

## Psychological models of adjustment to chronic illnesses

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### Abstract:

The uncontrollable and unpredictable nature of a chronic illness, in addition to experience of fear, anger, uncertain about future and sorrow makes a person to perceive the disease as a dangerous factor. During the 20th century theories of coping has aroused from two traditions including psychodynamic thought and cognitive psychology. Over time, three concepts of a search for meaning in the experience; an attempt to gain a sense of control or mastery over the illness; and an effort to restore self-esteem were considered as effective factors in adjustment to chronic illness. In later studies, researchers gradually became interested in the structure of coping, and contextually-based models of coping as well as the sociological model, integrative, biopsychosocial model, and interactive model were presented. With increasing knowledge and understanding of the consequences of chronic disease, personal resources such as demographic characteristics, intellectual ability and personality characteristics as well as health-related factors such as disease severity, location and type of disability, health-care environment and treatment procedures were added to previous factors of psychological models. Recently acute stressor or critical events such as initial diagnosis, change in prognosis, progression, and/or disability were also considered in presenting a model of psychological adjustment to chronic illnesses. Further progress on the issue of psychological adjustment to chronic illness was the understanding of the role of stress on the immune system. In this way stressor ultimately impacts on disease/syndrome activity, which in turn influences physical adjustment outcomes, via interactions between psychosocial variables that influence neuroendocrine and immune mechanisms.

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## Introduction

With the advancement of medicine, the reduction of mortality, and the increase in life expectancy resulting from it, chronic diseases are one of the most challenging human issues today. There are a range of definitions of chronic illness. In response to the question of what is chronic illness it can be said most chronic illnesses share five important biological characteristics:

- 1) They are systemic, affecting multiple body systems and a wide range of physical and social functions;
- 2) They are lifespan problems, that is, they develop over many years though most become clinically visible only in late middle age, that is 60 years of age and over,
- 3) They can be controlled but few can be cured;
- 4) Many, though not all, have an insidious character, that is, they impinge gradually on an increasingly wide range of activities; and
- 5) many are characterized by relatively quiet, tonic phases, punctuated by severe, episodic flares or dramatic onset of complications (1).

Burish and Bradley (1983) distinguished between acute, infectious diseases and chronic illnesses on four primary dimensions:

- (a) The cause, for which acute illnesses are a result of infectious agents, while chronic illnesses often are a result of lifestyle choices;
- (b) Time-line, for which acute illnesses are brief and last a somewhat predictable period of time, while chronic illnesses “have a slow, insidious onset and endure over a long and indefinite period”

- (c) Identity, for which the individual has an idea of what is wrong and is able to readily identify the symptoms that are connected to specific causes, whereas chronic illnesses may not have a single, specific cause and may not manifest obvious symptoms until the illness is in an advanced stage (e.g., cancer or heart disease); and
- (d) Outcomes, for which acute illnesses will be cured over time with proper treatment, while chronic illnesses will continue to exist (despite treatment), for the remainder of a person's life.

Chronic illness, due to the changes and limitations it causes, have the potential to profoundly impact people's day-to-day lives. Most individuals cope reasonably well with such a crisis. Some individuals emerge with a more mature outlook and a richer appreciation of life, but others are demoralized and suffer lasting psychological problem (2).

Although some patients with chronic illness can give meaning to the disease and focus on the positive experience of being infected and consider it as a factor in their personal growth (3), most people consider the onset of a chronic illness as a negative event. This is evident not only by individuals' reactions (e.g., anxiety, anger, depression) when a chronic illness occurs, but also by the reactions (e.g., frustration, anxiety, confusion, avoidance) of family members and friends. Living with chronic illness is often challenging (2). Being diagnosed with an illness confronts the individual with a new reality. The uncontrollable and unpredictable nature of a chronic illness, in addition to experience of fear, anger, uncertainty about future and sorrow makes a person to perceive the disease as a dangerous factor, so his or her daily life becomes a challenge. Shifts in goal orientations, a new role as "patient", impairments in bodily function and uncertainty regarding the future are some of these challenges. According to Charmaz & Rosenfeld (2010) the presence of a chronic illness alters an individual's sense of self, as the previously held healthy identity is replaced by an illness identity that includes physical impairments, emotional reactions to physical symptoms, and cognitive constructions of the illness. A chronic illness heightens one's awareness of the body, challenges previously held beliefs about the self, influences relationships with others, and may alter an individual's plans for the future. Chronic illness also undermines the stability of the self by introducing a degree of uncertainty into life. Thus, an individual with a chronic illness must learn how the sense of self can accommodate the illness. (4).

