Palliative Care at Home

Practices and Challenges

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Assumptions

Conclusions

What we assume about Palliative Home Care

1. There is no place like home: common preference
2. For the benefit of the patient: increase their QOL
3. In the interests of the society: minimize hospital stay
4. Lastly, dying at home is a desired outcome

2 Changing context of Home & Family

Insights from HK Census 2011

Traditional Family: Duty to care?

Cultural & moral:

- filial piety
- family interest above own interest

Caregiving:

- obligations of eldest son
- assigned to daughter-i- law
- female as “natural” caregivers

A review of the historical and social process contributing to care and caregiving in Chinese families. Holroyd E, Machenzie A. J Adv Nursing 1995;22(3):473-479.

Changes in a decade: HK Census

Marital Status

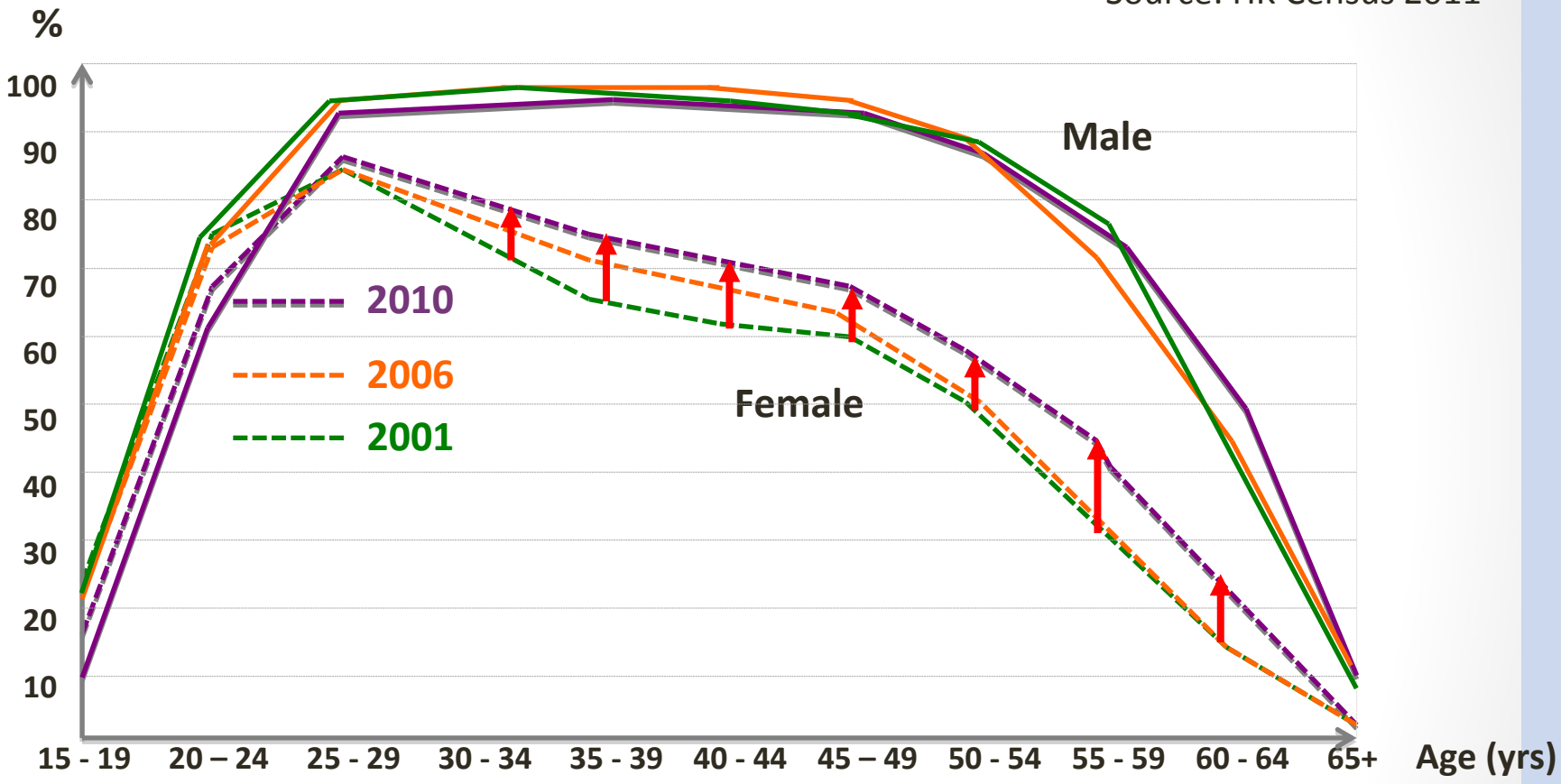
	2001		2011	
	M	F	M	F
Never married %	33.9	30.1	33.5	29.9 ↓
Now married %	61.7	57.2	61.2	54.8 ↓
Widowed %	2.2	9.4	2.1	9.7 ↑
Divorced/Separated %	2.1	3.3	3.1 ↑	5.5 ↑

Source: HK Census 2011

- **More single women**
- **More widows**
- **More divorce and separation**

Labour Force Participation Rate

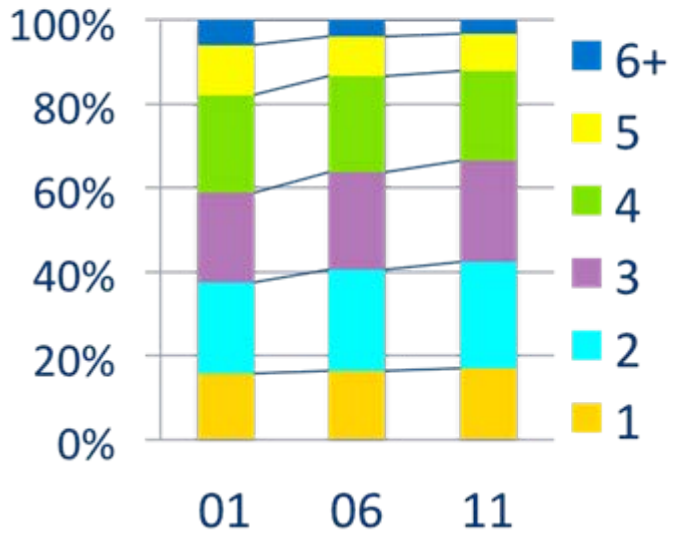
Source: HK Census 2011



- More women (“natural caregivers”) at work

Household Composition

Composition	2001	2011
One-person %	15.6	17.1 ↑
Couple only %	13.2	15.0 ↑
Couple + unmarried children %	43.1	39.4 ↓
Couple + at least 1 parent + 1 unmarried child %	4.6	3.7 ↓
Average domestic household size	3.1	2.9 ↓



- **More people living alone**
- **Less “classical ” family**
- **Smaller household size**

