The Chinese University of Hong Kong
The Nethersole School of Nursing
CADENZA Training Programme

CTP 003: Chronic Disease Management and End-of-life Care
(Module II)

Web-based Course for
Professional Social and Health Care Workers

香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust

Chapter 2
Psychosocial spiritual care in end-of-life

Lecture Outline

1. Spirituality in end of life
   - The concept of spirituality
   - The essence of spiritual care unit
   - Guidelines for providing spiritual care in clinical situations
   - Spiritual needs of end-of-life patients
   - Spiritual assessment
   - The role of psychosocial spiritual care in end-of-life

2. Psychosocial spiritual care in a multi-disciplinary team context

- Care for the professional carer
- The art of working in a palliative care unit: coping skills to prevent burn out
- The role of the multi-disciplinary team in providing spiritual care

WHO Definition of Palliative Care

- “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
- Integrating the psychological and spiritual aspects of patient care is one of the aspects.

(WHO, 2012)

Spirituality in end-of-life

- A 1997 Gallup Poll surveyed 1200 Americans
- The result found that over 50% of the respondents reflect a need for companionship and spiritual support in end of life.
- The source of comfort:

family	81%
good friends	61%
clergy	36%
doctor	30%

- Nearly 40% of the respondents expressed the importance of a doctor to care for their spirituality.

(Chochinov & Cann, 2005)

The concept of spirituality

- Spirituality is the essence of palliative care
- Dame Ciecely Saunders is the founder of St. Christopher's Hospice in England
- She was influenced by the ancient 'hospes' - places for pilgrims to rest and take care of the sick and the poor and perform the works of mercy contained in the Bible.

- Therefore, palliative care was founded under the concept of love and compassion in Christianity.
- The focus shifted from religion to spirituality when fewer people cared about religious.

(Wright, 2004)

Religion vs Spirituality

Religion	**Spirituality**
Focused in organizations Emphasis on defining orthodoxy and orthopraxy	Not organization bound
Meaning transmitted through creed and narratives of the community	Meaning discovered in the context of level individual
May provide a framework for spiritual growth	Concerned with self-directed spiritual growth

(McClement & Chochinov, 2010, p.1404)

An inclusive model of the spiritual domain

- Wright defined the perception of spirituality as:

  1. ***Personhood***:
    - values, beliefs, achievement

  2. ***Relationship***:
    - with self, others, the universe, a ‘life force’ or God

  3. ***Religion***:
    - prayer, vocation, commitment and worship

  4. ***Search for meaning***:
    - the question of life and death, mortality

  5. ***Transcendence***:
    - something beyond / something within

(Wright, 2004, p.220-221)

- Wright illustrates spirituality in a model which includes four domains:
  - Self, Others, Cosmos and Religion
- Religion occupies a significant place
- The four spiritual activities are:

1. Becoming
2. Connecting
3. Finding meaning
4. Transcending

- Wright concluded that the inclusive models of spirituality:
  - Ø recognise that patients are drawn from a multicultural society
  - Ø there is more than one spiritual source,
  - Ø same as the holistic concept of hospice which recognise values of acceptance and non-judgmental compassion.
- "All people are spiritual beings. Spirituality may be expressed both religiously and humanistically. "
- Spirituality is meaningful to all people with religion or without religion, also to the people with differences of faith.

(Wright, 2004 ; Wright, 2002,p.4)

11 Dimensions of spirituality at the end of life

- Vachon stated 11 dimensions of spirituality at the end of life:

1. meaning and purpose in life
2. self-transcendence
3. transcendence with a higher being
4. feelings of communion and mutuality
5. beliefs and faith
6. hope
7. attitude towards death

8. appreciation of life
9. reflection upon fundamental values
10. the developmental nature of spirituality
11. the conscious aspect

(Vachon, Fillion & Achille, 2009)

Chinese spirituality in end-of life

Chinese spirituality towards death and dying

- The three classical beliefs in Chinese culture are:
  - Ø Confucianism,
  - Ø Taoism,
  - Ø Buddhism
- Folk religion is also common

