Towards improving health-related quality of life in glioma patients and their informal caregivers
Boele, F.W.

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FUTURE PROSPECTS AND CONCLUSIONS

Below, recommendations for both clinical practice and future research are provided, as well as general conclusions from this dissertation.

Clinical implications

The studies described in this dissertation have contributed to a better understanding of the HRQOL issues of glioma patients and their informal caregivers. From the observational studies we now know that cognitive functioning and HRQOL are highly correlated in stable LGG patients, and that throughout long periods of stable disease, specific limitations in HRQOL may persist. Moreover, significant others of HGG patients in the acute disease phase were identified as having vulnerable HRQOL. In addition, a start was made to improve HRQOL in both glioma patients and their informal caregivers through intervention studies.

This knowledge is valuable in clinical practice, as it emphasizes that attention should be paid to HRQOL of both glioma patients and their informal caregivers throughout the disease trajectory. The findings from studies described in this dissertation suggest that it would be valuable to routinely screen both patients and informal caregivers for HRQOL issues and distress, as well as the wish for supportive care, to identify patients or caregivers with unmet needs for supportive care. Tailored advice and referral to health care services, including self-management tools and self-help interventions can then be provided as necessary.

Recommendations for further research

In order to accurately monitor HRQOL and supportive care needs, it is important to further clarify the concept of meaningful change in HRQOL in both neuro-oncology patient and informal caregiver populations. Moreover, obtaining knowledge on what constitutes a meaningful change can aid the interpretation of outcomes in clinical studies. Physicians, patients and family caregivers can then make better informed decisions on treatment options.

In addition, the potentially complex relationships between HRQOL, fatigue, cognitive deficits, depression, changes in personality and behavior, and caregiver burden require further research. Incorporating longitudinal measures in samples representative of the entire glioma patient or informal caregiver population is therefore recommended. Obtaining knowledge on the relationships between these variables can facilitate the design of, and increase the effectiveness of interventions targeted at improving any of these outcomes. Developing new interventions is important, but obtaining scientific evidence for the effectiveness of existing interventions that aim to improve HRQOL or decrease symptom burden deserves more attention in the neuro-oncology patient and informal caregiver setting as well. When initiating intervention studies for either glioma patients or informal caregivers, it is important to first perform a pilot study. This will provide insight into the prevalence and magnitude of the problems experienced by patients or informal caregivers, the experienced need for an intervention, and the barriers to and facilitators of participation.
General conclusions

To conclude, the observational studies that are included in this dissertation have contributed to a better understanding of HRQOL in glioma patients and their informal caregivers. However, the potentially complex relationships between HRQOL and (factors influencing) symptom or caregiver burden require further research. In three randomized controlled trials, attempts were made to improve HRQOL by targeting symptoms of fatigue, depression, or caregiver mastery, respectively. These studies have contributed to the advancement of evidence-based supportive care for the neuro-oncology patient and caregiver population. However, more research in this area is necessary and here, identifying barriers to and facilitators of patient and caregiver participation and retention is essential. In clinical practice, monitoring supportive care needs and referring to health care specialists as necessary seems worthwhile. These efforts are expected to benefit glioma patients and their informal caregivers, because they may provide some relief of the mental and physical consequences of living with a life-threatening disease.