Representations of illness: Patient satisfaction, adherence and coping

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Contents

CHAPTER 3

CHAPTER 4

CHAPTER 5

CHAPTER 6

CHAPTER 7

APPENDICES

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Abstract

Chapter 1 evaluates the self-regulatory model and other theoretical frameworks which have informed the six empirical studies described in this thesis. Chapter 2 reviews the literature on patients' satisfaction with care, adherence to treatment recommendations and coping with chronic illness. It highlights omissions in the literature which are addressed by the current research.

Chapter 3 provides a systematic description of people's representations of 37 different illnesses and examines the basis on which these illnesses are categorized. It was found that beliefs about symptoms, typical sufferer, and treatment were particularly important in discriminating between different illnesses.

Using data from interviews with patients visiting their GP (pre- and post-consultation), chapter 4 explores the relationship between patients' representations of their illness, and satisfaction and intentions to follow treatment recommendations. It was found that doctor-patient discrepancies about diagnosis and treatment were the sole predictors of satisfaction, but were not related to intentions.

In a follow-up study, chapter 5 investigates the predictors of satisfaction and adherence two weeks after the consultation. Several factors were found to predict satisfaction at time 2, but doctor-patient discrepancies were no longer related to ratings of satisfaction. Belief in the benefits of treatment was the principal predictor of adherence.

The primary aim of the two studies described in chapter 6 was to produce a shorter version of the 60-item COPE suitable for assessing coping in patients. The 32-item measure demonstrated construct validity with the longer version and acceptable internal reliability.

Chapter 7 explores the relationship between the different stages of the self-regulatory model in diabetic and hypertensive patients. It was found that beliefs about the costs and benefits of treatment were the principal predictors of dietary and exercise adherence. As predicted, strong relationships were found between patients' illness representations, coping strategies and appraisal of functioning.

The final chapter summarises the findings of the research and concludes that the self-regulatory model is a useful tool for understanding people's responses to illness and adaptation to chronic illness. Suggestions were made regarding ways in which the self-regulatory model might be extended to incorporate other conceptually compatible models. Theoretical, methodological and practical implications are discussed.

CHAPTER 1

Conceptual Framework

1.1 Introduction

Health research has shown an increasing recognition of the significant role people's beliefs about illness play in the interpretation of somatic experience and subsequent health seeking or preventive behaviour. The experience of disease is only partly explained by recourse to the biomedical paradigm since psychological, social, and cultural factors also contribute to the individual's understanding and response to illness. As highlighted by Mechanic (1978), lay beliefs "do not necessarily conform to scientific models, yet it is usually common-sense models that determine the use of medical facilities" (p. 17).

This recognition of the relationship between people's perceptions of illness and how they cope and respond to illness is exemplified in the "common-sense" or self-regulatory model of illness developed by Leventhal and colleagues in the mid eighties (Leventhal, Nerenz & Steele, 1984). This model provides the theoretical framework for the empirical studies discussed in this thesis. The current thesis is concerned with the impact of lay representations of illness on self-diagnosis, and on the interpretation and experience of illness. In a series of progressive steps, it systematically develops the exploration of illness representations from a lay perspective through to their application in patient populations. Study 1 explores the content of people's representations of a wide range of illnesses and how these illnesses are categorized. Studies 2 and 3 examine patients' representations of their own illness and the impact of doctor-patient discrepancies on their evaluation of the consultation and adherence to treatment. Studies 4 and 5 evaluate a measure (the COPE) for assessing coping amongst people suffering from illness and develops a shortened version for use in the final empirical study. Study 6 specifically explores the relationship between the different levels of the self-regulatory model in two chronically ill populations (diabetics and hypertensives). Thus it examines patients' illness representations, the coping strategies they employ, and their appraisal of their long-term adaptation to chronic illnesses (physical and psychological functioning).

This first chapter focuses on the conceptual foundations of the research. It explores the ways in which illness is conceptualized and treated within lay and medical paradigms and considers the potential implications of discrepancies between the two perspectives. The description and evaluation of the self-regulatory model (Leventhal, Nerenz & Steele, 1984) forms the main focus of the chapter together with a consideration of other theoretical models[1] that have informed the empirical work constituting this thesis. Chapter 2 reviews the relevant literature on satisfaction with care, adherence behaviour, and coping and adaptation to chronic illness. It is argued that the self-regulatory model provides a more comprehensive and flexible framework than other available theoretical models for understanding a wide variety of health behaviour and for integrating the diverse empirical work in this domain.

1.1.1 Illness and Disease

Several theorists have emphasized the importance of distinguishing between *illness* as a subjective experience and *disease* as a medical diagnosis based on anatomical or physiological changes and treated by a medical practitioner[2] (Eisenberg, 1977; Kleinman, Eisenberg & Good, 1978; Helman, 1981; Twaddle, 1980). According to Helman (1981), "disease is something an organ has: illness is something a man has" (p. 544). Many psychosocial factors including past experiences, culture, beliefs and social norms affect the experience of illness. This distinction between illness and disease has several implications for the medical consultation. It suggests that the patient and health professional may have distinct assumptions about the problem presented in the consultation; the patient presents the doctor with symptoms of illness which the doctor then translates into the disease model. Indeed, Williams and Wood (1986) argue that doctor and patient have different objectives. Patients adopt a "narrative construction" in order to make sense of their illness within the context of their life experiences. Thus, patients attempt to make sense of the disruption caused by illness, whereas doctors focus on the aetiology of disease. The process of translation between illness and disease is therefore likely to be unsuccessful if a) the doctor fails to elicit the patient's experience (i.e. the illness model) or b) if s/he is unable to translate the disease model into lay terms (i.e. to provide a model which makes sense to the patient).

1.1.2 Biomedical and biopsychosocial models of health and illness

Closely linked with the distinction between disease and illness are two perspectives of viewing health and illness: the traditional biomedical model and the biopsychosocial model of health psychology. The medical profession is frequently criticised for having an overly reductionist biomedical view of disease which focuses on the organic disruption of "normal" biological functioning. From this perspective, the health professional's job is to identify the disease using both the patient's symptom report and physical examination, and thereby prescribe treatment to cure, alleviate or postpone the disease state. Its many critics argue that such an approach ignores the impact of social, cultural and

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[1] The Health Belief Model (Janz & Becker, 1984) and Explanatory Models (Kleinman, 1980).

[2] At least in western societies.

psychological processes (Eisenberg, 1977; Helman, 1981; Kleinman, 1980: Mechanic, 1980). Clearly, health, illness and medical care seeking are influenced by social (e.g. standard of living), cultural (e.g. definitions of what constitutes illness) and individual factors (e.g. personal beliefs). Moreover, outcomes such as treatment efficacy are also influenced by social and psychological factors (Edelmann, 2000).

In recognition of this complex interaction between biological, psychological and social factors, the biopsychosocial model has become the dominant perspective in health psychology. It assumes that susceptibility to disease, the experience of illness and patterns of recovery reflect social and psychological factors as well as physiological ones. Whilst this is gaining increasing recognition among health professionals, many continue to operate within the dictates of the biomedical model resulting in discrepancies between the patients *experience* of illness and the health professional's biomedical perspective.

1.1.3 Seeking medical care

"A phenomenon often approached with fascination by practitioners, lay persons, and social scientists alike is the tremendous variation among people in their responses to what appear to be similar medical conditions" (DiMatteo & DiNicola, 1982,p.112).

The onset of symptoms generally begins the decision-making process leading to the seeking of medical care. However, there is great variability in the attention people give to their physical symptoms and in their concomitant response in dealing with the health threat (Mechanic, 1978; Pennebaker, 1982, 1983). Symptom reporting and care-seeking also vary between cultures (Good & Good, 1980; Mechanic, 1972; Zborowski, 1952; Zola, 1966). People seek out information from a variety of sources in order to label their somatic state. Research has indicated the importance of lay referral; people discuss their health problems with friends and family before deciding to seek medical advice (Sanders, 1982; Scrambler & Scrambler, 1984; Scrambler, Scrambler & Craig, 1981; Prohaska, Funch, & Blesch, 1990; Zola, 1973). Various studies have indicated that people experience symptoms regularly over a period of time, yet the majority of symptoms go untreated (Pennebaker, 1982) or are treated by self-medication (Levin & Idler, 1983). Indeed, it is claimed that between 75% and 90% of people experience clinically pertinent symptoms, but only a third seek medical help (Hannay, 1979; Kellner, 1986). Research indicates that self-care is more likely when symptoms are perceived as minor rather than severe (Haug, Wykle & Namazi, 1989) and when they have minimal disruptive impact (Stoller, Forster & Portugal, 1993). However, it is well documented that even when people experience symptoms suggestive of serious diseases such as cancer and heart disease, they delay seeking medical care (Matthews, Siegal, Kullar, Thompson, & Varat, 1983). This may either reflect a form of denial or the time taken to diagnose one's condition successfully (Leventhal, Nerenz & Steele, 1984). In a study of cardiac patients, Cowie (1976) found that medical advice was sought only when sufferers and their significant others could no longer account for the experienced symptoms within the framework of their everyday lives. More recently, Horne (1999) reported the greatest delays when people experienced atypical symptoms i.e. when there were discrepancies between the symptoms typical of myocardial infarction and those actually experienced. Such findings serve to highlight the inherently subjective nature of the illness experience in which both social and psychological factors influence people's decision to seek medical care.

1.2 Theoretical models for understanding health related behaviour

There has been a gradual movement towards research based on theoretical underpinnings with the development and maturing of health psychology as a discipline. Earlier work was fragmentary and tended to lack an integrative theoretical framework making the interpretation and generalizability of the findings problematic. In contrast, "an explanatory model can direct us toward effective interventions by pinpointing causal processes which are amenable to change" (Leventhal, Meyer & Nerenz, 1980; p. 9). Despite the apparent trend towards the use of psychological models with the widespread application of the Health Belief Model (Rosenstock, 1966) and Theory of Planned Behaviour (Ajzen, 1985) amongst others, Marteau and Johnston (1987) argue that "there has been a relative neglect of psychological models and paradigms " (p.83) with an overdependence on the medical perspective and a lack of attention given to people's beliefs and experiences.

As already stated, Leventhal's self-regulatory model is the primary theoretical framework underpinning the empirical studies in this thesis. It is argued that it is a more comprehensive model for understanding people's interpretation of symptoms and adaptation to illness than other available models. It is discussed at length below (1.3). However, the Health Belief Model (Rosenstock, 1966) and Kleinman's Explanatory Models of illness (Kleinman, 1980) are also particularly relevant to the area under investigation and their contributions are also discussed (section 1.5).

1.3 The self-regulatory model

The self-regulatory model developed by Leventhal and colleagues (Leventhal, 1986, 1990; Leventhal & Cameron, 1987; Leventhal & Diefenbach, 1991; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Easterling, Coons, Luchterhand, & Love, 1986; Leventhal, Meyer, & Nerenz, 1980; Leventhal & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984; Leventhal, Safer, & Panagis, 1983; Leventhal & Scherer, 1987; Leventhal, Zimmerman, & Gutmann, 1984) provides a framework for the whole process of how people perceive their illness and how they respond to it at each stage of their illness progression. It is viewed by its proponents as a more comprehensive framework than other available models of illness behaviour[3]. In particular, Leventhal (1995) criticizes other models for their failure to account for how the individual conceptualises the illness threat. Previous models were fundamentally based on a top down processing framework, that is they imposed theory onto individual experience to determine the amount of variance explained by the model. In contrast, the self-regulatory model is based on bottom-up processing. According to Leventhal (1995), the model is flexible enough to account for **individual** experiences, rather than imposing an elaborate theory onto the individual. Indeed, this emphasis on the individual as an active processor of information has contributed to the increasing popularity of the systems approach in studies dedicated to planning and improving patient care (Earll, 1993; Petrie, Weinman, Sharpe & Buckley, 1996; Petrie & Weinman, 1997).

The self-regulatory model views behaviour as goal directed where the individual actively constructs a representation of his or her condition and regulates his behaviour on the basis of the representation. Unlike previous models it examines the relationship between people's conceptualisations of health threats, their coping behaviours and evaluation of outcomes, at both a cognitive and emotional level.

"The basic theme ... is that individuals are motivated to regulate or minimise their health-related risks and to act to reduce these health threats in ways consistent with their perceptions of them" (Leventhal, Nerenz, & Steele, 1984; p. 219).

The self-regulatory model was a refinement of prior theories which viewed people as active information processors who identify problems and construct plans for coping (Kelly, 1955: Neisser, 1967). It was developed on the basis of earlier work on the persuasive impact of fear messages on health-related behaviour, such as smoking cessation and tetanus injections (Leventhal, 1970). Leventhal and collegues were interested in investigating how people construct strategies to deal with health threats and how fear arousal contributed to such behavioural responses. They found that adherence to preventive recommendations was dependent on information about the danger **and** about a specific course of action. Fear on the other hand, was not related to behavioural change, although high levels of fear led to a breakdown of coping.

In describing the self-regulatory model, Nerenz and Leventhal (1983) stressed that it is a model of "an adaptive system" where adaptation is a result of a series of mediating factors, such as coping

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[3] For example, the theory of planned behaviour, the health belief model and the self-efficacy approach.

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responses (see Fig. 1.3.1). The model consists of three basic components: 1) a series of stages for guiding adaptive action, 2) parallel processing consisting of emotional and cognitive representations, 3) a hierarchically organised system. These are described in detail below.

Fig 1.3.1: The self-regulatory model of illness behaviour (Leventhal, Diefenbach & Leventhal, 1992)

1.3.1 Stages

The feedback model is composed of a series of stages which guide adaptive behaviour (see Figure 1.3.1):

1. The representation: interpretation of a potential threat and a guide for coping efforts and the setting of goals through which coping efforts are evaluated.
2. Coping: planning, selecting and performing the action seen as appropriate to the representation.
3. Appraisal/monitoring: evaluating coping strategies and outcomes against personal goals.

Research indicates that illness representations are made up of five components: identity, cause, time line, consequences and cure/controllability (these are discussed in more detail in section 1.4.1). However, the model recognizes that patients' representations of their illness are not necessarily well organised or complete and integrated (Nerenz and Leventhal,1983). Consequently, the appropriate coping strategy (and the criteria for appraisal) may not be clear to the patient, particularly in the early stages of illness. Consistent with Mechanic's (1978) view of lay models, Nerenz and Leventhal state that "one should not expect illness cognitions to be logically organized or biomedically valid" (p. 27).

A number of factors are likely to shape the development of the representation itself, such as the somatic experience (e.g. symptoms), external information (e.g. from family, media and health professionals), situational factors (e.g. stress at work) and past experience with illness (e.g. that illnesses always have symptoms). Thus the development and elaboration of the individual's representation is based on a number of both internal and external factors, the meaning of which is constantly reassessed in the appraisal stage.

The self-regulatory model may also be conceptualised in terms of Lazarus' (1966) differentiation into primary and secondary appraisal. Primary appraisal occurs with the development of the representation of threat, whilst secondary appraisal involves an evaluation of available coping resources. These two stages are interdependent and result in feedback regarding both the efficacy of the coping strategy and the adequacy of the representation of threat itself. The content of an illness representation shapes the individual's choice of coping strategy and his evaluation of its outcome. Thus, "representations are a map for coping efforts" (Nerenz & Leventhal, 1983). It appears that the concrete aspects of the representation, particularly the symptoms, are critical in guiding coping and the appraisal process (Cameron, Leventhal, & Leventhal, 1993; Petrie & Weinman, 1997). In Meyer, Leventhal & Gutman's (1985) study, 71% of hypertensives who believed that the treatment had a positive effect on their "symptoms" adhered to the treatment regime and also had better blood pressure control, whereas only 30% of those who found the treatment had no effect on their symptoms were adherent. Not surprisingly, patients who had more elaborate representations were found to employ clear coping strategies. Self-treatment, such as stress management or modification of one's diet may also be employed to supplement medical treatment in the alleviation of symptoms or to remove the factors seen as causing the disease in the first place.

The self-regulatory model recognises the temporal, dynamic nature of illness representations which are modified according to changing somatic sensations, new information from the media, friends and practitioners. The coping strategies employed and the appraisal process are also modified in line with changes in the representation. Evidence suggests that when people are diagnosed with a chronic illness, they initially employ an acute model of illness consistent with previous illness experiences, but this shifts to a chronic model over time (Meyer et al., 1985; Leventhal, Easterling, Coons, Lucherhand, & Love, 1986).

1.3.2 Parallel Processing

Leventhal's (1970) early work with the impact of fear messages suggested that there were at least two "partially independent processing systems" operating when people responded to health threats: cognitive and emotional regulatory systems. The former represents the "psychologically objective" representation of the health threat and the development of a coping plan to deal with the perceived threat (danger control). Emotional regulation represents the "psychologically subjective" processing system which involves the emotional response to the threat and the coping plan devised to manage this emotional reaction and the cognitions specific to it (fear control). The existence of two distinct regulatory systems is consistent with coping literature which distinguishes between problem-focused and emotion-focused strategies (Folkman & Lazarus, 1980).

It was found that the coping strategies for emotional regulation were different from those for the cognitive representation of the threat. The two systems would sometimes compete with each other and at other times complement each other. According to Averill (1987), emotional arousal may inhibit preventive action or decisions to seek care, since emotion and behaviour are two conflicting aspects of the objective health threat. For example, a middle-aged man may experience chest pain following a large, heavy meal and suspect a mild heart attack. However, in response to the considerable fear and distress he may experience at the prospect of serious illness, he suppresses such thoughts and decides he is simply suffering from a bout of indigestion. He thus delays seeking medical care in an attempt to suppress the unpleasant emotional response. However, emotional reactions do not necessarily lead to denial responses which conflict with the rational response to danger. In the above example, immediate medical advice may be sought in order to allay or manage the fear and distress.

Leventhal suggests several ways in which emotional states can influence illness representations: a) indirectly affecting the onset and progress of disease; b) adding emotional symptoms to the physical ones thereby making self-diagnosis and the decision to seek medical care more difficult; c) affecting the attention given to the physical state and its consequent interpretation; d) influencing behavioural responses to somatic changes e.g. whether or not to seek medical care. Additionally, the emotional state itself may become a target for self-regulation aside from the "objective" physical state. The seeking of medical care may therefore reflect the attempt to manage emotional rather than physical symptoms.

According to Leventhal (1986), it is the interaction between emotion and symptoms in illness episodes which is primarily responsible for differences in symptom reporting related to environmental factors e.g. social reinforcement, sex and psychological status. Evidence suggests that emotional state influences the reporting of symptoms. People are more likely to report symptoms when they experience negative affect, irrespective of objective health status (Croyle & Uretsky, 1987; Griffin, Friend, Kaell, Bennett & Wadhwa, 1999). On the other hand, emotional responses may be elicited by environmental or somatic cues that stimulate an underlying cognition of danger. Easterling and Leventhal (1989) investigated the relationship between worry about cancer, perceived risk and symptom cues among 54 ex-cancer patients and 81 women with no cancer history. They found that for women who perceived substantial cancer risk, neutral symptoms evoked worry about cancer by activating existing threat cognitions and increasing participants' perception of risk.

1.3.3 Hierarchical Organisation

Leventhal et al. (1980) hypothesized that there are at least two types of memory structure which underlie each stage of the model (i.e. the representation, coping procedures and appraisal for the cognitive and emotional processes). Each stage is hierarchically organised from abstract information at the top to concrete, situation-specific material at the bottom (Leventhal & Nerenz, 1983). Concrete representations are based on *perceptual* processes (e.g. behaviour is guided by symptoms) whereas abstract representations reflect *conceptual* processes (e.g. the belief that all illnesses have symptoms). Concrete or schematic processing involves perceptual memories or schemata which play a role in automatic emotional reactions. When faced with an illness threat, incoming information is combined with memories of schematic structures, which may relate either to prior episodes of illness or to generalised prototypes of illness. Abstract or conceptual processing is more in line with what is typically regarded as cognitive processing, reflecting abstract rules. Abstractions, causal inferences and outcome expectations are based on the individual's judgements about illness episodes e.g. the more severe the pain, the more serious the injury (Leventhal & Everhart, 1979).

Like the parallel processing systems of emotion and cognition, abstract and concrete representations may be compatible or may be conflictual. Discrepancies between abstract and concrete representations may result in emotional conflict as the individual tries to resolve inconsistencies. Work with asymptomatic illnesses such as hypertension is particularly demonstrative of the independence of abstract and concrete representations. Meyer et al. (1985) found that the 80% of patients currently in treatment said that hypertension was asymptomatic (abstract representation), and yet 92% felt that they could tell when their own blood pressure was raised. Thus, although these patients acknowledged the medically accepted view in their abstract representation, their concrete perceptual experience resulted in a conflicting view (i.e. they believed that they did not conform to the medical norm). According to Meyer et al., patients were fully aware of the inconsistency of their views.

There is considerable evidence suggesting that people attempt to integrate concrete (symptoms) and abstract (labels) components to establish the illness identity. In a laboratory study participants were randomly assigned to one of two conditions after measurement of blood pressure (Zimmerman, Linz, Leventhal & Penrod, 1982). Although all readings were normal, half the participants were told that their blood pressure was normal and half that it was elevated. When asked to report any symptoms experienced in the previous three months, those assigned to the latter group reported significantly more symptoms. Using a slightly more sophisticated design, Bauman, Cameron, Zimmerman, and Leventhal (1989) found that participants told that they had elevated blood pressure underwent a cognitive search process in which they searched for symptoms which were consistent with their prior beliefs about the disease. A high BP reading in conjunction with attributions of stress resulted in intentions to take action to confirm the disease label. In addition, the interpretation of health related cues (symptoms, diagnostic information etc.) was dependent on prior beliefs about the disease and environmental cues. Participants reported more symptoms when they believed that BP was influenced by environmental factors and when they had been given high daily stress ratings.

As already discussed, similar findings have been found with hypertensives who appear to search for concrete symptoms as evidence of disease, even with the abstract knowledge that hypertension is asymptomatic. This has various implications for subsequent behaviour, such as seeking medical advice and adhering to treatment regimes. In Meyer et al.'s (1985) study, patterns of adherence reflected the patients' concrete representation through symptom monitoring rather than a more objective but abstract view that hypertension is asymptomatic. Thus, just as people seek labels for their symptoms (by going to a doctor for example), it is also apparent that people are equally eager to find symptoms to correspond with their label. Clearly, symptoms provide an instant and highly accessible means of feedback not only about one's current state of health but also about the causes of illness (e.g. headaches increase when under stress) and the efficacy of one's treatment (medication reduces headaches).

Nerenz's (1979) study with patients receiving chemotherapy for malignant lymphoma indicates how discrepancies between concrete and abstract views can result in distress. He found that of those patients who could monitor their lymph nodes, those whose nodes disappeared quickly with treatment were more distressed than those whose nodes shrank slowly. The former group of patients continued to have chemotherapy and experience the negative consequences of treatment and yet they no longer had a concrete sign that disease was present. In this case, the treatment itself created a discrepancy between the label of disease (i.e. cancer which requires treatment) and the symptoms experienced (i.e. no visible signs of cancer).

1.3.4 Self regulation and coherence

The degree of coherence of the components of the self-regulatory model has important implications for the individual's response to illness threats. According to Leventhal et al. (1992), the model must form a coherent system in order to facilitate behavioural change. They suggest that there are at least three domains in which the issue of coherence is salient. Firstly, coherence of the stages of self-regulation. That is consistency between the illness representation and resulting coping strategies, and between the appraisal of coping and the expected outcome. Factors such as treatment side effects can undermine coherence since the negative effects of treatment are more readily perceptible than its effects on recovery. Thus, adhering to treatment may actually be perceived as an unsuccessful means of coping which conflicts with the abstract representation of treatment as a means of restoring health.

The second domain refers to coherence of the individual's self-regulatory system with the systems of his/her culture and medical model. This has received particular attention in anthropological studies and frameworks such as Kleinman's explanatory model (see section 1.5.2). For example, adherence is found to be higher when the practitioner and patient share common representations, agree on any treatment regimens and have congruent outcome goals (Kleinman, 1980). Discrepancies between patient and practitioner are likely to result in non-adherence, particularly for non-Western patients with cultural beliefs which differ dramatically from Western beliefs. However, such discrepancies arise even where the biomedical model is the norm of a culture. A lack of congruence between medical and lay perspectives may occur in terms of the representation itself or the goals of treatment. Meyer et al.'s (1985) study revealed that patients differed from medical opinion on a number of dimensions, particularly time line and symptomatology (i.e. by incorporating symptoms into their representation). Similarly, patients and health professionals frequently have different views as to the outcome goals of treatment, as evidenced by work with diabetics (Cohen et al., 1994; see 1.5.2). For patients the principal goal is to eradicate the symptoms, effect a cure or minimise the social consequences of illness, whereas for practitioners the primary aim is to exert control over the patients physiological state and prevent further deterioration or complications.

Thirdly, the issue of coherence arises between the self-regulatory process and the individual's personality. An individual's representation of illness will to some degree reflect aspects of their personality such as optimism-pessimism, beliefs about self-efficacy, negative affectivity and so forth. Such factors have implications for attention to and interpretation of somatic states, choice of coping strategies, and criteria used for evaluating outcomes.

Nerenz and Leventhal (1983) also suggest ways in which the patients' representations of their condition may be fitted into their self-system, specifically with regard to chronic illness. From their work with cancer patients, they suggested three ways in which this may be done:

1. Total: the self is the disease, the disease is the self. Life revolves around the label of the illness.
2. Encapsulated: an aspect of the self is diseased but the rest is disease-free. This entails a recognition of role limitations without taking over everyday living.
3. At risk: the self is in permanent awareness of the potential threat of acute outbursts of illness, and acts to minimise this threat. Indeed, this may itself increase the risk of illness through prolonged anxiety and negative arousal.

Clearly, the nature of the relationship between people's representation of illness and their self concept will influence how they cope with the health threat and subsequent adaptation to illness. For example, individuals who view the self as diseased (group 1) are likely to modify their lifestyle to fit in with their treatment regimen (e.g. avoiding eating out to maintain a diet plan) whereas those who adopt an encapsulated perspective are more likely to adapt their treatment to fit with their lifestyle (e.g. eating out but observing dietary restrictions). Environmental factors are also seen to play a role in linking illness representations to the self-system through cultural forces, interpersonal communication and private experience.

1.4 Illness representations: cognitive processing

Considerable research has also focused on the nature and organization of the illness representations themselves, using a variety of methodologies to explore the structure and implications of peoples' cognitive representations of illness.

The self-regulatory model considers symptom perception to play an important role in the formation of representations and in guiding behaviour. Leventhal (1986) highlights the problem inherent in using symptoms as indicators of disease since the meaning ascribed to symptoms may differ depending on whether a lay or medical model is used. In order to understand how people interpret their illness experience and why the meanings attributed to similar symptoms are frequently very different and result in a wide variety of behavioural responses, it is necessary to examine the processes by which people conceptualise and categorize illness. Schematic processing is important because it gives meaning and structure to people's perceptions and experiences. The memory of previous illness episodes plays a role in the modification of current perceptions (Bishop & Converse, 1986) and general health beliefs (Lau & Hartman, 1983; Lau, Bernard & Hartman, 1989). Indeed, it is suggested that schemas developed over time for minor illnesses may be used as standards against which more serious or chronic illnesses are compared and are likely to influence the individual's response to the more chronic condition (Lau & Hartman, 1983, Leventhal; Meyer et al., 1985). Essentially, body sensations undergo schematic processing in becoming recognized symptoms. New symptoms may either be fitted into an existing schema or stimulate the development of a new schema (possibly indicative of a serious illness) if it cannot be incorporated into previous schemas.

Work investigating the structure and development of illness representations has applied models of categorization developed in cognitive psychology, particularly prototype theory (Rosch, 1978). These models suggest that people have well-developed schemata, or idealized representations of the features of categories (see Medin & Smith, 1984). Consistent with the self-regulatory approach, people are viewed as active processors of information. Meaning is attributed to stimuli (internal or external) on the basis of the pre-existing schemata that the person has for the stimuli stored in memory (Fiske & Taylor, 1984). In the case of illness, people have schemata or prototypes about different illnesses, which serve as standards against which people evaluate information about the symptoms that they experience.

The prototype model allows for considerable flexibility since representations are not rigidly defined, but rather correspond to "fuzzy" categories. Thus, in attempting to understand a collection of symptoms, an individual will select a prototype which corresponds to the "best fit" i.e. one resembling his or her symptoms most closely. This matching process between symptoms and prototype is reflected in the analogy of "family resemblance" (Rosch & Mervis, 1975; Smith & Medin, 1981). For example, an individual may not experience all the symptoms suggested by their prototype of meningitis, but there may be enough resemblance to make an initial self-diagnosis and to seek medical care for further clarification. This was rather aptly described by Wittgenstein over 30 years ago:

> "Consider for example the proceedings we call "games". I mean board-games, card-games, ball-games, Olympic games and so on. What is common to them all? ...if you look at them you will not see something that is common to *all*, but similarities, relationships, and a whole series of them at that ... I can think of no better expression to characterise these similarities than "family resemblances". (Wittgenstein, 1963; pp. 31-32)

The nature of disease representations has been investigated in a number of experiments conducted by Bishop and colleagues in America (see Bishop, 1991). An initial study examined people's ability to identify various illnesses on the basis of the prototypicality of symptoms (Bishop and Converse, 1986). Disease prototypes were firstly elicited by asking participants to rate the degree of association between a variety of symptoms and diseases. Participants were then presented with high prototype sets of symptoms (six symptoms associated with the illness), medium prototype sets (four related and two unrelated symptoms), low prototype sets (two related and four unrelated symptoms) or random sets (all symptoms unrelated). As predicted, those participants who had received the high prototype set of symptoms were more likely to rate the symptoms as indicating a disease and to feel more confident about their identification. It is interesting to note however, that whilst participants were more likely to suggest a diagnosis for the high prototype set, there was no significant difference between the prototypicality sets in the accuracy of diagnosis, although the results were in the predicted direction.

Prototype theory also suggests that people find it easier and quicker to recall features which are consistent with their prototypes of an illness since prototypical features are more readily available, enabling rapid information processing and superior recall at a later date. In a second study participants were once again presented with sets of symptoms varying in prototypicality and then asked to recall the symptoms. Not only did participants recall symptoms from high prototype sets more accurately and rapidly, but participants who had received a low prototype set also showed a tendency to recall more symptoms consistent with their prototype of the illness. Not surprisingly, recall of prototypically consistent symptoms was enhanced when participants were given a specific label for the illness. Presumably, high prototypicality sets enabled coherent organization of symptoms within a specified disease category.

1.4.1 The content of illness representations

In their interviews with hypertensive and cancer patients, Leventhal and colleagues (1980, 1982, 1984) identified four components of illness representations (see components 1-4 listed below). Lau and Hartman (1983) investigated whether the same components would also be found in people's descriptions of common illnesses as opposed to chronic conditions. Their findings confirmed the existence of the four components, but also identified a fifth component relating to people's beliefs about treating illness:

1. **Identity**: disease label and symptoms.
2. **Cause**: ideas about how the disease was contracted e.g. injury, infection or genetic weaknesses.

3. **Time line**: expectations of the illness duration and characteristic course i.e. whether the threat is acute, cyclical or chronic.
4. **Consequences**: expected outcome and sequelae of the disease. The impact of disease may be perceived in terms of physical, social or economic factors.
5. **Cure and/or control**: beliefs about how one recovers from or controls a disease.

Lau and Hartman viewed the cure component as particularly relevant to acute conditions with their emphasis on recovery from the disease but subsequent studies have found that it is also employed in understanding and adapting to chronic illness (e.g. Moss-Morris, Petrie & Weinman, 1996). The use of self-care activities appears to be an important aspect of the cure component for both acute (Lau & Hartmann, 1983) and chronic conditions (Leventhal et al., 1986), and is influenced by beliefs about both cause and time line. Examining illness episodes over time, Lau, Bernard & Hartman (1989) found that over half the respondents spontaneously mentioned each of the components, with the label and time line most frequently cited (99.5% and 72% respectively), although respondents did not necessarily use all of the components when describing a single illness. The components were also found to be relatively stable over time and across different illnesses, with direct implications for care seeking. People with strong identity (symptoms rather than labels) and cure beliefs (i.e. who associated a number of symptoms with their illness and perceived it as treatable) were more likely to visit a doctor when feeling ill, irrespective of health status.

Whilst research has supported the existence of the five components, one would expect to find interrelationships between the individual components which together make up a cohesive schema. Indeed, Lau and Hartmann (1983) found a close relationship between the cause and cure components. In their study with diabetics, Hampson, Glasgow & Toobert (1990) found that time line and consequences were highly correlated and combined them to form a seriousness component. Leventhal and Nerenz (1982) found that the components formed three basic schemas of disease with subsequent implications for health behaviour: acute model (specific cause and short time line), cyclical (recurrent cause and longer time line), and chronic (multiple causes and long-term duration).

Bishop, Briede, Cavazos, Grotzinger, and McMahon (1987) used a slightly different method to investigate the make-up of representations, but with essentially the same findings. Subjects were given symptom sets varying in prototypicality and disease severity and asked to record other free-associations about the hypothetical person's situation. More than 90% of associations fell into the above components with no variation according to the seriousness of the symptom lists. Additionally, interesting relationships arose between the associations made and the prototypicality of symptom sets. They found that subjects with high prototype sets tended to demonstrate "category-based" processing (Fiske & Pavalchak, 1986), where associations were made on the basis of the overall disease entity, whereas low prototype sets resulted in more "piece-meal" processing in which inferences were made on the basis of individual symptoms.

"In processing illness information, then, people do their best to relate symptoms to a given disease entity and, when successful, make associations to the overall set of symptoms. When unsuccessful at relating symptoms to a specific disease, attempts at understanding the symptoms in a holistic fashion are thwarted. People will continue attempts to understand their symptom experience but will do so on the basis of individual symptoms" (Bishop, 1991, p. 11).

There were also considerable differences between label and cause associations. In particular, serious but random symptom sets produced the highest frequency of label associations, but fewer causal associations than other sets. This has clear face validity since random, yet serious symptoms cannot be easily assimilated into a prototypical category and are therefore likely to provoke high concern and additional efforts to produce a satisfactory label. Such findings are supported by findings with autoimmune disorders. Patients who are unable to construct a cohesive representation which accounts for their serious symptoms experience considerable distress (Park, 1994).

An alternative approach to the investigation of disease representations has examined the underlying dimensions using factor analysis, as opposed to the constituent components generated by respondents. Turk, Rudy and Salovey's (1986) Implicit Models of Illness Questionnaire was constructed on the basis of Leventhal and Lau's work to produce a "generic implicit illness model". Factor analysis yielded four dimensions: seriousness, personal responsibility, controllability, and changeability. Whilst Turk et al. interpreted their findings as inconsistent with those of Leventhal's components, others have argued that they are simply measuring "different, but complementary aspects of the same phenomena" (Bishop, 1991), namely the ways in which people evaluate representations rather than the content per se. Indeed, it seems entirely logical that these dimensions be incorporated into the descriptive components described previously. Thus, causal attributions entail an evaluation of personal responsibility, perceived consequences an evaluation of illness severity, and so forth.

Lau & Hartman (1983) identified three factors underlying the cause and cure components of representations using attributional scales: stability (temporal consistency of symptoms), locus (internal/external attributions), and controllability. This is consistent with previous attributional research (Weiner, 1974).

Finally, Bishop (1987) examined lay conceptions of physical symptoms as opposed to conceptions of diseases. He concluded that there are four basic dimensions used by lay people to organize symptoms and that these dimensions can be related to the individual's predictions about their behaviour in response to those symptoms: a) virally caused leading to self-care; b) psychological versus physical causation, the latter leading to professional consultation; c) symptoms located in the upper versus the lower part of the body, the latter leading to professional consultation; d) the extent to which symptoms are disruptive to activities, leading to reduction in activity and/or self-care.

1.4.2 The relationship between disease representations

Thus far, considerable research has provided evidence for the internal structure of illness representations, but this provokes further question as to the relationship between representations of different illnesses. Surprisingly, there has been a relative paucity of research in this area. Bishop (1991) examined the perceived relationship between 22 diseases on the basis of ratings on 18 different characteristics. He also investigated the implications for how people respond to disease victims. Diseases appeared to be organized along two main dimensions: contagiousness and seriousness, with the former closely related to people's willingness to interact with disease victims. Moreover, people tended to respond to individual diseases in terms of the general disease category; for example, flu is perceived a prototypical contagious disease against which other contagious diseases are compared. People did not appear to differentiate between various modes of transmission (i.e. airborne vs. sexually transmitted) which clearly has implications for the perception of diseases such as HIV.

Lalljee, Lamb and Carnibella (1993) specifically examined the inter-relationship between 35 different illness using a somewhat different approach. Rather than using scale ratings they asked subjects to group the illnesses on the basis of their similarity. Thus subjects were free to group the illnesses using any categories or dimensions deemed appropriate rather than being limited to predetermined characteristics. Cluster analysis produced seven clusters (see table 1.4.1) which highlight the importance of features other than symptoms in organizing diseases on the basis of their similarity. For example, features such as cause, type of person, anatomical location and illness severity appeared to play a role in distinguishing different clusters of illnesses.

Table 1.4.1: Results of cluster analysis of 35 illnesses (Lalljee et al., 1993)

Cluster	Illness
1	AIDS, syphilis, hepatitis
2	Cholera, typhoid, malaria, smallpox, TB, rabies
3	Cancer, leukaemia, multiple sclerosis, polio
4	Asthma, bronchitis, pneumonia, cold, flu, headache
5	Chicken pox, measles, german measles, mumps, whooping cough, glandular fever, tonsillitis
6	Arthritis, rheumatism, diabetes, dermatitis
7	Ulcer, gastro-enteritis, heart disease, stroke, high blood pressure

* Polio was clustered with different illness depending on the clustering method.

N.B. Cluster 6 was very 'loose' where arthritis and rheumatism were joined later by diabetes and finally by dermatitis.

A second study explored this issue further by examining the content of the prototypes for 12 different illnesses selected from four of the above clusters. The findings provided clear support for the previous study where illnesses within a cluster shared many common features, and differed from illnesses in other clusters. Additionally, people appeared to use "conceptual" processing (Fiske, 1985) whereby they conceptualised illness as "a coherent pattern marked by several features" rather than consisting of independent elements. In a final study which explored the role of prototypes in the diagnosis of illness, Lalljee et al. demonstrated that information about illness cause and the type of person presenting with symptoms were used by people to make judgements about the illness. This finding highlights the salience of factors other than symptoms in influencing decision-making about illness. In the experiment, subjects were given a vignette in which symptom information was paired with person/environmental cause information which varied in its prototypicality. They found that the closer the prototypes from which the person-cause and symptom information were drawn (on the basis of the initial cluster analysis), the more likely that diagnosis was based on the person-cause information. The results indicated that subjects attempted to integrate the available information about the illness; purely symptom-based diagnoses were made only when symptom and person information were incompatible.

1.4.3 Implications for the interpretation of symptoms and care seeking

The above research on the nature and organisation of illness representations not only enhances our understanding of how people perceive and organize stimuli arising from illness experiences, but also how this diagnostic process impacts on subsequent interpretation of the illness experience and determines behavioural responses, such as visiting the doctor. The delineation of components of representations indicates the importance of examining the features people use in diagnosing an illness using pre-existing prototypes. Although most research has focused on symptoms, the work of Leventhal and colleagues and Lalljee et al. (1993) indicate the importance of accounting for factors such as time line and person information in order to develop a more comprehensive picture.

Pennebaker's work (1982, 1984) has also contributed to this body of work by providing a theoretical and experimental analysis of the psychology of physical symptoms and emphasizing the importance of patients' cognitive models of their medical condition. According to Pennebaker, bodily sensations undergo schematic processing in becoming recognized symptoms. The perception of symptoms reflects an individual's schema or cognitive representation rather than a random process of symptom monitoring. Perceptual biases often occur between an individual's physiological state and his or her perception of that state. Lacroix (1991) refers to studies in which biofeedback is used to control physiological activities. Whilst biofeedback is frequently an effective form of treatment and brings about changes in symptom reports, the physiological changes are not correlated with symptom report changes i.e. with subjects' awareness of these changes. Patients' representations of their illness thus serve both as a means for organizing perceptions of symptoms and associated emotions, and as a guide for symptom monitoring.

Once a schema has been selected by the patient, this may then lead to perceptual biases and inaccuracies in the symptoms experienced, as the schema or prototype provides suggestive information about other symptoms that could be present (Pennebaker & Skelton, 1991). Thus, "schemas may create the behaviour they seek to explain" (Kleinman, 1982). In the light of afore mentioned studies indicating the regularity of symptom experience, this provides considerable scope for symptom elaboration and subjective interpretation. Indeed, the influence that people's expectations and beliefs have on their somatic experiences is well documented in the literature on placebo effects (Lau et al., 1989). This clearly has implications for the reporting of symptoms and decisions about how to treat the illness. People are likely to report symptoms which are consistent with their pre-existing schema, thus leading to biases which may influence diagnosis and treatment accuracy. Similarly, peoples' choices about treatment will be influenced by illness representations and symptomatological interpretation. For example, high symptom reporters are more likely to interpret other events in illness related terms (Skelton, 1980, cited in Pennebaker, 1982). Such reasoning suggests that the patient's schema provides the link between disease and illness (Lacroix, 1991), explaining individual differences in people's experiences of disease. It also highlights the subjectivity of symptoms, which contrasts with the objective status commonly assigned to symptoms by the medical model (Higgins, 1984).

Although beliefs about one's physiological state appear to be an important determinant of adherence and care seeking behaviour (Meyer et al., 1985; Gonder-Frederick & Cox, 1991), several experiments indicate that people are not very accurate in judging their internal state. However, accuracy does not appear to be a unidimensional construct since the level of accuracy varies for different symptoms (Pennebaker, 1984, Gonder-Frederick & Cox, 1991). In a laboratory experiment with hyper-, hypo-, and normotensives, Pennebaker and Watson (1988) investigated participants' ability to estimate systolic blood pressure changes under a number of conditions. Participants also provided ratings of symptoms and moods following blood pressure measurements. They found that participants could monitor changes in blood pressure moderately well in a laboratory environment, with 68% of participants having at least one significant relationship between a reported symptom and blood pressure reading. However, whilst some symptoms were significantly associated with physiological changes, the relationship between symptoms and blood pressure was an idiosyncratic one with considerable variation between participants. Furthermore, although medicated hypertensives were most confident about their beliefs and ability to monitor their blood pressure, the relationship between symptoms, emotion and blood pressure was lowest for these hypertensives. Since accurate beliefs were positively related to accurate blood pressure estimates, Pennebaker and Watson suggested that education may be valuable in order to change inaccurate beliefs and facilitate accurate blood pressure monitoring.

Other studies have investigated accuracy of estimates in more naturalistic settings. Bauman and Leventhal (1985) examined people's ability to monitor their blood pressure at the work site, using a within-subjects design. Their participants included workers with both normal and elevated blood pressure (n = 20 and 24 respectively) who provided estimates of systolic blood pressure, and self reports of symptoms and emotions twice a day for 10 days. In accordance with the self-regulatory model, participants' predictions of blood pressure were most strongly related to reported symptoms, somewhat less to ratings of mood, and least to actual systolic blood pressure. Moreover, feedback about the accuracy of predictions had little effect on the participants' beliefs. This supports previous work in which people use symptoms (and mood states) to monitor blood pressure despite information that hypertension is an asymptomatic disease.

In a number of studies, Lacroix (1991) examined the implications of "schema accuracy" on outcome measures, particularly focusing on discrepancies between patients' illness schemata and the views of their doctors. He found that schema accuracy was related to both functional adjustment and return to work for respiratory patients and people suffering with back pain. Thus, patients with an accurate understanding of their symptomatology were found to function at a higher level than those holding inaccurate schemata. Lacroix suggested that such patients are better able to keep their symptoms in perspective (e.g. by adopting the "encapsulated" perception of self in relation to the illness state, see section 1.3.4) and are also able to accommodate more severe symptomatology through appropriate adjustment.

