

Palliative Care and Dementia: Research and Practice

Wednesday, 27 August 2013

5:00pm – 7:00pm



AAG
Australian
Association of
Gerontology

Summary of Presentation

The event featured presentations from internationally renowned palliative care researchers, Professor Lorna Rosenwax and Prof Bev McNamara from Curtin University and two leading palliative care clinicians, Michelle Harris and Felicity Beaulieu, from the Bethanie Group who have been involved in implementing a range of innovative service improvements in residential aged care facilities to better meet the care needs of residents with dementia and their families.

Prof Lorna Rosenwax began by presenting figures on the prevalence of Dementia in Australia. Figures from the Australian Institute of Health and Welfare (AIHW) illustrate that today there are circa 298,000 people living with dementia in Australia. Without the development of cure or prevention methods, this figure is expected to reach 400,000 by 2020 and 900,000 by 2050. Prof Rosenwax and Prof McNamara have done extensive research on hospital use of people with dementia living in Western Australia in the last year of life. Some of the findings of their research were that age is an important factor in hospital use with younger people tending to stay in hospital longer on average than their older counterparts; socioeconomic status was not a significant factor in hospital use; males on average tend to spend 20% longer in hospital than females; and specialist palliative care in the community makes a big difference for people with dementia, with those receiving specialist palliative care being seven times more likely to die at home.

Prof Bev McNamara presented an overview of the research on dementia and palliative care from the last decade. Conclusions of systematic reviews throughout this time have been the same – that there is a lack of scientific evidence on efficacy of treatments for palliative care of people with dementia and further research is needed. Prof McNamara then compared palliative illness trajectories for people with cancer, chronic illness and dementia, arguing that planning of palliative care should not be around prognosis but around a needs based model. She also discussed the concept of ‘a good death’ and stated that some of the factors we associate with a good death, such as control of pain, awareness of death and preparedness for death may not be readily available for a person with dementia and we need to further explore what a ‘good death’ is for a person with advanced dementia.

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Michelle Harris argued that the current aged care climate is poorly equipped to provide the support that palliative care and dementia care require. To date we have limited insight into what suffering is to a person with dementia and we currently provide care based on what we think is best. Late diagnosis of dementia is the norm and the diagnosis itself threatens ones status as a person. Michelle argued that this needs to change so that more respect is given to the person.

Michelle then spoke about the experiences of the Bethanie Group. She argued that the culture of the residential aged care facility is very important and staff are the biggest asset in facilitating conversations about dementia. The Bethanie group are currently piloting a new model of care for people with dementia at a residential aged care facility in the Northern Perth suburbs. The changes are designed to improve the culture at the facility and include: increasing awareness of the psychosocial and wellbeing, increasing chaplain involvement and improving support and coordination of volunteers. Other changes include the creation of new roles, the creation of a dementia specific wing and changes around clinical governance.

Felicity Beaulieu spoke about plans of the Bethanie Group for the future. Bethanie plans to continue to work with the University of Western Australia to deliver education and training to support staff working in aged care. In addition volunteers will receive increased training and the whole organisation will place further emphasis on valuing the lives of clients. Felicity concluded by discussing the 'fellow travellers' in palliative care, the family and friends of the person with dementia and how they can be best supported.