

## The Burden of the Last Journey of Advanced Cancer Patients

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International Symposium on  
Death, Dying & Bereavement  
11 July 2007

Mr. Chan:

A man with head & neck cancer

- Feb 2003 Cancer of the pharynx  
- Removal of pharynx and radiotherapy to pharynx
- Dec 2004 Carcinoma of tongue  
- Removal of nearly all the tongue
- Mar 2006 Recurrence in floor of mouth  
- Removal of floor of mouth, muscle replaced by that of his chest and axilla
- Sep 2006 Further local recurrence  
- Further removal of oral structure
  - Oct 2006 Tumour found in his lung

Mr. Chan:

A man with head & neck cancer



What I found on first encounter:

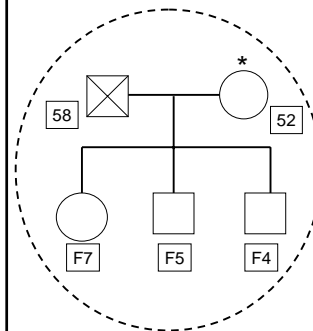
- Very thin, with a hole in his throat
- Withdrawn
- Miserable looking
- In distress because of back pain and breathlessness

Losses as he survives:

- Unable to speak
  - Unable to swallow
    - Unable to sleep through the night
      - Unable to take care of himself

Mr. Chan:

A man with head & neck cancer

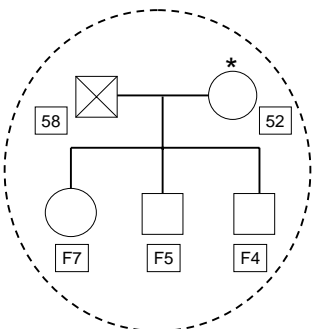


The role of his wife:

- Immigrate from China x 6 yrs
- Received little education
- Main caregiver of patient
- Administration of drugs
- Coordinating follow up visits
- Doing household work
- Stress over finance
- Buy Ling Zhi
- Emotional outlet for patient

Mr. Chan:

A man with head & neck cancer

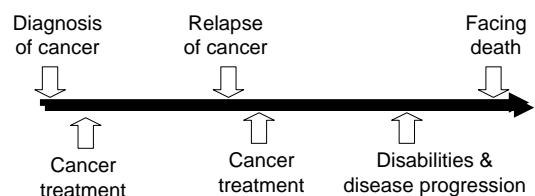


The feelings of his wife:

- Never ending distress: new things keep coming up
- Each time ending up in worse than before
- Seeing him suffers is stressful
- Things getting out of control
- 'Luckily' my husband's condition is getting worse – he is unable to shout or throw temper at me

## Stress & crisis

### Of the cancer journey

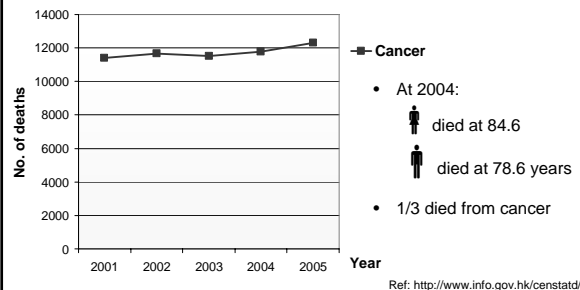


### Cancer as A source of suffering

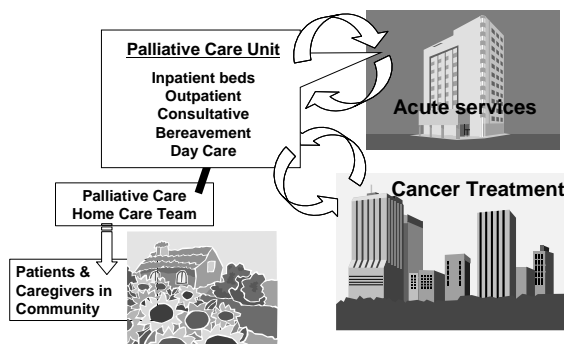
- pain & multiple symptoms
- loss of image
- loss of role & function
- loss of dignity
- uncertainty about future
- regret & guilt about past
- hopelessness
- broken relationships
- loss of connectedness
- loss of meaning



