

Living with Your Dying Beloved Family Member:

Dialogue between East and West

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Introduction

- ▶ **What do the following situations have in common?**
- A 36 year-old mother learns that the tingling in her arm has been diagnosed with multiple sclerosis.
- A 64 year-old man, experiencing chest pains, is told that he is having a heart attack.
- A 28 year-old architect finds that he is HIV positive.
- A 41 year-old physician finds a lump in her breast.
- During a routine examination, a 69 year-old man is informed that he has a spot on his lungs.



Introduction

- ▶ In all of these cases, individuals and their families are facing moments of crisis, terrible trials, and frightening encounters with mortality.



Introduction

- ▶ In each situation, each must decide upon a course of action – when to seek medical help, how to choose the best treatment.



Introduction

- ▶ **The experience of life-threatening illness is one of the most difficult situations that individuals and their families ever have to face.**



Introduction

- ▶ From the first mounting suspicions about dangerous symptoms through the crisis of diagnosis and long periods of chronic illness – whether the result is recovery or death – leaves an indelible mark on all individuals, their families and even the people who care for them.



Introduction

- ▶ In the last 50 years, there has been another revolution in medical care as evidenced by the growth of hospice and palliative care.



Introduction

- ▶ **What we have learned from Hospice and Palliative care:**
 - Care in life-threatening illness must be holistic.
 - Life-threatening illness is not only a medical crisis; it is a social, psychological, and spiritual crisis as well.
 - It does not only affect the individual with the illness but also affects the family as well.



Introduction

- ❖ In this presentation, people are only referred to as dying when they are in the final, terminal phase of life-threatening illness.
- ❖ In the terminal phase the illness has progressed to such a point that recovery is highly improbable, health has declined, and death is like to occur within a specific time frame.



The Phases of Life-Threatening Illness

- Prediagnostic
- Acute/Diagnosis
- Chronic
- Recovery
- Terminal
- Death



Prediagnostic Phase

- ❖ This phase precedes diagnosis. Here someone recognizes symptoms or risk factors that make him or her prone to illness.
- ❖ In this phase, the individual now needs to select strategies to cope with the threat.



Prediagnostic Phase

❖ Tasks of the prediagnostic phase

- Recognizing the danger or risk.
- Coping with anxiety and uncertainty.
- Developing and following through on a health-seeking strategy.



Acute Phase

- ❖ This phase centers on the crisis of diagnosis. At this point an individual is faced with diagnosis of life-threatening illness and must make a series of decisions about how to cope with the crisis.



Acute Phase

❖ Tasks of the acute phase

1. Understanding the disease
2. Examining and maximizing health and lifestyle
3. Maximizing one's coping strengths and limiting weaknesses
4. Examining internal and external resources and liabilities



Chronic Phase

- ❖ During this period the individual is struggling with the disease and its treatment. Many people in this phase may be attempting to live a reasonable normal life within the confines of the disease.



Chronic Phase

- ❖ In this phase, rehabilitation therapies may significantly enhance the quality of life and facilitate adjustment. In addition, this period is punctuated by a series of illness-related crises.



Chronic Phase

❖ Tasks of the chronic stage

- 1) Managing symptoms and side effects
- 2) Carrying out health regimens
- 3) Preventing and managing health crises
- 4) Managing stress and examining coping
- 5) Maximizing social support and minimizing social isolation



Chronic Phase

❖ Tasks of the chronic phase

6. Normalizing life in the face of disease
7. Dealing with financial concerns
8. Preserving self-concept
9. Refining relationships with others throughout the course of the disease



Chronic Phase

❖ Tasks of the chronic phase



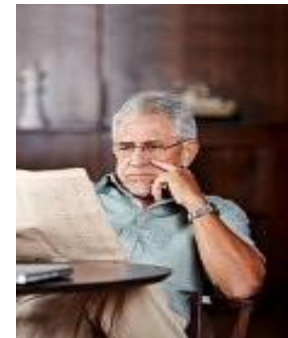
10. Ventilating feelings and fears

11. Finding meaning in suffering, chronicity, uncertainty and decline

Recovery/Remission Phase

❖ Tasks of the recovery/remission phase

- 1) Dealing with psychological, social, spiritual, and financial aftereffects of illness
- 2) Coping with fear and anxieties about recurrence
- 3) Examining life and lifestyle issues and reconstructing one's life
- 4) Redefining relationships with caregivers



Terminal Phase

- ❖ In this phase, the disease has progressed to a point where death is inevitable, no longer merely a possibility. Death has now become the individual's and the families central crisis.



Terminal Phase

❖ Tasks of the terminal phase

- 1) Dealing with symptoms, discomfort, pain and incapacitation
- 2) Managing health and institutional procedures
- 3) Managing stress and examining coping
- 4) Dealing effectively with caregivers



Tasks of Dealing with Life-Threatening Illness

- 1) Responding to the physical facts of the disease
- 2) Taking steps to cope with realities of the disease
- 3) Preserving self-concept and relationships with others in the face of disease
- 4) Dealing with the affective and existential/spiritual issues created or reactivated by disease



Effective Professional Caregivers

❖ Seven Sensitivities

1. Sensitivity to the whole person,
2. Sensitivity to the problem of pain and discomfort,
3. Sensitivity to honest, open, and mutual communication,



Effective Professional Caregivers

❖ Seven Sensitivities

4. Sensitivity to the individual's autonomy,
5. Sensitivity to the individual's needs,
6. Sensitivity to cultural differences,
7. Sensitivity to treatment goals.

(Doka, 2014)



Thank You!

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