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## BMJ Supportive & Palliative Care

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## Features

### Living with economic hardship at the end of life

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## Abstract

**Background** Dying patients and their families often face an added burden of economic hardship, especially if they have become ill in the years before expected retirement. In Australia, patients can fall through the cracks of the national system of social protection because there are gaps in the access to and provision of healthcare and social assistance at the end of life.

**Design** A mixed-method, prospective case study of individuals and their family carers, recruited from a specialist palliative care service in Melbourne, Australia, is presented. Participants were interviewed and followed up over 6 months and completed a 2-week diary of all services used and out-of-pocket costs.

**Results** Mean out-of-pocket spending was \$A369 per month (median: \$A176, IQR: 356) (\$A1=US\$1=€0.73=£0.62; January 2011). Households with economic hardship were more likely to have a patient who was male, had ceased paid employment earlier than expected due to illness, reported a reduction in income due to illness, had less access to financial resources and used significantly fewer health-related community services. Three factors shaped the participants' experience of hardship: (1) the premature loss of employment capacity and income; (2) the affordability of care and; (3) a welfare system that could not accommodate their complex needs.

**Conclusions** These results demonstrate the multidimensional nature of the economic burden experienced at the end of life and imply the need for nuanced solutions to better support patients and their families. If terminally ill people wish to die at home and are to be supported to do so, policies must take account of the shift in economic burden from the health system onto families.

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