Psychosocial Adjustment

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Introduction

In previous editions, this chapter was titled “Adaptation.” The literature uses the terms “adaptation” and “adjustment” interchangeably. Although either term could be used, this author prefers the term “adjustment,” as the term better describes a process as well as a final outcome. Adjustment refers to the changes in life that are made continuously when one has a chronic illness. Adjustment is not static, but dynamic.

What is interesting about the terms “adaptation” and “adjustment” is that psychologists describe these terms as psychological adjustment or adaptation, whereas in nursing the more common phrase is psychosocial adjustment or adaptation. “Psychosocial” is a broader term and takes into account the social environment as well as the psychological state of being, that one cannot be separated from the other. “Psychosocial” is, therefore, a more inclusive term, while “psychological” is one-dimensional. Thus, in the discipline of psychology, studies describe psychological adjustment, while psychosocial adjustment is encountered more frequently in nursing. However, to be true to each author’s intent in the studies and articles described in this chapter, whatever term the author has used in the article—“adjustment” or “adaptation”—will be used to describe the study.

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 healthcare. Although a disease focus may be 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 with chronic conditions. In other words, the disease focus of the healthcare system does not and cannot 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 this 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 in understanding certain components of adjustment has been made, many questions remain unanswered.
Conceptualizing Psychosocial Adjustment

An early description of adjustment (and a continuing one) is the absence of a diagnosed psychological disorder, psychological symptoms, or negative mood in an individual. One example of a 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). Even in Visotsky’s study with patients with polio in 1961, there was a movement to discount a psychological disorder being necessary in the definition of adjustment. The presence of a psychological disorder is important, but other variables should also 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 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) absence of psychological disorders, (3) 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, absence or presence of a psychological disorder or returning to work can be verified with a degree of certainty. In contrast, other elements cannot be measured objectively.

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

- 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.

Chronic Illness Affects Adjustment in Multiple Life Domains and Roles

Caring for patients with chronic illness includes more than addressing the physical domain; it crosses interpersonal, cognitive, emotional, social, and behavioral domains. Psychosocial adjustment of the individual and family is a holistic process, in which each domain of life affects the others. 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 include returning to work. Anxiety, in the emotional domain, may affect the ability to socialize in the interpersonal domain or impact blood pressure in the physical domain. Emotional adaptation could be the absence of depression, and interpersonal and social adaptation may 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 of breast cancer and same prognosis 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 that 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. 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, and other variables that science has yet to identify.

**Adjustment Involves Positive and Negative Dimensions**

Typically, one thinks of psychosocial outcomes of chronic illness as being negative, as evidenced by distress, anxiety, worry, and other negative states. As stated previously, one definition of positive adjustment is the absence of a psychological disorder. However, there may be another 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.” There may be positive aspects of chronic disease, but how patients come to view the disease in this way remains a mystery. Current research on benefit-finding, addressed later in this chapter, may be helpful in understanding this phenomenon.

Adjustment is a process that is neither linear nor lockstep, but dynamic. The list of variables that influence this process are numerous and varied. However, an obvious influence on adjustment is a negative change in health status. When such a change occurs, the lived experience of the individual and family needs to incorporate different data into their mental model of the illness, and progress made in previous steps toward adjustment may disappear.

This chapter provides an overview of psychosocial adjustment in individuals with chronic illness. Given that entire books have been devoted to coping, adaptation, and adjustment, the scope of this chapter is necessarily limited. However, classic sources and models are included, along with interventions for healthcare professionals.

**Impact**

**Influences on 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, but perhaps that is not always the case.

Most concepts addressed in the first section of this text deal with psychosocial adjustment. Whether it is powerlessness, uncertainty, intimacy, or social isolation, all of these factors 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 in a patient with Stage IV lung cancer. Unfortunately, researchers 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 make generalizations about their findings.

For an individual with chronic illness, this illness is now a life experience. In contrast, for family members, it will be remembered as a “past experience” at some point in their lives. This experience, with their own corresponding illness perceptions, becomes assimilated into these persons’ memory for future reference.

