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**Talking about end-of-life care for older people
in a rural New Zealand community**

A thesis presented in partial fulfilment of the requirements for the degree of

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“For all of us who cannot know anything for sure, death is the ground on which the whole world can speculate in common. It is also the ground on which we can stand together, to support each other, and to show each other, especially to the dying and the bereaved, that our minds and spirits are with them, that neither they nor (we hope) we die alone.”

Young & Cullen (1996)

Abstract

Rural experiences are under-represented in the end-of-life care literature. In addition, population projections indicate that the numbers of older rural people are increasing. In an attempt to better understand their needs, this study considers how older people experience end-of-life (EOL) care in a rural New Zealand setting. Having responded to local media and community notices, seven participants, who in the last eighteen months had cared for someone over the age of 65 with a terminal illness, spoke about their experience of rural EOL care. Their stories were then transcribed and analysed, using narrative analysis. Participants spoke about similar issues, but from different, sometimes conflicting, perspectives. Positioning themselves primarily as carers, rather than as rural people, the participants' stories nevertheless reflected their social location for caring, as they talked about exhaustion and needing 24 hour support; limited access to specialist palliative care services; and the difficulties of caring for people with complex needs. At the same time they spoke of the joys and rewards of caring. The ambivalence and conflict evident in the stories indicates the participants' location in a particular place and time in the history of dying. Caught between two paradigms of care, these participants vacillate between the desire for the empathic, compassionate care of yesteryear and the best that modern medical technology can offer. Discussing when to continue and when to stop medical intervention produced the most conflicting perspectives. However, all agreed that having time to form therapeutic relationships is a key component of EOL care. Overall, the stories demonstrate that the multiple and complex experiences of older rural people render stereotypical assumptions about rural life and dying at home problematic. However, as this study demonstrates, simply talking with people provides access to and understanding of their lived realities. Incorporating this kind of approach in future rural EOL care planning will move us closer to achieving contemporary goals of positive ageing and dying well.

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