Quality of Life: Overview

• Traditional View - Quality of life measured in terms of
  – Length of survival
  – Signs of disease
• However, patients perceive some illnesses and treatments as “fates worse than death”
  – They threaten valued life activities too much

Quality of Life: What Is Quality of Life?

• The degree to which a person is able to maximize his or her
  – Physical,
  – Psychological,
  – Vocational, and
  – Social functioning
• It also addresses disease or treatment related symptomatology
• It is an important indicator of recovery from, or adjustment to, chronic illness.
Quality of Life: Why Study Quality of Life

• Documentation helps improve interventions for those who are chronically ill
• Research helps pinpoint which problems are likely to emerge for particular patients
• Impact of unpleasant treatments can be seen and reasons for poor adherence identified
• Therapies can be compared
• Decision-makers have information about long-term survival and quality of life

Emotional Responses of Chronic Illness: Denial

• Defense mechanism by which people avoid the implications of an illness
• Denial is a common early reaction to the diagnosis of a chronic illness
  – This illness is not severe
  – This illness will go away soon
  – There will be few long term implications

• Immediately after the diagnosis, denial can serve a protective function
  – Keeps patient from dealing with full range of problems posed by illness
  – Denial can reduce days in intensive care
  – Denial can reduce side effects of treatment

• During the rehabilitative phase, denial may have adverse effects
  – High deniers at this time show less adherence to treatment regimen
Emotional Responses of Chronic Illness: Anxiety

- Anxiety is common after diagnosis:
  - It increases when people
    - Are waiting for test results
    - Are anticipating adverse side effects
    - Are awaiting invasive medical procedures
- Anxiety is high when
  - Substantial lifestyle changes are expected
  - People feel dependent on health care professionals

Emotional Responses of Chronic Illness: Anxiety

- Assessment and treatment of anxiety may be needed
- Anxiety may increase over time
  - Concern about possible complications
  - Concern about implications for the future
  - Concern about the impact of the disease on work and leisure-time activities

Emotional Responses of Chronic Illness: Depression

- When the acute phase of chronic illness has ended
  - Then full implications begin to sink in
  - Depression is common
  - Often is debilitating
- Assessing depression is problematic
  - Depressive symptoms, such as fatigue or weight loss, are also symptoms of disease or side effects of treatments
Personal Issues in Chronic Disease: Overview

• Self-Concept
  – A stable set of beliefs about one’s personal qualities and attributes

• Self-Esteem
  – A global evaluation of one’s qualities and attributes
  – Whether one feels good or bad about one’s qualities and attributes

Personal Issues in Chronic Disease: The Physical Self

• Body Image
  – Perception and evaluation of one’s physical functioning and appearance

• Body image plummets during illness
  – Body image can be restored, but it takes time

• Exceptions: Facial disfigurement and burns
  – Patients whose faces are disfigured may never accept their altered appearance

Personal Issues in Chronic Disease: The Achieving Self

• Achievement is important to self-esteem and self-concept
  – Satisfaction from job/career
  – Pleasure from hobbies/leisure activities

• Does the chronic illness threaten these?
  – If it does, self-concept may be damaged
  – If not, they may take on new meanings
Personal Issues in Chronic Disease: The Social Self

- Rebuilding social self
  - An important part of readjustment
- Interactions with family/friends provide
  - Critical source of self-esteem
  - Information
  - Help and emotional support
- Fears about withdrawal of support are common worries of the chronically ill

Personal Issues in Chronic Disease: The Private Self

- Major threats to self, because illnesses create
  - Need to be dependent on others
  - Loss of independence
  - Strain of imposing on others
- Adjustment to chronic illness impeded
  - Patient’s secret dream seems shattered
  - Alternate paths to fulfillment need discussing

Coping with Chronic Illness: Coping Strategies

- Coping strategies
  - Similar to those employed to deal with other stressful events
  - One notable difference: Chronically ill report fewer active coping methods (planning, problem solving) and instead use more passive coping methods (positive focus and escape/avoidant)
Coping with Chronic Illness:
Coping Strategies

- Avoidant coping is associated with increased psychological distress
  - Related to poor glycemic control among insulin-dependent diabetics
- Active coping efforts are more consistently associated with good adjustment
- Multiple Strategies may be helpful when a strategy is matched to a particular problem

Coping with Chronic Illness:
Patients’ Beliefs

- Patients must integrate their illnesses into their lives
  - Develop a realistic sense of the illness
  - Understand restrictions imposed by it
  - Follow the regimen required
- Patients need to adopt an appropriate model for their disorder
  - Acute models won’t be effective

Coping with Chronic Illness:
Patients’ Beliefs

- People develop theories about where their illness came from
  - Stress
  - Physical injury
  - Bacteria
  - God’s will
  - Self-Blame? Another person? Environment? Fate?
- Research on the consequences of self-blame is inconclusive
Coping with Chronic Illness: Patients’ Beliefs

- Are patients who believe they can control their illness better off?
  - Yes, it is usually adaptive to have a belief in control and a sense of self-efficacy
- Patients with chronic obstructive pulmonary disease with high self-efficacy expectations lived longer than those with lower expectations
- However, when real control is low, efforts to induce it or exert it may backfire

Rehabilitation and Chronic Illness: Overview

- Chronic illness raises specific problem-solving tasks
  - Depends critically on patient co-management of the disorder
  - Tasks include
    - Physical problems
    - Vocational problems
    - Problems with social relationships
    - Personal issues concerned with the illness

Rehabilitation and Chronic Illness: Who Uses Long-Term Care - Figure 11.1

Some problems are so severe that they can only be handled through institutionalization
Rehabilitation and Chronic Illness: Physical Problems

