CHAPTER 1

The Illness Experience

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> *Chronic illness . . . is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form disrupting normal rules of reciprocity and mutual support.* (Bury, 1982, p. 169)

Introduction

Bury's words from 40 years ago remain true today. Predictability of life disappears. Change is the constant. There is a new normal of life for both the patient and family.

From the perspective of the patient:

> *It is Sunday, 2:08 a.m. I am wheeled into a sterile, white examination room, obviously used for "codes," patients like me, deemed to be in serious trouble. I look at the reinforced glass in the windows separating my room from the other side. The curtains are drawn, and I cannot see out, but on my side I can read the words on the glass, changing with each window:*
>
> *O_2 ___L-m___by___*
> *Medication Dose Time*
> *IV Fluid Rate*
> *Defibrillation*
>
> *Beth puts her arms around me and holds me. She doesn't deserve this, I think. Why must she go through all of this again? (Hsi et al., 2004, pp. 164–165)*

From the perspective of the family caregiver:

> *I was in one of the family lounges [in the hospital], when a Code Blue was called for room 2110. I screamed. That was Randy's room. He had no pulse or blood pressure. With treatment, he responded within a minute. Everything after that is a blur. Many drips were running, the ventilator pressure required continuous adjustment, blood was being drawn for tests… The tears flowed. The unexpected—or maybe it is to be expected with cancer—had happened again. (Larsen, 2013, p. 31)*

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Although the terms *disease* and *illness* are often used interchangeably, there is a distinct difference between them. "Disease" refers to the pathophysiology of a condition. "Illness," in contrast, is the human experience of a disease and refers to how the disease is perceived, lived with, and responded to by individuals, their families, and healthcare professionals. Illness is the social meaning of the disease (Conrad & Barker, 2010). The pathophysiology of disease and the medical model of care predominate treatment; however, to provide holistic care, one needs to recognize and understand the illness experience of the patient and family.

Defining chronic illness is complex. An early definition from the Commission on Chronic Illness (Mayo, 1956) included impairments and deviations from the normal that had one or more of the following characteristics: permanency; residual disability; nonpathologic alteration; and required rehabilitation or a long period of supervision, observation, and care. Disability may depend not only on the kind of condition and its severity, but also on the implications it holds for the person. The degree of disability and altered lifestyle—part of traditional definitions—may relate more to the *patient's perceptions and beliefs* about the disease than to the disease itself.

Although definitions of chronic disease are important, from a nursing perspective, we are far more interested in how the disease affects the patient and family from a psychosocial perspective. What is the illness experience of the patient and family? Perhaps the onus of defining chronic illness—and similarly, quality of life—should be given to the patient, as only the patient understands and "knows" the illness experience. However, that aside, the following definition of chronic illness is offered:

> *Chronic illness is the lived experience of the individual and family diagnosed with chronic disease. The individual's and family's values impact their perceptions and beliefs of the condition and thus their illness and wellness behaviors. Their values are influenced by demographic, socioeconomic, technological, cultural, and environmental variables. The lived experience is "known" only to the individual and family. (Larsen, 2016, pp. 5–6)*

The illness experience—that is, the *lived* experience of the individual and family with chronic disease—includes their perceptions and beliefs about the condition; their physical, psychological, social and emotional responses to the illness; and their health and/or illness behaviors associated with the experience. Illness perceptions are foundational to understanding individual and family health and illness behavior. Perceptions are subjective and unique. Often the individual with a chronic disease may have a different perception of the condition than family members. Stories from the patient and family chronicle the illness experience, as they are the ones who are perceiving and living with the chronic disease. Healthcare professionals play a part in that experience; however, the primary players are the patient and family.

This chapter provides an overview of the illness experience that includes perceptions, beliefs, and behavior demonstrated by individuals and families with chronic disease. This is a sociologic view of the disease as experienced by the patient and family, rather than a medical view. The body of knowledge about the illness experience, most of which resides within the discipline of psychology, is vast. This chapter is an overview and is not meant to be a comprehensive review.

The chapter also follows the illness experience of this author, as my husband and I experienced his esophageal cancer.

> *Cancer. It's esophageal cancer, Stage IIIB. There's been no mistake. The pathology report has not been confused with someone else's. Randy has cancer. We sit*

> *quietly in the oncologist's office, Randy, son Brett, and I. No one says a word. There are no words to speak, no questions that we need answered now. We are stunned. We had a normal life before . . . before cancer. (Larsen, 2013, p. xv)*

The Lived Experience

The lived experience includes the patient's and family's illness perceptions, beliefs, and behaviors; however, there is much more to the experience. It is what the patient and family are experiencing at that point and place in time and *their interpretation* of what is happening. It could be loneliness, stigma, loss, powerlessness, and a myriad of other feelings and beliefs as well as the physical symptoms. The patient and family are living on a roller coaster, never knowing what the next curve will bring. Is this new symptom an exacerbation of my illness? Is what I'm experiencing during treatment normal? What is normal?

> *We [nurses] advocate that an illness shouldn't take over an individual's life, that the individual is more than the illness. But in reality, one's life is often one's illness. Life revolves around doctor appointments, tests, how many times you've vomited today, fatigue, IV antibiotics for an infection somewhere, and so it goes. (Larsen, 2013, p. 37)*

Chronic illness research is grounded in empirical, analytical methodology that examines relationships between variables; identifies social determinants of health or illness; and uses instruments that measure self-concept, quality of life, hope, illness perceptions, illness behavior, and so forth. However, if we, as healthcare professionals, view the behavior of patients with chronic illness as a "statistically significant result" or a *p* value or a Pearson's *r*, we are doing patients and their families a disservice. Research studies reduce patients to an aggregate so that we can say *most* patients' and families' illness perceptions or behaviors are this or that. But consciously or unconsciously, we know, in our relationships with patients and families, that the effects of chronic illness are much more than numbers.

Living with chronic disease is a complex and dynamic process. In a review of research from 2003 to 2013, Ambrosio and colleagues performed a concept analysis of "living with chronic disease." They concluded that living with chronic disease was a process that incorporated five attributes: acceptance, coping, self-management, integration, and adjustment (Ambrosio et al., 2015). Depending on how patients progressed through these tasks, outcomes could vary. From the review of the literature, the researchers proposed that there were four ways of living with chronic illness:

> *Disavowal*: No acceptance, lack of control and balance, long-lasting.
>
> *False Normality*: No acceptance, partial control and balance, long-lasting and vulnerable to disruption.
>
> *The New Normal*: Acceptance developed, total control and balance, long-lasting and less vulnerable to disruption.
>
> *Disruption*: Acceptance needed again, control and balance breakdown, temporary [caused by distressing factors] (Ambrosio et al., 2015, p. 2364).

Living as a family with chronic illness is an ongoing process whereby family members co-create a context for living with others. They also co-create a context for an alternative way of living. Families strive for a "flow" in everyday life and being able to manage new situations (Arestedt et al., 2014). Balancing communication within and outside the family is important for the well-being of the family. Each family member has a different perspective of communication. Some may need to talk more often about dealing with the chronic illness as a family, while others want to talk through things only once.

Arestedt and colleagues (2015) describe that working with families with chronic illness is not just about the illness, but more importantly the family's beliefs about the illness. The authors identified: (1) beliefs about the illness, (2) beliefs about the family, and (3) beliefs about health care. Beliefs about illness included the views that illness is a part of life, and illness is a threat to life. A belief about family was that the family is important in illness. Lastly, a belief about health care was that encounters with health care were struggles.

Head and neck cancer and its treatment have a significant effect on the life of those affected and their families. There are a variety of physical problems. However, the damage to self-esteem and changes to body image often may be more difficult. In a unique qualitative study, Isaksson and colleagues interviewed 56 patients with head and neck cancer at 6, 12, and 24 months post-treatment to assess how they lived their lives. Four different illness trajectories emerged from the 56 patients. The first group (15 patients) regarded their disease as a period in their lives that they had left behind. They rarely thought of the disease; it did not affect their mental state and life went on as before. Group 2 considered their current circumstances as "no big deal." This group of 9 patients, however, was unable to put the experience behind them. The third group of 12 patients considered that they had a different life, but that it was "hardly worse" than before. Twenty patients made up group 4 and considered their life as being worse. There was no difference between the groups in age or gender, and a chi-square test yielded no significant differences regarding tumor stage and the different illness trajectories (Isaksson et al., 2016).

Loss is part of the lived experience of chronic illness; however, the professional literature describing loss and its effect on patients and families is sparse. Is loss just accepted as normal in chronic illness? There are physical losses, such as mobility, eating issues, fatigue, communication dysfunction, and so forth; however, what we do not acknowledge are the psychosocial responses that accompany each physical loss or the general psychosocial responses that one may experience from having a chronic illness. As an example, sharing a meal is a social activity. How many of us like to eat by ourselves, particularly in a restaurant? Few of us do, as conversation and socialization are part of the eating experience. However, what if someone cannot eat? Perhaps there is a feeding tube in place or such severe nausea that eating is not possible. In addition to being unable to eat, the individual has the loss of this social activity as well. And often the psychosocial loss may be more profound to the patient's well-being than the physical loss.