A systematic review of psychosocial factors and adjustment to chronic pain in persons with disabilities identified other variables impacting adjustment (Jensen, Moore, Bockow, Ehde, & Engel, 2011). Criteria for studies to be included in the review were as follows: (1) adults with physical disability who reported having pain, (2) one measure of a psychosocial predictor domain, and (3) one measure of pain or patient functioning.

The review included 29 studies with 5 disability groups, including patients with spinal cord injury (SCI), muscular dystrophy (MD), multiple sclerosis (MS), acquired amputation, and cerebral palsy (CP). The findings indicated that measures of key psychosocial factors were all associated with important pain-related domains across the five different disability groups (p. 155). It was suggested by the results of this review that reasonable goals of treatment might include the following: (1) increase the use of coping strategies such as task persistence, acceptance of disability, behavioral activities, exercise, ignoring pain, and coping self-statements; (2) increase the belief that the patient can control pain and its effects; and (3) help the patient seek and obtain more general social support (not including support from others with pain). The findings provide support for a comprehensive biopsychosocial model for understanding chronic pain in adults with physical disabilities.

Researchers found a relationship among spirituality, psychosocial adjustment to illness, and health-related quality of life in 253 patients with Stage 4 or 5 chronic kidney disease and dialysis patients (Davison & Jhangri, 2013). Spirituality was measured by the Spiritual Well-Being Scale, which is designed to evaluate both religious and existential constructs of spirituality. Psychosocial adjustment, as measured by the Psychological Adjustment to Illness Scale (PAIS), was highly correlated with health-related quality of life (HRQoL); however, existential well-being (EWB) remained a significant predictor of HRQoL. The authors concluded that spirituality is a unique factor in patients’ HRQoL, independent of their psychosocial adjustment (p. 170).

**Coping**

How does coping “fit” with psychosocial adjustment? Or is it a stand-alone entity? Richard Lazarus’s 1966 book, *Psychological Stress and Coping*, was an initial scholarly work that expanded how coping was conceptualized. 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).

What we have learned is that 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 in a complex, dynamic process that involves the
person, the environment, and the relationship between them.

How coping is related specifically to adjustment has not been clearly described (Sharpe & Curran, 2006, p. 1154). Intellectually, it is believed that coping strategies contribute to adaptation and may be mediators, but most likely interact with other factors in contributing to adaptation (Stanton & Revenson, 2007).

Two current studies are offered as examples of coping and adjustment. The relationship among attachment, coping, and self-regulation theory with 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 measurable 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. Three attachment styles were found to have a significant effect on task-oriented coping strategies. Notably, positive illness perceptions and more usage 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 chronic obstructive pulmonary disease (COPD) or congestive heart failure (CHF). 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., 2013). The authors suggest that psychological interventions may reduce illness intrusiveness by targeting an 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 providers. However, current research suggests that many individuals may also 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 crises may present 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. 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 uninformative and inaccurate (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 may be specific to MS or may be applicable with other chronic diseases.

A systematic review of the qualitative literature on post-traumatic growth and life-threatening illness revealed several common themes: reappraisal of life and priorities, trauma equals development of self, existential reevaluation, and a new awareness of the body (Hefferon, Grealy, & Mutrie, 2009).

Could positive life changes be a component of psychosocial adjustment? Or should they be considered psychosocial adjustment? One could assume that finding benefits from serious illness would contribute to better adjustment to the illness, but research results on this topic are mixed (Carver, Lechner, & Antoni, 2009).

Next, we consider how we, as healthcare professionals, influence the process of psychosocial adjustment in patients and families.

Interventions

Researchers’ broad goals are to understand the process of adjustment, predict outcomes, and, by having predictive ability, modify interventions to meet the needs of patients. A framework that meets those goals is preferable for practice; however, a perfect model does not exist. What follows are sample models/frameworks gleaned from the literature. The differences in the frameworks presented here demonstrate the variance 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 human aspects and experiences of the individual who happens to have a chronic illness, while diminishing social and cultural explanation of disease (Mirowsky & Ross, 2002). Physical complaints and signs or symptoms of disease become the hallmarks of interaction and reaction in the healthcare arena. A biological model may cause healthcare professionals to pay too little attention to the patient and his or her social context (Suls, Luger, & Martin, 2010, p. 16).