Cameron, Leventhal and Leventhal (1993) investigated people's decisions to seek medical care. They found that people visited the doctor when they had well-developed representations of a serious health threat, perceived themselves as unable to cope, had received advice to seek care and were experiencing life stress. The presence of atypical symptoms was not by itself sufficient to trigger care seeking. In view of the strong representations held by care-seekers, Cameron et al. suggested that medical professionals must "distangle any previous misconceptions that patients may have developed" (pp. 273), so that new information will not conflict or compete with patients' own beliefs.

Although the self-regulatory model is presented as the most comprehensive framework for understanding how people respond to health threats, it is not without its limitations. Despite the importance placed on parallel processing of emotional and cognitive representations, the majority of work to date has focused primarily on cognitive processes. Additionally, although the self-regulatory model recognises the dynamic relationships between illness representations, coping and appraisal, very little systematic research has been conducted which explores the nature and direction of relationships between these stages. However, these limitations reflect the relative paucity of empirical work specifically addressing these issues rather than a necessary weakness in the theoretical underpinnings of the model.

1.5 Contributions from other theoretical models

Two additional models have influenced the theoretical design of the empirical work conducted in this thesis. It is argued that whilst both models have their limitations, each has valuable contributions to make to the continuing development of the self-regulatory model.

1.5.1 The Health Belief Model

The Health Belief Model (Rosenstock, 1966) has been widely applied to the investigation of health behaviour, and until recently was the primary theoretical approach used in understanding people's responses to illness. The model was originally formulated to understand people's failure to adopt

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preventive health behaviour, but was later expanded to explain behaviour such as adherence to medical regimes (Becker, 1974).

The model consists of four main elements (see Fig. 1.5.1):

1. *Perceived susceptibility*: the individual's perception of vulnerability to contracting a particular disease (or complications arising from a disease).
2. *Perceived severity:* the individual's beliefs regarding the consequences or impact of contracting a disease. This may include an evaluation of both the clinical consequences (e.g. disability, pain) and the possible social consequences (e.g. job loss, family disruption).
3. *Perceived benefits and barriers:* the individual's beliefs about the pros and cons of engaging in health actions, such as preventive behaviour (attending screening) or adhering to treatment. Benefits relate to the perceived efficacy of available actions (e.g. medication reducing symptoms), whilst barriers refer to the possible negative aspects of action (e.g. side-effects of treatment).
4. *Cues to action:* stimuli which arouse perception or stimulate action. Such cues may be internal, such as experiencing symptoms, or external, such as receiving advice or reading an article about health.

Figure 1.5.1: Basic Elements of Health Belief Model (adapted from Janz & Becker, 1984)

The first two elements are viewed as constituting the perception of risk and the motivation for action, whilst the third element reflects the cost-benefit analysis which is seen to determine the individual's preferred path of action. "Cues to action" were subsequently included to account for the stimulus required to trigger the decision-making process. In addition, demographic and social-psychological factors are viewed as external factors influencing an individual's perceptions and evaluation of threat.

Taking adherence as an example, an individual who did not perceive herself as vulnerable to the consequences of the disease would be less motivated to adhere to her treatment regime than someone who acknowledges this vulnerability. However, a motivated individual may be non-adherent if she perceives the costs of the recommended treatment to outweigh the benefits in comparison to some other form of treatment.

The Health Belief Model has been extensively documented and applied to a wide range of health behaviours with varying degrees of success in predicting and modifying behaviour (see Janz & Becker, 1984). From a review of 46 studies, Janz and Becker found the dimension of perceived barriers to be most predictive of health behaviour, followed by susceptibility, perceived benefits and severity. However, the differential predictive power of the individual elements varies according to the type of behaviour examined; for example, perceived severity is more powerful in predicting sick role behaviour compared with preventive health actions, whereas susceptibility may prove irrelevant to the individual when a diagnosis has already been given.

The HBM has been criticised for its methodological inadequacies and difficulties arising from operationalizing the individual components (e.g. the use of different questions across studies to measure the same beliefs). Such difficulties together with the development of more sophisticated models has led to a decline in the application of the HBM in recent years, although it remains popular in adherence research (e.g. Bond, Aiken & Somerville, 1992; Brownlee-Duffeck, Peterson, Simonds, Kilo, Goldstein, & Hoette, 1987; Glasgow, McCaul & Schafer, 1986; Harris & Linn, 1985). Whilst the HBM has greatly contributed to our understanding of health behaviour, it has a number of limitations which are outlined below before going on to consider how it might be usefully incorporated into the self-regulatory model.

Although the HBM incorporates conceptual frameworks from theories of learning, attitude and motivation, emphasizing the importance of cognitive processing by the individual, it was pointed out over two decades ago that a more complex decision-making model was needed to explain health behaviour (Kasl, 1974). The conceptualisation of motivation is itself rather ambiguous and there is no distinction between motivation and the perception of risk. Weinstein (1987) argued that such dimensions may not even be considered by the individual and that other factors such as advice (e.g. smoking is bad for your health) may increase the saliency of the threat without affecting perceptions of either severity or susceptibility.

The lack of consideration of social and contextual factors has also resulted in questions regarding the validity of the HBM. The components of the HBM have been criticised as unrealistic in that they are treated as if operating within a vacuum which does not take into account the individual's social context (Kasl, 1974; King, 1984). By assuming that people are rational in their decisions about health the HBM also fails to account for the role of emotional responses to illness threat (Leventhal, 1990). The assumption that behaviour is based purely on conscious decision-making is clearly inadequate when considering the experience of illness which may evoke strong affective reactions, e.g. stress, anxiety and denial. Indeed, the management of emotional responses to an illness experience may well produce a behaviour or outcome which conflicts with the rational, conscious response (see section 1.3.2). Good (1986) has also argued that such a cost-benefit approach does not allow for the analysis of cultural factors and beliefs and adopts the biomedical model as the norm. This is manifested in its original design which aimed to help health professionals to persuade people to act rationally by following the doctor's orders and using preventive health care, where health beliefs were evaluated according to their "proximity to empirically correct knowledge".

A further inadequacy of the HBM is that it fails to take account of people's perceptions of illness and the cognitive processes which precede the components of the HBM. As King (1984) argues: "... a major element missing from the HBM is the process of <u>causal</u> explanation of illness. There is no account of how patients interpret the cause of an illness (if indeed they do so at all), under what conditions they seek such explanations and how these explanations affect belief and behaviour." (pp.58)

Furthermore, the impact of coping is not incorporated into the model (or at most the absence of such skills is viewed as a barrier to action), nor does it account for the role of the individual's appraisal of his actions on subsequent beliefs and behaviour (Leventhal, 1987). Previously unsuccessful behaviour is assumed to influence the individual's attitudes towards perceived barriers (Janz & Becker, 1984), but the model offers no explanation of the processes underlying this appraisal process and its subsequent impact.

Such criticisms highlight the inadequacies of the HBM as a single theoretical explanation of health behaviour, but this is not to say that its constructs are not valuable when combined with a more comprehensive framework such as the self-regulatory model. Indeed, as already stated, the HBM has proved moderately successful in predicting adherence to treatment, with beliefs about the costs and benefits of treatment proving particularly effective in predicting adherence in chronic illness (see 2.4.2.2 for further elaboration). In contrast the relationship between illness perceptions and adherence is still relatively unexplored within the self-regulatory model. Several studies indicate that illness representations alone demonstrate relatively weak relationships with adherence (Hampson, 1997; Horne, 1997), suggesting that additional constructs such as specific beliefs about the costs and benefits of treatment may provide a link between illness representations and adherence behaviour (this is discussed at greater length in chapter 7, specifically 7.1.3).

1.5.2 Explanatory Models

The notion of "explanatory models" of illness (EM) has its roots in cognitive anthropology rather than psychology but has considerable conceptual overlap with Leventhal's illness representations. Both focus on the way people conceptualize and make sense of illness, but the principal focus of the EM approach is on discrepancies between patient and practitioner models of illness (Kleinman, 1980, 1982, 1986). According to Kleinman, explanatory models are "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman, 1980). In essence, research using this framework is concerned with examining the transaction between lay (illness) and medical (disease) EMs in the consultation and the impact of such interactions on patients' experience of illness and their health behaviour. EMs consist of 5 major clinical areas:

1) Aetiology
2) Time and onset of symptoms
3) Pathophysiology
4) Course of sickness (severity/sick role)
5) Treatment

According to Kleinman and other proponents of this approach, by focusing on the dimensional differences between the patient and practitioner, areas of conflict are revealed with their potential impact on subsequent behaviour. Indeed, Kleinman and others have indicated that incongruence between patient and practitioner models negatively correlates with outcome variables, such as patient satisfaction, adherence to treatment, and use of health-care facilities (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Kleinman, 1980).

In their ethnographic study with Type I and Type II diabetics, Cohen et al. (1994) compared the EMs of patients and health professionals and found major discrepancies in several areas. The lowest level of congruence was found for time and mode of onset, and discrepancies also occurred for aetiology, pathophysiology, and severity. Health professionals were largely unaware of the explanatory models of their patients. Although discrepancies were not significantly related to measures of blood glucose control, they found that professionals and patients had very different orientations to the disease process which meant that many of the problems faced by diabetic patients were unknown to the staff. Professionals viewed diabetes primarily as a pathophysiological problem (i.e they used a biomedical framework), whilst patients emphasized the impact of the disease on their life style and social domain. This is consistent with the findings of Williams and Wood (1986) discussed in 1.1.1.

Research on explanatory models has provided a framework for understanding how discrepancies between cognitive systems may impact on subsequent behaviour, and unlike other models places considerable emphasis on the role of social and cultural factors. Moreover it suggests ways in which the self-regulatory approach can be extended to include the impact of others, namely the health professional, on patients' responses to the experience of illness. This is explored in Studies 2 and 3 (chapters 4 and 5).

1.6 Conclusions

In summary, the self-regulatory model is grounded in more general theories of social cognition which account for the processes by which new experiences are integrated with prior schematic knowledge. Considerable empirical support exists as to the structure and organization of illness representations. These representations form the foundation of the self-regulatory model by directing people's interpretation of illness and concomitant emotional and behavioural responses. Although research has tended to focus on the significance of symptoms, the work of Leventhal and colleagues and Lalljee et al. (1993) has demonstrated that other features of illness, such as cause and time line are important both in organizing people's representations and directing their behaviour. Chapter 3 investigates the role these various features play in categorizing a wide range of different illnesses.

An outline of the principles of the self-regulatory approach indicate that it is a more comprehensive framework than other models, which explains the processes involved in people's responses to health threats. The self-regulatory model focuses on the processes by which people use illness representations in guiding their behavioural responses, emphasizing the interpretative processes which convert a somatic sensation into a symptom and how this is used in coping and appraisal. It also recognizes the interaction between emotional and cognitive processing which together influence subsequent action and evaluation through the setting of acceptable goals.[4]

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[4] Although, as indicated in section 1.4, investigations into the structure of people's representations has largely focused on the cognitive dimension.

According to Leventhal et al (1997), other cognitive decision models are incomplete in that they lack a conceptualisation of the emotional and cognitive representation of the disease threat (e.g. the Theory of Planned Behaviour) or they lack differentiation of the health threat (e.g. the Health Belief Model). Moreover, other models lack recognition of an emotional component in directing the interpretative and behavioural stages. Unlike other theoretical models, the self-regulatory approach provides a dynamic framework for understanding peoples' responses to illness threat. It has proven useful in understanding a variety of health and illness behaviours, including deciding that one is ill (Baumann, Cameron, Zimmerman, & Leventhal, 1989), seeking medical care (Lau et al, 1991), adherence to preventive and medical treatments (Leventhal & Cameron, 1987; Meyer, Leventhal, & Gutmann, 1985), and responses to stressful medical procedures (Easterling & Leventhal, 1989).

Moreover, the self-regulatory model is flexible enough to encompass other more specific models. Indeed, Leventhal and Cameron (1987) propose that other theories should be incorporated into the self-regulatory systems framework, providing a bridge between different approaches and insight into the experience of illness. In this chapter it has been argued that two models in particular have contributions to make to the self-regulatory framework. Critics of the self-regulatory approach argue that it remains an essentially individualistic model and fails to take into account cultural and contextual factors (e.g. Cohen et al., 1994; Ogden, 1995). Leventhal et al. (1997) responded to this challenge by arguing that a) the self-regulatory model attempts to explore the mediating effects of contextual factors at each stage and b) the underlying constructs of illness representations are universally applicable, if variant in their labelling. Indeed, the illness representation approach has considerable overlap with the anthropological perspective of Explanatory Models (Kleinman, 1980). However, proponents of the Explanatory Model paradigm argue that the self-regulatory approach fails to look at the interaction between patient and practitioner models of illness (Cohen, Reimer, Smith, Sorofman, & Lively, 1994). This omission is addressed in chapter 4.

Additionally, although Leventhal and colleagues (Leventhal & Cameron, 1987; Leventhal, Diefenbach & Leventhal, 1992) argue that the self-regulatory model provides a framework for understanding adherence to treatment recommendations, few empirical studies have explicitly explored the relationship between illness representations and adherence. In contrast, many studies have continued to use the Health Belief Model as a framework for predicting adherence to treatment recommendations. The utility of both models to the understanding of adherence is explored in chapters 5 and 7. The following chapter reviews the literature relating to satisfaction, adherence and coping with illness.

CHAPTER TWO

Satisfaction, adherence and coping with chronic illness

2.1 Introduction

In the previous chapter, it was argued that the self-regulatory model provided a comprehensive framework for understanding people's interpretation of illness. This framework is used in the current thesis to examine patients' evaluation of primary care consultations, adherence and coping with chronic illness. The present chapter reviews the literature in these three main areas to provide a context for the subsequent empirical chapters and evaluate the contribution of previous research and theory to these key areas. Firstly, the impact of illness beliefs on patient satisfaction is considered within the context of the satisfaction literature. Then a review of the processes associated with the self-regulation of illness is presented, specifically in relation to adherence and coping behaviour. The impact of such processes is discussed in relation to patient quality of life and functioning in chronic illness. Particular emphasis is placed on patients' subjective evaluation of illness and its consequences, since patients' perceptions and appraisal of their condition ultimately direct their illness behaviour.

2.2 Satisfaction with medical care

Satisfaction is a subjective evaluation of quality of care, which reflects the meeting of patients' needs and expectations and the provision of an acceptable standard of service (Wilkin, Hallam, & Doggett, 1992). Patient satisfaction has become increasingly recognized as an important "immediate" measure of outcome (Pendleton, 1983) for two main reasons. Firstly, the past decade has seen an increasing emphasis placed on consumer opinion and evaluation of care services. As a result, satisfaction has become recognized as "a legitimate and desired outcome in itself" (Williams, 1994; p. 510), both in terms of meeting patients' needs and increasing service efficiency. Secondly, a large body of evidence has demonstrated that patient satisfaction is linked with adherence to treatment regimens, problem resolution and better understanding and retention of medical information (DiMatteo & DiNicola, 1982; Fitzpatrick, 1984; Hall, Roter & Katz, 1988; Inui & Carter, 1985; Ley, 1982; Pascoe, 1983; Winefield, 1995).

As discussed in the previous chapter, it is proposed that congruency between patient and doctor models of illness plays an important role in determining patients' evaluation and response to the encounter. Clearly though, other factors such as communication style and the quality of information given by the doctor will influence both patients' evaluation of the consultation and the degree to which any cognitive discrepancies are addressed within the encounter. Considerable research has accumulated investigating the antecedents and consequences of patient satisfaction, ranging from an exploration of sociodemographic variables to the communication processes operating within the consultation itself. However, a number of different approaches have been adopted with differing methodological and theoretical foundations, precluding direct comparisons. Indeed, many studies of patient satisfaction lack a clear theoretical basis, making interpretation of their findings problematic. Despite such limitations, the studies reviewed below identify areas in which difficulties may arise and provide suggestive evidence as to their impact on patients' self-regulatory processes.

2.2.1 Patient characteristics

Several patient sociodemographic characteristics have been associated with satisfaction, although many of the findings are weak or inconsistent, particularly those relating to social class, education and ethnicity. In a meta-analysis, Hall and Dornan (1990) conclude that "sociodemographic characteristics are a minor predictor of satisfaction, at best" (p. 816). They found that higher satisfaction was significantly related to being older and having less education and marginally associated with higher social status and being married. However, they found considerable heterogeneity between different studies on all variables.

Patient age has demonstrated the most consistent relationship with satisfaction; a number of studies have found that older patients express higher satisfaction with their care than younger patients (DiMatteo & Hays, 1980; Fitzpatrick, 1984; Hall & Dornan, 1990). In a review of studies which also incorporated ethnicity, Nzegwu (1993) found that older patients (55 years and over) were more satisfied than younger patients (less than 34 years) in both GP and Outpatient settings for all ethnic groups.

One explanation for such findings is that older patients adopt a less critical approach to their care which has been associated with their tendency to adopt a more passive role. Greene, Adelman, Friedman, and Charon (1994) undertook a study to look at the determinants of satisfaction in an older patient sample (60 years and over) and found that patients preferred a style of communication characteristic of the traditional doctor-patient relationship. Affective factors, such as doctor support and engagement with the patient were particularly salient. However, their study was subject to a number of limitations; the relatively small sample (N=81) was predominately female (79%), black (72%), and from low socioeconomic and educational levels which is likely to influence expectations and attitudes towards the consultation. Other theorists argue that older patients' tendency to be more satisfied with their care may actually reflect differences in doctor-patient communication within the consultation, whereby older patients receive more information and more courtesy than younger patients (Hall, Roter & Katz, 1988).

Studies have also found that females and patients from higher social classes are more satisfied (e.g. Pascoe, 1983). Again, this may well reflect differences in the consultation itself; a number of studies have demonstrated that the nature of the consultation differs according to the patient's gender (Hall et al., 1988; Stewart, 1983; Verbrugge & Steiner, 1981) and social class (Dungal, 1979; Hall et al., 1988; Pendleton, 1981; Ross, Mirowsky, & Duff, 1982). In general, female patients and those from higher social classes received more information, more communication overall, and more positive interaction. The relationship between satisfaction and education is particularly inconsistent. This may reflect the existence of other moderating variables which interact with educational level in determining patient satisfaction.

2.2.2 Consultation Factors

2.2.2.1 Information giving

In a meta-analysis of 41 studies, Hall et al. (1988) found that the amount of information provided by the doctor was the most significant predictor of satisfaction. However, reports of satisfaction with information given are often lower than general or other specific measures of satisfaction (Hall & Dornan, 1988). Indeed, patients appear to want more information than doctors are willing to give. A recent analogue study indicated that 81% of patients expected the fullest possible information to be given about an injury during surgery whilst only a third of doctors shared this opinion (Hingorani, Wong, & Vafidid, 1999). Berry, Michas, Gillie, & Forster (1997) also found that discrepancies existed between the information lay people and doctors regarded as important. Patients were most concerned about the side-effects of their treatment, what the treatment does, and necessary lifestyle changes. These received low ratings from doctors, who viewed information about the interaction effects of medication as most important.

Ley and colleagues have reported a number of studies investigating the role of cognitive factors, namely understanding and memory of medical information, on satisfaction and adherence (Kincey, Bradshaw, & Ley, 1975; Ley, 1982, 1988). Satisfaction is seen to mediate between cognitive factors and behaviour, providing the necessary motivation to adhere to treatment recommendations. In a review, Ley (1982) demonstrated that satisfaction was associated with patients' understanding and retention of the information presented during the consultation. Self-report studies indicated that between 7% and 53% of patients do not understand what they have been told, which increases to between 53% and 89% when behavioural measures are used (Ley, 1982b). Pendleton (1981) agreed that clear exposition of information was essential to ensure a satisfactory consultation, but argued that such high levels of forgetting partly reflect experimental design. Pendleton found that when important information was distinguished from unimportant material, patients were able to remember the majority of the information received in the consultation.

Ley demonstrated that patient satisfaction and adherence could be improved when medical information is presented in a manner which can be understood and remembered. This led Ley to suggest several strategies to enhance patient memory of information: 1) simple written instructions; 2) explicit categorisation of the material presented; 3) avoiding use of medical jargon; 4) repetition of important material; 5) use of primacy and recency effect[1]; 6) use of specific rather than general advice statements. Satisfaction with the *type* of information given in the consultation does, however, remain an issue (see Berry et al., 1997).

2.2.2.2 Doctor Characteristics

Others argue that it is the socio-emotional aspects of the consultation which are central determinants of satisfaction. Several early studies found that doctors' interpersonal skills had a significant impact on patient satisfaction and commitment to the therapeutic relationship (Ben-Sira, 1976; Mechanic, 1978). Korsch, Gozzi, and Francis (1968) found three main characteristics associated with patient satisfaction: friendliness (as opposed to business-like), an understanding of the patients' concerns, and an ability to accommodate patients' expectations. Others have found a strong relationship between doctors' liking for their patients and patient satisfaction with the visit (Hall, Epstein, DeCiantis, & McNeil, 1993; Like & Zyzanski, 1987). Several studies have emphasized the importance of the doctor's "bedside manner", namely his ability to convey warmth, support and reassurance (DiMatteo, Linn, Chang & Cope, 1985; Hall et al., 1988; Jefferys & Sachs, 1983; Squier, 1990). When patients were asked about the qualities they most appreciated in their doctor, 87% made reference to his manner or personality (Cartwright, 1967). However, Hall et al. (1988) found that patients' perceptions of the practitioner as concerned and caring did not result in patient satisfaction and adherence in the absence of adequate information.

Demonstrating links between patients' perceptions of the doctor's competence and satisfaction have proved problematic due to difficulties in separating the instrumental and affective dimensions of

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[1] I.e. stating key information at the beginning (primacy) and end (recency) of the transaction.

doctor behaviour (Thompson et al. (1992) cited in Kenny, 1995). It has been suggested that many patients base their evaluation of competence on their satisfaction with the doctor's affective behaviour rather than his/her technical competence per se (Ben-Sira, 1982, 1985). However, a study by Evans, Kiellerup, Stanley, Burrows, and Sweet (1987) suggested that patients were able to distinguish between affective and instrumental dimensions. Whilst patients felt satisfied with the treatment they received from the consultation, they reported lower levels of satisfaction with affective components such as the doctor's demonstration of caring and respect. Indeed, Hall et al. (1988) argue that whilst instrumental or task orientated behaviours may result in evaluations of both an affective and technical nature, the doctor's affective manner does *not* trigger evaluations of technical competency.

In a recent Australian study, Kenny (1995) examined a number of factors associated with patient satisfaction. Two hundred and seventy two patients completed a questionnaire and interview following their consultation with either a GP or a medical specialist. Doctors were unaware that their consultations were being assessed. Fifty two percent of patients were very satisfied with the consultation and only 5.5% expressed dissatisfaction. None of the latter communicated their dissatisfaction directly to the doctor. Factor analysis of the questionnaire revealed that 58% of the variance in satisfaction ratings and 52% of the variance in patients' perceptions that their requests had been met were accounted for by the level of interpersonal warmth and respect (54%) and to a lesser extent, the amount of information given by the doctor (4%). Furthermore, these two factors were highly correlated suggesting that affective and technical competence dimensions cannot be easily separated.

Kenny concludes that the interpersonal skills of the doctor and the degree to which patients' expectations are met had a major impact on satisfaction. However, whilst this study explored a number of variables previously associated with satisfaction, it was based on data collected after the consultation. This is particularly problematic when assessing the impact of factors such as the degree to which expectations have been met.

2.2.2.3 Doctor-patient communication

" Most of the dissatisfaction reported has to do with poor levels of communication. In fact a quarter of all cases of malpractice handled by medical defence organizations involved a failure in communication among professionals or between them and their patients." (Nzegwu, 1993; pp.194)

Considerable research has focused on the impact of doctor-patient communication and negotiation on patient satisfaction with the consultation. Not surprisingly, most studies demonstrate a relationship between various facets of the communication process and subsequent satisfaction with the consultation (DiMatteo, Prince & Taranta, 1979; Hall et al., 1988). Whilst medical competence is a necessary requirement of a successful consultation, a doctor's understanding of the patient's concerns has also been shown to promote a more productive relationship (Pendleton, 1981, Strasser, 1992). The classic study by Byrne and Long (1976) indicated that problematic consultations were ones in which the doctor did not discover the reason for the patient's visit. The importance of communication is highlighted by the finding that patients frequently fail to adequately describe their symptoms and problems to the doctor. Korsch et al. (1968) found that 65% of patients' expectations and 76% of patients' worries were not mentioned to the doctor.

Hall et al. (1988) identified two main functions of the doctor-patient relationship from reviewing communication literature: task (information giving) and socio-emotional (interpersonal competence). Galassi, Schanberg and Ware (1992) later added patient participation as a further function of the consultation. Indeed, several studies have highlighted patients' desire to play an active role in their care with subsequent benefits for outcome variables (Delbanco, 1992; Greenfield, Kaplan, & Ware, 1985). In an intervention study, Greenfield et al. (1985) found that increasing patient participation in a group of ulcer patients resulted in reports of fewer limitations in physical and role-related activities compared with a control group. Although it did not increase patient satisfaction, patients in the experimental group stated a preference for a more active role in their care after the intervention.

The importance of patient participation and reassurance from the doctor was illustrated in Pendleton's (1981) study of 283 general practice patients. Three main factors were predictive of satisfaction: a) relief arising from the perceived thoroughness of the doctor's examination, b) the patient's involvement in the decision-making process and understanding of the information presented, and c) being treated empathically by the doctor. In a further study, medical students who were trained to recognize patients' feelings and patients' efforts at communicating subsequently demonstrated more empathic behaviour when interviewing patients compared with those allocated to a control group.

Stewart (1984), however, found that patient-centred consultations were not significantly related to satisfaction and pill counts but they did result in higher self-reported adherence. Overall, it was found that doctors behaviour, particularly when they requested patients' opinions and when they helped patients to express their own opinions, had a positive effect on patient self-care behaviour and patient satisfaction.

2.2.2.4 Doctor-patient congruence

As discussed in chapter 1, congruence between the model of illness suggested by the doctor and that held by the patient is central to the patients' interpretation of the consultation and subsequent behaviour. However, surprisingly few studies have directly examined the impact of doctor-patient agreement on patients' subjective interpretation of care. Becker (1985) suggested three ways in which disagreement between doctor and patient may occur in the diagnostic process:

a) Discrepancies between patients' beliefs or representations of their condition and those of the doctor. This is particularly salient to both Leventhal's illness representation framework and Kleinman's notion of explanatory models.
b) Lack of confidence in the doctor's diagnosis due to doubt in the doctor's competency or when the patient's concerns are not adequately dealt with.
c) Rejection or denial of the diagnosis due to fear or an unwillingness to accept vulnerability to illness. This most often relates to life-threatening and chronic diseases, where an initial denial phase is a common coping response.

In an early study, Freemon, Negrete, Davis & Korsch (1971) found that agreement was associated with both patient satisfaction and adherence to treatment. Like and Zyzanski (1987) argued that high levels of satisfaction on the part of both patient and practitioner arise when doctor and patient agree on the desired outcome of the encounter and when both strive to achieve it. "An understanding of the patient's perspective is a core clinical task" (Like and Zyzanski, 1987, p.355). This may require considerable interviewing skills when patients' requests are not readily communicated. This highlights the importance of communication between patient and doctor in order that a mutual understanding emerges.

Boland and colleagues investigated level of agreement between doctors and patients regarding the factors motivating patients' visits (Boland, Scheitel, Wollan, & Silverstein, 1998). They found that complete agreement was achieved in 63% of cases and "major agreement" in 17% of cases. However, there was "low agreement" in 20% of cases when the doctor failed to identify the patient's central reason for the visit. Gender appeared to play a role, with communication difficulties most apparent when female patients were visiting a male doctor. Multiple reasons for a visit also proved problematic for effective communication between patient and doctor. However, such disagreements did not have a negative impact on satisfaction with the consultation.

Several other studies have explored the frequency and impact of disagreement between patient and doctor on several dimensions for a variety of different complaints. Wartman, Morlock, Malitz & Palm (1983) compared doctor and patient reports of anxiety, discomfort/pain and activity limitation. They investigated the impact of doctor-patient discrepancies on doctors' prescribing behaviour and patients' satisfaction. Five hundred and fifteen patients completed questionnaires at the time of the visit and were followed-up one week post-visit to assess satisfaction. They found high levels of incongruence between patients and doctors, with doctors underestimating the three dimensions 35% of the time; underestimation was most prevalent for the degree of activity limitation (56%). Discriminant analysis revealed that patients' dissatisfaction was related to incongruence over levels of anxiety; patients who reported more anxiety and whose doctors underestimated their anxiety levels were more likely to feel dissatisfied. In contrast, agreement between patients' and doctors' reports of discomfort (high) resulted in a prescription.

However, Wartman et al.'s sample was based in American departments of Adult Medicine and Urgent Care which may have considerable impact on patients' reports of distress as compared with General Practice. The sample was also unrepresentative as it was biased towards middle-aged and middle-class patients. In addition, patients' satisfaction was measured a week after the consultation rather than immediately after the visit, and patient expectations were not assessed prior to the consultation.

Doctor-patient agreement regarding causal attributions was investigated in a study by Risdale, Evans, Jerrett, et al. (1994) with 220 patients presenting with fatigue (together with a matched sample of patients not complaining of tiredness). A lack of agreement was found between the doctor's view of what was causing the tiredness and the patients. Only in 31% of cases was there doctor-patient agreement after six months. Whilst 60% of patients thought fatigue had physical causes, 57% of doctors believed it to be psychological in origin. Only 8% of patients changed their beliefs to recognize a psychological component. This highlights the difficulties of modifying patients' representations of their illness. Unfortunately, Risdale et al. did not assess the effect of congruency on patients' satisfaction with the consultation, although when disagreement remained unresolved, patients were found to consult the doctor more often than the control group.

Salmon, Peters & Stanley (1999) conducted a qualitative study to explore patients' perceptions of doctors explanations for somatisation disorders (N = 188). They found that doctors' explanations were frequently incongruent with those of patients. Patients' accounts of their doctors' explanations were grouped into three types: rejection (denial of reality of the symptoms), collusion (acquiescing to patients' beliefs), and empowerment (explanations were exculpating and involved the patient). Patients felt most satisfied with the latter category of explanation with concomitant implications for reducing the heavy demands placed on healthcare by such patients through the assertion of greater control over their condition. Although these findings relate to patients with somatisation disorders, the wider issue of patient involvement in the negotiation of sickness has implications for addressing difficulties posed by doctor-patient incongruence.

Doctor-patient agreement has been found to have an impact on recovery. Bass, Buck, Turner, Dickie, Pratt, and Robinson (1986) investigated which of the doctor's actions influenced outcome in 193 patients with new episodes of common nonrespiratory tract symptoms. Multiple regression analysis revealed that doctor-patient agreement about the nature of the problem was the only factor related to resolution of patients' symptoms at one month (after controlling for demographic, psychological and social variables). Later resolution of symptoms (after three months) was associated with the doctor paying attention to psychosocial problems (referral, provision of counselling etc). Interestingly, resolution of symptoms was not associated with any technical aspects of care such as the prescription of drugs.

However, agreement was based on information obtained at the one month follow-up rather than immediately following the consultation, so symptom cessation could have resulted in perceived agreement rather than having a causal relationship with outcome. Other studies do, however, suggest a causal relationship between initial agreement and outcome (Starfield et al., 1981; Stewart et al., 1989). The body of evidence thus indicates that considerable disagreement does occur between doctor and patient, but its precise impact on satisfaction is unclear and may potentially be mediated by factors such as the doctor's interpersonal skills and level of patient involvement in the consultation.

2.2.2.5 Meeting patient expectations

A related area of interest is the increasing recognition given to patients' expectations prior to the consultation and the degree to which these are met (Like & Zyzanski, 1987; Salmon, Sharma, Valori, & Bellenger, 1994; Webb & Lloyd, 1994; Williams, Weinman, Dale, & Newman, 1995). Indeed, Vuori (1991) argues that satisfaction is based on two main factors: patients' expectations about the type of care they will receive and their perceptions about the care they have received, although Vuori acknowledges that these factors are influenced by a number of other variables such as culture, education, experience and psychological state.

Linder-Pelz (1982) found that patients' general beliefs about the doctor had an important impact on satisfaction, irrespective of whether they were seen as meeting patients' needs. This suggests that at least some factors of patient evaluation of care arise from factors which they bring to the consultation and which are independent of actual care received. Despite the importance of such general beliefs, congruence between patients' expectations and the perceived outcome of the consultation was the major determinant of patient satisfaction, regardless of treatment efficacy.

Williams, Weinman, Dale, & Newman (1995) conducted a study in the UK with 504 patients investigating the types of expectations held prior to primary care consultation and the degree to which congruence between expectations and outcome (i.e. what they felt they received) affected satisfaction. They defined expectations as "patients needs, requests or desires prior to seeing the doctor" (p. 194). Principal components analysis of the Patients Intentions Questionnaire (PIQ)[2] revealed three components, of which "explanation of the problem" (of the cause, course and prognosis of the problem) explained the highest amount of variance in patients' expectations and wishes, followed by "emotional support" and "tests and diagnosis". Within the "explanation of problem" factor, a desire for the GP to understand the problem was the most frequently stated item (by 90% of the sample). It is interesting to note that medical treatment was low on the list of patients' expectations, which is consistent with previous research (e.g. Salmon & Quine, 1989). In terms of satisfaction, patients who had a higher proportion of their needs met reported increased levels of satisfaction (using the MISS[3]) compared with those who had fewer of their expectations met within the consultation. Consistent with previous research, patients reported high levels of satisfaction (see section 2.2.3), and had a high proportion of their expectations met. Discrepancies between expectations and outcome were higher for "explanation of problem" and "tests" than for the support items.

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[2] The PIQ consists of 42 statements about what patients want from the doctor during a consultation (Salmon & Quine, 1989).

[3] The Medical Interview Satisfaction Scale (Wolf, Putnam, James & Stiles, 1978).

In addition to highlighting the importance of meeting patients' expectations, the study provides a quantitative analysis of the degree to which expectations were met within the consultation, an omission of several previous studies.

2.2.3 Measurement issues

Locker & Dunt (1978) highlighted a major problem inherent in much satisfaction research, namely that when asked to evaluate the care received, the majority of patients state that they are very satisfied. Lebow (1983) reviewed 50 satisfaction studies and found an average of 77.5% of patients were satisfied. Wensing, Grol, and Smits (1994) reviewed 40 studies between 1980 and 1991, and found that the mean minimum percentage of dissatisfied respondents was 10.4%, whilst the maximum was 28%.

Despite research which advocates the positive benefits of patient participation, Williams (1994) argues that such high reports of satisfaction suggest that people are not critical of their care and prefer to adopt a more passive role. He criticises current research for assuming that patients have expectations about the care they receive, when in many cases, such values and expectations may rather be artefacts of survey designs. However, Williams accepts that "the total non-existence of expectations is unlikely", and suggests that it is the transgression of negative expectations which results in dissatisfaction. Such difficulties are echoed by Pascoe (1983) who argues that the subjective nature of satisfaction results in a wide latitude of acceptance; thus dissatisfaction will only occur when standards fall greatly below these expectations. Williams concludes that satisfaction research needs to identify the ways in which patients perceive their role within health care, rather than assuming that all patients are active evaluators of the service.

Despite reports of high overall satisfaction, when patients are questioned about specific aspects of their care, using both qualitative and quantitative methods, differences in reported satisfaction for the various areas of care do occur (Locker & Dunt, 1978; Pendleton, 1981). For example, research indicates that patients express dissatisfaction in the following areas: thoroughness of examination, waiting time, time spent in consultation, GPs listening skills, clarity and adequacy of explanations, despite reporting general satisfaction with their care (Nzegwu, 1993). Richardson et al (1990) highlighted inconsistencies in patients' reports about their hospital experiences. Although patients reported high levels of satisfaction, more detailed questioning revealed that some patients were not actually aware of what was wrong with them, whilst quality of care was deficient for other patients, indicating that communication between professionals and patients was inadequate. Like Williams

(1994), Richardson et al suggest that more qualitative data is needed to uncover the full experiences of patients and bring to light inadequacies of medical care.

2.2.4 Summary and conclusions

The diverse body of research investigating patient satisfaction has identified a number of factors associated with a successful consultation, ranging from patient and doctor characteristics to communication factors within the consultation. What is clear, however, is that people bring to the consultation beliefs about their illness, expectations about what should occur in the transaction and a desire for information about their condition. Moreover, such factors influence their evaluation of the encounter. There is also evidence that discrepancies arise between patients and their doctors in various areas of care, but there is still very little research which investigates the impact of such incongruent beliefs on outcomes such as patient satisfaction.

It was argued in chapter 1 that the self-regulatory model provides a comprehensive framework for understanding patients' responses to illness. However, no research has investigated the role of illness representations on patient satisfaction. Moreover, drawing from the complementary paradigm of Kleinman's explanatory models, it is argued that discrepancies between the beliefs of patients and health professionals are fundamental to understanding satisfaction. According to the self-regulatory model, illness representations guide an individual's response to the illness experience, such as deciding to seek care. The representation proposed by the doctor in the consultation will thus be evaluated by the patient in relation to their own representation, whether this is through unconscious or conscious processing. As previous research has shown, incongruence between patients and doctors results in problematic consultations and dissatisfaction. However, the picture is clearly a complex one which remains relatively unexplored in the current literature. When disagreement arises, the patient may be able to integrate the proposed representation into his/her own, particularly if it is accompanied by adequate explanation. Alternatively, they may accept the new representation on the basis of their faith in the doctor's medical competence, or they may reject the doctor's proposals in favour of their original model. Factors such as a caring bedside manner are thus likely to act as mediating factors in this process. Such factors are explored in chapters 4 and 5 in relation to both patient satisfaction and adherence to treatment regimens.

2.3 Adherence

The concept of compliance or adherence to medical regimens raises a number of questions regarding patients' role in managing their condition - a role that has been given increasing recognition in recent years. The traditional term "compliance" suggests a deferment on the part of the patient to the doctor's instructions, indicative of a passive patient role. This contrasts with the self-regulatory perception of the individual as an active problem solver, in which the patient's treatment decisions are based on his or her illness representations, prior experiences, and life-style constraints.

Patient non-adherence is not necessarily a consequence of misunderstood instructions, deliberate deviance by the patient, or particular patient characteristics, but may rather be a rational act in light of other factors taken into consideration by the patient. Weintraub (1976) referred to such informed decision-making as “intelligent noncompliance”. Consistent with the self-regulatory approach, Conrad (1985) argued that non-compliance actually reflects patients’ attempts to assert control over their condition. The self-regulatory model views decisions about whether to follow treatment recommendations as reflecting an important coping mechanism. In recognition of such factors, "adherence" has become a more widely accepted term in the literature, replacing the traditional authoritarian concept of compliance or obedience[4].

Thus, in order to understand adherence, we must explore the relationship between patients’ beliefs about their illness and their decisions about their treatment.

"...what is missing from much of the work is an understanding of the ways in which patients think and feel about their illnesses and treatments and how these impact on their behaviour...patients do retain, and always have the ability ultimately to decide what happens to the doctor's orders." (Donovan & Blake, 1992; p. 508)

Moreover, patients’ past experiences of illness and its treatment are an important influence on their current beliefs and behaviour (Leventhal & Cameron, 1987). For example, if past adherence to a regime did not yield a concomitant decline in symptomatology, then faith in the efficacy of medical treatment may decline, particularly when supported by subsequent experiences, such as the adverse side-effects of drugs. Treatment may also be evaluated against specific patient

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[4] Although adherence is now the most commonly employed term, it has recently been suggested that it should be replaced by “concordance” to more accurately reflect the fact that decisions about treatment represent a process of negotiation between patient and health professional (Alder & Dowell, 1999).

outcomes that only partly arise from medical sources, for example, overall quality of life (Arluke, 1980; Stimson, 1974).

According to the self-regulatory model, non-adherence may arise as a result of discrepancies between patients' and medical representations of the illness problem, or between people's concrete and abstract representations. Whilst people seek medical care in order to find an abstract label for their symptoms, they do not necessarily follow treatment in accordance with the label. Frequently, people use their concrete symptoms rather than abstract labels as the basis for decisions about taking medication, even when this is inconsistent with medical directives (Bauman & Leventhal, 1985; Meyer et al., 1985). Similarly, other components of patients' illness representations, such as how long they perceive the illness will last (time line), influence patterns of adherence.

In terms of successful treatment, an incorrect self-regulative system (e.g. hypertension is acute) must be replaced by one that is both cohesive for the individual and medically valid. In the long term, adherence "depends on the individual's cognitive representations of the current status and the goal state, plans for changing the current state, and techniques or rules for appraising progress" (Leventhal & Cameron, 1987, p. 127).

In recent decades, the practical value of understanding the factors associated with adherence has resulted in a large body of research in this area. Leventhal and colleagues argue that this has given great insight into the processes of adherence, but that future development entails an integration of approaches (see Leventhal & Cameron, 1987). They argue that the self-regulatory approach is "a more comprehensive model of the cognitive, emotional, and behavioural aspects of the compliance situation" (p. 131), which provides a framework for organizing prior research. Previous research is reviewed below, with a particular emphasis on chronic complaints since a self regulatory framework is especially salient to illnesses for which self-management plays a central role. Specifically, issues surrounding adherence for people with hypertension and diabetes will be discussed since both illnesses form the focus of the final empirical study in this thesis (chapter 7).

2.3.1 The problem of adherence

Given that some studies report up to 50% of patients who do not fully follow their treatment regimens, non-adherence may be as common as adherence to treatment regimens! This clearly has important implications for patients' health as well as financial ramifications for the medical profession, indicating that resources might be saved or used more effectively. Adherence is a multi-factorial problem which varies considerably according to regimen and disease characteristics, as well as factors associated with the individual.

Estimates of nonadherence range from 20% for acute complaints (e.g. antibiotic treatment) to 50% for chronic conditions (e.g. diabetes), and up to 70% for chronic asymptomatic diseases (e.g. hypertension) (DiMatteo & DiNicola, 1982). Adherence to regimens which require lifestyle changes, such as diet or exercise are even lower, and an individual's adherence may vary considerably with different aspects of the regimen (Christensen, Terry, Wyatt et al., 1983; Harris & Linn, 1985). The complexity and duration of the treatment regimen are also found to be important factors; adherence declines with the number of drugs prescribed (Blackwell, 1979; Botelho & Dudrak, 1992; Hulka, Cassel, Kupper, & Burdette, 1975), the frequency of doses (Meichenbaum & Turk, 1987), and with the duration of the regimen (Turk & Speers, 1984). As a regimen becomes more complex it causes greater disruption to daily living and thus increases the potential for non-adherent behaviour. It is therefore important to recognize that adherence to a recommended treatment comes within the wider context of a patient's experiences, beliefs and lifestyle practicalities.

The assessment of adherence is also multidimensional, both in terms of its behavioural indices (keeping appointments, regular check-ups, taking medication etc.) and its measurement (self-report, physiological indices, pill-counts etc.). Clearly the criteria used to determine which patients are adherent must also be taken into account when considering estimates of adherence. Podell and Gary (1976) suggest that as a general rule "one third of patients take their medication as prescribed, one-third of them sometimes adhere, and one-third never adhere" (cited in O'Brien, Petrie, & Raeburn, 1992). The conceptual and methodological problems inherent in measuring adherence to therapeutic regimens is discussed elsewhere (e.g. Gordis, 1979; O'Brien et al., 1992; Turk & Meichenbaum, 1991).

2.3.2 Patient characteristics

The recognition that beliefs and experiences play an important role in patients' decisions to adhere to treatment regimens has resulted in a move away from research which attempted to distinguish "good" from "bad" patients or "compliers" from "non-compliers". No specific personality traits have been consistently linked with non-adherence, although coping styles have been associated with patterns of adherence (Cohen & Lazarus, 1983; Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). Additionally, research examining the impact of patients' sociodemographic characteristics have traditionally yielded mixed results (Haynes, Taylor, and Sackett, 1979; Ley,1979b; Meichenbaum & Turk, 1987), possibly due to the interactional nature of such factors.

