Chapter 1

INTRODUCTION

CHRONIC MEDICAL PROBLEMS: THE CONTEXT

Chronic medical problems have become increasingly prevalent in recent years. People are living longer and medical problems which might previously have carried considerable mortality risk can now be managed more effectively. Turner and Kelly (2000) have suggested that these improvements in the way chronic diseases are medically managed may sometimes be at the expense of patient quality of life. Scandlyn (2000) has suggested that chronic illness challenges views of life as orderly and having continuity, a challenge which can have significant psychological consequences. Increasing technological advances in medical science and practice form one of the factors responsible for changes in the epidemiology of disease, and have also resulted in a need for greater information and support. This is particularly true for patients who have to endure debilitating and demanding treatments. The publicity which is afforded medical advances often results in patients and their families having increased expectations that all medical problems can be cured. This in turn can make it difficult for patients to accept the personal consequences of a chronic medical problem and to embrace a 'coping' model when it comes to managing their illness.

A multidisciplinary emphasis means that patients are coming into contact with a greater number of health professionals. This involves a need to interact with more people and, for some, increased demands on already limited psychological resources. The move towards care in the community and day care means that patients may spend a longer time in non-hospital settings. This can result in some patients feeling unsupported psychologically and may be one of the factors that mediate psychological problems. Many chronic medical problems require a self-management approach to regulate the course and impact of patient symptoms and problems. Collaborative relationships must be established with health care staff and patients are often expected to

adopt a more active role in managing their problems than might be expected with an acute medical problem. Holman and Lorig (2000) have highlighted some further differences between acute and chronic illnesses. These are outlined in Table 1.1. This comparison highlights the factors which can contribute to psychological problems associated with chronic medical problems. Indefinite outcomes and the associated pervasive levels of uncertainty surrounding diagnosis and prognosis are often central to the psychological problems associated with chronic medical problems and their treatment.

Table 1.1 Differences between acute and chronic diseases

	Acute disease	Chronic illness
Onset	Abrupt	Usually gradual
Duration	Limited	Lengthy, indefinite
Cause	Usually single	Usually multiple and changes over time
Diagnosis and prognosis	Usually accurate	Often uncertain
Technological intervention	Usually effective	Often indecisive, adverse effects common
Outcome	Cure	No cure
Uncertainty	Minimal	Pervasive
Knowledge	Professionals knowledgeable; patients inexperienced	Professional and patients have complementary knowledge

From Holman and Lorig (2000), Data Supplement—Box, electronic, *British Medical Journal* (reprinted by kind permission of authors and British Medical Journal).

THE PSYCHOLOGICAL IMPACT

Psychological dimensions of chronic disease are often overlooked (Turner & Kelly, 2000) as most patients adjust well to the psychosocial aspects of their chronic medical problem. Adjustment can become more difficult, however, when patients experience a decline in physical health status (Cassileth et al., 1984). It is generally accepted that around 20–25% of patients with chronic medical problems experience clinically significant psychological symptoms. The diagnosis of a chronic disease can stigmatise patients, by virtue of limited independence and/or the negative impact on daily routine (Scandlyn, 2000). Chronic medical problems often

necessitate changes in behaviour by virtue of the increased self-care demands, and these, too, can result in stigmatisation. Holman and Lorig (2000: 526) have summarised the way in which the lives of patients with chronic medical problems are changed:

> With chronic disease, the patient's life is irreversibly changed. Neither the disease nor its consequences are static. They interact to create illness patterns requiring continuous and complex management. Furthermore, variations in patterns of illness and treatments with uncertain outcomes create uncertainty about prognosis. The key to effective management is understanding the different trends in the illness patterns and their pace. The goal is not cure but maintenance of pleasurable and independent living.

Patients with chronic medical problems often find themselves undertaking a delicate balancing act where they must balance the need to be in control of their lives with the fact that there will be times when it will be more functional for them to surrender control to significant others. Patients may have coexisting psychological problems. These can often complicate the management of medical problems and make it difficult for therapists to tailor cognitive behavioural assessments, formulations and treatment plans in a way that takes account of biological, psychological and physical variables. Some patients with histories of psychological problems have increased vulnerabilities to develop psychological problems as a result of the diagnosis of a chronic medical problem. This may occur at the time of diagnosis and/or during the course of the illness in response to elements of treatment or events which occur during the course of the disease. There are a further group of patients for whom the chronic medical problem itself confers a psychological vulnerability to experience problems triggered by other life events. It is also being increasingly acknowledged that psychological problems can result in physical morbidity in their own right. Prat et al. (1996) reported that, when medical factors are controlled for, the risk of myocardial infarction increases four- to five-fold as a result of the presence of depressive symptoms.

