

Setting Research Priorities for Palliative Care: A consultation process conducted by the PCRNV

Brief Report

12th March 2015

Background

The purpose of the Palliative Care Research Network Victoria (PCRNV) is to work towards developing sustainable, state-wide research collaboration, based on a priority-driven and clinically-relevant research agenda.

An important objective for the PCRNV is to establish defined research priorities for the next five years to assist the PCRNV Scientific Committee, PCRNV members and other Victorian palliative care researchers to target research efforts to those areas considered to be a priority by clinicians, researchers and the international literature. This document provides a brief overview of the process and results.

Process

1. Literature review.
2. Workshops with PCRNV Scientific Committee to develop draft research priorities.
3. Workshop with the Palliative Care Clinical Network (PCCN).
4. Survey completed by PCRNV members (n=31), the Palliative Care Community during the Palliative Care Victoria Conference (n=84), PCCN (n=15) and Consumers (n=9).
5. Results were presented back to the PCRNV Executive and Scientific Committees for final discussion, refinement and endorsement.

Results

The results of the survey provided support that the seven draft priority areas were considered important by all participant groups. None of the suggested areas were rated below a 7.3 (on average) by the total group.

Table 1: Mean ratings (0-10) on importance of priority (n=128).

Measuring outcomes	8.3
Non-malignant disease and transition to PC	8.2
Family interventions	8.1
Implementation research	8.1
Special populations	7.7
Consumer involvement	7.6
Cost-effectiveness	7.3

Qualitative feedback from participants was analysed for key themes to determine if the PCRNV should consider any additional priority areas. While there were many individual suggestions, there was no specific theme that was suggested by multiple participants.

Outcomes

The research priorities have been re-categorised into four primary areas of inquiry and four key methodologies (see page 3). The four priority areas of inquiry will be used to guide the PCRNV's research effort, with the key methodologies being considered important to incorporate (where possible) within the context of any specific research project.

Table 2: Summary of research priorities.

Primary Areas of Inquiry	Key Methodologies*
<p>Non-malignant disease and transitions to palliative care Palliative care has traditionally focussed on the care of people with cancer. It is less regularly incorporated into the care of people with non-malignant disease such as severe organ failure. Hence research is needed to determine optimal timing and processes for involving palliative care for people with non-malignant disease in addition to those with cancer.</p>	<p>Implementation research While we are developing more evidence that will potentially change how we deliver palliative care, there are gaps in getting this knowledge into practice. It is important to investigate strategies to translate relevant evidence so that it can be readily implemented into palliative care practice.</p>
<p>Family interventions Several systematic reviews have acknowledged that there is a gap in research focusing on providing psychosocial support to family carers and improving outcomes for families. There is a need to develop and evaluate new interventions to improve psychosocial wellbeing and bereavement outcomes for families of patients receiving palliative care.</p>	<p>Measuring outcomes Traditional outcome measures in medicine and health care focus on curing disease, saving lives, and assisting the patient to a state of health and functioning in the shortest amount of time. However, these traditional outcome measures have limited relevance in palliative care. Research to identify the best ways to measure optimal palliative care is required. Some possible outcome measures may include patient reported outcome measures such as quality of life, health data related to management of symptoms, episodes of “futile” treatment, time spent in hospital, or admissions to the emergency department.</p>
<p>Special populations While much research has been conducted to further the effectiveness of palliative care, there has been a lack of studies involving special populations, including culturally and linguistically diverse populations, socioeconomically disadvantaged populations, paediatric and neonatal populations and the ageing population. There is a need for research to understand the needs and epidemiology of specific populations to assist with service development and planning.</p>	<p>Cost Effectiveness In an age of increasing health care costs, palliative care needs to demonstrate cost-effectiveness. Some of the benefits of palliative care are difficult to cost. Research is required to determine optimal ways to examine cost-effectiveness strategies in palliative care.</p>
<p style="text-align: center;">Consumer Involvement*</p> <p style="text-align: center;">There is a need to better understand how we engage consumers in planning, policy and research in health care. This is particularly relevant for palliative care. We need to determine the most effective ways to engage consumers in palliative care service planning, policy and research.</p>	

***Note:** Consumer involvement is recognised as a primary area of inquiry and also a methodology that should be considered for all areas of inquiry. Please note that the methods listed above are not necessarily directly related to the areas of enquiry as listed.