

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.¹

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.² 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.²

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),³ 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.⁴ 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;⁵ 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.⁶ 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.⁷ 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.^{8,9}

We review prospective (observational) and experimental research in 1996–2005 on four innovative areas in adjustment to chronic illness. We focus on approaches that explain how patients can successfully adjust and review the physiological, emotional, behavioural, and cognitive aspects of the process. First, we discuss pathophysiological factors focusing on the role of cytokines, such as those that reduce activity and affect mood, and that have been shown to interfere with attempts to engage in activities important to patients. As such, to deal with the consequences of cytokines and to remain active is of utmost importance for adjustment. Second, we address the role of dealing with emotions in adjustment processes. For some time, the adaptive role of focusing on emotions has been regarded with suspicion, but a growing consensus has indicated that the confrontation of negative emotions associated with chronic illness could contribute to adjustment. Third, we

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 "emotio*" with "control", "repress*", "suppress*", "express*", "non-express*", or "intens*", or the terms "alexithymia", "ambivalence", or "affect 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.¹⁰ 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 (TNF α) 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.¹¹ 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.¹² In cancer, these cytokines contribute to fatigue, memory and concentration problems, depression, and anxiety.¹³

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.^{14–17}

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 TNF α , a substantial improvement of physical functioning, quality of life, and fatigue can be seen (panel 1). 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.

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.^{18–29} This improvement was sustained with prolonged drug use (up to 5 years).¹⁹ Effect size was about 0.6 SD units,^{20,25} regarded as a moderate change; percentage change varied between 40%^{22,23,26,29} and 80%.²⁵

Quality of life

Summary scores of the short form 36, measuring physical functioning, improved.^{18,20–22,24,25,28,29} Effect size was more than 0.5 SD units,^{20,25} regarded as a moderate change; percentage change was about 40%.^{22,25} Improvement on the summary score of the short form 36, measuring mental wellbeing (which did not differ greatly from the general population at baseline),²¹ was generally small (about 15%).^{20–22,24,25,28,29}

Fatigue and vitality

Substantial improvement was seen on the fatigue scale of the Functional Assessment of Chronic Illness Therapy questionnaire.²⁹ Change on the vitality scale of the short form 36 was as large as the change seen on physical functioning scales.^{18,20}

*TNF α 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 TNF α blockade.

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.³⁰ 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.³¹ Nowadays, graded exercise tailored to the patients' abilities and disease severity is thought to lead to improved physical, functional, and emotional outcomes.^{32,33} 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.

Emotion regulation: to feel or not to feel

Patients with chronic illness typically have anxiety, depression, and other negative emotions.² 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.³⁴ 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.³⁵

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.³⁶ 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.³⁷ 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.³⁸ 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.⁶⁵ Emotional disclosure interventions⁶⁶ 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,⁶⁷ 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

Panel 2: Prospective and experimental studies of associations between emotion regulation and adjustment to chronic illness

Prospective studies

Psychological adjustment

- Emotional control before diagnosis of breast cancer predicted increased psychological distress after diagnosis.³⁹ Control did not predict increased distress 15 months later in rheumatoid arthritis⁴⁰
- Emotional processing and affect intensity not only predicted positive affect scores in rheumatoid arthritis,⁴¹ but also negative affect⁴¹ and increased distress in patients with breast cancer and rheumatoid arthritis after 3–15 months^{40,42}
- Mood repair and mood clarity predicted reduced pain-related psychological distress in rheumatoid arthritis and osteoarthritis^{41,43}
- Expression of emotion predicted reduced distress after diagnosis of breast cancer and 3 months after diagnosis,^{39,42} and did not predict distress in rheumatoid arthritis after 15 months⁴⁰

Physical adjustment

- Alexithymia and ambivalence over expression of emotions predicted an increase in self-reported disease activity in rheumatoid arthritis after 15 months⁴⁰
- Non-expression of emotions predicted rapid disease progression in HIV after 6 months to 9 years⁴⁴
- Repression of emotions⁴⁵ and emotional control^{46,47} predicted increased mortality in cancer, whereas other studies showed no association with survival,^{48–50} and one study in Japan showed moderate anti-emotionality to predict survival³⁸
- Emotional expression resulted in improved self-perceived health status and reduced number of medical visits in breast cancer after 3 months,⁴² and no change in perceived health in rheumatoid arthritis after 15 months⁴⁰
- Emotional expression predicted survival in breast cancer⁴⁶

Experimental studies

Psychological adjustment

- Emotional expression in several chronic diseases led to decreased distress, mood improvement, or reduced intrusions up to several months after the intervention,^{51–55} or resulted in no change or change in only one minor outcome variable^{56–61}

