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Illness Behavior

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*Illness is the night-side of life, a more onerous
citizenship. Everyone who is born holds dual
citizenship, in the kingdom of the well and in the
kingdom of the sick. Although we all prefer to
use only the good passport, sooner or later each
of us is obligated, at least for a spell, to identify
ourselves as citizens of that other place.*
    Susan Sontag, *Illness as Metaphor,* 1988, p. 3

INTRODUCTION

Society establishes both formal and informal
guidelines that influence the behavior of its mem-
bers. The behavior of an individual with a chronic
condition is shaped by these societal influences as
well. The individual who fully recovers from an ill-
ness returns to prior behaviors and roles. However,
when there is only partial recovery or continuing
illness, as with a chronic disease, the individual
has to modify or adapt previous behavior and roles
to accommodate societal expectations, their own
expectations, and their health status. This chapter
provides an overview of the illness experience and
corresponding behavior demonstrated by those
with chronic illness. It is not meant to be a com-
prehensive review of the entire body of knowledge,
which is vast.

Historical Perspectives

Disease involves not only the body, but it also
affects one's relationships, self-image, and behav-
ior. The social aspects of disease may be related
to the pathophysiologic changes that are occur-
ring, but may be independent of them as well. The
very act of diagnosing a condition as an illness has
consequences far beyond the pathology involved
(Conrad, 2005).

> When a veterinarian diagnoses a cow's
> condition as an illness, he does not
> merely by diagnosis change the cow's
> behavior…but when a physician diagno-
> ses a human's condition as an illness, he
> changes the man's behavior by diagnosis:
> a social state is added to a biophysiologi-
> cal state by assigning the meaning of ill-
> ness to disease (Freidson, 1970, p. 223).

The earliest concept of illness behavior was
described in a 1929 essay by Henry Sigerist. His
essay described the "special position of the sick"
(cited in Young, 2004). Talcott Parsons developed
this concept further and described the "sick role"
in his 1951 work, *The Social System.*

Sick Role

Sickness has typically been viewed by sociologists as a form of deviant behavior (Cockerham, 2001, p. 157). This view was corroborated by Parsons' development of the sick role. Parsons, a proponent of structural–functionalist principles, viewed health as a functional prerequisite of society. From Parsons' point of view, sickness was dysfunctional and was a form of social deviance (Williams, 2005). From this functionalist viewpoint, social systems are linked to systems of personality and culture to form a basis for social order (Cockerham, 2001, p. 160). Parsons viewed sickness as a response to social pressure that permitted the avoidance of social responsibilities. Anyone could take on the role he identified; therefore, the role was achieved through failure to keep well.

The four major components of the sick role include:

■ The person is exempt from normal social roles.
■ The person is not responsible for his/her condition.
■ The person has the obligation to want to become well.
■ The person has the obligation to seek and cooperate with technically competent help (Williams, 2005, p. 124).

The Impaired Role

Gordon (1966) developed the impaired role in response to the sick role. He saw the sick role as being more applicable to individuals with acute illness and injuries. When the sick role is applied to long-term chronic illness, the role is less useful. A more appropriate role for those with chronic illness is the "impaired" role (Gordon, 1966). Although less well known than the sick role, it better addresses the needs of those with chronic illness.

Gordon (1966) identified behaviors, responses, and expectations of several socioeconomic groups toward illnesses that differed in both severity and duration. He found, among all groups, that prognosis was the major factor in defining someone as "sick," and that once someone was so defined, behaviors were consistent with Parsons' model. When prognosis worsened, all groups encouraged increased exemption from social responsibility. Socioeconomic groups varied in terms of who was defined as sick, with members from lower socioeconomic groups equating sickness with functional incapacity.

Gordon identified two illness role statuses. The first was the sick role, as previously defined by Parsons, which was a valid role when the prognosis was grave and uncertain. The second role, which Gordon called the impaired role, was considered appropriate for conditions in which the prognosis was known and was not grave. When individuals were seen in the impaired role, "normal" social expectations and responsibilities were expected (Gordon, 1966). In other words, if society did not consider the individual "sick," it was expected that the individual return to normal behavior, within the limitations of the condition.

The impaired role assumes the following characteristics:

■ The individual has an impairment that is permanent.
■ The individual does not give up normal role responsibilities, but is expected to maintain normal behavior within the limits of the health condition. Modification of life situations may be necessitated by the disability.
■ The individual does not have to "want to get well," but rather is encouraged to make the most of remaining capabilities.

Inherent in the impaired role is the attitude that retaining sick role behaviors prevents the individual from managing their own care. However, once the impaired role is accepted, activities that help maintain control of the condition, prevent complications, lead to resumption of role responsibilities, and result in full realization of potentialities are

acceptable. The impaired role incorporates rehabilitation concepts and maximization of wellness.