In this model, the relationship between the healthcare professional and the patient with chronic illness is one of objectivity, biological pathology, diagnosis, and signs and symptoms, all of which require medical interventions. Healthcare professionals tend to shield themselves from the human aspects of chronic illness, while their technical skill sets, techniques, and procedures become the focus of interaction with the patient (Freeth, 2007). Power and expertise are held exclusively by the healthcare system. The individual with chronic illness may become disempowered to engage in healthcare decisions and rely solely on the healthcare professional.

The biomedical model is insufficient in providing holistic health care to individuals and families with chronic illness (Waisbond, 2007), as it fails to acknowledge the illness experience. Specifically, this model does not acknowledge the person with the chronic condition, who holds knowledge and expertise about the factors...
that influence his or her 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 the probable 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. 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 in adjustment, 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**

The chronic care model (CCM) first appeared in the literature in 1998 (Wagner, 1998) and was later refined by Wagner and colleagues (2001). Subsequent research into interventions with chronic illness has resulted in best practices and a national program for improving chronic illness care (Robert Wood Johnson Foundation, 2006–2011).

A key component of the CCM is patient self-management to address deficiencies in the medical model of the healthcare system in managing chronic conditions. 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 healthcare system or healthcare organization; (2) clinical information systems; (3) decision support; (4) delivery system design; (5) self-management support; and (6) community, including organizations and resources for patients with chronic illness (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, HgbA₁c 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.

Two recent systematic reviews of the CCM and chronic illness further describe this model’s use and impact. In a review focusing on individuals living with HIV, two of the components of the model, decision support (DS) and clinical information systems (CIS), were assessed for their effectiveness in improving care by changing healthcare professional behavior. Overall, DS and CIS interventions may modestly improve care for individuals living with HIV; nevertheless, the researchers found that the interventions have a greater impact on process measures than on patient outcome measures (Pasricha et al. 2012, p. 127).

Other work with the CCM has involved individuals with diabetes who were being treated in primary care settings (Stellefson, Dipnarine, & Stopka, 2013). This systematic review, unfortunately, identified only nine randomized clinical trials (RCTs). The review concluded that the CCM is effective in improving the health of individuals with diabetes who receive care in a primary care setting. Positive clinical indicators, such as improved HgbA₁c levels, have been cited as indicators of the model’s success. However, process outcomes (e.g., self-efficacy for disease management and clinical decision making, perceived social support, knowledge of diabetes self-care practices) were not addressed in the studies included in this review.
COMMON SENSE MODEL OF SELF-REGULATION

The common sense model of self-regulation (CSM) (Leventhal et al., 2012), based on biomedical and cognitive models, has become the preferred model in psychological adaptation studies. 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 common sense model has been used extensively as a framework in research in chronic illness. Examples of its application follow:

• 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, 2013).
• 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 (Brelan, McAndrew, Burns, Leventhal, & Leventhal, 2013).

BIOPSYCHOSOCIAL MODEL

Engle (1977, 1980) conceived a model that integrates biological, psychological, and social processes in physical illness and health, medical diagnosis, medical treatment, and recovery (Suls et al., 2010, p. 18). This model is not dominated by a single domain, but instead uses a multilevel approach to diagnose, explain, and treat any medical issue. Engle’s goal was to understand the full complement of influences at multiple levels of analysis. The interaction of the domains means that a change in one domain results in changes in other domains. Further, it suggests that any interventions involving all of the domains will fare better than a treatment grounded in one domain (Suls et al., 2010). Challenges exist for interdisciplinary research, however, and research that acknowledges all domains continues to be difficult (Suls, Krantz, & Williams, 2013).

Examples of Interventions to Assist and Support the Patient

The literature provides an abundance of descriptive studies defining and measuring adaptation...
and coping, but few interventional studies exist. It appears that coping and adjustment can, in some way, be measured by specific concepts (e.g., well-being, hope, lack of a psychological disorder), but we are unable to conceptualize those findings into clear interventions or ways healthcare professionals can assist patients with psychosocial adjustment. The distinct attributes of each individual and his or her family make generalizations of interventions difficult.

**Self-Management**

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

Swendeman, Ingram, and Rotheram-Borus (2009) identify three broad categories in chronic disease self-management: physical health, psychological functioning, and social relationships. Elements related to physical health are knowledge and behavior to maintain health status, whereas elements related to psychological functioning include self-efficacy and empowerment as well as emotional status and shifts in identity. Social relationship elements relate to collaborative partnerships with healthcare professionals, family members, and social support.

