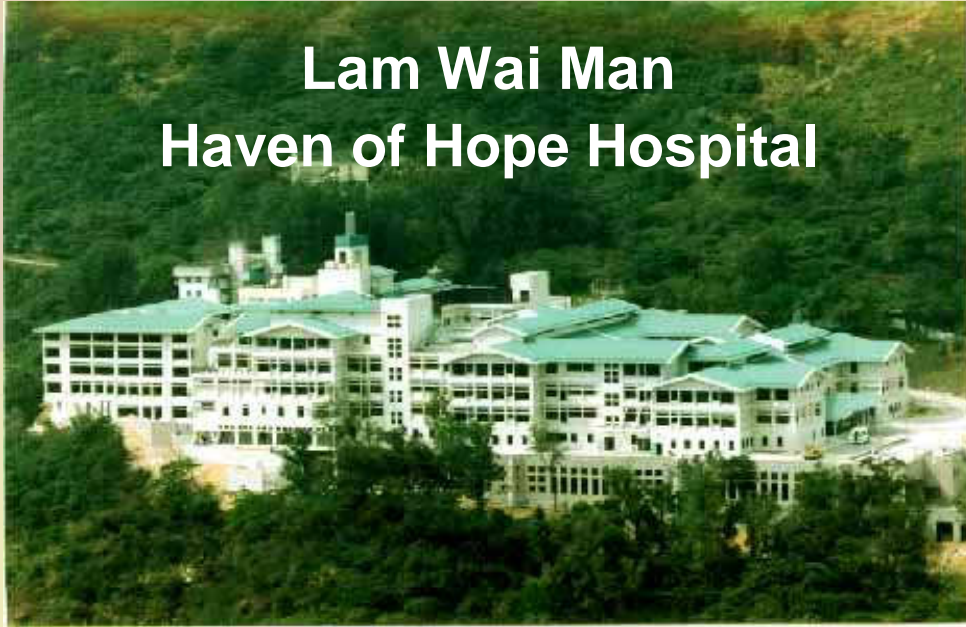


Hong Kong Pain Society ASM 2010  
**SPIRITUAL PAIN**

Lam Wai Man  
Haven of Hope Hospital



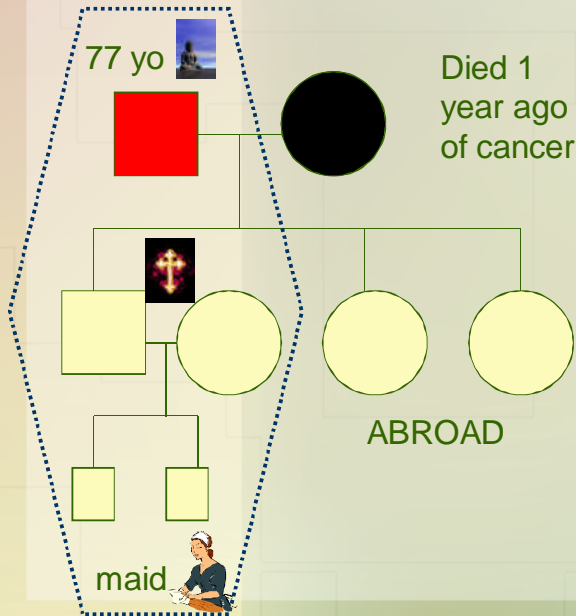
**Starting  
from  
patients'  
stories...**

...





# The Story of Mr Lonely



Retired clerk

Cared by maid

Daytime alone

CA rectum,  
liver/adrenal/LN  
metastases, IVC  
invasion

Decided not for  
chemotherapy and  
referred palliative care  
unit



## Pain

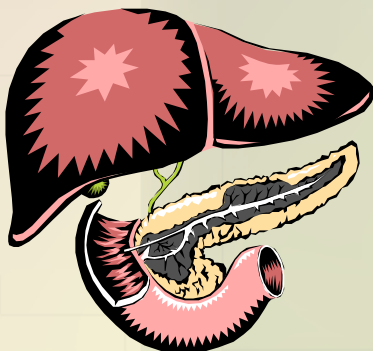
Liver distending pain

Morphine: vomiting and  
myoclonic jerks

Opioid rotation

Transdermal fentanyl  
patch (4.2mg patch  
every 72 hours)

Pain score (NRS) 6-7 to  
2-3/10





## Suboptimal Pain Control

Severe pain NRS 7-8/10

Worse at night

Repeated breakthrough fentanyl injections (total fentanyl dose up to 1600 ug/day)

