



Australian  
National  
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CENTRE for  
PALLIATIVE  
CARE

# **Pilot Implementation Study of I-CoPE**

An innovative model to  
support patients with high-  
grade glioma and their carers  
across key care transitions

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Investigative Team**

**July 2014**

## PREFACE

This is a final report of a pilot study that focused on implementing I-CoPE, an innovative model to support patients with high-grade malignant glioma and their carers across key care transitions in the early stages of their disease trajectory.

The study was funded by the Australian Primary Health Care Research Institute (APHCRI) as part of the Clinical Handover/ Transitions of Care Funding Stream, which was supported by a grant from the Australian Government Department of Health. The Clinical Handover Funding Stream was focused on the following priority areas: (1) Identifying and targeting high risk, vulnerable patients who are likely to resort to acute hospital services for ongoing support; (2) Exploring transitions of care managers; and (3) Support for family members and carers to effectively move patients through transitions of care.

Ethics approval for this project was obtained from St Vincent's Hospital Melbourne Human Research Ethics Committee (LRR 140/13).

## ACKNOWLEDGEMENTS

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## Background

### RATIONALE

#### Benefits of supportive and palliative care

The World Health Organisation and National standards mandate that palliative care be available to patients with advanced, incurable disease.<sup>1-3</sup> Over the last 20 years in Australia, the specialization of palliative care has advanced considerably, with specialist palliative care services now servicing almost all health care settings.<sup>4</sup> Of the 144,000 people who die annually in Australia, the proportion whose death is anticipated is approximately 50%.<sup>4</sup>

Palliative care has established benefits for patients with advanced cancer including improved symptom relief, quality of life, and communication around health care goals.<sup>5-7</sup> These benefits extend to the patient's family, enhancing caregiver quality of life and bereavement outcomes after the patient's death.<sup>8, 9</sup> Public health benefits have also been demonstrated in terms of reduced hospitalizations and better maintained performance status following a single, individualised palliative care case conference.<sup>10</sup> Benefits also extend to costs, given reduced aggressive and futile care at the end of life, reduced presentation to emergency department, and greater likelihood of death at home for those patients who receive palliative care.<sup>5, 11</sup>

### THE NEEDS OF PEOPLE WITH GLIOMA

#### The unique illness trajectory of high grade glioma

There are particular features relating to the disease trajectory of people with high grade glioma (HGG; see Figure 1) that create a unique and imperative need to better tailor care, particularly around times of care transition. Patients with HGG face a terminal prognosis with a median survival of just 14.6 months for patients well enough to tolerate standard chemoradiotherapy treatment protocols.<sup>12</sup> Additionally, patients with HGG negotiate multiple profound, often devastating physical, cognitive and behavioural changes from an early stage of their illness.<sup>13</sup> In particular, early cognitive decline means carers need specialist support as often patients are often unable to participate significantly in decision making and planning.

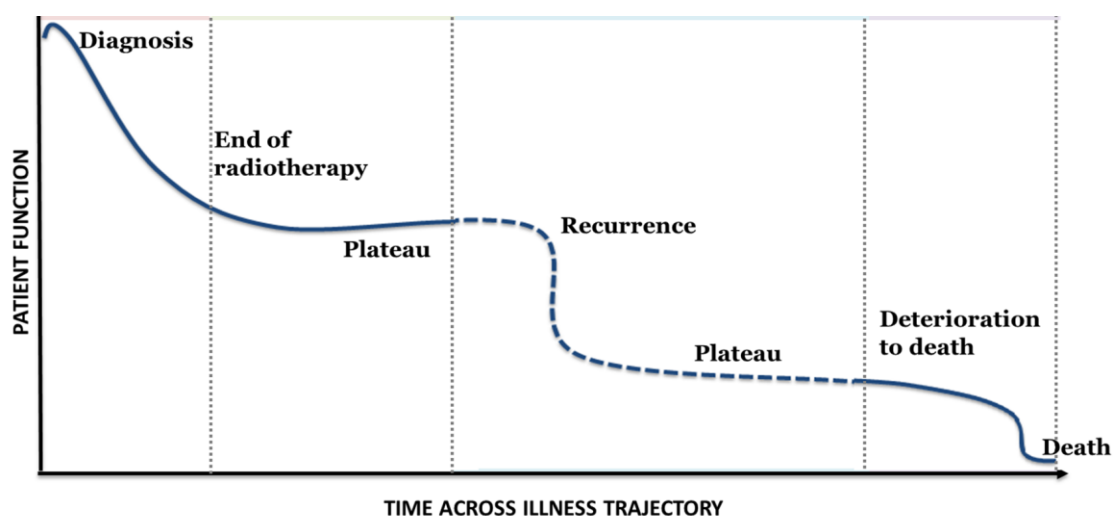


Figure 1. The 'typical' high grade glioma illness trajectory<sup>13</sup>

Moreover, the HGG illness course is characterised by sudden acute deteriorations, followed by periods when their clinical condition plateaus, albeit at a lower level.<sup>13</sup> Many patients live in a prolonged state of dependency with high attendant care needs, yet the uncertainty around how the illness course may progress often means carers are unprepared for their role. The sudden unexpected changes also mean referrals to palliative care are often late in the disease trajectory, at which point inpatient care is inevitable since community supports are not in place.<sup>14, 15</sup> These factors, which are unlike other traditional cancer trajectories, create extraordinary challenges to providing responsive care for patients and supporting carers in the community.

### Supportive care needs

Patients with HGG and their carers have described their particular need for improved individualised information, care-coordination, continuity of care, emotional support, and proactive preparatory caring advice throughout the trajectory.<sup>16,17</sup> This is particularly important at times of care transitions, as carers are relied upon by the current health system to provide the care required by patients in the community, but receive limited formal support to undertake the role. Qualitative data indicates that this lack of support, information and preparation exacerbates the burden of caring and suffering,<sup>16</sup> and likely accounts for the high rates of distress previously reported by up to 63% of a patients,<sup>18</sup> and 72% of carers.<sup>19</sup>

Research to date has focused on describing the patient and caregiver experience,<sup>20, 21</sup> with little attention given to establishing best methods of providing care<sup>22</sup> or developing and trialing specialist interventions or models to educate and support patients and their carers.<sup>23</sup> Indeed recent systematic reviews suggest the most pressing priority is to find effective methods to provide support and education for caregivers of patients with HGG.<sup>22-24</sup> Our earlier research<sup>13,25</sup> established this should occur simultaneously with improving assessment of needs, to delineate a proactive needs-driven model which makes tailors support around times of care transition.

### Inconsistencies and barriers to palliative care access

Despite known benefits of palliative care to patients and their carers and the poor prognosis of patients with HGG, there are inconsistencies in the provision of end-of-life care and it is clear that many patients are not referred in a timely manner.<sup>26</sup> In Victoria, just 12% of patients with HGG who have poor prognostic disease and subsequently die within 120 days of diagnosis are referred to palliative care prior to hospital discharge.<sup>14</sup> These local patterns are reflected internationally, whereby the median survival times following admission to hospice programs range from 22-35 days.<sup>8, 27</sup> These patterns are suboptimal given the likelihood of death outside hospital in a Victorian cohort of patients with HGG was associated with referral at least 120 days before death.<sup>15</sup>

The reasons inhibiting timely engagement with palliative care are complex. Clinicians' concerns about impacting patients' hope, the perceived quality or lack of familiarity with palliative care services, and their perceptions of the likelihood of patients' acceptance of the referral are significant barriers to appropriate engagement.<sup>28</sup> When referral to palliative care is raised, some patients and family carers express fear and negative reactions<sup>29</sup> while others report interest in its components, namely access to symptom control, psychological support, family support and communication tasks.<sup>17</sup> Carers of patients with HGG report uncertainty around knowing what they will need, given limited understanding of what to expect in the event their relative deteriorates.<sup>16</sup> Meanwhile, patients with HGG nearing their death<sup>17</sup> and their bereaved family carers<sup>16</sup> report they wish they had access to palliative care earlier in the illness course.

# CARE TRANSITIONS IN HIGH GRADE GLIOMA

## Care transitions based on disease and treatment parameters

Our earlier pilot work identified key gaps in the early disease stages of HGG associated around times of care transition, when patients move between acute hospital, ambulatory and primary care management. From these gaps in care, a model was defined which specifically aims to: 1) Provide remote monitoring and management for high-risk, vulnerable patients who are likely to resort to acute hospital services for ongoing support; 2) Effectively institute a key care worker who can appropriately support the transition of the patient through the aforementioned settings; and 3) Focus and tailor support, information and education for patients' carers to ensure they are able to engage in the primary health care process, enabling patients to remain in the community.

In this study, we focused on instituting screening and supports at care transitions based on predefined disease and treatment parameters across the illness trajectory of people diagnosed with HGG. At each transition point, the following supports are enacted through a patient care coordinator:

- > Staged, routine information
- > Regular screening for needs and responses instituted
- > Facilitation of information transfer and patient movement between sites of care
- > Highlighting and formalizing GP involvement in care delivery
- > Active engagement of family caregivers
- > Consideration of routine referral to palliative care for patients with known poor prognostic factors expected to deteriorate rapidly.

## The interface of primary care with specialist palliative care

Primary care providers have an important role in the care and management of people living with a life-limiting illness such as HGG, and the support of their primary carers and families. Palliative Care Australia outlines the necessity of engaging primary care providers to continue to be full and effective partners in the provision of supportive end of life care to the majority of people who die of an expected illness.<sup>30</sup> Despite this, general practitioners (GP) in primary care settings face the difficult challenge of supporting complex care needs of palliative care patients and their families, often with minimal support and sometimes nil prior exposure to rare disease trajectories. Data suggests GPs in Australia see a median of just 5-6 patients per year.<sup>31</sup> Having better communication with a patient care coordinator throughout the care process, including individualised patient screening results which identify unmet care needs is likely to enhance primary care management. If successful, this model will have broader implications as a model for the primary care management of other patients with complex care needs and end-stage diseases.

## AIMS

The current study aims to conduct a pilot implementation and evaluation of an innovative model designed to support patients and their carers through transitions of care.

The model involves the provision of Information, Coordination, Preparation and Emotional support (I-CoPE) over three key identified care transitions, for people newly diagnosed HGG and their carers.

These particular care transitions correspond to specific points early in the patients' illness trajectory when support has been identified as inadequate by patients<sup>17</sup> and their carers<sup>18</sup>, and health care professionals<sup>26</sup>.

Care transitions focused on predefined disease and treatment parameters in the current study are:

- > Following patient's pathological diagnosis after biopsy and/or resection in the acute hospital (I-CoPE 1);
- > Following discharge (7-10 days post discharge) from acute hospital (I-CoPE 2);
- > Following the completion of standard radiotherapy protocol when patients are longer attending the acute hospital outpatient services on a daily basis (I-CoPE 3).