Fife's classic work in 1994 conceptualized the meaning of serious illness and described how this meaning affects self. The meaning assigned to a serious illness is related to what individuals perceive has been gained or lost relative to their identity in relationships, to events, and to the future. Roles are altered. Changes occur. Loss of control is probably one of the most important dimensions relative to self that occurs with a life-threatening illness (Fife, 1994). One loses the idea that life is predictable. Suddenly, the self is vulnerable. Patients may feel like their life is of little value to anyone. The future is unclear.

Life becomes a struggle to maintain control over the defining images of self and one's life. Meanings of self and illness change as the disease progresses or recedes. Experiencing chronic illness may result in an individual's self-concept being tied to the past, present, or future. Time plays a central, albeit hidden, role in shaping self-concept (Charmaz, 1991). Life may be going smoothly, but getting "bad news" may catapult one into a crisis. An exacerbation turns a "good day" into a "bad one" and creates a new, distinct reality with its own rules, rhythm, and tempo.

In American culture, we hide suffering. By keeping the ill, elderly, disabled, and dying out of view, we manage to keep the story of the damaged body, physical weakness, or limitation at arm's length. Society puts a positive spin on everything. In the play *Wit*, by Margaret Edson, the primary character is a professor of English literature who is hospitalized for terminal ovarian cancer. The play opens with the main character, Vivian, speaking to the audience:

> *Hi, how are you feeling today? Great. That's just great. . . . Of course, it is not very often that I feel fine. I have been asked, "how are you feeling today" while I was throwing up into a plastic washbasin. I have been asked as I was emerging from a four-hour operation with a tube in every orifice, "How are you feeling today?" I am waiting for the moment when someone asks me this question and I am dead. I'm a little sorry I'll miss that. (Edson, 1999, p. 5)*

Does this excerpt sound familiar? Is it something that you would ask a patient? Is that how we, as professional caregivers, are perceived by others?

> *Randy's nurse enters his room and asks how Randy is doing. Doesn't he see Randy throwing up green crap continuously in the emesis basin? Doesn't the nurse remember that 15 minutes ago when he was in the room, he asked the same question while Randy vomited? Why do I have to answer a stupid, rhetorical question for this nurse? Why doesn't this nurse "get" what is going on?*
>
> *—Pamala*

Partners of individuals with chronic illness have a corresponding sense of self-loss. They not only perceive the downward spiral of their partner, but must also cope with their internalized expectations of themselves as a partner. Have I done what needs to be done? Am I being helpful to my partner? What else can I do? Partners must cope with their own sense of failure (Weingarten, 2013).

The meaning of serious illness and adaptation to it varies among individuals. Medical sociologists have attempted to describe the effects to self from chronic illness from two different perspectives. The first perspective, and the most dominant way of thinking, is that chronic illness is a biographical disruption. Reeve and colleagues (2010) state that the core assumption within biographical disruption is the impact of the illness on personal meaning and disruption to core assumptions about the world, the future, and most important, the self. It is a patient's personal responsibility to maintain a coherent self. The role of the caregiver is to focus on individual creative capacity rather than the processes of disruption. One's sense of value and meaning in life come under threat with death as the ultimate biographical disruption. This perspective is based primarily on the classic work of Bury and Charmaz. The second perspective comes from the work of Williams (2005), who suggests adding the concepts of timing and purpose, commitment, and expectation that serious illness, for some individuals, may be part and parcel of normal everyday life, thus coining the phrase "normal illness" (p. 61).

Having a chronic illness is more than "learning to live with it"; it means struggling to maintain control over the defining images of self and one's life. Charmaz (1983) coined the phrase "loss of self" from interviews with individuals with chronic illness in the 1980s. The chronic condition and the experience of that illness influence loss of self. Charmaz describes the illness experiences of patients as living a restricted life, experiencing social isolation, being discredited, and burdening others. Slowly, the individual with chronic illness feels their self-image disappear; this loss of self occurs without the development of an equally valued new one.

There are times in chronic illness when an individual feels a sense of alienation from the body, perhaps because intellectually they are trying to protect themselves from an awareness of loss. Conway (2013) refers to this condition as the damaged self. Others have referred to the threatened self (Nanton et al., 2016).

American culture often defines and identifies individuals based on their occupation. At a social gathering, one is asked, “What do you do for a living? Where do you work?” Such inquiries are an easy way to start a conversation between strangers. With disability and chronic disease, however, there are no easy answers to those questions. One stammers and stutters and finally says, “I retired early because of my COPD.” Work occupies a central place in the lives of most people, and most adults experience this part of their lives through paid employment. Paid employment gives one social identity.

It is difficult to estimate how many individuals with chronic disease or injury have to leave employment every year. Nearly all people whose work lives are affected by a serious illness—whether acute, chronic, or terminal—face common issues: the centrality of work in their lives; the uncertainty of how illness will affect their future and how to negotiate the necessary steps, which include disclosing their illness; and deciding whether to stay at work, take a leave of absence, or leave completely (Walker, 2010). Leaving work because of the onset or progression of a chronic illness has an enormous impact on a person’s life. Apart from the obvious effect on income, some of this importance may be explained through the changed identity that results from the end of an individual’s work life. When a person retires, it is presumed that their social identity changes. However, leaving a job because of illness is an involuntary action and is often accompanied by an unwanted social identity.

Consistent with other studies, Dowling and colleagues (2013) observed that employment, lost productivity, and burden of illness varied substantially across subgroups of cancer survivors. As might be expected, survivors who had cancers associated with short survival, or who had multiple cancers, consistently experienced the highest levels of burden compared with individuals with other, single-site cancers.

In a systematic review of 18 studies, researchers described the influence of significant others to their partners with chronic illness returning to work. Twenty-seven cognitive and behavioral factors were identified that could be either a positive incentive to return to work or a barrier. Examples of cognitions included: work as a cause of the disease; believing that a return to work would lead to a deterioration of the patient’s condition; and an exaggerated protective attitude. Examples of behaviors included: enabling a discussion about a return to work; emphasizing what a patient can still do; and providing dubious support (Snippen et al. 2019).

For patients and families who are of working age, financial losses are common. The patient may or may not be able to return to work. Disability and health insurance may or may not be included in the patient’s work benefits, and if included, it may provide little financial respite. A family member may quit a job to provide care for a loved one. Similarly, for others who are retired or without work, the financial loss may be just as devastating. Life savings may be drained to pay for treatment. For an older adult, there may not be a family caregiver who is available to help; thus, a paid caregiver may be required, adding to the cost of the illness. A long-term illness may bring financial ruin to a family.

Countless physical losses coexist with chronic disease, and these losses vary significantly across diseases. Examples include sensory losses, such as loss of hearing or eyesight; nausea and vomiting, causing the patient to be unable to eat; chronic pain; bladder and bowel incontinence; changes to the physical body such as a stoma, an amputation, or change in facial appearance; loss of mobility; loss of intimacy; fatigue; and the effects of treatment. Lastly, and perhaps most important, these physical losses often result in loss of independence.

There is little focus in this text on death from chronic illness; however, it is a reality for many patients and families. Death of a loved one frequently means the loss of an attachment figure, a person to whom one has had and still has a deeply significant emotional bond. Tie and Poulsen (2013) view terminal illness as a threat to attachment bonds. Given the demands on both the healthy and sick partner dealing with a terminal illness, there is a high potential for adjustment injury.

Permanent separation brings with it a myriad of reactions, such as despair, loneliness, hurt, and anger. The "why" questions come fast and furious. Why them? Why now? Why was Joe down the street cured of his disease and my spouse was not? Why didn't I get a chance to say goodbye? Why did she have to suffer so much before dying? And then comes the fairness issue—"It's not fair." And then you realize, again, that life is not fair and never has been.

> *The day we knew would come came yesterday. The pain in Randy's chest is more cancer. There are only two choices: a clinical trial or hospice. It was Randy's decision that he not be in a clinical trial, saying that he knew the results would help someone, but he was tired and didn't want to do this anymore. (Larsen, 2013*, p. 42)

The experience of dying involves the ultimate confrontation with the limits of language. How does a person describe this experience—dying from a chronic condition? How does a person describe the suffering he or she might have and how do they react to it? They grieve. Patients and families grieve a life that will not be.

> *Last night he [Randy] was talking about the fall 2012 elections and said, "it's hard to believe that I won't know the outcome." (Larsen, 2013, p. 47)*

When death is expected and the physical pain is not severe, individuals can think and perhaps describe their feelings about death and dying. In recent years, several authors have described their failing health and imminent death. Such authors and their books include: *Closing the Chart* (2004) by Hsi et al.; Kalanithi's *When Breath Becomes Air* (2016); and *The Unwinding of the Miracle: A Memoir of Life, Death, and Everything That Comes After* by Yip-Williams (2019). However, for many, the pain may be intense even with medication, or perhaps medication is given for sedation, and with decreased cognitive function, expressing one's thoughts is difficult or impossible.

