End of Life Care:

Planning an approach to intervene in family struggles

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(Some materials were prepared by Ms Ng Tzer Wee, a palliative care leader in Singapore)

Part I:

Issues, Assessment Framework & Intervention

End-Of-Life Realities

- Technology has blurred the lines between who is dying and who is not
- Belief that it is better to do something rather than nothing
- Creating an ‘effect’ is not equal to creating a ‘benefit’ for the patient
- Hospice is perceived to be abandoning hope
- One cannot be fully prepared for end-of-life realities because of what we do not know beforehand

End-Of-Life Realities

- Most people want ‘natural’ death for their family members, but do not know what that looks like
- Most people die from chronic and prolonged illness as opposed to acute illness
- Many are overwhelmed by ‘choices’ and decision making
- Healthcare is disease focus as opposed to holistic care

Social Work Focus & Responsibilities at EOL Care

- Person/family centered & holistic care
- Self-determination and informed consent
- Ensure access of care for all people
- Symptom management
- Strengths focused
- Psychosocial interventions as priority

Multidimensional Assessment

Biopsychosocial & spiritual in focus:

- Physical
- Social / cultural
- Psychological
- Spiritual
- Practical

Assessment Framework

- Past and current medical situation
- Family's structure and roles
- Stage in the life cycle
- Communication patterns
- Spirituality/meaning
- Cultural values and beliefs
- Socio-economic factors / resources
- Past experience with illness, disability, dying
- Past and present coping

Psycho-social Interventions

- Crisis intervention
- Individual counseling
- Family counseling & therapy
- Family meeting / conferencing
- Patient / family education
- Cognitive-behavioral intervention
- Psycho-educational, support and therapy groups
- Care management, referrals and discharge planning
- Advocacy
- Bereavement and follow up

What's our role as MSWs?

1. Help patients & families prepare / ask questions
2. Focus on the significant impact of any conversations concerning the illness on the patient and family
3. Subtly challenge family or even team members but do not try to take sides
4. Allow different members air time

What's our role as MSWs?

5. Be on the same page as your team
6. Help manage emotions/tensions
7. Use basic communication skills
8. Engage in therapeutic conversations

Dilemmas in decision-making

1. Common / shared understanding of the patient's medical condition, treatment & prognosis
2. Care or no care versus choice of prolonging life and quality of life
3. Substituted judgment versus best interest of the patient
4. Isolated past patient statements versus current medical & social circumstances

Advance Care Planning

- Advance Care Planning : (ACP)

- a process of medical decision-making about future care when the patient is seriously ill and unable to make decisions about their own care

- Not a ' one off ' event (it is a process)

- Advanced Medical Directive : (AMD)

- a component of ACP in written or oral form stating the specific instructions for a life-threatening situation

- A ' one-off ' event

Advance Care Planning

- Understand patient's personal values
  - E.g. to fight till I die or die fighting
- Identify goals and burdens of treatment and care
  - i.e. 'comfort' at all costs, 'life' at all costs, balance between both
  - Will treatment come 'with a price'
- It is an ongoing process
  - Patients priorities, needs and desires change with time and disease progression

Pain and Symptom Management

- Common symptoms in advance cancer
  - Anorexia (loss of wish to eat), nausea, anxiety, pain, weakness, delirium, constipation, diarrhea, dyspnea (breathlessness)
- Symptom Assessment
  - Identify symptoms
  - Degree of symptom and related distress
  - Impact on patient, carer, family and quality of life

Spiritual Issues

- MEANINGS
  - E.g meaning of illness, suffering, death etc
- VALUE
  - E.g what value of mine is being threatened, what's valuable that will persist beyond death
- RELATIONSHIP
  - E.g. am I loved? Any estranged relationship

Helpful Tool - FICA

- F – **Faith** and beliefs
- I – **Importance** of spirituality in the patient's life
- C – Spiritual **community** of support
- A – How does the patient wish spiritual issues to be **addressed**

Helpful Tool – SPIRIT

- S – spiritual belief system
- P – personal spirituality
- I – integration with a spiritual community
- R - ritualized practices and restrictions
- I – implications for medical care
- T – terminal events planning

Ethical Principles in End-Of-Life Care

- Respect for persons (e.g. ability to decide for self, free from coercion)
- Beneficence (i.e. taking positive action to benefit patients, remove that which is harmful, promote or do good)
- Nonmaleficence (i.e. strive to prevent/remove unnecessary harm, avoid ineffective interventions)
  - That intended to be helpful can create unintended harm e.g. truth telling
- Justice (i.e. fairness in access to care)

