Dying with Dementia

Family members’ experiences and observations of end-of-life care

BROADMEAD Care Society

Excellence in Care for Veterans and Seniors

Operating The Lodge at Broadmead, Veterans Health Centre and Nigel Services
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- A publicly-funded, non-profit care home to 225 people
- 60% are Veterans
- 75% have cognitive impairment
- Focus on Person-Centred Practice
Community partner - Veterans Affairs Canada

- Dementia Care Program since 2003
- Focus on end-of-life dementia care
- “The Dementia Difference” education includes content on support for family members
- Improved quality of life
Study Goals

- To identify aspects of end-of-life care most important to family members
- To identify implications for practice
Central Research Question

How did family members of Veterans who died within the previous 12 months experience the care they and their relative received?
Methods

- Semi-structured interview
- External consultant
- 12 family members
- 1:1 or telephone
- Content analysis
Interview topics for family members:

- Preparedness for resident’s dying/death
- Sources of information about dying/death
- Experiences of inclusion during the dying process
- Observations of the relative’s quality of life until death
- Experiences of comfort and support
- Aspects of physical, emotional and spiritual care
- Grief and sources of support
- What was well done/could be improved
- What was most important
Results – what family members valued

- Knowing the person
- Quality of life until death
- Acts of kindness
What family members wanted

- Accurate health info
- Care conferences as health declines
- Spiritual care
- Information on grief and PTSD
Conclusions

- Confirmed the value of a person-centred approach right through to death
- Caring behaviours make a lasting impression
- Clear 1:1 and team communication essential
- The staff were applying the information learned in The Dementia Difference education
Implications for Practice

- Personal histories
- Death on the table
- Clarify goals of care through conferences
- Share appreciation for care with staff
Contact Information

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