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HOSPITAL  
AUTHORITY

# Palliative Care in Hong Kong: Lessons & Clinical Innovations

Dr. Doris Tse Man Wah

Chief of Service

Department of Medicine & Geriatrics / ICU

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



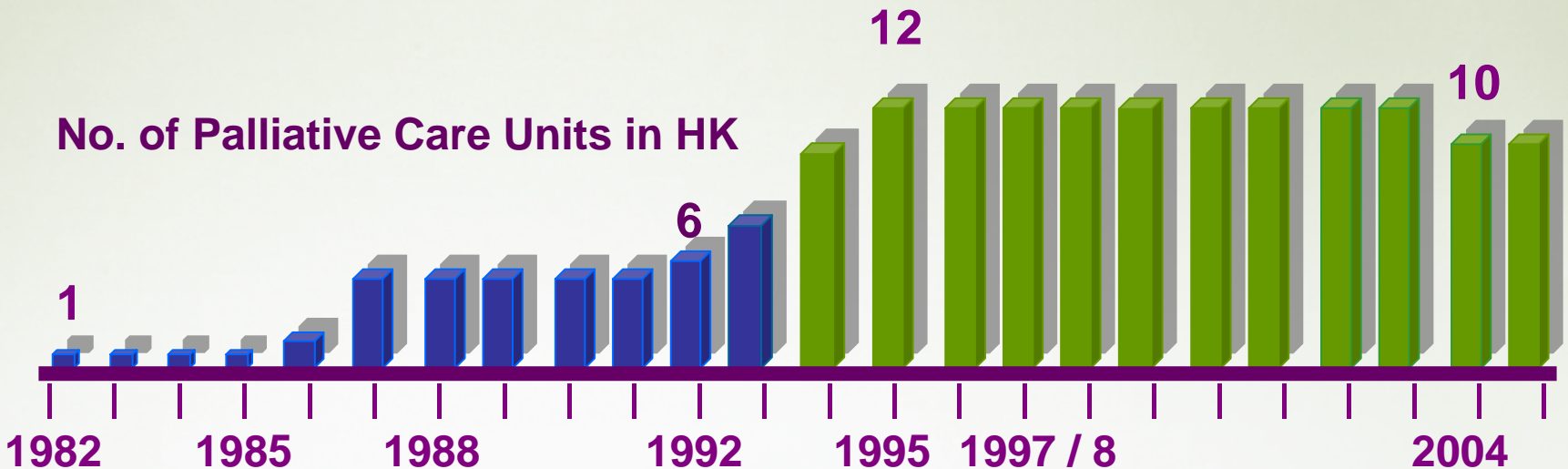


Palliative Care in Hong Kong:  
Started 25 years ago

# Palliative Care Development: Milestones

From NGO to government funded & coordinated →

No. of Palliative Care Units in HK



1<sup>st</sup> Home care team

NGO: Society for the Promotion of Hospice Care

Pioneered in Our Lady of Maryknoll Hospital

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

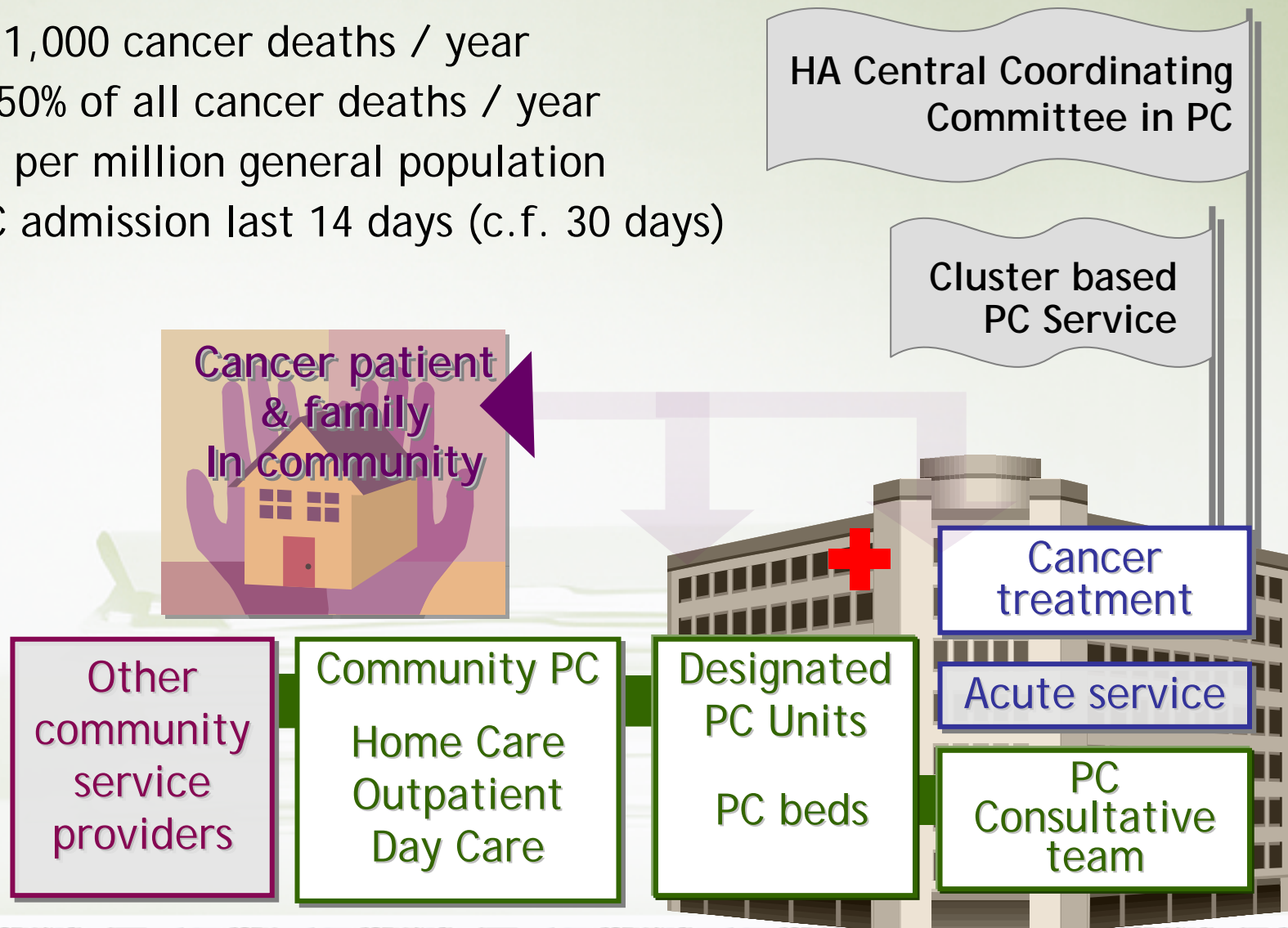
Towards specialist led service

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

Year	Sample	AUDIT
1996- 98	3600	Symptom control: pain, nausea, vomiting, dyspnoea
1999	> 300	Management of constipation
2000	> 350	Mouth care
2000	> 270	Palliative Care Performance Inventory 
2003	> 250	Communication with patients
2004	> 200	Communication with care givers
2005	All units	TRENT audit

## Palliative Care Performance Inventory: audit of 279 patients

PC Performance Items	Patient rated importance (5 = most important)	Patient rated satisfaction (5 = most satisfied)
Reduce physical discomfort	4.3	4.1
Adequate rest	4.3	4.1
Concern & support	4.2	4.1
Having peace in mind	4.1	4.0
Express needs & feelings	4.0	3.9
Information on treatment	4.1	3.9
Improve self care	4.0	3.8
Respect personal beliefs	3.6	3.9
Respect autonomy & choice	3.5	3.6
Encourage visits	4.2	4.1
Comfortable environment	4.3	4.2