The effect of age on adherence patterns has been investigated in a number of studies. Adherence is frequently viewed as particularly problematic for older patients (Richardson, 1986). However, Sherbourne et al. (1992) found that younger patients were less likely to adhere than older patients, although their sample consisted of patients with chronic disease and was therefore predominately of middle-age to elderly range. In a review, Haynes, Taylor, and Sackett (1979) outlined 18 studies which showed a positive effect of age on adherence, seven with a negative influence and 64 in which age had no effect.

A comprehensive study by Lorenc and Braithwaite (1993) highlighted the complexity of the age-adherence relationship. They investigated the effect of age on adherence to both short-term and long-term medication (using pill counts). They found that age per se was not a sufficient discriminator of adherence levels, but was moderated by living conditions. The lowest levels of adherence to antibiotics were found for older patients living alone, whilst older patients who lived with a spouse or relative were the most adherent. Interestingly, adherence to long-term treatment was higher for all patients, which contrasts with many previous studies. For acute and chronic cases combined, informational (e.g. accurate knowledge of regimen) and attitudinal factors (e.g. belief in taking the medication exactly as prescribed) appeared to be the most important determinants of adherence.

2.3.3 Consultation factors

2.3.3.1 Provision of information

Clearly, patients must have adequate knowledge and understanding of their treatment regime if they are to adhere fully. As discussed in the previous section, a large percentage of patients do not fully understand or remember the doctor's instructions, especially when given verbally (vs. written instructions), with obvious implications for adherence (Ley, 1982). Indeed doctors spend only 10% of the consultation giving information to the patient (DiMatteo, 1985). Other studies indicate that patients frequently desire more information, although few patients actually ask the doctor to explain areas of doubt (McEwen, Martin, & Wilkins, 1983) or are themselves willing to ask questions (Ley, 1988). Moreover, evidence suggests that doctors and patients hold different views about the type of information that is important (Berry, Michas, Gillie, & Forster, 1997). When doctors explain drug regimens in detail or clarify unclear recommendations, their patients are more likely to adhere to their treatment (Hulka et al., 1975; DiMatteo & DiNicola, 1982). However, whilst the provision of information may be a necessary requirement, it is certainly not adequate to secure patient adherence to recommended treatments.

2.3.3.2 Doctor-patient communication

As discussed in the previous section (2.2), patient satisfaction with the interpersonal qualities of the doctor and with communication in the consultation are associated with adherence (DiNicola & DiMatteo, 1982; Lassen, 1991; Noble, 1998; Sherbourne et al., 1992; Squier, 1990). In a large-scale longitudinal investigation, satisfaction with the interpersonal quality and financial aspects of care predicted general adherence to long-term treatment (Sherbourne, et al., 1992). However, satisfaction with the technical quality of care was inversely related to adherence in heart disease patients, possibly reflecting a greater belief in the ability of the doctor to deal with the possible complications of disease.

Similarly, the fulfilment of patients' expectations, respect for their concerns and the provision of sufficient information about their condition has been associated with higher levels of adherence (Becker, 1985). Hall et al. (1988) found that whilst provider behaviour had a weaker relation to adherence than to satisfaction, adherence was associated with more information, specific questions concerning adherence, positive verbal communications, and the encouragement of patient involvement.

Lassen (1991) found that the level of communication in the consultation was an important determinant of adherence, particularly in terms of whether the doctor was sensitive to the needs and concerns of the patient. Adherence was strongly correlated with patients' expectations about the consultation and their ideas about health problems. Patients' opinions about the quality of information and explanation they received from the doctor, and whether the doctor discussed patients' perceived obstacles to adherence also determined patterns of adherence, consistent with Hall et al. (1988).

Examining a number of patient characteristics, beliefs and behaviours, Ettlinger and Freeman (1981) examined short-term adherence using pill counts for 119 patients prescribed an antimicrobial drug in general practice. They found that continuity of care improved medication adherence. Adherence was also associated with whether patients felt that they knew the doctor well. Ettlinger and Freeman conclude that "identification of the patient with his doctor may be a greater influence on compliance than symptomatic improvement" (p. 1193). Whilst the doctor-patient relationship may be an important determinant of patterns of adherence, other studies indicate that a major reason for discontinuing treatment is relief from symptoms (e.g. Caldwell, Cobb, Dowling, & deJongh, 1970).

Despite the positive relationship between doctor-patient communication and adherence, findings regarding the impact of consultation length are ambiguous, with some studies reporting a positive relationship (Beisecker & Beisecker, 1990; Kenny, 1995) and others a negative one (Freemon et al., 1971). This presumably reflects the importance of content rather than length per se; if patients have had their concerns and demands met within the consultation they are more likely to adhere, irrespective of the actual duration of the visit (DiMatteo, Prince & Taranta, 1979).

2.3.3.3 Doctor-patient congruency

The impact of discrepancies between the models of illness held by patient and doctor on adherence has received minimal attention in the literature. Becker, Drachman & Kirscht (1972) found that mothers' "degree of certainty" score for the doctor's diagnosis of their children (reported agreement and confidence in doctor) was predictive of adherence. Investigating the impact of discrepancies between lay and medical models of ulcers, Roth and colleagues found that when treatment conflicted with patients' causal models, adherence rates declined (Roth, Caron, Ort, et al., 1962). This concords with the findings of Meyer et al. (1985) with hypertension patients, where discrepancies between patient and medical models regarding symptomatology and illness duration resulted in lower rates of adherence.

Whilst doctors express difficulties in changing the beliefs of their patients (Pendleton, 1981), few studies have investigated how to facilitate patients' belief modification within the consultation and its concomitant impact on adherence. In a classic study by Inui, Yourtee & Williamson (1976) a group of doctors were given a tutorial in which they were informed about the problems of adherence to hypertension regimens and possible methods for altering patients' beliefs, another group of doctors served as a control with no training. Inui et al. found that patients of doctors in the experimental group were more knowledgeable about hypertension, more adherent (40% increase) and achieved better blood pressure control than patients in the control condition (67% compared with 36%).

More recently, focus has been placed on "medication concordance" which has been proposed as an alternative conceptualisation to that of adherence (Alder & Dowell, 1999). Alder and Dowell suggest that non-compliance (and presumably non-adherence) refers to the failure of the patient to take their medication whereas non-concordance refers to a failure of understanding between the patient and doctor. They argue that "a concordant model of prescribing aims to optimise health gain, rather than compliance" with the emphasis on improvements in health as the outcome measure rather than compliance. Similar sentiments have also been aired in the BMJ by Chen (1999) who calls for "a radical change in consulting styles and a deeper understanding of patients' health beliefs" which requires a "metamorphosis of the profession".

Indeed, there is increasing evidence to suggest that patients want to be involved in the decision-making process and agree on treatment plans suggesting that a participatory relationship between patient and health professional is an important means of enhancing adherence (Hall et al., 1988; Squier, 1990). A considerable body of research suggests that a sense of control over life events is positively related to health status and adherent behaviour (Greenfield, Kaplan, & Ware, 1985; Haug & Lavin, 1981; Kaplan, Greenfield, & Ware, 1989; Vertinsky, Thompson, & Uyeno, 1974). Patients may stop taking medication in order to restore control over their illness and its treatment, and as a means of appraising the efficacy of the treatment itself (Conrad, 1985). Providing patients with a sense of control over their treatment appears to improve both adherence and recovery (Rodin & Langer, 1977; Greenfield et al., 1985).

People clearly vary in the amount of control they want in a medical situation. England and Evans (1992) found that patients attending a cardiovascular risk management clinic varied considerably in their reports of control over treatment decision-making, even when all were given the opportunity to choose their treatment. People who felt that they had control over their health in general were more likely to report control over their treatment decision. This study highlights the problems inherent in encouraging patient participation and involvement in decision-making, since patients may not perceive control despite the invitation to actively participate and so may require additional encouragement by the health professional.

2.4 Adherence and chronic illness

The beliefs and experiences of patients are particularly salient in chronic illness. Self-management of chronic conditions is essential to their control and yet non-adherence amongst such patients is typically high. Unlike the treatment of acute conditions, long-term regimens may have little immediate impact on the condition itself, and may even make it appear worse because of treatment side-effects, whilst also imposing greater limitations on the individual's daily life. Moreover, several investigations have found minimal associations between adherence and health outcomes in chronic patients (Glasgow, McCaul, & Schafer, 1987; Hays, Kravitz, Mazel, et al. 1994), which has serious implications both for patient behaviour and the future of adherence research. On the other hand, the negative impact of non-adherence may evolve over long periods of time, only causing complications after a prolonged period. Ultimately however, adherence (a process-of-care measure) must be linked with improvements in clinical outcomes to prove a valid assessment (Haynes, McKibbon, Kanani, et al., 1999).

A qualitative study conducted by Donovan and Blake (1992) highlights some of the problems inherent in long-term treatment and the potential implications for adherence. Semi-structured interviews were conducted with 54 rheumatology patients before and after their consultation with a specialist and until they were discharged or the study ended. Several layers of non-adherence were reported by patients: complete stoppage of medication, reducing dosages (most common), and taking more than prescribed (least common). Patients reported wanting more information about the drugs and generally disliking having to take medication. Fear, or direct experience of side-effects was the most common reason for non-adherence to treatment, consistent with previous findings (Christenson, 1978). Those who did adhere also feared side-effects but reasoned that the benefits of the treatment outweighed the costs. This is consistent with the cost-benefit analysis proposed by the Health Belief Model (Kaplan & Simon, 1990). Other non-compliers were afraid of becoming dependent on the drugs or that the efficacy of the medication would gradually be reduced over time. Further costs of treatment included the unpleasantness/stigma of taking medication or wearing supports and the need to attend clinics regularly for tests. Benefits included either immediate symptom improvement or the possibility of long-term relief.

Donovan and Blake also found that decisions about treatment and dosages provided patients with a means by which they could exert control over their illness (e.g. by reducing their dosage), consistent with the self-regulatory approach. Many patients also used alternative remedies or treatments in addition or instead of orthodox medicine.

"Patients complied with medical advice when it made sense to them and seemed effective. It made sense if it accorded with their own lay beliefs, and was possible to carry out within the constraints of their everyday lives." (Donovan & Blake, 1992; p. 511)

Similar findings were found in relation to epileptic patients (Conrad, 1980). Using a patient-centred approach, it was found that 42% of patients reported "self-regulating" their medication in order to resume some sense of control over their lives. Modification of medication regimens appeared to relate to four main areas: testing (reducing or stopping medication to check whether seizures still occurred), controlling drug dependence (stopping medication to prevent dependence and reassert control of one's life), destigmatization (avoiding taking medication in public), and practical practice (changing dosages to reduce the risk of a seizure under certain circumstances such as highly stressful situations).

Such findings are supported by Horne's (1995, 1996, 1997) investigation of lay representations of medicines as an extension of the self-regulatory model. Horne developed a questionnaire to examine patients' beliefs about medicine in general and about their specific medication, and related these to patterns of adherence. It was found that people have relatively coherent beliefs about medicine which often conflict with medical knowledge, and that it is these representations which influence patterns of adherence.

Whilst 80% of patients believed in the efficacy of their medicine, 30% also reported anxiety about their medication; such patients expressed fears about drug dependency and long-term effects even though their fears were medically unwarranted (e.g. fear of addiction to insulin). Moreover, patients holding such beliefs were less likely to take the medication they were prescribed. This highlights the importance of doctors eliciting patients' fears about medication and correcting any misconceptions they may hold. Fear of addiction led some patients to either alter dosages or stop the medication for periods of time. Although the majority of people surveyed expressed positive attitudes to medicine in general, 30% believed that medicines were unnatural/over-used or that they were addictive.

2.4.1 Diabetes and hypertension

As previously discussed, illnesses such as diabetes which require a complex management regimen, and those which are asymptomatic such as hypertension, have particularly poor records of adherence[5]. For both illnesses, treatment may actually cause an apparent decline in the patient's condition; modification of the recommended regimen may reduce the unpleasant consequences of treatment whilst also enabling the patient to gain a sense of control over a life-long complaint. This can result in serious, even life-threatening complications (DCCT, 1993; Hart, 1993; West,

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[5] A more detailed outline of diabetes and hypertension is given in Chapter 7.

1982). However, the relationship between adherence and treatment outcomes is a complex one, and strict adherence does not necessarily result in control of blood pressure (Haynes, Taylor, Sackett, et al., 1980) or blood glucose (Brownlee-Duffeck, Peterson, Simonds, et al., 1987; Cox, Gonder-Frederick, Pohl, & Pennebaker, 1986; Harris & Linn, 1985; Glasgow, McCaul, & Schafer, 1987).

Research also indicates that symptomatology plays an important role in determining adherence for both complaints (Gonder-Frederick & Cox, 1991; Meyer et al., 1985).

"Perceived symptoms and the inferences made about those symptoms play an especially important role in the day-to-day management of chronic diseases in which patients are required to monitor and regulate their own health status" (Gonder-Frederick & Cox, 1991).

The role of symptom interpretation in the generation of individual representations is an important feature of the self-regulatory model, in contrast to other explanatory models. For example, symptoms are assigned a peripheral role in the health belief model, viewed solely as triggers to beliefs regarding susceptibility and illness severity. In contrast the self-regulatory model recognizes that symptom beliefs are used to understand, monitor, and help cope with illness (Leventhal, Meyer, & Nerenz, 1980). Examination of responses to illnesses such as diabetes and hypertension thus enables an understanding of the complex role and impact of symptom perception.

2.4.2 Hypertension

Hart (1993) suggests that the "rule of halves" applies to hypertension, where "half the people with high blood pressure are not known. Half those known are not treated. Half those treated are not controlled." Treatment of hypertension generally involves a combination of medication, diet, and exercise, although adherence research has focused primarily on factors associated with medication usage.

Adherence and control of hypertension are not consistently predicted by sociodemographic variables (Degoulet, Menard, Vu, et al., 1983) except for age (Weingarten & Canon, 1988). Continuity of care has however been found to improve adherence to hypertensive treatment (Finnerty & Mattie, 1973).

Research has particularly focused on interventions which aim to reduce stress or increase knowledge. Indeed, education for poorly controlled hypertensives does appear to improve control, in contrast to the lack of success of formal patient education for poorly controlled diabetics. Basler, Brinkmeier, Buser, et al. (1982) examined the effects of several group therapy procedures on adherence to treatment, blood pressure reduction and weight loss in 107 obese hypertension patients. The interventions entailed a combination of dietary advice, education and relaxation techniques. Patients in all treatment groups showed a reduction in blood pressure, improved adherence to medication and a reduction in body weight.

Similarly, Haynes (1979) found that a combined program of several educational and behavioural components (education, personalised regimen, self-monitoring, increased supervision, and positive reinforcement) was effective in increasing adherence to hypertensive medication. However, when the components were implemented individually, they failed to increase adherence, making it difficult to evaluate which aspects of the intervention were effective.

2.4.2.1 *Patients' beliefs and illness representations*

Surprisingly few studies appear to have investigated the impact of patients' beliefs on adherence patterns in hypertensive patients. Studies that have investigated the beliefs of hypertensives are frequently descriptive rather than theoretically based since their focus is on specific cultural groups (Grant & Hezekiah, 1996; Heurtinroberts, 1993; Schoenberg, 1997). However, Richardson, Simonsmorton & Annegers (1993) investigated the effect of perceived barriers on adherence to medication and found that barriers were particularly important in predicting levels of adherence for younger patients and those at an early stage of treatment.

The impact of patients' representations about hypertension on adherence was clearly demonstrated in the work of Meyer, Leventhal and colleagues (Meyer et al., 1985; Baumann & Leventhal, 1985). Many patients start out with a very misleading conception of hypertension, seeing it as meaning "tension" or "nerves" and are unaware that it is asymptomatic and that treatment is life-long (Blumenhagan, 1980). Indeed patients may stop taking their treatment because they feel better or because the symptoms they associate with blood pressure have stopped (Hart, 1993). A recent survey in the US revealed that awareness and control of hypertension was decreasing rather than increasing, with more than one third of hypertensives believing that their blood pressure was under control when it was not and almost a quarter stopping their medication because of side-effects (James, 1999).

In Meyer et al.'s study, patients new to treatment were more likely to discontinue with the programme when they perceived hypertension as an acute condition and when they had reported initial symptoms to the practitioner. Similarly, patients in the continuing treatment group were more likely to take their medication and have controlled blood pressure when they believed the treatment had beneficial effects on their symptoms. Other research suggests that hypertensives may use "high-monitoring" coping styles in which they are highly sensitive to internal and external symptoms (Miller, Leinbach, & Brody, 1989).

Although symptom beliefs appear to be important determinants of patients' decisions about their treatment, the relationship between symptoms and blood pressure is often spurious and inaccurate. An early study found no relationship between commonly reported symptoms of hypertension (headache, dizziness, fatigue, palpitations, insomnia, anxiety and depression) and levels of blood pressure. Breathlessness was the only symptom which showed any significant relationship, but it was related more to obesity than blood pressure (Robinson, 1969). More recent studies have similarly demonstrated the inaccuracy of supposedly "typical" symptoms of hypertension (Bauman & Leventhal, 1985, Pennebaker, 1984).

Consistent with the self-regulatory approach, Meyer et al. found that representations of hypertension change over time; patients in the continuing treatment group were found to monitor their symptoms more than those new to treatment. Changes also evolved in patients' perceptions of the duration of the disease, moving from an acute model to one of chronic illness. This study indicates the role of patients' beliefs about illness threat in guiding adherence. The authors conclude that doctors must correct patients' symptom models, since continuing to use unreliable indicators of blood pressure may reduce patients' adherence to treatment and subsequent control of their condition.

2.4.3 Diabetes

There are two types of diabetes: insulin dependent diabetes mellitus (IDDM or Type I) which generally develops early in life and accounts for about 20% of all diabetes, and non-insulin dependent diabetes mellitus (NIDDM or Type II) which develops later in life (usually over 40 years). Treatment for diabetes aims to maintain blood glucose (BG) at normal levels, avoid incidences of hypoglycaemia (low blood sugar) and hyperglycaemia (high blood sugar), and prevent diabetic complications. About 20% of diabetics have their condition controlled solely through diet, 40% of Type II patients use a combination of diet and glycaemic medication, and 40% of patients use insulin (both Type I patients and Type IIs for whom oral medication is no longer effective) (Willis, 1996).

According to Rosenstock (1985) "inadequate patient compliance with prescribed treatment may be the most serious obstacle to effective management of diabetes" (p. 610). However, the management of diabetes is complex and entails long-term changes to the life-style of the diabetic. Studies reveal that only a small percentage of diabetics adhere totally (Surwit, Scovern & Feinglos, 1982). Cerkoney and Hart (1980) measured a number of self-care activities and found that only 7% of Type I patients adhered to all the behaviours necessary for good control. Indeed, adherence to diabetic regimens is multidimensional and frequently inconsistent across areas; a diabetic may strictly adhere to their medication programme, but not follow dietary advice.

Adherence is generally highest for insulin injection/medication, but even here Type I patients may not follow medical advice about how much insulin to take and when to take it (Kelleher, 1988; Morris et al., 1997). The lowest rates of adherence are generally found with regards to exercise (Ary, Toobert, Wilson, & Glasgow, 1986), and diet (Harris & Linn, 1985). Significant deviations from dietary guidelines have been reported by approximately 75% of diabetics (Christensen, Terry, Wyatt et al., 1983). In such circumstances, patients are often faced with conflicting pressures, such as the social pressure to eat and drink versus medical advice (Goodall & Halford, 1991). Additionally, some patients do not appear to consider dietary recommendations (or exercise) to be part of their diabetic treatment (Bloom Cerkoney & Hart, 1980; Kravitz, Hays, Sherbourne et al., 1993).

Adherence for monitoring of blood glucose levels (through blood and/or urine tests) is also low, with estimates varying between 30% and 57% (Cerkoney & Hart, 1985; Christensen et al., 1983), despite the importance of monitoring in order to balance food intake, physical activity and insulin requirement. Monitoring of BG is a particularly problematic area for adherence, since it may be found confusing (e.g. how to interpret the results), unpleasant or simply inconvenient. In addition, many diabetics feel that they can tell when their BG is high or low by monitoring bodily sensations, although this has been found to be a highly unreliable method in many cases (Gonder-Frederick & Cox, 1991). Monitoring BG levels may also prove frustrating by highlighting failure to control the disease, particularly when the patient has adhered to the recommended treatment.

"Maintaining the correct balance of food, activity, and medication is like walking a tightrope. On one side is the danger of hypoglycaemia; on the other side hyperglycaemia. In the background is the fear of complications." (Kelleher, 1988)

Complications are related to duration of the disease, particularly with Type I. Mounting evidence suggests that complications are associated with poor glycaemic control and that metabolic balance can minimize complications (DCCT, 1993; West, 1982), although for NIDDM additional factors such as hypertension, obesity, smoking and lipid disorders are also important. Clearly then, treatment aims to improve glycaemic control and thereby minimize complications. Unfortunately however, there is no simple link between glycaemic control and complications; even when diabetes is well-managed, complications may still arise. This makes the management of diabetes even more difficult for patients when adherence to medical advice does not appear to be yield successful outcomes.

2.4.3.1 Knowledge

Knowledge and education about diabetes is particularly important for its management due to the complexity of the treatment regime. In a sample of diabetics from a hospital clinic, 27.5% did not know why urine tests were necessary, 60% of Type II patients wanted more information about medication, and 94.5% wanted more information about diet (Mason, 1985).

However, educational intervention does not necessarily lead to improved self-management and diabetes control (Cox, Gonder-Frederick, Pohl, & Pennebaker, 1986). Whilst knowledge about diabetes appears to be a necessary prerequisite to its management, it is not a sufficient condition for its control nor does it necessarily result in good self-care behaviour (Beggan, Crogan & Drury, 1982; Jenkins, 1995). Knowledge may however function as an indirect predictor of self-care behaviour through motivation; only if an individual is motivated does knowledge result in enhanced self-care (Pennings-Van der Eerden, 1990). McCaul, Glasgow & Schafer (1987) found that motivational factors (including self-efficacy & environmental support) were better predictors of self-care than knowledge factors, accounting for 20% of the variance in adherence.

2.4.3.2 Patients' Beliefs

Several theorists have argued that research into diabetes self-management has lacked theoretical foundations and conceptual rigour (Glasgow, McCaul, & Schafer, 1986; Rosenstock, 1985; Skyler, 1981), although the past two decades has seen an increase in the application of the HBM to diabetes research. Such research has highlighted the importance of patients' beliefs in understanding adherence behaviour, although the proportion of variance explained by the model is often quite low, particularly prospectively (O'Brien et al., 1992). Rosenstock argues that the model should be expanded to include other factors, such as self-efficacy. It is argued in this thesis that the self-regulatory model provides a more comprehensive framework for understanding adherence. However, it is proposed that approaches such as the HBM might be usefully incorporated into the self-regulatory framework (discussed at more length in chapter 7). The contribution of both approaches to understanding diabetes self-management is discussed below.

Cerkoney & Hart (1980) found that health beliefs were correlated 0.5 with overall regimen adherence in Type I patients. Specifically, cues to action and perceived severity were most strongly correlated with adherence scores. However, the sample was very small (N=30) and non-random, and although both self-report and direct observational methods were used, the scoring of adherence was rather arbitrary (where observation scores were given twice the weight compared with self-reports).

Specifically investigating barriers to adherence amongst Type I patients, Glasgow at al. (1986) found that participants reported the largest number of barriers in relation to diet and exercise, and the fewest in relation to insulin injections. This is clearly consistent with reports of adherence previously documented. High levels of perceived environmental and social barriers were associated with low levels of self-reported adherence. However, frequency of reported barriers demonstrated less consistent relationships with objective measures of adherence and “were not strongly predictive of future adherence (at 6 months)”. Clearly, barriers to self-care behaviours are likely to operate within the wider context of other beliefs and contextual factors.

Using a sample of 93 male Type II patients, Harris & Linn (1985) correlated health beliefs with reports of adherence and physiological measures of control collected at a follow-up interview. Patients’ beliefs were measured using the Diabetes Health Belief Scale which also included structural elements, such as social support. Adherence was measured by patients’ self-report and nurses’ evaluation of medication, diet, exercise, foot care and urine testing[6]. Diabetes control was measured by urine tests, fasting BG and G Hb (Glycosylated haemoglobin reflects mean blood glucose concentration over the past 3-4 months).

As in previous research, patients adhered most to medication and least to dietary regimens. Beliefs about illness severity were most strongly related to adherence. Health beliefs (treatment perceived as beneficial, belief in cues to action, low perceived susceptibility to complication and belief in benefits of support) were better predictors of control than adherence itself. These findings suggest that the positive attitude of the patient may play a more important role in the control of their diabetes than actual adherence to treatment. Harris and Linn (1985) suggest that health beliefs may directly affect

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[6] It was not stated how patients' and nurses' ratings were aggregated to yield an overall adherence score.

control through the physiological effects of anxiety rather than acting indirectly through adherence. However, the data were purely correlational. Moreover, the sample was limited to Type II, poorly controlled, older men making the generalizability of such findings to other diabetic populations problematic.

A study with non-hospitalised Type II patients investigated the relationship between a number of psychosocial variables and both adherence and glycaemic control (Wilson, Ary, Biglan, et al., 1986). The psychosocial measures included general measures of stress, depression, and anxiety together with diabetes-specific health beliefs, knowledge and social support. They found that regimen-specific health beliefs (e.g. discomfort and perceived effectiveness of self-care) and degree of perceived social support together accounted for between 18% and 24% of the variance in self-care behaviours beyond that explained by demographic factors (age and sex). However, none of the variables predicted glycaemic control.

Brownlee-Duffeck, Peterson, Simonds et al. (1987) examined the health beliefs of 143 Type I diabetics. They found that health beliefs were predictive of both adherence (40%) and metabolic control (measured by G Hb) (16%). For older patients, perceived benefits were most predictive of adherence (26% of variance), whilst perceived costs were more important for younger patients (accounting for 25% of the variance), and severity and susceptibility were most predictive of metabolic control (8% and 11% respectively). They also found that adherence was only modestly correlated with metabolic control (8 of the 16 adherence items - largely those pertaining to dietary adherence). However, the finding that perceived susceptibility to complications was associated with poorer metabolic control is incompatible with the Health Belief Model. It can, however, be incorporated into the self-regulatory model where susceptibility in young diabetics instigates an emotional coping response of denial which indirectly influences metabolic control. Indeed, a small-scale qualitative study with IDDM patients found that fear of complications was associated with maladaptive coping strategies and lower rates of adherence (Lawson, Harvey, Lyne, & Bundy, 1996).

2.4.3.3 Illness Representations

Most research using the self-regulatory framework has focused on the impact of symptom beliefs (associated with high or low blood glucose (BG) levels) on monitoring and self-care amongst diabetics. In one study, 68% of Type II patients stated that such beliefs directed their decisions about self-care (Hamara, Cassmeyer, O'Connell et al., 1988). The accuracy of these beliefs is thus of central importance in successful regulation of the diabetic condition and in directing appropriate self-care, especially since many patients rely on their symptom perceptions instead of testing for BG levels (Hampson, Glasgow, & Toobert, 1990). A number of studies have found that a high percentage of patients (Type I) have at least one symptom associated with BG levels, but that no specific symptoms covary with BG across patients (Gonder-Frederick & Cox, 1991; Pennebaker, Cox, Gonder-Frederick, et al., 1981; Gonder-Frederick, Cox, Bobbitt, & Pennebaker, 1989).

O'Connell, Hamera, Schorfheide, and Guthrie (1990) examined the accuracy of symptom beliefs in a sample of Type II patients. Although 88% of subjects had at least one symptom that was significantly correlated with BG levels (using a symptom checklist), subjects' symptom beliefs were not related to actual BG. Symptom beliefs for high BG levels were particularly inaccurate, with negative correlations for 45% of subjects. However, the accuracy of symptom beliefs for low BG was positively correlated with metabolic control (accuracy was not related to illness duration), presumably reflecting subjects' ability to respond appropriately to low BG levels (e.g. through food intake).

In a number of studies, Gonder-Frederick & Cox (1991) investigated subjectively perceived symptoms, symptom beliefs, and ability to estimate blood glucose levels in Type I patients, and examined the influence of these representations on regulatory health behaviours. As in previous studies, they found that diabetics believed that they could recognize BG symptoms and then take action to correct these perceived levels. Frequently however such self-treatment is not appropriate since it relies purely on the evaluation of symptoms, without verification by BG tests.

Indeed, Gonder-Frederick and Cox found various symptom belief errors among the diabetic patients, particularly false alarm beliefs. Patients monitored for symptoms of BG levels even though these were actually unrelated to BG fluctuations. This parallels Meyer et al.'s (1985) findings for hypertension and relates to the "illusory correlation phenomenon" (Fiske & Taylor, 1984), where people make judgements of covariation when there is no actual relationship.

Studies examining the accuracy of subjective BG detection have also revealed that diabetic patients make potentially serious errors in their perception of BG. They have found that patients tend to normalise BG fluctuations by underestimating high BG levels and overestimating low BG levels (i.e. failure to recognize covariations, Fiske & Taylor, 1984), this was unrelated to participants' confidence in their ability to detect BG fluctuations. Clinical intervention has however been found to improve patients' ability to detect symptoms and estimate BG, by providing systematic feedback (i.e. improving judgements of covariation).

Moving beyond symptom beliefs, Hampson and colleagues have investigated the "personal models" or representations of Type II patients in several studies, finding that they were predictive of dietary intake and exercise in both female and elderly patients (Hampson et al., 1990; Hampson, Glasgow, & Foster, 1995; Hampson, 1997). Controlling for demographic factors, belief in the efficacy of treatment was most consistently related to self-management (both concurrently and prospectively). Personal models did not, however, predict either blood glucose testing or medication taking. Whilst most beliefs were consistent with medical opinion, several dimensions demonstrated individual variation: cause (level of self-blame), symptoms, treatment value, and illness severity. These initial investigations suggest that a self-regulatory approach to diabetic care can be used to predict and improve self-management.

2.4.4 Adherence and Quality of Life

Many studies have examined the determinants of adherence, but there has been a lack of research examining the relationship between adherence and long-term outcomes, particularly patients' quality of life. It is frequently assumed that establishing good control of illness through a balanced regimen (particularly in the case of illnesses such as diabetes) results in better physical health and thereby improves quality of life. However, as previously discussed, the relationship between adherence and somatic state is often complex for illnesses such as diabetes and hypertension. Intensive control of illness through a complex treatment regimen may have a detrimental effect on short-term perceptions of quality of life (Nerenz et al., 1992).

As Kaplan (1990) points out, "physiologic and biochemical measures do not necessarily have meaning. They gain their meaning through systematic correlations with health outcomes" (p. 1218). Quality of life is essentially a subjective experience and does not necessarily directly reflect physical status. In a study with hypertensives, Jachuck, Brierley, Jachuck, and Wilcox (1982) found that all the doctors in the study felt that medication had improved the quality of life of their patients, but only half of the patients agreed. There is also evidence which suggests that the relationship between adherence and health outcomes may be relatively weak (e.g. Hays et al., 1994).

2.4.5 Summary and conclusions

A review of the literature has revealed that non-adherence remains a significant problem, particularly in chronic illnesses such as diabetes and hypertension which require lifestyle changes as well as long term medication. Research in recent years has increasingly recognised the active role that patients' play in making decisions about whether to follow medical recommendations. Consultation factors such as the quality of information provided during the encounter and the communication skills of the doctor are important facets of this process. Such factors influence both patients' knowledge and beliefs about their illness and the treatment regimen. However, in common with the satisfaction literature, very few studies have explored the potential impact of doctor-patient discrepancies on adherence.

Approaches such as the health belief model have been important in advancing the application of theory to understanding and predicting adherence, especially in diabetes. The self-regulatory model, however, provides a broader framework for viewing adherence as a coping mechanism guided by patients' illness representations. With a few exceptions (e.g. Hampson, 1997; Horne, 1997; Meyer et al. 1985), most research using the self-regulatory paradigm has focused on the importance of symptom beliefs in directing behaviour. Whilst this has been valuable in understanding how people monitor their illness, further work needs to be conducted to explore the relationship between people's illness representations and patterns of adherence.

Additionally, most research has focused upon the factors associated with adherence, and in some cases, the relationship with physiological control of illness (e.g. blood pressure or blood glucose in the case of hypertension and diabetes respectively). As discussed in chapter 1, the self-regulatory model is also concerned with how the individual appraises the success of their coping efforts, for example in terms of their psychological and physical functioning. Indeed, the psychosocial and functional outcomes of adherence are clearly important in understanding people's responses to chronic illness which has wide reaching ramifications for the individual's life style[7]. It is therefore surprising that there is such a paucity of research on the relationship between adherence and functioning. Kaplan (1990) argues that the most important consequences of chronic illness reside in long-term outcomes such as patient functioning and quality of life. This is addressed more fully in the following sections.

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[7] Indeed, the distinction between disease and illness is relevant here (see Chapter 1). The literature has focused on disease (i.e. physiological outcomes) rather than illness (i.e. functional outcomes from the perspective of the patient).

2.5 Coping and adaptation to chronic illness

The self-regulatory model views coping as part of a set of mediating factors in response to the illness representation that determines whether individuals are successful in their adaptation to illness. As discussed in the previous section in relation to adherence, illness representations guide the selection of coping strategies, which are then appraised by the individual. Coping responses fall into two basic categories: strategies which address instrumental problems associated with the illness (e.g. symptoms and pain) and those which regulate the emotional distress resulting from the illness threat.

The general model of coping proposed by Folkman and Lazarus (1980) is compatible with the self-regulatory approach. They view coping as "the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (Folkman & Lazarus, 1980). Like Leventhal and colleagues, they view coping as a dynamic process which is a function of both situational and personal factors. The effort involved in managing a stressor distinguishes it from the more general concept of adaptation which relates to the effectiveness of coping and may also entail automatic responses, whereas "coping effort is independent of the outcome" (Lazarus, 1993).

According to Folkman and Lazarus, coping involves two-stages of cognitive appraisal (and reappraisal). An individual firstly determines whether the situation represents a threat (primary appraisal) and secondly assesses possible responses to the perceived threat (secondary appraisal). However, in recognition of the evolving nature of coping, these two processes are viewed as interdependent, since an individual's resources may influence the interpretation of a potential stressor (Cohen and Lazarus, 1983).

2.5.1 Functions and outcomes of coping

Pearlin and Schooler (1978) outlined four types of coping functions: 1) prevention of stress, 2) alteration of the problem, 3) change in the meaning of the situation, and 4) management of symptoms. Miller (1992) argues that coping is successful when it "preserves the integrity of the individual", as well as enabling the individual to function effectively in personal relationships, social roles and maintain a positive self-concept. Thus effective coping has important implications for the social functioning of patients as well as their physical health. Furthermore, the appraisal stage of self-regulation involves the evaluation of coping mechanisms in terms of whether the individual has progressed towards the adaptive goals suggested by the initial representation. This process will reflect the individual's appraisal of both functional status and psychological well-being.

In terms of Folkman and Lazarus' conceptualization, coping has two major functions: it is either problem-focused (doing something to alter the stressful situation) or emotion-focused (modifying the emotional distress associated with the stressor). Thus, social functioning, morale and somatic health are viewed as *outcomes* of coping rather than functions per se. Nevertheless, how people deal with their illness influences their long-term adjustment and quality of life. Coping with illness not only has an impact on the physical demands and consequences of long term illness, but also on the accompanying psychosocial aspects (Lubkin, 1986). Research has therefore focused on investigating the relationship between coping strategies and adaptational outcomes in order to determine how patients can most effectively cope with long-standing and often debilitating illnesses. The measurement of coping is discussed in detail in Chapter 6 (6.2).

2.5.2 Coping strategies and their relationship to adjustment

Whilst research generally associates problem-focused strategies with more successful adaptation to chronic illness (e.g. Suls & Fletcher, 1985), the effectiveness of such strategies is mediated by a number of factors, such as illness controllability and the temporal stage of illness. Problem-focused strategies tend to be more adaptive when something can be done (e.g. self-care activities), whereas emotion-focused strategies may be more adaptive for non-controllable diseases or situations (Felton & Revenson, 1984; Lazarus, 1993). Similarly, strategies which regulate emotional distress may be more effective immediately following diagnosis of chronic illness, but dysfunctional at later stages of adaptation (Levine et al., 1988). Indeed an absence of emotional reactions may even inhibit recovery (Cohen & Lazarus, 1979).

Other research suggests that a combination of problem-focused and emotion-focused strategies may be most adaptive (Martelli, Auerbach, & Alexander et al., 1987). This finding is congruent with the principles of the self-regulatory model, since an individual is viewed as adopting coping responses which deal with managing both the health threat and the concomitant emotional response. However, although the two strategies may serve to facilitate each other, the two functions may also interfere with each other (Cohen & Lazarus, 1983).

Leventhal and colleagues relate the different styles of coping to the hierarchical organization of representations. They suggest that "many of the discrepancies that arise between problem-focused and emotion-focused coping are probably due to differences in the levels at which problem- and emotion-based representations are created" (Leventhal, Nerenz & Steele, 1984; p.220). Problem-focused strategies are likely to be based on abstract information, whereas emotion-focused strategies are more influenced by concrete, automatic processing.

However, this binary distinction between problem- and emotion-focused coping is clearly too simplistic, since each strategy encompasses different coping responses, some of which may be more adaptive than others (this is discussed at greater length in chapter 6). Auerbach (1989) highlighted the importance of recognizing the complex, dynamic nature of chronic illness which often entails multiple stressors with differing coping demands. He argued that research which treats chronic disease as a unitary stressor has limited theoretical and practical value. Such warnings are iterated by Lazarus (1993) who stressed that the context in which coping strategies occur must be considered before generalizations about their adaptational value are made. Accordingly, only by examining the specific threats associated with chronic disease can we hope to understand the problems faced by patients. "Emotion- and problem-focused coping modes may thus sometimes overlap and become indistinguishable as people deal with complex situations" (Auerbach, 1989; p. 393).

Cohen, Reese, Kaplan, and Riggio (1986) found that patients with rheumatoid arthritis employed different coping strategies to deal with pain than those they used to cope with threats to their self-esteem. However, Sommerfield, Curbow, Wingard, et al. (1996) examined coping responses to various problems associated with long-term survival of bone marrow transplantation and found little differentiation in terms of problem type. They suggested that whilst illness entails distinct types of stressors, they share a "common underlying origin" due to the common experience of the illness. Similarly, Vitaliano, DeWolfe, Mairuro et al. (1990) proposed that "coping may be similar among subjects with different specific stressors within a common problem category because the demand characteristics of their predicaments call for more commonality in responses than the specific stressors call for differences" (p. 590).

Several studies have found that successful adaptation to illness is associated with employing a variety of coping mechanisms. Remien, Rabkin, Williams, and Katoff (1992) found that active involvement (with treatment) was important for both rheumatoid arthritis patients and AIDS victims. However, long-term AIDS survivors made use of numerous coping strategies rather than one single style in order to deal with the many stressors associated with their condition. They were also more practical and realistic in their health beliefs. Similar findings have been reported for breast cancer patients (Jarrett, Ramirez, Richards, & Weinman, 1992). Coping flexibility has also been associated with greater well-being in healthy samples (Lester, Smart, & Baum, 1994).

Flexible coping and problem-solving skills are particularly important in the management of diabetes due to the complexity of the treatment regime (Glasgow et al., 1995). Toobert and Glasgow (1991) examined the relationship between problem solving skills and self-care in 126 non-insulin dependent diabetics. Use of problem solving strategies were most frequently reported for dietary self-care and least for glucose testing. In a prospective analysis, they found that the problem solving measures were significant predictors of levels of dietary and exercise self-care/adherence at a six month follow-up. However, there was no significant relationship between problem-solving skills and glycaemic control, which is consistent with other studies (e.g. McCaul et al., 1987). Whilst the study supports previous findings that problem-solving skills are important in self-care of chronic conditions such as diabetes, the study did not examine the impact of problem solving on adjustment to illness.

Felton and colleagues conducted a longitudinal study to investigate the relationship between coping and psychological adjustment in 170 hypertensive, diabetic, cancer and rheumatoid arthritis patients (Felton, Revenson, & Hinrichson, 1984; Felton & Revenson, 1984). At the initial interview, diabetics perceived themselves as having the most control over their condition, and both hypertensives and diabetics showed higher levels of adjustment and lower levels of functional impairment compared with cancer and rheumatoid arthritis patients (Felton et al., 1984). However, the coping styles employed by respondents were not related to disease type. Additionally, adjustment was only modestly predicted by coping strategies, prompting questions as to the direct impact of coping on adjustment. However, consistent with other findings, cognitive strategies were associated with positive affect whilst emotional strategies were associated with negative affect, lower self-esteem and poorer adjustment. Similar findings were reported at follow-up (7 months) in which coping strategies were once again weakly related to adjustment, while illness controllability had a more pronounced effect (Felton & Revenson, 1984).

A small (N=45) but longitudinal study with rheumatoid arthritis patients suggested that whilst coping was unrelated to disability levels, both coping and disability had an impact on psychological adjustment six months later (Revenson & Felton, 1989). Emotion based strategies were negatively related to psychological adjustment whereas information-seeking was related to increases in positive affect. Increased disability was related to lower levels of acceptance and increased negative mood. This is consistent with previous work which suggests that acceptance of limitations is related to better adjustment in rheumatoid arthritis patients (Park, 1994), and better metabolic control in Type I diabetic patients (Murawski, Chazan, Balodimos, & Ryan, 1979).

Whilst emotion-focused and disengagement coping strategies have a negative impact on functioning, problem-focused strategies appear to have positive impact on psychological well-being but not on behavioural functioning (e.g. Moss-Morris, Petrie, & Weinman, 1994). Several studies have found that behavioural and mental disengagement, and venting emotions are associated with poorer psychological adjustment, slower recovery and increased distress (Carver, Pozo, Harris et al., 1993; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Moss-Morris et al., 1994; White, Richter, & Fry, 1992). Avoidance coping has also been associated with non-adherence to treatment recommendations (Sherbourne et al., 1992), poor glycemic control in IDDM patients (Frenzel, McCaul, Glasgow, & Schafer, 1988), and greater psychological distress (Bloom, 1982), although it may be adaptive for short-term stressors (Suls & Fletcher, 1985).

2.6 Illness representations and self-regulation

The abundance of research examining how people cope with illness has enhanced our understanding of the relationship between various coping strategies and adjustment to the demands of illness. In contrast, few studies have systematically investigated the impact of patients' illness representations (using all five components) on coping and adaptation. However, in a recent systematic review, Scharloo and Kaptein (1997) identified more than 100 studies which assessed at least one of the five dimensions of illness representations in relation to a range of chronic conditions. The impact of control and causal attributions on adaptation is particularly well documented and is discussed in the following sections. Moreover, there is an increasing interest in applying the self-regulatory model to clinical populations as evidenced by a recent collection of studies (Petrie & Weinman, 1997). However, such research is still in its infancy (see section 2.6.3).

2.6.1 Control

Research suggests that beliefs about illness controllability influence adaptation (Felton & Revenson, 1984; Taylor, Lichtman & Wood, 1984). A sense of control over one's illness is generally adaptive for controllable illnesses, but may be maladaptive when an illness is severe and uncontrollable (Burish, Carey, Wallston et al., 1984; Taylor, 1995). However, perceptions of control over treatment decision-making appear to have beneficial effects on both adjustment and recovery (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Kaplan, 1991; Rodin, 1986).

Affleck et al. (1987) found that patients with rheumatoid arthritis reported more personal control over their symptoms but felt that practitioners exercised more control over the course of the disease. Perceived control over medical care and treatment predicted positive mood and psychosocial adjustment, whilst perceived provider control over daily symptoms was associated with negative mood. Interestingly, a study comparing medical staff's attributions with those of patients with Type I diabetes found that patients tended to rate themselves as more responsible for both positive and negative outcomes than did the medical staff, who emphasized chance to a greater extent than did patients (Gamsu & Bradley, 1990). However, the impact of perceived responsibility on outcome variables was not assessed, although previous studies have found a relationship between perceptions of control and both choice of treatment regimen and occurrence of complications (Bradley, Gamsu, Moses, et al., 1984; Bradley, Gamsu, Knight, et al., 1986).