Appeared calm and restful despite a high pain score; enjoyed company and conversation with staff



## Psycho-socio-spiritual state

Loneliness

Fear:

Inability to handle pain when home alone / night-time

Grandchildren's future

Sense of burden to family

Low mood; wish for hastened death; request for euthanasia

No fear about death

When pain happened at night, I feel alone in facing the pain, annoyed, restless, fear, and do not know what to do

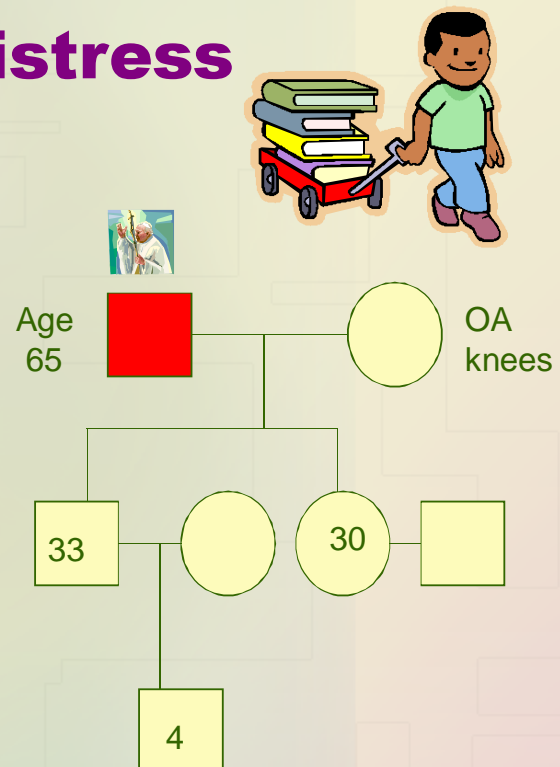


## Multidisciplinary Team Management

- Medical: fentanyl, mianserin, alprazolam
- Clinical psychologist: supportive therapy, grief expression, interventions on his ruminations of negative thoughts
- Chaplain: sharing on religious belief of both sides
- Ward staff: encouraged visits, day leaves, ward activities
- → **Pain improved and dose of fentanyl reduced**

## The Story of Mr Distress

- Retired engineer
- CA lung with T9 cord compression and paraplegia
- Severely distressed by mild (2-3/10) back pain, calling for help
- Family distress and staff distress



## Loss of control

- Used to be problem solver in work and family; Sudden loss of control precipitated grief, anxiety and fear, burden to family, hopelessness, suicide idea
- Management:
  - Chaplain: prayer; presence; bible; listening; hymns
  - Priest: rituals according to his religion
  - CP: psychotherapy to enhance coping
  - PT/OT: Maintenance exercises
  - Medical: Anxiolytics and analgesics
- Outcome: Slowly but gradually came to terms with the dependent state

## What is Spiritual Pain - Theoretical Framework

## Total Pain -

*Dame Cicely Mary Saunders*  
1918-2005

- Nurse, physician, social worker, writer
- Pioneering the modern hospice movement



## Total Pain

*“Pain is the resultant of the conflict between a stimulus and the whole individual (Rene Leriche) – a good definition for us, who are concerned with the whole person, with a whole experience suffered, endured, passed through,.... Trying to be aware of all aspects of the person and group involved.” Cicely Saunders*

Cicely Saunders. Spiritual Pain. Hospital Chaplain 1988 (March)

## Total Pain

Emphasizing the importance of listening to the patient's story and of understanding the experience of suffering in a multifaceted way.

The idea of total pain as incorporating physical, psychological, social, emotional and spiritual elements.

Marcia Meldrum. History of Pain. APS Bulletin 2000 10(4)

## Pain and Suffering

Suffering: the perception of threats to the intactness of the person as a whole entity.

– Eric Cassel

Eric Cassel, The nature of suffering and the goals of medicine, NEJM 1982, 306:639-645.

