6.5 Palliative care: a welfare perspective

An increasing need for palliative care

Palliative care ‘improves the quality of life of patients and their families facing the problems 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’ (WHO 2002).

Palliative care in Australia is provided in various health and welfare settings and is characterised by regional diversity in terms of the types of services available. Services providing palliative care include: neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services. More specialised care may be provided by specialist palliative care services, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services (DoHA 2010).

In Australia, as in many other parts of the world, the demand for palliative care services is increasing due to the ageing of the population and increases in the prevalence of cancer and other chronic diseases that accompany ageing (WHO 2014).

- Australia has seen a 52% increase in palliative care hospitalisations since 2002–03, with 57,614 hospitalisations in 2011–12 (AIHW 2014).
- In high-income countries, an estimated 69%–82% of those who die need palliative care (Murtagh et al. 2014).

Social and economic impact

Poor access to end-of-life care services and resources most profoundly affects people from lower socioeconomic groups (Lewis et al. 2011; Wood et al. 2004). Data on admitted patient care in Australia’s public and private hospitals (Figure 6.5.1) show that:

- In 2011–12, people who lived in areas classified as having the lowest socioeconomic status (group ‘1’) had the highest rate of palliative care-related separations in public hospitals (26 per 10,000 population) (AIHW 2014).
- The rate of palliative care-related separations in public hospitals was lowest for those living in the highest socioeconomic status areas (group ‘5’) (14 per 10,000 population).
- In private hospitals, the rate of palliative care-related separations was highest for those living in the highest socioeconomic status areas (5 per 10,000 population).

Available evidence points to several possible reasons for the distinction in access between socioeconomic groups for palliative care patients and their carers, including:

- an increased risk of disease and/or injury and reduced access to health care within disadvantaged groups that translates into an increased demand for palliative care services (Lewis et al. 2014)
- the tendency of disadvantaged groups to present to health services with more advanced diseases that require more complex social and economic support (Lewis et al. 2014)
SNAPSHOT

- a more limited awareness among disadvantaged groups of the assistance that non-hospital-based palliative care services and community-based support services can provide and a greater likelihood of people in these groups to die in an institutionalised setting rather than at home (Lewis et al. 2014; Decker & Higginson 2007)
- a lack of informal carers for low socioeconomic groups acting as barriers to home hospice services (Kvale et al. 2004).

![Figure 6.5.1: Palliative care-related hospitalisation rates, by socioeconomic status, public and private hospitals, 2011–12](image)

Welfare needs of carers of palliative care patients

People who need palliative care often have complex health needs that require coordination from multiple components of the health system (PCA 2011). The Senate Community Affairs References Committee report in 2012—*Palliative Care in Australia*—noted the significant contribution made by carers in helping people navigate the health system, and the need for more support for carers’ health and welfare needs. Carers providing support to individuals receiving palliative care often report unmet health and welfare needs, including:

- incomplete information provision and lack of communication, leading to poor continuity of care, service provision and support from health and community services (Ventura et al. 2014; Thomas et al. 2010)
- psychosocial needs, respite care and spiritual needs (Ventura et al. 2014)
- the provision of financial assistance while caring for a loved one at the end of life (Ventura et al. 2014; Thomas et al. 2010).

Providing palliative care to single-person households where there is no caregiver is also a challenge that is gaining greater recognition. Although the number of single-person households in Australia is increasing (25.4% of Australians aged over 65 live alone) (ABS 2013), there is a reduced likelihood of this group of Australians being cared for and dying at home (Aoun et al. 2014).
What is missing from the picture?

There are very limited national data on palliative care that can be used to report on the welfare needs of palliative care patients and their carers. The AIHW is investigating potential additional data sources to give a better overview of the national response to the palliative care needs of Australians at the end of life.

Where do I go for more information?

More information on palliative care in Australia is available on the AIHW website. The report Palliative care services in Australia 2014 is available for free download.

References


