

## CHAPTER 3

# Psychosocial Adjustment

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### ► Introduction

The terms “adaptation” and “adjustment” are used interchangeably in the literature. Nursing literature typically uses the term “adjustment versus adaptation” to refer to the changes in life, the process, that are made continuously when one has a chronic illness. The process of adjustment is not static, but dynamic.

Individuals with chronic illness unconsciously or consciously chart a course to navigate the challenges of a chronic disease. Throughout the course of their illness, they must rely on a healthcare system in which pharmaceuticals and technology are the hallmarks of quality health care. Although a disease focus is appropriate to meet the physical needs of the individual, particularly in the acute phase, this perspective does not meet the social, psychological, and emotional needs of patients and their families with chronic conditions. In other words, the disease focus of the healthcare system does not manage the illness experience of the patient and family. This chapter builds on the previous chapter, “The Illness Experience.”

Classic work by Visotsky, Hamburg, Goss, and Lebovits (1961), in studying patients with

polio, posed an initial question regarding adaptation. The researchers asked their patients how it was possible to deal with the stressor, polio, and which coping behavior(s) assisted them with achieving a successful outcome. Decades later, researchers continue to ask the same question. Although progress has been made in understanding certain concepts of adjustment, many questions remain unanswered. Additionally, few interventions have been identified that support or assist patients and their families with psychosocial adjustment to a chronic illness.

### Conceptualizing Psychosocial Adjustment

In the 1950s and 1960s, when illness behavior and psychosocial adjustment were initially being discussed, a common description of adjustment was the absence of a diagnosed psychological disorder, psychological symptoms, or negative mood in an individual. One example of a psychologically diagnosed condition is *trauma- and stressor-related disorder*, defined as the development of clinically significant emotional or behavioral symptoms in response to an identifiable stress or stressor (American Psychological Association,

2013). A stressor could be a chronic condition. In Visotsky's study of patients with polio in 1961, there was a movement, even then, to discount an absence of a psychological disorder as being necessary in the definition of adjustment. The presence of a psychological disorder is obviously important, but other variables should be considered in a definition.

Fife (1994) views the construction of meaning as a central aspect of adaptation to serious illness. The concept of meaning commonly refers to the relationship between individuals and their world, as well as to the individuals' unique perceptions of their place within that world (p. 309). In the face of chronic disease, individuals are forced to redefine the meanings they have assumed to be true in their lives.

In a classic review article on psychological adjustment to chronic disease, deRidder, Geenen, Kuijer, and van Middendorp (2008) identified five elements of successful adjustment: (1) successful performance of adaptive tasks, (2) the absence of psychological disorders, (3) the presence of low negative affect and high positive affect, (4) adequate function status (e.g., going to work), and (5) satisfaction and well-being in various life domains (p. 264). Some of these elements are easily "measured." For example, the absence or presence of a psychological disorder or returning to work can be verified with a degree of certainty. In contrast, the other elements cannot be measured objectively.

There is little consistency in defining adjustment. Each author/researcher defines the term based on his or her own theoretical framework or the specific outcome(s) that a study measures—for example, quality of life (QOL), self-concept, optimism, well-being, and so forth. Perhaps combining deRidder and colleagues' work with some broad concepts from Hoyt and Stanton (2012) provides a clearer picture of adjustment. These concepts include:

- Adjustment to chronic illness is multidimensional and includes intrapersonal and interpersonal dimensions. Dimensions of adjustment are interrelated.

- Heterogeneity is the rule, not the exception.
- Adjustment involves both positive and negative dimensions.

Moss-Morris (2013) states that it is time to become united in defining psychosocial adjustment. She argues that there is no consistent definition of psychosocial adjustment and no standardized way of measuring it. Within health psychology, adjustment is more typically defined by outcomes such as preserving function and low negative effects in the face of illness (p. 682).

The need to separate the *process* of adjustment from the *outcome* of adjustment is also an issue as the outcome may vary over time. Lastly, Moss-Morris suggests that researchers develop a standardized tool that measures psychosocial adjustment—one that includes psychological, physical, and social outcomes.

## Chronic Illness Affects Adjustment in Multiple Life Domains

Caring for patients with chronic illness includes more than addressing the physical domain. Care crosses interpersonal, cognitive, emotional, social, and behavioral domains with the domains interrelated. Therefore, a change in one domain affects adjustment in another domain (Hoyt & Stanton, 2012). Cognitive adaptation might include self-reflection. Adaptation in the behavioral domain may be a return to work. Anxiety, in the emotional domain, may affect interpersonal socialization or impact blood pressure in the physical domain. Emotional adaptation could be the absence of depression, and interpersonal and social adaptation might be the willingness to be "social" again and resume previous roles.

## Heterogeneity is the Rule, not the Exception

If 20 women of the same age with the same stage and type of breast cancer were placed in a room, each individual would adjust, or not adjust, to

her chronic condition differently. Some women would be considered “well adjusted,” whereas others might be considered maladjusted. The remaining individuals would fall somewhere in the middle. A person’s individual determinants and uniqueness affect the ability of each individual to adjust to the illness. Although adjustment commonalities exist among individuals with chronic illness, there is significant variability as well.