## OBJECTIVES

The specific objectives of this study are:

- > To conduct a pilot implementation and program evaluation study, primarily testing feasibility, acceptability and applicability of an innovative model, I-CoPE, for supporting patients with HGG and their carers.
- > To assess barriers and facilitators to broader dissemination (relevance to primary health care management of other palliative populations, cost-effectiveness considerations, and care coordinator experiences).
- > To examine the short-term efficacy of I-CoPE on patient and carer reported outcomes over a three month follow-up period (unmet information and support needs, quality of life, psychological wellbeing, and preparedness to care).

## HYPOTHESES

The study collected key patient and carer reported outcomes and health service utilisation data to assess the efficacy of this innovative model which targets care transitions.

We hypothesised:

- > I-CoPE will be an acceptable, applicable and feasible model of care, resulting in improved patient experiences (enrolment data, screening outcome data, and cost considerations).
- > I-CoPE will result in positive patient and carer outcomes in the short-term (less distress, fewer unmet needs, better quality of life, greater preparedness to care).
- > I-CoPE will better support patients with HGG and their carers to transition between acute hospital, ambulatory and primary care services (increased remote primary care management/ appropriate acute hospital access to supports).



## Methods

### STUDY DESIGN

This is a pilot implementation and program evaluation study of an innovative model, I-CoPE, for supporting patients and their carers through key care transitions. A pilot trial design was utilised where a small number of eligible participants were all invited to receive all service components the I-CoPE model and outcomes were recorded (see Figure 2 - study schema).

Program evaluation data were collected over the three month period of follow-up, including acceptability and feasibility summary statistics and qualitative data, cost-effectiveness considerations, and health service use data.

Short-term patient/carer outcome data were collected longitudinally prior to, during, and after the implementation of the I-CoPE model over a 3 month period as follows: T0 (baseline/pre-intervention), T1 (2 weeks post T0), and T2 (12 weeks post T0).

### ELIGIBILITY CRITERIA

#### Patients

Participants in this study met the following eligibility criteria:

- > Patient had a biopsy confirmed diagnosis of high-grade primary malignant glioma (HGG), defined by the ICD Classification system as Astrocytoma, Glioblastoma, Oligodendroglioma, Ependymoma, and Gliosarcoma.
- > Patient was able to provide informed consent, as deemed by the treating team.
- > Patient was considered eligible for radiotherapy with a view to undergo treatment.
- > Patient was able to understand written and spoken English.

In addition, eligible patients were able to nominate an informal carer for participation. However if patients did not wish to nominate an informal carer, they were still eligible to participate by themselves.

Patients with a disease-related speech or language deficit which precluded them from participating in the study questionnaires were still invited to undergo the I-CoPE screening procedures should they wish to nominate an informal carer who opted to participate.

#### Carers

Carers met the following eligibility criteria:

- > Carer was nominated (by the patient) to participate.
- > Carer was able to understand written and spoken English.
- > Carer was involved in the informal care and support of the patient (but did not have to be residing in the same residence or providing full-time care).

### RESEARCH PROCEDURES

This project involves a pilot implementation of I-CoPE at the Neuro-Oncology service of a major metropolitan hospital. Patients were approached (along with their carers) during their first inpatient admission in the week following biopsy and/or resection. Participants were given an oral and written summary of the study and ethical considerations were explained. Patients and their carers who consented then completed outcome measures simultaneously with the implementation of I-CoPE over a three month follow-up period. At each measurement point, patients and carers were contacted by post and recorded outcome data individually.

## STUDY SCHEMA

Participants commenced the I-CoPE model during their inpatient admission when they received their diagnosis of their HGG, and ceased I-CoPE at the conclusion of their planned chemo-radiotherapy treatment.

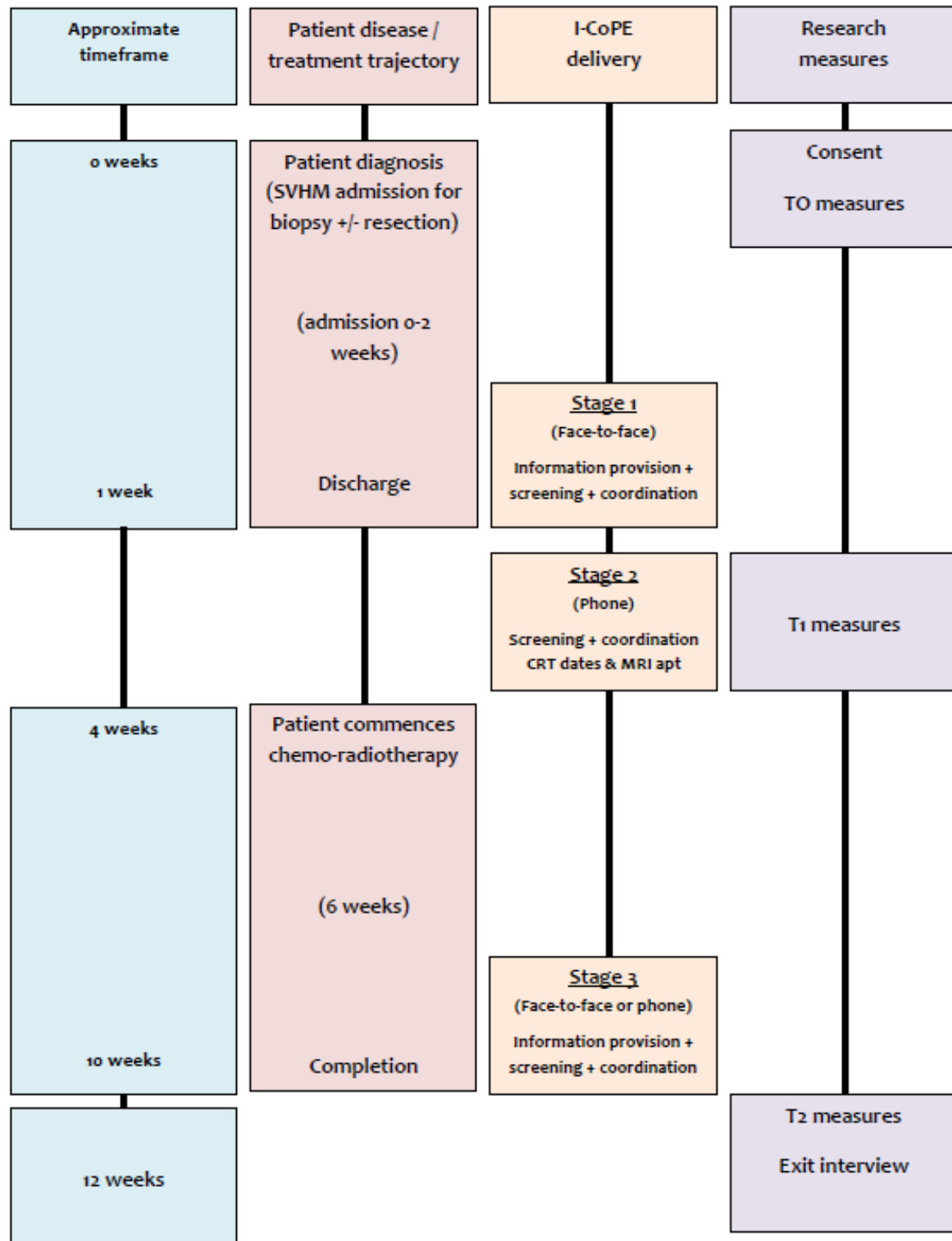


Figure 2. Study Schema

## THE I-COPE INTERVENTION

I-CoPE is an innovative model focused around care transitions to deliver an equitable, standardised approach to provide *information, coordination, preparation & emotional support* to patients following a new diagnosis of HGG and their carers.

I-CoPE is delivered by a suitably qualified health care professional (e.g. patient care coordinator/ clinical nurse specialist) over three stages, and the content is tailored to patient and carer needs at each stage (see Figure 3).

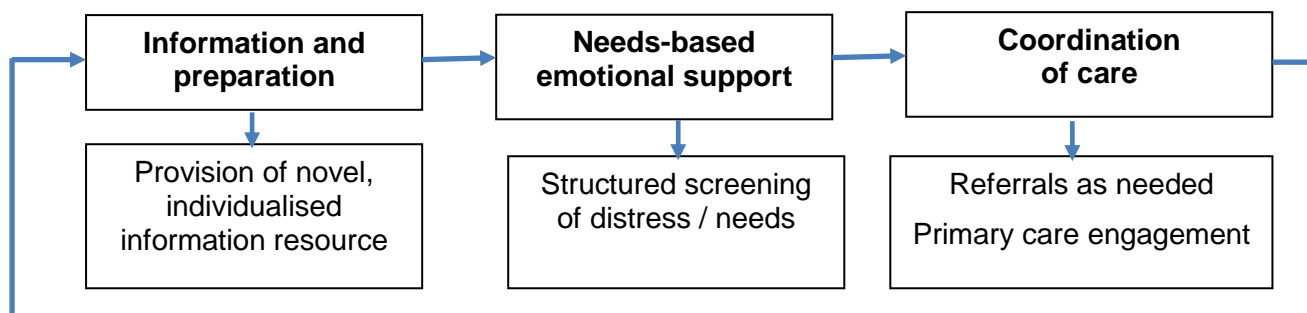


Figure 3. Outline of I-CoPE model at each care transition

### Needs-based screening and emotional support

The standardised screen involved administering the National Comprehensive Cancer Network distress thermometer and associated problem check-list,<sup>32</sup> including a screen for practical, physical, family, emotional and spiritual/existential problems. This tool has been shown to be successfully administered to cancer patients and their carers using community-based telephone outcalls<sup>33, 34</sup> and is well validated for use with brain cancer patients with clearly defined cut-off scores to identify clinically relevant distress.<sup>35-40</sup> Any concerns identified through the screening process were followed up clinically, including streamlining referrals back to the primary care setting where applicable. All screening outcomes were recorded.

### Coordination of care

Coordination of care involved liaising with interdisciplinary members of the patient's treating team as required to ensure seamless provision of care. Additionally, patients were able to nominate for their general practitioner (GP) to receive information through the I-CoPE screening process. At each stage, the patient's GP and, if applicable, their local/community cancer nurse coordinator were forwarded communication from the I-CoPE interactions, including a summary of the screening results. Any outstanding issues requiring follow-up were highlighted to the primary care team, and a care plan was formulated.