Illness Perceptions

Each individual has a different perception of something that is known to them. It may be minor, such as a football game, your neighborhood, or the elementary school your child attends. If 10 people were asked their perceptions of these minor events or things, chances are that each would have a different perception. The situation is similar with chronic illness. With illness, each individual and family member has their own perception of the disease.

Patients and their families do not develop their own illness beliefs and perceptions within a vacuum, but rather are molded by everyday social interactions, past experiences, sociodemographic factors, and their culture. How one lives during an illness, implements coping strategies, and generally responds to the illness is based on one's perceptions. These perceptions may be irrational or invalid. However, right or wrong, these perceptions form the basis of patients' and families' behavior when confronted with a chronic disease.

The literature uses several terms for the same construct: *illness representations, illness perceptions, illness narratives,* and *beliefs about illness*. All of these terms refer to a set of cognitions about the subjective experience of an illness (Cameron et al., 2016). All refer to how the patient (and family) view the illness and the events surrounding it. Illness perceptions belong to individuals, are interpreted by individuals, and may not conform to science. Rarely does a diagnosis of a chronic condition “make sense” to patients and families, so they create a model, in their minds at least, to see some clarity, some rationale, some sense, some meaning. There is a need by patients and families to make sense of the health threat. The models are based on their perceptions of the diagnosis, the illness experience, the treatment, and the consequences, which, in turn, form the basis of their response and behavior. Often these models do not make sense to outsiders, including healthcare professionals. Sometimes the models are based on inaccurate information. The model is dynamic throughout the illness, as new data become available.

> *The journal where I kept track of all of Randy’s medical entries, weight, oral intake, tube feedings and medications was very detailed. I believed that if I had all of the details on paper, then perhaps I could make some sense of what was going on. Maybe I could figure this out.*
>
> —*Pamala*

A systematic review by Arat and colleagues (2018) explored factors that might be modifiable in changing a patient’s illness perceptions. If such factors could be identified and then modified, perhaps the meaning of the chronic illness might change for the patient and thus the illness behavior. Fifteen studies were included in the review. Five categories of factors were identified: illness-related factors, psychosocial factors, medication beliefs, information provision and satisfaction with the information received, and quality of care.

Medication beliefs were correlated with emotional representations, but not with cognitive beliefs. Patients were concerned about the potential harm of using the medication or if medications were overprescribed. Receiving information about the disease and its treatment helped patients perceive a higher personal control of the situation. In patients with diabetes, a higher perceived quality of care led to a better understanding of the condition. Regarding psychosocial correlations with illness perceptions, depression and anxiety were strongly associated with negative perceptions.

Why are illness perceptions of interest to healthcare professionals? The primary reason is that perceptions directly influence the emotional—and often the physical—response that patients and families have to chronic illness. A patient’s perception may lead to adherence or nonadherence to treatment. Thus, understanding the patient’s perception is key in understanding patient and family needs and developing a treatment regimen and/or understanding why a treatment regimen succeeds or fails (Petrie & Weinman, 2006). Micelli and colleagues (2019) add that medical professionals can provide education about a patient’s diagnosis and then develop interventions that challenge patients’ illness perceptions.

Leventhal and colleagues developed the common-sense model of self-regulation (CSM) in the 1980s to describe the different steps individuals and families go through in responding to a health threat. Illness perceptions are part of the self-regulation process that takes place in the face of a health threat. Illness perceptions change over time as the disease or condition goes through different stages. According to the CSM, symptoms produce both cognitive and emotional responses that are processed in parallel (Anisman, 2016). Emotional representations are integral to cognitive representations. The cognitive representation is identified as having five main components:

- Identity of the illness: Connecting the symptoms with the illness and having an understanding of the illness. What happens if the name or label of the disease is not easily identified or the diagnosis does not fit the symptoms?

- Timeline: Duration and progression of the illness. "New" patients with a chronic illness might have an acute care framework of their disease, while continuing patients have a chronic view.
- Causes: Perceived reason for the illness. Patients need a "cause" instead of believing that the disease was a random event. Most patients form hypotheses about the causes, asking, "Did I not exercise enough?" "Did I smoke too much even though I quit 20 years ago?" "Did the environment contribute to my disease?"
- Consequences: The physical, psychosocial, and economic impact of the illness to the patient and the family. This component is the patient's overall evaluation of the seriousness of this disease.
- Perceived control: A belief that the disease can be controlled, managed or cured (Hagger et al., 2017)

The CSM also includes emotional representations (perceptions) that affect an individual's affective response or behavior to the illness. The emotional responses may be negative reactions such as anger, hurt, anxiety or fear as well as positive reactions.

Leventhal and colleagues' (2012) explanation of perceptions leading to behavior makes one think that cognitive and emotional responses fit together like pieces of a puzzle, and there is a linear progression from identity to control or curability. But it isn't that simple. Imagine that a chronic disease has affected either you or someone in your family. You may have had some knowledge of the disease prior to diagnosis, but now that the condition is "yours," your perception may change. Plus, you begin to search the internet, which provides more information than you can possibly absorb. You begin with the idea that this condition is controllable, and perhaps curable; however, you find too much data online that tell you otherwise. Thus, your perceptions about the illness change overnight, with your emotional responses and behaviors following suit.

Illness Perceptions of Patients and Their Partners

The support and influence of one's partner during a chronic illness cannot be overestimated. However, what happens when the patient and partner have different illness perceptions? How does that affect the patient's responses and illness behavior?

In a study examining the associations of the beliefs of men with prostate cancer and their spouses' beliefs about the controllability and timeline of the disease, findings indicated that spouses' belief that the disease would be of short duration mediated the effect of the patients' beliefs that it would last a long time. In turn, this led to improved patient quality of life 6 months later (Wu et al., 2013).

Twiddy and colleagues investigated the effects of discrepancy in illness representations on distress in stroke patients and their carers at 3 months and 6 months post-stroke. Carers were more pessimistic than patients about the symptoms, timelines, and consequences of stroke. Such discrepancy in illness perceptions has implications for adjustment for both the patient and the partner. These findings stress the importance of the patient's and partner's illness perceptions, as the discrepancy was as strongly associated with patient and carer distress as was physical disability (Twiddy et al., 2012).

In a study with 111 post–myocardial infarction (MI) patients and their partners, findings indicated that generally partners shared the same illness perceptions regarding symptoms and consequences of MI; however, their perceptions were significantly different than the patients when it came to the duration of the illness. Partners perceived that the duration of the illness would be much longer than the patient did. Partners were more pessimistic than patients, and perceived MI as being less controllable than the patients did (Qin et al. 2019).

Researchers examined the illness perceptions of patients with clinically diagnosed and screen-detected type 2 diabetes and compared those results with their partners'. Patients (aged 40–75) and their partners completed the Brief Illness Perception Questionnaire. The route to diagnosis had minimal influence on the patients' illness perceptions; however, partners of patients diagnosed through screening, versus clinical symptoms, had very different illness perceptions as compared with the patient. At 3 years after diagnosis, the partners remained overwhelmed with the diagnosis (Woolthuis et al., 2013).

Illness perceptions may be related to more readmissions in patients with chronic illness. In a review of illness perceptions and the six medical diagnoses included in the Hospital Readmissions Reduction Program (HRRP), researchers found that favorable illness perceptions were associated with better health outcomes, while unfavorable illness perceptions were associated with worse outcomes and more readmissions (Sawyer et al., 2019). The six diagnoses in the HRRP included heart failure, chronic obstructive pulmonary disease, myocardial infarction, coronary artery bypass graft, pneumonia, and total hip and/or knee arthroplasty. The HRRP requires the Centers for Medicare and Medicaid (CMS) to reduce payments to hospitals with excess readmissions. The researchers concluded that interventional studies are needed to improve illness perceptions to make them more positive and less threatening.

Illness Perceptions of Patients and Physicians

The formation of the patient's perception of a chronic illness is a complex, multidimensional process involving much more than the physical symptoms. This complexity makes it difficult for the physician and nurse to treat the patient if their professional perceptions do not match the patient's illness perceptions. Immediately, there is likely to be a disconnect in the communication between the physician, patient, and family.

Recent studies suggest that better communication between the physician and patient may affect a patient's illness perceptions, and thus the patient's behavior and adjustment. In a study by Karademas and colleagues (2016), the researchers found that the amount of information provided by the physician (e.g., an increase in information) moderated the relationship of general maladaptive beliefs to illness representations, and consequently to behavior and adjustment (Karademas et al., 2016).

