

Palliative Care Dementia Interface: Enhancing Community Capacity Project

Final Report

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Executive Summary

2.1 Identifying Information

- 1.1 Program/project title: Palliative Care Dementia Interface: Enhancing Community Capacity Project
- 1.2 Time period: 7 April 2003 to 31 March 2006
- 1.3 Organisations: University of Western Sydney (Auspice and Lead Agency); Sydney West Area Health Service (Western Cluster); Blue Mountains Division of General Practice.
- 1.4 Project Manager and Project Contact person: Professor Esther Chang, Director of Research, School of Nursing, College of Health and Science, University of Western Sydney.

2.2 Setting

The project used action research to identify the needs of people with severe and end stage dementia, prior to implementing a model of care designed to provide best practice palliation to this group.

Most people in the final stages of dementia (called in this document the severe and end stages of dementia, which together can last from one to three years) live in residential aged care facilities. The project focussed on understanding the needs not only of the person with dementia, but their family members, and health professionals caring for them- residential aged care facility staff, area health service specialist staff who may be required to provide a consultation service, and the general practitioners of the person with dementia.

The project was undertaken in the greater western Sydney area.

2.3 Background

The final stages of dementia have similarities to advanced cancer, in that the condition is not reversible or responsive to treatment, and limits life expectancy.^{1,2} Symptoms found in advanced cancer, such as pain, dyspnoea, coughing and anorexia, are also found in the final, end stage of dementia.¹ Unlike people who are dying of cancer, people with end stage dementia generally have a period of prolonged dwindling, when they become increasingly frail, and experience a gradual decline in functional ability.³ Additionally, many older people with chronic disease such as dementia also have one or more co-morbidities that may hasten death.⁴ The result is a medical prognosis that is ambiguous, in that they may be sick enough to die at any time, or they could live for many months.³ Furthermore, as Aminoff⁵ notes, the treatment of end stage dementia is much more difficult than end stage heart disease, lung disease or cancer, due to the complex medical, cognitive, emotional, ethical and social considerations that accompany dementia.

Despite the fact that death from dementia is accompanied by multiple symptoms that require management, to date there has been little palliative care input into the care of people with dementia. It is recognised within the National Palliative Care Strategy⁶(p6) that there are people and population groups who pose particular challenges in relation to access to palliative care services. People with dementia are noted to be one of the most challenging client groups within the palliative care scope of practice.

Rarely do state-funded area health service palliative care services provide palliation to people with dementia. This group have traditionally been almost invisible, usually spending the final year(s) of their lives in residential aged care facilities, both out of sight and out of mind of almost everyone except the

key providers of care in that domain- the residential aged care facility staff, general practitioners and the family members and loyal friends of the person with dementia.

For almost a decade the palliative care specialist nurses in this area have been providing limited consultation and education to the staff caring for people with malignancies in residential aged care facilities. The palliative care specialist nurses and their managers recognised that many other people within the facilities could benefit from their assistance, including people dying of dementia. The project was developed in consultation with the partner organisations to identify what the needs were prior to considering future service delivery.

2.4 Project Aim/ Objectives

Aim of the project

The project aimed to understand the needs of the key providers of care to people in the final stages of dementia, and use this information to develop, implement and evaluate a model of care to this client group. The overarching aim of the project was to build capacity to undertake care of people dying from dementia.

Project Objectives

The objectives of this project were to:

- identify the needs and deficits of both the people delivering the care and the health services involved in care delivery to people dying from dementia;
- share the information learnt about the needs and deficits so all the key groups who deliver care can work together to improve the care;
- improve the knowledge and practice of the key providers of care, by designing and implementing education programs related to dementia palliative care;
- develop and implement an appropriate model of palliative care delivery to the target population by developing best practice guidelines and policies; and
- evaluate the model of care, make changes if necessary, and determine what is sustainable outside the project.

2.5 Methodology

The project used an action research methodology to collect qualitative and quantitative data regarding the needs of the people with dementia and their key providers of care.

