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

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BACKGROUND

Brain damage as the result of primary brain tumours is well documented. This includes neurologic symptoms (eg headaches, dizziness) and cognitive impairments (eg memory problems).[1-3] In contrast, the prevalence and correlates of behavioural impairments has received little systematic study.

Damage to the frontal regions and their connections can lead to a wide range of changes which can be grouped into three different 'syndromes'[4] (i) disorders of regulation such as social disinhibition, physical and verbal aggression and lack of insight (ii) disorders of activation such as apathy and perseveration, and (iii) disorders of executive cognitive function, the integrative component that marshalls cognitive processes in order to pursue goal directed behaviour. These types of changes are offered referred to as personality change.

Clinical experience strongly suggests that patients and families struggled with the impact of these types of behavioural and cognitive changes. It is suggested that cognitive and psychological impairments are more debilitating and difficult to manage in comparison to motor or speech disturbances[5]. Ongoing canvassing of consumers through brain tumour support groups and patient advocacy groups revealed that more assistance and information on the management of cognitive changes was required. Healthcare providers also reported a strong need for practical strategies and training to better address this management issue.

PURPOSE

The purpose of the research study was to:
a) Investigate the prevalence of behavioural and cognitive changes within the primary brain tumour population, throughout the continuum of treatment. This would also allow the most prevalent impairments to be identified and guide the development of resources.
b) Develop a set of information resources for health professionals, carers and patients in reference to the challenging behaviours identified. Including strategies to minimise the disabling impact of such behaviours.

METHOD

a) Prevalence Study

Ethics approval was granted from both institutions.
A concurrent record of patients from Royal North Shore Hospital and Liverpool Health Services was developed. This included all patients undergoing treatment for a histological confirmed primary brain tumour between and inclusive of 10/2007–10/2008.

Patients who agreed to participate were then invited to nominate a family member who could also participate. The rationale was that impairments such as lack of insight may result in patients underreporting their deficits. Therefore it was essential to interview both patient and the family member to elicit any variance.

Inclusion criteria:

I. Histological confirmed primary brain tumour
II. Minimum 18 years of age at time of diagnosis
III. Cognitively able to complete the measures
IV. Under the active management of the neuro-oncology service at the Liverpool Hospital Cancer Therapy Centre and Royal North Shore Hospital.

Inclusion criteria II. and III. were also applied for the carer/family member.

Exclusion criteria:

For both patients and family members:
I. Inability to speak English
II. Severe psychiatric disorders (including substance abuse) or cognitive deficits from pre-existing conditions.

Three neuro-behavioural rating measures[1,5,6] were selected on the basis that:
(i) their validation samples included people with a primary brain tumour,
(ii) they all had a self-rating and a proxy report version, and
(iii) all had good reliability and validity. In addition two measures of functional capacity were selected.

Patients and relatives completed the following:
- A data protocol including sociodemographic and clinical characteristics data (sex, age, marital status, education, tumour type, location, treatment undertaken, date of diagnosis).
- The Frontal Systems Behaviour Rating Scale (FrSBe).[5] This scale measures executive impairment. pre and post brain tumour and includes three subscales. These include disinhibition, apathy, and executive dysfunction (including working memory, organisation, planning and problem solving).
- The Overt Behaviour Scale (OBS).[6] This scale measures the presence of challenging behaviours; aggression, inappropriate sexual behaviour, perseveration, wandering, inappropriate social behaviour and lack of initiation.
- The Emotional and Social Dysfunction Questionnaire (ESDQ).[1] Measures the presence of anger, helplessness, emotional dyscontrol indifference, inappropriateness, fatigue, maladaptive and insight
- Karnofsky Performance Scale (KPS).[7] Allows the clinician to measure daily function.
- The Sydney Psychosocial Reintegration Scale (SPRS).[8] Allows measurement of reintegration across the domains of occupation, relationships and independent living.

Data was scored and entered into SPSS for data analysis and included descriptive data and paired sample t-tests. Fior analyses involving multiple comparisons, the significance level was adjusted using a Bonferroni correction in order to control for Type 1 error.

b) Development of Resources

A structured literature and web based review was performed. Searches included any information/ resources available for consumers on information and practical strategies for managing challenging behaviours specifically in those people with brain tumours.

Reflecting on clinical experience and preliminary findings from the prevalence study results, 16 draft information sheets were developed. Eleven resource sheets were also drafted to complement the information sheets.

A consumer focus group was convened to review the information and resource sheets for comments on appropriateness, usefulness, correct language and ease of application. Information and resource sheets were also distributed to the state wide multidisciplinary Cancer Institute NSW Oncology Group (NSWOG) Neuro-Oncology for wider comment and evaluation from other health professionals involved in the care of patients with brain tumours.

Based on feedback, final versions of information and resource sheets were completed. The target audience of the information sheets was varied. It was expected that information would be relevant and practical to both health professionals and consumers.

A table for distribution amongst Health Professionals and consumer groups was devised.

