

Improving Brain Tumour Care Online

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Research

Patients with brain tumours are cared for primarily through neurosurgery departments and outpatient clinics at tertiary hospitals in capital cities, by specialist doctors, nurses and allied health staff at appointments that occur every few weeks or months. This model of care is extremely difficult for patients who live any distance from the hospital (particularly rural or regional patients), and for those with disabilities due to their brain tumour, particularly those who can't drive or use public transport due to epilepsy or physical or cognitive disability. Patients can become extremely isolated, and as brain cancer is a relatively rare disease, it can be difficult for patients and their carers to access support groups or other avenues to share experiences and ease the burden of this terrible disease.

We aim to build an online community to help overcome these physical and geographical barriers, allowing people with brain tumours to connect with their treating team, and with each other, for support, education and care.

The first part of this project was a review of the literature to assess other online management tools designed for cancer patients. Our published review found that despite a large number of publications describing online resources for cancer patients, few were properly tested to ensure they were actually beneficial. Furthermore, we found that existing online platforms were often developed based on researchers' understanding of patient's needs, without engaging with patients or considering their preferences. Using funding from our Brain Foundation Grant we have undertaken the second part of this project, and surveyed brain tumour patients at the Royal Melbourne Hospital to assess their needs and preferences for online resources. This needs analysis will help to tailor future platforms specific to the needs of brain tumour patients with the ultimate aim of improving their quality of life.

Outcome

We surveyed 201 brain tumour patients at the Royal Melbourne Hospital. We found that our population was isolated, both by distance, (34% lived >50km from the hospital), and functionally, with 46% of patients unable to drive, 36% not partnered and 58% not working, making this group ideal for online resources. We found that most patients used the Internet (86%), and many of those (72%) used social media. Importantly, 43% of Internet users were turning to social media specifically for information, communication, interaction or problem solving related to their brain tumour. The majority of patients used social networking sites (33%), wikis (28%) and blogs (13%) for this purpose. Patients preferred privacy and flexibility, and valued when a health professional contributed to the social media site. They reported subjective benefits to daily functioning and activities from social media use, however no difference in objective quality of life measures was found between social media users and non-users.

This study is the first to examine Internet and social media use in disease management for brain tumour patients. By examining the preferences of our patients, we have created recommendations to direct design of future online communities and interventions for this vulnerable population.

