

NSWOG NEURO-ONCOLOGY PROJECT

Final Report

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Addressing the behavioural and cognitive sequelae of adults with Brain Tumour: Trialling a Behavioural Consultancy Model

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Contents

Key findings

Executive Summary

Chapters

1. Introduction
2. Objective I: Chart the prevalence of behavioural and cognitive sequelae among people with PBT
3. Objective II: Interventions to Address Behavioural & Cognitive Impairments
4. Objective III: Managing challenging behaviours after brain tumour: An Information Resource for patients, family and health providers
5. Objective IV: Provide a training program for Health Professionals
6. Conclusions

References

Appendix I: Dissemination of the Research

Appendix II: Excerpt from 'Synapse' Official Journal of the Brain Injury Associations of Australia, June 2009, 29-30.

Tables:

- 2.1 Measure subscales sampling the three clinical 'syndromes' describing behavioural impairment.
- 2.2 Sample demographic and clinical characteristics of patients with PBT
- 2.3 Prevalence of behavioural disturbances
- 4.1 Review of Existing Cancer / Brain Tumour Information (n=17)
- 5.1 Improvements suggested by participants
- 5.2 Workshop Evaluation – "Something I can do better"
- 5.3 Workshop Evaluation – "What I liked the best"

Figures:

- 2.1 Agreement between brain tumour patients and relative informants in rating presence of behavioural impairment
- 3.1 Percentage of time spoken
- 3.2 Incidences of target behaviour
- 3.3 Family education workshop: Knowledge of strategy use pre and post workshop
- 4.1 Example of the information resources
- 5.1 Percentage of participants by profession
- 5.2 Percentage of participants by work organisation
- 5.3 Health professionals' knowledge of strategy use, pre and post workshop

Key Findings

The Behavioural Consultancy project had four objectives:

(i) Examine the prevalence of behavioural sequelae after Primary Brain Tumour (PBT)

- This was the first systematic prevalence study of behavioural impairment after PBT.
- Patient-reported (n=54) prevalence rates for behavioural disturbances or cognitive impairments ranged from:
 - 7% (Emotional Dyscontrol, Helplessness, Euphoria) to a high of 40% (Executive Impairment), with rates for significant clinical issues including Apathy, Inertia, Anger and Inappropriate Behaviour ranging between 20-35%.
- Family-reported (n=37) prevalence rates for behavioural disturbances or cognitive impairments ranged from
 - 8% (Euphoria) up to 60% (Apathy) with rates for significant behavioural impairments including Disinhibition, Executive impairment, Anger, Indifference, Fatigue, and Initiation problems ranging between 22-36%.

(ii) Trial a Behavioural Consultancy Model to intervene with the person with PBT and family members to minimise the impact of such impairments

- One patient with socio-behavioural impairments secondary to PBT was successfully treated with an individually designed neuro-behavioural intervention.
- Seven family members participated in a pilot carer education program to equip families to better manage the behavioural and cognitive sequelae of PBT – results from post- versus pre-workshop tests indicated that carers made a statistically significant improvement in their knowledge in managing these changes.

(iii) Develop information resources about the behavioural and cognitive sequelae of PBT for patients and their families

- A review found few existing information resources provided information about the nature and management of cognitive/behavioural impairments of PBT
- Comprehensive targeted information resources about the behavioural and cognitive sequelae of BT were developed, including 16 fact sheets and 11 resource sheets
- Information sheets produced in hard copy, as well as CD format - in addition PDF files were provided and are available through the Cancer Institute NSW website.

(iv) Trial a training workshop to educate staff in cancer services about management approaches in dealing with behavioural/cognitive sequelae

- A training program was provided to staff from neurosurgical departments/cancer therapy services (n=46) focussing on the management of behavioural and cognitive changes after PBT – results indicated that staff made a statistically significant improvement in their knowledge and skills in managing these changes (preworkshop vs postworkshop scores, t-test).

Conclusions

- There was a higher than expected prevalence of behavioural/cognitive impairments in a population of patients with PBT (covering malignant and benign tumours)
- Several types of psychosocial interventions show initial promise as effective treatment and management approaches

Executive Summary

Aim

To conduct a pilot project to evaluate the efficacy of a Behavioural Consultancy Model in addressing impairments in the behavioural and cognitive domains of executive functioning among adults with Primary Brain Tumour (PBT).

- Prevalence study on the behavioural and cognitive sequelae of PBT to be completed (n=50)
- Trial the Behaviour Consultancy Model as a means of working with the person with PBT, family members and service providers to minimise the impact of such sequelae
- Develop information resources about the behavioural and cognitive sequelae of PBT for patients, their families and health professionals
- Trial a training workshop to educate staff in cancer services and neurosurgical departments about management approaches in dealing with such sequelae

Introduction

Behavioural and cognitive changes have been noted in patients diagnosed with a primary brain tumour (PBT). Both patients and family members report that dealing with such changes can prove to be overwhelming and distressing. In addition, there is limited data on the prevalence of such sequelae, particularly behavioural impairments. More importantly, there are few reports on approaches to the treatment of such sequelae. Reflecting this, existing patient and family information resources provide little guidance on strategies for managing behavioural and cognitive impairments. Finally, many staff in cancer services have only limited knowledge or skills to assist people with PBT and their families minimise the impact of such impairments on their daily lives, community participation and quality of life.

Methods

1. Prevalence Study

- 57 patients with PBT from Liverpool Hospital and Royal North Shore Hospital and 37 carers/family members were interviewed
- Participants were administered a series of questionnaires to determine prevalence of behavioural and cognitive changes after the PBT diagnosis
- Data was scored and entered onto SPSS for ensuing data analysis

2. Trial the Behavioural Consultancy Model

- Nine patients were identified from the prevalence study with regard to behavioural and cognitive changes
- One PBT patient and their family participated in the Behavioural Consultancy Model intervention
- An additional intervention program was delivered to seven carers and ten PBT patients as an education workshop on managing behavioural and cognitive changes after a PBT
- The cases of four PBT patients who received a successful Behavioural Intervention from an Acquired Brain Impairment Behavioural Consultancy Service in another state were retrospectively reviewed

3. Development of Information Resources

- A structured review of all the information resources currently available to consumers about the behavioural and cognitive sequelae was undertaken, including:
 - Literature review using various search engines to identify articles published in peer reviewed journals using search terms spanning behavioural and cognitive impairments
 - Web-based search for electronic patient and family information resources.

4. Trial a Workshop for health professionals

- A one-day health professional workshop was developed for health professionals working with PBT patients
- The topics covered in the workshop included:
 - An outline of the prevalence of behavioural and cognitive sequelae of PBT
 - A case study utilising an intervention with a PBT patient
 - Principles of behaviour management and the Behavioural Consultancy Model
 - Strategies for dealing with the cognitive/behavioural changes in PBT patients
 - A group activity to develop a management plan for presented case studies
- Workshop participants completed measures to assess their level of skill and knowledge pre- and post workshop as well as a general workshop evaluation

Results

1. Prevalence Study

- Patient-reported (n=54) prevalence rates for behavioural disturbances or cognitive impairments ranged from
 - 7% (Emotional Dyscontrol, Helplessness, Euphoria) to a high of 40% (Executive Impairment), with rates for significant clinical issues including Apathy, Inertia, Anger and Inappropriate Behaviour ranging between 20-35%
- Family-reported (n=37) prevalence rates for behavioural disturbances or cognitive impairments ranged from
 - 8% (Euphoria) up to 60% (Apathy) with rates for significant behavioural impairments including Disinhibition, Executive impairment, Anger, Indifference, Fatigue, and Initiation problems ranging between 22-36%

2. Trial the Behavioural Consultancy Model

- In the single case study, the three target behaviours demonstrated a notable change over a two hour time frame, immediately after the intervention. These included:
 - A 71% decrease in time spent speaking
 - A decrease in average number of interruptions from 2.2 to 0.94
 - An increase in average questions asked from 0.2 to 0.75
 - Although behavioural improvements degraded over time with repeated assessment at 3 and 5 months, they did not return to baseline levels
- The family intervention (education workshop) participants demonstrated a significant increase in their knowledge of strategy use in managing challenging behaviours ($t=3.33$, $p<.05$) when compared to pre intervention
- A retrospective review of four case studies provided qualitative data that improvements in challenging behaviours were achieved after utilising a behavioural consultancy intervention.

3. Development of Information Resources

- The review of information resources found that half to two-thirds of the resources had little or no information about cognitive/behavioural impairments and associated strategies to manage these impairments
- Drawing on the results of the prevalence study (Objective 1) and the review, 16 types of behavioural and cognitive impairment were identified
- 16 Draft Information sheets were then developed
- 11 additional Resource sheets were developed to provide tools and strategies for managing the behavioural and cognitive changes
- Stakeholders were polled for their opinion and feedback of the draft resource.
 - A focus group consisting of PBT patients and their carers
 - Disseminating the materials via email through the NSW Oncology Group to health professionals working with neuro-oncology patients
 - A readability analysis was undertaken to ensure that the resources met recognised standards or readability for public health information
 - Materials underwent final review by Cancer Institute NSW staff
- 1,000 hard copy Resource kits were produced as well as electronic PDF files
- Information Resources have been disseminated to:
 - Participants of the focus group and family education workshop
 - Health professionals who attended the staff workshop
 - Consumers at the Cancer Institute NSW Consumer Day during Brain Tumour Awareness Week, October 2008
 - Professional associations relating to PBT patients including:
 - Oncology Social Work Australia
 - Royal Australian and New Zealand College of Radiologists
 - Cancer Nurse Society of Australia
 - Australian and New Zealand Association of Neurologists
 - Australian and New Zealand Society of Palliative Medicine
 - Neurosurgical Society of Australasia
 - Royal Australian College of General Practitioners
 - APS College of Neuropsychologists
 - Australasian Neuroscience Nurses Association
- Promoted at the World Federation of Neuro-oncology conference, Japan, 2009

4. Trial the workshop for health professionals

- 46 participants attended the workshop and 43 participants completed the pre- and post- workshop questionnaires and workshop evaluation form
- Significant improvements in post workshop knowledge in managing the behavioural and cognitive changes of PBT were demonstrated by participants ($t = 10.76, p < .001$)
- Workshop evaluation was extremely positive, participants rated all workshop components greater than 4 on a 5-point scale (where 1=very poor and 5=very good)
- Participants noted that they had improved skills (40.2%) and improved knowledge (26.2%) in managing behavioural/cognitive impairments after the workshop

Discussion

- This project has increased awareness that behavioural/cognitive impairments represent an important clinical management issue for affected patients and their carers, with resultant implications for the delivery of existing psychosocial care for patients with PBT.
- Further investigation is needed to both confirm the prevalence of, and to screening for behavioural impairments in a longitudinal multi-centre study, and also to examine the effects on patient functional status and quality of life.
- The information resources developed to specifically address behavioural and cognitive impairment in primary brain tumour patients represent a unique, valuable and accessible resource for patients, carers and health professionals alike.
- Further testing of the efficacy of treatment interventions including tailored individual neuro-behavioural programs, family education and staff training programs are needed to help alleviate the impact of these impairments on patients and their families. .

Chapter I

Introduction

Many results of brain damage associated with primary brain tumour (PBT) have been comprehensively reported. Neurologic symptoms^{1,2}, cognitive impairments³⁻⁵ and mood-related disturbances⁶ have been extensively investigated. In paediatric tumours, the presence of behavioural impairments have also been documented.⁷ Both patients and family members report that dealing with these changes resulting from the brain damage, can prove to be overwhelming and distressing, yet little is known about the extent of these impairments and importantly, suitable management approaches.

