



Issues at the End of Life

Health
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(CMED2006)
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Describe the challenges faced by people with terminal illness

Describe the common features of the bereavement process

Suggest ways to support people facing terminal illness, death, and bereavement

Learning Objectives

At the end of the lecture, student should be able to:

- Describe the challenges faced by people with terminal illness
- Describe the common features of the bereavement process
- Suggest ways to support people facing terminal illness, death, and bereavement



Part 1

Death & Dying

Consider These Questions

What is terminal illness?

Is life itself a terminal illness?
Or at least a terminal condition?

What was the reaction when you first discovered that you are going to die?





Is Death a State or a Process?

Persistent vegetative state:
due to extensive and
irreversible brain damage a
patient is highly unlikely ever
to achieve higher functions
above a vegetative state

Clinical death: first few
minutes following heart stop

Brain death: Cessation of
cognitive function and reflexes
but may ventilated and
cardio-paced; recovery of
consciousness not likely;
legally dead

Is Death a State or a Process?



Social death: deceased person no longer treated as a person but objectified as a corpse

Living on through your legacy or other people's memory of you?



Causes of Death

Leading causes in HK are Cancer, Pneumonia & Heart disease

Different from the 100 years ago because of changes in nature of work, better nutrition, better infrastructure development & better living conditions, and that more children survived

Different cause of death means different experience of death and dying



Part 2

Responses to Terminal Illness



Acceptance

Anger

Bargaining

“Depression”

Denial

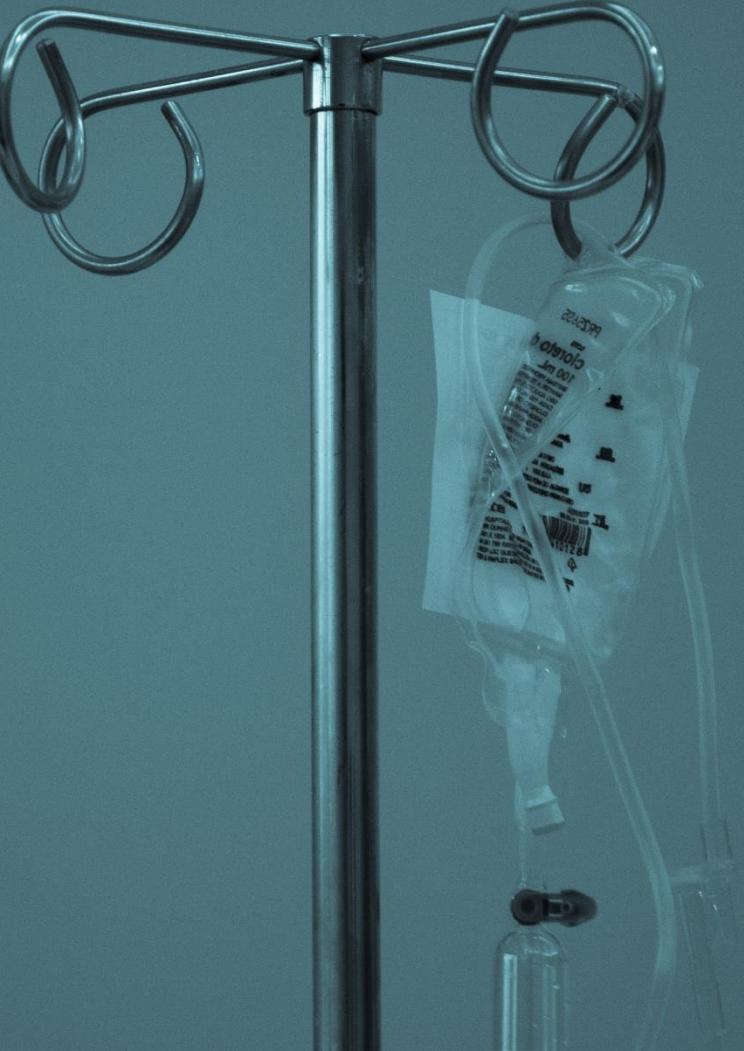
Reaction to Grief

“Five Stages of Grief” Model by
Elisabeth Kubler-Ross

Not considered evidence-based, but the individual states (rather than stages) themselves are commonly observed in people facing terminal illness

