INTRODUCTION

Persons with chronic illness chart a life course to successfully navigate the challenges that are inherent within themselves and their families, their relationships, or the setting in which they find themselves. Throughout the course of their illness individuals must rely on a healthcare system in which pharmaceuticals, machines, and a wide array of technology have become the hallmarks of “quality health care.” Although the disease focus may be appropriate intermittently during the trajectory of a chronic illness to meet acute physical needs of the individual, this perspective does not meet the social, psychological, and emotional needs of clients with chronic conditions. In other words, the disease or biomedical focus of the healthcare system does not address the holistic needs of the individual and therefore is not enough to manage the illness experience of the client and family.

Early work by Visotsky, Hamburg, Goss, and Lebovits (1961) in studying clients with polio posed some initial questions regarding adaptation. They asked their clients how they dealt with this stressor, polio, and what coping behaviour(s) could predict favourable outcomes. Fifty years later the same questions are being asked. Although we have made progress in understanding certain components of adaptation, many questions remain unanswered.

The lens for viewing chronic illness is determined by numerous variables within the individual affected as well as how healthcare professionals, the system, and the setting providing care view the chronic condition. The elderly woman with arthritis who has been socialized to the primacy of medicine in the healthcare system may rely solely on her physician-prescribed pharmaceutical treatment of her joint pain and fatigue. On the other hand, a young man with hepatitis C gathers information from a wide variety of sources regarding the treatment and management of his chronic condition and maintains control of his treatment plan. The adaptation mechanisms of the elderly woman and the young man are very different as well. Each individual brings to the illness his or her own uniqueness—personality traits, past experiences, culture, values—to influence the adaptation process in his or her own way.
Defining Adaptation

The terms “adjustment” and “adaptation” are used interchangeably in the literature (Stanton & Revenson, 2007) and in this chapter as well. Sharpe and Curran (2006) define adjustment as a response to a change in the environment that allows an organism to become more suitably adapted to that change. Most definitions of adjustment or adaptation, however, allude to the lack of a psychological disorder being present. An early description of adjustment (and a continuing one) is the absence of a diagnosed psychological disorder, psychological symptoms, or negative mood (Stanton, Revenson, & Tennen, 2007). Even in Visotsky et al.’s study in 1961 in clients with polio, there was a movement to discount that definition. Although the presence or absence of a psychological disorder may be a part of adjustment, it is only one indicator of it.

Adjustment to illness has been operationalized as good quality of life, well-being, vitality, positive affect, life satisfaction, and global self-esteem (Sharpe & Curran, 2006). Conversely, “adjustment disorder” is defined as the development of clinically significant emotional or behavioural symptoms in response to an identifiable stress or stressor (American Psychiatric Association, 2000).

There is little consistency in the literature in defining adaptation or adjustment. Each author/researcher defines adaptation or adjustment differently based on their own theoretical framework or outcome measurement. As one example, Kiebles, Doerfler, and Keefer (2010) in their study of adjustment to inflammatory bowel disease defined adjustment as a composite of perceived disability, psychological functioning, and disease-specific and health-related quality of life.

This chapter provides an overview of adaptation in individuals with chronic illness. With entire books devoted to coping and adaptation, the depth of this chapter is limited. However, classic sources from different parts of the globe and models are included, along with interventions appropriate for individuals and families with chronic illness.

IMPACT

Conceptualization of Adjustment

The psychological and social consequences of chronic diseases demand significant adjustments from individuals. Stanton and Revenson (2007) identified five attributes of adjustment: (1) chronic illness necessitates adjustment in multiple life domains, (2) there are positive and negative outcomes of adjustment, (3) adjustment is dynamic, (4) adjustment can be described only within the context of each unique individual, and (5) heterogeneity is the rule rather than the exception in adjustment. Each of these concepts is further described below.

Chronic Illness Necessitates Adjustment in Multiple Life Domains

Adjustment in chronic illness is multifaceted and is more than just physical; it crosses interpersonal, cognitive, emotional, and behavioural domains. Adjustment is a holistic event in the client, with all domains being interrelated. Therefore, a change in one domain may affect adjustment in another domain (Stanton, Collins, & Sworowski, 2001; Stanton & Revenson, 2007; Stewart, Ross, & Hartley, 2004). According to Stanton and colleagues (2007), related conceptualizations of adjustment to chronic illnesses include “mastery of disease related adaptive tasks, preservation of functional status, perceived..."
quality of life in several other domains, absence of psychological disorder and low negative affect” (p. 567). Cognitive adaptation might involve personal self-evaluation or self-reflection. Adaptation in the behavioral domain includes returning to work or resuming the role of the “breadwinner” of the family. Anxiety, in the emotional domain, may affect the ability to socialize in the interpersonal domain or influence blood pressure in the physical domain. Emotional adaptation could be the absence of depression, and interpersonal adaptation may be the willingness to be “social” again. Again, each domain may affect the other.

Adjustment Involves Both Positive and Negative Outcome Dimensions

Typically, we think of outcomes of chronic illness as being negative, as evidenced by distress, psychological dysfunction, relationships in disarray, and so forth. As stated previously, one definition of positive adjustment is the absence of a diagnosed psychological disorder, psychological symptoms, or negative mood (Stanton et al., 2007). However, there may be a positive side of chronic illness as well.

