

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
 - Physical, social, psychological discomforts and incapacitation
 - Stresses of special treatment and care facility
 - New relationships with caregivers
- Preserving and maintaining
 - Emotional balance in the face of increasing uncertainty and losses
 - Self-image and sense of competence
 - Important interpersonal relationships
- Preparing for uncertain future
 - Arrange to handle a variety of affairs
 - Debts
 - Will
 - Messages for friends, neighbors, co-workers
 - Funeral and burial arrangements
 - Providing for the welfare of those left behind
 - Anticipate and plan for future medical care needs
 - Finances, possessions
 - Reunions with significant others
 - Anticipate and prepare for future pain, discomfort, and loss of abilities
- Coping with anxiety
 - Fear of unknown
 - Fear of loneliness
 - Fear of loss of family and friends
 - Fear of loss of self-control
 - Fear of loss of body parts and disability
 - Fear of suffering and pain
 - Fear of sorrow
 - Fear of loss of identity
 - Fear of regression
 - Fear of mutilation, decomposition, premature burial
- Coping with losses
 - Activities
 - Roles
 - Responsibilities
 - Social relationships
 - Unfinished and incomplete tasks, goals, and plans
 - Values
 - Life meanings
 - Self and identity and with the death encounter
 - Abilities to take care of one's self
 - Basic emotions, thoughts, behaviors
- Decisions
 - Slow down or speed up the dying process
 - 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

National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program.