

Psychosocial and Functional Aspects of Chronic Illness and Disability

■ THE EXPERIENCE OF CHRONIC ILLNESS AND DISABILITY

The way individuals experience chronic illness or disability encompasses many different areas and is influenced by numerous factors, including the following:

- Personal factors (such as gender, race, age, coping styles, and past experience)
- Social and family relationships and social support
- Socioeconomic status
- Culture
- Environment (physical, social, and political)
- Activities (including those related to daily living, recreation, school, and work)
- Goals of the individual

The extent to which a health condition is disabling depends on the interplay between the individual's health condition and these factors. Limitations that individuals experience may not be so much a function of their health condition as a function of elements in their environment. Individual reactions to chronic illness and disability vary considerably. The individual with a health condition that has associated limitations may not place as much importance on the condition and its associated features as do members of society. Social groups establish their own standards

with regard to idealized physical and emotional traits, roles, and responsibilities. Individuals with chronic illness or disability who do not fit the societal determined "norm" may find that, regardless of their strengths and abilities, society as a whole focuses more on the limitations associated with the condition than on what they are actually able to do.

People vary in terms of their personal resources such as tolerance to symptoms, functional capacity, general ability to cope, and social supports. Consequently, each individual must be considered in the context of all aspects of his or her life, and specifically in terms of the individual's capacity to function within his or her environment.

Functional capacity goes beyond specific tasks and activities. It also includes significant events and relationships with family, friends, employers, and casual acquaintances. No relationship exists in isolation. Just as individuals' reactions to illness or disability influence the reactions of others, so the reactions of others affect individuals' self-concept and perception of their own strengths and abilities.

Participation in family, social, and work activities assumes interaction and the capacity to perform a variety of activities. As interactions or capacities change, or as they become limited or restricted, alterations in roles and relationships also occur. Although some changes and adjustments may be made with

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relative ease, other changes can have repercussions in many areas of daily life. The meaning and importance that individuals and their families attribute to these associated changes influence their ability to accept the condition and to make necessary adjustments. The health condition itself is only one factor that determines individuals' ability to function effectively.

Disease and Illness

Words are powerful conveyers of concepts. Using a standard definition of terms facilitates communication and understanding of what each term implies. The term *disease* is derived from the medical model, which refers directly to changes in structure or function of body systems. The *medical model* focuses on treatment and elimination of symptoms. The term *illness* refers to individuals' perception of their symptoms and how they and their families respond to symptoms they are experiencing (Morof, Lubkin, & Larson, 2002). It is important to understand both concepts.

Professionals working with individuals with chronic illness or disability must understand symptoms, functional ability, and progression of a condition so that they can understand individuals' experience, and facilitate their ability to achieve optimal functional capacity. Insight into the nature of the individuals' health condition helps guide professionals in assessments and interventions as well as in understanding each individual's functional capacity and general experience (Dudgeon, 2002). It is also important for professionals to have insights into individuals' perception of their condition, the personal relevance and meaning it has for them, and their goals so that interventions can be directed toward meeting specific needs and goals (Shaw, Segal, Polatajko, & Harburn, 2002).

There must be an understanding of the individual's strengths, resources, and abilities, as well as how these will affect functional

capacity. Professionals also need an understanding of clients' personal factors, activities, and social and physical environments to effectively assess how the condition will affect an individual's daily life and goals in relationship to functional capacity at home, at work, and in the community.

Medical Terms Related to Chronic Illness and Disability

Although understanding the experience of the individual in regard to his or her health condition is crucial, understanding terms and concepts utilized by the medical community as a whole is also important to facilitate communication and avoid misinterpretation. Two key terms that influence the treatment of a health condition by medical personnel are concepts of *acute* and *chronic*. Acute refers to sudden onset of symptoms that are short term and affect functional capacity on a short-term basis. Chronic refers to symptoms that last indefinitely and are attributed to a cause that may or may not be able to be identified. Some conditions begin acutely but are not resolved, thus becoming ongoing and chronic.

When health conditions are chronic, depending on the nature of the condition and the circumstances, *activities and participation* may be affected and changes in activities may be needed to accommodate manifestations of the condition. In some instances, if symptoms of the condition progress or as other personal, social, or environmental factors change, accommodations may be needed to manage the condition. The course of an illness over time, plus actions taken by individuals and their families to manage or shape the course of the condition, is called a *trajectory* (Corbin, 2001). This concept is important to professionals working with individuals with chronic illness and disability because it implies a continuum and emphasizes the social and environmental effects of the condition.

The *course* of the condition refers to the nature or stages of the chronic illness or disability. Some conditions are classified as *stable*, meaning that the condition is being managed, symptoms are not progressing, and the health status of the individual is not deteriorating. In other instances, conditions are known as *progressive*, meaning that symptoms continue to progress and health and/or functional capacity continue to decline. Other conditions are classified as *episodic*, meaning that symptoms may not always be present, but flare up occasionally. The term *degenerative* refers to conditions in which there is continuing breakdown of structure or function. Some conditions have periods of *exacerbations* (periods when symptoms become worse) and periods of *remissions* (periods of time when symptoms remain stable or do not progress).

The course of chronic illness or disability can have a major influence on individuals' experience of the condition as well as on their functional capacity. For instance, individuals who have a progressive condition have continuing adaptation and adjustment as their health and function continue to decline, whereas individuals with a stable condition may have an initial period of adjustment but no ongoing functional loss.

■ STRESS IN CHRONIC ILLNESS AND DISABILITY

Change is an unavoidable part of life. Change of job, change of home, change of family composition, or changes brought about through the normal aging process are all events that everyone experiences. Depending on individuals' perceptions and the circumstances involved, change may be positive or negative. Whether positive or negative, change requires some adjustment or adaptation, which produces a certain degree of stress.

Chronic illness and disability produce significant change and consequently stress

associated with both physical imbalance and psychological turmoil as individuals must deal with a change of customary lifestyle, loss of control, disruption of physiological processes, pain or discomfort, and potential loss of role, status, independence, and financial stability. When individuals have confidence in their ability to maintain control over their destiny, and when they believe that changes—although inevitable—are manageable, stress is less pronounced. When individuals perceive the changes associated with chronic illness or disability as insurmountable or beyond their ability to cope, stress can be overwhelming.

The degree of stress associated with chronic illness or disability is often related to the degree of threat it represents to individuals. Potential threats posed by chronic illness or disability include the following:

- Threats to life and physical well-being
- Threats to body integrity and comfort as a result of the illness or disability itself, diagnostic procedures, or treatment
- Threats to independence, privacy, autonomy, and control
- Threats to self-concept and fulfillment of customary roles
- Threats to life goals and future plans
- Threats to relationships with family, friends, and colleagues
- Threats to the ability to remain in familiar surroundings
- Threats to economic well-being

In addition to threats associated with chronic illness or disability, another consideration is the individual's perception of the meaning or purpose of life itself. Although a chronic illness or disability may still produce stress if individuals feel that their life has no meaning or that they have already fulfilled their purpose in life, the stress experienced may be quite different from that experienced by individuals who believe that they still have a significant purpose to fulfill.

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Responses to stresses imposed by threat of chronic illness or disability depend on individuals' perceptions of the impact the condition has on various areas of life as well as on individuals' capacity to cope. Stress cannot be easily quantified, but it can be interpreted in relationship to behaviors exhibited by individuals who are experiencing chronic illness or disability. When demands exceed psychological, social, or financial resources, stress may be manifested in a variety of ways, such as non-compliance with recommended treatment, self-destructive behaviors such as substance abuse, behavioral consequences such as irritability or hostility, or inward manifestations such as depression.