Confucianism	•moral development and interpersonal relationships (familial relationships).
Taoism	•strong naturalistic view , Yin and yang
Buddhism	•the cycle of reincarnation.
Folk religion	•ancestor worship which is an act of respect and seeking of blessing from the ancestor. •extend the line of descendants and a form of immortality

(Chan, Lam, Chun, Dai &Leung, 1998)

Essence of spirituality in terminally ill patients

- A qualitative study was held in Taiwan.
- Six subjects were interviewed.
- They were asked to describe their thoughts, feeling, beliefs, and experiences related to the essence of spirituality.
- Four constitutive patterns
    1. communion with self,
    2. communion with others,
    3. communion with nature and
    4. communion with higher being
  - and ***ten themes*** emerged in Chinese culture.

(Chao, Chen & Yen, 2002)

1. Communion with Self

Theme	Illustration
1. Self-identity	The discovery of the authentic self
2 .Wholeness	•A human being is full of contradictions but still whole •The patient's thoughts about death and their hopes for life •Reminiscence / life review is a good therapy
3. Inner peace	•Negotiating conflicts for self-reconciliation •Inner peace comes from self-reconciliation of conflicts and concluding that his or her being is valueable

(Chao et al., 2002)

2. Communion with others

Theme	Illustration
1: Love	Caring relationships but not over-attach to others
2 : Reconciliation	To forgive others and to be forgiven by others

(Chao et al. , 2002)

3. Communion with Nature

Theme	Illustration
1 . Inspiration from nature	The resonance of the beauty of nature
2 . Creativity	• Spirituality nurture imagination •Art, music and aroma inspire people's creativity

(Chao et al. , 2002)

4. Communion with a Higher Being

Theme	Illustration
1: Faithfulness	Trust and reliable
2: Hope	Remaining possibilities
3: Gratitude	Thanks giving and grace embracing

(Chao et al. , 2002)

Spirituality and spiritual care for terminally ill patients in Hong Kong

- A study on Chinese terminally ill patients was conducted in 2007 in Hong Kong.
- 15 participants diagnosed with cancer were interviewed.
- The participants' age ranged from 53-89 with a mean of 62.9.
- Six were Christian, one was Catholic, three were Buddhist, and five had no particular religion
- ***A framework*** on spirituality was constructed containing ***four themes*** and ***seven sub-themes***.

Four themes on spirituality

- Mok derived 4 themes and sub-themes from her study

Theme	Sub-themes
1. Life is an integrated whole	• Integration of mind and spirit • A unique personal belief and experience
2. Acceptance of death as a life process	• Harmony with self and nature • Letting go
3. Finding meaning in life	• Receiving and giving love in relationships and connectedness • Having faith in God/higher power • Being a good person
4. Having a sense of peace	

(Mok, 2010,p.364)

Spiritual strengths of older people facing death

Spiritual / Existential tasks for older people

- There are still tasks ahead for older people when facing death:
  - to find purpose and meaning in life
  - transcending loss
  - finding new intimacy with God and/or others
  - finding hope in the face of despair

(Thompson & Chochinov, 2009)

Spiritual needs at the end of life

Spiritual pain/ suffering

- Cicely Saunders suggested 4 aspects of pain:

  psychological, social, emotional and spiritual, that together make up ‘total pain’.
- Spiritual pain and existential suffering are common at the end of life.
- It will be expressed in the form of losing one’s will to live, and heightened desire to die.

