Living, loving, dying: health promoting palliative care and rural compassion

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The unmet need for palliative services in rural areas is well-documented, stemming from variable combinations of factors such as geographical isolation, workforce shortages, barriers to information and support and higher rates of chronic diseases and cancers.[1,2] As remoteness increases, so too do mortality rates—affected by poor access to specialist and primary care services and higher incidences of socioeconomic disadvantage.[3]

Health Promoting Palliative Care (HPPC) acknowledges the potential for improvements in EofL care when health care services and informal community supports complement each other[4]—an interrelationship which is particularly relevant to rural communities. HPPC embeds public health principles into EofL care, privileging strategies to minimise the difficulties of dying, caring and grieving; as well as promoting a community development model of care-giving.[5,6] Compassion—a human and tender response to the distress and suffering of others[7]—is a key component of HPPC as well as an ethical imperative which drives much of EofL care.

This presentation reports on a project conducted in rural Tasmania with carers who had looked after someone who had died from a life-limiting illness within the previous three years, or who were still caring for someone in the advanced stages of a life-limiting illness. We conducted 17 interviews with 19 participants (in two instances there were two people present, both partners).

Results were categorised thematically, into six groups:

- support to die at home
- isolation
- difficult people, difficult relationships
- control
- talking about dying
- grief and bereavement.

Conclusions

This research enriches understandings about rural HPPC from the perspectives of people living in a rural area of Australia, who cared for someone until their death and who were continuing to grieve. Their experiences demonstrate the appropriateness of a HPPC approach that is focussed on enhancing inter-relationships and community compassion. Participants constructed a nuanced profile of rural compassion, as comprised of complex intersections: geographical isolation and therapeutic space; personalised, innovative care and a lack of basic services; community-wide support and private expressions of grief.

References

1. Goodridge G, Lawson J, Rennie D, Marciniuk D. Rural/urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life. Rural and Remote Health. 2009;10(1349):Online.
2. White K. Rural Palliative Care: Exploration of the Pivotal Role of Primary Healthcare Providers. CancerForum. 2007;31(1).
3. Australian Institute of Health and Wellbeing. *Mortality inequalities in Australia 2009–2011*. Canberra: AIHW; 2014.
4. Rosenberg JP, Mills J, Rumbold B. Putting the 'public' into public health: community engagement in palliative and end of life care. *Progress in Palliative Care* 2016; 24 (1): 1-3.
5. Abel J, Walter T, Carey LB, Rosenberg J, Noonan K, Horsfall D, Leonard R, Rumbold B, Morris D. Circles of care: should community development redefine the practice of palliative care? *BMJ supportive & palliative care* 2013; 3 (4): 383-8.
6. Kellehear A. Commentary: Public health approaches to palliative care: the progress so far. *Progress in Palliative Care* 2016; 24 (1): 36-8.
7. Kellehear A. Third-wave Public Health? Compassion, community and end-of-life care. *International Journal of Applied Psychoanalytic Studies* 2004; 1 (4): 313-23.

Presenter

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