A study with patients diagnosed with mild ulcers found that when patients were given a choice about their treatment (either medication or diet) they recovered more quickly than a control group who were given no choice (Rodin, 1986). Similarly, Partridge & Johnston (1989) investigated control beliefs in a sample of stroke and wrist fracture patients and found that perceived control over recovery at the beginning of physiotherapy predicted actual recovery from disability.

Such findings strongly support the view that control beliefs enhance outcomes. However a study with newly diagnosed diabetics also highlights some of the difficulties which may arise when outcomes are not completely under the individual's control. Lowery and Du Cette (1976) examined the impact of locus of control on adaptation in newly diagnosed diabetics. They found that patients with an internal locus of control knew more about their condition, particularly aspects that were controllable such as diet and medication. However, they also expressed more difficulties in coming to terms with their illness as the disease progressed, presumably because their condition deteriorated despite their efforts at control. Overall then, beliefs in personal control are associated with better adjustment except when those beliefs are undermined, such as when illness severity increases or when treatment outcome is poor.

2.6.2 Causal beliefs

People develop theories about illness causation in order to make sense of their condition. Such beliefs do not necessarily accord with medical opinion (Blumhagen, 1980; Helman, 1984), but do appear to influence adaptation to illness. Indeed, patients often desire more causal information from their doctors (Greenberg, Jewett, Gluck et al., 1984). Several studies have demonstrated a relationship between causal beliefs and better adjustment (Tennen, Affleck, & Gershman, 1986; Turnquist, Harvey & Anderson, 1988).

In attempting to understand this relationship between causal beliefs and adjustment, many studies have investigated how people's perceptions of responsibility for their condition influence their adaptation. For example, an early study by Bulman and Wortman (1977) found better adjustment amongst spinal cord injured patients who regarded themselves as responsible for their condition. It is argued that self-blame enables the individual to assume control over illness, by preventing reoccurrence, controlling future outcomes, or coming to terms with the condition (Bulman & Wortman, 1977; Tennen et al., 1986). However, other studies suggest that self-blame can result in poor adjustment and feelings of recrimination (Bombardier, D'Amico & Jordan, 1990; Kiecolt-Glaser & Williams, 1987). No clear relationship has been found between chance/fate attributions and adjustment, although blaming others appears to be maladaptive (Affleck et al., 1987, Bulman & Wortman, 1977; Remien et al., 1992)

However, the relationship between causal beliefs and adaptation may be a phenomenon limited to western cultures. Sissons Joshi (1994) demonstrated the complex interaction of culture and beliefs in a study which examined the causal beliefs of British and Indian diabetic patients. Patients' causal theories reflected differing cultural values and pressures, and only in the British sample were causal beliefs related to better adjustment and coping.

2.6.3 Chronic illness and the self regulatory model

Few studies have examined the relationship between all five components of illness representations, coping and adaptation. According to the self-regulatory model, people's illness representations guide coping which is appraised in terms of its impact on their condition (i.e. is coping successful). Meyer et al.'s (1985) early work with hypertensives indicated that patients' illness representations were important in guiding their coping responses in relation to their treatment (e.g. "hypertension is acute therefore I can stop treatment when I feel better"). Recent studies have provided further support as to the relationship between patients' representations and coping (Heijmans, 1998, 1999;

Moss-Morris et al., 1996). For example, Moss-Morris et al. (1996) examined the relationship between illness representations, coping and adjustment in chronic fatigue syndrome (CFS) sufferers in a cross-sectional study. They found that patients' representations and coping were "related in a conceptually logical fashion" (p. 21). Perceptions of control were associated with adaptive strategies whilst beliefs that CFS was chronic, had serious consequences and a strong identity (more symptoms) were related to emotion-focused strategies.

Several studies have also found that illness representations are *better* predictors of disability and adaptation than coping (Earll, 1994; Earll & Johnston, 1994; Heijmans, 1998, 1999; Moss-Morris, Petrie & Weinman, 1996). This is consistent with previous findings that coping strategies demonstrate relatively weak relationships with adjustment (e.g. Felton & Revenson, 1984). Johnston (1996) argues that such findings indicate that coping per se is not as important in predicting disability as previously implied. She suggests "we need to look beyond coping models" and focus instead on the role of mental representations.

In Moss-Morris et al.'s (1996) study, illness representations (particularly illness identity, controllability and consequences) accounted for between 30% and 42% of the variance in disability and psychological well-being. In contrast, coping explained only 7%-28% of the variance. Moreover, illness representations continued to predict disability and sickness related unemployment six months later (Moss-Morris, 1997). Similar findings have also been reported in two Dutch studies with patients suffering from CFS and Addison's disease (Heijmans, 1998, 1999), and a UK study with motor neurone disease (Earll, 1994; Earll and Johnston, 1993, 1994). In each of these studies, illness representations were found to be stronger predictors of outcome than coping.

Illness representations have also been found to be important predictors of recovery following myocardial infarction (Petrie, Weinman, Sharpe, & Buckley, 1996). Specifically, beliefs about the controllability of the illness predicted attendance at a rehabilitation clinic. Perceptions that myocardial infarction is an acute condition with few consequences predicted physical and social disability in addition to return to work. Sexual dysfunction was related to strong identity beliefs. In a study of chronic lower back pain and chronic respiratory patients, Lacroix (1991) found that the accuracy of symptom perceptions was directly linked to function and return to work in chronic respiratory patients. In contrast, there was no relationship between the medical severity of the condition and adaptive functioning.

Although still limited in number, these findings with a variety of different clinical populations are generally supportive of the self-regulatory approach. They indicate that patients' representations of illness are important in understanding the adjustment process. Moreover they additionally suggest that patients' representations exert a more powerful effect on adjustment than coping.

2.7 Conclusions and implications

The self-regulatory model is receiving increasing attention within the health care setting with its common-sense approach and promise of practical application. It is proposed that the self-regulatory model provides a comprehensive framework for understanding people's responses to illness. However, it is still a relatively new model and the research reviewed both in this chapter and the previous one suggests several areas requiring further development, which is the focus of the current thesis. Moreover, the self-regulatory model was not proposed as a "complete model" per se, but rather as a framework amenable to further development and addition (Leventhal & Cameron, 1987). In chapter 1 it was suggested that other conceptual frameworks might also inform further development of the self-regulatory model. The current chapter has reviewed the contribution of previous research and theory to the understanding of patient satisfaction, adherence, coping and adjustment to chronic illness. This has highlighted areas requiring further investigation which are addressed by the series of empirical studies that follow.

Firstly, as discussed in chapter 1, the next chapter continues work at the conceptual level of the model, in particular the identification of the components which are most central to the classification of illnesses. Study 1 investigates lay representations of 37 different illnesses and their significance in the classification of these illnesses.

Secondly, research to date using the self-regulatory approach has purely focused on the representations of patients[8]. Additionally, it has not considered the impact of patients' representations on how they evaluate their medical care. It is proposed however, that attention should also be paid to the interaction between patients' and health professionals' representations. This is in line with Kleinman's explanatory approach. Despite the importance of patients' beliefs or representations with regard to behaviour and adjustment, doctors are not good predictors of these beliefs (Cohen et al., 1994; Lorig, Cox, Cuevas, Kraines, & Britton, 1984) nor of patients' perceptions of functional impairment (Calkins et al., 1991; Wartman et al., 1989). However, there remains very little research that explores a) the extent of doctor-patient congruence and b) the

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[8] With the exception of recent work on spouse's illness representations (Heijmans, De Ridder & Bensing, 1999), but this is not discussed here.

impact of discrepancies upon outcomes such as satisfaction and adherence to treatment. This omission is surprising in light of the increasing emphasis on patient involvement with their care. This is addressed in chapter 4, which explores the impact of doctor-patient discrepancies on patients' evaluation of their care and on their intentions to follow treatment recommendations (Study 2). Chapter 5 reports a follow-up study that investigates how patients' representations change over time (and how patients deal with discrepancies) and the impact of patients' representations on their subsequent satisfaction with the consultation and adherence to treatment (Study 3).

> *"The impact of the disease is not necessarily the impact of the objective features of the disease but that of the patient's and family's understanding and experience of the illness. Their mental representations of the condition may or may not coincide with that of the doctor. Awareness of the patient's perceptions can be valuable both in the diagnostic phase and in the treatment or management phase" (Earll and Johnston, 1993, p. 442).*

Thirdly, this chapter has indicated that adherence remains a serious challenge to the maintenance of optimum health. Although Leventhal & Cameron (1987) argue that the self-regulatory model provides a more comprehensive model than previous frameworks for understanding adherence, few studies have explored the relationship between patients' representations of illness and patterns of adherence. An important question then, is whether patients' representations can actually predict adherence. Research suggests (e.g. Horne's work on representations of medicine) that other factors beyond illness representations may be important to our understanding of adherence. The relationships between representations and adherence is therefore an important area of investigation, both because it is relatively unexplored within Leventhal's framework and because the literature suggests that the predictive power of the self-regulatory model may be enhanced by the addition of further constructs pertinent to adherence. In particular, previous research suggests that constructs from the health belief model, such as the costs and benefits of treatment may be particularly salient for chronic complaints such as hypertension and diabetes. As previously discussed, chapter 5 examines adherence in a mixed sample of patients recruited from general practice. In addition, the final empirical study reported in chapter 7 explores the utility of both patients' representations and their health beliefs in predicting adherence to diabetic and hypertensive treatment regimens.

Finally, further work needs to be conducted which explores the relationships between the different stages of the self-regulatory model (i.e. between illness representations, coping, and outcome appraisal). The literature reviewed in 2.6.3 indicates that patients' illness representations have important implications for their physical and psychological well-being across a range of illnesses. Indeed, there is mounting evidence that illness representations may actually be more powerful predictors of adjustment than coping strategies. Clearly then, further research needs to be conducted which examines the relationship between representations, coping and outcome measures. This is the focus of chapters 6 and 7. The aim of Chapter 6 is to investigate the suitability of a coping measure (the COPE) for use with populations of ill people (Study 4) and to develop a shorter measure (Study 5). Chapter 7 explores the relationship between illness representations, coping and functioning in two samples of chronic patients (Study 6).

The following six empirical studies therefore attempt to address the above omissions in the literature and thereby extend the theoretical and practical utility of the self-regulatory model. The implications of the findings together with methodological issues arising from the studies are discussed in Chapter 8.

CHAPTER 3

Lay classification of illness

3.1 Introduction

A schema is a "cognitive structure that represents knowledge about a concept or type of stimulus, including its attributes and the relations among those attributes" (Fiske & Taylor, 1991; p. 98). The literature reviewed in chapter 1 suggests that people possess well-structured schemata of the typical features associated with different illnesses and these schemata are a principal means by which people interpret and react to their own experiences of illness. Thus, in order to understand people's management of illness we must firstly explore how lay people conceptualize and categorize illness. Study 1 establishes lay people's representations of a wide spectrum of illnesses commonly treated in general practice (see 3.3). This enables a comparison with the representations which people hold about their own illness when seeking medical care. This is described in chapter 4. Additionally, study 1 investigates the basis upon which illnesses are clustered together and examines which features are most salient in distinguishing between different illnesses. This is discussed in more detail below.

3.1.2 The categorization of illness

Lau and Hartmann (1983) stress the importance of defining schemata as "*consensual* representations of knowledge", and investigating the composition of these representations in the lay population. The work of Bishop and his colleagues has been pioneering in understanding how people organize information about illness in terms of prototypical categories[1]. However, much of the research in this area has focused on the content of illness representations rather than the relationships between the various features or components of people's representations[2], despite evidence which suggests that the features are inter-related rather than independent of each other (e.g. Medin & Shoben, 1988; Lau & Hartman, 1983). Moreover, it seems likely that some features are more important in the categorization of illnesses than others. For example, strong beliefs regarding illness identity and cure are associated with seeking medical care (Lau et al., 1989). However, no research to date has investigated the relative importance of the different features in the *categorization* of illness. A related issue is whether all illnesses are categorized in the same way.

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[1] The notion of prototypes is discussed in chapter 1 (p.12). Prototypes refer to idealized representations of the features of categories, in this case, illnesses.

[2] The term feature and component are used interchangeably in this chapter, although the latter specifically refers to the five components of illness representations outlined by Leventhal and colleagues.

Previous research has tended to focus on a limited range of illnesses and primarily on symptoms rather than the other components of illness representations outlined by Leventhal (beliefs about cause, time line, consequences and cure). Moreover, the work of Lalljee et al. (1993) suggested that people's beliefs about the type of person likely to contract the illness are important in organizing people's interpretation of illness. The salience of person information in discriminating between different illnesses has not, however, been investigated in any subsequent studies. Study 1 therefore aimed to lay the foundations of the current research by a) systematically exploring lay representations of illness for a much wider spectrum of illnesses than previously investigated and b) investigating the role of person information (in addition to Leventhal's components) in discriminating between different clusters of illnesses.

The current study was thus an extension of Lalljee et al's earlier study (study 2). It used their cluster analysis as a basis for investigating the classification and organization of illnesses. However, the focus of the current thesis is on people's everyday conceptions of illness, particularly illnesses with which people have prior experience and contact. According to Lau et al. (1989) such illnesses are "the vehicles through which people learn to think about illness" (p. 196). This suggests that people's representations for commonly experienced illnesses form the basis for interpreting and responding to new ones. The illnesses included in the current study were therefore generated by participants asked to list common illnesses for which they would visit a doctor. This provides a framework for how people mentally organize illnesses within their day-to-day experience, and identifies those features which are most relevant to people's classification of such illness. For example, in Lalljee et al.'s original study, several illnesses were clustered together by respondents because they were seen as diseases contracted by people living in the "third world". Person information may be particularly salient in classifying such illnesses simply because they are unfamiliar to the typical respondent.

The current study also investigated the illness representations of 40 illnesses rather than the 12 selected by Lalljee et al. This enabled a more thorough exploration of the features used in classifying a wide range of illnesses. Whereas Lalljee at el. focused on the *similarities* between illnesses (i.e. illnesses within a cluster were viewed as more similar than those in other clusters), the current study was also concerned with the *differences* between clusters i.e. whether certain features are more salient than others in distinguishing between different clusters of illness.

The current study also enabled the examination of interconfusability between illnesses of different clusters and the relationship between different features. For example, perceptions of severity and treatment may distinguish meningitis from flu, but both may be seen to share similar symptoms and cause. This clearly has important practical implications. Indeed, the possible ramifications of confusion over representations of different illnesses was demonstrated in a study by Gutmann et al. (1981) (cited in Nerenz and Steele, 1983) who found that bypass patients who had interpreted their cardiac distress as gastric pain had delayed seeking medical care for an average of two hours. Patients were unable to differentiate between gastric pain and heart problems because the symptoms are so similar. Such a delay therefore appears to reflect representational confusions. The identification of features in which there is considerable overlap between different illnesses has not been previously explored in a systematic fashion, despite its implications for everyday identification and diagnosis of illness.

Previous studies of this kind have predominately been undertaken with student samples. However, since the focus of this study was on ***lay representations*** of illnesses, it was important that the sample reflected a wide sector of the population, rather than a subsection such as students. Additionally, most previous research on the structure and organization of illness representations has been conducted in the US. The current study explored the content and classification of illness in a UK sample.

In summary, study 1 establishes lay representations for many more illnesses than have previously been explored. It focuses on common illnesses for which people are likely to visit their general practitioner, thus enabling a comparison with patients' representations of their own illness in study 2. In addition to describing the content of people's illness representations, the current study explores the relative power of the various features in discriminating between different illnesses. The study also extends the work of Lalljee et al. (1993) by evaluating the role played by person information in discriminating between illnesses. Finally, study 1 explores ways in which illnesses may be misclassified on the basis of shared features with other illnesses.

3.2 Aims

- To provide a systematic description of lay people's representations of 40 different illnesses.
- To investigate the relationship between features and to determine which features are most important in distinguishing between different clusters of illnesses.
- To examine patterns of "interconfusability" between illnesses, i.e. the extent to which illnesses are incorrectly classified into outlying illness clusters on the basis of shared features.

3.3 Preliminary study: Selection of illnesses

In order to generate a wide range of illnesses 57 participants were asked to list common illnesses for which they would visit a doctor. The participants included 21 undergraduate students, 16 student teachers and 20 members of the general population, with an age range of 19 to 70 years. Thirty five of the participants were female and 22 male. Participants produced between one and 12 illnesses each. A total of 61 distinct "illnesses" were generated in total, although this also included a number of symptoms (e.g. chest pain) and non-specific complaints (e.g. virus). Forty illnesses (including those most frequently cited by participants) were selected from this list to provide a wide spectrum of illnesses of both an acute and chronic nature (Fry, 1979, 1994). These can be found in Table 3.3.1. When non-specific medical problems were repeatedly listed, a "common" condition which corresponded with the original general category was selected from a medical text book (Fry, 1994; e.g. back problems-sciatica/lumbago, skin problems-dermatitis, vision problems-cataract, liver disease-cirrhosis).

Table 3.3.1: Illnesses selected from participants' lists

Anaemia	Cold	Haemorrhoids	Mumps
Angina	Cystitis	Hernia	Peptic Ulcer
Arthritis	Dermatitis	High Blood Pressure	Pneumonia
Asthma	Ear infection	Irritable Bowel Syndrome	Rheumatism
Appendicitis	Eczema	Laryngitis	Sinusitis
Bronchitis	Flu	Lumbago	Sciatica
Breast Cancer	Gastroenteritis	Lung Cancer	Shingles
Cataract	German Measles	Measles	Thrombosis
Chicken pox	Glandular Fever	Meningitis	Tonsillitis
Cirrhosis	Heart Disease	Migraine	Venereal Disease

3.3.1 Clustering of illnesses

The clustering of illnesses on the basis of similarity judgements was based on Lalljee et al.'s (1993) original cluster analysis of 35 illnesses (see Appendix 1 (p.A1) for Lalljee at al.'s original cluster analysis). However, 22 of the illnesses selected for the current study were not included in Lalljee et al.'s original analysis. In order that all 40 illnesses could be similarly classified into clusters, a second study was carried out to classify these additional 22 illnesses. Forty undergraduate students were given a questionnaire during a psychology practical. The questionnaire contained the clusters obtained from the initial cluster analysis, plus a list of 11 illnesses (the 22 "new" illnesses were split randomly into two lists; half the participants were given the first 11 illnesses, half the second 11). The participants were asked to select the cluster into which each illness best fitted. There was also a miscellaneous category if the illness could not be allotted to any of the available clusters. The study revealed a high level of agreement about the categorization of the illnesses. Only three of the illnesses could not be clearly placed into any of the clusters (haemorrhoids, hernia, and cataract). These illnesses were therefore excluded from further analysis. This consensus suggests that the category structure derived from Lalljee et al.'s cluster analysis is both easy for people to use and also one which people readily use to categorize illnesses. The results of the classification can be found in Table 3.2.2. For ease of interpretability, the five primary clusters have been assigned labels (since these are the basis for the subsequent discriminant analysis). However, these clearly involve intuitive judgements about their content. They are intended only to enhance the accessibility of the text.

MAIN STUDY: THE CONTENT AND CLASSIFICATION OF ILLNESS REPRESENTATIONS

3.4 METHOD

The choice of features was based on the components identified by Leventhal and colleagues (symptoms, causal beliefs, time line, consequences, and cure), together with Lalljee et al's identification of person information as an important basis of classification. An emphasis was placed on the **typical** features of illnesses.

3.4.1 Participants

300 participants (142 male, 158 female) completed the questionnaire. Ages ranged from 16 to 89 years, with a mean age of 35.8 years (SD = 14.5). Half of the participants were recruited by students during a practical and asked to fill out the questionnaire; the students were each requested to find two *non-student* participants to complete the questionnaire. The remainder of participants were members of the general population recruited at a train station. Only the responses of British participants were included in the study. The majority were Caucasian, representing a wide variety of occupational groups.

3.4.2 Materials

The questionnaire consisted of five pages: a cover sheet with instructions and questions regarding the subject's demographic status (age, sex, occupation, nationality, and ethnic group), each of the

Table 3.3.2 Classification of illnesses into clusters the basis of their similarity

PRIMARY CLUSTER	SUBORDINATE CLUSTERS	ILLNESSES
1* (cancers/genital)	1a	Cystitis V.D
	1b	Meningitis
	1c	Lung Cancer Breast Cancer
2 (common illnesses)	2a	**Asthma** **Bronchitis** **Pneumonia**
	2b	**Cold** **Flu** Sinusitis Laryngitis Migraine Ear infection
3 (contagious illnesses)	3	**Measles** **Chicken pox** **German Measles** **Mumps** Shingles **Tonsillitis** **Glandular fever**
4 (muscular, joint and skin disorders)	4a	**Arthritis** **Rheumatism** Lumbago Sciatica
	4b	Anaemia
	4c	**Dermatitis** Eczema
5 (cardiac and internal organ disorders)	5a	**Ulcer** **Gastroenteritis** Irritable Bowel Appendicitis Cirrhosis
	5b	**Heart Disease** Angina Thrombosis **Hypertension**

Illnesses in bold refer to those illnesses included in Lalljee et al's original analysis.

*Clustering of illnesses differentiated this primary cluster into 3 distinct groupings i.e. the three subordinate clusters in this group were more distinct than the subordinate clusters constituting the remaining primary clusters. However, description of the analysis is based on the joint membership of these five illnesses, hence the current labelling (see also page 77).

N.B. Additionally, it may be noted that the primary clusters could be further grouped into three main clusters: main cluster 1 consisting of subordinate clusters 1a, 1b, and 1c; main cluster 2 consisting of primary cluster 2 and 3; main cluster 3 consisting of primary clusters 4 and 5.

remaining four pages contained the name of an illness and six questions pertaining to the illness (see Appendix 2 (p.A2) for an example of the questionnaire). The questions were:

1. What are the typical symptoms of this illness?
2. What sort of person typically gets this illness?
3. Why/how does one typically get this illness?
4. How serious is this illness?
5. For how long does this illness typically last?
6. What might be done to treat this illness?

3.4.3 Design

Each participant received questions about four different illnesses. Each of the 40 illnesses was presented to a total of 30 participants in two different sets (15 participants received each set); each set differed in its combination of illnesses (randomly selected) and the order of presentation of the illnesses to counteract any order effects. There were 20 different sets of questionnaires in total. Incomplete responses to any single illness were excluded as were questionnaires completed by non-British participants.

3.4.4 Procedure

Participants were approached by the investigator and asked if they would be willing to participate in a study looking at people's beliefs about different illnesses. The instructions on the questionnaire emphasized that respondents should not be concerned with the correctness of their answers but should respond according to what they believed to be the typical features of each illness.

3.5 ANALYSIS

3.5.1 Content analysis

Participants' free responses to the six questions were content analyzed to determine lay people's representations of the 37 illnesses (three of the original 40 illnesses were excluded due to their failure to be classified into any of the existing clusters). Responses were frequently complex and were therefore divided into their component parts and coded accordingly. Although a response could sometimes be coded into several categories, no category was coded more than once per response. The responses to each of the questions were coded into between 18 and 78 categories as follows: the typical symptoms were coded into 78 categories, the typical person into 45 categories, the typical cause into 53 categories, the severity into 18 categories, the typical time line into 23 categories, and the treatment into 46 categories. Each question also had two additional categories for miscellaneous responses (for responses given by only one participant) and "don't know" responses when participants were unable to answer the question. See Appendix 3 (p. A4) for further details.

3.5.1.1 Reliability study

The reliability of the coding scheme was assessed for a selection of the illnesses. Twenty completed questionnaires were selected at random, one from each of the questionnaire sets. A single illness was chosen from each of the questionnaires to ensure a wide coverage of different illnesses from each of the clusters.

Three judges received payment for participating (£5). They were given the original questionnaires plus a booklet containing the content analysis categories (mentioned above) for each of the six questions together with instructions about how to categorize the questionnaires. The judges were instructed to categorize the content of each answer for the 20 illnesses by breaking down each response into its component parts and selecting the best-fitting category from the booklet. They were given several examples for clarification. The judges were asked to be as specific as possible and were advised that although a response could be coded into several categories, no category should be used more than once per response.

To establish inter-rater reliability, the number of elements on which there was agreement was divided by the number coded by the investigator. As indicated by Table 3.3, there was high inter-rater reliability between judges for all of the questions. Additionally, overall agreement with the investigator for all questions combined was 89%, 91%, and 94% for each of the three raters.

Table 3.5.1 Inter-rater reliability for content analysis of features

	Q1 Symptoms	**Q2 Person**	**Q3 Cause**	**Q4 Severity**	**Q5 Time**	**Q6 Treatment**
% Agreement*	88-97	85-96	89-96	81-95	90-95	91-94

* Range of agreement between judges and investigator.

The results of the content analysis for each feature is outlined below (see Appendix 3 for the detailed analysis of individual illnesses and features; p.A4). Discussion of the results is focused on the **primary clustering** of illnesses (see Table 3.3.2, p.75). However, as noted on p. 75, the original clustering differentiated the illnesses in cluster 1 into three distinct groupings (i.e. three primary clusters). Due to the small number of illnesses in these three clusters, description is based on their joint membership in main cluster 1. It is of interest that few illnesses from these three original clusters were listed by participants in the current study as illnesses for which they would visit the doctor. This appears to reflect the type of illnesses involved (sexually transmitted, third world, and cancers) which are predominately illnesses of a relatively severe nature and ones which are presumably less likely to be personally familiar to most participants.

3.5.2 Discriminant analysis

Discriminant function analysis was used to clarify the patterns and trends which emerged from the content analysis. Stepwise discriminant analysis was used to give an indication of which variables best discriminated among the groups of illnesses and to indicate which groups were misclassified with each other. Stepwise discriminant analysis (Wilks) was conducted for each of the six components. Groups of illnesses for analysis were based on the primary clusters in Table 3.3.2 (p.75). Five clusters of illness were therefore entered into the analysis, with each cluster containing between 5 and 9 individual illnesses.

The independent variables were the frequencies of the features for each question (i.e the number of participants' listing each feature). Only modal responses and those exceeding a frequency of 10 were entered into the analysis for each illness. Some categories were also collapsed by two judges to provide more inclusive categories (e.g. iron replaced by dietary supplements) which were used in the analysis. The number of categories for each feature were as follows: symptoms = 37, person = 16, cause = 17, severity = 8, time line = 10, treatment = 17. Details of the categories may be found in Appendix 4 (p.A15).

3.6 RESULTS

3.6.1 Symptoms

Illnesses within cluster 1 (cancer/genital complaints) were not homogeneous in terms of symptomatology, with minimal overlap between the illnesses in this cluster. There was, however, overlap with illnesses from other clusters. For example, lung cancer was seen as having similar symptoms to bronchitis and pneumonia in cluster 2, namely breathing difficulties and coughing (53% and 47% of respondents respectively). Similarly, the symptoms of meningitis in cluster 1 mirrored those of flu from cluster 2 (fever 40% and headache 37% of respondents). The remaining illnesses in cluster 1 were distinct in their perceived symptomatology. Cystitis was associated with pain on urination (60% of respondents), V.D with genital sores, discharge and itching (minimum 40% of respondents), and breast cancer with lumps on the breast (93% of respondents).

A wide range of symptoms were listed for illnesses from primary cluster 2 (common illnesses), presumably reflecting participants' familiarity with these conditions. Asthma, bronchitis, and pneumonia (subcluster 2a) were differentiated from the other illnesses in primary cluster 2 by their association with breathing difficulties (97%, 57%, and 43%). The typical symptoms characterizing the remaining illnesses in cluster 2 were headaches (listed by 38% of participants), and a blocked nose (30%). However, ear infection was typically associated with earache (87%) and laryngitis with a sore throat (77%).

All illnesses from primary cluster 3 (contagious illnesses) were associated with fever symptoms (10% to 60% of respondents). However, measles, chicken pox, german measles, and shingles were typically associated with spots or skin rashes (minimum 40%), and mumps and glandular fever with swollen glands (93% and 90% respectively). Tonsillitis, like laryngitis in cluster 2, was characterized by a swollen throat (87%). Thus, symptoms of the illnesses in this cluster focused primarily on the skin or throat area.

Typical symptoms associated with illnesses in primary cluster 4 (muscular, joint and skin disorders) appeared to fall into four sub-categories with no relationship between these sub-clusters. This largely reflects the original clustering of illnesses into three subordinate categories (see Table 3.3.2) except that the four illnesses in subcluster 4a fell into two pairs on the basis of symptomatology. Arthritis and rheumatism were characterized by joint pain (83% and 73% respectively), while lumbago and sciatica were characterized by back pain (80% and 50% respectively). Dermatitis and eczema (subcluster 4c) were associated with skin rashes and dry/itchy skin (minimum 40%). Anaemia was singled out by symptoms of fatigue (80%) and pallor (53%).

Illnesses from primary cluster 5 (cardiac and internal organ disorders) appeared to fall into two main symptoms groups, again reflecting the original classification of illnesses. In the subcluster 5a, heart disease and angina predictably shared symptoms of breathing difficulties and chest pain (minimum 33%). Although these symptoms were also associated with the other two illnesses in this subcluster (thrombosis and hypertension), the latter were typically characterized by blood clots and headaches respectively (30% and 33%). The illnesses in subcluster 5a appeared to be linked by anatomical location, with symptoms such as stomach pain for ulcer and gastroenteritis (63% and 33%

respectively), abdominal pain for appendicitis (50%), diarrhoea for gastroenteritis and irritable bowel (60% and 50% respectively), and liver pains for cirrhosis (33%).

Stepwise discriminant analysis of primary clusters

Thirty seven independent variables were entered in the analysis and 23 were selected[3]. Although three functions were significant ($\chi^2 = 302.05$, df = 92, $p<.0001$), the first accounted for the majority of the variance accounted for by the set of functions (98.8%) and is therefore the only one included in Table 3.6.1(a). It distinguished cluster 5 (cardiac and internal organ disorders) from the other illness clusters (see Table 3.6.1(b)). The symptoms contributing to this function were drawn from all illnesses in this cluster (from both subordinate clusters 5a and 5b). The second and third functions both distinguished cluster 2 (common illnesses) from the other groups and were characterized by symptoms of the throat and nose.

Table 3.6.1(a) Discriminant functions for symptoms

Function	Eigenvalue (canonical R)	Variable	Standardized discriminant function coefficients
1	2685.58	Chest pain	27.85
	(.99)	Liver pain	20.31
		Diarrhoea	19.70
		Stomach pain	18.60
		Blood clots	15.59
		Congested chest	15.19
		Abdominal pain	11.54

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[3] Only variables significant for the first function are presented in Table 3.6.1(a). For all subsequent analysis, only those variables with the highest standardized discriminant function coefficients are presented in the tables given alongside each analysis. This is to aid interpretability for the reader.

Table 3.6.1(b) Group centroids for the first discriminant function

Primary Cluster	Group centroid
1	-29.12
2	-18.39
3	-30.03
4	-27.91
5	89.59

People's perceptions of the symptoms associated with illnesses were very good predictors of group membership with 92% of illnesses correctly classified into their appropriate primary clusters (see Appendix 5, Table 1; p.A17). Although clusters 2 and 3 (common and contagious illnesses respectively) appeared to have several symptoms in common, there was no interconfusability in their classification. Twenty percent of illnesses from cluster 1 (cancers/genital) and 14% from cluster 3 were misclassified into cluster 4 (muscular, joint & skin disorders), presumably on the basis of skin-related symptoms (e.g. rash).

3.6.2 Person information

Once again, there was no clear interrelationship between illnesses in primary cluster 1 (cancers/genital) regarding beliefs about the typical person. Women were typically seen as suffering from cystitis and breast cancer (67% and 47%), particularly older women in the latter case (47%), whilst promiscuous people were seen as most likely to contract V.Ds (57%). The typical person perceived as susceptible to lung cancer resembled the bronchitis sufferer in cluster 2a or the heart disease patient in cluster 5b, namely someone who smokes (80%) and is older (23%). Meningitis was associated with "anyone" (53%) and children/younger people (50%).

Illnesses in primary cluster 2 (common illnesses) were viewed, not surprisingly, as likely to occur in anyone (minimum 46%), with the exceptions of bronchitis which was linked with smokers and older people (57% and 33% respectively) and pneumonia which was associated with elderly people (60%).

Primary cluster 3 (contagious illnesses) was clearly distinguished by its association with children/young people (all responses exceeding 50%), with the exception of shingles which was seen as more likely to afflict older/elderly people (37%).

There was some variability in beliefs about the typical person for illnesses in cluster 4 (muscular, joint and skin disorders), although as was the case with perceptions of symptoms, beliefs about the person fell into four groups. Elderly people were seen as the typical sufferers of arthritis and rheumatism (57% and 47% respectively). Lumbago and sciatica were also associated with older people (20% and 33% respectively), but 17% and 23% of respondents stated they did not know the type of susceptible person. Anaemia was predominately associated with women (40%), and dermatitis and eczema with anyone (43% and 33%) and children (40% for eczema).

Illnesses from primary cluster 5 (cardiac and internal organ disorders) were largely associated with people with particular lifestyles, although gastroenteritis, irritable bowel syndrome and appendicitis were attributed to anyone (57%, 57%, and 77% respectively), and cirrhosis was singled out by its association with heavy drinkers (87%). Heart disease, angina, thrombosis, and hypertension were associated with smokers, and overweight, unfit, and older people (10% to 47%).

Stepwise discriminant analysis of primary clusters

Sixteen independent variables were entered into the analysis, and 12 were selected. Three discriminant functions were significant. The first function ($\chi^2 = 119.27$, df = 40, $p<.0001$) accounted for 48.5% of the variance accounted for by the set of functions and distinguished primary cluster 3 from the other primary clusters (see Table 3.6.2 (b)), which reflects the homogeneity revealed by the content analysis. It is therefore surprising that promiscuity had the highest discriminant coefficient, since it is clearly unrelated to illnesses such as measles and glandular fever. However, further examination indicates that it does not significantly correlate with function 1 ($r = .04$) compared with the highly significant correlation for children ($r = .58$). This incongruent finding may also reflect the relative positioning of group centroids[4]. The second function ($\chi^2 = 71.56$, df = 27, $p<.001$) discriminated cluster 1 from the other groups and was strongly characterized by the promiscuous person associated with VDs, and to a lesser degree by older women and smokers, reflecting susceptibilities to breast and lung cancer respectively. This suggests that "promiscuous" is unique to this cluster and discriminates from illnesses in other clusters. Function 3 ($\chi^2 = 32.18$, df = 16, $p<.01$) maximally distinguished cluster 5 (cardiac and internal organ disorders) from cluster 4 (muscular, joint & skin disorders) and was primarily composed of lifestyle variables (in addition to the generic "anyone"), most notably people who are stressed and drink heavily.

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[4] Ranked linearly, the group centroid of primary cluster 1 (.81) is adjacent to that of primary cluster 3 (3.58) and "promiscuous" is a highly salient feature of primary cluster 1.

Table 3.6.2 (a) Discriminant functions for typical sufferer

Function	Eigenvalue (canonical R)	*Variable*	*Standardized discriminant function coefficients*
1	4.33	Promiscuous	1.17
	(.90)	Children	0.98
		Adult	0.73
2	2.98	Promiscuous	4.31
	(.87)	Smoker	1.2
		Older women	1.2
3	1.24	Stress	1.07
	(.74)	Anyone	0.97
		Heavy drinkers	0.96
		Older people	0.93

Table 3.6.2(b) Group centroids for discriminant functions

Primary Cluster	Function 1	Function 2	Function 3
1	.81	3.79	.01
2	-.76	.25	-.91
3	3.58	-1.08	.62
4	-.53	-1.37	-1.28
5	-2.07	-.45	1.42

Classification of illnesses on the basis of person information also proved to be a good predictor of group membership, with 82% of illnesses correctly classified into their appropriate primary clusters (see Appendix 5, Table 2; p.A17). Not surprisingly, most misclassification (66%) was into cluster 2 (common illnesses), since this cluster was typically associated with "anyone" and therefore had considerable overlap with the other clusters. Cluster 5 (cardiac & internal organ disorders) was the least successfully classified (67%), with misclassification into cluster 2 and cluster 4.

3.6.3 Causal Beliefs

As expected, causal beliefs were closely related to people's beliefs about the type of person seen as likely to contract the illness, for example, the type of lifestyle that an individual has. The illnesses in primary cluster 1 (cancers/genital illnesses) were once again seen as having quite discrepant causal patterns. V.Ds were associated with sexual intercourse (90%), lung disease with smoking (77%), and breast cancer with heredity (27%). Cystitis and meningitis were attributed to infection and contagion respectively (both 37%).

There was considerable overlap for primary clusters 2 (common illnesses) and 3 (contagious illnesses) in participants' causal beliefs. Most illnesses from both clusters were seen as resulting from either infection or contagion (37%-90%). There were, however, several anomalies from cluster 2: asthma was seen as hereditary (50%), migraine as due to stress (43%), and laryngitis as resulting from voice strain (33%).

Once again, illnesses from primary cluster 4 (muscular, joint and skin disorders) fell into four groups, with subordinate cluster 4a split into the same two pairs. Arthritis and rheumatism were perceived as either having hereditary origins (20% and 40% respectively) or as a result of wear and tear (30% and 23% respectively), whilst lumbago and sciatica were seen as resulting from muscle strain (40%). Dermatitis and eczema were attributed to heredity (27% and 47% respectively) and allergies (33% and 23% respectively). Anaemia was due to dietary deficiencies (80%).

Consistent with perceptions of the typical person likely to contract illnesses from primary cluster 5 (cardiac and internal organ disorders), causal beliefs centred around lifestyle factors such as stress, dietary deficiencies, lack of exercise, heavy drinking, and smoking. Two illnesses did not fit this causal pattern, namely gastroenteritis and appendicitis which were associated with contaminated food (57%) and an infected appendix (37%) respectively.

Stepwise discriminant analysis of primary clusters

Seventeen variables were entered into the analysis and 9 were selected; three discriminant functions were significant. There was, however, considerable overlap in the content of these functions (see Table 3.6.3(a)). Function 1 ($\chi^2 = 116.01$, df = 36, $p<.001$) accounted for 49.4% of the variance accounted for by the set of functions and maximally distinguished primary cluster 4 (muscular, skin & joint disorders) from clusters 1, 3, and 5 (see Table 3.6.3(b)). Function 1 was characterized by general wear and tear and physical strain associated with the inflammatory and back disorders (subordinate cluster 4a), and allergies more associated with skin disorders (subordinate cluster 4c). The second function (χ^2 = 68.36, df = 24, p<.001) primarily discriminated illnesses from both clusters 2 and 3 (common and contagious illnesses) from the other illnesses. Function 3 (χ^2 = 29.02. df = 14, p<.01) maximally differentiated cluster 3 from cluster 2. However, the group centroids of clusters 3 and 4 were relatively closely positioned and the function was characterized by a combination of features from these clusters, namely contagion (from cluster 3) and wear and tear/strain (from cluster 4).

Table 3.6.3(a) Discriminant functions for causal beliefs

Function	Eigenvalue (canonical R)	*Variable*	*Standardized discriminant function coefficients*
1	4.19	Allergy	1.56
	(.90)	Muscle strain	1.15
		Wear & tear	1.04
2	2.88	Contagion	0.94
	(.86)	Infection	0.88
		Allergy	0.67
3	1.13	Contagion	0.71
	(.73)	Wear & tear	0.71
		Muscle strain	0.66

Table 3.6.3(b) Group centroids for discriminant functions

Primary Cluster	Function 1	Function 2	Function 3
1	-1.79	-.61	-.33
2	.99	1.65	-1.29
3	-1.39	1.89	1.48
4	3.29	-1.16	.82
5	-1.48	-1.90	-.31

Causal information correctly classified 73% into their appropriate clusters (see Appendix 5, Table 3; p.A17). There was some interconfusability between clusters 1 (cancers and genital illnesses) and 3 (contagious illnesses), for which infection/contagion appeared to provide the bridge (i.e. illnesses in clusters 1a, 1b and 3 were frequently attributed to infection/contagion)[5]. There was also some interconfusability between clusters 2 (common illnesses) and 4 (muscular, joint and skin disorders), perhaps reflecting the heredity component in both clusters, although several illnesses from cluster 2 were misclassified into other clusters, since it had several anomalies within the cluster (see earlier description of content analysis).

3.6.4 Beliefs about severity

People's perceptions about the seriousness of illnesses in primary cluster 1 (cancers and genital) appeared to be the principal distinguishing feature of this cluster, in which illnesses were seen as "very serious" or "life threatening" (minimum 33%). Only cystitis, which was viewed as "not serious" (53%), differed from this pattern.

Primary cluster 2 (common illnesses) was clearly divided into its two sub-clusters on the basis of representations about severity. Asthma, bronchitis, and pneumonia (subordinate cluster 2a) were seen as "very serious" (37%, 33%, and 43% respectively), whereas the remaining illnesses (subordinate cluster 2b) were viewed as "not serious" (30%-90%). Similarly, illnesses from primary cluster 3 (contagious illnesses) were also perceived as "not serious" (30%-67%). Only shingles did not fit this pattern; indeed, people's representations of the severity of shingles were varied, with 17% stating that they did not know the degree of severity.

For primary cluster 4 (muscular, joint and skin disorders) there was considerable variability amongst the illnesses regarding their perceived seriousness. Arthritis and rheumatism were both seen as debilitating/painful (50% and 43% respectively), and dermatitis, eczema, and lumbago as "not serious" (minimum 33%). However, there was no clear consensus regarding either sciatica or anaemia.

The majority of illnesses from primary cluster 5 (cardiac & internal organ disorders) were perceived as either "very serious" or life-threatening (minimum 30%). However, peptic ulcer had a range of responses and irritable bowel syndrome was perceived as "not serious" (47%).

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[5] This is consistent with Bishop's (1991) work on attitudes towards victims of disease in which flu was perceived as a prototypical contagious disease against which other contagious diseases (e.g. sexually transmitted diseases) were compared.

Stepwise discriminant analysis of primary clusters

Eight independent variables were entered into the analysis, and 5 variables were selected. Although 3 functions were significant, their discriminatory power was rather lower than the previous analyses, with much less differentiation between group centroids (see Table 3.6.4(b)). This is also likely to reflect the fewer categories of levels of severity, resulting in greater overlap between groups. Function 1 ($\chi^2 = 58.74$, df = 20, $p<.001$) maximally discriminated primary cluster 1 (cancers/genital) from primary clusters 3 and 4 (contagious and muscular/joint/skin disorders) on the basis of the serious and life-threatening nature of such illnesses. Function 2 ($\chi^2 = 31.41$, df = 12, $p<.01$) was characterized by beliefs that an illness was "quite serious", which maximally differentiated cluster 3 (contagious illnesses) from cluster 4 (muscular/joint/skin disorders), despite the fact that respondents typically labelled such illnesses as not very serious. This was reflected in the final function (low severity) which distinguished clusters 2 (common illnesses) and 3 (contagious) from clusters 4 (muscular/joint/skin) and 5 (cardiac/internal organs) ($\chi^2 = 12.45$, df = 6, $p<.05$).

Table 3.6.4(a) Discriminant functions for perceived severity

Function	Eigenvalue (canonical R)	*Variable*	*Standardized discriminant function coefficients*
1	1.41 (.77)	Life-threatening	1.24
2	.84 (.68)	Quite serious	0.99
3	.39 (.53)	Not serious	1.20

Table 3.6.4(b) Group centroids for discriminant functions

Primary Cluster	Function 1	Function 2	Function 3
1	1.28	-.10	-.18
2	.43	-.51	.89
3	-1.60	1.16	.22
4	-1.12	-1.27	-.59
5	.97	.66	-.51

Despite the lower discriminatory power of severity, 65% of illnesses were correctly classified (see Appendix 5, Table 4; p.A17). Indeed perceptions of severity proved a very accurate predictor of group membership for illnesses in cluster 4 (muscular, joint & skin disorders: 100%). Not surprisingly, there was considerable interconfusability between clusters 1 (cancers/genital) and 5 (cardiac/internal organs) due to beliefs about the serious nature of illnesses in both groups. The misclassification of illnesses from cluster 2 (common illnesses) and 3 (contagious illnesses) into several other clusters (1 & 4 and 2 & 4 respectively) reflects the greater variability in perceptions of illness severity among the illnesses in these clusters, ranging from not at all serious (e.g. cold) to very serious (e.g. pneumonia).

