

POLICY OPTIONS

Pilot implementation of I-CoPE: An innovative model to support patients with glioma and their carers across key care transitions

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Policy context

MEETING THE SUPPORTIVE & PALLIATIVE CARE NEEDS OF AUSTRALIANS

The care of people with progressive, chronic and eventually fatal illness represents a substantial challenge to Australian health systems and resources. They have significantly needs for support and ultimately for palliative care, and have been demonstrated to have improved quality of life, improved quality of dying and less use of aggressive therapies at the end of life when receiving such support. Currently there is substantial variation in the provision of supportive and palliative care, despite the proven benefits of these forms of care for people with advanced illness.

An approach to disease management which models the delivery of aspects of care upon particular points being reached in the course of the illness, or its trajectory, ensures that care does not vary with individual doctors or health providers. It also ensures equity of access to care and the maintenance of health care standards across a population. This is particularly the case when considering access to and engagement of palliative care for people with progressive, eventually fatal illness.

This study was situated to provide a standardized, equitable approach to care for patients with progressive, eventually fatal illness. The project successfully pilots a model of care (called I-CoPE) based upon standard responses at points reached in an illness trajectory. Patients with high grade glioma, the exemplar illness of this project, were provided with staged information, screening for concerns, emotional support and care coordination based upon stages reached in their illness course. This model or approach has relevance in engagement with palliative care for patients with other progressive, eventually fatal illnesses such as COPD and heart failure, and as such, this approach represents a paradigm shift in care provision for these patient cohorts.

The study established that such an approach was feasible and highly acceptable to patients and their carers and health professionals. It demonstrated that staged provision of information consolidated the relationship with the patient care coordinator, ensuring that this person was contacted at times of uncertainty or clinical change, instead of direct presentation to emergency departments, which was the previous response.

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 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.

Policy options

- > An approach which delivers supportive and palliative care as routine, when points of an illness course are reached, ensures equitable, high quality care.
- > Progressive, eventually fatal illnesses have a series of points signaling clinical change throughout their course. The provision of routine care responses according to these points, which is built into clinical guidelines, has the potential to ensure standardized, equitable access to care.
- > Routine engagement of palliative care dependent upon illness stage represents a paradigm shift removing individual clinician preconceptions or fears, and enhancing patient and family caregiver support.
- > An approach of building palliative care engagement at particular designated points in the illness course represents a means of enhancing patient and family caregiver support, improving end of life care and reducing health care costs for all Australians with progressive, eventually fatal illness.
- > Such a routine, equitable approach to care has implications for people suffering chronic, progressive and eventually fatal illnesses such as chronic obstructive pulmonary disease, heart failure and chronic kidney disease.

Key findings

The positive preliminary results of this pilot implementation of the I-CoPE model 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.

Key Outcomes of the I-CoPE Model

I-CoPE Model Outcome	
Acceptability	> Acceptability was demonstrated by the 95% enrolment rate of patients and their nominated carers, with only one patient, and one carer declining to participate in the I-CoPE model.
Applicability	> Applicability of the I-CoPE components (information and education, coordination, preparation and emotional support) was evident by the full cohort's (100%) continued I-CoPE participation, in the context of a busy treatment schedule and new terminal diagnosis.
Feasibility	<p>The I-CoPE model was feasibly delivered:</p> <ul style="list-style-type: none">> The mean duration of I-CoPE screening for patients and carers was 80 minutes (range: 40-160) and 69 minutes (range 45-130) respectively.> There were manageable spontaneous unplanned calls to the patient care-coordinator (median of 2 carer and 0 patient calls).> There was appropriate primary care engagement achieved.> Rudimentary cost estimations show real term delivery costs of \$154.38 per patient and carer dyad.

I-CoPE Model Outcomes (Continued)	
Communication and screening outcomes	<ul style="list-style-type: none"> > Patient and carer reported distress during the I-CoPE screening process fluctuated akin with the illness trajectory, highlighting the relevance of repeated screening to re-address emerging concerns at times of transition. > Patient and carer concerns followed different trajectories, confirming their distinct needs for support and information which should be separately addressed. > Patient concerns remained focused in the existential/ spiritual domain, while carer concerns shifted from a practical to emotional focus over time.
Primary care engagement	<ul style="list-style-type: none"> > Patients valued the opportunity for their general practitioner to be involved in their care plan, with all patients (100%) opting to enrol their GP to receive I-CoPE correspondence.
Health service use	<ul style="list-style-type: none"> > Most (70%) patients had the one diagnostic admission, and subsequent emergency department presentation was low (30%). Of those who did present, half (50%) were planned via the I-CoPE patient coordinator. > The total median length of stay across the three month period was just 12 days (range 5-50 days). > Use of supportive and palliative care modalities was high (60% Social work, 35% palliative care consultation, 30% psych-oncology, and 15% community palliative care).
Relevance to other eventually fatal illnesses	<ul style="list-style-type: none"> > Qualitative interviews with health professionals confirmed the relevance of the concept of identifying transition points to herald pre-defined responses and supports to the settings explored: renal care, heart failure and dementia care.
Patient short-term efficacy	<p>From T0 (baseline) to T1 (post ICOPE 1 and 2), patients reported:</p> <ul style="list-style-type: none"> > Fewer unmet supportive care needs ($d = 2.7$: large change) > Fewer unmet information needs ($d = 0.8$: large change) > Improved brain cancer specific quality of life ($d = 0.8$: large change)
Carer short-term efficacy	<p>From T0 (baseline) to T1 (post ICOPE 1 and 2), carers reported:</p> <ul style="list-style-type: none"> > Fewer unmet supportive care needs ($d = 1.0$: large change) > Fewer unmet information needs ($d = 0.6$: medium change) > Improved quality of life ($d = 0.7$: medium change) > Lower carer burden ($d = 1.1$: large change) > Increased preparedness to care ($d = 0.7$: medium change)

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