The impaired role, sometimes called the "at-risk" role, is seen as a transitional state, one in which individuals make changes in a variety of role behaviors in which they engaged before the illness. This role has some obligations, such as carrying out the medical regimen, but requires much less reduction in other social roles than does the sick role. One important difference between the two roles is that the impaired role is associated with more uncertainty than is the sick role.

Using Parsons' work as a basis, Mechanic (1962) proposed the concept of illness behavior as the way in which given symptoms may be differently perceived, evaluated, and acted (or not acted) upon by different persons (p. 189). His work in this area was initiated because he believed it was essential to understand the influence of norms, values, fears, and expected rewards and punishments on how an individual with illness acts. Mechanic's latest definition defines illness behavior as the "varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilize various sources of formal and informal care" (Mechanic, 1995, p. 1208).

Around the time of Mechanic's earlier work, Kasl and Cobb (1966) identified three types of health-related behavior: illness behavior, health behavior, and sick role behavior:

> Health behavior is any activity undertaken by a person believing himself to be healthy, for the purpose of preventing disease or detecting it in an asymptomatic stage.
>
> Illness behavior is any activity, undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy. Sick-role behavior is the activity undertaken, for the purpose of getting well, by those who consider themselves ill.

McHugh and Vallis (1986) suggest that perhaps instead of categorizing behavior as health-related,

illness-related, or sick-role–related that it makes more sense to look at illness behavior on a continuum. By doing this, the term illness behavior can be broadly defined, and this characterization is more helpful, since the distinction between health and illness behaviors is arbitrary at times (p. 8).

Throughout the chronic illness literature, the term illness behavior is used in different ways and with different meanings. It has been used synonymously with the "sick role" (Turk & Salovey, 1995). Pilowsky (1986) supports the notion that patients who present with illness behaviors that are not congruent with the physical illness exhibit "abnormal" illness behavior. These behaviors would include excessive or inadequate response to symptoms, including but not limited to hypochondriasis, somatization, and denial of illness (Kirmayer & Loper, 2006).

Displaying extreme behavior over the result of a minor health issue, for instance, an ingrown toenail, may be termed abnormal illness behavior. But how do we as healthcare professionals describe behavior as normal or abnormal when it is not we who are diagnosed with the chronic condition and have the resulting illness experience?

Influences to Illness Behavior and Roles

Illness behavior is shaped by sociocultural and social-psychological factors (Mechanic, 1986). What follows in this section are examples of these factors.

Culture of Poverty

The culture of poverty (see Chapter 12) influences the development of social and psychological traits among those experiencing it. These traits include dependence, fatalism, inability to delay gratification, and a lower value placed on health (Cockerham, 2001, p. 123). The poor, who have to work to survive, often deny sickness unless it brings functional incapacity (Helman, 2007). Different cultures may define and interpret health and illness in a variety of ways (see Chapter 12).

Demographic Status

Marital status may influence illness behavior as well. In general, married individuals require fewer services because they are healthier, but utilize other services because they are more attuned to preventive care (Thomas, 2003). Searle, Norman, Thompson, and Vedhara (2007) examined the influence of the illness perceptions of clients' significant others and their impact on client outcomes and illness perceptions. Differences in illness representations of significant others and clients have shown to influence psychological adaptation in chronic fatigue syndrome and Addison's disease (cited in Searle et al., 2007). Searle and colleagues sought to understand illness representations in clients with type 2 diabetes and their partners. However, in this study, almost without exception, there was agreement between the illness representations of patients and their partners. Another aim of the study was to determine the influence of the partner or significant other on the clients' illness representation. There was some evidence to suggest that partners' representations did partially mediate clients' representations on exercise and dietary behaviors (Searle et al., 2007).

Gender may influence illness behavior and "help-seeking" behavior in chronic conditions. Sociologic analysis has suggested that women are more likely than men to seek medical help (Bury, 2005). Morbidity rates demonstrate that women are more likely to be sick than men and thus seek more professional medical help (p. 55). Lorber (2000) states that women are not more fragile than men, but are just more self-protective of their health status.

Increasing age often brings chronic conditions and disability. However, older individuals in poor health (as measured by medicine's standard measures) often do not see themselves in this way. What may influence older adults' perceptions of their illness and subsequent behavior may not even be considered by healthcare professionals as "relevant." Kelley-Moore, Schumacher, Kahana, and Kahana (2006) identified that cessation of driving and receiving home health care were two markers that self-identified older adults' illness perceptions, causing them to consider themselves disabled.

Past Experience

One's learning, socialization, and past experience, as defined by their social and cultural background, mediate illness behavior. Past experiences of observing one's parents being stoic, going to work when they were ill, avoiding medical help, all influence their children's future responses. If children see that "hard work" and not giving in to illness pays off with rewards, they will assimilate those experiences and mirror them in their own lives. Elfant, Gall, and Perlmuter (1999) evaluated the effects of avoidant illness behavior of parents on their adult children's adjustment to arthritis. Even after several decades, children's early observations of their parents' illness behaviors appears to affect their own adjustment to arthritis. Those clients whose parents avoided work and other activities when ill with a minor condition reported greater severity of arthritis and its limitations, depression, and helplessness when compared with clients whose parents did not respond to minor illness with avoidance (p. 415).