Adjustment can *only* be viewed from the perspective of the individual. Physical changes and function may or may not be pertinent to the individual’s adjustment. As the lived experience of illness is different for each individual and family, so is psychosocial adjustment. The process and outcomes differ because of past experiences, age, gender, ethnicity, socioeconomic status (SES), and other variables that science has yet to identify.

## Adjustment Involves Positive and Negative Dimensions

Typically it is assumed that the psychosocial outcomes of chronic illness are negative. However, there may be a positive side of chronic illness. It is not unusual to hear individuals with chronic illness make comments such as “Having this disease has been the best thing that ever happened to me—it made me wake up and see what was important.” However, how patients come to view the disease in this way remains a mystery.

Adjustment is a process that is neither linear nor lockstep, but dynamic. Numerous variables influence this process. However, a common influence to adjustment is a negative change in health status. When such a change occurs, the individual and family incorporate new data into their mental model of the illness, and progress toward adjustment may regress.

This chapter provides an overview of psychosocial adjustment in individuals with chronic illness. Given that entire books are devoted to coping, adaptation, and adjustment, the scope of this chapter is necessarily limited.

## ► Impact

### Influences to Psychosocial Adjustment

The impact of a chronic illness diagnosis, and subsequent treatment, on an individual and family is felt in all dimensions of their lives. However, it may not be the only factor influencing adjustment. That is, other life influences may come into play that may or may not be related to the illness. There may be issues with a child or a grandchild, financial issues (which may or may not be related to the illness), issues related to owning a business, and so forth. Many years ago, this author interviewed a middle-aged woman who had recently become blind. Options were being reviewed for vocational rehabilitation. During the visit, it became evident that the person was not focusing on what we were discussing, and finally she voiced her concerns. Her 16-year-old daughter was currently hospitalized in an inpatient psychiatric facility. As healthcare professionals, we often make the assumption that the patient’s illness is the focal point of their life; however, that is not always the case.

Powerlessness, uncertainty, intimacy, and social isolation all contribute to an individual and family’s psychosocial adjustment. However, another factor to consider in adjustment is the type of chronic illness and its prognosis. Is this chronic illness treatable, potentially fatal, curable, life-shortening, or disabling? The psychosocial adjustment in a patient newly diagnosed with type 2 diabetes is vastly different from that of a patient with stage IV lung cancer. Unfortunately, research studies often group patients with a variety of chronic diseases at different stages of their illness into one sample, perhaps titled “chronic somatic disease,” making it impossible to draw legitimate conclusions and generalizations from their findings.

In a review article titled “Adjusting to Chronic Health Conditions,” Helgeson and Zajdel (2017) provide a summary of recent research identifying influences to psychosocial adjustment.

In examining demographic factors, typically women report poorer psychosocial adjustment, more depression, and greater physical limitation as compared with men (p. 548). A lower SES is related to poorer adjustment to chronic disease. Typically, Whites are better adjusted, while Blacks and Latinos show more distress and less psychosocial adjustment.

Often illness dimensions influence psychosocial adjustment. Co-morbid conditions affect the process and outcome of psychosocial adjustment (Helgeson & Zajdel, 2017; Schulze, Maercker, & Horn, 2014). Self-concept may be an issue, as some individuals associate their self-concept with disease. Similarly, there may be stigma associated with the disease, real or perceived. The literature has become increasingly more sophisticated in recognizing that influences to psychosocial adjustment do not act in isolation of one another (Helgeson & Zajdel, 2017, p. 562).

## Coping

What is the relationship of coping to psychosocial adjustment? There are currently two main models of coping related to psychosocial adjustment. Richard Lazarus's book, *Psychological stress and coping* (1966), was an initial scholarly work that expanded how coping was conceptualized at that time. Coping is a process that unfolds in the context of a situation or condition that is appraised as personally significant, and as taxing or exceeding the individual's resources (Lazarus & Folkman, 1984). The coping process is initiated in response to the individual's appraisal that important goals have been harmed, lost, or threatened (Folkman & Moskowitz, 2004). Coping is a complex, multidimensional process that is sensitive both to the environment and its demands and resources, and to personality traits that influence the appraisal of stress—in this case, chronic illness—and the resources for coping (Folkman & Moskowitz, 2004). Coping is not a stand-alone concept or phenomenon, but rather is embedded within a complex, dynamic process that involves the person, the environment, and the relationship between them.

A second framework of coping is associated with the common-sense model (CSM). In recent years, it has been used extensively as a framework in research studies. From a health threat, the patient and family develop illness perceptions which, in turn, inform coping strategies. Coping is defined as one's reaction to adverse events that require adjustment (Tiemensma, Gaab, Voorhaar, Asijec, & Kaptein, 2016).

Recent studies are offered as examples of coping and its relationship with adjustment. One hundred patients with chronic obstructive pulmonary disease (COPD) were part of a study that examined QOL and the part illness perceptions and coping contributed to QOL. A better understanding of COPD was associated with more proactive coping strategies and thus a better QOL. Also, a higher level of perceived personal control led to better coping strategies and increased QOL. The authors conclude it is important to develop self-management interventions that target a patient's illness perceptions to increase proactive coping strategies and ultimately affect QOL (Tiemensma et al., 2016).