#### Stage 1 I-CoPE Communication Outline:

- > Patient's diagnosis and treatment intent
- > What the patient has been told from the specialist team
- > Common side effects / red flags to look out for at this stage
- > Who they can contact about patient concerns or questions
- > Recommended shared care plan involving primary care team
- > Patient's involvement in I-CoPE
- > I-CoPE 1 screening results (Stage 1)
- > Any outstanding issues requiring further community follow-up

### Stage 2 I-CoPE Communication Outline:

- > Patients commencement on chemo-radiotherapy
- > I-CoPE 2 screening results (Stage 2)
- > Any outstanding issues requiring further community follow-up

### Stage 3 Communication Outline:

- > Patients completion of radiotherapy and planned MRI surveillance appointment
- > I-CoPE 3 screening results (Stage 3)
- > Any outstanding issues requiring further community follow-up
- > Ongoing recommended shared care plan involving primary care team

### Information, education and preparation

Novel I-CoPE information resources were developed based on our earlier research<sup>13,16,17</sup> which identified gaps in the provision of structured, staged information. In line with the defined I-CoPE transition points, written information resources were provided in a staged approach at the time of the I-CoPE interactions. The resource is individualised to each patient, with specific diagnostic information completed by the patient care coordinator. Information booklets were supplemented with additional (more specific) resources as required in response to concerns raised through the screening process. An example of this is information pertaining to talking to young children about terminal illness, which was not broadly needed by a majority of patients, but provided to those with this need raised in response to screening.

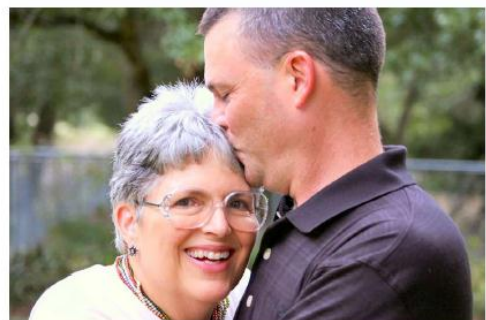
### Stage 1

“What now? After the diagnosis of a brain tumour”

- > Introduction to the I-CoPE resource
- > Important contacts
- > Introduction to the brain tumour team
- > Individualised list of patient’s care team
- > Individualised tumour information
- > Common questions after treatment for a brain tumour: seizures and medications, dexamethazone and side effects, driving, returning to work, legal and financial assistance
- > Appointment schedule
- > Appointment notes
- > Medication register
- > Recommended resources
- > What now?

## What now?

After the diagnosis of a brain tumour



After the diagnosis of a brain tumour

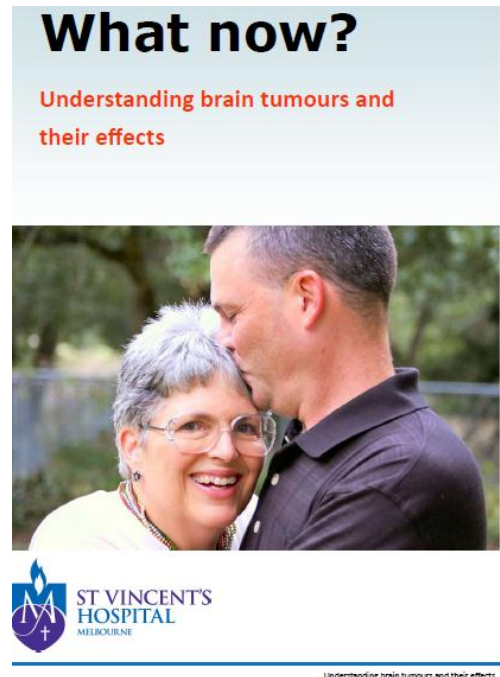
## Stage 2

No written resource was provided at the time of stage 2, though additional needs for information not covered in the first resource that were raised at this point in time were attended to by the patient care coordinator as required.

## Stage 3


“What now? Understanding brain tumours and their effects”

- > Symptom and Behaviour factsheets:
  - Anger; Attention and concentration; Communication; Disorientation; Being self-centred; High level thinking or executive impairments; Fatigue; Impulsivity; Inappropriate social behaviour; Lability; Lack of motivation; Neglecting personal care; Memory; Low mood; Perseveration; Stress and anxiety.
- > Caring for someone with a brain tumour
- > Resources:
  - Cancer treatment centres
  - Palliative and respite care services



## I-CoPE Fidelity

To ensure I-CoPE was delivered in a systematic and consistent manner, a standardised I-CoPE diary (standard operating procedure) was used by the patient care coordinator. Clinical interactions and outcomes were documented in a standardised format within this diary (see Figure 4) and regularly reviewed by the research coordinator, to ensure fidelity to the I-CoPE Manual. In addition, a random selection (30%) of all I-CoPE interactions were observed by the research coordinator to ensure the I-CoPE screening process was carried out in a consistent approach, as set out in the I-CoPE Manual.



**ST VINCENT'S  
HOSPITAL**  
MELBOURNE


# I-CoPE Implementation Study

Recruitment CRF

<b>STAGE ONE I-COPE</b>	Date <u>  </u> / <u>  </u> / <u>  </u> <small>DD MM YY</small>
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**CHECKLIST**

- ☐ Introduction to I-CoPE Patient Coordinator & plan
- ☐ I-CoPE information resource 1 provided
- ☐ I-CoPE screen 1 conducted      ➡      ☐ Notified researcher to send patient/carer outcome measures
- ☐ I-CoPE screen 1 documented
- ☐ I-CoPE screen 1 actioned (if applicable)
- ☐ I-CoPE screen results sent to patient's GP and regional cancer care coordinator



<b>Patient DT score ( /10):</b>	➡ If DT > 4, discuss routine support referral
<b>Specific problems identified:</b> 1) 2) 3) 4)	<b>Description:</b>
<b>Actions taken:</b>	<b>Referrals:</b> _____ <input type="checkbox"/> Offered <input type="checkbox"/> Accepted _____ <input type="checkbox"/> Offered <input type="checkbox"/> Accepted
<b>Carer DT score ( /10):</b>	➡ If DT > 4, discuss routine support referral
<b>Specific problems identified:</b> 1) 2) 3) 4)	<b>Description:</b>
<b>Actions taken:</b>	<b>Referrals:</b> _____ <input type="checkbox"/> Offered <input type="checkbox"/> Accepted _____ <input type="checkbox"/> Offered <input type="checkbox"/> Accepted

**Adverse Events:**

☐ No
 

☐ Yes ➡ Complete SAE form

Figure 4. Example of the I-CoPE Diary

# PRIMARY OUTCOMES

## Program evaluation outcomes

### Acceptability of I-CoPE

*Model accrual rates* were used to broadly demonstrate that the components of the I-CoPE model were acceptable to participants. In addition, patient characteristics, including histology, age, sex and marital status were collected to compare eligible patients who participated with those who declined. The program was considered to be broadly acceptable to eligible HGG patients if these characteristics did not significantly vary between these two groups.

*Patient and carer experiences* and their perceived quality of care were also assessed to determine acceptability using the Functional Assessment of Chronic Illness Therapy-Treatment Satisfaction Patient Satisfaction scale (FACT-TS-PS).<sup>41</sup> Overall care experience was rated using a one-item five-point response scale from 'poor' to 'excellent' (0-4). In addition, satisfaction was measured on two specific domains using a four-point response scale: communication with physicians and treatment staff, including their explanations, personal interactions, comprehensive care and decision-making (16 items, 0-48), and trust of their treatment staff (4 items, 0-12). Higher scores indicated higher satisfaction and more positive patient and carer experiences. Internal consistency, test re-test reliability, convergent and construct validity have been established for the FACT-TS-PS.<sup>41</sup>

### Applicability of I-CoPE

*Applicability* was determined by model retention rates, and a detailed review of each participant's I-CoPE diary completed by the patient care coordinator who delivered I-CoPE.

### Feasibility of I-CoPE

*Feasibility* was assessed by examining the number of I-CoPE interactions undertaken and comparing these against planned interactions to determine if patients could feasibly participate in this model alongside their active medical treatment. If at least 60% of patients adhered to the model it was considered feasible. Summary statistics were collated on feasibility considerations such as documented duration of planned I-CoPE sessions and number of spontaneous unplanned patient and carer interactions with the patient care coordinator. Finally, average rudimentary cost estimations were calculated based on actual duration times and costs collated across the I-CoPE delivery period.

## Primary care communication and engagement

Each participant's I-CoPE record/ diary, completed by the patient care coordinator who delivered I-CoPE, were examined to collate summary statistics on the following:

- > Number of enrolled general practitioners (GPs) within the framework of I-CoPE
- > Number of planned interactions with GP
- > Number of spontaneous unplanned interactions with GP
- > Number of health concerns raised directed to primary care by patient care coordinator
- > Number of community supportive care referrals

## Acute hospital service use

A case review of the patient's medical records was undertaken to collate summary statistics on the following aspects of acute hospital service use during the 3-month follow-up period:



- > Number of admissions per patient
- > Total length of stay
- > Diagnostic admission length of stay, and bed days in neurosurgery, oncology, rehabilitation, the intensive care unit and/or palliative care
- > Emergency department (ED) presentations per patient and planned ED presentations via I-CoPE
- > Supportive and palliative care use
  - Palliative care consultation use
  - Community palliative care referral
  - Psycho-oncology referral
  - Social work referral

### Barriers and facilitators to broader dissemination

#### Relevance to primary care management of other populations

In view to assessing barriers and facilitators to broader dissemination, the relevance of I-CoPE to the management of other patient populations with eventually fatal illness was assessed via qualitative interviews with key health care professionals involved in care. Interviews were brief and structured, with the direct aim of assessing the feasibility of broader dissemination to other settings, including renal (n=2), cardiology (n=2) and dementia (n=2). Participants were purposely sampled to seek physician and/or nursing perspectives from each setting (n=6). A directed thematic analysis was undertaken by two researchers and focused on coding information pertinent to the following questions:

1. Within your setting, do you see relevance of the I-CoPE components to improving support at times of care transition?
2. Within your setting, are there *currently* care transition points which signal the enactment of routine supports and/or responses?
  - > If yes, what are these points?
  - > If no, are there identifiable care transitions based on disease or treatment parameters which could herald particular supports and/or responses?
3. Within your setting, are there any barriers and/or facilitators to disseminating a model such as I-CoPE?

#### Experiences of I-CoPE patient care coordinator

The patient care coordinator's field notes were audited to extract information regarding practicability of I-CoPE delivery, with the view of identifying any barriers that were encountered in the current study that may translate to other settings, should broader dissemination be undertaken.