In another vein, how parents respond to their children's health complaints may later influence how the children, as adults, cope with illness. Whitehead and colleagues, and (1994) studied the influence of childhood social learning on the adult illness behavior of 383 women aged 20 to 40 years of age. Illness behavior was measured by frequency of symptoms, disability days, and physician visits for menstrual, bowel, and upper respiratory symptoms. Findings included that childhood reinforcement of menstrual illness behavior significantly predicted adult menstrual symptoms and disability days, and childhood reinforcement of cold illness behavior predicted adult cold symptoms and disability days. The study's data supported the hypothesis that specific patterns of illness behavior are learned during childhood through parental reinforcement and modeling, and that these behaviors continued into adulthood (p. 549).

Illness Representations

Clients and their families do not simply develop their own illness beliefs and perceptions within a vacuum, but they are molded by everyday social interactions (Marks, Murray, Evans, Willig, Woodall, & Sykes, 2005). Social representation theory is concerned about how societal belief systems influence and shape interpretations of illness of clients and their families. A classic study by Herzlich in 1973 (Marks et al., 2005) used social representation theory as a framework in a sample of French adults. The individuals considered activity to be the defining part of health and illness. If you were active, you were healthy. If you were inactive, it meant you were ill. Herzlich described three lay reactions to illness:

- Illness as destructive: The experience of those actively involved in society
- Illness as liberator: The experience of those with excessive social obligations
- Illness as an occupation: The experience of those who accept illness and feel they must contribute to its alleviation (Marks et al., 2005, p. 231).

Levanthal, Levanthal, and Cameron (2001) describe five attributes of illness representations. These include:

- The identity of the threat or the symptoms that define it
- The time line for development and duration of the disease, treatment regimen, and time needed for cure, treatment, or death
- The causes of the threat (internal or external)
- The anticipated and experienced consequences of the disease
- The controllability of the condition (Levanthal et al., 2001, p. 22)

According to Levanthal and colleagues these attributes form the basis of lay models of illness and guide and shape how we select and use coping strategies (p. 22).

IMPACT AND ISSUES RELATED TO ILLNESS BEHAVIOR

As we describe illness behavior, it is important to reiterate the difference between the terms disease and illness. Disease is the pathophysiology, the change in body structure or function that can be quantified, measured, and defined. Disease is the objective "measurement" of symptoms.

Illness is what the client and family experience. It is what is experienced and "lived" by the client and family, and includes the "meaning" the client gives to that experience (Helman, 2007). Both the meaning given to the symptoms and the client's response, or behavior, are influenced by the client's background and personality as well as the cultural, social, and economic contexts in which the symptoms appear (p. 126).

The Illness Experience

The diagnosis of a chronic disease and subsequent management of that disease brings unique experiences and meanings of that process to both the client and family. The biomedical world disregards illness and its meaning and prefers to think of the disease. Disease can be quantified and measured, and it can be considered a "black and white" concept. Disease fits into our medical model framework. Illness, and its meaning, does not fit into a neat little box; it is not a black and white concept, but consists of many shades of gray and is difficult to measure and categorize. Kleinmann, who has written since the 1970s about illness behavior and its meaning, becomes concerned that researchers have "reduced sickness to something divorced from meaning in order to avoid the hard and still unanswered technical questions concerning how to actually go about measuring meaning and objectivizing and quantitating its effect on health status and illness behavior" (Kleinmann, 1985, p. 149). While realizing the importance of this

scientific work, Kleinmann sees it as "detrimental to the understanding of illness as human experience, since they redefine the problem to subtract that which is mostly innately human, beliefs, feelings. . ." (p. 149).

The common sense self-regulation model (Leventhal et al., 2001) seeks to explain that individual illness perceptions influence coping responses to an illness. This perspective explains that clients construct their own illness representations to help them make sense of their illness experience. It is these representations that form a basis for appropriate or inappropriate coping responses (Leventhal et al., 2001). Stuifbergen and colleagues (2006) used a convenience sample of 91 women with fibromyalgia to explore their illness representations. Overall, the women had fairly negative perceptions of their illness. Emotional representations explained 41% of the variance in mental health scores. Using the model of Levanthal and colleagues (2001), less emotional distress predicted more frequent health behaviors and more-positive mental health scores; whereas those women who perceived their fibromyalgia to have more serious consequences and as less controllable, were more likely to have higher scores on the Fibromyalgia Impact Questionnaire (p. 359).

Price (1996) describes individuals with a chronic disease as those developing an illness career that responds to changes in health, his or her involvement with healthcare professionals, and the psychological changes associated with pathology, grief, and stress management (p. 276). This illness career is dynamic, flexible, and goes through different stages of adaptation as the disease itself may change.

