Palliative Care in Hong Kong: Lessons & Clinical Innovations

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Caritas Medical Centre
Palliative care, Death & Dying in Hong Kong

- East meets West
- Modern contrasting with traditional
- Longest life expectancy
- Lowest infant mortality
- Cancer is the No. 1 killer
- Patients with multiple chronic illnesses
Palliative Care in Hong Kong:
Started 25 years ago
Palliative Care Development: Milestones

From NGO to government funded & coordinated

No. of Palliative Care Units in HK

- 1982: 1
- 1985: 1
- 1988: 6
- 1992: 12
- 1995: 10
- 1997/8: 10
- 2004: 10

Pioneered in Our Lady of Maryknoll Hospital

1st Home care team

NGO: Society for the Promotion of Hospice Care

Palliative Medicine as a Specialty

HK Society of Palliative Medicine
HK Hospice Nurses’ Association

Post graduate hospice nursing course

First independent Hospice: Bradbury Hospice
Palliative Care Development in Hong Kong

The keys...

- Integral part of public health care system
- Mainly cancer, non cancer: AIDS, ESRD, COPD
- Interdisciplinary, comprehensive service
- Territory wide coverage
- Towards specialist led service
- Large scale audit to ensure quality care
Palliative Care Service Delivery in Hong Kong

- About 11,000 cancer deaths / year
- Serve >50% of all cancer deaths / year
- 38 beds per million general population
- Each PC admission last 14 days (c.f. 30 days)
## Territory wide audit of palliative care service

Coordinated by Quality Assurance Subcommittee, COC in Palliative Care

<table>
<thead>
<tr>
<th>Year</th>
<th>Sample</th>
<th>AUDIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996-98</td>
<td>3600</td>
<td>Symptom control: pain, nausea, vomiting, dyspnoea</td>
</tr>
<tr>
<td>1999</td>
<td>&gt; 300</td>
<td>Management of constipation</td>
</tr>
<tr>
<td>2000</td>
<td>&gt; 350</td>
<td>Mouth care</td>
</tr>
<tr>
<td>2000</td>
<td>&gt; 270</td>
<td>Palliative Care Performance Inventory</td>
</tr>
<tr>
<td>2003</td>
<td>&gt; 250</td>
<td>Communication with patients</td>
</tr>
<tr>
<td>2004</td>
<td>&gt; 200</td>
<td>Communication with care givers</td>
</tr>
<tr>
<td>2005</td>
<td>All units</td>
<td>TRENT audit</td>
</tr>
</tbody>
</table>
## Palliative Care Performance Inventory: audit of 279 patients

<table>
<thead>
<tr>
<th>PC Performance Items</th>
<th>Patient rated importance (5 = most important)</th>
<th>Patient rated satisfaction (5 = most satisfied)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce physical discomfort</td>
<td>4.3</td>
<td>4.1</td>
</tr>
<tr>
<td>Adequate rest</td>
<td>4.3</td>
<td>4.1</td>
</tr>
<tr>
<td>Concern &amp; support</td>
<td>4.2</td>
<td>4.1</td>
</tr>
<tr>
<td>Having peace in mind</td>
<td>4.1</td>
<td>4.0</td>
</tr>
<tr>
<td>Express needs &amp; feelings</td>
<td>4.0</td>
<td>3.9</td>
</tr>
<tr>
<td>Information on treatment</td>
<td>4.1</td>
<td>3.9</td>
</tr>
<tr>
<td>Improve self care</td>
<td>4.0</td>
<td>3.8</td>
</tr>
<tr>
<td>Respect personal beliefs</td>
<td>3.6</td>
<td>3.9</td>
</tr>
<tr>
<td>Respect autonomy &amp; choice</td>
<td>3.5</td>
<td>3.6</td>
</tr>
<tr>
<td>Encourage visits</td>
<td>4.2</td>
<td>4.1</td>
</tr>
<tr>
<td>Comfortable environment</td>
<td>4.3</td>
<td>4.2</td>
</tr>
</tbody>
</table>
Dear IAHPC,

My mom died on 30 Aug. 2006 in Hong Kong and she had a terrible, painful death; thanks to clearly unnecessary NG tubes and central line just an hour before her death.

