

Partnering to Provide Palliative Care: The lived experience of carers accessing after- hours palliative care support provided by a non-government organisation in partnership with a regional local health district

OBJECTIVES

Caregivers are fundamental to achieving effective home based palliative care. The burden on carers is often greatest after-hours when the usual sources of specialised care are not routinely accessible. A lack of after-hours home visiting palliative care support services outside of metropolitan areas means that many rural people experience frequent unplanned hospital admissions or are unable to die in their preferred place of care. The aim of this study was to explore the experience of carers receiving after-hours visiting palliative care provided in partnership between a Local Health District (LHD) and Non-Government Organisation (NGO) in rural and regional NSW.

METHOD

A hermeneutic phenomenological approach with purposive sampling of 10 bereaved carers who accessed after-hours palliative care support was adopted. Data was generated through semi-structured interviews. Inductive thematic analysis was used to identify the essential meanings of the experience.

RESULTS

Emergent themes included collaboration, an anticipatory approach to care, accessibility to after-hours support and perceptual transformation as common denominators in the carers positive experience of this model. Communication between carers and health professionals created a sense of connection and collaboration that supported carers in their advocacy and which participants experienced as a 'team' approach. Participants valued knowing what to expect as they faced evolving challenges and having plans in place to manage situations pre and post death. Access to after-hours support contributed to a sense of security and confidence and was perceived by participants as fundamental in reducing carer stress, preventable hospital admissions and facilitation of death at home. All participants reported that caregiving at home was experienced as a profoundly meaningful endeavor which, despite its challenges, contributed to an increased awareness of their own resilience and a willingness to repeat the journey for other loved ones in future with the knowledge that access to after-hours specialist support was available.

CONCLUSION

The continuity of service afforded by this integrative partnership were perceived as crucial by carers to facilitate successful home care of the dying and hospital avoidance. The strengths and challenges relating to this partnership model will inform future palliative care service development and practices that are scaleable to other services, with potential applications being extension of packages from terminal and deteriorating phases to unstable phases.

KEYWORDS

palliative Care, carer, after-hours care, non-government organisation, partnership, rural.



Pauline Smith
Mid North Coast Local Health District

Pauline.Smith1@health.nsw.gov.au

Pauline Smith is a community based Clinical Nurse Consultant in Palliative Care in the Hastings Macleay Clinical Network of the MNCLHD. Her role involves service development and provision of clinical leadership. She has a Masters in Palliative Care (Flinders University) and her primary focus is development of sustainable models of care that ensures patients and carers receive equitable access to quality, evidenced based palliative care in the place of their choice.

Visit heti.nsw.gov.au and search 'Rural Research Capacity Building Program' then click 'view completed projects'