## SECONDARY OUTCOMES: SHORT-TERM EFFICACY

### Unmet supportive care needs

#### Patients

Patient reported unmet supportive care needs were assessed using the 34-item Supportive Care Needs Survey - Short Form (SCNS-SF34).<sup>42</sup> Unmet needs were



summed across five domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality needs. The SCNS-SF34 assesses whether need has been experienced, and the magnitude of that need on a five-point response scale. Higher scores indicate a higher level of need on the domain, or global score. Construct and criterion validity, and internal consistency of the SCNS-SF34 has been determined.<sup>42</sup>

### **Carers**

Carers unmet support needs were assessed using the 14-item Carer Support Needs Assessment Tool (CSNAT)<sup>43</sup>, which captures various practical, emotional, spiritual and communication needs on a four-point response scale. A global score of unmet support needs was summed from the 14 items, with higher scores indicating a greater level of unmet need. The CSNAT has good face, content, and criterion validity and sensitivity to change.<sup>44</sup>

## **Unmet information needs**

### **Patients and Carers**

Unmet information needs were assessed using the 17-item Patient Information Needs Questionnaire (PINQ),<sup>45</sup> which captures unmet needs for information on a four-point response scale. The PINQ provides two distinct domains of unmet information need: 'disease-orientated' information (9 items) about disease and treatment and 'action-orientated' information (8 items) about accessing help and solving practical needs or concerns. Higher scores indicate a greater level of unmet information need of the specific domain. Internal consistency, construct validity, and convergent validity for the PINQ have been determined.<sup>45</sup>

## **Quality of Life**

### **Patients**

Patient-reported Quality of Life (QOL) was measured using the Functional Assessment Cancer Therapy – Brain cancer module (FACT-BR).<sup>46, 47</sup> This instrument evaluates the socio-emotional wellbeing (FACT-G; 33-items) and disease and treatment specific QOL of patients with Brain cancer (BrCS scale; 15-items) on a five-point response scale. The FACT-BR is sensitive to fluctuations in patient level of functioning on the basis of treatment status and overall performance. The FACT-BR evaluates patient functioning across 5 domains: physical well-being, social and family well-being, emotional well-being, functional well-being, and brain-cancer specific symptoms. Higher scores indicate greater quality of life.

### **Carers**

Carer-reported quality of life was measured using the 35-item Caregiver Quality of Life Index for Cancer (CQOLC).<sup>48</sup> This instrument specifically measures the QOL of carers of cancer patients on a five-point response scale across four key areas of QOL including carer burden, disruptiveness, positive adaptation and financial concerns. Given the focus of I-CoPE, a carer burden factor score and a total CQOLC score were utilised. Higher scores indicate poorer perceived QOL and higher burden. The CQOLC has acceptable convergent validity, test-retest reliability and internal consistency.<sup>48</sup>

## **Preparedness to care**

### **Carers**

Carer-reported preparedness to care for their loved one was assessed using the 8-item Preparedness for caregiving scale (PCS).<sup>49</sup> A mean score of valid responses indicates how carers perceive their readiness for the role on a five-point response scale, with

higher scores indicating greater preparedness. The PCS has good construct validity and internal consistency in palliative care populations.<sup>50-52</sup>

### Psychological wellbeing

Psychological wellbeing was assessed using the 21-item Depression Anxiety and Stress Scale (DASS-21).<sup>53</sup> The DASS-21 is a clinical measure of the severity and frequency of three distinct negative emotional states: depression (7 items), anxiety (7 items) and stress (7 items) measured on a four-point response scale. Items are summed to yield a total score for each domain, with higher scores indicating greater psychological wellbeing. The DASS-21 has been shown to have high internal consistency and to yield meaningful discriminations in a variety of settings.<sup>53</sup>

## STATISTICAL ANALYSES

### Primary outcomes

#### Program evaluation outcomes

Feasibility and applicability were assessed using percentages and summary statistics (e.g., means and standard deviations). Acceptability was assessed using appropriate group comparison statistics (Fisher's exact test or independent samples t-test).

### Secondary outcomes

#### Short term efficacy

After checking the relevant statistical assumptions, changes in scores on the secondary outcomes between T0 (baseline) and T1 (post I-CoPE 1 and 2) were assessed using paired-samples t-tests. Given the exploratory nature of planned analyses as part of a pilot trial, a two-sided  $p$  value of 0.05 was considered significant. This ensured that any small effects were not missed, despite inflating the chance of obtaining a Type II error. As such, given the expected small sample size in line with this pilot study design, emphasis was placed on the *magnitude* and *direction* of change.

Statistical analyses on the secondary outcomes at T2 were not undertaken given the cohort is not yet completed for this time point, precluding meaningful results for the pilot trial at this point.

# Results

## PARTICIPANTS

### Description of the cohort

#### Patients

Twenty patients participated in the I-CoPE model, including 11 males and 9 females ranging in age from 28 to 82 years (mean age= 60.4). Eighty percent (16/20) of patients had a WHO grade IV glioblastoma multiforme, and 20% (4/20) had a grade III anaplastic astrocytoma or oligodendroglioma. The most common tumour locations included parietal (7/20, 35%), temporal (5/20, 25%), and frontal (3/20, 15%) lobes. Ninety percent (18/20) had their tumour resected, while 10% (2/20) had a biopsy only. In keeping with study eligibility, all patients were planned for further chemo-radiotherapy treatment though not all patients completed these planned treatments due to worsening health.

At the time of diagnosis, 53% of patients were retired, 34% were employed full-time, and 13% were employed part-time. The majority of patients were married or partnered (15/20, 75%), Australian-born (15/20, 75%), and had secondary education (14/20, 70%). Thirty percent (6/20) had TAFE or tertiary qualifications. Fifty percent (10/20) reported they suffered from another chronic medical condition.

#### Carers

Seventeen carers participated in the I-CoPE model, including 9 females and 8 males ranging in age from 28 to 85 years (mean age = 57.3). Carers were either the patient's spouse (10/17, 59%), child (5/17, 29%), parent (1/17, 6%) or friend (1/17, 6%). The majority of carers were permanently living in the same residence as the patient (11/17, 65%). A further two carers had temporarily relocated to provide care (2/17, 12%) and the remaining four carers lived independently (4/17, 23%). At the time of study enrolment, the majority of carers were in full-time (7/17, 41%) or part-time (2/17, 12%) employment, or had previously retired (6/17, 35%).

# PRIMARY OUTCOMES

## Acceptability

### Model accrual rates

Over the recruitment period, 26 patients were admitted to the neuro-surgical ward with a new diagnosis of HGG (see Figure 5). Of these, four patients (4/26: 15%) did not meet eligibility criteria as they were not planned for treatment due to poor health or other elective reasons, and one patient (1/26: 4%) was diagnosed over the holiday period when there was no staff cover. The remaining 21 patients (21/26: 25%) were approached for study inclusion.

Patient accrual to the I-CoPE model was excellent, with 20 patients (20/21: 95%) agreeing to participate and only one patient declining to participate (1/21: 5%). Eighteen patients also nominated a carer (18/20: 90%), of whom seventeen (17/18: 94%) also opted to participate. The two patients who did not have a suitable 'significant other' they wished to nominate, reported this was due to language or privacy reasons. The one patient and one carer who declined both separately indicated they were too overwhelmed to consider completing study questionnaires.

Overall these notably high patient and carer accrual rates in the context of a new terminal diagnosis suggest that the I-CoPE model is both clinically relevant and broadly acceptable to both patients and their carers. Given there was only one patient and carer who declined, planned between-group analyses between decliners and responders were not necessary to determine if I-CoPE was less acceptable to a particular sub-group of patients/carers.

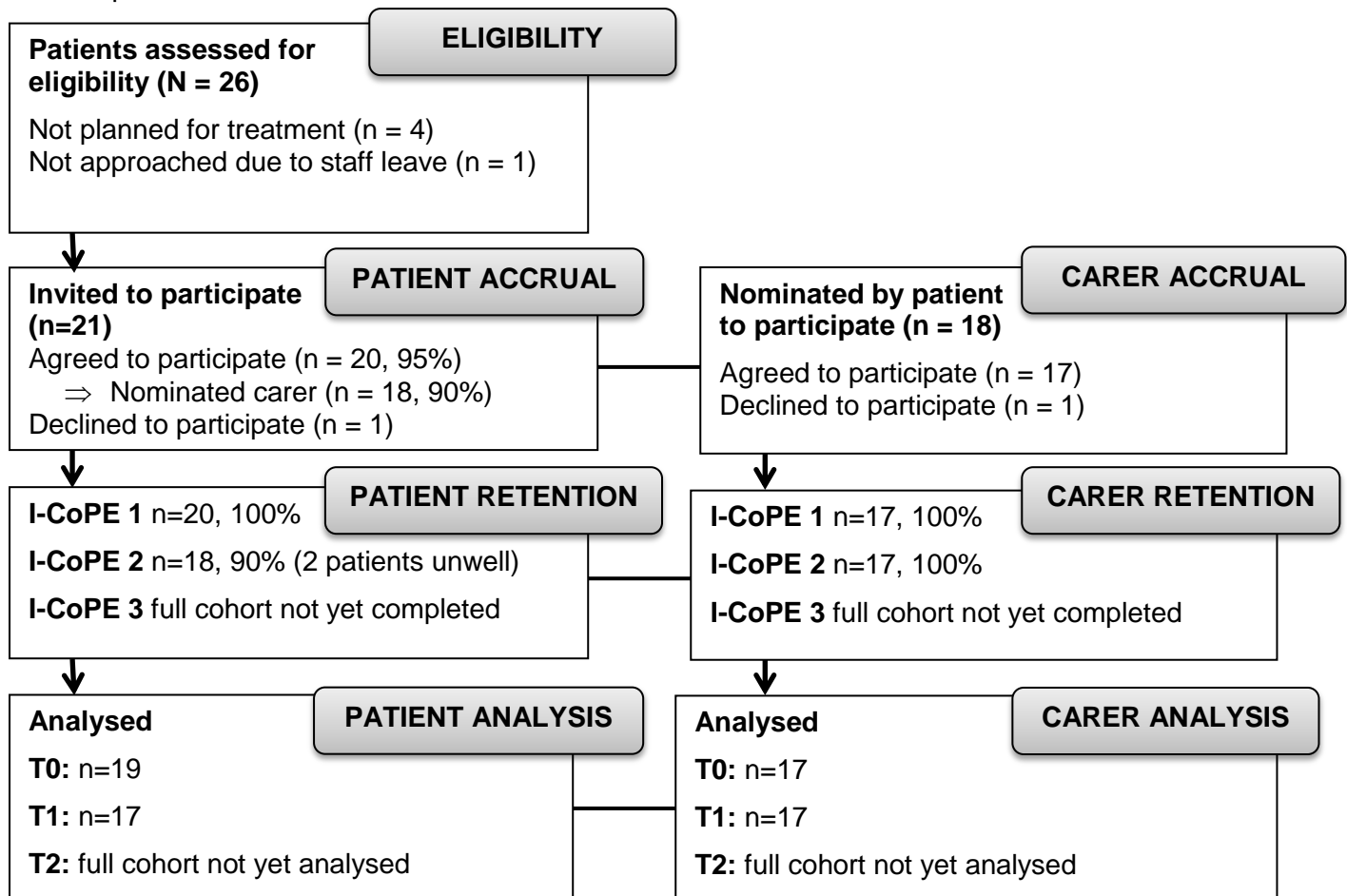


Figure 5. Consort Diagram

## Patient and carer experiences

At the conclusion of I-CoPE, patients rated their experiences and satisfaction of care over the three months from diagnosis. Overall, patient and carer experiences were favourable. To date, patients rated the overall care received as 'very good' (median score 4 out of 5, representing 'very good overall care'), while carers rated the overall care received as 'excellent' (median score 5 out of 5 representing 'excellent overall care').