**Personality;  
Character**

**Past; Life  
experience; illness  
experience**

**Family**

**Cultural  
background**

**Roles**

**Relationships**

**Body**



**PERSON**

**Political being: rights  
and obligations**

**Activity and actions**

**Habits and routines**

**Unconscious realm**

**Secrets, dreams,  
fantasies**

**Perceived future;  
hope**

**Transcendent  
dimension, life of the  
spirit**

## **Spiritual Pain**

- Spirit – the animating or vital principle in man, the breath of life.
- The essence of spiritual pain in terminally ill – *“the whole area of thought of moral values throughout life is threatened, leading to bitter anger and unfairness of what is happening... and above all, a desolating feeling of meaninglessness.”*

Cicely Saunders. Spiritual Pain. Hospital Chaplain 1988 (March)



# Spiritual Pain

A state of conflict between one's belief system and current reality. Spiritual pain is the experience of conflict and disharmony between a person's hopes, values, beliefs and their existential experience with life. People often experience spiritual pain when a certain life experience completely shatters the view of life or a purpose in life they had previously held. - *Kearsley*

Kearsley J. Spiritual pain: I have become like a broken pottery. Spiritual Pain in health care. Proceedings of a 1-day seminar held by Karuna Hospice Service, Brisbane, 2003.

# Spirituality

- **Spirituality**: the aspect of humanity that refers to the way individuals seek and express **meaning and purpose** and the way they experience their **connectedness** to the moment, to self, to others, to nature, and to the significant or sacred.

Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliative Medicine* 2009;12(10): 885-904.

# Healing Connections (Balfour Mount 2007)

Experience  
of suffering  
and  
anguish

## Healing CONNECTIONS

1. With Self
2. With Others
3. With Phenomenal World
4. With Ultimate Meaning

Experience  
of wholeness  
and integrity

Balfour Mount. Healing Connections: On Moving from Suffering to a Sense of Well-Being, Journal of Pain and Symptom Management, 2007

# The Four Constitutive Patterns of Spirituality in Taiwanese (Co-Shi Chantal Chao)

## COMMUNION

With Self	With Others
With Nature	With Higher Being

Co-Shi Chantal Chao. The Essence of Spirituality of Terminally Ill Patients, Journal of Nursing Research, 2002.

## Spiritual Pain – Conceptual Framework

- Definition: pain caused by extinction of the being and meaning of the self
- Three dimensions of a human being –
  - A being founded on temporality
  - A being in relationship
  - A being with autonomy

Hisayuki Murata. Spiritual pain and its care in patients with terminal cancer: construction of a conceptual framework by philosophical approach. *Palliative and Supportive Care* 2003, 1:15-21.

## Spiritual Pain – Conceptual Framework

A being with ...	Spiritual pain – Loss of ...	Spiritual Care Recovery of ...
Temporality	Future	Future beyond death
Relationship	Others	Others beyond death
Autonomy	Autonomy / control	Autonomy towards death

Explore inner self  
Restructure values

Hisayuki Murata. Spiritual pain and its care in patients with terminal cancer: construction of a conceptual framework by philosophical approach. *Palliative and Supportive Care* 2003, 1:15-21.

## Spiritual Pain – Experiencing LOSS

- Qualitative study of 12 hematological malignancies survivors
- Experience of disconnection with normal / expected relationships or satisfaction with life due to **experience of losses**:
  - physical (hair, pain, fertility..)
  - identity (role, work, education, self..)
  - relationship (family, friends..)
  - existential (loneliness...)

Pam McGrath. Creating a language for 'spiritual pain' through research: a beginning. Support Care Cancer 2002, 10: 6370646.

## Sources of Spiritual Pain in Facing Death – Fears

- Nine types of fear and anxieties about death which may become a source of spiritual pain:
  - Fear of pain
  - Fear of loneliness
  - Fear of unpleasant experiences
  - Fear of becoming a burden to family / society
  - Anxieties towards the unknown
  - Fear of death due to fear of life / sense of life task incomplete / fear of personal extinction / fear of judgment and punishment after death

Alfons Deekon. An Enquiry about Clinical Death – Considering Spiritual Pain. Keio J Med 2009; 58(2):110-119.

## **Types of Spiritual Pain in Facing Death – Losses**

1. Loss of self-determination
2. Loss of meaning
3. Guilt
4. Loneliness and isolation
5. Loss of hope

Alfons Deekon. An Enquiry about Clinical Death – Considering Spiritual Pain. Keio J Med 2009; 58(2):110-119.