Decision-Making

- Enhanced decision-making
  - Create calm contained environment
  - Use simple language
  - Vocabulary consistent with patient / family experience
  - Maximize continuity of staff

Decision-Making (1)

- Withdrawing and withholding of therapy
- DNR
- AND (Allow Natural Death)
- Medical futility

Decision-Making (2)

- Hydration and nutrition
  - Symbolic significance of food and water
  - Treatment or basic sustenance
  - Not proven to improve quality of life
  - May do harm
  - May indirectly provide comfort to patient/family

Ethical Principle of Double Effect

- 'intention' – what one does in an action from what one allows to happen as the result of that action

  Action ----- effect "pain and symptom control"

  Action ----- effect "possible respirator depression"
  - Distinction between the direct and indirect intention is known as 'principle of double effect'

Principle of Double Effect - Palliative Sedation

- Relief of intolerable pain, symptoms is moral imperative
- Symptoms cannot be adequately controlled despite aggressive efforts
- Principle of double effect
  - Act must be beneficial or at least neutral
  - Good effect is intended (relief of suffering)
  - Negative foreseen and unavoidable
  - Good effect is direct outcome of act
  - Good effect outweighs possible negative effect

Language

- Words = powerful drugs used by mankind
- VICTIM
  - victim of cancer, victim of environmental danger
  - A word that seems ‘negative’ can have ‘positive’ effect
- POSITIVE
  - Positive thinking VS the biopsy is positive
  - Different definition of ‘positive’, it can be opposites and confusing to many
  - What impact does it have on patients if we say “BE POSITIVE”??

Language

- The important thing about any word is how you understand it.
- Help patients understand the words we use.
- “How do you understand the word ‘positive’?
- We can then start where patients are and patients may not be so burdened.

Grief and Bereavement

- Common myths
  - All losses are the same
  - Time heals
  - It’s crucial to not make any major decisions during the first year
  - The goal of grief is to forget and ‘let go’
  - Everyone grieves in the same way
  - People require therapy to get through grief
  - Children do not grieve
  - If you truly love someone, you will grieve more intensely

Grief and Bereavement – Normal Grief

- Social Work Role
  - Educate
  - Validate
  - Support
  - Provide tools
  - Facilitate
- Questions
  - What have I lost? What is still intact? What really matters? What have I learned? What are the possibilities now? What are the obstacles to these possibilities? What do I need to achieve these possibilities?

Grief and Bereavement – Complicated Grief

- Syndromes
  - Absent mourning (maintain denial or remain in shock)
  - Inhibited mourning (suppressed or repressed)
  - Delayed mourning (put on hold)
  - Complicated mourning (e.g. guilt, unresolved conflicts)
  - Chronic mourning (intensity does not ease over time)
- High risk factors
  - Multiple losses, lack of support, difficult losses, feeling stuck, sudden death

Grief and Bereavement – Complicated Grief

- Social Work Role
  - Assess and treat impediments to the progression of a healthy process so that the individual is able to grieve in a more productive manner

End-Of-Life Practitioner needs to know about…

- Burnout (psychological strain of working with different stressors)
  - Factors contributing to burnout
  - Symptoms of burnout
- Secondary traumatic stress (symptoms mirror those experienced by clients, 'bear witness' to traumatic stress in others)
- Compassion fatigue (helplessness, confusion, isolation)

End-Of-Life Practitioner needs to know about…

- Vicarious traumatization (cognitive and emotional changes experienced by professionals who work with traumatized individuals)
- Traumatic response (feeling continues beyond sessions, intensify, impact personal life and relationships)

Part II:

Patient & Family Struggles

Who are your patients & families facing family struggles at the end of life?

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1. Families with personality issues or have conflictual relationships
2. Families who have unique ideals, beliefs and values
3. Families who are stuck in their life situation or circumstance
4. Families who had previous bad experiences with healthcare workers / MSWs

Who are your patients & families facing family struggles at the end of life?

5. Patients and / or their families with heightened fear of the unknown, suffering and death /dying
6. Families who reject assistance / help or who are shut-off (probably due to a lack of trust)
7. Patients and / or their families who go against medical advice or are non-compliance (having their own agenda)

Who are your patients & families facing family struggles at the end of life?

8. Patients and / or their families who have no personal opinion / decision or who are fickle-minded (lack of decision-making capacity; no prior knowledge of what patient wants)
9. Patients and / or families who are not communicating openly (such as not telling the truth; or they have family secrets)

What are their struggles?