Individuals in the same situation do not necessarily experience the same degree of stress, and the amount of change or adjustment required is not necessarily an indicator of the amount of stress perceived. Individuals who are able to adapt and cope effectively and mobilize resources are more successful in managing stress and achieving more stable outcomes.

Coping

Coping is a constellation of many acts rather than a single act, is constantly changing, and is highly individualized. Coping mechanisms are learned and developed over time. Individuals use them to manage, tolerate, or reduce stress associated with significant life events and to attempt to restore psychological equilibrium after a stressful or traumatic event. Everyone has a variety of coping mechanisms developed through life experiences, although each individual relies on a predominant coping style to reduce anxiety and restore equilibrium when confronted with a stressful situation. Coping is manifested through behavior. Coping behavior is *effective* and *adaptive* when it helps individuals reduce stress and enhance attainment of their fullest potential. It is *ineffective*

and *maladaptive* when it inhibits growth and potential or contributes to physical or mental deterioration. Coping may be required not only for dealing with the initial diagnosis, but also for managing subsequent events. Conditions that are progressive with compounding limitations necessitate ongoing coping and adjustment to incorporate additional changes into daily life.

Individuals cope with illness and disability in different ways. Some actively confront their condition, learning new skills or actively engaging in treatment to control or manage the condition. Others defend themselves from stress and the realities of the diagnosis by denying its seriousness, ignoring treatment recommendations, or refusing to learn new skills or behaviors associated with the condition. Still others cope by engaging in self-destructive behavior, actively continuing behavior that has detrimental effects on their physical condition.

Effective coping must be viewed in the context of each individual's personal background and experiences, life situation, and perception of his or her own circumstances. Individuals tend to use coping strategies that have worked successfully for them in the past. When old strategies are no longer effective or are not appropriate to the new situation, new coping strategies must be implemented to neutralize events surrounding the chronic illness or disability and to adjust to any associated limitations. Effective coping enables individuals to attain emotional equilibrium, to achieve a positive mental outlook, and to avoid incapacitation from fear, anxiety, anger, or depression.

Coping, however, does not occur in a vacuum. The social environment in which individuals find themselves can facilitate or discourage effective coping. In general, an environment that helps individuals gain a sense of control through active participation in decision making and take responsibility for

their own destiny as much as possible best equips them to cope effectively with chronic illness and disability.

Coping Strategies

Coping strategies are subconscious mechanisms that individuals use to cope with stress. All individuals have predominant coping strategies that they use to reduce anxiety and restore equilibrium when they are confronted with stress. The coping strategies that individuals used in the past are often those employed when individuals are confronted with the stress of chronic illness or disability. Use of coping strategies reduces anxiety, helping individuals to achieve balance and productivity in their lives. Although coping strategies can be helpful, their overuse can also be detrimental.

Denial

Diagnosis of chronic illness or disability and the associated implications can be devastating and provoke anxiety. *Denial* is a coping strategy individuals use to negate the reality of a situation. In the case of chronic illness or disability, individuals may deny that they have the condition by avoiding recommended treatment or by denying the implications of the condition. In the early stages of adjustment, denial may be beneficial in that it enables individuals to adjust to the reality of their situation at their own pace, preventing excessive anxiety. When denial continues, however, it can prevent individuals from following medical recommendations or learning new skills that would help them reach their optimum potential.

Denial of the chronic illness or disability can have far-reaching effects on others as well if, by denying the condition, the affected individual places others at risk. For example, proper precautions can greatly reduce the spread of some contagious diseases, such as tuberculosis or HIV infection. Individuals in active denial of their condition or its ramifications may

neglect to take anti-tuberculosis medications regularly or may have unprotected sex in the case of HIV, putting others in jeopardy. Some individuals may put others at risk by denying their limitations, such as individuals who are legally blind but continue to drive even though driving has been prohibited.

Regression

In *regression*, individuals revert to an earlier stage of development, so that they become more dependent, behave more passively, or exhibit more emotionality than would normally be expected at their developmental level. In the early stages of chronic illness or disability, returning to a state of dependency experienced in an earlier stage of development can be therapeutic, especially if treatment of the condition requires rest and inactivity. When individuals remain in a regressive mode, however, it can interfere with their adjustment and attainment of a level of independence that allows individuals to reach their optimal functional capacity. For example, after a myocardial infarction (heart attack), individuals may be encouraged to walk several miles each day to increase their strength and endurance; some, however, may continue to stay in bed, asking that family members wait on them.

Compensation

Individuals using *compensation* as a coping strategy learn to counteract limitations in one area by becoming stronger or more proficient in another area. When function is lost in one area, individuals may find ways to excel in another sphere. Compensatory behavior is generally highly constructive when new behaviors are directed toward positive goals and outcomes. For example, individuals who are unable to maintain their level of activity because of physical limitations associated with their condition may turn to creative writing or other means of self-expression. Compensation as a coping strategy can be detrimental, however, if the new

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behaviors used in compensating for limitations are self-destructive or socially unacceptable. For example, an individual who experiences disfigurement as a result of a disability may become promiscuous as a way of compensating for his or her perception of physical unattractiveness.

Rationalization

As a coping strategy, *rationalization* enables individuals to find socially acceptable reasons for their behavior or to excuse themselves for not reaching goals or not accomplishing tasks. Although rationalization can soften the disappointment of dreams unrealized or goals not reached, it can also produce negative effects if it becomes a barrier to adjustment, prevents individuals from reaching their full potential, or interferes with effective management of the medical condition itself. For example, an individual with visual impairment who is a student may rationalize that he or she failed the test because of the difficulty with vision, rather than admitting that he or she failed the test because they went to the beach with friends rather than studying for the test.

Diversion of Feelings

One of the most positive and constructive of all coping strategies can be the *diversion* of unacceptable feelings or ideas into socially acceptable behaviors. Individuals with chronic illness or disability may have particularly strong feelings of anger or hostility about their diagnosis or the circumstances surrounding their condition. If their emotional energy can be redefined and diverted into positive activity, the results can be beneficial, making virtue out of necessity and transforming deficit into gain. As with all coping strategies, diversion of feelings can have negative effects if feelings of anger or hostility are channeled into negative behaviors or socially unacceptable activities. For example, an individual with diabetes may have neglected to follow foot care precautions, which resulted in lower leg amputation.

Rather than acknowledging self-anger, the individual may instead express hostility and blame toward family members.

Emotional Reactions to Chronic Illness or Disability

Sudden, unexpected, or life-threatening chronic illness or disability engenders a variety of reactions. How individuals view their condition, its causes, and its consequences greatly affects what they do in the face of it. They may view their condition as a challenge, an enemy to be fought, a punishment, a sign of weakness, a relief, a strategy for gaining attention, an irreparable loss, or an uplifting spiritual experience. Although the emotional reactions of individuals experiencing chronic illness or disability vary both in type and in intensity, the following reactions are common. Although each emotional reaction is discussed individually, it is important to note that reactions are often experienced simultaneously.

Grief

Grief is a normal reaction to loss. Individuals with chronic illness and disability may experience loss of a body part; loss of function, role, or social status; or other perceived losses that result in a reaction of grief. Although the grieving and the progression through stages of grief vary from person to person, a common initial reaction to chronic illness or disability is shock, disbelief, or numbness with the diagnosis or its seriousness being denied or disputed. As individuals acknowledge the reality of the situation, the grief reaction may be more pronounced.