(In alphabetical order)

Acceptance, Anger,
Bargaining, Denial,
“Depression”



Terminally Ill Patients

How people react to the knowledge of their impending death depends on

- Psychological makeup
- Education
- Religious belief (e.g., about afterlife)
- Experience with death and terminal illness



Main Causes of Depression in Patients

Pain and other physical distress (e.g. nausea)

Worry about spouse / children

Shame over physical appearance

Physical mutilation

A sense of isolation

A photograph of a woman with short brown hair and glasses, wearing a blue hospital gown, sitting in a hospital bed. She is holding a white coffee cup with a blue lid and is looking down at it with a somber expression. The background shows a hospital room with a white wall and a light switch.

Main Causes of Anxiety in Patients

Uncertainty regarding dying

Responsibilities, e.g. family

Possibility of pain

(Anxiety tends to be in relation to dying and not death per se)



Main Causes of Suicide in Patients

Early studies indicated serious physical illness was a principle cause of suicide (even if there is no psychiatric illness)

Note that the patient's assessment of the quality of remaining life may be close to the truth – suicide may therefore not be an irrational choice



Factors Influencing Patient's Attitudes

State of organic disease – increasing disability may be affected by treatment

Patient's conscious knowledge of their condition – varies from ignorance to full awareness; may be inconsistent

Patient's emotional response to his or her condition – such as the reaction of distress or acceptance



Factors Influencing Patient's Attitudes

The characteristics of the person and his or her style of coping with crises

Interactions between the dying person and the significant people around him or her – these people are not necessarily logical or consistent

The current environment – e.g. home or hospital

A close-up photograph of a person with dark curly hair and glasses, lying in bed. They are resting their head on their hand, looking weary or distressed. The scene is dimly lit, with a red blanket visible in the background.

Tool 91: Reaction Towards Death & Dying

A person's behaviour might be a reaction to the fact that they are going to die – because death is universal and unavoidable

Common reactions include: agreement, anger, bargaining, denial, and “depression” – as well as trying to understand their own existence and the meaning of life and death

A photograph of a man with long, disheveled hair and a beard, wearing a light-colored t-shirt and dark pants. He is sitting on a concrete bench, leaning forward with his head resting in his hands, looking very distressed. The background shows a metal railing and some urban structures.

Tool 92: Mental Health Issues in Dying People

A person's (particularly a patient) anxiety, depression, and suicidal ideation might be explained by the fact that they are dying

These are in turn affected by bio-psycho-social factors including pain, social support, and knowledge

Part 3

Medical Staff & Dying



Medical Staff— Dying Patients

Dying patients receive little emotional support from staff

Medical professionals sometimes regards dying patients as representing medical model “failure” and contradict the image of hospital’s cure

Therefore they withdraw to avoid this contradiction





Communication or lack thereof

Staff uncomfortable about death and about talking about death

Staff might also be emotional or vulnerable themselves and therefore do not want to talk about death

Many physicians try to deal with this situation by not telling the patient of their death – even though >90% of patients wants diagnosis, prognosis, & to discuss treatment alternatives



Awareness of Dying (Anselm Strauss)

Whether the patient is aware or not

- Closed awareness (only staff know)
- Suspected awareness (patient suspects & tries to find out)
- Mutual pretense awareness (both parties know but pretend not)
- Open awareness (both parties know and acknowledge the fact) – the best option



Issues in Management of the Dying Patient

The type of care that a patients gets depends upon age and social status of patient, but also practical matters

E.g., patients may die sooner, which may disrupt ward, or live longer than expected and cause logistical problems

Doctor's conflict – "trying every possibility for prolonging life" versus "not doing enough" ("you let him die!")