# We only die once: No trial & error

*A mail to International Association of Hospice and Palliative Care*

*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

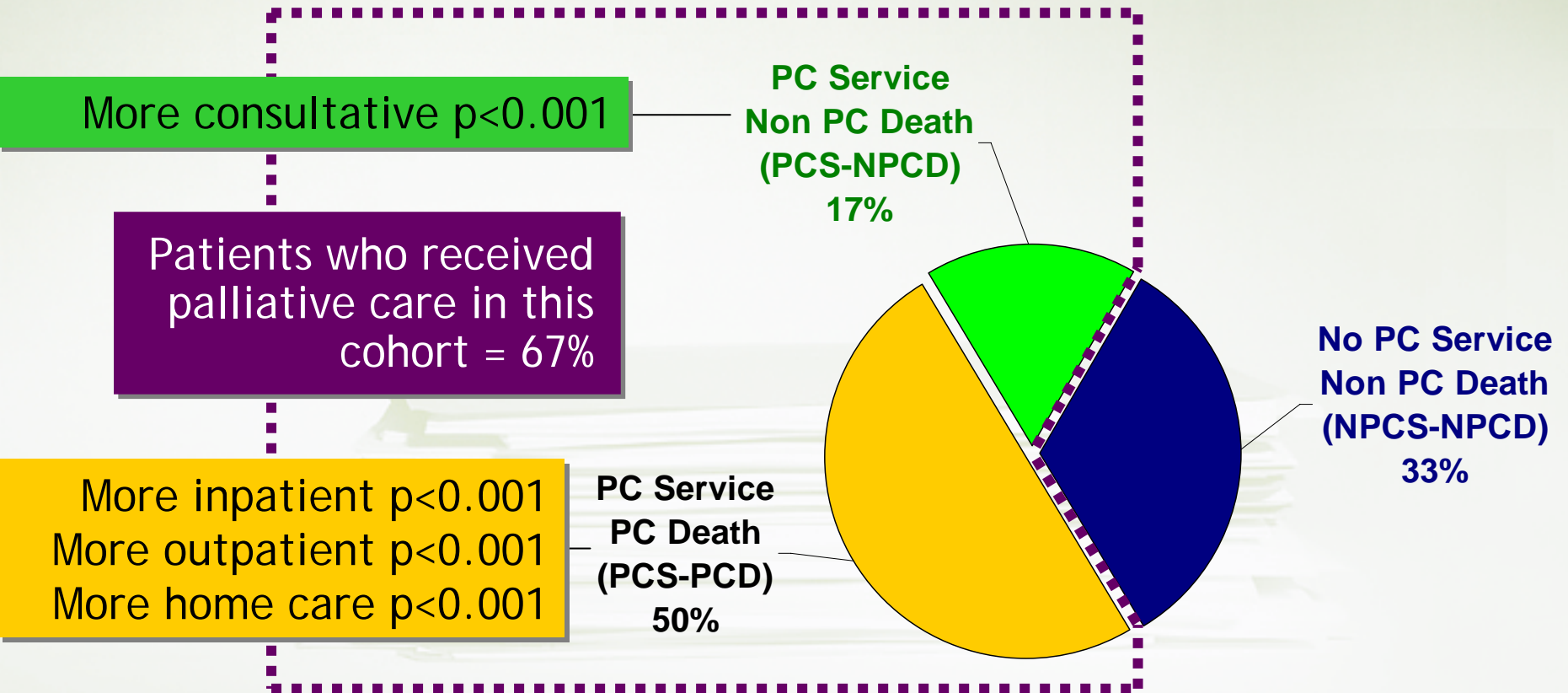
Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM  
Palliative Medicine Jul 2007 (In press)

- 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



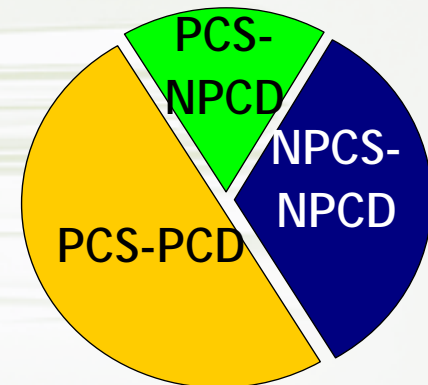
# Impact of PC on cancer deaths: last 6 months

Tse D et al

Admissions to acute wards & ICU:

PCS-PCD < PCS-NPCD & NPCS-NPCD

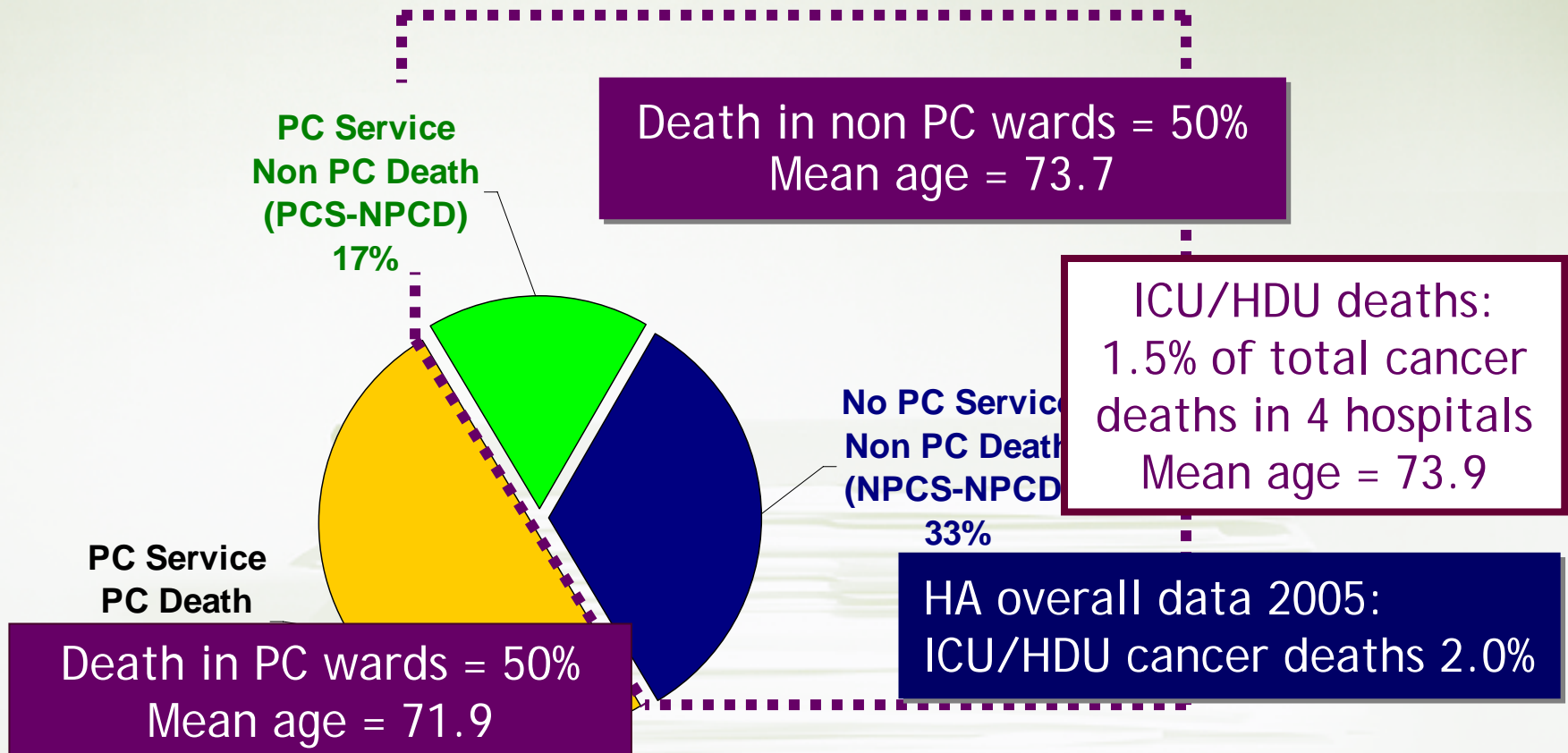
Acute ward admissions (mean)	2.2	3.0	2.7	P=0.013**
Duration of stay in acute wards (days)	19.7	32.0	30.0	P<0.001** *
ICU/HDU admissions (mean)	0.004	0.070	0.199	P=0.000** *



# Impact of PC on cancer deaths: last 2 weeks

Tse D et al

## Place of death



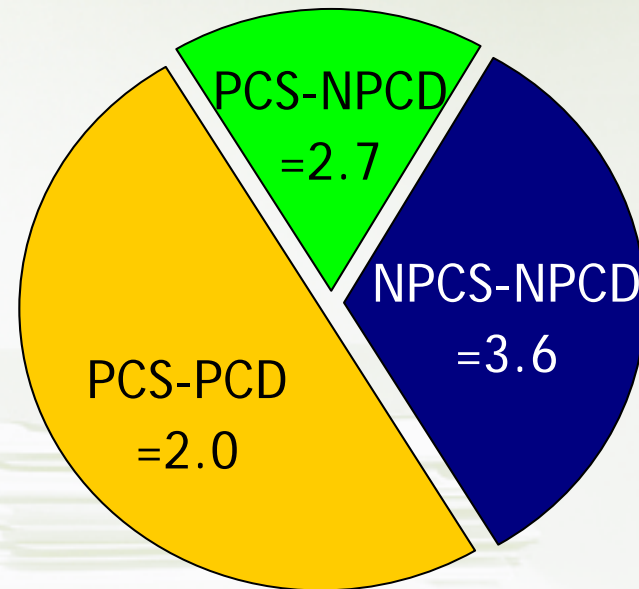
# Impact of PC on cancer deaths: last 2 weeks

Tse D et al

Interventions initiated:

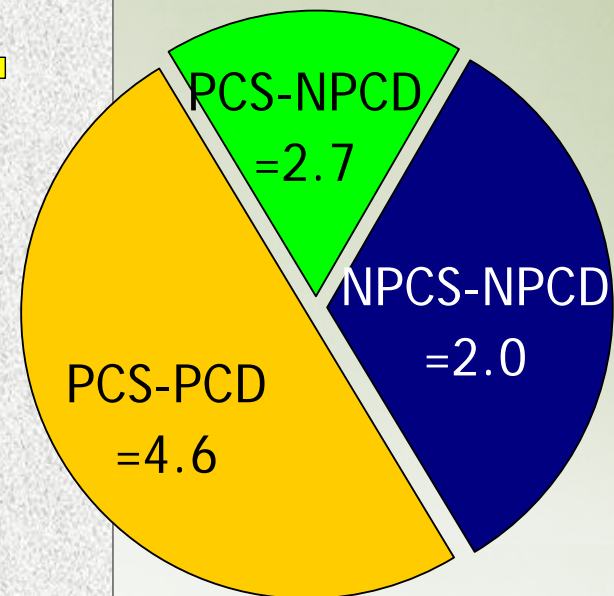
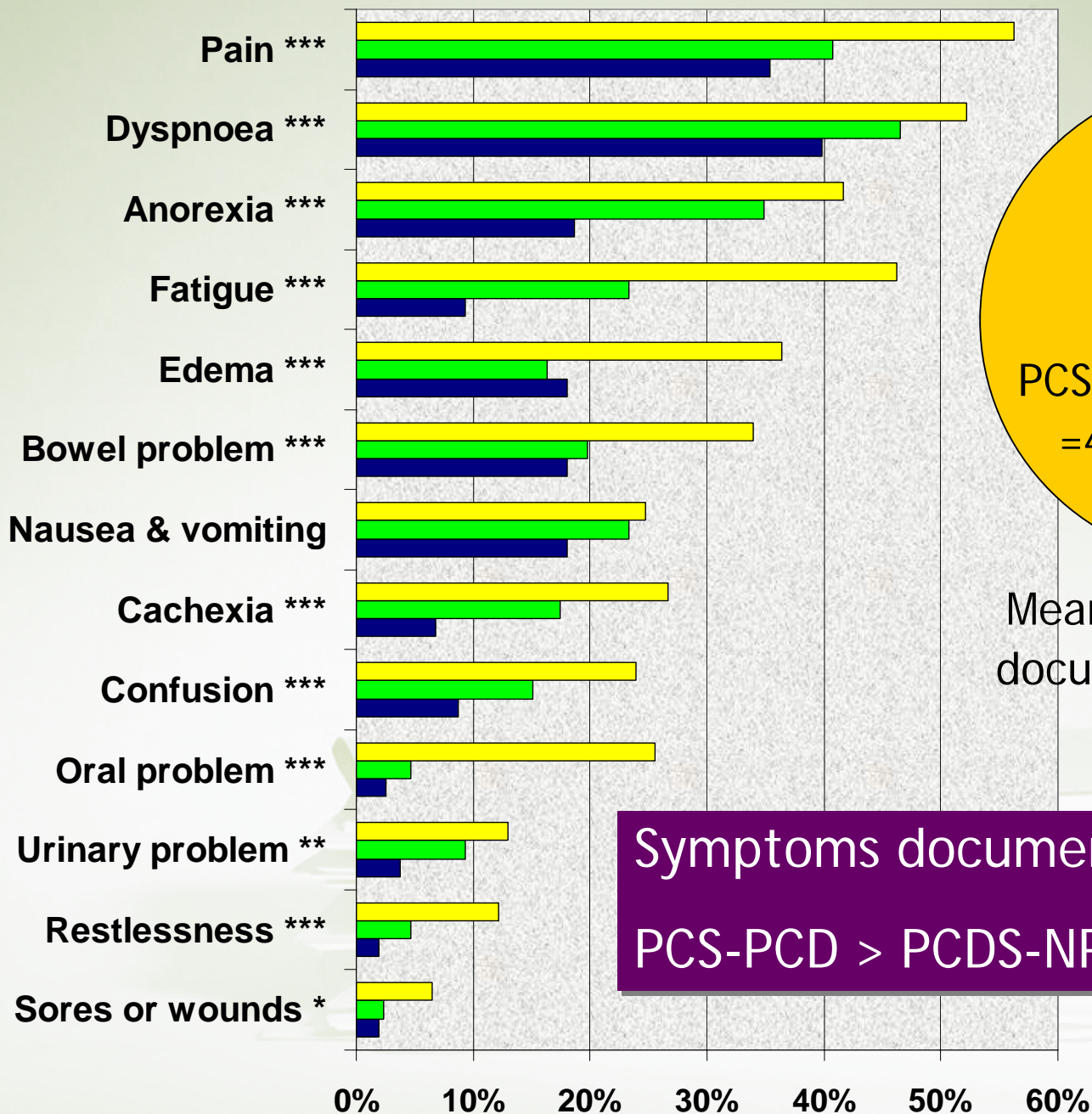
PCS-PCD < PCS-NPCD < NPCS-NPCD

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



Mean no. of interventions

P < 0.001\*\*\*



Mean no. of symptoms documented by doctors  
 $P < 0.001^{***}$

Symptoms documented by doctors:  
 PCS-PCD > PCS-NPCD > NPCS-NPCD

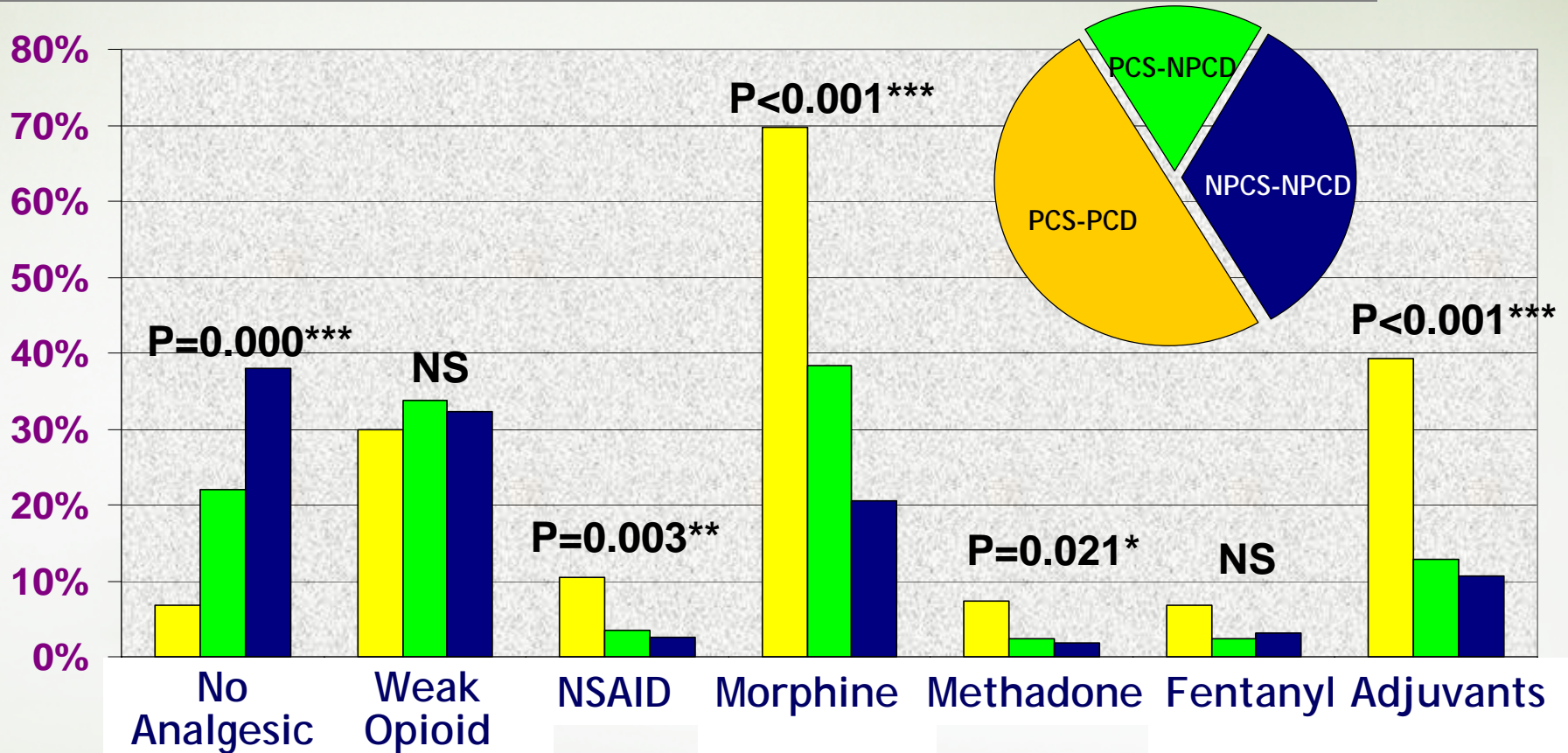


# Impact of PC on cancer deaths: last 2 weeks

Tse D et al

Analgesics prescribed:

PCD-PCS > PCS-NPCD > NPCS-NPCD

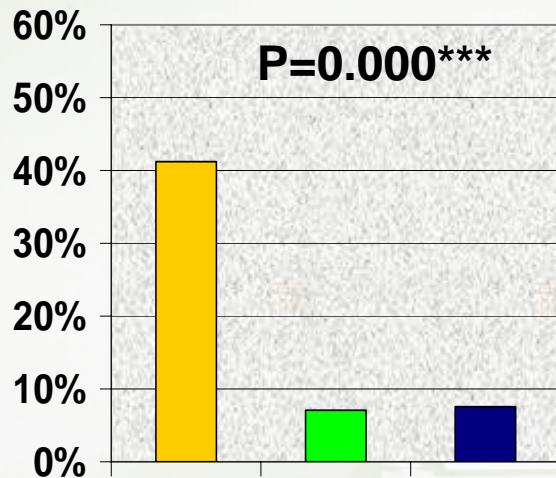


# Impact of PC on cancer deaths: last 2 weeks

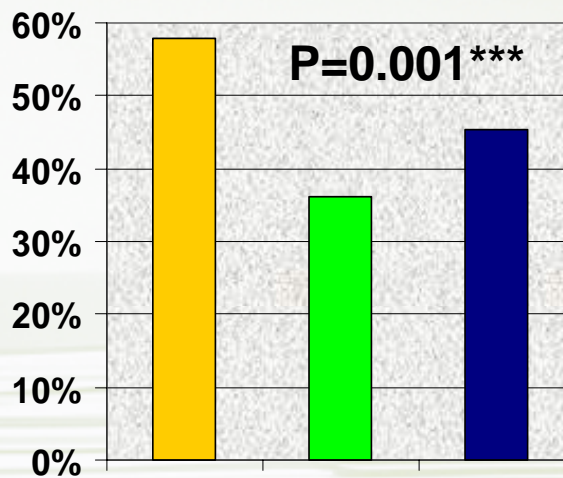
Tse D et al

Sedatives & Conscious level:

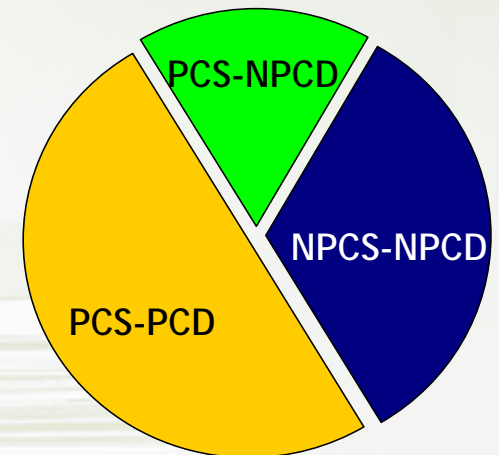
PCD-PCS > PCS-NPCD & NPCS-NPCD



Sedatives prescribed



Conscious at 72 hrs before death

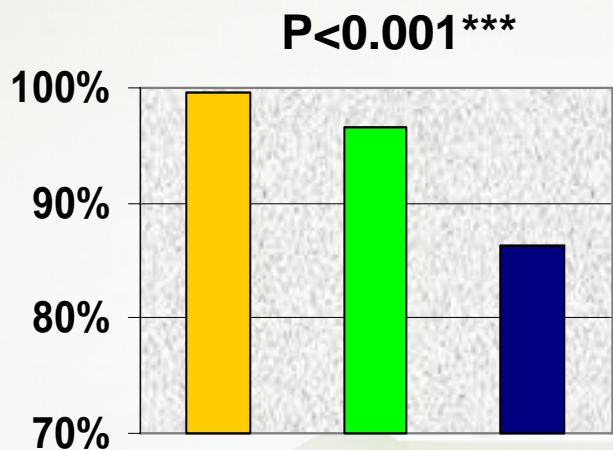


# Impact of PC on cancer deaths: last 2 weeks

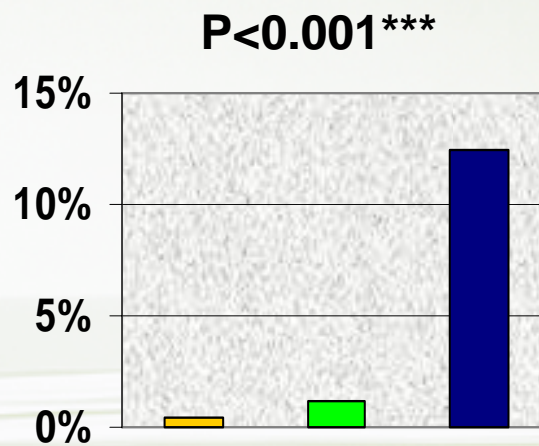
Tse D et al

DNR Order present & No CPR performed:

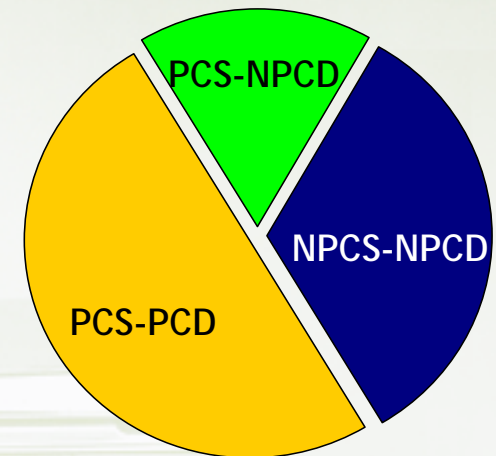
PCD-PCS > PCS-NPCD > NPCS-NPCD



DNR order present



CPR performed



# Impact of PC on cancer deaths

Tse D et al

## DNR & CPR in advanced cancer: comparing 3 places

	Mean age (yrs)	DNR documented	CPR performed
Taiwan Liu et al (1999)	56.5	64.4%	16.9%
Korea Oh et al (2006)	65.0	86.7%	7.9%
HKSAR Tse et al (2007)	72.6	94.7%	4.5%

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** |

# Impact of PC on cancer deaths in Hong Kong

Tse D et al

## 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

## 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?

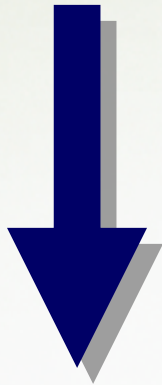




Supporting cancer patients at home in HK :  
A way forward & A challenge

# Caring for cancer patients at home in Hong Kong

## (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

*Holroyd E. The Hong Kong Nursing Journal 1993;62(6):23-26.*

*Holroyd E, Machenzie A. J Adv Nursing 1995;22(3):473-479.*

# 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

Pain control	72%
Edema & lymphedema	59%
Oral problems	52%
Constipation	42%
Dyspnoea	32%
Nausea & vomiting	28%



Wounds / drains	23%
Devices	13%
Ryle's tube	5%
Foley	4%
Ostomy	3%

# 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

*Loke A, Liu F, Szeto Y. Cancer Nursing 2003;26(4):276-283.*

Caregivers at home were facing:

Psychological stresses > physical stresses

- Tired, worrisome & Irritable

*Chan C & Chang A. Cancer Nursing 1999;22(4):260-5.*

# 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%

# Caring for cancer patients at home in Hong Kong

## (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

*Mok E, Chan F, Chan V, Yeung E. International Journal of Palliative Nursing 2002;8(3):137-145.*

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

*Loke A, Liu F, Szeto Y. Cancer Nursing 2003;26(4):276-283.*

# 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

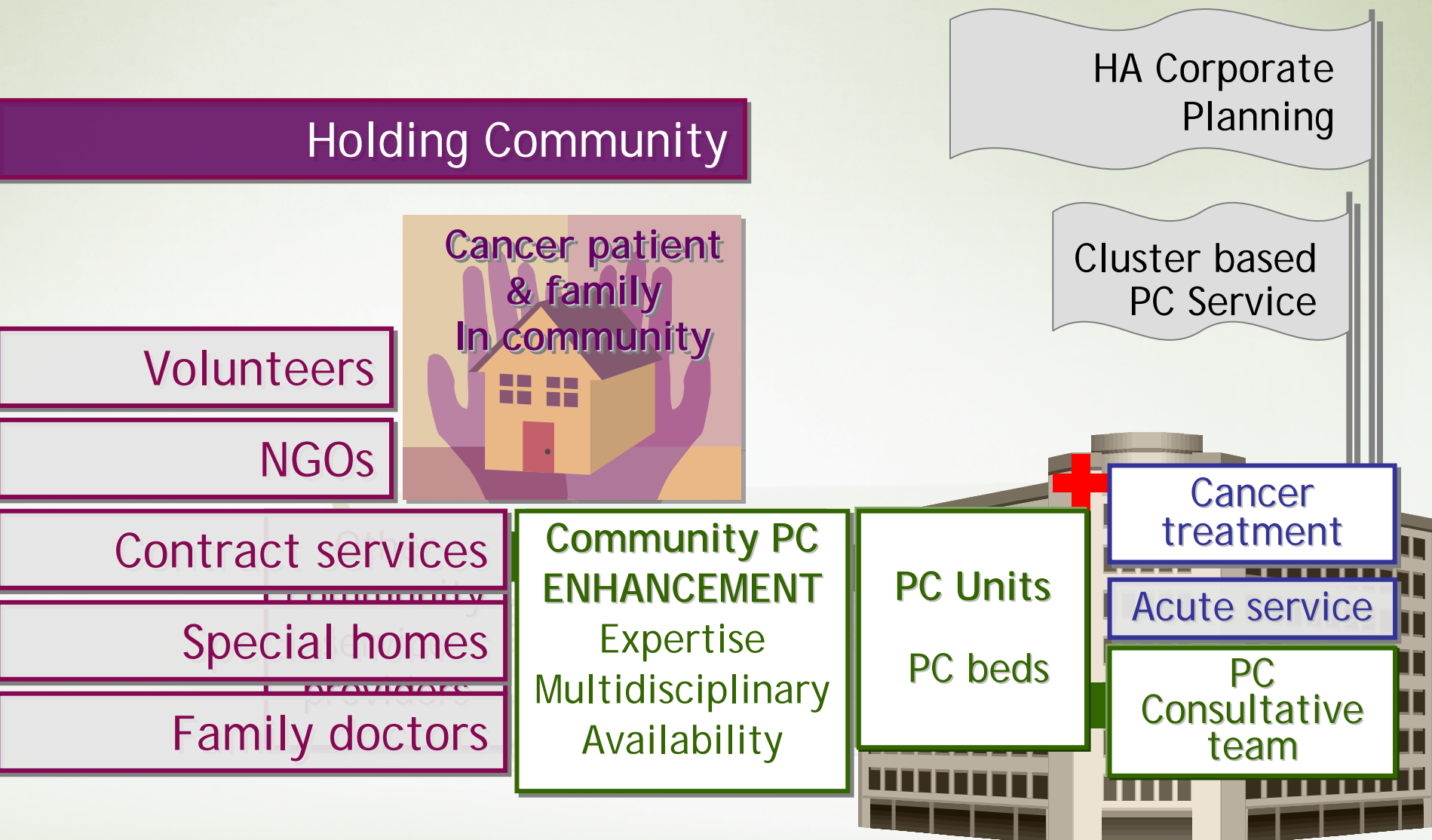
Common features of 6 caregivers:

- Female, young, educated
- Available 24 hours a day
- Lives with family in a spacious home
- Good and stable financial resources
- Good support from family members
- Access to support services

A choice for all?