In a similar study, Paschali and colleagues (2015) concluded that the more illness- and treatment-related information provided by physicians, the more positive the illness perceptions. These positive perceptions, in turn, resulted in better physical functioning and better adjustment to cancer (Paschali et al., 2015).

Ninety-nine patients with multiple sclerosis (MS) from six sites in Canada rated their relapse frequency, general health, and quality of life; reviewed descriptions of eight health domains and selected the three most important; and completed a utility assessment. Their neurologists completed the same instruments. Neurologists identified physical function domains as important, while patients placed more emphasis on mental health domains. There was a lack of congruence between neurologist and patient ratings in clinical outcomes (exacerbations or flares), general health, and quality of life. Neurologists significantly *underestimated* the number of flares, as compared with the patients' assessment; considered the patients' health status better than the patients themselves; and rated the patients' quality of life better than the patients did. These findings suggest that neurologists have an incomplete understanding of patient perceptions (Kremenchutzky & Walt, 2013).

Perceptions of patients and gastroenterologists were compared regarding irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD). Physicians and patients had differing views in terms of disease chronicity, personal control, and physical and psychological causes of the illness. The differences in perception may influence the patient–physician relationship and could adversely affect treatment adherence and outcomes (Levy et al., 2014).

Illness Behavior

Illness behavior varies greatly according to illness-related, patient-related, and physician-related variables and their complex interactions (Sirri et al., 2013). The disease model may be the basis for treatment of patients; however, it does not take into account the behavioral responses of the patient and family. The concept of illness behavior provides an explanation for clinical phenomena that do not fit the disease model (Sirri et al., 2013).

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*. Parsons viewed health as a functional prerequisite of society. From his point of view, sickness was dysfunctional and was a form of social deviance (Williams, 2005). According to Parsons, sickness permitted individuals to avoid their social roles and responsibilities; however, the person had the obligation to seek medical help.

Definitions of Illness Behavior

Using Parsons's work as a basis, Mechanic's classic work (1962) proposed the concept of illness behavior as symptoms being perceived, evaluated, and acted (or not acted) upon differently by different persons. He believed that it was essential to understand the subjective perception of the individual, including that person's norms, values, fears, and expected rewards and punishments, to determine how an individual with illness acts. Mechanic (1995) defined 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).

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 themselves as ill, different behaviors may be displayed. A behavior could be the individual's emotional response to the diagnosis. The illness behavior might be a behavior geared toward health—for example, when an individual with lung cancer stops smoking.

Influences to Illness Behavior

Chronic illnesses require that a variety of tasks be completed to meet the requirements of the medical regimen. However, there is a lack of norms for those with chronic illness. What is expected of a patient recovering from cancer surgery? An exacerbation of rheumatoid arthritis? A flare-up of inflammatory bowel disease? Are sick-role behaviors discouraged or not? These individuals enter into and remain in a type of impaired, "at-risk" role. Implicit behaviors for this role are not well defined, leading to role ambiguity. Given this lack of norms, influences on the patient include the degree of disability (with different attributes of disability producing different consequences), visibility of the disability (the less visible the disability, 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. They may alter their previous definitions of self to one with limitations and look to what the future may impose on them.

In a study examining narratives of older adults with cancer, the impact of the disease may be different than in younger adults. Hannum and Rubinstein (2016) suggest that older adults diagnosed with cancer may revise their sense of personal identity (who they are in the world) and agency (how they act in the world) mediating some negative psychosocial effects of the disease. For the older adults in this study, restructuring time into smaller units was important. Time became more fractured and fragmented for them. Data analysis revealed three time periods for the older adults: *Recalled Past* (past time), *Perceived Present* (illness time), and *Imagined Future* (future time).

Using a sample of 300 patients with various chronic illnesses, one group of researchers (Janowski et al., 2013) found differences in the frequency of health behavior according to gender, with women demonstrating more healthy habits than men. In addition, older adults performed more health-promoting behaviors than younger adults. Higher education was associated with less frequent health-promoting behaviors, and marital status (e.g., being widowed) was associated with more frequent health-promoting behaviors.

One's education, 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, and avoiding medical help, for example, all influence their children's future responses. If children see that "hard work" and not giving in to illness pays off with rewards, they assimilate those experiences and mirror them in their own lives.

One cannot minimize the impact of past experiences of the individual and family on how they deal with their own chronic illnesses or with chronic illnesses developed by their children, parents, or siblings. Each of those experiences affects how the individual and family perceive the current health challenge. These experiences could be positive as well as negative. In some cases, a negative healthcare experience with a relatively minor injury/illness could have a stronger influence than a positive experience with serious illness. As healthcare professionals, we should not underestimate the patient's and family's perception of their illness and its effect on their behavior and physical and psychosocial outcomes.

> *How will my adult children process their 64-year-old father's cancer and now his death? How have they viewed his illness? How will they assimilate his death into their lives? This is now one of their "past experiences" with chronic illness. Life expectancy continues to increase, and there are more cancer survivors than ever; however, their father wasn't one of them. Their paternal great-grandfather died of a stroke in his late 80s, their paternal grandfather died of acute leukemia at age 73, and now their father has died of cancer at age 64. These past two deaths do not reflect national statistics. Are they thinking, "Maybe one of us will die of cancer in our 50s"?*
>
> *—Pamala*

The Legitimization of Chronic Illness

Most chronic diseases have specific diagnostic criteria that verify the disease's presence and, therefore, indicate the appropriate treatment. With some illnesses, 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. Patients may begin to "doctor hop," hoping to find someone who can identify their condition. 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 professionals and society in general are skeptical of your symptoms? And if your illness perceptions are askew, what will your behavior be? Two articles on fibromyalgia reflect the quest for diagnosis and the "lived experience" of a disease that is often misunderstood.

Researchers explored the experience of diagnosis of patients with fibromyalgia. Typically, years are spent consulting physicians to confirm the diagnosis. During this time persons were continually questioned as to whether they were genuinely ill, whether their illness was of a psychological nature and whether the person sincerely wished to recover. Even when firmly established that fibromyalgia was the diagnosis, patients continued to feel belittled and blamed by healthcare professionals. For patients, the diagnosis did not provide a meaningful explanation of their suffering and had limited ability to legitimatize the disease (Mengshoel et al., 2018).

Sim and Madden (2008) conducted a metasynthesis of qualitative studies on the illness experience of persons with fibromyalgia. Most studies discussed pain as the most frequently mentioned symptom. Pain was characterized by a number of dualities, often of an ambiguous or conflicting nature such as diffuse and shifting, constant and varied, present when active or resting. Persons reported being ill and well at the same time. Although pain had a dramatic impact on everyday life, others reported that fatigue was more debilitating. Searching for and establishing a diagnosis was a pivotal stage of the person's illness experience. Generally, individuals with fibromyalgia greeted a diagnosis with relief, that their symptoms had been validated. However, this initial relief quickly evaporated in the face of an unsuccessful search for an effective treatment. Seeking legitimacy of the disease from healthcare professionals, family, and friends continued long after diagnosis.

Illness Perceptions/ Behavior and Chronic Disease

The literature about the effects of illness perceptions and beliefs on behavior and treatment continues to grow. What follows are some representative studies that demonstrate current and continuing work in this area.

Cardiovascular Disease

A study by Pickett and colleagues (2013) examined the relationship between hypertension beliefs and self-care behaviors necessary for blood pressure control. After assessing a sample of 111 community-dwelling African Americans, researchers reached three conclusions: (1) a number of patients believed that the primary cause of hypertension was stress; (2) patients' attribution of hypertension to stress was negatively associated with keeping doctor appointments; and (3) patients' belief that hypertension is a chronic condition was positively associated with keeping doctor appointments and medication adherence. There was no significant relationship between illness representations and eating a healthy diet, engaging in physical activity, or maintaining a healthy weight. Researchers suggest that healthcare professionals carefully assess patients' beliefs about hypertension as part of an effort to more effectively treat and control blood pressure.

The purpose of Greco and colleagues' study was to investigate the role of illness perceptions and self-efficacy beliefs in the relationship between illness severity and health satisfaction in patients with cardiovascular disease. Each patient in the study was enrolled in a cardiac rehabilitation program and had a history of 5+ years of chronic disease. Disease severity was unrelated to health satisfaction. Findings suggest that the management of patients' illness perceptions led to a personal sense of control and a higher quality of life (Greco et al., 2015).

A study of Black women with hypertension sought to understand how the women's perceptions of hypertension were related to their lifestyle. With a sample of 204 women, findings indicated that the women did not perceive a relationship between hypertension and their limited physical activity or their diet. The results of this study support prior research (Stallings, 2016).

In a meta-analysis examining the association between illness representations (perceptions) and psychological distress in stroke survivors, Pai and colleagues (2019) found that negative illness representations were positively associated with depression and anxiety. Of the seven studies in the meta-analysis, however, none of the studies explored whether there was a moderator between illness perceptions and depression and anxiety.