After repeated confrontations with elements of loss, normal adaptation results in gradual change in emphasis and focus that enables individuals to accept the loss emotionally and to make adjustments and adaptations that are necessary to reestablish their place within the everyday world. When the grief reaction is prolonged, individuals may develop a patho-

logical grief reaction, which may become more disabling than the chronic illness or disability itself.

Fear and Anxiety

Individuals normally become anxious when confronted with a threat. The presence of a chronic illness or disability can pose a threat because of the potential loss of function, loss of love, loss of independence, or loss of financial security. Threats cause anxiety. Some individuals fear the unknown or unpredictability of the condition, which provokes anxiety. For others, hospitalizations that immerse them in a strange and unfamiliar environment away from home, family, and the security of routine produces anxiety. When conditions are life-threatening, fear and anxiety may be associated not only with loss of function, but also with loss of life. Fear and anxiety associated with chronic illness or disability can place individuals in a state of panic, rendering them psychologically immobile and unable to act.

Assisting individuals to regain a sense of control over their situation through information and shared decision making can be an important step in reducing anxiety and facilitating rehabilitation. It is important to note that fear experienced by individuals may have both rational and irrational aspects. Fear and anxiety are oftentimes future oriented, having to do with perceptions of what could occur rather than based on what is actually known in the present.

Anger

Individuals with chronic illness or disability may experience anger at themselves or others for perceived injustices or loss associated with their condition. They may believe that their chronic illness or disability was caused by negligence or that their condition was avoidable. If they perceive themselves as victims, their anger may be directed toward the persons or circumstances they blame for the condition or situation. If they believe that their own actions

were partly to blame for the chronic illness or disability, the anger may be directed inward.

Anger can also be the result of frustration. Individuals may vent their frustration and anger by displacing hostility toward others, even when those parties have no relationship to the development of the chronic illness or disability and no influence over its outcome. Anger may also be an expression of the realization of the seriousness of the situation and associated feelings of helplessness. At times, anger may not be openly expressed but rather hidden in quarreling, arguing, complaining, or being excessively demanding, in an attempt to gain some control. Helping individuals express anger in appropriate ways and enabling them to regain a sense of control over their situation can help to resolve anger that would otherwise be detrimental to successful rehabilitation.

Depression

With the realization of the reality, seriousness, and implications of the chronic illness or disability, individuals may experience feelings of depression, helplessness and hopelessness, apathy, and/or feelings of dejection and discouragement. Signs of depression include sleep disturbances, changes in appetite, difficulty concentrating, and withdrawal from activity. Not all individuals with chronic illness or disability experience significant depression and, in those who do, depression may not be prolonged. The extent to which depression is experienced varies from person to person. Prolonged or unresolved depression can result in self-destructive behaviors, such as substance abuse or attempted suicide. Individuals with prolonged depression should be referred for mental health evaluation and treatment.

Guilt

Guilt can be described as self-criticism or blame. Individuals or family members may feel guilt if they believe they contributed to, or in some way caused, the chronic illness or disability. For instance, individuals who develop

lung cancer or emphysema after years of tobacco use, or those who experienced a spinal cord injury owing to an accident that occurred because they were driving while intoxicated, may experience guilt because of the role they played in the development of their chronic illness and disability. In other instances, they may experience guilt because they believe their chronic illness or disability places a burden on their family, or because they are unable to fulfill former roles. Still other scenarios of guilt include the concept of *survivor guilt*, in which an individual survives a situation when others in the same situation did not. For example, an individual who, although sustaining severe injuries, survives a tornado when none of his or her family members did may experience intense guilt, questioning why he or she survived when other family members perished.

Family members may also experience guilt because of feelings of anger or resentment they have toward the individual. Guilt may also be associated with blame if family members believe the individual is actively to blame for his or her chronic illness or disability. For instance, if an individual develops cirrhosis of the liver due to heavy drinking, but had been told previously to cut down on alcohol consumption because of impending liver failure, family members may actively blame the individual for his or her condition, causing the person to experience more guilt.

Guilt may be expressed or unexpressed and can occur in varying dimensions. It can be an obstacle to the successful adjustment to the condition and its limitations. Self-blame or blame ascribed by others is detrimental not only to the individual's self-concept, but also to rehabilitative efforts as a whole. Guilt that affects rehabilitation potential or well-being is an indication that referral to appropriate professionals for evaluation and treatment may be appropriate.

■ CHRONIC ILLNESS AND DISABILITY THROUGH THE LIFE CYCLE

Development is not static or finite but rather a continual process from infancy to old age and death. Each developmental stage is associated with certain age-appropriate behaviors, skills, and developmental tasks, which allow for psychological and cognitive transitions from one stage to another. Individuals' age and developmental stage influence their reactions to chronic illness or disability and the problems and consequences they experience.

Each developmental stage of life has its own particular stresses or demands, apart from those experienced as a result of illness or disability. Chronic illness and disability at various stages of development can influence the independence and self-control associated with the developmental stages and can impede development of qualities and life skills associated with different developmental stages. The needs, responsibilities, and resources of adults differ from those of children; as a consequence, the impact of chronic illness or disability in later years is different from the impact of chronic illness or disability experienced in young adulthood.

Family members and others generally adjust their behavior to accommodate and appropriately interact with individuals as they pass from one developmental stage to the next. When individuals experience chronic illness or disability, however, others may modify expectations of age-appropriate behavior. These modified expectations may then interfere with the individual's mastery of the normal skills required to meet the challenges of future developmental stages.

All aspects of development are related, so each developmental stage must be understood within the context of the individual's past and

current experiences. Individuals with chronic illness or disability must be considered in the context of their particular developmental stage and the way in which the changes and limitations associated with their condition influence attitudes, perceptions, actions, and behaviors characteristic of stage of development. Individuals' stage of development serves as a guideline not only in assessing their functional capacity, but also in determining potential stressors and reactions.

Problems and stresses at different developmental stages are similar whether individuals do or do not have a chronic illness or disability. Although there are no clear lines of demarcation between life stages and all individuals certainly develop at different rates, there are some commonalities associated with different life stages.

Ideally, those with chronic illness or disability should be encouraged to progress through each stage of development as normally as possible, despite their condition. Individuals whose emotional, social, educational, or occupational development has been thwarted may be more handicapped by their inability to cope with the subsequent challenges of life than by any limitations experienced because of illness or disability per se.

Chronic Illness or Disability in Childhood

Although the majority of children with chronic illness or disability and their families adapt successfully, children with chronic illness or disability are at increased risk of emotional and behavioral disorders (Gledhill, Rangel, & Garralda, 2000). In early life, children develop a sense of trust in others, a sense of autonomy, and an awareness and mastery of their environment. During these years, they begin to learn communication and social skills that enable

them to interact effectively with others. They also learn that limits are set on their explorations, expressions of autonomy, and behaviors. Important to their development is a balance between encouraging initiative and setting limits consistently.

Chronic illness or disability can impede attainment of normal developmental goals. Repeated or prolonged hospitalizations may deprive children of nurturing by a consistent and loving caregiver. Physical limitations associated with the condition or treatment may prevent normal activities, socialization, and exploration of the environment. In some cases, overly protective family members may restrict activities or prohibit the child from displaying normal emotional expression. In other instances, overly sympathetic parents may condone inappropriate behaviors rather than correct them.

Conditions affecting development of communication skills may also affect children's interaction with the environment as well as their future development. Developmental disabilities (conditions present at birth or occurring during childhood) require adjustments throughout individuals' development. Limitations associated with such a developmental disability must be confronted and compensated for with every new aspect of normal development. Maintaining awareness of normal developmental needs and facilitating of experiences that foster normal development will enhance children's ability to reach their full potential.

