

CHAPTER 2

The Illness Experience

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

Pamala D. Larsen

INTRODUCTION

Commonly, healthcare providers are educated in the medical model and understand its applicability and use in practice. Clients enter a healthcare system with symptoms, which are then diagnosed based on pathological findings, and as such are treated and/or cured with medical treatment. For acute disease, this is the pattern. One isn't concerned about the client's illness behavior associated with appendicitis, tonsillitis, or a fractured leg. An individual may be concerned that the tonsillitis will return, the fractured leg may not heal normally, or there may be an adverse event associated with the appendectomy, but by and large, these concerns pass quickly because of the acuteness of the event. The United States' acute care-focused healthcare system acts upon the pathology that is present, with the goal that an individual will fully recover from the condition and return to prior behaviors and roles.

What happens however, when the recovery is incomplete or the illness continues or becomes chronic in nature? The individual and family

have to modify or adapt previous behavior and roles to accommodate the chronicity of the condition. Societal expectations, their own expectations, and their health status all influence illness behavior. This chapter provides an overview of the illness experience and corresponding behavior demonstrated by those with chronic illness—it presents a sociological view of illness rather than a medical view of illness. It is not meant to be a comprehensive review of the entire body of knowledge, which is vast.

Historical Perspectives

Chronic disease involves not only the physical body, but it also affects one's relationships, self-image, and behavior. The social aspects of disease may be related to the pathophysiologic changes that are occurring, 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). Freidson (1970) discussed this more than 40 years ago in his writings about the meaning that is ascribed to a diagnosis by an individual

and family (p. 223). It is not merely pathology or a diagnosis anymore, and the individual and family develop their own meanings and perceptions of the condition, and ultimately their own, unique illness behaviors. The earliest concept of illness behavior was described in a 1929 essay by Henry Sigerist. His essay described the “special position of the sick” (as cited in Young, 2004). Talcott Parsons developed this concept further and described the “sick role” in his 1951 work, *The Social System*. A brief examination of the sick role provides context to the illness experience, perceptions, and behavior.

Sick Role

Talcott Parsons, a proponent of structural–functionalist principles, viewed health as a functional prerequisite of society. From Parsons’s 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, as 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)

Although the sick role may have been accepted when developed by Parsons in the 1950s, it is no longer considered relevant today. American culture for the most part has embraced a role of self-care and self-management of disease and participation with care providers to obtain optimal health. Parsons’s sick role was based on assumptions about the nature of society and the nature of illness during a previous period of time (Weitz, 2007).

Using Parsons’s work as a basis, Mechanic (1962) proposed the concept of illness behavior as symptoms being perceived, evaluated, and acted (or not acted) upon differently by different persons (p. 189). 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 (1995) 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” (p. 1208).

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

1. *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.
2. *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.
3. *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, because the distinction between health and illness behaviors is arbitrary at times (p. 8).

A more current definition of illness behavior suggests that illness behavior “includes all of the individual’s life which stems from the experience of illness, including changes in functioning and activity, and uptake of health services and other welfare benefits” (Wainwright, 2008, p. 76). Simply put, when an individual defines him/herself as ill, different behaviors may be displayed. A behavior could be as simple as seeking medical treatment or as complex as the individual’s emotional response to the diagnosis. As more acute conditions become chronic in nature, there is more interest in how individuals behave in these circumstances. Individuals with chronic illness are living longer and are creating new norms of illness behavior.

Illness Perceptions

According to Rudell, Bhui, and Priebe (2009), two theories have dominated illness perception research: 1) the explanatory model (EM) from Kleinmann (1985); and 2) illness representations (IR) as a part of the self-regulatory theory (Leventhal, Leventhal, & Cameron, 2001). Explanatory models are associated with mental illness as Kleinmann is a cross-cultural psychiatrist and anthropologist. Leventhal and colleagues, on the other hand, based their research on psychological theory. They argue that there is both a cognitive and an emotional representation

of illness (Rudell et al., 2009). Although both models hold credence for individuals and families with chronic illness, this text uses the work of Leventhal and colleagues as a basis for the discussion of illness perceptions and behaviors.

Prior to focusing on behaviors, a discussion of illness perceptions is needed, as they are the basis for the behaviors exhibited by individuals and families. The literature uses two terms, *illness representations* and *illness perceptions*. Both refer to how the client (and family) view the illness. Illness representations belong to clients and are interpreted by clients and may not conform to scientific beliefs (as cited in Lee, Chaboyer, & Wallis, 2010; Diefenbach, Leventhal, Leventhal, & Patrick-Miller, 1996). In a majority of studies, illness representations are measured by the Illness Perception Questionnaire, the Illness Perception Questionnaire-Revised, or the Briet Illness Perception Questionnaire. Each of these questionnaires assesses the cognitive and emotional responses to illness (www.uib.no/ipq). For purposes of this chapter, the words will be used interchangeably, although medical sociologists might question that decision.