### Cancer as A major cause of death in HK

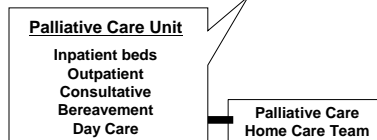


### Palliative Care Service Delivery in Hong Kong



### Palliative Care Service Delivery in Hong Kong

- About 11,000 cancer deaths / year
- Serve >50% of all cancer deaths / year
- Serve small % of non cancer patients
- 38 beds per million general population
- Estimated average of 1.5 admissions to PC wards
- Each admission last 14 days



### Hong Kong: Indicators of Good Death

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

### Palliative Care Performance Inventory: Audit of 279 patients under palliative care in HA

PC Performance Items	Perceived importance (5 = most important)	Patient's satisfaction (5 = most satisfied)
Reduce physical discomfort	4.3	4.1
Adequate rest	4.3	4.1
Concern & support	4.2	4.1
Face everyday peacefully	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 / religious beliefs	3.6	3.9
Respect autonomy & choice	3.5	3.6
Private time	3.9	4.1
Encourage visits by friends/family	4.2	4.1
Comfortable environment	4.3	4.2
Complete unfinished business	3.5	3.2
Participate in social activities	3.4	3.6
Food preference	3.9	3.8

Is Palliative Care making a difference to the dying journey after near 25 years of development?

Local Study:  
Impact of Palliative Care on Cancer deaths in Hong Kong

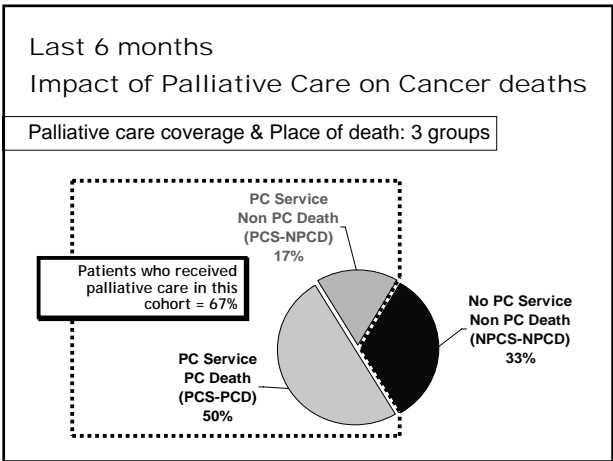
A study of 494 cancer deaths  
Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM Palliative Medicine Jul 2007 (In press)

- 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 Palliative Care on Cancer Deaths in Hong Kong

Last 6 months →

Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM. Palliative Medicine Jul 2007



