EUROPEAN JOURNAL OF CANCER 48 (2012) 226–232

ELSEVIER

Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com

Decision-making in the end-of-life phase of high-grade glioma patients

Eefje M. Sizoo [a,*], *H. Roeline W. Pasman* [b], *Janine Buttolo* [a], *Jan J. Heimans* [a], *Martin Klein* [c], *Luc Deliens* [b,d], *Jaap C. Reijneveld* [a,e], *Martin J.B. Taphoorn* [a,f]

[a] *Department of Neurology, VU University Medical Centre, Amsterdam, The Netherlands*

[b] *Department of Public and Occupational Health and the EMGO Institute for Health and Care Research, VU University Medical Centre, Amsterdam, The Netherlands*

[c] *Department of Medical Psychology, VU University Medical Centre, Amsterdam, The Netherlands*

[d] *End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium*

[e] *Department of Neurology, Academic Medical Centre, Amsterdam, The Netherlands*

[f] *Department of Neurology, Medical Centre Haaglanden, The Hague, The Netherlands*

ARTICLE INFO

Article history:
Available online 5 December 2011

Keywords:
End-of-life
Gliomas
Decision-making
Competence
Palliative care
Neuro-oncology

ABSTRACT

Background: During the disease course of high-grade glioma (HGG) patients, the goal of therapy eventually shifts from primarily life-prolongation to primarily sustaining the quality of life as good as possible. End-of-life care is aimed at prolongation of life with good quality, but inevitably also may require medical decisions for prevention and relief of suffering with a potential life shortening effect. Few data are available on this end-of-life decision (ELD) making process in HGG patients, with decreased consciousness, confusion or cognitive deficits preventing them to participate. In this study the ELD-making process in HGG patients is described.

Methods: Physicians and relatives of a cohort of 155 deceased HGG patients were identified to fill in a questionnaire regarding the end-of-life conditions (patients' ELD preferences, patients' competence) and ELD-making (forgoing treatment and the administration of drugs with a potential life-shortening effect) for their patient or relative. Data were analysed with descriptive statistics.

Findings: Of 101 patients, physicians completed surveys including questions about ELDs (62% response rate). More than half of the patients relatively early became incompetent to make decisions due to delirium, cognitive deficits and/or decreasing consciousness. In 40% of patients the physician did not discuss ELD preferences with his/her patient. At least one ELD was made in 72% of patients, most often this comprised the withdrawal of dexamethasone. Palliative sedation was performed in 30% of patients and physician assisted death in 7%.

Interpretation: ELDs are common practises amongst HGG patients, although their preferences towards ELDs are frequently unknown to the physician. Because the majority of patients become incompetent towards death, participation in ELD-making is only possible with advanced care planning. Hence, timely discussion of ELD preferences is encouraged.

© 2011 Elsevier Ltd. All rights reserved.

---

[*] *Corresponding author:* Address: Department of Neurology, VU University Medical Centre, P.O. Box 7057, 1007 MB, Amsterdam, The Netherlands. Tel.: +31 2044 44219; fax: +31 2044 42800.

E-mail address: e.sizoo@vumc.nl (E.M. Sizoo).

0959-8049/$ - see front matter © 2011 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2011.11.010

1. Introduction

High grade gliomas (HGG) are the most frequently occurring primary malignant brain tumours. Despite intensive treatment with surgery, radiotherapy and chemotherapy, patients with HGG cannot be cured from this disease and the prognosis is poor. Median survival ranges from less than one to more than 5 years depending on histological subtype, tumour grade, age and performance status at time of diagnosis.[1,2]

Inevitably, the end-of-life phase will come when tumour directed treatment is no longer possible and the patient's condition declines. During this end-of-life phase, symptom burden will increase and in the end become high. Disease specific symptoms such as focal neurological deficits, headache, epileptic seizures, confusion and cognitive deficits prevail.[3–6] In most patients, intracranial pressure gradually increases towards death resulting in headache and progressive loss of consciousness.[3,5] End-of-life care is aimed at maintaining quality of life as long as possible, but also may require medical end of life decisions (ELDs) for the prevention and relief of suffering: in some instances these decisions may hasten death.

