Health-related quality of life in high-grade glioma patients and their partners in the end-of-life phase: a retrospective multi-centre analysis

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Exploring and documenting the end-of-life phase in HGG patients: duration; residence (at home, nursing home, hospice, hospital); transfers between care settings, medical problems; palliative treatment/care; end-of-life decisions and cause of death...

Ethical review	Approved WMO
Status	Recruiting
Health condition type	Nervous system neoplasms malignant and unspecified NEC
Study type	Observational non invasive

Summary

ID

NL-OMON32132

Source
ToetsingOnline

Brief title
HRQOL in the end-of-life phase of HGG patients

Condition

- Nervous system neoplasms malignant and unspecified NEC
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Synonym
malignant brain tumour, malignant glioma

Research involving
Human

Sponsors and support

Primary sponsor: Vrije Universiteit Medisch Centrum
Source(s) of monetary or material Support: St. Jacobusstichting Den Haag

Intervention

Keyword: End of life, High Grade Glioma, HRQOL, Palliative care

Outcome measures

Primary outcome

Clinical data from medical records in the corresponding hospitals; data from medical records of primary care physicians. Data from questionnaires sent to general practitioners, relatives and other caregivers. Data collected from interviews with relatives of HGG patients, general practitioners, and other caregivers.

Secondary outcome

The information about the end-of-life phase in HGG patients and potential shortcomings obtained in this pilot study, will be used to design a prospective, nation-wide study in the future in which we attempt to improve the end-of-life care for the patients and their relatives.
Data obtained can also be translated into improved guidelines for the caregivers of HGG patients.

Study description

Background summary

Patients with high-grade gliomas (HGG) have a dismal prognosis and cannot be cured of their disease. Following surgery, radiation therapy and chemotherapy they will eventually die from tumour progression. Although there is a growing

interest for the patient*s health-related quality of life (HRQOL) before and during tumour treatment, little is known of the end-of-life phase of these patients. It is anticipated that patients will suffer from neurological and cognitive deficits, personality changes, epilepsy, side-effects of medication, and/or fatigue and depression, and that these symptoms will also have a large impact on HRQOL of their partners/proxies. Enhancing the HRQOL of both patients in the end-of-life phase and their partners is of importance. Improvement of both (the organization of) medical care, counselling of the patient and the partner/proxy, and education of caregivers may be relevant issues in this respect.

Study objective

Exploring and documenting the end-of-life phase in HGG patients: duration; residence (at home, nursing home, hospice, hospital); transfers between care settings, medical problems; palliative treatment/care; end-of-life decisions and cause of death on the basis of (a) data from medical files; (b) questionnaires to general practitioners and other professional caregivers, and relatives of deceased HGG patients; (c) structured interviews in a selection of general practitioners, other professional care-givers, and partners/proxies of deceased HGG patients on encountered medical problems, HRQOL and needs of HGG patients and their partners/proxies as well as on the organization of care for these patients

Study design

Multi-centre retrospective descriptive study.

Study burden and risks

HGG patients themselves are not involved directly in this study. For their relatives, there may be an emotional burden by interviewing them on the medical experiences of their loved one, HRQOL and needs of the relatives. There is a chance of emotional distress caused by the interview. According to the relative*s wish, the interview may be done either at home or at the outpatient clinic. For the caregivers who are interviewed, the main burden will be an investment of time. Future patients and their relatives may benefit from this study, the same holds true for their caregivers. In our view, the burden associated with participation is proportionate to the potential value of the research for future HGG patients, their relatives and caregivers.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

relatives of deceased high grade glioma patients >18 yrs at time of diagnosis, diagnosed in 2005 and 2006

Exclusion criteria

all patients who did not (yet) die or whose dead was not retraceable

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Health services research

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	27-10-2008
Enrollment:	200
Type:	Actual

Ethics review

Approved WMO

Date:	08-09-2008
Application type:	First submission
Review commission:	METC Amsterdam UMC

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
CCMO	NL23655.029.08