Damage to the frontal regions and their connections can result in a diverse range of behavioural changes.⁸ Work by Cummings and others have delineated three clinically observable 'syndromes' under which such behaviours can be grouped.^{9,10} Disorders of regulation, associated with lesions to the orbital prefrontal circuit, are typified by behaviours such as social disinhibition, physical and verbal aggression, limited insight and loss of social judgement. Disorders of activation, such as apathy, adynamia and perseveration, are linked to impairment of the anterior cingulate circuit. Disorders in executive cognitive function, the integrative component that marshals cognitive processes including attention and memory in order to pursue goal-directed behaviour, are associated with damage to the dorsolateral prefrontal circuit. These types of behaviours have been observed in a number of neurologic diseases and injuries.¹⁰⁻¹² They are often collectively referred to as personality change.¹³

The neural structures and circuits delineated by McKeith and Cummings¹⁰ are vulnerable to the local effects of frontal region neoplasms or the remote effects of tumours located in other brain regions. In the most detailed study of this area to date, Andrewes et al.¹⁴ devised the Emotional and Social Dysfunction Questionnaire to document a range of emotional changes and social difficulties secondary to brain damage arising in a sample of neurosurgical patients. However, the study sample comprised patients with a range of neurological disorders and only 54% had PBTs, so the true prevalence of behavioural impairment remains unknown.

Objective I: To chart the prevalence of challenging behaviours among a sample of people with PBT

The first objective of the study was to chart the prevalence of challenging behaviours in patients with PBT. The approach involved replicating the findings from the study by Andrewes et al.¹⁴, but in a single diagnostic group of patients with PBT derived from two sites. In addition, we proposed to extend the findings by including a measure (FrSBe) that captures data on the cognitive components of executive functioning.

Furthermore, in addition to understanding the extent of such problems, the causes of behavioural impairment needed to be explored. Studies into the origins of cognitive impairments associated with PBT have identified a number of potential causes including the tumour itself (both low grade and high grade), tumour progression, tumour-related neurological complications, epilepsy, and side effects from cancer treatments.^{3,5} Therefore, it is not known whether similar variables correlate with behavioural change after PBT.

Objective II: Provide treatment of behavioural and cognitive impairments

Reflecting the limited documentation of impairments to executive functioning and challenging behaviours, there are few reports of treatment approaches to managing such sequelae among patients with PBT. Specialist neurorehabilitation programs are well established for the treatment of various brain-damaged populations including traumatic brain injury and stroke.^{15,16} There are some emerging accounts of rehabilitation being provided to patients with PBT to address the functional and psychosocial consequences of their condition.¹⁷⁻²⁰ However, these treatment programs are primarily centre-based and can provide only limited assistance in the home and community settings, which is where the assistance in managing challenging behaviours and executive impairments is most needed.

Importantly, new approaches to address these problems are being developed. The Acquired Brain Injury Behavioural Consultancy services provide expert consultation and intervention to assist families and service providers in the management of challenging behaviours among people with neurological conditions. Initial evidence suggests that the Consultancy model has been effective in reducing the severity of such behaviour.²¹

A recent review of 138 admissions to one Behavioural Consultancy service identified 14 referrals for people with PBT.²² The challenging behaviours for these referrals included verbal aggression, inappropriate sexual behaviour and lack of initiation. These behaviours were associated with risks of accommodation breakdown, legal problems, family distress, and loss of employment.

Looking more broadly at the efficacy of Consultancy interventions, Kelly et al.¹¹ reported on a sample of 28 clients treated by a Consultancy service for whom pre and post-intervention measures of challenging behaviours were scored using the Overt Behaviour Scale. Mean pre-treatment score for the sample was 11.0 (SD 13.0) and at 4 months after treatment had commenced, the mean score had decreased (signifying a reduction in challenging behaviours) to 7.5 (SD 10.0). This indicated an effect size of approximately .27 (mean change/pre-treatment standard deviation). Family members of the clients rated this change as representing a significant reduction in the intensity and impact of the challenging behaviours. Furthermore, given the association between challenging behaviours and reductions in community participation, any amelioration of such impairments may also improve the level of participation of the person with PBT.

Objective III: Lack of information for patients and their families

A brief review highlighted how the issues of executive impairments and Challenging Behaviours (CB) are nearly invisible in the national and international patient BT information literature. An examination of the leading information resources from cancer or brain tumour organisations in Australia, the United States of America, and Canada found that there was little or no mention of personality/behavioural changes. The Canadian booklet included half a page on memory impairments in a 172-page booklet. The American book included 10 lines on what was termed 'mental disturbances' (namely, impairments in behaviour and cognition) in a 140-page Primer.

The findings from Andrewes and colleagues¹⁴ suggest that there is an information gap in addressing these important issues. Resources for other brain-damaged groups provide significant amounts of information detailing common behavioural and cognitive impairments, and strategies that can be used to minimise the impact of such impairments.

Objective IV: Lack of staff training

More importantly, there are few reports on approaches to the treatment of the behavioural and cognitive sequelae. Reflecting this, existing patient and family information resources provide little guidance on strategies for managing behavioural and cognitive impairments. Finally, many staff in neurosurgical departments and cancer services have limited knowledge or skills to assist people with BT and their families to minimise the impact of such impairments on their daily lives, community participation and quality of life.

The need for specialised training to work with people who have behavioural and cognitive impairments has been addressed in the broader neuro-rehabilitation literature.²³ Reflecting this, an important component of the Behavioural Consultancy model has been to provide clinically relevant staff training.

Part (iv) of the study will involve the provision of a training workshop for staff working in the area of neuro-oncology, modelled on the training provided by the Consultancy. The training content will be adapted to focus specifically on the needs of people with PBT and their families.

In summary the objectives of this project were to:

1. Undertake a prevalence study on the behavioural and cognitive sequelae of PBT.
2. Trial the Behaviour Consultancy Model as a means of working with the person with PBT, family members and service providers to minimise the impact of such sequelae.
3. Develop information resources about the behavioural and cognitive sequelae of PBT for patients, their families and health professionals.
4. Provide a training workshop to educate staff in cancer services about management approaches in dealing with such sequelae.

Chapter 2

Objective 1: Chart the prevalence of behavioural and cognitive sequelae among people with PBT

Introduction

In seeking to chart behavioural and cognitive impairments, the current study employed standardised neuro-behavioural self-report questionnaires. Given the possible problems with the reliability of the patient self-reports due to impairments in memory and insight, relative (proxy) and clinician ratings on the prevalence of behavioural/cognitive impairments were also collected. The behavioural/executive impairment domains that the measures document were also mapped onto the three 'clinical syndromes' proposed by Cummings and colleagues (see Table 2.1).^{9,10}

Methods

Sample

Ethical approval was provided by Sydney South West and Northern/Central Coast Area Health Service Human Research Ethics Committees. All active cases of the neuro-oncology services at Liverpool Hospital and Royal North Shore Hospital in Sydney Australia were reviewed over a 12 month period (from October 2007), to prospectively recruit patients who met the study criteria.

Patients were considered for inclusion at any stage along the cancer journey (from recently confirmed diagnosis to palliative care) and irrespective of treatment modality.

Inclusion criteria for patients were

- histologically confirmed PBT of any grade or histology,
- aged ≥ 18 years at time of diagnosis and
- cognitively able to complete the measures.

Recruited patients were invited to nominate a relative who might also participate. Family members needed to be first degree relatives who were also ≥ 18 years old at the time of the study. Patients and/or relatives were excluded if

- inability to speak English
- the presence of severe psychiatric or substance abuse issues, as defined by the treating medical consultant.

Measures

Three paper-and-pencil neuro-behavioural rating measures were used (see Table 2.1). The measures were selected because they had all been validated on samples that included people with PBT, with self-rating and proxy report versions. Reliability and validity for the three measures are reported in Table 2.1. One measure of depressive symptoms previously used with brain-damaged populations was also selected. Higher scores indicated higher levels of the target problem on all four measures.

Table 2.1. Measure subscales sampling the three clinical 'syndromes' describing behavioural impairment

Regulation disorders	Activation disorders	Executive Cognitive Function disorders
FrSBE (Three subscales P, R) Disinhibition (15 items, $\alpha = .71$) Impulsive, childish, breaks rules, silly	Apathy (14 items, $\alpha = .72$) Neglect personal appearance, does nothing, lost interest in activities	Executive Dysfunction (17 items, $\alpha = .81$) Disorganised, forgetful, doesn't learn from mistakes, poor attention
ESDQ¹ Anger (P=7 items, $\alpha = .89$) Easily annoyed, irritable Emotional dyscontrol (P=8 items, $\alpha = .92$) Excess or wrong emotional displays Helplessness (P=9 items, $\alpha = .90$) Scared or worried, without hope Indifference (P=8 items, $\alpha = .77$) Lacks sensitivity, doesn't care Inappropriate (P=6 items, $\alpha = .60$) Causes embarrassment, over excitable Euphoria (P=6 items, $\alpha = .65$) Disregard for wellbeing, relationship difficulties, denies problems Maladaptive (R=9 items) Childish, over excited, overtalkative Insight (R=4 items,) Unaware of difficulties noted by others	Fatigue (P=4 items, $\alpha = .70$) Tired, requires more sleep Inertia (P=3 items, $\alpha = .71$) Requiring prompts, lack of interest in activities	
OBS (All categories P,R,C) Verbal aggression (4 items) Shouts at others, makes threats Physical aggression (x3 categories @ 4 items) Aggression against objects, self, others Inappropriate sexual behaviour (6 items) Lewd talk, inappropriate touch, coercive sexual behaviour Wandering/Absconding (6 items) Wander into others rooms, gets lost, escapes secure area Inappropriate social behaviour (5 items) Socially awkward, nuisance, oppositional, danger to self or others	Perseveration (3 items) Repetitious questioning, picks at skin until injured Adynamia (1 item) Needs prompting daily or multiple times daily	

¹ Cronbach's α coefficients calculated for Patient version of the FrSBe and ESDQ subscales.

P=Patient version, R=Relative version, C=Clinician version

Other Relative ESDQ subscales Anger=8 items, Emotional dyscontrol=6 items, Helplessness=8 items, Indifference=7 items, Inappropriate=6 items, Fatigue=4 items

Emotional and Social Dysfunction Questionnaire (ESDQ)¹⁴

The ESDQ is a measure emotional and social dysfunction among brain-damaged populations with a self-rating (51 items) and partner version (52 items) grouped into 8 subscales (e.g. for Partner version - Anger, Helplessness, Emotional Dyscontrol, Indifference, Inappropriateness, Fatigue, Maladaptive, and Insight). Respondents rate all items on a 10-cm visual analogue scale with the anchors being “no problem” and “big problems” producing 8 subscale scores. Exploratory factor analysis for the partner version found an eight-factor solution accounting for 69% of the variance, and similarly, an eight-factor solution for the self-rating version accounting for 64% of the variance. Internal consistency for the self-rating subscales ranged from .79 to .93, and from .78 to .94 for the partner version. Good concurrent validity with other generic measures of emotional functioning was also reported.⁸

Frontal Systems Behaviour Scale (FrSBe)²⁴

The FrSBe is a 46-item paper-and-pencil behavior rating scale that measures impairments of the behavioural and cognitive domains of executive functioning. There are self-rating and partner versions. The FrSBe includes a Total Score, as well as scores on three subscales related to the three frontal systems behavioral syndromes: Apathy (14 items), Disinhibition (15 items), and Executive Dysfunction (17 items). The scale has good reported reliability and validity.

Overt Behaviour Scale (OBS)¹¹

The OBS is a 34 item scale that measures 9 categories of challenging behaviours among brain-damaged populations including aggression, inappropriate sexual behaviour, perseveration, wandering, inappropriate social behaviour, and adynamia. The OBS produces a cluster (0-9), severity (0-34) and clinical weighted severity score (0-77). Inter-rater reliability and stability coefficients for the OBS total score was strong (.97 and .77 respectively). Initial evidence of convergent and divergent validity was shown by the differential pattern of correlations with other measures. Moderate to strong coefficients (range .37 to .66) were observed between the OBS and other measures that had behavioural content. Responsiveness was demonstrated with a significant decrease in OBS scores in the expected direction over the 4-month period.