Carers reported a high satisfaction with the communication with their care team (mean = 38.0) and very high satisfaction with their level of confidence and trust in their care team (mean = 11.3). Though not as favourable as feedback received from carers, patients also reported satisfactory experiences, including average satisfaction with communication with their care team (mean = 31.0) and moderate satisfaction with their level of confidence and trust in their care team (mean = 8.6).

Both patients and carers on average reported they would recommend the model of care to others (median score 2 out of 2: 'yes - would recommend').

## Applicability

### Model retention rates

Patient retention over the I-CoPE model delivery period was excellent (see Figure 6), with to date, only two patients ceasing participation (2/20: 10%) over the three stages given their increasing poor health/ cognitive decline and eventual death, prior to the delivery of I-CoPE 3. Consistent with this, the enrolled carers of patients who died prior to I-CoPE 3 therefore also did not complete stage 3 (2/17: 12%).

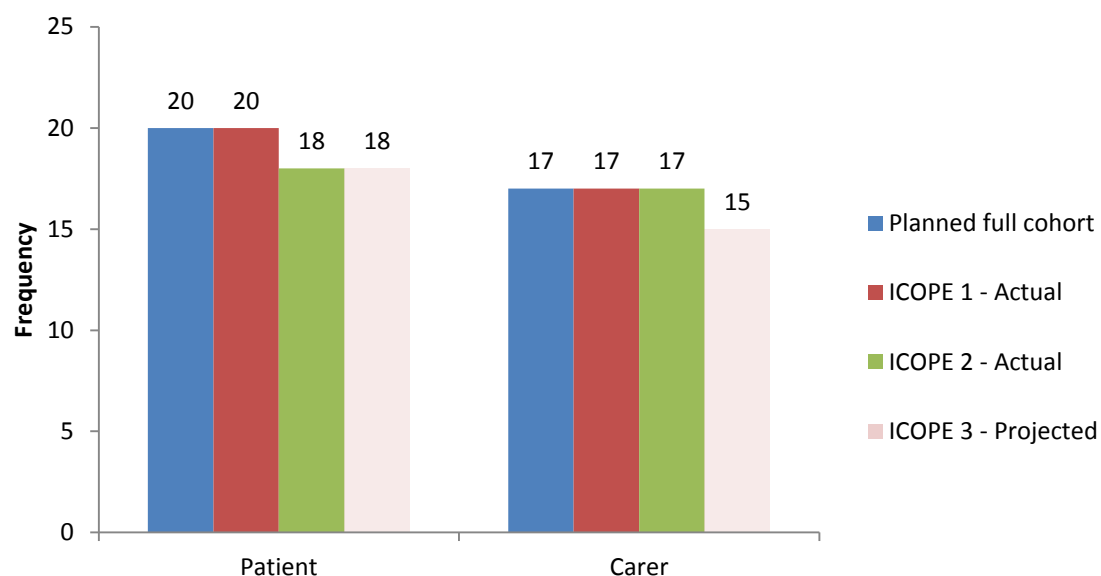


Figure 6. Planned, Actual and Projected I-CoPE Delivery

## Feasibility

### Duration of planned I-CoPE screening interactions

The mean time taken to complete I-CoPE screening for patients and carers was 80 minutes (range: 40-160) and 69 minutes (range 45-130) respectively (see Table 1). On average, I-CoPE 1 was the longest duration for both patients and carers, consistent with the face-to-face delivery format. I-CoPE 2 tended to be the shortest duration.

Table 1. Duration of planned screening interactions

	Mean duration (minutes)			
	I-CoPE 1 Face-to-face	I-CoPE 2 Phone	I-CoPE 3 Phone	TOTAL
<b>Patients</b>	45 (range: 15-90)	13 (range: 5-45)	26 (range: 5-60)	80 (range: 40-160)
<b>Carers</b>	27 (range: 10-60)	21 (range: 10-45)	19 (range: 5-30)	69 (range: 45-130)

### Unplanned I-CoPE interactions

A review of the I-CoPE diaries revealed carers tended to contact the patient care coordinator in between planned I-CoPE screening interactions more frequently than patients, who very rarely called (see Table 2). On average, additional unplanned calls were manageable (median of 2 unplanned carer calls and 0 patient calls), suggesting the screening points and frequency were mostly sufficient to respond to emergent needs outside of unexpected emergency situations. As anticipated, there were a few exceptions who were high users.

Table 2. Spontaneous unplanned interactions with patient care coordinator

<b>Spontaneous unplanned interactions</b>	
Carer voluntary use, n (%)	16/17 (80) Median 2 calls (range 0-11)
Patient voluntary use, n (%)	4/20 (20) Median 0 calls (range 0-2)

### Rudimentary I-CoPE cost considerations

Rudimentary costs are estimated (see Table 3) based on actual mean duration times and costs collated across the I-CoPE delivery period. The three-month model is estimated in real output terms at \$154.38 per patient/carers.

Table 3. Rudimentary I-CoPE cost considerations

I-CoPE Component	
Screening, support and coordination nurse time/ cost per patient and carer	Total est. time per patient/carers = 3 hrs Total est. I-CoPE screening = 2.5 hrs Total est. other coordination tasks = 0.5 hrs Total cost est. nursing time \$120
Information resources per patient	I-CoPE resource 1 est. cost \$8.00 item I-CoPE resource 2 est. cost \$9.00 item
Phone costs per patient	I-CoPE 2 patient/carers est. time = 34 minutes I-CoPE 2 est. cost (@ 22c /min) \$7.48 I-CoPE 3 patient/carers est. time = 45 minutes I-CoPE 3 est. cost (@ 22c /min) \$9.90
Total est. I-CoPE delivery costs per patient/carers	\$154.38

## Barriers and facilitators to broader dissemination

### Primary care communication and engagement

A review of the I-CoPE diaries revealed that patients valued the opportunity for their general practitioner (GP) to be involved in their care plan, with all patients (20/20, 100%) opting to enrol their GP to receive I-CoPE correspondence.

Additionally, a small number of GPs (3/20, 15%) spontaneously contacted the care transition manager to seek advice or to determine the best course of action concerning an enrolled patient. In one example, a regional GP contacted the care transition manager to arrange a direct admission for neurosurgical review in the setting of possible tumour recurrence, instead of sending the patient to the local ED to ultimately be transferred to the metropolitan neurosurgical unit. The unsolicited call resulted in seamless patient care and enabled rapid information transfer and planning.

The Care Transition Manager was also able to directly refer identified concerns raised through the I-CoPE screening process for management in primary care. On four occasions, enrolled patients were sent to their GP for concerns such as wound care, or advance care planning. Community supportive care referrals were also facilitated via the enrolled patients' GP in response to identified concerns, including strength post-surgery (physiotherapy), weight loss during radiotherapy (dietician), and coping/adjustment issues (psychology). Three patients were referred to community palliative care services.

Table 4. Summary of primary care engagement

Primary Care Engagement	Targeted	Actual
Number of enrolled GPs	20	20
Number of planned interactions	3 letters per patient	3 letters per patient (unless patient deceased before end of follow-up)
Number of spontaneous unplanned interactions initiated by GP	As required	3 (out of 20 enrolled GPs, 15%) voluntarily phoned the care transition manager to seek advice over the 3-month follow-up period
Number of health concerns directed to primary care	As required	On 4 occasions, concerns identified through the I-CoPE screening process were referred directly to the GP (e.g. wound care, advance care planning).
Number of community supportive therapy referrals	As required	2 community counselling referrals 3 community palliative care referrals 1 community dietician referral 1 community physio referral

### Health professional feasibility reflections

#### *Practicality of I-CoPE*

Of note, a review of the I-CoPE diaries (documented by the health professional delivering the three stages of I-CoPE) revealed the feasibility of the screening process to patients. Of note, patients with poor health and/or speech or language difficulties were still able to tolerate the screening communication using the planned framework of the Distress Thermometer.

### *Timing of transition points*

The timing of the selected transition points was practical to carry out, and the specific points on the illness trajectory were relevant to patients' and carers' emergent needs. Results indicate that the needs raised at I-CoPE 2 were commonly similar to those addressed at I-CoPE 1, but this point was considered necessary to clarify treatment plans and served as a flag to coordinate appropriate treatment appointments. The patient care coordinator reported that duration of screening was manageable relative to usual care, as needs were being addressed and therefore calls from patient and carer seemed fewer.

### *I-CoPE delivery format*

The selected face-to-face initial I-CoPE 1 delivery format, followed by the phone format for follow-up I-CoPE screens worked well. Specifically, it allowed for sufficient rapport to be developed in person and for the patient and carer to be orientated to the distress thermometer screening process prior to follow-up care being phone based.

### *Health professional satisfaction with I-CoPE*

Qualitatively, the patient care coordinator expressed satisfaction with the I-CoPE model of supportive care and coordination for patients with HGG and their carers. The satisfaction was primarily related to (1) improved communication experiences, allowing safety for challenging discussions to occur within the I-CoPE framework, and (2) the provision of greater role definition, structure, and consistency of care.



# SCREENING & COMMUNICATION OUTCOMES

## Patient and carer distress overtime

Patient and carer reported distress was significant at each I-CoPE screening conducted at times of transition, with a high proportion meeting the clinically significant cutoff  $\geq 4$  (see Table 5). On average, carers reported greater distress than patients.

Table 5. Distress Thermometer Scores

	I-CoPE 1 Mean DT*	I-CoPE 2 Mean DT*	I-CoPE 3 Mean DT*	TOTAL Mean DT*
<b>Patients</b>	4.3 (range: 0-9)	2.9 (range: 0-6)	5 (range: 0-8)	4.07
<b>DT <math>\geq 4</math></b>	60%	53%	63%	
<b>Carers</b>	5.4 (range: 2-8)	4.5 (range: 2-7)	4.7 (range: 2-8)	4.87
<b>DT <math>\geq 4</math></b>	88%	71%	67%	

\* Higher scores indicate greater distress/ level of concern (range= 0-10)

Figure 7 shows while carer distress remained reasonably stable at a clinically significant level, patient distress changed overtime. This reveals the relevance of re-addressing needs at times of transition and repeatedly assessing changing concerns.