Van Erp and colleagues (2016) asked if coping was a mediator of illness perceptions in patients with inflammatory bowel disease (IBD). With a sample of 211 patients with IBD, results demonstrated a statistically significant relationship between illness perceptions and coping, after controlling for disease severity, in adjustment to IBD. Illness perceptions and coping influenced QOL and activity impairment. The researchers close their article with the following salient question: how do we modify illness perceptions?

A number of studies focus on dyadic coping. If chronic disease, in general, is considered a we-disease and not a disease of an individual (Kayser, Watson, & Andrade, 2007), then it makes sense to consider dyadic coping, not individual coping, as a factor in psychosocial adjustment. The dyadic coping process is an interplay between nonverbal stress signals of one or both members of the dyad, the perception and decoding of those signals by the other partner, and his/her reaction and joint coping

efforts (Traa, DeVries, Bodenmann, & Den Oudsten, 2015).

Cancer is viewed as a “we-stress” or dyadic stressor. Dyadic coping has two primary objectives: reduction of stress by both partners and preservation or enhancement of relationship functioning.

The primary aim of Traa and colleagues’ (2015) systematic review was to examine which forms of dyadic coping were related to better or worse relationship functioning in couples with cancer. Among the findings was a possible bonding effect of the couple with cancer (p. 92). Facing cancer as a we-disease strengthened relationships. The review showed the importance of stress communication (e.g. cancer-related communication), supportive behaviors, and adequate dyadic coping for the maintenance and even the enhancement of relationships (p. 94).

The relationship among attachment, coping, self-regulation theory and adjustment in chronic illness has been studied less than other concepts. Bazzazian and Besharat (2012) explored the possibility that attachment theory could be part of a model of health as a basis for coping and self-regulation theory that would explain individual differences in adjusting to a diagnosis of type 1 diabetes. The aim of the study was to develop a model of adjustment. Three hundred young adults with type 1 diabetes completed the Adult Attachment Inventory, the Brief Illness Perception Questionnaire, the task-oriented subscale of the Coping Inventory for Stressful Situations, and the well-being scale of the Mental Health Inventory. Attachment styles determined the flexibility of coping strategies. Notably, positive illness perceptions and greater use of task-oriented coping strategies predicted better adjustment to type 1 diabetes.

To understand relationships among coping style, locus of control, perceived illness intrusiveness, and disease severity, data were analyzed from 227 older veterans with either COPD or heart failure (HF). Regression analysis revealed that illness intrusiveness was associated with younger age and greater disease severity, less

internal locus of control, and avoidant/emotion-focused coping. Avoidant/emotion-focused coping, but not active coping, mediated the relationship between illness severity and illness intrusiveness (Hundt et al., 2015). The authors suggest that psychological interventions may reduce illness intrusiveness by targeting the avoidant/emotion-focused coping style and associated behaviors.

## Benefit-Finding

Traditionally, the negative sequelae that follow a diagnosis of a chronic and/or life-threatening illness have been the focus of healthcare professionals. However, current research suggests that some individuals may experience positive life changes as a response to a serious illness. The concept of positive life changes is not new, but rather dates from Caplan’s (1964) work, which discussed the possibility that a crisis may present growth opportunities through constructive resolution of greater personality integration and the development of coping capabilities.

This positive life change has been called stress-related growth, benefit-finding, and post-traumatic growth (PTG). All three terms are used in the literature to refer to the positive life changes that people make while coping with negative life events (Park, Lechner, Antoni, & Stanton, 2009).

Positive life changes typically occur in the domains of relationships, self-concept, life philosophy, and coping skills (Park, 2009, p. 11). Park defines stress-related growth as the actual or veridical changes that people have made in relation to their experience with an identified stressful or traumatic event (p. 12). Park acknowledges that different types of physical illness raise different challenges and, in fact, likely influence the levels and types of growth possible. Dimensions of illness that may be considered include symptom onset, presumed etiology, threat to life, life disruption, recovery trajectory, chronicity, permanence of change, and life context. Because illnesses differ greatly on these dimensions, generalizations about



perceptions of growth in the context of illness may be misleading (pp. 22–24).

Benefit-finding may be a predictor of concurrent and future adjustment (Pakenham & Cox, 2009). In a study examining data from 388 patients with multiple sclerosis and 232 of their carers, at baseline and 12 months later, seven distinct benefit-finding dimensions emerged: compassion/empathy; spiritual growth; mindfulness; family relations growth; lifestyle gains; personal growth; and new opportunities. The researchers suggested that these dimensions are specific to MS but may be applicable with other chronic diseases.

Could positive life changes be a component of psychosocial adjustment? Or could they be considered psychosocial adjustment? Helgeson and Zajdel (2017), in their review of adjusting to chronic health conditions, note that benefit-finding or PTG may be a result of chronic illness. Patients construe benefits as a part of their mental model. However, the interpretations of PTG research results are mixed (p. 554).

## ► Interventions

A researcher's broad goal is to understand the process of adjustment, predict outcomes, and by having predictive ability, identify interventions that meet the needs of patients and families. A framework that meets those goals is preferable for practice; however, a perfect model does not exist. What follows are sample models/frameworks from the literature. The differences in the frameworks presented demonstrate the differing views in understanding adjustment.

