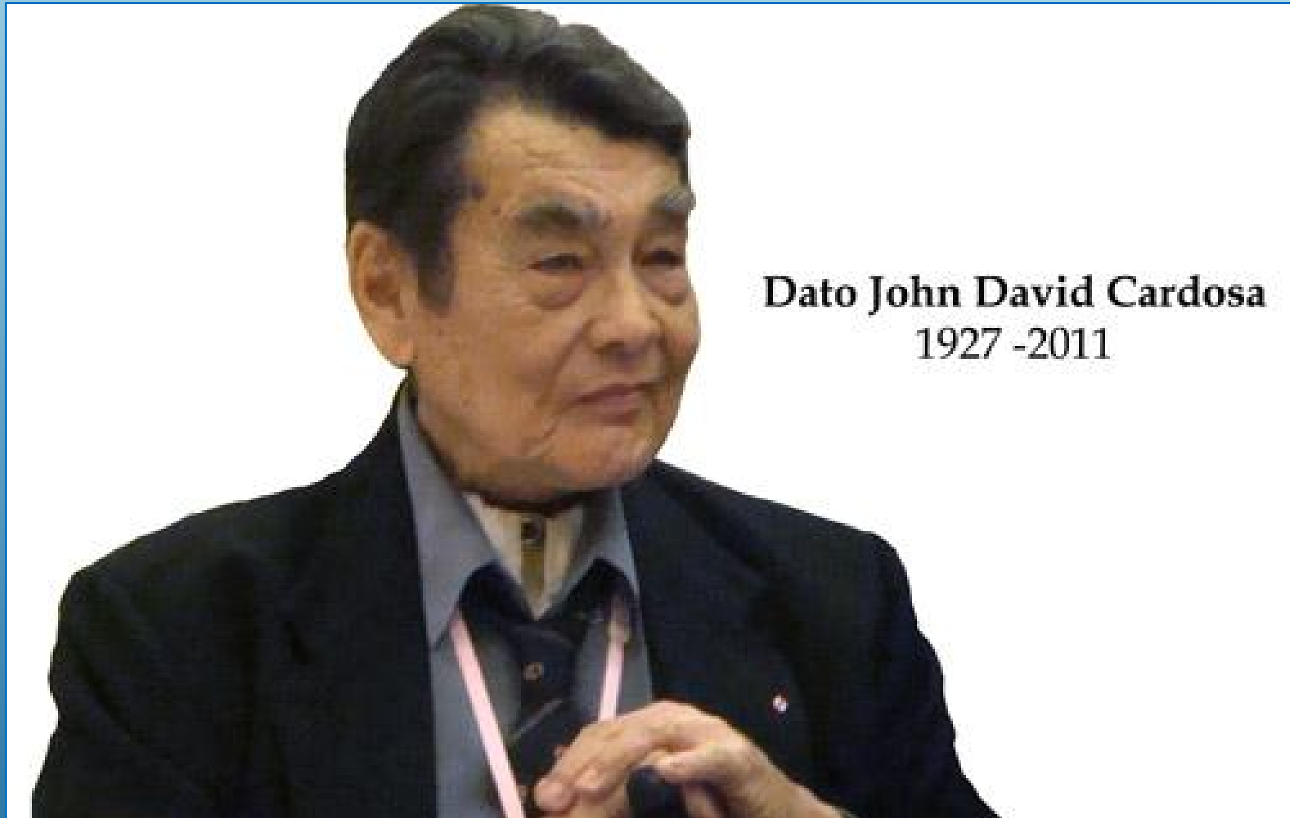
PALLIATIVE AND HOSPICE CARE – PAST, PRESENT AND FUTURE

DATO’SERI DR T DEVARAJ

A MORAL IMPERATIVE



* Public meeting

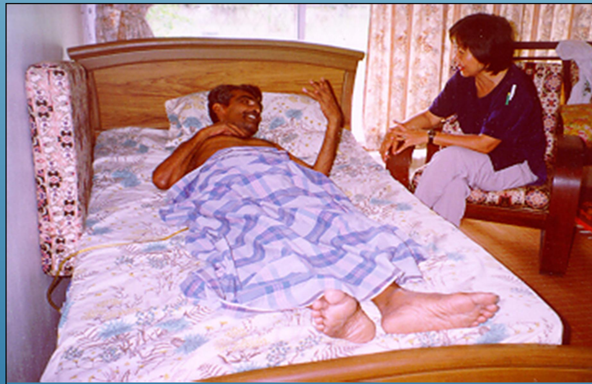
* Recruitment volunteers

* Training – mentors local / Singapore

* YWCA, HPP

Ms Rita M

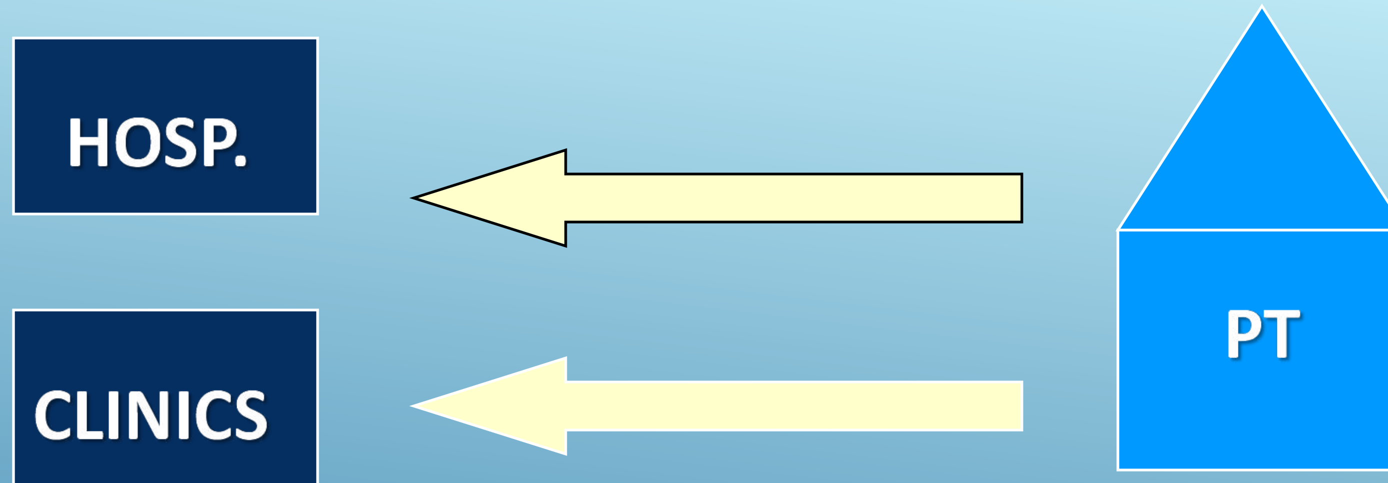
Sister Geraldine Tan



Mrs Cheng Bolton

Puan Mariana Merican

HEALTH CARE DELIVERY MODEL



TAKING CARE TO THE HOME

ADDRESSING PROBLEMS

- ✓ **PHYSICAL - pain, breathlessness, other symptoms**
- ✓ **PSYCHOLOGICAL - anxiety, fear, anger, depression**
- ✓ **SPIRITUAL - why?, punishment, forsaken**
- ✓ **SOCIAL - changing roles, who will care, $**

AND

supporting patient and family

- ✓ **better care**
- ✓ **coping**

Penang Hospice Society

WAVES AND RIPPLES

First National P C Conference 1993

Palliative Care in Kota Kinabalu 1993 / PCU 1995

NCSM / NCSMPB - Launching grants / TNG / donations

MMA Branches

Malaysian Hospice Council 1995 / registered 1998

Ministry of Health

Rumah Hospis Pulau Pinang 2001 – 2009

"You can start tomorrow"

Dr Mary
1932-2020 Barnes

Tan Sri Abu Bakar Sulaiman

Datuk Dr Ranjit Matthew Oomen
1947-2019

PATIENT AND FAMILY

Perception - need such a service

Health professionals

- **humbling**
- **learning curve / better professionals ?**
- **better persons ?**

" A Physician is obligated to consider more than the diseased organ, more even than the whole man – he must view the man in his world.

Harvey Cushing (1869 -1939)

A NEW EXPERIENCE

LESSONS FROM HHP

PT/FLY welcomed medical care at home

- can be empowered / family bonding
- choices – site of care, where to die
- our cultures not averse to death
- family costs lower

Good communication vital

