

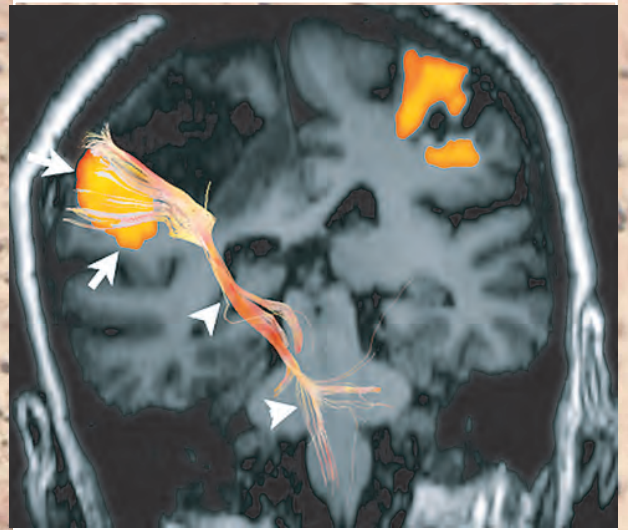
European Association of NeuroOncology Magazine

Neurology · Neurosurgery · Medical Oncology · Radiotherapy · Paediatric Neuro-
oncology · Neuropathology · Neuroradiology · Neuroimaging · Nursing · Patient Issues

**Low-Grade Gliomas, Changes in
Personality and Character
Maintaining Relations: A Case Study
of a 49-Year-Old Male with an
Oligodendroglioma**

Zwinkels H

*European Association of
NeuroOncology Magazine 2012; 2 (3)
137-139*



Homepage:

[www.kup.at/
journals/eano/index.html](http://www.kup.at/journals/eano/index.html)

Online Database Featuring
Author, Key Word and
Full-Text Search



THE EUROPEAN ASSOCIATION OF
NEUROONCOLOGY

Member of the 

Low-Grade Gliomas, Changes in Personality and Character, Maintaining Relations: A Case Study of a 49-Year-Old Male with an Oligodendroglioma

Hanneke Zwinkels

Medical Center Haaglanden, The Hague, The Netherlands

■ Introduction

Patients with low-grade gliomas can be affected in several ways but all meet a disease with a limited life expectancy, with signs and symptoms like seizures and focal deficits. The treatment of a low-grade glioma and its symptoms may consist of neurosurgery, radiation therapy, chemotherapy, antiepileptic drugs, and corticosteroids. Symptoms like cognitive disorders and personal and character changes are described and are the subjects of investigation. These cognitive deficits can be caused by the tumour, by tumour-related epilepsy, by tumour treatment, and by psychological distress [1]. Health care professionals like clinical nurse specialists and nurse practitioners play an important role in the guidance of the patient and their partners through the disease by informing, educating, and supporting them [2]. Psychosocial support in behavioural and character changes could be part of the care, how nurses can pay attention to these possible, sometimes subtle changes in function and cognitive abilities is explored by a search in the literature with search terms such as personality and character changes and through the description of a case study of a patient with a low-grade oligodendroglioma.

■ Background

Patients with low-grade gliomas have a more favourable prognosis than patients with high-grade gliomas, they can undergo surgical resection, they may receive radiotherapy and chemotherapy at some point in the course of their disease but disease progression is inevitable, patients will eventually die because of their tumour. Median survival of low-grade oligodendrogliomas and mixed gliomas is 16.7 years. Despite this relatively favourable prognosis patients and their partners are being confronted with an incurable disease, cognitive deficits, and emotional decline. How patients and their partners deal with this knowledge and which difficulties they will meet has been subject of many studies.