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

# Palliative Care Service Delivery in Hong Kong



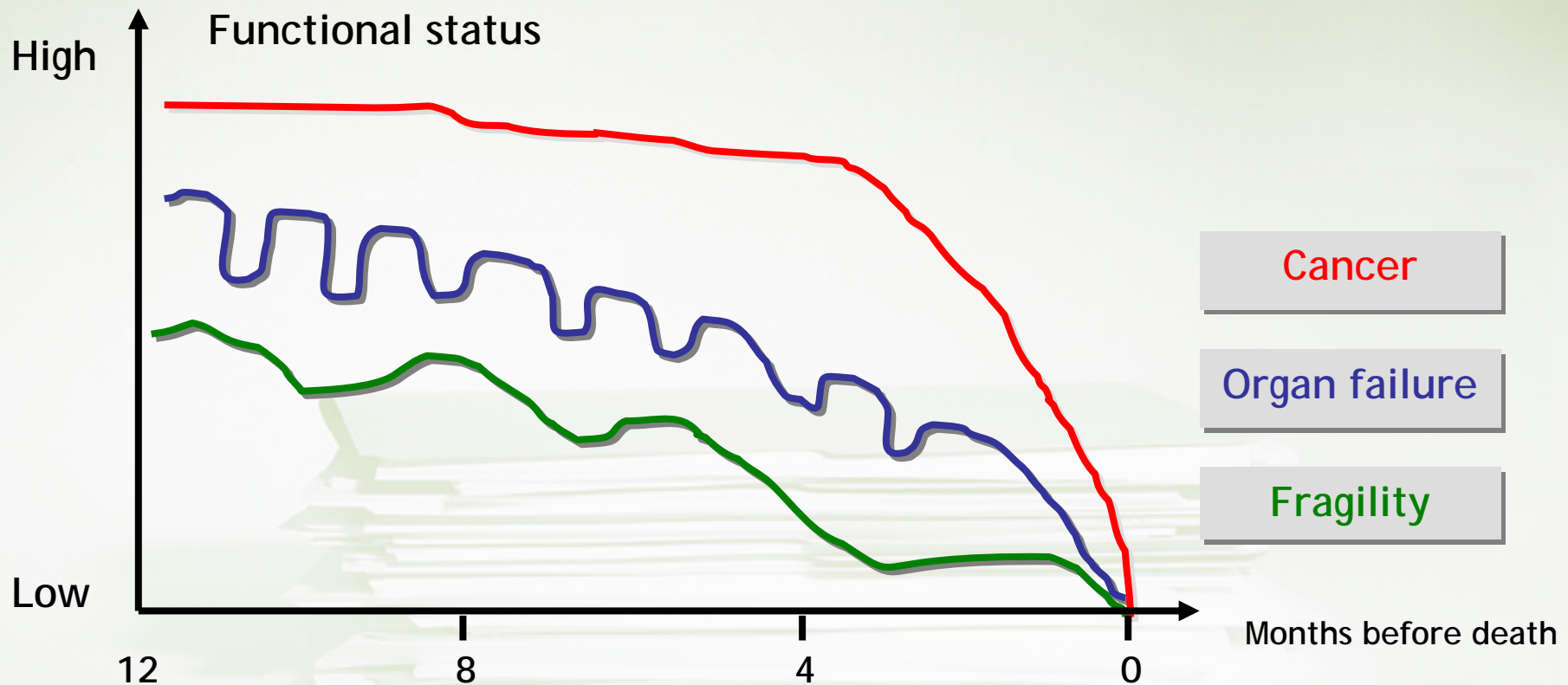




Palliative care for non-cancer in HK :  
The challenge of patients with multiple chronic illnesses

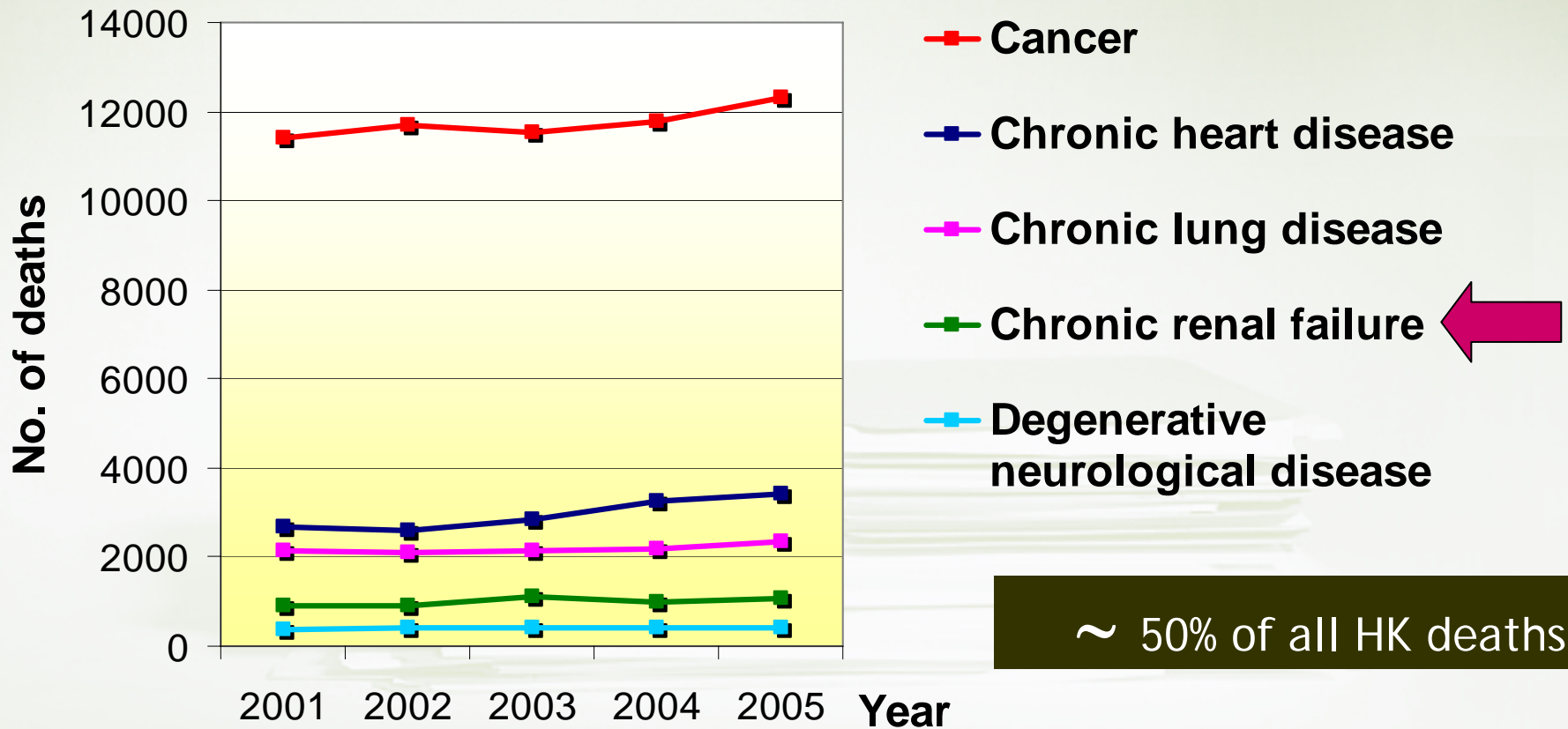
# The needs of palliative care beyond cancer

## Insights from functional decline in last year of life



# The needs of palliative care beyond cancer

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



# The needs of palliative care beyond cancer

要達到理想的治療效果

I, \_\_\_\_\_, now decided to choose

- Dialysis treatment
- Palliative treatment

明愛醫院醫務社會工作部

▲ 提  
▲ 協  
及拉

治療方案  
疾病及  
擬訂照顧  
服務

我, \_\_\_\_\_

- 透析治療
- 紓緩性治療
- 自行安排私營治療

- Palliative care specialist collaborates with renal physicians
- Symptom control guidelines
- Education seminars
- **A study on ESRD patients to look for answers**

(由社工代為安排)