Loss of Self

Charmaz (1983) coined the phrase, loss of self, with her research in the 1980s, interviewing individuals with chronic illness through a symbolic interactionist perspective. The influences to the loss of self develop from the chronic condition(s) and the illness experience. Charmaz describes clients' illness experience as living a restricted life, experiencing social isolation, being discredited, and burdening others. Slowly the individual with chronic illness feels their self-image disappear: a loss of self, without the development of an equally valued new one (p. 168).

In another study of 40 men with chronic illness, Charmaz (1994) describes different identity dilemmas than with women. Charmaz sees these men as "preserving self." As men come to terms with illness and disability, they preserve self by limiting the effect from illness in their lives. They intensify control over their lives. Many assume that they can recapture their past self, and they try to do so. They may devote vast amounts of energy to keeping their illness contained and the disability invisible to maintain their masculinity. At the same time, they often maintain another identity at home . . . thus a public identity and a private identity to preserve self (p. 282).

Moral Work

Townsend, Wyke, and Hunt (2006) in their qualitative study describe the moral dimension of the chronic illness experience. Their work speaks to the fact that moral work is integral to the illness, similar to the biographical and everyday "work" of Corbin and Strauss (1988) . The participants in their study spoke about the need to demonstrate their moral worth as individuals, that it was their moral obligation to manage symptoms alongside their daily life (p. 189).

Devalued Self

In a qualitative study of Chinese immigrant women in Canada, Anderson (1991) describes how these women with type 1 diabetes have a devalued self, not only from the disease but also because of dealing with being marginalized in a foreign country where they do not speak the language. Similar to the "loss of self" described by Charmaz, Anderson speaks of women who need to reconstruct a new self. Influencing this devalued self

are the interactions with healthcare professionals. Interactions with care providers, which were frequently negative in nature, added additional sources of stress to further devalue these women.

Continuity and Discontinuity

Secrest and Zeller (2007) describe the continuity and discontinuity of self following stroke. Although similar to the "loss of self" concept of Charmaz, Secrest and Zeller use these terms from gerontology literature, specifically Atchley's continuity theory of normal aging. They see continuity and discontinuity as dimensions of quality of life (Secrest & Zeller, 2007).

Who Legitimizes Chronic Illness?

With some illnesses, especially when symptoms are not well defined and diagnostic tests may be ambiguous, receiving legitimization from the physician or other healthcare professionals may be difficult and frustrating. Denial of opportunity to move into the sick role leads to "doctor hopping," placing clients in problematic relationships in which they must "work out" solutions alone (Steward & Sullivan, 1982). As a result, symptomatic persons may be left to question the truth of their own illness perceptions.

As examples, two current chronic conditions often defy diagnosis and are slow to respond to treatment. Chronic fatigue syndrome (CFS) and fibromyalgia are typically seen as diseases of young women. In both diseases there is uncertainty with respect to etiology, treatment, and prognosis. They have been contested illnesses, in that some question their existence (Asbring, 2001). Without legitimatization from physicians or the healthcare system, these clients are labeled as hypochondriacs or malingerers. Some of these clients are referred to psychologists or psychiatrists when a physical diagnosis cannot be made and diagnostic tests results are normal.

When a diagnosis is finally made, the client frequently shows an initial somewhat joyous response to having a name for the recurrent and troublesome symptoms. This reaction results from the decrease in stress over the unknown. These clients have an enormous stake in how their illnesses are understood. They seek to achieve the legitimacy necessary to elicit sympathy and avoid stigma, and to protect their own self-concept (Mechanic, 1995).

Asbring (2001) identifies two themes from her qualitative study in which women with CFS or fibromyalgia were interviewed. She describes an earlier identity partly lost, and coming to terms with a new identity. Asbring uses the term "identity transformation" in the women she interviewed. However, she also saw illness gains in these women. The illness and its limitations provided the women with time to think and reflect on their lives and perhaps rearrange priorities. Therefore, the illness experience of these women may be seen as a paradox with both losses and gains (p. 318).

Larun and Malterud (2007) examined 20 qualitative studies in a meta-ethnography about the illness experiences of individuals with CFS to summarize the illness experiences of the individuals as well as the physicians' perspectives. Across studies, clients spoke of being "controlled and betrayed by their bodies" (pp. 22–23). Although physical activities were mostly curtailed, individuals spoke of the mental fatigue that affected memory and concentration, and conversations that were hard to follow, and several clients felt that their learning abilities had decreased (p. 24). One of the themes that emerged was stories about *bodies which no longer held the capacity for social involvement.* For some individuals the most distressing part of the illness were the negative responses from family members, the workplace, and their physicians, who *questioning the legitimacy of their illness behavior* because of the dynamic symptoms of CFS (p. 25). Thus their physicians' beliefs about CFS influenced the clients' perceptions of the disease and thereby their illness experience. To summarize, the researchers' analysis determined that clients' sense of identity becomes more or less invalid and that a change in identity of the individuals was experienced.

