

Priority Project Reports

Neuro-Oncology

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

Project Description: To conduct a pilot project to evaluate the efficacy of a Behaviour Consultancy Model in addressing impairments in the cognitive and behavioural domains of executive functioning among adults with Brain Tumour (BT).

Deliverables as detailed in project contract

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

Description of activities undertaken (including barriers/challenges in completing the project)

1. Prevalence Study

Activities:

- 62 primary brain tumour patients were from Liverpool Hospital and Royal North Shore Hospital and 42 carers/family members were interviewed.
- See Appendix I for a breakdown of participation and reasons for exclusion.
- Participants were administered a series of questionnaires to determine prevalence of cognitive and behavioural changes after the BT diagnosis, see Appendix 2 for a description of the questionnaires administered.
- Data was scored and entered onto SPSS for ensuing data analysis.
- Prevalence data is outlined in Appendix 3.

Challenges:

- Accessing participants outside of the Sydney Metropolitan area.

2. Trial the Behavioural Consultancy Model

Activities:

- Nine patients were reviewed from the prevalence study with regard to cognitive and behavioural changes.
- One BT patient and their family participated in the Behavioural Consultancy Model intervention (Appendix 7).
- An additional intervention program was delivered to seven carers and ten BT patients as an education workshop on managing cognitive and behavioural changes after a BT (Appendix IV).
- The cases of three BT patients who received a successful Behavioural Intervention from the ABI Behavioural Consultancy Service in Melbourne were retrospectively reviewed.

Challenges:

- Identifying and engaging suitable participants for the intervention program.

3. Development of Information Resources

Activities:

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

The review aimed to identify information about cognitive/behavioural impairments and associated strategies to manage these impairments.

- Details of resources identified are outlined in Appendix 5, Table A5.
- Drawing on the results of the review, 16 types of behavioural and cognitive impairments were identified.

- 16 Draft Information sheets were then devised.
- 11 additional Resource sheets were developed to provide tools and strategies for managing the cognitive and behavioural changes.
- Consumers were polled for their opinion and feedback of the draft resource:
 1. a focus group consisting of BT patients and their carers and
 2. disseminating via email through the NSW Oncology Group, the information sheets to health professionals working in BT.
- Appendix 6 details a list of the Information Sheets and Resource Sheets.

Challenges:

- Limited procedures available to guide the web based review of the existing patient literature.

4. Workshop for health professionals

Activities:

- A one-day health professional workshop was developed and delivered to 46 health professionals working with BT patients.
- The topics covered in the workshop included:
 - an outline of the prevalence of cognitive and behavioural sequelae of BT,
 - a case study on using an intervention with a BT patient
 - the principles of behaviour management and the Behavioural Consultancy Model
 - strategies for dealing with the cognitive and behavioural changes in BT 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 workshop evaluation.
- Forty-three participants completed the questionnaires and this information is summarised in Appendix 7.

Challenges:

- No existing measures available to assess the outcome of the workshop.

5. Dissemination of Information Sheets and Project Results

Activities (Dissemination of Information Sheets)

1. Information Sheets were distributed to:
 - participants of the focus group
 - health professionals who attended the workshop
 - consumers at the Cancer Institute NSW NSWOG Neuro-Oncology Brain Tumour Support & Education Forum 28/10/08 during Brain Tumour Awareness week.
2. Email link to Information Sheets on the Cancer Institute NSW website.
3. Future distribution of Information Sheets:
 - display in Cancer Therapy Centre at Liverpool Hospital
 - contact professional associations relating to BT patients including:
 - Royal Australian College of General Practitioners
 - APS College of Neuropsychologists
 - Australasian Neuroscience Nurses Association
 - Oncology Social Work Australia
 - Cancer Nurse Society of Australia.

Activities (Dissemination of Project results)

1. Information has been presented at the following professional venues (see Appendix J for more detail):
 - Medical Grand Rounds, Liverpool Hospital during BT awareness week.
 - Australasian Neuroscience Nurses Association Conference, 22–24 October 2008.
 - Clinical Oncology Society of Australia 2008 Annual Scientific Meeting, 18–20 November, Sydney.

Project Deliverables

Project Deliverables	Project Achievements
1. Prevalence study	First major prevalence study of challenging behaviours in primary BT patients.
2. Intervention to BT patients and their families to address cognitive and behavioural sequelae of BT.	The first pilot of a family education program that aimed at proving strategies to manage cognitive and behavioural sequelae of primary BT.
3. Development of information resources.	Development of comprehensive targeted information resources about the cognitive and behavioural sequelae of BT. These included 16 fact sheets and 11 resources presented as 1000 printed packages in a display folder. In addition PDF files were provided and are available through the Cancer Institute website: http://www.cancerinstitute.org.au/cancer_inst/nswog/groups/neuro.html
4. An education program for health professionals working in cancer services to increase knowledge and skills in the cognitive and behavioural sequelae of BT.	Completion of a highly successful workshop which provided training to staff in neuro psychological services for cognitive and behavioural sequelae after a primary BT.
5. Dissemination of project results.	Research results have successfully been presented in a number of forums to health professionals. Final report to NSWOG. Final report to the Cancer Institute NSW.

Comments

- Initial proposal stated that five–10 individual intervention programs would be undertaken.
- Only one case study was completed.
- Nine BT patients were reviewed for an intervention but only one was able to participate in the research due to a variety of reasons including:
 - the BT patient had returned to work,
 - they became too ill to participate,
 - were unavailable to participate in the research due to overseas travel,
 - the family were feeling overwhelmed or
 - the identified issues had resolved to a more manageable level.
- Variations on the intervention included:
- A retrospective analysis of three BT patients
- Provision of a group education and workshop for BT patients and their carers on managing the cognitive and behavioural sequelae of BT.

Describe how this project may impact upon potential clinical outcomes.

- This project has demonstrated for the first time, the difficulties relatives may face in managing challenging behaviours after diagnosis of a primary BT.
- The researchers have provided preliminary evidence that many of these problems are treatable with neuro behavioural interventions as specified in the Behavioural Consultancy Model.
- A carer education program to equip families to better manage the cognitive and behavioural sequelae of a brain tumour has been demonstrated to improve carer's skills and knowledge in managing these changes.
- A staff education program to assist staff in managing the cognitive and behavioural changes has indicated that staff assessed their knowledge and skills as higher.
- Successfully piloted three models of intervention which included a single case study, family training and staff training.

Project Awards

- The Neurosurgical Society of Australasian prize, Australasian Neuroscience Nurses Association Conference, 22-24 October 2008.
- COSA Best of the Best Poster presentation, Clinical Oncology Society of Australia 2008 Annual Scientific Meeting, 18-20 November, Sydney.

References

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