The social consequences of disease such as stigmatization as well as changes in social, marital and family relationships, are other concerns of a person with chronic illness. Stigmatization is the process by which the society induce negative meaning on the individual behavior, signs or something about the patient. Goffman (1963) define stigma as a social mechanism by which individuals and groups are discredited; it reduces social status and creates 'spoiled identities'(5). He conceptualizes three types of stigma including *physical deformity* which is related to visible changes, *character blemishes* such as dishonest or weakness that society may view as causing an illness, and *tribal stigma* by which those of a particular race or religion are seen as different form or in opposition to the norm (6). The nature of chronic illness, typically means that the patient will rely long term on caregiving and support from their immediate family and significant others. Therefore, the effect of the disease is not only on the individual but also on all those who are in contact with the patient. Chronic illness and disability affect all facets of life, including social and family relationships, economic well-being, activities of daily living, and recreational and vocational activities. Although the extend of impact is dependent on the nature of the condition, individual personality, the meaning of the illness, individual current life circumstances and the degree of family and social support, the patient needs to go through an adjustment process to maintain their quality of life (7).

Albeit, adapting to chronic illness is a phrase commonly used in health psychology, the writings in this regard indicate that there is a little consistency in defining and explaining adjustment. Each author / researcher defines the term based on his or her own theoretical framework. Although some authors has defined adjustment based on preserving functional status and low negative affect in the face of illness, but preserving functional status in the face of progressive loss of physical functioning may not always be realistic. In some circumstances, such as receiving a diagnosis or disease progression, the absence of distress may be considered maladaptive. It is therefore important to view adaption as an ongoing process and to separate the process of adaption from the desired outcome from this process.

According to the Britannica Encyclopedia adjustment has been defined as a relative process that, through a change in people's lifestyles in stressful situations, maintains one's balance and ability to meet one's needs. Adjustment is a complex concept and has a physiological, psychological and social aspects (8).

It can be said that during the 20<sup>th</sup> century the theories of coping has aroused from two traditions including psychodynamic thought and cognitive psychology.

Freud did not write directly about the psychology or nature of persons with disabilities, however, many of his ideas can be applied directly to understanding attitudes toward disability and adjustment to disability processes. Concepts such as castration anxiety, fear of loss of love, ego strength, secondary gain, and the death instinct are related issues to disability and adjustment. Central to an understanding of one's reaction to disability and to persons with a disability is Freud's concept of castration anxiety. To the person with a disability, the disability may represent a form of castration; to the able-bodied person, the sight of a person with a disability may evoke the threat of castration. According to some authors such as Fisher & Greenberg, (1985) castration anxiety has been associated with a fear that one's body will be hurt or damage. Thus, in the case of both males and females, disability or threat of disability could evoke considerable feelings of anxiety and inferiority resulting from Oedipal issues (9). Freud cited the use of drugs and defense mechanisms of displacement and sublimation, as well as the avoidance and withdrawal of reality as ways to deal with suffering. It was left to Anna Freud (1936/1966) to further elucidate the concept of the ego's defense mechanisms and the modalities by which the ego seeks to defuse anxiety. In general, it can be said ego defenses has the major role in psychodynamic models of coping. According to Valliant (1977) defense mechanisms were ordered along a continuum of "adaptation" (or level of maturity), ranging from those viewed primarily as immature, primitive, indeed even psychotic (e.g., delusional projection, distortion) to those seen as mature and successful (e.g., sublimation, humor. Norma Hann (1969) is one of the prominent authors with a focus on psychoanalysis who has proposed a tripartite model of ego process that includes coping, defense and fragmentation. Defending and coping (along with fragmentation) were further trichotomies into distinct categories of ego processes, ranging from the more dysfunctional group of fragmentary processes (e.g., delusional, concreteness, depersonalization), to the more "neurotic" class of defensive processes (e.g., isolation, regression, displacement), and to the more functional category of coping modalities (e.g., logical analysis, sublimation, substitution). Hann focus the cognitive process, which result in the valuation of stress, is consistent with her overall focus on the function of ego processes. The individual is actively constructing his or her experience and is not a victim of a situation. Furthermore, stress does not automatically lead to deterioration. Stressful experiences can enhance functioning, resulting in greater insight or empathy. As in any situation, even in times of stress, the ego processes come in to play and lead the individual to cope, defend, or fragment, in order to adapt to the situation (2).