CASE STUDY

Ms. Janet Brown is a 36-year-old woman, who was recently diagnosed with fibromyalgia. She has been a client at the clinic where you work for several years, calling in every few weeks and/or having frequent appointments. Typically her clinical symptoms have been vague; however, she has often seemed frantic about them. Her recent diagnosis initially seemed to make her be more content and settled. However, now it seems that she is escalating in her behavior and talking about no one caring about her (including her family), that your clinic does not "understand" her, and is just generally being unreasonable on the phone and in person.

Discussion Questions

1. How do you make sense of this client's illness behavior? Is it abnormal?
2. What strategies might you use to deal with this client?
3. How could you apply the frameworks for practice mentioned in this chapter to this client situation?

Professional Responses to Illness Behavior and Roles

Healthcare professionals generally expect those entering the acute hospital setting to conform to sick role behaviors. Most people entering the hospital for the first time are quickly socialized and expected to cooperate with treatment, to recover, and to return to their normal roles. Provider expectations and client responses are in line with social expectations and fit with the traditional medical model of illness as acute and curable. When clients are compliant and cooperative, healthcare professionals communicate to them that they are "good patients" (Lorber, 1981). When clients are less cooperative, the staff may consider them problematic.

But the percentage of individuals with chronic illness entering hospitals is increasing, and these conditions cannot be cured. Such admissions occur when symptoms flare or acute illnesses are superimposed. Many of these individuals have had their chronic illnesses for long periods and have had prior hospital experiences. Multiple contacts with the health care system result in loss of the "blind faith" that the individual once had in that system. Individuals with chronic illness are seeking a different kind of relationship with health care professionals (Thorne & Robinson, 1988). The extent to which a client with chronic illness is included in the formulation of his or her treatment plan will likely influence the assumption of responsibility for it and, ultimately, its success (Weaver & Wilson, 1994).

Being in Gordon's "impaired" role is integral to the daily lives of the chronically ill. Although willing to delegate some responsibility for care to healthcare professionals, they prefer to retain as much control of their regimens as possible. These clients have developed their own competence over time dealing with their illnesses, and they have come to expect acknowledgment of that competence in their health care relationships (Thorne & Robinson, 1988).

Thorne's (1990) study of individuals with chronic illness and their families found that their relationships with healthcare professionals evolved from what was termed "naive trust" through "disenchantment" to a final stage of "guarded alliance." She proposed that the "rules" that govern these relationships should be entirely different for acute and chronic illness. Although assuming sick role dependency may be adaptive in acute illness,

where medical expertise offers hope of a cure, it is not so in chronic illness. Chronically ill individuals are the "experts" in their illnesses and should have the ultimate authority in managing those illnesses over time.

When individuals with chronic illness are hospitalized, they view the situation quite differently from the healthcare professionals with whom they interact. Clients with multiple chronic disorders may focus on maintaining stability of quiescent conditions to prevent unnecessary symptomatology, whereas staff are more likely to focus on managing the current acute disorder (Strauss, 1981). In addition, clients who have had multiple prior admissions are more likely to use their hospital savvy to gain what they want or need from the system. During hospitalization, these individuals may demand certain treatments, specific times for treatment, or routines outside of hospital parameters. They may keep track of times that various routines occur or complain about or report actions of the staff as a means to an end they consider important. All of these demands increase staff work and stress, and frequently the client is labeled a "problem patient" (Lorber, 1981).

In a grounded theory study in the United Kingdom, Wilson, Kendall, and Brooks (2006) explored how patient expertise is viewed, interpreted, defined, and experienced by both clients and healthcare professionals. With nursing playing a key role in empowering clients with chronic disease to self-manage their conditions, knowing how that client expertise is viewed (by the care provider) is extremely important. Generally, in this study of 100 healthcare professionals (physicians, nurses, physical therapists), the nurses found the expert patients to be more threatening than other healthcare professionals did. The nurses had issues with accountability, perceived threats to their professional power, and potential litigation. The data from the study demonstrated that the nurses lacked a clear role definition and distinct expertise in working with patients with chronic disease and were unable to work in a flexible partnership with self-managing patients (p. 810).

Lack of Role Norms for Individuals with Chronic Illness

Chronic illnesses require that a variety of tasks be performed to fulfill the requirements of both the medical regimen and the individual's personal lifestyle. Despite residual disability that limits activity, society does not identify the chronically ill as individuals who are experiencing illness. Assuming sick role behaviors is discouraged. These individuals enter and remain in the impaired role, but implicit behaviors for this role are not well defined by society, leading to a situation of role ambiguity. Given this lack of norms, influences on the client include the degree of disability (with different attributes of disability producing different consequences), visibility of the disability (the lower the visibility, the more normal the response), self-acceptance of the disability (resulting in others' reciprocating with acceptance), and societal views of the disabled as either economically dependent or productive. Without role definition, whether disability is present or not, individuals are unable to achieve maximum levels of functioning. Individuals must adapt their definitions of themselves to their limitations, and to what the anticipated future imposes on them by the chronic condition (Watt, 2000).

