PROJECT TITLE: Translating a Supportive Educational Intervention for Carers of Patients with High-Grade Glioma into practice

FIELD OF RESEARCH CODE: 1110; 1112

PROJECT SYNOPSIS:

High-grade glioma (HGG) is a rapidly terminal, progressive disease with median survival of 15 months for glioblastoma (GBM), the most common histology1. Compounding the distress of a terminal diagnosis for patients and their carers, HGG also deprives patients of function and cognition and sometimes can bring changes to personality2. Hence, unlike many other cancers, carers need to take an active role from the time of diagnosis. The impact of the disease on the patients’ ability to function leads to reduced carer quality of life and increased distress and burden3. Patients may experience neurological changes that can lead to paralysis, seizures and vision and hearing loss. Not only is the short life expectancy distressing for carers, but the cognitive changes associated with HGG also lead to changes in family roles and relationships. The family carer may also need to take on the role of primary communicator.
and medical decision maker. Carers of patients with HGG report inadequate preparation for their role, a lack of individualised support and information, and high levels of distress.

Randomised controlled trials conducted in order to improve support for carers of patients with HGG have been limited. We developed an intervention (known as Care-IS) to specifically provide additional support to carers because they were presenting with higher distress than patients, despite dyads having access to trained neuro-oncology patient care coordinators. We hypothesise that if we can further support and educate carers by providing support delivered by a nurse, this may reduce carer distress, increase preparedness for caring and in turn assist patients throughout their disease trajectory through reducing unplanned healthcare visits and hospital admissions. The overall aim of our randomised controlled trial was to enable family carers of patients with HGG to sustain their caregiving role and minimise their distress. The primary objective was to assess the efficacy of a supportive educational intervention (delivered by nurses) for family carers in improving the primary carer preparedness to care and reducing their distress.

Data collection for the RCT is now complete and analysis is underway. Research now needs to be conducted to understand which components of the intervention were effective and what support is most beneficial for carers. The next project will be to translate this intervention into practice within Australia and trial the intervention with other rare cancer groups. Thus, the proposed PhD will consist of

1. Determining what support is most beneficial for carers by analysing each component of the intervention and extensive data that was collected for the RCT
2. Reviewing and revising the Care-IS intervention to best address HGG carers needs
3. Reviewing the Care-IS intervention for other vulnerable cancer populations
4. Translating the Care-IS intervention into practice

The HDR student will work with the researchers and clinical team to determine the best way to implement the intervention. Implementation will be assessed using the consolidated framework for advancing implementation science facilitating assessment of barriers/enablers to implementation across multiple sites. Implementation outcomes will include site adherence, acceptability, adoption, appropriateness, feasibility, fidelity and sustainability. The following factors will be assessed: system (environment, culture), staff (attitudes, skills), intervention characteristics and implementation process (barriers/enablers). During the PhD project the student will assess these implementation factors and develop, pilot and test strategies to improve implementation with the clinical team using an action research model.

This project will lead to future funding opportunities locally, partnership grants and NHMRC/ Cancer Australia grants.

FEASIBILITY AND RESOURCING – DESCRIPTION OF THE SUPPORT THIS PROJECT WILL RECEIVE:

This project builds on our previous funded work and is supported by an academic and clinical team with input from neuro-oncology, psycho-oncology, psychiatry, allied health, statisticians and health economists. The candidate will receive support from this team and will also work with key national cooperative research groups in neuro-oncology and psycho-oncology. We have applied for additional funding through MRFF.
This project will be based in the School of Nursing, Midwifery and Paramedicine at Curtin University. The student will also receive supervision from A/Prof Lauren Breen (School of Psychology) and Professor Anna Nowak (experienced neuro-oncologist and researcher, SCGH/UWA).

THE SIGNIFICANCE OF THE PROJECT/ PROGRAM FOR THE ENROLLING SCHOOL OR INSTITUTION:

A/Prof Georgia Halkett has a longstanding research program on education and support for patients with cancer and their carers. This project extends this work and will lead to translation and to further income-generating research.

This project implements an intervention in which nurses or allied health professionals support carers of cancer patients. This project aligns with Cancer and Palliative Care Research projects within the School of Nursing, Midwifery and Paramedicine with the highly relevant focus on nursing practice. It is also relevant to the School of Psychology due to its focus on carer anxiety and distress and improving psychosocial support.

Students must express interest in this scholarship opportunity by emailing the Project Lead listed below. Please provide a copy of your current curriculum vitae and detail your suitability to be involved in this strategic project.

PROJECT LEAD CONTACT:

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