

HKEC Symposium on Community Engagement XI
港島東醫院聯網醫社合作研討會 (十一)

Seminar 3: Palliative Care - From hole to whole
講座三：紓緩治療 - 真 · 圓滿

Cheering@home and Social Dignity
for patients in late stage of life
為居家寧養患者找回生活、拾回尊嚴

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「安・好」居家寧養服務

Cheering@Home End of Life Project

捐助機構 Funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

合作夥伴 Project Partner:

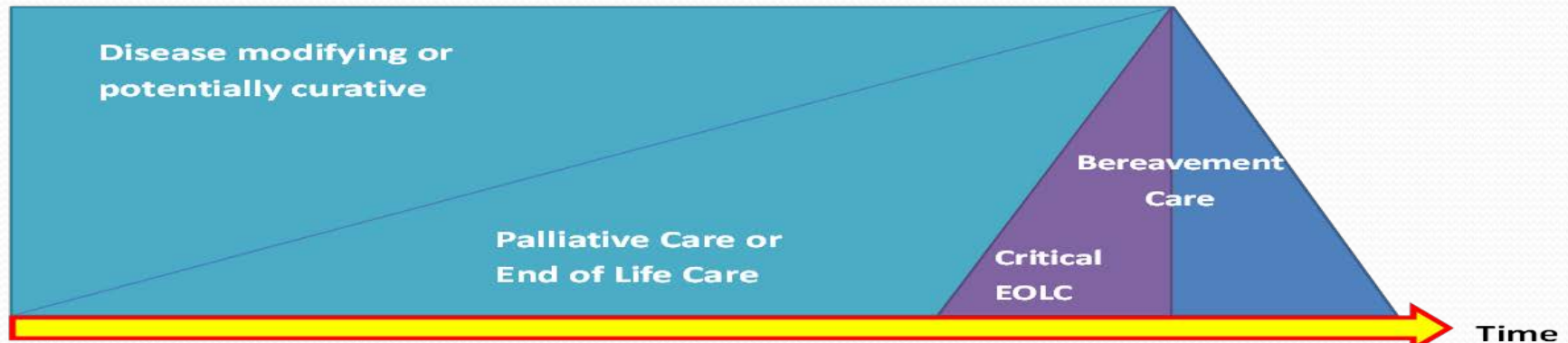


Project Background

- Rapidly ageing population and demand for palliative care among older terminally ill clients.
- Focus on palliative care
 - ✓ Relief from pain and other distressing symptoms
 - ✓ Affirms life & regards dying as a normal process
 - ✓ Integrates psycho-spiritual support to patients & families as actively as possible
 - ✓ Offers a support to help the family cope during the patient's illness and in their own bereavement
 - ✓ Bereavement counselling

Project Insights

A Model of the Dying Role - Emmanuel, Bennett and Richardson(2007)



Practical Task

Medical needs
Equipment loan
Funeral Navigation

Personal Task

Supportive Counselling
Activities for Final Growth
Spiritual Support
Anticipatory Grief
Bereavement

Relational Task

Family Communication
Legacy Capstone

Project Insights

Dignity Model - Chochinov HM 2002

Dignity Model, which shows three major categories of factors that affect the patient's sense of dignity:

Illness-Related Issues:

How the illness itself affects personal feelings of dignity

Dignity-Conserving Repertoire:

How a patient's own perspectives and practices can impact their sense of dignity

Social Dignity Inventory:

How the quality of interactions with others can enhance or detract from one's sense of dignity

Dignity Theme

Illness-related concerns

- Level of independence
- Cognitive acuity
- Functional capacity
- Symptom distress
- Physical distress
- Psychological distress
- Medical uncertainty
- Death anxiety
- Enduring pain

Social dignity inventory

- Privacy boundaries
- Social support
- Care tenor
- Burden to others
- Aftermath concerns
- Transgenerational unity

