

Certificate Course in Paediatric Palliative Care
Nursing:
**Exploring the spiritual needs of children
and parents in PPC in Hong Kong**

陳智豪 Chan Chi Ho, Wallace
PhD., RSW, FT, Diplomate of Logotherapy
Associate Professor
Department of Social Work
The Chinese University of Hong Kong

What's your impression on "spiritual"
needs? Or what are your feelings
when talking about "spiritual"?

Significance of Spiritual care

- Spiritual Care recognized in the WHO definition of palliative care

*Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening disease, through the prevention and relief of suffering by means of early identification, treatment of **pain and physical, psychosocial and spiritual** problems.*

- The US Psychosocial Standards of Care Project for Childhood Cancer: Spirituality recognized as instrumental in contributing to the well-being of children with cancer and their families during treatment and through bereavement
- The US National Consensus Project guidelines for quality palliative care: Spiritual, Religious and Existential Care is one of the eight essential domains
- Spiritual Care is a fundamental part of holistic nursing care
- Pediatric palliative care included the recognition of the spiritual and existential needs of children and families (Ferrell, Wittenberg, Battista & Walker, 2016)

Significance of Spiritual care

- Parents of children who are in the intensive care unit rely on faith in God, religion, or spirituality for coping and prognostication (Arutyunyan, Odetola, Swieringa & Niedner, 2018)
- Parental religious and spiritual beliefs affect **medical decision making**
- Support of terminally ill patients' spiritual needs will lead to better **quality of life** in end of life (Gijsberts *et al.*, 2019)
- Spirituality helps to overcome parents' **fears and to find hope** (Robert *et al.*, 2019)
- Religion helps children to **cope with treatment and strengthen their hope for cure**
- **Positive impact on children's care** when children with advanced cancer talk about their spiritual concerns with nurse (Kamper, Van Cleve & Savedra, 2010)
- Positively influence the **patient-practitioner relationship** (Kelly, May & Maurer, 2016)
- Lack of spiritual support by medical team members lead to **higher risk of depression** and reduced sense of spiritual meaning and peace (Pearce *et al.*, 2012)

Need or spirituality: What is spirituality?

- ▶ Spirituality = Religious?
- ▶ Broader than Religious beliefs and affiliation
- ▶ A complex, multi-dimensional and abstract concept
- ▶ No single definition prevails
- ▶ All people have spirituality, no matter your age or stage of development

Definition of spirituality (Weathers, McCarthy & Coffey, 2016)

- ▶ Antecedent: A belief system or worldview, every person has a responsibility to care for the spirit and every person is accountable for their daily life choices, the experience of a difficult life event
- ▶ Three important attributes: **Connectedness, Transcendences & Meaning in life**
- 1. **Connectedness**
A sense of connectedness to oneself, others, nature or the world, and a higher power, god, or supreme being
- 2. **Transcendences**
- the ability to see beyond the boundaries of the self, the environment, and present limitations
- the capacity to self-transcend and transcend suffering
- 3. **Meaning in Life**
- ▶ Consequence: Alleviation of suffering, a sense of well-being, enhanced ability to adapt and cope with adversity, a **sense of peace (平安)**, and inner strength

Definition of spirituality (Weathers, McCarthy & Coffey, 2016)

- ▶ **Definition:**
Spirituality is a way of being in the world in which a person feels a sense of connectedness to self, others, and/or a higher power or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering.

Spirituality in HK Chinese Context (Mok, Wong & Wong, 2009)

- ▶ Similar to the western definition of spirituality with two additional or unique aspects
- 1) The fulfillment of personal responsibility
- ▶ Being a good person give Chinese patients a life purpose in their remaining life
- ▶ Emphasize the fulfillment of the responsibility of being parents and taking care of other family members
- ▶ Reflect the Chinese Confucian background (Fulfill individual responsibility to be a good and ethical person)

Spirituality in HK Chinese Context (Mok, Wong & Wong, 2009)

- 2) Acceptance of death as a life process
- The cultural beliefs of Taoism and Buddhism facilitate the acceptance
 - Taoism: Humankind is an inseparable part of the cosmos and believers seek harmony with the universe
 - Buddhism: Life will lead to suffering as everything about life and the self is temporary
 - Provide an explanation of illness as part of life
 - The sense of being in harmony with the universe and letting go facilitate acceptance of dying

What is spiritual care? (Gijsberts, Liefbroer, Otten & Olsman, 2019)

- Spiritual care means that spiritual caregivers pay attention to patient's spirituality and their hope
- Try to be present, to empower and to bring peace to patients and patients' relatives
- Spiritual care includes communication and ritual work
- A good understanding of spirituality is required to provide high quality of spiritual care

Competency to provide spiritual care

- Important but are you competent to provide spiritual care to patients and parents ?
- Spiritual Care Communication is the most difficult areas of communication for nurse (Ferrell et al., 2016) (Arutyunyan et al., 2018)
- Great anxiety and hesitate to discuss spiritual and religious concern with patients
- Medical Staff think spiritual care is important but not competent to provide (Gijsbert et al., 2019)
- Example in Swiss: More than half of the 579 medical staff think it is important but only 38% feel competent
- Reason: Lack of time, comfort, training and uncertainty

Dying Patient's Spiritual Needs (Herman, 2001)

- 1) Need for religion (Pray, Read bibles, Read inspirational materials, Go to church, Listen to music)
- 2) Need for companionship (Talk with family and friends, contribute and help others)
- 3) Need for involvement and control (Involve in decision and choices, involve with family situation)
- 4) Need to finish business (Finish life tasks by doing life review)
- 5) Need to experience nature (Go outside and have a walk)
- 6) Need for positive outlook (Smiles and happy thoughts)

