# Issues at the End of Life

Health Psychology (CMED2006)
LKS Faculty of Medicine
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# 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

# Is Death a State or a Process?

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

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

# 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

# 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

# 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

# Tool 92: Mental Health Issues in Dying Ppl

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)

# 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!")

# 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 particularly, 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

# 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”

# 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

# 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

# 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.

# 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, 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, is a retired teacher, as well as a smoker of 50 years.

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

# 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
- 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

# Reading / References


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

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