INTERVENTIONS

There is no magic list of interventions to assist and support clients and their families with their illness experience. Our current healthcare system with its acute care focus, fix and cure model, and a prescription for each symptom, does not fit with caring for individuals long term. These clients do not need their illness behavior "fixed: or "cured," but instead need a healthcare professional that will listen and understand the illness experience and not the disease process. What follows are suggestions that assist and support clients and their families.

Frameworks and Models for Practice

Caring for a client with chronic illness requires a framework or model for practice that differs from that of caring for those with acute, episodic disease. The frameworks that follow are examples, and are not intended to be all-inclusive.

These frameworks and models should not be confused with the disease management models discussed in Chapter 19. Disease management models address the physical symptoms of the condition. Some of those models assign an algorithm to the condition where clients receive certain "care" when their blood work is at an inappropriate level, or their symptoms "measure" a certain degree of seriousness. These models manage the disease, but not the illness. Illness frameworks and models address the illness experience of the individual and family that occurs as a result of changing health status.

Chronic Illness and Quality of Life

In the early 1960s, Anselm Strauss, working with Barney Glaser, a social scientist, and Jeanne Quint Benoliel, a nurse, interviewed dying patients to ascertain what kind of "care" was needed for these clients (Corbin & Strauss, 1992). As a result of those early interviews, Strauss et al. (1975/1984) published a rudimentary framework that addressed the issues and concerns of individuals with chronic illness. Although the term "trajectory" was coined at that time, it did not become fully developed until 20 years later. His framework was simple, but it was an early attempt to examine the illness experience of the individual and family as opposed to the disease perspective. If care professionals could better understand the illness experience of clients and families, perhaps more appropriate care would be provided. Basic to this care was understanding the key problems that include:

- The prevention of medical crises and their management if they occur
- Controlling symptoms

- Carrying out of prescribed medical regimens
- Prevention of, or living with, social isolation
- Adjustment to changes in the disease
- Attempts to normalize interactions and lifestyle
- Funding—finding the necessary money
- Confronting attendant psychological, marital, and familial problems (Strauss et al., 1984, p. 16)

After identifying the key problems of the individual and family with chronic illness, what followed were basic strategies, family and organizational arrangements, and the consequences of those arrangements (Strauss et al., 1984, p. 17).

The Trajectory Framework

From the work of Strauss and colleagues in the 1960s and 1970s, the trajectory framework was further refined in the 1980s. Corbin and Strauss (1992) developed this framework so that nurses could: (1) gain insight into the chronic illness experience of the client; (2) integrate existing literature about chronicity into their practice; and (3) provide direction for building nursing models that guide practice, teaching, research, and policymaking (p. 10).

A trajectory is defined as the course of an illness over time, plus the actions of clients, families and healthcare professionals to manage that course (Corbin, 1998, p. 3). The illness trajectory is set in motion by pathophysiology and changes in health status, but there are strategies that can be used by clients, families, and healthcare professionals that shape the course of dying and thus the illness trajectory (Corbin & Strauss, 1992). Even if the disease may be the same, each individual's illness trajectory is different, and takes into account the uniqueness of each individual (Jablonski, 2004). Shaping does not imply that the ultimate course of the disease will be changed or the disease will be cured, merely that the illness trajectory may be shaped or altered by actions of the individual and

family so that the disease course is stable, fewer exacerbations occur, and symptoms are better controlled (Corbin & Strauss, 1992).

Within the model, the term "phase" indicates the different stages of the chronic illness experience for the client. There are nine phases in the trajectory model, and although it could be conceived as a continuum, it is not linear. Clients may move through these phases in a linear fashion, regress to a former phase, or plateau for an extended period. In addition, having more than one chronic disease influences movement along the trajectory as well. Another term used in the model is biography. A client's biography consists of previous hospital experiences, and useful ways of dealing with symptoms, illness beliefs, and other life experiences (White & Lubkin, 1998).

The initial phase of the trajectory model is the pretrajectory phase, or preventive phase, in which the course of illness has not yet begun; however, there are genetic factors or lifestyle behaviors that place an individual at risk for a chronic condition. An example would be the individual who is overweight, has a family history of cardiac disease and high cholesterol, and does not exercise.

During the trajectory phase, signs and symptoms of the disease appear and a diagnostic workup may begin. The individual begins to cope with implications of a diagnosis. In the stable phase, the illness symptoms are under control and management of the disease occurs primarily at home. A period of inability to keep symptoms under control occurs in the unstable phase. The acute phase brings severe and unrelieved symptoms or disease complications. Critical or life-threatening situations that require emergency treatment occur in the crisis phase. The comeback phase signals a gradual return to an acceptable way of life within the symptoms that the disease imposes. The downward phase is characterized by progressive deterioration and an increase in disability or symptoms. The trajectory model ends with the dying phase characterized by gradual or rapid shutting down of body processes (Corbin, 2001, pp. 4–5).

