Psychological adjustment to chronic disease

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This Review discusses physiological, emotional, behavioural, and cognitive aspects of psychological adjustment to chronic illness. Reviewing the reports of the past decade, we identify four innovative and promising themes that are relevant for understanding and explaining psychological adjustment. In particular, the emphasis on the reasons why people fail to achieve a healthy adjustment has shifted to the identification of factors that help patients make that adjustment. To promote psychological adjustment, patients should remain as active as is reasonably possible, acknowledge and express their emotions in a way that allows them to take control of their lives, engage in self-management, and try to focus on potential positive outcomes of their illness. Patients who can use these strategies have the best chance of successfully adjusting to the challenges posed by a chronic illness.

Introduction

Chronic illnesses are disorders that persist for an extended period and affect a person’s ability to function normally. Some chronic diseases (eg, rheumatoid arthritis) need long-term pharmacological treatment and are often characterised by progressive physical disability and pain. Others (eg, diabetes) can be medically controlled, but only at the cost of strict adherence to disease management regimens. Thus, a chronic illness has the potential to induce profound changes in a person’s life, resulting in negative effects on quality of life and wellbeing.

After the medical diagnosis of chronic illness, patients are confronted with new situations that challenge their habitual coping strategies. As a result, they must find new ways of coping to adjust to their altered condition. We use the terms adjustment and psychological adjustment interchangeably to refer to the healthy rebalancing by patients to their new circumstances. Most patients eventually reach a state of good psychological adjustment, but for about 30% of patients, the adjustment phase is prolonged and sometimes unsuccessful.

At least five key elements of successful adjustment to a chronic illness have been identified: the successful performance of adaptive tasks (eg, adjustment to disability, maintained emotional balance, and preservation of healthy relationships), the absence of psychological disorders, the presence of low negative affect and high positive affect, adequate functional (eg, work) status, and the satisfaction and wellbeing in various life domains. Several models have been proposed on how patients could achieve these outcomes, including: the model of cognitive adaptation, which emphasises illness acceptance and perceptions of control over illness; the personality model that emphasises the role of personality factors (such as optimism or neuroticism) in adjustment; and the stress and coping model that emphasises strategies used by patients to deal with adaptive tasks imposed by disease. The authoritative stress and coping model acknowledges that chronic illness consists of several challenges, but at the same time, it highlights—more than other models of adjustment—processes of appraisal and coping that explain why some patients successfully identify and act on opportunities to manage these tasks whereas others might fail to do so. More recently, the stress and coping model has been extended with the model of self-regulation, which allows patients to deal with illness more proactively. Both models show the active role that patients may have in adjusting to the challenges posed by their condition, and they have been used to study processes of adjustment in diverse chronic conditions including cancer, diabetes, HIV-infection, asthma, and rheumatoid arthritis.

Search strategy and selection criteria

We used the Web of Science (1996–2005) to search reviewed topics. General search terms referred to psychological adjustment, including: “adjust*”, “adapt*”, “distress”, “depress*”, and “anxi*”. Other searches included terms covering chronic disease (“chronic disease”, “chronic illness”, or a specific disease). For effects of blockades of proinflammatory cytokines, we used “rheumatoid arthritis” or “RA” in the title with one of the drugs (“infliximab”, “etanercept”, “adalimumab”, “remicade”, “enbrel”, “humira”), or other words referring to blockade with TNFα. For associations between emotion regulation and adjustment to chronic illness, we combined “emotion” with “control”, “repress”, “suppress”, “express”, “non-express”, or “intens”, or the terms “alexithymia”, “ambivalence”, or “aff ect intens*”. For positive moods and self-management, we used “self-management”, “self-care”, “dietary behavi*”, or “exercise”. For relations between benefit finding or growth and adjustment benefit finding, we used “positive emotion”, “benefit finding”, “post-traumatic growth”, or “stress-related growth”. Full articles of studies published in English and that included adolescents or adults were used. Abstracts and references of all identified articles were also examined for importance, relevance, and overlap.
examine self-management in adjustment and highlight studies that indicate the adaptive benefits of patients’ willingness and ability to engage in self-management. Finally, we discuss how chronic illnesses can have positive consequences by showing that a crucial part of adjustment could entail a process of patients finding a benefit from the condition. These findings could explain why people with chronic illnesses, despite the negative physical consequences of their disease, report a quality of life that is notably similar to that of healthy people.

The challenge of patients remaining active despite cytokine activity

Infectious and inflammatory processes can induce a constellation of non-specific symptoms, often called sickness behaviour, including weakness, malaise, inability to concentrate, depressed mood, lethargy, anhedonia, and anorexia. Therefore, in addition to dealing with the behavioural, cognitive, and emotional challenges of disease, patients must also cope with these physiologically-induced symptoms to preserve an active life.