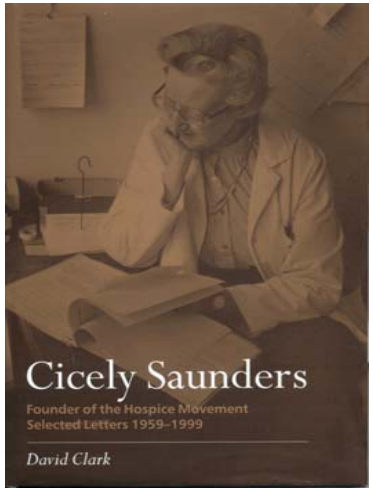
3 Changing Scene of Palliative Care

Palliative Care: Global Trend

"Hospice" for Sick travelers

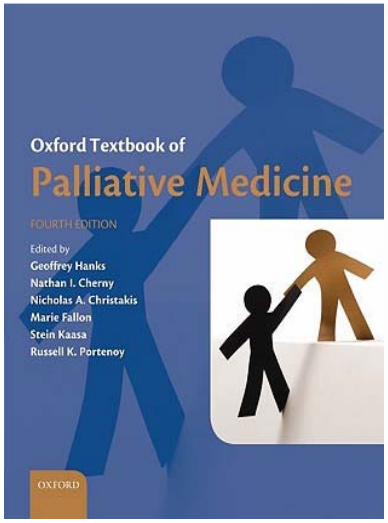
1600's

Modern Hospice Movement



1970's

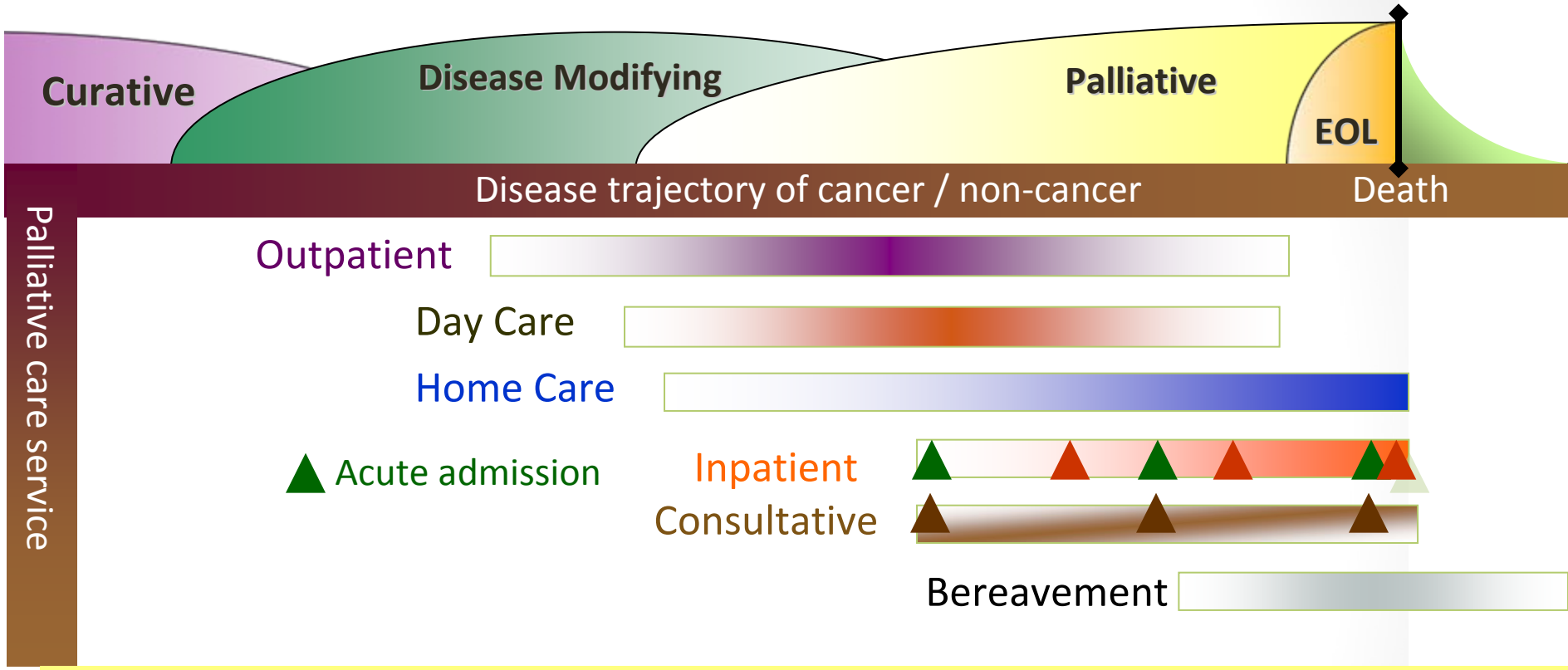
A Specialty



Contemporary

- **From charity programs to public funded health care**
- **From patchy practice to equitable access**
- **From anecdotal experience to evidence based**

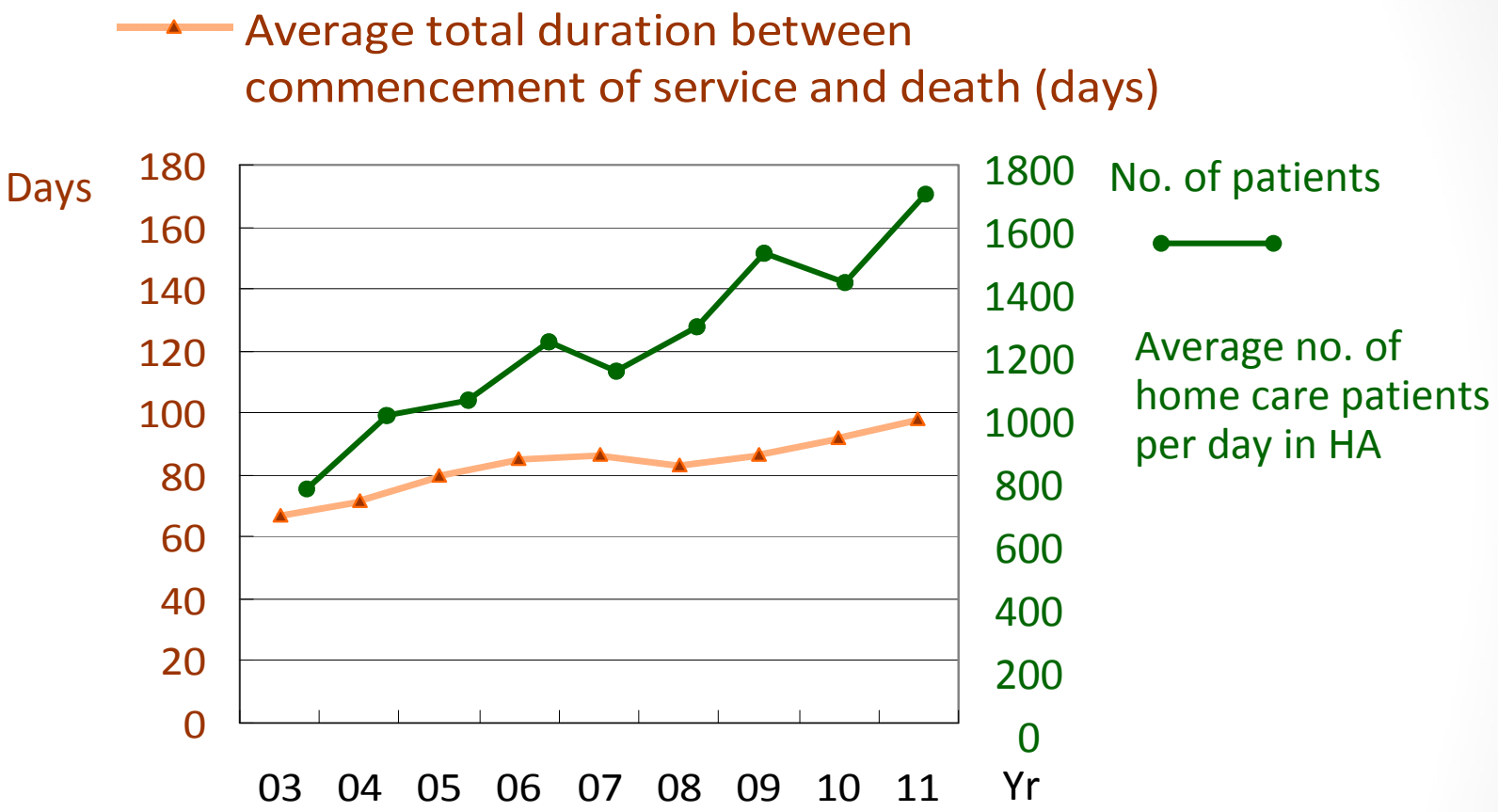
Disease Trajectory & Palliative Care in HA