Good care reduces suffering , better QOL, survival benefit

“It is in the shelter of each other that people live” – Irish proverb

“The secret about the care of a patient is the caring of the patient”

Pedsody F W. Jama 1927; 88: 877-82

CLINICAL ACUMEN IN HOME CARE

- Lack of information
- Uncertainties – PT and Family

  Professional carers

  - do tests

  - often working alone

FINAL MILESTONE – FEARS, BELIEFS

FEARS – more manner dying, than dying

suffering – much ? protracted ?

being alone

what happens after death ?

BELIEFS – return to God

will be with loved ones

"neither the sun nor death can be looked at closely"

La Rochefoucold 1613-1680

LIFE AND DEATH TODAY A PARADOX

- life easier, living longer, not in perfect health all the time
- increasing medical knowledge / technology leads to
- push (do everything) and pull (go on trying) leads to over medicalization, postponing death
- dying becoming harder for patient, family
- professional carers – difficult decisions
- acceptance helps

DEATH AND THE LIVING

- Carers may need support
- Reminder of our mortality
- Personal fears about dying and death
- Opportunity evaluation own life

  - what matters in life

MYSTERY OF LIFE 1

"..a time to be born and a time to die.."

Ecclesiastes 2: 1-8

"It is He who giveth life and who taketh it

And to Him shall all ye be brought back"

Surah Yunus: 56

"..no room for the cornfields……..

Navajo Indians

" a person does not die but has "shonile" or gone down like the sun

passing from an earthly life to another state to join ancient spirits"

Zulu culture

"to the one that is born, death is certain and certain is the birth for one who has died. Therefore for what is unavoidable thou should not grieve".