For most children, entering school expands their world beyond the scope of their family. Before children attend school, the values, rules, and expectations that they experience are, for the most part, largely those expressed within the family. When they enter school, however, they are exposed to a larger social environment. Not only do they learn social

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relationships and cooperative interactions, but they also begin to develop a sense of initiative and industry. Children gradually become aware of their special strengths. As new skills begin to develop, school-aged children gain the capacity for sustained effort that eventually results in the ability to follow through with tasks to completion. The approval and encouragement of others and acceptance by their peers help children to build self-confidence, further enhancing development.

When children with chronic illness or disability enter school, they may not need specific special education placement, but they may require coordinated school interventions to maximize attendance and facilitate educational and social growth. Children with chronic illness or disability may experience school-related problems reflected in their psychological well-being, interactions with other children, or academic performance. When physical or cognitive limitations affect children's ability to perform skills normally valued at this developmental stage, acceptance by peers may be affected. School attendance may be disrupted by the need for repeated absences, resulting in an inability to interact on a consistent basis within the peer group, which in turn may diminish social interactions.

In an attempt to shield the child from hurt and emotional pain, family members may further isolate the child from social interactions, creating the potential for reduced self-confidence. Reluctance of sympathetic family members to allow the child to participate in activities in which the child may experience failure can interfere with the child's ability to accurately evaluate his or her potential. Encouragement of social interactions and activities to the greatest degree possible allows the child the opportunity to develop the skills and abilities that are needed for later integration into the larger world.

Chronic Illness or Disability in Adolescence

Perceptions of and interactions with peers become increasingly important as adolescents further define their identity apart from membership in their family. With the need to establish independence, adolescents begin to emancipate themselves from their parents and may rebel against authority of parents or others. Physical maturation brings a strong preoccupation with the body and appearance. Adolescents' need to identify themselves as a person attractive to others often becomes paramount. Awareness of and experimentation with sexual feelings present a new dimension with which the adolescent must learn to cope. Dating and expression of sexuality are important aspects of maturation. Any alteration in physical appearance caused by the condition can influence adolescents' perception of body image and self-concept, thwarting expression of sexual feelings.

Adolescents with physical disabilities may be at risk for secondary disabilities associated with psychosocial factors. Illness or disability during adolescence can disrupt relationships with peers, resulting in delayed social and emotional development. Limitations experienced because of the condition, its treatment, or sympathetic and protective reactions by family members may become barriers to the adolescent's attainment of independence and individual identity. Parents may be over-protective to the point of infantilizing the adolescent, decreasing self-esteem and self-confidence.

In the attempt to become independent, characteristics of normal adolescent development, such as rebellion against authority or the need to be accepted by a peer group, may sometimes interfere with treatment necessitated by chronic illness or disability. If adoles-

cents deny limitations associated with their disability or ignore treatment recommendations, there can be further detrimental effects on physical and functional capacity.

Chronic Illness or Disability in Young Adulthood

In young adulthood, individuals establish themselves as productive members of society, integrating vocational goals, developing the capacity for intimate relationships, and accepting social responsibility. When chronic illness or disability occur during this stage of the life cycle, associated limitations—rather than interests or abilities of individuals—may define social, vocational, and occupational goals.

Physical limitations may also inhibit individuals' efforts to build intimate relationships or to maintain relationships that they have already established. At this developmental stage, established relationships are likely to be recent, and the level of commitment and willingness to make necessary sacrifices may be variable. Depending on the nature of the condition, procreation may be difficult or impossible. If the individual already has young children, childcare issues may be the source of additional concerns in light of the functional limitations inherent in a specific chronic illness or disability. Young adults who had not yet fully gained independence or left their family of origin at the time of the onset of chronic illness or disability may find gaining independence more difficult. In some cases, the family's overprotectiveness may prevent individuals from having experiences appropriate to their own age group.

Chronic Illness or Disability in Middle Age

Individuals in middle age are generally established in their careers, have committed relation-

ships, and are often providing guidance to their own children as they leave the family to establish their own careers and families. At the same time, middle-aged individuals may be assuming greater responsibility for their own aging parents, who may be becoming increasingly fragile and dependent. During middle age, individuals may begin to reassess their goals and relationships as they begin to recognize their own mortality and limited remaining time.

Illness or disability during middle age can interfere with further occupational development and may even result in early retirement. Such changes can have a significant impact on the economic well-being of individuals and their families, as well as on their identity, self-concept, and self-esteem. It may be necessary to alter established roles and associated responsibilities within the family. At the same time, individuals' partners, even when the relationship is a long-term one, may be reevaluating their own life goals. They may perceive chronic illness or disability as a violation of their own well-being and may choose to leave the relationship. Responsibilities for children and aging parents add more financial and emotional stress to that experienced as a result of illness or disability.

Chronic Illness or Disability in Older Adulthood

Ideally, older adults have adapted to the triumphs and disappointments of life and have accepted their own life and imminent death. Although physical limitations associated with normal aging are variable, older adults often experience diminished physical strength and stamina, as well as losses of visual and hearing acuity. Illness or disability during older adulthood can impose physical or cognitive limitations in addition to those caused by aging. The spouse or significant others of the same

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age group may also have decreased physical stamina, making physical care of individuals with chronic illness or disability more difficult. When older adults with chronic illness or disability are unable to attend to their own needs or when care in the home is unmanageable, they may find it necessary to surrender their own lifestyle and move to another environment for care and supervision. Many individuals in the older age group live on fixed retirement incomes, so the additional expenses associated with chronic illness or disability may place a significant strain on an already tight budget. Not all older individuals, of course, have retirement benefits, savings, or other resources to draw on in time of financial need.

■ MULTICULTURAL ISSUES IN CHRONIC ILLNESS AND DISABILITY

Adjustment and adaptation to chronic illness and disability are also related to a variety of cultural aspects, including race, gender, ethnicity, spiritual/religious beliefs, and sexual orientation. Cultural factors shape individuals' perception of self as well as define views of chronic illness and disability and their meaning in the context of culture. Concepts about causes of and reasons for various health conditions, values, and accepted ways of managing a condition are all cultural variables that determine attitude, adjustment, expectations, and outcomes related to chronic illness and disability.

■ OTHER ISSUES IN CHRONIC ILLNESS AND DISABILITY

Self-Concept, Self-Esteem, and Social Identity

Self-concept is tied to self-esteem and personal identity, and includes individuals' perceptions and beliefs about their own strengths and weaknesses, as well as others' perceptions

of them. *Self-esteem* can be defined as "the evaluative component of an individual's self-concept" (Corwyn, 2000, p. 357). It is often thought of as individuals' assessment of their own self-worth with regard to attained qualities and performance (Gledhill, Rangel, & Garralda, 2000).

Self-concept influences the perceptions of others about an individual. A negative self-concept can produce negative responses in others, just as a positive self-concept can increase the likelihood that others will react in a positive manner. Individuals' self-esteem is related to their self-concept and how others respond to them. Consequently, self-concept has a significant impact on interactions with others and the psychological well-being of the individual.

Social identity is a term that refers to an individual's self-concept that is derived from perceived membership in a social group (Tajfel & Turner, 1986). Depending on the social context, individuals may have different social identities at different levels according to their internalized perception of group membership. For example, an individual may identify himself or herself as a medical student, but may also identify himself or herself as a member of the Young Republicans or Young Democrats, or according to an ethnic group, such as Native American. Group membership involves defining the self in terms of characteristics of the group rather than as an individual. Group membership can be an aspect of self-concept and can provide grounds for group comparisons. The more individuals view group membership as central to their self-definition, the stronger their social identity with the group (Haslam, 2001).

