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Responding to urgency of need in palliative care: The development of a decision aid for Palliative Care triage

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Funding

State Government Victoria

Department of Health

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Background

- Demand for services is increasing
- Increasingly diverse patient population & referral sources
- Literature:
    - Philip JA, Le BH, Whittall D, Kearney J (2010) The development and evaluation of an inpatient palliative care admission triage tool. Journal of palliative medicine 13 (8):965-972
    - Tan H, O'Connor M, Wearne H, Howard T (2012) The evaluation of a triage tool for a community palliative care service provider. Journal of palliative care 28 (3):141-148
    - Issues: Inter-rater reliability and face validity

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Factors Relevant to Triage

- Phase of disease
- Prognosis
- Performance status
- Control of pain and other symptoms
- Presence of confusion
- Psychosocial distress
- Potential for catastrophic event
- Daily syringe driver or hygiene needs
- Adequacy of care environment

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Project Aim

Overall: To develop and evaluate a specialist palliative care triage assessment decision aid, or suite of aids, to facilitate the equitable, efficient and transparent allocation of inpatient palliative care admissions, inpatient palliative care consultations and community palliative care consultations by urgency of need

Stage One: To explore the experience of health professionals when triaging the palliative care needs of their patients

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Methods

Mixed methods project with a sequential design:

- Stage 1 – qualitative exploration
- Stage 2 – discrete choice experiment
- Stage 3 – validation study
- Stage 4 – post-implementation evaluation

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Population and Method

- 20 purposive-sampled palliative care and general health professionals
- Inpatient, consultation liaison and community palliative care services
- Metropolitan and regional settings
- Semi-structured focus groups
- Deductive thematic analysis by two researchers

Population

	N (%)
Palliative Care Physician	7 (35)
Inpatient unit	4 (20)
Inpatient consultation liaison	5 (25)
Community	6 (30)
General Practitioner	1 (5)
General Physician	1 (5)
Palliative Care Nurse	9 (45)
Inpatient unit	1 (5)
Inpatient consultation liaison	5 (25)
Community	5 (25)
Generalist (District) Nurse	1 (5)
Allied Health	1 (5)

Population

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		N (%)	Mean (range)
Gender			
	Female	15 (75)	
	Male	5 (25)	
Age			
			51.5 (35-66)
Work setting			
	metropolitan	15 (75)	
	regional	5 (25)	
Years of practice			
	…in healthcare		26.4 (8-42)
	…in Palliative Care		14.8 (0-29)

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Results

- Problem severity
- Performance status
- Phase of disease
- Dynamic factors
- Communication needs
- Barriers and challenges for implementation

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Physical Suffering and Distress

- *'I think from a community perspective the red flags are often easy – they've got out of control pain or they've got nausea or vomiting, or they've got acute respiratory distress and those are the ones I think most nurses go, oh ok, there's a level of urgency with those.'* Nurse

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Psychological Suffering and Distress

- *'Their anxiety was such a big thing. It was just urgent for them.'* Nurse

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Caregiver Distress and Burnout

- *'You'd hope if there was physical things with symptoms that there would be a plan or something in place that could be followed even if it feels a bit chaotic. But if a carer is there really struggling, it's never going to work without the support.'* Allied Health Clinician

Performance Status

- Unhelpful in isolation
- *‘It can't be really about performance status particularly, can it, because there's an awful lot of people out there who – in nursing homes who have a terrible performance status, who are perfectly comfortable and don't need admission, so I'm not sure that's going to be very helpful.’* Doctor

Phase of Disease

- Mixed responses
- *'If people are saying I want to go home to die and they are getting more terminal, then it's a no brainer.'* Nurse
- *'But if they're dying fast and reasonably comfortable there, you're going to leave them where they are, aren't you.'* Doctor
- *'I think phase of care is such a sort of variably applied commodity to patients and I think to be honest the definitions are so poorly understood and probably not necessarily indicative of clinical care.'* Doctor

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Mismatch of Needs and Care

- *'There is an item of adequate care environment which kind of is open to interpretation and perhaps captures, you know, that changing performance status, they're no longer able to be cared by the frail wife.'* Doctor
- *'It's the rate of change which is really important. So somebody is going along all right and then suddenly goes whoosh. It's that rate of change when it's suddenly changing, you know, it speeds up and then start to change quickly. That's often when people need help…'* Doctor

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Impending Mismatch

- *'It can be urgent and actually get in and set it up, you know, make sure you've got emergency medications, the bed, everything else that you might need to enable them to stay at home… Because especially if it's a Friday afternoon, you know, and they start to deteriorate over the weekend. That's the urgency…And you could switch that round too though with the urgency of someone who's in an acute bed in hospital who's deteriorating, entering that too and wanting to go home.'* Nurse

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Urgent and Complex Communication Needs

- *'You can have someone with an inappropriate goal of care but they're not really receiving inappropriate treatment… It's actually when it's impacting on the experience of the patient. So if the patient you feel is suffering as a consequence of inappropriate goals, then that's urgent.'* Doctor
- *'Rather than allowing that person to be sent off for one more investigation and they're clearly dying, it's – you know, you might want to get them moved urgently to establish clearer goals of care and a way forward.'* Doctor

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Challenges for Implementation

- Local politics, relationships and bed pressures
- *'It doesn't often help with consultants who say "We need the bed. Get them out."'* Nurse
- Reliability of referrer
- *'It's not always possible to rely on the referrer's ideas about the degree of suffering... sometimes you make decisions based on what you know of the referrer, the place, the person as well as the bare bone facts of what you've got – been given.'* Doctor

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Conclusions

- Triage of palliative care needs is complex, dynamic and contextual
- Palliative care clinicians tread carefully to raise palliative care understanding and acceptance amongst patients, public and peers
- Improving objectivity, equity and transparency of palliative care triage is possible
- These results inform a future discrete choice experiment to weigh the relative importance of triage factors and generate a decision aid

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