3.6.5 Beliefs about time line

Overall, perceived duration of illness demonstrated much greater within cluster variability, and there was a lack of consensus among participants as to the typical time line of the illnesses. Thus, identification of prototypical time lines for both individual illnesses and clusters was problematic. In primary cluster 1 (cancers/genital), cystitis and meningitis were both seen as acute illnesses, lasting for less than a week (30%) and between 2 and 4 weeks (23%) respectively. The remaining illnesses were seen as more chronic, either lasting a lifetime (lung cancer: 27%) or until treated (V.D: 43% and breast cancer: 27%).

Illnesses from primary cluster 2 (common illnesses) were typically seen as lasting for a week or less (23%-73%), with the exception of bronchitis and pneumonia which were also viewed as acute illnesses, but of longer duration (2-4 weeks: 46% and 43% respectively) and asthma which, in contrast, was perceived as chronic (67%).

Illnesses from primary cluster 3 (contagious illnesses) were also seen as acute, predominately of between 1 and 2 weeks duration. However, tonsillitis and glandular fever were perceived as lasting between 2 and 4 weeks (30% and 20% respectively), and shingles for 4 to 8 weeks (20%).

With the exception of anaemia, which was seen as lasting until it is treated (43%), all illnesses from primary cluster 4 (muscular, joint and skin disorders) were labelled as chronic and as lasting a lifetime (20%-80%). However, a high percentage of respondents stated they did not know the duration of lumbago and sciatica (both 27%).

There was considerable variation in the perceived duration of illnesses in cluster 5 (cardiac and internal organ disorders), although cirrhosis, heart disease, angina, and hypertension were all seen as chronic illnesses (37%-63%). Ulcers were also seen as long-term illnesses which typically lasted until they were treated (30%). In contrast, gastroenteritis was seen as an acute illness, lasting less than a week (40%). Several illnesses (irritable bowel, appendicitis, and thrombosis) were difficult to classify due to lack of consensus and high rates of "don't know" responses (17%-30%).

Stepwise discriminant analysis of primary clusters

The discriminatory power of illness time line was rather low, as would be expected from the variability demonstrated in the content analysis. Ten independent variables were entered into the analysis, and 7 were selected (see Table 3.6.5(a)). Only one function was significant ($\chi^2 = 68.42$, df = 20, $p<.001$), accounting for 82.5% of the variance accounted for by the set of functions. This was characterized by perceptions of illness as acute and discriminated primary cluster 3 (contagious illnesses) from the other primary clusters (see Table 3.6.5(b)).

Table 3.6.5(a) Discriminant functions for time line

Function	Eigenvalue (canonical R)	*Variable*	*Standardized discriminant function coefficients*
1	3.77	1-2 weeks	1.33
	(.89)	4-8 weeks	0.89

Table 3.6.5(b) Group centroids for first discriminant function

Primary Cluster	Group centroid
1	-1.06
2	-0.23
3	3.66
4	-1.16
5	-1.13

Time line did not prove to be a particularly good predictor of group membership, correctly classifying only 57% of the illness (see Appendix 5, Table 5, p.A18). It was, however, successful in classifying illnesses perceived as having a short time line i.e. clusters 2 (common illnesses: 78%) and 3 (contagious illnesses: 100%). In contrast, only a single illness from cluster 5 was correctly classified, with misclassification into clusters 1 (cancers/genital), 2 (common illnesses) and 4 (muscular/joint/skin) which contained a combination of acute and chronic complaints. Similarly, there was interconfusability between clusters 1 and 2.

3.6.6 Beliefs about cure/treatment

Primary cluster 1 (cancers and genital illnesses) was differentiated into two groups in terms of treatment; the cancers in cluster 1c were associated with surgery (43% and 97%) whereas the illnesses in subordinate clusters 1a and 1b were seen as typically treated with drugs/medication. Illnesses from primary cluster 2 (common illnesses) were also seen as typically treatable with medication (40%-73%), with the following exceptions. Use of an inhaler was seen as the most common treatment for asthma, and for colds and flu, aspirin and rest were deemed the most appropriate treatments (60% and 73% respectively).

Medication (13% - 80%) and rest (6% - 57%) were listed as treatments for all seven illnesses in primary cluster 3 (contagious illnesses). However, cream was the most typical treatment cited for chicken pox (47%), and vaccination for measles (33%), although the latter is presumably seen as preventive rather than as treatment per se.

Once again, illnesses from primary cluster 4 (muscular, joint and skin disorders) fell into four groups with respect to typical treatments, with subordinate cluster 4a splitting into its two pairs. Medication was seen as the principal treatment for arthritis and rheumatism (53% and 37% respectively), and rest for lumbago and sciatica (33% and 30% respectively). Anaemia (cluster 4b) was seen as treatable through dietary supplements (70%), and dermatitis and eczema (cluster 4c) by creams (80% and 67% respectively).

Although medication and surgery were the most typical treatments for illnesses from primary cluster 5 (cardiac and internal organ disorders), lifestyle variables such as diet and exercise were also common, reflecting beliefs about the typical person (e.g. unfit people) and cause (e.g. lack of exercise) of these conditions. In subordinate cluster 5b, medication was perceived as the typical treatment for angina (73%), thrombosis (30%) and hypertension (70%), whilst exercise was seen as the typical treatment for heart disease (50%). Surgery was typical for ulcer (53%) and appendicitis (97%) in subordinate cluster 5a. Diet was the typical treatment for irritable bowel (40%), but was also salient for ulcer (47%) in cluster 5a, and heart disease (33%) and hypertension (37%) in cluster

5b. Consistent with beliefs about person and cause, alcohol reduction was seen as the principal treatment for cirrhosis (60%). Finally, drinking fluids was the typical treatment for gastroenteritis (53%).

Stepwise discriminant analysis for primary clusters

Seventeen independent variables were entered into the analysis for treatment beliefs, and 12 were selected. Three functions were significant accounting for 50.4%, 23.4%, and 15.3%, respectively, of the variance accounted for by the set of functions (see Table 3.6.6(a)). Function 1 ($\chi^2 = 115.71$, df = 48, $p<.001$) maximally discriminated primary cluster 4 (muscular, joint and skin complaints) from primary cluster 5 (cardiac/internal organs), and was characterized by painkillers, dietary supplements, and creams (see table 3.6.6(b)). The second function ($\chi^2 = 70.29$, df = 33, $p<.001$) maximally distinguished cluster 2 (common illnesses) from cluster 4 (muscular/joint/skin) and included a number of primarily non-prescription medications. In the final function ($\chi^2 = 40.43$, df = 20, $p<.01$), illnesses from clusters 2, 4, and 5 were differentiated from cluster 1 (-2.29) in their emphasis on diet as treatment compared with the more direct intervention of medication and radiotherapy associated with cluster 1.

Table 3.6.6 (a) Discriminant functions for treatment beliefs

Function	Eigenvalue (canonical R)	*Variable*	*Standardized discriminant function coefficients*
1	4.22	Dietary supplements	1.25
	(.90)	Painkillers	1.04
		Cream	1.01
2	1.96	Aspirin	0.77
	(.81)	Drops/sprays	0.59
		Inhaler	0.57
		Medication	0.41
3	1.28	Diet	0.70
	(.75)		

Table 3.6.6(b) Group centroids for discriminant functions

Primary Cluster	Function 1	Function 2	Function 3
1	-0.85	-0.31	-2.29
2	1.54	1.85	0.45
3	0.36	0.12	-0.70
4	2.07	-2.11	0.63
5	-2.96	-0.13	0.87

Treatment was a very strong predictor of group membership, correctly classifying 89% of illnesses (see Appendix 5, Table 6; p.A18). Indeed all illnesses in clusters 1 (cancers/genital), 4 (muscular/joint/skin), and 5 (cardiac/internal organs) were accurately classified. Single illnesses from clusters 2 (common illnesses) and 3 (contagious illnesses) were misclassified into groups 1 and 4, which may reflect the common treatments of medication and rest across these clusters.

3.7 DISCUSSION

Content analysis of responses to the 40 illnesses demonstrated that the clustering of illnesses on the basis of their similarity (Lalljee et al., 1993. See also p. 74 for classification table) was based on a number of different features. It also indicated that some features, such as symptoms, person information, and beliefs about cure/treatment, were more important than others in discriminating between illnesses. However, all illnesses were not clustered on the same basis. Thus it was not the case that illnesses were always most similar to others in the same cluster, but rather that particular features were important in leading to judgements of similarity and in distinguishing illnesses from each other. This suggests that any given feature would have produced a different clustering had it been the sole basis of the judgements underlying the clustering.

Illnesses in primary cluster 1 (Cancers/genital) were heterogeneous in terms of symptoms, person, cause and time line, with beliefs about severity (very serious) providing the link between illnesses in this cluster[6] and discriminating it from illnesses in other clusters, except primary cluster 5. Although illnesses in cluster 5 (cardiac/internal organ disorders) were also perceived as very serious, they differed in symptomatology from those in cluster 1. In terms of subclusters within primary cluster 1, treatment beliefs (surgery) distinguished the cancers (subcluster 1c) from the illnesses in subordinate clusters 1a and 1b. Primary clusters 2 (common illnesses) and 3 (contagious illnesses) overlapped on

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[6] With the exception of cystitis, which was not regarded as serious but was linked to VD in terms of symptomatology and cause.

several features, specifically, time line (acute) and cause (infection/contagion). They were, however, differentiated on the basis of symptoms. Primary cluster 2 was also discriminated from other illnesses by treatment beliefs, specifically regarding non-prescription drugs which particularly related to illnesses in subcluster 2b (flu etc). The two subclusters within cluster 2 (asthma vs. flu) were differentiated from each other on a number of features, such as symptomatology, type of person, and severity.

Not surprisingly, illnesses from primary cluster 3 (contagious illnesses) were the most homogenous in terms of all of the features[7]. Only shingles was distinct in terms of person and severity but was linked with the other illnesses by shared symptoms. Illnesses in primary cluster 3 were discriminated from other illnesses by the typical sufferer (children) and with the exception of illnesses in cluster 2, time line (acute). Primary cluster 4 illnesses (muscular/joint/skin disorders) were originally differentiated into three subclusters. This was largely supported in the current analysis, except that subcluster 4a formed two distinct clusters (arthritis/rheumatism and lumbago/sciatica) in terms of symptoms, person, cause and treatment. Thus there were four rather than three distinct subclusters in this group of illnesses, and people's beliefs regarding the features of these illnesses tended to be heterogeneous. However, all illnesses in primary cluster 4 were seen as chronic with the exception of anaemia, which did not clearly link with the other illnesses on any of the features. Indeed, this was originally placed in a distinct subcluster (4b). Primary cluster 5 (cardiac/internal organ disorders) was primarily distinguished from the other clusters by its symptomatology. Symptoms together with person information also differentiated between cluster 5a (ulcer etc) and 5b (heart disease etc.), whereas causal and severity beliefs appeared to form the link between these two subclusters which led to the perceived similarity.

The study thus supported the use of Leventhal's components in the classification of illnesses. It also substantiated Lalljee et al.'s (1993) findings that person information was important in guiding people's classification of illness. Whilst all features or components appeared to be used by people in classifying illness, there appeared to be some variation in the extent to which people held beliefs relating to the individual features. A high percentage of participants were able to volunteer information about the symptoms, typical sufferer, and severity of illnesses (94%-95%), whereas between 12% and 16% of respondents were unable to respond to questions about time line, treatment, and cause. Obviously, this may in part reflect difficulty with a few of the illnesses, for which

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[7] They were not differentiated into subordinate clusters in the original classification based on similarity judgements (p. 74).

participants had less well-developed representations. In particular, cystitis, meningitis, sinusitis, lumbago, sciatica, and irritable bowel syndrome all had a minimum "don't know" response rate of 20% for these features (and a maximum of 43%). However, even with these illnesses, many participants were still able to construct representations on the basis of symptoms, typical person, and severity.

Consistent with previous research findings, symptoms were the best discriminator of illness clusters (92% correct classification). In addition, secondary features such as anatomical location of symptoms, appeared to play a role in classification, particularly in linking illnesses from primary cluster 5 (cardiac and internal organ disorders). This is consistent with previous findings (Bishop, 1987; Lalljee et al., 1993). People's beliefs about the type of person typically suffering from an illness were also quite comprehensive, with a high response rate (93%) and successful classification of illnesses into their clusters (82%). The main cause of misclassification on the basis of beliefs about the typical sufferer arose as a result of over-classification of illnesses into primary cluster 2 (common illnesses) for which "anyone" was the prototypical response.

Consistent with Lalljee et al.'s findings, person and causal beliefs were closely related, particularly with regard to life-style factors (e.g. a person who is overweight with poor diet as a cause of illness). A relatively high percentage of respondents (16%) reported not knowing the cause of individual illnesses. This may partly reflect the nature of the study in which people's *abstract* representations were elicited, rather than concrete beliefs held about one's own condition. Previous studies indicate that people's causal beliefs are important in directing their behaviour and adjustment (e.g. Tennen et al., 1986; Turnquist et al., 1988; Watts, 1982). It would therefore be of interest to investigate the extent to which people seeking medical care have formed causal beliefs. In addition to discriminating between clusters of illness and accurately classifying 73% of illnesses into their respective clusters, causal beliefs provided a bridge between illnesses within subordinate clusters (e.g. infection linking cystitis and V.D in primary cluster 1; heredity linking joint and back complaints in subcluster 4a).

Beliefs about treatment/cure were also related to perceptions of both person and cause, consistent with previous findings e.g. improving one's diet (Lau & Hartman, 1983). Although 12% of respondents were unable to identify the typical treatment associated with individual illnesses, it proved a very accurate predictor of cluster membership (89%). Whilst medication was frequently listed by participants as appropriate treatment for a wide range of illnesses, other beliefs about treatment were more discriminative. Self-care, such as rest and non-prescription drugs were widely cited for the non-serious illnesses in subcluster 2b, and lifestyle factors proved particularly important for those illnesses in primary cluster 5 (cardiac and internal organ disorders). This clearly has further implications for the kind of expectations people hold when they seek medical care for their own condition. In Lau and Hartman's (1983) study, 84% of respondents were able to describe why they had recovered from a recent illness. The current study indicates that beliefs about treatment are also important discriminators of illnesses, and are therefore likely to be salient when people go to the doctor. It remains to be seen whether patients' beliefs about treatment are sufficiently powerful to influence their evaluation of and response to medical care. It would be particularly interesting to examine whether discrepancies between patients' and doctor's beliefs about treatment influence patients' satisfaction and adherence to recommended treatment. This is explored in Chapters 4 and 5.

The perceived severity of an illness has frequently been identified as a major factor which discriminates between illnesses (e.g. Bishop, 1987; Turk et al., 1986), and one that also influences illness outcomes. In the current study, although 94% of participants had beliefs about illness severity, there was considerable variability within the primary illness clusters. This resulted in lower discriminatory power and less accurate classification of illnesses into primary clusters (65% correct). Severity did, however, prove successful in discriminating the life-threatening illnesses (primary clusters 1 and 5), and in predicting membership of cluster 4 (muscular, joint and skin disorders). Thus, it appears that perceptions of severity may discriminate between the bipolar extremes of non-serious and life-threatening conditions, but be less useful in differentiating illnesses falling between these two extremes.

Time line was less useful in categorizing illnesses, both in terms of the higher number of "don't know" responses and the lower group membership prediction in the discriminant analysis (57% correct). Lau and Hartman (1983) also found that time line was most infrequently mentioned spontaneously by their respondents when describing illness (by 26% of respondents). In another study by Bishop, Briede, Cavazos, et al. (1987), time line only accounted for 3% of respondents' descriptions of a hypothetical illness. In the current study, time line proved successful in predicting group membership of primary clusters that contained the more acute illnesses (2 and 3: common and contagious illnesses). In general however, primary clusters tended to contain illnesses of both an acute and chronic nature, indicating that time line was not an important element in people's classification of illnesses in the current study. Previous findings suggest that time line may be a more central component in directing people's responses to long-term disease (Meyer et al., 1985)[8].

The inclusion of such a range and number of illnesses enabled the exploration of patterns of interconfusability between illnesses from different clusters. It has already been demonstrated that some features were better discriminators than others and that illnesses were clustered on the basis of a number of different features. However, whilst symptoms proved effective in linking illnesses within clusters and in discriminating between clusters, they were also a principal source of interconfusability, especially of respiratory related conditions. This has particular implications when the illnesses share symptoms, but differ in terms of severity or treatment, as was the case with lung cancer - bronchitis and meningitis - flu. Beliefs about the typical sufferer demonstrated similar patterns of interconfusability, in which both lung cancer and bronchitis were attributed to people who smoke. The misclassification of illnesses has further implications for perceptual biases that may occur in people's self-diagnosis (Pennebaker, 1982). If categorization results in the selection of an incorrect prototype, then the individual is likely to seek out other symptoms and features of the selected prototype, but may also ignore disease-relevant symptoms. It is important, therefore, to determine whether such misclassifications occur when people visit the doctor. It might be expected that diagnostic disagreements between the patient and doctor arise when different illnesses share one or more feature. Study 1 therefore provides the groundwork for the next study, which examines patterns of disagreement between patients and doctors.

In summary, Study 1 has demonstrated the use of illness representations in classifying illnesses at an abstract level, namely when lay people's representations are elicited. If, as Lau and Hartman (1983) suggest, people have common illness schemata which they use in interpreting actual illness, then these features will also play a significant role in people's response to their own illnesses (concrete representation). Study 2 therefore compares patients' concrete representations with the abstract representations elicited in the current study. It also explores the basis of diagnosis disagreement between patient and doctor and investigates the implications of such discrepancies for satisfaction and intentions to follow treatment recommendations. This is discussed in chapter 4.

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[8] Meyer et al. found that patients who perceived their hypertension as acute rather than chronic were less likely to adhere to their treatment regimen.

CHAPTER 4

Study 2: The Medical Consultation

4.1 Introduction

The previous study focused on people's abstract representations of illness. The current study extends this by looking at people's representations of their own illness(es) when they consult a general practitioner. This second study also explores patients' more general perceptions of health care, incorporating the lay, folk and professional sectors (Kleinman, 1980). However, the study's main focus is the consultation process itself. Specifically, the study investigates the role of illness perceptions in the consultation and the impact of these perceptions, together with other consultation factors, on satisfaction and intentions to follow treatment recommendations.

4.1.1 Patients' illness representations

Study 1 indicated that people had relatively well-developed representations of a wide range of illnesses and that the features of these representations could be used to classify illnesses to varying levels of accuracy (symptoms had the highest accuracy with 92% and time line the least with 57%). Although suggestive of the way people form a mental picture of illnesses and of potential misclassifications that may arise, the study was concerned with people's *abstract* representations of a variety of illnesses and how these influenced the process of categorization. This therefore prompts the question as to whether patients' representations of their own condition are the same as people's abstract representations of illnesses.

Previous studies suggest that people have more defined and well developed representations when they perceive themselves as ill (Park, 1994), and for illnesses of which they have direct experience (Hampson & Glasgow, 1996). Complex representations have been found to be more integrated, possibly because the experience of illness increases involvement and motivation which results in more elaborate cognitive processing (Petty & Cacioppo, 1986; Chaiken, 1987). Cognitive theory suggests that people's prototypes about illness serve as standards against which people then evaluate information about actual symptoms they experience (Bishop, 1991). People's illness representations emerge from a plethora of knowledge bases and experience (e.g. media, previous experience of illness) and guide their decisions about the management of their illness. They influence whether people decide to visit a health professional, as well as their evaluations of the care they receive and their decisions whether to take further action.

The current study investigated the content of people's illness representations when they were visiting a doctor for a specific complaint. It explored whether patients have coherent representations along the dimensions specified by Leventhal and colleagues and whether specific features of those representations were particularly well formed and relevant to people's decisions to seek professional help. For example, Lau et al. (1989) found that people with strong identity and cure beliefs were more likely to visit the doctor. Other studies suggest that symptoms per se are not enough to trigger care seeking, but must be accompanied by perceptions of illness severity and disruption to lifestyle (Cameron et al., 1993).

The relatively large sample under investigation also enabled a direct comparison between people's abstract beliefs about different illnesses and patients' concrete beliefs about the same illnesses (using only those illnesses included in Study 1). It was therefore possible to determine whether representations differed when considering one's own condition in comparison to an abstract label of an illness. Additionally, the current study examined whether the nature of patients' representations or the type of illness played a role in doctor-patient disagreement. For example, disagreements may occur more frequently for those illnesses with greater ambiguity regarding particular features of the representation.

4.1.2 Doctor-patient concordance, patients' satisfaction and intentions to adhere to treatment

Study 2 also focused on patients' beliefs about their current illness and expectations about the consultation. The findings of study 1 together with previous research findings suggests that both identity and treatment beliefs will be particularly salient features of patients' representations. For example, Lau et al. (1989) found that Leventhal's model predicted 29% of the variance in propensity to visit the doctor. However, the impact of patients' illness perceptions on their *evaluation* of the consultation has not been explicitly explored.

A related area of interest is the degree of doctor-patient concordance in relation to illness representations. Whilst the issue of concordance is a major focus of Kleinman's research with explanatory models, the self-regulatory model has focused solely on patients' beliefs about illness. Yet, previous studies have found that disagreement between patient and doctor can lead to communication difficulties and dissatisfaction with care (Cohen et al., 1994; Kleinman, 1980), with further implications for uptake of health care (Risdale et al., 1994) and health status (Bass et al., 1986). Thus it is of particular interest to compare the patient's and doctor's diagnostic and treatment beliefs, and determine the impact of agreement on intermediate outcomes, such as patient satisfaction. It was hypothesized that disagreement would be associated with lower patient satisfaction.

Previous research reviewed in Chapter 2 has indicated a number of other factors which potentially influence patients' evaluation of the medical consultation and subsequent behaviour. Factors pertaining to the consultation itself may be more significant in predicting immediate evaluation than patients' more general beliefs about their illness. Communication is particularly important, since the success of communication will determine whether differences of opinion (between the doctor and patient) are addressed and dealt with in the consultation. Thus, doctor-patient communication may be facilitated when patients have had the opportunity to develop a relationship with the doctor through successive consultations, and when they get on well with the doctor. A related issue is the number of times a patient has consulted the doctor for his/her current complaint. Disagreements between patient and doctor about diagnosis and treatment are presumably more likely to occur when patients are seeing the doctor for the first time about a particular complaint. In contrast, patients who visit the doctor regularly about a chronic complaint such as hypertension are less likely to disagree with the diagnosis, although they may not necessarily feel satisfied with the consultation.

Length of consultation might also be expected to influence satisfaction, with a longer consultation enabling more in-depth communication about a patient's condition. However, evidence for a relationship between consultation duration and satisfaction has been mixed. Several studies have demonstrated a positive effect of consultation length (Hall et al., 1988; Kenny, 1995; Smith, Polis and Hadac, 1981), whilst others have failed to find a significant relationship with satisfaction (Freemon et al., 1971; Weinberger et al., 1981).

One of the reasons for the increasing focus on patients' satisfaction is its association with adherence to treatment. One would also expect that a lack of concordance between patient and doctor, particularly with regard to treatment, would reduce the likelihood of patients deciding to follow treatment recommendations. In the current study, patients were simply asked about their *intentions* to follow treatment recommendations. It is likely, however, that self-reports of intentions will substantially overestimate the level of actual behaviour, as is the case with all adherence self-reports. Nevertheless, it was hypothesized that satisfaction would predict participants' determination to adhere.

4.1.3 Perceptions of lay, folk and professional systems

Kleinman (1980) argues that there are three overlapping sectors of health care in all cultures: the popular, folk, and professional sectors. Each has its own basis for understanding and responding to illness. The popular or informal sector consists of everyday ideas about health and illness and plays an important role in influencing people's understanding and perceptions of illness. It is suggested that 11 "lay consultations" occur for every medical consultation (Scambler & Scambler, 1984). The current study was interested in two related questions. Firstly, who did people turn to when discussing their illness and were they important in directing care seeking? Secondly, did lay referral have an impact on patients' representations of their illness?

The folk sector lies between the popular and professional sectors and consists of specialist healers. In the West, this traditionally consists of practitioners of alternative medicine although the distinction between folk and professional is becoming increasingly blurred with some complementary practices being integrated into the professional sector e.g. the availability of acupuncture and homeopathy in the NHS. Since a major focus of the current study was to examine people's evaluation of their medical care, a related issue is the degree to which patients share the doctor's biomedical model and believe in the treatment it prescribes. Advocates of alternative forms of treatment may be less willing to accept unconditionally the medical diagnosis or the prescribed treatment if these differ from their own. Indeed, the philosophical foundations of most complementary therapies are very different from the biomedical one.

The increased popularity of complementary medicine in recent years has been attributed to a parallel dissatisfaction with allopathic medicine and fears about the side-effects of medical drugs (Donnelly, Spykerboer, & Thong, 1985; Furnham & Bhagrath, 1993; Furnham & Vincent, 1997; Moore, Phipps & Marcer, 1985). However, there is also evidence to suggest that people view therapies such as homeopathy and osteopathy as "complementary" to orthodox medicine (Druss & Rosenheck, 1999). Many people use orthodox and complementary medicine side by side, particularly for disorders difficult to treat using conventional methods e.g. chronic disorders, pain, and life threatening illness (Ernst, 1997). Thus, favourability towards complementary practices does not necessarily indicate dissatisfaction with orthodox medicine. In a German study, Himmel, Schulte, & Kochen (1993) found that 40% of patients had been treated with complementary therapies, and 58% of patients preferred complementary therapies to allopathic medicines. However, they did not report significantly lower levels of satisfaction with the GP consultation than those who did not prefer such therapies. The current study explored people`s use of the "folk sector" through assessing their willingness to use popular complementary practices. Secondly, favourability towards complementary practices was taken as an indirect indicator of faith in the biomedical model; it was hypothesized that greater willingness to use complementary medicine would be associated with lower satisfaction with medical care and lower intentions to follow treatment recommendations.

The third sector identified by Kleinman is the professional sector, representing the biomedical model in western culture. Previous research has suggested several triggers for seeking care, many of which revolve around people's perceptions of their illness. For example, symptoms play an important role in decisions to visit a doctor, particularly when their cause is unknown or their duration extended, highlighting people's search to label and understand their condition (Ingham & Miller, 1986; Locker, 1981). Perceptions of severity may also be a relevant cue which determines whether someone can justify a visit to the “interminably busy GP". The current study thus explored the motivations behind people's decisions to seek medical care.

A related issue is people's expectations about the nature of the doctor-patient relationship. Evidence reviewed in Chapter 2 indicates that the doctor's "bedside manner" is given considerable credence by patients (Hall et al., 1988; Kenny, 1995; Squier, 1990). Good communication skills are particularly important in facilitating patients' involvement as well as providing reassurance and support, a major component in many consultations (Pendleton, 1981). The current study thus investigated people’s perceptions of the qualities associated with a good doctor.

In summary, the following study examined patients' representations of their condition when they consulted a medical practitioner. It considered the role that patients' beliefs and other aspects of the consultation may play in patients' satisfaction with the consultation and subsequent intentions to follow treatment. Finally, it examined patients’ perceptions of the lay, folk and professional sectors of health care.

4.2 Summary of aims and hypotheses

Patients' illness representations

- An exploration of the representations people have of their own condition when they are visiting their general practitioner.
- A comparison of patients’ representations with those elicited from lay people in Study 1 to determine:

a) whether patients' concrete beliefs differed from people's abstract beliefs about illnesses.

b) whether any patterns emerged regarding the structure of the illness representations of patients with discrepant beliefs from those of the doctor.

Satisfaction and intentions to adhere to treatment

- Patients' qualitative evaluations of the consultation will be content analysed to assess specific aspects of care which are perceived as satisfactory and those which require improvement.
- It is hypothesized that doctor-patient concordance about diagnosis and treatment (objective measure) will be significantly lower for dissatisfied patients.
- It is hypothesized that doctor-patient concordance (subjective rating by patient) will account for a significant amount of variance in overall satisfaction beyond that explained by demographic and consultation factors.
- It is hypothesized that: a) doctor-patient concordance, and b) satisfaction will be significantly lower for patients visiting the doctor for the first time about their current complaint.
- It is hypothesized that satisfaction will explain a significant amount of the variance in patients' stated intentions to adhere to treatment.

Perceptions of lay, folk and professional systems

- An exploration of the role of lay referral in patients' decision to visit the doctor.
- An examination of patients' willingness to use complementary medicine[1].
- An investigation of patients' motivations underlying their decisions to seek medical care.
- An investigation of patients' perceptions of the characteristics of a good general practitioner.

4.3 Method

A structured interview format was chosen in order to elicit *patients' representations* of their illness and of medical care. It was also hoped that interviews would be more accurate than questionnaires in portraying patients' true evaluation of the consultation. Wensing et al. (1994) found that oral interviews were more discriminative than written ones in a review of 40 satisfaction studies.

Pilot study: A small pilot study (N = 12) was conducted to ensure question comprehensibility and determine the average interview duration. Only minor modifications were made in the wording of the questions.

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[1] Patients willingness to use complementary medicine was used as an indicator of their favourability towards complementary practices.

The main body of data is based on interviews with 304 patients. However, during the course of interviewing it became apparent that several additional factors may be operating in the patients' evaluation of the consultation. Several questions of a qualitative (five questions) and quantitative nature (five questions) were therefore added to the pre- and post-consultation interview schedule to a) determine whether agreement was still the primary determinant of patient satisfaction, b) ascertain whether there were specific aspects of the consultation in which patients would like to see improvement (see below for further detail). Of the 304 interviews, 181 patients were interviewed using the extended interview schedule.

4.3.1 Participants

To recruit patients, all general practices in Oxford were contacted by telephone and asked whether they a) would be interested in participating in the study and b) had a room available for interviewing. Further details were then sent to practices expressing an interest. Six surgeries and eight doctors (7 male, 1 female) agreed to participate in the study. A total of 331 patients were interviewed from these six practices. Of these, 304 (140 males, 164 females) completed both the pre- and post-consultation interview and were therefore included in the study. The sample was predominately Caucasian and all occupational groups were represented. Patients presented with a variety of both chronic and acute complaints (see Appendix 6 for a complete listing, p. A19). The average duration of patients' current complaint was just over two years (mean = 25.5 months, SD = 56.7). Ages ranged from 16 to 92 years, with a mean age of 44 years (SD = 17.0). Mean age of completing formal education was 18 years (SD = 4.1). Half the participants were married and 35% single. The remainder were divorced (6%), widowed (5%), cohabiting (3%), or separated (1%). Since patients were invited to take part by the receptionist it was not possible to assess the percentage of patients who refused to take part in the study.

4.3.2 Materials (See Appendix 7a & 7b)

Demographic Questionnaire: details of the patient's age, sex, marital status, occupation, age of completing formal education, and ethnic group. Appendix 7a (p. A20).

Doctor's Report: details of the patient's symptoms, the doctor's diagnosis and prescribed treatment. Appendix 7b (p. A21)

4.3.3 Design of structured interview

4.3.3.1 Pre-Consultation Structured Interview (see Appendix 8a, p. A22)

Illness representations

Open questions were used to elicit patients' illness representations. Identity was assessed with two questions: 1) "what do you think is wrong with you?", 2) "Could you describe your symptoms?". Two open questions also assessed the causal component: 1) "what do you think has caused your problem?", 2) "Why do you think it started when it did?". The second question was intended to draw out the patient's own causal reasoning rather than a regurgitation of the medical causal model (see Hilton, 1986). Consequences were assessed with a 4-point fixed response question regarding seriousness (not at all - extremely) and an open question regarding illness disruption ("To what extent does your problem interfere with your daily activities?"). Beliefs about cure/treatment were assessed with two open questions: 1) "What kind of treatment do you expect to receive?", 2) "Apart from the treatment recommended by this doctor, what other kinds of treatment do you think could help you get better?". [2]

Perceptions of lay and medical care

To assess the relevance of the lay sector in participants' decision-making, patients were asked if they had spoken to anyone else about their condition and what they had thought was wrong with them. To assess participants' willingness to use complementary therapies, 11 therapies were listed (plus an option to specify another. See Appendix 8a, p.A22 for full list). Patients were asked whether they would use each treatment and if so, what they would use it for. In order to obtain the list of common complementary therapies, 28 subjects (students) were asked to list treatments outside conventional medicine which either they or other people would use. The 11 most commonly reported therapies were selected.

Extended interview: Since a number of participants had spontaneously mentioned that others had advised them to seek medical care for their complaints, a further question was included in the extended interview to ascertain the frequency with which care was sought on the basis of recommendation ("Did anyone advise you to come to the doctor today? Who?"). Two additional qualitative questions were included to assess participants' general reasons for seeking medical care ("How do you decide to visit a doctor?) and perceptions of "good doctoring" ("What do you think are the most important qualities of a good doctor?").

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[2] Participants were not asked about the type of person who contracts the illness as the study was concerned with their beliefs about their own illness. Additionally, participants were only asked about the current duration of their illness rather than how long they believed it would last.

Consultation factors

The doctor-patient relationship was assessed by two questions. Firstly, the number of times the patient had visited the doctor was used as an indirect index of how well they might know each other (Ettlinger & Freemon, 1981).

Extended interview: Additionally, patients in the extended interview were asked directly "generally how well do you get on with the doctor" (1 = very badly to 5 = very well). Patients were also asked about the number of visits made to their GP for their current complaint and the duration of their illness. Finally, level of patients' concern was assessed on a 5-point scale (1 = not at all concerned to 5 = extremely concerned).

4.3.3.2 Post-Consultation Interview (Appendix 8b, p.A24)

The post-consultation interview focused primarily on assessing patients' evaluation of the consultation, in terms of doctor-patient concordance, satisfaction with the consultation and intentions to follow treatment recommendations.

Concordance

To determine doctor-patient diagnostic concordance, patients were asked to report back the doctor's diagnosis ("Would you mind telling me what the doctor said was wrong with you?"). This enabled an objective assessment of concordance by comparing the patient's and the doctor's reports. Additionally, patients were asked to rate on a 5 point scale the extent to which they agreed with the doctor's diagnosis (1 = not at all to 5 = completely).

Satisfaction

Satisfaction was assessed with a combination of fixed response and open questions, since qualitative questions may help to reduce the positive bias commonly found in patients' evaluations of health care (Weinstein, 1979). Overall satisfaction with the consultation ("How satisfied were you with the consultation?") was assessed with a 5-point rating scale (1 = not at all satisfied to 5 = completely satisfied). Participants were also asked "Is there anything about your condition that you would like to have explored more fully in your consultation?".

Extended interview: An important function of measuring satisfaction is to provide an indicator of aspects of care which can be improved. Four additional open-ended questions were included in the extended interview to ascertain whether there were specific aspects of the consultation in which patients would like to see improvement, such as more time spent with the doctor and the provision of more information[3]. Participants were also asked to rate their level of concern following the consultation on a 5 point scale (1 = not at all concerned to 5 = extremely concerned).

Treatment

Participants were asked several specific questions about the doctor's treatment recommendations. Firstly, they were asked to describe the treatment recommended by the doctor and to rate the clarity of the doctor's instructions on a 5-point scale (1 = very unclear to 5 = very clear). Patients were asked to rate (on a 5-point scale) their intentions to adhere to any treatment recommendations (1 = definitely won't to 5 = definitely will). They were also asked whether they intended to seek further treatment elsewhere.

Extended interview: three additional questions were included in the extended interview schedule. Participant's were asked to describe the instructions given by the doctor and to rate how well they remembered these instructions (1 = not at all to 5 = completely). Additionally, patients were asked whether they anticipated any difficulties arising from the treatment.

The pre-consultation interview lasted approximately 10 minutes, the post-consultation interview was shorter, lasting approximately five minutes. However, there was considerable variation between participants with some interviews lasting considerably longer than this.

4.3.4 Procedure

On their arrival at the surgery, the receptionist gave adult patients (over 16 years) an information sheet inviting them to participate in a study to investigate people's ideas about illness and attitudes towards health care. They were informed that the study required an interview both before and after their consultation and that their medical care and appointment with the doctor would not be affected. Consenting patients completed the demographic questionnaire and were interviewed by the investigator in a private room both before and immediately after their consultation. Prior to the interview, participants were asked if they had any questions about the study and if they consented to the interview being tape-recorded. With participants' approval, interviews were audio-taped and erased following transcription. Questions from the interview schedule were always asked in the same order. During the pre-consultation interview, participants were given an identifying number to show the doctor and return to the investigator during the post-consultation interview. This ensured patient confidentiality. A sub-sample of participants (N = 150) were also asked if they

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[3] "Do you think the doctor spent enough time with you?", "What was good/bad about it (the consultation)?", "Would you have liked it to be different in any way? How?", "Would you have liked more information about anything?".

would be willing to complete a follow-up postal questionnaire at a subsequent date. Consenting patients gave their names and addresses.

The doctor completed his report following the consultation and presented it to the investigator providing the patient had given his/her verbal consent. Ninety nine percent of patients gave their consent.

4.4 Results

Unless stated otherwise, all results relate to the complete sample (N = 304)[4] and are two-tailed. Qualitative data (responses to open-ended questions) were content analysed. To assess reliability of coding, 20 questionnaires were analysed by an independent coder who was blind to the aims of the study. This coder was given a list of categories for each open-ended question. These categories are described in detail in the relevant sections. Two additional categories were provided for a) miscellaneous responses and b) no response (i.e. when the participant did not respond to the question). Reliability ranged from 83%-100% (see individual sections for details).

4.4.1 Patients' Illness Representations

4.4.1.1 Identity

In the pre-consultation interview, virtually all patients held beliefs about what was wrong with them (a label), with only 6% of patients having no idea at all[5]. When asked about their symptoms, 5.6% of patients reported none, with the remainder reporting between one and five symptoms (mean = 1.91, SD = 1.28).

Thus, for the majority of patients, having both a label and symptoms appeared to be an important pre-requisite for deciding to visit the doctor. However, the following participant illustrates how the need to establish a coherent identity for an illness by matching symptoms with a label motivated the decision to seek medical advice:

> *I looked at my medical book and I was going through my symptoms and all the possibles, but I couldn't pinpoint the area, so I couldn't diagnose what was wrong with me. So, I thought I had better come and see an expert. (Patient 324: female, 27 yrs)*

Conversely, a label of disease appeared to trigger the search for concrete symptoms:

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[4] It will be clearly stated when the results refer only to responses from the extended interview (N = 181).

[5] Even for first time visitors (N = 126), 90% had already self-diagnosed.

> *I feel alright, so I don't know what symptoms you're supposed to have with high blood pressure. (Patient 211: male, 49 yrs)*

These responses suggest that identity is a key component in making sense of one's illness and furthermore, a lack of coherence can create confusion (e.g. when there are no symptoms to fit a given label) or motivate care seeking when self-diagnosis based on symptoms is not possible.

4.4.1.2 Cause

Responses to both causal questions[6] were coded into four categories: a) cause unknown (16.6% of patients); b) cause attributed to own behaviour (16.4%) e.g. lifestyle factors; c) cause attributed to uncontrollable factors (47.4%) e.g. accidents, stress, genetic factors and viruses; d) a combination of self-blame and uncontrollable factors (9.5%):

> *"I would say, to be honest, and I've thought a lot about it, eating the wrong food before I had the first heart attack - not knowing what correct diet I should have had. I think it is a fault partly on my behalf and partly on the medical side for not advising people what they should eat and not eat." (Patient 102: male, 62 yrs)*

There was 95% inter-rater reliability (between the investigator and the independent judge) for the above coding scheme.

Asking patients about the onset of the illness in addition to a more general causal probe helped to elucidate patients' often complex causal attributions which were not always revealed in their initial response. The following patient attributed his hypertension to being overweight, but when asked about the onset of his hypertension, added:

> *"I wouldn't know really, but my only idea is that my father dies and it was after that that it came up. Whether it was a reaction to that I don't know. That's what I think." (Patient 120: male, 63 yrs)*

4.4.1.3 Consequences

The consequences of illness were assessed with two questions about perceived seriousness (4-point fixed response scale) and extent of interference with daily activities (open-ended). The majority of

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[6] "What do you think has caused your problems?" and "Why do you think it started when it did?"

patients viewed their illness as not at all/not very serious (rating 1: 71%) with only 4% perceiving their condition as extremely serious (rating 4). The mean response was 2.1 (SD = .74).

Responses to the question assessing interference with activities were coded into four categories: a) no interference (23.7%), b) minimal interference (28.6%), c) moderate interference (29.6%), and d) complete disruption (18.1%). Inter-rater reliability was satisfactory, with 95% agreement between the investigator and independent judge.

Since 52.3% of patients reported minimal or no disruption, interference was presumably not a motive for their visit to the doctor.

4.4.1.4 Cure/treatment

Eighty percent of patients had expectations regarding the type of treatment they would receive from the doctor for their main complaint. Patients' responses were categorized into: a) medication (50%), b) reassurance/advice/support (21.4%), and c) referral/tests (9.5%). There was 100% coding agreement between the investigator and independent judge.

Whilst medication was by far the most commonly expected treatment, reassurance and further exploration were also important outcomes of the consultation for 30.9% of patients. For example:

> *"Probably a reduction in the current level of concern that I've got about it (insomnia). I'm hoping for a "don't worry too much about it, it might go. If it doesn't then come back and see me". I don't particularly seek medication. I don't like the idea of having to do that. But if that's suggested for a while, then fine." (Patient 122: male, 39 yrs)*

Patients were also asked about other types of treatment that might help their recovery. The responses were coded into five categories, again with 100% inter-rater reliability. When more than one treatment was mentioned only the first was recorded. Overall, quite a high percentage of patients (42.2%) mentioned other treatments they considered potentially helpful in the recovery process. The most frequently cited was complementary medicine (15.1%). This frequency may partly reflect the influence of previous questions about the use of various complementary therapies. Patients also mentioned lifestyle changes (8.9%), specialist care (7.9%), rest (5.9%), and home remedies (3%). Four responses could not be classified.

4.4.2 Comparison of patients' and abstract representations of illness

The second aim relating to illness representations was to compare patients' representations of their condition with those elicited from lay people in Study 1 to determine whether patients' concrete beliefs differed from people's abstract beliefs about illnesses. To enable this comparison, only the responses of patients complaining of illnesses used in Study 1 were selected for analysis. Since the emphasis was clearly on patients' perceptions of their illness, classification was based on patients' diagnoses (pre-consultation) rather than the medical diagnoses given by the doctor. Table 4.4.2.1 presents the distribution of illnesses in each of the clusters described in chapter 3. Only 97 patients reported illnesses included in Study 1, from three of the five primary clusters. Not surprisingly, illnesses were not evenly distributed. Almost half were from cluster 2 (common illnesses) and none from either cluster 1 (cancers/genital) or cluster 3 (contagious and predominately childhood illnesses).

Table 4.4.2.1: Distribution of illnesses into clusters from Study 1

Cluster 2 (N = 46)		**Cluster 4 (N = 24)**		**Cluster 5 (N = 27)**	
2a	Asthma (13)	4a	Arthritis (8)	5a	Ulcer (3)
	Bronchitis (3)		Rheumatism (2)		Irritable bowel (3)
	Pneumonia (1)		Rheumatoid (2) arthritis		Appendicitis (1)
2b.	Cold (3)			5b	Heart Disease (6)
	Flu (6)	4b	Anaemia (2)		Angina (1)
	Sinusitis (7)	4c	Dermatitis (1)		Hypertension (13)
	Migraine (5)		Eczema (9)		
	Ear infection (8)				

Patients' responses for symptoms, cause and treatment were content analysed to produce the following number of categories (see Appendix 9a (p.A26) for full list of categories): symptoms (20), cause[7] (12), treatment[8] (8). Inter-rater reliability was 90% for symptoms, 88% for cause, and 93% for treatment. Data for perceptions of illness severity was based on the four categories already coded[9]. Content analysis of patients' responses can be found in Appendix 9b (p.A27).