Dignity conserving repertoire

Dignity conserving perspectives

Continuity of self

Role preservation

Generativity/legacy

Moral transcendence

Maintenance of pride

Hopefulness

Autonomy/control

Resilience/fighting spirit

Fortitude/Spiritual surrender

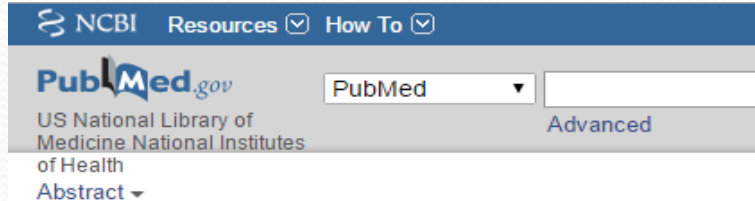
Dignity conserving practices

Living in the moment

Maintaining normalcy

Seeking spiritual comfort

Project Insights



Most of EOL intervention focus prominently on pain and symptoms controls, while **holistic care and familial support are limited**

Chinese older patients were not anxious about death, but instead **desire advance care planning to relieve family burden**

Expressed a deep loss of independence owing to their limited functional capacity and no longer carry out many of their everyday activities independently, enjoy food, engage in hobbies...

New themes of dignity are identified : **enduring pain, moral transcendence, spiritual surrender and transgenerational unity**

[Age Ageing](#). 2013 Jul;42(4):455-61. doi: 10.1093/ageing/af003. Epub 2013

Living and dying with dignity in Chinese society: perceptions in Hong Kong.

Ho AH¹, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, Tse

Author information

Abstract

BACKGROUND: the empirical Dignity Model has profoundly influenced patients in the West, as it provides practical guidance and intervention to reduce distress at the end-of-life.

OBJECTIVE: to examine the concept of 'living and dying with dignity' and the generalisability of the Dignity Model to older terminal patients in Hong Kong.

METHODS: using qualitative interviews, the concept of dignity was explored with terminal cancer patients with terminal cancer. Framework analysis with both deductive and inductive methods was employed.

RESULTS: the three major categories of themes of the Dignity Model were broadly supported. However, the subtheme of death anxiety was not supported, while two subthemes of generativity/legacy and resilience/fighting spirit manifested differently in the Chinese context. Furthermore, four new emergent themes were identified: enduring pain, moral transcendence, spiritual surrender and transgenerational unity.

CONCLUSION: these findings highlight both a cultural and a familial importance of cultural awareness and competence for working with Chinese older patients. A culturally sensitive and family oriented approach to palliative care intervention is recommended.

Project Objectives

- To have **quality of care to clients and caregivers**, we provide intensive psychosocial, tangible support and spiritual support
- To have **meaningful of life**, we bring happy moments to patients and their families, reduce the sick role and support patients to settle unfinished business
- As Death is relational issue, we **focus on family relationship and restoration with loved one**
- To develop Community Palliative Care in HK, we strive to have **joint-effort with HA to provide seamless support**

Summary on 3 major service domains

Key Elements .		
The Practical Element which involves concrete tasks of preparation	1.	Medical support (with HA PC Nurse Support)
	2.	Escorting service for follow up
	3.	Personal care service and in-home support
	4.	Medical and rehabilitation equipment lending service
	5.	Nursing mentor for family carers' training
	6.	Funeral planning and navigation
	7.	Complementary Therapy
	8.	Resource information and connection provided
The Relational Element which involves engaging with others	1.	Family work facilitating family communication
	2.	Facilitating production of legacy capstone for family members
The Personal Element which involves tasks that foster personal growth and finishing one's life story	1.	Supportive counselling
	2.	Cheer-up activities for final growth phase to reduce sick role and provide fun and lively atmosphere
	3.	Linking with spiritual support network
	4.	Anticipatory grief work
	5.	Bereavement counselling