Social identity can influence how individuals think, act, and feel based on their perception of group inclusion or exclusion. If an individual views a group positively, his or her perception of inclusion in the group can boost self-esteem. Perceptions of exclusion from the group can,

however, have the opposite effect. Likewise, if an individual perceives a group negatively but identifies as part of the group, the person's self-esteem can be negatively affected.

Body Image

Body image, which is an important part of self-concept, involves individuals' mental view of their body with regard to appearance, sexuality, and ability to perform various physical tasks. It is influenced by bodily sensations, social and cultural expectations, and reactions of and experiences with others (White, 2000). Body image is influenced by each individual's personal conception of attractiveness, which is also determined by social and cultural influences and is related to both self-concept and self-esteem.

Body image is influenced by biological, cultural, social, and historical factors. It changes over time as alteration of appearance, capabilities, functional status, and social role occurs over the life cycle. Individuals' perceptions of their body are associated with more than cosmetic concerns; they also influence individuals' general health, personal relationships and intimacy, and general well-being (Biordi et al., 2002).

Chronic illness or disability may modify body image by requiring an alteration of self-view to accommodate the associated changes. The following factors influence the degree of alteration:

- Visibility of the change
- Functional significance of the change
- Speed with which the change occurred
- Importance of the physical change or associated functional limitations to the individual
- Reactions of others (Moore, Franzep, Hennessey, Kunz, Ferrando, & Rabkin, 2000)

Body image is a reflection of individuals' image of themselves as well as how they

believe others see them. Individuals' feelings and thoughts about their body image influence not only social relationships, but also psychological characteristics and perceptions of the world. The degree to which the alteration of self-view is perceived by the individual in a negative way influences social and intrapersonal interactions, functional capacity, and success or failure in the workplace (Cusack, 2000).

The extent to which individuals incorporate change into their body image also depends on the meaning and significance of the change to the particular individual. The degree of physical change or disfigurement is not always proportional to the reaction it provokes. A change considered minimal by one individual may be considered catastrophic by another person.

Changes do not have to be visible to alter body image. Burn scars on parts of the body normally covered by clothing or the introduction of an artificial opening or stoma such as with colostomy may cause significant alteration in body image even though physical changes are not readily apparent to others.

The concept of body image is complex and individually determined. Body image is not only the way individuals perceive themselves, but also the way they perceive others as seeing them. Negative views of body image can be a barrier to psychological well-being, social interactions, functional capacity, and workplace adjustment. Consequently, the ultimate goal is to help individuals adapt to changes brought about by chronic illness or disability, integrating changes into a restructured body image that can be assimilated and incorporated into daily life.

Stigma

Stigma is a socially constructed concept that is a universal phenomenon and has evolved throughout history. The concept is generally

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associated with individual feelings of shame due to disapproval of others and guilt resulting from being discredited or devalued by others. Stigma is something that precludes an individual's full social acceptance. The degree of stigma varies from setting to setting, and from person to person. Although the concept of stigma is universal, it is socially constructed. As a consequence, a number of factors within different societies as well as within different cultures may modify what is considered stigmatizing.

Overall, stigma is related to what a certain society considers to be deviations from the norm in a number of different areas. These areas are defined by societally determined categories, which include those attributes, characteristics, and behaviors that individuals exhibit in each category. Because these categories are based on the expectations of the "majority," they define what is considered acceptable or "the norm" based on majority standards. Categories may include age, race, gender, ethnic background or nationality, religion, occupation, or social roles. Individuals who meet the expectations of the majority regarding appearance, behavior, or group association are generally accepted and valued. Individuals who deviate from the expectations of the majority regarding what is acceptable in these categories are labeled as different from the majority and, therefore, less desirable. Thus individuals deviating from these expectations are often stigmatized. Because stigma is socially defined, it can vary from setting to setting, depending on the views of the majority. What is stigmatizing in one setting may not be stigmatizing in another venue.

Most stigmas are viewed as anxiety provoking and threatening to others. For example, older adults are often stigmatized because aging is a reminder of mortality and vulnerability. Individuals from different ethnic backgrounds, nationalities, or religions may be stigmatized because of lack of understanding

by the majority of the meanings of traditions or beliefs in different groups. Individuals with HIV/AIDS are often stigmatized based on moral judgments. Likewise, individuals with chronic illness or disability often experience stigma owing to negative value judgments. Stigma results in discrimination, social isolation, disregard, depreciation, devaluation, and, in some instances, threats to safety and well-being.

The power of stigma may overshadow the positive characteristics of individuals who experience the stigma. Individuals who are stigmatized may find it difficult to overcome the social reactions of others regardless of their positive attributes. For example, individuals with psychiatric disability may face continued stereotypes and prejudices regarding psychiatric disability regardless of their level of success in the workplace or community (Lyons & Ziviani, 1995).

Individuals with chronic illness and disability continue to experience stigma. Modern society's emphasis on youth, attractiveness, self-sufficiency, and productivity contribute to the tendency to devalue those who are perceived as deviating from these valued characteristics (Saylor, Yoder, & Mann, 2002). Stigma can have a profound effect on the ability to regain and maintain functional capacity and on the individual's acceptance of his or her illness or disability. Gender and race or ethnic background may be secondary sources of prejudice and subsequent stigma, causing additional stress and creating additional barriers to effective functioning (Nosek & Hughes, 2003).

Stigma affects not only the individual, but also members of his or her family. Family members may experience social isolation and prejudice because of their association with the individual. Family members' ability to cope with their family member's chronic illness or disability may be severely compromised by societal stigma. If there are unresolved family

problems, societal stigma may merely exacerbate the shame and guilt they may already feel.

Stigma has an impact on individuals' self-concept and self-esteem, and can produce barriers that prohibit affected persons from reaching their full potential. In an effort to avoid stigma, individuals may deny, minimize, or ignore their condition or treatment recommendations. If the condition is not readily discernable, hiding the disability may be more easily accomplished. As time goes by and the individual's attempt to hide the chronic illness or disability becomes reinforced, they may become proficient in concealing the condition so as to reduce the associated stigma. Although stigma may be reduced in this way, pretending not to have the condition can become detrimental. Not only may denial interfere with needed treatment, but it may also delay acceptance of and adjustment to the condition (Saylor, Yoder, & Mann, 2002).

Although efforts to reduce or obliterate stigma in society should continue, stigma is most likely to be overcome through positive interactions with individuals. It is possible to reduce the negative implications of societal stigma by helping individuals establish a sense of their own intrinsic worth.

The Impact of Uncertainty

Uncertainty in the lives of individuals with chronic illness and disability can exist for a variety of reasons, but is often related to concerns about an unknown future, the erratic nature of symptoms, the unpredictability of progression of the disease, or the ambiguity of symptoms. Some chronic illnesses and disabilities have immediate and permanent effects on functional capacity; in other cases, the course of the illness or disability is more variable. Deterioration may occur slowly over the span of several years or rapidly within months. Some conditions have periods of remission, when symptoms become less noticeable or

almost nonexistent, only to be followed by periods of unpredictable exacerbation, when symptoms become worse. In some cases, the same condition progresses at different rates for different individuals—progressing rapidly for some, but slowly for others. With some conditions, it is difficult to determine when or if the condition will reach the point of severe disability or whether a dramatic change of functional capacity will take place.