Physical adjustment

- Emotional expression in several chronic diseases led to a reduction in health-care use, improved physical functioning, fewer symptoms reported, or reduced self-perceived disease activity up to several months after the intervention,^{51–54,57,59,60} or resulted in no change⁵⁶
- Emotional expression led to improvements in clinical and laboratory observations (eg, pulmonary function in asthma, joint score in rheumatoid arthritis, CD4+ lymphocyte counts in HIV) up to several months after the intervention,^{51,58,62,63} or resulted in no change^{53,54,56,59,60,64}

nervous system.⁶⁸ The inhibition of emotions can also delay help-seeking behaviour when it hampers symptom recognition and, when help is sought, compromise the communication with health-care providers. Such inhibition can also lead to patients failing to practice health-protective behaviours and adhere to treatment.⁶⁷

Alternatively, different mechanisms have been proposed to explain why acknowledgment and expression of emotions are beneficial for patients.⁶⁹ Although the acknowledgment and experience of negative emotions can be adaptive because they focus attention toward threats, elicit action, and provide feedback on progress toward important goals,⁶⁷ repeated reflection on or rumination about negative feelings without expressing them is not deemed healthy.^{42,70} Some processing of emotions is needed before being beneficial. Patients thinking and talking or writing about emotions will make their experience less intensive and invasive (habituation), whereas it can also increase insight into why emotions are experienced and how their effect can be reduced (cognitive reappraisal). Furthermore, expression of emotions can decrease emotional distress and restore psychophysiological balance, and create opportunities for social support and enhanced closeness with others, benefit finding, and improved self-regulation.^{35,70}

Overall, when confronted with chronic illness it seems better for patients to generally express than to deny or inhibit emotions, as long as this strategy surpasses the unbridled spouting of emotions and helps to achieve more insight. Evidence on the role of emotion regulation in adjustment to chronic illness implies that patients acknowledging and dealing with the negative emotions surrounding chronic illness is not necessarily bad for adjustment. Although styles of emotion regulation are a stable characteristic of a person and can be difficult to change, interventions that aim to teach more effective styles to regulate emotions have proven beneficial for individuals who consistently use ineffective emotion regulation styles in adjusting to their chronic condition.⁶⁵

Self-management: improvement of mood and health behaviour

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.⁷¹ 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,⁷² rheumatoid arthritis,⁷³ asthma or chronic obstructive pulmonary disease,⁷⁴ diabetes,⁷⁵ and heart failure⁷⁶). 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,⁷⁷ suggesting that they find disease management difficult to integrate into their lives. Indeed, many patients have a great fear of lifestyle changes^{78,79} and report more non-adherence to diet and exercise than to medication use or check-up appointments and symptom monitoring.^{79,80} An explanation for the non-use of self-management might be the large amount of time and effort needed,⁸¹ and patients might not always have immediate benefits in terms of symptom improvement or a sense of improved wellbeing.⁷⁶ 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.⁸² The presence of clinical depression has been shown to disrupt adequate self-treatment in diabetes,^{80,83} COPD,⁸⁴ and HIV.⁸⁵ 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.⁸⁶ Major depression and poor self-management can even be regarded as independent outcomes resulting from cytokines and other pathophysiological mechanisms.⁸⁷ Clinical forms of anxiety have also been suggested to compromise self-management, but this association has not been studied extensively.⁸³

Even when patients do not meet criteria for clinical diagnosis of depression (or anxiety), they can have some form of psychological distress,⁸⁸ 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.⁸⁹ Like major depression, mild forms of distress have been associated with reduced self-management in cross-sectional studies of different chronic conditions, including COPD,⁹⁰ diabetes,⁹¹ HIV,⁷² and asthma.⁹² 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,⁹³ whereas a study of individuals with rheumatoid arthritis showed that a

Panel 3: Positive moods and self-management

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 satisfaction⁹⁵ and self-management behaviour were reported, which in turn increased glycaemic control after 1 year.⁷⁵ 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,⁹⁶ 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.⁹⁷ Similar effects of self-management on psychological adjustment have been shown in prospective studies of patients with heart failure⁹⁸ and patients who had had cardiac surgery.⁹⁹ 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,^{76,98} whereas others report improved quality of life and mood after some time.^{71,73,93} 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.

decline in the ability to perform self-management activities predicted the subsequent onset of depressed feelings.⁹⁴

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)⁷³ but share an emphasis on improving skills

such as problem-solving and goal-setting.¹⁰⁰ These self-management skills are recognised and appreciated by many patients, including those from ethnic groups,¹⁰¹ 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 moods 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.¹⁰²

Cognitive processing: beyond negative outcomes

Although health-related quality of life of patients with chronic conditions is generally lower than that of healthy controls,¹ this difference is less pronounced or even absent in aspects of mental health.^{1,103} Individuals can use various cognitive strategies to counteract the negative effect of illness on their wellbeing. Much research has addressed Howard Leventhal's model of illness representations,¹⁰⁴ showing that patients' beliefs (eg, about the course and consequences of their illness) can affect adjustment in chronic conditions such as diabetes.¹⁰⁵ Only recently, attention has been paid to post-traumatic growth and benefit finding,^{106–108} as well as response shift.¹⁰⁹