## **How does spiritual pain manifest?**

# Manifestations

Existential suffering:

Desire for hastened death / reduced will to live (Breitbart, Chochinov); Requests for euthanasia (Y Mak); Suicide ideation and attempt; End of Life Despair (McClain); Hopelessness (Duggleby, Herth); Demoralization (Kissane); Reduced sense of dignity (Chochinov); Existential Distress (Morita)

Emotional Distress: fear, anxiety, guilt/shame, anger, depressed, isolation, intense grief, need for reconciliation, Demand for control

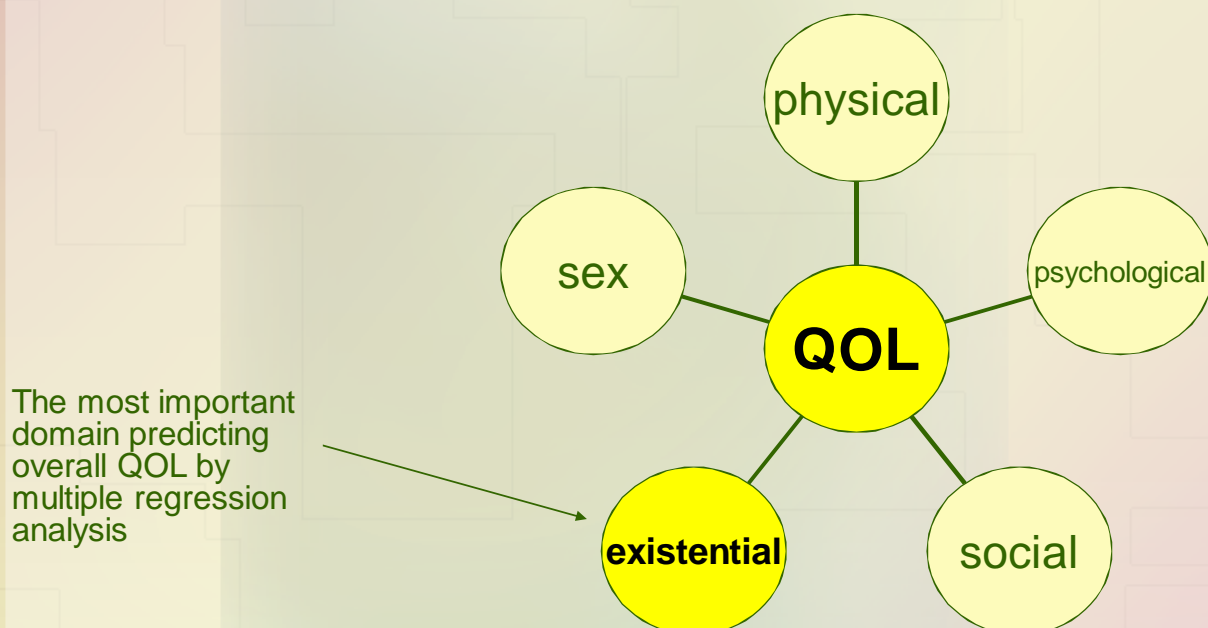
Physical: Poorer control of pain and other symptoms

Religious struggles and concerns: anger, abandonment, crisis of faith, guilt

Social: Withdrawn, isolation; Self-perceived burden (Wilson); Family / staff distress

Poor quality of life

# Quality of Life McGill QOL-HK



Raymond SK Lo. Cross-cultural validation of the McGill quality-of-life questionnaire in Hong Kong Chinese, Palliat Med 2001.

# Euthanasia

- The desire for euthanasia is not confined to physical or psychosocial concerns, but incorporated **hidden existential yearnings for connectedness, care and respect**, understood within the context of the patient's lived experience
- In-depth interviews with 6 in-patients in a palliative care hospice

*Voice of the terminally ill: uncovering the meaning of desire for euthanasia, Palliative Medicine 2005, Yvonne Mak*



# Demoralisation

- David Kissane
- **Demoralisation**: Hopelessness, loss of meaning or purpose in life, Persist across 2 weeks, without major depression superseding as the primary disorder (2000)
- Demoralisation Scale (2004)

*Psychospiritual and existential distress – the challenge for palliative care, Australian Family Physician 2000, David Kissane*

*The Demoralization Scale: a Report of Its Development and Preliminary Validation, J Palliat Care 2004, David W Kissane.*

# How to detect and assess Spiritual Pain?

## Improving the Quality of Spiritual Care as a Dimension of Palliative Care - The Report of the Consensus Conference

- Based upon prior literature and previous guidelines and conference proceedings
- Spiritual Care – a fundamental component of palliative care
- Proposed model for in-patient and out-patient settings



## **Spiritual Screening**

- Quick determination of whether a person is experiencing a serious spiritual crisis and need referral; helps identify which patients need in-depth assessment
- Simple screening questions in the course of initial patient and family screening

Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliative Medicine* 12(10): 885-904, 2009

## **Spiritual History**

- Aim for a better understanding of their spiritual needs or resources
- Part of a comprehensive holistic assessment of an individual
- May apply some available tools: FICA, SPIRIT, HOPE
- Be alert to clues of spiritual pain

Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliative Medicine* 12(10): 885-904, 2009

## FICA

<b>F</b>	Faith, Belief, Meaning
<b>I</b>	Importance, Influence
<b>C</b>	Church, Community
<b>A</b>	Apply, Address

*Puchalski CM, Taking a spiritual history allows patients to understand patients more fully. J Pall Med 2000; 3: 129-137*

## SPIRIT

<b>S</b>	Spiritual belief system
<b>P</b>	Personal spirituality
<b>I</b>	Integration
<b>R</b>	Rituals/ restrictions
<b>I</b>	Implications
<b>T</b>	Terminal events

Maugans TA. The SPIRITual history. Fam Med 1996; 5:11-16.

# HOPE

<b>H</b>	Hope
<b>O</b>	Organized religion
<b>P</b>	Personal spirituality
<b>E</b>	Effects of care and decisions

Anandarajah G, Hight E. Spirituality and Medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *AM Fam Physician* 2001; 63: 81-89.

## Spiritual Assessment

- A more extensive process of active listening to a patient's story conducted by a board-certified chaplain that summarizes the needs and resources and include a spiritual care plan with expected outcomes that is communicated to the rest of the treatment team.

Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliative Medicine* 12(10): 885-904, 2009

## **Interdisciplinary communication**

- Identify the spiritual concern and issues that lead to distress or suffering, or that cause or affect other psychological or physical problems
- Incorporate spiritual care plan into a multidimensional treatment plan
- Inter-professional rounds / meetings
- Document, evaluate and follow-up

Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliative Medicine* 12(10): 885-904, 2009

## **Management of Spiritual Pain**

## **Spiritual Care Interventions**

- Therapeutic Communication
- Healing Environment
- Specific Therapies:
  - Meaning Based
  - Religion Based
  - Self Care

## **Therapeutic Communication**

- Compassionate presence
- Reflective listening, query about important life events
- Open ended questions to elicit feelings
- Support patient's sources of spiritual strengths
- Inquiry about spiritual beliefs, values and practices
- Listening to patient's story
- Therapeutic use of touch
- Continued presence and follow-up

## **Meaning Based Therapy**

- Meaning-centered psychotherapy
- Dignity conserving therapy
- Hope enhancing interventions
- Narrative therapy
- Life review

## **Religion Based Therapy**

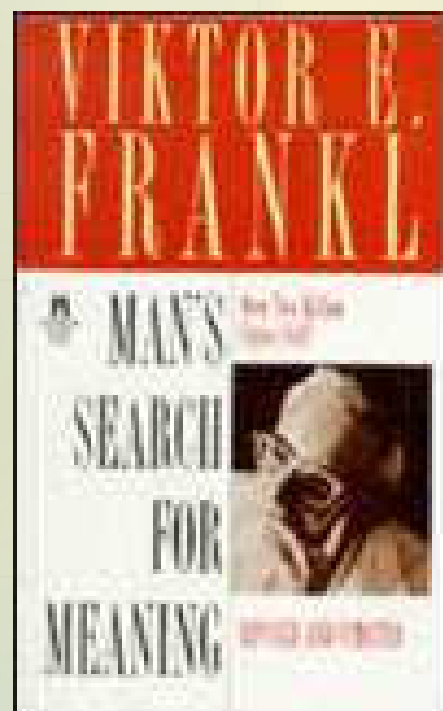
- Respect patient's own religious belief
- Rituals and practices
- Sacred readings, prayer, sacred music / hymns

## Self Care

- Guided imagery, progressive relaxation, breathing practices, contemplation, massage, meditation, mindfulness, yoga, tai-chi, qigong.....
- Spiritual support groups
- Exercise
- Art therapy – music, art, dance
- Journaling....