This shift from a pessimistic view to a more positive of coping led to consider the environmental factor, especially the individual appraisal of the situation in which stress is experienced, as an important factor in adaption. Based on this view Lazarus and Folkman's (1984) stress and coping styles theory was presented and applied to chronic illness. According to this theory coping was described as the thoughts and actions that occur in response to the experience of overwhelming demands such as illness threat and two main coping styles have been used to categorize coping strategies including emotion-focused (focusing on one's affective domain) and problem- (or task-) focused (focusing on the external environment) coping. While problem-focused coping is aimed specifically at the stressor, emotion-focused coping is aimed at reducing the emotions that arise from that stressor. Problem-focused is more about taking practical action, such as information-seeking, whereas emotion-focused coping relates to changing the way a situation is interpreted. Generally, problem-focused is considered more useful in contexts where practical actions can be performed to alleviate distress. When this situation is more uncontrollable, emotion-focused coping is considered more appropriate. (10).

Finding has largely corroborated the validity of Lazarus and Folkman's model. Studies have supported the mediating role of coping on emotion, the influence of appraisal on coping, the distinction between problem- and emotion-focused coping and the variability of appraisal and coping as a function of intra situational contextual change and the variability of some forms of coping, typically problem-focused across situations.

Despite the fundamental differences between Han's psychodynamic and Lazarus and Folkman's cognitive theories, there are other areas of commonality.

- a) Each model focuses on the processes by which an individual adapts to the environment. Both consider the person environment fit as central.
- b) The efficacy of adaptive behavior, based on final outcome is important for both theories.
- c) Both theories emphasis the central role of cognition in adaptation. Hann (1977) notes that optimal coping responses can occur when the individual is able to rationally examine a situation, while Folkman and Lazarus (1991) place a great deal of emphasis on the role of appraisal in the coping process (2).

## Coping

These two theories proposed three important issues in the coping with chronic illnesses. First by giving the individual an active role in responding to the situation, the patient's sense of control and management power increases relative to the consequences of illness. Today's findings also show that the belief that disease can be controlled and managed can affect the quality of life and the symptoms of the disease. Being active, exercise, reduce stress and get enough rest, to take things slowly, plan and prioritize, set and adjust goals, and work towards these goals as "self-management strategies" help patients promote health and well-being (11). It has been shown that when patients believe that the disease is controllable they have better participant in Cardiac Prevention and Rehabilitation programs (12). The second important issue emphasized by the mentioned theories is the effect of patient's beliefs about the disease on adaption. Illness cognition, i.e. the way people *perceive* the situation they encounter, has been recognized as a crucial determinant of health-promoting behavior (13).

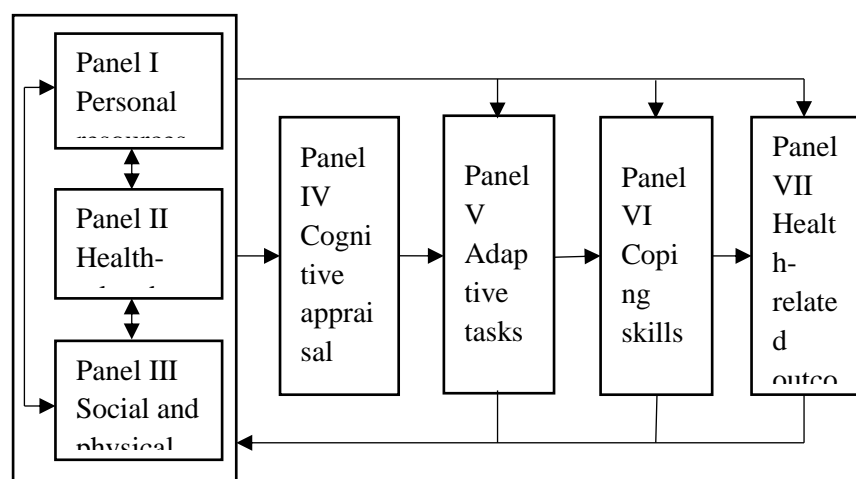
Finally, it can be said that the effectiveness of a behavior in adapting, depends on the individual, the condition of the disease and its environment or context.

Along with the theory of psychoanalysis and Lazarus and Folkman theory of coping, Taylor (1983) proposed a cognitive adaptation model to threatening events, such as serious illness. Taylor argued that the process of adjustment centered around three themes: a search for meaning in the experience; an attempt to gain a sense of control or mastery over the illness; and an effort to restore self-esteem (14). Researches have shown the importance role of these concepts in adjustment with chronic illness.