及  
醫務社會工作部

末期腎衰竭

與醫護人員  
商



# Palliative care: A choice in ESRD?

## 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)

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

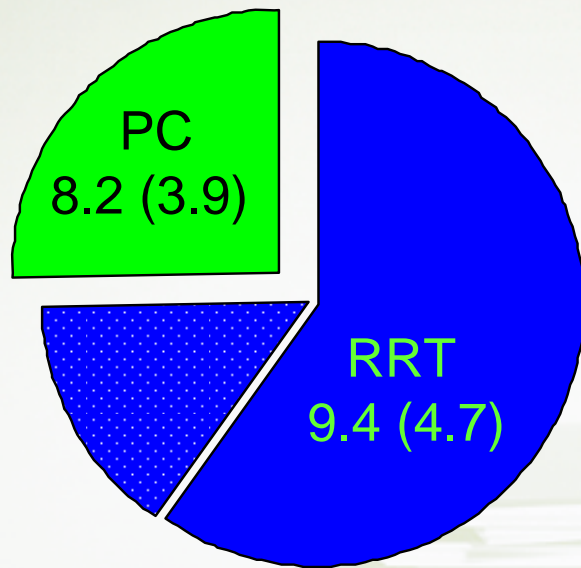
Analysis:

- 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

Top 10

Tiredness	73.7%
Cold intolerance	70.9%
Pruritus	63.7%
Lower torso weakness	59.2%
Difficulty sleeping	58.7%
Skin changes	48.0%
Limb numbness	48.0%
Dry mouth	43.6%
Cough	42.5%
Pain	41.3%
Loss of appetite	40.8%

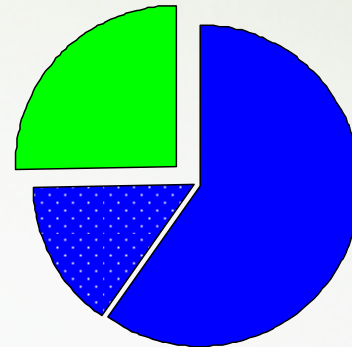
# Palliative care: A choice in ESRD?

Yong et al

Symptom prevalence (23 items) : RRT vs PC



More prevalent in PC



More prevalent in RRT

Other 19 symptoms: NS

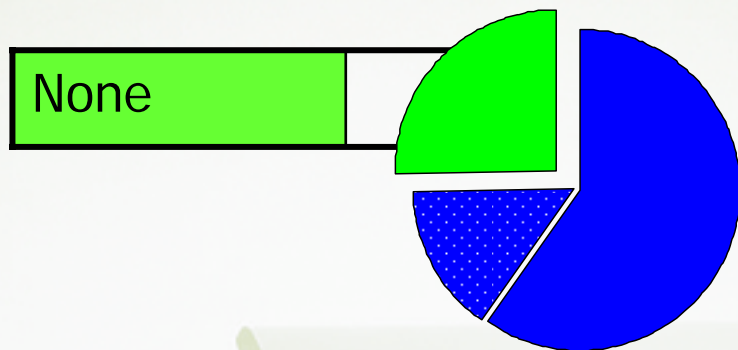
Skin changes	0.003**
Halitosis	0.045*
Problem with sex	0.001***

# Palliative care: A choice in ESRD?

Yong et al

## Symptom intensity (23 items) : RRT vs PC

More severe in PC



More severe in RRT

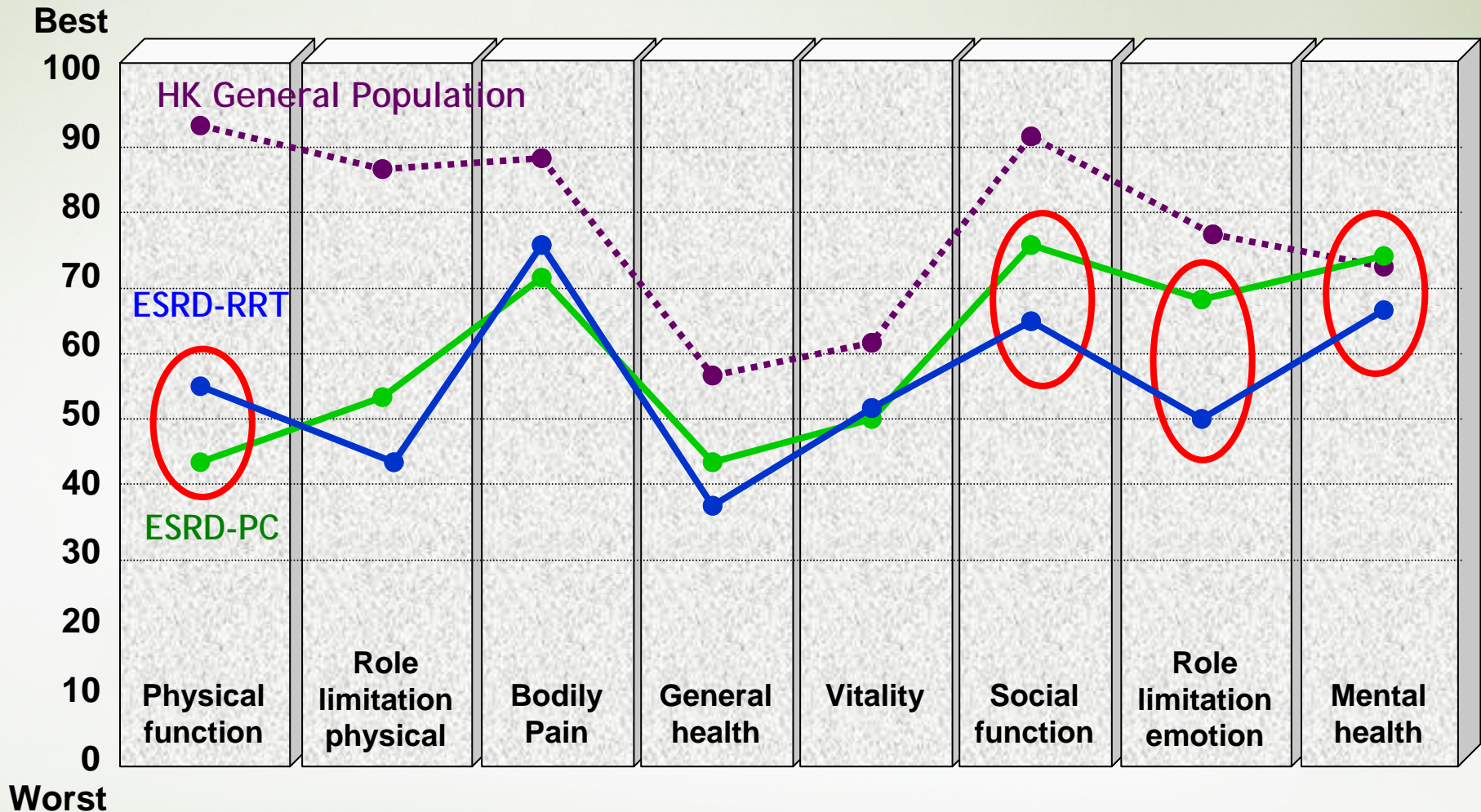
Pruritus	0.021*
Limb numbness	0.043*
Change in taste	0.029*
Problem with sex	0.043*
Bloated abdomen	0.040*

Other 18 symptoms: NS

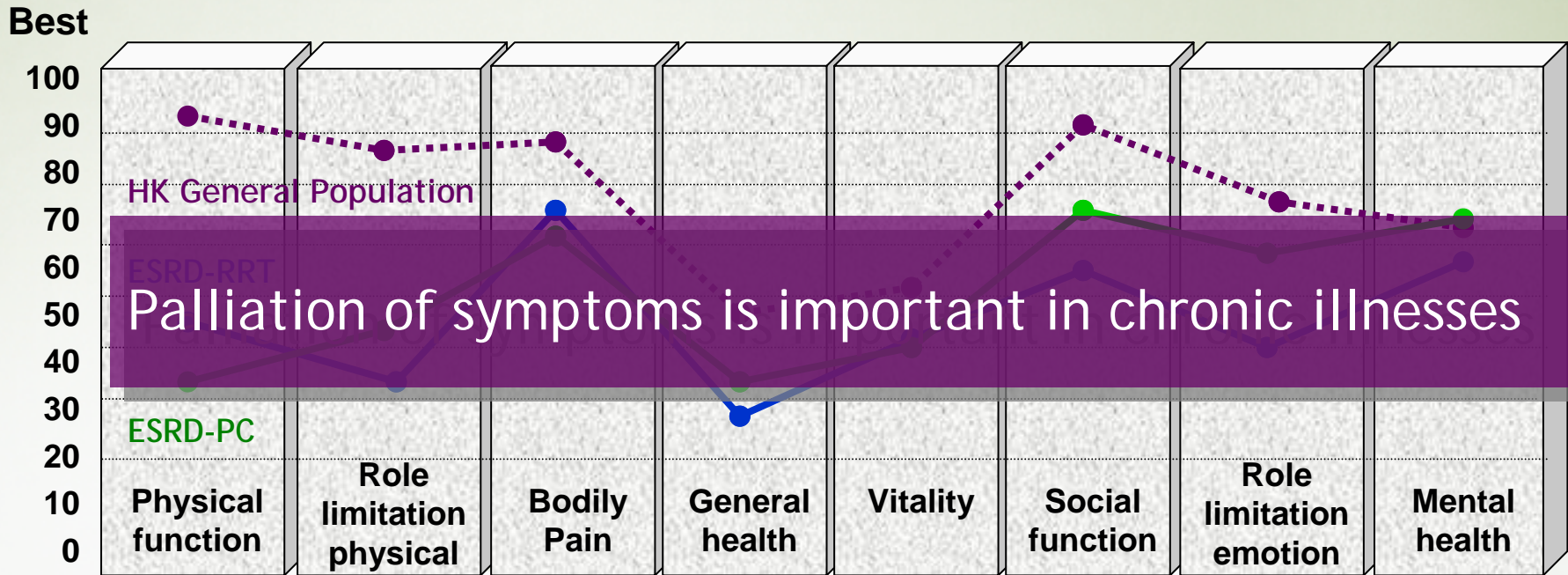
Life prolongation treatment is not an immunity to symptom burden