Why are illness perceptions of interest to healthcare providers? The primary reason is that these perceptions directly influence the emotional response that clients and families have to the illness (Petrie & Weinman, 2006). How one behaves due to the illness, implements coping strategies, and generally responds to the illness is based on one’s perceptions. Clients and their families do not simply develop their own illness beliefs and perceptions within a vacuum, but they are molded by their everyday social interactions (Marks et al., 2005), their past experiences, and their culture.

Clients and families build mental models to make sense of an event (Petrie & Weinman, 2006). Thus, when a client and family face a

health threat, a model of that event is developed. The idea behind a model is that clients can then visualize the threat and become active problem solvers. Within those models are their perceptions of the diagnosis, the illness experience, the treatment, and the consequences, which in turn, forecast how they will behave and/or respond to the crisis. Often these models may not make sense to an outsider, and often they may be built on faulty information. The model is dynamic, changing as new data from healthcare providers, their own experiences, and other sources are presented to the client and family and become incorporated into the model.

Leventhal and colleagues (2001) identified five dimensions that represent a client's view of their illness: 1) identity of the illness—connecting the symptoms with the illness and having an understanding of the illness; 2) timeline—duration and progression of the illness; 3) causes—perceived reason for the illness; 4) consequences—what will be the physical, psychosocial, and economic impact of the illness; and lastly 5) controllability—can this disease be controlled or cured? After identification of these dimensions, Leventhal and colleagues believe that coping and appraisal follow.

However, is it that simple? Leventhal and colleagues' explanation leads one to believe that everything fits into a neat little box and there is a natural, linear progression from identity to control/curability. Imagine that a chronic illness has either entered your life or affected someone in your family. You may have had some sort of identity of it prior to diagnosis, but now that the condition is "yours," that perception changes. Plus, you have the Internet to provide you with more information than you can absorb. You begin with the idea that this condition is controllable, and perhaps curable, but you find a plethora of websites and data that tell you

otherwise. Thus, your beliefs and perceptions of the situation can be changed overnight, and in turn, your attitudes and behaviors do so as well.

Clients and families with chronic illness need to make sense of their illness. They construct models of the illness in an attempt to be logical and inject sense into their lives. Often the diagnosis of a chronic condition doesn't make sense to clients. The model is created to make the situation rational to the individual and family. The model is dynamic and fluid throughout the illness or threat; it's what clients and families with chronic illness "hang their hat on"—it helps them cope.

The literature about the effects of illness perceptions and beliefs on behavior and treatment is vast. What follows are some representative research studies that demonstrate current and continuing work in this area. Although there is work with clients who have a number of different chronic illnesses or injuries such as spinal cord injury (deRoos-Cassini, de St. Aubin, Valvano, Hastings, & Horn, 2009), the majority of studies have focused on heart disease.

Heart Disease

Several studies have explored the relationships among quality of life, adherence to and choice of treatment, and illness beliefs/perceptions. Juergens, Seekatz, Moosdorf, Petrie, and Rief (2010) studied 56 patients undergoing coronary artery bypass grafting (CABG). Participants were assessed using the Illness Perception Questionnaire-Revised (IPQ-R) prior to and 3 months post-surgery. The researchers concluded that patients' beliefs before surgery strongly influenced their recovery from surgery. They added that perhaps patients could benefit from some pre-surgery cognitive interventions to change maladaptive beliefs (p. 553). Similarly, Alsen, Brink, Persson, Brandstrom, and Karlson (2010) found that patients' illness perceptions

influenced health outcomes after myocardial infarction. Broadbent, Ellis, Thomas, Gamble, and Petrie (2009) indicate that a brief in-hospital illness perception intervention changed perceptions and improved rates of return to work in patients with myocardial infarction.

In a sample of clients with atrial fibrillation, patients' perceptions about their symptoms and medication at diagnosis affected their health-related quality of life (Lane, Langman, Lip, & Nouwen, 2009). Negative illness beliefs were significantly predictive of higher levels of depressive symptomology at 3 and 9 months in clients with coronary artery disease (Stafford, Berk, & Jackson, 2009). Illness beliefs were also significantly associated with depressive symptomology and health-related quality of life in clients with coronary artery disease. In a study examining adherence to secondary prevention regimens, illness beliefs contributed to adherence to those behaviors (Stafford, Jackson, & Berk, 2008).

Two representative studies in hypertension have included the relationships between treatment and illness perceptions. Chen, Tsai, and Chou (2010) tested a hypothetical model of illness perception and adherence to prescribed medications. Using a sample of 355 hypertensive patients, findings suggested that adherence could be enhanced by improving the patient's perception of controllability. Other researchers have argued that illness perceptions/beliefs about hypertension have played a role in the choice of medication for treatment of hypertension (Figueiras et al., 2010).

