

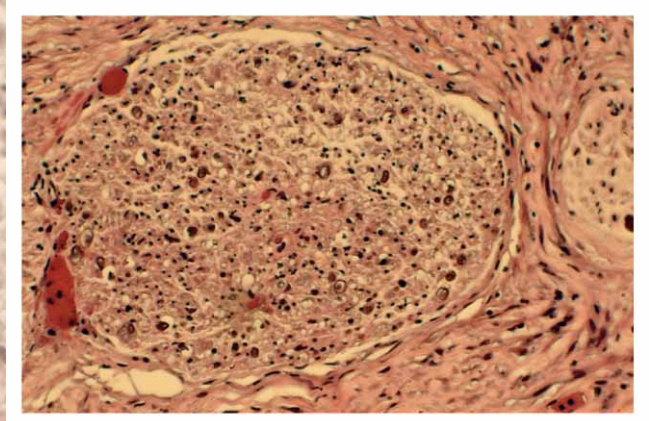
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The Growing Role of Neuro-Oncology Nurses

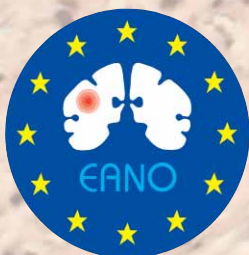
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The Growing Role of Neuro-Oncology Nurses

Hanneke Zwinkels

In June 2001, I started at the neuro-oncological outpatient clinic within a multidisciplinary care team consisting of neurosurgeons, neuro-oncologists, neuroradiologists and radiotherapists. As a trained oncology nurse, I started seeing patients and their families in consulting hours, learning from them what they needed in the course of their disease. Realizing that the chance of dying from a tumour was bigger than to recover from it, I found the challenge in wanting to be involved in the “voyage of the patient and his family”. Consequently, I searched for literature and articles about primary brain tumours to gain knowledge for what was my main task: supportive care and coordination of care for this patient group. What have I learned during the past 10 years?

■ A Specialty?

Neuro-oncology patients are different from oncology patients as well as from neurology patients because they do not only have a limited life expectancy due to the malignancy, but they also encounter neurological signs and symptoms like epilepsy and focal deficits such as hemi-paresis and aphasia, and on top of that they may be affected by cognitive deficits. To perform neuro-oncology nursing with a focus on clinical care and anti-tumour therapy, symptomatic care and research activities all within a multidisciplinary team, special skills, and knowledge are required. In my opinion, neuro-oncology nursing is a specialty in nursing and in oncology care and cure. In the United Kingdom and in the Netherlands, national focus groups of neuro-oncology nurses have been established that share and exchange knowledge.

■ Growing Awareness

Over the past 10 years, a growing awareness has occurred within neuro-oncology care and cure. This means awareness of the needs of patients and their families in guidance throughout their disease concerning possible problems in coping, anxiety, fear, and depression, in finding their way in special resources in their home environment, in obtaining access to care and cure with a low threshold in case of emergencies or sudden questions and in shared responsibility in treatment and end-of-life decision-making.

In several European countries, specialized neuro-oncology nurses are included in a care team to act as the most direct contact for patients, their caregivers, and all the healthcare professionals involved in the clinical management of the patient with a brain tumour. The nurse deals with clinic scheduling, symptom management, medication/steroids, psychological support, and referral to other agencies, as part of the process of advancing patient care. Neuro-oncology nurses therefore function as the “spider in the web” and by coordination and continuation of care improve the quality of neuro-oncology care.

■ Literature

Neuro-oncology nursing research has resulted in several publications, mainly from the USA, the UK, and some

Scandinavian countries, probably due to the development of more extended roles and education of nurses in these countries. Most publications investigated specialist nurse functions and the type of relationships a specialized nurse in neuro-oncology can fulfill. Moreover, articles about symptom clustering for patients with brain tumours are found and their effect on the functional status and quality of life, which can give direction to symptom assessment and necessary nursing interventions. Psychosocial and cognitive aspects of neuro-oncology patients are described in various articles by doctors and (neuro-) psychologists: these publications grant insight into the supportive care that neuro-oncology patients require.

■ Supportive Care

Problem areas that can be identified during counselling by neuro-oncology nurses include fear and anxiety related to seizures or focal and cognitive deficits, fatigue, uncertainty, work-related problems, housing, children, changes in behaviour, partner issues, as well as problems with coping and dying. Supportive care consists of informing and educating patients and their families about the disease and its signs and symptoms, treatments, side effects, medication, listening to their needs and problems and trying to find the best way in support and guidance through the disease process or referral to other health care personnel.

■ Task Reallocation

Task reallocation is the process by which certain duties and responsibilities, which previously fell exclusively to medical staff care, are reassigned to other healthcare professionals such as the nurse practitioner and the physician assistant. My role as a specialist nurse has been extended over the years and has developed to the role of nurse practitioner. Through training, education, and experience I gained responsibility for treating patients with temozolomide (TMZ) using a protocol. This role includes prescription of chemotherapy, anti-emetics and other necessary co-medication, while the neuro-oncologist acts as supervisor. In evaluating toxicity of TMZ, the nurse practitioner decides on dose-delay and dose-adjustment by protocol. She can also perform neurological exams to evaluate a patient's condition and discuss her findings with the attending physician. Research into TMZ toxicity has

optimized guidance and treatment of patients receiving TMZ using evidence-based practice guidelines.

■ Survey

The European Association of Neuro-Oncology – of which I am the nurse board member – would like to address all medical disciplines concerning neuro-oncology, but EANO also has an interest in creating awareness with nurses and other health care professionals dedicated to the neuro-oncology patient. Not only nurses but also social workers, physiotherapists, speech therapists and (neuro-) psychologists are responsible for supportive care of the neuro-oncology patient. We would like to know which possibilities exist for the neuro-oncology patient in Europe and want to try to increase knowledge of European colleagues. To which professional does the responsible physician refer his neuro-oncology patient? For that reason a survey will be performed to gain insight in European neuro-oncology supportive care.

■ Summary

Specialized neuro-oncology nurses can play a key role in the care and cure of patients with brain tumours by monitoring and managing symptoms of the disease and side effects of treatments, they can be easily accessible for patients and their family carers: they are in a position to communicate occurring problems with responsible physicians. Neuro-oncology nursing to me is a fascinating field within oncology nursing which has a focus on the guidance of patients and their family carers from diagnosis until death, in order to improve the quality of life of neuro-oncology patients. To optimize quality of multidisciplinary care, I would like to endorse that specialist nurses in neuro-oncology should participate and contribute to a good future perspective!

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