It is not unusual to hear individuals with chronic illness say things like “having this disease has been the best thing that ever happened to me—it made me wake up to see what was important.” There may be positive aspects of chronic disease, but how clients come to view it in this way is not known. Folkman, Moskowitz, Ozer, and Park (1997), in their study of HIV-positive and HIV caregiving partners of men with AIDS, found that although study participants reported high levels of depressive symptoms, they also demonstrated positive morale and positive states of mind when compared with the general population norms.

One way to describe these paradoxical findings is a concept called response shift. Sprangers and Schwartz (2000) coined this phrase to describe a change in the meaning of one’s self-evaluation of a target construct as a result of (1) change in an individual’s internal standards of measurement, (2) change in the individual’s values, or (3) reconceptualization of the target construct.

Although anecdotally we consider negative outcomes of chronic illness more common, research demonstrates that positive adjustment may more accurately represent the adjustment experience of most individuals with chronic disease (Stanton & Revenson, 2007). This is because it is understood that a disease that disrupts life should not only preclude the experience of joy but sometimes create avenues for positive coping and growth.

Adjustment Is a Dynamic Process

Adjustment to chronic illness is neither linear nor lockstep (Stanton & Revenson, 2007). As exacerbations occur—as in rheumatoid arthritis or multiple sclerosis—the cancer recurs, or the physical limitations of heart failure increase, each change requires readjustment or readaptation. In addition, changes may not be limited to changes in one’s physical condition that affect adaptation but changes in the rest of the individual’s life. A spouse losing his or her job, a child getting seriously injured, and a parent no longer able to care for him- or herself are examples of factors that affect the adaptation of the client with chronic illness.

Adjustment Can Be Viewed Only from Within the Context of the Individual

There is variability in adaptation, and that is to be expected. From the context of the individual,
the physical symptoms, the functional changes, and the uncertainty may or may not be pertinent to the individual. Each stressor of the illness has a different relevance for each individual and as a result elicits a different reaction from each individual. The context of each individual is different, whether it is age, gender, ethnicity, or socioeconomic status. Other influencing contextual variables to adaptation to chronic illness include “interpersonal processes, personality attributes, cognitive appraisals, and coping processes” (Stanton et al., 2007, p. 570). The 35-year-old married woman newly diagnosed with breast cancer with three grade school–aged children has a different context than the 80-year-old woman with the same diagnosis. Although that is an extreme example, the variation that exists among individuals cannot be underestimated.

Heterogeneity Is the Rule, Not the Exception

Anecdotally, we know that if we put 20 women of the same age with the same stage of breast cancer and same prognosis in a room, each of those individuals will adapt to their chronic condition differently. Some will be considered by most as “well adjusted,” whereas others might be considered maladjusted. The remaining individuals may fall somewhere in the middle. The person’s individual determinants and uniqueness affect the ability of the individual to adapt to the illness. Although commonalities exist among individuals with chronic illness, there is significant variability as well.

Differences in individual adjustment abound in the literature. Helgeson, Snyder, and Seltman (2004) in a study of women with breast cancer from 4 to 55 months after diagnosis found that 43% of the sample evidenced high and stable psychological quality of life, 18% had a somewhat lower quality of life, 26% evidenced low psychological functioning, and 12% had an immediate and substantial decline in psychological function.

Dew and colleagues (2005) identified five groups of distinct distress profiles in heart transplantation patients over several years: (1) consistently low distress, (2) consistent, significant levels of distress, (3) high distress for the initial 3 months, (4) high distress at 3 years, and (5) fluctuating distress.

THE SELF IN CHRONIC ILLNESS

Chronic illness changes the body and forces identity changes (Brink, 2009). Before illness, most individuals take their health for granted. Any disruption of normality may cause a threat to the self (Charmaz, 1995). Bury (1982) conceptualized this as a biographical disruption. The meaning of the illness and biographical disruption vary in significance for the individual and family. One’s self-concept and self-confidence may change due to chronic illness. Morea, Friend, and Bennett (2008) refer to the illness self-concept. According to the authors, the illness self-concept is the integration of illness into the self that in turn affects the adjustment to chronic illness.

Brink (2009), in her study with patients post-myocardial infarction, identified two different behaviours in her model: self-modifying and self-protecting behaviours. For example, self-protecting behaviours may block lifestyle changes. Individuals with self-modifying behaviour reoriented themselves to the situation and accepted the consequences of the illness. Identifying a client’s behaviour can better help the healthcare professional in planning appropriate interventions.
MODELS

As researchers we have a broad goal to understand the process of adaptation, predict outcomes, and modify interventions to meet the needs of our clients. A model that is able to perform all those activities is preferable for practice; however, a perfect model does not exist at this time. What follows are sample models from the literature.

Biomedical Model

The medical model provides a framework for assumptions about the nature of health and illness. The client is a complex set of anatomical parts and interrelated systems. Anatomical, physiological, and/or biochemical failures translate into aetiologies of ill health, thus promoting a disease-oriented approach to care. This theoretical perspective of chronic illness is reflected in the language and actions of healthcare professionals who refer to “the diabetic in room 328” rather than to Mrs. Sanchez, who has diabetes.

Pathophysiology, pharmacotherapy, and technology are emphasized and become prominent in the diagnosis and intervention of all illness and disease, albeit acute or chronic. Antonovsky (1979) considered the medical model a dichotomous model. If pathology is present, then there is illness, and wellness or health is not possible. Explanatory assumptions and theories are used for determining the cause of symptoms, and uniformity of causality and treatment of disease are inferred.