Work Participation

Hoving, van der Meer, Volkova, and Frings-Dresen (2010) completed a systematic review of illness perceptions and participating in work (however, only three studies met the authors' criteria for review). They found that nonworking

clients perceived more serious consequences, expected their illness to last a long period of time, and reported more symptoms and emotional responses. The working clients had a strong belief in the controllability of their condition and a better understanding of the disease (its identity).

Influences on Illness Behavior

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 13) 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 13). Individuals with chronic illness in the culture of poverty will have different looking illness perceptions and behaviors depending on their unique ethnic origins.

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 been 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 II 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 partially mediated 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 for nonfatal and chronic illness (Bury, 2005). Morbidity rates demonstrate that women are more likely to be sick than men and thus seek more professional medical help (Bury, 2005, 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 influenced older adults' illness perceptions, causing them to self-identify as disabled.

Past Experience

One's education and learning, socialization, and past experience, as defined by one's 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 Perlmutter (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 appear 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 to clients whose parents did not respond to minor illness with avoidance (Elfant et al., 1999, p. 415).

What if parents and adolescents have differing views on illness perceptions? The illness perceptions of 30 adolescents and their parents were compared to see the effects on the adolescents' outcomes (Salewski, 2003). Parents' illness representations had little impact on their children's outcomes. In families with high similarity between the parents' perceptions and the adolescents' perceptions, the adolescents reported more well-being (Salewski, 2003, p. 587).

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 (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 (Whitehead et al., 1994, p. 549).

In a small study examining illness perceptions in clients with critical illness in a medical intensive care unit, as well as their surrogates, it was hypothesized that perceptions would vary by demographic, personal, and clinical measures (Ford, Zapka, Gebregziabher, Yang, & Sterba, 2010). Although client/surrogate factors, including race, faith, and pre-critical illness quality of life were significant, clinical measures were not. Researchers concluded that clinicians should recognize the variability in illness perceptions and the possible implications this might have for patient/surrogate and health-care provider communication.

One cannot minimize the impact of the past experiences of the individual and family on how they deal with their own chronic illnesses, their children's, parents', and/or siblings'. Each of those experiences affects how the individual and family perceive their current health challenge. These experiences could be positive as well as negative. A negative healthcare experience with a relatively minor injury/illness could have a stronger influence than that of a positive experience

with serious illness. As healthcare providers, do not underestimate the client's and family's perception of their illness and its effect on outcomes.

IMPACT AND ISSUES RELATED TO ILLNESS BEHAVIOR

As illness behavior is described, 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. As Wainwright (2008) states,

disease within the medical model is materialist and assumes that the mechanisms of the body can be revealed and understood in the same way that the working of the solar system can be understood through gazing at the night sky. (p. 77)

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 and Subsequent Behavior

The diagnosis of a chronic disease and subsequent management of that disease bring unique experiences and meanings of that process to the client and family. The biomedical world

disregards illness and its meaning and focuses instead on disease. Disease can be quantified and measured, and it can be considered a “black-and-white” concept. Disease fits into the medical model’s framework.

Illness, and the unique meaning that each of us attaches to it, does not fit into a neat little box; it is not black and white, but consists of many shades of gray and thus defies measurement and categorization. Illness is a subjective label that reflects both personal and social ideas about what is normal as much as the pathology behind it (Weitz, 1991). Kleinmann (1985) expressed concern 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 quantifying its effect on health status and illness behavior” (Kleinmann, 1985, p. 149). While realizing the importance of this scientific work, Kleinmann (1985) sees it as “detrimental to the understanding of illness as human experience, because 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 Phillips, Voelmeck, & Browder (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 Leventhal 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 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.

Powerlessness

This construct is a major component of the illness experience. As such, an entire chapter in this book has been devoted to this subject (see Chapter 12).

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 on 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 his or her 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 they create a public identity and a private identity to preserve self (Charmaz, 1994, p. 282).

Moral Work

Townsend, Wyke, and Hunt (2006) describe the moral dimension of the chronic illness experience in their qualitative study. 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 (Townsend et al., 2006, p. 189).

Devalued Self

In a qualitative study of Chinese immigrant women in Canada, Anderson (1991) describes how these women with type I 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 discusses women who need to reconstruct a new self. Influencing this devalued self were the interactions with healthcare professionals, which were frequently negative in nature, adding to their stress.

Similarly, eight older women with a chronic disease were asked to describe the meaning of

living with a long-term illness. Five themes emerged: loss and uncertainty, learning one’s capacity and living accordingly, maintaining fellowship and belonging, having a source of strength, and building anew. However, clearly the guiding premise of each woman was that chronic illness brought about reassessment and formation of a new understanding of self, and a sense of being revalued by the world (Lundman & Jansson, 2007).