Total Pain

Physical	•Co-morbid causes •Caused by treatment •Caused by cancer
Psychological	•Anxiety •Fear of suffering •Depression •Past experience of illness
Social	•Loss of role and social status •Loss of job •Financial concerns •Worries about future of family •Dependency
Spiritual	•Anger at fate/ anger with God •Loss of faith •Finding meaning •Fear of the unknown

(International Association for The study of pain, 2009)

http://www.iasp-pain.org/AM/Template.cfm?Section=Home&Template=/CM/ContentDisplay.cfm&ContentID=8705

Elements of spiritual pain

- Loss of control
- Feeling burdensome to others
- Hopelessness
- Loss of will to live
- Fear of death
- Unfinished business/ incomplete life task

(Chochinov & Cann,2005; Deeken, 2004)

Elements of spiritual pain

- Existential concerns (lack of meaning)
- Abandonment by God or others
- Anger at God or others
- Concerns about relationship with deity
- Conflicted or challenged belief systems
- Despair and hopelessness
- Grief/ loss
- Reconciliation
- Isolation
- Religious-specific
- Religious/ spiritual struggle

(Puchalski, Ferrell, Virani, Otos- Green, Baird, Bull, Chochinov, Handzo, Nelson,-Becker, Prince-Paul, Pugliese & Sulmasy, 2009)

