

Economic hardship at the end of life: the experiences of patients and carers receiving specialist palliative care
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Keywords:

Specialist palliative care; economic hardship; out-of-pocket spending; end of life care

Introduction/Background:

Palliative care patients and their family carers have complex needs and must access a range of support services to manage at home and maintain their quality of life.. Paying for these services can impose a financial burden on households that may have already fallen into economic hardship due to long term chronic illness, sudden loss of income or the general stresses of low fixed incomes and high living expenses. This paper describes the use of health and community services by patients enrolled in specialist palliative care at the Calvary Health Care Bethlehem service in Melbourne, Victoria. their associated out-of-pocket spending and its impact on their economic circumstances at the end of life.

Methodology:

A mixed-method prospective design. Patients enrolled in specialist palliative care (n=30) and their nominated carers (n=22) participated in semi-structured interviews regularly over a six month period. Each patient also completed a care diary recording health and community service use and out-of-pocket spending over a 2 week period.

Findings:

Sixty percent of participants reported experiencing economic hardship and this was felt most severely by those recently out of the workforce due to illness and individuals who didn't own their home. Most commonly people reported difficulty paying for medical expenses, including medical tests and medications and used their limited savings and borrowed money to maintain their living expenses. In a two-week period, patients attended on average two health care appointments and used two community services and spent a median of AUD\$88 on medical and supportive care expenses. The majority of participants felt they were struggling financially and faced difficulty accessing the social welfare supports currently in place.

Policy Implications:

This research provides a basis to explore the additional policy supports required to assist patients and their families to better cope with the economic pressures at the end of life.