Depression, Anxiety and Stress Scale (DASS)²⁵

The DASS is a 42-item self-assessment questionnaire that measures state related levels of depression, anxiety and stress. Alpha coefficients for the three scales are 0.91 (Depression), 0.84 (Anxiety) and 0.90 (Stress). The scale's authors also report good convergent validity of the depression and anxiety scales with other measures that discriminate between these two constructs.

Other data

A data protocol was devised to collect information on demographic, clinical and psychosocial variables (see Table 2.1). A clinician-rated Kamofsky Performance Score (KPS)²⁶ (0-100) was also documented.

Materials and Methods

Patients with PBT who met the study criteria were mailed an information letter and followed up with a phone call to ascertain if they wished to participate. After providing informed consent, patients completed the four measures in a face-to-face interview conducted by the study research staff at the hospital's outpatient clinics or at the respondent's home. Patients and relative informants independently completed the measures during the same appointment. Overall, the majority of patients tolerated the test battery well, which took between 30-60 minutes to administer. Only one patient discontinued due to an inability to comprehend items on the measures. No patient discontinued the battery due to fatigue or cognitive overload. Some respondents completed the measures by hand, others through oral administration. Interviewing research staff also rated the respondent on the OBS and KPS. Patient's clinical information for the data protocol were extracted from hospital medical files.

Statistical Methods

Data were entered into SPSS version 17.0. Descriptive statistics were generated for all variables. Inspection for normality found that only two variables from the study measures had non-normal distributions using the criterion specified by Tabachnick and Fidell.²⁷ Following Andrewes et al.¹⁴ a square root transformation was performed on the two subscale scores (Emotional Dyscontrol, Hopelessness, ESDQ Patient version). The subscales then met the criterion for normality, enabling the use of parametric statistics for subsequent analyses.

To report on the prevalence rates, dichotomous variables recording caseness (yes versus no) were generated for the ESDQ, FrSBe and OBS variables. Caseness refers to behaviours that are clinically significant (i.e., require further assessment or intervention).

ESDQ caseness percentages for each subscale represented the number of patient and relative scores that exceeded 95% of the control group Patient and Relative scores respectively (i.e. approximating a score two standard deviations above the control group mean)¹⁴. FrSBe caseness percentages represented scores 1.5 standard deviations (i.e. t-score of 65 or greater) or more above results derived from a non brain-damaged normative sample.²⁴ OBS caseness scores were calculated to represent the most severe behaviours in each of the nine categories.

To examine the relationship between demographic or clinical variables and the 12 behavioural variables (OBS Clinical Weighted Score, the three FrSBe and eight ESDQ self-rated subscale scores) (see Table 2.3), a series of t-tests and three-factor analyses of variance (ANOVAs) were conducted. Independent variables comprised sex, age, treatment timing (time post-diagnosis, treatment stage), tumour features (grade, site, lateralisation), treatment modality (neurosurgical intervention, radiation therapy, radiation dose, chemotherapy), epileptic seizures and use of corticosteroids (see Table 2.2). The significance level was adjusted using a Bonferroni correction (0.05/12, $\alpha=0.004$) in order to control for Type I error due to multiple comparisons.

Various aspects of rating reliability and validity were examined. Internal consistency for the patient reports on the FrSBe and ESDQ subscales was tested using Cronbach's alpha. Reporting patterns for depressed versus non-depressed groups was examined by t-tests, once again applying a Bonferroni correction. In order to focus on significant clinical depression, only patients with DASS cut-off scores in the severe and extremely severe range were allocated to the depressed group. Patients falling in the mild, moderate or no symptom bands were grouped as non-depressed.

Comparison of agreement between relative informants, clinicians and patients was possible for a subset (n=37) of the larger sample. Dichotomous caseness variables were created for the clinician-rated OBS, as well as the relative FrSBe, ESDQ and OBS scales (only the six ESDQ subscales with self and relative versions). These variables were compared to the patient self-report caseness variables. Percentages were generated for four conditions across each variable (patient yes/relative no, relative yes/patient no, patient/relative yes/yes, patient/relative no/no). Finally, Pearson product-moment correlation was employed to examine the association between behaviour variable scores and the KPS score.

Results

In total, 154 patients with PBT from the two hospitals were reviewed and 85 met the inclusion criteria. The remaining 71 were too unwell/cognitively impaired n=41, non English speaking n=5, severe psychiatric problems n=4, not contactable n=21. From the 85, a total of 57 agreed to participate and completed the study protocol, a 67% response rate. Visual inspection of histogram for time post-diagnosis identified 3/57 patients who were outliers (greater than 10 years post-diagnosis) leaving a total sample of 54 patients. Sample demographic and clinical characteristics are detailed in Table 2.2.

Table 2.2: Sample sociodemographic and clinical characteristics of patients with PBT

Variable	Patient (n=54) ¹	Variable	Patient (n=54)
Age (years), Mean (SD) ²	51.8 (16.0)	Neurosurgical intervention, n (%)	
Time post-diagnosis (months), Median (IQR) ²	4.0 (24.0)	Biopsy	12 (22.2)
Sex, n (%)		Resection (gross total or sub-total)	42 (77.8)
Male	24 (44)	Radiation Therapy, n (%)	
Female	30 (56)	Yes	32 (59.3)
Education (years), Mean (SD)	11.5 (2.9)	None	22 (40.7)
Histological diagnosis, n (%)		Chemotherapy, n (%)	
Astrocytoma G1/2	6 (11.1)	Yes	17 (31.5)
Astrocytoma G3	4 (7.4)	Temozolomide	16 (29.6)
Glioblastoma Multiforme	16 (29.6)	Other	1 (1.9)
Oligodendroglioma/		None	37 (68.5)
Oligoastrocytoma	4 (7.5)	Epileptic seizures, n (%)	
Meningioma	15 (27.8)	Yes	25 (46.3)
Other ³	9 (16.7)	No	29 (53.7)
Tumour grade, n (%)		Corticosteroids, n (%)	
High grade	21 (38.9)	Yes	10 (18.5)
Low grade	12 (22.2)	No	36 (66.7)
Benign	21 (38.9)	Unknown	8 (14.8)
Tumour site, n (%)		Depression subscale, DASS, n (%)	
Frontal/Temporal	29 (53.7)	Normal	33 (61.1)
Other	25 (46.3)	Mild	4 (7.4)
Tumour lateralisation, n (%)		Moderate	6 (11.1)
Left-sided	24 (44.4)	Severe	7 (13.0)
Right-sided	22 (40.7)	Extremely severe	3 (5.6)
Midline	8 (14.8)	Mean, SD	9.8 (10.5)
		Karnofsky Performance Score, n (%)	
		100-90	19 (35.2)
		80	23 (42.6)
		70-50	12 (22.2)
		Mean, SD	80.7 (10.6)

¹ For analysis of age and time post diagnosis, group divided by median split ≥ 53 yrs vs < 53 yrs; and ≥ 4 mths vs < 4 mths respectively.

² Other includes Craniopharyngioma n=2, Epidermoid tumour n=1, Ependymoma G2 n=2, Medulloblastoma n=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

⁴ DASS=Depression, Anxiety and Stress Scale

Forty-five family members were identified by patients of whom 37 also participated (For details, see Table 2.3). In the other nine cases, no family member could be identified (n=7) or the relative did not speak English (n=2). Relative informants mean age 48.1 ± 16.2 years, female (n=25, 68%), average years education 12.0 ± 3.2 years, relation to patient spouses (n=26, 70.3%), adult children (n=5, 13.5%), parents (n=4, 10.8%), siblings (n=2, 5.4%).

(i) Prevalence of behavioural disturbance (n=54)

The first column on Table 2.3 provides data on the prevalence of self-reported behavioural disturbances among the patients. Rates of behavioural disturbance that met the various caseness criteria ranged from 7% (Emotional Dyscontrol, Helplessness, Euphoria) to a high of 40% (Executive Impairment). Rates for significant clinical issues including Apathy, Inertia, Anger and Inappropriate Behaviour ranged between 20-35%. These levels of caseness were observed in behaviours associated with disorders of regulation, activation and executive dysfunction.

Table 2.3: Prevalence of behavioural disturbance

Variables	All patients n=54	Family n=37	Clinician n=37
	n (%) case	n (%) case	n (%) case
FrSBe			
Apathy ¹	19 (35.2)	22 (59.5)	
Disinhibition ¹	9 (16.7)	10 (27.0)	
Executive impairments ¹	22 (40.7)	13 (35.1)	
ESDQ			
Anger	11 (20.4)	11 (30.6)	
Emotional Dyscontrol	4 (7.4)	6 (16.7)	
Helplessness	4 (7.4)	6 (16.7)	
Inertia (Patient only)	18 (33.3)	- -	
Fatigue	11 (20.4)	9 (25.0)	
Indifference	5 (9.3)	13 (36.1)	
Inappropriate Behaviour	12 (22.2)	3 (8.3)	
Euphoria (Patient only)	4 (7.4)	- -	
Maladaptive Behaviour (Relative only)	- -	8 (22.2)	
Insight (Relative only)	- -	4 (11.1)	
OBS, category severity score n (%)			
Verbal Aggression	15 (27.8)	10 (27.0)	3 (8.1)
Physical Aggression	9 (16.7)	7 (18.9)	3 (8.1)
Perseveration	8 (14.8)	6 (16.2)	9 (24.3)
Wandering / Absconding	2 (3.7)	2 (5.4)	- -
Inappropriate Social Behaviour	3 (5.6)	4 (10.8)	8 (21.6)
Initiation Problems	14 (25.9)	8 (21.6)	9 (24.3)
Clinical Weighted Score, Mean (SD)	10 (18.5)	5 (13.5)	6 (16.2)

¹ T-scores FrSBe =Frontal Systems Behaviour Scale, ESDQ=Emotional and Social Dysfunction Questionnaire, OBS=Overt Behaviour Scale

Patients also rated their functional level prior to diagnosis on the three FrSBe subscales. Paired t-tests were calculated to examine whether there was any difference in the pre- versus post diagnosis rating scores. Compared to their pre-diagnosis functioning, patients reported significant increases in Apathy (pre-diagnosis mean 49.5 ± 14.0 ; $t=-4.7$) and Executive Impairment (pre-diagnosis mean 51.9 ± 13.6 ; $t=-4.6$) but not Disinhibition (pre-diagnosis mean 51.9 ± 13.6 ; $t=ns$).

(ii) Demographic and clinical correlates of behavioural impairment (n=54)

Results from the analyses testing demographic and clinical correlates of behavioural impairments found that only one clinical variable, epileptic seizure history, demonstrated a consistent pattern of association with the behavioural variables. Patients experiencing epileptic seizures reported significantly higher levels of inertia on the ESDQ ($t=3.3$, $p=0.002$) and Challenging Behaviours on the OBS ($t=3.07$, $p=0.003$). In addition, several other subscale scores were higher in the seizure group at the 0.05 level (FrSBe: Apathy, Disinhibition and Executive dysfunction; ESDQ: Anger, Helplessness and Fatigue). Given these strong findings, the distribution of patients reporting epileptic seizures (yes versus no) across tumour grade (high, low, benign) was examined using a chi-square test. The overall statistic was significant ($\chi^2=6.6$, $p<0.036$) and examination of the raw data indicated a higher than expected number of patients reporting seizures among the low grade tumours. Most of the other analyses were non significant, although patients with a frontal/temporal tumour were more likely to report a higher score on the ESDQ Indifference subscale.