Bhagavad Gita Chapter 11, verse 27

MYSTERY OF LIFE 2

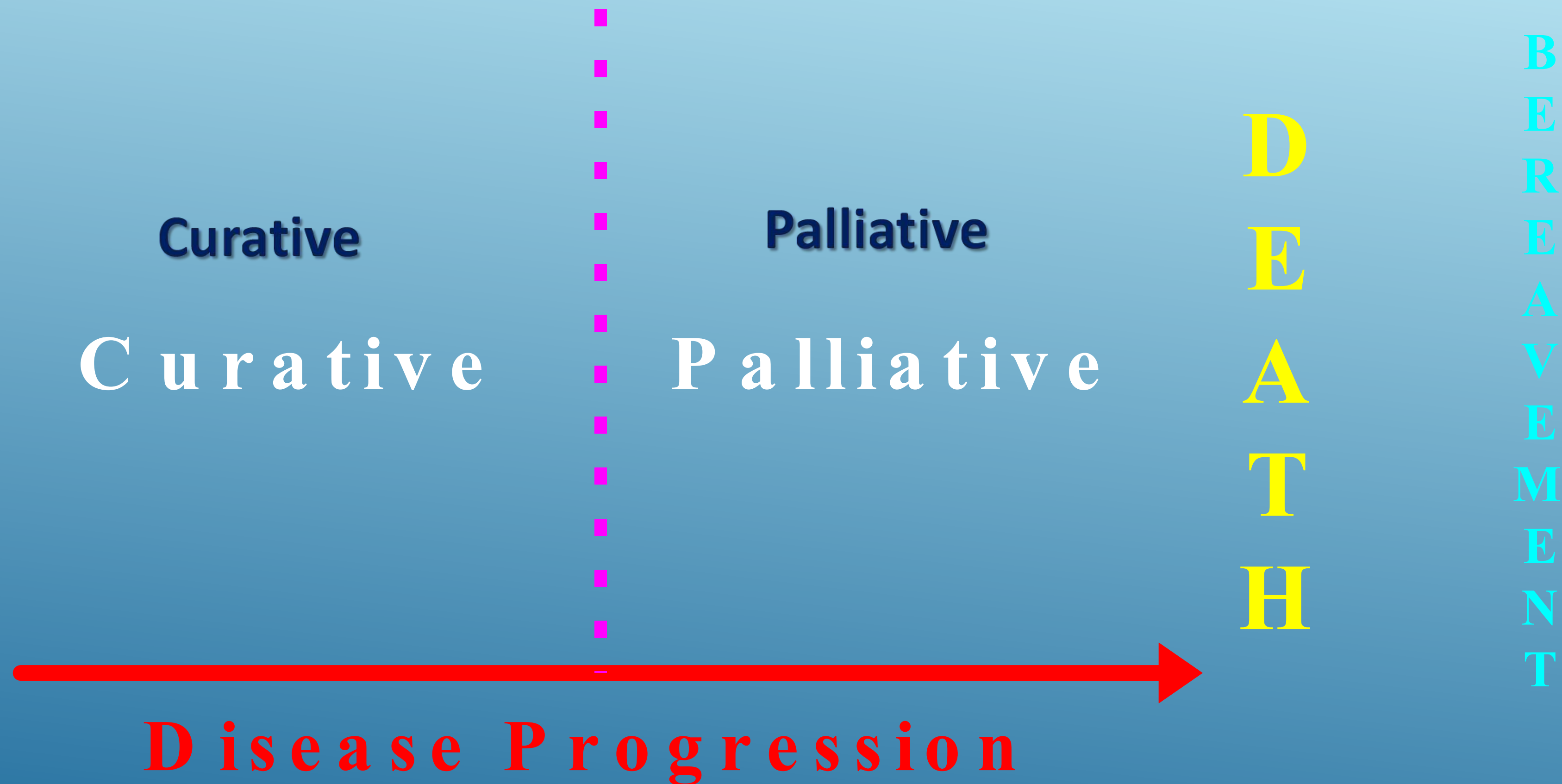
LIFE IS UNCERTAIN

DEATH IS CERTAIN

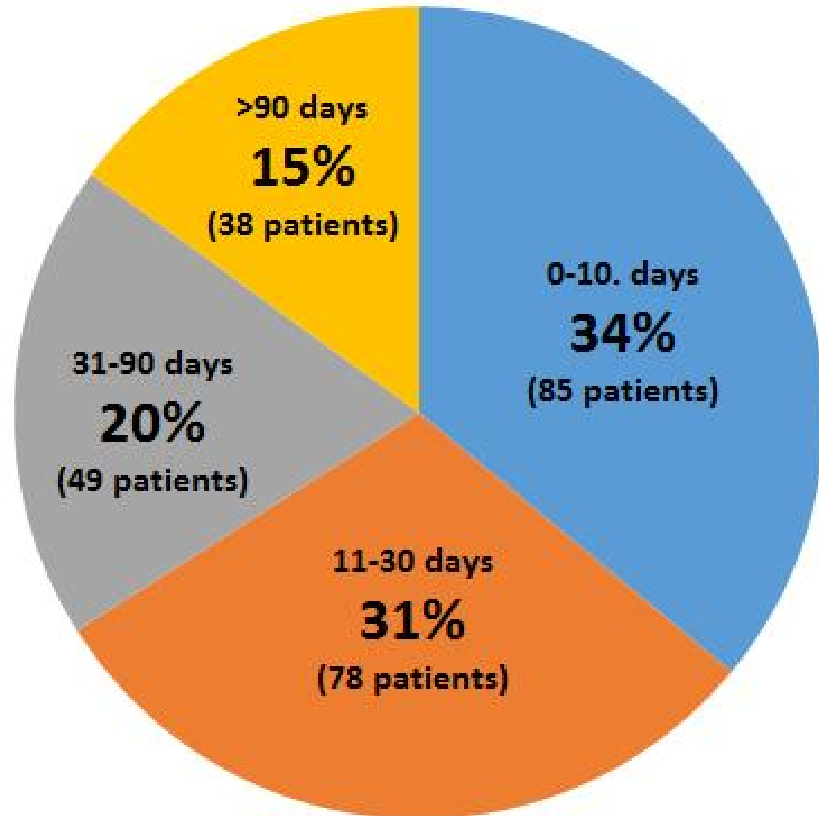
PERCEPTION LIFE : purpose, meaning

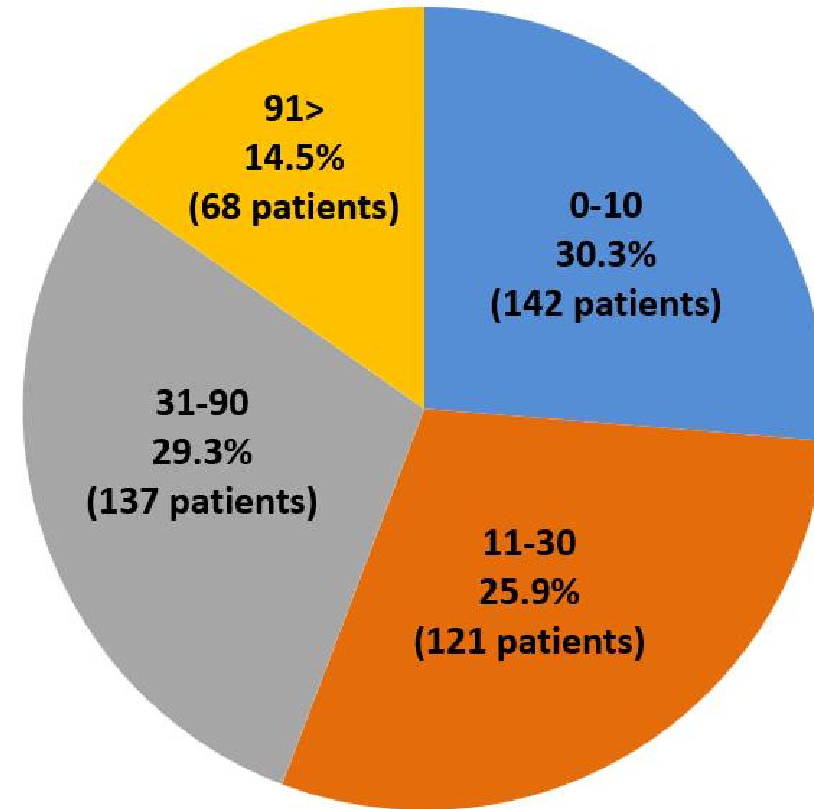
PERCEPTION DEATH : returning to God
be with loved ones
better place

REALITY OF REFERALS - Cure - Care Model



WHY SUCH CARE NOT GIVEN BEFORE ?