Willing to talk about spirituality? Western and Chinese perspective

Western Perspective:

- A research collected 162 surveys from parents of children hospitalized for >48 hours in pediatric intensive care unit in a tertiary academic medical center (Arutyunyan et al., 2018)
- 48% of the parents whose children is seriously ill would like the medical staff to ask about their spiritual or religious belief
- **61% of the respondents talked about their spiritual views if asked but will not talk voluntarily**
- Only 16% of the respondents would not like the medical staff to ask about their spiritual and religious view
- More comfortable to discuss with hospital chaplain or community provider
- **Only 38% of the respondents hope their physician to pray with them**

Willing to talk about spirituality? Western and Chinese perspective

- Another research surveyed primary caregivers of children referred to palliative care <1 year prior at a pediatric academic medical center (Kelly, May & Maurer, 2016)
- 2/3 of the respondents (16/24) want assessments of their religious and spiritual needs
- None of them think that it is offensive and uncomfortable to ask
- **Respondents did not specifically want medical staff to assess religious and spiritual needs but willing to answer**
- Encourage medical staff to ask patient's spiritual needs

Willing to talk about spirituality? Western and Chinese perspective

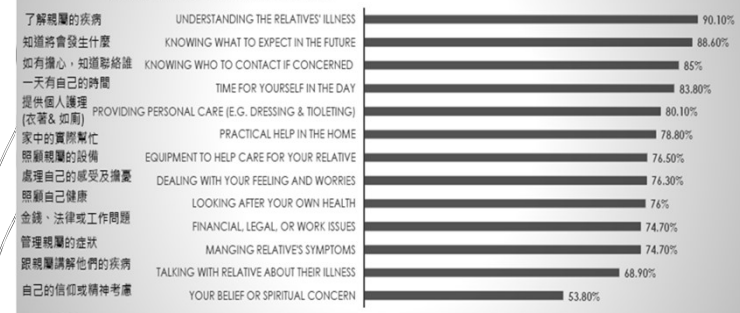
Chinese Perspective

- Chinese People do not expect nurses give attention to patient's spiritual concern (Mok et al., 2009)
- Spiritual needs is less important compare to other practical needs (Chan, 2019)

Explanations:

- Meet the urgent needs first like getting practical information (more pragmatic)
- Lack of trust between nurse and patients
- Spiritual care is less concerned

Percentage of caregivers expressing need for more support with each domain in Carer Support Needs Assessment Tool
照顧者需要更多臨終照顧支援的項目



(Chan, 2019)

Ways to assessing spiritual needs (卓妙如, 2002)

- 1) Active listening: Listen to patients and parents
- 2) Presence: Stay closely with the patients
- 3) Authentic sincere communication: Explore meaning in life and spirituality with patients
- 4) Availability: Provide assistance when patient's in needs
- 5) Quality, unrushed time: Enough time to have in-depth discussion
- 6) Truth-telling: Understand the remaining wishes and show respect
- 7) Sharing: Share any kinds of experience
- 8) Humor: Relax and decrease the level of sadness

Ways to assessing spiritual needs

- Self Awareness: Explore your own spirituality (Narayanasamy, 1999)
- Facilitate and empower patient's finding meaning in life through love, faith, hope and a sense of completion (Mok et al., 2009)
- Communicate with families about anger towards god (Ferrell et al., 2016)
- Remind the patient's family member not to blame their child's illness and death
- Address patients and families' cultural and ritual tradition
- Acknowledge child's belief and help parents understand the child's vision

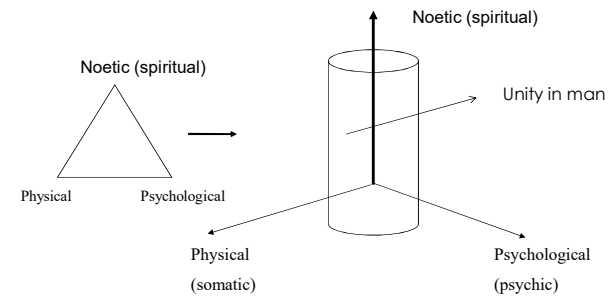
意義治療 Logotherapy

- Founder: Viktor Frankl



Viktor Frankl (1905-1997)

Dimensional Ontology



Noetic dimension: The unique Human Dimension

- the spiritual dimension of human beings; the unique human dimension
- “medicine chest” of logotherapy, which contains various inner resources, such as love, the will to meaning, purpose in life, creativity, conscience, the capacity for choice, sense of humor, commitment to tasks, ideals, imagination, responsibility, compassion, forgiveness (Fabry, 1994, p.18)

Implications in assessing spiritual needs

- Spiritual component is important
- But we are still a person: limited by physical and psychological dimensions
- Beware of the limitations; understand the difficulties
- But remains hopeful

The spirit is willing but the flesh is weak.



But the key is

- At least.....we have the spirit
- At least.....our spirit is willing

Fulfilling the spiritual needs of children patients and their families in PPC?

- The key may not be: Health care professionals do/provide something to fulfill their needs
- Paradoxically, being “spiritual” is by nature transcendental: One looks beyond oneself and is directed to something meaningful (e.g. a meaningful act or a meaningful relationship)
- Spiritually fulfilled: when one comes “self-less” ; do something meaningful and we becomes spiritually fulfilled

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Thank You

- Email: chchan@swk.cuhk.edu.hk
Chan Chi-ho, Wallace