RESULTS

Prevalence Study:

A recruitment list of 154 patients with a histological confirmed primary brain tumour was established between the two campuses. Of these 154 patients, 85 met the inclusion criteria with 57 patients able to participate in the prevalence study. From these 57 participants, 37 carers/family members were identified and agreed to participate.

The sample sociodemographic and clinical characteristics can be seen in Table 1. The overall prevalence rates for the presence of behavioural or cognitive change ranged from 7%–40%. Brain tumour patients and their family members/carers reported significantly increased prevalence of challenging behaviours on two of the subscales of the FRSBE (apathy and executive function) post diagnosis of brain tumour (see Chart 1).

On the OBS, challenging behaviours were reported by up to 32% of brain tumour patients (see Chart 2). On the ESDQ (see Chart 3) 33% of patients reported inertia, 22% reported inappropriate behaviour and 33% reported anger. There was significant agreement between patients and relatives on the presence or absence of behavioural impairments.

Table 1

Sample sociodemographic and clinical characteristics of patients with primary brain tumour

Variable	Patient (n=54)[1]	Variable	Patient (n=54)
Age (years), Mean (SD)[2]	51.8 (16.0)	**Radiation Therapy, n (%)**	
Time post-diagnosis (months), Median (IQR)[2]	4.0 (24.0)	Yes	32 (59.3)
		None	22 (40.7)
Sex, n (%)	24 (44)	**Chemotherapy, n (%)**	
Male	30 (56)	Yes	17 (31.5)
Female		Temozolamide	16 (29.6)
Histological diagnosis, n (%)	6 (11.1)	Other	1 (1.9)
Astrocytoma G1/2	4 (7.4)	None	37 (68.5)
Astrocytoma G3	16 (29.6)		
Glioblastoma Multiforme		**Epileptic seizures, n (%)**	25 (46.3)
Oligodendroglioma	4 (7.5)	Yes	29 (53.7)
Oligoastrocytoma	15 (27.8)	No	
Meningioma	9 (16.7)	Unknown	
Other[3]		**Corticosteroids, n (%)**	10 (18.5)
Tumour grade, n (%)	21 (38.9)	Yes	36 (66.7)
High grade	12 (22.2)	No	8 (14.8)
Low grade	21 (38.9)	Unknown	
Benign		**Karnofsky Performance Score, n (%)**	12 (22.2)
Tumour site, n (%)	29 (53.7)	50-70	23 (42.6)
Frontal/Temporal	25 (48.3)	80	19 (35.2)
Other		90-100	80.7 (10.6)
Tumour lateralisation, n (%)	24 (44.4)	Mean, SD	
Left-sided	22 (40.7)		
Right-sided	8 (14.8)		
Both			
Treatment stage[3]**, n (%)**	3 (5.6)		
Post-Surgery	15 (27.8)		
Treatment (RT Chemo)	35 (64.8)		
Post-treatment	1 (1.9)		
Palliative			

[1] A total of 57/85 recruited. 3/57 patients who were outliers (greater than 10 years post-diagnosis) leaving a total sample of 54 patients.

[2] Other includes Craniopharyngioma n=2, Epidermoid tumour n=1, Ependymoma G2 n=2, Medulloblastoman =1, Pituitary Adenoma n=2, Schwannoma n=1.

[3] Post treatment=disease monitored no new treatment regimen, Palliative=no further active treatment indicated other than supportive care.

Chart 1

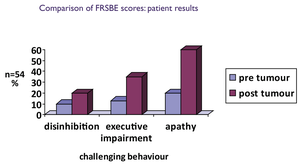


Chart 2

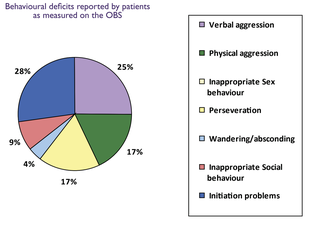
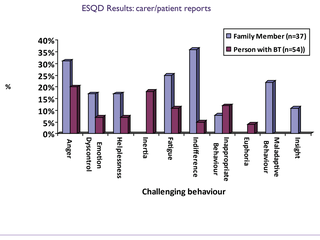


Chart 3



The presence of epileptic seizures demonstrated a strong correlation with behavioural variables including higher levels of inertia on the ESDQ (t= 3.3, p=0.002) and challenging behaviours on the OBS (t=3.07, p=0.003). Patients with a frontal/temporal tumours scored higher on the ESDQ Indifference subscale.

In terms of functional variables, on the SPRS, people with brain tumour had lowered occupational levels, but their relationships and independent living skills were largely preserved. As brain tumour patients total participation score decreased so did their score on the Karnofsky Rating Scale for both self rating (Pearson's r = .70, p=.000, n = 53) and for rating by a family member/carer (Pearson's r = .72, p = .000, n = 39).

