



Improving the provision of end-of-life care in chronic illness, dementia, cancer

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New Zealand has one of the highest rates of deaths in residential aged care of any developed country and it is going up significantly (8%) over the past 15 years. This is likely due to people living longer with increased frailty over 2 – 4 years and people being discharged from hospital to residential care for end-of-life care instead of dying at home or in hospital.

The ELDER Study explored quality of death in residential aged care from staff and family perspectives. Participants had a diagnosis of cancer, dementia, or chronic disease. Deaths reported for a 3-month period were recorded and retrospective surveys of staff and qualitative interviews of staff and family were completed. These results were compared against a study done on Quality of Death Last week of life from six European countries.

The main results were:

1. The primary diagnosis made no difference in symptoms experienced in the last week of life, the dying process was the same. The process of care between home and residential care during this period was also similar.
2. People with dementia and chronic disease had more geriatric symptoms of concern for longer than traditional cancer “palliative care patients”. Points to consider include:
 - Ambiguous clinical course, death is unpredictable.
 - Recognition of reversible deterioration is key.
 - Traditional “palliative care” models do not fit the needs of advanced frailty, including people with MND.
3. Overall families were satisfied with end-of-life care provided. However, the term “palliative” meant last weeks of life to them. Using alternative approaches such as goals of care and advanced care planning may be less distressful for families.



4. Education and guidelines are needed for common geriatric issues and interventions for those with dementia and chronic disease living in residential aged care.

5. Areas for improvement include bereavement support after death and compassion for families. Transitioning from home to residential care is one of the most difficult transitions in a person's life often with no psychology support for the person and their families. It is important to consider this emotional impact in their continuum of care.