HOSPCE CARE OUTCOMES
HOSPICE CARE REDUCES COSTS OF DYING, IMPROVES PATIENT CARE

ALSO

hospital admissions and readmissions

length of hospital stays

use of ICU's

Less inappropriate diagnostics, interventions associated with improved PT/Caregiver satisfaction

Better symptom control

Choice of where to die

From Executive Summary

Cost – Effectiveness of PC: a review of the literature

Canadian Hospice Palliative Care Association, 2012

DELIVERING WHOLE PERSON CARE AT HOME - IDEAL

Family

Primary healthcare team
- Medical doctor
- Home care nurse
- others

Friends

Patient at home

Physiotherapist

Occupational therapists

Social workers

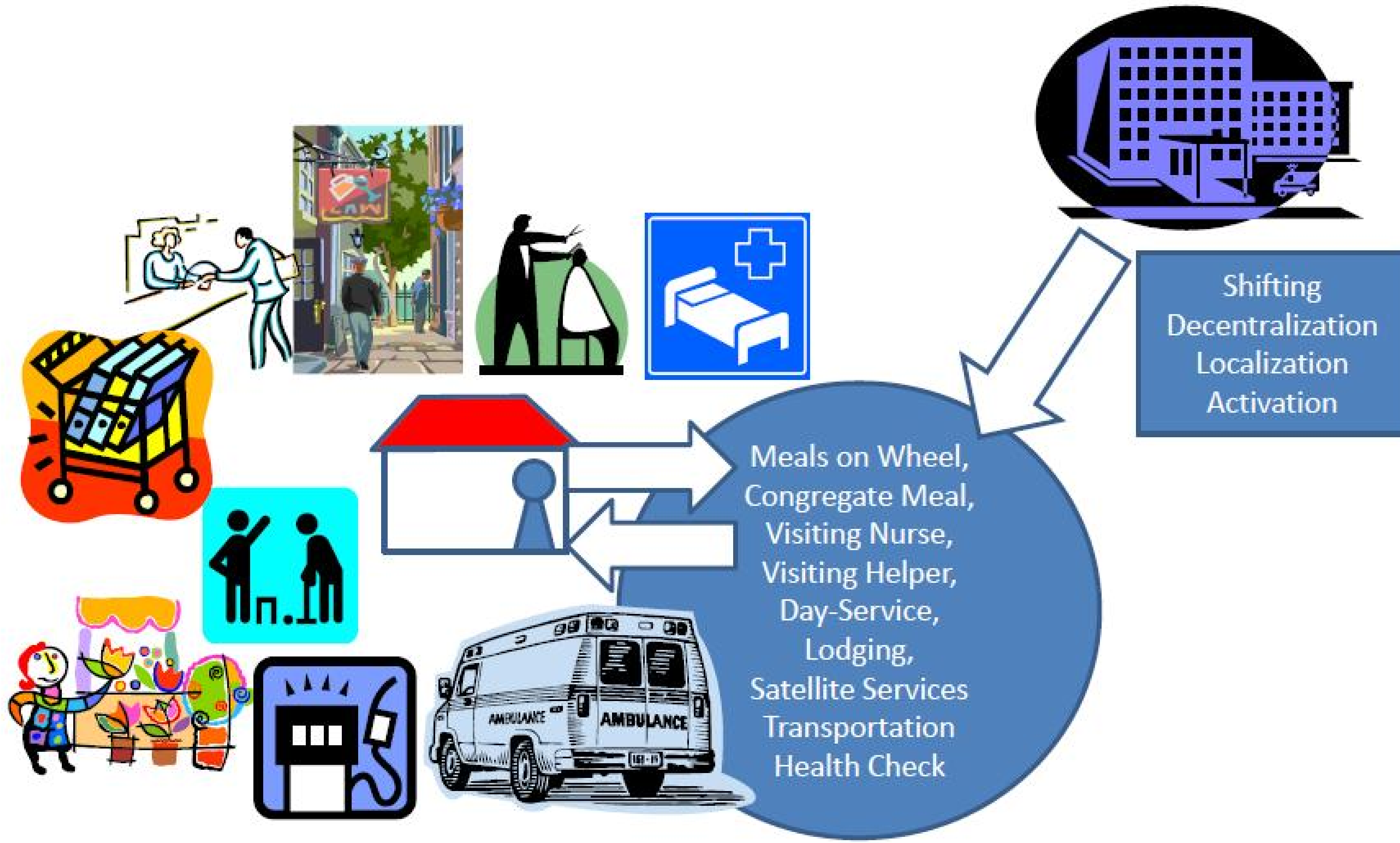
dietician
speech therapist
stoma care

Lay volunteers

Hospital based specialists

IT can help

Community-based Comprehensive Care



SOURCE: Takeo Ogawa, Ph.D
Kumamoto Gakuen University

THREE DECADES ON

Knaul, F.M. et al. Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage. The Lancet Commission Report. Lancet 2018. 391 (10128):p. 1391-1454. Country rank UK 1, S'pore12, Malaysia 42.

Eric A. Finkelstein et al Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. Journal of Pain and Symptom Management Vol 63 No, 4 April 2022. Country Rank : UK 1, Singapore 23, Malaysia 62.

WAYS FORWARD - PRIORITIES

A. Bridging the gap

B. Home care new models

C. Consensus on what is palliative care will help

D. Supportive environment

E. Structural impediments

ACCESS ABYSS IN PALLIATIVE CARE 1

*MOH (2022) - 148 hospitals - only 25 have PC services

1,077 K K's - few have DPC services

inadequate resources(>30 programmes)

*increase resources (GDP ration from 2% to 4%)

*inpatient care PLUS care in homes

*early referrals / coordinated care

*involve GP's (9,830 – 2022)

*fund 50% operational costs of Hospice NGO's

ACCESS ABYSS IN PALLIATIVE CARE 2

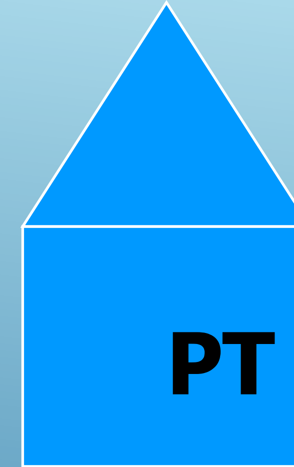
NGO'S ROLES

* increase current services
* help set up home services in towns
* advocacy – public, health professionals, government
* innovate – modify HHP model to suit KK's resources
* encourage GP's involvement S