Palliative care:

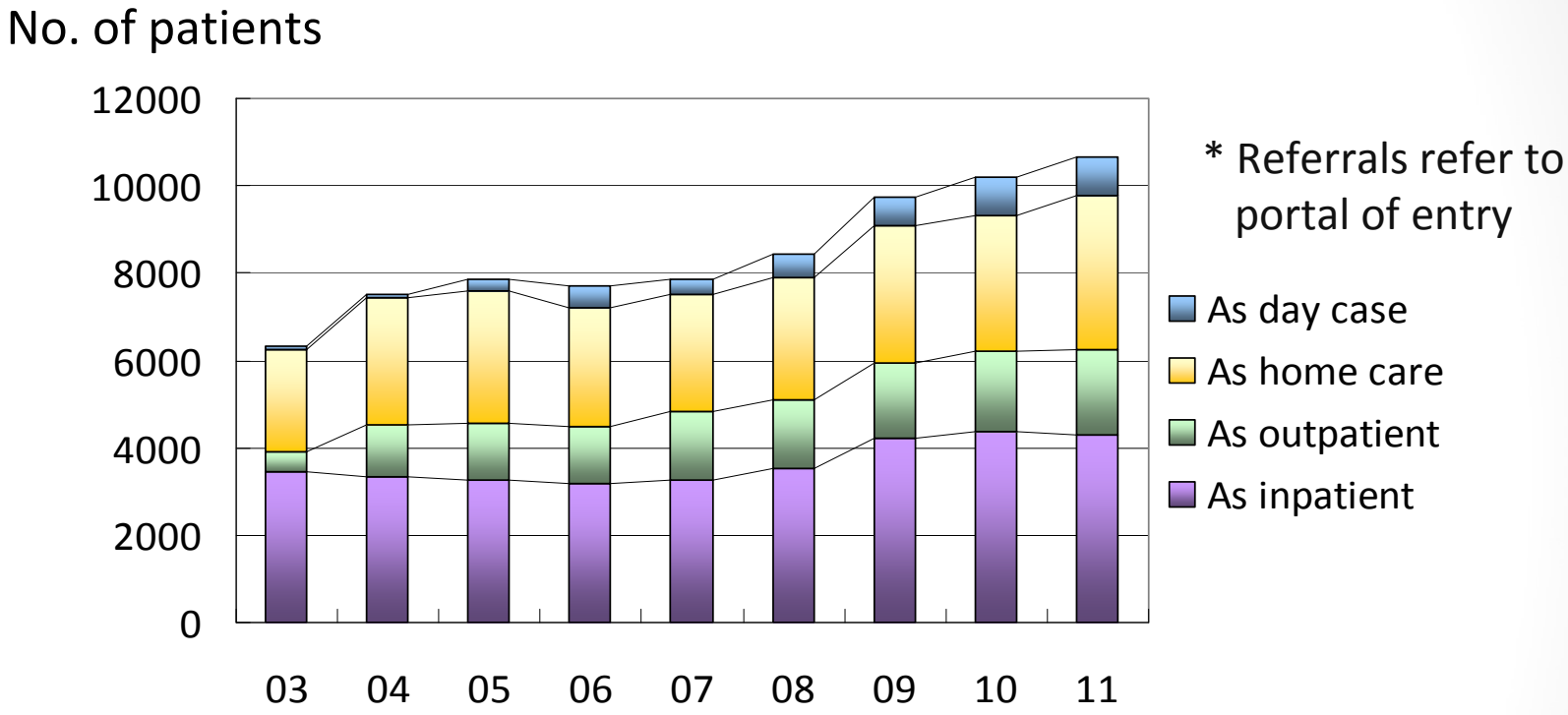
- **Is applicable early in the course of disease (WHO)**
- **Not limited to EOL care**
- **Provides different care modalities along the disease trajectory**
- **Applies to cancer and non-cancer**

Duration of HA PC Cancer Service



- **Earlier referral as palliative care service develops**
- **Late referral often limits service to EOL inpatient care**
- **But it needs time to come to terms with dying**

HA Palliative Care Referrals

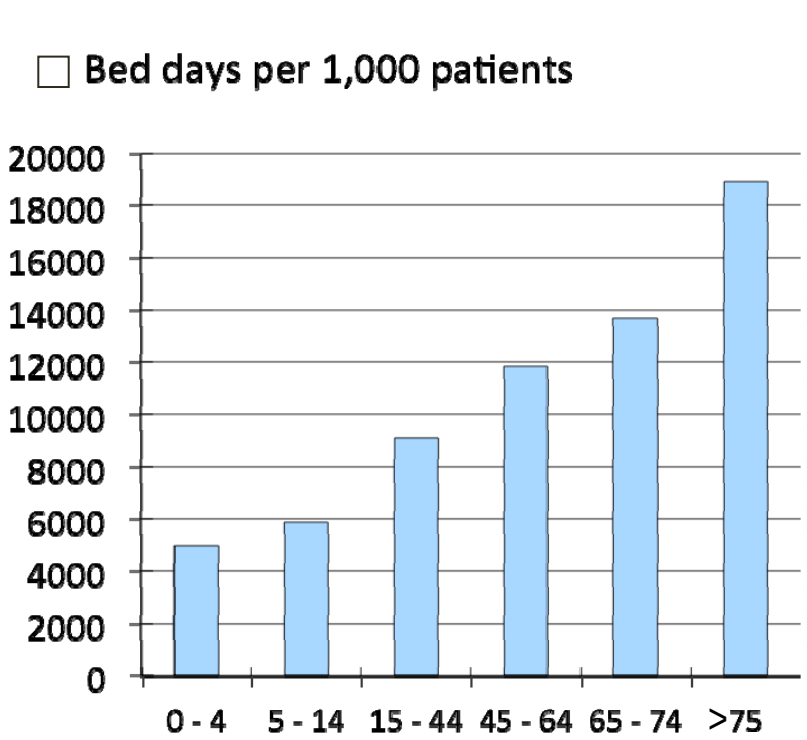


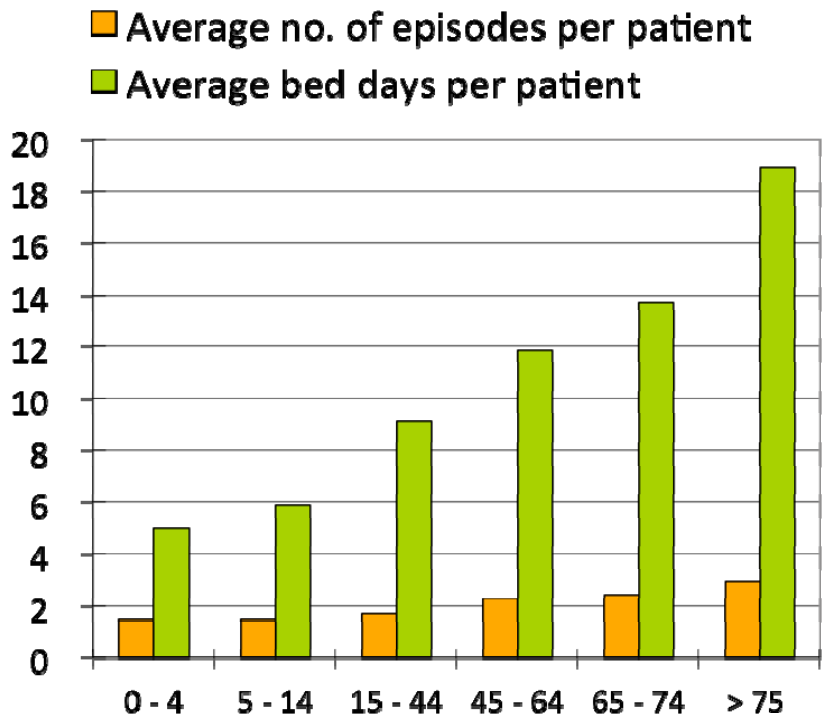
- **Patients eventually receive a combination of services**
- **Increase in actual number of referrals to all modalities**
- **Trend more prominent in ambulatory care**