- Physical Rehabilitation
  - A program of activities geared toward helping patients
  - Use their bodies as much as possible
  - Sense changes in the environment so as to make appropriate physical accommodations
  - Learn new physical management skills
  - Learn a necessary treatment regimen
  - Learn how to control the expenditure of energy

Rehabilitation and Chronic Illness: Physical Problems

- Physical problems include those that
  - Arise as a result of the chronic illness
  - Emerge as a consequence of treatment
- Comprehensive programs may need to include
  - Pain-management programs
  - Training in adaptive devices
  - Behavioral interventions
- Adherence is essential to consider

Rehabilitation and Chronic Illness: Vocational Issues

- Patients may need to change/restrict work activities
- Many individuals face discrimination
  - Heart, Cancer, HIV patients
  - Organizations may believe that the chronically-ill are not worth the time/resource investment due to a poor prognosis
- Loss of insurance coverage through work adds a huge financial burden
Epilepsy and the Need for a Job
Redesign Box: 11.4

• Colin S. had spinal meningitis in infancy
  – Age 11: Petit mal epileptic seizures (blackouts), soon followed by grand mal seizures (convulsions)
  – Successful control through medication during his teens and twenties
  – Early 30s: Seizures returned, threatening his career as a caseworker doing in-home evaluations
  – Colin’s employer shifted his work to a desk job monitoring cases, thus keeping a valuable worker

Rehabilitation and Chronic Illness:
Social Interaction Problems

• Disabled individuals elicit ambivalence from acquaintances
  – Verbal signs may be of warmth, affection
  – Gestures, body posture may convey rejection
• Distant relationships are more adversely affected than are intimate relations with close friends and family

Rehabilitation and Chronic Illness:
Social Interaction Problems

• Intimate others may be
  – Distressed by the loved one’s condition
  – Worn down by pain/dependency of loved one
  – Ineffective at giving support because their own support needs are not met
• The family is a social system
  – Illness in one member affects the lives of other members
Rehabilitation and Chronic Illness: Caregiving Role

• Substantial strain on primary caregiver
  – Typical caregiver: Women in her 60s caring for an elderly spouse
  – Also common: Care for parents and disabled children
    • Role commonly falls to women
• Caregivers are at risk for
  – Distress, depression, declining health

Rehabilitation and Chronic Illness: Positive Changes

• Chronically ill people may
  – Perceive a narrow escape from death
  – Reorder their priorities
  – Find meaning in smaller activities of life
• Two studies compared quality of life in cancer patients with normal samples of people free of disease
  – Cancer samples had greater quality of life than non-ill samples

Rehabilitation and Chronic Illness: When the Patient is a Child

• Children may be confused because they don’t understand the diagnosis and treatment
• Children cannot follow the treatment regimen without help from family
• Children must be exposed to isolating and terrifying procedures
• Some children adjust successfully, but others show a variety of problems
Psychological Interventions and Chronic Illness: Overview and Pharmacology

- Adverse effects of chronic disease
  - Anxiety, depression, disturbances in interpersonal relationships
- Evaluation for depression and anxiety
  - Should be standard in chronic care
- Pharmacological treatment
  - May be appropriate when major depression is associated with chronic illness

Psychological Interventions and Chronic Illness: Individual Therapy

- Differs from therapy with patients who have primarily psychological complaints
- Therapy is more likely to be episodic rather than continuous
  - Chronic illness raises crises and issues intermittently
- Collaboration with family and physician is critical
- Psychological defenses should be respected rather than challenged
- Therapist should have a comprehensive understanding of the illness and treatment

Psychological Interventions and Chronic Illness: Brief Interventions

- Brief Psychotherapeutic interventions
  - Telling what to expect during treatment
    - Forestalls anxiety
  - Group coping skills training successful
    - Enhances perceptions of control
  - Therapy conducted over the telephone
    - Benefits patients by enhancing personal control
  - Music, art, and dance therapies
    - Improve patients’ responses to chronic illness
### Psychological Interventions and Chronic Illness: Education, Internet, Writing

- **Patient Education Programs** are designed:
  - To inform patients about the disorder and its treatment
  - To train them in methods for coping with the disorder and its corresponding limitations
- **The Internet**:
  - Provides information in a cost-effective manner
  - Patients/Families access appropriate Web sites
- **Expressive Writing**:
  - Writing about cancer benefits the terminally ill

### Psychological Interventions and Chronic Illness: Relaxation and Stress Management

- **Relaxation training**:
  - Widely used with the chronically ill
  - Decreases anxiety and nausea from chemotherapy
  - Decreases pain for cancer patients
  - Used with stress management/blood pressure monitoring to treat essential hypertension
- **MBSR: Mindfulness-based stress reduction**:
  - Focus on reality of present moment
  - Long-term efficacy unknown, reduces stress

### Psychological Interventions and Chronic Illness: Exercise

- **Exercise interventions**:
  - Most commonly undertaken with MI patients
  - May or may not have a direct impact on mood
  - Physical fitness is reliably improved
  - Exercise improves quality of life
Psychological Interventions and Chronic Illness: Social Support/Family Support

- Social support resources
  - Influence health outcomes favorably
  - Can be threatened by chronic illness
- Interventions can teach patients to
  - Recognize potential sources of support
  - Draw on these resources effectively
- Family support
  - Enhances patient's physical/emotional functioning
  - Promotes adherence to treatment

Psychological Interventions and Chronic Illness: Support Groups

- Group of individuals who meet regularly
  - Share some common problem or concern
- Support groups are believed to help people cope because
  - People learn techniques that others have used successfully to combat problems
  - They provide opportunities to share concerns and exchange information with similar others
- Support groups may promote better health and long-term survival