Various studies have evaluated the effect of surgical and oncological treatments on cognitive status and quality of life (QoL) in low-grade gliomas. Klein et al [3] studied the impact of radiotherapy on QoL and cognitive functions in a group of mid-term to long-term survivors of low-grade gliomas and found neurological impairment to be rare, but serious disturbances in cognitive and affective status were frequently and equally found in both the control group and the group who received radiotherapy. Their conclusion was that disturbances in cognitive and affective status in these patients were likely to be tumour-related rather than radiotherapy-related. Douw et al [4] studied the impact of radiotherapy on cognitive func-

tions of the same group of long-term survivors of low-grade gliomas at a mean of 12 years after first diagnosis. They found that patients who did not have radiotherapy had stable radiological and cognitive status, while patients with low-grade gliomas who received radiotherapy showed a progressive decline in attentional functioning. Because radiotherapy can delay progression but has no influence on overall survival, they suggested that the risk of long-term cognitive and radiological compromise that is associated with radiotherapy should be considered when treatment is planned.

Påhlson et al [5] demonstrated the usefulness of neuropsychological assessment as a complement to detect cognitive dysfunction in patients (n = 35) with low-grade gliomas, while this impairment was not detected by neurological examination and was only to some extent reported by the patients themselves. Gustafsson [6] evaluated the need of support by describing function, quality of life, and coping with illness-related problems in patients with low-grade gliomas. The study showed that difficulties in role, cognitive and emotional functioning had a great impact on quality of life, more than physical problems. This has an obvious social impact on family life.

Salander and Spetz [7] followed 25 patients and their spouses during the whole course of the disease and detected 4 different social processes influenced by different ways of coping and communication within their relationship. Awareness, recognition, and (in-) ability to communicate lead to sharing certain perceptions or drifting apart. These processes are (1) the patient does not seem to be aware, the spouse is aware but pretends not to be, (2) both are aware, but the patient does not want to share, they drift apart, (3) both are aware, they do/do not talk openly about the gravity of the situation; nevertheless there is a joint platform, and (4) neither patient nor spouse seems to be aware, they carry on living as before. This could imply a possible burden in maintaining a relationship, as has been described by Edvardsson and Ahlström [8] for low-grade gliomas. They concluded that being next of kin to a person with a low-grade glioma could lead to extremely stressful emotions, being invisible and neglected, changed relations and roles and problems enabling strength in everyday life. In their study, they made a distinction between male and female caregivers: most statements occurring in all 4 themes were by females next of kin. This probably has an impact on the relationship between patients and their spouses, it affects commitment and the ability to maintain the relationship. Glantz et al [9] investigated the meaning of gender in the rate of partner abandonment in patients with serious medical illness, 214 had a malignant primary brain tumour, 193 had a solid tumour with no nervous system involvement, and 108 had multiple

sclerosis. They found that there was a > 6-fold increase in risk for divorce or separation after diagnosis when the affected spouse was a woman. Marriage duration at the time of illness was also correlated with separation among brain tumour patients, there was also a trend toward an increased separation in patients with frontal lobe tumours that may reflect the concurrent neurobehavioral changes commonly observed in these patients.

Janda et al [10] identified 6 important themes to improve guidance through the disease process by interviewing patients and their carers and refined them into 5 important recommendations. To improve care, patients should be assigned a case manager, should receive proactive dissemination of information, education and psychosocial support, should have access to assessment of neuropsychological functioning, facilitation of easier access to welfare payments and services facilitating communication about difficult illness-related topics. In a cross-sectional survey among 75 patients and 70 partners Janda et al [11] scored unmet supportive care needs and found that both patients and their partners scored high on changes in mental or thinking ability, and for the partner in behavioural aspects and personality changes of the person with the brain tumour and adjustment to it. It has to be said that the response rate was low and that the investigators interpreted the group as patients and partners actively seeking support.

■ Case Study

A male patient was diagnosed at the age of 34 with a suspect low-grade glioma in the left frontal lobe in 1995 after a tonic clonic secondary generalized seizure, after which he had a second seizure in February 1996. Epileptic activity was controlled by diphantoine until September 2001 when he experienced again a tonic clonic seizure. Because of the pregnancy of his spouse the intended biopsy was postponed until December 2001. After the biopsy and the diagnosis anaplastic oligodendroglioma (with deletion of 1p and 19q) radiation therapy was applied. Because of the impact of the illness in this phase on this young couple, they were referred to a psychologist for psychosocial support. Neuropsychological investigation to determine ability to work revealed inability for resumption, because of less attention and concentration, less initiative, and fatigue. In February 2004, the activity of the epilepsy and focal deficits on the right part of his body increased and he was operated in March 2004, the tumour was resected. Treatment afterwards existed of oral chemotherapy with temozolomide, after recurrence of the tumour treatment consisted of procarbazine, lomustine, and vincristine and currently bevacizumab with irinotecan. In guiding the patient and his wife the nurse practitioner spoke with them about the impact of the changes in behaviour and cognition on their relation and in the spring of 2009 the spouse decided to make an important step. She could no longer take care of her partner, her children and herself without being afraid of losing herself and becoming very unhappy. Her husband now lives in an institution for patients with non-congenital brain damage. *"I don't want to relieve myself from the responsibility to take care of my husband, I want to be loyal to my commitment but it is not that much fun anymore ... My love is still there but my feeling of loneliness is prevailing."*