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[7] Including responses from both the following questions: "What do you think has caused your problem?" and "Why do you think it started when it did?"

[8] Including responses from both the following questions: "What kind of treatment do you expect to receive?" and "Apart from the treatment recommended by this doctor, what other kinds of treatment do you think could help you get better?"

[9] Not at all serious, not very serious, serious, extremely serious.

Patients' perceptions of symptoms, cause, seriousness and treatment largely mirrored those of the lay sample in chapter 3[10]. There were, however, some notable differences. In terms of symptomatology, hypertensive patients revealed an interesting deviation from the lay sample. The majority of hypertensives (85%) stated that they had no symptoms whereas only 7% of participants in Study 1 perceived hypertension as asymptomatic. This is the reverse of Meyer et al.'s (1985) findings in which hypertensive patients perceived hypertension as asymptomatic in the abstract but symptomatic in their own case.

Although causal beliefs were broadly similar for both the lay and patient samples, three minor differences emerged. Firstly, pollution was a more frequent causal attribution for asthma in the patient sample (31% vs. 10%), whilst heredity was less frequently cited (15% vs. 50%). Secondly, stress was perceived as more salient for illnesses in subordinate cluster 4c (skin disorders) in the patient sample (60% vs. 12%), whereas heredity was mentioned less frequently (20% vs. 37%). Finally, heredity was more frequently cited by patients as the cause of their hypertension (38% vs. 13%), whereas stress was mentioned less frequently (31% vs. 53%).

There was a general trend for patients to view their illness as less serious compared with the abstract perception of lay participants. This trend was particularly apparent for ulcer in subordinate cluster 5a and cardiac disorders in cluster 5b. In contrast, migraine was seen as serious by 60% or patients compared with only 10% of lay participants (although the sample size of migraine sufferers was small: N = 5).

Treatment beliefs were very similar for both patient and lay samples. Patients presenting with colds were more likely to mention medication as opposed to non-prescription drugs, but this presumably reflects their decision to visit the doctor as opposed to self-medicate. Additionally, whilst lifestyle changes were the main treatments cited by lay participants for heart disease (e.g. exercise was cited by 50% of participants), they were not mentioned by patients.

4.4.2.1 Patterns in doctor-patient disagreement

An additional aim of comparing patient and lay representations was to explore any patterns in the representations of patients' who had diagnosis beliefs different from those of the doctor. Two measures of disagreement were examined: a) subjective (patients rated the extent to which they

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[10] These similarities will not be reported here to avoid repetition.

agreed with the doctor)[11], b) objective (patients' pre-consultation beliefs were compared with the doctor's diagnosis to yield an objective measure of congruence)[12]. Both groups of cases are presented in Table 4.4.2.2. Disagreement (subjective and objective) was found across a variety of different illnesses. Unfortunately, the small size of this subset of patients did not allow generalisations to be made about patterns in the representations of these patients. Nevertheless several observations could be made (see below).

Table 4.4.2.2: Cases of subjective and/or objective diagnosis disagreement between patient and doctor

Patient No.	Patients' diagnosis	Doctor's diagnosis	Subjective rating of agreement (1-5)	Objective measure of agreement (Y/N)
	Cluster 2a			
341	Asthma	Dysphagia	5	No
	Cluster 2b			
47	Flu	Tonsillitis	4	No
453	Flu	Bronchitis	5	No
434	Cold	Ear infection	4	No
528	Migraine	Migraine	3	Yes
538	Sinusitis	Sinusitis	4	Yes
	Cluster 4a			
501	Arthritis	Neuromuscular	5	No
	Cluster 4b			
150	Anaemia	Viral infection	4	No
548	Anaemia	Vasovagal	5	No
	Cluster 4c			
115	Eczema	Allergy	4	No
224	Eczema	Fungal infection	5	No
	Cluster 5a			
255	Irritable bowel	Diarrhoea	1	No

Of the seven patients who stated that they did not fully agree with their doctor's diagnosis, five were coded as disagreement (objective measure). In two cases (No. 47 and 434), alternative diagnoses were

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[11] "To what extent did you agree with the doctor's diagnosis?" (5 point rating scale: "not at all" (1) to "completely" (5)).

[12] This is described in more detail in section 4.4.4.2.

made by the doctor, although when the patients were asked what the doctor had said[13], both reported that no explicit diagnosis had been made. In the remaining cases, the doctor made reference to either causal factors (allergy/infection) or symptoms (diarrhoea) rather than providing a diagnosis per se. In the two cases (No. 528 and 538) in which the doctor's diagnoses matched the patients' pre-consultation diagnosis, both patients stated that they wanted more information (causal/treatment) regarding their illness.

There were five further cases in which the doctors' and patients' diagnoses were coded as incongruent (objective measure) but the patients reported full agreement with the doctor. In all but one case, the patients reported an acceptance of the doctor's diagnosis. In the remaining case (No. 501), the patient reported the doctor's diagnosis as arthritis, in line with her original beliefs (rather than neuromuscular as reported by the doctor).

4.4.3. Doctor-patient concordance, satisfaction and intentions to adhere to treatment

4.4.3.1 Satisfaction: Qualitative responses

Participants with the extended interview (post-consultation) were asked several questions about the consultation[14] to: a) encourage full evaluation of the consultation, and b) discover which aspects of the consultation patients would like to see improved, specifically with regard to information and duration of the visit.

Good and bad aspects of the consultation

Given patients' unwillingness to criticise their care openly (Lebow, 1983), it was not surprising that many more participants gave reasons for the consultation being "good" as opposed to "bad" (see table 4.4.3.1). Inter-rater reliability was 83% and 95% respectively. Only 12% of patients mentioned unsatisfactory aspects of the consultation. These most commonly related to something that was not adequately covered during the consultation (e.g. patient wanting tests or more information) or to the doctor's approach (see quotation below).

> *"The only thing I wondered about is the thing you get looked at and then the computer gets looked at - I find it slightly dehumanising. Just slightly. But the computer's a part of many people's lives. It was sort of "hello" and then onto the computer, rather than talk to you*

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[13] "Would you mind telling me what the doctor said was wrong with you?" (post-consultation).

[14] "Do you think the doctor spent enough time with you?"; "What was good/bad about it (the consultation)?"; "Would you have liked it to be different in any way? How?"; "Would have liked more information about anything?".

> *about what you're coming about and then work with the computer." (Patient 323: Female, 43 yrs)*

Table 4.4.3.1 Participants' evaluation of "good" and "bad" aspects of their consultation

"Good" consultation	**%[a]**	**"Bad" consultation**	**%[a]**
Bedside manner	14	Everything not covered	7
Technical competence	14	Approach	3
Shared perspective	13	Other	2
Thoroughness	13		
Reassurance	9		
Satisfactory outcome	6		

[a] Of total sample participating in extended interview (N=181)

However, the doctor's approach or bedside manner was more frequently associated with positive aspects of the consultation. In particular, participants focused on the listening skills and caring nature of the doctor:

> *" It's good because he listens while you talk. He doesn't just try and tell you what's wrong with you, which is good. And he tries to help you out." (Patient 128: female, 30 yrs)*

> *"The fact that I could mention the personal details, like the problems I'm having with sex. I feel you can mention the little bits that make the difference." (Patient 420: female, 36 yrs)*

A related issue of patient participation or discussion leading to a *shared* perspective was mentioned by 13% of patients:

> *"Reviewing my notes with the doctor, rather than just being told what was going on. A discussion of the options, since we talked about an eradication of the pain and I said I didn't want painkillers, and we discussed the options that I had, limited though they are, with muscular back pain, though that was discussed too. So, a full and mutual discussion, rather than just a talk from a doctor on what my options were." (Patient 441: male, 36 yrs)*

Instrumental dimensions of the consultation were also mentioned by participants. In particular, patients considered the doctor's technical or professional competence (14%) and the perceived thoroughness of the consultation (13%).

> *"I thought it was good how he actually got a chart out and showed me the human body...He not only told me what was wrong, but he told me what was actually causing it. He showed me how to do some back exercises to strengthen it which should ease the problem, so I thought that was rather good, rather than just giving me some tablets for it." (Patient 409: Female,, 32 yrs. Diagnosed with sciatica)*

Finally, 9% of patients mentioned feeling reassured by the consultation and 6% cited satisfaction with its outcome, usually their treatment.

Length of consultation

During the course of interviewing, many participants spontaneously mentioned the importance of time for an adequate consultation, but when patients were asked in the extended interview whether they had spent enough time in the current consultation, 97% answered in the affirmative. However, a qualitative difference appeared to exist between patients' *expectations* and their *desires* (Williams et al., 1995). For example, the following patient states that the doctor spent enough time with him but when later asked if they would have liked the consultation to be different in any way responds with:

> *"Well, perhaps longer, but obviously he's got other people to see." (Patient 129: Male, 31 yrs).*

Thus patients may have liked longer consultations but also recognized the inevitable constraints imposed by the health care system.

Improving the consultation

Twelve percent of participants (from the extended interview) would have liked the consultation to be different in some way and 11% would have liked more information[15]. The range of responses for both questions together with the small numbers made coding difficult. Responses to the difference question included: a more sensitive approach, a more thorough consultation (e.g.

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[15] "Would have liked it to be different in any way?" and "Would you have liked more information about anything?".

desiring an examination or more information), and logistical changes (e.g. a shorter waiting time). Inter-rater reliability was 90%. Desires for additional information most commonly related to: causal, diagnostic or treatment information. There was 100% inter-rater reliability.

Patients who requested something different or wanted more information were less likely to be satisfied with the consultation ($t = -4.53$, $p<.001$ & $t = -3.61$, $p<.01$ respectively; $df = 179$) and more likely to report disagreement with the doctor ($t = -2.93$, $p<.01$ & $t = -2.34$, $p<.05$ respectively; $df = 179$). A t-test was also conducted to assess the relationship between requests for more information and perceived clarity of instructions (5 point rating scale). As expected, patients who were satisfied with the amount of information rated any instructions as clearer than those who wanted more information ($t = -2.31$, $df = 88$, $p<.05$).

4.4.3.2 Concordance between patient and doctor: Reliability study

In order to obtain an objective measure of doctor-patient concordance in addition to participants' own subjective evaluation of agreement[16], patients' pre-consultation beliefs about the illness label and treatment were compared with the doctor's diagnosis and prescribed treatment (elicited from the doctor's report post-consultation). Responses were coded as either in agreement or disagreement by the investigator. In order to assess coding reliability, four independent judges were each paid £5 to take part in a reliability study. Judges were given 80 pairs of diagnoses (from patient and doctor) and asked in each case to state whether they thought the diagnoses agreed or disagreed. The 80 cases included pairs coded by the investigator as in agreement and disagreement, plus all ambiguous cases. Similarly, 72 pairs of treatment expectations/ recommendations were presented to the judges. Inter-rater reliability was calculated using Kappa. For diagnosis, agreement was "substantial" ($k = 0.61$), whilst for treatment it was "almost perfect" ($k = 0.83$)[17]. Level of doctor-patient concordance was the same for both diagnosis and treatment (86%).

Not surprisingly, congruence regarding diagnosis and treatment were associated with significantly higher self-reported agreement ($t = -4.45$, $df = 298$, $p<0.001$ and $t = -2.16$, $df = 301$, $p<.005$ respectively). Despite the highly significant relationship between the "objective" and self-report measure of diagnosis agreement, for some participants the traditional role of the doctor was

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[16] "To what extent did you agree with the doctor's diagnosis?" (1 = not at all to 5 = completely).

[17] Landis and Koch (1977) provide kappa value benchmarks, where 0.41-0.60 = "moderate", 0.61-0.80 = "substantial", and 0.81-1.00 = "almost perfect".

paramount and took precedence over their own beliefs even when the doctor's diagnosis differed from their own. This is clearly illustrated in the following examples:

> *"I never disagree or agree because I don't know anything about it. I just accept what they say." (Patient 44: female, 29 yrs).*

> *"I've simply got to agree. I come here because I've given myself to him to agree with whatever he says. (Male, 55 yrs).*

As predicted, objective concordance was significantly lower for dissatisfied patients, both in terms of diagnosis ($t = -4.04$, $df = 298$, $p<0.001$) and treatment concordance ($t = -2.88$, $df = 301$, $p<.01$). This suggests that agreement between the patient's beliefs and the diagnosis and treatment proposed by the doctor are important determinants of satisfaction level, thus supporting the study's primary hypothesis. There were no significant gender differences in agreement for either diagnosis ($\chi^2 = .52$) or treatment ($\chi^2 = 1.44$).

Not surprisingly, lack of congruence between the views of the patient and doctor appeared to have the greatest implications when the discrepancy was not resolved during the consultation. For example, the following participant disagreed with the doctor over which medication (for back pain and irritable bowel) had caused a reaction (blurred vision). The patient had looked up the symptoms in a medical dictionary and modified her treatment on this basis:

> *"I'd have liked the courage to have sat there and say, say why I didn't believe him because I'd read it in the MINS magazine. I haven't got the courage to say "look here, it says it here". I said what I thought, but not why I disagree as much. I mean, it's clear in my mind which tablets it was .... I told him which tablets I thought it was and why, not quite in as much detail I don't think, and he said it's more likely to be the other tablets and that he wasn't convinced....I don't agree that that was the cause and I also don't think, in a way, that I'm being treated for what is wrong with me" (Patient 255: Female, 46 yrs).*

The potential to resolve such differences lies in good communication skills and adequate reassurance of the patient, as illustrated by this participant's comments:

> *"He reassured me that the problem is going to go away... Which before I went in I thought I'd need more than that, I thought it was a matter of hospital treatment even, to actually disperse the blood clots. But he's assured me that it will go away in due course." (Patient 515: Male, 49 yrs).*

4.4.3.3 Satisfaction: Quantitative analysis

In common with the qualitative responses, overall satisfaction scores were skewed in favour of positive evaluation of the consultation (mean = 4.79, skew = -2.90). However, the percentage of participants dissatisfied or only moderately satisfied with their consultation (16%) was actually slightly higher than that found in the open-ended responses. Self-reported agreement with the doctor was also positively biased, with only 12% of patients reporting less than complete agreement (mean = 4.82, skew = -3.57). In accordance with recommendations by Tabachnick & Fidell (1996) in dealing with skewed variables, satisfaction and agreement scores were reflected and inversely transformed prior to analysis of the data.

Relationship between illness perceptions and satisfaction: One way ANOVAs were conducted to determine differences in satisfaction scores according to patients' beliefs about cure (none, medication, reassurance, referral) and cause (none, controllable, uncontrollable, combination). There were no significant differences for either cure (F = .23) or causal beliefs (F = 1.05). The relationship between satisfaction and the remaining components was assessed with Pearson's correlations. There was no significant association with symptoms (r = -.05) or consequences (severity: r = .04 and disruption: r = -.01).

Consultation variables: Mean scores for patients' satisfaction and predictor variables from the consultation are shown in table 4.4.3.2. Patients had consulted the doctor an average of six times about their current complaint, reflecting the chronic nature of many of the illnesses presented. Patients knew their doctor relatively well (mean number of previous visits = 20) and felt that they had a good relationship with their doctor (mean = 4.75). As expected, levels of concern declined from pre- to post-consultation (t = 7.5, df = 176, p<.001). Of those patients given instructions about their treatment, the majority rated them as clear (mean = 4.65).

Table 4.4.3.2 Means and Standard deviations of consultation variables

Variable	N	Mean	SD
Pre-consultation			
No. of visits to Dr	304	19.82	31.88
No. current visits	304	5.53	22.73
No. of complementary therapies	304	4.94	2.83
Relationship with Dr [ab]	146	4.75	0 .51
Concern [b]	179	3.13	1.12
Post-consultation			
Satisfaction	304	4.79	0.53
Agreement	304	4.82	0.53
Concern [b]	179	2.49	1.24
Clarity [c]	209	4.65	0.64

[a] only applicable to patients who have visited doctor previously (N = 146).
[b] only patients participating in extended interview (N = 181).
[c] only applicable when instructions given by doctor.
N.B. All variables were 5 point rating scales with the exception of number of visits to the doctor and number of complementary therapies patients were willing to use.

It was hypothesized that agreement would account for a significant amount of variance in satisfaction beyond that explained by demographic and consultation factors. Prior to a regression analysis, it was first necessary to explore the relationships between the potential predictor variables of satisfaction (see below)[18].

Demographic factors: satisfaction was not significantly related to age (r = .02) or education (r = -.02). There were also no significant gender differences (t = .44).

Consultation factors: Correlations between consultation variables are presented in Table 4.4.3.3. Satisfaction was significantly associated with only three variables: self-reported agreement, post-consultation concern and perceived clarity of instructions. Patient agreement with the doctor was also related to clarity of instructions, but not to concern.

The remaining variables demonstrated predictable relationships with each other. As expected, frequency of visits to the doctor was significantly related to patients' evaluation of the doctor.

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[18] Favourability towards complementary medicine (frequency of therapies which patients stated they would be willing to use) was also included since it was seen as an indirect index of belief in the biomedical model.

Frequency of visits was also associated with the number of visits for the current health problem, both of which were significantly positively related to post-consultation concern. It was hypothesized that favourability towards complementary medicine would be associated with lower satisfaction, but it failed to demonstrate a relationship with any of the consultation variables.

Table 4.4.3.3 Correlations between consultation variables

Variables	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*
Pre-consultation								
1. Visits to Dr								
2. Current visits	.66***							
3. Complementary medicine	-.11	-.08						
4. Dr relationship	.17*	.05	-.08					
5. Concern 1	.14	.12	.03	.02				
Post-consultation								
6. Satisfaction	.06	.06	-.09	.07	-.04			
7. Agreement	.00	.07	-.06	.02	.08	.49***		
8. Concern 2	.28***	.22**	.11	-.08	.56***	-.22**	-.08	
9. Clarity	.05	.05	-.11	.18	-.04	.30***	.21**	-.02

* p<.05, ** p<.01, *** p<.001

Three regression analyses were conducted to assess the relative contribution of these three significant variables to satisfaction. Separate analyses were undertaken due to the differing number of participants who had rated their agreement (N = 304), post-consultation concern (N = 179)[19], and clarity of instructions (N = 209)[20]. Firstly only agreement was entered into a simple regression. It accounted for 23% of the variance in satisfaction (Beta = .48, Adjusted $R^2 = 0.23$, F (1, 303) = 92.57, p<0.001). Secondly, agreement and clarity were entered into a stepwise regression. Agreement accounted for 20% of the variance (Beta = .45, F (1, 208) = 52.96, p<.001), with clarity adding a further 4% (Beta = .22, F (2, 208) = 34.39, p<.001). Finally, all three independent variables were entered into a stepwise regression. Agreement and concern were selected, but only accounted for 14% of the variance (F (2,88) = 8.31, p<.001)[21].

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[19] Only patients who participated in the extended interview.

[20] Only applicable to patients who received instructions from the doctor.

[21] Agreement (Beta = .31, p<.001), Concern (Beta = -.26, p<.001).

In summary, the hypothesis that doctor-patient concordance would account for a significant amount of variance in satisfaction beyond that explained by demographic and consultation factors was confirmed, maximally explaining 23% of the variance.

Visiting the doctor for the first time: 41% of patients were consulting for the first time about their current complaint. It was hypothesized that agreement and consequently satisfaction, would be lower for patients visiting the doctor for the first time about their current complaint. However, there were no significant differences in reported agreement (t = -.95) or satisfaction (t = -.10) between those visiting for the first time and those making follow-up visits. However, Chi square analysis was used to assess the association between first time/multiple patients and objective agreement. There was a significant association with treatment agreement ($\chi^2 = 6.46$, p<.01) but not diagnosis agreement ($\chi^2 = 2.05$) and satisfaction. Thus, the hypothesis was only partially supported.

4.4.3.4 Treatment: intentions to adhere and concerns about treatment

Seventy four percent of participants were given treatment for their condition (N = 224). Not surprisingly, *intentions* to adhere were very high (mean = 4.95, SD = .24), with 95% of patients stating that they would "definitely" follow treatment recommendations[22]. It was hypothesized that satisfaction would predict patients' intentions to adhere to treatment. However, Pearson's correlations with the same predictor variables as outlined in the previous section (4.4.3.3) indicated that only age (r = .15, p<.05) and favourability towards complementary medicine were significantly associated with intentions (r = -.22, p<.001). Neither satisfaction nor doctor-patient agreement was significantly associated with patients' intentions (r = .05 and .07 respectively).

Only 12% of patients perceived any difficulties arising out of the treatment[23]. The most common response was concern about the potentially deleterious effects of medication (7% of participants):

> *" There's a certain psychological dependency that I'm quite aware of.... I'm very worried about being very dependent on them and also becotide is a steroid and there's been a lot in the papers about it stunting people's growth and I just wonder if it's had any side-effects on me....especially after having taken them for about 15 years. I'd just like to know a bit more about it perhaps, but I'll wait until I'm a bit more settled." (Patient 254: Female, 24 yrs)*

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[22] "How determined are you to follow the treatment prescribed by the doctor?" (1 = Definitely won't to 5 = Definitely will).

[23] "Can you see any difficulties that might arise out of this treatment?"

> *"...one doesn't know what sort of side effects to expect. That would have been something, I would have thought they would probably know what side-effects there would be and he would probably have made me aware of it. But he didn't." (Patient 516: Male, 79 yrs).*

Other participants mentioned concerns over the condition being fully resolved by the completion of treatment (3%) or practical difficulties (2%) such as rubbing cream on one's back. There was 95% inter-rater reliability between the investigator and independent judge for the coding of treatment concerns.

4.4.4 Perceptions of lay, folk and professional systems

4.4.4.1 Role of lay referral

It has already been demonstrated that the majority of patients in this study had well formed representations of their condition, suggesting that an interpretative process involving the individual and others precedes seeking professional care[24]. Indeed, 75% of patients had discussed their condition with someone else before seeking treatment, most commonly family and friends (43.3%). Others sought advice from health experts in both professional and folk sectors e.g. pharmacists and complementary practitioners (12.5%). A smaller minority discussed their illness with work colleagues (4.6%), whilst 15.1% of patients consulted multiple sources.

In the majority of cases, the patient and other(s) whom the patient had consulted agreed about what was wrong (53.5% agreeing compared with 6.5% disagreeing). Indeed, patients' self diagnoses often emerged as a result of shared discussion with others:

> *"...my friend thinks it's the same as I think it is. In fact we came to these conclusions together...Mostly I think you talk to your friends about things and compare your ideas" (Patient 56: female, 32 yrs)*

One participant even jokingly likens herself and her husband to doctors, trying to unravel the cause of her symptoms:

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[24] This is likely to be an ongoing process for patients who have made multiple visits to the doctor for a particular complaint. Lay consultation was high both for first time patients and for those who had made at least one previous visit (79% and 74% respectively).

> *"He said the same, although he said it seemed funny that I'd taken the course for 5 days and it wasn't until they finished that it started....As I say, we've both been trying to be doctors" (laughs). (Patient 539: female with allergic reaction to medication, 65 yrs)*

In the remaining 40% of cases no specific diagnosis was offered in the lay consultation. In some cases, no opinion was given e.g. "*They don't really comment - you just talk generally*". Others most commonly made reference to: a) causal factors e.g. smoking too much, stress and other lifestyle factors, and b) a recommended course of action, most commonly visiting a doctor.

When patients were explicitly asked (in the extended interview) whether anyone else had advised them to consult their GP, just over half (56.4%) stated that they had made their own decision independently. The remainder were advised by family, friends or other health professionals.

4.4.4.2 "Folk" sector: Complementary Medicine

The main aim was to examine patients' willingness to use complementary therapies. Patients were given a list of different therapies and asked: a) which they would consider using, and b) for which problems[25]. The mean number of therapies which patients would consider using was 5 (ranging from 0 to 12). Women were more favourable towards complementary medicine than men (Female = 6.3, Male = 5.6; t = 2.05, $p<.05$). Age and education also demonstrated a significant relationship with the number of therapies considered ($r = .21$ and $-.22$ respectively; $p<.001$). Figure 4.4.4.1 indicates the percentage of patients willing to try the various complementary therapies. Not surprisingly, the more commonly available therapies such as massage and herbal remedies were considered by the highest frequency of patients (79% and 67% respectively). Acupuncture, aromatherapy, chiropractic, and osteopathy were also popular, with over 40% of respondents considering their use for a wide variety of disorders.

Although some patients chose complementary medicine in preference to orthodox medicine and criticized the latter for failing to encompass a holistic approach, most said they would seek alternative treatment only when conventional methods failed or on recommendation from their doctor.

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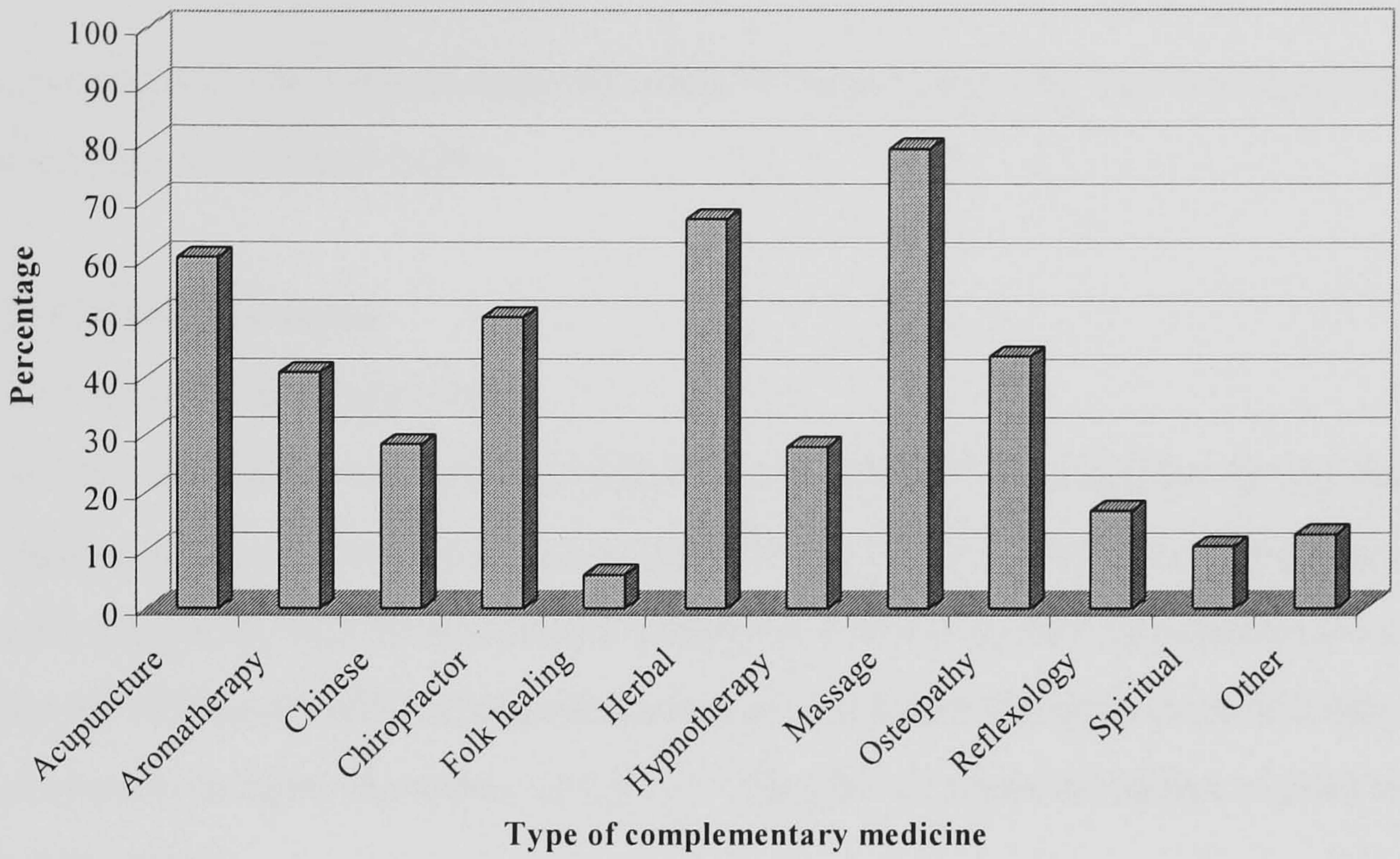
[25] "Would you use any of the following types of treatment for any health problems? If yes, for which problems?: acupuncture, aromatherapy, chinese medicine, chiropractor, folk healing, herbal remedies, hypnotherapy, massage, osteopathy, reflexology, spiritualist, other".

> *I'd honestly go to traditional medicine first. If you've got trust in the G.P, you feel that's the natural way to go. If at the end of the day I felt I was getting nowhere I think I would look elsewhere. (Patient 55: Male, 52 yrs)*

Figure 4.4.4.1: Willingness to use complementary therapies



Thus, such therapies were generally viewed as a useful supplement to orthodox medicine, rather than as an alternative to it, and they were perceived as most valuable for disorders that could not easily be addressed and treated by conventional medicine e.g. back problems, life threatening conditions and psychological disorders.

> *I think if I had recurring backache or something that I felt the doctors couldn't do anything for, or I'd just be on drugs for a long time. (Female, 24, about acupuncture)*

Interestingly, many patients cited the media as a major source of their knowledge about complementary therapies. Additionally, patients frequently reported a desire to know more about alternatives to conventional medicine and, by and large, relied on their doctor for this information. The considerable financial cost of such `alternatives' was a frequent reason given by patients for their reluctance to turn to complementary therapies.

Whilst the majority of patients were willing to try some of the listed forms of complementary therapies, if only under desperate circumstances, others were more sceptical of "alternative" methods:

> *"It's not that I don't believe that people can get benefit from those. It's just that, as far as I'm concerned it seems a bit sort of dodgy. I mean it's probably OK. All those treatments are probably legitimate, but you hear so many stories about people just setting themselves up as some health giving guru and they're nothing different to me, only wearing a different hat. "Quacks" as they used to be called, or charlatans." (Patient 37: male 31 yrs)*

Some, particularly older patients, believed solely in "proper medicine" and would not consider looking outside the medical sphere.

4.4.4.3 Professional sector

Decisions to seek professional care

Patients were asked how they decided whether to visit a doctor[26] to determine the key factors which motivated people to seek medical care (see Table 4.4.4.2 below). Participants' responses were coded into seven categories, with 90% inter-rater reliability. Whilst over 30% of patients gave a general indicator of "feeling unwell", a comparable number emphasised the importance of illness severity and level of concern or worry about their condition. Often this involved the failure to fulfil work or family obligations:

> *"I have to feel really ill and think that maybe I won't be able to go to work. It's work basically, not being able to do my job, then I'll go and see a doctor." (Patient 509: female, 43 yrs)*

Table 4.4.4.2 Reasons for seeking medical care

Reasons for seeking medical care	*Percentage of patients**
Feeling unwell	33.1
Worried/concerned	30.9
Persistent symptoms	23.2
Regular appointment	11.6
Unable to treat oneself	10.5
Experiencing pain	9.4
Unable to self-diagnose	8.3

* Percentages exceed 100% since some respondents' responses could be coded into more than one category.

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[26] "How do you decide whether to visit a doctor?" (Extended interview only).

This suggests that many people are unwilling to take their problem to the doctor unless it is perceived as "really bad". However, if illness is sufficiently serious and debilitating, seeking medical care plays an important role in justifying adoption of the "sick role" both to oneself and others.

Another major factor in people's decisions to visit a doctor was the duration of symptoms. Twenty three percent of patients stated that they would only seek medical care when symptoms persisted over a period of time ranging from days to weeks. As the following quote illustrates, perceptions of symptom duration were frequently associated with perceptions of severity:

> *"If I feel that there's something wrong and it persists over quite a period of time. If like I had a cold and it went on I wouldn't come to a doctor about that, but if I had a chest infection and it was carrying on over a couple of weeks, if I was feeling grotty" (Patient 150: female, 30 yrs)*

Often, home remedies were the primary course of action, followed only later by medical recourse:

> *"Generally, if I apply "home remedies" and they don't do any good then I'll come down to the doctor" (Patient 243: female, 28 yrs)*

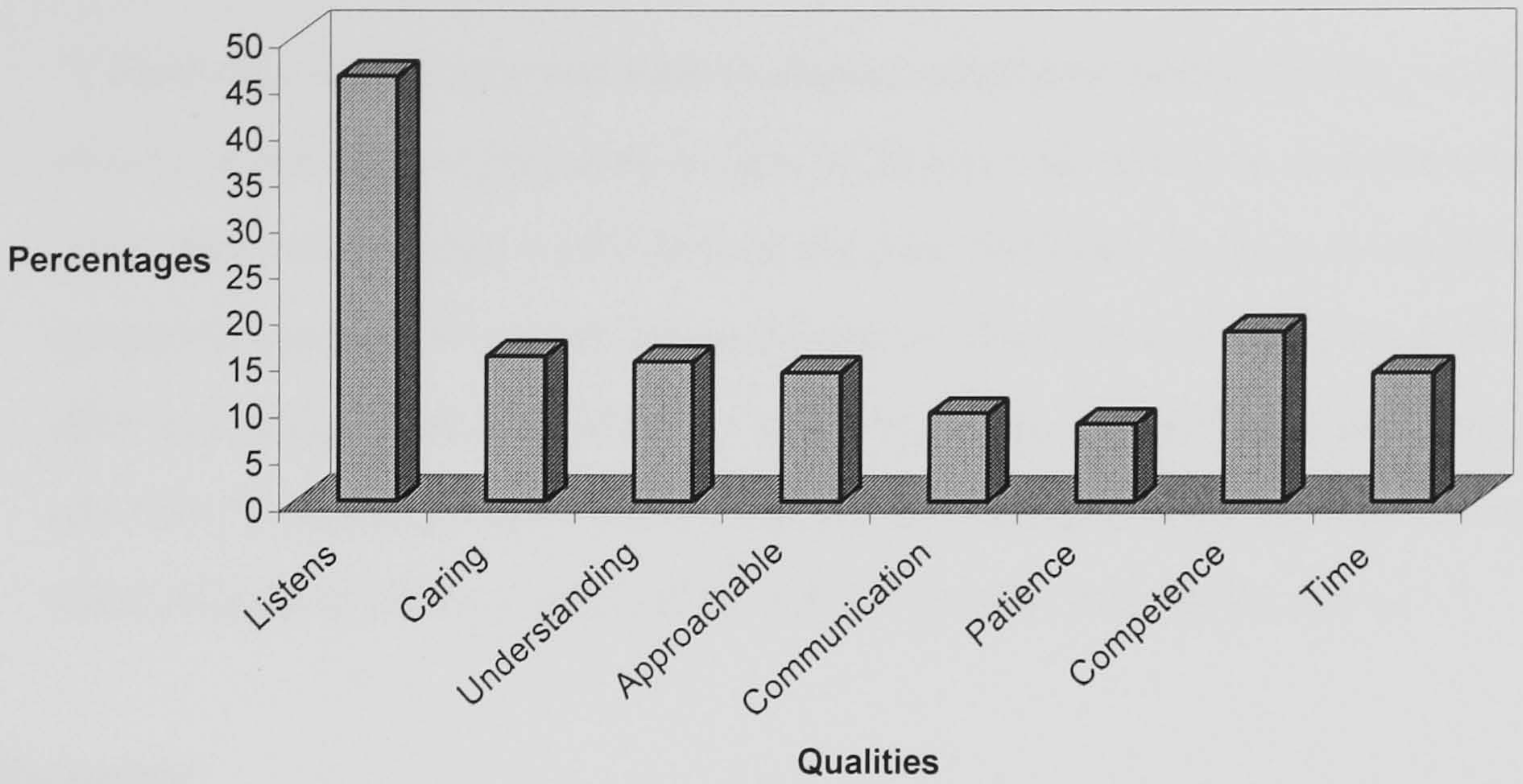
Thus, seeking medical care may be the result of discussion with others, decisions about the duration, nature and treatment of symptoms and experimentation with home remedies.

Perceptions of a good G.P

The final issue focused on patients' perceptions about what constitutes a "good GP" ("What do you think are the most important qualities of a good doctor?"). Inter-rater reliability was satisfactory, with 96% agreement between the investigator and independent judge regarding the coding of patients' responses. Figure 4.4.2 indicates that interpersonal aspects of the consultation were perceived as the most important qualities of a doctor, particularly good listening skills (mentioned by 45.8% of respondents). For example:

> *"One that just listens. Some of them just tend to get the prescription pad out before you've even told them what's wrong with you, and I don't think that every time you come to a doctor you need to take tablets away with you. Sometimes people just need reassurance. So, someone who's patient and gives you time"* (Patient 150: male 30 yrs).

Figure 4.4.2: Important qualities of a GP



Technical competence was the second most frequently cited quality (mentioned by 18% of patients). For some, professional knowledge was the primary concern and the consultation was viewed as a "functional" interaction as opposed to a relationship based on support and understanding:

> *"It would be so easy to say a listening, caring doctor and all that. But all I really need from a doctor is to explain how I see my current health position and for him to assess the situation, come up with a diagnosis and either advise me what to do or prescribe for me…I don't regard it as a social occasion…It's functional. I come, I say something is wrong and I trust his professional knowledge to tell me what he thinks is wrong and what is the best course of treatment.* (Patient 315: male 60 years)

Most patients expected doctors to have both interpersonal and technical expertise, but it was the former which received the most emphasis:

> *Personality first and then his qualifications and his feeling for the patient, which I find very much so with Dr. M. – you feel as though you're talking to someone who understands what you're going through."*

This contrasts with some previous work which has found that patients in general practice took empathy for granted, but were more critical about technical competence (Vuori, 1991). The qualitative data from the current study suggests that patients tended to link technical competence with good interpersonal skills, i.e. adequate communication skills are a prerequisite of medical expertise. For example:

> *"I think they should give you time to discuss what your symptoms are, so therefore they should be patient and prepared to have a bit of a chat with you, at least within reason. 'Cos often you feel that, well I have in the past, felt that I've gone in and rattled off my symptoms and you've got an instant diagnosis. And I've had experiences in the past where after a prolonged series of visits for different things, the real problem, I mean a physical one now, emerged. Simply because the doctor wasn't perhaps picking up vital bits. So I think time for a decent consultation really."* (Patient 302, Male, 38yrs).

4.5 Discussion

4.5.1 Patients' Illness Representations

The findings suggest that people have relatively well-developed representations of their illness or condition when they seek medical care. Indeed, 94% of patients had beliefs about the illness identity, 80% about cure, and 83% about cause. In terms of the perceived consequences of illness, most patients viewed their condition as relatively minor, with over half reporting minimal or no interference. Thus, consistent with previous studies, virtually all patients had already self diagnosed their condition before consulting their GP. The majority had also formed ideas about what had caused their condition and how it should be treated. In the light of recent evidence that doctors perceive the majority of patients as expectant of medication,[27] it is interesting to note that only half of patients expected to receive medication for their condition. Over 20% of patients expected to receive reassurance and/or advice from the doctor. The findings provide support for Lau et al.'s (1989) finding that people with strong identity and cure beliefs are more likely to visit the doctor. However, patients' representations were not related to how satisfied they felt with the consultation.

A comparison of patients' concrete representations of their condition with the abstract representations of lay people in Study 1 revealed very few differences in the content of representations across the two studies. This supports the robustness of the findings in Study 1.

The most interesting difference was between hypertensive and lay participants' symptom beliefs. Hypertensives were more likely to perceive their condition as asymptomatic compared with the lay sample. However, previous studies (e.g. Meyer et al., 1985) have found that hypertensives

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[27] Consider, for example, the recent publicity regarding the over-prescription of antibiotics.

associate idiosyncratic symptoms with their own condition despite recognizing that hypertension is asymptomatic in general. One explanation for this counter finding might be improvements in patient education during the past decade.

An additional trend was for patients to view their condition as less serious than the lay sample (with the exception of migraine). This may well reflect adaptation to illness, particularly chronic complaints. It may also reflect a difference in the perception of seriousness, with patients focusing on the impact it has on their daily functioning and lay people focusing on the medical consequences.

The second aim of selecting illnesses from Study 1 was to identify patterns in diagnostic disagreements between the patient and doctor. It might be expected that the misclassifications identified in Study 1 also operate when patients visit the doctor. Unfortunately, the number of patients with discrepant diagnosis beliefs from those of the doctor[28] was too small to make generalizable claims. Additionally, in several cases, the doctor did not provide a specific diagnosis. In two cases the illness diagnosed by the doctor (bronchitis and ear infection) was from the same primary cluster as the patient's diagnosis (flu and cold), and in one case, a different cluster (tonsillitis - flu) but with similar symptoms and cause. For those patients who had discrepant beliefs with the doctor but reported full agreement (N = 5), the majority reported acceptance of the doctor's opinion over their own (i.e. accepting the opinion of "the expert").

When considering the comparison with Study 1, it is interesting to note that only a third of the illnesses presented by patients to general practice coincided with the illnesses from Study 1. Yet the illnesses selected in Study 1 were drawn from examples provided by participants asked to list common illnesses for which they would visit a doctor. Looking at the actual distribution of illnesses in Study 2 (Appendix 6, p. A19), this is likely to reflect, in part, the relatively high number of patients with psychological/psychosocial disorders (13%), physical injuries (11%) and miscellaneous illnesses (12%). Additionally, diagnoses did not necessarily conform to the medical labels used in study 1 (e.g. back ache), and no diagnosis was given in 6% of cases.

4.5.2 Doctor-patient concordance and satisfaction with care

Despite patients' seemingly high expectations about the interpersonal skills of their doctors, ratings of satisfaction were high. This is consistent with most studies of satisfaction (e.g. Wensing et al., 1994).

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[28] Discrepant by subjective rating of agreement (N = 7); discrepant by objective comparison of patients' pre-consultation beliefs with the doctor's diagnosis (N = 10).

Interestingly, open response questions asking about specific aspects of care yielded higher reports of satisfaction than the fixed responses (88% compared with 84%), despite evidence that asking about more specific aspects of the consultation produces higher reports of dissatisfaction (Locker & Dunt, 1978). Although reports of dissatisfaction were low, patients' suggestions for improving the consultation fell into two main categories: a) thoroughness in dealing with all the relevant issues, and b) style or approach to consulting.

Patients' evaluations of the positive qualities of their consultation were consistent with their descriptions of the general qualities of a good doctor. Thus, bedside manner was deemed particularly significant alongside technical/professional competence. Although explicitly mentioned by only 13% of patients, the desire for patient participation suggests that patients do not wish to be passive receivers of medical care. Moreover, the relatively well established illness representations of these patients indicate that they bring their own models of illness to the consultation. Participants' comments regarding the duration of the consultation also highlighted the difference between patients' expectations about the consultation and what they would actually like to happen, which is consistent with recent distinctions in the literature (Williams et al., 1995). Such a distinction might also be applied to the assessment of doctor-patient concordance, since patients may, on the basis of previous experiences, expect to receive medication from the doctor, whilst actually *desiring* a different form of treatment.

As hypothesized, objectively measured concordance, both in terms of treatment and diagnosis (comparing patient's pre-consultation beliefs with those of the doctor), was significantly lower for dissatisfied patients. It was also hypothesized that patients' subjective agreement would account for a significant amount of variance beyond that explained by demographic and consultation factors. This was supported. Despite the low variability in satisfaction scores, almost a quarter of the variance was explained by subjective reports of agreement alone. Thus, from a number of potential predictors of satisfaction, doctor-patient agreement was the most powerful in predicting overall satisfaction.

The hypothesis that both agreement and satisfaction would be lower for patients presenting with their complaint for the first time received only minimal support. Only concordance regarding treatment was significantly lower for patients consulting for the first time (i.e. the treatment recommended by the doctor did not match that expected by the patient). It may be that patients presenting for the first time are more flexible in incorporating the doctor's diagnosis and recommendations.