- Stage 1a used focus groups (6) and interviews (24) to understand the needs of family members, residential aged care facility staff, general practitioners, and specialist aged care, dementia care and palliative care staff from the area health service in relation to people in the final stages of dementia.
- Stage 1b collected data regarding pain in people with severe or end stage dementia, using the Abbey Pain Scale⁷ three times per day for 7 days (36 people); surveyed the family members using the Satisfaction with Care in the End of Life with Dementia (SWC-EOLD) Scale⁸ (36); conducted file audits on the files held in the residential aged care facilities of residents with severe or end stage dementia (36).
- Stage 2 involved participatory action research, when the results from Stage 1 were disseminated to the four residential aged care facilities involved in the data collection, and consensus on the elements of the model of care reached. A model of care including education; clinical support; Family Information Booklet to aid communication; pain management flowchart and use of pain assessment tools (Abbey Pain Scale and NOPPAIN⁹); and a learning package

about pain were developed and implemented in a selected residential aged care facility in the greater western Sydney area.

- The project was evaluated by repeating the file audits (7); SWC-EOLD Scale (7); focus groups with the residential aged care facility staff involved in the intervention (2); surveys of area health service staff involved in the project (19); and surveys of organisations and individuals to review the Family Information Booklet.

2.6 Results

The overarching aim of the project was to build the capacity of the key providers of care to undertake care of people with severe or end stage dementia.

- Area health service specialist staff from the palliative care service definitely are now better able to undertake care of people with severe or end stage dementia. This finding was revealed from the results of the evaluation survey, and by comparing data from field notes taken during the intensive clinical intervention with the comments from their focus group held at the beginning of the project. Selected aged/ dementia staff are also more skilled and able to provide this care, although this finding is not consistent throughout the entire aged/dementia care team.
- Residential aged care facility staff have improved confidence and skills, as shown through the focus group results at the end of the project, although they continue to have deficits in their knowledge relating to dementia palliative care, and require ongoing clinical support and governance to sustain any changes.
- General practitioners were difficult to engage during the project, and were not evaluated to see if their capacity had been improved. Nurses from the residential aged care facility reported during a focus group that the general practitioners had improved their skills as a result of the intervention.
- The project had planned to write best practice guidelines for dementia palliative care. These were not developed to the extent planned as we found that the registered nurses in residential aged care facilities do not access this type of guideline, due to resource constraints in residential aged care facilities (low ratio of nurses to residents; poor skill mix) leaving them with insufficient time to consult guidelines. Experiential learning using their own residents as case examples proved more successful than more formal education sessions.
- Unexpected findings relate to the number of times we encountered people with dementia who had never been diagnosed with the condition, or who were wrongly diagnosed; the lack of access to information and support for family members throughout the dementia trajectory; and residential aged care facility staff needing to access education in their own unpaid time due to inadequate education budgets in residential aged care facilities.

2.7 Discussion

The major achievement of this project was to build the capacity of area health service community-based staff so that people in the final stages of dementia are now accepted as appropriate to refer to palliative care services. A second, and gratifying, achievement was to see the confidence and skills of the nurses in the residential aged care facility develop as they were exposed to teaching from skilled, experienced nurses from the palliative care and dementia teams from the area health service.

The principle factors behind the success of the project are threefold. Firstly, the management of the community sector of the area health service allowed their most skilled nurses from palliative care and dementia care to be involved for approximately 50 hours of intensive education within the residential aged care facility; and allowed clinicians from the aged care, dementia care and palliative care teams to sit on both the Steering Committee and Working Party of the project, again taking a large number of hours away from their regular duties to do so. Secondly, the project was a partnership with the University, who provided support, encouragement and advice to the project, and helped develop the

research and evaluation skills of the area health service staff. Thirdly, the project relied on the goodwill of the Director's of Nursing of the residential aged care facilities where data was collected. In total, 12 of the 19 high-care facilities in this region provided focus group or interview participants, or collected data for the project. The remaining residential aged care facilities were involved via the local Directors of Nursing meeting, providing encouragement and advice when required.

2.8 References

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