

The GAINS study: nurse-led support for carers of people with high-grade glioma (HGG)

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Glioma carers- Assessment of Individual Needs and Support: Protocol for a single arm pilot study [HREC: 89349]

Introduction:

- A high-grade glioma (HGG) diagnosis can have devastating impacts for patients and their carers, with carers reporting diverse unmet needs and significant distress.
- Our recent systematic review identified no supportive care interventions addressing the unmet needs of carers during the radiation phase of treatment.
- A nurse-led, supportive intervention delivered during radiation is an opportunity to address carers' unmet needs early in the illness trajectory.

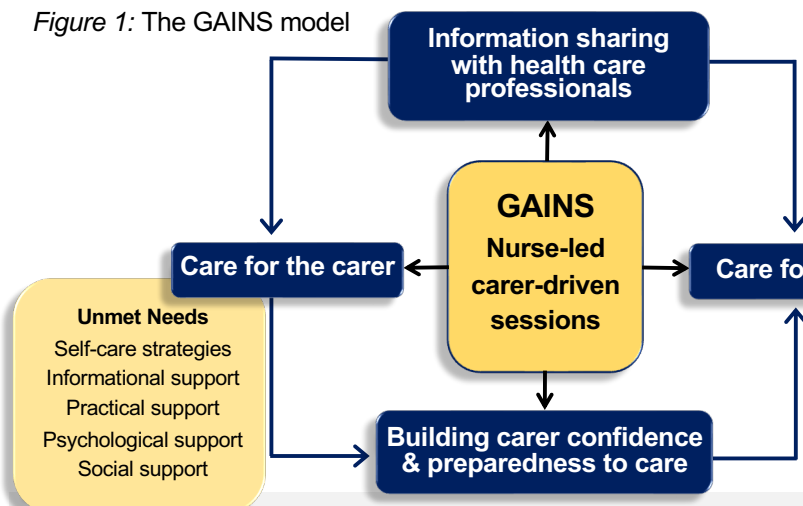
Objectives:

- To examine the feasibility, acceptability, and preliminary effects, of a nurse-led intervention to identify and address the unmet needs of carers for people with HGG.
- To explore GAINS from the perspective of carers, patients, and health care professionals (HCP) caring for the patient-carer dyad

Methodology: (see Figure 1)

- Single group, pre-post study design.
- Eligibility: Twenty (n=20) adult carers of people with newly diagnosed HGG, planned for a minimum 15 fractions (15#) of radiation at Princess Alexandra Hospital, Brisbane.
- Carers will complete a neuro-oncology-specific Caregiver Needs Screen identifying priority areas, with nurse support to manage their unmet needs.
- Face-to-face or telephone sessions.
- Minimum two sessions to meet feasibility requirements.

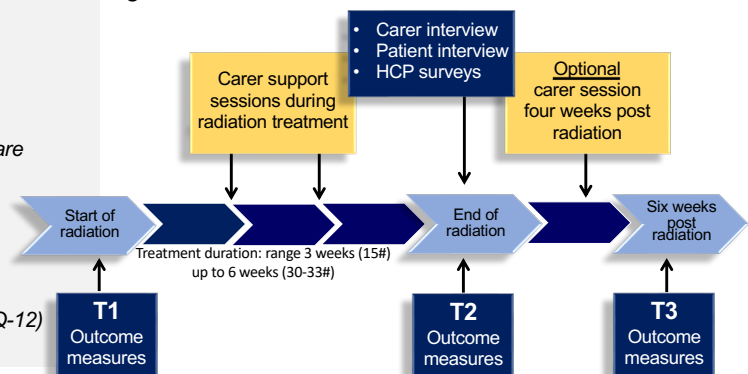
Figure 1: The GAINS model



Outcome Measures @ T1, T2, T3 (see Figure 2)

- Preparedness to care *Preparedness for Caregiving Scale (PCS)*
- Competence / confidence *Caregiver Reaction Scale (CRS)*
- Caregiver strain *Family Appraisal of Caregiving Questionnaire- Palliative Care (FACQ-PC)*
- Positive appraisal of caregiving *FACQ-PC*
- Family well-being *FACQ-PC*
- Psychological distress *FACQ-PC & General Health Questionnaire (GHQ-12)*

Figure 2: Timeline for data collection



Conclusion: The GAINS study commenced recruitment at Princess Alexandra Hospital, Brisbane in 2023.

- Eleven (n=11) carers are currently enrolled or have completed all study components.
- Preliminary findings indicate most carers prefer face-to-face sessions to explore diverse needs, with duration of sessions ranging 20-60 minutes. All carers have completed a minimum two sessions (range 3-5 sessions).