

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

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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,  $p=0.003$ )**

# Pre-post intervention comparison results (I)

- 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.

Symptoms	Mann Whitney Z score	P value	Pre intervention mean (s.d)	Post intervention mean (s.d)
Constipation	-2.234	0.026	0.57(0.94)	0.89(1.05)
Cough	-1.958	0.05	0.41(0.86)	0.16(0.50)
Dizziness	-2.252	0.024	0.29(0.68)	0.08(0.32)
Pain	-3.308	0.001	0.629(0.98)	0.229(0.46)

# Pre-post intervention comparison results (II)

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

Symptoms	Mann Whitney Z score	P value	Pre intervention mean (s.d)	Post intervention mean (s.d)
Pain	-3.229	0.001	1.03(1.19)	0.28 (0.52)

# Pre-post intervention comparison results (III)

- 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.

# Pre-post intervention comparison results (III)

- Caregivers in the post-intervention phase also had better satisfaction:
  - Informal caregiver satisfaction improved:
  - Caregiver's own ( $p < 0.019$ ) and Patient by-proxy ( $p < 0.038$ ).

	<b>Pre-intervention mean (s.d)</b>	<b>Post- intervention mean (sd)</b>	<b>P value</b>
<b>Satisfaction</b>			
<b>Caregiver</b>	<b>7.83(1.50)</b>	<b>8.56 (1.26)</b>	<b>&lt;0.05</b>
<b>Patient (by proxy)</b>	<b>7.54(1.64)</b>	<b>8.24 (1.35)</b>	<b>&lt;0.05</b>

# **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**