Uncertainty of prognosis or progression of the condition can make planning and prediction of the future difficult and can sometimes render an individual immobile. The unpredictability of chronic illness or disability can be frustrating for both affected individuals and those around them. There may be reluctance to plan for the future at all, so that inability to predict the future becomes more disabling than the actual physical consequences of the condition itself. In other instances, given the unpredictability of their condition, individuals may elect to follow a different life course than they would have otherwise chosen. Decisions not to have children, to cut down on the number of hours spent in the work environment, or to suddenly relocate to a different part of the country may be misinterpreted by those unaware of the individual's condition or its associated unpredictability. For those conditions in which symptoms or residual effects are unapparent to others, such decisions may be met with misunderstanding or criticism. Criticisms of such decisions may be particularly distressing to individuals who do not wish to disclose or share intimate details of their condition with the casual observer.

Insecurity about the course of the condition may also be reflected by the attitude of those closest to the individual who, in an attempt to protect the person from potential future loss, withdraw emotional interactions or support. Uncertainty of progression of a condition imposes particular challenges for individuals and their families and can be a source of

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stress. Emphasizing the importance of living in the present, rather than dwelling on events that may or may not occur, can help to reduce the amount of stress and anxiety experienced as well as enhance the quality of life currently experienced.

Invisible Disabilities

Some chronic illnesses or disabilities have associated physical changes that can be objectively assessed by others or have functional limitations that necessitate the use of adaptive devices. The *visibility* of a condition has often been associated with stigmatization and marginality (Livneh & Wilson, 2003). Some conditions, such as diabetes or cardiac conditions, have no outward signs that alert casual observers to individuals' condition. The term *invisible disability* refers to these latter conditions. Because there are no outward physical signs or other cues to indicate limitations associated with chronic illness or disability, others have no basis on which to alter expectations with regard to individuals' functional capacity. Although this lack of reaction can be positive (in the sense that it prevents actions by others that are based on prejudice or stereotypes), it can also be negative in the sense that it can enable individuals to deny or avoid acceptance of their condition and its associated implications.

The degree to which a condition remains invisible may be a function of the closeness of the observer's association with the individual. Although casual acquaintances may not notice the limitations, those more closely involved with the individual in day-to-day activities may more readily observe them. Other conditions under normal circumstances may offer no visible signs or cues, no matter how close the association with the individual.

The unapparent aspect of the limitation in invisible disability may be a unique element related to individuals' adjustment and acceptance of their limitation. Without environ-

mental feedback to create a tangible reality of the condition, individuals with invisible disability may postpone adaptation or ignore medical treatment or recommendations necessary for control of the condition and prevention of further disability.

Sexuality

Human sexuality is more than genital acts or sexual function. It is intrinsic to a person's sense of self (Hordern & Currow, 2003). It is an ever-changing, lived experience, affecting the way individuals view themselves and their bodies (Hordern, 2000). Sexuality encompasses the whole person and is reflected in all that individuals say and do. It is an important part of identity, self-image, and self-concept. Each person is a sexual being with a need for intimacy, physical contact, and love. The effects of chronic illness or disability on sexuality are multifactorial and can affect all phases of sexual response (McInnes, 2003).

Expression of sexual urges is one form of sexuality. Chronic illness or disability can affect sexual expression through physical limitations, depression, lack of energy, pain, alterations in self-image, or the reactions of others. In some conditions, the main barrier to sexual expression may be problems with self-concept and bodyimage; with other conditions, physical changes may present physical barriers, which affect sexual function directly. In other instances, attitudes of others or of society as a whole can be a major barrier to sexual expression. For example, although there has been increased acceptance of expression of sexuality by adults with intellectual disability, sexual expression that includes marriage or desire to start a family remains contentious (Cuskelly & Bryde, 2004).

Regardless of the types of limitations associated with chronic illness or disability, sexual expression remains an important part of function that should be addressed (McBride & Rines, 2000). In some instances, it may be nec-

essary to help individuals overcome their own misperceptions and fears to establish a means for sexual expression. In other instances, individuals may need assistance to overcome barriers or to learn methods of sexual expression different from those used previously. In any case, sexual adjustment is a significant element in the restoration of an individual's optimal functional capacity.

Family Adaptation to Chronic Illness and Disability

Family is the social network from which individuals derive identity and with which individuals feel strong psychological bonds. Family has different meanings for different people and is not always related by blood or law. Family provides protection, socialization, physical care, support, and love. Each individual within the family structure plays some role that is incorporated into everyday family function.

Chronic illness or disability has both emotional and economic impacts on families as well as on individuals. Family reactions to chronic illness and disability may be similar to those experienced by the individual and may include shock, denial, anger, guilt, anxiety, and depression. Families must make adaptations, adjustments, and role changes both as a unit and as individual family members. The way in which families react and adapt to chronic illness and disability will influence affected individuals' subsequent adjustment. Whether families foster independence or dependence, show acceptance or rejection, or encourage or sabotage compliance with restrictions and recommended treatments has profound effects on individuals' ultimate functional capacity.

Specific issues for families when a family member develops chronic illness or disability are loss related to normal family functioning and loss related to functioning of the individual. There may be a strong desire to be a "normal" family again. Family members' prior expectations for the individual's future or

"what might have been" may lead them to experience anger, resentment, or disappointment if they see chronic illness or disability as interfering with achievement of their expectations.

Family members can also act as advocates for the individual. They may need to become more involved with health professionals and service agencies or become increasingly assertive to obtain necessary services. If individuals with chronic illness or disability require significant care or therapies to be administered at home, family members may become fatigued because of the extra responsibility and tasks required, especially if respite services are limited.

Families, like individuals, have differing resources, depending on life circumstances, previous experiences, and the personalities involved. Individual family members may be called upon to provide not only emotional support, but also physical care, supervision, transportation, or a variety of other services necessitated by the individual's condition. In addition, changes of roles or financial circumstances due to chronic illness or disability may alter goals and plans of other family members, such as college plans of a sibling or early retirement plans of a parent. The amount of care and attention required by individuals with chronic illness or disability may create emotional strain among family members, resulting in feelings of resentment, antagonism, and frustration. Role change and ambiguity may make it necessary to redefine family relationships as new and unaccustomed duties and responsibilities arise.

Quality of Life

Successful rehabilitation means more than assisting individuals to reach their optimal functional capacity; it also means assisting individuals to achieve and enhance quality of life. *Quality of life* is subjective in nature with no universal meaning. No two people define the term in quite the same way. Although

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quality of life may be viewed by some as optimal functioning at the highest level of independence, others may place greater emphasis on life itself, regardless of level of function. Only the individual can determine the personal meaning of the quality of life. Individual value systems, cultural backgrounds, spiritual perspectives, and the attitudes and reactions of those within the environment all influence the interpretation of quality of life.

Each individual's situation and experience are unique. Perceptions of the same condition and its impact vary from individual to individual (Burker, Carels, Thompson, Rodgers, & Egan, 2000; Crews, Jefferson, Broshek, Barth, & Robbins, 2000). People with similar conditions, symptoms, and limitations may perceive their condition in totally different manners.

The perception of chronic illness or disability depends on characteristics of the condition and treatment, age and developmental stage of the individual, the degree of limitation and the extent of disability experienced, and the manner in which characteristics of the condition affect the individual's definition of quality of life. Symptoms or limitations that one individual accepts and to which he or she adapts may be perceived as overwhelming and intolerable to another individual. The impact of chronic illness or disability on the overall quality of life often determines daily choices and day-to-day management of the condition.

Assessment of quality of life is made difficult by the ambiguous nature of the concept. Attempts to discover and accurately measure quality of life have caused considerable confusion and resulted in the development of multiple indicators. Indicators of quality of life have ranged from physiologic parameters, to the ability to return to work, to the ability to participate in social activities, to the number of psychological problems experienced by the individual. In addition, studies of quality of life have often identified discrepancies between

the judgment of service providers and that of consumers regarding quality-of-life outcomes (Leplege & Hunt, 1997).

