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Report

Palliative care for elderly people with dementia in Melbourne

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Abstract

The purpose of this study was to investigate dementia and palliative care in Melbourne.

In Melbourne, end-of-life care for elderly people with dementia is included in palliative care. Mainly, care is characterized by nurses carrying out palliative care such as pain control psychologically including prescribing painkillers; also derive there are pastoral care workers who help patients. Most nurses a sense of satisfaction after caring for a person with dementia in their final moments, but there are some nurses with little experience who become very emotional after a persons death and upset. Emotional care for staff is carried out by pastoral care workers or priests, and words of gratitude from families go a long way toward helping the nurses.

Key words: elderly people with dementia, palliative care, Melbourne

1. Introduction

I had the opportunity to visit Melbourne and observe dementia and palliative care from the 9th to the 23rd of September, 2006.

The present population of Melbourne is 3,700,000. Just as in Japan, the percentage of aged people in Australia is increasing, as is the number of elderly people with dementia[1] (November 30, 2007).

In Australia, each state determines its own measures to provide aged and palliative care. End-of-life care for elderly people with dementia is included in the wider area of dementia care called palliative care. No particular distinction is made for end-of-life care for elderly people with dementia. Education and training programs for care workers include dementia and palliative care.

In each respective facility, a certain quality of services is guaranteed party regarding. In order to ensure this allocation there are thorough inspections by a third records, the environment, and personnel etc[2]. (Asahi Newspaper, 7 December, 2006). Due to this process, I felt that there was less of a difference in between facilities than there is in Japan. However, with Australia being a nation of immigrants, people of different races live together, and so pamphlets etc. Were available in several languages. In contrast to monocultural Japan, several races of people live together and suitable consideration is given to all cultures.

Interviews with care workers in Melbourne clarified the following regarding dementia and palliative care.

2. Outline of facility and circumstances of dementia care.

1) The aged care facilities provided by Austin Health[3], a large public health facility in Melbourne, comprise two units (of 30 beds each). Seventy-five percent of the residents are elderly people with dementia. Fees are paid from pensions or privately. Families may choose between a private room and a large ward for end-of-life care, as required. A general practitioner attends once a week for consultations and medical prescriptions, but does not administer intravenous drips. If a resident's condition worsens then they are transferred to hospital.

Staff allocation

Day shift	1 registered nurse, 5 enrolled nurses
Evening shift	1 registered nurse, 3 enrolled nurses
Night shift	1 registered nurse, 1 enrolled nurse

* In a private nursing home, there would be one registered nurse, one enrolled nurse, and four personal care assistants (PCA) per day shift.

There is a CAM (Cognitive Assessment & Management) unit that has 27 beds; of these, eight beds are used for the assessment of patients who have severe peripheral symptoms.

Perception of end-of-life stage of elderly people with dementia: Unable to eat or drink, spend a lot of time asleep, unable to recover from infection, a fall, delirium or showing a disinclination to fight off illness. It may last a few hours or a few weeks.

Circumstances of dementia care: care involves assisted cleanliness, assisted movement, and recreational activities. If residents display peripheral symptoms such as aggression, disturbing other residents, or wandering then they are sent to CAM. If it continues to be difficult to treat the resident then they are sent to a dementia unit in a different facility.

Circumstances of palliative care: control of symptoms, pain management, wishes of the family, offer peace of mind, provision of everyday living support; no special care is undertaken for people with dementia. The average length of stay in CAM is four to six weeks; however, if the patient has cancer, the stay may be very short.

Wishes of the family: the family are well-known to the care workers due to the residents long stay in the facility. When the resident is admitted the family's wishes as to the level of medical intervention required is confirmed.

Discrepancy in values: Australians view death "as not such a bad thing". They think that it is good for someone to die doing something they like. People also understand the risks and have the right to take them. Most Australians feel that if they develop dementia then there is no need to fight to extend their life. However, Italians and Greeks place more emphasis on longevity as opposed to the quality of life, and would do anything to live longer.

Self determination: up until six to ten years ago this was the medical model (medical intervention). However, since the Aged Care Act was adopted, the residents rights and right-to-choose are respected.

Care workers thoughts on implementation of palliative care: care workers find it difficult when a resident in a nursing home dies, especially a long-term resident. Nurses in nursing homes undertake death education as part of their nursing training and are therefore used to it. However, it is difficult for a young nurse to deal with a resident's death. It is here that the gratitude expressed by the family towards the care workers becomes a strong source psychological support for them. Also, once a year, a memorial service is held for all residents who passed away the previous year. It helps care workers to attend this service and express their feelings.

Needs for palliative care: at first, most elderly people with dementia are afraid of entering a nursing home. One resident said "My wife abandoned me in this nursing home". However, six weeks later when his family came to take him out for the day, the resident wanted to return to the nursing home after just two or three hours. He called the nursing home "my home". For this to happen, it is necessary to observe and understand the residents well. Nurses are trained to have a flexible attitude. Nurses are used to giving priority to their duties at work, but if care is conducted with the resident as a priority, things fall into place. The residents condition changes according the care approach made and the personality of the nurse. Nurses who like to be in charge, who are intimidating, and can't back down are not suitable. Calm, collected nurses are required.

2) Broadmeadows Health Services[4] has a 30-bed geriatric assessment and management unit (GEM) and a 20-bed palliative care unit amongst its services. The facility is part of Northern Health. Of the GEM patients, 60% return to their own homes, and 40% are transferred to nursing homes. Most patients in the palliative care unit die there.

Staff allocation

1. Palliative care unit

Day shift:	Including the head nurse, there are six staff in total, with a ratio of four patients per nurse.