(iii) Reliability in rating behavioural impairment

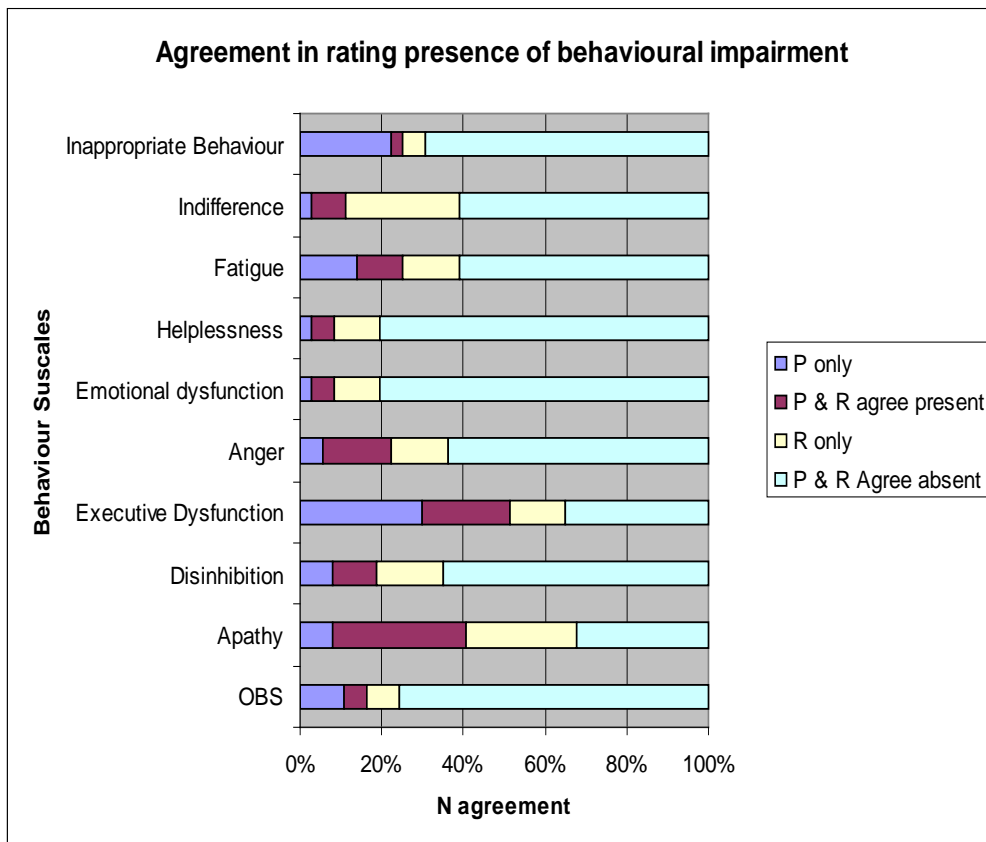
The internal consistency reliabilities for the patient self-reports (n=54) were found to range from adequate to excellent for all ESDQ and FrSBe subscales save Inappropriate Behaviour and Euphoria (see Table 2.1). To examine the influence of depressed mood on behavioural rating patterns, the patient sample was divided into depressed (n=43) and non-depressed (n=10) groups. Results from t-tests found that depressed patients rated their behaviour as significantly worse on two subscales, FrSBe Apathy ($t=-3.0$) and ESDQ Helplessness ($t=-4.1$), with a trend at 0.05 for ESDQ Fatigue and Indifference.

The numbers of relatives, clinicians and patients rating the presence (and absence) of significant behavioural impairment (i.e. caseness) are displayed in Figure 1. The percentages of patients reporting behavioural impairment in the absence of relative reports ranged from 3-29%. The percentage agreement between patients and relative informants on the presence of an impairment ranged from 2-32%. Finally, the percentages of family members reporting impairments which were not identified by patients ranged from 5-26%.

(iv) Functional status as a correlate of behavioural impairment

The patient, relative and clinician ratings (n=37) on the behavioural variables were correlated with the KPS using the Pearson product-moment correlation procedure. There were no significant correlations between the patient self-reported behavioural scores and the KPS. In contrast, there were a number of significant negative correlations between the relative informant behavioural ratings and the KPS at both the $p=0.01$ (FrSBe Apathy $r=-0.48$ and Executive Dysfunction $r=-0.47$; ESDQ Fatigue $r=-0.46$) and $p=0.05$ levels (ESDQ Helplessness $r=-0.38$, Inappropriate $r=-0.37$ and Insight $r=-0.39$). The only clinician-rated score also strongly negatively correlated with the KPS (OBS Clinical Weighted Score $r=-0.55$, $p=0.01$). Age was not a confounding factor, because no association was found between age and behaviour variables.

Figure 2.1. Agreement between brain tumour patients and relative informants in rating presence of behavioural impairment



P = Patients with primary brain tumour
R = Relative informants

Discussion

This study is the first to systematically document the prevalence of a wide range of behavioural impairment after PBT, finding that rates of 7-60% were present at clinically significant levels (i.e. caseness). Notably, the presence of these behaviours was evenly distributed across patients with high grade, low grade and benign tumour diagnoses. This underscores the fact that Challenging Behaviours are a clinical feature for a significant proportion of the PBT population, irrespective of histology, tumour type and treatment interventions delivered.

In particular, there has been little documentation of behaviours characteristic of disorders of regulation. Previous reports have documented elevated levels of anger as a psychological state⁶, but the current report provides detail on the more severe presentation of this serious clinical issue (i.e. verbal and physical aggression). Other types of dysregulation including Indifference and Inappropriate Behaviour have not been previously reported among adults with PBT but are commonly observed among other neurologic populations.¹⁰⁻¹²

More reports have documented disorders of activation such as apathy and the current study reinforces such findings.^{3,5} Similarly, the prevalence of executive cognitive impairments using standardised cognitive tests have also been documented.³ Overall, the prevalence of behavioural impairments is a further reminder of the vulnerability of all regions of the frontal systems and their connections to the effects of PBT.

The strong correlation between behavioural impairment and a history of epileptic seizures was unexpected. However, epileptic seizures are a notable risk factor for more severe cognitive impairment in adults with PBT and similar mechanisms may account for the current results.^{3,5} The significant concentration of seizures in the low grade tumour group is consistent with earlier findings that epileptic seizures were the main effect in this group.²⁸ The even spread of behavioural impairments across high grade, low grade and benign tumours has implications for psychosocial care, as it suggests that neuro-oncology patients with both malignant and benign tumours and their families will need support to manage such deficits.

Patients with PBT demonstrated a moderate degree of accuracy in reporting the presence or absence of the behavioural impairments. Relative informants were able to provide important additional information about the presence of such impairments in a proportion of cases. Finally, some caution needs to be exercised in interpreting the finding of correlations between the behavioural measures and the KPS. It is not clear whether the behaviours are a symptom of lower functional status, or how they play a causative role.

As a consequence, these results highlight and help build awareness for health professionals working in the field regarding these high prevalence rates and the importance of including screening questions about behavioural impairments in clinical assessments.

Chapter Three

Interventions to Address Behavioural & Cognitive Impairments

The second objective of the project was to provide interventions to individual patients and their families who were experiencing difficulties in managing challenging behaviours (CBs). Untreated cognitive/behavioural impairments associated with PBT have the potential to adversely affect functional status and quality of life.¹ As identified from Objective 1, prevalence rates for these impairments are high with patients reporting between 7 to 40% and relatives/carers reporting prevalence rates of between 8 and 60%.

Current research is reporting unmet needs for support and carers in managing CBs.²⁹ Clinicians and families alike have highlighted the lack of knowledge and skills among family members that would enable them to play a more effective supportive role, particularly in managing difficult behaviours and cognitive impairments, as well as the provision of emotional support to the patients.³⁰ The sole evaluated education program published to date was French-Canadian, which had some success in increasing the knowledge and confidence of the carer participants, but did not improve their levels of skill or psychological adjustment.³¹

In order to address these behaviours a 'Behavioural Consultancy' approach was proposed which is a psychosocial intervention to manage the person with CBs within their naturalistic environment. This approach has been found to effective in reducing the impact of CBs in a broader population of patients with brain impairments.^{21,11} The Consultancy approach uses compensatory strategies that can be implemented by the person with a PBT, or utilised by family members (carers) and staff to structure the environment to minimise the impact of CBs.²¹

Aims

1. This study piloted interventions with both the PBT patient and their carer to address CBs after PBT utilising the Behavioural Consultancy model
2. Piloted a family education workshop as a means of increasing management skills
3. Reviewed previous cases that had been treated under this model for treatment efficacy

3.1 Pilot Single Case intervention

Methods

Sample

Participants for the individual and family interventions were recruited from the prevalence study sample (see Chapters 1 and 2).

Nine individual clients who were reporting high levels of CBs following their PBT diagnosis were reviewed for appropriateness of treatment. Eight of the clients reviewed were unable to participate in more comprehensive treatment due to a number of reasons including the symptoms resolving over time, the PBT patient became too unwell or they were unavailable due to return to work or travel commitments.

One case study was undertaken which involved a woman aged 57 who had been diagnosed with a right-sided temporal grade 2 Astrocytoma, five years previously. She had undergone surgical tumour resection and was classed as stable at the time of assessment.

Measures:

The behaviours targeted for change included:

- (i) the time spent talking [minutes, seconds]
- (ii) the number of questions asked and
- (iii) the number of interruptions made while other people were speaking.

Procedures:

The intervention evaluated the efficacy of skill-based training and environmental changes in managing a number of challenging behaviours. Following a brief neuropsychological screen, the following steps were taken:

- client observed in a social situation and baseline measures obtained on the target variables
- individual treatment program designed and implemented by a Clinical Psychologist which involved:
 - education about the CBs and cognitive deficits,
 - teaching of micro skills including: active listening, controlled breathing, and appropriate questioning
 - the participant and her carer were primed with a list of appropriate questions to ask at the next social event, which occurred the day after the intervention
- Participant was again monitored at three and five months post intervention in similar social situations

Results

Clinical Presentation:

The client presented with normal affect but notable behavioural problems relating primarily to communications skills including lack of turn taking, poor conversational quality with excessive and irrelevant detail, over disclosure and perseveration. The client would also fixate on someone and appeared oblivious to social cues that the conversation was boring or to normal conversation termination signals. She demonstrated a lack of insight into her difficulties but was aware that sometimes her family were quite 'rude' towards her.

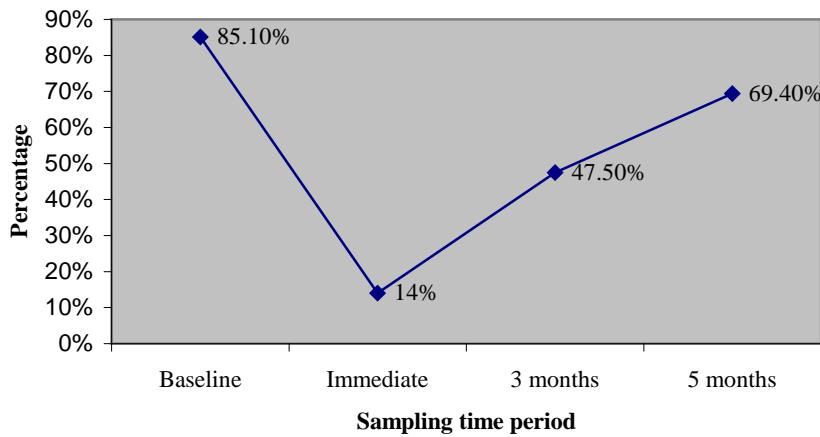
Neuropsychological Assessment:

A brief neuropsychological screen was undertaken which included memory testing, assessment of communication skills including verbal generativity and emotional processing. The results indicated that the client had preserved memory in both the verbal and visual domain but had profound deficits in her ability to process emotional information such detecting lies or sarcasm.

