Experiences of informal caregivers in managing the care and the death in the rural palliative care home setting.

Two considerable challenges to palliative care provision in Australia are the ageing population and the death denying cultural norms of Australian society. Given the certainty that everyone will die, most likely after the effects of living with long-term chronic illness, an even greater challenge is bringing death and dying to the forefront of community consciousness. Public health models of palliative care propose that this consciousness would enable people greater involvement in end of life planning as a natural part of life, gain more control over their own life, and death, and reduce the financial burden of current medical practices.

These challenges become more complex in rural areas where access to palliative care and resources are much more limited than in larger metropolitan areas. Within this context this study is investigating the lived experience of caregivers who chose to care for the dying at home, with the support of a specialist palliative care team.

This study applied a phenomenological methodology to understand the perspective of carers who managed care, symptoms, medication administration and the home death; their bereavement experience; and the possibility of an emerging cultural change enabling design of future services that meet the needs of respective communities, especially rural areas.