

European Association of NeuroOncology Magazine

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Editorial

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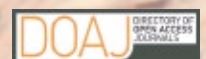
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Editorial

As the editor of the EANO Neurooncology Magazine I want to thank Kathy Oliver for raising the issue of **palliative care** so courageously.

Indeed as Mrs Oliver rightly points out the term of “palliative care” is used ambiguously, and is often confused with “end of life care” amongst others. And although all patients with neurooncological diseases are significantly affected in the course of the disease, and many people suffering from a brain tumor have a poor prognosis, the scientific research in palliative care and end of life setting is still taking only a minor part in neurooncologic scientific journals and congresses. This does not stop there, as we all note large differences in the practical, legal and ethical aspects of palliative care in different countries of the world. In addition there are also major cultural concepts in regard to treating patients and these aspects have an impact on facets of palliative care.

It is very useful that the WHO offers a definition, and it is also most useful, that large organizations such as the World Federation of Neurology (www.wfneurology.org) and the European Association of NeuroOncology (www.eano.eu) have established research groups to foster this topic and also guidelines on palliative care in neurological disease are being developed. It is a topic, which is all about human beings and involves patients, carers, and all persons concerned with the treatment of patients.

Frequently the question is asked if palliative care for patients with brain tumors is any different from general palliative care, and experience has taught us it is. Patients with brain tumors may have pain, weakness and ill-being in common with other cancer patients. But in all neurooncology patients the brain is affected and many tumors not only cause focal symptoms, seizures etc, but can influence our most precious functions which are cognition, language and often personality. We also know that these changes can be different in high-grade glioblastoma, in comparison to low-grade glioma and that the need for palliative care of any kind of tumors and neurooncologic malignancy arises at different points of the disease.

Even more complex, at least culturally, is the end-of-life phase which has been subject to many discussions and opinions. The end of life is not always clearly defined, and often hopes and sometime irrational wishes and needs appear. It is an important and unavoidable stage of the disease, and for physicians it is often not easy to comply with patient's or family's therapeutic wishes and concentrate on the best well-being of the patient under the given circumstances. Numerous experiences and studies have taught us that many symptoms in the end-of-life situation need special attention and treatment.

And this does not end here, as patients, relatives and carers may wish to increase all efforts for survival, even when death is, sadly, inevitable. Studies have shown, that in the last days of tumor diseases, helplessness is often reflected by unnecessary ancillary examinations.

And after the patient's death, relatives and carers often feel left alone and deserted, as their focus of attention is not in need anymore. Carer counseling and debriefing is imperative after the patient's death, and significantly helps to lift burden from their shoulders.

Palliative care, end-of-life care and awareness of the carers' needs has to be taken seriously by all disciplines and professions, and we have to strive to implement these concepts into our daily practices and across all cultures.

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