Self-management programs based on enhancing self-efficacy have proved highly successful in reducing symptoms and encouraging behavior change in many chronic illnesses. Self-efficacy may be considered a personal context variable; thus, it may be a determinant in the appraisal of the illness, the coping strategies used by the individual, and the outcome (physical, emotional, and social adjustment). Although self-efficacy is specific to the task and situation, programs that encourage development of self-efficacy can influence adaptation.

To accomplish self-management, individuals with chronic illness need to apply the following skills: problem solving, decision making, resource utilization, forming partnerships with healthcare professionals, and taking action (Lorig & Holman, 2003). 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.” Oftentimes studies using cognitive-behavioral interventions are not included in such reviews. For example, in this chapter, this author has chosen to separate out psychologically based strategies.

McCorkle and colleagues identified 16 interventional studies that met their 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 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 treatment studies demonstrated decreased psychosocial concerns, less distress, better health-related quality of life, and better psychological adjustment (McCorkle et al., 2011); however, only short-term outcomes were measured, not long-term outcomes.

Lastly, self-management programs have often been coordinated by lay leaders. A Cochrane review identified 17 randomized clinical trials...
RCTs) involving 7,442 participants. Although the interventions shared similar structures and components, the studies demonstrated heterogeneity in conditions studied, outcomes collected, and effects (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007). Foster and colleagues concluded that such programs may lead to small, short-term improvements in participants’ self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise. Nevertheless, there is no evidence to suggest that such programs improve psychological health, symptoms, or health-related quality of life, or that they significantly alter healthcare use.

Motivational Interviewing

When Miller and Rollnick (1991) originally developed motivational interviewing (MI), their intent was that counselors who worked with clients with drug and alcohol problems would benefit the most from application of this intervention. After the success of their 1991 book, it became apparent that MI could be used with others who struggle with ambivalence about change. Rollnick, Miller, and Butler (2008) define motivational interviewing as a refined form of the familiar process of guiding (p. ix.). Rollnick et al. (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)

Dart (2011) describes the four main principles of MI as follows: (1) express empathy, (2) support self-efficacy, (3) develop discrepancy, and (4) roll with resistance. Therapeutic communication is important in each and every interaction with the patient. MI is a form of communication that allows patient involvement, respect for each patient as an individual with his or her own agenda, and acceptance of a patient’s choices (p. 13).

A search of the Cochrane Library of Systematic Reviews does not reveal a review dealing with motivational interviewing and chronic illness. A total of 11 proposed or completed studies about chronic illness and motivational interviewing were listed in the Cochrane Central Register of Controlled Trials from 2005 to the present. Results from the completed studies were mixed. The Health Aging Project (HAP) tested nurse coaching as an intervention to support healthy behavior change in older adults. Nurses were trained in motivational interviewing. The coaching took place on the phone and via email to discuss health behaviors. The intervention group had significantly less illness intrusiveness and health distress than the control group at 6 months, but it is not known whether these outcomes resulted from actual behavior change (Bennett et al., 2005).

Sixty older adults with chronic heart failure were randomly assigned to an interview group (the MI group) or a control group to examine whether a physical activity intervention based on motivational interviewing would improve quality of life in these patients. Over the 5 months of the study, there was a general trend toward improvements in self-efficacy and motivation scores (Brodie, Inoue, & Shaw, 2008).

Solomon and colleagues (2012) examined the effectiveness of a telephone-based counseling program based on motivational interviewing 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 in regard to adherence to their medication regime.

Peer and Social Support

As common as self-help and self-support groups are for those with chronic illness, one would
expect the research literature to be clear as to their value. Unfortunately, that is not the case. Anecdotal articles exist, but there are few research-based articles. In addition, 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. The education is expected to strengthen the individual’s sense of control over the disease, reduce feelings of confusion, and enhance decision making (p. 221). The peer support provides emotional support, thereby enhancing self-esteem, minimizing aloneness, and reinforcing coping strategies.