Friedman et al. (1995) have suggested that there are a number of pathways by which psychological variables influence patient interface with health care services. They also propose that these pathways are influenced by psychological interventions and that, as such, it is possible for such interventions to have a positive impact on both the quality of clinical care and the financial costs of health care delivery. These pathways are outlined in Table 1.2.

The information and decisional support pathway relates to patient–health service contact, which is mediated by the need for information and assistance relating to the need to distinguish symptoms or acquire information

Table 1.2 Pathways relating to patient–health service interface (Friedman et al., 1995)

Information and decisional support	Social support
Psychophysiological	Undiagnosed psychological disorder
Behaviour change	Somatisation

about medical problems. The psychophysiological pathway typically relates to patients experiencing deleterious effects as a result of the negative impact of stress on conditions such as arthritis. Pathways related to behavioural changes relate to the impact of behaviours such as diet, smoking or exercise in relation to medical problems such as cancer, diabetes or heart disease. Chronic medical problems can result in isolation and Freidman et al.'s social support pathway outlines how some patients' interactions with the health care system are mediated by the need for social support. A further group of patients present with physical symptoms which are the result of an undiagnosed psychological problem or disorder. This may relate to somatisation, where emotional distress is expressed in physical terms. Many of the psychosocial correlates and mediators of adjustment to chronic medical problems can be understood with regard to these pathways. Indeed, cognitive behavioural therapy (CBT) often targets one or more of these. Friedman and his colleagues present evidence that addressing patient health service use as a result of these pathways can result in significant cost offset.

UNDERSTANDING VARIATIONS IN PSYCHOSOCIAL ADJUSTMENT

It is accepted that the physical and psychosocial functions of patients with the same medical conditions vary widely. There is a huge variation in the subjective impact of medical conditions of the same objective severity. Two patients may have the same degree of physical disease or damage but yet have markedly different psychological responses to that physical illness. The variation in the ways in which patients make sense of and respond to illness has been examined according to the self-regulation model of Leventhal (Leventhal, Diefenbach & Leventhal, 1992). This emphasises the importance of the illness representation held by the patient (Weinman et al., 1996). These are often disease specific in nature and, as such, components of illness representations may relate differently to adjustment and quality of life depending upon the nature of the disease process (Heijmans and de Ridder, 1998). It has been shown that the illness representation held by the patient can account for variations in emotional

reactions to symptoms (Prohaska et al. 1987) and self-care behaviours (Petrie et al., 1996). Patients with more negative views of their illness are more likely to be depressed (Murphy et al., 1999). Patients who view their illnesses as more serious, chronic and uncontrollable tend to be more passive, report more disability, have poorer social functioning and more mental health problems (Heijmans, 1999). Patient perceptions of control over their symptoms and/or the course of their disease often relate to mood states such as depression (Devins et al., 1981; Thompson et al., 1993; Affleck et al., 1987; Helgeson, 1992). Perceived control has been shown to predict recovery from disability (Johnston et al., 1999). Cognitive components such as core beliefs, intermediate beliefs and thoughts often account for the differences in psychological responses to illness. Lacroix et al. (1991) have illustrated how the symptom schema held by patients influences what they believe is wrong with them. They demonstrated how a patient with a range of physical symptoms tended to make different attributions about their cause than his physicians. The symptoms and the explanation of both patient and physician are outlined in Table 1.3, which is an excellent illustration of how cognitions are central to the appreciation of patients' experiences of their symptoms.

There has been an increasing emphasis on the importance of the role of meaning in understanding psychopathology (Brewin & Power, 1999). Barton (2000) has suggested that greater emphasis should be afforded

Table 1.3 Importance of symptom schemata (Lacroix, et al., 1991)

Patient complained of choking sensation, runny nose, headache, sore throat, shortness of breath, back pain, muscle pain and soreness, dizziness, skin rash and fatigue.