CASE ILLUSTRATION

翠婆婆

ABOUT OUR PATIENT

History and problems

Happy and healthy old lady

Female

Aged over 90

Walk with stick

Lives alone

ADL independent



Bilateral cataract
with OT

Asthma

Bilateral OA knee

Fell on the street
in 2008



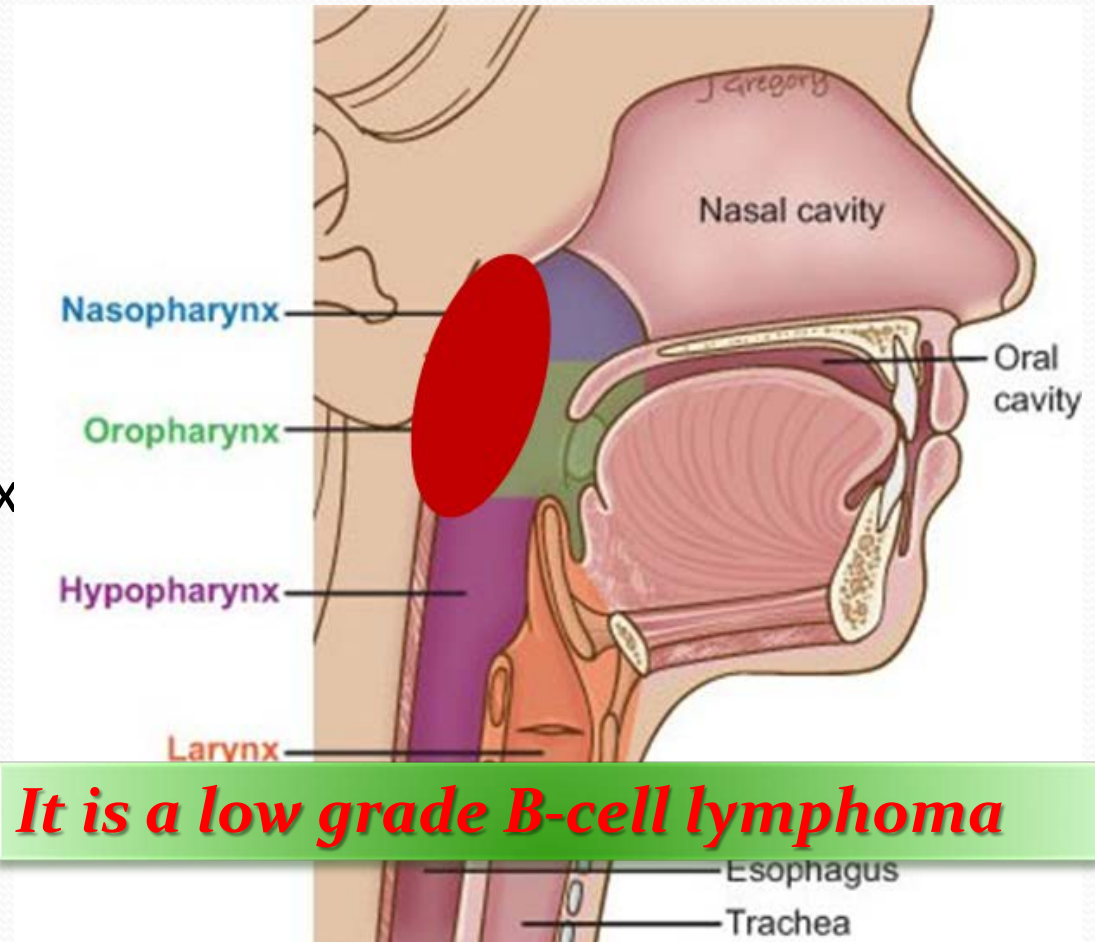
One day ...

Spontaneous epistaxis

Seen by ENT

Tumour in nasopharynx

Biopsy done



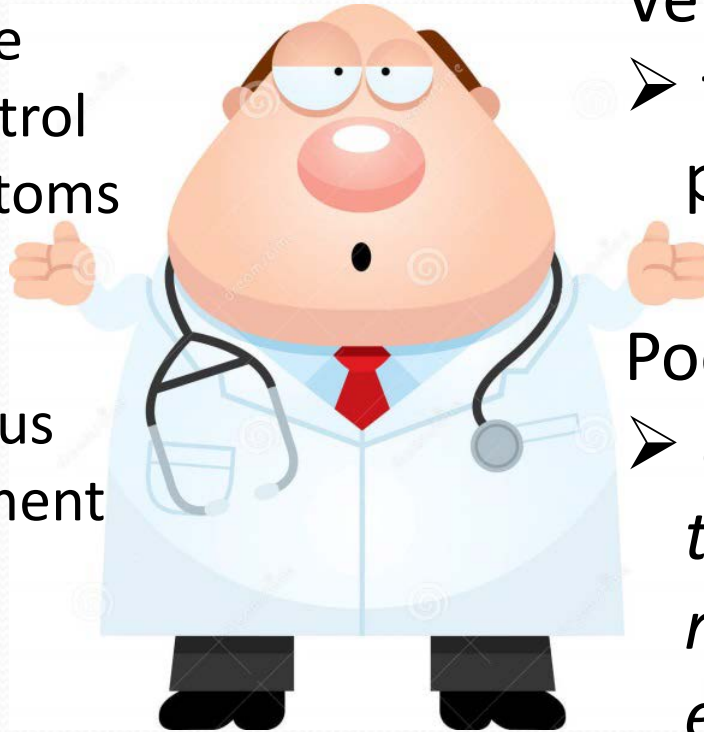
Treat or not treat?