A close-up photograph of a female healthcare professional with long brown hair, wearing blue scrubs. She is holding a pink stethoscope in her hands, forming a heart shape with the tubing. Her hands are adorned with several rings, and she has pink-painted fingernails. The background is a plain, light-colored wall.

Better Management of the Dying Patient

Adequate pain control (under-
or over-medication)

Social support (from nurses,
physicians, and family)

Family should be encouraged
to interact and help

Patient may want to discuss
dying

Tool 93: (Mis)Management of a Dying Patient

A dying patient's behaviour (especially their struggle) might be explained by how they are being managed (and communicated to) by medical staff

In particular, there is often a lack of communication from medical staff, as well as inadequate pain control and social support





Part 4

Where Does Death Occur?



Question...

Where do you want to die?

How do you want to die?

What do you want to die of?

Do you think you can actually
achieve that?



Where does Death actually occur?

In the early 1900's death usually occurred at home in presence of family and friends, and therefore most people are familiar with death

Nowadays death is more likely in institutions (in HK, >90% in hospital)



Reasons for Reduced Home Death

Advances in diagnostics and treatment by “high tech” means requires centralized facilities. i.e. Hospital based

Smaller nuclear families lack resources in terms of numbers and space to nurse and care for sick persons

Worry that death at home affect the value of the property

A photograph showing a person lying in a hospital bed, viewed from the side. The person is wearing glasses and has a nasal cannula. The bed has a control panel with several buttons and a small screen displaying some information. In the background, there are wooden cabinets and a red medical cart. The overall atmosphere is somber and clinical.

Disadvantages of Dying in Hospital

Most people never confront death in their own family and are therefore totally unprepared for it in later life

Patients often faces death in an alien environment loss of roles and status; and become another patient with the subsequent loss of control

Not surrounded by loved ones; might even die “alone”

A photograph showing a woman from behind, pushing an elderly person in a wheelchair across a grassy field. The sun is low in the sky, creating long shadows and a warm glow. In the background, there are trees and a fence.

Hospice Death as an Alternative

Hospice is a style of terminal care

Patients are not given life-saving treatment

Symptomatic treatment aimed at improving quality of life and minimizing suffering

A close-up photograph of a young woman with dark hair pulled back, smiling warmly at the camera. She is wearing a black t-shirt with a logo that includes a cross and the text "theCape". A stethoscope hangs around her neck. In the background, another person's face is partially visible, looking towards the camera.

Principles of Hospice Care

- Death is normal and should be faced and accepted
- Family should be involved with care of patient
- Feelings of patient and family should be addressed
- Control and decisions of care should be with patient and family
- Care should be palliative (focus on quality of life)
- Bereavement care should be provided following death

Tool 94: Environment for Facing Death

A dying patient's behaviour and experience might be explained and predicted by their pain, social support, and the physical environment