Cognition

After a third seizure in 2001, the patient became less aware of his situation, where he was, who he was speaking to, for example his wife was pregnant and he forgot that they had agreed the name of the unborn child was to be kept a secret. In this period, priority was given to the birth of their firstborn and he was admitted to the hospital a week thereafter to undergo biopsy. After surgery, he was unable to accomplish concrete daily activities and assist his wife in the care for their child, he for instance did not take initiative to hold his son. He was afraid of having a seizure while holding the baby, he thought of him as a puppy which needed to be fed and did not take any initiative to cuddle his son. He also was afraid to be home alone. Taking initiative, planning, and organizing things, accomplishing concrete daily activities are aspects of the disease which were gone from this moment. The patient's parents took over and he became a child again depending on them, while his wife was at work and his son was in day care. *"He more and more became child of his parents than man of his wife..."*. Shared responsibility in financial matters was over, the spouse imitated his signature in important matters. Initiative later in this process to look for help and psychosocial support came from the spouse, the patient relied on his wife in these matters as well.

Emotions and Behaviour

The couple had been married for several years when the patient had his first seizure, they had a good relation and were both happy with their work and social status. After the first seizure in 1995, the patient experienced fear of the dark, fear of water – he had been very fond of all kind of water sports before his illness –, and fear of driving the car alone. Because he related the occurrence of seizures to the unexpected ringing of bells, he developed a fear for doorbells, alarm bells, and phones ringing suddenly.

In the first period after the diagnosis he was quiet, feeling discouraged, and cried for about a week after which he recovered from this feelings and continued his life. In 2002, after the diagnosis of the tumour – *"it got a name and a life expectancy"*, he was feeling sad and was able to share that in a certain way with his spouse by telling her of being afraid to leave her behind and not being able to see his child grow older. After radiation therapy, he became more tired, there was more need to sleep, resulting in staying in bed during the morning while his wife was working, his son was in day care, and his parents were caring. He now and then went back to his work, but after 2 years' sick leave after his diagnosis and treatment he was discharged and stayed at home. He was a person with low interest in being able to work, it was necessary but did not have his heart.

He became more directed to himself, had less social contacts, the days his wife was at home, he went back to bed just before lunch and his wife was not able to get him out of his bed when she wanted to. *"It became a silent battle, he did not do anything"*. After recurrence of the tumour in 2004 with an increase in epileptic activity he was at some point more emotional about his treatment options and future. The second operation in March 2004 resulted in a subtle damage, a slight hemiparesis of his right leg and arm and some speech distur-

bances, because of this the expression of feelings became more difficult, he became even more introvert. He later on became more easily irritated, the reason for this irritation could be frustration because of the fact his children were overruling him in their play and he was slower due to his physical restrictions. *"He is not aggressive in any way, he doesn't hit his children or is verbally aggressive, he just struggles with his words"*.

The patient kept having unreal expectations towards his treatment and his options. He still wants to prolong his driving license and thinks he is still able to drive his scooter.

Maintaining the Relationship

In 2001, after the third seizure and admittance to the hospital, the birth of his child and the biopsy, the patient was no longer able to experience empathy for his wife or child. Before these events he was concerned about his pregnant wife, went shopping, took care of preparing dinner, cleaned the house, but afterwards these aspects of taking care within their relation disappeared. *"Loneliness entered ..."* Retrospectively, this symptom was also present in 1995 but it disappeared after a short period.