I would like to start a memorial fellowship at the (private) hospital where she died, because they clearly need to learn more about palliative end-of-life care....
Cancer as a major killer in Hong Kong:
Has palliative care made a difference?
Impact of PC on cancer deaths in Hong Kong

A study of 494 cancer deaths
Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM
Palliative Medicine Jul 2007 (In press)

- 4 HA hospitals with physician specialist led palliative care units:
  - Caritas Medical Centre
  - Haven of Hope Hospital
  - Ruttonjee TSK Hospital
  - United Christian Hospital

- Cancer deaths in 2005 in 4 hospitals constituted 20% of HK total
- A total of 494 cancer deaths selected for analysis
- Utilization of palliative care & other services in last 6 months
- The death episode: last 2 weeks of life
Impact of PC on cancer deaths: last 6 months
Tse D et al

Palliative care coverage & Place of death: 3 groups

Patients who received palliative care in this cohort = 67%

More inpatient $p<0.001$
More outpatient $p<0.001$
More home care $p<0.001$

More consultative $p<0.001$

- PC Service
- Non PC Death (PCS-NPCD) 17%
- PC Service
- PC Death (PCS-PCD) 50%
- No PC Service
- Non PC Death (NPCS-NPCD) 33%
Impact of PC on cancer deaths: last 6 months

Tse D et al

Admissions to acute wards & ICU:
PCS-PCD < PCS-NPCD & NPCS-NPCD

<table>
<thead>
<tr>
<th></th>
<th>PCS-PCD</th>
<th>PCS-NPCD</th>
<th>NPCS-NPCD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute ward admissions (mean)</td>
<td>2.2</td>
<td>3.0</td>
<td>2.7</td>
<td>P=0.013**</td>
</tr>
<tr>
<td>Duration of stay in acute wards (days)</td>
<td>19.7</td>
<td>32.0</td>
<td>30.0</td>
<td>P&lt;0.001**</td>
</tr>
<tr>
<td>ICU/HDU admissions (mean)</td>
<td>0.004</td>
<td>0.070</td>
<td>0.199</td>
<td>P=0.000**</td>
</tr>
</tbody>
</table>
Impact of PC on cancer deaths: last 2 weeks

Tse D et al

Place of death

Death in non PC wards = 50%
Mean age = 73.7

Death in PC wards = 50%
Mean age = 71.9

ICU/HDU deaths:
1.5% of total cancer deaths in 4 hospitals
Mean age = 73.9

HA overall data 2005:
ICU/HDU cancer deaths 2.0%

PC Service
Non PC Death
(PCS-NPCD)

17%

No PC Service
Non PC Death
(NPCS-NPCD)

33%

PC Service
PC Death
Impact of PC on cancer deaths: last 2 weeks

Tse D et al

Interventions initiated:

PCS-PCD < PCS-NPCD < NPCS-NPCD

- CVP line***
- Transfusion***
- Ryle’s tube***
- Parenteral nutrition*
- Foley’s catheter**
- Antibiotics***
- Surgery***
- Assisted ventilation***
- Endoscopy***
- CAT scan***

Mean no. of interventions

PCS-PCD = 2.0
PCS-NPCD = 2.7
NPCS-NPCD = 3.6

P < 0.001***
Symptoms documented by doctors:

- PCS-PCD > PCDS-NPCD > NPCS-NPCD

Mean no. of symptoms documented by doctors

P<0.001***
Impact of PC on cancer deaths: last 2 weeks
Tse D et al

Analgesics prescribed:
PCD-PCS > PCS-NPCD > NPCS-NPCD

No Analgesic | Weak Opioid | NSAID | Morphine | Methadone | Fentanyl | Adjuvants
---|---|---|---|---|---|---
NS | NS | P=0.003** | P=0.001*** | P=0.021* | NS | NS

P=0.000*** | P<0.001*** | P<0.001***
Impact of PC on cancer deaths: last 2 weeks
Tse D et al

Sedatives & Conscious level:
PCD-PCS > PCS-NPCD & NPCs-NPCD

Impact of PC on cancer deaths: last 2 weeks
Tse D et al

Sedatives prescribed
Conscious at 72 hrs before death

P=0.000***
P=0.001***
Impact of PC on cancer deaths: last 2 weeks

Tse D et al

DNR Order present & No CPR performed:

