

The Prevalence of Behavioural Sequelae in Patients with Primary Brain Tumour and the Development of Information Resources

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ABSTRACT

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Background

Health professionals who care for patients diagnosed with primary brain tumours often report behavioural and cognitive changes. These changes can present management challenges for staff especially where generalist staff may not be equipped to care for such sequelae. Families/carers also commonly describe these changes and report that these are the most difficult and challenging aspects of the diagnosis. Limited literature exists documenting both the prevalence and management of cognitive and behavioural changes in patients with brain tumours.

A research project was funded by the Cancer Institute NSW to:

- a) Examine the prevalence of such behaviour changes within the brain tumour population
- b) Develop a set of information resources for health professionals, carers and patients.

Methods

A consecutive series of 47 patients with histopathologically confirmed primary malignant and benign brain tumours and 37 family member/carers were recruited. A series of self report questionnaires including the Frontal Systems Behaviour Rating Scale (FRSBE), the Overt Behaviour Scale (OBS) and the Sydney Psychosocial Reintegration Scale (SPRS), were administered to both the BT patient and their family member/carer to assess the prevalence of behavioural and/or cognitive changes.

Results

Both BT patients and their family members/carers reported significantly greater impairment on all three subscales of the FRSBE (apathy, disinhibition, executive function) after the BT when compared to pre-diagnosis. On the OBS, challenging behaviours (e.g., verbal and physical aggression, perseveration, adynamia) were reported by up to 32% of BT patients and 24% of their family members/carers. On the SPRS, people with BT had lowered occupational levels, but their relationships and independent living skills were largely preserved.

Information resources (Fact Sheets, n=17) were developed based on the prevalence findings. Each Fact sheet includes a description of the behavioural or cognitive change, a case example, practical strategies for management and links to related information/support groups.

Conclusions

This study is one of few to document the prevalence of behavioural and cognitive sequelae in patients with brain tumours. We expect the innovative Fact sheets developed to be a key resource available online to assist both clinicians, patients and carers in management these challenging sequelae.