Chronic Sorrow

The concept of chronic sorrow was first described by Olshansky in 1962 when he was working with parents of children with learning disabilities. His conclusion was that chronic sorrow was a natural response to a tragedy instead of becoming neurotic (p. 193). Two more recent studies discuss the existence of chronic sorrow in individuals with chronic illness. Sixty-one clients with multiple sclerosis were interviewed about chronic sorrow and also screened for depression. Thirty-eight of the 61 clients met the criteria for chronic sorrow. The participants in the study described feeling sorrow, fear, anger, and anxiety. Frustration and sadness were constantly present, or were periodically overwhelming (Isaksson, Gunnarsson, & Ahlstrom, 2007, p. 318). Seven themes were identified: loss of hope, loss of control over the body, loss of integrity and dignity, loss of a healthy identity, loss of faith that life is just, loss of social relations, and loss of freedom (Isaksson et al., 2007). Implications for healthcare providers included providing psychological support for these individuals. How does one provide the appropriate help when the client perceives such significant losses? What realistic help can healthcare professionals provide?

Similarly, Ahlstrom (2007) interviewed 30 adults of working age with an average disease duration of 18 years. Sixteen of the 30 adults

experienced chronic sorrow. The losses in this study are consistent with other studies on chronic sorrow even though the group was heterogeneous regarding diagnosis.

The Legitimization of Chronic Illness

With some illnesses, especially when symptoms are not well defined and diagnostic tests may be ambiguous, receiving legitimization from a physician or other healthcare professional 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. How do you build a mental model of your illness (as a basis for problem solving) if healthcare providers and society in general are skeptical of your symptoms?

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 legitimization 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 test results are normal.

When a diagnosis is finally made, the client frequently shows a somewhat joyous initial

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) identified 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* with 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 (Asbring, 2001, 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” (Larun & Malterud, 2007, pp. 22–23). Although physical activities were mostly curtailed, individuals spoke of mental fatigue that affected memory and concentration, they described difficulty with following conversations, and several clients felt that their learning abilities had decreased (p. 24). One of the themes that emerged was telling stories about *bodies that 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

questioned 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 therefore 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.

Dickson, Knussen, and Flowers (2008) describe the personal loss and identity crisis in their study of 14 individuals diagnosed with CFS. Participants talked about the illness that is their life and controls every aspect of their daily lives. Self-comparison took place between the participants' former selves and their "ill selves." Skepticism from others brought further crises of self.

Lastly Nettleton (2006) describes interviews with 18 neurology patients in the United Kingdom

with MUS—medically unexplained symptoms. Not having a diagnosis limits legitimate access to the sick role and the ability to build a mental model of the illness. One of the biggest hurdles is that society does not grant permission to be ill in the absence of a disease with a name.

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,

CASE STUDY



Mary Ellen is a 35-year-old woman with unexplained neurological symptoms. She is a relatively new client to the clinic where you work. However, she has been seen by your clinic several times over the last 3 months. Originally her diagnosis was "probable multiple sclerosis." However, that diagnosis has been ruled out. Mary Ellen's clinical symptoms include double vision (at times), transient numbness and tingling down the right side of her body, and general weakness and fatigue. Although she has been employed full time as a staff associate at the county assessor's office, she has been forced to go on short-term disability. In her phone call to the office this morning, she is frustrated. She states, "I feel like no one is believing me—that you people think that I am making this up. I'm going to lose my job if you can't figure this out. I'm not a psych case."

Discussion Questions

1. How do you make sense of this client's illness behavior?
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?

healthcare professionals communicate to them that they are “good patients” (Lorber, 1981). When clients are less cooperative, the staff may consider them problematic or nonadherent.

The percentage of individuals with chronic illness entering hospitals is increasing, and often these admissions are due to superimposed acute illness or exacerbations of the chronic condition. Additionally, older adults in particular may have more than one chronic condition. Many of these individuals have had their chronic illnesses for long periods and have had prior hospital experiences. Multiple contacts with the healthcare system result in loss of the “blind faith” that the individual once had in that system. Individuals with chronic illness seek a different kind of relationship with healthcare professionals, in which there is “give and take” and that can empower the client. The extent to which a client with chronic illness is included in the formulation of his or her treatment plan likely influences the assumption of responsibility for it and, ultimately, its success (Weaver & Wilson, 1994).

Thorne’s (1990) study of individuals with chronic illness and their families found that their relationships with healthcare professionals evolved from what was termed “naïve 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 illness 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. Individuals with chronic illness 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 than do the healthcare professionals with

whom they interact. Clients with multiple chronic conditions may focus on maintaining stability of their chronic conditions to prevent unnecessary symptoms, whereas their healthcare providers are more likely to focus on managing the current acute disorder. 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. In a grounded theory study in the United Kingdom, Wilson, Kendall, and Brooks (2006) explored how client 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 (Wilson et al., 2006, p. 810).