## Logotherapy

- Will to meaning despite intense suffering – “*the hopelessness of our situation did not detract from its dignity or meaning*”
- Three sources of meaning:
  - Attitude
  - Creativity
  - Experience
- Logotherapy



# Meaning-Centered Group Psychotherapy

8 week sessions consisting of didactics, discussion and experiential exercises around themes related to meaning and cancer

1	Concepts of meaning and sources of meaning
2	Cancer and meaning
3	Historical sources of meaning: Legacy - Past
4	Historical sources of meaning: Legacy – Present and future
5	Attitudinal sources of meaning: Encountering life's Limitations
6	Creative sources of meaning: Responsibility, creativity
7	Experiential sources of meaning: nature, art, humor
8	Termination, goodbyes, hopes for future

*Spirituality and meaning in supportive care: spirituality and meaning-centered group psychotherapy interventions in advanced cancer, Supportive Care in Cancer 2001, William Breitbart.*

## Meaning-Centered Group Psychotherapy (MCGP)

- 90 advanced cancer patients (Stage III/IV) randomised to MCGP or supportive group psychotherapy
- Significantly greater improvements in spiritual well-being and a sense of meaning, treatment gains even more substantial 2 months after completion
- Improvement of anxiety and desire for death

Breitbart. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot RCT. *Psycho-Oncology* 19(1):21-28, 2010



## Dignity Therapy

- Dignity: The quality or state of being worthy, honoured, or esteemed
- Dignity Model – a therapeutic map  
– *Harvey Max Chochinov*
- Dignity Therapy

*Dignity in the terminally ill- a developing empirical model, Social Science and Medicine 2002, Harvey Max Chochinov*

## Dignity Therapy

- Dignity Psychotherapy Question Protocol
- Tape-recorded interview
- 1-2 sessions; < 1 hour
- Transcribed, edited, returned to patient: **Generativity Document**
- RCT underway: Hospice patients / nursing home residents

*Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life, J Clinical Oncol, 2005, GM Chochinov.*

## Dignity Therapy - Framework of Questions

- Important parts of life history
- Things to be remembered
- Roles, accomplishments
- Things to be said
- Hopes and dreams for loved ones
- Life lessons to pass it on
- Words of comfort and solace to family

## Narrative Therapy

234 patients with cancer pain with baseline pain score of at least 5/10 (Boston)

1. Group 1: Narrative (n=79) -wrote a story about how cancer affected their lives for at least 20 minutes once a week for three weeks
2. Group 2: McGill Pain Questionnaire
3. Group 3: Control – usual care

OUTCOME:

1. No significant differences in pain and well-being scores in the three groups
2. Those whose narratives had high emotional disclosure had significantly less pain and reported higher well-being scores than patients whose narratives were less emotional

Emotional Disclosure Through patient Narrative May Improve Pain and Well-Being: Results of a RCT in Patients with Cancer Pain. Cepeda et al, JPSM 2008; 35:623-631

## Life Review

- Four sessions of a Structured life review interviews by a clinical psychologist with 12 patients in a Palliative care unit in Japan
- The mean overall QOL score and spirituality subscale score of the SELT-M Questionnaire significantly increased after the life review from 2.57 +/- 0.61 to 3.58 +/- 1.0 (p=0.013) and 2.57 +/- 0.61 to 3.14 +/- 2.25 (p=0.023)

Life Review Interview on the spiritual well-being of terminally ill cancer patients. Michiyo Ando et al. Support Care Cancer (2007) 15:225-231.

## Living With Hope Program

1. Video on hope
2. 1 of 3 hope activities in one week:
  1. Write a letter (or ask someone to write for you) to someone you want +/- give it to the person
  2. Begin a Hope Collection
  3. Begin an 'About Me' Collection
- Treatment group: higher hope and QOL than control

*Living With Hope: Initial Evaluation of a Psychosocial Hope Intervention for Older Palliative Home Care Patients, JPSM 2007, Wendy D Duggleby.*

## **Culture - Healing Environment**

- Leadership
- Physical environment
- Work practices and standards
- Team reflection / communication / support / Training and education
- Attend on own spiritual needs; reflective practices

## **Creating Healing Environments**

- Pilot initiative to build a culture that attend to the spiritual needs of patients, their families and professional caregivers
- Narrative results: more positive culture, stronger sense of teamwork and community, improved staff satisfaction, less sick leaves, more ready to provide spiritual care to patients and to other team members as well..

## **Watch with me.**

***“Who in there in all the world who listens to us? Here I am – this is me in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can’t express, my terror, my abandonment? Oh, listen to me on a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. Oh God, is there no one to listen?”***

*Seneca, Ancient Rome*

***“....unless we are occupied in our own search for meaning, we may not create the climate in which patients can be helped to make their own journeys of growth through loss.”***



*Dame Cicely Saunders*