"It always seems impossible until it is done" Nelson Mandela

TAKING CARE TO THE HOME
- NEW MODELS

HOSPITAL SUPPORT TEAM



HEALTH SUPPORT TEAM

Dame C Saunders
1918 - 2005

holistic care
compassion
and
modern medicine

↓ suffering terminally ill

die with dignity

place to die peacefully

THE EVOLUTION OF THE HOSPICES

"In many ways I think this is the most exciting way forward, helping to move support and symptom control to an earlier stage of the disease. It emphasizes that hospice treatment is not merely a last resort but can be practiced in the general and teaching hospital"

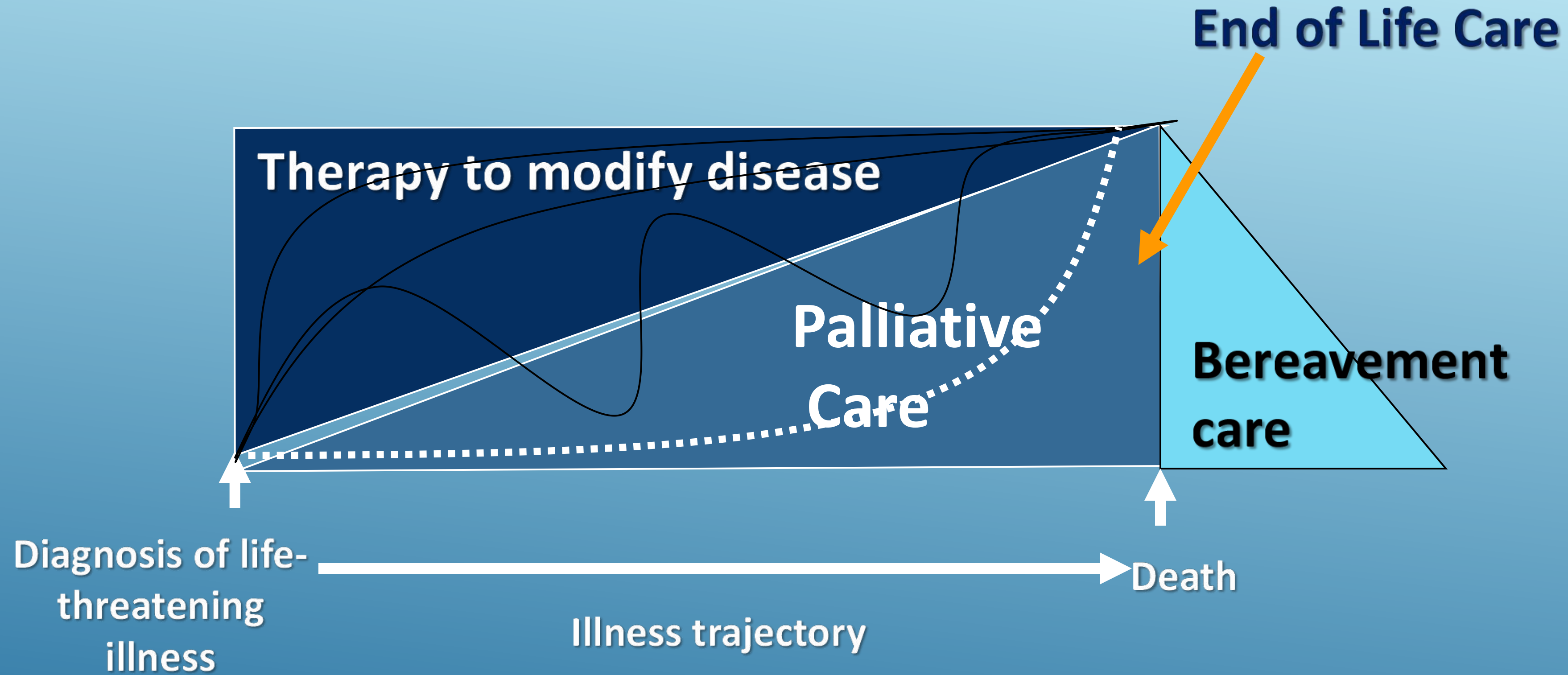
"It is only when such care is spread through the National Health Service in general, in both hospitals and the community, as well as in hospices, that these people will have the help they need"

Dame Cicely Saunders

Parthenon Publishing Group 1988 & Free Inquiry

1991/92 Vol 12 No.1

Hospice Palliative Care: A New Model



Palliative Care - Can be delivered concurrently with therapy to modify disease
- As main focus of care

Modified – Dr Romayne Gallagher – University of British Columbia

GLOBAL ATLAS OF PALLIATIVE CARE
2ND ED 2020

- Hospice care is end of life care provided by health professionals and volunteers. They give medical, psychological and spiritual support, The goal of care is to help people who are dying have peace, comfort and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programmes also provide services to support a patient’s family.
- Palliative Care – as defined by WHO 2022 (Adults/ Children)s
- What is the relationship between curative and palliative care?

“The aim of palliative care is to relieve suffering in order to improve quality of life for those with serious health related suffering…..

WE SAY WE CARE FOR THE TERMINALLY ILL…….

But we tell everyone that the principles of palliative care are applicable, whatever the illness, whether simple or complex, early or advanced, curable or life-threatening, at home or hospital.

………true but very confusing!

Derek Doyle 2003

OTHER TERMS

" comfort care, supportive care, end of life care, care of the dying, care from the beginning, person centered care, hospice-palliative care …"

LOCAL PUBLIC, HEALTH PROFESSIONALS PERCEPTIONS

Hospice is for terminally ill

Hospice is for the dying

Morphine use only when dying

Hospice means no hope

Hospice is where people go to die

Think Point:

Is not hospice movement to blame ?

P C – WHY, WHEN ?

Saunders

1967

suffering

Terminally ill

Death

WHO 1990

Not responsive to curative Rx

Death

WHO 2002

Quality of life in LTI

Death

MY TAKE WHEN CARE NEEDED

- Patient centered care
- Care involves all health professionals
- Problems addressed appropriately from diagnosis
- Will minimise suffering regardless of disease outcome
- What patients want – get well (cure), feel better (control), care and comfort

PERSON WITH MAJOR ILLNESS

- Will have many problems directly arising from disease
- Problems – physical, psychosocial, spiritual
- All problems need to be addressed
- Focus on problems only at end of life
  - inadequate care over disease trajectory
  - negative perception - care necessary only for dying

Think point:

care as appropriate from diagnosis better alternative

be the responsibility of all clinicians

MESSAGE FOR ALL CLINICIANS

"you can start tomorrow"

Dr Mary Baines
National Palliative Care Conference,
November 1993

WHAT IS PALLIATIVE CARE?