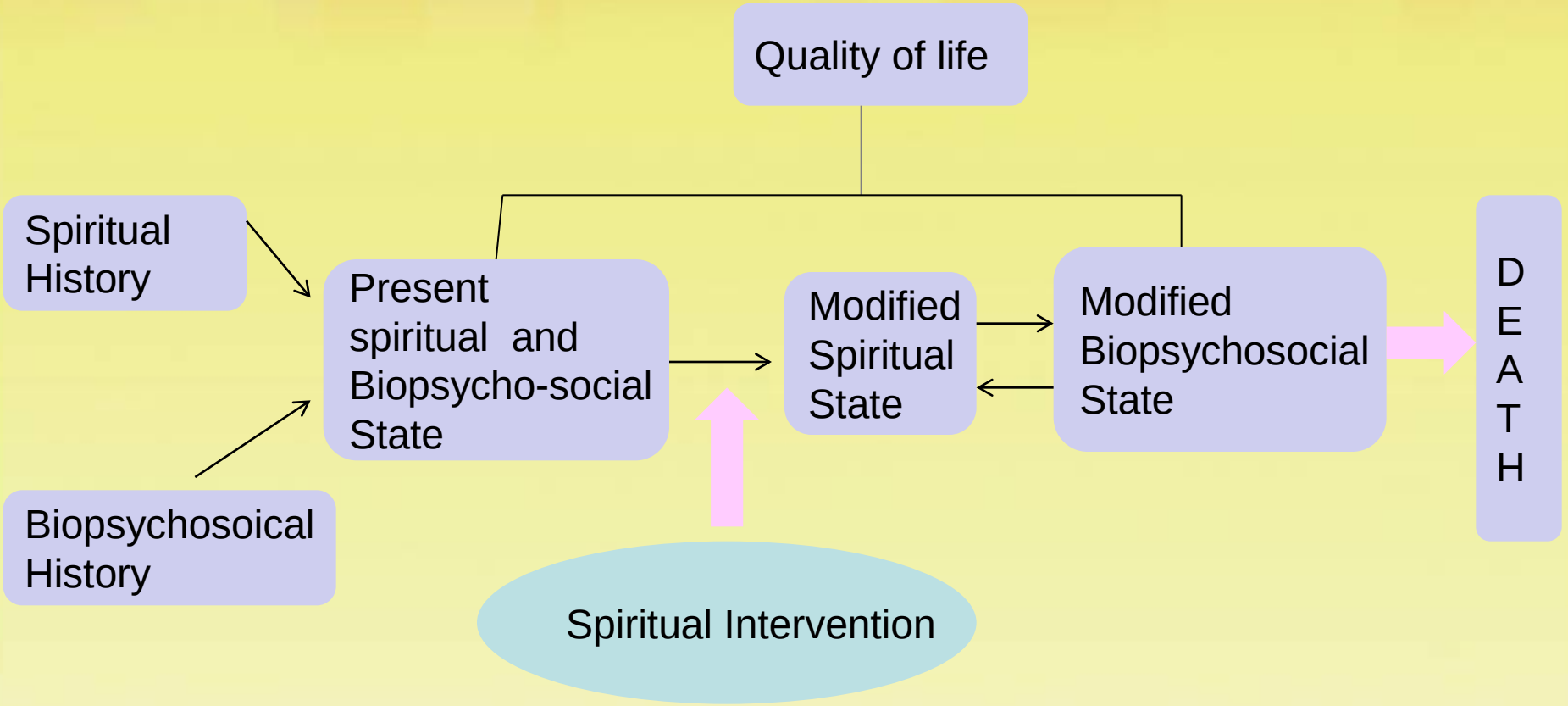
Spiritual Care

Bio-psychosocial-spiritual model

- Humans are intrinsically spiritual.
- Human beings are in a relationship - biologically, psychologically socially, and transcendently.
- Sickness is a disruption of that relationship.
- Healing is the restoration of patient's relationship between body, mind, environment, and the transcendent.
- Each aspect can be affected by a person's spiritual history; each aspect can affect other aspects.
- The concept is illustrated in a model.

(Sulmasy, 2002)

Spiritual care Model



The bio-psychosocial-spiritual model of the care of dying patient
(Sulmasy, 2002, p.27)

Four measurable spiritual and religious domains in the model

Category	**Element**
Religiosity	Strength of belief, prayer and worship practices, intrinsic versus extrinsic.
Spiritual/ religious coping and support	Response to stress in terms of spiritual language, attitudes, practices, and sources of spiritual support.
Spiritual well-being	Spiritual state or level of spiritual distress as a dimension of quality of life. FACIT is one of the measurement tools. For more information, visit the link: http://www.facit.org/FACITOrg/Questionnaires
Spiritual needs	Conversion, prayer, ritual, spiritual issues.

(Sulmasy, 2002, p27)

Is religious care identical to spiritual care?

Religious Care vs Spiritual Care

Spiritual Care	Religious Care
• on a one-to-one relationship, • completely person-centred • not concerned about personal conviction or life orientation	•in the context of shared religious beliefs, values, liturgies and lifestyle of faith community.
People should always be spiritual.	People not necessarily religious

• Everyone, whether religious or not, needs support and care

(Scottish Executive Health Department, 2002)

The essence of spiritual care

- Affirms the value of every individual
- Personal relationship
- Empathy
- Non-judgmental love
- Affirming the worth of each person in the eyes of God
- Someone to be there, to listen and to love
- Sharing the patient's journey and helping a person to find meaning

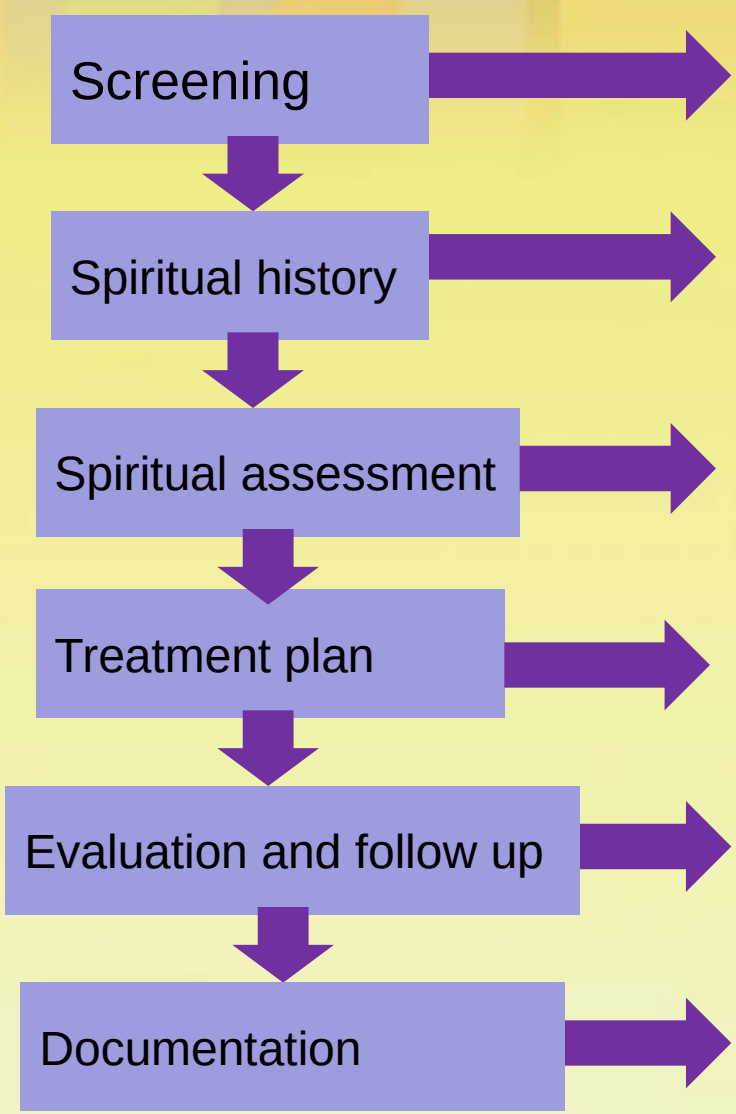
(Wright, 2002)

