in a randomized controlled trial (chapter 3.2).

1.3 Section 4: Summary, general discussion and conclusions

In Section 4, a general summary is provided (chapter 4.1), followed by a discussion on the main findings of this dissertation (chapter 4.2). In chapter 4.3 the methodological limitations are discussed. Finally, recommendations for clinical practice and future research are provided (chapter 4.4).