

RESEARCH DIRECTIONS

Caring at the end of life

Associate Professor Debbie Horsfall of the School of Social Sciences and Psychology with Associate Professor Rosemary Leonard of CSIRO, Dr John Rosenberg of the Calvary Centre for Palliative Care Research, Australian Catholic University, Dr Gillian Batt of the Cancer Council NSW, Ms Kerrie Noonan and Ms Niki Read are researching informal community care networks for people dying at home. This project is funded by the Australian Research Council through its Linkage Projects grant scheme.

'In our ageing society there are about 140,000 deaths every year in Australia with many of these people spending their final year of life at home,' says Associate Professor Horsfall. 'So quality of care at the end of a person's life in a home environment is very important and while palliative care resources are limited, informal caring networks make a big difference and promote self-sufficiency in the community. The average length of community-based palliative care is 119 days of which 117 care-days are provided by family, friends, neighbours and community members. While this caring can take its toll physically and psychologically, the positive effects and personal rewards that it brings are less well-known and include increased intimacy and expressions of love and a higher level of personal satisfaction and commitment. This project seeks to understand the details of how these caring networks function for the principal carers and also the wider care network and community, so that they may be better supported by formal health providers and health policies.'

Given that the end of a person's life is a sensitive time for all involved, the research methods include a photovoice technique successfully used in a previous project and participatory network mapping techniques. Focus groups and interviews will be used with formal service providers, carers and caring networks. Differences in urban, regional and rural support networks will also be examined.



Death and dying have become highly medicalised in the past 50 years so community knowledge about end-of-life care has diminished. Refocusing this care to a more social approach emphasising relationships and community capacity will help mobilise care networks and maintain them. The research will inform national palliative and public health policy with the aim of positively impacting carers and caring practices, giving dying Australians a supportive, loving and more meaningful death.

Project Title: Caring at end of life: Understanding the nature and effect of informal community care networks for people dying at home.

Funding has been set at: \$243,044

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