Grouped by patient into six clusters:

(1) shortness of breath, fatigue, choking sensation and runny nose *Attribution to cold*
(2) shortness of breath *Attribution to chest muscles getting tired*
(3) headache *Attribution 'unknown'*
(4) back pain and sore muscles *Attribution to improper positioning in wheelchair*
(5) skin rash *Attribution to dry skin*
(6) dizziness *Attribution to moving too quickly*

Medical staff opinion on his presentation:

(1) sore throat, choking sensation and runny nose *Due to tracheotomy*
(2) shortness of breath *Due to respiratory failure*
(3) back pain, sore muscles and muscle pain *Due to spinal injury*
(4) skin rash *Due to medication side effects*
(5) headache and fatigue *Due to depression*
(6) dizziness *Due to brain injury*

within cognitive therapy of depression to the meanings attached to precipitating events. Psychological disorders are often associated with the presence of unwanted or painful meanings. Beck (1991), in considering his early work on the development of cognitive therapy, stated how he was 'struck by how ascertaining the idiosyncratic or special meanings people attached to events helped to explain what otherwise might have represented quite inexplicable affective and behavioural responses' (p. 369). The idea that meaning is central to adjusting to physical illness is beginning to appear in the health psychology and nursing literature (O'Connor, Wicker & Germino, 1990). Patients need a framework for ascribing meaning to illness (Holland et al., 1998). Indeed, Fife (1995) has suggested that patients seek meaning to understand experience and situation within life schemas. The ability to find meaning or purpose amidst misfortune may influence psychosocial adjustment.

It has been suggested that therapists need to understand the cognitive interpretative framework from which patients derive meaning for their experiences, and that psychological interventions which do not take account of this may adopt a hit and miss approach (Buick, 1997). Buick (1997) has further argued that the cognitive representations held by patients are central to understanding the types of meanings ascribed by patients to their illness experiences. Cassel (1982), in his article on the nature of suffering and the goals of medicine, stated that: 'Another aspect essential to an understanding of the suffering of the sick person is the relation of meaning to the way illness is experienced.'

The way in which meanings are processed can be as important as the meaning content. The recent emphasis on meta-cognitive processes within CBT is a reflection of the acknowledgement that the processing can be as important as the content of the meanings and interpretations associated with psychological adjustment. Understanding the meanings attached to the diagnosis and management of chronic medical problems is crucial when applying CBT to the problems and issues faced by people with these physical health problems. The cognitive behavioural model is particularly well suited to embrace this approach to the psychology of illness as it places the meaning-making capacity of patients at the heart of the therapeutic endeavour. The consequences on an individual of having a serious illness diagnosed are often understood in terms of patient's pre-existing self-beliefs and assumptions about the world in which he or she lives. Clinicians talk of assumptions being 'shattered' (Fawzy et al., 1990) or 'challenged' (Lepore & Helgeson, 1998), and the need for reformulation of these assumptions and/or for their amendment has also been reflected on the writings of academics in this area (Taylor, 1983; Fife, 1994, 1995). The central role within CBT on meanings and interpretation is one of the reasons why this form of treatment is particularly suited for

application to the psychological components of chronic medical problems. The remaining factors which make it particularly so will be outlined in the following section.

WHY CBT?

Enright (1997) has suggested that 'it is logical to assert that there is no psychological or physical problem that cannot potentially be assisted by a cognitive behavioural approach' (p. 1812). CBT can be applied to the assessment and treatment of almost every chronic medical problem, and there are a number of factors which make CBT particularly suited to addressing the problems associated with long-term medical problems. First, chronic medical problems are often associated with the sorts of psychological problems for which CBT has proven efficacy, is the treatment of choice and/or has an established role in their management (see DeRubeis and Crits-Cristoph, 1998); it may even be cheaper than medication when maintenance therapy and related costs are taken into account (Antonucci, Thomas & Danton, 1997). Cognitive behaviourally based interventions form the majority of the American Psychological Association's Division of Clinical Psychology Task Force on Psychological Interventions 'empirically validated therapies' (Chambless, 1998). The importance of adopting a self-management approach, the need for patients to establish collaborative relationships with health care staff, and the active role patients are encouraged to adopt in the management of their illness, each lend themselves to the philosophy and central tenets of CBT. The collaborative nature of the relationship between patient and therapist and the emphasis on building a repertoire of skills for the management of psychological problems are particularly relevant for CBT as well as medical self-management. The current UK health service emphasis on patients having access to evidence-based and cost-effective treatments should make it more likely that patients will be able to access CBT. Although there is a significant amount of evidence on the efficacy of CBT as an intervention for anxiety and depressive disorders, many of these studies have been conducted with patients with no significant medical problems. There is no reason to expect CBT to be any less effective in treating psychological morbidity when it co-exists with a medical problem. However, it is only in the area of cancer and chronic pain that research has specifically established CBT's role (see Chapters 5 and 6). Guthrie (1996) has highlighted some of the difficulties with psychological therapy for chronic medical illness. Research in this area is difficult and challenging; it presents researchers with the challenge of many confounding variables and problems associated with recruiting patients with longstanding medical problems.