# HRQOL by SF-36 : HK general population vs RRT vs PC



# HRQOL by SF-36 : Correlation with no. of symptoms

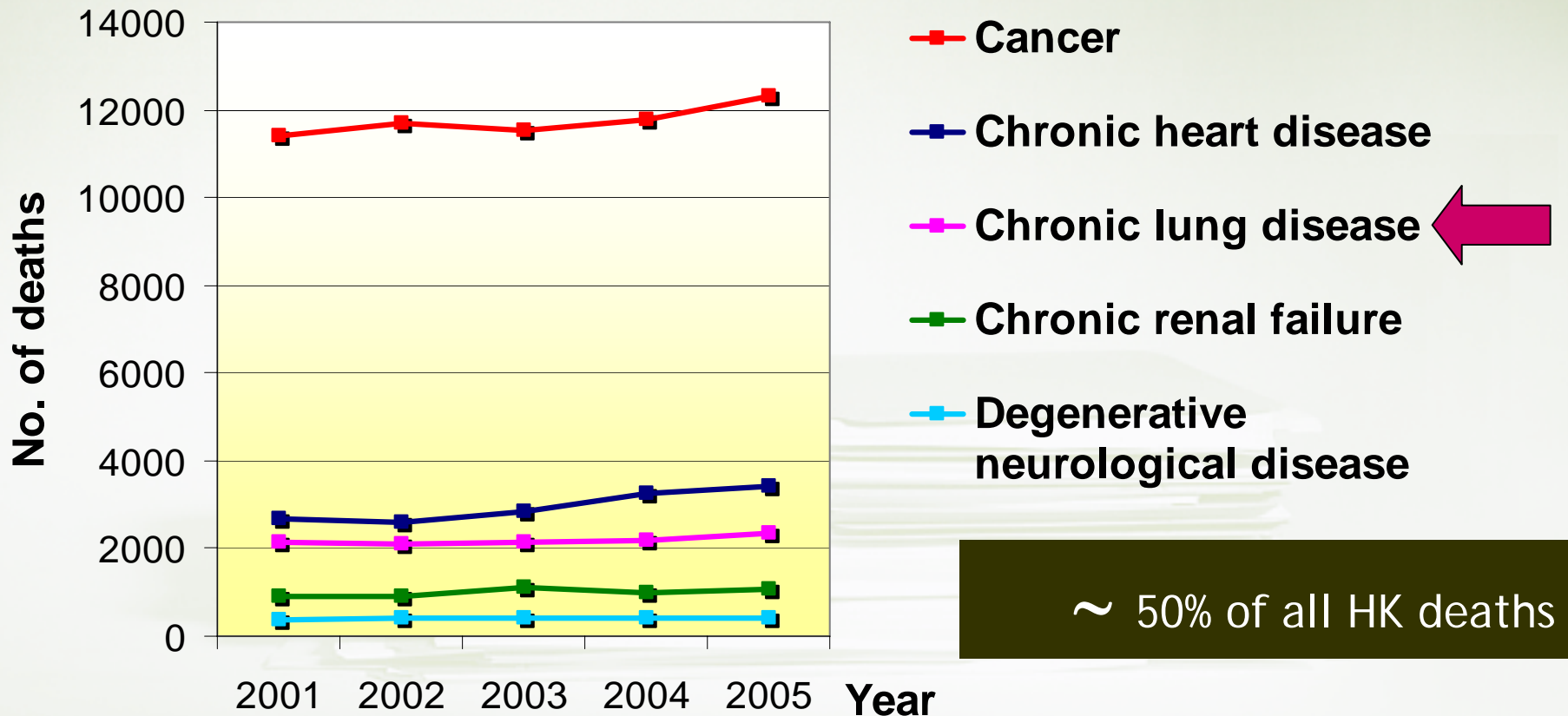


$r$	-0.316	-0.453	-0.424	-0.402	-0.446	-0.345	-0.415	-0.350
$p$	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

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



# 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)*

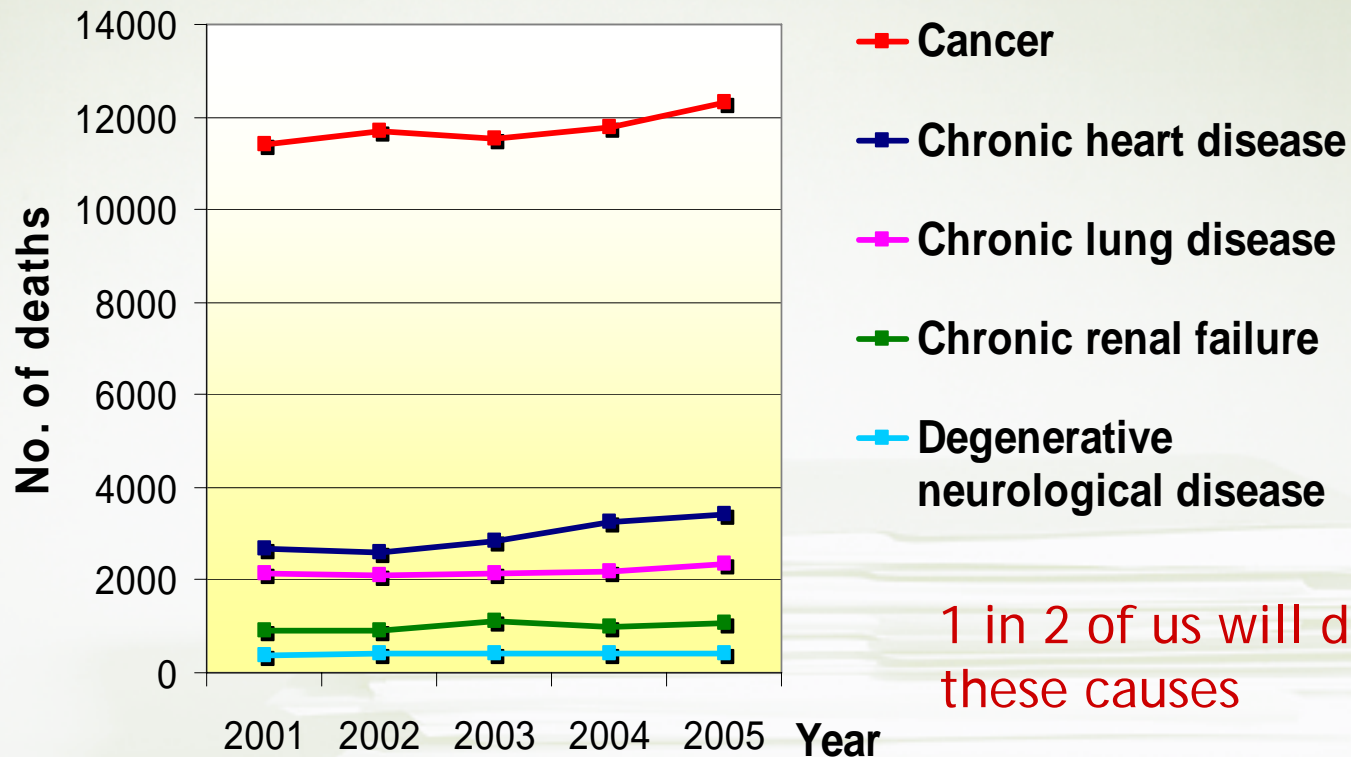


Hong Kong :

A place to live? or A place to die?