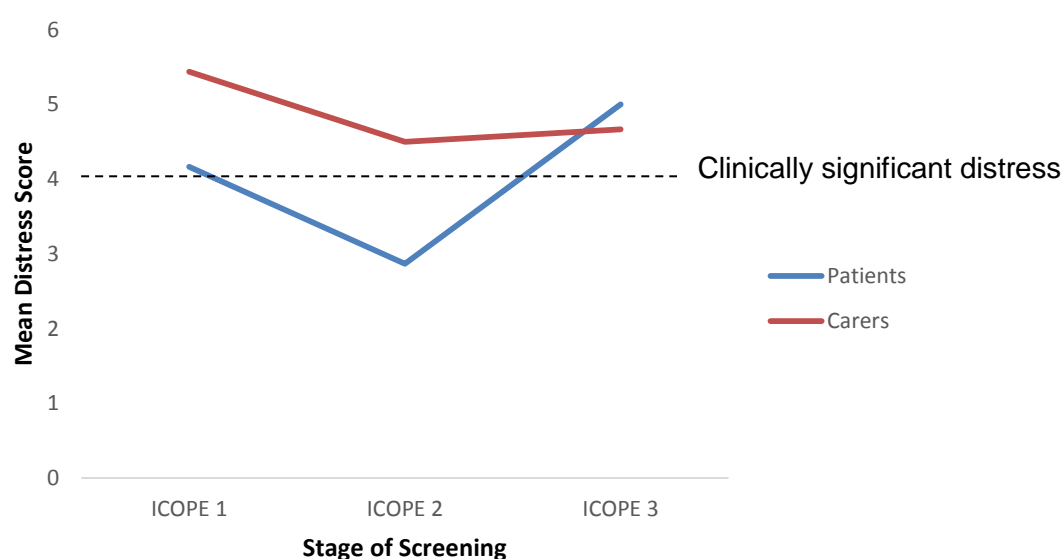


Figure 7. Patient and carer reported distress over time

### Patient and carer concerns overtime

Figure 8 shows the type of concerns raised by patients at each transition point when during I-CoPE screening, and the concerns overall. Concerns raised by patients were overall most prevalent in the spiritual or existential domain (33% of all concerns), such as fears of the unknown, fears of death and dying, and a stated desire to maintain quality of life.

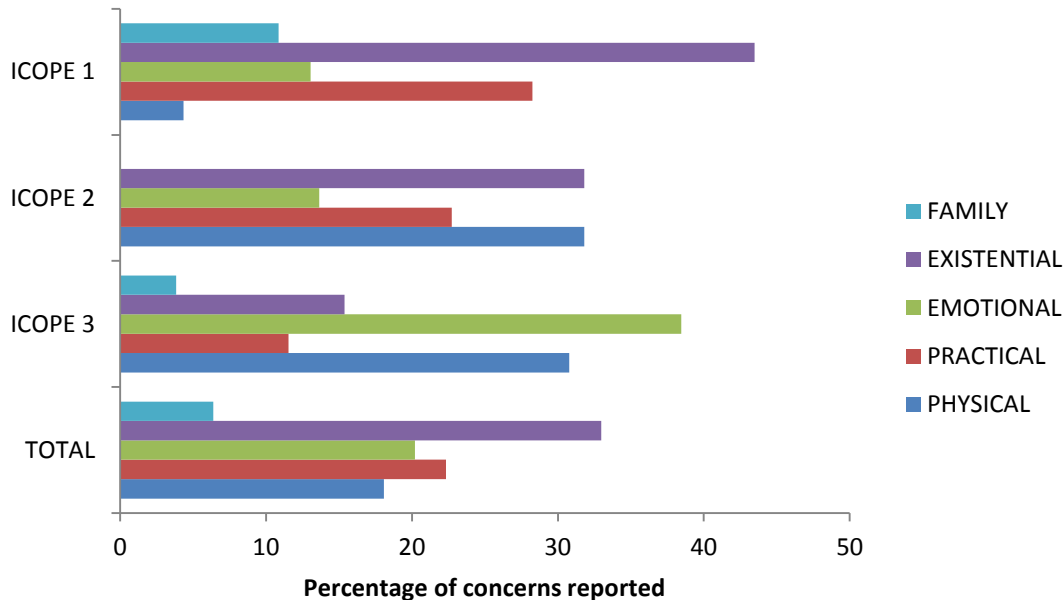


Figure 8. Patient concerns raised during I-CoPE screening

Figure 9 shows concerns raised by carers were overall most prevalent across practical (34% of all concerns) and emotional (29% of all concerns) domains. It was interesting to note that while focus at the earlier points was perhaps necessarily on practical concerns about caring responsibilities and questions about treatment, emotional concerns were most prevalent by I-CoPE3 (38% of all concerns) such as worry and anxiety about how their loved one was coping.

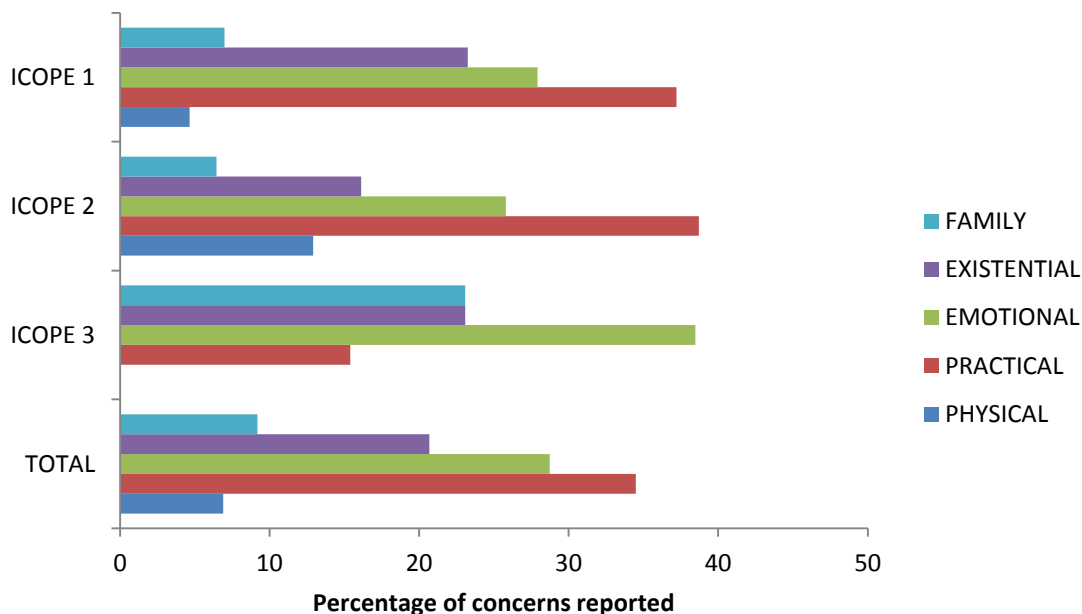
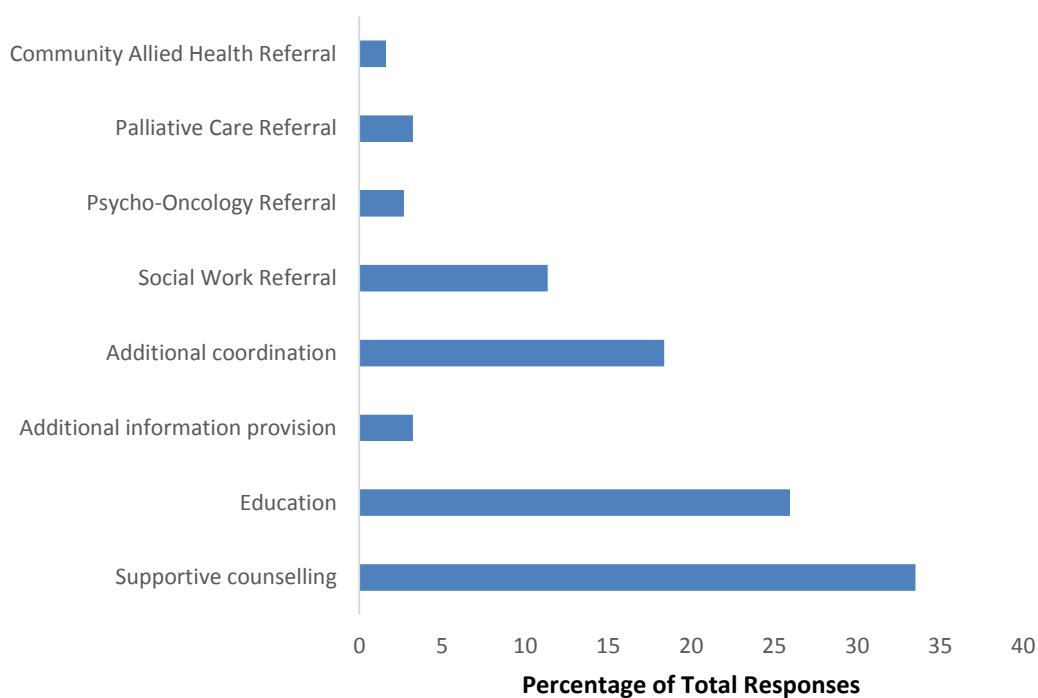


Figure 9. Carer concerns raised during I-CoPE screening

### I-CoPE responses and referral outcomes

Figure 10 shows the type of responses and referral outcomes resulting from all I-CoPE screening interactions. Supportive counselling was the most common response (34% of all responses provided). Of note, information provision and coordination tasks noted below are in addition to the routine components of I-CoPE. For example, all patients and carers received the I-CoPE information resource, but when additional information was requested and provided that was noted as a response.



*Figure 10. Type of screening responses*

# ACUTE HOSPITAL SERVICE UTILISATION

Table 7 shows the acute hospital service utilisation of enrolled I-CoPE patients during the three month follow-up period post diagnosis. Most patients had one admission, and the subsequent emergency department presentation was low (30%). Of those who were admitted, half (50%) were planned via the I-CoPE patient coordinator. The median length of stay across the three month follow-up period was just 12 days (range 5-50 days). For the 35% of patients requiring rehab post-surgery, the median bed days in rehab was 10 days (range 5-19). Of note, use of supportive and palliative care modalities was high for this cohort enrolled in I-CoPE.

*Table 7. Acute hospital utilisation by I-CoPE patients*

<b>Total admissions</b>		
Total admissions per patient, n (%)	1	14/20 (70)
	2	6/20 (30)
Total length of stay (LOS) across admissions	Median: 12 bed days Range: 5 - 50 bed days	
<hr/>		
<b>Diagnostic admission</b>		
Neurosurgery use, n (%)	20/20 (100)	Median 8.5 bed days (range 5-27)
Rehab use, n (%)	7/20 (35)	Median 10 bed days (range 5-19)
ICU use, n (%)	2/20 (10)	Median 2 bed days
Oncology use, n (%)	1/20 (5)	
Palliative care use, n (%)	0/20 (0)	
<hr/>		
<b>Supportive &amp; palliative care use</b>		
Palliative care consultation use, n (%)	7/20 (35)	
Palliative care community referral, n (%)	3/20 (15)	
Social work referral, n (%)	12/20 (60)	
Psycho-oncology referral, n (%)	6/20 (30)	
<hr/>		
<b>Emergency department (ED) utilisation</b>		
ED presentations per patient, n (%)	0	14/20 (70)
	1	5/20 (25)
	2	1/20 (5)
Planned ED presentations via I-CoPE, n	3 presentations	

## SECONDARY OUTCOMES: SHORT-TERM EFFICACY

### Unmet supportive care needs

#### Patients

Patients' mean unmet supportive care needs were compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 8 shows patients report significant reductions in unmet patient care and support needs and unmet health system needs, both of a large effect size. Needs relating to physical and daily living and psychological concerns were greater, though these changes were small and non-significant.