The psychological effects of these pathophysiological processes are mediated by cytokines. Several studies have shown that proinflammatory cytokines such as tumour necrosis factor α (TNFα) and interferon alfa seem to promote the psychological symptoms seen with several chronic diseases. Proinflammatory cytokines contribute to the vital exhaustion (loss of energy, increased irritability, and feelings of demoralisation) seen with acute myocardial infarction. In diabetes, increased concentrations of proinflammatory cytokines are produced by adipose tissue, and by monocytes and macrophages seen with increasing age, and could contribute to depression and so-called sickness behaviour. In cancer, these cytokines contribute to fatigue, memory and concentration problems, depression, and anxiety.

Immunotherapy with cytokines has also been shown to promote these symptoms. In uncontrolled prospective trials with interferon-alfa infusions, patients frequently report fatigue (70–100%), depressive symptoms (21–58%), and depression according to diagnostic criteria (9–45%) as well as anorexia, pain, cognitive slowing, confusion, lethargy, mania, inner tension, anxiety, and reduction in goal-directed behaviour.

Evidence suggests that cytokines mediate disease-induced inactivity and distress. In patients with rheumatoid arthritis who do not respond to conventional disease-modifying antirheumatic drugs, reduced disease activity can be achieved by blockade of proinflammatory cytokines. Immediately after blockade of TNFα, a substantial improvement of physical functioning, quality of life, and fatigue can be seen (panel I). The finding that proinflammatory cytokines can promote—and by blockade reduce—these symptoms shows that physiological factors are a real obstacle to the psychological adjustment to chronic illness.

The malaise and behavioural inactivation associated with illness is generally regarded as adaptive, especially during acute infection and inflammation. By inducing rest, this response conserves energy and promotes healing, and thus stimulates adjustment similar to the desire for food in response to hunger, pain in response to injury, and the fight-or-flight response to threat. However, these adaptive mechanisms can also have adverse consequences in chronic conditions. In diabetes, hunger can make adjustment to a healthy diet difficult, whereas pain due to rheumatic disease can inhibit healthy physical activity, and the fight-or-flight response can endanger patients with cardiovascular disease. Thus, symptoms (such as fatigue and pain) that are beneficial during an acute illness can become obstacles to psychological adjustment in chronic disease.

Chronic pain has been suggested not only to lead to pain-avoidance behaviour but also to persistence or even overuse of activities, both of which can lead to disability. Furthermore, patients with other chronic diseases are faced with the challenge to pace their activity and find a new balance in their lives. Only a few decades ago, the common recommendation given to patients with chronic inflammatory diseases such as rheumatoid arthritis was to rest. Nowadays, graded exercise tailored to the patients’ abilities and disease severity is thought to lead to improved physical, functional, and emotional outcomes. Inactivity in response to acute illness is natural and often beneficial. But one of the challenges facing patients with chronic illness is to engage in those activities that can improve functional ability and emotional status in the face of real cytokine-related symptoms that make activity difficult.

Panel 1: Effects of blockade of proinflammatory cytokines* on psychological adjustment in patients with rheumatoid arthritis, as shown in relevant studies

**Disability in daily activities**

Disability scores have been shown to improve after the first week of medication. This improvement was sustained with prolonged drug use (up to 5 years). Effect size was about 0.6 SD units, regarded as a moderate change; percentage change varied between 40% and 80%.

**Quality of life**

Summary scores of the short form 36, measuring physical functioning, improved. Effect size was more than 0.5 SD units, regarded as a moderate change; percentage change was about 40%. Improvement on the summary score of the short form 36, measuring mental wellbeing (which did not differ greatly from the general population at baseline), was generally small (about 15%).

**Fatigue and vitality**

Substantial improvement was seen on the fatigue scale of the Functional Assessment of Chronic Illness Therapy questionnaire. Change on the vitality scale of the short form 36 was as large as the change seen on physical functioning scales.

*TNFα was blocked with infliximab (remicade), etanercept (enbrel), or adalimumab (humira). Most studies were double-blinded clinical trials in which the effect of conventional treatment with methotrexate only was compared with the effect of treatment with methotrexate combined with TNFα blockade.
Emotion regulation: to feel or not to feel

Patients with chronic illness typically have anxiety, depression, and other negative emotions. How these individuals cope with these emotions can affect how well they adjust to their illness. Emotion regulation is a term encompassing several conscious or unconscious styles of experiencing, processing, and modulating emotions. Two main categories of emotion regulation have been distinguished: avoidance and inhibition of emotions, and expression and acknowledgment of emotions. Although the first category—when generally applied—is associated with maladaptive outcomes such as an increase in disease occurrence and risk of disease progression, increasing evidence has shown that the habitual acknowledgment and expression of emotions can promote good adjustment.

