An Initiative to Improve End-of-Life Care for Non-Cancer Patients in Hospitals: Preliminary findings

at the Together 2009 Palliative Care Conference, Australia

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Palliative care for all

• Concept of palliative care well established and reaching out to non-cancer patients
Need of palliative care for non-cancer

- Unmet needs and suffering amongst non-cancer patients at end of life
- Guidelines and policies have been established
Translation to clinical care

• Despite growing amount of literature, description of models of actual service provision is sparse
• Burden of non-cancer palliative care is escalating with the ageing population
• Substantial gap between literature and application in clinical care
Engaging our colleagues

• Specialist palliative care can extend support, though a general end of life care approach is needed amongst health professionals of different specialties
Aim of our programme

- To improve quality of end-of-life care for non-cancer patients in an extended care and rehabilitation hospital through a continuous improvement initiative
Background setting of study

• 227 beds of medical and geriatric wards of Shatin Hospital in Hong Kong

• Patients were transferred in from sister hospital Prince of Wales Hospital, the teaching hospital of Chinese University of Hong Kong
Design of the study

• A quasi-experimental non-equivalent groups design, which included pre-intervention and post-intervention phases, separated by a wash-out phase (3 months) for developing the intervention and training the staff for the initiative.
Methodology

• Pre-intervention phase:
  - documentation of patients’ symptoms, and survey on the needs and QOL of patients, caregivers, and professionals’ QOL.

• Washout period:
  - a three month period during which recruitment and assessment stopped, and training programme for staff commenced

• Post-intervention phase:
  - a non-overlapping batch of patients from the same wards to be recruited and outcomes to be compared with the pre-intervention sample
Criteria of patient recruitment

- Patients with advanced non-cancer diseases and not opting for active treatment
  - chronic heart failure, COPD, chronic renal failure, liver disease, dementia, stroke and other neurological conditions, dementia and frailty
- Agreement for do not resuscitation;
- Fulfilling the poor prognostic indicators
The EOL training programme for staff

- Literature review
- Lectures
- Tutorials
- Case vignettes
- Role plays
- Communication training
- Focus groups on staff attitude
- Development of end of life care manual, educational leaflets
- Adoption of palliative care unit symptom checklists; guidelines and pathways
Implementing the programme

• Through a continuous quality improvement initiative, with feedback and incremental change
• Involving all staff and promote staff ownership of the initiative
Experiences and challenges during the implementation

- Attitude and cultural change is required, and needs to be effected carefully with continual feedback mechanism in planning the incremental changes.
- Reluctance to talk to patients and relatives about death, amongst HCP.
- Perception that EOL communication are mostly about psychological, spiritual or religious matters, best left to ‘trained’ personnel.
- Lack of understanding of the need of patients and families to express their wishes regarding EOL situations.
- Misconceptions among some HCP and administrative staff that EOLC only revolves around the classification of DNR in terminal phase.
- Uncertainty regarding whom should be ‘labelled’ to receive EOLC.
- Concerns regarding logistics, unclear interface with acute hospitals and OAH.
Pre and post intervention comparison

• Symptom control
• QOL of patients
• QOL and costs of care of families
• QOL and carer burden for hospital staff
• Utilisation of hospital services
Outcome measures for patients

Communicable patients:

- Shatin Hospital Palliative Care Symptom Check List (SCL) (min. 0 – max. 4 in symptom severity), modified from Support Team Assessment Schedule
- The Pain Assessment Chart (PAC) (min. 0 – max. 4 pain severity)
- The Chinese Geriatric Depression Scale (CGDS-4) (min. 0 – max. 4)
- Abbreviated Chinese Death Anxiety Inventory (CDAI) (min. 0- max. 4)
- The McGill Quality of Life Questionnaire- Hong Kong Version (MQOL)
- One-item, 10-point satisfaction scale on quality of care in Shatin Hospital.

Non-communicable patients (Comatose/ aphasic/ cognitively impaired)

- The SCL with additional items on behavioral expressions of depression, fear, anxiety, agitation, resistance to care, skin breakdown, pain.

Data were obtained through direct interviewing communicable patients, or proxy-rating by ward nurses of non-communicable cases.
Outcome measures for carers

• Short-Form 12 (SF-12) (-ve difference score = worse QOL)
• Chinese version Cost of Care Index (CCCI) (min. 20 – max. 80, level of stress)
• One-item, 10-point satisfaction scale, on caregivers’ perception on quality of care
• One open question on aspects of satisfaction and dissatisfaction.

Informal caregivers were assessed within three days of patient admission. Questionnaires were delivered face-to-face or by phone.
Outcome measures for staff

- Chinese Maslach Burnout Inventory (CMBI) (best mean score = 1, worse = 4) with 3 subscales: Emotional exhaustion, lack of personal achievement, depersonalization.