Intervention:

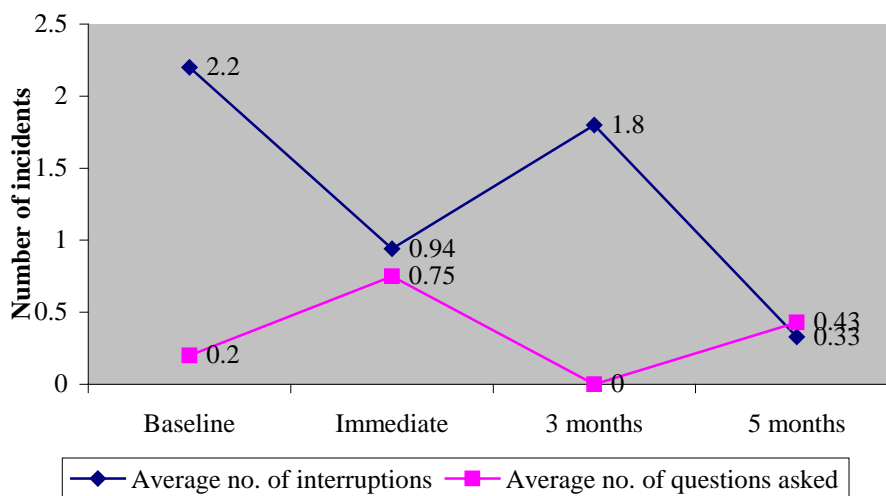
Immediately following the intervention a notable change was observed in all three target behaviours with the improvements degrading over time. With regard to the percentage of time spoken (baseline = 85.1%), initially there was a decrease of 71.1% after the intervention. These improvements then degraded over time as can be seen at 3 months (47.5%) and 5 months (69.4%) post intervention, see Figure 3.1.

Figure 3.1: Percentage of Time Spoken



The average number of interruptions also decreased initially and there was an increase in the number of questions asked as per the required behavioural change. Figure 3.2 gives a graphical representation of the changes.

Figure 3.2: Incidences of target behaviour



3.2 Family Education Workshop

Methods

Sample:

For the carer intervention, all 42 carers who had participated in the broader prevalence study, were invited to attend a Family Education Workshop in the use of compensatory strategies to manage CBs. Seven carers attended the workshop with their family member with PBT.

Measures:

The Strategies Use Measure was a 9-item purpose designed measure. Seven items assessed skills in utilising strategies for managing a range of behavioural and cognitive impairments (e.g. 'using memory strategies', 'using prompts') and two items assessed knowledge of behavioural and cognitive problems after PBT. Respondents completed a 5-point Likert scale for each item (1='very low' to 5 ='very high'). In addition, workshop participants completed a workshop evaluation to provide feedback about the workshop content and process.

Procedures:

Three health professionals including an Oncologist (ESK), Clinical Neuro-surgical Nurse Consultant (KW) and Clinical Psychologist (DW) delivered the half-day workshop. The workshop program comprised five sections:

- (i) Education regarding the reasons for behavioural and cognitive changes,
- (ii) Types of behavioural and cognitive changes experienced following PBT
- (iii) Strategies for managing behavioural and cognitive changes after a PBT
- (iv) Small group discussions about family members' individual experiences of behavioural and cognitive changes
- (v) Opportunity to brainstorm their own strategies for managing these changes in their family members.

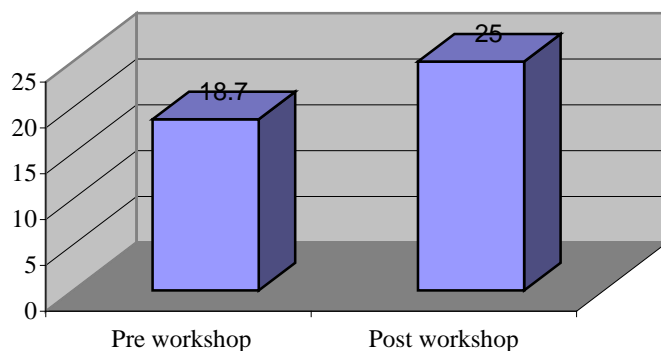
Patients with PBT attended the didactic sessions but were engaged in separate discussion groups to discuss their own experiences with a clinician. A pre-post impact evaluation administering the Strategies Use Measure was employed.

Results

In the family intervention, participants demonstrated significant post-intervention increases in perceived knowledge of Strategy Use ($t = 3.33$, $p < .05$) (see Figure 3.3). The significant result was remarkable given the small number of participants attending the workshop.

Participants also completed a workshop evaluation form. Subjective evaluation on the content and delivery of the workshop was rated between 'good' and 'very good'. Comments included "I am happy I came", "I learnt a lot from the staff and patients", "Support is fantastic". In terms of how the workshop could have been improved, the most common response was for "More time".

**Figure 3.3: Family education workshop:
Knowledge of strategy use pre and post workshop**



Paired sample t-test $t= 3.33, p<.05$

3.3 Retrospective review of Previous Cases treated employing a Behaviour Consultancy Intervention

In addition to the single case design, four PBT patients who had previously undergone treatment in a community setting in another state of Australia using a Behaviour Consultancy approach were retrospectively reviewed. Psychologists with expertise in behaviour management had undertaken the assessment and treatment.

Case Study I

Background: The client was male aged in his mid fifties, married with children, living in his own home and employed part-time in a professional occupation. There was a premorbid history of depression which was treated with medication and recreational drug use. In 1997, he was diagnosed with a pituitary adenoma, managed pharmacologically, and a temporal meningioma, treated surgically. The tumour remained stable on serial MRI scans. Neuropsychological assessments indicated very superior intelligence, with mild fluctuations in attention and some distractibility. There was evidence of average new learning and memory but poor self monitoring and decreasing ability to interpret social cues.

Tumour location: Pituitary and Left Temporal Meningioma

Medication: Cabergoline to control prolactin levels and Testosterone.

Problem Behaviour: Making sexist/racist and other offensive comments on a weekly basis, lack of consideration for others and an inability to pick up on social cues in the workplace despite feedback from employer.

Intervention: Interventions devised and implemented by a clinical neuropsychologist included role plays, coaching, with the goal of taking on of a new work persona, assertiveness skills and finally social skills training and learning self monitoring. In addition the client was referred to a personal counsellor, joined a yoga group and engaged in regular meditation.

Outcome: There was a notable improvement, whereby, the client found employment, successfully held down the job and was contacted by others to undertake more work. The client continued with the individual counselling and the yoga group. The client remained insightful of his cognitive impairments and on self-assessment reported no communication difficulties.

Case study 2

Background: The client is currently single and living with his father. He was previously a full time factory worker, but is now unemployed. There were no reported premorbid psychological or psychiatric issues. The client was diagnosed with a pilocytic astrocytoma in 2000 for which he underwent surgical resection. He was being managed with Carbamazepine and Amisulpride at the time of assessment.

Problem Behaviour: Post-operatively, the client was noted to have a decrease in cognition, dysarthria and was more irritable. Furthermore, the client demonstrated verbal aggression on a daily basis, shoplifted and damaged a store. Neuropsychological tests indicated a decrease in intelligence, attention, memory and poor executive functioning.

Intervention: The client had not received any previous rehabilitation or intervention following his surgery. Following an assessment, the client was provided with individual counselling to address his psychological distress, in addition environmental changes were implemented. This included the development of more structure through participation in regular activities and supervision when attending the shops.

Results: As a result of these simple interventions, no further issues were reported. This included a total cessation of stealing behaviour and physical aggression, with reports of verbal aggression reducing to no more than once a week.

Case study 3

Background: The client was married with no children, lived in her own home and premorbid employment was in a full time professional position. The client was diagnosed with a craniopharyngioma in August 2006. The client underwent surgical resection in December 2006 followed by adjuvant radiation and then underwent second surgery for recurrence in May 2007. Following treatment, the client developed blindness and diabetes. She was unemployed at the time of assessment.

Problem Behaviour: The client demonstrated a number of CBs which included: verbal aggression on a daily basis, perseverative behaviour, lack of initiation and refusal to do things. The client underwent neuropsychological testing which indicated that she had difficulties in sustaining attention, impaired reasoning, organisation and in her delayed recall and was demonstrating confabulation.

Intervention: The client had been taking both insulin and thyroxine and a testosterone implant was then implanted. A number of enjoyable activities were organised to give the client a more structured environment and to increase her social interaction. This included a fitness program, computer and gardening activities. Information on managing the client's challenging behaviours and respite services were provided to her husband and family members. The client was also provided with a support worker and prescribed anti depressant medication. She was issued with a personal organiser to assist in time management and provided with behavioural guidelines referred to as rules of engagement.

Results: As at September 2008, the client's problem behaviour had settled. The client's verbal aggression had reduced to once a month, repetitive questions were asked once a week, non-compliance only occurred once per week but the lack of initiation remained unchanged.

Case study 4

Background: The client was divorced with one child and lived with his parents. His occupational duties included outdoor work, such as truck driving and tree planting for the council. In 2000, the client was diagnosed with a left parietal anaplastic astrocytoma.

Medical Treatment: The client underwent surgical resection, adjuvant radiation therapy followed by adjuvant chemotherapy for 10 months.

Problem Behaviour: The client's problem behaviours included a range of sexually inappropriate behaviour which he tended to exhibit in the work place. This included sexual talk once a month, surprising his female co-workers with kisses once a month, encroaching on people's personal space by standing too close and bringing pornographic magazines to his workplace which he would show to his co-workers. Neuropsychological testing showed a decrease in reasoning, working memory, organisation, memory and new learning.

Intervention: The client had received no rehabilitation after his tumour and only vocational rehabilitation from an employment agency. The client and his father received coaching on client's inappropriate sexual behaviour with regard to the sexual harassment laws. The client explored more acceptable sexual outlets, received education on appropriate behaviour in the workplace and information on case management/ leisure options.

Results: No further incidents were reported and the file was closed after six months.

Discussion

The pilot trials and case studies provide an initial indication that psychosocial methods in a Behavioural Consultancy approach can be an effective treatment for behavioural/cognitive impairment in a PBT population.

At the individual level, a reduction in the problem behaviours were demonstrated after a short and focussed behavioural intervention that was provided to both the PBT patient and a family member. Similarly, the case reports from the Consultancy service also suggest that this approach can be effective. There are two issues that arise from these case studies that are relevant for future research:

- Given the unique nature of each case, it is not clear that randomised controlled trials will be a viable approach to further testing the efficacy of these types of interventions. However, further single case studies with rigorous design meeting gold standard criteria³² will build further evidence of the efficacy of such individualised approaches.
- The degrading of performance after the initial favourable impact suggests that the original intervention needed to be more intensive; that including close family members in the training of program principles was an important means to maintain the program structure, or that booster sessions might be needed.

Intervention at the carer level through the provision of psycho-education provides preliminary support that such workshops may enhance the care of PBT patients by carers having increased knowledge of strategy use. This intervention addresses the experience of spouses who find that managing emotional disturbances and behaviours without adequate knowledge and skills is problematic³³. Future studies can further examine the efficacy by:

- Testing the efficacy of the intervention by conducting a randomised controlled trial with a comparison group receiving an Information Resource only
- Using a broader range of measures
- Undertake more extended follow-up past the immediate post-workshop impact results
- Develop objective measures to establish and test skill acquisition rather than self-report alone

Overall, these pilot interventions indicate that a Consultancy approach is a feasible and potentially effective approach and should be tested as per the suggestions outlined above.

Chapter 4

Managing challenging behaviours after brain tumour: An Information Resource for patients, family and health providers

The behavioural and cognitive changes after PBT can result in a number of negative effects for relatives. Qualitative research has suggested that coping with personality change cause anxiety in relatives.³³ Spouses have reported that the erratic emotional behaviour of their partner was the most difficult to deal with due to lack of knowledge and skill.³⁴ Relatives have asked for information on how to deal with cognitive deficits and behavioural changes^{31,35-36} and recent reviews have also identified that relatives and patients need support in this area.³⁷ Despite this, the same studies have found that (i) there is a lack of information about such changes; (ii) that when such information is available, it is often disorganised and fragmented; and (iii) this information is rarely tailored to the individual needs of relatives.