Last 6 months  
Impact of Palliative Care on Cancer deaths

Admissions to non PC wards in last 6 months:  
PCS-PCD < PCS-NPCD & NPCS-NPCD

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

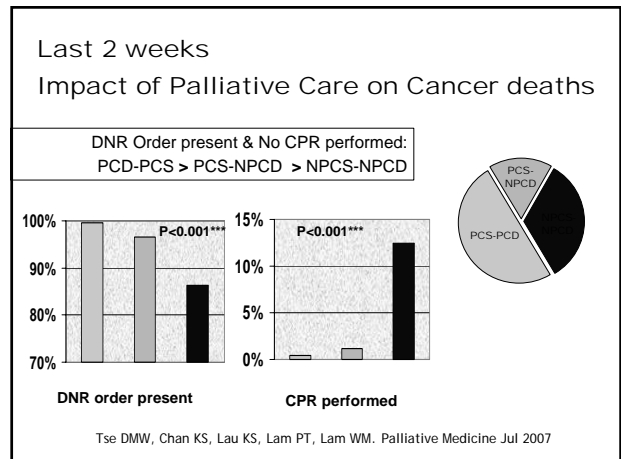
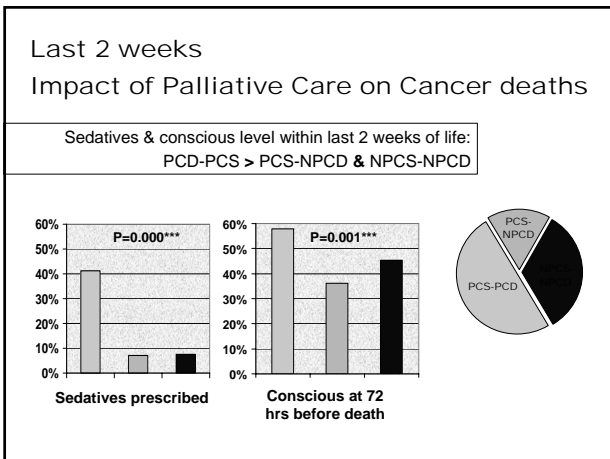
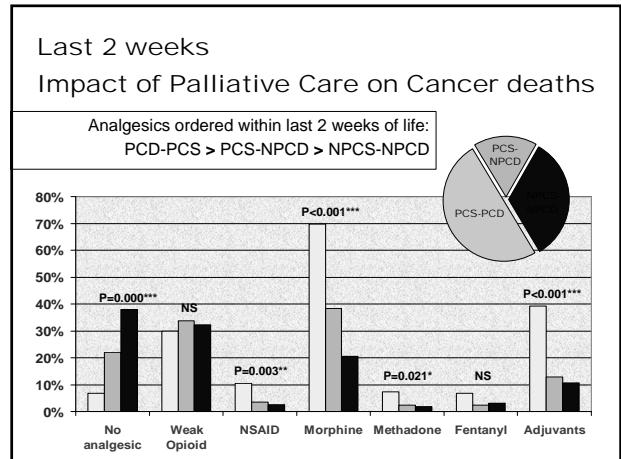
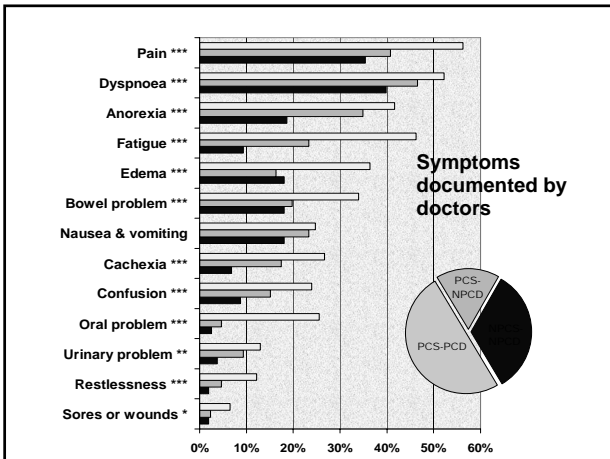
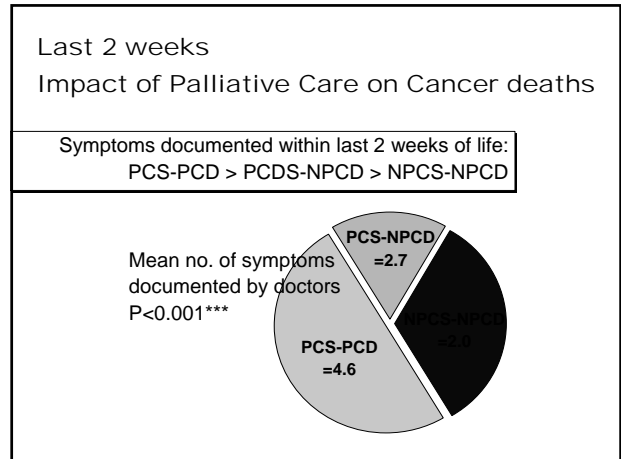
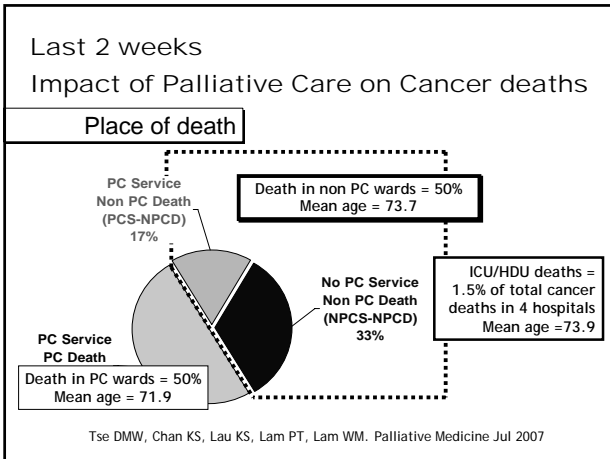
Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM. Palliative Medicine Jul 2007