## Frameworks for Understanding Adjustment in Chronic Illness

### Biomedical Model

Although one might not consider the biomedical model pertinent when discussing psychosocial adjustment, this model is often used in the

acute phase of chronic illness. The medical model provides a framework for treating the pathology of illness. In this model, the patient is a complex set of anatomic parts and interrelated body systems. Anatomic, physiologic, and/or biochemical failures translate into disease, thus promoting a disease-oriented approach to care. Pathophysiology, pharmacotherapy, and technology are emphasized and become prominent when intervening in illness and disease, whether acute or chronic. The biomedical paradigm tends to medicalize all human conditions, suggesting that symptoms can be controlled and cured with biomedical strategies. This model reduces the individual to a disease and fails to recognize the illness experience of the patient and family. Specifically, this model does not acknowledge that the individual and family have knowledge and expertise about the factors that influence the physical symptoms of chronic disease—in other words, the expert patient.

For example, at the end of the month, Mrs. Jones becomes anxious that she will not have enough money to purchase prescriptions for her hypertension. Although she has adequate funds, Mrs. Jones's stress and worry exacerbate her hypertension. At her doctor's appointment, Mrs. Jones does not inform her physician that a possible cause of her elevated blood pressure is related to her stress about money. The physician responds to Mrs. Jones's hypertension with a change of medication to manage her symptoms, possibly an unwarranted change. This kind of quantification of all signs and symptoms of disease fails to address the total illness experience of the individual.

Despite the limitations of the biomedical model, it is the foundation of evidence-based practice and provides the gold standard for treatment and intervention. This model provides measurable goals for treatment and patient outcomes relative to morbidity and mortality.

### Chronic Care Model

A key component of the chronic care model (CCM) is patient self-management to address deficiencies

in the medical model of the healthcare system. Within this model, six major elements interact to produce high-quality care and evidence-based interventions for persons with chronic conditions in health systems at the community, organization, practice, and individual levels: (1) the organization of the healthcare system; (2) clinical information systems; (3) decision support; (4) delivery system design; (5) self-management support; and (6) community, resources and policies (Wagner et al., 2001).

The CCM has been widely adopted as an approach to ambulatory care. It has guided national quality improvement initiatives and been an integral part of patient-centered medical home models (Coleman, Austin, Brach, & Wagner, 2009). However, this model focuses on the mortality and morbidity of the patient and family, not the illness experience. In other words, HgbA<sub>1c</sub> levels, blood pressure readings, medication adherence, appropriate results from pulmonary function tests, and so forth are objective measures, thereby identifying the CCM as a biomedical model.

In a systematic review of the CCM and type 2 diabetes, many of the studies were found to include only a few components of the model, not all six of them. The use of isolated components of the CCM did not improve clinical outcomes; however, the authors believe that it is possible that better results could be obtained through the use of all six components (Baptista et al., 2016, p. 6).

Similar results occurred in a review of older adults with co-morbid conditions. A structured review was conducted by searching six electronic databases and combining the terms, hospital, ambulatory, elderly, chronic disease, and integration. Four articles met the inclusion criteria. All four studies used only three components of the CCM: clinical information sharing, community linkages, and supported self-management. Studies did note improved patient care transitions. The authors suggest that all components of the CCM be included to support care transitions (Sendall, McCosker, Crossley, & Bonner, 2016).

## Common-Sense Model of Self-Regulation

The CSM of self-regulation (Leventhal et al., 2012), based on biomedical and cognitive models, has become the preferred model in psychological adaptation studies. The model is also called the SRM (self-regulation model) in the literature. This model proposes that the patient's illness beliefs and representations of that illness influence adaptation to the illness and health outcomes. According to the CSM, patients develop cognitive and emotional representations of their condition to "make sense" or find meaning in the illness. Leventhal and colleagues identify five dimensions that represent a patient's view of his or her illness:

- Identity of the illness: Connecting the symptoms with the illness and having an understanding of the illness.
- Timeline: Duration and progression of the illness.
- Causes: Perceived reason for the illness.
- Consequences: What will be the physical, psychosocial, and economic impact of the illness?
- Controllability: Can this disease be controlled? Cured?

After identification of these dimensions, Leventhal and colleagues posit that the information gathered from these dimensions becomes the patient's illness perceptions and these, in turn, guide coping and ultimately affect outcomes through the choice of actions arising from these illness perceptions (Benyamini, 2011, p. 293). There is significant evidence that an adaptive perception of a curable/controllable illness is related to better health and functioning (Hagger & Orbell, 2003). The CSM has been used extensively as a framework in research in chronic illness. Examples of the CSM's use in research include the following studies:

- Explanation of outcomes after mild traumatic brain injury: The contribution of injury belief and Leventhal's common sense model (Snell, Hay-Smith, Surgenor, & Siegert, 2013).

- Predicting self-care behaviours of patients with type 2 diabetes: The importance of beliefs about behavior, not just beliefs about illness (French, Wade, & Farmer, 2013).
- Can the common sense model predict adherence in chronically ill patients: A meta-analysis (Brandes & Mullan, 2014).
- Using the common sense model of self-regulation to review the effects of self-monitoring of blood glucose on glycemic control for non-insulin treated adults with type 2 diabetes (Breland, McAndrew, Burns, Leventhal, & Leventhal, 2013).