Palliative Care in Aging Population

Growing older means

- **Higher mortality**
- **More cancers and chronic diseases**
- **More public hospital bed utilization**





Age Group

Source: HA Statistical Report 2009 - 2010

Palliative Care in Aging Population

Growing older and older means

- **More likely to die from chronic disease than cancer**

Coexisting disease of patients who died from cancer and non-cancer in 4 HA hospitals in 08

	Cancer (n=183)	Organ failure (n=656)
Mean age	71.1 (±12.4) yrs	79.1 (± 9.5) yrs
DM	24%	31%
COPD	14%	8%
Stroke	12%	22%
IHD	11%	30%
CHF	8%	13%
CKD	6%	11%
Dementia	5%	14%
Cancer		8%

Comparing Non-cancer and Cancer deaths in HK: A retrospective review.
KS Lau, DMW Tse, TWT Chen, PT Lam, WM Lam, KS Chan. JPSM 2010;40(5):704-714.

4 Home as Place of Care

Palliative Home Care Interventions

- Assessment & monitoring
- Procedures & treatments
- Education
- Information giving
- Coping empowerment
- Liaison

Patient &
Family caregiver with needs
AT HOME

- Symptom burden
- Medications
- Medical equipment / aids
- Bodily care
- Psychosocial & spiritual issues
- Advance care planning
- End-of-life care

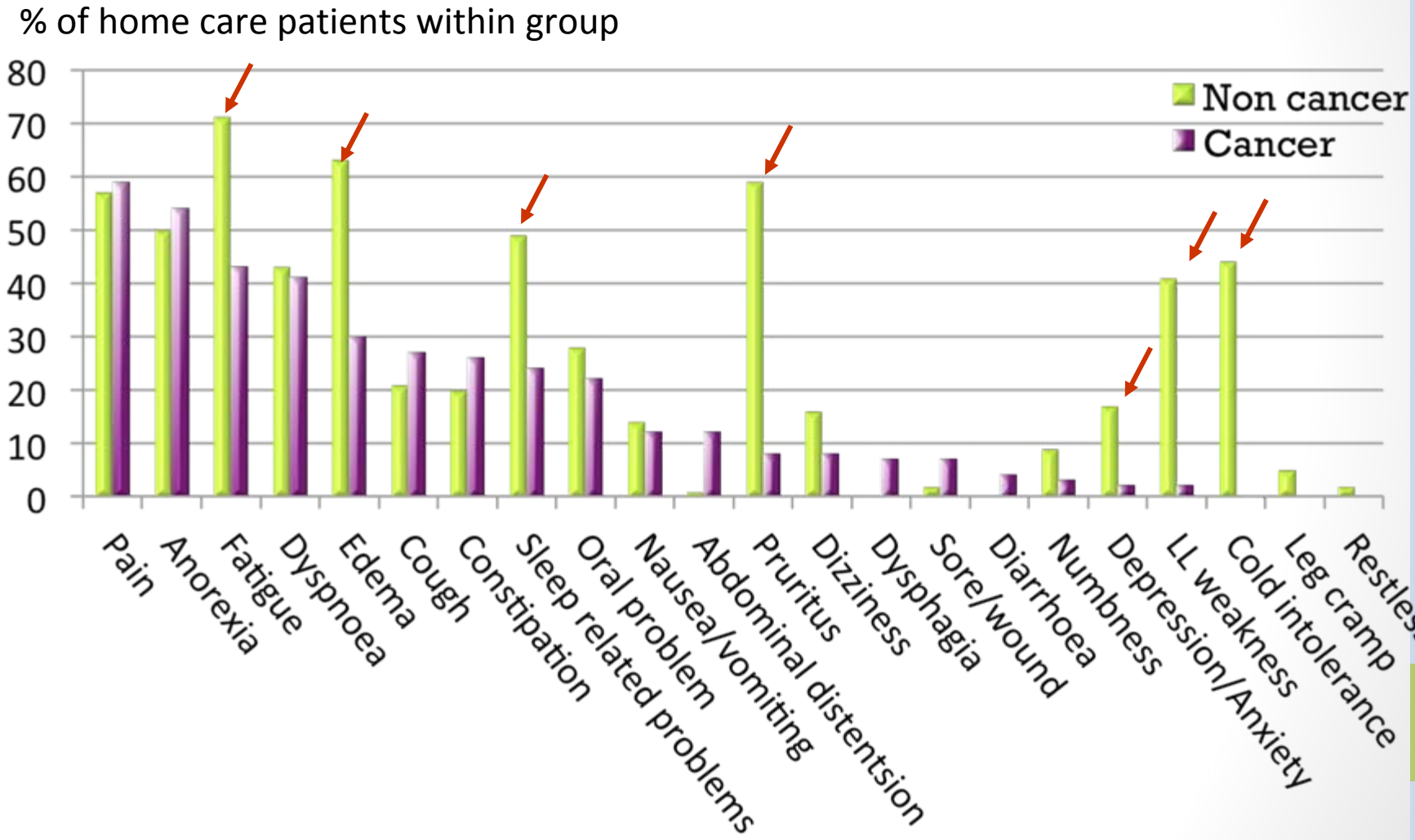
Palliative Home Care Interventions

CMC home care data	166 cancer	90 non-cancer
Average age (range)	72.8 (32-102) yrs	74.0 (43-91) yrs
Duration under home care	120.0 days	176.0 days
No. of home visits / patient	6.5	8.0
No. of drugs checked / visit	7.5	9.6
No. of symptoms present / visit	3.7	5.8

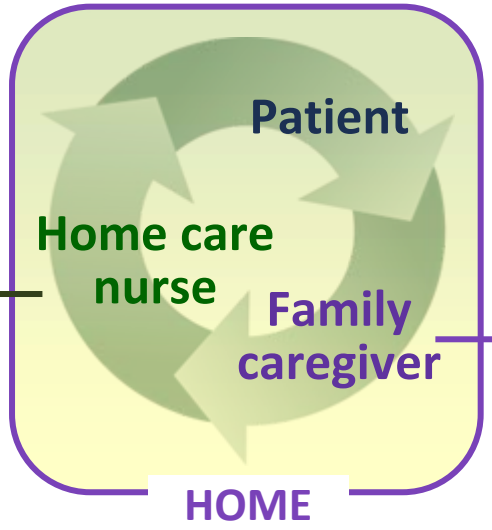
- **Needs of non-cancer palliative care patients at home no less than advanced cancer**

Symptoms evaluated and documented by home care nurse

CMC data: 166 cancer 90 non-cancer



Social Milieu of Palliative Home Care



A professional delivering care

- Solo practice
- Unfamiliar place
- Domestic environment

A natural caregiver?

- But also a care receiver
- Could be a facilitator or a barrier
- Well being related to patient's well being in complex manner

Unique opportunity to:

- **Assess patient in own natural habitat**
- **Assess family dynamics, functioning and coping**
- **Address burden of caregiving on site**
- **Empower and support caregiver to maintain patient's well being**

Social Milieu of Palliative Home Care

There is no place like home...