Cancer

Richardson and colleagues (2016) performed a systematic review and meta-analysis of the relationship of the common-sense illness representation model with health and coping outcomes in people with cancer. Thirty-eight studies were included in the meta-analysis. Analysis of the studies revealed small to moderate effect sizes for the relationships between illness perceptions and coping behaviors (particularly between control perceptions, problem-focused perceptions, and cognitive reappraisal), and moderate to large effect sizes between illness representations and illness outcomes (in particular between identity consequences, emotional representations, and psychological distress). The authors caution that more high-quality studies are needed to accurately portray a cause and effect relationship between illness representations and coping behaviors (Richardson et al., 2016).

Researchers sought to explore the relationship of illness representations and breast cancer survivors' fear of the recurrence of the disease. Illness representations accounted for a significant amount of the variance of fear of recurrence in a study with 117 women at least 1 year post-treatment (Freeman-Gibb et al., 2017). The women in the sample were recruited from three breast cancer internet discussion boards.

In a systematic review of illness perceptions and women with breast cancer, Kaptein et al. (2015) reviewed 12 studies from 2012 to 2015. Findings included that illness perceptions in women with breast cancer were associated with major outcomes in the course of the disease. Those outcomes included both medical and behavioral outcomes such as fear of recurrence, distress, quality of life, satisfaction with medical care, use of traditional healers, and risk perception. The concluding statement from the authors was: "Listen to your patient's story. Only then will you be able to help her best" (p. 123).

In a study by Micelli and colleagues (2019), participants with advanced gastrointestinal cancer were asked how they perceived their illness in terms of stress. Participants who were single, never married, or divorced perceived more stress than individuals who had a partner. This supports previous research. Consistent with the comon-sense model, negative illness perceptions were associated with greater perceived stress. Lastly, older participants reported lower levels of stress and had more positive perceptions of their illness.

Chronic Somatic Disease

Some researchers suggest that beliefs about behavior may be as important as illness perceptions about a disease. In one study, 453 patients with type 2 diabetes were recruited to participate in a randomized controlled trial of blood glucose self-monitoring. The study compared the extent to which self-care behaviors of patients with type 2 diabetes are predicted by patients' beliefs about those behaviors as compared with their illness perceptions. The researchers concluded that beliefs about behaviors were at least as important in predicting health-related behaviors, suggesting that behavior change interventions with patient groups might be more effective if they targeted beliefs about behavior, rather than beliefs about illness (French et al., 2013).

In a sample of 113 patients with asthma, Achstetter et al. (2019) found that illness representations predicted a change in asthma control. Patients with a better understanding of their illness and who believed that they had the power to control their asthma had a greater improvement in asthma control. The researchers concluded that assessing illness beliefs at the beginning of an intervention could help identify patients who had a lower probability of treatment success and modify their intervention accordingly.

End-stage renal disease (ESRD) is associated with high morbidity and mortality rates. Parfeni, Nistor, and Covic (2013) reviewed research related to illness perceptions and survival among patients with ESRD. Five studies met the researchers' criteria for inclusion in the review. Four of the studies showed that a negative perception of illness was associated with an increased risk of death; however, one study failed to find any relationship. The researchers concluded that a positive change in a patient's perception of an illness may improve outcomes.

The illness experience of the patient and family continues to mystify healthcare professionals. The literature about the relationship(s) is vast and continues to grow, indicating the importance of these concepts in developing a treatment plan and patient adherence to the plan. What is clear in these studies is that seeing the illness through the lenses of the patient and family is critical in supporting them throughout the experience and improving patient outcomes, both physically and psychosocially.

Professional Responses to Illness Behavior

Healthcare professionals expect patients entering the acute care setting to conform to sick role behaviors, at least initially. Most people entering the hospital for the first time are quickly socialized into the healthcare system and are expected to cooperate with treatment, recover, and return home to their normal roles. Professional expectations and patient responses are in line with social expectations and fit with the traditional medical model of illness as acute and curable. Healthcare professionals "like" patients who are adherent and cooperative and do not question their care. When patients are less cooperative or question them, staff may consider the patients difficult, problematic, or nonadherent.

When individuals with chronic illness are hospitalized for an acute disorder, they view the situation quite differently than the healthcare professionals with whom they interact. Patients with multiple chronic conditions may focus on maintaining stability of their chronic conditions to prevent unnecessary symptoms, whereas their healthcare professionals are more likely to focus on managing the current acute disorder. In addition, patients who have had multiple prior admissions are more likely to use their hospital savvy to gain what they want or need from the system. They have learned the formal and informal hospital "rules." They have learned which nurses and nursing assistants provide the best care and which do not. For instance, if the patient is assigned a certain nurse who has not met the needs of the patient in the past, the family may become more vigilant and more visible during the hospital stay or refuse to have that nurse care for the patient.

> *When Randy was in SICU during the summer of 2011 when everything fell apart, I became acquainted with several family members of other patients in ICU. We were often in the family lounges together, in the cafeteria, or just talking in the hall. ICU is a lonely place for family members. I hope that nurses who work there realize that. One person I remember distinctly was a mother of a 20-year-old college student who had a traumatic brain injury. The prognosis was vague. The mother had flown in from Florida, had no social support, and was unfamiliar with Colorado, our town, and the hospital. She had asked me a previous time if this was a "good" hospital. I overheard a conversation between one of the nurses and this mother in which the nurse was being abrupt with her, telling the mother to be patient, that the doctor had other patients to see, and he would contact her when he could . . . all spoken in a stern, paternalistic voice. I was shocked at this nurse's behavior. Did she not realize what this mother was going through? Was she not aware of the illness experience of this mother? I went directly to the patient care coordinator of the SICU and asked that Randy never be assigned this nurse. The nurse's behavior was unacceptable, and I did not want her to care for my husband.*
>
> —*Pamala*

Patients with chronic illness seek a different kind of relationship with healthcare professionals—one where there is "give and take," and that empowers the patient. The extent to which a patient with chronic illness is included in the formulation of their treatment plan may influence the success of the plan. Although assuming sick role dependency may be adaptive behavior in acute illness, where medical expertise offers hope of a cure, the same is not true in chronic illness. Individuals with chronic illness are the "experts" in their illnesses and should have the ultimate authority in managing their illnesses over time.

The relationship between the patient, family, and physician cannot be underestimated. In a systematic review of the interactions between patients and physicians and self-care in heart failure, 22 of the 24 studies examined reported that poor interactions with healthcare professionals affected patients' self-care in a negative manner (Currie et al., 2015, p. 528). Poor information regarding medications was especially challenging for patients. Patients wanted more than a "pamphlet" to read. The researchers concluded that the patient–healthcare professional relationship is critical in enhancing self-care in heart failure.

Interventions

There is no "magic" list of interventions to assist and support patients and their families during the illness experience. The current healthcare system—with its acute care focus, fix-and-cure model, and medication for each symptom—does not fit with caring for individuals on a long-term basis. These patients do not need their illness behavior "fixed" or "cured," but instead need a healthcare professional who listens and understands the illness experience.

Understanding illness roles and behaviors in planning interventions allows the healthcare professional to maximize the value of the time spent with the patient. One such intervention, patient and family education, could be improved by integrating knowledge of the patient's perceptions and roles. Additionally, the patient who is still in a highly dependent phase will not benefit from education. As nurses, we often think patient education is the key to everything; however, the timing of that education is critical. As improvement in physical status occurs, emphasis on the desire to return to normal roles creates motivation to learn about the condition and appropriate care to maximize health. As the patient moves into the "at-risk" role and becomes aware of the necessity to maximize their potential, education provides a highly successful tool both in the hospital and at home.

Although we know that illness perceptions and beliefs are related to behaviors and coping, Simpson et al. (2013) argue that targeting illness beliefs in isolation is unlikely to effect any significant psychological change, given the number of demographic, sociocultural, and psychosocial factors that influence the process. These authors support a formulation-based approach in which illness beliefs and a range of other factors are included as intervention targets. For example, information-giving, support groups, group therapy, and techniques to improve self-esteem might be useful.

Social Media

The effect of social media in society cannot be underestimated. The literature is vast describing how social media can assist patients and families in the self-management of disease (see Chapter 7, Self-Management). Sharing the "lived experience" of chronic illness via social media may be a part of self-management.

In this hyperconnected world, it may be hard to believe that there are those who feel alone and socially isolated. However, patients with chronic illness often feel that way. Social media can form emotional communities for those with chronic illness (Petersen et al., 2020). Patients and families can share stories about their illness experience. Being able to interact with others with similar health problems can help alleviate the aloneness they feel. Online health community (OHC) is another term that is used in the literature to describe an online source of support for persons with health conditions. Online health communities may include listservs, discussion forums, private messaging, chat rooms, blogs, Facebook, Twitter, Instagram, and other platforms (Wang et al., 2017).