Impact of Palliative Care on Cancer Deaths in Hong Kong

Last 2 weeks →

Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM. Palliative Medicine Jul 2007

# ENABLE International Symposium on Death, Dying and Bereavement 2007



## Last 2 weeks Impact of Palliative Care on Cancer deaths

### 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 in HK:

1. HA Guidelines on withholding or withdrawing life sustaining treatment
2. DNR form & its promulgation in HA

## Age Factor Comparing age <70 (32%) & age > 70 (68%)

### Last 6 months

	Age < 70	Age ≥ 70	P value
M : F	1 : 2.6	1:1.6	.013*
Mean no. of co-morbidity (SD)		More	.000***
Utilization of PC service			NS
Utilization of ICU/HDUNS			NS
Surgery	24.5%	20.6%	NS
Chemotherapy	36.8%	3.3%	0.000
Radiotherapy	20.0%	1.2%	0.009

Tse DMW, Chan KS, Lau KS, Lam PT, Lam WM. Palliative Medicine Jul 2007

## Age Factor Comparing age <70 (32%) & age > 70 (68%)

### Last 2 weeks

	Age <70	Age ≥ 70	p value
Mean no. of interventions initiated (SD)	2.49 (1.47)	2.71 (1.93)	.007*
Pain	57.1%	42.3%	.002**
Mean no. of symptoms	3.81 (2.86)	3.28 (2.41)	.013*
No analgesic	14.9%	21.9%	0.07
Morphine	59.1%	43.5%	.001**
Adjuvant analgesics	31.2%	22.8%	.048*
DNR documented	95.5%	94.7%	NS
CPR performed	4.5%	4.7%	NS

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## Message (1) Transforming PC values to changes

### Cancer patients who received palliative care were

- less admissions and stay in non PC wards / ICU
- less invasive interventions initiated in last 2 weeks
- more symptoms documented by doctors and nurses
- 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

## Message (2) Meeting the challenge of aging population

### Meeting the challenges of an aging population

- Elderly as the vulnerable added to the dying as vulnerable
- The need to know more about the preferences of the elderly
- The need to know more about pain control in elderly
- Differentiating equal practice from equity

## Message (3) Treatment burden in last 6 months

### During last 6 months, each cancer patient

- Attend OPD 5 times
- Attend A&E 3 times
- Admitted into hospital 3 times
- Stayed in hospital for 30 days
- And one in 5 had surgery done,
- While one in 7 had chemotherapy or radiotherapy