Utilising the data elicited from the prevalence study (Ch 2) and the interventions, (Ch 3) it was proposed to develop a comprehensive set of information resources.

The principles underlying this objective were:

- (i) Readability – the resource should meet recognised standards for communication of health information.
- (ii) Accessibility – the resources should be easily available without cost in electronic and hard copy.
- (iii) The resources have the capacity to be tailored to individual needs.
- (iv) The resources have a dual focus on patient and family.

Reinforcing the need for these information resources, the prevalence component of the project (Objective 1) found via carer-report that between 7% and 60% of people with brain tumour (PBT) displayed some degree of CB including executive impairment, behavioural disturbance, or social/emotional dysfunction.

Review of existing resources

A structured review was conducted to identify information resources addressing behavioural and cognitive sequelae. Databases were searched for articles published in peer review journals using search terms such as brain tumour, neoplasm, cognition and behavioural impairments. In addition, to identify patient information resources, we searched the internet using Google and Google Scholar, and followed by a snowballing technique using links on relevant websites identified in the initial search. The two search terms employed were 'cancer organisations' and 'brain tumour organisations'. Websites related to these subjects were then reviewed with a focus on information relating to 'brain tumour changes', 'behavioural changes', 'cognitive changes' and 'management strategies'.

Seventeen key English language information resources (web-based or hard copy) on BT from Australasia, North America and the United Kingdom were reviewed to quantify the amount of information describing cognitive and/or behavioural changes and strategies for managing these changes. Fifty three per cent of the resources contained minimal or no information about cognitive/behavioural changes after PBT. When looking at strategies to manage the changes, 71% of resources contained minimal or no information at all.

Table 4.1: Review of Existing Cancer / Brain Tumour Information (n=17)

Information Content	Information available		
	Yes	Minimal [†]	None
Behaviour	47%	29%	24%
Cognition	42%	29%	29%
Strategies	29%	18%	53%

[†]Minimal: 1 or 2 sentences

Development process

Initial topics and consultation

With input from the prevalence study and the clinical experience of the project team, 16 information topics were identified for the information resource. A template was also developed to guide the structure for each of the 16 topic areas. In addition, a number of additional resource topics were identified that comprised broader meta-strategies relevant to managing a number of the behavioural and cognitive changes.

The template for each sheet included:

- definition of the problem
- prevalence statistics
- symptom list
- de-identified case-study
- self-management strategies for the person with PBT and carer(s)
- management strategies for the carer
- key questions to ask health professionals and
- web-links to further information

After the initial drafts of the information sheets and resource topics were completed they were circulated for consultation. Specifically:

- A focus group comprising of family members and people with PBT spent a half-day session reviewing the drafts and providing feedback to the project team
- Drafts were circulated to medical, nursing and allied health staff of the CI NSW Neuro-oncology Group (NSWOG), a state-wide network of expert health professionals
- A review was also conducted by staff at the Cancer Institute NSW

Readability analysis of initial drafts

Following modifications based on the feedback, a readability analysis was undertaken using the Flesch-Kincaid readability index Grade 7 reading age as the benchmark (equivalent to the reading age of an average 13 year-old). Analysis of the existing drafts for 10 of the Fact sheets found a mean readability index of 9.7 (range 7.7-12.0), three to five grades higher than our target benchmark. The sheets were revised to improve readability and a second readability analysis found that all sheets then met the Grade 7 benchmark. Finally, the sheets were formatted using disability-friendly design principles. See Figure 4.1 for examples of the final product.

Additional resources

In addition to the information and strategies reported in the Fact sheets, a Clinical Psychologist (DW) developed 11 additional resource sheets. These provided more complex strategies as well as meta-strategies that could be applied to a number of the cognitive/behavioural impairments. Topics include: anger management, stress management, relaxation, activity scheduling, coping with depression, mindfulness, goal setting, memory tips, timetabling, checklist for getting ready and problem solving.

Fact sheet topics

The fact sheets address the following 16 topics.

Fact Sheet Title

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

Who has utilised these resources?

The resource is available free of charge in both hard copy and electronic formats. The hardcopy version comprises a folder with a collation of the 16 Fact sheets and additional resource sheets. Patients and their families can thus access the full resource or select the sheets that meet their specific needs. Similarly, the resource has also been created into CD format with each Fact Sheet as a separate file. The resource can also be accessed from the web.

Website: http://www.cancerinstitute.org.au/cancer_inst/patients/

Over 100 requests for the resources have been received and the sheets disseminated to:

- Neurosurgical units
- Cancer Therapy Centres and networks
- Community-based cancer support staff
- Royal Australasian College of General Practitioners
- Cancer consumer/survivor networks
- Palliative Care services and facilities

Future plans

An e-mail feedback feature has been installed on the website to enable the authors of the Information Sheets can be contacted by anyone using the resources who have inquiries.

In 3-5 years it may be timely to review the resources, and use collated feedback to write up a new edition of the Information sheets.

Figure 4.1: Examples of the information resources

Chapter 5

Provide a training program for Health Professionals

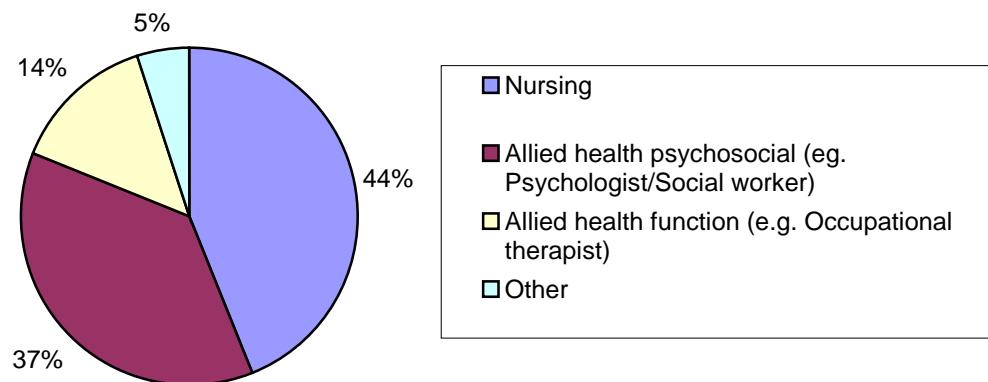
The fourth objective of the research was to provide education on CBs to health professionals working with patients suffering from PBT. The need for specialised training to work with people who have behavioural and cognitive impairments has been addressed in the broader neurorehabilitation literature.²³ A systematic review of the literature indicated that appropriate training for staff working with PBT patients and their families is currently lacking³⁷ with staff feeling at a loss in managing the changes after PBT.³⁰

Method

Sample

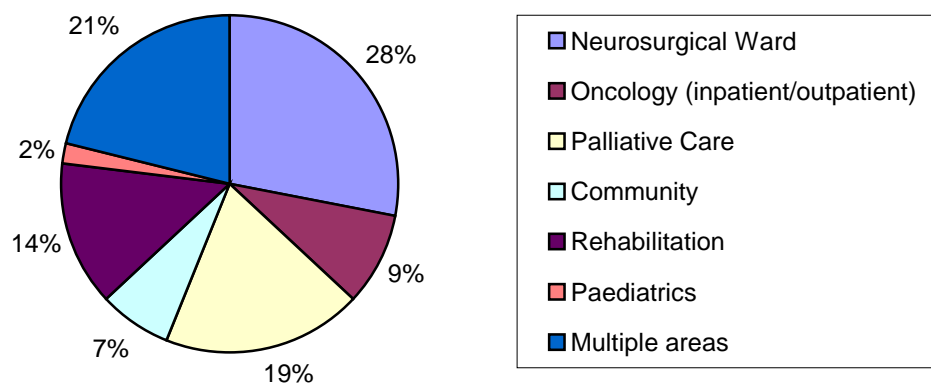
Allied health staff (n=46) from neurosurgical and cancer services were recruited to attend a one-day training workshop in the Consultancy approach. A total of 43 participants completed the workshop questionnaires, a 93% return rate. This consisted of 38 females and 5 males who had worked in the area of brain tumours between 0 – 20 years (M=7.49). They came from 5 different area health services across NSW in addition to organisations external to the health service. The majority of attendees at the workshop were from a nursing background with the actual percentages detailed in Figure 5.1.

Figure 5.1: Percentages of participants by profession



Participants of the workshop came from a range of work environments including inpatient, outpatient and community organisations. The breakdown of participants by work organisation is identified in Figure 5.2.

Figure 5.2: Percentage of participants by work organisation



Measures

A purpose-designed 16-item Strategies Use Measure was devised to assess workshop outcome. Strategy Use encompassed items such as 'providing praise for positive behaviours', 'giving prompts / providing cues' and 'modifying the physical environment'. Items were rated on a 5-point Likert scale (where 1 = 'very low' and 5 = 'very high') measuring the participant's skills and knowledge in managing CBs.

A workshop evaluation form was also devised allowing participants to evaluate all sections of the workshop using a 5-point Likert scale (where 1 = very poor and 5 = very good) and also give the opportunity to provide qualitative information about the areas for improvement.

A protocol eliciting demographic information about the participant was also administered and included information about their profession, years of experience working with brain tumour patients and work location.

Procedures

Program: The workshop ran for 6 hours with the program delivered by a multi-disciplinary team including a Clinical Nurse Consultant (KW), Senior Social Worker (GS), Clinical Neuropsychologist (Guest speaker) and Clinical Psychologist (DW). The topics covered in the workshop included:

- The journey of a brain tumour patient
- A description of challenging behaviours
- An outline of the prevalence of behavioural and cognitive sequelae of PBT
- Strategies for dealing with the behavioural and cognitive changes following PBT
- The Golden Rules of behaviour management and the Behavioural Consultancy Model
- A case study presentation on using an intervention with a PBT patient

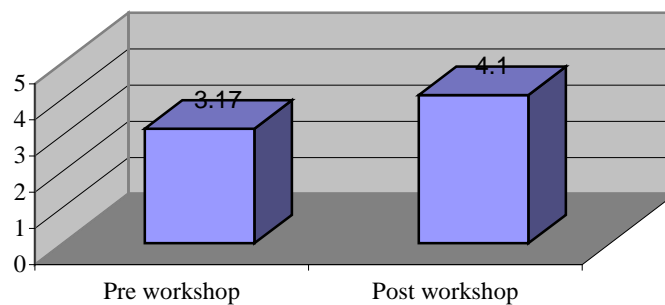
Participants also engaged in a group activity that involved the development of a management plan for three different case studies in PBT patients demonstrating challenging behaviours. The group exercise was facilitated by staff involved in the research project and coordinated by the Clinical Neuropsychologist.

Evaluation: Staff completed the data protocol and Strategy Use Measure prior to the workshop commencing. At the end of the day, they completed the post-version of the Strategy Use Measure as well as the workshop evaluation.

Results

Staff attending the full-day workshop indicated a significant improvement in their knowledge about managing behavioural and cognitive changes when compared to prior to the workshop ($t = -10.76, p < .001$) (see Figure 5.3). Results from the workshop evaluation indicated that the training was well received by participants, with scores for all workshop sessions rated greater than 4 (on a scale 1 = very poor to 5 = very good).

Figure 5.3 : Health professionals' knowledge of strategy use pre and post workshop



(Paired sample t-test $t = 10.76, p < .001$)

Workshop Evaluation by Participants

The workshop appeared to be well received by participants (n=40) with all sections of the presentation, on average, being rated more than 4 (where 1 = very poor and 5 = very good). Improvements as suggested by participants are displayed in Table 5.1.