- Palliative care is basically just good medical care, and it can be delivered by any care provider who has the approach and skills in an environment of support
- All specialists, family doctors and nurses should accept responsibility for the delivery of good care, relying on specialized palliative care staff and programs only for the most difficult or unusual problems

Ian Maddocks
Emeritus Professor of P C
Flinders University

ILL PATIENT’S EXPECTATIONS

Get well (cure)

Feel better (control)

Care and Comfort

?

must I be dying to get good care

PERCEPTIONS OF STAKEHOLDERS

- Health professionals – “we are already caring”
- Public – hospice is for the dying
- MOH – low priority, job of family or welfare

Y O U

WHAT WOULD YOU

WANT

WHEN ILL ?

PC AS A SPECIALITY

- +ve : diseases of an organ expertise
- -ve : caring as specialist function

  caring, as ethics, cuts across all disciplines, levels care

  dangers of vertical development

  silo thinking, silo services

"caring is integral to good medical practice"

HOSPICE CARE

IS

GOOD MEDICAL PRACTICE

PALLIATIVE CARE – A SHIFTING PARADIGM
FROM NEJM AUGUST 19, 2010

- Study of PC intervention in 151 newly diagnosed non-small-cell lung cancer by Temel et al.
- Results: as cf standard care group, the intervention group had better quality of life, lower rates of depression and a 2.7 month survival benefit
- Editorial: The study by Temel et al. represents an important step in confirming the beneficial outcomes of a simultaneous care model that provides both palliative care and disease-specific therapies at the time of diagnosis.

Think Point: why not advocate good medical care by clinicians from diagnosis?

A PERSPECTIVE FROM USA

Generalist plus Specialist Palliative Care - Creating a More Sustainable Model

Timothy E Quill M.D., Amy P. Abernethy M.D.

(Dept. of Medicine, PC Division, University of Rochester Medical Center)

NEJM March 6, 2013

THE CHALLENGE

reestablish

whole person care

as good medical practice

involving all clinicians

instead of marginalizing them

VISION OF NATIONAL P C POLICY

Providing compassionate care throughout the health care system......

so that everybody wherever they live, rural or urban will have such care

NEED SUPPORTIVE ENVIRONMENT FOR GOOD CARE

- Patient centered
- Health system

    - levels of care, primary care led, seamless care
- Resources adequate - trained staff, $
- Professional carers
    - caring attitude
    - competent
    - Compassionate

Think point:

Can we attain developed status in health care if mind sets do not change?

COMMON GOALS EXPECTED OF HC SYSTEM

universal coverage

access equity

efficient use of resources

equity in financing

consumer choice

control of expenditure

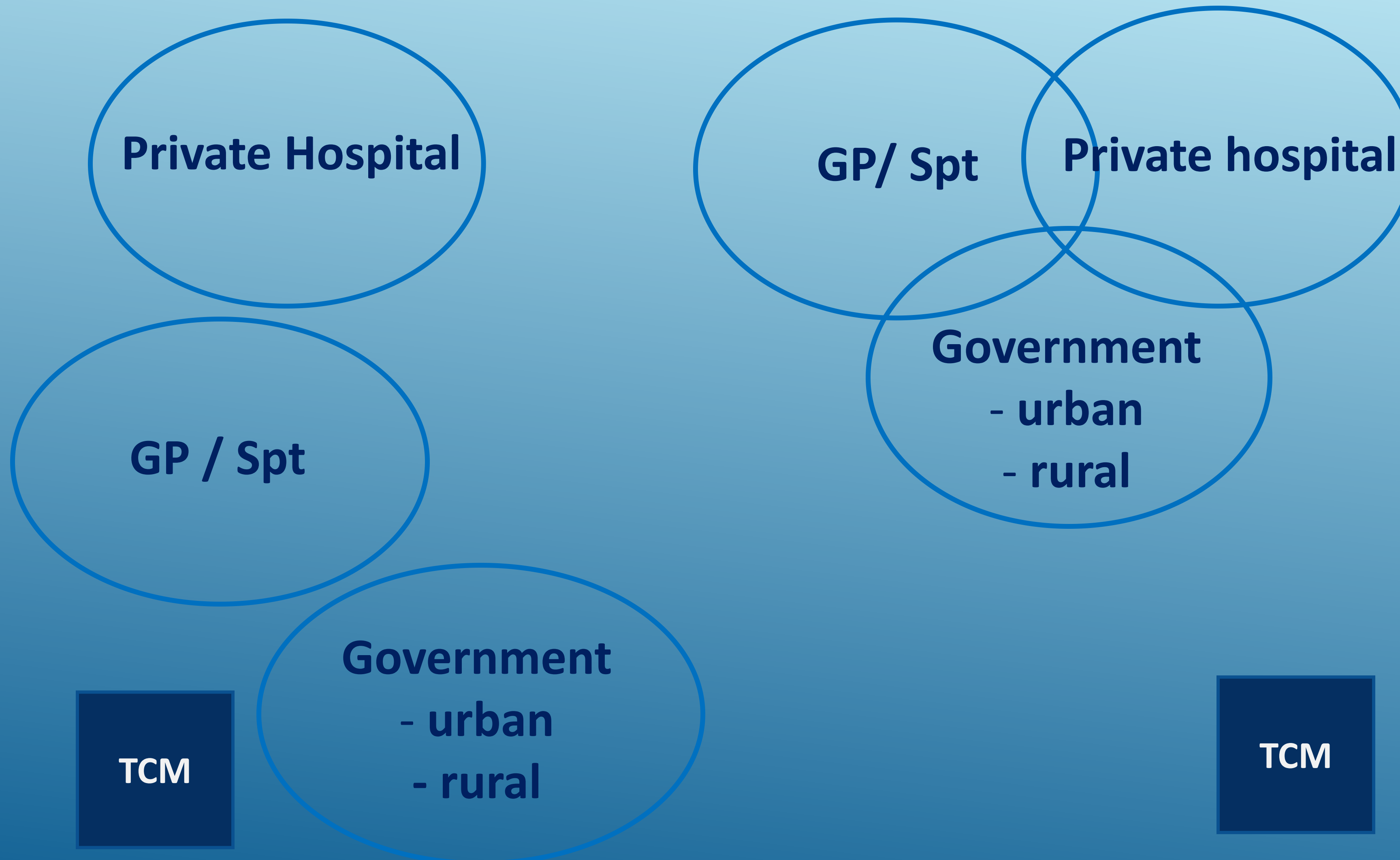
clinical freedom for providers

meeting needs and curbing costs

"Only 10-20% of health outcomes are determined by health care access an quality"

