

Report on the Symposium on Palliative Care in Advanced and Progressive Dementia

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The above symposium and workshop were successfully held on Nov 30- Dec 1 2001. The conference was jointly organised by HK Alzheimer's Disease and Brain Failure Association, Hong Kong Society of Palliative Medicine, HK Dietitians Association Ltd, and HK Hospice Nurses' Association. The overseas speakers were Professor Volicer, Clinical Director of the Geriatric Research, Education and Clinical Center (GRECC), USA; and Ms Hurley, Associate Director for Education and Program Evaluation, Bedford, GRECC, USA. There was good attendance in the programme by various disciplines. The main points covered in the lecture and workshops are summarised as follows.

Nutritional support for persons with advanced dementia

115 persons attended this informative evening lecture.

Professor Volicer classified dementia into mild, moderate, severe, and terminal stages. Eating difficulties and dysphagia are especially prevalent in the severe and terminal stages. In a cross-sectional survey in US dementia patients receiving long term care, 24% could self feed; 18% needed help with feeding; 26% refused feeding; 25% choked and refused further food; and 7% choked persistently on food (Volicer, 89).

In the early stages, memory impairment, poor judgment, and apraxia predispose patients to eating problems. In the later stages, behavioural and neuromuscular conditions may cause further difficulties. However malnutrition is not unavoidable in demented individuals. In fact, one study showed that with intensive feeding assistance, demented patients could achieve similar nutritional status and mortality rates as did the non-demented patients of the same age and somatic health (Franzoni 1996). Patients with advanced Alzheimer's disease must have their special needs met to avoid malnutrition.

Caregivers need to assess patients' abilities and develop individualised treatment plans. Simple strategies like proper utensils, finger foods can often help maintain self-feeding. Improved eating environment would also help. Attention to tastes and food preferences can help stimulate appetite. Better control of behavioural disturbances eg wandering, agitation, will be necessary. Modified diet texture eg puree may reduce choking. When demented patients refuse food, any underlying depression should be considered and treated. Dronabinol has also been used in HIV patients with some success.

Caloric needs of demented individuals vary. While agitated behaviour eg pacing, and infection may increase caloric needs, the bedfast patient may require fewer calories to maintain weight. A high density and low volume diet can often meet the needs of a chair/bed

bound patient. Nutritional supplementation can often be achieved through a mixture of commercial products, yogurts, juices and ice cream.

Professor Volicer ended with urge and promotion of prevention of tube feeding in advanced dementia. Multivariate analysis had shown that tube feeding itself is an independent risk factor for aspiration (Pick 1996). The odds ratio of aspiration while on tube feeding was 7.9 (CI 4-15.5) in this study. In another study, nasogastric tube scored the highest for mean discomfort rating at 8.8 ± 1.9 out of 10 amongst all interventions in one study (Morrison 1998). There are many other disadvantages and complications associated with tube feeding. A palliative philosophy of care, continuous effort to feed by natural means, and good communication with patients and families are essential. The health worker should consider the ethical and medical issues, as well as patients' personal beliefs and cultural backgrounds, in guiding patients and families through the final stages of the diseases. A video on natural feeding for patients with Alzheimer's disease was also shown.

Case-based discussion on ethics in relation to clinical management and behavioural issues in advanced dementia

68 persons attended this workshop and generated fruitful discussion.

3 interesting cases were presented for discussion. The first case was a 65 year old gentleman with insulinoma and liver secondaries, who had persistent hypoglycaemia at night. Patient had poor appetite, and found it difficult to consume more than 250 ml of any fluid. Mealtime was not pleasurable. Discussion was on the possible palliative care approaches which could be adopted to help his symptoms, and also on whether he should receive a nasogastric tube insertion.

Second case was a 88 year old gentleman with anal carcinoma who had a sudden deterioration after completion of radiotherapy. There was a very close relationship between patient and his only daughter. Daughter was well educated and fully understood the disease and prognosis. She however requested active cardiopulmonary resuscitation when her father developed cardiac arrest. Discussion was on the medical, ethical, family and cultural issues on cardiopulmonary resuscitation surrounding this case.

Third case was on a 71 year old demented gentleman who had disturbing behavioural problems with yelling, agitation, eating up diapers, stripping off clothes and sexual disinhibition. Patient was stabilised in psychiatric ward but there were difficulties in managing him at the old age home. Old age home staff and relatives had conflicts in opinion on the management eg whether using safety vest or simply locking him up in a room. Discussion was on how to handle these behavioural problems in dementia.

Prof Volicer and Ms Hurley commented on the cases and aspects on autonomous decisions, decision making capacity and ethical framework for collaborative decision making. The use of habilitation approach and simulate presence therapy in dementia patients with behavioural problems were also briefly discussed.

Palliative care in advanced and progressive dementia

145 persons attended this symposium

Professor Volicer delivered a comprehensive lecture on the wide-ranging aspects of palliative care in advanced and progressive dementia. He introduced the types of dementia, namely Alzheimer's dementia, vascular dementia, Lewy body dementia and frontal dementia. The progression from early memory impairment, personality changes, through aphasia, apraxia, confusion to end stages of bedfast, mute, and intercurrent infections were discussed. The management goals throughout the illness would be quality of life, with special emphasis on dignity and comfort at the end stage. Appropriate management of medical issues, psychiatric symptoms, together with meaningful daily activities all contribute towards a better quality of life for patients. Meaningful activities include cueing and assistance for appropriate levels of ADL; physical activities to improve mood, strength and sleep; as well as cognitive and creative activities. Special programs focusing on individualisation of care, promotion of functional independence, and alternative therapies eg music, reminiscence, pet therapy should be employed.

A palliative care approach should be adopted for advanced dementia. One of the important medical management issues is pain. This is made difficult by patients' inability to report symptoms. Instead, indicators of pain are often non-specific, reflected in changes of sleep, mood, eating, mobility, behaviour, and ADL. There are many barriers of pain management in demented elderly, especially in long term care setting. Study has shown that demented elderly tended to receive less analgesic compared with cognitively normal elderly (Morrison & Siu 1998). There are many common misconceptions, eg pain is an expected part of ageing; older patients cannot tolerate opioids; cognitively impaired patients with pain cannot be assessed. In US, a discomfort scale has been employed, looking at non-verbal expression of symptoms eg noisy breathing, negative vocalisation, sad/frightened facial expression, tense body language etc. Early results are promising.

Hospice care program for late stage Alzheimer's disease has been successfully implemented in Professor Volicer's GRECC. In general, "high touch" comfort care is promoted. Cues for ADL, gentle guidance, judicious use of appliances, attention to safety, strategies to decrease incontinence and improve natural feeding are all important care issues. Advance care planning, do not resuscitate issues, proxy planning model are routinely discussed with families. Patients are reviewed and the most suitable level of care is chosen from 5 levels: 1. aggressive care; 2.DNR only; 3.no transfer to acute hospitals; 4. no antibiotics; 5. no feeding tubes. In general, CPR has a very low success rate (Applebaum 1990); and transfer to acute hospital may actually incur higher mortality than treated at long term care centres (Fried 1997).

Professor Volicer concluded the lecture with a quote by A.Luria: "People do not consist of memory alone. They have feeling, will, sensibility, and moral being. It is here that you may touch them, and see a profound change."