Palliative Care in Australia

Submission to Senate Standing Committees on Community Affairs

Working Together Group[1] and Palliative Care Victoria Quality Improvement

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[1] CareSearch, NSAP and PCOC are working together to develop an aligned approach to change management in palliative care.

Fundamental to any policy, service delivery or care consideration regarding care for Australians coming to the end of their life, is the need to be able to identify individuals and families with palliative care needs. Issues concerning chronic disease and population ageing are significant drivers of health system reform, and also have significant implications regarding individual care and service provision for those whose health needs are non-curative as they transit to end of life care. However, framing the delivery of appropriate care by the health system and by individual health professionals requires a shared understanding of who are these Australians with palliative care needs. This step then informs approaches to meeting these needs. Palliative Care Australia's document on A Guide to Palliative Care Service Development: A Population Based Approach has highlighted a needs based approach to specialist palliative care provision[1]; however, this presumes that palliative care patients, or those with palliative care needs, are being identified.

More attention has been directed to essential practices that should be provided as part of palliative care[2-3]. The important issue of defining who should be receiving these services is less clear. A recent systematic review has demonstrated that even in clinical research, there are marked variations in the characteristics of populations of patients being studied as "palliative"[4]. A growing literature around the need for, and most appropriate provision of, palliative care to patients with non malignant conditions echoes these themes.

Indeed, there are many practical issues that arise from this ambiguity about people with palliative care needs. First, it is difficult to assess the "true" rate of need within the population when there is uncertainty about who should be regarded as palliative and who is being counted in projections. For example, while Australian GPs report that they only manage four or five palliative care patients (mainly cancer) in a year[5], many other patients in their practice could be seen to have palliative care needs such as those with end-stage organ failure[6-7] or the frail aged.[8]

Second, without a base for understanding who has palliative care needs and who is providing this care, appropriate models of service delivery cannot be implemented and evaluated. Clients of specialist palliative care services are only a small proportion of Australians who will die expected deaths and who could therefore have palliative care needs.

Third, the training needs of those directly involved in supporting patients with palliative care needs may not be recognised. Having the ability to clearly identify palliative care patients and the professionals and services providing care to these patients would improve our ability to target the support and education that we offer to these health professionals and services. It would also enable services to better understand what support and education is needed. For example, it is only recently that the significant role that residential aged care facilities play in enabling residents to "die in place" has been acknowledged. The demand for training and education in this sector continues to grow. Similar demands may also arise in the medical specialties associated with chronic disease to enable appropriate support and care for patients as their disease advances and progresses.

Fourth, without a shared understanding that a patient may have palliative care needs, important prompts for conversations and decision may be missed. Practically, this may reduce the patient's ability to be involved in care discussions, decisions about treatment choices, and the ability to plan and prepare for death and the consequences of their demise for their partner, family and friends. Identification of individuals who have a life-limiting illness and who would benefit from a palliative approach in improving their quality of life would enable these individuals to make informed choices

about their care. Without this awareness, patients may unwittingly be subjected to expensive and continuing, active, and sometimes radical treatments and interventions. Such interventions can have uncertain effects on longevity but may also have adverse side effects and a reduction in quality of life.

Recent and definitive baseline data on people with palliative care needs could support decisions around training and education, and service and care models. Directions for developing relevant data include:

1. Auditing the proportion of people in acute hospital beds who could be regarded as having palliative care needs and an assessment of the relative value of the treatments being received. An associated assessment of the patient/family's awareness of their health circumstances could also be illuminating.
2. An audit of the last twelve months of care for people whose death was foreseeable (or not unexpected) could clarify who is providing care and the type of care being provided in different settings and across different conditions. This could include an analysis of the costs and relative benefits of different treatment approaches and interventions, including hospitalisations.
3. Modeling of the implications for care provision of "deferred dying" may also be valuable. Given that the population is ageing and living longer, at the population level these deaths have been deferred. Given, that life cannot be indefinitely extended; projecting the timing of any increasing demand for palliative care of the ageing population is important.

If we are to be able to provide Australians with the quality end of life care and appropriate options for palliative care, there is a need to better understand the nature and circumstances of those Australians who have palliative care needs.

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