The biomedical paradigm tends to medicalise all human conditions in which 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 (Sakalys, 2000) and diminishes social and cultural explanation of disease (Mirowsky & Ross, 2002). Physical complaints and signs or symptoms of disease become the hallmarks of interaction and discourse within the healthcare arena.

The relationship between the healthcare professional and the client 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, whereas their skill sets, techniques, and procedures become the focus of interaction with the client (Freeth, 2007). Power and expertise are held exclusively by the healthcare system, and the interactions between the healthcare professional and the client are directive and unbalanced. The individual with chronic illness becomes disempowered to engage in his or her own healthcare decisions and relies solely on the healthcare professional.

The biomedical model is insufficient in providing health care to individuals with chronic illness (Waisbond, 2007), because it fails to acknowledge the breadth and depth of the illness experience. This model reduces chronic illness to just biological processes, conceptualises a separation of a mechanistic body from other aspects of the individual, and emphasises finding a cure or a fix. The medical 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, who is retired and surviving on old age security payments, becomes anxious that she will not have enough money to...
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purchase her prescriptions for her hypertension. Although she is able to financially manage otherwise, Mrs. Jones’ stress and worry exacerbate her hypertension. Mrs. Jones’ physician does not anticipate that the probable cause of her elevated blood pressure is related to her stress. The physician responds to Mrs. Jones’ hypertension with a change of medication to manage her symptoms. The quantification of all signs and symptoms of disease fails to address the total illness experience of the individual. With increased attention to genetic research and genetic technologies, the biomedical theories of disease continue to be reinforced, with less emphasis on the individual’s social context and experiences (Dixon-Woods, 2001).

Despite the limitations of the biomedical model in adaptation, its usefulness is apparent during the acute phase of chronic illness. Although the focus of the biomedical model is limited to disease and organic dysfunction, this model is central for adaptation to chronic illness, particularly at the time of diagnosis when individuals and families are overwhelmed with a new diagnosis and sorting out the facts about the illness. In addition, during periods of illness exacerbations the biomedical model helps explain signs and symptoms and may provide a source of retreat and relief, depending on the stage of the chronic illness. There are times when individuals and families need current information about the chronic illness, signs and symptoms, the anticipated trajectory of the illness course, the array of treatment modalities, and traditional as well as alternative strategies. The biomedical model is the foundation for evidence-informed healthcare practice and provides the gold standard for treatment and intervention. Consequently, this model provides measurable goals for treatment and client outcomes relative to morbidity and mortality.

Lazarus and Folkman Model

Although there are other stress and coping models, none is better known than the one developed by Richard Lazarus and Susan Folkman (1984). Their model, a cognitive phenomenological theory of stress, views adaptation to chronic illness through the lens of adapting to stressors. It is a transactional model of stress and coping, meaning that antecedent variables, such as personality traits, past experiences, and disease and treatment variables, act via mediating variables, such as coping strategies, to facilitate outcomes and, in this case, adaptation. Stressors are mediated by primary appraisal, which is the individual’s gauge of the significance and importance of the stressor. Primary appraisal is influenced by the background, experiences, culture, ethnicity, and personality of the individual and is therefore characterized by stability across situations (Folkman, Lazarus, Gruen, & DeLongis, 1986).

The second step of the model is secondary appraisal of the situation. The individual asks the question, “What can I do about this situation?”, and this leads to the coping strategies used to manage the stressor. Secondary appraisal is influenced by the physical and social environment and may be context specific (Stewart et al., 2004). To adapt involves applying the coping strategies that are most appropriate to the situation. Individuals use both problem-focused coping and emotion-focused coping. Originally, Lazarus and Folkman presumed the goal for all individuals was to use problem-focused coping and that emotion-focused coping yielded poor adaptation to the stressor, in this case the illness. However, work since 1986 has supported a place for emotion-focused coping as well as problem-focused coping (Stewart et al., 2004).
Engel’s Biopsychosocial Model

Clearly, a model that could address both the biological and psychosocial aspects of chronic disease is a preferred one for health care. Engel (1977) was perhaps one of the earliest authors of such a model that offered a welcome alternative to the narrow biomedical model of understanding illnesses. Engel’s model suggests “that to understand and respond adequately to patients suffering and to give them a sense of being understood, clinicians must attend simultaneously to the biological, psychological, and social dimensions of illness” (Borrell-Carrio, Suchman, & Epstein, 2004, p. 576).

Engel’s model outlined three ways in which a psychosocial factor could influence a health outcome: direct, indirect, and moderating. A direct effect is a belief or value of the client that would preclude him or her from a specific medical intervention. An indirect effect is defined through a mediational process (Stewart et al., 2004). An example is an individual’s current symptoms, for instance, nausea and vomiting, decreasing the client’s motivation to participate in a prescribed exercise regimen and thereby decreasing physical functioning. A moderating effect alters the causal relationship between a psychosocial factor and a health outcome.

Livneh and Antonak Model

Livneh and Antonak (1997), working from previous models, proposed that variables associated with chronic illness and disability could be organized into four main categories/steps: (1) disability related (e.g., type of condition, such as terminal vs. nonterminal), (2) sociodemographic factors of the individual (e.g., gender, age, ethnicity), (3) individual differences or personality (e.g., coping strategies, locus of control, personal meaning of the condition), and (4) physical and social environmental factors (e.g., social support, stigma). The interactions of these classes of variables significantly affected adaptation.

Livneh and Antonak (1997) also saw the adaptation process as different from adaptation itself. They theorized that the process of adaptation was fluid and dynamic, whereas adaptation status was the result or outcome of the process (Stewart et al., 2004).