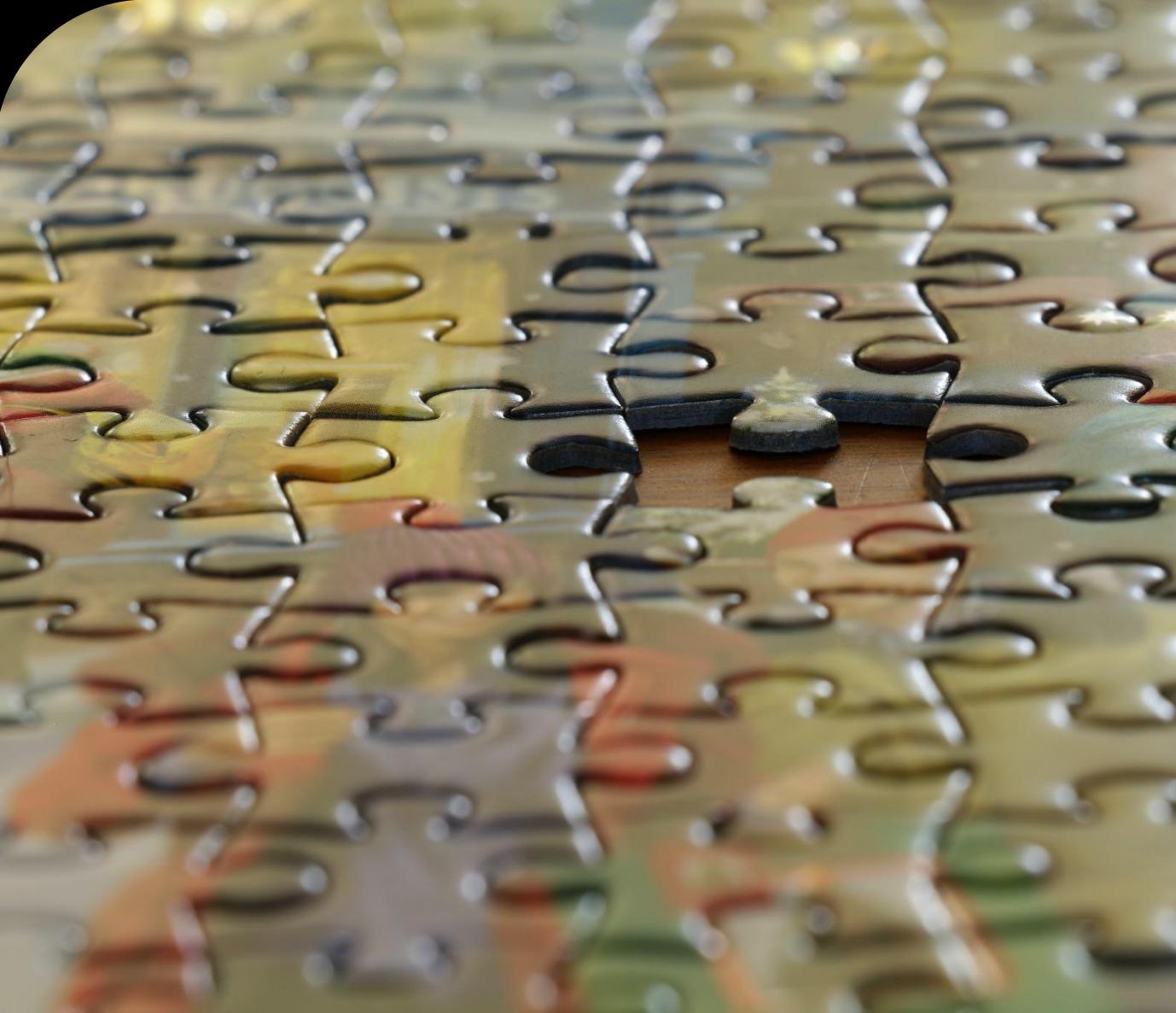
Home generally provides better environment than hospitals, and hospice care might be the answer





Part 5

Loss... and bereavement



Loss

Loss is an inescapable feature of life and occurs regularly from our earliest years, increasingly so in late life

Loss of object, ability, memory; loss of one's youth or one's career; loss of parent, spouse or child...

Almost always painful

A photograph showing a green deck chair with a matching footrest on a sandy cliff edge. The chair is facing the ocean, which is calm with some distant waves. The sky is clear and blue. In the background, there are low hills or mountains under a clear sky.

Loss and Attachment

Just as attachment to the lost “object” was built up probably over many years, so adaptation to this loss can also take years

May occur before loss materializes (anticipatory grief or loss), as in dying patient / spouse



Loss in Health Care Setting

Common but no less difficult for the person having to bear the loss (e.g. loss or reduction of function or ability)

We, as healthcare professionals, can also suffer from, and be negatively impacted by, loss – of patients, colleagues, etc.

A photograph of a person's hand reaching out towards the horizon. The background is a soft-focus landscape with a warm, orange glow from the sun on the horizon, transitioning into cooler blues and purples in the sky. The hand is positioned in the lower-left foreground, with fingers slightly spread.