Stress of Family Caregivers

Difficulties encountered by **family caregivers**

Restricted social life	52.4%
Bonding with care receiver	52.4%
Physical demand of caring	47.6%
Emotional reaction to caring	42.9%
Lack of family support	33.3%
Financial consequences	19.1%
Lack of professional support	4.8%

Loke AY et al. Cancer nursing 2003

Care giving stress may intensify as patient deteriorates further:

- **Functional decline**
- **Increasing anxiety, fear, guilt and spiritual distress in patients**
- **Anticipatory grief as death is approaching**

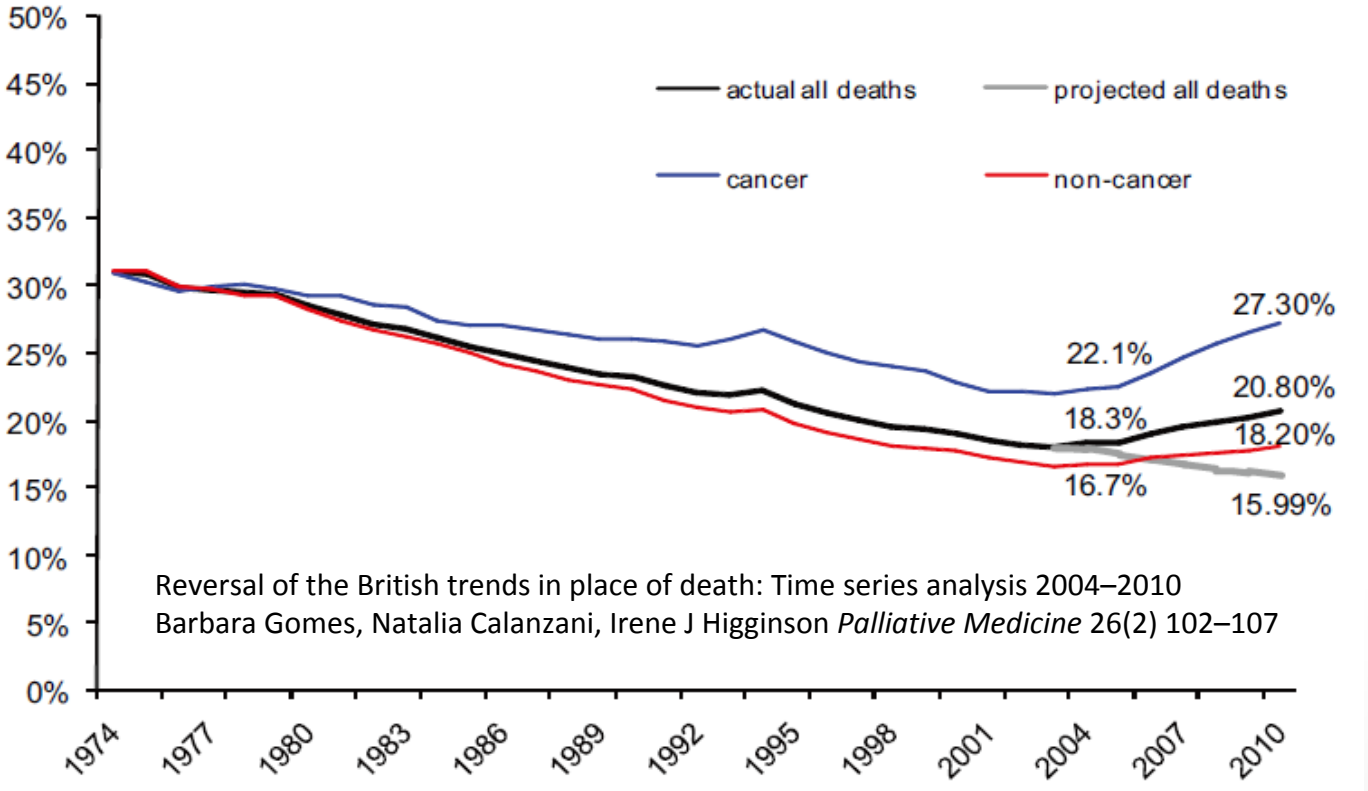
Wong KY et al. Cancer Nursing 2004

5 Home as Place of Death

Moving away from
"Institutionalized death"

Can we reverse the trend of home deaths?

- No. of British home deaths halved from 1974 to 2003
- But increase in home deaths from 18.3% in 2004 to 20.8% in 2010
- Decrease in % of hospitals deaths
- Government EOL Care Programme (established in 2004)
- National EOL Care Strategy (published in 2008)



Reversal of the British trends in place of death: Time series analysis 2004–2010
Barbara Gomes, Natalia Calanzani, Irene J Higginson *Palliative Medicine* 26(2) 102–107

Preference of the general public

What is important for a good death?: 738 HK subjects

	Mean
No physical torture 死前唔駛受病痛長時間折磨	8.78
A painless death 臨死之前能夠盡量減少身體上的痛楚	8.59
Not dependent on others 臨終前生活各方面都唔駛靠人幫	7.93
Reconcile with family 死前能夠同家人或親友和好	7.84
Financial planning for family 知道自己唔駛擔心家人以後生活	7.71
Finish family obligation 死前完成對家庭責任	7.66
Fulfill last wishes 死之前能夠完成埋未了心事	7.38

	Mean
Pre-arrange funeral 能夠生前安排或決定點處理自己身後事	7.04
Psychologically prepared 心理上已預備好自己將會死去	7.01
No regrets 諗番自己一生，會覺得無咩遺憾	6.61
Body kept clean 身體能夠保持整齊清潔	6.39
Body not tampered 死後身體完整	3.63
Extravagant funeral 能夠風光大葬	2.73
Dying at home 能夠係屋企死	2.72

CH Chan, HY Chan, Faye Chan

Preference of local nursing home residents

Cross-sectional survey in 140 HK nursing homes involving 1600 cognitively normal Chinese older adults

- Mean age 82.4 years
- 88.0% preferred to have advance directives
- Around one-third prefer to die in their nursing homes
  - being residents of government subsidized nursing homes as one of the independent predictors

Advance Directive and End-of-Life Care Preferences Among Chinese Nursing Home Residents in Hong Kong. WC Leung et al. J Am Med Dir Assoc 2011; 12:143–152)

Preference of PC Patients: UCH

121 patients under specialized palliative care in UCH

- Mean age 72.6 years
- Three-quarters lived with family; one-third had no daytime carer
- Half were partially or totally dependent in ADL
- 94% were symptomatic

	PPC	PPD
Home	37%	19%
Hospital (PCU)	45% (27%)	66% (40%)
OAH	2%	0%
Undecided	16%	15%

Factors affecting patient's choice	
Medical support	48%
Impact on family	37%
Availability of carer	33%
Time with family	29%
Degree of comfort	27%
Symptom control	25%

Attitudes and expectations of patients with advanced cancer towards community palliative care service in Hong Kong. Hong TC et al. 2010 Hospital Authority Convention, Hong Kong, 10-11

Preference of PC Patients: CMC

64 advanced cancer patients under palliative care in CMC completed questionnaire on PPC and PPD

Woo et al (unpublished data)

PPD \ PPC	Home	OAH	PCU	Non PC	Others	Total PPD
Home	6	1				7
OAH		1				1
PCU	8	1	26	2		37
Non PC	3		1	13		17
Others					2	2
Total PPC	17	3	27	15	2	64

Non PC = Hospital but not PCU

PPC same as PPD

PCU as most PPC (42.2%) and PPD (57.8%)

