UNDERSTANDING THE PSYCHOLOGICAL AND SOCIAL EXPERIENCE OF A DYING PERSON

Awareness of Impending Death

- For most of us, the inevitability of our own death can be denied, repressed, or otherwise not considered
- For the dying person, awareness of impending death can not be avoided
  - Awareness of approaching death is integrated
  - Life's activities, relationships, goals and meanings are reorganized and restructured in light of approaching death
- How does a person realize that they are dying? (Adapted from Rando, 1984)
  - Direct statement from a physician, other health care professional, family member, or other
  - Overheard comments by physicians, other health care professionals, family members, or others
  - Changes in the behavior or language of others
  - Changes in medical care procedures
  - Changes in physical placement (e.g., transfer from hospital to extended care facility)
  - Self-diagnosis
  - Awareness of bodily sensations

Four Types of Death (Sudnow, 1967)

Social

- Shrinking social network as lifestyle changes
- Other withdraw from dying person, defensively
  - Anxiety
  - Intense anticipatory grief
  - Uncertainty about role with dying person
  - Discomfort with awareness of own mortality

Psychological

- Regression and dependency as the person is no longer able to function as autonomously as before
- Grief with experience of multitude of losses
  - Activities
  - Roles
  - Abilities
  - Long-term goals and aspirations
  - Relationships
  - Personality
  - Basic sense of identity and self
- Other emotions
  - Fear
  - Depression
  - Anger
  - Guilt and shame
- Hope
  - It is surprising to some that a person who is dying can be hopeful
  - However, hope does not have to be directed toward the distant future
  - Hope can be for…
    - Accomplishment of short term goals
    - Relief from pain and suffering
    - Self efficacy in immediate tasks and activities
    - Satisfaction in relationships
    - Strong and positive self-esteem
- Biochemical changes in emotions, cognitions, and behavior due to progression of illness and medications
• Withdrawal of others limiting social relationships
• Withdrawal from the world outside the self and increasing awareness of inner life

**Biological**

• Organism as a human entity no longer exists
• Life support may be used, but consciousness and awareness in self-sustaining mind-body organism is not present

**Physiological**

• Cessation of all vital organs and systems

**Tasks of the Dying Person (Moos & Tsu, 1977; Rando, 1984)**

• Awareness of and coping with
  o Physical, social, psychological discomforts and incapacitation
  o Stresses of special treatment and care facility
  o New relationships with caregivers

• Preserving and maintaining
  o Emotional balance in the face of increasing uncertainty and losses
  o Self-image and sense of competence
  o Important interpersonal relationships

• Preparing for uncertain future
  o Arrange to handle a variety of affairs
    ▪ Debts
    ▪ Will
    ▪ Messages for friends, neighbors, co-workers
    ▪ Funeral and burial arrangements
  o Providing for the welfare of those left behind
  o Anticipate and plan for future medical care needs
  o Finances, possessions
  o Reunions with significant others
  o Anticipate and prepare for future pain, discomfort, and loss of abilities

• Coping with anxiety
  o Fear of unknown
  o Fear of loneliness
  o Fear of loss of family and friends
  o Fear of loss of self-control
  o Fear of loss of body parts and disability
  o Fear of suffering and pain
  o Fear of sorrow
  o Fear of loss of identity
  o Fear of regression
  o Fear of mutilation, decomposition, premature burial

• Coping with losses
  o Activities
  o Roles
  o Responsibilities
  o Social relationships
  o Unfinished and incomplete tasks, goals, and plans
  o Values
  o Life meanings
  o Self and identity and with the death encounter
  o Abilities to take care of one’s self
  o Basic emotions, thoughts, behaviors

• Decisions
  o Slow down or speed up the dying process
  o Selection of surrogate decision makers
How Can a Health Care Professional Help the Dying Person with Social and Psychological Concerns?

- Provide time and space for communication (see Module 2: Communicating Bad News)
  - Be available to listen to concerns
  - Communicate your ability to be present with the dying person verbally and nonverbally
  - Clarify to make sure that you understand concerns
  - Provide clear, simple information on how person’s symptoms, problems, and concerns can be addressed
  - Ask clarifying questions to make sure that you understand the person and that the person understands the end of life care team

- Communicate respect and acceptance of the dying person
  - Develop an awareness of the values and beliefs of the dying person and family
  - Allow the dying person as much control as is possible in end of life care and living situation
  - Maintain realism about expectations for the person’s needs and care, but avoid direct questioning of coping mechanisms such as denial
    - Allow the person to use coping resources even when these seem to minimize the seriousness of the situation
    - Coping mechanisms, such as denial, may be the best or only way for the person to live with a highly stressful and discouraging reality without being overwhelmed

- Avoid withdrawing prematurely from the dying person
  - As health care professionals, we may have difficulty with our own grief and pain in seeing someone die
  - A natural response is to withdraw from these difficult and painful emotions
  - It is extremely important to be aware of this response, however, and to avoid abandoning the person who is dying

- Accept that dying may be very difficult for the person
  - Avoid minimizing painful emotions when they are expressed
  - Avoid communicating an overly positive view of dying, especially when it is clear that the person’s experience is not good
    - Important for health care professionals to be aware of their wishes or desired that people die a “good” death
    - While working to make the process of dying better for our patients, it is important to recognize that often death is not beautiful

- Avoid telling the dying person something that is not true
  - This will erode trust and confidence in you as a health care professional
  - Contributes to anxiety and fear in the dying person
  - Can undermine the person’s self-confidence as well as trust in the end of life care team

- Provide a holistic assessment and treatment plan (see Module 3: Whole Patient Assessment)
  - Convey respect for full range of concerns that the dying person may have—physical, social, psychological, spiritual, financial, etc.
  - Ensure that the dying person can recognize all the members of the end of life care team and understands their roles and how they can help

- Communicate your commitment to provide care for the dying person and ensuring that her or his concerns and needs in dying are addressed

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