Petersen and colleagues (2020) sought to understand the meaning of and use of social media to manage patients' conditions and related social isolation. There was some ambivalence in using social media noted in a sample of 50 individuals with a chronic condition. Through data obtained from 50 qualitative semi-structured interviews, risks were identified in participating in OHCs. Specifically, patients with chronic illness were concerned about trolling, inappropriate postings, and impersonation. Inaccurate, untrustworthy, or biased information was another concern. Despite those risks, participants felt that being a part of an online community provided connections and had improved their own and other patients' lives.

At least one chronic disease society has set up its own online community. COPD360 social is an interactive and disease-specific online community and social network dedicated to connecting people living with chronic obstructive pulmonary disease (COPD) to evidence-based resources. Members are encouraged to share their own stories through blogs, images and videos. Since it was developed in 2014, the community has grown to over 30,000 members in 120 countries. One of the components of it is *Find People Like Me* to connect like members with similar experiences or interests (Stellefson et al., 2018).

Diabetes online communities (DOC) exist throughout the world. A 2013 study of 1352 posts on a large diabetes Facebook group had over 30,000 members with contributions in 11 languages. Oser and colleagues (2020) report that the primary reason for most DOC appear to be the need for peer support versus health information. The researchers see social media as a way of helping individuals with unmet psychosocial needs.

Facebook has a platform for Facebook groups, which it defines as "a space to communicate about shared interests with certain people" (Partridge et al., 2018). This group feature allows patients and/or health professionals to interact through posts. Groups can be either open, closed, or private. Analysis of the publicly available Facebook groups showed that the majority of groups were focused on creating awareness of the health condition.

Patient-initiated blogging has become a popular means to describe one's illness experience and communicate with others facing similar experiences. Although blogging is a communication tool, perhaps there is more significance to it than merely its communication role. Perhaps it may be psychosocially beneficial to share personal experiences with others, or to become aware that your experiences as a patient with chronic illness are similar to others' experiences. The mere act of writing down experiences may also be a type of "therapy," or emotional catharsis, for the individual. If individuals can write down what is happening to them, perhaps they can more easily "see" their experience and be able to problem-solve issues.

Instagram has provided persons with fibromyalgia a place to "post your journey." Fibromyalgia is often considered a stigmatized condition. Instagram has helped patients in providing an online space that offers acceptance, support and guidance (Berard & Smith, 2019).

An online health community in China has developed what is called a virtual mood wall. The purpose of such a wall is to share one's emotions and negative thoughts. User members post a sticky note with a short message to the mood wall (Liu et al., 2019).

Mindful Presence

Many times when caring for an individual as a professional caregiver, there is little you can do to relieve the pain, nausea, or other undesirable symptoms of a chronic disease. It's frustrating. You want to make the patient "feel better," but there is little in your power to do anything useful or helpful. As caregivers, we believe we should be doing something—*anything*. In this case, mindful presence may be one of the few things that you have to offer the patient.

Mindfulness may be defined as a deep awareness of self and others and to living in the moment (Prince-Paul & Kelley, 2017). It has been suggested that mindfulness is a concept that forms the basis of therapeutic nursing interventions such as presence, empathy, and patience of self and others. White (2013) views mindfulness as a transformative process whereby one develops "being present" with acceptance, attention, and awareness (p. 282).

Mindful presence is paying attention to presence, on purpose, in the present moment and nonreactively. Mindful presence is an *unhurried* presence (Beng et al., 2015). A nurse's full attention is focused on the patient; however, it is not related to a task. Fahlberg and Roush (2016) describe a perfect situation for a mindful presence as being "when we can't *do* anything. When there are no tasks to complete. We can take time to sit with the patient and family. We can be there *with* them [patients]. Watching. Listening. Witnessing. Learning. Becoming" (p. 14). Some strategies that can help incorporate mindful presence into nursing care include these: slow down, sit down, focus, learn who the patient and family are as people and what their priorities are, and empathize (Fahlberg & Roush, 2016).

Benner (1984) refers to "presencing: being with a patient" as one of the activities associated with the Helping Role (p. 57). "Presence… conveys both present time and person present, a 'now' and an awareness attentiveness in it. Presence requires practice and emphasizes personal experience. You have to be there" (Childs, 2007, p. 369).

Within a mindful presence, mindful patient-centered communication can occur. Patients can choose to talk or not. They have a safe place to express their thoughts. The patient may not want advice or an educational intervention, but merely the opportunity to be heard without judgment. Communication also includes silence on the part of the nurse.

And now to our journey with esophageal cancer…

> *This is our story, Randy's and mine. Even though he has been gone since 2012, it is still our story, not mine. My journal encouraged me to tell our story. I found comfort in expressing my thoughts, ugly as they might be. I can't explain why it made a difference. When I began to be interested in self-publishing my journal, others would ask why I would want to publish a journal that contained such personal thoughts. I hoped then, and also now, that by doing so, someone else may be helped by my words. Perhaps others have similar thoughts and are afraid to express them. On a mission trip to Vietnam in 2018, one of the volunteers, who was a recent widow, started telling me about the book she had read on the oncology unit of our local hospital and how helpful it had been when her husband was dying of cancer. I casually mentioned that I had written such a book as well. Moments later, it was clear that she was referring to my book.*
>
> *However, I wanted to publish my journal for healthcare professionals as well. They see patients and families in limited ways and don't realize the wholeness of the illness experience for the patient and family. Before Randy's illness, I thought I knew what my patients were going through. I realize now how naïve I was. The illness experience is much more than I imagined. I cannot emphasize enough that professional nurses need to listen more and talk less. The patient and family are the experts in chronic illness, not the healthcare team.*
>
> *—Pamala*

Research

Research studies continue to be published that identify relationships between variables and the illness experience and ultimately illness behavior and psychosocial adjustment. However, lacking are interventions to change or modify the illness experience or mental model of the illness that the patient and family have. Many relationships have been identified, but each article ends with a statement that can be paraphrased as, "and now we need to develop interventions to address these concerns." Unfortunately, this author repeated this same concern in the 10th edition of this book as well. It has remained the same since the prior edition; there are no intervention studies, just suggestions. The chronic illness population and their families are still waiting.

Outcomes

The illness experience is unique for each patient and family. Many variables influence it, as described in this chapter, but there may be other influences that psychosocial scientists have not yet identified. The illness behavior that exists during a chronic illness is not deviant, nor does it need to be "fixed." Rather, it is a response to an illness threat and perception. Healthcare professionals need to support patients and families and more fully understand the lived experience of their illness. As healthcare professionals, we are efficient and effective in working within the disease model.

However, the patient and family are functioning in both the illness mode and the disease mode. Caring for a patient and family with chronic illness requires the art of nursing to be placed on the same level as the science of nursing. The art of nursing is critical in establishing relationships with patients and understanding their illness experience.

Evidence-Based Practice Box

From a medical diagnostic standpoint, fibromyalgia is often seen as an example of a contested disorder. The diagnosis of fibromyalgia is explained by an abnormal amplification of stimuli in the central nervous system with chronic musculoskeletal pain and excessive fatigue endured by the patient. The path to diagnosis is hardly clear. The aim of this study was to examine the role of diagnosis in patients with fibromyalgia and to better understand the process and consequences of receiving that diagnosis. The researchers performed a meta-ethnography of qualitative studies describing those experiences. Twenty-eight studies were included. Years were spent consulting physicians to confirm the reality of the symptoms and to make sense of the illness. Relief was felt at finally receiving a diagnosis. However, that relief quickly waned as therapies proved ineffective, and healthcare professionals in general questioned whether the patients were truly ill. The diagnosis of fibromyalgia did not provide a sense of meaning to the patients, and they often felt blamed when they didn't "recover." The researchers concluded that the diagnosis had limitations in validating and making sense of the patient's illness experience and did not provide a social legitimation of their illness.

Data from Mengshoel, A. M., Sim, J., Ahlsen, B., & Madden, S. (2018). Diagnostic experience of patients with fibromyalgia: A meta-ethnography. *Chronic Illness, 14*(3), 194–211. doi:10.1177/17423953

CASE STUDY 1-1

Sharon is a 46-year-old wife, mother, and attorney. For the past few weeks, she has been bothered with intermittent abdominal pain, bloating, and generally not feeling well. Two weeks ago, she weighed herself and found she had gained 8 pounds while eating very little of late. A few days ago, she visited her family practice physician, and after a brief history and physical exam, she was referred to a gynecologist for an exam, followed by blood work and a transvaginal ultrasound. Sharon and her husband, Dan, are in the clinic today to learn the results. The ultrasound revealed a large mass in her abdomen suspected to be ovarian cancer. Her CA-125 was 700 (normal is 35 or less). Sharon and Dan are stunned. They are told of scheduling surgery as soon as possible and the potential for chemotherapy if it is indeed cancer. After the physician leaves the room, you, the RN who schedules surgery and provides education and follow-up information to patients, enter the consulting room. The couple remains silent for a bit, and then Dan screams out that the diagnosis has to be wrong, and they need a second opinion. Sharon sits there, eyes closed, and says nothing.