The experience of dealing with illness is not all negative. Individuals have reported positive outcomes from various diseases (eg, breast^{52,70,110–114} cancer,^{115,116} rheumatoid arthritis,¹¹⁷ multiple sclerosis,¹¹⁸ myocardial infarction,¹¹² HIV/AIDS,¹¹⁹ and fibromyalgia¹⁰⁶), 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,^{112,113} 83% of HIV-positive women,¹¹⁹ 73% of patients with rheumatoid arthritis,¹¹⁷ and 58% of individuals with myocardial infarction¹¹² 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.^{70,110,111,113,116,118} 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^{120,121} or increased levels of distress,¹¹⁵ worsened physical functioning,^{115,120} or more negative changes as a result of the experience.¹²¹

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^{70,111,116,122,123} and, perhaps counter-intuitively, minority status,^{111,114} but generally not with sex,^{116–118,122,123} and inconsistently with socioeconomic status and education.^{111,113,114,116} Consistent with the theoretical assumption that an event should be intense to provoke growth or benefit finding,^{107,108} some

cancer studies have suggested that heightened physical threat (ie, poor disease stage or increased physical symptoms)^{111,114} and raised perceived stress¹¹³ 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.¹²³ With respect to time since diagnosis, findings are inconsistent.^{111,117,123} Theoretically, a positive correlation would be expected because time is needed to work through the event to experience growth.^{113,118,122} One prospective study⁷⁰ 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,^{113,122} dispositional hope,^{106,113} and extraversion.¹²²

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^{111,122} or with an extended follow-up.¹²⁴ Benefit finding that is early in the adjustment process could represent a form of avoidance,¹³⁰ or early benefit finding could be qualitatively different from benefit finding later on.¹¹⁴ Research shows that benefit finding that is induced⁵² or that is a result of an intervention¹¹⁰ 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.¹⁰⁹ 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.¹⁰⁹ 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.^{116,131–133} Evidence has also shown the occurrence of reconceptualisation^{132,134} and reprioritisation.^{134,135}

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.⁸ 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.¹³⁶ About 35% of young adults report at least one chronic condition² and more chronic illnesses occur in older adults. While the average age of the population increases, so does the occurrence of chronic

Panel 4: Prospective and experimental studies examining relations between benefit finding or growth and adjustment

Prospective studies

Positive affect

Benefit finding in survivors with breast cancer (1–5 years after diagnosis)¹¹¹ and rheumatoid arthritis and multiple sclerosis (on average 10 years after diagnosis)¹²² predicted increased positive affect after 5 years and 1 year, respectively. Two studies in patients recently diagnosed with breast cancer (4 months post-diagnosis¹¹⁴ and post-treatment completion¹¹³) showed no relation with positive affect after 3–12 months.

Negative affect, depression and mental functioning

Benefit finding in patients with breast cancer (3, 6, and 12 months after diagnosis) predicted decreased negative affect and depression after 4–7 years;¹²⁴ In patients recently diagnosed with breast cancer (4 months after diagnosis),¹¹⁴ benefit finding predicted increased negative affect after 3–9 months and worsened mental functioning after 3 months for women with more severe stages of disease (relations were weak or absent for women with less severe stages). Other studies of breast cancer (1–5 years after diagnosis¹¹¹ and post-treatment completion,¹¹³ respectively) showed that rheumatoid arthritis^{117,122} and multiple sclerosis¹²² showed no effects on negative affect,^{111,122} mental functioning,¹¹¹ or psychological distress.¹¹⁷

Disability, physiology, and mortality

In patients with rheumatoid arthritis (average 10–16 years after diagnosis) benefit finding was related to reduced disability in one study¹¹⁷ but not in another.¹²² Studies of breast cancer did not find relations between benefit finding and self-reported physical functioning^{111,114} or perceived health.¹¹³ In HIV-positive men (on average 8 months after bereavement), benefit finding was related to a more favourable immune status (CD4 T cells) after 2–3 years and decreased AIDS-related mortality after a follow-up of 4–9 years.¹²⁵ In the only prospective study before 1996, benefit finding in patients with heart attacks (7 weeks after the attack) was related to a reduced likelihood of heart attack recurrence and morbidity at 8 years of follow-up.¹²⁶

Experimental studies

- A cognitive-behavioural stress management intervention for recently diagnosed patients with breast cancer led to increased benefit finding at 9-month follow-up.¹¹⁰ At 3-month follow-up, increased benefit finding was related to improved immune status (lymphocyte proliferation)¹²⁷ and reduced concentration of testosterone¹²⁸ and serum cholesterol¹²⁹ immediately after intervention
- Benefit finding that is induced experimentally (ie, patients writing about positive thoughts and feelings regarding the experience of having breast cancer) reduced medical visits for cancer-related morbidities at 3 months' follow-up in patients recently diagnosed with breast cancer.⁵² Benefit finding reduced psychological distress in women with high cancer-related avoidance. No effects were seen on perceived quality of life or physical symptoms

illnesses.¹³⁷ 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.¹³⁸ Additionally, the current focus on patients' autonomy and active participation in illness management should not lead to an overestimation of the patient's responsibility.¹³⁹ 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.¹⁴⁰

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.^{141,142} 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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