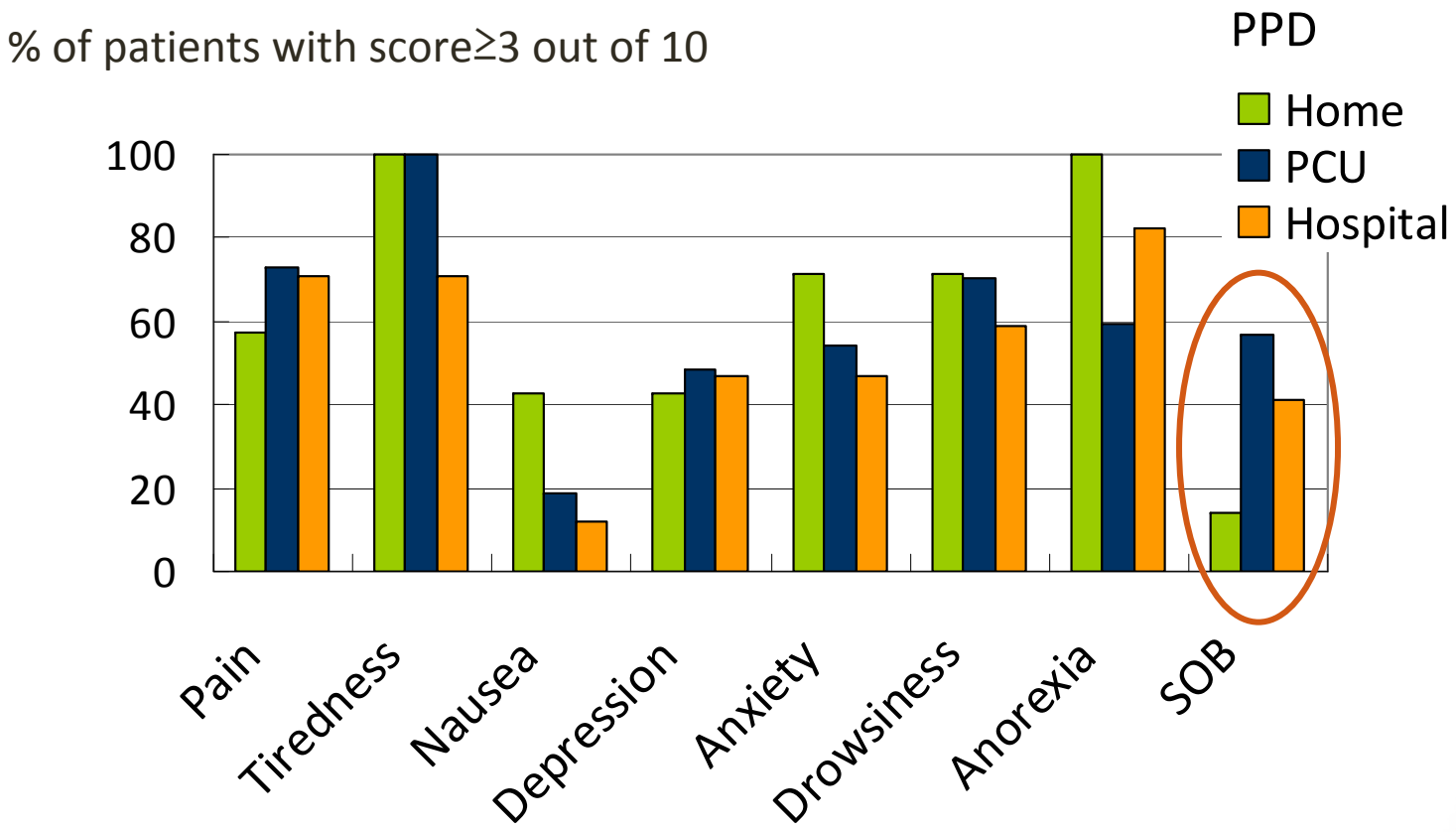
Home as PPC in 26.6% of patients, but as PPD in only 10.9%

Preference of PC Patients: CMC

	Home (n=7)	PCU (n=37)	Non PC (n=17)
Mean age (yrs)	72.3	66.0	74.0
Male %	85.7%	54.1%	66.7%
Day or night time caregiver available	71.4%	73.0%	71.8%
OAH resident	14.3%	5.4%	5.4%
Lived in self owned flat	0.0%	27.0%	41.2%
On long term home oxygen	0.0%	10.8%	17.6%
Palliative performance score (100 = full)	64.3	71.1	71.8

Preference of PC Patients: CMC

PPD & Symptoms (Edmonton Symptom Assessment Scale)



Preference of PC Patients: CMC

To what extent do you agree with the statement regarding your PPD?

	Home (n=7)	PCU (n=37)	Non PC (n=17)
1. It is a comfortable environment.	3.57	4.03	3.71
2. It is a familiar environment with familiar faces.	4.14	3.54	3.00
3. It gives me privacy e.g. bodily care and emotional expressions.	3.86	3.84	3.53
4. I have autonomy in my daily activities or routine.	3.86	3.59	3.29
5. I am being accompanied by family members/people of my choice.	3.86	3.73	3.59
6. The caregivers of this place are confident in caring for me.	4.20	4.14	4.12
7. The caregivers of this place will have time to care for me.	3.14	3.78	3.76
8. The caregivers of this place will have adequate knowledge & skills.	3.14	4.00	3.94

(1 to 5, 5=strongly agree) Home as PPD with score< 3.5 or lowest in the row

Preference of PC Patients: CMC

To what extent do you agree with the statement regarding your PPD?

	Home (n=7)	PCU (n=37)	Non PC (n=17)
9. It will bring positive experience to my family.	3.71	3.95	3.88
10. I have access to appropriate medical advice or care readily.	3.29	4.00	4.00
11. I will be kept comfortable physically.	4.00	4.03	3.53
12. I feel being valued or respected.	4.14	4.03	3.82
13. I have peace in mind.	4.00	4.00	4.06
14. I am not perceived as a burden.	3.43	3.54	3.82
15. It helps in reliving my anxiety about death.	3.15	3.65	3.53
15. My choice is consistent with contemporary social culture.	3.71	3.70	3.76
16. My choice is consistent with my family culture.	3.57	3.70	3.71

? Make it a better place

? Make it more available

Congruence Between Preferred and Actual Place of Death

Christina L.et al. J Pain Symptom Manage 2010;39:591e604

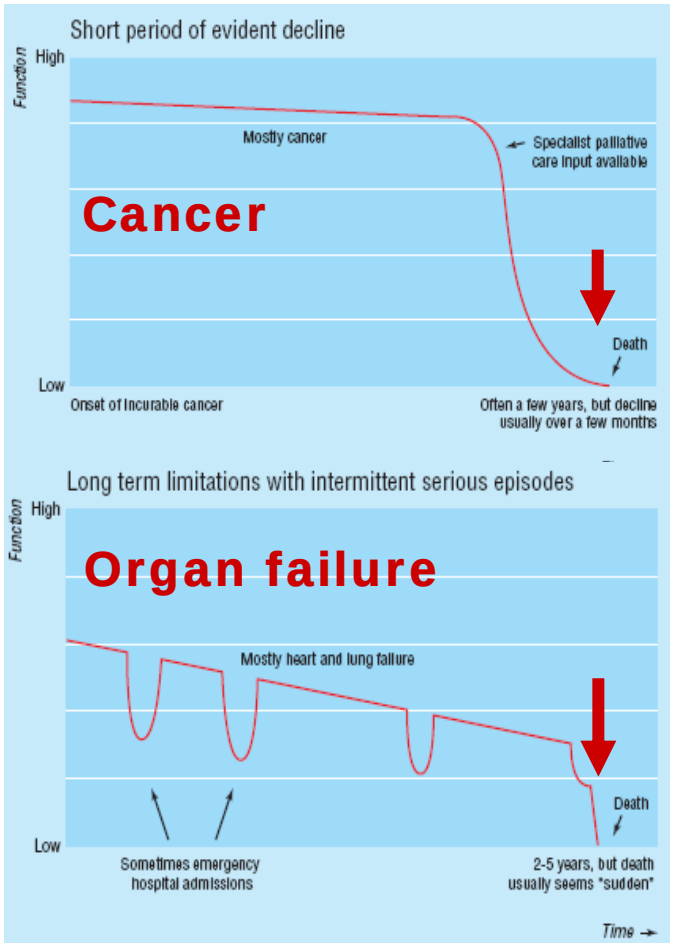
Studies	Congruence
18 studies (overall)	30%-91%
8 (specialized home care)	59%-91%
1 (physician-led home care)	91%
10 (without specialized home care)	30% - 71%