Table 5.1 Improvements suggested by participants

Suggested improvements	% of responses (No.)
Logistics such as venue, font size, timing, more speakers, criticisms of presentation style	21% (7)
Information about acute care setting	17% (5)
Provision of resources such as the fact sheets (not available from the printers at the time of the workshop)	9% (3)
Information about drugs/medication	9% (3)
More detail wanted including statistics, skills/ strategies, frameworks, more evidence-based information, more case studies.	28% (9)
More information on PBT – types, progression, different treatment for different types of PBT	9% (3)
More information on forensic systems after PBT - eg guardianship	3% (1)
Broader examples	3% (1)
Nurse based management	3% (1)

In completing the workshop evaluation form, participants identified what they had gained from the workshop (see Table 5.2) and what they liked about the workshop (see Table 5.3).

Table 5.2: Workshop Evaluation – “Something I can do better”

Area of perceived improvement	% of responses (No.)
Improve patient care	14% (6)
Improved knowledge	26% (11)
Improved skills	40% (17)
Increased confidence	5% (2)
Ability to educate other staff/ carers	14% (6)

Table 5.3: Workshop Evaluation – “What I liked the best”

Comment	% of responses (No.)
Information content of the workshop	38% (27)
Qualities of the speakers	15% (11)
Venue	4% (3)
Resources	11% (8)
Opportunity to network	4% (3)
Support and reassurance	4% (3)
Group work, activities	28% (9)
Structure of the workshop	7% (5)
Overall workshop and other comments	4% (3)

Discussion

The pilot training program for health professionals was generally well received by participants and the comments provided will be incorporated into future training programs. This will include:

- provision of a case study of challenging behaviours in an acute care or inpatient setting in addition to the community based case studies
- more information about the reasons for the development of CBs, and
- provision of the information sheets at the time of the workshop rather than have them mailed to participants at a later date

The workshop requires further evaluation with amore rigorous pre-, post-work and follow-up design, and the use of a comparison group who receives no training (or information sheets alone). Finally, finding some options for the in-vivo testing of skill acquisition (e.g. role plays) rather than pencil and paper self-report would strengthen the validity of the findings.

Chapter 6

Clinical implications, models of care and future research directions

Overall, the findings relating to the substantial prevalence rates of behavioural and cognitive impairments have several implications for models of acute and longer-term psychosocial care for patients with PBT. However, any such discussion based on the findings of this project need to be prefaced with the following qualifications.

First, the study was cross-sectional and studied PBT patients across a range of trajectories, from newly diagnosed to long-term survivors. Results from this project are still preliminary and need to be replicated in a longitudinal study in a broader population, ideally with a comparison group in another cancer site. This will help clarify whether such impairments fluctuate and resolve during the recovery phase after treatment, or are part of the longer-term effects of the tumour and treatment interventions delivered.

Second, it is important to note that the current prevalence rates may be conservative, as few patients, particularly in the high grade sub-group who had progressive or recurrent disease elected to participate in the study. Although this reflects one of the methodological challenges in studying this patient population, the sub-group of high grade glioma patients may well include some of the most impaired, and furthermore represent the patient group with potential to most benefit from brief, appropriate targeted interventions in keeping with their life expectancy. Conversely, this study has found that indeed patients with benign PBT diagnoses and low grade patients with longer survivorship trajectories also demonstrated behavioural impairments and executive dysfunction. It maybe therefore that different tailored interventions need to be developed that adequately reflect the broad spectrum and anticipated life expectancies of various neuro-oncology patients.

Third, the correlation between behaviour impairments and cognitive functioning needs exploration, as well as the impact of behavioural impairments on health-related quality of life.

Given these qualifications, it is important to ask how well do current service systems and models operate in identifying and treating behavioural and cognitive impairments. A number of service initiatives have been developed to provide support to enhance survivorship and quality of life after PBT. The service models that address follow-up documented in the literature include medical follow-up in outpatient clinic; a doctor and nurse outpatient follow-up; nurse provided phone-based outpatient follow-up; holistic rehabilitation/therapy services and neuropsychological rehabilitation. However, few of these services have been devised to support patients with PBT and their families in addressing the problems of behavioural impairment and executive dysfunction.

Within the Australian context, the higher than anticipated levels of behavioural impairment and executive dysfunction pose challenges for existing medical and psychosocial care systems. The literature documents lack of staff knowledge, skills and thus confidence in both assessing and then managing behavioural impairments in particular.³⁰ Even health care professionals including clinical psychology and allied health staff dealing with the cancer population may lack the specific skills to effectively address behavioural management issues. Therefore, it is important to examine means of upgrading the existing service system capacity to efficiently detect and then respond in such cases.

With respect to the improved assessment and detection of behavioural impairment, the possible options include selecting a series of validated measures from existing neuro-cognitive batteries. In addition, these neuro-cognitive measures could well be supplemented with various behavioural measures. As a direct result of the current project, a spin-off study is currently underway attempting to identify the optimal screening measures to detecting cognitive (Montreal Cognitive Assessment tool; MoCA³⁸) and behavioural (Overt Behaviour Scale-Screen; OBS-Screen) impairments after PBT. The study is also examining the relationship between these impairments and QoL in functional, affective and participation domains. Results of this project will form a guide as to which brief screening behavioural and cognitive tools might be used optimally to screen for behavioural impairment to allow for targeted interventions in affected patients.

The subsequent challenge is to develop interventions, whether psychological or pharmaceutical, to effectively manage such issues when they arise.³⁰ In cases where a significant impairment is identified, referral to a dedicated Neuropsychologist or a Behavioural Consultancy service may be required. However, given the limited access and availability of this specific group of health professionals nationally, particularly in regional areas, a more pragmatic strategy may be to up-skill various health professionals already working in the field. To this end, the workshop trialled in the current project may form the template for the development of broader state-wide training initiatives. A further area of investigation is to pilot a psycho-educational intervention building elements from the patient and carer workshop and utilising the educational resources (Fact sheets) developed. Furthermore, any psycho-educational intervention would ideally need to be highly transportable, and potentially deliverable in both metropolitan and rural settings by staff from medical, nursing or allied health in a manner which was cost-effective.

In terms of delivering such interventions, a multi-disciplinary team approach is still considered the optimal. This may also mean the development of partnerships with agencies outside the neurosurgery/cancer service spectrum. It is important to note that this project was produced through an interdisciplinary collaboration, combining the knowledge, skills and experience of two Neurosurgical Departments, Cancer Therapy Services and a local Brain Injury Rehabilitation Unit. Finally, although the focus of this project has been on PBT patients, some of the broader results detailing these behavioural impairments and executive cognitive dysfunction may well be relevant to other cancer sites, or those suffering from treatment-related cognitive impairments, or to patients with brain metastases.

This project has been important in bringing attention to the prevalence of behavioural and cognitive impairments among patients with a PBT and in the development of suitable resources to manage these changes. In addition it has highlighted a number of promising areas for future research. It is a tribute to the Cancer Institute that they were able to see the value of this area of study and also able to provide sufficient funding to complete the project.

References

1. Heimans JJ, Taphoom MJB. Impact of brain tumour treatment on quality of life. *J Neurol*. 2002; 249: 955-60.
2. Levin VA, Leibel SA, Gutin PH. Neoplasms of the central nervous system. In: De Vita VT, Hellman S, Rosenberg SA, editors. *Cancer: principles and the practices of oncology*. Philadelphia PA: Lippincott Raven, 1997: 2022-82.
3. Taphoom MJB, Klein M. Cognitive deficits in adult patients with brain tumours. *Lancet Neurol*. 2004; 3: 159-68.
4. Brown PD, Jensen AW, Felten SJ, et al. Detrimental effects of tumor progression on cognitive function of patients with high-grade glioma. *J Clin Oncol*. 2006; 34: 5427-33.
5. Klein M, Taphoom MJB, Heimans KK, et al. Neurobehavioural status and health-related quality of life assessment of adults with primary malignant brain tumours. *Int J Radiat Oncol Biol Phys*. 2003; 55: 992-99.
6. Taphoom M, Heimans JJ, Snoek FJ, et al. Assessment of quality of life in patients treated for low grade glioma: A preliminary report. *J Neurol Neurosurg Psychiatry*. 1992; 55: 372-76.
7. Schultz KAP, Ness KK, Whitton J, et al. Behavioural and social outcomes in adolescent survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2007; 24: 3649-56.
8. Stuss DT, Gow CA, Hetherington CR. "No longer gage": Frontal lobe dysfunction and emotional changes. *J Consult Clin Psychol*. 1992; 60: 349-56.
9. Cummings JL. Fronto-subcortical circuits and human behaviour. *Arch Neurol*. 1993; 50: 873-80.
10. McKeith I, Cummings J. Behavioural changes and psychological symptoms in dementia disorders. *Lancet Neurol*. 2005; 4: 735-42.
11. Kelly G, Todd J, Simpson G, et al. The overt behaviour scale (OBS): a tool for measuring challenging behaviours following ABI in community settings. *Brain Inj*. 2006; 20: 307-19.
12. Comaggia CM, Beghi M, Provenzi M, et al. Correlation between cognition and behaviour in epilepsy. *Epilepsia* 2006; 47: 34-39.
13. Prigatano GP. Personality disturbances associated with traumatic brain injury. *J Consult Clin Psychol*. 1992; 60: 360-68.

14. Andrewes DG, Kaye A, Aitken, S, et al. The ESDQ: A new method of assessing emotional and social dysfunction in patients following brain surgery. *J Clin Exp Neuropsychol.* 2003; 25: 173-189.
15. Turner-Stokes L. Evaluation of the evidence for rehabilitation following acquired brain injury. *Brain Impair.* 2005; 6: 161-8.
16. Cicerone KD, Dahlberg C, Kalmar K, Langenbahn, DM, Malec JF, Bergquist TF, et al. Evidence-based cognitive rehabilitation: Recommendations for clinical practice. *Arch Phys Med Rehabil.* 2000; 81: 1596-1615.
17. Bell KR, O'Dell MW, Barr K, Yablon SA. (1998). Rehabilitation of the patient with brain tumour. *Arch Phys Med Rehabil*, 79 Suppl 1: S37-46.
18. Haut MW, Bloomfield SM, Kashden J, Haut JS. Brain tumours. In Frank RG, Elliott TR, editors. *Handbook of rehabilitation psychology.* Washington, DC: American Psychological Association. 2000. p. 359-76.
19. Sherer M, Meyers CA, Bergloff P. Efficacy of postacute brain injury rehabilitation for patients with primary malignant brain tumours. *Cancer*, 1997; 80: 250-257.
20. Meyers CA, Boake C, Levin, VA, Ratcliff DD. Symptom management, rehabilitation strategies, and improved quality of life for people with brain tumours. In Levin VA, editor, *Cancer in the nervous system.* New York: Churchill Livingstone; 1996. p. 449-62.
21. Todd J, Loewy J, Kelly G, Simpson GK. Managing challenging behaviours after acquired brain injury: How to put in place interventions that work. *Brain Impair.* 2004; 5: 42-52.
22. Kelly G, Brown S, Hoskin K. Brain injury and mental health issues: Managing challenging behaviours. 29th Annual Conference of the Australian Society for the Study of Brain Injury, Sydney. 2006.
23. Jackson H, Manchester D. Towards the development of brain injury specialists. *NeuroRehabilitation.* 2001; 16: 27-40.
24. Grace J, Malloy P. *Frontal Systems Behaviour Scale.* Lutz, Florida: Psychological Assessment Resources, Inc; 2001.
25. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: MacLeod CM, Editor. *Evaluation of Chemotherapeutic Agents.* New York, NY: Columbia University Press; 1949. p.191-205.
26. Lovibond SH, Lovibond PF. *Manual for the depression, anxiety, stress scales.* Sydney, Australia: Psychology Foundation; 1995.
27. Tabachnick BG, Fidell LS. *Using multivariate statistics.* 3rd ed. New York: HarperCollins; 1996.

