



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



**Caroline Short, Hunter New England Local Health District**

## Aim

The aim of this research is to explore and describe the lived experience of informal caregivers managing pain and other symptoms in the last few days of life, including care of the dying, managing the death, and the bereavement experience in the palliative care rural home setting.

## Methods

Interpretive phenomenology was used to guide the study. Ten semi-structured interviews were conducted with people in their homes in rural NSW. The data was thematically analysed using framework analysis with a Health Promoting Palliative Care (HPPC) theoretical framework.

## Findings

Five major themes reflected caregiver experience, 'in it together', 'sense of control', 'developing confidence and ability', 'redefining cultural norms', and 'living with loss'. Caregiver identity and choices were connected to their loving relationship with the patient, which drove their desire to fulfill wishes. A sense of control was gained from staying at home, often driven by hospital and treatment experiences, home being the locus of control. Staged education and support from health professional's increases caregivers capacity and resilience, enabling managing symptoms, medication, the home death, comfort caring for the body and with the body remaining in the home, defying modern cultural norms and perceptions. After-hours contact with palliative care professionals was considered to be essential, as was their connection to the GP's. Family remained the mainstay of bereavement support however other important needs were identified on a personal and public health level; unique rural issues were revealed as well as a plausible rural model of specialist palliative care.

## Implications for practice

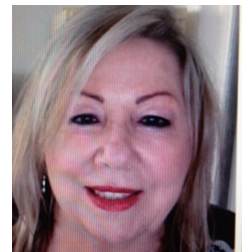
The findings evidence a rural model of palliative care inherent with the conditions that drive caregivers' satisfaction in achieving a home death, within a legal, ethical and safe framework. The results also evidence the conditions that drive a less satisfactory experience from a caregiver perspective. There are clear indications that a public health approach to palliative care has the potential to improve the bereavement

## Keywords

Palliative care, Rural, Home death, Medications, Framework analysis

*For the full report on this project visit our website, follow the link to the Rural Research Capacity Building Program and click on 'view completed projects'*

Caroline Short is a Clinical Nurse Consultant who has worked in specialist palliative care for 23 years, leading and developing the service. While completing a Master's Degree in Public Health Caroline developed a deep interest in Health Promoting Palliative Care and Compassionate Communities philosophies. Belief in these philosophies as essential frameworks for practice has led to their application to everyday practice. Essentially this approach involves a team partnership with the community in thinking creatively to apply these philosophies, which lead to formalised research to investigate the lived experience of caregivers in the palliative care home setting in rural New South Wales.



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