Lack of Role Norms for Individuals with Chronic Illness

Chronic illnesses require a variety of tasks be performed to fulfill the requirements of both the

medical regimen and the individual's personal lifestyle. However, there is a lack of norms for those with chronic illness. What is expected of a client recovering from cancer surgery? An exacerbation of rheumatoid arthritis? A flare-up of inflammatory bowel disease? Assume sick-role behaviors are discouraged, or not? These individuals enter and remain in a type of impaired, "at-risk" role. 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 less 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 because of the chronic condition (Watt, 2000). What is normal illness behavior?

INTERVENTIONS

There is no "magic" list of interventions to assist and support clients and their families with the illness experience. The 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 they need a healthcare professional who 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

A review of the literature since the last edition of this book did not yield any new frameworks for caring for those with chronic illness. With chronic illness increasing, evidence-based frameworks need to be developed. As stated previously, not all healthcare providers have the skills to care for those with long-term illness. Meeting the psychosocial needs of clients with chronic illness, alone, is an ominous task. 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 a 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 determine what kind of "care" was needed for these clients (Corbin & Strauss, 1992). As a result of those early interviews, Strauss and colleagues (Strauss & Glaser, 1975; Strauss et al., 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. Strauss and colleagues' framework was simple, but it was an early attempt to examine the illness experience of the individual and family as opposed to the disease. If health-care professionals could better understand the illness experience of clients and families, perhaps more appropriate care would be provided. Basic to this care is understanding the key problems of chronic illness, including:

- 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, Strauss and colleagues (1984) suggested basic problem-solving strategies, family and organizational arrangements, and then re-evaluating the consequences of those arrangements.

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 policy-making (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. 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

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 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 the work of Thorne and Paterson (1998), who analyzed 292 qualitative studies of 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). 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 the wellness-in-the-foreground perspective, the “self” is the source of identity rather than 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, allowing 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 include disease progression and lack of ability to self-manage the disease, stigma, and 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

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.

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

- Modifying the environment to afford clients more means of control
- Helping clients set realistic goals and expectations
- Increasing clients' knowledge about their illness and its management

- Increasing the sensitivity of health professionals and significant others to the powerlessness imposed by chronic illness
- 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 be improved by integrating knowledge of illness roles is education (see Chapter 15). The client who is still in the highly dependent phase cannot benefit from education. As 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, education provides a highly successful tool both in the hospital and at home.

Evidence-Based Practice Box

Ten full-time nursing students, all diagnosed with at least one chronic illness, were interviewed to examine their illness experience. Participants looked for ways to be ordinary because they perceived they were different from the norm. Chronic conditions included systemic lupus erythematosus, Raynaud's syndrome, rheumatoid arthritis, psoriasis, chronic back pain, irritable bowel syndrome, fibromyalgia, relapsing-remitting multiple sclerosis, type I diabetes mellitus, chronic urinary tract infections, anorexia/bulimia, and adrenal hyperplasia. Using Colaizzi's

phenomenological method, four major themes emerged: 1) needing to be normal, 2) dealing with the behaviors of others, 3) enduring the restrictions of illness, and 4) learning from self to care for others. Throughout the students' experiences, they tried to negate their illness or their abnormal behavior and maintain their valued social role as students. Participants felt that their chronic illness created an inner strength and gave them intuitive knowledge about the body and how to better understand the needs of others.

Source: Dailey, M. (2010). Needing to be normal: The lived experience of chronically ill nursing students. *International Journal of Nursing Education Scholarship*, 7(1), Article 15. 10.2202/1548-923X.1798.

Self-Management

The participants in the study by 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 (Kralick et al., 2004, 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 self-manage their symptoms and manage their selves. 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 II 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, in which they experienced a feeling of teamwork/working together (p. 301).

Such communication enhanced their relationships with clients.

Kaptein, Klok, Moss-Morris, and Brand (2010) reviewed 19 studies that examined how illness perceptions could impact an individual’s control of asthma. Using the Common Sense Model of Self-Regulation as a basis, the authors created their own model of how these perceptions affected self-management. The conclusion of the authors was that self-management was determined mainly by behavioral factors and not sociodemographic factors. One of those behavioral factors was illness perceptions. They note that changing a client’s illness perceptions is called for to help the client and healthcare provider achieve optimal asthma control (Kaptein et al., 2010, p. 199).

Research

Do we understand and can we place in an appropriate context the meaning of illness for 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. Bijsterbosch and colleagues (2009) noted that illness perceptions did change over time and were related to the progression of the disability (p. 1058). Illness

perceptions regarding the number of symptoms attributed to osteoarthritis (OA), and the level of perceived control and perceived consequences of OA were predictive of more disability.

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?

This author poses another question. What can we do as healthcare providers to change illness perceptions of clients? A growing body of evidence shows that more negative views of illness held by clients are associated with poorer outcomes (Petrie & Weinman, 2006). What can we do to effect change in chronic sorrow? How can we give clients a sense of hope? How do we value clients so that they don't feel they have devalued lives? Chronic illness is the condition as the client and family experience it. What can we do to make a difference in the lives of our clients and families?