In cross-sectional studies, maladjustment to chronic illness is commonly related to styles of emotion regulation characterised by avoidance and non-expression. Examples include patients having difficulty identifying and describing emotions (alexithymia), being unaware of emotions (repression), avoiding the expression of emotions (emotional control, suppression, anti-emotionality), and being ambivalent about expressing emotions. Although patients are often advised to face and express emotions, cross-sectional relations between adjustment and the acknowledgment and expression of emotions have been inconsistent. However, these cross-sectional findings do not prove that emotion regulation affects adjustment; it is equally possible that the distressing emotions experienced during chronic illnesses affect emotion regulation.

Prospective studies examining which types of emotion regulation affect adjustment show that, at least in the North American and western European cultures, the regular use of avoidant non-expressive styles of emotion regulation is disadvantageous for psychological adjustment and survival. In less emotionally expressive Asian cultures, non-expressive emotion regulation styles have proven advantageous, suggesting that the congruence between one’s general style to handle emotions and the style advocated in one’s cultural system determines whether the emotion regulation style is adaptive or maladaptive. Acknowledgment and intense experience of emotions are suggested to be beneficial for adjustment as long as those emotions are expressed and processed; the mere uncontrolled expression of emotions without processing can be maladaptive (panel 2).

Expression of emotions is often a component of psychological interventions in chronically ill patients. Emotional disclosure interventions have provided the most convincing evidence that expression can improve psychological and physical adjustment, sometimes even on objective markers of disease activity (panel 2). Beneficial effects have been noted after disclosure (mostly written, but also oral) by participants from varying cultural backgrounds and socioeconomic status, as well as in diverse chronic conditions, including cancer, HIV, asthma, and rheumatoid arthritis.

Physiological and psychological mechanisms have been proposed to explain the negative effect of avoidant and non-expressive emotion regulation styles on adjustment. Although denial and non-expression of emotions can be a useful initial coping strategy to deal with the stress that accompanies the diagnosis of a chronic disease, failure to acknowledge and express emotions can leave these emotions unresolved. These unresolved emotions can affect patients’ health negatively by, for example, chronic raised activity of the sympathetic nervous system, and increased levels of stress hormones, such as cortisol, which can further exacerbate the physical and mental symptoms of chronic illness.
Management of chronic illness is characterised by many responsibilities regarding medication use, lifestyle changes, and behaviour to prevent long-term complications—generally referred to as self-management of disease. Many studies have shown that patients who engage in healthy diet, exercise, or other aspects of self-management have physical benefits in terms of fewer symptoms, better functional capability, and fewer complications than those who do not in various diseases (eg, HIV/AIDS, rheumatoid arthritis, asthma or chronic obstructive pulmonary disease, diabetes, and heart failure). However, the extent to which self-management can also affect psychological adjustment is much less understood. Studies have shown a low adherence to self-management regimens; only about 15–25% of patients improve their health practices after diagnosis, suggesting that they find disease management difficult to integrate into their lives. Indeed, many patients have a great fear of lifestyle changes and report more non-adherence to diet and exercise than to medication use or check-up appointments and symptom monitoring. An explanation for the non-use of self-management might be the large amount of time and effort needed, and patients might not always have immediate benefits in terms of symptom improvement or a sense of improved wellbeing. The burden of self-management could be the reason why patients who show signs of poor psychological adjustment face particular difficulties in self-management.

Many studies on adjustment and self-management have highlighted the role of major depression as a risk factor for non-adherence to self-management recommendations, with depressed patients frequently reporting indecisiveness and reduced self-confidence about self-management. The presence of clinical depression has been shown to disrupt adequate self-treatment in diabetes, COPD, and HIV. Although depression is thought to precede poor self-management instead of the other way around, the cross-sectional design used in such studies precludes conclusions about the causal link between self-management and psychological adjustment. Symptoms of depression, such as reduced energy or motivation, can clearly interfere with self-management, but the inability to undertake self-management can also lead to feelings of helplessness and hopelessness. Major depression and poor self-management can even be regarded as independent outcomes resulting from cytokines and other pathophysiological mechanisms. Clinical forms of anxiety have also been suggested to compromise self-management, but this association has not been studied extensively.