- The Chinese Death Anxiety Inventory, 12-item subscale on death and dying anxiety, and 11-item subscale on after-death anxiety (min.1, max.5)

- SF-12
Statistical analysis

• Sample size was calculated using the power analysis “G*Power”. N=80 was needed for each pre and post group, with 80% power and estimated effect size up to d=0.7

• Students’ t test was used to compare continuous variables

• Mann Whitney U test was used to compare patient characteristics, symptom scores, health service utilisation data and other variables
Consent and ethical approval

• Written informed consent were obtained from communicative patients and caregivers

• Consent by proxy were obtained from caregivers’ of non-communicative patients

• Ethical approval was obtained from Joint CUHK-NTEC Clinical Research Ethics Committee
Results

• 80 patients (mean age. 83.6 yrs, 68% female), and 30 caregivers were recruited in pre-intervention

• 117 staff were interviewed pre-intervention (pre-intervention phase from June 2007- March 2008)
Profile on the pre intervention results

- **Most common diseases:** Dementia (30%), stroke (21.3%), COPD (13.8%), chronic heart failure (11.3%), renal failure (10%)
- **Most common symptoms:** Lower-limb weakness (92.5%), fatigue (86.2%), oedema (85%), dysphagia (58.2%) and pain (48.8%)
- **Most severe symptoms:** Lower-limb weakness (3.06, s.d. 1.26), fatigue (2.06, s.d.1.24), dysphagia (1.96, s.d.1.89), pain (1.51, s.d.1.91) and skin breakdown (0.99, s.d.1.26)
- **Carergivers’ QOL:** physical QOL (-6.29) and mental QOL (-4.83) were both lower than HK population norm
- **Carergivers’ stress** on CCSI (45.9, s.d.6.45) was moderate.
- **Professional staff QOL:** had below-average physical QOL (-5.47), average mental QOL (-1.14)
- **Professional staff burnout:** had moderate-high burnout on emotional exhaustion (2.52, s.d. 0.52)
Post intervention

- **89 patients** (mean age 85 yrs, 61% female) were recruited in the post intervention phase (post intervention phase from May 2008-Jan 2009)
Comparable demographics of pre and post gp

- No significant difference in baseline data between pre-post groups in age, gender and diagnoses (apart from fewer CHF in post gp: n of 5 vs 14, p=0.015; and fewer stroke in the post gp: n of 5 vs 17, p=0.003)
Comparing all cases:

- Better improvement in symptom control.
- Pain (p=0.001), dizziness (p=0.024) and cough (p=0.050) were reduced, while constipation (0.026) increased.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Mann Whitney Z score</th>
<th>P value</th>
<th>Pre intervention mean (s.d)</th>
<th>Post intervention mean (s.d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>-2.234</td>
<td>0.026</td>
<td>0.57(0.94)</td>
<td>0.89(1.05)</td>
</tr>
<tr>
<td>Cough</td>
<td>-1.958</td>
<td>0.05</td>
<td>0.41(0.86)</td>
<td>0.16(0.50)</td>
</tr>
<tr>
<td>Dizziness</td>
<td>-2.252</td>
<td>0.024</td>
<td>0.29(0.68)</td>
<td>0.08(0.32)</td>
</tr>
<tr>
<td>Pain</td>
<td>-3.308</td>
<td>0.001</td>
<td>0.629(0.98)</td>
<td>0.229(0.46)</td>
</tr>
</tbody>
</table>
Pre-post intervention comparison results (II)

- Comparing only the death cases (pre: 22; post: 43)
  - Also improvement in pain control.

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</thead>
<tbody>
<tr>
<td>Pain</td>
<td>-3.229</td>
<td>0.001</td>
<td>1.03 (1.19)</td>
<td>0.28 (0.52)</td>
</tr>
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Patients in the post-intervention phase also had:

- Fewer no. of blood specimens taken: pre-post difference of 3.44 times, 95% CI= -0.62 – -0.86 (p = 0.009)
- Fewer x-rays taken: pre-post difference of 0.72 times, 95% CI = -1.15 – -0.30, p=0.001
- Fewer transfer back to the acute hospital: pre-post difference of 5.05 days, 95% CI= -7.86 – -2.24, p=0.001

More follow up by the frail elderly clinic: pre = 3 (5.2) vs. post = 11 (23.9), p=0.005; and community outreach team: pre = 11 (19) vs. post = 24 (52.2), p<0.001.
Caregivers in the post-intervention phase also had better satisfaction:

- Informal caregiver satisfaction improved:
- Caregiver’s own (p<0.019) and Patient by-proxy (p<0.038).

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention mean (s.d)</th>
<th>Post-intervention mean (sd)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>7.83 (1.50)</td>
<td>8.56 (1.26)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Patient (by proxy)</td>
<td>7.54 (1.64)</td>
<td>8.24 (1.35)</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>
Discussion (I)

• The feasibility and practicability of a quality improvement programme to enhance end of life care in a general medical service is confirmed.

• Effectiveness in symptom control, caregiver satisfaction, and reducing unnecessary use of hospital services is demonstrated.
Discussion (II)

• The symptom profile and needs of older non-cancer patients at end of life are shown to be different and requiring attention
Discussion (III)

- Implementation of a quality improvement programme requires careful attention to attitude and culture of staff
Limitations of study

• Not a randomised controlled trial
• Sample size may not be representative
• Patients mainly from the older age group and results may not be generalised to younger age groups
• A model of close liaison with specialist palliative care is yet to be explored
Conclusions

• It is possible to improve end of life care for elderly patients in a general medical service, through staff education, culture and system change