## Examples of Interventions that Assist and Support the Patient and Family

The literature provides many descriptive studies defining and measuring adaptation and coping, but few interventional studies exist. Coping and adjustment can, in some way, be measured by specific concepts (e.g., well-being, hope, self-concept, lack of a psychological disorder), but science is unable to conceptualize those findings into clear interventions or ways healthcare professionals can assist patients in the adjustment process. The distinct attributes of each individual and his or her family make the generalization of interventions difficult.

## Self-Management

Self-management has long been used as an intervention for a number of the concepts that this text addresses, such as uncertainty, powerlessness, adherence, and QOL. By managing their own care, patients perceive that they have more control over their chronic illness and, therefore, often experience a better QOL. Because of the importance of self-management, an entire chapter in this text has been devoted to the subject. Thus, this chapter addresses the concept briefly.

Self-management interventions are often Internet-based or technology-based. Researchers

from New Zealand suggest that mobile technology (mHealth) may have the potential to deliver behavior change interventions. In a randomized controlled trial, one group had usual care, cardiac rehabilitation, while the other group had cardiac rehabilitation and a 24-week mHealth program using text messages and a supporting website. The mHealth program used a social cognitive framework. The outcome was adherence to healthy lifestyle behaviors. There was positive adherence at 3 months, but it was not sustained at 6 months (Dale et al., 2015).

Self-management could be assisted by an automated telephone communication system (ATCS) that can deliver voice messages and collect health-related information from patients. ATCS can supplement or replace telephone contact between patients and healthcare professionals. Multimodal ATCS, where calls are delivered as part of a multicomponent intervention, likely decreased both cancer pain and chronic pain as well as depression, but other ATCS types were less effective. ATCS had little, if any, effect on outcomes related to HF, hypertension, mental health, or smoking cessation (Posadzki et al., 2016).

Peer leaders instead of professional leaders were used in a study of hypertension self-management groups among veterans in Wisconsin. The peer-led educational groups were less effective in decreasing systolic blood pressure in the veterans than the professionally led didactic seminars (Whittle et al., 2014).

Providing remote feedback to patients with asthma between clinic visits might be beneficial to keep patients “on track.” In a Cochrane intervention review, researchers assessed the efficacy and safety of home telemonitoring with healthcare professional feedback between clinical visits. However, evidence from the 18 studies reviewed did not support the widespread implementation of telemonitoring with healthcare professional feedback (Kew & Cates, 2016).

McCorkle and colleagues (2011) present a literature review of the scientific advances in self-management in cancer in the treatment,



post-treatment, and end-of-life phases of the cancer continuum. Their review uses terms such as “illness self-management,” “self-care,” “psycho-educational interventions,” and “cognitive-behavioral interventions.” McCorkle and colleagues identified 16 interventional studies that met the criteria for inclusion in the review. Studies were clustered by interventions during the treatment, post-treatment, and end-of-life phases, with the majority of the studies occurring during treatment. Programs included educational programs, nurse coaching, uncertainty management, monitoring, counseling, skills training, information, and general knowledge about the disease and treatment. There was no standardized “intervention” for self-management. What became apparent was that all of the 16 studies were time limited; specifically, treatment interventions ranged from 4 to 20 weeks long, post-treatment interventions were 8 to 10 weeks long, and interventions in the end-of-life studies were offered until death. The studies demonstrated decreased psychosocial concerns, less distress, better health-related QOL, and better psychological adjustment (McCorkle et al., 2011); however, only short-term outcomes were measured, not long-term outcomes.

## Motivational Interviewing

Motivational interviewing (MI) was originally developed for counselors who worked with clients with drug and alcohol problems (Miller & Rollnick, 1991). After the success of their 1991 book, Miller and Rollnick thought that MI could be used with other patients who struggle with ambivalence about change. In 2013 Miller and Rollnick defined MI as “a collaborative conversation style for strengthening a person’s own motivation and commitment to change” (p. 12). Rollnick, Miller, and Butler (2008) further describe MI:

*MI is not a technique for tricking people into doing what they do not want to do. Rather, it is a skillful clinical style*

*for eliciting from patients their own good motivations for making behavior changes in the interest of their health. It involves guiding more than directing, dancing rather than wrestling, listening at least as much as telling. The overall “spirit” has been described as collaborative, evocative, and honoring of patient autonomy. (Rollnick et al., 2008, p. 6)*

The three core MI communication skills are informing, asking, and listening. Informing is conveying knowledge about a condition or treatment. Asking is specifically asking questions that will help the guide better understand the patients’ problems and perspectives. Listening is described as an active activity (Douaihy, Kelly, & Gold, 2014). What follows are some representative studies of the use of MI in chronic disease. The results of MI as an intervention in chronic disease have been mixed.

Cheng and colleagues (2015) in a Cochrane systematic review examined studies to investigate the effects MI had on improving motivation in stroke patients. Specifically, the studies looked at motivating patients to complete their activities of daily living (ADLs). There was insufficient evidence to support the use of MI.