- According to Puchalski, this is an inter-professional spiritual care model.
- The patient and clinician work together in a process of discovery, collaborative dialogue, treatment and ongoing evaluation and follow up.
- Health care professionals should take an appropriate spiritual history from the patient.
- Clinicians identify the presence of a spiritual issue and make the referral.

(Puchalski et al., 2009)

Spiritual assessment

The procedure of making spiritual assessment



Quick determination : whether a person is facing spiritual crisis.

Interviewing : understand their spiritual need and resources.

More extensive process: conducted by a chaplain,.

Integrate information: put the spiritual assessment into the patient's treatment plan.

Reevaluate: the impact of intervention.

Documentation: Showing the impact and effectiveness of the intervention to team.

(Puchalski et al., 2009)

Goal of taking spiritual history

- One of the spiritual assessments is taking spiritual history.
- Ask the patient to share spiritual and religious beliefs .
- Hear patient's beliefs and values.
- Assess for spiritual distress.
- Provide compassionate care during the process.
- Allow the patient to find inner resources of healing and acceptance.
- Understand patient's spiritual and religious beliefs as a factort hat might affect health-care decisions.
- Indentify appropriate spiritual practices
- Make the proper referral.

(Puchalski et al., 2009)

Spiritual Assessment Tool

1. FICA
2. HOPE

FICA: Spiritual Assessment

- Christina M. Pulchalski developed the acronym 'FICA' to be used in performing a spiritual assessment.

F	Faith, Belief, Meaning	What is your faith tradition?
I	Importance and Influence	How important is your faith to you?
C	Community	What is your church or community of faith?
A	Address/ Action in Care	How do your religious and spiritual beliefs apply to your health? How might we address your spiritual needs?

- For more information and details of the assessment, contact *The George Washington Institute for Spirituality and Health at* www.gwish.org

HOPE Questions

- HOPE questions are a formal spiritual assessment developed by Gowri Anandarjah (2001). It consists of four domains.

H	Sources of Hope, meaning, comfort, strength, peace, love and connection
O	Organized religion
P	Personal spirituality and Practices
E	Effects on medical care and end-of-life issues

- For an example of the questions, please refer to the following link:

  http://www.aafp.org/afp/2001/0101/p81.html

(Anandarjah & Hight, 2001)

Spiritual intervention for end-of-life patient

- ØFinding hope
- ØSearch for meaning
- ØDevelop a therapeutic environment
- ØUse of religious resources
- ØUse of connectedness
- ØOther interventions

Finding Hope

- Hope for end-of-life patient:
  - Hope for relief of pain
  - A peaceful death
  - Being well cared for and supported
  - The well-being of their family
  - Life after death
  - Living day by day