Chronic Illness and the Life Cycle

Rolland's (1987) illness trajectory model encompasses three phases: (1) crisis, (2) chronic, and (3) terminal. The crisis phase has two subphases consisting of the symptomatic period prior to diagnosis; and the period of initial adjustment just after diagnosis.

The chronic phase is the period between the beginning of treatment and the terminal phase. Rolland (1987) was one of the first authors to describe chronic illness, and in this case the chronic phase, as the "long haul," the day to day living with chronic illness. Lastly, the terminal phase is divided into the preterminal phase, where the client and family acknowledge that death is inevitable, and the period following death (Jablonski, 2004, p. 54).

Shifting Perspectives Model of Chronic Illness

This model resulted from work of Thorne and Paterson (1998), who analyzed 292 qualitative studies with chronic physical illness that were published from 1980 to 1996. Of these, 158 studies became a part of a metastudy in which client roles in chronic illness were described. The work of Thorne and Paterson reflects the "insider" perspective of chronic illness as opposed to the "outsider" view, the more traditional view. This change in perspective is a shift from the traditional approach of patient-as-client to one of client-as-partner in care (p. 173). Results from the metastudy also demonstrated a shift away from focusing on loss and burden, and an attempt to view health within illness.

Analysis of these studies led to the development of the Shifting Perspectives Model of Chronic Illness (Paterson, 2001). The model depicts chronic illness as an ongoing, continually shifting process where people experience a complex dialectic between the world and themselves (p. 23). Donnelly (1993) first spoke of individuals with chronic illness living in the "dual kingdoms of the well and the sick" (p. 6). Paterson's model considers both

the "illness" and the "wellness" of the individual (Paterson, 2003). The illness-in-the-foreground perspective focuses on the sickness, loss, and burden of the chronic illness. This is a common reaction of those recently diagnosed with a chronic disease. The overwhelming consequences of the condition, learning about their illness, considerations of treatment, and long-term effects contribute to putting the illness in the foreground. The disease becomes the individual's identity.

Illness-in-the-foreground could also be a protective response by the individual and be used to conserve energy for other activities. However, it could be used to maintain their identity as a "sick" person, or because it is congruent with their need to have sickness as their social identity and receive secondary gains (Paterson, 2001).

With wellness-in-the-foreground, the "self" is the source of identity and not the disease (Paterson, 2001, p. 23). The individual is in control and not the disease. It does not mean, though, that the individual is physically well, cured, or even in remission of the disease symptoms. The shift occurs in the individual's thinking that allows the individual to focus away from the disease. However, any threat that cannot be controlled will transition the individual back to the illness-in-the-foreground perspective. Threats could be disease progression, lack of ability to self-manage the disease, stigma, or interactions with others (Paterson, 2001).

Lastly, neither the illness perspective nor the wellness perspective is right or wrong, but each merely reflects the individual's unique needs, health status, and focus at the time (Paterson, 2001). In Paterson's research published in 2003, one of her study participants was concerned that those reading about the Shifting Perspectives Model might interpret the two perspectives as "either/or," that one has to have either wellness or illness in the foreground. This individual states:

> I think there is danger when researchers think there is a right way to have a chronic illness. There is only one way . . . the one you choose at the moment . . . generally I live in the orange. If red is illness and yellow represents wellness, then I like to be a blend of both things . . . in the orange . . . It is not a good idea for me to be completely yellow because then I forget that I have MS and I do stupid things that I pay for later. And if I am totally in the red, I am too depressed to do anything (Paterson, 2003, p. 990).

Dealing with Dependency

Miller (2000) discusses dependency in individuals with chronic illness and links it with the sense of powerlessness that these individuals often confront. Chronic illness is fraught with unpredictable dilemmas. Even when an acute stage is past, the client's energy for recovery may be sapped by the uncertainty about the future course of the illness, the effectiveness of medical regimens, and the disruption of usual patterns of living. Awareness of behavioral responses and when they occur can help the professional avoid premature emphasis on independence until the client can collaborate in working toward a return to normal roles (see Chapter 11).

Miller (2000) recommends several strategies for decreasing clients' feelings of powerlessness as they work toward independence:

1. Modifying the environment to afford clients more means of control
2. Helping clients set realistic goals and expectations
3. Increasing clients' knowledge about their illness and its management
4. Increasing the sensitivity of health professionals and significant others to the powerlessness imposed by chronic illness
5. Encouraging verbalization of feelings

Utilizing knowledge of illness roles in planning interventions allows the healthcare professional to maximize time spent with the client. One such intervention that could benefit from integrating knowledge of illness roles is teaching (see Chapter 14). The client who is still in the highly dependent phase cannot benefit from teaching. As

EVIDENCE-BASED PRACTICE BOX

A sample of 23 people in their early fifties was recruited from a community health survey in Scotland. All participants had four or more chronic illnesses. Through interviews, the aim of the study was to identify how individuals with multiple chronic illnesses negotiate their daily lives. They shared with the researchers that they had a moral obligation to manage their symptoms as well as manage their daily lives. Many talked about the importance of paid employment, and some considered being unemployed a "loss." Others continued with the employment despite considerable risks to their health. Being employed was important to participants' identities. "The participants faced moral concerns as they tried to be 'responsible' patients, living 'normal' lives. The ability to manage illness alongside social obligations in daily life was framed as a sense of duty" (p. 190). The findings of this study demonstrate that recognizing and understanding the constant dilemmas that those with chronic illness face is critical in working with these clients. Controlling the disease and its accompanying symptoms may not always be your clients' priority, but it may be your priority. This mismatch in priorities needs to be recognized.