Common Sense Model of Self-Regulation

The common sense model of self-regulation posits that the client’s illness beliefs and representations of that illness influence adaptation to the illness and health outcomes (Leventhal, Leventhal, & Cameron, 2001). According to the model, patients develop cognitive and emotional representations of their condition to “make sense” or find meaning in the illness. Leventhal and colleagues (2001) identified five dimensions that represent a client’s view of their illness:

1. **Identity of the illness**: connecting the symptoms with the illness and having an understanding of the illness
2. **Timeline**: duration and progression of the illness
3. **Causes**: perceived reason for the illness
4. **Consequences**: the physical, psychosocial, and economic impact of the illness
5. **Controllability**: whether the disease could be controlled or cured

After identification of these dimensions, Leventhal and colleagues believed that coping and appraisals follow. Significant evidence showed that an individual’s representation and perception of the illness will determine what
common sense health behaviours and coping mechanisms were used to deal or cope with it. As such, “coping decisions will differ as a function of the meaning individuals assign to their symptoms (i.e., their illness representations), and this interpretive process will reflect their past illness experiences, social expectations, information from friends, media and medical practitioners” (McAndrew et al., 2008, p. 196).

**Moos and Holahan Model**

Stewart and colleagues (2004) suggested that an ideal model for adaptation should address four criteria: (1) the reciprocal influences of biological, psychological, social, and behavioural variables of the client and the disease process; (2) the broad application to clients with a wide range of chronic illnesses and conditions; (3) the ability to address the influences of culture, gender, ethnicity, and life stage of the client; and (4) the ability to predict the level of client adaptation, which will then lead to appropriate interventions for the client.

Currently, a search of the literature does not identify any “ideal” models that can meet the preceding criteria. Moos and Holahan (2007), however, developed a simple model that provides a framework to view adaptation. Because of its ease of use and understanding, more detail is provided on this model. Moos and Holahan’s framework (Figure 5-1) is a way of conceptualizing coping and integrating it into a broader model.

The common sense model has been used extensively as a framework in research in chronic illness. Several examples follow:

- Curable/controllable illness is related to better health and functioning (Hagger & Orbell, 2003)

**FIGURE 5-1** Conceptual model of the determinants of health-related outcomes of chronic illness and disability.

• Prediction of disability by illness beliefs in clients with rheumatoid arthritis (Graves, Scott, Lempp, & Weinman, 2009)
• Use of common sense model to improve adherence with cardiac rehabilitation programs among women with heart disease (Shifren, 2003)
• Application of the model to understand diabetes-related distress (Paddison, Alpass, & Stephens, 2010)
• Using common sense model to analyze patient descriptions of cancer-related fatigue (Barsevick, Whitmer, & Walker, 2001)

According to the model, five sets of factors are associated with the selection of appropriate coping skills and the resulting health-related outcomes, in this case, adaptation. The model includes three factors that influence cognitive appraisal: (1) personal resources (panel I), (2) health-related factors (panel II), and (3) the social and physical context (panel III). Cognitive appraisal (panel IV) then dictates what adaptive tasks (panel V) need to be accomplished. Panels I through V mediate the choice of coping skills (panel VI), leading to Panel pII, the outcome.

**Personal Resources and Culture**

This broad category includes intellectual ability, ego and self-confidence, religion, and prior health-related and coping experiences. Demographic characteristics, such as age, gender, ethnicity, culture, and education, are included in this category as well. Personal resources include personality—which may be viewed as either a risk factor or protective factor (Stanton et al., 2007)—locus of control, optimism, and autonomy. Individuals who have a more internal locus of control, higher self-confidence and self-efficacy, and a stronger sense of coherence are more likely to rely on problem solving than other aspects of coping (Moos & Holahan, 2007).

In Canada a discussion on coping and adaptation must encompass the sociopolitical realities of the country. Canada as a country presents itself as a model for multiculturalism, described by Leong and Wong (2003) as a “socio-political policy that endorses diversity, inclusiveness and equality, while recognizing the legitimacy and values of ethnic differences and cultural heritage” (p. 4). Ethnic group membership is associated with many psychological processes such as identity, group pride, and discrimination (Stanton et al., 2007). Each ethnic group or culture may have different values and beliefs that affect illness perceptions that, in turn, may affect adaptation (Cohen & Welch, 2000). For some cultures chronic disease and disability may produce stigma such that adaptation is not possible. Degazon (1995), while exploring ethnic identification and coping strategies, found a significant relationship between the ethnic groups with which the individual is identified and the coping strategy used.

Social and cultural factors are known to influence individuals’ appraisal of stress and shape their coping responses. Iwasaki and Bartlett (2006) emphasized that “culture plays a central role in explaining leisure stress-coping mechanisms” of people with First Nations origin who have diabetes “whether these are tied to collective strengths, cultural identity, spiritual renewal, or physical/behavioural benefits” (p. 321). Aboriginal people’s seemingly positive adaptation and coping with diabetes mellitus could be explained by “their recognition of the importance of spirituality, culture, values and traditions,” which reinforces their “hopes for
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healing” (Sunday et al., 2001, p. 80). In a similar study Demers, Robichaud, Gelinas, Noread, and Desroisiers (2009) explored the association of behavioural strategies and social participation among older adults and suggested that behavioural coping strategies were important as a mechanism for reducing the effects of stressful events or difficulties associated with aging. These studies examined coping specifically; however, the relationship of coping with adaptation is uncertain. In addition, it is clear that little is known about the implications of culture and ethnicity in disease-related adaptation (Stanton et al., 2007).