OUTCOMES

Illness behavior is not deviant and does not 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 as well. 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



- 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 healthcare experiences influence your practice with these clients?
- Dealing with "expert" patients can be difficult. Often your own "power" as a healthcare professional is threatened. How do you deal with "expert" patients and make it a collaborative relationship?
- There are no norms for individuals with long-term illness. What does this mean and how does it apply to the clients with chronic illness that you care for?
- Differentiate between health and illness behavior and give examples of each for someone with end-stage heart failure, endometriosis, or esophageal cancer.
- How do healthcare professionals influence the illness behavior of clients and families in positive ways or negative ways?
- Apply each of the frameworks for practice described in this chapter to clients with chronic illness that you care for.
- Reflect on your own past and present health and illness experiences. What influences your own illness behaviors?

For a full suite of assignments and additional learning activities, use the access code located in the front of your book and visit this exclusive website: <http://go.jblearning.com/lubkin>. If you do not have an access code, you can obtain one at the site.



REFERENCES

- Ahlstrom, G. (2007). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Nursing and Healthcare of Chronic Illness* in association with *Journal of Clinical Nursing*, *16*(3a), 76–83.
- Alsen, P., Brink, E., Persson, L., Brandstrom, Y., & Karlson, B. W. (2010). Illness perceptions after myocardial infarction: Relations to fatigue, emotional distress, and health-related quality of life. *Journal of Cardiovascular Nursing*, *25*(2), E1–E10.
- Anderson, J. M. (1991). Immigrant women speak of chronic illness: The social construction of the devalued self. *Journal of Advanced Nursing*, *16*, 710–717.
- Asbring, P. (2001). Chronic illness—a disruption in life: Identity transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, *34*(3), 312–319.
- Bijsterbosch, J., Scharloo, M., Visser, A. W., Watt, I., Meulenbelt, T. W., Huzinga, J., et al. (2009). Illness perceptions in patients with osteoarthritis: Change over time and association with disability. *Arthritis and Rheumatism*, *61*(8), 1054–1061.
- Broadbent, E., Ellis, C. J., Thomas, J., Gamble, G., & Petrie, K. J. (2009). Further development of an illness perception intervention for myocardial infarction patients: A randomized controlled trial. *Journal of Psychosomatic Research*, *67*, 17–23.
- Bury, M. (2005). *Health and illness*. Cambridge, UK: Polity Press.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of health and illness*, *5*(2), 168–195.
- Charmaz, K. (1994). Identity dilemma of chronically ill men. *The Sociological Quarterly*, *35*(2), 269–288.
- Chen, S. L., Tsai, J. C., & Chou, K. R. (2010). Illness perceptions and adherence to therapeutic regimens among patients with hypertension: A structural modeling approach. *International Journal of Nursing Studies*, *8*(2), 235–245.
- Cockerham, W. C. (2001). The sick role. In *Medical sociology* (8th ed., pp. 156–178). Upper Saddle River, NJ: Prentice-Hall.
- Conrad, P. (2005). *The sociology of health and illness: Critical perspectives* (7th ed.). New York: Worth Publishers.
- Corbin, J. (1998). The Corbin & Strauss chronic illness trajectory model: An update. *Scholarly Inquiry for Nursing Practice*, *12*(1), 33–41.
- Corbin, J. (2001). Introduction and overview: Chronic illness and nursing. In R. Hyman & J. Corbin (Eds.), *Chronic illness: Research and theory for nursing practice* (pp. 1–15). New York, Springer.
- Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Corbin, J., & Strauss, A. (1992). A nursing model for chronic illness management based upon the trajectory framework. In P. Woog (Ed.), *The chronic illness trajectory framework: The Corbin and Strauss nursing model* (pp. 9–28). New York: Springer.
- Dailey, M. (2010). Needing to be normal: The lived experience of chronically ill nursing students. *International Journal of Nursing Education Scholarship*, *7*(1), Article 15.10.2202/1548-923X.1798.
- deRoon-Cassini, T., de St. Aubin, E., Valvano, A., Hastings, J., & Horn, P. (2009). Psychological well-being after spinal cord injury: Perception of loss and meaning making. *Rehabilitation Psychology*, *54*(3), 306–314.
- Dickson, A., Knussen, C., & Flowers, P. (2008). ‘That was my old life; it’s almost like a past-life now’: Identify crisis, loss and adjustment among people living with chronic fatigue syndrome. *Psychology and Health*, *23*(4), 459–476.
- Diefenbach, M. A., Leventhal, E. A., Leventhal, H., & Patrick-Miller, L. (1996). Negative affect relates to cross-sectional but not longitudinal symptom reporting: Data from elderly adults. *Health Psychology*, *15*(4), 282–288.
- Elfant, E., Gall, E., & Perlmutter, L. C. (1999). Learned illness behavior and adjustment to arthritis. *Arthritis Care and Research*, *12*(6), 411–416.
- Figueiras, M., Marcelino, D., Claudino, A., Cortes, M., Maroco, J., & Weinman, J. (2010). Patients’ illness schemata of hypertension: The role of beliefs for the choice of treatment. *Psychology and Health*, *25*(4), 507–517.
- Ford, D., Zapka, J., Gebregziabher, M., Yang, C., & Sterba, K. (2010). Factors associated with illness perception among critically ill patients and surrogates. *Chest*, *138*, 59–67.