Source: Townsend, A., Syke, S., & Hunt, K. (2006). Self-managing and managing self: Practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness, 2*, 185–194.

improvement in physical status occurs, emphasis on the desire to return to normal roles creates motivation to learn about the condition and necessary procedures for maximizing health. As the client moves into the impaired role and becomes aware of the necessity to maximize remaining potential, teaching provides a highly successful tool both in the hospital and at home.

Self-Management

The participants in the study of Kralick, Koch, Price, and Howard (2004) identified self-management as a process that they initiated to bring about order in their lives. This is in sharp contrast to how most healthcare professionals describe self-management in a structured patient education program that assists clients in adhering to their medical regimen. The participants saw self-management as creating a sense of order, and a process that included four themes: (1) recognizing and monitoring the boundaries; (2) mobilizing the resources; (3) managing the shift in self-identity; and (4) balancing, pacing, planning, and prioritizing (pp. 262–263). Kralick

and colleagues suggest that self-management is a combination of a process by clients and families and a structure of patient education.

The Women to Women project has been instrumental in helping women with chronic illness in rural states manage their illnesses. Through a computer intervention model that provides education, support groups, and fosters self-care, women have successfully managed their illness responses (Sullivan, Weinert, & Cudney, 2003).

Clients with chronic illness use multiple techniques to manage symptoms, maintain social roles, be the "good patient" and maintain some degree of normality. Townsend, Wyke, and Hunt (2006) describe the moral obligation of individuals to both self-manage their symptoms and manage their self. Although individuals are trying to manage both symptoms and social roles, the priority is always given to behaviors that typify a "normal" life and identity management over managing the symptoms of the disease (p. 193).

Critical to working with clients and families in self-managing both their disease and their illness is appropriate client–healthcare provider communication. Thorne, Harris, Mahoney, Con,

and McGuiness (2004) interviewed clients with end-stage renal disease, type 2 diabetes, multiple sclerosis, and fibromyalgia to determine what clients perceived as priorities. Across all diseases, the concepts of courtesy, respect, and engagement were important. Certainly courtesy and respect are fairly clear in their meaning. Engagement was described by clients as an extension of courtesy and respect. An example would be a healthcare professional engaged with a client in problem solving and care management, and there would be a feeling of teamwork and working together (p. 301). Such communication enhanced their relationships with clients.

Research

Do we understand and can we place in an appropriate context the meaning of illness for our clients? Why do some individuals ignore symptoms and refuse to seek medical advice, while others with the same condition seek immediate care and relief from their "social roles" at the slightest symptom. A relatively minor symptom in one individual causes great distress, whereas more serious health conditions in others cause little concern.

Stuifbergen and colleagues (2006) suggest that it is unclear from the literature how illness perceptions change over time and how specifically these perceptions are influenced. These researchers believe that if illness perceptions can be altered, then interactions with those in a positive manner could be encouraged.

Mechanic (1986/1995) asks a question that is still pertinent today. What are the processes or factors that cause individuals exposed to similar stressors to respond differently and present unique illness behavior? There is such variation in how individuals perceive their health status, seek or not seek medical care, and function in their social and work roles. What causes these differences?

OUTCOMES

Illness behavior is not deviant or need to be fixed. However, we need to support our clients and understand the lived experience of the illness. As healthcare professionals, we are efficient and effective working within the disease model. However, the client lives in the illness model. Because nursing is an art and a science, there is a strong "fit" with the illness model. The best outcome for clients with chronic illness would be the healthcare professional supporting and assisting the client through the illness experience.

STUDY QUESTIONS

1. Differentiate between health and illness behavior and give examples of each.
2. Describe the "fit" of the sick role and "impaired" role with someone with chronic obstructive pulmonary disease (COPD). With metastatic cancer.
3. How do healthcare professionals influence the illness behavior of clients and families?
4. How could you apply each of the frameworks for practice described in this chapter to your own population of clients with chronic illness?
5. What influences your own illness behaviors?
6. Using this chapter as a guide, how would you support and work with an individual that has either CFS or fibromyalgia? How do your own past experiences influence your practice with these clients?
7. Dealing with "expert" patients can be difficult. Often your own "power" as a healthcare professional is threatened. How do you deal with "expert" patients?
8. There are no norms for individuals with long-term illness. What does this mean and how does it apply to your population of clients with chronic illness?

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