The uniqueness of each individual influences how the chronic condition is appraised, what coping strategies are used, and how and if adaptation can be achieved. For instance, pessimists report higher levels of hostility and depression on the day before coronary artery bypass graft surgery than do optimists (Maes, Leventhal, & deRidder, 1996). Clients who are optimists tend to cope in a more active, problem-oriented way as opposed to pessimists, who tend to use more avoidant or passive ways of coping. It is not clear how specifically these personality traits influence and affect coping. Carver, Scheier, and Weintraub (1989) noted that the impact of personality characteristics on coping is modest and that coping preferences exist independently of personality factors. Although coping preferences could be viewed as personality attributes, they may influence coping indirectly through their impact on appraisal (Maes et al., 1996).

Socioeconomic class affects health outcomes directly and through environmental mechanisms, including access to care and risky and protective health behaviours (Stanton et al., 2007). Although it can be conceptualized as a determinant of adaptation, the pattern is not unidirectional (Stanton et al., 2007). Chronic conditions often influence work patterns and work disability. Work-related disability and loss of a job can decrease an individual’s socioeconomic status.

Health-Related Factors

These factors include the type of onset and progression of the chronic condition, the location of symptoms, the prognosis, and the type of disability. Disease and treatment-related factors are often considered exogenous variables in adaptation (Stanton et al., 2001). A disease factor could be the stigma that the individual (and/or family) associates with the condition. Other disease factors could include a change in body image, declining mobility, extreme fatigue, and so forth. However, the existence and impact of disease factors may actually be influenced significantly by other determinants, such as ethnicity, socioeconomic status, and social support. For example, aboriginal individuals with diabetes suggested their stress was compounded by broader structural systems and dynamics at different levels: “socio-economic, cultural, historical and political levels” (Iwasaki & Bartlett, 2006, p. 321). Many studies do not reveal significant relationships of disease-related factors with adjustment (Stanton et al., 2001). The disease stage of a chronic condition is related inconsistently to adjustment (van’t Spijker, Trijsburg, & Duivenvoorden, 1997).

The characteristics of the disease and of treatment contribute to the appraisal of the disease-related event. Surgery, monitoring of physical symptoms (e.g., blood glucose), diet, radiation, chemotherapy, and all the side effects...
of treatment are important components in how the client appraises the situation.

**Social and Physical Context**

This context includes the relationships between the individuals with the chronic disease, their family members, caregivers, and social network. House (1981) described social support as supportive behaviours and resources of individuals’ social ties that include emotional support, intimacy, positive interaction, and tangible support. A supportive social context can enhance self-efficacy, transforming appraisal of a health condition as a challenge rather than a threat, and enhance reliance on approach coping. When family members or friends do not convey interest, individuals with serious chronic conditions may avoid talking about their problem and be less likely to cope with the illness-related demands (Norton et al., 2005).

In general, social support is related to positive adaptation in several chronic diseases (Stanton et al., 2001). However, studies differ in how social support is conceptualized. Social support has been used as a coping strategy, a coping resource in the environment, and considered dependent on personality attributes and coping of the individual (Schreurs & deRidder, 1997). Interpersonal relationships can both aid and hinder adaptation to chronic illness, especially in cultures such as the aboriginal people of Canada. For such cultures, “the potential for social support to negatively influence health becomes increasingly apparent” (Richmond & Ross, 2008, p. 1425). For women in particular, interpersonal relationships are vital components of their adjustment to major stressors (Cummins, Ireland, Resnick, & Blum, 1999; Revenson, 1994).

**Cognitive Appraisal**

Appraising the illness is the first step in deciding the adaptive tasks that need to be accomplished. This is also the step in the adaptation process where the illness is appraised as either a challenge or a threat. How the illness is appraised, whether it is controllable or threatening, determines appropriate adaptive tasks and subsequent coping strategies. Using Lazarus and Folkman’s model, primary appraisal of the “threat” or “event” includes the appraisal of harm or loss that has already occurred, or threatened harm or loss (Folkman & Greer, 2000), and includes an evaluation of its personal significance (Walker, Jackson, & Littlejohn, 2004). Secondary appraisal occurs when one assesses the situation’s controllability and compares it with one’s available coping resources.

The individual who appraises a diagnosis of multiple sclerosis as a death sentence will make very different decisions regarding treatment than another individual who sees hope. With such different appraisals, coping and adjustment will be very different in these two individuals.

**Adaptive Tasks**

Moos and Holahan (2007) identified seven adaptive tasks. Three of the seven tasks are related to the health condition and its treatment and the other four are more general and could apply to all life crises and transitions, not just chronic illness. The tasks are (1) managing symptoms, (2) managing treatment, (3) forming relationships with healthcare providers, (4) managing emotions, (5) maintaining a positive self-image, (6) relating to family members and friends, and (7) preparing for an uncertain future (Moos & Holahan, 2007).
CASE STUDY

It was 5 months after Dan was reunited with his wife and two daughters that he began to experience sleep disorders, night sweats, nightmares, and “flashbacks” of the horrors of war he had experienced while he was deployed to Afghanistan. There he had seen many of his buddies killed and injured. He, too, was injured by enemy fire but had healed and recovered. Dan found himself withdrawing from his family, and he no longer wanted to participate in his children’s sporting events. He was experiencing conflict and difficulty at work. At a recent visit with his healthcare provider Dan was diagnosed with posttraumatic stress disorder. Dan was devastated. He believed he had left his fears and memories of violence in Afghanistan. Dan had assumed he would return to his previous happy life with his family. Doubts and questions about his future rushed over him. What would he and his family need to do to return to and maintain secure and safe relationships? Would he be able to return to work? Would he be able to enjoy his children’s activities and events? Would his life ever return to “normal”? Where would all of this end?