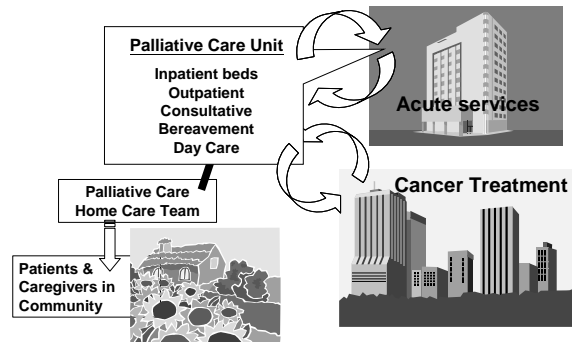
Message (4)

The luxury of staying at home

Dying in a strange place:

- In these 4 hospitals, no cancer deaths occurred at home in 2005
- These patients stayed in hospital for average of 18 days before they died
- BUT, If you only have 2 weeks to live, Where would you like to stay?
- From 1999 to 2003, of 1300 patients under care, only 6 died at home Liu FCF & Lam CCW (2005)

Palliative Care Service Delivery in Hong Kong



Palliative Care, Patients, Caregivers, Community

Stress of Caring for cancer patients at home

3-Dimensional approach in categorisation:

1. Direct care to patient (extrapersonal)
2. Intrapersonal tasks
3. Interpersonal ties

Neuman B 1989  
Clark & Rakowski 1983

Stress of Caring for cancer patients at home

1. Direct care (Extrapersonal)

- Administration of drugs, observation of side effects,...
- Wound care and dressings
- Toileting
- Bathing
- Dressing
- Laundry
- Preparing food
- Seeking alternative medicine
- Assistance with mobility
- Emotional support to patient



Stress of Caring for cancer patients at home

2. Intrapersonal tasks

- Dealing and coping with own emotions
- Resolving uncertainty
- Struggling with acceptance of illness
- Compensating for personal time

3. Interpersonal ties

- Interaction with medical professionals
- Meeting needs of other family members
- Interaction with other relatives
- Managing finance and other social tasks

## Local Study :

### The stress of care giving

*The difficulties faced by informal caregivers of patients with terminal cancer in Hong Kong and the available social support*

Alice Yuen Loke, Faith Liu, Yan Szeto. *Cancer Nursing* 2003;26(4):276-283.

- Exploratory study on 21 informal caregivers (M:F= 1:2.5)
- 20/21 perceived difficulties in caring
- 4 major difficulties reported:
  1. Relationship with the patient 11/21
  2. Emotional reactions to caring 9/21
  3. Physical demands in care giving 10/21
  4. Restriction in social life 16/21

## Local Study :

### The stress of care giving

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- Reasons for care giving among the sample
  1. Duty to care 16/21
  2. Love & affection 12/21
  3. No alternative 6/21
  4. Family expectation 4/21
  5. Piety 1/21

## Local Study :

### The stress of care giving

*Stress associated with tasks for family caregivers of patients with cancer in Hong Kong* C Chan & A Chang. *Cancer Nursing* 1999;22(4):260-5.

- Cross sectional survey on 26 informal caregivers (M:F= 1:5.5)
- Caregivers experienced significantly more psychological distress 0.36 (SD=0.22) than physical distress 0.24 (SD=0.22)
- 3 most common stress items, all psychological:
  1. Feel tired most of the time (62%)
  2. Often get worried about things (59%)
  3. Easily upset or irritated (55%)

## Local Study :

### The stress of care giving

*Stress associated with tasks for family caregivers of patients with cancer in Hong Kong* C Chan & A Chang. *Cancer Nursing* 1999;22(4):260-5.