MI was found to promote adherence and improved well-being in predialysis patients with advanced chronic kidney disease. Forty-two patients had 90-minute monthly sessions for 6 months. After the intervention, patients reported significantly higher levels of adherence, lower depression and anxiety, and increased health-related QOL (Garcia-Llana, Remon, del Paso, Celadilla, & Selgas, 2014; Cheng et al., 2015).

Solomon and colleagues (2012) examined the effectiveness of a telephone-based counseling program based on MI to improve adherence to a medication regimen for osteoporosis. The study, which had a sample size of 2,087, did not reveal any statistically significant improvement in the experimental group regarding adherence to their medication regimen (Solomon et al., 2012).

## Peer and Social Support

As common as self-help and support groups are for those with chronic illness, one would expect the research literature to be positive as to their value. Unfortunately, that is not the case. Anecdotal articles exist, but there are few research-based articles that have demonstrated the positive effects of such groups. Additionally, research commonly looks at support groups for a short period—6, 10, 12, and 15 weeks—whereas a chronic illness could be present for 30, 40, or 50 years.

Stanton and Revenson (2007) suggest that healthcare professionals can improve the interpersonal context of patients by teaching them to develop and maintain social ties, recognize and accept others' help and emotional encouragement, or change their appraisals of the support they are receiving. Psychosocial interventions should be directed toward individual-level change and may include cognitive-behavioral, educational, and interpersonal support components.

Support groups may provide emotional support as well as an educational focus. Education is expected to strengthen the individual's sense of control over the disease, reduce feelings of confusion, and enhance decision making (p. 221). Peer support provides emotional support, thereby enhancing self-esteem, minimizing aloneness, and reinforcing coping strategies.

Social support has long been recognized as a way to support and improve health in individuals and families. Embuldeniya and colleagues (2013) completed a meta-ethnography of 25 papers about peer support in chronic disease. Individuals across the studies experienced a sense of alienation, loneliness, or frustration that prompted the need for peer support (p. 10). Peer support interventions are highly variable in format from small groups led by a mentor or a lay person, one-to-one in person, by telephone, and web-based interventions. Thirteen themes were extracted from the data, some during the intervention and some after the intervention was concluded. Themes during the intervention included sense of connection, experiential

knowledge, finding meaning, and isolation. A theme during the intervention regarding mentee-specific experiences was sharing. Themes during the intervention specific to mentor experiences included helping, reciprocity, role satisfaction, and emotional entanglement. The impact after the intervention included changed outlook, changed behavior, changed knowledge, and empowerment.

Strom and Egede (2012) suggest that social support is a multifaceted experience that involves volunteer associations and formal and informal relationships with others. Social support is a perception that one is accepted, cared for, and provided with assistance from certain individuals or a specific group, or the realization of actual support received from another (p. 770). Strom and Egede's review concluded that higher levels of social support influence more positive outcomes in participants; however, these authors note that because most of the studies reviewed were cross-sectional studies, causality could not be inferred between social support and diabetes outcomes (p. 780).

In addition to face-to-face social/peer support groups, chronic disease social groups commonly appear on Facebook and Twitter. One group of researchers looked at both Facebook and Twitter and identified groups of patients with colorectal cancer, breast cancer, and diabetes (De la Torre-Diez, Diaz-Pernas, & Anton-Rodriguez, 2012). There were 216 breast cancer groups, 171 colorectal cancer groups, and 527 diabetes groups on the two platforms. Although all disease groups addressed prevention and research, the social value of the groups to patients with chronic disease was the most significant outcome.

## Cognitive and Behavioral Interventions

Pakenham (2007) highlights the need for practitioners to facilitate patients' cognitive processing of the implications and meaning of their illness. A blend of cognitive-restructuring strategies, patient-centered approaches, and

existential approaches may be helpful to the patient and family.

Cognitive-behavioral strategies can be used to teach coping skills to patients with chronic illness (Folkman & Moskowitz, 2004). Sharpe and Curran (2006) have also encouraged the use of cognitive-behavioral therapy (CBT). Such programs include strategies with the aim of facilitating a realistic, but optimistic attitude toward illness and/or facilitating more adaptive coping strategies. Programs typically include education about the illness, goal setting and pacing, relaxation strategies and attention diversion skills, cognitive therapy, communication skills, and management of high-risk situations (such as exacerbations of the illness).

In an update of a Cochrane review, Anie and Green (2015) reviewed studies about the use of psychological interventions in individuals with sickle cell disease. Psychological interventions were aimed at improving the ability of individuals with sickle cell disease to better cope with disease and pain. The results of the review were mixed, leading authors to conclude that there is a need for better designed studies with specific interventions to test.

Nineteen studies comparing psychosocial interventions versus usual care in a sample of 3,204 men with prostate cancer were reviewed. The review demonstrated that psychosocial interventions may have small, short-term beneficial effects on certain domains of well-being, such as the physical component of general health-related QOL and cancer-related QOL, when compared with usual care. However, the review failed to demonstrate a statistically significant effect on other domains, such as symptom-related QOL, self-efficacy, uncertainty, distress, and depression (Parahoo et al., 2013).