CBT: AN OVERVIEW

This book is written from the perspective of the approach to CBT advocated by Aaron T. Beck (Beck, 1976, Beck et al., 1979). However, CBT has increasingly become a range of therapeutic approaches. There has also been a tendency to dilute CBT by dispensing with crucial elements and/or to amalgamate CBT with other therapeutic approaches (as in the case of so-called cognitive behavioural counselling). CBT is not counselling, and referring to it as such immediately changes the central emphasis. Counselling is generally regarded as an unstructured and non-directive form of psychological support or intervention. CBT is a structured form of therapy and naming it cognitive behavioural counselling is unhelpful. It is becoming accepted that the structure of CBT is important. Shaw et al. (1999) have reported that a therapist's ability to structure therapy relates favourably to treatment outcome. Many practitioners profess to be using CBT when they are in fact using cognitive or behavioural strategies or treatment techniques which are applied in isolation and without sufficient reference to a formulation or as an amalgamat with other therapies. Some practitioners decide to dispense with agenda-setting or homework, and prefer to incorporate cognitive or behavioural strategies as part of an eclectic approach to psychological therapy. The evidence base for the efficacy and effectiveness of CBT is significant, whereas the evidence base for counselling is not—and the two should not be confused.

The cognitive model emphasises three 'levels' of cognition: schema (or core beliefs), assumptions (or intermediate beliefs) and automatic thought or images. The importance of information-processing variables such as biases and memory are also acknowledged. Core beliefs are global and absolutistic, such as 'I am helpless', 'Others pity me' or 'Cancer is always fatal'. Intermediate beliefs (or assumptions), which are more cross-situational in their emphasis and can be thought of as 'rules for living', can be outlined in conditional or unconditional format. An example of a conditional belief would be: 'If I do as the doctor tells me then I will have no symptoms.' Unconditional intermediate beliefs are of the format: 'I must always do as the doctor tells me.' Automatic thoughts are situation specific and easier to identify than core beliefs or intermediate beliefs. Each 'layer' of cognition relates meaningfully to the next. Core beliefs, assumptions and automatic thoughts ('They all look so ill—I will crack up if I end up like that') are thematically linked. Beckian CBT emphasises the importance of understanding the influence of a patient's experiences on his or her belief system. Beliefs and schema are formed as a result of experiences and exposure to events, people and situations. This approach emphasises the importance of critical incidents which, when congruent

with the content of existing beliefs, can serve to trigger them. These in turn result in information being processed by patients in a particular manner.

The model emphasises the importance of understanding stable mental representations and their impact in determining how information is processed. Gelder (1997) has outlined how CBT approaches to psychological problems take account of attention and memory. Anxiety and mood disorders are associated with greater levels of self-focused attention (Ingram & Smith, 1984; Wells, 1985). Contact with medical services often results in patients having to pay greater attention to themselves than they might do otherwise, and this can exacerbate pre-existing problems and/or may precipitate problems with an attentional bias which results in an exaggerated self-focus. It is accepted that emotions are associated with the way in which information is retrieved from memory. Metacognitive factors are being incorporated into the conceptualisations of psychological disorders (Nelson et al., 1999; Papageorgiou & Wells, 1999). Assessment measures, such as the Metacognitions Questionnaire (see Wells, 1997) and the Thought Control Questionnaire (Wells & Davies, 1994; Reynolds & Wells, 1999), have also been developed to enable therapists to assess these elements of patient experience. There has also been an increased interest in understanding the nature and function of imagery in psychological disorders and as a component to target for change in treatment.