28. Wessels PH, Weber WE, Raven G, et al. Supratentorial grade II astrocytoma: biosocial features and clinical course. *Lancet Neurol.* 2003; 2: 395-25.
29. Edvarsson, T., Ahlstrom, G. Being the next of kin of a person with a low-grade glioma. *Psychooncology.* 2008; 17: 584-91.
30. Catt S, Chalmers A, Fallowfield L. Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncol.* 2008; 9: 84-91.
31. Cashman R, Bernstein LJ, Bilodeau D, Bovett G, Jackson B, Yousefi M, et al. Evaluation d'un programme d'education a l'intention des soignants des personnes diagnostiquees d'un gliome malin. *Can Oncol Nurs J.* 2007; 11-15.
32. Tate RL, McDonald S, Perdices M, Togher L, Schultz R, Savage S, et al. Rating the methodological quality of single-subject designs and n-of-1 trials: Introducing the Single-Case Experimental Design (SCED) Scale. *Neuropsychol Rehabil,* 2008; 18:385-41.
33. Salander P. Brain tumor as a threat to life and personality: The spouse's perspective. *J Psychosoc Oncol.* 1996; 14: 1-19.
34. Sherwood PR, Given BA, Doorenbos AZ, Given CW. Forgotten voices: Lessons from bereaved caregivers of persons with a brain tumour. *Int J Palliat Nurs.* 2004; 10: 67-75.
35. Janda M, Eakin EG, Bailey L, Walker D, Troy K. Supportive care needs of people with brain tumours and their carers. *Support Care Cancer.* 2006; 14: 1094-103.
36. Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro Oncol.* 2008; 10: 61-72.
37. Davies E, Higginson IJ. Communication, information and support for adults with malignant cerebral glioma: a systematic literature review. *Support Care Cancer.* 2003; 11: 21-29
38. Nasreddine ZS, Phillips NA, Bedirian V. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005; 53: 695-99.

Appendix I

Dissemination of Research

Project Awards

The Neurosurgical Society of Australasian prize, *Australasian Neuroscience Nurses Association Conference*, 22-24 October 2008, Sydney.

COSA Best of the Best Poster presentation, *Clinical Oncology Society of Australia 2008 Annual Scientific Meeting*, 18-20 November, Sydney.

Nominated, Hoshima Young Investigator Award, *3rd Quadrennial Meeting of the World Federation of Neuro-Oncology, 6th Meeting of the Asian Society for Neuro-Oncology (ASNO)*, May 11-14, 2009, Yokohama, Japan.

Published Abstracts

Simpson GK, Koh E-S, Simpson T, Wright K, Firth R, Whiting D, Younan K. The impact of cognitive and behavioural sequelae in patients with primary brain tumours on family members. *Asia-Pacific Journal of Clinical Oncology*, 2008; 4 [Suppl 2]: A136.

Koh E-S, Simpson GK, Whiting D, Wright K, Simpson T, Firth R, Younan K. Patient functional status is strongest correlate of challenging behaviour after brain tumour, *Neuro-oncology* (in press).

Simpson T, Wright K, Whiting D, Simpson GK, Koh E-S, Firth R, Younan K. Managing challenging behaviours after brain cancer: a resource for patients, carers and health providers. *Neuro-oncology* (in press).

Whiting D, Simpson GK, Koh E-S, Simpson T, Wright K, Firth R, Younan K. Multi-tiered intervention study for patients, carers and health providers to address challenging behaviours after brain tumour. *Neuro-oncology* (in press).

Conference presentations (oral and posters)

2009

Simpson GK, Koh E-S, Simpson T, Wright K, Firth R, Whiting D, Younan K. The prevalence of behavioural sequelae in patients with primary brain tumour and the development of information resources. *The 10th Quadrennial Congress of the World Federation of Neuroscience Nurses*, Toronto, Canada May 23-27, 2009. [Poster]

Invited Workshop (In preparation)

Koh E-S, Whiting D, Agar M, Krishnasamy M. Workshop: Cognitive and Behavioural Impairment in Cancer: Reasons and Resources for Management. *Clinical Oncology Society of Australia, 2009 36th Annual Scientific Meeting*, Gold Coast, 17-19 November.

2008

Wright KM, Simpson GK, Firth R, Simpson T, Whiting D, Koh E-S, Younan K. The prevalence of cognitive and behavioural sequelae of adults with a Brain Tumour. *Australasian Neurosciences Nurses Association 36th Annual Scientific Meeting*, 22nd to 24th October, 2008, Bondi, Sydney

2007

Wright KM, Simpson GK, Firth R, Simpson T. Addressing the cognitive and behavioural sequelae of adults with a Brain Tumour. *Australasian Neuroscience Nurses Association 35th Annual Scientific Conference*.

Related Presentations

Wright, KM. "The Prevalence of Cognitive and Behavioural sequelae of adults with a Brain Tumour- Trialling a Behaviour Consultancy model". Final report presentation to NSWOG Committee / Brain Tumour "Round Table" 13 February 2009.

Wright KM. "The Prevalence of Cognitive and Behavioural sequelae of adults with a Brain Tumour- Trialling a Behaviour Consultancy model". Liverpool Hospital Advance Practice Nurse/Midwife Committee Meeting Presentation 12 November 2008.

Wright KM. "The Prevalence of Cognitive and Behavioural sequelae of adults with a Brain Tumour – How to turn a Clinical Problem into a research project". Graduate Certificate in Neuroscience Nursing – University of Technology, Sydney, 5 November 2008.

Koh, E-S, Wright KM. "Re-training the Brain: A cognitive behavioural intervention for neuro-oncology patients". Medical Grand Rounds, Liverpool Hospital, 10 October 2008.

Other dissemination (Fact Sheets)

Japanese Brain Tumour Association have expressed an interest in translating the Fact Sheets

Peer reviewed journals (submitted)

Simpson GK, Koh E-S, Whiting D, Wright KM, Simpson T, Firth R, Younan K. Prevalence and correlates of behavioural impairment after primary brain tumour. *Neuro-oncology*.

Non-Peer reviewed journals

'Synapse' - Official Journal of the Brain Injury Associations of Australia, June 2009

Behaviours that Challenge Our Understanding. (Reprint of Anger Management Fact Sheet) See Appendix II.

Appendix II

Excerpt from 'Synapse' Official Journal of the Brain Injury Associations of Australia June 2009, 29-30.

ANGER MANAGEMENT

Your anger is a normal human feeling. Everyone experiences anger, and it can serve some useful functions. The aim of anger management is to express your feelings but to stay in control whenever possible. You can learn to use various strategies for managing anger and staying in control.



1 IDENTIFY TRIGGERS

Anticipate situations where you are more likely to experience anger. This can be different for each person, but you will begin to see what is likely to trip an angry outburst. Examples can include noisy environments, at the end of the day when feeling fatigued, and 'hot' topics which

cause an intense emotional response. Over a period of a week, record your moods, and note the situation when you felt angry or lost control. If you can avoid this situation, do so, or make changes to the situation so it will be less stressful.

For example, turn off the television when you have a conversation with someone, undertake tasks when you are feeling less fatigued, avoid topics that cause strong emotion, and educate your family on these issues.

2 EARLY WARNING SIGNALS

Learn to identify the early signals that you are becoming angry to alert you to use strategies in order to stay in control. Learning to recognise when one is angry involves understanding the 'signals' that are often indicators that emotions are high. The key to recognising these early signals is to develop self-awareness. Strong emotions like anger have three parts: body signals, thought signals and actions signals. Below are some examples of anger signs.

Body signals

- Muscle tension in neck, shoulders, jaw, stomach or chest
- Increased heart rate
- Increased sweating
- Shaking
- Clenching fists
- Grinding teeth
- Hot face
- Shoulders raising.

Thought signals

- Changes to your thoughts
- Jumbled thoughts
- Irrational thinking
- Thoughts racing
- Overgeneralising
- Jumping to conclusions.

Examples:

- "The children are deliberately making a mess"
- "He/she always nags me".

Action signals

- Unable to sit still, agitation, getting up and moving around
- Voice getting louder, higher, more abrupt
- Pointing your finger
- Shaking your fist
- Hitting something.

Record your early warning signals, and implement your anger management strategies before your anger escalates out of control.

Step one - Personal coping strategy

This is a short statement of up to five words to remind you when to intervene if you are becoming angry.

Examples:

- Calm down Charlie Brown
- Shit happens
- It's okay, walk away
- Let it go.

Step two - walking away

We often use walking away as a communication tool (e.g. we slam down our pen and stomp away, slamming the door). We then let the other person know that we are angry, even though we haven't said anything — we use body language to communicate our anger. In order to walk away properly we need to be calm and not communicate our anger.

The problem with walking away is that we start thinking unhelpful thoughts. To stop the thoughts we need another technique.

3 DISTRACTION

You need to undertake an activity to take your mind away from your unhelpful thoughts. Examples include counting backwards, thinking about a fantasy holiday or pulling weeds in the garden.

Rules:

Don't do anything that is automatic so that you can still think about what made you feel angry (e.g. ironing, washing dishes).

Focus on the distraction task, immersing yourself in the physical sensations (this is called mindfulness).

Keep doing the activity until the thoughts go away.

Don't undertake an activity or task that you find frustrating, such as something that takes too much attention.

Do what is a good activity or task to use for distraction? An example of a good activity is to go outside, sit in the sun and pat the dog. Focus on the feel of the dog's fur, talk to the dog, feel the sun on your face, and notice any breeze around your face. Listen to the outdoor sounds

— the traffic, the breathing of the dog, any noises it makes in response to your attention.

Summary:

- Personal coping strategy
- Walk away
- Distraction.

Let your wife, partner or family members know what you are doing, and give them this article to read. They can assist in the process; you don't have to do this alone.

4 RELAXATION

In order to be more in control of your anger, it is important to learn to relax. There are various relaxation techniques you can use.

Diaphragmatic breathing

Practise deep breathing (also called diaphragmatic breathing) by following the instructions detailed below. This will aid in the relaxation process.

1. Place one hand on your stomach, just above your waistline, and the other on the middle of your chest. Use your hands to assist the breathing process as they can tell you what part of the body you are moving.

2. Open your mouth and let out a big sigh, as if you are feeling tired and overwhelmed. As you do this, you will feel your shoulders lower and relax. Don't empty all the air out of your lungs. Just release any tension in your shoulders.

3. Now just wait for a few moments.

4. With your mouth closed, inhale slowly through your nose and with your lower hand, feeling your stomach expand. Only inhale as much as is comfortable and then stop. At this time you should not feel any movement in your chest or shoulders.

5. After inhaling, just pause again for a

few moments, for as long as you feel comfortable.

6. Now open your mouth and exhale by contracting your stomach; feel your hands lower.

7. Pause.

8. Continue the exercise repeating steps four to seven for a few minutes.

Use your hands to control the exercise; if you are feeling your chest rise then you are not breathing into your diaphragm. If you feel dizzy, you may be breathing too quickly. This is not a problem — just slow down your breathing.

5 SELF-TALK — CONTROLLING YOUR THINKING

When you're angry, your thinking can become exaggerated and irrational. Develop a list of things to say to yourself before, during and after situations in which you could get angry. You may find it helpful as these things focus on how you are managing the situation rather than what you think other people should be doing.

Before:

- "I'll be able to handle this. It could be rough, but I have a plan."
- "If I feel myself getting angry, I'll know what to do."

Practise your strategies of personal coping statement and controlled breathing.

During:

- "Stay calm, relax, and breathe easy."
- "Stay calm, I'm okay, she's not attacking me personally."
- "I can look and act calm."

After:

- "I managed that well. I can do this. I'm getting better at this."
- "I felt angry, but I didn't lose my cool."

This article is reprinted with the permission of the Cancer Institute NSW. Click on the publications link at <http://www.cancerinstitute.org.au> for a practical range of fact sheets on brain tumours, or phone 02 8374 5600. The Cancer Institute NSW was established as a response to the need to further decrease the devastating impact of cancer on our society.