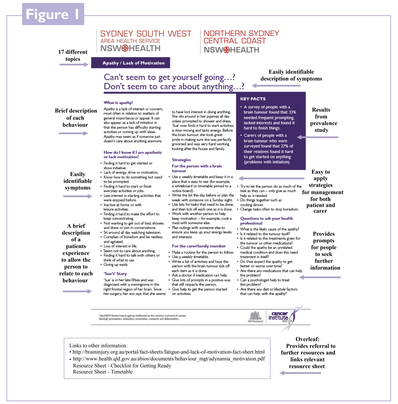
Development of Resources:

The results of the web based and literature review identified 17 information resources available. A total of 53% of these contained no information or only minimal content (1-2 sentences) about behavioural impairments. Furthermore, 71% provided no information or minimal content (1-2 sentences) on practical management strategies for challenging behaviours.

Based on these findings and preliminary data from the prevalence study, the following information sheets and resource sheets were developed.
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.
A total of 17 fact sheets were developed including an overview and 16 behavioural and cognitive changes. These are detailed below:
(See Figure 1 for example).

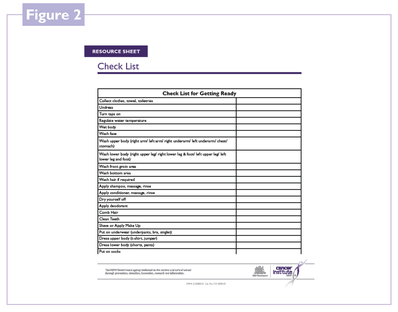
1. Can't seem to get yourself going…? Don't care about anything…? Apathy/Lack of motivation
2. Are you having trouble with your temper…? Anger.
3. Are you feeling tense, nervous and overwhelmed…? Stress and Anxiety.
4. Do you feel exhausted or tired a lot of the time…? Fatigue.
5. Can't seem to think straight…? High level thinking problems.
6. Can't seem to say or do the right things at the right time…? Inappropriate social or sexual behaviour.
7. Do you feel that you are on an emotional roller coaster…? Lability.
8. Do you keep forgetting things…? Memory.
9. Are you having difficulty staying on task…? Attention and Concentration.
10. Can't find the word or talk too much…? Communication.
11. Feeling lost, not knowing where you are…? Disorientation/Appearing confused.
12. Do you repeat yourself or get stuck like a broken record…? Perseveration.
13. Do you only think about yourself and not see anyone else's point of view…? Egocentricity.
14. Do you sometimes act without thinking…? Impulsivity.
15. When how you look no longer seems to be important… Neglecting personal care/looking after yourself.
16. Do you feel sad, tearful, can't seem to enjoy yourself…? Low mood – Depression.

Figure 1



Throughout the development of the information sheets it was apparent that the inclusion of practical resources alongside the informative data was paramount. This lead to the development of eleven further resource sheets to accompany and were referenced by the information sheets.
(see Figure 2 for example).

Figure 2



Topics included:
- Anger management
- Stress management and relaxation techniques
- Stress management
- Activity scheduling
- How to cope with depression
- Mindfulness exercise
- Goal setting
- Memory tips
- Timetable
- Checklist for getting ready
- Problem solving

The facts sheets were professionally printed and distributed throughout the network of health professionals and consumer groups. Other relevant parties were notified via mail informing them of the electronic availability of the resource.

Full text of facts sheets are available: http://www.cancerinstitute.org.au/cancer_inst/publications/index.html#factsheets

CONCLUSION

This study is one of first to systematically document the significant prevalence of behavioural and executive cognitive sequelae in patients with primary brain tumours. Understanding the prevalence within the population allows for appropriate and efficient healthcare planning. By quantifying the prevalence this will add strength to proposals when lobbying for resource provision for this population. This data suggests that there is a great need for available supports and practical resources. The fact sheet and resource sheet series is the only one of its kind currently available. It is the vision of the research team to ensure that these are made widely and easily available.

Nursing implications of these findings are useful. A better understanding of the high proportion of patients with behavioural and executive cognitive sequelae in this population may contribute to prompt adequate and safe discharge planning, appropriate patient and family education prior to discharge and the provision of adequate follow up services and referrals to supports on discharge. Patient care could be improved if nursing staff are aware that the management of such deficits are a priority of care. The fact sheet series may prove to be an invaluable tool for nursing staff to implement management themself and also to assist carers in developing the necessary skills to care for their loved ones.

Some issues with the research have been identified. It is possible that prevalence figures could be greater than that documented due to selection bias with more unwell/poor performance status patients declining recruitment. Recruitment into the study was at times problematic due to the natural history of primary brain tumours, in particular malignant brain tumours. Future research could consider replicating results found in this pilot study but with a larger study sample size. This will allow the needs of such populations to be assessed more thoroughly.

Although the search for resources did identify behavioural and cognitive changes being described they were lacking practical strategies for patients, families and staff to employ. The development of the Fact Sheet series will be an invaluable resource for anyone involved in the management of patients with primary brain tumours.

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