- Freidson, E. (1970). *Profession of medicine*. New York: Dodd, Mead.
- Helman, C. G. (2007). *Culture, health and illness* (5th ed.). London: Arnold.
- Hoving, J. L., van der Meer, M., Volkova, A. Y., & Frings-Dresen, M. H. W. (2010). Illness perceptions and work participation: A systematic review. *International Archives of Occupational & Environmental Health*, 83(6), 595–605.
- The Illness Perception Questionnaire. Retrieved August 2, 2011 from <http://www.uib.no/ipq>
- Isaksson, A., Gunnarsson, L.O., & Ahlstrom, G. (2007). The presence and meaning of chronic sorrow in patients with multiple sclerosis. *Journal of Nursing and Healthcare of Chronic Illness* in association with *Journal of Clinical Nursing*, 16(11c), 315–324.
- Jablonski, A. (2004). The illness trajectory of end-stage renal disease dialysis patients. *Research and Theory for Nursing Practice: An International Journal*, 18(1), 51–72.
- Juergens, M. C., Seekatz, B., Moosdorf, R. G., Petrie, K. J., & Rief, W. (2010). Illness beliefs before cardiac surgery predict disability, quality of life and depression 3 months later. *Journal of Psychosomatic Research*, 68, 553–560.
- Kaptein, A. A., Klok, T., Moss-Morris, R., & Brand, P. L. P. (2010). Illness perceptions: Impact on self-management and control in asthma. *Current Opinion in Allergy and Clinical Immunology*, 10, 194–199.
- Kasl, S. V., & Cobb, S. (1966). Health behavior, illness behavior, and sick-role behavior. *Archives of Environmental Health*, 12, 531–541.
- Kelley-Moore, J. A., Schumacher, J. G., Kahana, E., & Kahana, B. (2006). When do older adults become “disabled”? Social and health antecedents of perceived disability in a panel study of the oldest old. *Journal of Health and Social Behavior*, 47, 126–141.
- Kleinmann, A. (1985). Illness meanings and illness behavior. In S. McHugh & M. Vallis (Eds.), *Illness behavior: A multidisciplinary model* (pp. 149–160). New York: Plenum.
- Kralick, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness management: Taking action to create order. *Journal of Clinical Nursing*, 13, 259–267.
- Lane, D. A., Langman, C. M., Lip, G. Y. H., & Nouwen, A. (2009). Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. *Journal of Psychosomatic Research*, 66, 203–210.
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies. *Patient Education and Counseling*, 69, 20–28.
- Lee, B., Chaboyer, W., & Wallis, M. (2010). Illness representations in patients with traumatic injury: A longitudinal study. *Journal of Clinical Nursing*, 19, 556–463.
- Leventhal, H., Leventhal, E. A., & Cameron, L. (2001). Representations, procedures, and affect in illness self-regulation: A perceptual-cognitive model. In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *Handbook of health psychology* (pp. 19–47). Mahwah, NJ: Lawrence Erlbaum Associates.
- Lorber, J. (2000). Gender and health. In P. Brown (Ed.), *Perspectives in Medical Sociology* (3rd ed., pp. 40–70). Prospect Heights, IL: Waveland Press.
- Lorber, J. (1981). Good patients and problem patients: Conformity and deviance in a general hospital. In P. Conrad & R. Kern (Eds.), *The sociology of health and illness: Critical perspectives*. New York: St. Martin's.
- Lundman, B., & Jansson, L. (2007). The meaning of living with a long-term disease: To revalue and be revalued. *Journal of Nursing and Healthcare of Chronic Illness* in association with *Journal of Clinical Nursing* 16, 7b, 109–115.
- Marks, D. F., Murray, M., Evans, B., Willig, C., Woodall, C., & Sykes, C. (2005). *Health psychology: Theory, research and practice* (2nd ed.). Thousand Oaks, CA: Sage.
- McHugh, S., & Vallis, M. (1986). Illness behavior: Operationalization of the biopsychosocial model. In S. McHugh & M. Vallis (Eds.), *Illness behavior: A multidisciplinary model* (pp. 1–32). New York: Plenum.
- Mechanic, D. (1962). The concept of illness behavior. *Journal of Chronic Diseases*, 15, 189–194.
- Mechanic, D. (1986). The concept of illness behavior: Culture, situation, and personal predisposition. *Psychological Medicine*, 16, 1–7.
- Mechanic, D. (1995). Sociological dimensions of illness behavior. *Social Science and Medicine*, 41(9), 1207–1216.

