

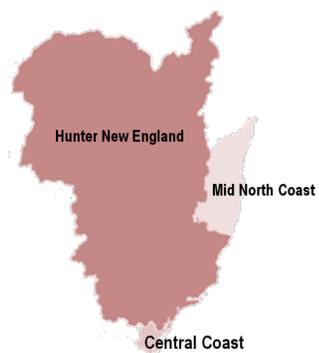
STRENGTHS AND WEAKNESSES OF END OF LIFE CARE IN A SAMPLE OF REGIONAL AND RURAL NSW

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Objectives

Many rural and remote areas of NSW have no access to specialist palliative care physicians or services. Access to palliative care services for rural and remote patients and families has been identified as an area in particular need of focused research. This research aimed to fill this knowledge gap by conducting a needs analysis for end of life care in rural and remote NSW.

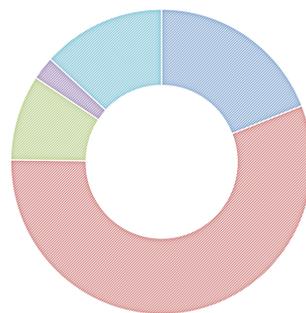
Methodology



Between December 2018 and January 2019, a survey was emailed to consumers, clinicians, managers, and researchers across the Hunter New England, Central Coast, and Mid North Coast Local Health Districts.

Respondents were asked to identify unmet needs for end of life care in their area as well as ideas for strategies or research projects to improve end of life care.

In total, 121 people across the three LHDs completed the survey. Respondents represented health services, universities, local neighbourhood groups, councils, and state and federal government.



■ Manager ■ Clinician ■ Researcher ■ Consumer ■ Multiple roles

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Implications

Current needs in rural end of life care were identified as:

More staff training

Medication management education was requested by both clinicians and managers. It was noted that pain relief for patients is often inadequate, leading to unnecessary suffering. Improving clinicians' ability to identify when a patient is nearing the end of life and communicate this to patients and their families would be beneficial for all – including clinicians. Failure to identify patients nearing the end of life contributed to poorer outcomes for patients, including inappropriate care.

Improved communication

Better communication between clinicians and patients and their families was raised as something that would improve the patient experience by enabling them to contribute to decision-making around their care. Under-use of advance care planning was identified across all LHDs as an important issue affecting patient outcomes. In many cases this was due to hesitancy among clinicians to have end of life discussions with their patients.

More physical resources

Requests for increased staff were common, including many requests simply for 'more' specialist services, community palliative care services, outpatient clinics, and allied health services. Limited support for dying at home was identified, with deficiencies noted in the availability of staffing and equipment. Hunter New England and Mid-North Coast LHD respondents felt that services were centralised, and that more distant areas of the LHD are under-resourced. In the Central Coast LHD, the lack of a hospice facility was noted.

Better coordination of care

Existing palliative care services were perceived as disjointed and difficult to navigate for patients, with a need to attend a range of different services to receive holistic care. Bridging the gap between acute medical services and those providing palliative care was viewed as something that would improve the experience of patients and families.

Respondents reported that improvements to rural end of life care could be achieved through:

- Exploring patients' and families' preferences for care, including methods of delivery of support
- Identifying culturally appropriate approaches for our culturally diverse community
- Exploring the role of general practice and primary care in rural palliative care
- Determining the bereavement needs of families in rural and remote NSW
- Ensuring resource allocation is equitable across the region
- Improving advance care planning, including training nurses and community workers to be ACP facilitators
- Training the specialist workforce to better recognise patients nearing the end of life
- Economic and resource analysis of different models of care (at home, hospital, hospice, or residential aged care facility).



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Mid North Coast Local Health District



The community palliative care services we have are excellent, but they are under-resourced and under-staffed

Lessons Learned

Palliative care staff across regional and rural NSW provide valuable insights into the service needs of this region, however resource limitations remain a challenge.

Collaboration between palliative care clinicians, researchers, patients and families is essential to ensure that appropriate and acceptable end of life care is delivered across rural and remote NSW.