Discussion Questions

1. What is your response to Dan and Sharon? How can you use mindful presence and communication in this situation?
2. Is it too soon to begin describing the surgery and chemotherapy with the couple?
3. What kind of information might they have about ovarian cancer that is fueling their illness perceptions?

CASE STUDY 1-2

Sharon was subsequently diagnosed with ovarian cancer, stage IIIc after surgery. She completed 6 months of chemotherapy. It is now a year since her diagnosis. However, her health is not good, and she has had more than her share of complications already. Her latest scan showed several spots on her liver and right lung. Her treatment options are diminishing: continue chemo with a second-line chemo drug or participate in a clinical trial in a neighboring state. Sharon and Dan are devastated. Sharon turns to you and asks, "What would you do?"

Discussion Questions

1. What do you say? How do you maintain professional boundaries while being honest with the couple?
2. How can you be a mindful presence in their midst?

Study Questions

1. Dealing with "expert" patients can be difficult, and many patients with chronic illness are "expert" patients. Often your own "power" as a healthcare professional is threatened. How do you deal with "expert" patients and make it a collaborative relationship?
2. There are no norms for individuals with chronic illness. What does this mean, and how does it apply to the patients you care for?
3. How do healthcare professionals influence the illness perceptions and behavior of patients and families in both positive ways and negative ways?
4. Reflect on your own health and illness experiences. What influences your own perceptions and behaviors about chronic illness?

References

Achstetter, L. I., Schultz, K., Fuller, H., & Schuler, M. (2019). Leventhal's common-sense model and asthma control: Do illness representations predict success of an asthma rehabilitation? *Journal of Health Psychology*, *24*(3), 327–336. https://doi.org/10.1177/1359105316651332

Ambrosio, L., Garcia, J. M. S., Fernandez, M. R., Bravo, S. A., Ayesa, S. D., Sesma, M. E. U., Caparros, N., & Portillo, M. C. (2015). Living with chronic illness in adults: A concept analysis. *Journal of Clinical Nursing*, *24*, 2357–2367. https://doi.org/10.1111/jocn.12827

Anisman, H. (2016). *Health psychology*. Sage.

Arat, S., De Cock, D., Moons, P., & Vandenberghe, J. (2018). Modifiable correlates of illness perceptions in adults with chronic somatic conditions: A systematic review. *Research in Nursing and Health*, *41*, 173–184. https://doi.org/10.1002/nur21852

Arestedt, L., Persson, C., & Benzein, E. (2014). Living as a family in the midst of chronic illness. *Scandinavian Journal of Caring Sciences*, *28*, 29–37. https://doi.org/10.1111/scs.12023

Arestedt, L., Persson, C., & Benzein, E. (2015). Families living with chronic illness: Beliefs about illness, family and health care. *Journal of Family Nursing*, *21*(2), 206–231.https://doi.org/10.1177/1074840715576794

Beng, T. S., Chin, L. E., Guan, N. C., Yee, A., Wu, C., Jane, L. E., & Meng, C. B. C. (2015). Mindfulness-based supportive therapy (MBST): Proposing a palliative psychotherapy from a conceptual perspective to address suffering in palliative care. *American Journal of Hospice & Palliative Medicine*, *32*(2), 144–160. https://doi.org/10.1177/1049909113509640

Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Addison Wesley.

Berard, A. A., & Smith, A. P. (2019). Post your journey: Instagram as a support community for people with fibromyalgia. *Qualitative Health Research*, *29*(2), 237–247. https://doi.org/ 10.1177/1049732318789102

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*, 167–182.

Cameron, L. D., Durazo, A., & Rus, H. M. (2016). Illness representations. In Y. Benyamini, M. Johnston, & E. C. Karademas (Eds.), *Assessment in health psychology* (pp. 45–59). Hogrefe.

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., (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Childs, D. (2007). Mindfulness and the psychology of presence. *Psychology and Psychotherapy: Theory, Research and Practice*, *80*, 367–376.

Conrad, P., & Barker, K.K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior 51*(S), S67–S79. https://doi.org/ 10.1177/0022146510383495

Conway, K. (2013). *Beyond words: Illness and the limits of expression*. University of New Mexico Press.

Currie, K., Strachman, P. H., Spaling, M., Harkness, K., Barber, D., & Clark, A. M. (2015). The importance of interactions between patients and healthcare professionals for heart failure self-care: A systematic review of qualitative research into patient perspectives. *European Journal of Cardiovascular Nursing, 14*(6), 525–535.https://doi.org/10.1177/1474515114547648

Dowling, E. C., Chawla, N., Forsythe, L. P., deMoor, J., McNeil, T., Rozjabek, H. M., Ekweme, D. U., & Yabroff, K. R. (2013). Lost productivity and burden of illness in cancer survivors with and without other conditions. *Cancer*, *119*(18), 3393–3401. https://doi.org/ 10.1002/cncr.28214

Edson, M. (1999). *Wit*. Faber and Faber.

Fahlberg, B., & Roush, T. (2016). Mindful presence: Being "with" in our nursing care. *Nursing 2016*, *46*(3), 14–15.

Fife, B. (1994). The conceptualization of meaning in illness. *Social Science and Medicine*, *38*(2), 309–316.

Freeman-Gibb, L. A., Janz, N. K., Katapodi, M. C., Zikmund-Fisher, B. J., & Northouse, L. (2017). The relationship between illness representations, risk perception and fear of cancer occurrence in breast cancer survivors. *Psycho-Oncology*, *26*, 1270–1277. https://doi.org/ 10.1002/pon.4143

French, D. P., Wade, A. N., & Farmer, A. J. (2013). Predicting self-care behaviours of patients with type 2 diabetes: The importance of beliefs about behavior, not just beliefs about illness. *Journal of Psychosomatic Research*, *74*, 327–333.

Greco, A., Steca, P., Pozzi, R., Monzani, D., Malfatto, G., & Parati, G. (2015). The influence of illness severity on health satisfaction in patients with cardiovascular disease: The mediating role of illness perception and self-efficacy beliefs. *Behavioral Medicine*, *41*, 9–17. https://doi.org/10.1080/08964289.2013.855159

Hagger, M. S., Koch, S., Chatzisarantis, N. L. D., & Orbell, S. (2017). The common sense model of self-regulation: Meta-analysis and test of a process model. *Psychological Bulletin*, *143*(11), 1117–1154. http://dx.doi.org/10.1037/bul0000118

Hannum, S. M., & Rubenstein, R. L. (2016). The meaningfulness of time: Narratives of cancer among chronically ill older adults. *Journal of Aging Studies*, *36*, 17–25. https://doi.org/10.1016/j.jaging.2015.12.006

Hsi, S. D., Belshaw, J., & Corbin-Hsi, B. (2004). *Closing the chart: A dying physician examines family, faith and medicine*. University of New Mexico Press.

Isaksson, J., Salander, P., Lillilehorn, S., & Laurell, G. (2016). Living an everyday life with head and neck cancer 2–2.5 years post-diagnosis: A qualitative prospective study of 56 patients. *Social Science & Medicine*, *154*, 54–61. https://dx.doi.org/10.1016/j.socscimed.2016.02.031

Janowski, K., Kurpas, D., Kusz, J., Mroczek, B., & Jedynak, T. (2013). Health-related behavior, profile of health locus of control and acceptance of illness in patients suffering from chronic somatic diseases. *PLoS One*, *8*(5), e63920. https://doi.org/10.1371/journal. pone.0063920

Kalanithi, P. (2016) *When breath becomes air*. Random House.

Kaptein, A. A., Schoones, J. W., Fischer, M. J., Thong, M. S. Y., Kroep, J. R., & van der Hoeven, K. J. M. (2015). Illness perceptions in women with breast cancer: A systematic literature review. *Current Breast Cancer Report*, *7*, 117–126. https://doi.org/10.1007/s12609-015-0187-y

Karademas, E. C., Paschali, A., Hadjulis, M., & Papadimitriou, A. (2016). Maladaptive health beliefs, illness-related self-regulation and the role of information provided by physicians. *Journal of Health Psychology*, *21*(6), 994–1003. https://doi.org/10.1177/13591053.4544072

Kremenchutzky, M., & Walt, L. (2013). Perceptions of health status in multiple sclerosis patients and their doctors. *Canadian Journal of Neurological Science*, *40*, 210–218.

Larsen, P. D. (2013). *Finding a way through cancer, dying and widowhood: A memoir*. Archway Publishing.

Larsen, P. D. (2016). Chronicity. In P. D. Larsen (Ed.) *Lubkin's chronic illness: Impact and intervention* (9th ed., pp. 3–19). Jones & Bartlett Learning.

Leventhal, H., Bodnar-Deren, S., Breland, J., Hash-Converse, J., Phillips, L., Leventhal, E., & Cameron, L. (2012). Modeling health and illness behavior. In A. Baum, T. Revenson, & J. Singer (Eds.), *Handbook of health psychology* (2nd ed., pp. 3–35). Psychology Press.