Discussion Questions

1. What personal resources, health-related factors, and social and physical factors are contributing to Dan’s cognitive appraisal of the situation?
2. Compare and contrast the biomedical model and the Moos and Holahan model for adaptation for Dan and his chronic condition.
3. Discuss the role of the nurse for Dan and his family.

OVERVIEW OF COPING

Richard Lazarus’s 1966 book, Psychological Stress and the Coping Process, was an initial scholarly work that expanded how coping was conceptualized. Since that time the coping literature has increased significantly, with researchers undertaking studies to understand why some individuals fare better than others when encountering stress in their lives (Folkman & Moskowitz, 2004). Coping is described by Folkman and Moskowitz as “the thoughts and behaviours used to manage the internal and external elements of situations that are appraised as stressful” (p. 745). It 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 in the last 45 years 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
Overview of Coping

stand-alone concept or phenomenon but embedded in a complex, dynamic process that involves the person, the environment, and the relationship between them.

Lazarus and Folkman (1984) described problem-focused and emotion-focused coping strategies. Problem-focused strategies alter person–environment relationships, and the purpose of emotion-focused strategies is to regulate internal states. Initially, problem-focused strategies were seen as “better” or as able to influence health outcomes in a more positive manner. However, since Lazarus and Folkman posited their original work, that view has changed. Emotion-focused coping strategies may specifically assist in developing and sustaining a sense of psychological well-being, despite unfavourable circumstances (Folkman & Greer, 2000).

Other theorists have used different terms to describe coping. In addition to problem-focused and emotion-focused coping, meaning-focused coping has been identified as a type of coping in which cognitive strategies are used to manage the meaning of the situation (Folkman & Moskowitz, 2004). Passive coping, which includes avoidance, and active coping, which is nonavoidance coping, were described by Shaw (1999). This two-factor structure of coping is incorporated into the coping framework as an antecedent to the behavioural intention to cope as well as to carry out the coping behaviour. It is likely that individuals may have a number of coping responses at their disposal, although each individual may have their own preferred styles based on their personality attributes (Shaw, 1999).

An issue in studying coping is that the coping strategy needs to be evaluated in the specific context in which it is used (Folkman & Moskowitz, 2004). Coping strategies are not inherently good or bad, but instead their effectiveness depends on the context in which they are used. Evaluation of the effectiveness of coping requires, first, selecting the appropriate outcomes and, second, paying attention to the fit between the coping and the situation (Folkman & Moskowitz, 2004).

Adaptation/Adjustment

What do we know about adaptation? It is a complex construct (like coping), it is multidimensional, and it is holistic. However, it is rarely measured holistically in studies. Consensus does exist regarding the centrality of an individual’s appraisal of their adjustment. It is the client’s adjustment and perception, not the healthcare professional’s (Stanton et al., 2001).

We also understand that emotionally supportive relationships set the stage for positive adjustment, whereas criticism, social constraints, and social isolation induce risk (Stanton et al., 2007). Active approach-oriented coping strategies manage disease-related challenges and may bolster adjustment, whereas concerted efforts to avoid disease-related thoughts and feelings are predictors of distress. Two basic conclusions come from the descriptive research literature: Most individuals appear to “adjust” well to chronic illness, and there is considerable variability in adjustment both across studies and across individuals within single studies (Stanton et al., 2001).

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. Some of these are easily “measured.” For example, absence or presence of a psychological disorder could be ascertained with a degree of certainty. However, other conceptualizations cannot.

Maes and colleagues (1996) believed that definitions of adjustment are too simplistic, as many studies operationalise adjustment in terms of psychological outcomes and neglect the medical, cognitive, or social outcomes. Positive adjustment is not merely the absence of pathology. Typical indicators of adjustment in research are positive and negative effects and represent two very different dimensions. Therefore, using only lack of depressive symptoms to indicate adjustment will yield a partial picture of adjustment (Stanton et al., 2001). Maes and colleagues posit that although anxiety and depression are important markers of adjustment, assessment of everyday life behaviours and activities may be much more relevant.

deRidder and colleagues’ 2008 article appears to typify Maes and colleagues’ concern. The primary emphasis is on psychological effects, as noted by the title of the article, “Psychological Adjustment to Chronic Disease.” The more appropriate term, from this author’s point of view, is psychosocial adaptation, because it more clearly defines and describes the whole person than does psychological adaptation, which is too narrow.

The concept of hardiness was studied in the 1970s (Kobasa, 1979) and into the late 1980s (Pollock, 1989). Brooks (2003) analyzed 125 articles published from 1966 to 2002 to determine the significance of hardiness in adaptation. This “personal resource,” within Moos and Holahan’s (2007) framework, demonstrated a significant relationship to psychological, psychosocial, and physiological adaptation. Higher levels of hardiness had positive outcomes in clients with chronic illness (Brooks, 2003).

The current literature on hardiness is scarce; however, Brooks (2008) used a cross-sectional survey design involving 60 participants to look at the effect of health-related hardiness. Individuals who had higher health-related hardiness had better psychosocial adjustment to their illness. Additionally, individuals with higher health-related hardiness had a higher self-perception of their health status (Brooks, 2008).