Table 8. Patients unmet supportive care needs

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	<i>p</i>	<i>d</i>	Magnitude of change	Direction of change
Unmet supportive care needs	34-170*	70.3 (25.2)	73.8 (26.6)	>.05	0.1	Small effect size	Fewer unmet needs
Physical and daily living	5-25*	8.2 (5.8)	9.5 (3.5)	>.05	0.2	Small effect size	Greater unmet needs
Psychological need	10-50*	19.1 (9.9)	22.3 (13.1)	>.05	0.2	Small effect size	Greater unmet needs
Patient care and support	5-25*	10.0 (4.3)	30.5 (11.3)	< 0.001	2.7	Large effect size	Fewer unmet needs
Health system and information	11-55*	30.7 (13.4)	8.0 (2.7)	< 0.001	2.7	Large effect size	Fewer unmet needs

\* Higher scores indicate greater unmet supportive care need

#### Carers

Carers' mean unmet supportive care needs were compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 9 shows carers report significant reductions in unmet supportive care needs of a large effect size.

Table 9. Carers unmet supportive care needs

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	<i>p</i>	<i>d</i>	Magnitude of change	Direction of change
Unmet supportive care needs	0-42*	15.7 (8.0)	8.7 (5.5)	.01	1.0	Large effect size	Fewer unmet needs

\* Higher scores indicate greater unmet supportive care need

## Unmet information needs

### Patients

Patients' mean unmet information needs were compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 10 shows patients report marginally significant reductions in unmet information needs (large effect size) and practical 'action orientated' information needs (medium effect size). Unmet disease and treatment orientated information (e.g. information about survival) remained stable.

Table 10. Patients unmet information needs

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	<i>p</i>	<i>d</i>	Magnitude of change	Direction of change
Unmet information needs	0-51*	23.5 (15.8)	18.2 (13.2)	.08	0.7	Medium effect size	Fewer unmet needs
Unmet disease and treatment orientated information	0-27*	15.5 (10.2)	14.3 (10.3)	> .05	0.2	Small effect size	Fewer unmet needs
Unmet practical/ action orientated information	0-24*	8.0 (7.0)	3.9 (3.8)	.06	0.8	Large effect size	Fewer unmet needs

\* Higher scores indicate greater unmet information need

### Carers

Carers' mean unmet information needs were compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 11 shows carers report marginally significant reductions in unmet practical 'action orientated' information needs, and non-significant reductions in unmet disease and treatment orientated information, both of which were of a medium effect size.

Table 11. Carers unmet information needs

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	<i>p</i>	<i>d</i>	Magnitude of change	Direction of change
Unmet information needs	0-51*	26.8 (8.9)	19.9 (8.4)	> .05	0.6	Medium effect size	Fewer unmet needs
Unmet disease and treatment orientated information	0-27*	18.5 (6.5)	14.3 (6.2)	> .05	0.5	Medium effect size	Fewer unmet needs
Unmet practical/ action orientated information	0-24*	8.3 (3.3)	5.6 (3.2)	.08	0.6	Medium effect size	Fewer unmet needs

\* Higher scores indicate greater unmet information need

## Preparedness to care

### Carers

Carers' mean preparedness to care was compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 12 shows carers report marginally significant increases in preparedness for the caring role of a medium effect size.

Table 12. Preparedness to care

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	p	d	Magnitude of change	Direction of change
Preparedness to care	0-32*	14.3 (6.5)	19.1 (7.1)	.06	0.7	Medium effect size	Increased preparedness

\* Higher scores indicate greater preparedness to care

## Quality of life (QOL)

### Patients

Patients' mean QOL was compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 13 shows patients report marginally significant improvements in general QOL and significant improvements to brain cancer specific QOL, with both changes of a large effect size.

Table 13. Patient quality of life

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	p	d	Magnitude of change	Direction of change
General QOL (FACT-G)	0-104*	63.7 (12.7)	73.4 (20.7)	.06	0.8	Large effect size	Increased QOL
Brain Cancer specific QOL (FACT-Br)	0-180*	111.1 (23.0)	124.9 (32.2)	.05	0.8	Large effect size	Increased QOL

\* Higher scores indicate greater quality of life

### Carers

Carers' mean QOL was compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 14 shows carers report significant improvements in QOL of a medium effect size and significant decreases in carer burden of a large effect size.

Table 14. Carer quality of life

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	p	d	Magnitude of change	Direction of change
QOL	0-136*	56.2 (20.3)	46.2 (23.7)	.08	0.7	Medium effect size	Improved QOL
Carer burden	0-40*	22.8 (8.6)	17.0 (8.5)	.009	1.1	Large effect size	Decreased burden

\* Higher scores indicate poorer quality of life

## Psychological wellbeing

### Patients

Patients' mean psychological wellbeing was compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 15 shows patients report decreases in psychological wellbeing, though changes were small and non-significant.

Table 15. Carers psychological wellbeing

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	p	d	Magnitude of change	Direction of change
Stress	0-21*	6.4 (6.8)	8.2 (9.0)	> .05	0.4	Small effect size	Poorer psychological wellbeing
Anxiety	0-21*	3.6 (3.1)	5.1 (6.1)	> .05	0.4	Small effect size	Poorer psychological wellbeing
Depression	0-21*	3.3 (3.6)	5.3 (6.6)	> .05	0.7	Medium effect size	Poorer psychological wellbeing

\* Higher scores indicate poorer psychological wellbeing

### Carers

Carers' mean psychological wellbeing was compared between baseline assessment (T0) and following I-CoPE 1 and 2 (T1). Table 16 shows carers report non-significant improvements in psychological wellbeing, of a medium effect size.

Table 16. Carers psychological wellbeing

Short-term outcome	Possible range	T0 M(SD)	T1 M(SD)	p	d	Magnitude of change	Direction of change
Stress	0-21*	15.8 (7.7)	12.4 (6.9)	> .05	0.5	Medium effect size	Improved psychological wellbeing
Anxiety	0-21*	6.9 (5.8)	5.3 (5.1)	> .05	0.4	Small effect size	Improved psychological wellbeing
Depression	0-21*	7.3 (6.4)	4.7 (5.1)	> .05	0.6	Medium effect size	Improved psychological wellbeing

\* Higher scores indicate poorer psychological wellbeing



## RELEVANCE TO OTHER END-STAGE ILLNESSES

Issues pertaining to the dissemination of a model such as I-CoPE were explored in qualitative interviews with health care professionals in various end-stage care settings. Tables 17, 18 and 19 highlight the findings. Care transitions points were not currently formally enacted in usual care. Despite this, the concept of identifying transition points to herald pre-defined responses and supports was relevant to the settings explored: renal, heart failure and dementia. All health professionals noted the importance of selecting appropriate points based on symptom and/or survival data, supported and supplemented by health professional consensus to confirm the clinical relevance and practicality of points.

### Renal care setting

Table 17. Exemplar qualitative data from the setting of renal failure

Renal	
Do you see relevance of the I-CoPE components to improving support at times of care transition?	<p><i>"I think that the model and the idea behind it is a really useful and valuable one. Part of the value in this model and how you've set it up in regards to these trigger points. Having a mostly pre-determined response, but flexible around the needs of the patient, makes a lot of sense."</i></p> <p><i>"The idea of having an integrated response in regards to information giving is really valuable - integrated into the patient's needs, but also integrated into primary care and the care being given by the specialist groups."</i></p>
Are there <i>currently</i> care transition points which signal the enactment of routine supports and/or responses?	<p><i>"Not in routine practice currently, no."</i></p> <p><i>"There's lots of information and support for people who are being considered for transplant. There's information for people having dialysis. There's less support and information and focus for people who don't fit in either of those categories - and that seems to be the most obvious gap in that support for renal people."</i></p>
Are there <i>potential</i> identifiable care transitions based on disease and/or treatment parameters which could herald particular support/responses?	<p><i>"You could say chronic renal failure of significance in terms of the effect on the person, is only an issue when you get to X level of renal disease and beyond that point things become more predictable. So if you say, stage 4 disease, it's more predictable that these people are the most at risk of having renal related admissions, or the most at risk of renal dialysis, and so maybe these are the points of inserting this kind of idea."</i></p>
Are there any foreseeable barriers and/or facilitators to disseminating a model such as I-CoPE?	<p><i>"Defining the trajectories within renal care is difficult. It doesn't challenge the relevance or the importance of the idea; it may just make the content and delivery much more challenging."</i></p>

## Cardiology care setting

Table 18. Exemplar qualitative data from the setting of heart failure

Heart Failure	
Do you see relevance of the I-CoPE components to improving support at times of care transition?	<p><i>"One-off screenings would be very helpful. Psychological distress of chronic illness is very significant and I think we don't know because no one asks."</i></p> <p><i>An educational resource would be great, because I don't think patients' understand their diagnosis at all, so I think they miss out on their planning. They need similar to what you've produced - "You've got heart failure what does this mean?" There are no formal written information resources I've seen.</i></p>
Are there <i>currently</i> care transition points which signal the enactment of routine supports and/or responses?	<i>"I think that transition points probably don't exist currently, but I suppose the way I see heart failure, they could."</i>
Are there <i>potential</i> identifiable care transitions based on disease and/or treatment parameters which could herald particular support/responses?	<p><i>"The way I see it, there are three stages of heart failure and each transition requires a different response."</i></p> <p><i>"A one-off review and palliative care introduction for people at diagnosis of heart failure (who are not on the transplant list) to say this is a significant illness and an illness that is not curable. Once you've got a diagnosis of heart failure, you've got about a 20% risk of dying in 12 months. For most people, it will be the cause of their death, but I don't think that's explicitly communicated."</i></p> <p><i>"There's also the transition when people start to become symptomatic and are presenting to hospital often multiple times. Once I notice the admissions getting closer together, I know wheels will start to fall off and things will transition soon and that's when we need to start to think about bumping up supports."</i></p> <p><i>"There's also the clinically terminal group and they require support through what can be a pretty bumpy transition from someone who thinks they just have to go from heart failure clinic to someone who is dying of their disease."</i></p>
Are there any foreseeable barriers and/or facilitators to disseminating a model such as I-CoPE?	<i>"Resources are the biggest barrier I see to implementing this change to the way we provide care."</i>