Dibb and Yardley (2006) investigated the role that social comparison might play in adaptation using a self-help group as the context. Social comparison proposes that individuals with similar problems compare each other’s health statuses. Often this comparison occurs within self-help groups, which are composed of individuals with similar health issues. It has been suggested that downward comparison, when a comparison is made with a person who is doing less well, initiates positive affect by increasing self-esteem. Conversely, upward comparison with a person doing better may result in hope (Dibb & Yardley, 2006, p. 1603). Findings from this study, which involved 301 clients with Ménière’s disease, demonstrated that the strongest and most consistent effect of social comparison was that positively interpreted downward comparisons were associated with better functional and goal-directed quality of life (p. 1610).

According to the social-cognitive processing model, the expression of one’s thoughts and feelings about cancer—that is, “social sharing”—in a supportive way may facilitate psychological adjustment (Boinon et al., 2014). Studies have emphasized the links between positive social support and patients’ psychological adjustment, but have devoted less attention to the effects of negative support. In Boinon and colleagues’ study, women with breast cancer were surveyed at two points in time, after their surgery and after their adjuvant therapy. Results were consistent with this social environment-oriented approach and demonstrated that repressing one’s desire to talk about the experience of the disease after surgery is associated with an increase in psychological distress at the end of treatment. However, there was no beneficial effect of social sharing concerning the disease or of perceived emotional support on psychological adjustment. The researchers concluded that healthcare professionals should develop specific interventions to address the negative reactions of the social network and the way these are perceived and processed by patients. There should be encouragement to strengthen links with “well-meaning” family members and friends and focus on maintaining the feeling of social integration (Boinon et al., 2014).

Parry and Watt-Watson (2010) conducted a systematic review of peer support interventions for individuals with heart disease. Peer support—a specific type of social support that includes appraisal as well as informational and emotional support—has been shown to be an effective intervention for individuals with other chronic illnesses. Only six RCTs, with a total of 1,452 participants, could be identified for the 2010 review. The results suggested that peer support may improve self-efficacy in individuals with heart disease and post-coronary artery bypass graft (CABG) surgery, and may have a beneficial effect on the health and well-being of
individuals with heart disease who are recovering from a myocardial infarction (MI) and are post-CABG surgery. However, the authors note that there was little standardization of the training of the peer support persons or standardization of the peer support intervention, and interventions and outcomes were not theoretically or conceptually justified.

The role of social support in diabetes management is not well understood. 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 cannot be inferred concerning social support and its impact on diabetes management (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 to characterize groups concerning 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 most significant.

Psychologically Based Strategies

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).

McAndrew and colleagues (2008) developed two interventions based on the common sense model of self-regulation. The first intervention is a bottom-up concrete/behavioral approach that has been used with patients with diabetes. The approach begins with a focus on behavior to create an overarching view of diabetes as a chronic condition that requires constant self-regulation. The second intervention is conceived as a top-down or abstract/cognitive strategy that provides patients with asthma with a conceptual framework that focuses on asthma being present even when it is asymptomatic (p. 197). The authors suggest that patients may benefit from starting with one strategy or the other. However, it is expected that successful interventions will combine both approaches.

Three Cochrane Collaboration reviews are relevant to patients with chronic illness and the use of psychologically based strategies. Depression is common in patients with incurable cancer. When studies that used psychotherapy in patients with concomitant incurable cancer and depression were reviewed, the evidence supported psychotherapy as being useful in treating depressive states in patients with advanced cancer. However, there is no evidence to support the effectiveness of psychotherapy in patients with clinically diagnosed
depression (Akechi, Okuyama, Onishi, Morita, & Furukawa, 2008).

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 quality of life and cancer-related quality of life, when compared with usual care. However, the review failed to demonstrate a statistically significant effect on other domains, such as symptom-related quality of life, self-efficacy, uncertainty, distress, and depression (Parahoo et al., 2013).

Lastly, a review of psychological interventions for women with metastatic breast cancer and their effect on psychosocial and survival outcomes was conducted. Psychologically based interventions appear to be effective in improving survival at 12 months, but not at longer-term follow-up. These interventions are effective in reducing psychological symptoms only in some women with metastatic breast cancer (Mustafa, Carson-Stevens, Gillespie, & Edwards, 2013). The reviewers caution that there is a relative lack of data in this field, and that a number of the RCTs reviewed had reporting or methodological weaknesses.