Even when patients do not meet criteria for clinical diagnosis of depression (or anxiety), they can have some form of psychological distress, which could be regarded a signal of poor adjustment. Some of the most frequently reported sources of distress include worries about long-term complications, guilt or anxiety when problems in self-management occur, and fear about other potential negative effects of the disease. Like major depression, mild forms of distress have been associated with reduced self-management in cross-sectional studies of different chronic conditions, including COPD, diabetes, HIV, and asthma. Notably, the few available prospective studies of distress and self-management suggest a different pathway than assumed in studies of depression and self-management, and lend support to the assumption that poor self-management could precede decreased adjustment. For example, a cancer study showed that patients with decreased self-management predicted a reduced quality of life and increased mood disturbance after 8 months, whereas a study of individuals with rheumatoid arthritis showed that a
Not only can positive mood benefit self-management, but adequate self-management can also promote wellbeing. In patients with diabetes who reported increased levels of perceived competence and autonomous motivation for self-management, improved life satisfaction and self-management behaviour were reported, which in turn increased glycaemic control after 1 year. Engagement in self-management could also benefit psychological adjustment, both in the short term and long term, as shown in several prospective studies in cancer. Such results indicated that patients with head and neck cancer who took appropriate self-management measures after surgery were less anxious the next day, and women with cancer who exercised at least 90 min per week on 3 or more days reported less fatigue and emotional distress as well as higher functional ability and quality of life than less active women during treatment. Similar effects of self-management on psychological adjustment have been shown in prospective studies of patients with heart failure and patients who had had cardiac surgery. Only a few self-management interventions have also examined adjustment; although patients increase efforts in self-management when participating in the intervention, they have mixed findings regarding the effect on adjustment. Some studies show that self-management does not necessarily benefit adjustment, whereas others report improved quality of life and mood after some time. These findings suggest that patients can learn to appreciate the need of self-management as a result of participating in interventions, but that such benefits of improved wellbeing could take some time.

Most relevant studies have examined the association between poor adjustment and poor self-management. However, other studies have investigated the connection between good adjustment and engagement in self-management practices. These studies are rare, although their prospective design allows for an interpretation of the direction of the connection. Importantly, these studies show evidence of a bidirectional association between wellbeing and adherence to self-management regimens. Patients who can maintain good moods seem to be more willing to engage in lifestyle changes, and those who practice self-management behaviours also report improved wellbeing (panel 3).

These studies suggest a different connection between self-management and adjustment than has been assumed so far. Research on the association between depression and self-management has been driven by the assumption that depression precedes poor self-management, but the available cross-sectional studies can neither support nor refute this assumption. Moreover, the role of mild forms of psychological discomfort needs more research since such low levels of mood disturbance could impair self-management to the same extent as clinical manifestations of poor adjustment in terms of (major) depression. Perhaps even more important is the finding that good adjustment predicts increased participation in self-management and vice versa. This association could have important implications for self-management interventions, which vary greatly in approach (from education to cognitive-behavioural treatment) but share an emphasis on improving skills such as problem-solving and goal-setting. These self-management skills are recognised and appreciated by many patients, including those from ethnic groups, suggesting that they are valuable ingredients of self-management interventions. However, although good mood seems to promote engagement in self-management of illness, improvement of mood could prove valuable to self-management interventions since many patients report feelings of discomfort about disease, sometimes only after they have been dealing with disease for several years.

The experience of dealing with illness is not all negative. Individuals have reported positive outcomes from various diseases (e.g., breast cancer, rheumatoid arthritis, multiple sclerosis, myocardial infarction, HIV/AIDS, and fibromyalgia), such as an improved appreciation of life, enhanced sense of purpose, changes in life priorities, and improved personal relationships. About 60–85% of patients with breast cancer, 83% of HIV-positive women, 73% of patients with rheumatoid arthritis, and 58% of individuals with myocardial infarction have reported at least one positive change as a result of their illness. With multi-item scales used to measure benefit, patients have generally reported a small-to-moderate degree of perceived positive change. Moreover, survivors of breast cancer have reported more positive growth experiences than matched controls (who reported on a stressful event in the same period), even though the survivors have reported either similar or increased levels of distress, worsened physical functioning, or more negative changes as a result of the experience.

Some patients with chronic illness are more likely to report positive experiences than are other patients. Reports of positive changes are correlated with demographic variables such as young age, and, perhaps counter-intuitively, minority status, but generally not with sex, but inconsistently with socioeconomic status and education. Consistent with the theoretical assumption that an event should be intense to provoke growth or benefit finding, some
cancer studies have suggested that heightened physical threat (i.e., poor disease stage or increased physical symptoms) and raised perceived stress are related to an increased report of positive changes. However, a study exploring the curvilinear association between cancer stage and post-traumatic growth showed that very high levels of threat (stage IV breast cancer) resulted in reduced perceived benefit. With respect to time since diagnosis, findings are inconsistent. Theoretically, a positive correlation would be expected because time is needed to work through the event to experience growth. One prospective study showed that post-traumatic growth in patients with breast cancer increased consistently during the first 18 months after diagnosis. Benefit finding and growth have also been related to personality characteristics such as trait optimism, dispositional hope, and extraversion.