Kaplan and Milstein

HEALTH SERVICES IN MALAYSIA



HEALTHCARE OF SICKCARE ?
AZMAN UJANG, THE SUN SEPTEMBER 08, 2017

Two systems – public and private

“fragmented, not functionally integrated,

inefficient use of resources. patient dissatisfaction”

Care Model

Disease - curative model centered around hospitals, absence of primary care, seamless care

IN

Age of ageing, chronic diseases

HEALTH FOR ALL - ALMA ATTA 1978, ASTANA 2008
PRIMARY CARE

- First contact care – point of entry to health care system
- Provides continuity of care over time in sickness including acute and chronic illness and emergency domiciliary care and referrals for specialist care
- Continuity over time in health promotion, preventive care
- Comprehensive care, personalized care
- Serves to co-ordinate all health care needs of patient
- Continuing responsibility for individual patient follow-up

  and community health problems

THINK POINT: A Community doctor NEEDED BY PUBLIC, SPECIALISTS

PRIMARY CARE ORIENTATED COUNTRIES

- Have more equitable resource distributions
- Have health insurance or services that are provided by the government
- Have little or no private insurance
- Have no or low co-payments for health services
- Are rated as better by their populations
- Have primary care that inculcates a wider range of services and is family orientated
- Have better health at lower costs

Sources: Starfield and Shi, Health Policy 2002;60:201-18

van Doorslaer et al, Health Econ 2004;13:629-47

Schoen et al, Health Aff. 2005;W5:509-25

STRUCTURAL ISSUES

- No levels of care – primary, secondary, tertiary
- Two systems/not functionally integrated

    -Doctor hopping, hospital hopping

    -Health care seen as a product

    -Fees for service

Absence of Heath Care financing system

    - OOP 35 %

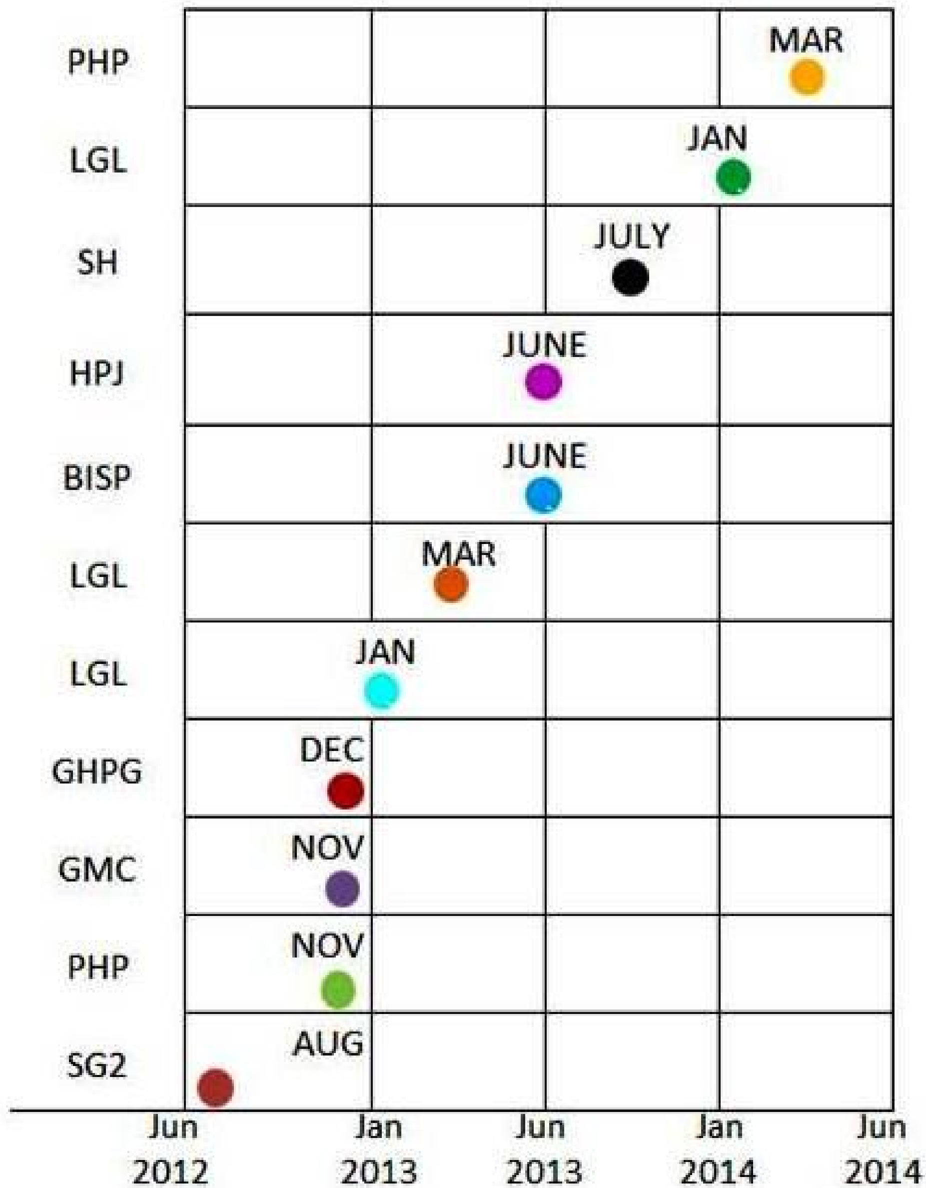
Expectations – public for quality services / quick service