Bereavement (Colin Murray Parkes)

According to Colin Murray Parkes, there are three components:

- preoccupation with thoughts of the lost person;
- painful, repetitious recollection of the loss experience;
- an attempt to make sense of the loss

Five stages: alarm, searching, mitigation, anger & guilt, and gaining a new identity

The Bereavement Process



Grief is the psychological response to bereavement

A feeling of hollowness, often marked by preoccupation with the image of the deceased person, expression of hostility toward others, and guilt over the death

Also restlessness, inability to concentrate on activities, yearning for the deceased, as well as anger or depression



Factors affecting Bereavement

Actual guilt: many loved ones feel guilt about not able to save the deceased or not treating them well enough, but there is likely to be more guilt if they actual caused the death of the deceased

Sudden and unexpected death: less time to prepare and process before, therefore need more time to process afterwards

Financial & practical difficulties



Health Impact of Loss & Bereavement

Increased risk of death, but also nervousness, depression, insomnia, trembling, loss of appetite, weight loss, reduced concentration, headaches, dizziness, indigestion, vomiting, menstrual irregularities, substance abuse

Can benefit from disease prevention (and health promotion in general)



Tool 95: Loss & Bereavement

A person's behaviour might be explained by the fact they are experiencing loss and maybe in the process of bereavement

Preoccupation with thoughts of the lost person; painful and repetitious recollection of the loss experience; and an attempt to make sense of the loss



Part 6

Behavioural Change

Case 19

Canice, 70

Retired teacher

Smoker for the past 50 years

Diagnosis:

Lung cancer (end-stage)

Life expectancy:

12 months

His doctor has just confirmed that Canice has end-stage lung cancer, and is considering whether (and how) he should be informed of this news. The life expectancy of someone like him is about 12 months (but 3 months and 24 months are also not uncommon), so she is also considering whether Canice should be referred to the palliative team and receive hospice care.

Case 19 Focus

Awareness & Communication

Reaction to Grief

Pros & Cons of Hospice care

Supporting his loved-ones and their
bereavement process



Part 7

Conclusion



Problems facing dying patients include:

- Grief (if not accepted), which might lead to anger, bargaining, denial, feel depressed
- Clinical depression, anxiety, suicidal behaviours
- Lack of communication from medical staff
- Lack of pain control & lack of social support
- Especially if dying in hospital (vs Home & Hospice)

Bereavement include 3 components:

- Preoccupation with thoughts of the lost person
- Painful, repetitious recollection of the loss experience
- An attempt to make sense of the loss

Conclusion

Common responses to terminal illness include acceptance, anger, bargaining, denial, “depression”, as well as clinical depression, anxiety, and suicidal behaviours

Dying patients often struggle because of a lack of communication from medical staff, as well as a lack of pain control and social support



Problems facing dying patients include:

- Grief (if not accepted), which might lead to anger, bargaining, denial, feel depressed
- Clinical depression, anxiety, suicidal behaviours
- Lack of communication from medical staff
- Lack of pain control & lack of social support
- Especially if dying in hospital (vs Home & Hospice)

Bereavement include 3 components:

- Preoccupation with thoughts of the lost person
- Painful, repetitious recollection of the loss experience
- An attempt to make sense of the loss

Conclusion

Most deaths occur in hospitals, but there are many advantages in dying at home or in a hospice

The 3 components of bereavement are preoccupation with thoughts of the lost person; painful, repetitious recollection of the loss experience; and an attempt to make sense of the loss

A photograph of a library aisle. On both sides, there are tall metal bookshelves filled with books. The books are arranged in rows, their spines visible. Above the bookshelves, several glowing incandescent lightbulbs hang from the ceiling by wires, casting a warm glow. The lighting is low, creating a quiet and scholarly atmosphere.

Reading / References

Taylor, SE (2018). Health Psychology (10th ed.). Chapter 12: Psychological Issues in Advancing and Terminal Illness. McGraw-Hill.



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