- Caregiver's education level inversely related to:
  - psychological symptoms ( $r=-0.41$ ,  $p<0.05$ ) and
  - total stress symptoms ( $r=-0.47$ ,  $p<0.05$ )
- Caregiver's perception of difficulty in performing tasks was positively related to:
  - Total stress symptoms ( $p<0.001$ )

## Home Care Team:

### Supporting patients & families (1)

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 caregivers 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%	Wounds / drains	23%
Edema & lymphedema	59%	Devices	13%
Oral problems	52%	Ryle's tube	5%
Constipation	42%	Foley	4%
Dyspnoea	32%	Ostomy	3%
Nausea & vomiting	28%		

Palliative Care Home Care Team

Patients & Caregivers in Community



## Home Care Team:

### Supporting patients & families (2)

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%

Palliative Care Home Care Team

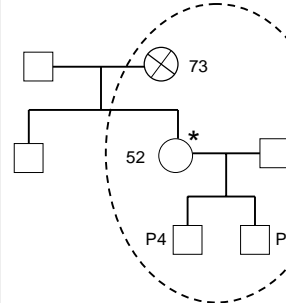
Patients & Caregivers in Community



Mdm Ho:  
A 73-yr-old lady with lung cancer

- Before 1999: Diabetes mellitus, hypertension, heart disease, stroke
  - On regular follow up and multiple medications
- 1999: Road traffic accident
  - Surgery to left knee, resulting in restricted mobility
- 2006: Diagnosed to have lung cancer
  - Surgery not feasible
  - Radiotherapy not feasible
  - Chemotherapy too toxic
  - Decided to try the expensive chemotherapy agents 3 monthly

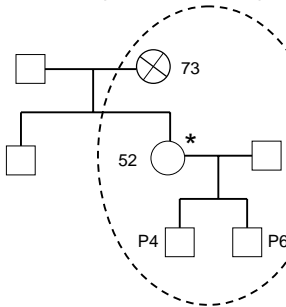
Mdm Ho:  
A 73-yr-old lady with lung cancer



The role of her daughter:

- Received little education
- Main caregiver of patient
- Administration of drugs
- Arrange transport van
- Coordinating follow up visits
- Doing household work
- Support self finance drugs

Mdm Ho:  
A 73-yr-old lady with lung cancer



The feelings of her daughter:

- A natural caregiver as she is not working
- Family members support her if needed
- Care work much appreciated by mother
- Willing to buy the drugs as long as mother benefits from it
- Things under control

Family:  
The duty to care?

Traditionally:

- Cultural & moral:
  - filial piety
  - family interest above own interest
- Kinship: residence of ties
  - obligations of eldest son
  - assigning to daughter in law
  - female as “natural” caregivers e.g. daughters

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

Family  
In the contemporary society

- Birth rate • 223rd of 223 countries i.e. lowest (2004)
- Life expectancy • 4th of 223 countries i.e. highest (2004)
- Kinship • Around 20% of people of age >60 have no kinship network (1990's)
  - Further 17% had only one other member in the household

*Provision of Nursing Care for HK Families: Future Implication*  
Eleanor Holroyd. The Hong Kong Nursing Journal 1993;62(6):23-26

Family  
In the contemporary society

- Workforce • Rising labour force from women: 42% in 1961 to 60% in 1990
  - Traditional “full time breadwinner + full time housewife” constitute < 50% of all families, & < 20% of families with dependent children
- Social expectation • Caregiver also expected to be self sufficient, independent and to contribute to society
- Autonomy & value • Personal goal in conflict with interest of family
  - Intrusion into time, space, life style



Last but not least ...

Last journey  
Burden of patient & family

- Attend OPD 5 times
- Attend A&E 3 times
- Admitted into hospital 3 times
- Stayed in hospital for 30 days
- And one in 5 had surgery done,
- While one in 7 had chemotherapy or radiotherapy

Last journey  
Burden of patient &

Transformation after  
a period of slowing down...

Palliative Care  
Making a Difference

If you are convinced that Palliative Care  
can make a difference to the dying journey.

Support its development so that  
Palliative Care can continue to make a difference

*"Unless a wheat grain falls onto the ground and it dies,  
it remains only a grain,*

*but if it dies,  
it yields a rich harvest.."*

St. John 12:23-28