- **PPD: Situational? Personal?**
- **Not a matter of aiming at home death for all**
- **But giving an option to die in their place of choice**
- **A real option means meeting the needs**

6 Preparing for End-of-Life

Diagnosing EOL
Advance Care Planning
EOL Care

Diagnosing EOL: Prognostic Telling



Functional decline in last 1 year of life

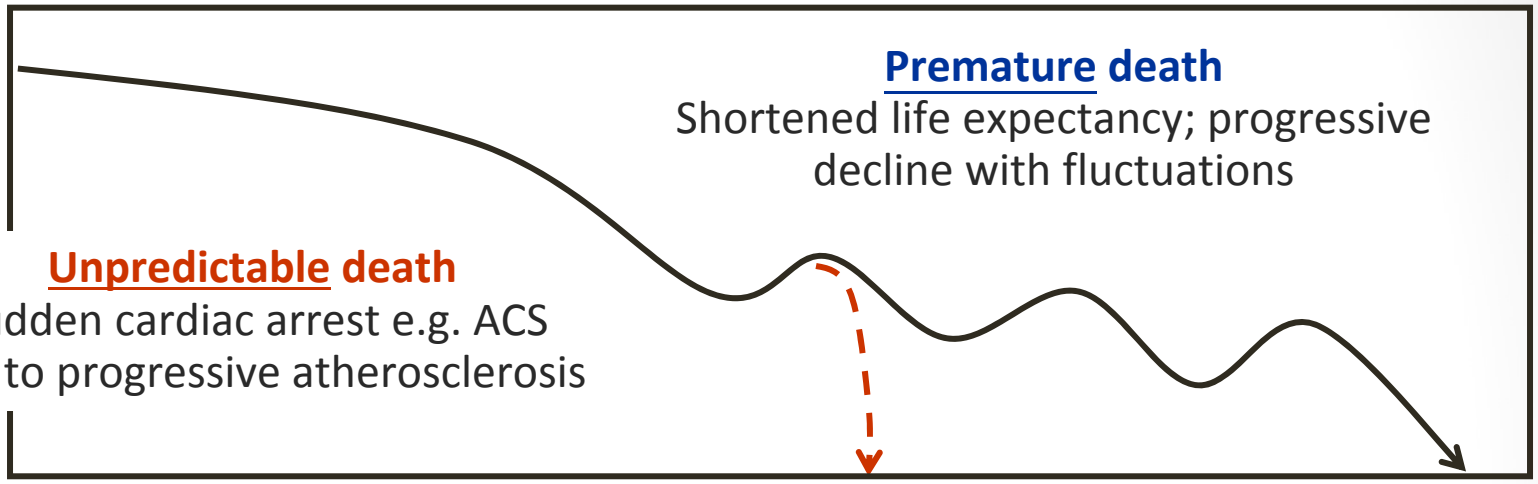
- Begins with relatively good functional status
- Evident decline over a few months before death
- Relatively predictable course

- Deaths of older age than cancer deaths
- Decline process marked by episodic exacerbation
- Prognostic telling more difficult

Lynn et al 2004

- **Unless we can diagnose EOL, one cannot prepare for death**

Prognostic Telling in ESRD



- **ESRD patients face premature deaths despite dialysis**
- **Unpredictable death not uncommon**
- **Less is known about the EOL profile of renal palliative care patients**

CMC data:

- 181 RPC patients (mean age 75.8 yrs) from 2006 to 2011
- 97 patients died after a median FU of 88.5 days (IQ range: 36.3-254.6)
- Survival at 3 months = 73.6%, 6 months = 55.6%, 12 months = 40.0%

EOL Profile of RPC Patients in CMC

Principle cause of death	% (n=97)
Uraemia	64.9%
ACS	12.4%
Pneumonia	7.2%
Septicaemia	3.1%
CHF	3.1%
CVA	3.1%
GI bleeding	2.1%
Others	4.1%

- Deaths occurred before or upon arrival to hospital in 7.2%

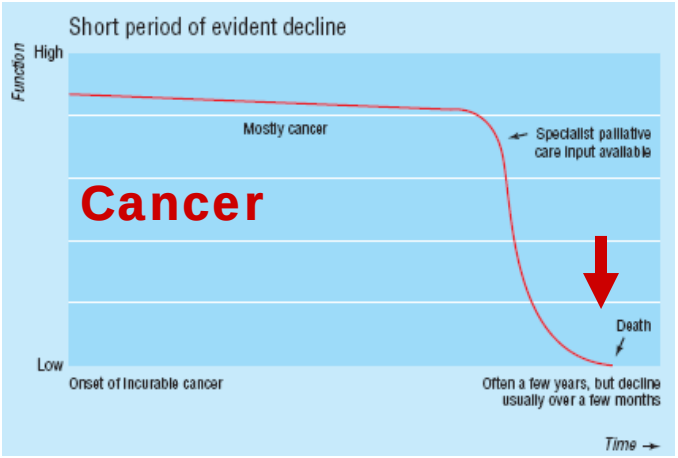
- Median LOS of death episode = 7 days (IQ range: 3-16)

Co-existing acute events	%
CHF	28.9%
Pneumonia	20.6%
Septicaemia / sepsis	19.6%
Hypoglycaemia	14.4%
ACS	12.4%
GI bleeding	11.3%
Hypothermia	11.3%
Arrhythmia	10.3%
Other organ failure	5.2%

Transition to EOL care remains a challenge in organ failure:

- **Rapid decline and short duration of death episode**
- **Some deaths occurred before admission & DNR not yet in order**
- **Dilemma when facing acute conditions: potentially reversible?**

Cancer deaths more predictable…



more manageable needs?

Insights from 108 advanced cancer patients on Multidisciplinary Team EOL Care Pathway

Y Poon et al.

- Adapted from Liverpool EOL Care Pathway
- Include symptom assessment and pre-emptive medication to facilitate symptom control