Overall, the findings indicate that doctor-patient concordance is an important predictor of satisfaction. With the increasing importance placed on patients' evaluation of care and its implications for adherence, doctors clearly need to be encouraged to elicit patients' own perceptions of their illness. This has become closely associated with "patient participation". Indeed, it has been suggested that patients should enter into an agreement about proposed treatments by signing their own prescriptions (Collier & Hilton, 1998). Others however, argue that this simply serves to distract from the principal task of enhancing communication in the consultation.

"Medication concordance may require a radical change in consulting styles and a deeper understanding of patients' health beliefs. The term refers more to a metamorphosis within the profession than us reinforcing our agenda on the patient" (Chen, 1999)

A combination of both attitude change and good communication skills may thus be required. The following quotation from a patient perhaps best exemplifies the complex relationship between doctor-patient concordance and satisfaction with care:

> *"Well I mean it was unsatisfactory in the sense that nothing can be done. But then again its what I expected anyway. As far as I'm concerned, doctors are rather like mechanics, trying to mess around with, you know, the 1940s mechanic trying to mess around with the 1980s car, or 1990s car. If it's something really obvious that they can right, then they're really helpful. But if it isn't, they're completely useless. I had a preconception about what might be done and it didn't happen, but it was explained to me why. So I suppose it was satisfactory from that point of view. In terms of treatment, well, there was no treatment, so how does one weigh these things up?" (Patient 21: Male, 28 yrs)*

4.5.3 Intentions to follow treatment recommendations

The hypothesized relationship between satisfaction and intentions to adhere was not supported. Intentions were higher for older people, consistent with previous studies of actual behaviour (Sherbourne et al., 1992), but were lower for those patients more favourable towards complementary medicine. Presumably, such patients perceived other alternatives for treating their condition and were less likely to follow treatment recommendations unquestioningly. However, the vast majority (95%) of patients for whom treatment was prescribed stated that they would definitely follow recommendations and only a small minority said they might consider treatment elsewhere. Thus, there was very little variability in people's responses.

However, previous research has shown high levels of non-adherence, with between 30% and 60% of patients failing to take medication as prescribed (DiMatteo, Sherbourne, Hays et al, 1993). Moreover the link between intentions and actual behaviour is frequently a tenuous one (Abraham & Sheeran, 1993). Patients' intentions immediately following the consultation may be influenced by a number of subsequent factors both internal (e.g. "do I really want to take antibiotics?") and external (e.g. collecting the prescription). A minority of patients mentioned potential difficulties of following the recommended treatment, most commonly concern about side effects or dependency. Such worries are consistent with several previous studies and are likely to hinder adherence to treatment (Horne, 1995, Donovan & Blake, 1992). Clearly a follow-up study is necessary to explore the relationship between intention and behaviour and identify the predictors of adherent behaviour.

4.5.4 Perceptions of lay, folk and professional systems

Role of lay referral

As found in previous studies, the majority of participants consulted the lay network, particularly friends and family, before turning to the professional sector. Almost half the patients (44%) had been advised to visit the doctor by those they had consulted. A second question related to whether lay consultation had an impact on people's perceptions of their illness. In the majority of cases there was agreement between the patient and those he/she had consulted. For some patients, lay consultation was a process of negotiation in which the patient's model of illness emerged through shared deduction and discussion. For others, lay consultation served a confirmatory role, whereby the opinions of others were sought to validate one's own beliefs. For 40% of patients, the primary function of the lay consultation was to suggest a course of action or discuss causal factors rather than provide a diagnosis. Thus, lay consultation appeared to serve two main functions. On the one hand it was a means of discussing or confirming a diagnosis, on the other it was a forum for considering how to treat the illness (e.g. by consulting a doctor).

Folk sector: Complementary medicine

Patients' attitudes towards complementary medicine were generally favourable, particularly towards the more "mainstream" or better known therapies such as massage and acupuncture. Consistent with previous studies, those most favourable towards complementary therapies were more likely to be female, younger and more highly educated (Vincent and Furnham, 1997). However, willingness to use complementary therapies did not reflect dissatisfaction with orthodox medicine or disenchantment with the biomedical model, as found in some earlier studies (Furnham

& Bhagrath, 1993; Furnham & Vincent, 1997). The majority of patients viewed such therapies as a useful adjunct to orthodox methods, especially in treating conditions not easily addressed by conventional medicine (e.g. back problems, anxiety, headaches, chronic pain). This is consistent with previous studies in both Europe and America (Druss & Rosenheck, 1999; Eisenberg, Kessler, Foster, & Norlock, 1993; Ernst, 1998; Himmel et al, 1993). This has implications for the relationship between complementary and orthodox medicine. Clearly, patients are increasingly seeking out complementary therapies as an additional source of health care and doctors are a key source of information in advising patients about such treatments. Thus, it is important that doctors acknowledge and familiarize themselves with this "parallel system".

Professional sector

Patients' decisions to seek conventional medical care demonstrated some overlap with Zola's (1973) early work describing common triggers to medical care[29], particularly with regard to interference, social sanctioning, and persistence of symptoms. In addition, over half of patients made spontaneous reference to illness representations, both cognitive and emotional (concern). Moreover, the components tended to be linked, for example severity and concern, symptoms and time line. Although symptoms were an important cue to care seeking, 19% of patients also identified the *absence* of an identity and knowledge about how to treat the problem (unable to self-diagnose/treat oneself) as a cue in deciding to visit the doctor. Consistent with several previous studies, self-medication or home remedies were commonly used prior to seeking professional treatment (Dunnel & Cartwright, 1972; Lau & Hartman, 1983; Wadsworth, Butterfield, & Blaney, 1977). Indeed, underlying the majority of patients' responses was a justificatory rationale for seeking care. Thus patients appeared to make considered decisions about whether a problem was sufficiently serious, worrying, debilitating and so forth, to warrant a visit to the doctor.

In exploring the qualities which patients valued in a general practitioner, characteristics associated with the doctor's bedside manner and interpersonal skills were cited most frequently by patients. This is consistent with previous findings (DiMatteo et al., 1985; Hall et al., 1988; Jefferys & Sachs, 1983; Squier, 1990). Particular emphasis was placed on the doctor's ability to listen, empathise and reassure the patient. It appears that, for the majority of patients, the doctor's technical expertise was taken for granted, but it was his or her interpersonal skills which were perceived as the crucial element to "good doctoring".

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[29] a) occurrence of an interpersonal crisis, b) social interference, c) vocational/physical interference, d) social sanctioning by others, e) recurrence and duration of symptoms.

4.5.5 Methodological issues

Although satisfaction was assessed with both open and fixed responses in order to maximise discrimination between satisfied and dissatisfied patients, overall satisfaction was measured using only a single item. Using a standardized measure such as the MISS which evaluates several dimensions of satisfaction may have produced greater variability in responses and provided a more elaborate picture of patients' evaluation of the consultation. However, it was not possible to use such a measure due to time constraints. Moreover, open questions were included to allow participants to present their own views about the strengths and limitations of the consultation.

Whilst reported levels of satisfaction were consistent with other studies, it must be noted that the sample of general practices willing to participate in the study was likely to be biased. Thus, those who participated were likely to be favourable towards research and possibly more confident about the responses of their patients. Indeed, from patients' comments, the majority of doctors included in the study were perceived as having excellent communication skills and were caring and responsive to patients' needs. Of course, it must be borne in mind that the participating doctors were aware which patients were taking part in the study due to the numbering system established to retain patient anonymity and this may have had an impact on the consulting style of the doctor. Additionally, although it was not possible to time the duration of each consultation, it was evident that many of the consultations exceeded the average six minutes, sometimes quite substantially. Thus the high reports of satisfaction may actually reflect very satisfied patients. The follow-up study reported in chapter 5 will enable further examination of this issue.

4.5.6 Conclusions

The current study has highlighted that patients have well developed and influential representations of their condition by the time they seek medical care. Indeed, an elaborate process of lay consultation and self-treatment occurs before the "patient" even reaches the professional sector. As hypothesized, lack of congruence between the doctor's and patient's representations was the principal predictor of patients' satisfaction with the consultation. Indeed, it proved more important than other factors identified from the satisfaction literature, such as the doctor-patient relationship. This suggests that it is important that health professionals elicit and respond to patients' representations to facilitate an effective and satisfactory consultation. However, satisfaction did not predict patients' intentions to follow treatment recommendations.

The current study focused on the immediate outcomes of the consultation, namely satisfaction and *intentions* to adhere. The next study, described in chapter 5, extends this by exploring patients' beliefs and experiences two weeks after the initial consultation. This follow-up study enabled the investigation of the predictors of subsequent satisfaction with the consultation and self-reported adherence to treatment recommendations.

CHAPTER 5

Study 3: Follow-up to assess satisfaction and adherence

5.1 Introduction

The third study extends the scope of Study 2 by following-up a sub-sample of the patients interviewed in the previous study. The main focus of the current questionnaire study was to assess changes in patients' beliefs over time, and also to determine the predictors of satisfaction and self-reported adherence to treatment two weeks after the original consultation.

5.1.1 Change in beliefs over time

Study 2 showed that lay consultation played an important role in the elaboration and development of people's perceptions of their illness and also in suggesting ways in which the individual may respond to their condition (e.g. going to the doctor). Thus the medical consultation is only one encounter which influences patients' perceptions and behaviour. A follow-up study enabled an exploration of any changes in beliefs over time, as the influence of the medical encounter declines and patients continue to elaborate their representations and discuss their condition with others.

Hunt, Jordan & Irwin (1989) explored the process by which women's illness explanations regarding very common but non-specific symptoms were constructed over a four month period both prior to and following a medical consultation. They found that the majority of women modified their explanations over time and incorporated the biomedical explanations, but only by *integrating* them into their prior models. This accords with Helman's (1978) classic work in which patients' adapted biomedical explanations to fit in with their prior beliefs. Similarly, despite fluctuations in beliefs at different time points, Hunt et al. found that people's original beliefs were long lasting and over half reverted back to their original beliefs.

The current study also enabled a comparison of patients' beliefs about what was wrong with them before and after the medical consultation to assess potential patterns of change, but in a more diverse patient sample than Hunt et al.'s study. Of particular interest were those patients who had discrepant beliefs from those of the doctor in their initial consultation. In Hunt et al.'s small study, 58% of patients (Total N = 23) received diagnoses that were different from their original beliefs; none of these completely dropped their prior views in favour of the medical diagnosis.

The current study also enabled an investigation of the relationship between changes in patients' beliefs and a) evaluation of the consultation (satisfaction), and b) behaviour (self-reported adherence). As discussed in chapters 2 and 4, having beliefs that are discrepant from those of the doctor is associated with dissatisfaction as well as influencing patterns of adherence to recommended treatment. Several studies have shown that patients actively modify treatment regimens to fit their own beliefs about their illness (Hunt et al., 1989; Meyer et al, 1985). This is certainly consistent with the self-regulatory approach.

5.1.2 Satisfaction

Consistent with many previous studies, patients' satisfaction with the consultation was relatively high in Study 2, with 84% reporting complete satisfaction. Whilst this may genuinely indicate "satisfied customers", it is also possible that this interpretation is overly optimistic. An important consideration is the context in which patients evaluated the care that they had received. Interviewing patients in the medical centre, immediately after their consultation may well have had an impact on their reports. Whilst patients were assured that the interviews were confidential, they may not have felt entirely comfortable with criticizing the consultation whilst still on the premises. Furthermore, they will not necessarily have had sufficient time to digest and process the contents of the consultation and its concomitant implications. One important influence that may impact on people's subsequent evaluations is lay consultation whereby patients compare their experiences with others and discuss the outcome of the consultation. It is therefore interesting to compare reports of satisfaction at two time points to determine whether any significant changes have occurred. Despite an anticipated increase in dissatisfaction over time, initial satisfaction was still hypothesized to be the main predictor of satisfaction at follow-up.

In Study 2, patients' rating of agreement with the doctor was the principal predictor of satisfaction following the consultation. The current study investigated its role in predicting satisfaction two weeks after the consultation. It was hypothesized that both agreement and satisfaction (time 1) would predict satisfaction at follow-up. Objective assessments of doctor-patient congruence were also related to satisfaction in the previous study. It was hypothesized that this objective assessment of lack of congruence (at the consultation) would be associated with lower reported satisfaction at follow-up.

5.1.3 Adherence

In the previous study, the hypothesized relationship between satisfaction and intentions to follow treatment recommendations was not supported. Only age and favourability towards complementary medicine were associated with intentions[1]. However, patients' intentions to adhere immediately after the consultation were very high, with little variability in responses. In light of the relatively high rates of non-adherence in all areas of medicine, it is likely that intentions would not have accurately predicted subsequent behaviour. Study 3 enabled the exploration of the relationship between intentions immediately after the consultation and self-reported behaviour two weeks later. In understanding the relationship between intentions and behaviour it is important to distinguish between different types of non-adherence, namely volitional and non-volitional. Whilst intentions may predict volitional non-adherence, they are unlikely to demonstrate a relationship with non-volitional non-adherence, since patients may *intend* to follow recommendations but simply forget to take the medication on occasions. Thus the explanations of volitional and non-volitional non-adherence are quite different.

In the current study, it was hypothesized that intentions immediately after the consultation would distinguish between those who systematically departed from their treatment and those who adhered or forgot occasionally (non-volitional non-adherence). Similarly, in line with Study 2's hypothesis, it was hypothesized that: a) lack of congruence between the patient's and doctor's views at the consultation (self-report), and b) dissatisfaction would both discriminate between volitional non-adherers and the other two groups[2].

Previous research discussed in chapter 2 suggested that a number of other factors may also play a role in determining patterns of adherence[3]. Consistent with previous findings, Study 2 indicated that older people and those less favourable towards complementary therapies were more likely to intend to follow treatment recommendations. Previous research has also indicated that adherence declines with the duration of the regimen (Turk & Speers, 1984). Research with chronic illness suggests that people modify their treatment over time in order to regain control over their illness and its treatment (Donovan & Blake, 1992; Conrad, 1985). Several other factors, such as

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[1] Patients' intention to follow treatment recommendations was positively correlated with age and negatively with favourability towards complementary medicine.

[2] Although self-reported disagreement and dissatisfaction were correlated ($r = .49$), it was hypothesized that they would account for separate portions of the variance in discriminating volitional non-adherers from the other two groups.

[3] These factors may impact on volitional and/or non-volitional non-adherence, hence a distinction is drawn between adherers, volitional and non-volitional non-adherers in the current study to determine which factors disriminate between these three groups.

perceiving one's condition as serious, feeling concerned, and experiencing disruption as a result of illness, may also have an impact on people's motivation to follow treatment recommendations.

In terms of correctly following treatment recommendations, the information received from the doctor must be clear and the patient must remember any instructions (Ley, 1988). It was hypothesized that patients' ratings of the clarity of the doctor's instructions (measured at time 1) would be significantly higher for patients who fully adhered to their treatment regimen.

Finally, patients' experiences of the treatment itself are likely to impact on their decisions about whether to discontinue treatment. Perceptions of treatment efficacy are likely to be particularly salient (Hampson, 1997). Studies using the health belief model as a theoretical framework have found that beliefs about both the benefits and costs of treatment are important in predicting adherence (Brownlee-Duffeck et al., 1987; Harris & Linn, 1985). When patients in Study 2 were asked whether they perceived any difficulties arising out of their treatment, the majority of those expressing concerns cited worries about side-effects. Study 3 explored the kinds of problems that patients experienced and assessed the impact of such difficulties on adherence.

Thus, a number of factors were hypothesized to influence adherence. However, consistent with the framework of self-regulation whereby people actively participate in treatment decisions, a distinction was drawn between volitional and non-volitional non-adherence. Intentions, satisfaction, doctor-patient concordance and perceived efficacy of treatment, were hypothesized to impact only on volitional non-adherence.

5.2 Summary of aims and hypotheses

Change

- An assessment of patients' beliefs about their illness two weeks after the consultation to determine: a) patterns of change in belief over time and b) the relationship between any changes and reported satisfaction and adherence at follow-up.

Satisfaction

- It is hypothesized that satisfaction at follow-up will be lower than satisfaction immediately following the initial consultation.
- It is hypothesized that satisfaction and self-reported agreement following the consultation will predict satisfaction two weeks later.

- Satisfaction at follow-up is hypothesized to be significantly higher for those patients who had diagnosis and treatment beliefs which were congruent with the doctor's (objective measure) at the time of the consultation.

Adherence

- Patients' self-reported adherence will be classified into three groups: complete adherence, non-volitional non-adherence (e.g. forgetting), and volitional non-adherence (deliberate departure from the regimen). The principal aim is to determine those factors which best discriminate between these three groups.
- Specifically, it is hypothesized that intentions, self-reported agreement with the doctor, satisfaction (time 1) and the perceived benefits of the treatment (time 2) will discriminate between those patients who do not adhere (i.e. volitional) and the remaining two groups.
- Patients' experiences of their treatment were also explored to identify the kinds of difficulties people experienced and to determine their impact on adherence.

5.3 Method

5.3.1 Sample

The questionnaire was sent to 145 patients previously interviewed in three of the practices from study 2, with a 63% response rate (N = 92). Prior consent had been obtained from all patients following the initial interviews; only 5 patients declined to participate. Of the 92 responders, 51 were female, 41 male. Ages ranged from 16 to 92 years, with a mean age of 48 years (SD = 17.9). Mean age of completion of education was 19 years (SD = 5.0). To evaluate potential biases between responders and non-responders, t-tests and chi square analyses were conducted comparing the two groups on demographic variables. Responders were significantly older ($t = 2.15$, $p<.05$) and had spent more time in formal education ($t = 2.20$, $p<.05$). There were no significant differences in marital status or gender.

5.3.2 Materials

Follow-up Questionnaire (See Appendix 10, p.A30)

The questionnaire predominately consisted of open-ended questions to elicit patients' own views where appropriate. The questionnaire was divided into three sections:

Part A: Patients' illness beliefs and current health status: consisting of several open questions asking about patients' reasons for consulting (at time 1) and their beliefs about what was wrong in order to assess whether these had changed since the consultation. Two questions also assessed whether patients perceived their beliefs to have changed over time and whether they felt their condition had changed since the consultation. Several questions concerning subsequent medical visits and use of other treatment were also included. Concern was assessed using a 5-point Likert scale (as in Study 2).

Part B: Beliefs about treatment and adherence: several open questions related to adequacy of treatment instructions and information. A single question asked respondents if they had agreed with the recommended treatment. In order to assess the potential role of lay consultation in treatment decisions, participants were asked if they had discussed their treatment with anyone, and if so, to state the views of those consulted.

Adherence: assessed using self-report. Participants were asked whether they had followed the treatment recommended by the doctor (Yes/No) and whether there were ever times when they had not taken their medication as prescribed. Two open questions asked participants to state reasons for any deviations. Although self-reports tend to produce overestimates of adherence, many studies have demonstrated substantial intercorrelations between self-reports and other methods of assessment (Becker, 1985; Ley, 1988).

Costs and benefits: an open question assessed problems associated with treatment, whilst the perceived benefits of treatment were assessed with a 5-point rating scale.

Part C: The consultation: a) satisfaction with the consultation was again assessed using a combination of fixed and open responses. There were two 5-point rating scales (overall satisfaction and extent to which concerns were met) and three open-ended responses;

b) self-reported diagnosis agreement (5-point rating scale); c) attitudes towards the doctor (a semantic differential scale on 9 characteristics identified as important in pilot work in study 2); d) lay consultation regarding the consultation (open-ended).

5.3.3 Procedure

As described in chapter 4, 150 consecutive patients were asked if they would be willing to take part in a follow-up questionnaire study. The 145 consenting patients gave their names and addresses and were sent a questionnaire and cover letter two weeks after their initial interview.

5.4 Results

All results are two-tailed unless otherwise stated. Qualitative data (responses to open-ended questions) were content analysed. To assess reliability of coding, 20 questionnaires were randomly selected and coded by an independent judge (see individual sections for details).

5.4.1 Changes in beliefs and health status over time

Patterns of change: Two methods were used to assess changes in patients' beliefs about what was wrong with them over time: a) patients were asked if their beliefs had changed since the consultation, and b) patients' original beliefs (pre-consultation) were compared with their beliefs at follow-up.

a) *Patients' view:* Only eight percent of patients reported having changed their beliefs since the consultation. Obviously, generalisations are not possible with such small numbers (N = 7). However, the majority of this group had not actually *changed* their beliefs about what was wrong with them but had continued to develop their representation of their condition (e.g. by considering additional causal factors). For example, one patient (516) originally labelled his condition as underlying heart problems with possibly "a touch of asthma", but the doctor addressed only the cardiac problem in the consultation. In the follow-up, the patient accepted the heart diagnosis and related medication, but continued to "wonder whether asthma comes into the picture somewhere". Thus, the majority of patients maintained their original beliefs, at least in some restructured format.

b) *Objective comparison*: A comparison of patients' beliefs before the consultation and at follow-up revealed three main patterns:

1) the majority of patients' held beliefs which were consistent with their original views and with the diagnosis reported by the doctor (78%).
2) an additional group had maintained their original beliefs about what was wrong with them despite these differing from the doctor's diagnosis (9%).
3) a final group of patients had changed their beliefs (11%). In the majority of cases this reflected information provided by the doctor either during the consultation or during subsequent visits (i.e. an acceptance of the doctor's perspective). Interestingly, only one of these patients actually reported a belief change.

To establish the reliability of this classification, an independent judge who was blind to the aims of the study was given 20 questionnaires along with copies of the original interviews and doctor's report to code into the above categories. There was 95% agreement between this judge and the investigator regarding the above classification.

As discussed in the Introduction, cases in which there were doctor-patient discrepancies regarding diagnosis (from Study 2) were of particular interest. There were 19 such cases in the follow-up sample, of which seven did not return the questionnaire. Of the remaining 12 cases, eight fell into category 2 above (i.e. they had maintained their original beliefs) and four in category 3 (i.e. they had reformulated their beliefs).

Relationship between change and outcomes: A one-way ANOVA was conducted to assess differences in satisfaction at follow-up for the three categories of "belief change". As hypothesized there were significant differences in overall satisfaction ($F = 6.6$, $p<.01$). Post-hoc tests (Scheffe) revealed that patients from both categories two and three reported lower satisfaction (means = 3.9 & 4.0 respectively) than those from category one (mean = 4.6; $p<.05$). An additional analysis was conducted to determine if satisfaction at time 1 (post-consultation) differed between the three groups. A one-way ANOVA revealed significant differences ($F = 5.82$). Post-hoc tests found that satisfaction was significantly lower for patients from group two compared with those from group one (means = 4.4 & 4.8 respectively; $p<.05$). Chi Square analysis was conducted to assess the relationship between belief change and adherence, but no significant association was found.

Changes in health status and concern: The majority of patients (55.5%) reported that their condition had improved since the initial consultation, 38% reported no change, and 5.5% a decline (1% did not respond). A comparison of ratings of satisfaction for these three groups indicated that satisfaction at follow-up was lower for the health decline group (mean = 3.8) compared with the other two groups (no change = 4.5, improved = 4.6). However, the difference was not significant ($F = 2.06$). Thirty percent had made a subsequent visit to the doctor, although this was not associated with reports of health status change ($\chi^2 = 1.73$) or satisfaction ($t = .31$). There were no differences in level of concern reported by patients at follow-up compared with at post-consultation (means = 2.45 and 2.49 respectively).

5.4.2 Satisfaction

Thirty percent of patients were not completely satisfied with their consultation at follow-up. This is almost double that reported in Study 2 (16%). Mean score for the satisfaction item was 4.57

(SD = .80, skew = -3.01, $p<.05$) which, as hypothesized, was significantly lower than initial satisfaction (mean = 4.79; t = 2.91, df = 88, $p<.005$). Consistent with the previous study, satisfaction was skewed to favour positive evaluation. However, in addition to the general satisfaction rating, patients rated the degree to which they felt their concerns and expectations had been met. This yielded a lower mean score and was less skewed than the satisfaction item (mean = 4.44, skew = -1.52, n.s); only 54% of patients felt that their concerns had been completely dealt with (i.e. scored 5). Since this item was highly correlated with the satisfaction item (r = .73, $p<.001$) the two items were combined to yield an "overall satisfaction" score[4]. This will be used in subsequent analyses (mean = 4.50, SD = .70). There were no gender differences in overall satisfaction (t = .30).

5.4.2.1 Relationship between satisfaction and predictor variables

The second hypothesis relating to satisfaction stated that doctor-patient agreement and post-consultation satisfaction would be the principal predictors of satisfaction at follow-up. Firstly, Pearson correlations were computed to assess the relationship between follow-up satisfaction and a) demographic variables, b) variables from the initial interview (pre- and post-consultation) and c) follow-up variables. These are summarised in Table 5.4.2.1 along with the means for the follow-up variables.

Overall satisfaction was significantly related to age (r = .21) but not to education (r = -.01), with older patients reporting higher overall satisfaction. Very few variables from the initial interview were significantly related to satisfaction at follow-up. As predicted, satisfaction 1 demonstrated the strongest relationship with satisfaction at follow-up (r = .47). However, the hypothesized relationship between agreement 1 and satisfaction at follow-up was not supported (r = .15). Apart from satisfaction 1, only concern (concern 1 = -.21 & concern 2 = -.28) was significantly related to satisfaction at follow-up, with lower levels of concern associated with higher reports of overall satisfaction, consistent with the previous study. However, several other variables also approached significance, namely perceived severity (r = -.20, $p<.065$), disruption (r = -.19, $p<.07$) and total number of previous visits (r = -.19, $p<.07$).

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[4] In order to reduce the skewness of the satisfaction measure.

Table 5.4.2.1 Pearson's correlations demonstrating the relationship between overall satisfaction at follow-up and variables from both the initial interview (study 2) and follow-up

Variables	*N*	*r*	*Sig. (2 tailed)*	
Demographics				
Age	90	.21	.05	
Education	90	-.01	n.s	
Pre-consultation				
Symptoms	87	-.05	n.s	
Severity	90	-.20	n.s	
Disruption	90	-.19	n.s	
No. total visits	90	-.19	n.s	
No. current visits	90	-.05	n.s	
Illness duration (mths)	90	.02	n.s	
Relationship with Dr	70	.16	n.s	
Concern	89	-.21	.05	
Post-consultation				
Satisfaction 1	90	.47	.001	
Agreement	90	.15	n.s	
Concern 2	90	-.28	.01	
Clarity[1]	41	.28	n.s	
Follow-up				**Means (SD)**
Concern 3	90	-.30	.01	2.45 (1.23)
Benefits (treatment)	57	.54	.001	3.91 (1.38)
Agreement 2	87	.78	.001	4.60 (0.69)
Dr evaluation	86	.60	.001	41.31 (4.75)[2]

[1] Only those patients who had received information about treatment rated the clarity of the instructions.

[2] Range = 9-45

All of the follow-up variables were significantly related to overall satisfaction. Concern continued to have a significant association with overall satisfaction; as might be expected, the three measures of concern were highly correlated with each other[5]. Perceiving one's treatment as beneficial and evaluating the doctor positively were also both highly related to overall satisfaction. Interestingly, despite the lack of relationship between agreement 1 and satisfaction at follow-up, agreement 2

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[5] Concern 1 & 2 (r = .56), concern 1 & 3 (r = .47), concern 2 & 3 (r = .61). All significant at p <.0001.

and overall satisfaction at follow-up were very highly correlated. However, there was no significant relationship between initial diagnosis agreement and agreement at follow-up (r = .13). These findings suggest that self-reported agreement at follow-up may have been an index of satisfaction rather than actual agreement, particularly since agreement at follow-up was significantly correlated with initial satisfaction (r = .31, p <.01). Agreement 2 was therefore not included in subsequent analyses.

Two hierarchical regression analyses were conducted to assess the contribution of the above variables to satisfaction at follow-up. Concern was treated as a single variable due to issues of collinearity (only concern 3 was included). In the first analysis, age was entered at step one. Variables from study 2 were entered at the second step (satisfaction 1, severity, disruption and number of visits) and follow-up variables were entered at the third step (concern 3, Dr evaluation) in a stepwise fashion. The results are summarised in Table 5.4.2.2.

Table 5.4.2.2 Results of hierarchical regression to predict satisfaction at follow-up

Variables	Multiple R	Beta	Sig	Adj R^2
1. Age	.22	.22	.05	.04
2. Satisfaction	.53	.49	.001	.27
Severity	.57	-.20	.05	.30
3. Dr evaluation	.72	.46	.001	.49

Age accounted for only 4% percent of the variance, with satisfaction 1 at step two and patients' rating of the doctor at step three each accounting for the largest portion of variance (23% and 19% respectively). Perceptions of illness severity accounted for a further 3% of the variance. Thus, older patients who were satisfied immediately after the consultation, perceived their illness as relatively minor and evaluated the doctor positively (follow-up) were more likely to report feeling satisfied with the consultation two weeks later.

A second hierarchical regression was conducted following the same structure but with the addition of the variable measuring the perceived benefits of treatment (see Table 5.4.2.3). Clearly this restricted the sample size since it included only those patients who had received treatment (N = 58). Thus, the results should be interpreted with regard to such limitations.

Table 5.4.2.3 Results of second hierarchical regression to predict satisfaction at follow-up (including perceived benefits of treatment)

Variables	Multiple R	Beta	Sig	Adj R^2
1. Age	.21	.21	n.s	.03
2. Satisfaction 1	.62	.58	.001	.35
3. Dr evaluation	.72	.41	.001	.49
Benefits	.79	.37	.001	.59

Despite the small sample, a similar pattern emerged in the second analysis although accounting for a larger percentage of the total variance. Perceived severity was no longer selected by the analysis and initial satisfaction alone accounted for a larger percentage of the variance (32%). Perceiving one's treatment as beneficial accounted for a further 10% of the total variance in satisfaction at follow-up.

Thus, as hypothesized, satisfaction following the consultation predicted a large percentage of the variance in satisfaction at follow-up. However, whilst agreement was the main predictor of satisfaction immediately following the consultation, it no longer predicted satisfaction two weeks later. In the previous study, the "objective" measure of doctor-patient concordance regarding diagnosis and treatment also predicted satisfaction. T-tests were therefore conducted to determine whether concordance continued to be associated with higher ratings of satisfaction. Although there was no significant difference in satisfaction for patients with concordant and non-concordant beliefs regarding treatment, the difference was significant for diagnosis concordance ($t = -2.01$, $df = 85$, $p<.05$). Thus, as hypothesized, satisfaction at follow-up was higher when doctor and patient agreed about what was wrong with the patient.

5.4.2.2 Open-ended responses

Reliability: the principal investigator categorized patients' responses to open-ended questions (see below). Twenty questionnaires were then coded by an independent judge to assess the reliability of the coding scheme. This judge was given a list of categories for each question and asked to record patients' responses in the relevant category. There was 95% agreement between the investigator and the independent judge.[6]

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[6] The number of responses on which there was agreement as to categorization was divided by the total number of responses coded by the investigator.

Satisfaction with treatment

Patients were asked to comment on the instructions they had received about treatment, from the perspective of both clarity and adequacy. Obviously this only applied to those patients receiving treatment (N = 58). Virtually all (98%) felt that the instructions were easy to understand, although many commented that they had not received explicit instructions regarding their medication but rather relied on instructions printed on the label. Eighty two percent were satisfied with the information they had received. A minority stated that they would have liked information about side-effects, about illness duration or about how the treatment worked. Those patients who requested more information were less likely to feel satisfied (t = -2.61, df = 53, p<.01). All but two patients stated that they agreed with the treatment they were given.

Interestingly, only 30% of patients said that they had discussed their treatment with others, which is much lower than the 75% who had discussed their condition with others prior to seeking medical care. Of these, the majority (23%) had spoken to friends and family, with 5% consulting a health professional.

Satisfaction with the consultation

Patients were asked several open questions about the consultation itself, focusing on understanding, information and ability to discuss issues with the doctor[7]. Answers to these questions were combined for analysis. Overall, 23% of patients felt that the consultation could have been improved in some way. Of those who elaborated their answers, the most common request was for more information about their condition and its treatment (11% of all respondents). A further 7% mentioned lack of time or difficulties with the approach of the doctor. Overall satisfaction was lower for patients reporting such issues (t = 3.9, df = 86, p<.001).

Surprisingly, more people had discussed the consultation with others (42%) compared with their treatment, although lay consultation was still lower than in the previous study. Again, most patients had spoken to family or friends (35%), rather than health professionals (5%) or others (2%).

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[7] "Was there anything the doctor said during the consultation that you did not really understand?", "Is there any additional information or advice about your condition that you would have liked from the doctor?", "Did you feel able to discuss everything that you wanted with the doctor?".

5.4.3 Adherence

As previously discussed, 58 patients in the follow-up had received treatment from the doctor (64%). Adherence to the treatment regime was coded into three categories:

1. *Total adherence*: following regime as recommended. Reported by 65.5% of sample (20 males, 18 females).
2. *Non-volitional non-adherence*: occasional missing of medication. Reported by 17% of sample (5 males, 5 females).
3. *Volitional non-adherence*: systematically departing from regime or medication never taken. Reported by 17% of sample (4 males, 6 females).

Reliability: An independent judge coded responses to 20 questionnaires (as before), revealing 100% agreement with the investigator using the above classification.

Means and standard deviations for the three groups on demographic, consultation and follow-up variables are presented in Table 5.4.3.1. ANOVAs indicate that there were no significant demographic differences between the three groups, in terms of age or years in education. Table 5.4.3.1 indicates that there were significant differences between the groups on only four variables, two from the consultation (favourability towards complementary medicine and intention to adhere) and two from the follow-up (overall satisfaction and perceived benefits of the treatment). Post-hoc Scheffe tests revealed that, in all cases, the non-adherent group was significantly different from the complete adherence group ($p<.05$ or greater) and in all cases except one (overall satisfaction) was also different from the non-volitional non-adherent group ($p<.05$ or greater). Thus, the volitional non-adherent group were more favourable towards complementary medicine and were less likely to report a high intention to adhere. They also reported lower levels of satisfaction, but only at follow-up, and perceived fewer benefits of treatment than the other two groups.

Table 5.4.3.1 Means (and SDs) for variables according to adherence group, with ANOVAs to compare groups means

Variables	Total adherence	Non-volitional non-adherence	Volitional non-adherence	F
Demographic				
Age	50.16 (15.55)	46.80 (16.90)	37.50 (7.38)	2.22
Education	18.03 (4.16)	21.50 (8.49)	18.60 (5.19)	1.72
Pre-consultation				
Complementary medicine	5.42 (2.49)	4.50 (2.37)	8.00 (3.06)	5.31**
Illness duration	31.81 (63.59)	59.19 (71.01)	10.11 (17.92)	1.53
Illness severity	2.15 (0.74)	2.50 (0.85)	2.55 (0.30)	1.54
Disruption	2.39 (1.00)	2.80 (1.14)	3.20 (0.79)	2.84
Concern 1	2.88 (1.14)	3.00 (1.12)	3.50 (0.97)	1.24
Post-consultation				
Satisfaction	4.83 (0.44)	4.90 (0.32)	4.75 (0.43)	0.51
Agreement	4.92 (0.36)	5.00 (0)	4.90 (0.32)	0.30
Concern 2	2.51 (1.26)	2.80 (1.34)	2.70 (1.49)	0.23
Clarity	4.64 (0.49	4.33 (0.58)	4.43 (1.13)	0.49
Intention	5.00 (0)	5.00 (0)	4.75 (0.46)	6.09**
Follow-up				
Overall satisfaction	4.58 (0.60)	4.60 (0.77)	3.95 (1.04)	3.22*
Concern 3	2.34 (1.12)	2.65 (1.45)	3.00 (1.33)	1.24
Benefits	4.30 (1.08)	4.30 (1.06)	2.22 (1.30)	13.19***

*p<.05, **p<.01, ***p<.001

The study's primary aim regarding adherence was to identify the factors which discriminated between the three categories of patients. It was hypothesised that several factors would predict group membership, but that doctor-patient agreement, post-consultation satisfaction and intentions to adhere would be particularly salient in discriminating between the volitional non-adherence group and the remaining two groups. However, the simple comparison of means above indicated that neither satisfaction 1 nor agreement differed significantly between the groups. They were therefore not included in the discriminant analysis. Due to the small sample of patients who had received treatment, only those variables with significant differences between the groups were entered into the analysis as independent variables (favourability towards complementary medicine, intention to adhere, perceived benefits and satisfaction at follow-up). It is recommended that the sample size of the smallest group (i.e. 10) should always exceed the number of predictor variables (Tabachnick & Fidell, 1996). The results of the direct discriminant analysis are summarised in Table 5.4.3.2.

Table 5.4.3.2 Discriminant functions for adherence

Function	*Eigenvalue*	*Variable*	*Correlations of variables with functions*	*Group centroids for each group*	
1	1.35	Benefit	.78	Volitional	-2.62
		Intention	.50	Non-volitional	0.45
		Complementary medicine	-.45	Complete	0.49
		Satisfaction	.21		

Only one function was significant ($\chi^2 = 35.74$, df = 8, $p<.0001$), maximally distinguishing the volitional non-adherent group from the other two groups. The correlations between the independent variables and discriminant function suggest that perceived benefits and, to a lesser extent, intentions to adhere, were the best predictors for distinguishing between the groups. Thus those who systematically departed from the treatment regimen perceived the treatment as less beneficial and were less likely to intend to follow the treatment after their original consultation.

5.4.3.2 Open-ended responses

Reliability: as detailed in section 5.4.2.2, the same independent judge was given a list of response categories for the questions below and asked to code patients' responses into the relevant categories. There was 100% inter-rater agreement with the classification scheme.

Reasons for non-adherence

Content analyses of patients' responses to questions asking why they had not followed treatment as recommended[8] indicated that 90% of the non-volitional group cited forgetting or inconvenience.

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[8] "Have you followed the treatment recommended by the doctor? If not, is there any particular reason why you didn't follow the treatment?" and "Were there ever occasions when you didn't take the medicine as prescribed for any reason?"

The most common reason cited for volitional non-adherence was side-effects (50%). Other patients mentioned ways in which they had modified the treatment, for example taking more analgesia than prescribed or trying to minimise side effects by missing doses.

Problems experienced as a result of the treatment

When asked specifically about any problems experienced as a result of the treatment, 31% of participants mentioned difficulties, the most common being side-effects (21%). However, the presence of side-effects was mentioned by all three groups of patients suggesting that they were only one of the determinants of non-adherence, presumably interacting with other factors in influencing the decision not to follow treatment recommendations. Other problems mentioned by patients were the short-term effects of medication such as painkillers, slow recovery, difficulties carrying out the treatment, and the boring nature of the treatment.

Relationship between categorical data and adherence

Chi square analyses were conducted to explore the relationship between adherence and categorical variables from the follow-up questionnaire. Due to the low frequencies in both the volitional and non-volitional non-adherence groups, it was necessary to collapse the data for analysis. Since the results already discussed clearly distinguished the volitional non-adherence group from the others, data was coded as either adherent (including patients in the non-volitional non-adherence group) or non-adherent. Due to the low expected frequencies in all analyses, Fisher's Exact test was used in all cases. Non-adherence was significantly associated with requesting more information about the treatment ($p < .05$) and with reporting issues that were not fully resolved in the consultation ($p < .01$). Similarly, non-adherence was associated with experiencing problems such as side-effects from the treatment ($p < .01$). There was no significant association between adherence and making subsequent visits to the doctor. Neither clarity of information nor agreement with the treatment at follow-up were included in the analyses due to the overwhelmingly affirmative responses.

The parametric tests clearly demonstrated no relationship between self-reported agreement at initial interview and subsequent patterns of adherence (see Table 5.4.3.1). Chi Square analyses were conducted to assess the relationship between the two objective measures of doctor-patient concordance and adherence. There was no significant relationship for concordance regarding diagnosis or treatment.

5.5 Discussion

5.5.1 Changes over time

A comparison between patients' original beliefs about what was wrong with them and those two weeks later revealed relative stability in people's perceptions of their condition. Just over 10% had actually changed their beliefs over time. This is considerably lower than that reported by Hunt et al. (1989) although their study took place over a four month period compared with the current study's relatively short two week interval. Interestingly, of those categorised as having changed their beliefs, only one actually reported that he had changed his beliefs. One explanation for this finding is that these patients had integrated the changes into their own illness model. Higgins and Bargh (1987) suggest that when people are faced with inconsistent information they modify their knowledge structure to incorporate discrepant information. Interestingly, the remaining patients reporting a belief change appeared (based on what they said at time 1 and 2) to have maintained their original beliefs. Their perceptions of change seemed to reflect a consideration of additional factors relating to their illness such as causal beliefs rather than a change in their perceptions of what was wrong with them.

An interesting group are those who maintained their original beliefs about what was wrong with them when these differed from those presented by the doctor. Of those patients with original identity beliefs discrepant from the doctor (i.e. lack of congruence at time 1), 67% maintained these beliefs (N = 8), whilst 33% (N = 4) changed their beliefs between time 1 and time 2. Thus, in over half of such cases, the patients did not adopt the doctor's diagnosis. Despite the small numbers involved, this clearly has implications for the communication process, since doctors are failing to convince a small subset of patients. Moreover, examining the impact of belief changes on outcomes revealed that those patients who maintained their original beliefs (which differed from those of the doctor) and those who changed their beliefs were less satisfied with the consultation than those whose beliefs were congruent with the doctor's diagnosis and remained consistent over time. Additionally, those who maintained their original beliefs were less satisfied with the medical encounter immediately after the consultation (Study 2). This is consistent with the findings of Study 2 in which discrepancies between patient and doctor were the main predictor of satisfaction. Adherence did not, however, differ between the three groups.

Over half of patients felt that their condition had improved over time, with only just over 5% reporting a worsening of their condition. Although patients who experienced a decline in their condition were less satisfied than the remaining patients, the difference was not significant. Clearly, the small numbers made comparisons problematic.

5.5.2 Satisfaction

As hypothesized, satisfaction at follow-up was significantly lower than immediately following the consultation. Aside from the potential effect of a different environmental context (home vs. surgery), this finding is likely to reflect the fact that patients had the opportunity to consider, discuss and re-evaluate their consultation. Thus, the time interval enabled patients to reconstruct the encounter on the basis of their initial impressions and their subsequent experiences (Stimpson & Webb, 1975). Lay consultation may well have played a role in this process. However, less than 50% of patients reported discussing their consultation with others, whereas 75% of patients in Study 2 had consulted with others before their visit to the doctor. Lay consultation may therefore be more important *prior* to the seeking of medical care (e.g. in providing initial advice).

The study's second hypothesis relating to satisfaction suggested that initial satisfaction and self-reported agreement would predict satisfaction at follow-up. It was only partially supported. As hypothesized, initial satisfaction was a primary predictor of satisfaction at follow-up, accounting for between 23% and 32% of the total variance (regressions 1 and 2 respectively). However, agreement at time 1, the principal predictor of initial satisfaction, was not related to satisfaction at follow-up. Consistent with several previous studies, older patients were more satisfied than younger ones (DiMatteo & Hays, 1980; Fitzpatrick, 1984; Hall & Dornan, 1990), although age accounted for a very small percentage of the regression variance (3-4%). Perceived severity of one's illness was the only other variable from time 1 to predict overall satisfaction, but again accounted for only a small percentage of the variance (3% in regression 1). Two variables from time 2 accounted for a significant percentage of the variance in overall satisfaction: evaluating the doctor in a positive light (19% and 14% of the variance in regression 1 and 2 respectively) and perceiving one's treatment as beneficial (10% of the variance in regression 2).

These findings suggest interesting changes occurring over time in patients' evaluation of the consultation. Clearly self-reported agreement with the doctor was no longer exerting a direct effect on overall satisfaction as measured at follow-up. Moreover, self-reported agreement at time 1 and time 2 failed to demonstrate any relationship with each other, yet agreement at follow-up was highly correlated with initial and particularly follow-up satisfaction. Additionally, the objective measure of doctor-patient congruence (time 1) was no longer associated with self-reported agreement at follow-up. This certainly suggests that self-reported agreement at follow-up better reflected a measure of satisfaction than actual agreement. This strongly suggests that over time patients' memory of their agreement with the doctor was influenced by how satisfied they felt with the consultation.