professionals – clinical freedom

state of the art

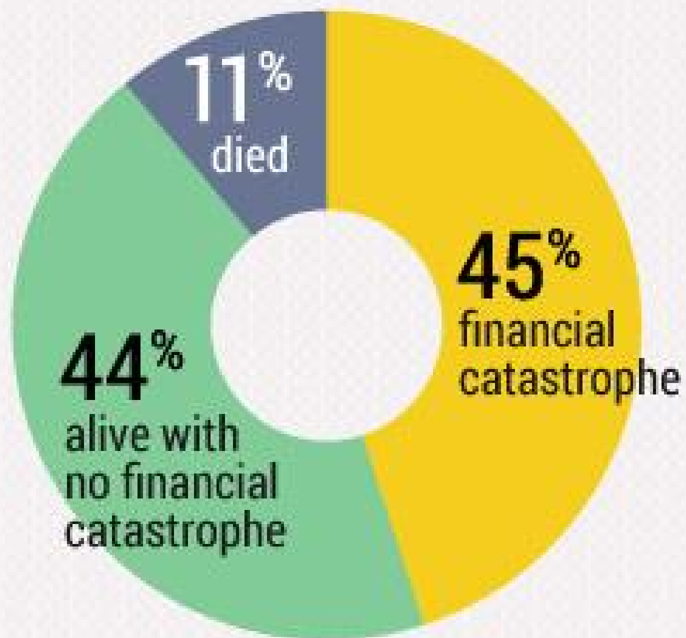
Commercial pressures

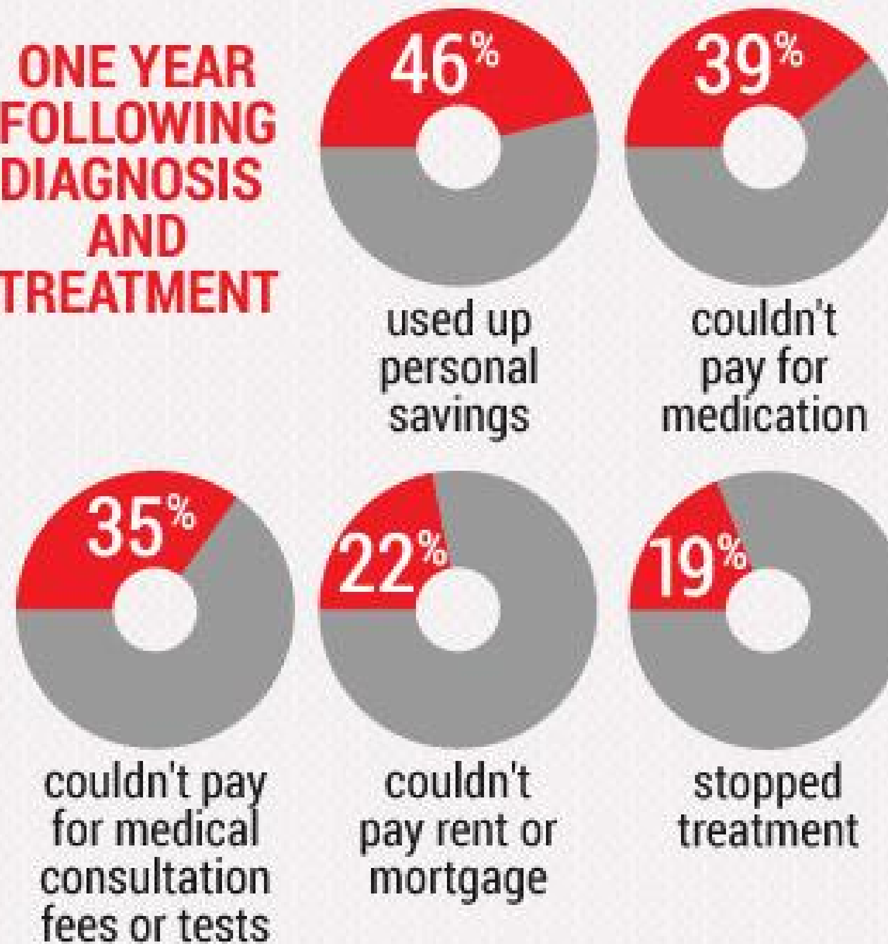
CHART SHOWING "HOSPITAL HOPPING"



- SG2-Sungai 2 Clinic
- PHP - Pantai Hospital Pg
- GMC - Gleneagles Pg
- GHpg - General Hospital Pg
- LGL - Loh Guan Lye Pg
- BISP - Beacon International Hospital
- HPJ - Hospital Putra Jaya, KL
- SH- Sunway Hospital KL

ECONOMIC IMPACT OF CANCER IN MALAYSIA





***Note:** 'Financial catastrophe': Out-of-pocket medical costs exceeding 30 per cent of annual household income*

Source: ACTION study, The George Institute for Global Health (2015)

Graphics: themalaymailonline.com

CARING – GLOBAL CONCERNS

NCD's, Ageing

long term care

*advances in medical K/T

??????

quality of care

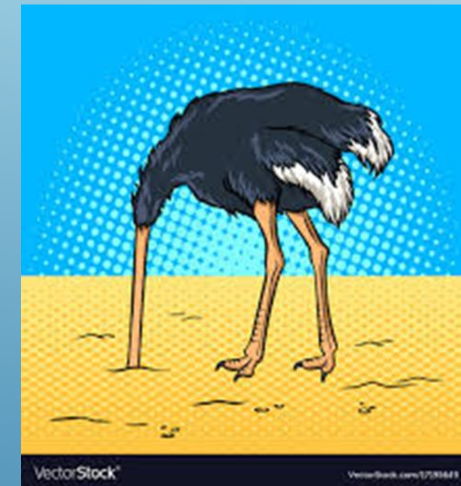
access to care

where to care

who will care

costs of care

moral dilemmas



" A CULTURE OF CARING - RESPONSIBILTY OF ALL STAKEHOLDERS "

EARTH WILL SURVIVE
HUMANKIND SURVIVAL AT STAKE
STEPHEN HAWKING (1942 - 2018)

- Climate change
- Environmental destruction
- Pollution
- Insecurities – foo, water KIV – a globe
- Geopolitics an Wars
- New epidemics

"need and greed"

"we are all part of the problem"

FUTURE OF P C

"What is certain is uncertainty"

Increasing service access:

NGO's – current will be marginal

setting up new NGO's unlikely

MOH – marginal till structural issues addressed

Others services – more marginal

"Dominant will be global factors"

KIV: palm reader photo

Facebook.com/ThinkPositivePower