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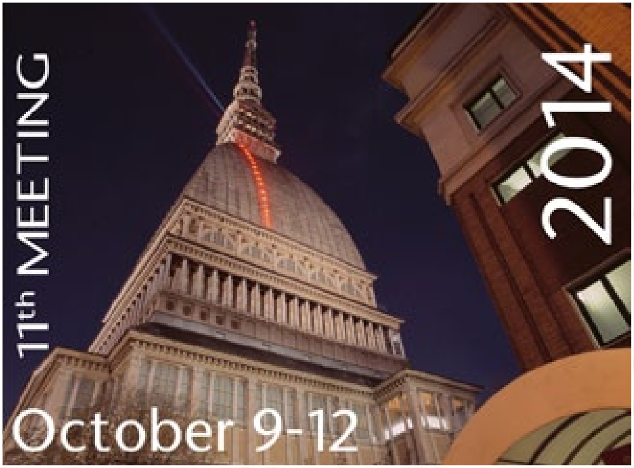

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Ethical Decision-Making in Glioma Patients

Hanneke Zwinkels

Introduction

Caring for patients with brain tumours often includes considering ethical issues and dilemmas. With respect for autonomy of the patient and with respect for relatives, health care professionals try to provide care with the interest of the patient in mind.

Patients with intracranial tumours are asked to make important decisions about their treatment. It is increasingly well-documented that people with intracranial tumours suffer from cognitive impairment. However, should we or do we take this into account when providing information about and seeking consent to treatment?

A study by Kerrigan et al [1], assessing the mental capacity of 100 people with radiologically suspected intracranial tumours to consent to neurosurgery using the MacArthur Competence Assessment Tool for Treatment showed that 25/100 patients with radiologically suspected intracranial tumours did not have the requisite mental capacity to consent to neurosurgery. Neurosurgeons identified incapacity in 13/25 (52 %) people. The authors did not find a relation between symptoms of anxiety or depression and capacity. The conclusion of the study was that mental incapacity is common in people with intracranial tumours and is under-recognised by clinicians seeking informed consent for neuro-oncological treatment. Decisions about treatment are often made in the absence of any objective evidence of cognitive function. They recommended that clinicians should do more to help people understand the nature of their disease and the risks/benefits of treatment and should adopt a more structured approach to confirm understanding.

Case

This case report outlines how the incapacity of the patient to judge and to comprehend her situation as well as the fact that she was at home and at a certain point was denied care by her sisters and home care nurses posed the nurse practitioner neuro-oncology (NP) in an unpleasant position. It was difficult to intervene, working at the outpatient clinic and being the contact person for care in the hospital. Besides, the husband – who was her legal representative – never asked the NP for help. Knowledge of the severe situation from information provided by the patient's sisters, who came to the outpatient clinic for help, led to an ethical dilemma for the NP.

A 42-year-old Dutch woman presented with episodes of flashes in her right visual field of both eyes, accompanied with speech disturbances, confusion, headache, and nausea. She had unintentionally lost a lot of weight (20 kilos) over the past 6 months. She was married to a man from Morocco and had 3 children (20, 11, and 9 years old). Brain imaging showed a left-temporal lesion, mainly in the hippocampus and splenium of the corpus callosum. She was prescribed levetiracetam (500 mg BID) and underwent biopsy to determine the pathology of the lesion.

Pathology showed a glioblastoma multiforme without methylation of the MGMT-promotor. It was decided that the patient should start with temozolomide combined with radiation followed by 6 adjuvant cycles of temozolomide. At the end of chemoradiation, the patient came – accompanied by her 2 sisters – to the outpatient clinic to speak with the NP. She was complaining about fatigue and because of that, difficulties in managing her household. The NP contacted the general practitioner (GP) to organise home care and help for guidance for the 2 young children.

Four weeks later, the patient and her husband (who was frequently away from home and not able to participate in the care for either the children or the household) came to the NP for the initiation of adjuvant treatment. They communicated that they had decided against starting home care because they felt that home care would disturb their privacy. The eldest daughter – who had only recently given birth to a boy – came to live with her parents and the patient's sisters helped her with her household, partly because of apraxia and fatigue.

In June 2013, shortly before the start of the fourth adjuvant cycle, the patient was admitted to hospital because of a secondary generalised seizure. Post-ictally, she suffered from confusion, inertia, and speech disturbances. The MRI made to evaluate the first 3 cycles showed a substantial increase of the tumour growing to the right temporal lobe and a satellite lesion in the left semiovale centre. The patient was not able to function adequately, muscle strength in both sides was normal but there was a subjective hypaesthesia in the right arm and leg.

Participation in a clinical research trial was suggested to the patient but she wanted to consider this and went to another centre for a second opinion, which caused some delay. Ultimately, she decided to undergo a new tumour treatment, which existed at that time – because the trial was permanently closed – of procarbazine, lomustine, and vincristine (PCV) chemotherapy.

At that time, the patient suffered from fatigue, inertia, worsened appetite, and memory problems. The NP spoke with her and her sisters about psychosocial help for the home situation by the home care oncology nurse. Besides, she was referred to the psychology outpatient clinic with her consent.

After the first cycle of PCV, the patient visited the emergency room together with her husband after a seizure: she had speech arrest, was confused, suffered from hemianopia, and lab results showed pancytopenia. We wanted to admit the patient to the hospital ward but her husband wanted to take her home. PCV was put on hold because of her pancytopenia. A brain CT showed an increase in the lesions as compared to the latest MRI but no acute problems (eg, herniation, hydrocephalus, haemorrhage), anti-epileptic drugs were increased and the patient went home.

The NP was contacted by the patient's sister who stated that the patient was doing worse: the patient was bedridden with more severe headache, more memory problems, and more fatigue. Besides, her husband had made her convert to the Muslim faith, while a few weeks earlier the patient had spoken of a Catholic funeral and discussed her last wishes with her sisters. Home care was still deterred and the specialised oncology nurse had made several attempts at speaking with both the patient as well as her husband, but appointments were subsequently cancelled by him. The NP contacted the GP who visited the patient and prescribed pain medication.

The patient was deteriorating rapidly and her sister contacted the NP again with the consent of the patient, and all appointments in the hospital were cancelled. The GP then was responsible for care and prescribed dexamethasone and pain medication, the family was aware of the fact that the end of life was near. The patient was alone most of the time without being taken care of, not able to go to the toilet or eat or drink. Because the patient's sisters were having problems with the lack of care from the husband, they withdrew their help and support to press him to allow home care to come. They asked the NP to intervene and arrange for hospice care, but shortly thereafter they withdrew this question because they were afraid of the husband and his anger about their involvement. The NP discussed this problem with the neurologist, who suggested to call the GP to arrange admission to the hospital ward and during admission, we would try to guide the patient and her family to transfer to a hospice. A social worker as well as an imam would try to speak with the couple. The spouse approved of this, he also would like to have an MRI made and his wife to start PCV again. During admittance the patient became more clear and adequate after tapering pain medication, the responsible physician noted neglect at home and a husband who refused delivered care. MRI showed progressive disease and leptomeningeal dissemination.

Patient, spouse, sisters, and the involved health care professionals came to an agreement on going home on the condition that care was accepted and that they would contact the hospital when the situation was deteriorating again, in which the GP played an important role during the end-of-life phase.

Reference:

1. Kerrigan S, Dengu F, Erridge S, et al. Recognition of mental capacity when consenting patients with intracranial tumours for surgery: how well are we doing? Br J Neurosurg 2012; 26: 28–31.

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