Individuals' perception of quality of life is among the main determinants of demand for services, compliance with treatment, and satisfaction with treatment and services provided. How some individuals assess the impact of their condition on their quality of life is determined by the degree to which they feel they have control over their life circumstances or destiny. Accurate knowledge about their condition and treatment, together with active participation in decision making about the management of the condition, can enable individuals with chronic illness and disability to make judgments that will enable them to enhance quality of life in terms of their own needs, goals, and circumstances.

Adherence to Prescribed Treatment and Recommendations

Most chronic illnesses or disabling conditions require ongoing treatment, medical supervision, or restrictions on activity to control the condition or to prevent complications. However, many individuals with chronic illness or disability fail to follow the recommendations prescribed, potentially imperiling their own well-being (Graham, 2003; Dunbar-Jacob, Erlen, Schlenk, Ryan, Sereika, & Doswell, 2000). Neglecting to take medications as prescribed, resisting restriction of activities, or engaging in behaviors that are likely to cause complications of chronic illness or disability can significantly influence individuals' medical prognosis and functional capacity (Dolder, Lacro, Leckband, & Jeste, 2003; Vergouwen, Bakker, Katon, Verheij, & Koerselman, 2003; Zygmunt, Olfson, Boyer, & Mechanic, 2002; Schmalings, Afari, & Blume, 2000). The best rehabilitation plan is of little value if individuals do not follow the treatments designed to manage their

symptoms or condition or to prevent complications or progression (Loghman-Adham, 2003; Kovac, Patel, Peterson, & Kimmel, 2002).

Although individuals who purposely behave in a way that makes their condition worse seem irrational, there are a number of explanations for nonadherent behavior. Illness or disability elicits many responses from individuals and their families. Different reactions, experiences, and motives direct behavior and can help or hinder adherence to treatment recommendations.

Individuals' lives are guided by a set of norms and values—expressed and unexpressed. Each individual has a personal, unique perspective on health, illness, and medical care itself. There is a remarkable difference in perceptions of and reactions to apparently similar medical conditions. The meaning of illness and the consequences ascribed to adherence to recommendations are based mainly on individuals' perceptions of the condition and its associated limitations as well as their perceptions of treatment recommendations and their implications. While some individuals react mildly to a condition that may devastate another, others display considerable emotional and physical discomfort with conditions that most people consider minor. Obviously, various psychosocial factors determine individuals' reactions to illness and, consequently, their reactions to the recommendations and advice given.

Chronic illness or disability disrupts the way individuals view themselves and the world, and it can produce distortions in thinking. Most individuals initially experience a feeling of vulnerability and a shattering of the magical belief that they are immune from illness, injury, or even death. With this realization, they may lose their sense of security and cohesiveness. Life may seem a maze of inconveniences, hazards, and restrictions. Nonadherence to recommendations may be an

attempt to exert self-determination, to regain a sense of autonomy and control, and to claim some mastery over individual destiny. In other instances, resistance to treatment recommendations may be a denial of the condition itself.

Nonadherence can also be a reflection of individuals' feelings about their life circumstances. For some individuals, having a chronic illness or disability is not a positive role; for others, it may be far preferable to the social role that they held previously. Some persons may vacillate between the wish to be independent and the wish to remain dependent. Chronic illness or disability can be a means of legitimizing dependency as well as a means of increasing the amount of attention received. Subsequently, individuals may be reluctant to return to their former roles and obligations. The motivation to retain the sick role is at times greater than the motivation to gain optimal function. As a result, ultimate rehabilitation is hampered.

Failure to adhere to recommendations is sometimes a response to guilt that has been incorporated into the reaction to or beliefs about illness or disability. If health and well-being are perceived as rewards for a life well lived, illness or disability may be viewed as punishment for real or imagined actions of the past. Adherence to medical advice may be perceived as interference with a punishment believed to be deserved. In other instances, individuals may feel guilty because they believe that the illness or disability is a direct result of their own negligence or overt actions.

Guilt or shame at being different may also hinder adherence to treatment recommendations. Some individuals may attempt to hide their condition from others and, therefore, fail to follow recommendations that they fear may call attention to their condition.

The impact of chronic illness or disability on an individual's general economic well-being can also affect his or her ability and

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willingness to follow treatment recommendations. While many occupations offer fringe benefits, such as paid sick days or even time off with pay in which to seek medical care, other occupations provide no such benefits. In the latter instances, days taken off from work because of illness or medical appointments can decrease income. The economic consequences of chronic illness or disability may also cause the opposite reaction. If an individual is receiving disability benefits and has little opportunity for satisfactory employment, he or she may not follow recommendations that would increase their ability to return to work, thereby decreasing or eliminating benefits.

Finally, quality of life is a relative concept, uniquely defined by each individual. If treatment recommendations, or side effects of treatment, result in pain, discomfort, or inconvenience greater than the benefit perceived by the individual in terms of his or her own subjective definition of the quality of life, compliance with prescribed recommendations may not be perceived as worth the psychological, social, or physical cost. Treatment can sometimes—but not always—be adjusted to make adhering to recommendations more palatable. Individuals' right to self-determination must be carefully balanced with assurance that the choice of nonadherence is based on information and full understanding of the consequences.

Some individuals readily adjust to the challenges, limitations, and associated behavioral changes necessitated by chronic illness or disability. Many individuals, however, actively sabotage treatment and recommendations, to their own detriment. In such instances, professionals' goals should be to attempt to understand the underlying problems and motivations of individuals and to help them make the necessary adjustments and adaptations to maximize their functional

outcomes. Rather than criticizing individuals with chronic illness or disability for disinterest, a lack of motivation, or failure to follow recommendations, it is important to identify the barriers that inhibit adherence and to recognize that such reactions may indicate difficulty in accepting the condition or adapting recommendations into the individual's own unique way of life. The best way to achieve adherence is to consider the individual's perceptions, goals, and environment and lifestyle, and to tailor recommendations to best meet those needs (Falvo, 2004).

**Client and Family Education
(Patient Education)**

Although medical care, support, and auxiliary services are important aspects of helping individuals reach their optimal potential, successful management of chronic disease or disability requires considerable individual and family effort. Regardless of the complexity of the condition, many individuals are now expected to carry out treatments in their home rather than depend on medical personnel in healthcare settings. Individuals' understanding of their condition and treatment is one of the basic components of self-determination and responsible care. Not only must they understand how to integrate these regimens into their daily routines and how to carry out daily care activities, but they must also understand preventive healthcare measures to help them retain function and prevent further disability or health problems (Falvo, 2004).

Because of increasing public awareness of the need for individuals to accept this greater role of responsibility and self-determination, a number of programs and counseling services have been established to help clients and their families reach this goal. Client and family education can take place individually or in a group setting, can be formal or informal, and

can include ongoing counseling or referral to resources for self-directed learning. Regardless of the type of setting in which educational services are delivered, the most effective client education will be that which considers the specific circumstances and goals of the individual (Falvo, 2004).

Stages of Adaptation and Adjustment

A host of personal, social, and environmental experiences, demands, supports and resources, and coping strategies interact to influence adaptation outcomes (Livneh, 2001). The process of adjustment includes a search for meaning in the experience and an attempt to regain control and self-determination over the events that affect one's life. Most individuals with chronic illness and disability experience some form of loss—either a direct physical loss or a more indirect loss of the ability to participate in some previously performed activity. Regardless of the nature of the loss, a variety of reactions may take place while individuals attempt to make necessary adaptations and changes.

