



Queensland University of Technology
Brisbane Australia

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It's okay to ask: development and pilot testing of a question prompt list for patients with brain tumours

D Langbecker, M Janda, P Yates

Background

Previous research identified that primary brain tumour patients have significant psychological morbidity and unmet needs, particularly the need for more information and support. However, the utility of strategies to improve information provision in this setting is unknown. This study involved the development and piloting of a brain tumour specific question prompt list (QPL). A QPL is a list of questions patients may find useful to ask their health professionals, and is designed to facilitate communication and information exchange.

Methods

Thematic analysis of QPLs developed for other chronic diseases and brain tumour specific patient resources informed a draft QPL. Subsequent refinement of the QPL involved an iterative process of interviews and review with 12 recently diagnosed patients and six caregivers. Final revisions were made following readability analyses and review by health professionals.

Piloting of the QPL is underway using a non-randomised control group trial with patients undergoing treatment for a primary brain tumour in Brisbane, Queensland. Following baseline interviews, consenting participants are provided with the QPL or standard information materials. Follow-up interviews four to six weeks later allow assessment of the acceptability of the QPL, how it is used by patients, impact on information needs, and feasibility of recruitment, implementation and outcome assessment.

Results

The final QPL was determined to be readable at the sixth grade level. It contains seven sections: diagnosis, prognosis, symptoms and changes, the health professional team, support, treatment and management, and post-treatment concerns. At this time, fourteen participants have been recruited for the pilot, and data collection completed for eleven. Data collection and preliminary analysis are expected to be completed by and presented at the conference.

Conclusions

If acceptable to participants, the QPL may encourage patients, doctors and nurses to communicate more effectively, reducing unmet information needs and ultimately improving psychological wellbeing.