How coping is related specifically to adjustment has not been clearly described (Sharpe & Curran, 2006). Intellectually, we believe coping strategies do contribute to adaptation and may be a mediator, but they probably interact with other factors in contributing to adaptation (Stanton & Revenson, 2007).

Berg and Upchurch (2007) advanced a model that speaks to dyadic coping and adjustment. Their development–contextual model of couples coping with chronic illness views chronic illness as affecting the adjustment of both the client and the spouse such that coping strategies enacted by the patient are related to those enacted by the spouse and vice versa. In a sample of 190 couples in which the women had rheumatoid arthritis, Sterba and colleagues (2008) demonstrated that couple congruence concerning women’s personal control over rheumatoid arthritis and its cyclic nature predicted better psychological adjustment in women longitudinally.

In the chronic pain literature acceptance is a more common concept than coping variables used to described how clients adapt to chronic pain. Acceptance includes responding to
Overview of Coping

Resilience

Resilience represents the “ability to survive and even thrive in the face of adversity” (Smith, Boutte, Zigler, & Finn-Stevenson, 2004, p. 214). It is linked to the constructs of coping and adaptation (Maluccio, 2002). Although resilience captures a wide range of experiences, it is most notably understood as the ability to adapt in the face of adversity. Resilience helps people cope (Black & Ford-Goeb, 2004). Kralik, vanLoon, and Visentin (2006) used interactional processes inherent in participatory action research to explore the concept of resilience. In this collaborative inquiry, data were gathered through email discussion groups. Data analysis revealed resilience meant having a strong sense of self-worth, the ability to benefit from experiences, and the capacity to adapt. Resilience is a process of reflection, learning, and action directed at overcoming adversity.

Interventions

The literature provides an abundance of descriptive studies measuring coping and/or adaptation, but few interventional studies exist. It appears that we can measure coping or adaptation but are unable to conceptualize those results into interventions or ways we can help clients better cope with or adapt to chronic illness.

Stanton and Revenson (2007) suggested that we improve the interpersonal context of our clients 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 are directed toward individual-level change and may include cognitive-behavioural, educational, and interpersonal support components. Support groups may provide emotional support as well as an educational focus. The education is expected to strengthen one’s sense of control over the disease, reduce feelings of confusion, and enhance decision making (Stanton & Revenson, 2007). The peer support provides emotional support and thus enhances self-esteem, minimizes aloneness, and may reinforce coping strategies.

An earlier study that is still referred to frequently in the literature is that of Folkman and colleagues’ (1997) coping effectiveness training with HIV-positive men. This interventional study, based on Lazarus and Folkman’s (1984) stress and coping theory, was effective in increasing the quality of life in these men. The training included (1) appraisal training to disaggregate global stressors into specific coping tasks, (2) coping training to tailor application of strategies, and (3) social support training.

Nurses may be wise to capitalize on a client’s religious beliefs and partner with clergy to effect adaptation (Loeb, 2006). Programs related to health education and screening, support groups, and physical activity that are based in a church may be helpful. Barg and Gullatte (2001) explained that church-based health programming can frame health information in a way that may better fit with a client’s view of life, that is, their relationship with God. It is also important for health practitioners to recognize and encourage culturally appropriate coping methods for diverse cultures. Cultural resilience, according to Walters and Simoni (2002), represents culturally relevant coping strategies that in the case of
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aboriginal women may include enculturation, spiritual coping, and traditional healing practices. These Walters and Simoni described as “indigenist” stress coping models.

From another perspective, Pakenham (2007) highlighted the need for practitioners to facilitate clients’ cognitive processing of the implications and meaning of their illness. A blend of cognitive-restructuring strategies, client-centred approaches, and existential approaches may be helpful to the client and family.

Cognitive-Behavioural Strategies

Cognitive-behavioural strategies can be used to teach coping skills to clients with chronic illness (Folkman & Moskowitz, 2004). Sharpe and Curran (2006) also encouraged the use of cognitive-behavioural treatments, as the research literature is clear that cognitive-behavioural treatment is effective in managing psychological distress associated with illness. 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/behavioural approach that was used with clients with diabetes. The approach begins with a focus on behaviour 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 clients who have asthma with a conceptual framework that focuses on asthma being present even when it is asymptomatic (McAndrew et al., 2008). The authors suggest that clients may benefit from starting with one strategy or the other. However, it is expected that successful interventions will combine both approaches.

Emotional Intelligence

Emotional intelligence describes the ability to understand, perceive, use, and manage the emotions of self and others (McKenna, 2007). Emotional intelligence training includes six spheres of emotional competence: emotional openness/adaptation, the impact on and of others, self-esteem/identity, management of stress, communication skills/social functioning, and goal management and motivation. It is suggested that emotional self-management can affect the adjustment of individuals with chronic illness, and this can be enabled by the use of emotional intelligence techniques by healthcare professionals (McKenna, 2007).