PCD-PCS > PCS-NPCD > NPCs-NPCD

Impact of PC on cancer deaths: last 2 weeks

DNR order present

CPR performed

P<0.001***

P<0.001***
Impact of PC on cancer deaths
Tse D et al

DNR & CPR in advanced cancer: comparing 3 places

<table>
<thead>
<tr>
<th>Place</th>
<th>Mean age (yrs)</th>
<th>DNR documented</th>
<th>CPR performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taiwan</td>
<td>56.5</td>
<td>64.4%</td>
<td>16.9%</td>
</tr>
<tr>
<td>Korea</td>
<td>65.0</td>
<td>86.7%</td>
<td>7.9%</td>
</tr>
<tr>
<td>HKSAR</td>
<td>72.6</td>
<td>94.7%</td>
<td>4.5%</td>
</tr>
</tbody>
</table>

Background work in Hong Kong:
1. HA Guidelines on withholding or withdrawing life sustaining treatment
2. DNR form & its promulgation in HA
Impact of PC on cancer deaths: age factor
Tse D et al

Preliminary findings on the older patients:

Last 6 months:
- Duration of referral to PC service: longer $P = 0.019^*$
- Utilization of PC services: NS
- Duration of stay in acute wards: longer $P = 0.014^*$
- Admission to ICU/HDU: NS

Last 2 weeks:
- No. of interventions initiated: NS
- DNR order in place: NS
- CPR performed: NS

Less is more?
- Symptoms documented: less $P = 0.005^{**}$
- Prescription of Morphine: less $P = 0.001^{**}$
MESSAGE (1) : Patients who received palliative care

- less admissions and stay in acute wards / ICU
- less invasive interventions initiated before death
- more symptoms documented by doctors
- less likely to receive no analgesics
- more likely to receive strong opioids
- not unduly sedated to unconsciousness before death
- more DNR order in place & less CPR performed

Impact of PC on cancer deaths in Hong Kong
Tse D et al
Impact of PC on cancer deaths in Hong Kong

Tse D et al

MESSAGE (2) : Facing the challenge of aging population

- Vulnerability of elder add to that of dying
- The need to know more about preferences of the elder
- The need to know more about pain control in elder
- Differentiating equal practice from equity
Impact of PC on cancer deaths in Hong Kong
Tse D et al

MESSAGE (3): The potential of consultative service
- Results suggested impact was possible beyond PC beds
- An opportunity to increase accessibility beyond beds
- A clinical ground for cross fertilisation

MESSAGE (4): The challenge of supporting patients at home
- If you only have 2 weeks to live, Where would you like to stay?
Supporting cancer patients at home in HK:
A way forward & A challenge
(1) Family in contemporary society

Traditional culture & kinship:
- filial piety
- family interest above own interest
- obligations of eldest son
- female as “natural” caregivers

- More elderly with no kinship network
- Rising labour force from women: 42% in 60’s to 60% in 90’s
- Caregiver also expected to be self sufficient
- Intrusion into time, space, life style not as tolerated

Caring for cancer patients at home in Hong Kong

(2) Physical burden of cancer patients at home

Data from 130 home care patients in Caritas Medical Centre

- Mean age 69 (36 - 90)
- Mean PPS 60 (30 - 90)
- Living alone 10%
- Old age home 20%
- Living with family 70%

PPS 60 =
1. Reduced ambulation
2. Unable to perform housework
3. Needs assistance in self care
4. Normal or reduced intake
5. Conscious or confused

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain control</td>
<td>72%</td>
</tr>
<tr>
<td>Edema &amp; lymphedema</td>
<td>59%</td>
</tr>
<tr>
<td>Oral problems</td>
<td>52%</td>
</tr>
<tr>
<td>Constipation</td>
<td>42%</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>32%</td>
</tr>
<tr>
<td>Nausea &amp; vomiting</td>
<td>28%</td>
</tr>
<tr>
<td>Wounds / drains</td>
<td>23%</td>
</tr>
<tr>
<td>Devices</td>
<td>13%</td>
</tr>
<tr>
<td>Ryle’s tube</td>
<td>5%</td>
</tr>
<tr>
<td>Foley</td>
<td>4%</td>
</tr>
<tr>
<td>Ostomy</td>
<td>3%</td>
</tr>
</tbody>
</table>
Caring for cancer patients at home in Hong Kong

(3) Difficulties & stresses experienced by caregivers

Caregivers at home were facing difficulties in:

- relationship with patient
- coping with emotional reaction
- physical demands in care giving and
- restrictions in social life


