

Brain Tumour Support Study Update

Why did we do this study?

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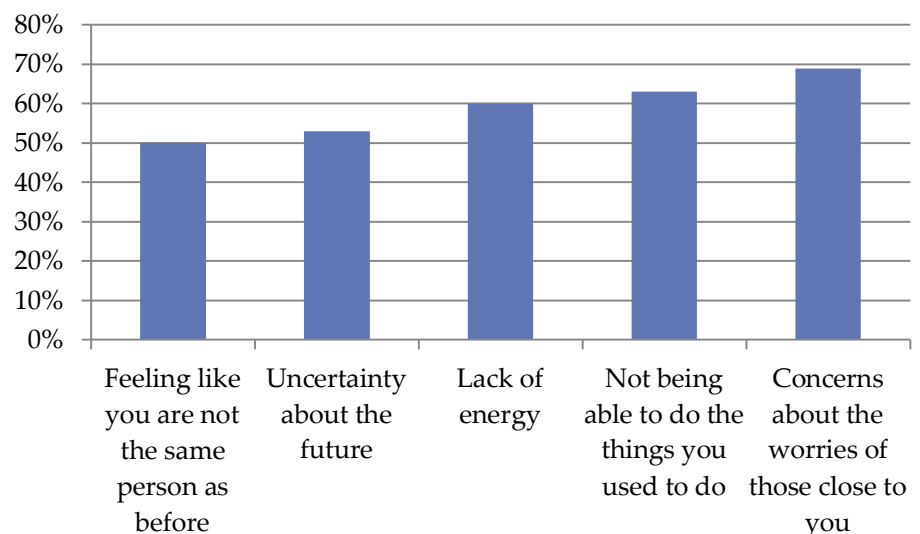
Previous research suggests that people diagnosed with brain tumours often need a range of allied health and community services to deal with the effects of their disease and treatment. However, we don't know what services are used, or if more or different services are needed. Understanding what services people use, together with the issues they face, will help us to develop services and interventions that address the critical unmet supportive care needs of people affected by brain tumours.

Firstly, thank you for your support and participation in the Brain Tumour Support Study. We'd like to update you on the outcomes of this study in this newsletter. To remind you, the Brain Tumour Support Study aimed to understand the concerns of people diagnosed with primary brain tumours early after diagnosis, and the services and supports used. Ultimately our goal is to figure out how to better support people with brain tumours and improve the care and support provided.

What we found

We invited adults recently diagnosed with primary brain tumours in Queensland to participate. Forty patients participated, 11 with the assistance of family members or carers. Just over half of participants were male, and almost two thirds had a malignant tumour.

We asked participants a series of questions to identify their most important 'unmet needs' during each interview – these are concerns that people have that have not been (adequately) dealt with. The five most important unmet needs identified from the initial interviews are shown below.



Use of supportive services

We asked participants about persons or services which had helped since their diagnosis. For each service, we asked if people were aware that the service existed, if they had ever been referred to this service by a health professional (whether or not as part of a formal referral process), and whether they had used the service.

Overall, all or almost all participants were aware of at least one type of information source or service (e.g. information booklets), health professional (e.g. physiotherapist), support service (e.g. support group) or source of practical assistance (e.g. social worker). Referrals were highest for health professionals, and lowest for support services. Use of services was greatest for health professionals, and lowest for sources of practical assistance.

Looking at individual services, over half of participants used a physiotherapist (56%), and just under half used information booklets about the diagnosis (47%) and information available on the internet (47%). In contrast, no participants reported using the services of Brain Tumour Alliance Australia, an exercise physiologist, or psychiatrist.

We also discussed with participants the reasons why people did or did not use services, especially when it was apparent that they may have helped them. One important reason that came up was that many participants weren't made aware of many services which are available, and which may be beneficial.

"I never know where these things are until all of a sudden someone will say, 'oh didn't you know you could've got that for free?' and I think oh really?!"

Where to from here?

This study was useful in highlighting the services that are not well known by people diagnosed with brain tumours, and which should be further promoted. We will be discussing these findings with health professionals and services, to encourage them to make patients aware of the services available. It also showed that more than half of patients experienced difficulties with issues such as lack of energy and uncertainty about the future, which new interventions should address.

We are currently planning our next studies, which will explore the issues experienced by caregivers, and how we can assist caregivers to support and care for patients. We are also planning to investigate the concerns of people who are long term survivors of high grade glioma (anaplastic astrocytoma or glioblastoma multiforme), with the aim of understanding the interventions or services needed to meet their needs.

If you would like to hear more, please get in touch

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