# Let Hong Kong be a place to die

## Meeting the challenge of chronic illnesses



1 in 2 of us will die from these causes

And recognize the needs beyond cancer

# Let Hong Kong be a place to die

## Hear the words of the dying

*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

# Let Hong Kong be a place to die

## 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

For their indicators of good death



# Let Hong Kong be a place to die

Hear the words of those with capacity to decide

## Model AD Form For HK People

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

A refusal by the competent

A basic right of the vulnerable

And promise a choice in the era of technology

# Let Hong Kong be a place to die

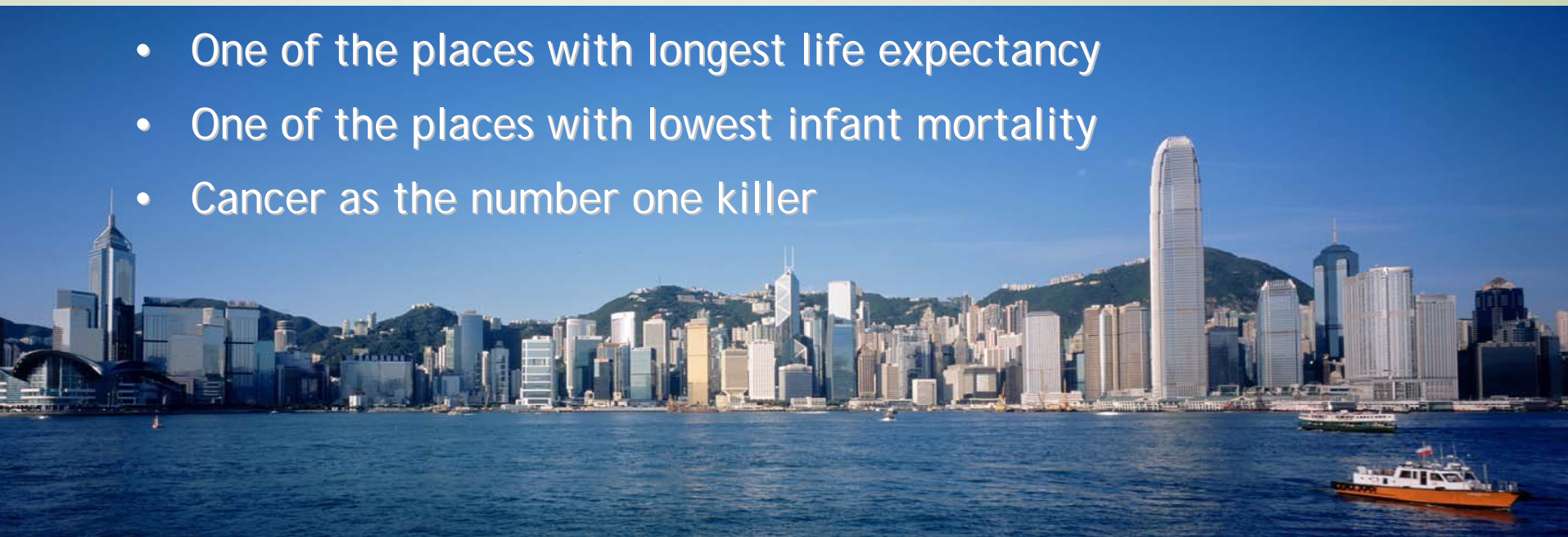
Death & dying should not be alienated in Medicine



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

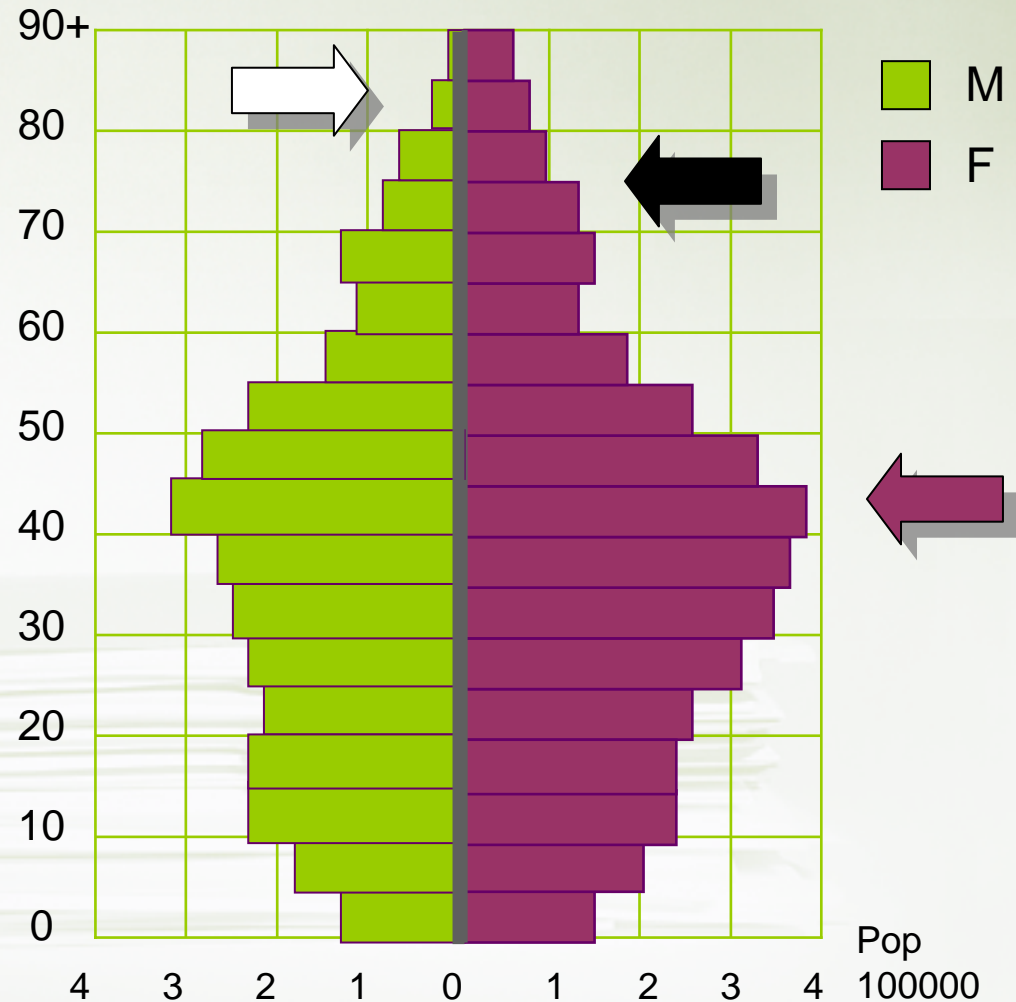


An advocate before becoming the vulnerable...

# A caregiver today, A care receiver tomorrow

@ 2005

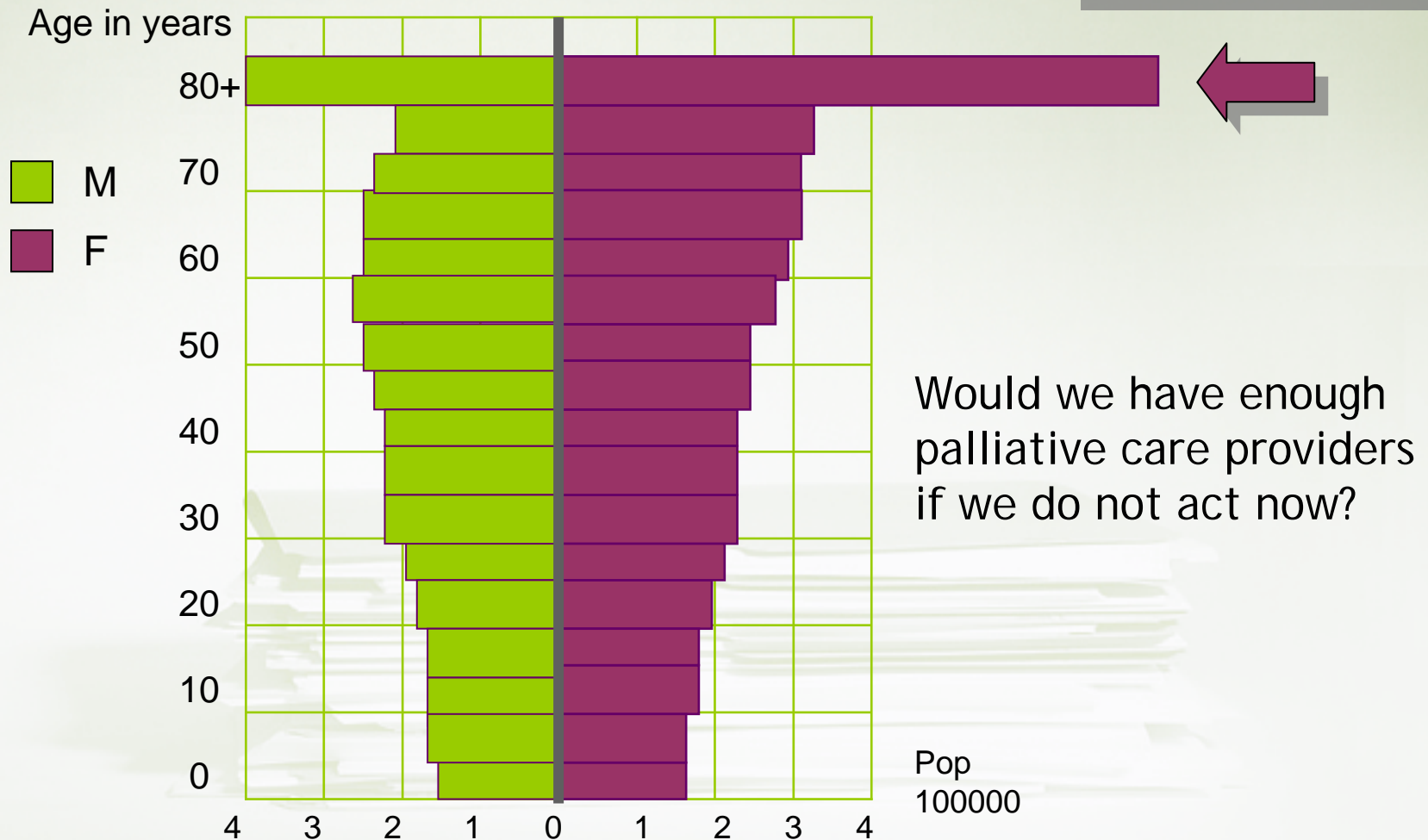
Age in years



Ref: US Census Bureau, International data

# A caregiver today, A care receiver tomorrow

@ 2050



Ref: US Census Bureau, International data



Safe landing

Healthy living

Good dying

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