## Models of adjustment to chornic illness

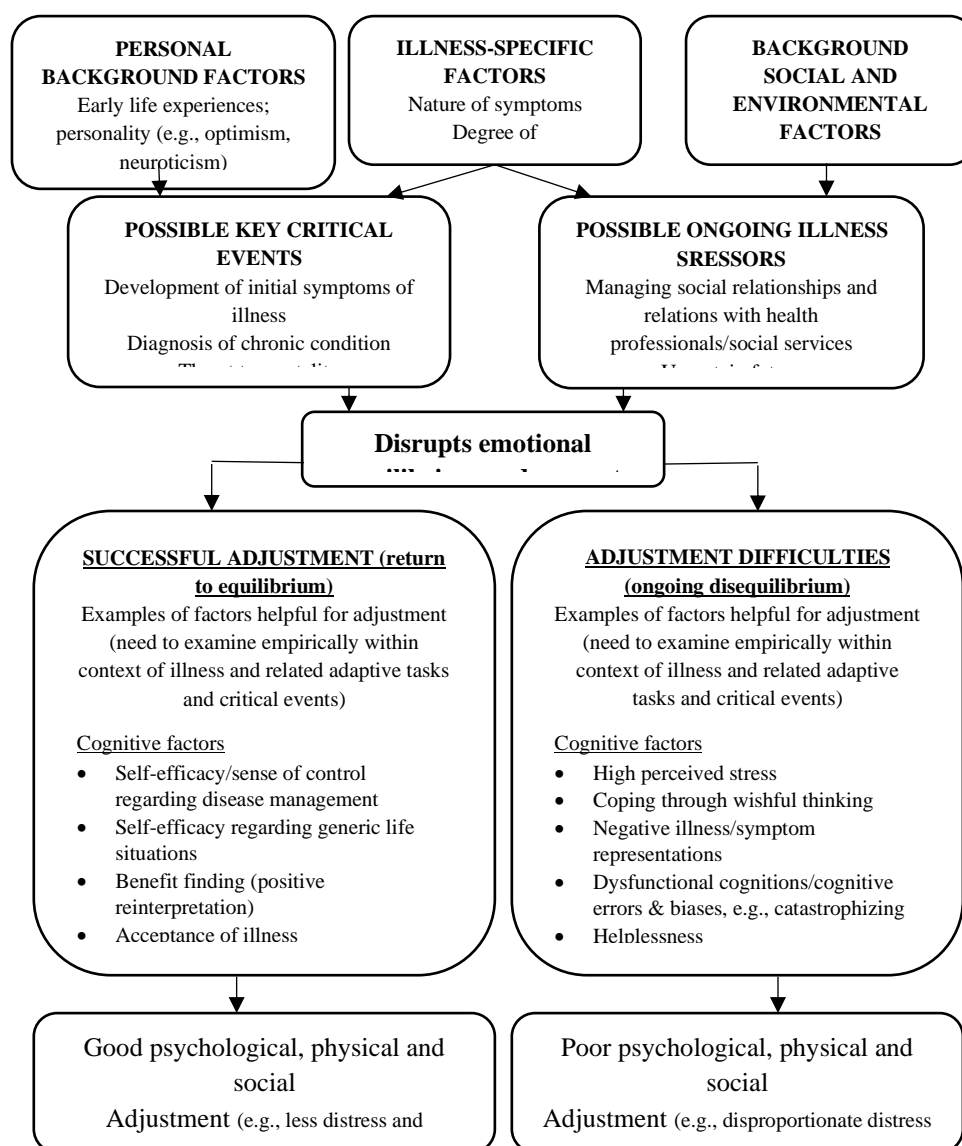
In later studies, researches gradually became interested in the structure of coping, and contextually-based models of coping and so the sociological model (Pearlin and Schooler's ,1978), integrative, biopsychosocial model (Billings & Moos, 1981, 1984; Moos & Schaefer, 1984), and interactive model (Endler and Parker's (Endler, 1983, 1997; Endler & Parker, 1990) were presented. Pearlin and Schooler's (1978) has shown that the efficiency of coping behaviors could be depend on individual's social contexts, such as marriage, parenting, household activities, and occupational settings. Findings of pearlin and Schooler showed the impress of social role in coping and adjustment process. Moos and his colleagues also has shown the effect of social and economic recourses in addition to other variables (2).