(Thompson & Chochinov, 2009)

- **Hope-fostering strategies**
  - ØSetting short-term goals
  - ØDrawing on their faith
  - ØLeaving a legacy
  - ØFinding meaning and purpose
  - ØConducting a life review

(Thompson & Chochinov , 2009)

Search for meaning

Type of meaning	Means
1. Meaning in past	• Personal / life achievement in the past
2. Meaning in present	• Meaning in suffering, illness and death • There is no easy answer, but most patient do not expect an answer, just be a listener • Encourage to live in the moment, and treasure the present relationship and communication
3. Meaning in future	• Hope for eternal life • Reunion with their loved one

- The caregiver cannot create meaning for a dying patient, but help them to discover their own meaning.
- Man's search for meaning is the primary motivation in life.

(Deeken, 2004; Frankl, 1984)

Develop a therapeutic environment

- Elements of creating a therapeutic environment:
  - Ø A patient-centred health care system.
  - Ø Honouring the dignity of all people.
  - Ø Practice compassionate presence.
  - Ø Use of reflective listening to query about important life events of the patient.
  - Ø Explore patient's sources of spiritual strength.
  - Ø Use of Open-ended questions.
  - Ø Practice continued presence and follow up.
  - Ø Practice " being" : be with the patient to avoid loneliness or death alone.

(Puchalski et al., 2009; Kellehear, 2009)

Religious resources

- Prayer
- Ritual
- Finding the meaning and lesson of suffering in the Bible/ Scripture
- As a Christian, obtaining God's help, comfort, forgiveness, and find strength in Christian community
- Ensuring hope and belief in life after death
- Experirncing Forgiveness of self and others / let go
- Being remembered

(Puchalski, Dorff & Virani, 2004)

- For Buddhists, inner peace in the dying process
- In Confucian tradition, being respected, honoured and remembered after life

(O’ Brien, 2008)

Use of Connectedness

- Four meaning-making categories (4Rs) that can open a conversation and connect with patient.

Remembering	Do you enjoy your life? Some memories that trouble you?
Reconciliation	Whom you would like to see? Anyone you want to say good-bye to?
Reassessing	Do you have any wishes? Is there any spiritual contribution you like to make?
Reunion	Is there anything you hope for? Is there thing you want us to remember you? What's that? Do you have any believe in afterlife?

(Thibault, 2000)

Other intervention

- Life review
- Guided visualisation for ‘meaningless pain’
- Progressive relaxation

(Puchalski et al., 2009)

Techniques for encounters with patients

Therapeutic encounter

- Be a real person.
- Practice :
  - compassion,
  - acceptance
  - awareness.
- It involves *being with* the patient rather than *doing to* the patient
- It is a state of :
  - Ø being open
  - Ø learning the patient's experience in a gentle, non-judgmental and compassionate way
  - Ø not observing and looking at, or even into, the patient

(Geller & Greenbery, 2002)

- The therapeutic relationship facilitates:
  - Ø communication and understanding
  - Ø listening
  - Ø connectedness, which enhance patient's meaning during life's end
- The essential element of successful spiritual care is the person who carries these technique.
- Attitude is more important than technique.

(Lam, 2007)

Guidelines for providing spiritual care

- Spiritual care or spiritual assessment is use to address a person's inner side which should be practiced according to culture
- Guidelines and policy are needed
- A comprehensive guidelines, including: the role of the chaplain, principle of spiritual care, administrative policy, and documentation are worked out by The Scottish Executive Health Department
- For the details, please refer to the following link:
- *GUIDELINES ON CHAPLAINCY AND SPIRITUAL CARE IN THE NHS IN SCOTLAND*
- http://www.scotland.gov.uk/Publications/2009/01/30110659/18

Psychosocial spiritual care in a multi-disciplinary team context

Care for the professional carer

- Professional caring people with compassionate hearts carry a heavy emotional load.
- When stress is untreated, the result is ‘burn out’ or ‘compassionate fatigue’.