Lastly, an update of a Cochrane review from 2004 and 2007 examined the effects of psychological interventions in women with metastatic breast cancer. Psychologically based interventions appeared to be effective in improving survival at 12 months, but not at longer term follow-up (Mustafa, Carson-Stevens, Gillespie, &

Edwards, 2013). The reviewers caution there is a little data in this field, and that a number of the RCTs reviewed had reporting or methodological weaknesses.

## Family-Based Interventions

COPD is a long-term chronic disease that affects both the patient and family. Family-based interventions have been shown to improve coping in other chronic diseases, but there has been little research with patients and families with COPD. Patients in both the experimental and control groups underwent 12 weeks of pulmonary rehabilitation (PR) composed of exercise training and psychosocial support and education. However, families were included for the psychosocial support and education in the experimental group but not with the control group. Patients and family members in the experimental group had significantly greater improvement in family coping than the control group. Family members in the experimental group also had greater change in sexual relationships and in psychologic distress. Patients in both groups experienced improvements in exercise tolerance, functional balance, knee extensors strength and HRQOL (Marques et al., 2015).

QOL is often used as a measure of psychosocial adjustment. Badr and Krebs (2013) conducted a systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. Research was reviewed from 1980 to 2012. Most studies were conducted with breast and prostate cancer populations. Although some interventions addressed cancer-specific issues, content was modified from marital therapy interventions developed for health populations or from existing CBT interventions developed for individuals coping with cancer. The standard length of CBT is typically 8 to 12 sessions, whereas the majority of the studies reviewed had brief CBT, 6 sessions or less. Overall, there were small effects in terms of improving QOL for patients and their partners (Badr & Krebs, 2013).

## Technology

Pal et al. (2013) assessed the effects of a computer-based diabetes self-management intervention on health status and health-related QOL for adults with type 2 diabetes. The 16 RCTs included in this review demonstrated a wide range of interventions, including clinic-based interventions, Internet-based interventions that could be used from home, and mobile phone-based interventions. The researchers concluded that computer-based self-management interventions to manage type 2 diabetes appear to have a small beneficial effect on blood glucose, and that effect was larger in the mobile phone subgroup. In contrast, no evidence supported benefits in other biologic outcomes or any cognitive, behavioral, or emotional outcomes.

Ressler and colleagues (2012) examined the relationship between blogging and chronic pain. A 34-item questionnaire was created, tested, and then promoted through online health/disease forums. The aim was to examine the perceived psychosocial and health benefits of blogging to communicate patients' health experiences. A total of 230 participants completed the entire survey. Overwhelmingly, bloggers replied that blogging made a difference in coping with their disease. Researchers identified five themes of patients' responses to the question, "Did blogging change how you dealt with the challenges of chronic illness or pain?"

- Reframing/ability to gain a broader perspective of illness
- Identifying patterns of illness
- Providing an expressive outlet
- Accountability
- Helping to cope with illness

Beatty and Lambert (2013) conducted a systematic review of Internet-based self-help interventions. In studies from 1980 to 2011, researchers examined relationships between Internet-based self-help management and the effects on psychological distress in patients with chronic illness. The findings revealed mixed evidence of efficacy

in relieving health-related distress (p. 619). The review found little support for one-half of the conditions being evaluated: diabetes, epilepsy, cancer, and fatigue, although the number of studies of each condition was small.

In a Cochrane intervention review, researchers reviewed 18 RCTs that evaluated Internet-delivery secondary prevention interventions for people with coronary heart disease. The quality of the studies was low and thus produced poor evidence. Few studies measured clinical events, and of those that did, a very small number of events were reported. The review concludes that there is no clear evidence of an effect on cardiovascular risk factors. The effects on healthcare utilization and cost-effectiveness were inconclusive (Devi et al., 2015).

A review of smartphone and tablet self-management applications for asthma was conducted. Marcano Belisario, Huckvale, Greenfield, Car, and Gunn (2013) identified only two RCTs, with a total of 408 participants, dealing with this topic. Because of the small number, a narrative synthesis approach was used with the data. There was not enough evidence to recommend the use of smartphone and tablet computer applications for the delivery of asthma self-management programs.

Researchers examined 42 studies of Facebook, Twitter, Wikipedia, and YouTube and their use with people with 10 chronic diseases. The goals were to evaluate clinical outcomes with the use of social media and develop a conceptual taxonomy to categorize, summarize, and analyze data. The overall impact on clinical outcomes was mixed, with 48% of studies showing benefit, 45% neutral or undetermined, and 7% suggesting harm. Of the 48% showing benefit, 85% of those individuals used either Facebook or blogs (Patel, Chang, Greysen, & Chopra, 2015).

Caution must be used in interpreting the effects of social media and chronic disease management. Most of the current studies used samples of white, female, college-educated, employed, and competent Internet users. If one looks at the common demographic of an

individual with chronic disease in the United States, that individual is African American, is less educated, and has lower income earnings (Merolli, Gray, & Martin-Sanchez, 2013).

Although it would seem that the use of technology could reach out to patients and families to inform, educate, and provide psychosocial support, the supporting evidence is not there. Poorly designed studies, lack of RCTs, and heterogeneity of individual disease groups within studies do not lend credibility to the small effects that studies have demonstrated.