An example of the application of this model to understanding a psychological problem would be a patient who, by virtue of exposure to adversity or loss in early life, developed negative beliefs regarding loss, failure and achievement. Blackburn (1998) has stated that the typical themes of core schemata are personal worth, moral worth, abnormality and personal ability. These beliefs will be activated by events which are thematically congruent with the beliefs. A patient with a core belief about worthlessness is more likely to experience activation of this belief following rejection than someone who has a similar experience but does not have this core belief. The activation of this belief leads to the tendency to process information according to the dominant cognitive structures which have been activated. This results in the patient experiencing thoughts and images which are associated with predictable emotional, behavioural and, in some cases, physical reactions.

There are an ever-increasing number of psychological disorders for which cognitive behavioural models and therapy protocols have been developed, many of which have been shown to be effective in research trials. These include CBT for depressive disorders (Beck et al., 1979; Dobson, 1989), panic disorder (Clark et al., 1994), generalised anxiety disorder

(Butler et al., 1991); obsessive compulsive disorder (Salkovskis, 1999), post-traumatic stress disorder (Dunmore, Clark & Ehlers, 1999); hypochondriasis (Warwick et al., 1996; Clark, Cook & Snow, 1998); bulimia nervosa (Ledanowski et al., 1997; Hay & Bacaltchuk, 1999), schizophrenia (Haddock et al., 1998; Jones et al., 1999, Tarrier et al., 1999) personality disorders (Davidson & Tyrer, 1996; Davidson, 2000) and bipolar disorders (Scott, 1996). Rachman (1998) has suggested that the application of psychological approaches to other branches of medicine has been slower than desirable and expected when compared with the developments in psychological models and therapies within psychiatry. In saying this, CBT has also been applied successfully to the management of irritable bowel syndrome (Greene & Blanchard, 1994), chronic fatigue syndrome (Price & Cooper, 1999) chronic pain (Morley, Eccleston & Williams, 1999) and cancer (Greer et al., 1992). It is true that advances in cognitive behavioural approaches to psychological disorder have not been matched by the application of the model to understanding psychosocial aspects of adjustment to physical illness. This is beginning to happen (e.g. Salkovskis & Rimes, 1997) as therapists begin to combine clinical observations with scientific findings (Gelder, 1997).

Readers requiring a comprehensive review of the scientific foundations of CBT are advised to consult Clark and Fairburn (1997). Readers interested in CBT generally are advised to consult excellent introductory texts on cognitive therapy such as those by Beck (1995), Leahy (1996) or Blackburn and Twaddle (1996), which provides both an introduction and an excellent illustration of cognitive therapy in practice.

The importance of empirical process within CBT and the acceptance of the need for rigorous evaluation mean that CBT is in a strong position to take advantage of the emphasis on clinical governance and clinically effective therapies. CBT is becoming increasingly accessible to patients, and both the public and media are becoming more interested in how CBT can be applied to psychological disorders (BABCP News, 2000). Clinical psychology has roots in behavioural theories and therapies; it is the discipline most commonly associated with CBT and has become increasingly cognitive in its emphasis in recent years (Rachman, 1998). Most clinical psychologists who have studied in the UK will have had some training in the use of cognitive and behavioural treatment strategies. There is also a small number of psychiatrists in the UK with specialist training in CBT as psychiatrists are required to treat a small number of cases under supervision using cognitive and/or behavioural therapy as part of their training for Membership of the Royal College of Psychiatrists. Clinicians from disciplines such as occupational therapy and social work are also beginning to be trained in CBT, and the expansion of training opportunities has been mirrored by the need to ensure

accreditation of suitably trained therapists. Evidence is beginning to emerge that current CBT training courses are effective in promoting skill development among trainees (Milne et al., 1999).

SUMMARY AND CONCLUSIONS

There are fundamental differences in the impact of acute diseases and chronic illnesses. Psychosocial response to illness rarely correlates highly with disease severity. Psychological variables are particularly important in understanding the way in which patients respond to the challenges which are associated with a chronic medical problem. The literature in this area emphasises the importance of meaning and it is this which makes CBT an ideal approach to helping patients to minimise the negative psychological impact of their illness. The sound evidence base for the application of CBT to the common psychological problems of the physically ill is particularly relevant to modern health care provision and its emphasis on evidence-based therapies. Despite these obvious links between CBT and the context of caring for those with chronic medical problems, therapists are not always clear on how they might tailor their assessments, formulations and treatments to take account of the idiosyncratic elements of working with someone who has a chronic medical problem. This requires an approach which addresses idiosyncratic elements of chronic illness experience while preserving the essential components of CBT theory and practice.