

COMMENTARY • Expanding the Boundaries of Palliative Care: an Australian Perspective

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In Australia, over the past three decades, interest in improving the care of dying patients has progressed from being the concern of a few health care professionals to being a widespread social concern. Until recently, palliative care services had focused on the needs of cancer patients and their families. The number of cancer patients requiring palliative care will not diminish and cancer is likely to remain the most common cause of premature death (before the age of 65) and the second most common cause of death overall (1). However, of late, palliative care has been called upon to engage with the care of individuals with other progressive, terminal conditions. Provision of palliative care to individuals with a wider range of illnesses has prompted palliative care providers and health policy leaders to distinguish between:

- a palliative care approach;
- specialist palliative care services; and
- end-of-life (terminal) care (2).

A Palliative Care Approach. The person's condition is not amenable to cure and the symptoms of the disease require effective symptom management. Provision of active treatment for the person's disease may still be important and may be provided concurrently with a palliative approach. However, the primary goal of a palliative care approach is to improve the ill person's level of comfort and level of function.

Specialist Palliative Care Services. This form of palliative care involves referral to a specialist palliative care team or health professional. This form of palliative care does not replace a palliative approach. Rather, involvement of a specialized palliative care service augments a palliative approach with focused, specific input, as required, usually in two ways: assessment and treatment of complex symptoms experienced by

the person; or information and advice to staff about complex issues (e.g., ethical dilemmas, family issues, or psychological or existential distress).

End-of-life (Terminal) Care. End-of-life care is appropriate when the individual is in the final days or weeks of life and care decisions and goals are focused on the dying person's physical, emotional and spiritual comfort, and on support for the family.

The distinctions between these three types of palliative care are helpful in exploring ways in which palliative care might be provided to different groups, in particular, individuals with nonmalignant diseases. Within the framework of individuals with nonmalignant diseases, two groups warrant specific attention: individuals living with neurological conditions and the aged care population.

People living with neurological diseases such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Huntington's disease, and Parkinson's disease face long-term, physical and psychological challenges. Neurodegenerative diseases usually evoke, in many health professionals, the most negative and despondent responses, which are then conveyed to patients and their families (3). The fact that we cannot significantly alter disease progression is sometimes interpreted to mean that there is nothing more to be done. This is incorrect and regrettable. It is specifically because we cannot reverse or even retard the disease process that we must do everything possible to alleviate symptoms, and offer appropriate psychological and spiritual support (4). The course of illness may be years or decades and may involve lengthy periods of dependency. A range of technologies and health care options may be used to ensure adequate nutrition, communication, cardiac and

respiratory functioning, bowel motility, and skin integrity. All of these care interventions require learning and adjustment on the part of the patient and family (5). The psychological and social factors associated with a neurodegenerative disease are as important as physical care, and healthy recovery of family members after their eventual bereavement is also essential. This is where a palliative approach has much to offer (4).

An Australian study was recently completed that examined the needs of these groups of patients and their families with the aim of identifying approaches to care that might be helpful in meeting the unique needs of these populations (6). Qualitative interviews with 130 patients, family members, and health professionals were undertaken. Patients had been diagnosed with one of four neurodegenerative conditions studied—ALS, MS, Huntington's disease, Parkinson's disease—and were recruited from three Australian states. Family participants were identified by the patient as primary carers and health professionals were selected for their clinical expertise with one of each of the four disease groups. An additional national sample of 503 patients and 373 of their family carers completed a survey about their needs for care and support. Results indicated that these patients and family members need various forms of palliative support, but also require access to rehabilitative services, genetic counselling, and financial assistance to help them cope with the long-term needs of the illnesses. Health professionals working with these groups of patients require expertise in management of these unique disease symptoms, advanced skills in family counselling, and sensitive interpersonal skills to help patients and families navigate the rehabilitation-palliative care pathway. Development and testing of a hybrid "package" of care, with the correct mixture of rehabilitation care, respite, and palliative care, was recommended. The ability to tailor a flexible package of care that could follow the patient to a range of care settings was also recommended. Further research is needed to better articulate the palliative care needs of these populations.

In Australia, over the last two decades, research has indicated that the proportion of people dying in residential aged care facilities (RACFs) has steadily increased (7). The increased number of residents dying in RACFs has led to the recognition that a palliative approach enhances the care already provided to both residents and the families (8,9). The particular setting of RACFs and the diverse profile of their residents create marked difficulties in using a

palliative approach. Not only do the majority of residents have dementia, they generally have comorbidities that involve physical, psychological, emotional, and social boundaries. The residents are generally highly dependent and require many medications, further complicating the provision of a palliative approach.

Recently, the Australian Department of Health & Aged Care funded the Australian Palliative Residential Aged Care (APRAC) Project to examine how a palliative approach to care might be incorporated into residential aged care (10). This project involved the development of evidence-based guidelines for a palliative approach in residential aged care facilities, development of competencies for all aged care staff, and educational programs to provide these competencies. Funding has now been provided to Palliative Care Australia (USD 2.5 million) to implement the guidelines and educational programs. More than 10,000 copies of the guidelines have been distributed to the aged care sector. This project has fostered broadreaching expectations within the public about the importance of a palliative approach at the end of life and has stimulated new research about how to apply a palliative approach in aged care (4).

In summary, two new directions for palliative care are being explored within the Australian health care context:

- a rehabilitative model of palliative care for individuals with neurodegenerative conditions; and
- a hybrid subspecialty that combines palliative care and aged care appropriate to the aged care sector.

Both of these new directions call upon the expertise of different care specialists, multidisciplinary teams, and flexible and responsive services. These new directions in palliative care challenge health providers to construct care models that are patient/family-centred, and pliable and resilient enough to respond to changes in the individual's condition and the family's diminishing resources over time. In many instances, these new models must be embedded within the community, allowing individuals challenged by neurodegenerative disorders or illnesses associated with aging to live and die at home. However, the models of care for these populations must also accommodate the needs of patients who will require "home substitutes" or residential care settings. Care providers who are knowledgeable about how to provide a palliative approach to care and quality end-of-life care must staff these care settings. The health

and aged care systems must also be well linked to ensure that care providers have access to specialized palliative care teams, who can augment the care provided with focused advice and further training.

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