EFNS/ENS Joint Congress of European Neurology: 31 May - 3 June 2014, Istanbul

**New research: Brain tumour patients with poor quality of life, but less psychological distress than expected**

Patients with recurrent brain tumour suffer functional impairments in everyday life, but demonstrate lower psychological distress than people affected by other cancers. Caregivers of brain tumour patients give their maximum for family members, but at the same time gain in self-esteem. Current studies presented at the Joint Congress of European Neurology in Istanbul provide new insights into the quality of life of patients and relatives caring for them.

**Istanbul, 3 June 2014** - A rarely-studied aspect of brain tumour research, until now, concerns the quality of life and mental state of patients and family members providing care. At the Joint Congress of European Neurology in Istanbul, Dr Alessandra Petruzzi (Fondazione Istituto Neurologico “Carlo Besta”, Milan) presented two recent studies by her research teams that throw a partially new light on psychosocial aspects both for patients and their relatives.

**Reactions to recurrent brain tumour**

One study deals specifically with the psychological patterns that occur in patients with recurrent brain tumour. How do they cope with the fact that the tumour has not been subdued despite all efforts? Various tests and questionnaires regarding psychological distress, anxiety and depression involved 81 patients in the study. Their functional status was likewise evaluated and consequently the degree of disease-related limitations in daily activity, self-sufficiency and self-determination assessed.

“The results are amazing and at first glance seem contradictory,” said Dr Petruzzi. The study participants suffered significantly greater functional limitations in everyday life compared to patients with primary brain tumours. They were also much worse off in their social and family well-being. Diagnosis of a relapse did not seem to further increase the anxiety of those affected, but they responded with greater depression than did people in comparison groups. “Despite all this, they demonstrated significantly lower psychological distress compared to patients with other tumours. Quite surprisingly, test group patients additionally showed far better average values for emotional well-being than had patients with primary brain tumour,” Dr Petruzzi noted.

The expert interpreted the study results as follows: “The fact that a brain tumour recurs can play a greater role in the condition of the patient than the actual functional limitations itself. The psychological response is understandably strong. The disjuncture between the almost universally detected poor life quality on the one hand and the low rated psychological distress on the other hand is certainly the most striking result of this study. It leads to the conclusion that those affected can nevertheless call up extremely well-preserved coping strategies in the emotional sphere, while managing to clearly assess their comprehensive situation and be well informed about their illness.”

**How are care-giving relatives of brain tumour patients coping?**

In another study Dr Petruzzi’s team examined quality of life and well-being of family caregivers of brain tumour patients. They have to cope with accompanying a loved one through all phases of a potentially short course of an illness that can have serious functional, cognitive and psychological consequences for
persons affected and, in the worst case, can end fatally. A hundred people were examined for this whose relatives were being treated at the Neuro-oncology Unit of the Fondazione Istituto Neurologico “Carlo Besta” in Milan.

The study results show that family caregivers need to take into account significant quality of life sacrifices. Above all, their mental health is accosted: they suffer significantly more often from anxiety and depressive disorders. Their burden mainly stems from an increasingly diminishing ability to provide care and from a slackening of their energy. Many report exhausted financial resources over time. Caregivers nonetheless respond with remarkably positive physical energy to the illness of their family member. The need and the will to help a loved one in an exceptional situation boosts the self-esteem of family caregivers.

“Most telling was the fact that the quality of life of caregivers does not significantly differ according to the degree of malignancy. That suggests that the diagnosis of a ‘brain tumour’ leads worried family members to a life whose clarity of thought is determined overwhelmingly by the concept of a terminal illness. There seems to be almost no room for differentiating according to better or worse chances of recovery,” Dr Petruzzi said in summary. "Both studies clearly indicate that in the diagnosis of brain tumour, a comprehensive approach must be adopted, including the mental health of victims and family members," the expert emphasized. In addition to psychological support, care-giving relatives would also require assistance with practical matters of everyday life, whether in obtaining a hospital bed for home care or in reconciling such care and their job.

Sources:
Congress Abstracts Petruzzi et al, Psychological patterns of patients; Petruzzi et al, What about caregivers of brain tumor patients? Focus on psychological reactions to the illness.

Press Office of the Joint Congress of European Neurology
B&K - Bettschart&Kofler
Dr Birgit Kofler
Mobile: +43-676-63 68 930
E-Mail: kofler@bkkommunikation.com
Skype: bkk_Birgit.Kofler