Distress in clinical settings

Triangular model of suffering

The interrelationship between the distress of the patient, family and healthcare provider (Cherny, 2010)

- The suffering of each of the three groups is interrelated so that the perceived distress may bring distress of others
- Working in palliative unit is stressful because of facing the distress of people (Cherny, 2010)

Team stress in palliative care

- A study interviewed 100 caregivers from variety of professional groups in palliative care units.
- The samples were taken from Canada, the United States, Europe and Australia.
- Stress factors, symptoms and coping techniques were examined.

Stress factors

- Communication problems with others in the caring system.
- Role ambiguity and role conflict of the staff.
- Communication problems within the team members.
- Communication problems with administration staff.
- Nature of the system or organisation.
- Insufficient resources and unrealistic expectations of the caring organisation.
- Patient / family coping problems in suffering, death and dying.
- Patient / family and communication problem

(Vachon, 1987)

- Staff conflict.
- Feelings of depression, grief, guilt, helplessness, and insecurity in facing the death of patient .
- Job/ home interaction conflict.
- Culture of niceness.
- Facing with patient's suffering, death, and dying.
- Personality and resilience of the staff.
- Being single and young.

(Vachon, 1987; Jamieson, Teasdale, Richardson & Ramirez, 2010)

Symptoms of burn-out

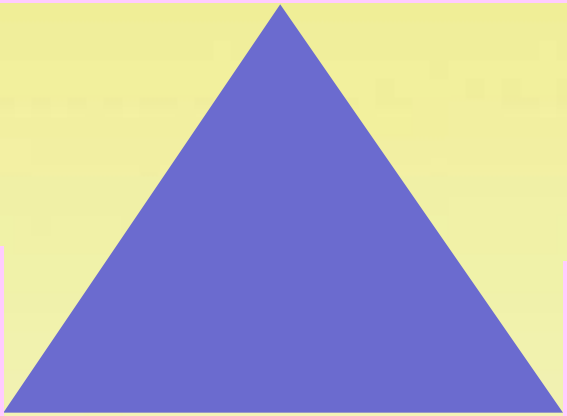
- Syndrome of emotional exhaustion.
- Depersonalisation.
- Reduced personal accomplishment.
- A sense of decline in effectiveness.
- Decreased motivation.
- Dysfunctional attitudes and behaviours at work.

(Mackereth, White, Cawthorn & Lynch, 2004)

Coping strategies

- 3Cs Model

Complementary therapies such as aromatherapy, massage, and reflexology.



Counselling: confidential counselling separate from the organisation, to enable employees or their family members to seek relief.

Clinical supervision offers an opportunity for staff to shed the emotional toll of work.

(Mackereth, 2004)

- Provide training on compassionate presence.
- Promote self care, self reflection, retreat, and attention to stress management in the health care setting.
- Boundaries needed to be recognised to ensure an appropriate therapeutic relationship.
- A sense of connectedness in the team to avoid a blaming culture.
- Open communication/ discussion within the team on making clinical decisions and on ethical issues.

(Puchalski, 2009)

The Role of Multi-disciplinary Team in Spiritual Care

- Psychosocial spiritual care is provided in a multi-disciplinary team approach.
- All team members have the responsibility for:
  - providing spiritual care, while the certified chaplain plays the key role.
  - promoting meaningful and compassionate care in a clinical setting.
- Spiritual care is offered instead of imposed.

(Puchalski et al., 2009; Rumbold, 2003)

Team member attitudes

- Recognise spirituality as an integral component.
- Perform spiritual care in a patient-centred, confidential, and respectful manner.
- Explore the patient's spiritual concerns, and make proper referral.
- Respect patient's autonomy to either address or not address spirituality.
- Collaborate with interdisciplinary professionals.
- Provide professionaland compassionate spiritual care.
- Take training in spiritual care.

(Puchalski et al., 2009)

Conclusion

Relationships

…are key to the spiritual care of terminally Ill patients.

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