CARE OF DEATH AND DYING

Introduction

- Birth and death are two aspects of life, which will happen to everyone.
- Dying and death are painful and personal experiences for those that are dying and their loved ones caring for them.
- Death affects each person involved in multiple ways, including physically, psychologically, emotionally, spiritually, and financially.
- Whether the death is sudden and unexpected, or ongoing and expected, there is information and help available to address the impact of dying and death.

Definition of death

Death is defined as:

1. "Cessation of heart- lung function, or of whole brain function, or of higher brain function.
2. "Either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain, including the brain stem" - (The President's Commission for the study of Ethical problems in Medicine and Biomedical and Behavioral Research, US, 1983).

Responses to dying and death

- Although each person reacts to the knowledge of impending death or to loss in his or her own way, there are similarities in the psychosocial responses to the situation.
- Kubler-Ross' (1969) theory of the stages of grief when an individual is dying has gained wide acceptance in nursing and other disciplines.
- The stages of dying, much like the stages of grief, may overlap, and the duration of any stage may range from as little as a few hours to as long as months. The process varies from person to person.

- Some people may be in one stage for such a short time that it seems as if they skipped that stage. Sometimes the person returns to a previous stage. According to Kubler-Ross, the five stages of dying are:

    1. Denial
    2. Anger
    3. Bargaining
    4. Depression
    5. Acceptance

They are widely known in the acronym 'DABDA'.

1. Denial

- On being told that one is dying, there is an initial reaction of shock.
- The patient may appear dazed at first and may then refuse to believe the diagnosis or deny that anything is wrong.
- Some patients never pass beyond this stage and may go from doctor to doctor until they find one who supports their position.

2. Anger

- Patients become frustrated, irritable and angry that they are sick.
- A common response is," Why me? "
- They may become angry at God, their fate, a friend, or a family member.
- The anger may be displaced onto the hospital staff or the doctors who are blamed for the illness.

3. Bargaining

- The patient may attempt to negotiate with physicians, friends or even God, that in return for a cure, the person will fulfill one or many promises, such as giving to charity or reaffirm an earlier faith in God.

4. Depression

- The patient shows clinical signs of depression- withdrawal, psychomotor retardation, sleep disturbances, hopelessness and possibly suicidal ideation.
- The depression may be a reaction to the effects of the illness on his or her life or it may be in anticipation of the approaching death.

5. Acceptance

- The patient realizes that death is inevitable and accepts the universality of the experience.
- Under ideal circumstances, the patient is courageous and is able to talk about his or her death as he or she faces the unknown.
- People with strong religious beliefs and those who are convinced of a life after death can find comfort in these beliefs (Zisook & Downs, 1989).

Physical signs of dying.

Dying is a different experience for everyone involved.

1. Confusion – about time, place, and identity of loved ones; visions of people and places that are not present
2. A decreased need for food and drink, as well as loss of appetite
3. Drowsiness – an increased need for sleep and unresponsiveness
4. Withdrawal and decreased socialization
5. Loss of bowel or bladder control – caused by relaxing muscles in the pelvic area
6. Skin becomes cool to the touch

7. Rattling or gurgling sounds while breathing or breathing that is irregular and shallow, decreased number of breaths per minute, or breathing that switches between rapid and slow
8. Involuntary movements (called myoclonus), changes in heart rate, and loss of reflexes in the legs and arms also mean that the end of life is near

Changes in body after death:

1. Rigor Mortis: body becomes stiff within 4 hours after death as a result of decreased ATP production. ATP keeps muscles soft and supple.
2. Algor Mortis: Temperature decreases by a few degrees each hour. The skin loses its elasticity and will tear easily.
3. Livor Mortis: Dependent parts of body become discolored. The patient will likely be lying on their back, their backside being the 'dependent' body part. The discoloration is a result of blood pooling, as the hemoglobin breaks down.

Hospice and palliative care

- Hospice is a specialized program that addresses the needs of the catastrophically ill and their loved ones particularly accepted in US and West.
- A team approach is provided in hospice that may involve physicians, nurses, social workers, clergy, home health aides, volunteers, therapists and family caregivers.
- Hospice workers can help a dying person manage pain, provide medical services and offer family support through every stage of the process, from diagnosis to bereavement.

Components of hospice care program include the following:

1. Client and family as the unit of care
2. Co-ordinated home care with access to available inpatient and nursing home beds
3. Control of symptoms(physical, sociological, psychological and spiritual)
4. Physician directed services

5. Provision of an interdisciplinary care team of physicians, nurses, spiritual advisers, social workers and counselors.
6. Medical and nursing services available at all times
7. Bereavement follow up after a client's death
8. Use of trained volunteers for frequent visitation and respite support
9. Acceptance into the programme on the basis of health care needs rather than the ability to pay

Palliative Care

- Palliative care is the active total care of patients whose disease is not responsive to curative treatment (World Health Organization).
- The relief of suffering is one of the central goals of palliative care in terminal illnesses.
- Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount.
- The goal of palliative care is the achievement of the best possible quality of life for patients and their families.
- Palliative care is a special care, which affirms life and regards dying as a normal process, neither hastens nor postpones death, provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care and offers a support system to help patients live as actively as possible until death and helps the family cope during the patient's illness and in their own bereavement.