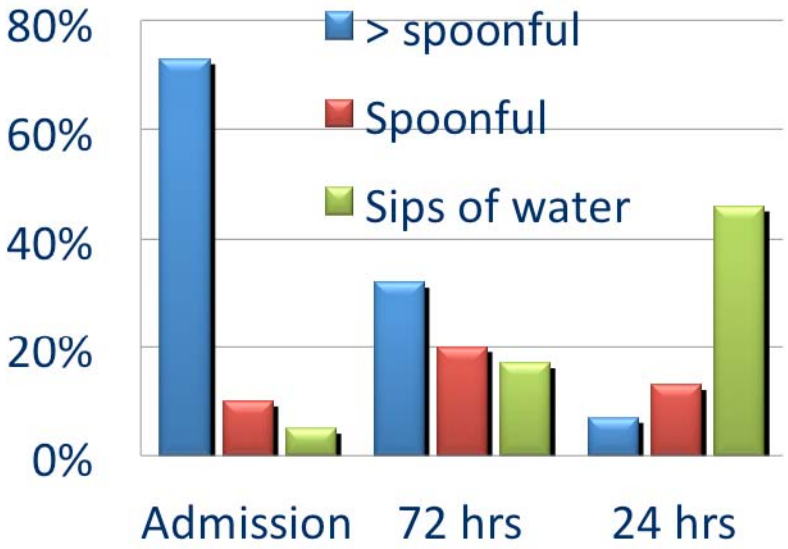
EOL Needs of Advanced Cancer

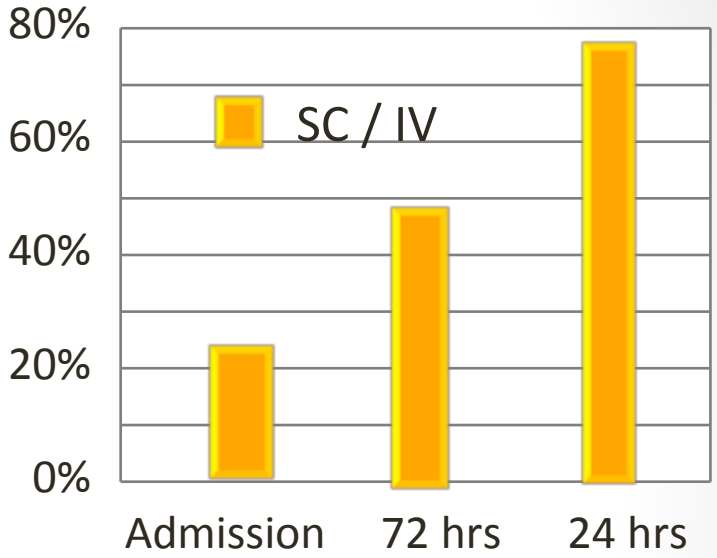
N=108

Symptoms requiring attention	%
Urinary retention/incontinence	87
Dyspnoea	59
Death rattle	37
Fever	26
Pain	24
Delirium	24
Bowel symptoms	23
Dry mouth	17
Cough	9
Nausea and vomiting	5
Bleeding	5
Convulsion	2
Emotional distress	1

Medication needs	Pre-emptive	Used
Oxygen	2%	91%
Analgesics	72%	72%
Buscopan	1%	39%
Antipyretics	25%	31%
Haloperidol	19%	24%
Midazolam	3%	6%
Transamin	3%	4%
Palliative sedation	3%	5%
Anticonvulsant	2%	1%

EOL Needs of Advanced Cancer





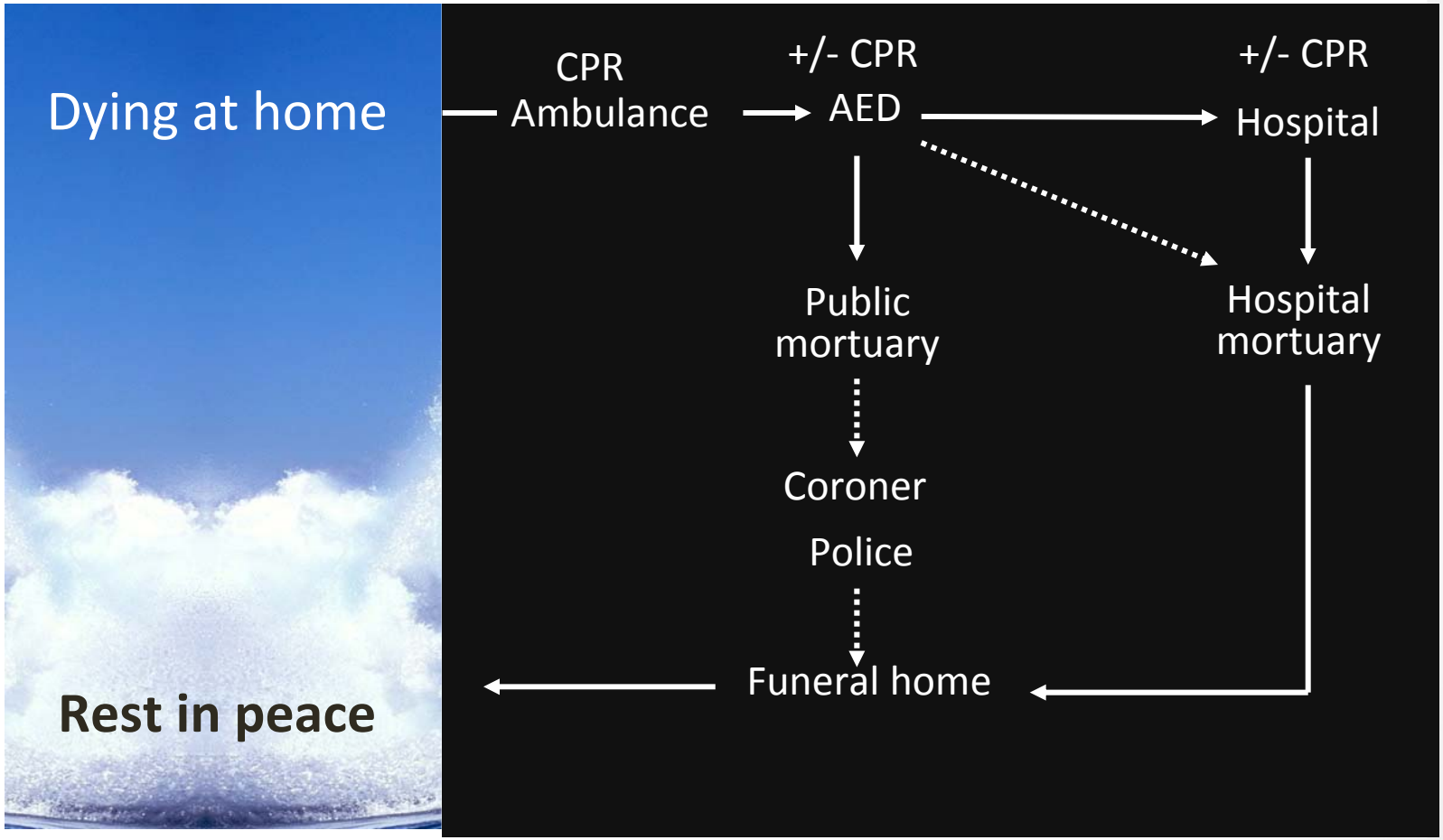
Time before death

- **Rapid decline of oral intake from 72 hours to 24 hours before death**
- **Increase in IV/SC infusion for drug delivery and symptom control**
- **72% of patients died within 3 days after initiation of EOL care pathway i.e. after predicting death by a palliative care professional**

End-of-Life in Place

End-of-Life in Place

End-of-Life in Place



Peaceful Dying at Home

A bridge over troubled water

1. Advance care planning and DNR in place
2. Professional support by home care
    - Intensity
    - Timeliness
    - Medical input
3. No-nuisance system for natural death
4. Policy on EOL care
5. Conducive family and social culture

Dying is not just a medical event limited to hospital ,
But a family, health care and social issue

7

Assumptions

Conclusions

Home as Preferred Place

- Preferred place of care has to be distinguished from preferred place of death
- Actual place of care/death often not congruent with the actual place of care/death
- Preference may change with environmental, individual and illness factors

THE FIRST CHALLENGE: TO KNOW MORE

Home as an option

- Our duty to care for those with a will to stay or die at home
- Gaps in existing Palliative Home Care
  - accessibility after office hours
  - on site medical support
  - intensity and timeliness to support EOL
- Leave a lot to be desired
  - health care policy
  - procedures related to natural death
  - social culture

THE SECOND CHALLENGE: TO DO MORE

Impact of Palliative Home Care

What should we look for:

- Less hospital bed days?
- Less readmissions?
- Lower costs?
- Better QOL?
- More satisfied with health care?

THE THIRD CHALLENGE: TO EVALUATE


No detour
after my death please
Rest in peace