Complementary and Alternative Therapy
Examples of different techniques that may be used in patients with chronic illness are included in the “Complementary and Alternative Therapies” chapter.

Technology
Perhaps the most well-known computer intervention involving women with chronic illness is the Women to Women (WTW) project developed by Clarann Weinert. This project was launched in 1995 and included three phases over a period of years. The last phase of the project was a two-group study design with 309 middle-aged, rural women with chronic conditions. Women were randomized into either the experimental group, which received the computer-based intervention, or the control group, which did not receive the intervention. Data were collected at baseline, at the end of the intervention, and 6 months following the project. Positive and negative psychosocial variables of interest to the researchers were social support, self-esteem, acceptance of illness, stress, depression, and loneliness (Weinert, Cudney, Comstock, & Bansal, 2011).

The 11-week computer intervention gave women 24-hour access to a peer-led virtual support group as well as a series of self-study health teaching units on web skills and the five skills of self-management (problem solving, decision making, resource utilization, forming partnerships with healthcare professionals, and taking action). The skills of self-management were derived from Lorig and Holman’s work (2003). At all three data collection points, the number of women participating was 250, indicating an 80.9% retention rate. Five of the six psychosocial outcomes were statistically significant at 6 months. The experimental group had higher scores on self-esteem and acceptance of illness and lower scores on depression, loneliness, and stress than did the control group. Although shortly after the intervention higher scores in social support were noted, that result was not maintained at 6 months. Although this computer intervention was successful, the authors caution that the results represent just one piece of the complex adaptation process as experienced by rural women living with chronic conditions (Weinert et al., 2011, p. 89).

As early as 2005, the Cochrane Collaboration published a review of interactive health communication applications (IHCA) for people with chronic disease. IHCAAs were defined as computer-based, usually web-based, information packages for patients that combine health information with at least one of the following: social support, decision support, or behavior change support. To assess the effects of IHCAAs for individuals with chronic disease, 24 RCTs
with 3,739 participants were included in the review. The IHCAs appeared to have largely positive effects on users, such as users becoming more knowledgeable and feeling better socially supported, and may have improved users’ behavioral and clinical outcomes compared to nonusers (Murray, Burns, See Tai, Lai, & Nazareth, 2005).

In 2013, the Cochrane Collaboration published two intervention reviews regarding technology and chronic disease. Pak et al. (2013) assessed the effects on health status and health-related quality of life of computer-based diabetes self-management interventions 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 biological outcomes or any cognitive, behavioral, or emotional outcomes.

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

**Other Interventions to Assist and Support the Patient**

Hope can be a psychosocial resource for older adults who are dealing with a chronic illness. A meta-analysis of qualitative research on the hope experience from 1980 to 2010 concluded that older adults may experience hope differently than younger adults. Resources for hope are both internal and external. Finding meaning and positive reappraisal are important to help older adults maintain hope (Duggleby et al., 2012, p. 1211).

The Healthy People documents have fueled interest in health promotion and wellness. Interestingly, an increasing number of studies have focused on the use of wellness interventions in chronic illness. Unfortunately, a consensus definition of a wellness intervention does not exist, as each researcher has used different actions as wellness interventions. Stuifbergen and colleagues (2010) conducted a review of studies that included patients with chronic illness and wellness interventions; 190 studies from 1990 to 2007 met the criteria for inclusion in the review. Most of these studies explored a wellness intervention with a sample of individuals with a single chronic illness (e.g., stroke, cancer, heart failure). Of the 190 studies, 89.5% reported positive effects from their wellness intervention, although the intervention and measurement of outcomes varied greatly (p. 133). Interventions ranged from 1 week of health education and coaching for older adults with cardiac conditions to 6 months of swimming for persons with asthma. Similarly, the outcome measurements varied from using standardized tools like the SF-36 or biological measures to self-reports of mobility, ADLs, and other outcomes. Although the immediate positive effects of interventions were encouraging, there was little, if any, follow-up with patients at a later date (p. 139).