Prospective studies examining the relation between growth or benefit finding and psychological adjustment have shown mixed results (panel 4). Research suggests that effects could depend on the time of assessment and length of follow-up. Positive effects on adjustment were recorded in samples in which benefit finding was assessed some time after diagnosis or with an extended follow-up. Benefit finding that is early in the adjustment process could represent a form of avoidance, or early benefit finding could be qualitatively different from benefit finding later on. Research shows that benefit finding that is induced or that is a result of an intervention shortly after diagnosis does lead to positive outcomes, including positive effects on physical adjustment.

Finding benefit or growth could be one of the cognitive strategies used to offset the negative effect of illness and could be viewed as part of a so-called response shift process. When diagnosed, individuals may change their internal standards of what constitutes health or other aspects of quality of life (recalibration), adjust their values and priorities (reprioritisation), or redefine what they think is important (reconceptualisation) to maintain an acceptable quality of life in the face of declining health. Most research has focused on recalibration and supports the assumption that individuals change their internal standards of aspects of quality of life over time or as a result of medical treatment. Evidence has also shown the occurrence of reconceptualisation and reprioritisation.

These findings are relevant to psychological interventions such as cognitive-behavioural therapy. Cognitive-behavioural therapy includes various strategies that promote a realistic but optimistic attitude to illness, but few attempts have incorporated elements of response shift or benefit finding into the approach. Encouragement for patients to identify advantages after the development of illness or to shift from a state of compromised function to improved function could prove to be valuable ingredients of cognitive behavioural therapy. Although chronic illnesses are undoubtedly stressful, traditional research focusing on the negative aspects provides an incomplete picture since many patients can find a new equilibrium by focusing on the positive aspects of illness.

**Discussion**

Psychological adjustment to chronic illness is tremendously important. An estimated 50% of people have a chronic physical condition, needing some form of medical intervention. About 35% of young adults report at least one chronic condition and more chronic illnesses occur in older adults. While the average age of the population increases, so does the occurrence of chronic...
illnesses. Moreover, the rapid developments in medical knowledge have resulted in a growing number of chronic diseases that previously were considered immediately life-threatening (cancer, AIDS) or characterised by rapid deterioration (asthma, diabetes).

This Review addresses how chronic illnesses challenge adjustment, by the possible malaise imposed by physiological processes, avoidant styles of emotion regulation, problems faced by patients attempting to change their lifestyle, or difficulties in accepting adverse consequences of disease. Although previous research has focused on explaining poor adjustment, recent developments have shifted to understanding the conditions under which patients can maintain their lives under favourable conditions. Many patients will eventually succeed in adapting to the changes imposed by chronic disease, especially if they can recognise the long-term demands needed for adjustment to chronic illness and the difference in dealing with acute illness. Appreciation of such long-term adaptive demands helps patients to resist the appeal of reducing activities. Long-term tasks of adjustment can also help individuals to confront and work through the negative feelings induced by illness and to engage in the demanding self-management behaviours that may improve their condition. Patients who can overcome the serious negative consequences of disease can eventually come to terms with disease and find benefit.

Of course, psychological adjustment cannot be enforced. Interventions advocating tyrannical positive thinking could bear a serious risk for maladjustment if patients deny the limitations imposed by disease. Additionally, the current focus on patients’ autonomy and active participation in illness management should not lead to an overestimation of the patient’s responsibility. Finally, most studies on adjustment to chronic illness have been done in white, middle-class populations and in specific chronic diseases, thus limiting the generalisation of findings to ethnic groups, patients with low socioeconomic status, and other chronic conditions.

Although studies have shown that psychological adjustment to chronic illness is possible, treatment could increase the burden for patients in the short term. To achieve psychological adjustment, patients need to face the reality of being chronically ill and make efforts to change their lives to adjust to the new circumstances imposed by their illness. In the small proportion of patients who have serious psychological problems, professional help should be considered. Psychosocial interventions have been designed to assist patients who have difficulty in adjustment. For the remainder of patients, health-care practitioners should consider encouraging them to engage in pleasant activities, acknowledge the emotions they have about the disease, challenge the barriers for engaging in self-management, and find meaning in small things.

Conflict of interest statement
We declare that we have no conflict of interest.

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