Palliative care is based on five major principles (Foley and Carver, 2001)

- It respects the goals, likes and choices of the dying person.
- It looks after the medical emotional, social and spiritual needs of the dying person.
- It supports the needs of the family members.
- It helps gain access to needed health care providers and appropriate care settings.
- It builds ways to provide excellent care at the end of life.

MANAGING DEATH ANXIETY

Some of the commonly used techniques to deal with death anxiety.

Spirituality

Religion is a prime source of strength and sustenance to many people when they are dealing with death. Different religious theories explain the inevitability and even necessity of death from different perspectives.

Existential Approaches in Management of Death Anxiety

- Death anxiety is inversely proportional to life satisfaction (Yalom, 1980).
- When an individual is living authentically, anxiety and fear of death decrease (Richard, 2000).
- Recognition of death plays a significant role in psychotherapy, for it can be the factor that helps us transform a stale mode of living into a more authentic one (Yalom, 1980). Confronting this realization produces anxiety.
- Frankl (1969) also contends that people can face pain, guilt, despair and death in their confrontation, challenge their despair and thus triumph. It also postulates that a distinctly human characteristic is the struggle for a sense of significance and purpose in life.
- Existential therapy provides the conceptual framework for helping the client challenge the meaning in his or her life.

Management of dying patient

Cassen (1991) suggests seven essential features in the management of the dying patient:

1. Concern: Empathy, compassion, and involvement are essential.
2. Competence: Skill and knowledge can be as reassuring as warmth and concern.
3. Communication: Allow patients to speak their minds and get to know them.
4. Children: If children want to visit the dying, it is generally advisable; they bring consolation to dying patients.
5. Cohesion: Family cohesion reassures both the patient and family.

6. Cheerfulness: A gentle, appropriate sense of humor can be palliative; a somber or anxious demeanor should be avoided.
7. Consistency: Continuing, persistent attention is highly valued by patients who often fear that they are a burden and will be abandoned; consistent physician involvement mitigates these fears.

Symptom Management

The management of individual symptoms in terminally ill follows a general stepwise approach (Dial, 1999):

- Assessment of the severity of the symptoms.
- Evaluation for the underlying cause.
- Addressing the social, emotional and spiritual aspects of the symptom.
- Discussing the treatment options with the patient and family.
- Using therapies designed as around the clock interventions for chronic symptoms.
- Reevaluating the control of the symptom periodically.

The major focus of most dying patients is the avoidance of pain. Controlling pain in terminally ill patients requires attention to the following:

- Potential etiology of pain
- Use of medications
- Use of nonpharmacological methods

Nursing care of a dying individual

The person who deals with the dying patient must commit (Schwartz and Karasu, 1997) to:

- Deal with mental anguish and fear of death,
- Try to respond appropriately to patient's needs by listening carefully to the complaints and

- Be fully prepared to accept their own counter transferences, as doubts, guilt and damage to their narcissism are encountered.

Management of the dying patient often elicits anxiety in nursing staff. Education and role playing can improve perspective taking and empathetic skills, respect each other's point of view as well as appreciate the situation of patient and their families.

- Developing a sense of control and efficacy.
- Encouraging peer groups for families coping with bereavement.
- Developing increased resourcefulness in dealing with death related situations.
- Recognizing that a moderate level of death anxiety is acceptable.
- Improving our understanding of pain and suffering will also improve communication and effective interactions.

Ethical and Legal Issues

The contemporary practice of palliative care raises important ethical issues that deserve thoughtful consideration.

- Patients have a right to refuse Life-sustaining treatment, even if they die as a consequence (Stanley, 1992). Here the patient must have the ability to comprehend the available choices and their risks and benefits, to think rationally and to express a treatment preference.
- Informed consent and refusal to life-sustaining treatment has three elements:
    - adequate information must be conveyed to the patient,
    - the patient must be able to decide, and
    - the patient must have freedom from coercion.

LIFE AFTER DEATH

Near Death Experience

- NDE is an altered state of consciousness usually occurring after traumatic injury and almost invariably involve risk of life.
- Some people belief that they were actually "in death". They report that after "dying" they left their body and floated away, become enveloped in a dark tunnel, and then enter a soothing light, later when they come back to life they are able to recall the events that occurred when they were dead. During the episode their entire past flash before them.
- Hallucinations caused by hyperactivation of amygdala-hippocampus-temporal lobe a response of oxygen starved brain, have been proposed as a physiological explanation.
- After effects of NDEs include: increase in spirituality, concern for others, appreciations of life and decrease in fear of death, materialism, and competitiveness.

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