Levy, S., Segev, M., Reicher-Atir, R., Steinmetz, A., Horev, N., Niv, Y., & Dickman, R. (2014).

Perceptions of gastroenterologists and patients regarding irritable bowel syndrome and inflammatory bowel disease. *European Journal of Gastroenterology & Hepatology*, *26*(*1*), 40–46. https://doi.org/10.1097/MEG.0b013e328365ac70

Liu, X., Pan, M., & Li, J. (2019). Does sharing your emotion make you feel better? An empirical investigation on the association between sharing emotions on a virtual mood wall and the relief of patients' negative emotions. *Telemedicine and e-Health*, *25*(10). https://doi.org/10.1089/tmj/2017.0327

Mayo, L. (Ed.) (1956). *Guides to action on chronic illness*. Commission on Chronic Illness. National Health Council.

Mechanic, D. (1962). The concept of illness behavior. *Journal of Chronic Diseases*, *15*, 189–194.

Mechanic, D. (1995). Sociological dimensions of illness behavior. *Social Science and Medicine*, *41*(9), 1207–1216.

Mengshoel, A.M., Sim, J., Ahlsen, B., & Madden, S. (2018). Diagnostic experience of patients with fibromyalgia: A meta-ethnography. *Chronic Illness 14*(3), 194–211. https://do.org/10.1177/1742395317718035

Micelli, J., Geller, D., Tsung, A., Hecht, C., Wang, Y., Ritambhara, P., Cheng, H., Marsh, W., Antoni, M., Panedo, F., Burke, L., Ell, K., Shen, S., & Steel, J. (2019). Illness perceptions and perceived stress in patients with advanced gastrointestinal cancer. *Psycho-Oncology 28*(7), 1513–1519. https://doi.org/10.1002/pon.5108

Nanton, V., Munday, D., Dale, J., Mason, B., Kendall, M., & Murray, S. (2016). The threatened self: Considerations of time, place, and uncertainty in advanced illness. *British Journal of Health Psychology*, *21*, 361–373.

Oser, T. K., Oser, S. M., Parascando, J. A., Hessler-Jones, D., Sciamanna, C. N., Sparling, K., Nease, D., & Litchman, M. L. (2020). Social media in the diabetes community: A novel way to assess psychosocial needs in people with diabetes and their caregivers. *Current Diabetes Reports*, *20*(10). https://doi.org/10.1007/s11892-020-1294-3

Pai, H.-C., Li, C.-C., Tsai, S.-M., & Pai, Y.-C., (2019). Association between illness representation and psychological distress in stroke patients: A systematic review and meta-analysis. *International Journal of Nursing Studies*, *94*, 42–50. https://doi.org/10.1016/j.ijnurstu.2019.01.015

Parfeni, M., Nistor, I., & Covic, A. (2013). A systematic review regarding the association of illness perception and survival among end-stage renal disease patients. *Nephrology Dialysis Transplant*, *28*, 2407–2414. https://doi.org/10.1093/ndt/gft194

Parsons, T. (1951). *The social system*. Free Press.

Partridge, S. R., Gallager, P., Freeman, B., & Gallagher, R. (2018). Facebook groups for the management of chronic diseases. *Journal of Medical Internet Research*, *20*(1), e21. https://doi.org/10.2196/jmir.7558

Paschali, A. A., Hadjulis, M., Papadimitriou, A., & Karademas, E. C. (2015). Patient and physician reports of the information provided about illness and treatment: What matters for patients' adaptation to cancer during treatment? *Psycho-Oncology*, *24*(8), 901–909. https://doi.org/10.1002/pon.3741

Petersen, A., Schermuly, A., & Anderson, A. (2020). Feeling less alone online: Patients' ambivalent engagements with digital media. *Sociology of Health and Illness*, *42*(6), 1441–1455. https://doi.org/10.1111/1467-9566.13117

Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, *6*(6), 536–539.

Pickett, S., Allen, W., Franklin, M., & Peters, R. (2013). Illness beliefs in African Americans with hypertension. *Western Journal of Nursing Research*, *36*(2), 152–170. https://doi.org/10.1177/0193945913491837

Prince-Paul, M., & Kelley, C. (2017). Mindful communication: Being present. *Seminars in Oncology Nursing*, *33*(5), 475–482.

Qin, X., Chen, J., Suo, R., Feng, L., Zhang, Y., & Jun, Y. (2020). The dissimilarity between myocardial infarction patients' and spouses' illness perception and its relation to patients' lifestyle. *Journal of Clinical Nursing*, *29*, 887–898. https://doi.org/10.1111/jocn.15132

Reeve, J., Lloyd-Williams, M., Payne S., & Dowrick, C. (2010). Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health*, *14*(2), 178–195. https://doi.org/10.1177/1363459309353298

Richardson, E. M., Schuz, N., Sanderson, K., Scott, J. L., & Schuz, B. (2016). Illness representations, coping and illness outcomes in people with cancer: A systematic review and meta-analysis. *Psycho-Oncology*, *26*, 724–737. https://doi.org/10.1002/pon.4213

Sawyer, A. T., Harris, S. L., & Koenig, H. G. (2019). Illness perception and high readmission health outcomes. *Health Psychology Open*, January–June 2019. https://doi.org/10.1177/2055102919844505

Sim, J., & Madden, S. (2008). Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. *Social Science & Medicine*, *67*, 57–67. https://doi.org/10.10o16/j.socscimed.2008.03.003

Simpson, J., Lekwuwa, G., & Crawford, T. (2013). Illness beliefs and psychological outcomes in people with Parkinson's disease. *Chronic Illness*, *9*(2), 165–176.

Sirri, L., Fava, G. A., & Sonino, N. (2013). The unifying concept of illness behavior. *Psychotherapy and Psychosomatics*, *82*, 74–81. https://doi,org/10.1159/000343508

Snippen, N. C., deVries, H. J., van der Burg-Vermeulen, S. J., Hagedoorn, M., & Brouwer, S. (2019). Influence of significant others on work participation of individuals with chronic diseases: A systematic review. *BMJ Open*, *9*, e021742. https://doi.org/10.1136/bmjopen-2018-021742

Stallings, D. T. (2016). Illness perceptions and health behaviors of black women. *Journal of Cardiovascular Nursing*, *31*(6), 492–499. https://doi.org/10.1097JCN.0000000000000276

Stellefson, M., Paige, S. R., Alber, J. M., & Stewart, M. (2018). COPD360social online community: A social media review. *Health Promotion Practice*, *19*(4), 489–491.

Tie, S., & Poulsen, S. (2013). Emotionally focused couple therapy with couples facing terminal illness. *Contemporary Family Therapy*, *35*, 556–567.

Twiddy, M., House, A., & Jones, F. (2012). The association between discrepancy in illness representations on distress in stroke patients and carers. *Journal of Psychosomatic Research*, *72*, 220–225. https://doi.org/10.1016/j.jpsychores.2011.12.004

Wainwright, D. (2008). Illness behavior and the discourse of health. In D. Wainwright (Ed.), *A sociology of health* (pp. 76–96). Sage.

Walker, C. (2010). Ruptured identities: Leaving work because of chronic illness. *International Journal of Health Services*, *40*(4), 620–643.

Wang, X., Zhao, K., & Street, N. (2017). Analyzing and predicting user participations in online health communities: A social support perspective. *Journal of Medical Internet Research*, *19*(4). https://doi.org/10.2196/jmir.6834

Weingarten, K. (2013). The "cruel radiance of what it is": Helping couples live with chronic illness. *Family Process*, *51*(1), 83-101. https://doi.org/10:1111/famp.12017

White, L. (2013). Mindfulness in nursing: An evolutionary concept analysis. *Journal of Advanced Nursing*, *70*(2), 282–294. https://doi.org/10.1111/jan.12182

Williams, S. J. (2005). Parsons revisited: From the sick role to . . .? *Health*, *9*, 123–144.

Woolthuis, E., deGrauw, W., Cardol, M., van Weel, C., Metsemakers, J., & Biermans, M. (2013). Patients' and partners' illness perceptions in screen-detected versus clinically diagnosed type 2 diabetes: Partners matter! *Family Practice*, *30*(4), 418–425. https://doi.org/10.1093 /fampra/cmt003

Wu, L. M., Mohamed, N. E, Winkel, G., & Diefenbach, M. A. (2013). Patient and spouse illness beliefs and quality of life in prostate cancer patients. *Psychology and Health*, *28*(4), 355–368. https://doi.org/10.1080/08870446.2012.72219

Yip-Williams, J. (2019). *The unwinding of the miracle: A memoir of life, death and everything that comes after*. Random House.

Young, J. T. (2004). Illness behavior: A selective review and synthesis. *Sociology of Health and Illness*, *26*(1), 1–31.