In our definition, ELDs include the withholding or withdrawing of life-prolonging treatment, and the administration of drugs with a potential or certain life-shortening effect. Examples of ELDs in HGG patients are withdrawal of chemotherapy or dexamethasone, withholding artificial food and fluid administration, non-admittance to the hospital or intensive care unit for treatment of infections, and palliative sedation.[7] A large European study revealed that 23–51% of all deaths are preceded by an ELD depending on the cultural and legal background.[8] In the Netherlands 44% of deaths are preceded by an ELD.[9] In some European countries (The Netherlands, Belgium, and Luxemburg), physician-assisted death such as euthanasia or physician-assisted suicide are allowed under strict conditions upon a well considered request.

Until date, little data are available on ELD decision-making in HGG patients. It can be hypothesised that discussing end-of-life issues with HGG patients becomes progressively more difficult during the course of their disease because of cognitive disturbances, confusion and decreasing consciousness.[10] Therefore, it has been suggested that advance care planning (ACP) should be encouraged early in the course of the disease.[10,11]

The aim of this study is to document to what extent HGG patients expressed wishes regarding end-of-life treatment, whether these wishes were lived up to, and to what extent patients were able to participate in ELD-making. In addition, we specifically focused on the patients' competence in cases where euthanasia was discussed, a procedure restricted to fully competent patients. Finally, the nature and frequency of ELDs made in HGG patients are described.

2. Patients and methods

2.1. Subjects

A retrospective descriptive study was performed sending questionnaires to physicians and relatives of deceased HGG patients from a cohort of adult HGG patients diagnosed in 2005 and 2006 in three tertiary referral centres for brain tumour patients (VU University Medical Centre and Academic Medical Centre Amsterdam Amsterdam, Medical Centre Haaglanden The Hague, The Netherlands). The physicians involved in end-of-life care of deceased patients of the cohort were approached for participation in the study. Participating physicians were asked to fill in a questionnaire regarding the end-of-life phase of the specific patient. If more than one physician was involved in end of life care for a specific patient (for example due to a transition in health care setting close before death), all physicians were approached for participation in the study. The closest relative of the deceased patient was identified by the physician who was involved in the end-of-life care or was retrieved from the medical chart. Identified relatives received a letter shortly explaining the aim of the study and were asked to send back a response form either allowing the researchers to further inform and contact him/her or declining any interest in participation. Relatives who allowed to be further informed received a questionnaire about the end-of-life phase of the deceased patient. The study protocol was approved by the Ethics Committee of the three participating hospitals and informed consent was obtained from all participating relatives.

2.2. Development of questionnaires

The questionnaire for physicians was developed using existing questionnaires developed in end-of-life research.[7,9,12] Questions were related to the last 3 months before death, and more specifically to the last week before death. The questionnaire was piloted in interviews with eight physicians: five general practitioners (GP), two nursing home doctors, and one neurologist. We adjusted the questionnaire according to the feedback gained in these interviews.

The questionnaire for relatives was developed along existing questionnaires regarding quality of life and advance care planning.[13,14] The questionnaire was piloted in five relatives with face-to-face interviews (two partners, one parent and two children of the deceased patients). The questionnaire was adjusted according to the feedback gained in these interviews. Questions were related to both the last 3 months and the last week before death.

2.3. Content of the questionnaires

The questionnaire for physicians comprised both open-ended and discrete questions and addressed to whether the physician discussed end-of-life preferences with the patient and what these preferences were; until what moment the patient was competent to decide on care and treatment and – if the patient was incompetent to decide – what the reason for this incompetence was. Furthermore, ELDs were enquired after via four core questions: (1) whether the physician had withheld any life-sustaining treatment, (2) had withdrawn any life-sustaining treatment, (3) had performed palliative sedation (defined as continuous and deep sedated or kept in coma), (4) had carried out euthanasia or physician-assisted–

Download English Version:

https://daneshyari.com/en/article/8446842

Download Persian Version:

https://daneshyari.com/article/8446842

Daneshyari.com