Psychosocial Rehabilitation

Breast cancer survivors attended a 1-week psychosocial rehabilitation course consisting of moderate physical activity, lectures, group work, and addressing concerns about returning to work. The workshop was led by a multidisciplinary team. The researchers used the common sense model of self-regulation as a framework for the study. Results demonstrated that illness perceptions of breast cancer survivors were not changed by a short psychosocial rehabilitation program (Jorgensen, Frederiksen, Boesen, Elsas, & Johansen, 2009).
Overview of Coping

Self-Management Programs

Based on the literature on chronic illness self-management, Swendeman, Ingram, and Rotheram-Borus (2009) identified three broad categories in chronic disease self-management: physical health, psychological functioning, and social relationships. Elements related to physical health were knowledge and behaviour to maintain health status, whereas elements related to psychological functioning included self-efficacy and empowerment as well as emotional status and identity shifts. Social relationship elements related to collaborative partnerships with healthcare professionals and family members and social support. Self-management programs based on enhancing self-efficacy are highly successful in reducing symptoms and encouraging behaviour change in many chronic illnesses (Newman, 2006). Self-efficacy could be considered a personal context variable and thus may be a determinant in the appraisal of the illness, the coping strategies used by the individual, and the outcome (the physical, emotional, and social adaptation). Although self-efficacy is task and situation specific, programs that encourage that concept could influence adaptation. Significant improvements in health dimensions were recorded for clients with chronic illness who attended a self-management course in Australia (Bell & Orpin 2006).

Self-Help Groups

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 examines such support groups for a short period—6, 10, 12, and 15 weeks—whereas a chronic illness can be present for 30, 40, or 50 years. Therefore, the outcome that we might see in such studies is greatly diminished as the studies demonstrate outcomes at one point in time.

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 status. Often, this comparison occurs within self-help groups, which consist of individuals with similar circumstances. It has been suggested that downward comparison, where comparison is made with a person who is doing less well, will initiate positive affect as it increases self-esteem. Conversely, upward comparison with a person doing less well may result in hope (Dibb & Yardley, 2006). Results of the study with 301 clients with Ménière’s disease demonstrated that positive social comparison was associated with better adjustment after controlling for other baseline variables, whereas negative social comparison was associated with worse adjustment over time.

Positive Life Skills

In a sample of 187 HIV-infected women, a positive life skills workshop was effective in increasing antiretroviral adherence, improving mental well-being, and reducing stress (Bova, Burwick, & Quinones, 2008). The workshop consisted of 10 weekly sessions with 6 to 15 women in each group. Workshop facilitators shared a vision of a safe, positive, and respectful environment for women to learn and experience. Part of the workshop involved reframing negative meanings.
**SUMMARY**

The literature on adjustment has been mostly spearheaded by the discipline of psychology. Thus, the theme of that literature is psychological adaptation versus psychosocial adaptation. Unfortunately, this narrow focus only addresses one component of adaptation. Psychosocial adaptation or adjustment better encompasses the totality of caring for the client and family. Examining the literature also demonstrates the lack of studies that focus on clients from different ethnicities, cultures, and socioeconomic groups. Most studies have been done with White, middle-class populations (deRidder et al., 2008). Thus, the generalisability of these studies is limited. What is clear is that we have a long way to go in understanding, effecting, measuring, and influencing adaptation. With the increasing number of individuals with chronic disease, continuing research and study need to be pursued in this area.

**Evidence-Informed Practice Box**

Adaptation in chronic illness is a multidimensional construct. Adjustment to chronic illness requires attention to medical management of the disease as well as cognitive, emotional, behavioural, and psychological factors of daily life. Multiple sclerosis (MS) is a chronic illness noted for unpredictability of symptoms and progression of illness as well as variability in day-to-day symptoms. The chronic and uncertain nature of MS requires coping and adjustment not only for persons with MS but for their families as well. Little research has been conducted to identify successful or unsuccessful adaptation to MS. Previous research focused on the experience of caregivers rather than how couples work in concert to navigate alterations in their roles and responsibilities.

Starks, Morris, Yorkston, Gray, and Johnson (2010) conducted a mixed methods study with couples in which one partner had MS. The purpose of the research was to identify strengths and adaptive coping behaviours as well as risk factors for relational stress. Data were collected through semistructured interviews with eight couples to explore how these couples defined and identified their relationships, how they navigated role changes, and how they received external support. Data analysis was guided by a conceptual framework of family adaptation to chronic illness. Results included two patterns of adaptation to MS: “in sync” or “out of sync.” Couples in sync were able to transition to managing MS as a chronic illness and to continue to do things of importance to them, including work and leisure activities with family and friends. These couples were able to adjust their goals and expectations to the realities of their lives and maintain a collaborative problem-solving style. Couples out of sync had experienced loss of roles, identity, and self-worth as a result of the rapid progression of functional losses. Differences in personal styles in these couples shifted from being complementary to oppositional in the face of increased demands and struggles.

This research identified mechanisms for adaptation that can assist healthcare professionals in caring for persons with MS and their families. This study provides a guide for healthcare professionals to
assess the possible risk factors for relational strain in couples with MS and identify families who might benefit from referrals to family therapy or other relational support. Further, results from this research have applicability for persons with other chronic illnesses and their families and provide a resource for healthcare professionals for interventions to facilitate adaptation to chronic conditions.

Source: Starks et al. (2010)

Study Questions

1. Why is adaptation to chronic illness important to the client and family with chronic illness?
2. Describe how different personal resources could affect adaptation.
3. Compare and contrast the key concepts of the models discussed in this chapter. What are the overlaps in these models? What are the missing elements in these models that would facilitate adaptation?
4. Apply the adaptation framework of Moos and Holahan to one of your clients with chronic illness. What fits? What does not fit?
5. From your perspective, what is social support’s relationship to adaptation? What is your experience with the role of social support in the adaptation of your clients?
6. Develop a generic teaching plan that addresses adaptation to chronic illness. What are key points that could then be individualized to clients?

References


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References