Low grade disease

- long term control
- prevent symptoms

Reasonable
performance status

- tolerate treatment
well



Very old lady

- treatment maybe
palliative intent only

Poor social support

- *able to go through
treatment and
recover from side
effects?*

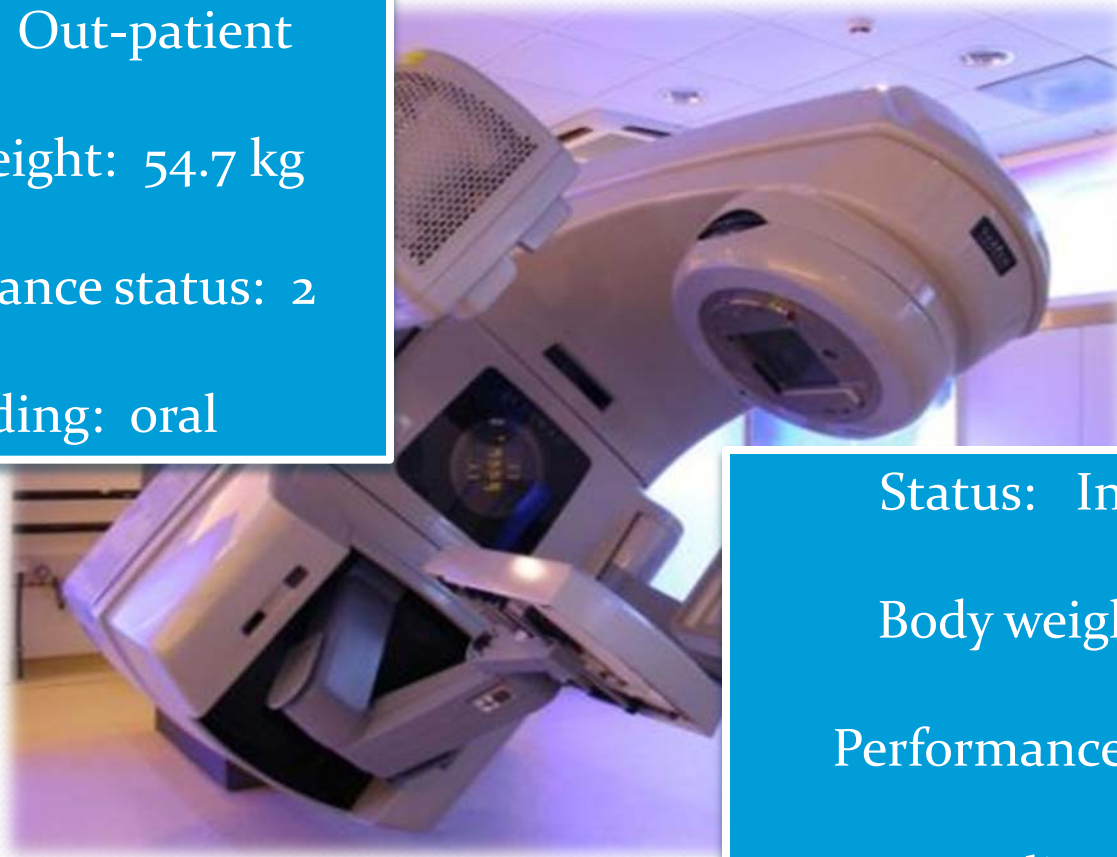
After 2 weeks of radiotherapy ...

