

Raise the Bar, Not the Threshold Value: Meeting Patient Preferences for Palliative and End-of-Life Care

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Despite increasing interest in economic evaluation of palliative and end-of-life care, research on patients' preferences and values to robustly inform such analysis in this setting is relatively scarce. In a recent Special Issue of *Palliative Medicine* on the economics of palliative and end-of-life care just one article focused on this controversial topic [1].

In large part this may be due to the complexities of palliative care, which aims to improve “the quality of life of patients and families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [2]. Clearly, palliative care is multidimensional and people value domains above and beyond health status. There is utility from the dying process; people have preferences for their place of care and place of death along the dying trajectory [3, 4] and derive benefit from preparing themselves and others for their impending death [5, 6]. Further, reducing families' and carers' distress and improving their well-being are integral aspects of care. People also value aspects such as not being a burden on family and friends, and receiving high-quality healthcare as much as, or even more than, improvements in health status or extension of life when receiving palliative care [7, 8].

Yet, clinicians and decision makers don't always accord the same value to these patient preferences [9]. Nearly two decades ago, Steihauser and colleagues [9] demonstrated that aspects of care critical to patients and their families, such as having funeral arrangements in place and not being a burden, weren't considered important by many physicians. More recently, Miyashita and colleagues [10] reported 91% ($n = 310$) of cancer patients rated “receiving consistent care from the same physician and nurse” as an attribute of a good death compared with just under half of oncologists.

Conventional survival- and quality-of-life-based evaluations routinely fail to even consider these preferences, misrepresenting patient and family priorities. Critically, such misaligned valuation can lead to inappropriate and inefficient use of expensive, suboptimal interventions and processes of death that fail to reflect key patient, family or societal preferences and needs. For example, clinical, public policy and economic evidence synthesis points to the use of medicinal cannabis for treating pain, the most common palliative care symptom, rather than much more commonly prescribed opioid-based therapies or ketamine [11–13]. Importantly, medicinal cannabis also appears to satisfy patient and family needs to finalise their affairs, remain in the community of choice and reduce family and carer distress [11, 12, 14].

The most commonly used measure in conventional cost-effectiveness analysis is the quality-adjusted life-years (QALYs) [15], which typically focuses on health alone as the sole indicator of value and does not cover key patient-valued domains in palliative care relating to finalising personal and financial affairs, process and place of death, and family and carer distress [5]. Consequently, capturing and valuing the multiple key domains of effect within conventional cost-effectiveness analysis in this setting is

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fraught with ethical (individual) and moral (community) dilemmas and challenges. Further, communities wish to support people's preferences for palliative and end-of-life care [16, 17]. However, such public support should not be misinterpreted as a call for higher threshold values for QALYs in this population [18], but rather as support for valuing key palliative care domains [3–6].

Evidence of community support for any preferential funding of palliative and end-of-life care is, at best, mixed [18–21]. Rather, efforts should be made to improve the coverage of domains important to palliative and end-of-life populations in health economic analysis to better inform societal decision-making [6, 22]. For example, Dzingina and colleagues [23] are developing a condition-specific preference-based measure from the Palliative Outcome Scale (POS), a validated and widely applied palliative care outcome measure, suitable for cost-utility analyses of palliative care interventions, which includes important, patient-valued domains such as quality of care [24, 25].

Despite this progress, some highly valued aspects of care, such as where healthcare services are delivered, are not amenable to integration with survival time in a QALY-type measure. Consequently, much more work is needed on developing alternatives to conventional methods to address these challenges, including greater deliberation on the appropriate philosophical framework [26]. Burgeoning progress is being made through the capability approach, a broader evaluative framework focusing on what a person is able to do and who they are able to be [26, 27]. The ICEpop CAPability-Supportive Care Measure (ICECAP-SCM), a capability well-being instrument, is being developed to assess whether people have the opportunity for a good death [28]. This preference-based measure, intended for use in the evaluation of palliative and supportive care interventions, has seven attributes (having a say, being with people who care about you, physical suffering, emotional suffering, dignity, being supported, being prepared) and work is currently underway to explore how people value these attributes [29]. Further, multi-criteria decision analysis [30, 31], discrete choice experiments [32, 33] and innovative methods, such as multiple outcomes cost-effectiveness analysis [34], offer promising alternatives to traditional methods in this space.

Such methods enable joint consideration of multiple key palliative care domains that reflect patient preferences, which is crucial for identifying and optimising appropriate palliative strategies, processes and outcomes. People with a life-limiting illness receiving palliation want strategies and therapies that enable them to finalise their personal and financial affairs, stay in their community of choice for end-of-life care and their place of choice for death (often, but not always, the same [3]), and reduce distress and burden to their families, friends and carers [3–6].

Quite simply, we need to raise the bar, not the threshold value.

Compliance with Ethical Standards

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Conflict of interest Nikki McCaffrey and Simon Eckermann declare no conflicts of interest.

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