## Dementia care setting

Table 19. Exemplar qualitative data from the setting of dementia care

<b>Dementia</b>	
Do you see relevance of the I-CoPE components to improving support at times of care transition?	<p><i>"It would be nice for someone with dementia or their carer to have a constant person supporting them along the trajectory from one end to the other. I think in dementia it all comes down to have a carer or family member that's proactive. If you don't have that, I don't know how you manage."</i></p> <p><i>"Once diagnosed with dementia, patients are often fairly unaware. So in this context it's really about supporting the carers. And I think there are a lot of similar challenges for carers in the dementia setting with those in the glioma setting - personality change is distressing."</i></p>
Are there <i>currently</i> care transition points which signal the enactment of routine supports and/or responses?	<i>"Dementia trajectory tends to be a lot more of a slow and gradual process, rather than a stepwise change in function. I don't think we work based on transitions currently."</i>
Are there <i>potential</i> identifiable care transitions based on disease and/or treatment parameters which could herald particular support/responses?	<i>"One transition is the time that people may start developing either behavioural or psychiatric symptoms. I think that would be the main transition point, and one that often ends up heralding a care placement."</i>
Are there any foreseeable barriers to disseminating a model such as I-CoPE?	<i>"I think there is a role for palliative care in dementia, but the way our palliative services are currently set up, means they're not currently very involved in dementia care. 75% or more of people in nursing homes have dementia so the services are used to looking after these needs. And GPs and aged care nurses are used to and familiar with this trajectory. I think it's not seen as a specialist problem."</i>

# Discussion

## Feasibility, acceptability and applicability of I-CoPE

The results of this pilot study highlight the feasibility, acceptability and applicability of the I-CoPE model of care. Acceptability was demonstrated by the 95% enrolment rate of patients and their nominated carers. Applicability of the I-CoPE components (information and education, coordination, preparation and emotional support) was evident by the full cohort's continued I-CoPE participation in the context of a busy treatment schedule and new terminal diagnosis. Finally the model was feasibly delivered: the collective patient and carer average duration of I-CoPE was 149 minutes; there were manageable spontaneous unplanned calls to the care-coordinator (median of 0 patient and 2 carer calls); appropriate primary care engagement; and a rudimentary delivery cost estimation of \$154.38 per patient and carer dyad.

## Patient and carer distress overtime

I-CoPE screening interactions with this patient and carer cohort revealed several important understandings and implications for future service delivery. Firstly, as anticipated, patient distress levels fluctuated akin with the illness trajectory (60% I-CoPE 1; 53% I-CoPE 2; 63% I-CoPE 3) highlighting the relevance of repeated screening and re-addressing concerns at times of transition. Overall, the proportion of clinically significant patient distress ( $\geq 4$ )<sup>32</sup> was high relative to earlier studies with HGG patients that have reported prevalence rates of 29%<sup>38</sup>, 36.7%<sup>35</sup>, 48.4%<sup>40</sup> and 52%<sup>36</sup>. It is possible the reporting of true distress may speak to the quality of the rapport established with the care coordinator during I-CoPE1, which was delivered face-to-face, and tended to be the longest interaction (mean duration = 45 minutes, vs. 13 and 26).

Secondly, patient and carer distress followed different trajectories, where patients tended to be most distressed at the conclusion of radiotherapy, whereas carers typically reported greatest level concern at diagnosis. Overall, carer distress tended to be greater than that of the patient. Consistent with earlier qualitative work<sup>16</sup>, these patterns highlight that patient and carer needs for support are distinct and need to be addressed independently. Carers should be provided with opportunities to discuss their needs outside the typical medical forum, where the patient's medical needs are the focus of information provision.<sup>13,16</sup>

Finally, it was interesting to note that concerns raised by patients were overall most prevalent in the spiritual or existential domain (33%). This was particularly apparent at diagnosis (I-CoPE 1) where concerns such as fears of the unknown, fears of death and dying, and stated desire to maintain quality of life accounted for 43% of all concerns raised. While this notable existential suffering is consistent with earlier qualitative work with patients with HGG<sup>17</sup>, such concerns remain outside the usual medical model of care<sup>13</sup> despite accounting for a significant proportion of patient distress. Contrastingly, carer focus at the earlier points was perhaps necessarily on practical concerns about caring responsibilities and questions about treatment. This shifted towards the transition at the end of radiotherapy treatment, when emotional concerns (38% of all concerns) such as worry and anxiety about how their loved one was coping, or dealing with uncertainty were most profound.

## Benefits to patients and their carers

The successful implementation of this multi-faceted I-CoPE model has demonstrated substantial benefits for the individual patients and carers involved. Benefits were demonstrated in this cohort of patients in terms of fewer unmet supportive care and information needs and improved brain cancer specific quality of life. Benefits to this cohort of carers were demonstrated in terms of fewer unmet supportive care and information needs, improved quality of life, lower carer burden, improved preparedness to care, and improved psychological wellbeing.

Benefits also included apparent improved capacity to navigate the system with ready contact with the care co-ordinator in the event of uncertainty or new concerns. Carers in particular were able to enlist additional supports where needed, spontaneously calling the care coordinator (median two contacts) outside the planned interactions over the three month follow-up period. Accordingly, benefits have been evident in the form of apparent improved understanding of the disease and its likely outcomes as they engage in conversations around goals of care, goals of a life well lived and need to attend to relationships and factor in these concerns in decision making. These interactions also enabled the appropriate and timely triage of concerns, which in three instances, resulted in planned admissions facilitating seamless care for the patient.

Importantly, these outcomes have been consistently reported by patients as being important in the last phase of their life.<sup>54</sup> Attending to such outcomes and clarity around goals of care has been consistently demonstrated to be associated with reduction of use of aggressive 'futile' therapies at the end of life.<sup>55</sup> While such longer term health care utilisation data is not available for this project, there is no reason not to believe the clear patterns from elsewhere would not be realised in Australia. In the short-term, health utilisation data over the three month follow-up suggests at minimum, enrolling patients onto the I-CoPE model did not lengthen diagnostic admission times and on occasion, facilitated direct necessary hospital admissions circumventing the need for emergency presentation.

### Benefits to health professionals

The I-CoPE model also had clear benefits for the health care professionals involved. Qualitatively, the care coordinator documented the clear advantages of the I-CoPE framework in terms of providing structure, consistency, and role definition. This framework enabled easier interactions with rich and full communication exchanges, clearer goals, and less wasted time (median I-CoPE duration 80 and 69 minutes for patients and carers respectively across three months) as patients and their carers present in a timely way with clear questions and concerns. Consistent with earlier studies with advanced cancer patients, utilising the Distress Thermometer<sup>32</sup> merely as a communication tool facilitated the initiation of conversations which may otherwise not have occurred, and enhanced appropriate psychosocial referrals.<sup>56-58</sup> Importantly, while earlier studies which have implemented screening for distress have had null findings on patient and carer QOL,<sup>59, 60</sup> our pilot results suggest the multi-faceted nature of I-CoPE positioned around care transitions in line with the illness trajectory shows early promise to achieve benefits. A randomised trial is required to confirm positive preliminary findings from this pilot study.

### Benefits to the health system

Benefits to the health system were also noted as outcomes of the I-CoPE model. In particular, the timely engagement of specialist palliative care consultation (35%) and referral to community palliative care (15%) was a direct outcome of the attendant I-CoPE screening for needs. Of note, this included the two patients (10%) who subsequently died in the three month follow-up period. Recent population-level data in the state of Victoria indicated the usual low rates of timely engagement, with just 12% of patients with HGG who are recognised as having poor prognostic disease and who subsequently die within 120 days of diagnosis being referred to palliative care prior to hospital discharge.<sup>14</sup> In this study, I-CoPE enabled this subset of poor prognostic patients to be linked into palliative care in a timely manner - an outcome which has many recognised public health benefits: enhanced patient QOL and caregiver bereavement outcomes,<sup>8,9,55</sup> reduced aggressive and futile care at the end of life, reduced presentation to emergency department, and greater likelihood of death at home.<sup>5,11</sup>

### Implications for others areas of care

The I-CoPE model was demonstrated to have relevance to the care of patients with other end-stage illnesses, whereby identifying relevant transition points around the specific



disease or treatment parameters may also help to facilitate similar benefits for patients and their carers and health professionals. In line with the aims of this study, the Australian and New Zealand Society of Palliative Medicine (ANZSPM) recently indicated the identification of specific 'trigger points' which signal times of transition, may guide difficult conversations and facilitate timely referral.<sup>3</sup> As such, the results of this pilot study have implications for a paradigm shift in how to approach other progressive, eventually fatal illnesses such as COPD. The underlying principle of this study was a structured intervention based upon disease trajectory. Such an approach has application for the introduction of other forms of support in a timely manner according to points reached on a disease trajectory. For example in COPD care, a referral prompted by a second admission to hospital in 6 months may prompt a review whereby aspects of palliative care are raised for that patient and family. Such an approach assists in a series of ways: it provides a prompt for clinicians, reduces individual variation in care, normalizes care, and ensures equity of access for all, despite illness, diagnosis, and individual clinicians.

Most particularly, as highlighted in the health system benefits above, the approach has implications for the timely engagement with palliative care, which appears to be important to achieve benefits for patients.<sup>3, 61</sup> Time is required to consider personal values and goals, and match medical care to the achievement of goals. Late referral leaves little time to establish confidence in community settings of care, limited ability to partake in complex communication tasks and attend to relationships – all tasks designated as important by patients close to the end of life.<sup>54</sup> In a Victorian cohort of patients with HGG, the time required to achieve increased likelihood of death at home, the preferred outcome of most patients<sup>62-64</sup>, was at least 120 days before death.<sup>15</sup>

### Considerations for broader dissemination

It is important to note that in order for outcomes to be achieved, we believe careful up skilling of staff with respect to communication skills is a necessity. I-CoPE is a model based upon communication – improved understanding, information, grounded decision making and care of another human being. Difficult discussions with patients and their carers were raised through the I-CoPE model and accordingly, adequate support for staff involved was required. We recognise that patient care coordinators more broadly are in a unique position to undertake these meaningful engagements with patients and their carers and would advocate for this group of staff to have the opportunity for communication skills development as required.

Additionally, in an expanded form of this model whereby engagement with palliative care is based upon illness trajectories for other patient groups with progressive, eventually fatal disease, it is necessary to consider the palliative care response, capacity and model of delivery. Such an approach extends beyond the current model of most palliative care services based upon admission to service and remaining a patient of the service until the point of discharge, usually death. New models of palliative care with greater capacity for patients to step in and out of services as required, or tiered levels of involvement based on need, would better support this type of approach.

### Conclusions

The positive preliminary results of this pilot implementation of I-CoPE into a tertiary Australian neuro-oncology service - both in terms of feasibility and acceptability of the I-CoPE model, and short-term efficacy with improved patient and carer reported outcomes - show promise for further testing via a randomised controlled trial and the potential for broader dissemination. We attribute the preliminary success of this study on the underlying principle of a model based upon predefined transitions in the disease trajectory. Such an approach has application for the introduction of other forms of support in a timely manner according to points reached on a disease trajectory.

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