Fife (1994) views the construction of meaning as a central aspect of adaptation to serious illness. Patients and families are challenged by a diagnosis of chronic illness and wonder what the “meaning of all of this” is. Searching for meaning has been a component of several psychological adaptation theories (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). Lee and colleagues designed a RCT using a
meaning-making coping process as the intervention. Seventy-four patients with breast and colorectal cancer were included in the sample. The experimental group received up to four sessions that explored the meaning of their emotional responses and their cognitive appraisal of the experience. Each face-to-face session of up to 120 minutes took place at either the patient’s home or the clinic (the patient’s choice as to location). The meaning-making intervention involved tasks that patients needed to complete during the sessions: (1) acknowledge the present, (2) contemplate the past, and (3) commit to the present, for the future. Outcome measures were based on the Rosenberg Self-Esteem Scale, the Life Orientation Test—Revised, and the Generalized Self-Efficacy Scale. Statistically significant improvements in self-esteem, optimism, and self-efficacy were found for the experimental group as compared to the control group.

Outcomes

The obvious outcome for an individual with chronic illness would be psychosocial adjustment, with each patient and family appropriately “adjusting” to the roller coaster of challenges that occur on a regular basis. But how should psychosocial adjustment be measured, and might it look different for each individual and family? And again, what about individuals with a terminal chronic illness? Can those individuals experience psychosocial adjustment? There are no answers, just questions.

Has our family adjusted to the fact that my husband, the father of our three children, a grandfather to 12, a brother and a son, has a cancer that is not going to be cured? It’s now down to a clinical trial or hospice. Have we “adjusted” to that fact or is adjustment even possible? We are all physically and emotionally exhausted. We just “are,” and that is all. The end is near and it’s not what any of us thought could happen 18 months ago. Where did those 18 months go? Did we try to “live” during that time, or were we always responding to the next emergency or complication? 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. The life of a patient and family with chronic illness and now that illness is ending with death. I didn’t know it was like this.

—Jenny

Evidence-Based Practice Box

Women with chronic illness in rural parts of the western United States confront multiple challenges, ranging from access to health care to social support. Weinert, Cudney, and Spring designed and implemented a three-phase, computer-based intervention to provide support and health information to middle-aged women with chronic illness. These women all lived in rural areas of the intermountain West. Women to Women (WTW) Phase One included 308 women who participated in either an intervention group or a control group. The WTW project targeted psychosocial concepts, such as social support, self-efficacy, self-esteem, empowerment, depression, loneliness, and stress, as indicators of psychosocial adaptation. The intervention had a positive influence on the chosen indicators of adaptation to chronic illness.

Phase Three of the project design includes two groups: a computer intervention group...
CASE STUDY 3-1

Alice is a 39-year-old mother of two who was recently diagnosed with Stage III breast cancer. She has been married for 15 years to her high school sweetheart. During a breast self-examination in the shower, Alice discovered the lump. Her lumpectomy is complete and she begins chemotherapy next week. She is angry that she has cancer and seems to be taking it out on everyone involved with her care, as well as her husband and children. You are her chemo nurse in the oncology office.

Discussion Questions
1. The goal of psychosocial adjustment at this point in Alice’s care does not seem possible. How would you develop trust and a relationship with her?
2. Which small steps could you take that will diffuse Alice’s anger and deflect it from her family?
3. How would you assess Alice’s psychosocial needs?

CASE STUDY 3-2

Bob, age 59, was diagnosed with multiple sclerosis when he was 35. Until recently, he was able to ambulate with a cane. Following his last exacerbation, during which he was hospitalized briefly, it appears that he will need a walker instead. This has been a real blow to Bob’s pride and he rarely uses the walker, preferring to use his cane instead. However, with his cane, he is a definite fall risk. He runs a small business and wonders what his employees and customers will think.

Discussion Questions
1. This is another change, and a downward one, for Bob. He was comfortable with the cane and appeared to be psychosocially adjusted, as evidenced by his optimism, well-being, and self-concept. Now it appears that his adjustment has been derailed. As his usual nurse in the MS clinic at a medical center, how can you intervene to assist Bob?
2. Which framework of practice would be most appropriate to use in working with Bob?
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 resources can affect adjustment.
3. Compare and contrast the key concepts of the frameworks discussed in this chapter. Although these models have been developed by psychologists, 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 are key points that could then be individualized to each patient?

References


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