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ABSTRACT

The 2018 National Palliative Care Strategy released by the Australian Government clearly states that ensuring care is high-quality and evidence-based is a guiding principle to ensuring all people experience the palliative care they need. [1] There is strong evidence that palliative care makes a difference to quality of life. [2] However, the evidence base of palliative care although growing is still emerging and faces challenges. In this relatively new field needed progress towards a more robust evidence base will require greater engagement and understanding across the community. Here we discuss the current status and opportunities as highlighted in some of the recent literature.

Levels and quality of evidence

Evidence informs our choice of appropriate treatment and services by highlighting potential benefits and harms of what we do.

Research provides evidence on health care interventions by posing questions that can be tested through rigorous study.

Randomised Controlled Trial (RCT) studies are a preferred study design for generating evidence because they limit as far as possible any sources of bias. However, not all RCTs are high quality, and study appraisal using approaches such as the [GRADE system](#) assists us to distinguish between studies. Less controlled observational studies, common in palliative care (PC), are more prone to bias but can be upgraded in this appraisal system if for example a dose-response relationship can be demonstrated.

Variation in research study design has led to development of the evidence hierarchy with potential for bias a key determinant. So RCTs rank highly as do systematic reviews that pool individual studies to examine consistency and generalisability of outcomes.

By appraising study quality systematic reviews alert us to evidence that despite robust design is compromised by poor quality reporting or conduct, and where less controlled studies provide high-quality evidence. [3] Systematic review quality should also be appraised.

Challenges and opportunities

The volume of published PC research is increasing. However, in the PC context few studies employ an RCT design. [4] Of those that do many have major study design flaws including lack of a primary outcome measure and poor quality of reporting. Recent review of 139 systematic reviews to inform the US National Consensus Project Clinical Practice guidelines for Quality Palliative Care found a substantial body of evidence exists to support clinical practice guidelines for quality palliative care, but the quality of evidence is limited. [2] This stemmed from inconsistency in study findings, lack of precise effect estimates, and large variation in study design with few RCTs. High quality evidence was only found for

home-based PC, but moderate to low quality evidence was also identified for other PC interventions. [2]

It has been suggested that the typically small number of participants in PC research may preclude RCTs, but collaboration across sites could be used to recruit the numbers required for a high-quality observational study or RCT. [4] Variation in evidence across PC means clinicians need to understand how to assess the quality and applicability of evidence that might influence care planning in the local context. [5] Studies where high mortality is experienced is another challenge to PC research that might be addressed through new approaches to data analysis. [6]

Many aspects of PC remain without a strong evidence base in part because of the perceived barriers to conducting research with people at a vulnerable time in their lives. [7] Many ethics review boards exclude participation of dying persons because they have little to no chance to benefit from the research. [8]

However, review of the dying persons' perspectives on participating in research found that they value the opportunity to participate and regard this as important for themselves and others. [8] Similarly, recent examination of the benefits and burdens of paediatric PC research participation found benefits for patients and families including the opportunity to engage in meaningful communication. [7] Overall parents reported that the positive impacts outweighed the negative. Clinicians also reported benefits including enhanced communication and support of patients and families, but also the burden of wanting to protect them at a vulnerable time.

These recent insights suggest ways that PC research might be or needs to be advanced. Collaboration between sites, and development of skills in research appraisal might foster increased confidence and engagement. Improving clinician and researcher communication skills to open-up

discussion with patients, carers and families about study participation may lead to new studies. Similarly, addressing well-intended protectionism by clinicians, researchers, and ethics committees may open the way for patient participation.

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