Evening shift: Including the head nurse, there are five staff in total, with a ratio of five patients per nurse.

Night shift: 2 registered nurses (in order to administer medicine)

2. Other staff

A patient service attendant (PSA), a worker who has the minimum of training, serve food, clean the ward, cleans the bed after hospital discharge, performs rubbish disposal, and the like. Pastoral care workers and priests conduct mental care.

Number of dementia patients: in the palliative care unit, one third of the patients have cancer and other patients have dementia.

Perception of the end-of-life stage for elderly people with dementia: basic systems are not functioning, bedridden, pressure sores become infected. End-of-life is considered when patients are unable to ingest food and drink, and so nutrition is difficult. Restlessness is the result of confusion rising from the body ceasing to function.

Circumstances of dementia care: primary care is conducted based on information from the family. Sufferers who feel uncomfortable are looked after by the same nurse if possible. Screening tests (MMSE: Mini-mental state examination) are carried out. After discharge, follow-ups are conducted to confirm whether cognitive abnormalities are temporary. Speech therapy and aromatherapy are carried out. Nurses are trained in response methods to dementia sufferers.

Circumstances of palliative care: palliative care is comfort care. When dementia sufferers are first admitted, they are confused, and this increases their chance of falls; therefore, alarm mats are used and a fall risk assessment is conducted. For bedridden patients, care mainly takes the form of washing and care of pressure sores. Other problems include pain management. It is difficult to assess the pain levels experienced by a dementia patient, but care is taken to observe signs of pain such as wincing. In the final stage, hypodermic medical treatment and sedatives (Midazepam, Clonozepam) are administered every four hours. Measures the ward can/cannot take are explained to the family on admission, and the family's wishes are noted.

Care workers thoughts on implementation of palliative care: care workers who have a lot of experience gain satisfaction from doing the work in the field they enjoy, keeping the patient comfortable, helping them live to their fullest, doing the best they possibly can. However, in cases where the care workers have less experience, they can get close to patients, and if the patient is in their 30s or 40s, or are close to their own age, then it can be difficult to control their feelings.

3. Palliative care for elderly people with dementia in Melbourne.

1) Perception of dementia care

People's perception of dementia differs depending on the national character. Most Asian people, Japanese included, feel that if they develop dementia then they want to live the best life they can. They also feel that if their family member had dementia, then they would want them to live as long as possible. However, during interviews in Melbourne the impression I got was a surprisingly negative one, with comments such as "I don't want to continue living with dementia", or even stronger, "I wish I were dead". In other words, rather than a national character, in Australia where values are varied, it is important to respect each individual's values.

2) Discrepancy regarding in the gap in care for elderly people with dementia

In Japan, there appears to be a big difference in the quality of care available between facilities. In Japan, facilities for elderly people, since changing to a contractual system, have commercialized care and improved services. On the other hand, facilities overwhelmed with operational duties have widened the care gap. Choosing a facility may be a hit-and-miss situation. In Melbourne, there is something familiar about every facility. This may be because, no matter which facility you choose, there is a basic standard of care provided. The reason for this is strict regulations regarding, in particular, records and staff allocation. Furthermore, everyone is provided with care on an equal basis.

3) View of life and death (perception of death)

There is a difference in the attitude toward dying and the rights of patients in regard to

the risks. In Japan, death is considered a delicate subject and is almost taboo. Also, if a patient has a fall or chokes, then the family demands an explanation as to how that could happen. However, in Australia, death is seen as "not such a bad thing", and if someone dies doing something they want to then that is a good thing. Further, everyone has the right to know the risks and to take them if they so wish. Sometimes that leads to falls and broken bones. If someone understands that they will fall and break a bone if they try to walk but they still choose to do so, even if they fall and break a bone or die, then it is alright because they made the decision themselves.

4) Approaches to dementia care

There are many varied approaches to dementia. Most Greeks and Asians would choose to take care of their family member at home if they had dementia, regardless of how hard it may be. In Melbourne, people usually care for their family at home with the help of the greater community, but when dementia becomes severe, then hospitalization or admission to a facility is advocated. Care of a severely demented person is very difficult; therefore, doctors repeatedly try to convince the family to admit the patient.

5) Palliative care for elderly people with dementia in Melbourne

In Melbourne, end-of-life care for elderly people with dementia is included in palliative care. Mainly, care is characterized by nurses carrying out palliative care such as pain control, including prescribing painkillers; also, there are pastoral care workers who provide emotional care. Most nurses gain a sense of satisfaction after caring for a person with dementia in their final moments, but there are some nurses with little experience who get very emotional after a persons death and become upset. Emotional care for staff is carried out by pastoral care workers or priests, and words of gratitude from families go a long way toward helping the nurses.

Conclusion

I have talked about lessons gained from interviews carried out at two institutions in Melbourne, but this is only a very small sample. Not all care in Australia is as I have explained. Also, adopting the lessons as is into dementia and palliative care in Japan will be inappropriate.

One Sunday, I went to church. I asked a lady volunteering at the kiosk there what she thought of nursing and care in Melbourne. The response was "I'm very pleased with it". The lady was 78 years old with three daughters. Coincidentally, one of her daughters worked in a facility as a care worker. Her daughter said that her duties and evaluations were hard, but it was fulfilling and satisfying work. If the people providing care are satisfied with their work then it follows that the people receiving care will also be satisfied. Are nurses and care workers in Japan satisfied with the care they provide? To provide care both parties are satisfied with, it is not enough to merely carry out the functions of daily care, but it is necessary to look back on work done and use it as a form of feedback for future care.

It is important to learn lessons from different cultures and, as we learn from each other, adapt the lessons, in order to improve the quality of care for all.

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