Care Received by Patients with Advanced Dementia in Their Final Days of Life
- A Retrospective Study

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Background

- In Hong Kong, patients with advanced dementia usually experience poor end of life care (EOL).

- Currently, there is no territory-wide policy or corporate guideline on EOL care for this group of patients.

- Local palliative care service serves mainly patients with advanced cancer and certain organ failure (e.g. renal, cardiac)
Background

- Home / Nursing home death is very rare

- During acute or inter-current illness, patients with advanced dementia are usually admitted to hospitals for acute care, where they usually experience a high level of symptom distress and receive aggressive medical intervention with inadequate palliative management and appropriate EOL care planning

- Lacks local data for EOL care of Advanced dementia in acute hospital
Disease trajectory

- Short period of decline
- Entry/re-entry
- Prolonged dwindling
- Sudden neurological impairment

- Cancer
- Organ failure
- Alzheimer
- Acute CVA
Palliative and end-of-life care

A palliative care approach

Adopt a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing. Information on end-of-life care is available from www.endoflifecare.nhs.uk

- Consider physical, psychological, social and spiritual needs.
- Ensure people with dementia have the same access to palliative care services as others.
- Primary care teams should assess the palliative care needs of people close to death. Communicate the result within the team and to other health and social care staff.
- Encourage people with dementia to eat and drink by mouth for as long as possible.
  - Specialist assessment and advice about swallowing and feeding should be available.
  - Dietary advice may be useful.
  - Do not generally use tube feeding in severe dementia if dysphagia or disinclination to eat is a manifestation of disease severity.
    - Consider nutritional support, including tube feeding, if dysphagia is thought to be transient.
    - Apply ethical and legal principles to decisions to withhold or withdraw nutritional support.
- Clinically assess fever in severe dementia (especially in the terminal stages).
  - Treatment with simple analgesics, antipyretics and mechanical cooling may suffice.
  - Consider palliative use of antibiotics after an individual assessment.
Objective & Method

- To study the care and treatment received by patients with advanced dementia during the last episode of hospitalization (i.e. death episode)

- Retrospective review of case note & electronic record

- 1 Sept 2010 - 30 June 2011

- Advanced dementia patients of any aetiology (FAST stage 7C or above OR its equivalent) with age ≥ 65 who passed away in acute wards under M&G in United Christian Hospital

- Non-funded project

- Hospital Authority Kowloon East / Central Cluster Ethics committee approval
# Functional Assessment Staging Tool (FAST) for Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Stage</th>
<th>Stage Name</th>
<th>Characteristic</th>
<th>Expected Uninjured AD Duration (months)</th>
<th>Mental Age (years)</th>
<th>MMSE (score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Normal Aging</td>
<td>No deficits whatsoever</td>
<td>--</td>
<td>Adult</td>
<td>20-30</td>
</tr>
<tr>
<td>2</td>
<td>Possible Mild Cognitive Impairment</td>
<td>Subjective functional deficit</td>
<td>--</td>
<td></td>
<td>28-29</td>
</tr>
<tr>
<td>3</td>
<td>Mild Cognitive Impairment</td>
<td>Objective functional deficit interferes with a person’s most complex tasks</td>
<td>84</td>
<td>12+</td>
<td>24-28</td>
</tr>
<tr>
<td>4</td>
<td>Mild Dementia</td>
<td>IADLs become affected, such as bill paying, cooking, cleaning, traveling</td>
<td>24</td>
<td>8-12</td>
<td>19-20</td>
</tr>
<tr>
<td>5</td>
<td>Moderate Dementia</td>
<td>Needs help selecting proper attire</td>
<td>18</td>
<td>5-7</td>
<td>15</td>
</tr>
<tr>
<td>6a</td>
<td>Moderately Severe Dementia</td>
<td>Needs help putting on clothes</td>
<td>4.8</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>6b</td>
<td>Moderately Severe Dementia</td>
<td>Needs help bathing</td>
<td>4.8</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>6c</td>
<td>Moderately Severe Dementia</td>
<td>Needs help toileting</td>
<td>4.8</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>6d</td>
<td>Moderately Severe Dementia</td>
<td>Urinary incontinence</td>
<td>3.6</td>
<td>3-4</td>
<td>3</td>
</tr>
<tr>
<td>6e</td>
<td>Moderately Severe Dementia</td>
<td>Fecal incontinence</td>
<td>9.6</td>
<td>2-3</td>
<td>1</td>
</tr>
<tr>
<td>7a</td>
<td>Severe Dementia</td>
<td>Speaks 5-6 words during day</td>
<td>12</td>
<td>1.25</td>
<td>0</td>
</tr>
<tr>
<td>7b</td>
<td>Severe Dementia</td>
<td>Speaks only 1 word clearly</td>
<td>18</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>7c</td>
<td>Severe Dementia</td>
<td>Can no longer walk</td>
<td>12</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>7d</td>
<td>Severe Dementia</td>
<td>Can no longer sit up</td>
<td>12</td>
<td>0.5-0.8</td>
<td>0</td>
</tr>
<tr>
<td>7e</td>
<td>Severe Dementia</td>
<td>Can no longer smile</td>
<td>18</td>
<td>0.2-0.4</td>
<td>0</td>
</tr>
<tr>
<td>7f</td>
<td>Severe Dementia</td>
<td>Can no longer hold up head</td>
<td>12+</td>
<td>0-0.2</td>
<td>0</td>
</tr>
</tbody>
</table>
Method – Data collection