Stages of adjustment are individual and varied. The shock of diagnosis and its consequent implications may have a numbing effect, so initially individuals may demonstrate little emotional reaction. As the reality of the situation becomes clear, individuals may experience a sense of hopelessness and despair, mourning for a self, a role, or a function that is lost. They may also experience feelings of anger, which alternate with depression. Many individuals go through a period of mourning and bereavement similar to that experienced when a loved one is lost. Mourning is a natural reaction to loss and allows time for reflection and reestablishment of emotional equilibrium. As individuals begin to appraise their condition realistically, examine the limitations that it imposes, and adjust to the associated losses, they may gradually seek alternatives and adap-

tations to achieve their integration into a broader world.

The ultimate outcome of adjustment is acceptance of the condition and its associated limitations, along with a realistic appraisal and implementation of strengths. Acceptance does not mean passivity regarding implications of the condition, but rather that individuals are ready to move toward reaching optimal functional capacity. The amount of time that individuals need to reach acceptance is dependent on personality, reactions of family and significant others, life circumstances, available resources, and the types of challenges that confront each individual. Some individuals never reach acceptance. Maladjustment and nonacceptance are characterized by immobility, marked dependency, continued anger and hostility, prolonged mourning, or participation in detrimental or self-destructive activities. Just as coping mechanisms are vital parts of human nature, serving to protect against stress, reduce anxiety, and facilitate adjustment, so overuse or maladaptive use of coping mechanisms can postpone or inhibit adjustment.

■ FUNCTIONAL ASPECTS OF CHRONIC ILLNESS AND DISABILITY

Functional effects of chronic illness or disability are many and varied. Each individual has different needs, abilities, and circumstances that determine how chronic illness or disability affects his or her functional capacity. The extent to which the individual experiences disability as a result of the condition depends to a great extent on his or her goals and perception of the condition, the environment, and the reactions of family, friends, and the societal and political environment. The severity of the condition as measured by diagnostic tests is not always an indication of functional

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capacity. Also, individuals' ability to function is not always directly correlated with the severity of the condition itself. Rather, function is determined by an interaction of factors related to the person and his or her environment. Individuals' reactions may differ even though they have similar chronic illness or disability.

Professionals working with individuals with chronic illness or disability need an understanding of the potential limitations or restrictions associated with a specific condition or treatment to help individuals and their families make appropriate changes to gain optimal functional capacity. The effects of chronic illness and disability are far-reaching and include psychological, social, and vocational effects as well as changes and adjustments in both general lifestyle and activities of daily living. The medical diagnosis per se is not as important as the individual's goals and the degree to which function in each area of the individual's life is affected. The interactive nature of function between each of the areas determines the extent to which individuals can reach their optimal potential. A focus on any one area without full consideration of the impact of chronic illness or disability on all other areas can dilute the effectiveness of the total rehabilitative efforts. Understanding and working effectively with individuals who have a chronic illness or disability requires a broad outlook that goes beyond medical diagnosis; it requires recognition that the most important factor is the individuals' ability to function with the condition within their environment and all areas of their life.

Personal and Psychological Issues in Chronic Illness and Disability

Individuals react both cognitively and emotionally to events that involve them. These reactions, in turn, affect the later course of those events. Personal and psychological factors are ever present in all aspects of chronic

illness and disability, and they influence individuals' response to the illness or disability. Sometimes psychological factors are part of the symptoms of the condition itself. These factors affect not only individuals' adjustment and subsequent functional capacity, but also their outcome and prognosis.

Lifestyle Activities Issues in Chronic Illness and Disability

Life activities consist of the daily tasks and activities of daily living within an individual's environment. They include the ability to perform tasks related to grooming, housekeeping, and preparing meals. They also include activities related to transportation, daily schedules, need for rest or activity, recreation, sexuality, and privacy. At times, limitations in performing the activities of daily living may result from environmental considerations that serve as barriers to effective functioning. Modifications such as widening doorways to permit the passage of a wheelchair, placing handrails in a bathroom, or installing more effective lighting may be required to increase functional capacity. Other modifications may be necessary because of the additional tasks and time commitments related to medical treatment of a specific condition. In some instances, restrictions of diet or activity, continued treatments, medical appointments, and related activities may require significant alteration of the individual's daily schedule.

Social Participation Issues in Chronic Illness and Disability

The social environment can be defined as individuals' perceived involvement in personal, family, group, and community relationships and activities. Social well-being is based on emotionally satisfying experiences in social activities involving those within the individual's social group. Chronic illness and disability

often lead to changes in social status. Individuals with chronic illness or disability may find themselves in a socially devalued role. As a result, they may experience changes in social relationships or interactions, or limit the number of social activities; any of these changes can result in social isolation. Even when individuals with chronic illness or disability attempt to remain socially active, they may have difficulty entering community facilities because of environmental barriers or because of prejudice or stereotyping. Many factors contribute to an individual's adaptation or adjustment to any social limitations associated with a particular medical condition.

Individuals' perception or misperception of the reactions of others in social groups may determine the level of acceptance that they receive. The degree to which individuals are able to adapt, accept, and adjust to their condition are determined in part by their interactions with others in their environment as well as by their interpretation of the reactions of others.

Vocational Issues in Chronic Illness and Disability

The significance of work in the rehabilitation of people with chronic illness and disability has been well documented (Cunningham, Wolbert, & Brockmeier, 2000). Work involves more than remuneration for services rendered and does not necessarily include only activity related to financial incentives. Work provides a sense of contribution, accomplishment, and meaning to life (Ben-Shlomo, Canfield, & Warner, 2002; Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001; Bond, Resnick, Bebout, Drake, Xie, & McHugo, 2001). Consequently, loss of ability to work extends beyond financial considerations to social and psychological well-being. Loss of ability to work means more than the loss of income; it also means the loss of a socially valued role. For many individuals,

work is not merely a major part of their identity, but a source of social interaction, structure, and purpose in life.

The degree to which chronic illness and disability affect individuals' ability and willingness to work depends on a variety of factors in addition to the limitations imposed by the illness or disability itself (Young & Murphy, 2002). These factors include the nature of the work, the physical environment of the work setting, and the attitudes of employers and co-workers. Psychosocial variables may also complicate functional capacity and, therefore, the rehabilitation process. At times, individuals with chronic illness or disability may continue to perform the same work they performed before the onset of the condition. At other times, certain work tasks, environmental conditions, or work schedules must be modified to accommodate limitations associated with the chronic illness or disability. If modifications cannot be made in these cases, individuals must change employment. Some individuals must assume disability status because appropriate modifications cannot be made or because their limitations are severe. Job stress or attitudes of employers or co-workers can also significantly interfere with individuals' ability to return to the workforce. Problems with transportation to and from work because of limitations associated with chronic illness or disability may make a return to work more difficult. In other instances, time required to carry out treatment recommendations related to the condition may make completing a full day at work virtually impossible.

Individuals' capacity to function at a job can depend on cognitive, psychomotor, and attitudinal factors as well as on the physical aspects of illness or disability. Accurate assessment of individuals' capacity to return to work consists of more than evaluation of physical factors alone. Success or failure at work is often determined by factors other than physical skill or ability. Individuals' fear of reinjury, vocational

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dissatisfaction, or legal issues can hamper return to work. Individuals' ability to relate to and interact with others within the work environment must also be considered. Interests, aptitudes, and abilities are always pivotal factors in determining vocational success, regardless of limitations. Effective rehabilitation that enables individuals to function effectively in their job often involves interdisciplinary efforts of many types of medical and nonmedical professionals to conduct assessment, evaluation, therapy, and vocational guidance.

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