Caregivers at home were facing:

Psychological stresses > physical stresses

- Tired, worrisome & Irritable

Caring for cancer patients at home in Hong Kong

(4) Interventions provided by palliative home care team

Data from Haven of Hope Hospital (141 patients)

- Symptom management 98%
- Drug supervision 86%
- Health system facilitation 93%
- Nursing procedures 28%
- Equipment & aids 24%
- Bridging community resources 38%
- Caregiver education 58%
- Psychosocial spiritual support 77%
- Coping empowerment 40%
- Grief work 15%
(5) Effectiveness of home care

Caregivers reported empowerment by home care nurses:
1. Engaging by commitment, involvement, accessibility
2. Providing information, knowledge and skills
3. Affirming self worth
4. Reassurance that patient is receiving good care from caregivers


Home care nurses perceived by caregivers as significantly more helpful than family or friends

Caring for cancer patients at home in Hong Kong

(6) Home death: A dream too far?

- Liu FCF & Lam CCW (2005): From 1999 to 2003, of 1300 patients, only 6 died at home

Common features of 6 caregivers:
- Female, young, educated
- Available 24 hours a day
- Lives with family in a spacious home
- Good and stable financial status
- Good support from family members
- Access to support network

Access to professional care:
- Competent experts with knowledge, skill, experience, confidence in EOL care
- Prepared to visit regularly
- Available when needed

A choice for all?
Palliative Care Service Delivery in Hong Kong

Holding Community

Cancer patient & family
In community

Volunteers
NGOs

Contract services
Special homes
Family doctors

Community PC ENHANCEMENT
Expertise
Multidisciplinary
Availability

PC Units
PC beds

Cancer treatment
Acute service
PC Consultative team
Palliative care for non-cancer in HK:
The challenge of patients with multiple chronic illnesses
The needs of palliative care beyond cancer

Insights from functional decline in last year of life

High

Functional status

Low

Cancer
Organ failure
Fragility

Lunney et al. JAMA 2003;289(18):2387-92
The needs of palliative care beyond cancer

Insights from mortality trend in Hong Kong:
Non cancer chronic debilitating illnesses

![Graph showing mortality trends in Hong Kong](#)

- Cancer
- Chronic heart disease
- Chronic lung disease
- Chronic renal failure
-Degenerative neurological disease

\[ \sim 50\% \text{ of all HK deaths} \]
The needs of palliative care beyond cancer

I, ________________, now decided to choose

- Dialysis treatment
- Palliative treatment

- Palliative care specialist collaborates with renal physicians
- Symptom control guidelines
- Education seminars
- A study on ESRD patients to look for answers
Symptom burden & quality of life in ESRD
Yong D, Kwok A, Suen M, Wong D, Tse D.

ESRD patients recruited from Caritas Medical Centre:
- Patients on RRT = 134 (27 on HD, 107 on PD)
- Patients opted for palliative care = 45 (CrCl<15ml/min)

<table>
<thead>
<tr>
<th></th>
<th>RRT (134)</th>
<th>PC (45)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>58.2 (11.4)</td>
<td>73.1 (7.1)</td>
<td>0.00**</td>
</tr>
<tr>
<td>Duration of RRT/PC in months (SD)</td>
<td>66.6 (70.5)</td>
<td>10.7 (6.9)</td>
<td>0.00**</td>
</tr>
<tr>
<td>Living with family</td>
<td>80.8%</td>
<td>70.3%</td>
<td>0.57</td>
</tr>
</tbody>
</table>

Analysis:
- Symptom prevalence and severity
- HRQOL as assessed by SF-36
Palliative care: A choice in ESRD?
Yong et al

Symptom prevalence (23 items): RRT & PC

Mean no. of symptoms as reported by patients (SD)
P=0.243

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiredness</td>
<td>73.7%</td>
</tr>
<tr>
<td>Cold intolerance</td>
<td>70.9%</td>
</tr>
<tr>
<td>Pruritus</td>
<td>63.7%</td>
</tr>
<tr>
<td>Lower torso weakness</td>
<td>59.2%</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>58.7%</td>
</tr>
<tr>
<td>Skin changes</td>
<td>48.0%</td>
</tr>
<tr>
<td>Limb numbness</td>
<td>48.0%</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>43.6%</td>
</tr>
<tr>
<td>Cough</td>
<td>42.5%</td>
</tr>
<tr>
<td>Pain</td>
<td>41.3%</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>40.8%</td>
</tr>
</tbody>
</table>

Top 10
Palliative care: A choice in ESRD?