Between the partners there was no longer a normal sexual relationship after the birth of the first son. When his wife decided for a second child she spoke about this with her parents, they supported her in her wish and understood the meaning of a second child for their daughter and grandchild. The second pregnancy soon was realized with more or less mechanic intercourse.

In 2009, the spouse stated that her husband's empathy was gone, he experiences his wife and sons in his thinking but not in his feeling and compassion. He asks about them but there is no longer any real interest, he does not anticipate on their needs. He does not realize the severity of his limitations and the effect of it on his relation with his wife and he does not have the power to restore it. Also comprehension has been lost for quite some time, he relies on his wife for decisions concerning their relation, family issues, and his well being. He relies on his physicians for his tumour treatment and on health care personnel in the institution he is in *"because my wife wants that"* for his daily activities. The structure in this unit contributes to his wellbeing and he participates in several activities in his tempo.

Conclusion

Several qualitative studies describe the existence of cognitive dysfunction and experienced changes in personality and character, influencing the QoL of patients and their partners. Besides, they also could have an impact on their relationship.

Psychosocial support for the patient and the partner should be available during the treatment of disease and its symptoms, but the question of how to guide and inform patients and their partners about possible personality and character changes is not addressed.

In guiding the patient and his spouse for several years, the nurse practitioner was easily accessible to discuss such changes. Because of the slow growth of a low-grade glioma with a successive neurocognitive, physical, and psychosocial worsening of symptoms, it is not always easy to recognize the severe impact behavioural changes can have on QoL. Retrospectively, these changes appeared to be present for a longer time than assumed.

In supporting the patient, health care professionals should approach not only the patient but also the spouse on the possible strains in everyday life, from diagnosis to death, including dealing with limitations of deficits such as possible emotional, cognitive, and behavioural changes. In low-grade glioma patients with a favourable prognosis but with possible cognitive deficits and emotional decline, health care professionals such as clinical nurse specialists are in a position to pay attention to cognitive and behavioural changes, which can best be addressed by open and honest conversation with both the patient and the spouse.

References:

1. Taphoorn MJB, Klein M. Review: cognitive deficits in adult patients with brain tumors. *Lancet Neurology* 2004; 3: 159–68.
2. Zwinkels H. The developing role of the neuro-oncology nurse: a Dutch perspective. *Br J Neurosci Nurs* 2008; 8: 390–3.
3. Klein M, Heimans JJ, Aaronson NK, et al. Effect of radiotherapy and other treatment-related factors on mid-term to long-term cognitive sequelae in low grade gliomas: a comparative study. *Lancet* 2002; 360: 1361–8.
4. Douw L, Klein M, Fagel S, et al. Cognitive and radiological effects of radiotherapy in low grade glioma patients: long term follow-up. *Lancet Neurol* 2009; 8: 810–8.
5. Pålsson A, Lena E, Ahlström, et al. Pitfalls in the assessment of disability in individuals with low grade glioma. *J Neurooncol* 2003; 65: 149–58.
6. Gustafsson M, Edvardsson T, Ahlström G. The relationship between function, quality of life and coping in patients with low grade gliomas. *Support Care Cancer* 2006; 14: 1205–12.
7. Salander P, Spetz A. How do patients and spouses deal with the serious facts of malignant glioma? *Palliat Med* 2002; 16: 305–13.
8. Edvardsson T, Ahlström G. Being the next of kin of a person with a low grade glioma. *Psychooncology* 2008; 17: 584–91.
9. Glantz MJ, Chamberlain MC, Liu Q, et al. Gender disparity in the rate of partner abandonment in patients with serious medical illness. *Cancer* 2009; 115: 5237–42.
10. Janda M, Eakin EG, Bailey L, et al. Supportive care needs of people with brain tumours and their carers. *Support Care Cancer* 2006; 14: 1094–103.
11. Janda M, Steginga S, Dunn J, et al. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns* 2008; 71: 251–8.

Correspondence to:

Hanneke Zwinkels, RN, MA ANP
Medical Center Haaglanden
PO Box 432, NL-2501CK The Hague
e-mail: hannekezwinkels@eano.eu