

Health Psychology, 6th edition
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Chapter Eleven:
Management of Chronic Illness

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

Emotional Responses of Chronic Illness: Denial

- 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

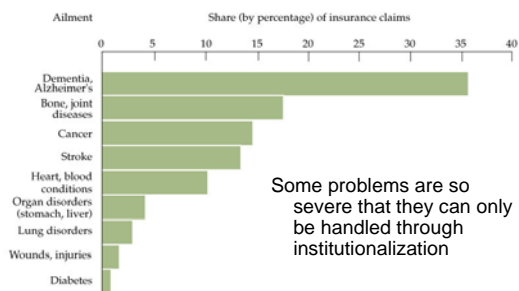
Coping with Chronic Illness: Patients' Beliefs

- 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



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