- **Demographic** (age, sex, aged home percentage, co-morbidities, median survival)
- **Profile of Death episode** (co-existing acute events, intervention initiated, symptom documentation, palliative measures, medication use and discontinuation, professional input, mean length of stays)
- **AD & Advance Care Plan** (% & timing of DNR)
- **Descriptive analysis**
Results - Demographics

- 173 patients fulfilled the inclusion criteria (out of 575, 30% of death for all patients ≥ age 65 during the period)
- Mean age 86.8 (SD 7.2)
- F:M = 1.4 : 1
- Aged home resident : home = 9.2 : 1
- Median survival (m) : 16.8 (6.8 – 33.7)
- Mean no. of co-morbidities : 2.2 (1.1)
Co-morbid conditions (N=173)
In-patient Care Utilization

- Mean no. of hospitalization in the preceding 12 months: 4.2 (2.7)
- Total duration of hospital stay (days) in the preceding 12 months: 33.2 (36.5)
- Mean length of stay (death episode) in days: 5.5 (5.4)
- Tube feeding at death: 44 % (including 8.1% inserted during the death episode)
Co-existing acute events
(N = 173, death episode)

- Pneumonia: 76.3%
- Septicaemia: 25.4%
- Acute cardiac event: 18.5%
- Acute organ failure: 9.8%
- Acute CVA: 4%
- Acute GIB: 2.9%
- Acute abdomen thromboembolism: 1.2%
- Acute thromboembolism: 0.6%
- Fracture: 0.6%
- Others: 9.2%

Mean no. of acute events: 1.5 (0.8)
Medical interventions initiated
(N=173, death episode)

Mean no. of interventions initiated : 3.2 (1.2)
Symptoms documented by physicians (N=173, death episode)

- Dyspnoea: 56.1
- Delirium: 30
- Anorexia & Cachexia: 15
- Pain: 6.4
- Urinary problem: 5.2
- Bedsore: 5.2
- Bowel problem: 4.6
- Edema: 3.5
- N&V: 2.9
- Other: 9.8

Mean no. of symptoms documented: 1.4 (1.0)
Palliative measures

- Advance directives with refusal of CPR: 1.2%
- DNR order in place: 83.8%
- The median first ever DNR order in days before death (25-75 percentile): 4 (1-23.5)
- Unnecessary medication discontinuation: 41%

- Medications for comfort:
  - Analgesics: 28.3% (strong opioids: 7.5%)
  - Anti-secretary agents: 2.3%
  - Anti-psychotic: 1.2%
  - Benzodiazepine: 0.6%
Professional input

- Allied health input: 33.5%
- Bereavement professional input: 1.7%
- Specialist palliative input: 1.7%
- Physical restrainer: 19.1%
**Conclusion**

- Majority died of pneumonia / septicemia
- An acute medical model approach has been using at EOL and considered suboptimal
- Lack measures for symptom control, comfort care and psychological support for family
- AD was rare & ACP was made in very late stage
Challenges & next steps - short term

- Education for hospital staff to change attitude with a palliative approach (Symptom control, QOL, dignity, access to PC, judicious use of tube feeding and antibiotics)

- Palliative EOL Care model should be adopted as guideline /policy
Challenges – medium to long term

- Improved co-ordination of care between CGAT, acute geriatric, specialist palliative care team as well as social services.

- Early ACP / AD should be promulgated in early stage of Dementia

- Public education
Limitations

- Retrospective study
- Single centre
- Lack of control
Thank You