😊 Status: Out-patient

😊 Body weight: 54.7 kg

😊 Performance status: 2

😊 Feeding: oral



Status: In-patient

Body weight: 51 kg

Performance status: 4

Feeding: tube

What next?

Self care?

- nutrition
- tube feeding
- slow recovery

Home or institutional care?

- social support
- inpatient rehab beds
- old-age home

Recovery?

- from disease
- from treatment side effects
- resume oral feeding

Patient & family concern?

- *Patient: I want to go home!*
- *Daughter: But I can't take care of her!*



Case Intake

- Case Intake Mid of March 2016
 - Referred by RH
 - High caring stress
 - Different expectation among family members
- Our Client : Want to go home
- Caregivers : (1) Stressful on caring mother
(2) Different opinion on caring plan
- Negative experience on residential home

CLIENT WISH

Independence • Autonomy • Spiritual Fulfillment

An illustration of two hands, one light-skinned and one dark-skinned, reaching out towards each other. The hands are positioned on the left side of the slide, with the fingers spread. The background behind the hands is a blue, torn-edge banner.

OUR MISSION

Medical – Social Partnership

A background illustration for the lower half of the slide. It features a landscape with a sunburst effect in the sky, many small birds flying, and a silhouette of a house with a chimney. The house is positioned within the letter 'O' of the word 'HOME'. The foreground is a dark, patterned area.

GOING HOME

Care Plan Intervention

1. From Tube Feeding to Oral Feeding
2. Enjoy psycho- spiritual life at home
3. Ally community resources to support EOL care
4. Relieving caring stress and anxiety

1. From Tube Feeding to Oral Feeding



Address client WILL & Training Motivation
Return Home
The mind of Buddha

PY Medical Team joined effort

- Speech Therapist
- Dietitian Advice
- Daily Training within two weeks

Relieve caregivers' stress :
How to take care mother at home
Ally community resources to support daily
meal services

2. Enjoy psycho- spiritual life at home
3. Ally community resources to support EOL care



回家 • 禮佛

Home • The Mind of Buddha

4. Relieving caring stress and anxiety



捐助機構：



合作伙伴：



家屬心聲

Caregiver Sharing on Relieving Stress and Anxiety

Case of Tsui

Key Elements		
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Service Snapshot:

Psycho – Spiritual Service



1st Day discharged fm Hospital
MY 1st WISH : HAIR CUT



MY WISH : Outdoor Activity

Service Snapshot:

Psycho – Spiritual Service



Meal Preparation



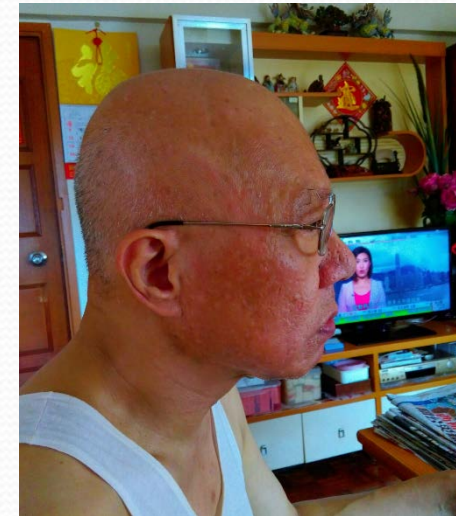
Contact Church Support



In-home CheerUp Activities



CheerUp Activities
Birthday Lunch



In-home Optometry Services

Service Snapshot:

Family Relationship Service



Legacy Capstone



**Family Gathering
and family Photo**

Service Snapshot

Tangible Service



**Rehabilitation Equipment
Support**



Occupational Therapy Home Visit

Service Snapshot

Tangible Service



Home Care Service and
Meal Service



Escorting Service

Knitting the web to provide continuums of Care



Family Involvement

- Major Caregivers
- Family Members

Medical Support

- Medical Team
- Home Nurse

Caring Environment

- Home Care Team
- Volunteer Support
- Community Support
- Church/Spiritual Support
- Community Readiness



Living & Dying with Dignity

THANK YOU