- Miller, J. F. (2000). *Coping with chronic illness: Overcoming powerlessness* (3rd ed.). Philadelphia: F. A. Davis.
- Nettleton, S. (2006). 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms. *Social Science and Medicine*, 62, 1167–1178.
- Olshanky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190–193.
- Parsons, T. (1951). *The social system*. New York: The Free Press.
- Paterson, B. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33(1), 21–26.
- Paterson, B. (2003). The koala has claws: Applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research*, 13(7), 987–994.
- Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, 6(6), 536–539.
- Price, B. (1996). Illness careers: The chronic illness experience. *Journal of Advanced Nursing*, 24, 275–279.
- Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 26, 203–221.
- Rudell, K., Bhui, K., & Priebe, S. (2009). Concept, development and application of a new mixed method assessment of cultural variations in illness perceptions: Barts explanatory model inventory. *Journal of Health Psychology*, 24, 336–347.
- Salewski, C. (2003). Illness representations in families with a chronically ill adolescent: Differences between family members and impact on patients' outcome variables. *Journal of Health Psychology*, 8(5), 587–598.
- Searle, A., Norman, P., Thompson, R., & Vedhara, K. (2007). Illness representations among patients with type 2 diabetes and their partners: Relationships with self-management behaviors [Electronic version]. *Journal of Psychosomatic Research*, 63(2), 175–184.
- Sontag, S. (1988). *Illness as metaphor*. Toronto: Collins Publishers.
- Stafford, L., Berk, M., & Jackson, H. L. (2009). Are illness perceptions about coronary artery disease predictive of depression and quality of life outcomes? *Journal of Psychosomatic Research*, 66, 211–220.
- Stafford, L., Jackson, H. J., & Berk, M. (2008). Illness beliefs about heart disease and adherence to secondary prevention regimens. *Psychosomatic Medicine*, 70, 942–948.
- Steward, D. C., & Sullivan, T. J. (1982). Illness behavior and the sick role in chronic disease: The case of multiple sclerosis. *Social Science and Medicine*, 16, 1397–1404.
- Stuifbergen, A., Phillips, L., Voelmeck, W., & Browder, R. (2006). Illness perceptions and related - outcomes among women with fibromyalgia syndrome. *Women's Health Issues*, 16, 353–360.
- Strauss, A., & Glaser, B. (1975). *Chronic illness and the quality of life*. St. Louis: Mosby.
- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., et al. (1984). *Chronic illness and the quality of life* (2nd ed.). St. Louis: Mosby.
- Sullivan, T., Weinert, C., & Cudney, S. (2003). Management of chronic illness: Voices of rural women. *Journal of Advanced Nursing*, 44(6), 566–574.
- Thomas, R. (2003). *Society and health: Sociology for health professionals*. New York: Kluwer.
- Thorne, S. E. (1990). Constructive noncompliance in chronic illness. *Holistic Nursing Practice*, 5(1), 62–69.
- Thorne, S. E., Harris, S. R., Mahoney, K., Con, A., & McGuinness, L. (2004). The context of health care communication in chronic illness [Electronic version]. *Patient Education and Counseling*, 54(3), 299–306.
- Thorne, S. E., & Paterson, B. (1998). Shifting images of chronic illness. *Image*, 30(2), 173–178.
- Townsend, A., Wyke, 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.
- Wainwright, D. (2008). Illness behavior and the discourse of health. In D. Wainwright (Ed.), *A sociology of health* (pp. 76–96). London: Sage.
- Watt, S. (2000). Clinical decision-making in the context of chronic illness. *Health Expectations*, 3, 6–16.
- Weaver, S. K., & Wilson, J. F. (1994). Moving toward patient empowerment. *Nursing and Health Care*, 15(9), 380–483.
- Weitz, R. (2007). *The sociology of health, illness, and health care* (4th ed.). Belmont, CA: Thomson Higher Education.
- Weitz, R. (1991). *Life with AIDS*. New Brunswick, NJ: Rutgers University Press.
- Whitehead, W. E., Crowell, M. D., Heller, B. R., Robinson, J. C., Schuster, M. M., & Horn, S. (1994). Modeling and reinforcement of the sick role during childhood predicts adult illness behavior. *Psychosomatic Medicine*, 56, 541–550.

- Williams, S. J. (2005). Parsons revisited: From the sick role to . . .? *Health, 9*, 123–144.
- Wilson, P. M., Kendall, S., & Brooks, F. (2006). Nurses' responses to expert patients: The rhetoric and reality of self-management in long term conditions: A grounded theory study. *International Journal of Nursing Studies, 43*, 803–818.
- Young, J. T. (2004). Illness behavior: A selective review and synthesis. *Sociology of Health and Illness, 26*(1), 1–31.