Further studies, in addition to the mentioned factors, has emphasized on the role of personality such as trait and state anxiety and its two-way relationship with situational/environmental and behavioral factors in the process of adaption. With increasing knowledge and understanding of the consequences of chronic disease personal resources such as demographic characteristics, intellectual ability and personality characteristics as well as health-related factors such as disease severity, location and type of disability, health-care environment and treatment procedures were added to previous factors of psychological models. Moos and Holohan (1985) have presented the following model of adjustment based on mentioned variables:



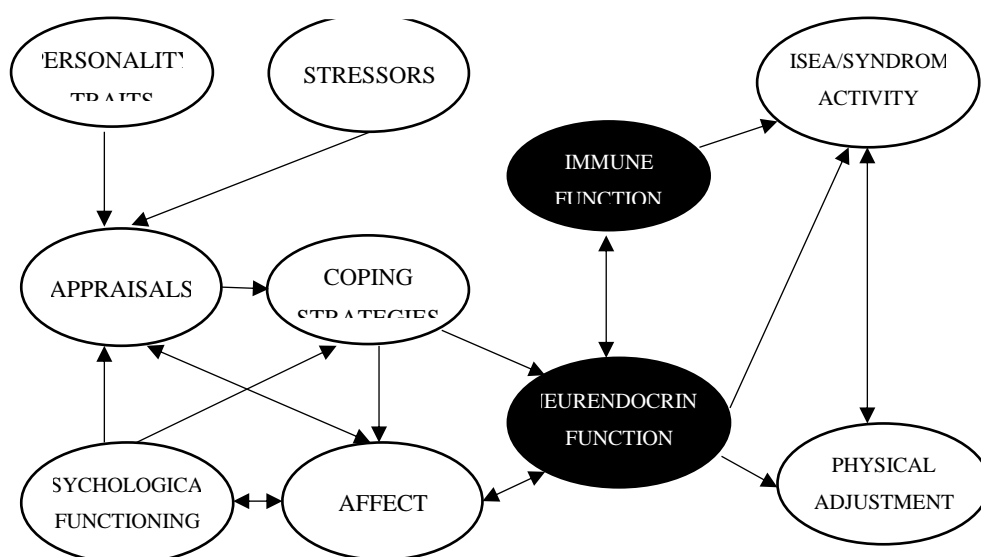
Recently Moos-Moris (2013) presented the idea that key acute stressor or critical events that can also impact adjustment such as initial diagnosis, change in prognosis, progression, and/or disability should be considered in presenting a model of psychological adjustment to chronic illnesses. For instance, it is important to note that factors that prove successful at one stage of the disease trajectory may change when the illness stressors change. For instance, if a disease becomes progressive, factors such as acceptance and self-compassion may become more important than active problem-solving strategies.

Moos Moris has proposed a working model of adjustment to chronic conditions, which addresses some of these limitations.



Further progress on the issue of psychological adjustment to chronic illness was the understanding the role of stress on the immune system. Continuation of research and increasing knowledge in this area showed that stress is effective not only in the coping with chronic disease but also in the disease activity and issues related to physical functioning via neuroendocrine and immune pathways. Stressful events take a toll on health. The field of psychoneuroimmunology is now providing key mechanistic evidence about the ways in which stressor – and the negative emotions that they generate – can be translated into physiological changes. There is a well-documented link between the central nervous system (CNS) and immune system. Under stress, CNS release stress hormones that perturb the balance and stability kept by many factions of immune system, with serious health consequences (16). Chronic stress can increase the peripheral production of proinflammatory cytokines, such as interleukin (IL)-6. High serum levels of IL-6 have been linked to risk for several conditions such as cardiovascular disease, type 2 diabetes, mental health complications, and some cancer (17). Findings in rheumatoid arthritis has shown that the effects of stress are mediated through endocrine levels, higher interpersonal conflict was associated with higher immune stimulatory hormones. These findings demonstrate links between psychosocial, neuroendocrine and disease activity. Based on these findings it can be concluded that an integrated biopsychosocial model presented by Walker (2004) could present more justified discussion in adjustment to chronic illness.

### Models of adjustment to chronic illness



According to this model stressor ultimately impact on disease/ syndrome activity, which in turn influences physical adjustment outcomes, via interactions between psychosocial variables that influence neuroendocrine and immune mechanisms.

Of course, reciprocally it is shown that positive affect has also a direct effect on behavioral and biological mechanisms that influence immune function. Furthermore positive affect acts as a buffer of behavioral and physiological responses to stress. Positive affect may directly alter immune function through the activation of neurological and neurotransmitters such as, catecholamine (18).

These findings may provide us the important information in line of prevention

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