## ► Outcomes

As seen from the literature, few interventions exist that can affect the psychosocial adjustment of the patient and family, and the studies that do exist have mixed results. Psychosocial adjustment is complex and looks different for each individual and family. How should psychosocial adjustment be measured, and might it look different for each individual and family? What about individuals with a terminal chronic illness? Can those individuals experience psychosocial adjustment? Currently, there are no answers, just questions.

*Has our family adjusted to the fact that my husband, the father of our three children, a grandfather of 12, a brother and a son, has a cancer that is not going to be cured? After 16 months of a cancer that never went into remission, the options now are a clinical trial or hospice. Randy has chosen hospice. Have we “adjusted” to that fact or is adjustment even possible? We are physically and emotionally exhausted. We just “are,” and that is all.*

*The end is near now and it’s not what any of us thought would happen 18 months ago. Where did the time go? Did we try to “live” during that time, or were we always responding to the next crisis? I look back at my journal*

*and note the many ups and downs, the days of despair, the days of hope. Regrets, yes; “what ifs,” always; “should haves,” of course. And now that illness is ending with death. I can’t comprehend it.*

—Pamala

## Evidence-Based Practice Box

In recent years, there has been an increased growth in family-based or dyad-based interventions to assist patients and families with psychosocial adjustment. A chronic disease affects not only the individual but also the family unit. Family dyads consisting of a patient with COPD and one family member were randomly assigned to a family-based (experimental) group or the usual care (control) group. Each group of patients had exercise training (pulmonary rehabilitation) three times a week as well as psychosocial support and education each week. However, in the experimental group, family members attended the psychosocial support and education groups along with the patient. In the control group, family members did not attend. Forty-two dyads participated in the study. Patients and family members in the experimental group had significantly greater improvements in family coping than the control group. Additionally, family members of the family-based intervention group had significantly greater changes in sexual relationships and in psychological distress compared with the control group. Both groups experienced significant physical improvements, e.g., exercise tolerance, functional balance, knee extensors strength, and health-related QOL after the intervention.

Source: Marques, A., Jacome, C., Cruz, J., Gabriel, R., Brooks, D., & Figueiredo, D. (2015). Family-based psychosocial support and education as a part of pulmonary rehabilitation in COPD: A randomized controlled trial. *Chest*, 147(3), 662–672. doi: 10.1378/chest.14-1488.



## CASE STUDY 3-1

Jenny is a 45-year-old woman, married, with two teenage children. Jenny is currently recovering from an exacerbation of her rheumatoid arthritis. Her disease was diagnosed when she was 30. Typically Jenny has been independent in her ADLs and uses a cane for ambulation. However, this last exacerbation lasted nearly a month, and she is struggling to regain her independence. She needs assistance with bathing, grooming, and dressing. Jason, her husband of 20 years, owns a small business and works an average of 65 hours/week. Their children are a 17-year-old boy and a 14-year-old girl. Lately there has been some trouble with their son, who is doing little homework, and is gone from home during the weekday evenings and most of the weekend. They suspect he is into the alcohol and marijuana scene.

You have been Jenny's home health nurse for the past 3 weeks and see her weekly. She also has a home health aide who assists her with her ADLs on a daily basis. You enter her home this morning for your weekly visit and find Jenny visibly upset and crying. Her son didn't return home from an evening out until 6 in the morning.

### Discussion Questions

1. How do you approach Jenny?
2. For now it seems like all of her focus is on her son and not her rehab. How do you respond to that? Shouldn't she be consumed about her son and not her own health at this precarious time? Why or why not?
3. From your perspective (this is your third visit), it doesn't seem like Jenny has much insight into her illness. In your mind you're thinking that she really hasn't adjusted to having a chronic illness, and you wonder what her mental model of the disease is. Is adjustment possible? How do you work with Jenny? Describe your assessment of her psychosocial needs.

## CASE STUDY 3-2

John is a 60-year-old man with early-onset Alzheimer's disease. He was diagnosed 2 years ago. Joan, his wife, has been his caregiver at home. It has become increasingly evident that John will soon need 24/7 care within the confines of a safe environment. Joan takes John to an adult day program 3 days/week. You are the RN for the day program, and you work with both the patients and the caregivers. When Joan drops off John this morning, she asks to speak to you. Joan has had a difficult time adjusting to her husband's illness, and you are wondering what she wants to talk about. When she enters the door of your office, Joan bursts into tears and says, "I can't take this anymore."

### Discussion Questions

1. How do you respond to Joan?
2. You can't imagine what this illness experience has been like for Joan . . . What words of comfort, if any, can you give her? Identify her psychosocial needs.
3. She has been reluctant in the past to join a support group or to look online for a blog on early-onset Alzheimer's. Should you suggest this to her? What other support might be helpful?

## Study Questions

1. Why is adjustment to chronic illness important to the patient and family with chronic illness? Why is it important to the healthcare professional?
2. Describe how different personal attributes affect adjustment.
3. Compare and contrast the key concepts of the frameworks discussed in this chapter. What could nursing bring to these models that could be applied to patients and their families?
4. Describe, from your perspective, the role of social support in adjustment, whether it be “perceived” social support or “real” social support.
5. Develop a generic teaching plan that addresses psychosocial adjustment to chronic illness. What key points could then be individualized to each patient?

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