Yong et al

Symptom prevalence (23 items): RRT vs PC

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnoea</td>
<td>0.039*</td>
</tr>
<tr>
<td>Skin changes</td>
<td>0.003**</td>
</tr>
<tr>
<td>Halitosis</td>
<td>0.045*</td>
</tr>
<tr>
<td>Problem with sex</td>
<td>0.001***</td>
</tr>
</tbody>
</table>

More prevalent in PC

More prevalent in RRT

Other 19 symptoms: NS
Symptom intensity (23 items) : RRT vs PC

More severe in PC

None

More severe in RRT

- Pruritus: 0.021*
- Limb numbness: 0.043*
- Change in taste: 0.029*
- Problem with sex: 0.043*
- Bloated abdomen: 0.040*

Other 18 symptoms: NS

Palliative care: A choice in ESRD?

Yong et al

Life prolongation treatment is not an immunity to symptom burden
HRQOL by SF-36:
HK general population vs RRT vs PC
HRQOL by SF-36: Correlation with no. of symptoms

Palliation of symptoms is important in chronic illnesses

Pearson correlation: All scales negatively correlated with no. of symptoms
The needs of palliative care beyond cancer

Insights from mortality trend in Hong Kong: Non cancer chronic debilitating illnesses

- Cancer
- Chronic heart disease
- Chronic lung disease
- Chronic renal failure
- Degenerative neurological disease

∼ 50% of all HK deaths
The needs of palliative care beyond cancer

Lessons from advanced COPD patients: QOL & physical discomfort

QOL Concerns in EOL questionnaire (QOLC-E)

4 positive QOL factors:
- support
- value of life
- food related concerns
- health care concerns

4 negative QOL factors:
- physical discomfort
- negative emotions
- sense of alienation
- existential distress

- QOL concerns:
  advanced COPD = advanced cancer

- However, for physical discomfort:
  advanced COPD > advanced cancer
  (4.82 vs 6.08, p<0.01)
  (0=very bad, 10=excellent)

Pang S, Chan KS, Chung B et al. (2005)
Hong Kong: A place to live? or A place to die?
Let Hong Kong be a place to die

Meeting the challenge of chronic illnesses

And recognize the needs beyond cancer

1 in 2 of us will die from these causes
Let Hong Kong be a place to die

A 56-yr-old man with incurable colonic cancer said in his first visit to the palliative care clinic:

“I come because I believe that I have the right to symptom relief by palliative care specialist in a modern place like Hong Kong.”

And recognize the right & access to palliative care
Hear the words of the public

Indicators of good death | Mean score (1-10)
--- | ---
No physical torture | 8.8
Painless death | 8.6
Not dependent on others | 7.9
Reconcile with family | 7.8
Financial planning for family | 7.7
Fulfill last wishes | 7.4
Pre-arrange funeral | 7.0
Psychologically prepared | 7.0
No regrets | 6.6
Keep body clean | 6.4

Perspective of 738 Chinese adults
Chan WCH et al.
Presented at 11th HKICC 2004

10=most important
1=least important

Let Hong Kong be a place to die
Let Hong Kong be a place to die

Model AD Form For HK People

- Save for basic and palliative care, I do **not** consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purpose of this form, form part of basic care.
- **I do not want** ...........

A refusal by the competent

A basic right of the vulnerable

And promise a choice in the era of technology

Hear the words of those with capacity to decide

Let Hong Kong be a place to die
Let Hong Kong be a place to die

Death & dying should not be alienated in Medicine

Death & dying should be a social issue
Palliative care, Death & Dying in Hong Kong

- One of the places with longest life expectancy
- One of the places with lowest infant mortality
- Cancer as the number one killer

An advocate before becoming the vulnerable...
A caregiver today, A care receiver tomorrow

@ 2005

Ref: US Census Bureau, International data
A caregiver today, A care receiver tomorrow

Would we have enough palliative care providers if we do not act now?

Ref: US Census Bureau, International data
Serving the dying is not a luxury
Serving the dying is not an ideal
Serve my dying as you served for my birth
Serve what I deserve
Then “luxury” will never become an excuse

Safe landing
Healthy living
Good dying