From a patient and family viewpoint:

… when patients and especially families struggle with treatment decisions, the struggle is often rooted in the questions' spiritual dimensions.

John Hardwig, Published in: Hastings Center Report 30, no. 2 (2000): 28-30.

What are their struggles?

From a patient viewpoint:

When I am dying, I am quite sure that the central issues for me will not be whether I am put on a ventilator, whether CPR is attempted when my heart stops, or whether I receive artificial feeding. Although each of these could be important, each will almost certainly be quite peripheral. Rather, my central concerns will be how to face my death, how to bring my life. to a close, and how best to help my family go on without me. A ventilator will not help me do these things-not unless all I need is a little more time to get the job done.

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Obtain values history of the patient

It allows a person to express basic desires, fears, and general life values that would be of assistance in interpreting advance directives or in making end-of-life care decisions

Arons, S. (2004), Current Legal Issues in End-of-life Care in Living with Dying (ed), Columbia University Press, New York.

Case Illustrations:

The Three Brothers
The Foreign Wife
Externalization of SELF
My DPS! It's MINE
My Death Is To Be Concealed
Needing a Friend, Not a Doctor
The Boy Who Shuts Off

Part III:

Specific Therapeutic Interventions

Life is like a …

String …

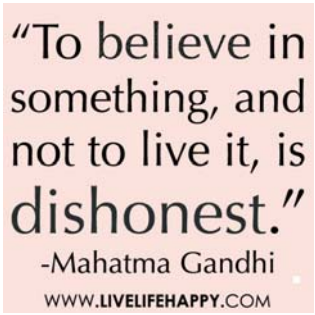
Sometimes, it is smooth-sailing,
Sometimes, it comes with obstacles – big and small.
At the end of it all, your life becomes stronger.

Transformational Thoughts ...

Will-Power:

People who had the Will to live had at least <u>one</u> of these things in their lives:

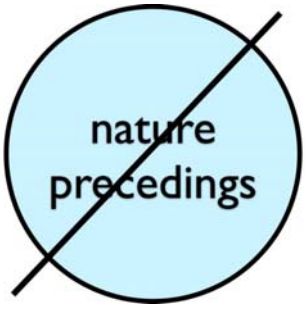
- ***Faith in God***
- ***Creative work***
- ***Someone to love***



Dr Viktor Frankl (1984), Austrian Psychiatrist

Transformational Thoughts ...

- **Accept the unchangeable**
- Letting-go / Let-it-be
- Goal for each day / living each moment / having alternative goals
- Positive thinking
- Believing suffering has a limit / end



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Transformational Thoughts ...

- **Holistic perspective of life**
- **Downward comparison (those worse than you)**

Esther Mok et al (2004),
(Dr Mok is a nursing professor with the Hong Kong Polytechnic University)

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A Patient's Challenges ...
Worry to make sense

- **<u>don't stop worrying</u> – you can't; worry only at the right time as long as it does not interfere with your daily activities; worry to make sense (deserving your worrying) and not make sense to worry (worry more)**
- **- coin therapy as illustration**

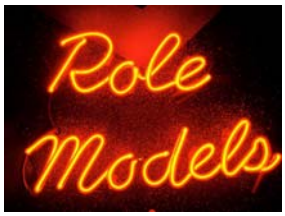
A Patient's Challenges ...
Overcoming emotional pain

1. **<u>Normalizing</u> a traumatic experience would be the first important step towards healing**

- we all have to learn to live with mishaps and misfortunes in life

Prof Cecilia Chan (2001),
Head of Social Work & Social Administration, HKU

A Patient's Challenges ... Overcoming emotional pain



2. **Learn from <u>positive role models</u> who have successfully transformed themselves**

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A Patient's Challenges ... Overcoming emotional pain

3. **<u>Adopt a let-it-be mentality</u>, appreciate life and people, and accept sacrifices in life**

- accept an ever-changing and unpredictability in life, accept life as it is and stop asking "why me?"

Prof Cecilia Chan (2001),
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A Patient's Challenges ... Overcoming emotional pain

4. **<u>Forgive</u> and <u>love</u> yourself**

- forgiveness frees us from bondage and liberates our energy for loving ourselves and others
- when we learn to love ourselves better, life will be more beautiful and fulfilling

Prof Cecilia Chan (2001),
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A Patient's Challenges ... Overcoming emotional pain

5. **Accept <u>support</u> from others, and in turn <u>commit</u> what you can to others**

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