Indeed, it appears that affective dimensions[9] are playing a more central role at follow-up compared with immediately after the consultation (Study 2). Both satisfaction and evaluation of the doctor were primary predictors of satisfaction at follow-up. However, when perceptions of treatment were also included in the equation (for the subset of patients who had received treatment), over 60% of the variance in satisfaction was accounted for, of which 12% was due to perceiving the treatment as beneficial. This supports the earlier contention that patients reconstruct the consultation on the basis of both initial affective impressions (e.g. "how am I feeling about the consultation now?") and perceptions of subsequent experiences (e.g. "does the treatment seem to be working?"). Viewing both the studies together, the findings suggest that a dual process may be operating, whereby perceived cognitive discrepancies play a significant role in initial evaluation of the consultation, but take on a secondary role at later stages, having only an indirect effect on satisfaction. At this point, affective factors and perceptions of subsequent experiences play a more central role in determining satisfaction.

These findings are consistent with theories in the field of social cognition which postulate that "evaluative impressions (one kind of affect) can be independent of memory for the details on which they were based (one kind of relevant cognition)" (Fiske & Taylor, 1994). The work of Srull and Wyer (1989) is particularly of note since they discuss the processes by which mental representations are transformed into social judgements and affective reactions (with specific reference to impression formation). Consistent with the above quotation, they propose that whilst initial evaluations are based on applicable trait concepts (or in this case, cognitive agreement), subsequent judgements and memory of specific behaviours are based on these evaluative responses. Thus, evaluative judgements (i.e. satisfaction) will influence the individual's memory of their agreement with the doctor, as found in the current study.

However, despite the apparent indirect effect of doctor-patient congruence on satisfaction at time 2, the objective assessment of congruence (in terms of diagnosis/identity and treatment) revealed

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[9] The definition of affect is problematic since it is " a generic term for a whole range of preferences, evaluations, moods and emotions" (Fiske & Taylor, 1994, p.410). In this context affect is used primarily to describe *evaluations*.

that, as hypothesized, discrepancies concerning the illness identity continued to result in lower levels of overall satisfaction at follow-up. Thus, both subjective (self-reported agreement) and objective doctor-patient congruence predicted satisfaction at time one, but only the latter predicted satisfaction at follow-up. This suggests that cognitive discrepancies between patient and doctor influence patients' evaluation of the consultation at time 2, both directly and indirectly (by influencing satisfaction at time 1).

5.5.3 Adherence

Sixty four percent of the follow-up sample reported receiving treatment from the doctor, of whom 17% deliberately departed from the regimen, 17% partially adhered (non-volitional non-adherence) and 66% fully adhered to the recommended treatment. The main aim was to identify the factors which discriminated between these three groups of patients. It was hypothesized that several factors discussed in the introduction were likely to distinguish between the groups. Of particular interest was the distinction between *volitional* non-adherence and non-volitional non-adherence/total adherence. It was hypothesized that doctor-patient agreement, satisfaction, intentions to adhere (time 1), and the perceived benefits of treatment (time 2) would discriminate between volitional non-adherence and the other two groups.

Initial comparisons between the three categories indicated that intention to follow treatment did differentiate between the groups; all those patients who expressed doubt (time 1) subsequently fell into the volitional non-adherence category. However, the predicted relationships between adherence and self-reported agreement or initial satisfaction were not supported, with no significant differences between the three groups for either variable. Satisfaction at follow-up was, however, significantly lower for the volitional non-adherent group compared with those who fully adhered. Thus, satisfaction did demonstrate a relationship with adherence, but only when measured at the same time point (i.e. at follow-up).

In Study 2, favourability towards complementary medicine was associated with less intention to follow the recommended treatment. Similarly, in the current study, patients who expressed a greater willingness to use complementary therapies were less likely to have adhered to their treatment. As suggested in chapter 4, such patients may be less willing uncritically to accept the biomedical model and the treatment it prescribes, particularly when it has deleterious effects. Study 2 also found that older patients were more likely to report the intention to follow treatment. However, age was not related to actual patterns of adherence in the current study.

Belief in the benefits of the prescribed treatment was the principal predictor of group membership in the discriminant analysis. As predicted, the analysis distinguished the volitional non-adherent group of patients from the other two groups. The importance placed on the specific consequences of the treatment complements the qualitative responses in which the costs of following the treatment, particularly side-effects, were cited by patients as a major reason for not following their treatment regimens. Thus, the principal determinant of adherence appeared to be the practical question of whether the treatment was having an effect on the patient's condition. This is consistent with previous findings in which adherent patients felt that the benefits of treatment outweighed costs such as side-effects (Donovan & Blake, 1992). It must be remembered that it is patients' *perceptions* of benefit that we are concerned with here. It is interesting to note that perceptions of benefit were highly correlated with initial satisfaction ($r = .48$, $p<.001$). Thus, although initial satisfaction was not exerting a direct effect on adherence, it may well be operating indirectly through having an impact on perceptions of benefit.

5.5.4 Practical implications: Communication

The results so far discussed indicate that there remains considerable scope for improving both satisfaction and adherence in the current sample. Eighteen percent of the sample had requested more information about their treatment and 23% felt that the consultation could have been improved, most frequently through the provision of more information. Patients who requested more information and felt that the consultation could have been improved reported lower satisfaction and were less likely to follow treatment recommendations. The importance of providing adequate information is particularly apparent when we consider that almost a third of patients reported problems associated with their treatment, most commonly side-effects. Moreover, half of patients who did not adhere to their treatment stated side-effects as a primary explanation. Clearly, it is not possible to eradicate the deleterious effects of treatment, but clear information about the benefits as well as potential side-effects of treatment may increase patients motivation to adhere.

Patients' requests for more information about both their condition and its treatment are compatible with the self-regulatory perspective of the patient as an active participant and evaluator of both the illness experience and its treatment. Whilst actual discrepancies between patient and doctor were relatively low, a significant number of these were not resolved within the consultation and patients continued to hold their original beliefs about what was wrong with them. Others did integrate the lay and biomedical perspectives, although this was still associated with lower satisfaction. These findings, together with those from Study 2 demonstrate that patients' perceptions of their illness and their expectations about treatment are important facets which should be acknowledged and acted upon during the consultation. One means of doing this is to provide patients with adequate information which addresses patients' doubts or concerns. Indeed, lower concern was associated with more satisfied patients in both studies (at the time of the consultation and at follow-up two weeks later). Furthermore, the method of communication must be clear and straightforward, unlike this patient's experience:

> *"He said I had probably had to take its course and leave and probably wasn't treatable with penicillin but prescribed it anyway, and didn't explain the difference between virus and infection" (Patient 313: Female, 29yrs)*

5.5.5 Conclusions

The current study demonstrated that some interesting changes had occurred over the two weeks since the initial consultation when patients were interviewed for Study 2. The majority of patients had retained their original beliefs about what was wrong with them, even if these differed from those of the doctor. A small minority had integrated the medical perspective with their own. Thus, patients' beliefs were relatively consistent over time. However, factors predicting satisfaction had changed over time. In Study 2, patients' agreement with the doctor was the main predictor of satisfaction, but the findings from the follow-up study suggest a more complex picture. Satisfaction two weeks after the consultation was predicted by initial satisfaction, age, perceived severity, perceptions of the doctor, and perceived benefits of treatment. Self-reported agreement with the doctor was no longer directly related to satisfaction, nor was it associated with agreement at follow-up. It is therefore argued that perceptions of doctor-patient concordance are particularly salient in the initial phases of evaluation but become superseded by affective factors over time, i.e how we *feel* about the consultation. That is not to say that discrepancies are not impacting on patients' evaluations; satisfaction continued to be significantly lower for patients with beliefs that were objectively discrepant with those of the doctor.

Belief in the benefits of the treatment was the principal factor discriminating volitionally non-adherent patients from the others. Indeed, perceiving one's treatment as beneficial was a central component for both satisfaction and adherence at follow-up. This is consistent with the tenet of the Health Belief Model in which the perceived costs and benefits of treatment are important factors underlying people's decisions whether to take action. The current study also highlighted the distinction between volitional and non-volitional non-adherence; patients who deliberately departed from the treatment regimen were distinct from both those who partially adhered and those who completely adhered.

Taken together with Study 2, this follow-up study suggests that there are several facets of the consultation and subsequent experience which influence both evaluation and adherence. Several of these can be addressed through effective communication, particularly the issue of belief congruence. This in turn is likely to impact on other aspects important in determining outcomes, such as how concerned the patient feels about their condition and how they feel about the doctor. Moreover, adequate communication, particularly with regard to information, can provide patients with realistic goals concerning their treatment and recovery and thereby facilitate adherence.

CHAPTER 6

Coping with chronic illness: Development of a short form COPE

6.1 General introduction to chapters 6 and 7

Studies 2 and 3 focused on the role of illness representations, specifically doctor-patient discrepancies, on satisfaction and adherence. Patients' representations of their illness were viewed within the wider context of the lay referral system and their expectations and experiences of the consultation. Whilst Study 2 demonstrated the importance of taking patients' representations into account in order to maximize satisfaction, the focus of the study was on *immediate* outcomes of the consultation, namely satisfaction and intentions to adhere to treatment (Pendleton, 1981). Study 3 examined an *intermediate* outcome (adherence) in a subset of the original sample. The findings suggested that illness representations only played an indirect role in decisions to follow medical recommendations. The perceived benefits of treatment were a much more powerful predictor of adherence. This suggests that other components, such as those from the Health Belief Model, may be more important in understanding adherence. This clearly warrants further investigation in a larger sample.

Moreover, the diverse and heterogeneous patient sample precluded a more explicit examination of the inter-relationship between the specific components of patients' illness representations and their impact on long-term outcome variables through the proposed mediating factor of coping style (Leventhal, Nerenz, & Steele, 1984). A more homogeneous group of patients would therefore enable an investigation of the relationship between the different stages of the self-regulatory model i.e. between illness representations, coping, and outcome appraisal. This was the main focus of the final empirical study (Study 6) which explored the relationship between illness representations, coping and functioning in two groups of chronically ill patients (diabetics and hypertensives). This is reported in the following chapter.

The current chapter focuses on issues surrounding the measurement of coping. The current two studies (4 and 5) arose out of the need for a suitable measure to assess coping in the following study. They may be viewed then, as a necessary diversion in the long-term goal of exploring the utility of the self-regulatory model. Whilst the COPE (Carver, Scheier, & Weintraub, 1989) is a widely used instrument for measuring the coping strategies of people with illness (e.g. Moss-Morris, Petrie & Weinman, 1996; Sommerfield et al, 1996), it lacks validation in samples of people dealing specifically with illness. In addition, the length of the 60 item COPE is problematic for the assessment of clinical populations, which require a large battery of measures to be completed, often in a limited time period. Therefore, the principal aim of these two studies was to develop a shortened version of the COPE suitable for using with patients.

6.2 Introduction to studies 4 and 5: Coping and its measurement

Coping behaviour is commonly assessed using self-report measures in which people are asked about the behaviour in which they engage in response to specific stressful events such as illness. Despite the wide use of such measures across a variety of stressful events and illness groups, not enough attention has been given to the psychometric properties of these scales. Indeed, Endler and Parker (1990) argue that most self-report measures suffer from a variety of methodological weaknesses and argue that "empirical support would be greatly advanced if more care and attention were directed at the theory, development, validation, and psychometric properties of coping measures" (p. 853).

A distinction can be made between the development of measures which are empirically driven (where factor analysis is used to identify dimensions underlying a diverse range of potential coping strategies) and those which are theoretically driven (a theoretical underpinning guides the content of the scale). Whereas most measures tend to follow the former approach and are therefore only loosely linked with theoretical frameworks, the development of the multidimensional COPE Inventory (Carver, Scheier & Weintraub, 1989) was based on the latter approach, guided by Lazarus's model of stress and a model of behavioural self-regulation developed by Carver and Scheier (1982).

The COPE reflects the trend towards multidimensional measures of coping and the recognition that Folkman and Lazarus' (1980) binary distinction between problem-focused coping (doing something to alter the stressful situation) and emotion-focused coping (regulating the emotional distress which is associated with a particular situation) may be too simplistic. Research has found that the widely used Ways of Coping measure (Folkman & Lazarus, 1985) generally falls into more than the proposed two factors (e.g. Aldwin & Revenson, 1987). Carver and colleagues acknowledged that the distinction between problem-focused and emotion-focused coping is important, but argued that the process of coping is more complex. They distinguished a number of processes within both types of coping, recognizing that both means of coping may involve several distinct activities which need to be measured separately. Whilst problem-focused coping is generally viewed as more adaptive than emotion-focused coping, Carver and colleagues argue that some types of problem-focused coping are more adaptive than others. Similarly, some forms of emotion-focused coping are likely to be more successful than others.

The construction of the COPE was therefore based on the sub-division of problem-focused and emotion-focused coping strategies into conceptually distinct scales. Carver et al. (1989) argued that in order to understand the potential range of coping strategies employed in response to a stressor and their concomitant implications for adaptation, conceptually distinct strategies must be measured separately.

The COPE can be used to measure either dispositional coping styles (by asking respondents what they *usually do* when under stress) or situation-specific (by asking respondents what they have *actually done* (or are currently doing) to cope with a specific event). It consists of 15 scales outlined in Table 6.1, each scale comprising of four items. Two of the 15 scales (Humour and Alcohol/Drug Use) were not reported in the original analysis, but were added subsequently.

Factor analysis of the COPE (principal components with oblique rotation, Carver et al, 1989) yielded 11 interpretable factors which supported *a priori* assumptions, with two exceptions: a) the Instrumental and Emotional Social Support items loaded on a single factor; b) Active Coping and Planning also loaded on a single factor. They were however retained as separate scales on the basis of their conceptual distinction. Carver et al. (1989) suggested that in certain circumstances or in certain populations "these conceptually distinct tendencies are also empirically distinct" (p. 274).

The large number of factors derived from this initial analysis and the low to moderate internal reliabilities of some of the subscales have however been criticized (Parker and Endler (1992). Nevertheless, the relatively stable test-retest reliability of the scales and considerable evidence of construct validity found by Carver et al. supported their contention that the COPE is a multidimensional measure of coping strategies.

Table 6.1: An outline of the 15 COPE subscales

COPE subscales and their description
Active coping: taking action and exerting efforts to remove or circumvent the stressor.
Planning: thinking about how to confront the stressor and planning one's active coping efforts.
Suppression of competing activities: suppressing one's attention to other activities in which one might engage in order to concentrate on dealing with the stressor.
Restraint coping: coping passively by holding back one's coping attempts until they can be of use.
Seeking of instrumental social support: seeking assistance, information, or advice about what to do.
Seeking of emotional social support: getting sympathy or emotional support from someone.
Positive reinterpretation and growth: making the best of the situation by growing from it, or viewing it in a positive light.
Acceptance: accepting the fact that the stressful event has occurred and is real.
Turning to religion: increased engagement in religious activities.
Focus on and venting of emotions: an increased awareness of one's emotional distress, and a concomitant tendency to ventilate or discharge those feelings.
Denial: an attempt to reject the reality of the stressful event.
Behavioural disengagement: giving up, or withdrawing effort from the attempt to attain the goal with which the stressor is interfering.
Mental disengagement: psychological disengagement from the goal with which the stressor is interfering, through daydreaming, sleep. or self-distraction.
Alcohol/drug use: turning to the use of alcohol or other drugs as a way of disengaging from the stressor.
Humour: making jokes about the stressor.

Surprisingly, to date there are very few published studies which have explicitly examined the psychometric properties of the COPE. Like Carver et al. (1989), they have all examined coping strategies in response to stressful experiences. In Fontaine, Manstead and Wagner's (1993) study the dispositional version of the COPE was completed by 420 British undergraduates, revealing a similar factor structure (using principal components analysis with varimax rotation) to Carver et al.'s original analysis. Only three items ("I turn to work or other substitute activities to take my mind off things", "I act as though it hasn't happened", and "I sleep more than usual") failed to load on any of the components above 0.40. The remaining items loaded predominantly on only one of the components. Consistent with the original analysis, Instrumental/Emotional Social Support and Active Coping/Planning loaded on two factors rather than forming four distinct components.

Whilst Carver et al. separated these factors into four distinct subscales on theoretical grounds, Fontaine et al. followed the factor structure and argued that they should not be separated, since they are likely to co-occur in practice. Additionally, the separation of factors into more than one subscale has been criticized (Endler and Parker, 1990). The items in the Positive Reinterpretation and Growth subscale loaded on separate factors, with one factor for Positive Reinterpretation and a separate one for Growth. They were therefore retained as distinct subscales by Fontaine et al.

In an American study (Phelps and Jarvis, 1994), 484 adolescents (14-18 years) completed the situation specific version of the COPE. Factor analysis (using principal components with varimax rotation) was conducted on the 15 subscales of the COPE rather than the 60 individual items. It produced the following four factors:

1. Active coping: active coping, planning, suppression of competing activities, and seeking instrumental social support.
2. Avoidant coping: denial, behavioural disengagement, and alcohol/drug disengagement.
3. Emotion-focused coping: seeking emotional social support, and focus on and venting of emotions.
4. Acceptance coping: restraint, positive reinterpretation and growth, acceptance, and mental disengagement.

Two of the 15 subscales (religion and humour) failed to load on any factor. This factor structure was largely consistent with the second order analysis using scale totals as raw data conducted by Carver et al., with two main deviations. In Phelps and Jarvis' analysis, emotional and instrumental social support were found to be empirically distinct, loading on Emotion-focused and Active coping respectively thus supporting Carver et al.'s contention that these two dimensions of social support are conceptually distinct. In addition, the Mental Disengagement subscale was found to load on an acceptance factor whereas in Carver et al.'s analysis it loaded on the avoidant factor. This may in part reflect differences in samples (i.e. adolescents versus students).

Other studies have examined the internal reliability of the COPE, both with undergraduates (Furnham and Rawles 1994) and with survivors of bone marrow transplantation (Sommerfield, Curbow, Wingard, Baker, & Fogart, 1996), but have not conducted factor analysis. Alpha reliability coefficients for the subscales in each of the studies were largely similar to those found in the original study, with the Mental Disengagement scale consistently scoring low on internal reliability (always below $\alpha = .45$), prompting doubts as to the coherence of this scale. Alpha coefficients for the Denial scale (.41) in Furnham and Rawles' study and the Suppression of

Competing Activities scale (.44) in Sommerfield et al.'s study were also unacceptably low, although the reliabilities of these scales were perfectly adequate in the other studies.

Although the above analyses do differ from the original factor structure, they are supportive of Carver et al.'s theoretical position. This does suggest that there is a relatively stable structure underlying the COPE. There is however a distinct lack of studies exploring the psychometric properties of the COPE (both in general and in the U.K), and none has done so in relation to coping with illness. Despite the fact that the COPE Inventory is a relatively new measure and has primarily been tested with undergraduates responding to stressful events, it has been used to measure the coping strategies employed by people faced with a variety of illnesses in a number of studies (e.g. Moss-Morris, Petrie & Weinman, 1996; Sommerfield et al, 1996). This lack of validation is clearly a serious omission since items which are inappropriate can seriously affect the reliability and validity of a measure (Ben-Porath, Waller, & Butcher, 1991; Stone, Greenberg, Kennedy-Moore, & Newman, 1991). Indeed, Stone et al. (1991) examined the applicability of coping items from the Ways of Coping Scale (WOC) to different kinds of stressful events by interviewing respondents. They found that subjects with health problems reported more items to be inapplicable to their case than did subjects encountering other stressful events such as interpersonal problems. Thus, items which are appropriate for coping with general stressful life events may not necessarily be applicable to coping with illness.

The length of the 60 item COPE also presents problems for studies which require a battery of measures to be completed in a limited time period by people who are ill. Indeed, several researchers have adapted the COPE for use with patient samples by reducing the number of items in each scale (e.g. Carver et al., 1993; Gallagher, 1995) or by excluding scales (Moss-Morris et al., 1996)[1]. However, the simple omission of selected items from a standardized measure in order to reduce its length is not considered methodologically acceptable (Parker & Endler, 1992). The primary aim of the present studies was therefore to produce a shortened version of the COPE which was appropriate for using with patients and had construct validity with the longer version. Study 4 examines the factor structure of the 60 item COPE for a sample of adults suffering from illness. This is used in chapter 5 to produce a shortened version which is re-tested with a sample of chronically ill individuals to assess construct validity.

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[1] Subsequent to the research reported here, Carver (1997) has published the "Brief COPE" in which 14 of the original (or modified) scales have been reduced to only 2 items. A different approach was adopted here for the methodological reasons cited in the text.

6.3 STUDY 4

6.3.1 Method

6.3.1.1 Participants

The sample consisted of 180 adults suffering from a range of illnesses. There were 68 males and 107 females (5 participants failed to state their gender) ranging in age from 16 to 79 years (mean = 39.28 years). Of the respondents, 108 were suffering from chronic illness and 71 had acute illnesses (see Appendix 11 for further details of sample, p.A35). The sample was drawn from two sources. One hundred and nine were respondents from a randomly selected sample (from the Personnel data base) of 40% of staff at Oxford Brookes University (n=605) who were asked to complete the questionnaire with regard to a recent or long-term illness. A total of 154 questionnaires were returned (a response rate of 25.5%); of these 45 were incomplete or were returned because the respondent had not recently been ill. A further 71 members of the general population suffering from a variety of illnesses were recruited using the snowball technique in which they were invited to participate in a study looking at how people cope with illness.

6.3.1.2 Measures

The full 60 item situation-specific version of the COPE was used which included the two exploratory scales (see Appendix 12, p.A36). Response choices were rated from 1 ("I didn't do this at all/I haven't done this at all") to 4 ("I did this a lot/I have done this a lot"). As responses were based on *either* a past or a current illness, the above two tenses were provided. Additional questions about the participants' age and sex, and details of their illness[2] were also included.

6.3.1.3 Procedure

All participants received a covering letter together with the COPE giving brief details about the study; they were told that the study was looking at how people respond when they are faced with illness. The remaining instructions followed the same format as those used in the original study. The staff sample were sent the COPE together with a return envelope through the internal mailing system, whilst the remaining participants were given the questionnaire and asked to return it as soon as possible.

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[2] Regarding illness label, duration of illness and whether medical assistance sought or time taken off work.

6.3.2 Results

6.3.2.1 Normative Data and Internal Reliability for the 15 Subscales

Normative data and alpha reliability coefficients for the 15 subscales of the COPE are presented in Table 6.3.1 to enable a comparison with Carver et al.'s findings. Means for each of the subscales showed a tendency to be lower than those found in the original study (see Carver at al., 1989). Planning, Restraint Coping, Positive Reinterpretation and Growth, Religion, and Focus on and Venting of Emotions all showed at least a two point difference in mean scores when compared with the American norms. The alpha reliability coefficients of the COPE subscales were largely higher than those of Carver et al. with four notable exceptions: Suppression of Competing Activities, Restraint Coping, and Behavioural and Mental Disengagement scales all had alphas below .60.

Table 6.3.1 Means, Standard Deviations and Alpha Reliability for the 15 A Priori Subscales of the COPE

COPE scales	*M **	*SD*	*Alpha*
Active coping	11.22 (11.89)	3.08 (2.26)	.72 (.62)
Planning	9.33 (12.58)	3.35 (2.66)	.82 (.80)
Suppression of competing activities	8.29 (9.92)	2.63 (2.42)	.57 (.68)
Restraint coping	8.01 (10.28)	2.67 (2.53)	.58 (.72)
Seeking emotional social support	9.60 (11.01)	3.42 (3.46)	.81 (.85)
Seeking instrumental social support	10.72 (11.50)	3.45 2.88)	.77 (.75)
Positive reinterpretation & growth	8.32 (12.40)	3.62 (2.42)	.85 (.68)
Acceptance	11.47 (11.84)	3.28 (2.56)	.77 (.65)
Turning to religion	5.64 (8.82)	3.12 (4.10)	.93 (.92)
Focus on & venting of emotions	8.16 (10.17)	3.76 (3.08)	.92 (.77)
Denial	5.93 (6.07)	2.81 (2.37)	.81 (.71)
Behavioural disengagement	6.24 (6.11)	2.30 (2.07)	.54 (.63)
Mental disengagement	7.94 (9.66)	2.53 (2.46)	.37 (.45)
Alcohol/drug use	6.28	3.35	.93
Humour	6.94	3.38	.91

* Range of possible values is 4-16.

Note: Numbers in parenthesis are the values obtained by Carver et al. (1989) in their original study with 978 undergraduates (using the dispositional COPE). The Humour and Alcohol/Drug Use scales were added subsequent to the original study and therefore no values are reported.

6.3.2.2 Factor Structure

To evaluate the construct validity of the COPE, principal components analysis using Varimax rotation was conducted on the 60 items. The analysis yielded 16 factors with eigenvalues greater than 1.0, 11 of which were easily interpretable (consistent with the scree plot (Cattell, 1978) which showed a gradual tailing off after factor 11) and accounted for 63.7% of the total variance. Principal components extraction with oblique rotation was also used to reassess the interpretability of this solution and examine the correlations among components but failed to converge in 25 iterations and therefore only the Varimax rotation will be reported.

To allow a comparison with the original factor structure, items loading above .3 (as recommended by Kline, 1994) on Carver et al.'s *a priori* scale assignment are presented in Table 6.3.2. Nine of the 11 factors corresponded to 9 of the theoretically derived scales, with two factors incorporating previously distinct scales. Thus, whilst the factor structure in Table 6.3.2 shows considerable similarities to the original study, there are some notable deviations. Firstly, the Active Coping, Planning and Instrumental Support items all loaded on the first factor. The loading of Planning and Active Coping on a single factor is, however, consistent with the original study, although Carver et al. viewed them as conceptually distinct and therefore separated them to emphasize the theoretical distinction. One of the items originally assigned to the Active Coping scale ("I did what has to be done, one step at a time") loaded instead along with items from Suppression of Competing Activities (.43). There is nothing counter-theoretical about this, as suppression is a strategy which is associated with active, problem-focused coping (Carver et al., 1989). Additionally, two of the Planning items had highest loadings on the factor pertaining to Positive Reinterpretation and Growth. The second major deviation from Carver et al.'s factor structure was that in the present analysis a single factor (Factor 2) captured items from both the Focusing on/Venting Emotion and Emotional Social Support *a priori* scales.

Other deviations from Carver at al.'s original factor structure are less interpretable, but largely reflect the failure of items to load on identifiable factors. One item each from the Suppression of Competing Activities scale ("I kept myself from getting distracted by other thoughts or activities"), Restraint Coping scale ("I made sure not to make matters worse by acting too soon") and Behavioural Disengagement scale ("I reduced the amount of effort I put into solving the problem") failed to load above .3 on any of the 11 factors. Only two items loaded significantly on the Behavioural Disengagement scale, with the remaining item ("I admitted to myself that I couldn't deal with it and quit trying") loading on the factor pertaining to Restraint Coping (.49). The Mental Disengagement scale proved problematic. The items failed to load on any single factor, with two items ("I turned to work or other substitute activities to take my mind off things" and "I daydreamed about things other than this") failing to load on any of the factors.

Table 6.32 COPE Scales: The 11 interpretable factors with items loading above .3 on the a priori factor

Scale name and items	*Loading*
Active Coping (16.3% of variance)	
I talked to someone who could do something concrete about the problem.	.80
I tried to get advice from someone about what to do.	.74
I took direct action to get around the problem.	.73
I concentrated my efforts on doing something about it.	.69
I talked to someone to find out more about the situation.	.61
I took additional action to try to get rid of the problem.	.55
I thought hard about what steps to take.	.53
I tried to come up with a strategy about what to do.	.51
I asked people who had had similar experiences what they had done.	.49
I thought about how I might best handle the problem.	.43 *
I made a plan of action.	.38 *
Emotion-focused Coping (9.2% of variance)	
I let my feelings out.	.87
I got upset and let my emotions out.	.86
I felt a lot of emotional distress and found myself expressing these feelings a lot.	.83
I got upset, and was really aware of it.	.81
I talked to someone about how I felt.	.50
I discussed my feelings with someone.	.50
I tried to get emotional support from friends or relatives.	.49
I got sympathy and understanding from someone.	.42
Positive Reinterpretation and Growth (7.6% of variance)	
I tried to grow as a person as a result of the experience.	.81
I looked for something good in what had happened.	.78
I learnt something from the experience.	.75
I tried to see it in a different light, to make it seem more positive.	.61
Humour (6.6% of variance)	
I made jokes about it.	.88
I made fun of the situation.	.88
I kidded around about it.	.85
I laughed about the situation.	.78

Scale name and items	*Loading*
Turning to Religion (4.9% of variance)	
I sought God's help.	.94
I put my trust in God.	.90
I prayed more than usual.	.89
I tried to find comfort in my religion.	.82
Alcohol/Drug Use (4.4% of variance)	
I drank alcohol or took drugs, in order to think about it less.	.91
I used alcohol or drugs to help me get through it.	.90
I tried to lose myself for a while by drinking alcohol or taking drugs.	.89
I used alcohol or drugs to make myself feel better.	.83
Denial (3.9% of variance)	
I pretended it wasn't really happening.	.88
I said to myself "this isn't real".	.77
I refused to believe that it was happening.	.72
I acted as though it wasn't even happening.	.68
Acceptance (3.4% of variance)	
I accepted that this was happening and that it couldn't be changed.	.78
I learnt to live with it.	.72
I got used to the idea that it was happening.	.66
I accepted the reality of the fact that it was happening.	.64
Suppression of Competing Activities (2.7% of variance)	
I focused on dealing with the problem, and if necessary let other things slide a little.	.77
I put aside other activities in order to concentrate on this.	.61
I tried hard to prevent other things from interfering with my efforts to deal with this.	.41
Restraint Coping (2.4% of variance)	
I held off doing anything about it until the situation permitted.	.75
I forced myself to wait for the right time to do something.	.58
I restrained myself from doing anything too quickly.	.37
Behavioural Disengagement (2.3% of variance)	
I gave up the attempt to get what I wanted.	.76
I gave up trying to reach my goals.	.73

* Items loading above .30 on the theoretically appropriate factor, but these were not their highest loadings.

Although the factor solution from the current study showed underlying similarities with that of the original study, Carver at al.'s (1989) factor structure may be criticised for including items which had very low loadings on their *a priori* scales: 5 items loaded below the basic criteria of .3 (Kline, 1994), and a further 16 had loadings below .5. Since the present study also aimed to reduce the length of the COPE, the following analyses were based only on those items with factor loadings of .5 and above (44 items).

6.3.2.3 Alpha Reliabilities

Cronbach alpha reliability coefficients, means and standard deviations for the factors derived from the current analysis are presented in Table 6.3.3. A comparison of these coefficients with those derived from Carver et al.'s proposed scales (Table 6.3.1) shows that, as expected, the removal of items loading below .50 and the increase in number of items in two of the scales (Active Coping and Emotion-focused scales) improved their reliability. In the latter case, the greater number of items increased observed score variance with no impact on error variance. The factor solution thus produced scales with high internal reliability, with the exception of the three scales consisting of only two items, two of which fell below .60 (Restraint Coping and Behavioural Disengagement).

Table 6.3.3 Cronbach's Alpha Reliabilities, Means, and Standard Deviations for the COPE Scales Derived from the 11 Factor Solution

COPE scales	*M*	*SD*	*Alpha*
Active coping	21.50 [a]	6.22	.86
Emotion-focused coping	13.19 [b]	5.13	.89
Positive reinterpretation & growth	8.32	3.62	.84
Humour	6.93	3.38	.91
Turning to religion	5.64	3.12	.93
Alcohol/drug use	6.28	3.35	.92
Denial	5.93	2.81	.81
Acceptance	11.47	3.28	.76
Suppression of competing activities	4.30 [c]	1.70	.62
Restraint coping	3.84 [c]	1.70	.58
Behavioural disengagement	3.12 [c]	1.50	.58

Note: Range of possible values is 4-16, with the following exceptions: [a] 8-32 (8 items), [b] 6-24 (6 items), [c] 2-8 (2 items)

6.3.2.4 Differences due to gender and illness chronicity

ANOVAs were conducted by gender and illness chronicity for each factor. Differences in terms of gender and illness chronicity were obtained for five of the 11 factors, although there were no interactions between gender and chronicity. Females scored higher than males on Active Coping (F = 4.50, df = 1/171, p < .035), Emotion-focused Coping (F = 14.68, df = 1/171, p < .0001), and Positive Reinterpretation and Growth (F = 4.95, df = 1/171, p < .027), whereas males scored higher on the Alcohol and Drug Use factor (F=4.34, df=1/171, p<.039). People with chronic illness scored higher than those with acute illness on Active Coping (F = 41.81, df = 1/171, p < .0001), Emotion-focused Coping (F = 6.32, df = 1/171, p < .01), Positive Reinterpretation and Growth (F = 9.56, df = 1/171, p < .002), and Acceptance (F = 4.11, df = 1/171, p < .044). There was however a significant association between gender and illness chronicity (Chi Square = 9.62, df = 1, p < .001), with more males reporting acute illness. Differences in terms of illness chronicity were therefore explored further by conducting t-tests for each gender separately. For males, those with chronic illness scored higher on Active Coping (t = 4.46, df = 66, p < .01) and Emotion-focused Coping (t = 2.3, df = 66, p < .025). Females with chronic illness also scored higher on Active Coping (t = 4.70, df = 105, p < .01), but additionally reported using Positive Reinterpretation and Growth (t = 2.86, df = 86. 35, p < .005) and Religion (t = 2.43, df = 96.48, p < .017) more than women with acute illnesses.

6.3.3 Discussion

Overall, the similarities between the factor solution from the current study and Carver et al.'s original study suggest that the COPE retains its underlying structure when used in a sample of people coping with illness. Although only 11 factors emerged in the present analysis, deviations from the original factor structure appear to have both face validity and empirical support from previous studies.

The loading of Active Coping and Planning on a single factor is consistent with all previous findings (Carver et al., 1989; Fontaine et al., 1993; Phelps & Jarvis, 1994) suggesting that the two strategies are invariably linked. The fact that Instrumental Social Support also loaded on the same factor as Planning and Active Coping is congruent with Phelps and Jarvis' findings. Like the current study, they found Instrumental and Emotional Support to be empirically distinct, loading along with active coping and emotion-focused strategies respectively. It also provides support for Carver et al.'s contention that the seeking of emotional and instrumental support are conceptually distinct and should therefore be viewed as separate scales. The fact that Emotional Social Support and Focus on/Venting Emotion loaded on a single factor again reinforces the distinction between active, problem-focused and emotion-focused coping. It is also consistent with Phelps and Jarvis' third factor (emotion-focused coping). Additionally, although seeking social support for emotional reasons loaded together with instrumental support in Carver et al.'s second order analysis, they found that emotional social support was significantly correlated with focus on and venting of emotions and appeared to function as a bridge between functional strategies such as active coping and planning and less adaptive strategies such as venting of emotions.

The Mental Disengagement scale proved particularly problematic, with items failing to load on any single factor. This together with its consistently low internal reliability (Carver et al, 1989; Fontaine & Jarvis, 1994; Furnham & Rawles, 1994; Sommerfield et al., 1996) appears to reflect the greater diversity of coping strategies encompassed by this COPE subscale. This lack of conceptual coherence therefore casts doubt over the utility of such a scale.

The gender differences were largely consistent with previous findings, where women reported using acceptance and emotion-focused strategies more than men who in turn were more likely to use avoidant strategies (Carver at al, 1989; Phelps & Jarvis, 1994). However, gender differences were less interpretable when comparing chronic and acute illnesses. Males with chronic complaints were more likely to use both active and emotion-focused coping strategies than those with acute illnesses, whereas females were more likely to use active and acceptance strategies. This may in part reflect the greater diversity of coping strategies employed when dealing with long-term illness. The prevalence of acceptance strategies when coping with chronic complaints is consistent with previous studies (Gallagher, 1995; Gudmundsdottir, Johnston, Johnston, & Foules, 1994).

6.4 STUDY 5

Modified Version of the COPE

The reduction of the COPE was based on both empirical and theoretical grounds in order to optimize the psychometric properties of the shortened version whilst retaining the construct validity of the scale for its application to chronic illness groups. The modified scale was based on the factor structure which emerged from Study 4 (described above) and therefore omitted the Mental Disengagement scale which failed to load on any of the factors.

As previously discussed, items with factor loadings below .50 were excluded to enhance the "purity" of the scale structure by eliminating items which were doing minimal work in each subscale. Whilst this increased the internal reliabilities of the subscales, it also resulted in three scales with only two items, two of which (Restraint Coping and Behavioural Disengagement scales) had alpha reliabilities marginally below the .6 criterion. Scales consisting of so few items are clearly subject to psychometric problems (Endler and Parker, 1990), and it was therefore decided that these scales might be omitted in the shortened version. Additionally, a previous study examining coping amongst sufferers of chronic fatigue syndrome excluded the Restraint Coping scale on the grounds that it was less relevant to chronic illness groups (Moss-Morris, Petrie, & Weinman, 1996). Previous studies with various chronic illness groups have, however, found Behavioural Disengagement to be predictive of poorer psychological adjustment and functioning, and slower recovery (Carver et al., 1992, 1993: Felton, Revenson, & Hinrichson, 1984; Moss-Morris et al., 1996). The two item Behavioural Disengagement scale was therefore included in the modified Inventory purely for exploratory purposes.

Two further scales (Turning to Religion and Humour) were omitted from the modified COPE principally for theoretical reasons since neither has shown significant relationships with functioning or psychological well-being in previous studies. Additionally, they have both consistently failed to load on any factor in second order factor analysis (Carver et al., 1989; Fontaine et al., 1992; Phelps and Jarvis, 1994).

The modified version of the COPE thus consisted of thirty-two items and seven sub-scales: Active Coping (8 items), Emotion-focused Coping (6 items), Positive Reinterpretation and Growth, Alcohol/Drug Use, Denial, and Acceptance (each consisting of 4 items), and Behavioural Disengagement (2 items).

6.4.1 Method

6.4.1.1 Participants

The sample consisted of 150 adults with chronic illness. There were 90 females and 60 males, ranging in age from 20 to 85 years (mean = 52.09 years). Seventy participants were in-patients of a Cardiology ward, 30 were out-patients at a chest unit, the remainder were out-patients with a variety of chronic complaints (see Appendix 13 for full details, p.A40).

6.4.1.2 Measures

The shortened version of the COPE was used, consisting of 32 items and 7 subscales (see Appendix 14, p.A41).

6.4.1.3 Procedure

Patients were invited to participate in a study of the ways in which people cope with illness. As described in the previous study, all participants received the COPE together with a covering letter about the study. Participants were asked to return the questionnaire as soon as possible. The response rate was 71% (although this figure does not take into account patients who declined to participate in the study prior to receiving the questionnaire).

6.4.2 Results

6.4.2.1 Normative Data and Internal Reliability for the subscales

The means, standard deviations and Cronbach alpha reliability coefficients for each of the subscales are presented in Table 6.4.1. The means for the scales were slightly higher than in the former study, with the exception of Alcohol/Drug Use. Consistent with Study 1 (see Table 6.3.3), the alpha coefficients of the six scales with four or more items exceeded .70, indicating high internal reliability. Only the two item Behavioural Disengagement scale failed to reach this criterion.

Table 6.4.1 Cronbach's Alpha Reliabilities, Means, and Standard Deviations for the COPE Scales in the Modified 32-item Questionnaire

COPE scales	*M*	*SD*	*Alpha*
Active coping	22.90 [a]	6.10	.84
Emotion-focused coping	13.51 [b]	4.56	.82
Positive reinterpretation & growth	9.61	3.53	.77
Alcohol/drug use	5.48	2.85	.86
Denial	6.25	2.87	.73
Acceptance	12.74	3.06	.78
Behavioural disengagement	3.10 [c]	1.51	.54

Note: Range of possible values is 4-16, with the following exceptions:
[a] 8-32 (8 items), [b] 6-24 (6 items), [c] 2-8 (2 items)

T-tests by gender were conducted for each of the scales. No significant differences between male and female scores for any of the scales were found.

6.4.2.2 Factor Structure

Principal components analysis (Varimax rotation) was used in order to assess the construct validity of the shortened version of the COPE. Seven factors were extracted with eigenvalues greater than 1.0, together accounting for 62.9% of the variance (see Table 6.4.2).

Table 6.4.2 COPE Scales:Items listed with loadings on the factor to which each item pertains

Scale name and items	*Loading*
Active Coping (17.7% of variance)	
I have taken direct action to get around the problem.	.83
I have taken additional action to try to get rid of the problem.	.71
I have tried to come up with a strategy about what to do.	.66
I have talked to someone who could do something concrete about the problem.	.64
I have concentrated my efforts on doing something about it.	.63
I have tried to get advice from someone about what to do.	.62
I have talked to someone to find out more about the situation.	.56
I have thought hard about what steps to take.	.59
Emotion-focused Coping (13.2% of variance)	
I have let my feelings out.	.83
I have got upset and let my emotions out.	.80
I have felt a lot of emotional distress and found myself expressing these feelings a lot.	.76
I have got upset, and have been really aware of it.	.66
I have discussed my feelings with someone.	.59
I have talked to someone about how I feel.	.47
Alcohol/Drug Use (8.9% of variance)	
I have used alcohol or drugs to help me get through it.	.91
I have drunk alcohol or taken drugs, in order to think about it less.	.90
I have tried to lose myself for a while by drinking alcohol or taking drugs.	.87
I have used alcohol or drugs to make myself feel better.	.77
Positive Reinterpretation and Growth (8.4% of variance)	
I have tried to grow as a person as a result of the experience.	.81
I have learnt something from the experience.	.79
I have looked for something good in what has happened.	.65
I have tried to see it in a different light, to make it seem more positive.	.52
Acceptance (6.7% of variance)	
I have accepted that this has happened and that it can't be changed.	.76
I have accepted the reality of the fact that it has happened.	.76
I have learnt to live with it.	.75
I have got used to the idea that it has happened.	.70
Denial (4.2% of variance)	
I have pretended it hasn't really happened.	.75
I have acted as though it hasn't even happened.	.71
I have said to myself "this isn't real".	.68
I have refused to believe that it has happened.	.64
Behavioural Disengagement (3.9% of variance)	
I have given up trying to reach my goals.	.71
I have given up the attempt to get what I want.	.70

Comparison with Table 6.3.2 shows that the component structure was in full accord with the scales generated by the previous study, with one minor exception. A single item from the Emotion-focused Coping scale ("I have talked to someone about how I feel") had a relatively weak loading of .47 and also loaded equally on the Active Coping scale. However, all other loadings were in accordance with expectations, suggesting that the factor structure of this shortened version is compatible with the longer COPE.

6.5 General Discussion

The current studies explored the psychometric properties of the COPE with people suffering from illness in the UK, and developed a shortened version of the COPE for use in chronically ill samples. In study 4, factor analysis yielded 11 factors, nine of which corresponded with the *a priori* COPE scales. The most notable deviation from this *a priori* structure involved the incorporation into a single factor of previously distinct subscales: Active Coping, Planning, and Instrumental Social Support (all loading on the Active-Coping factor) and Focusing on/Venting of Emotions and Emotional Social Support (both loading on the Emotion-focused Coping factor). Whilst this finding supports Carver et al.'s contention that emotional and instrumental social support are conceptually distinct, it also suggests that certain problem-focused coping strategies may co-occur, as may certain emotion-focused strategies. The utility of separating these subscales on the basis of their conceptual distinctiveness is therefore open to question, both theoretically and empirically. However, only further studies which investigate the relationship between coping strategies and health outcomes can clarify this issue.

The second major deviation involved the failure of the Mental Disengagement items to load on any single factor. However, this subscale has consistently proved problematic due to its incorporation of diverse strategies, reflected in the unacceptably low internal reliability of this subscale. The questionable validity of such a scale suggests that its continued use should be treated with caution. Indeed, more recently Carver has replaced the Mental Disengagement scale with a more focused Self-Distraction scale (Carver, 1997).

In study 5, the 32 item version of the COPE derived from study 4 demonstrated construct validity. Factor analysis yielded the expected seven factors which were in full accord with the component structure derived from the previous study. Internal reliabilities of the subscales were also satisfactory; only the two item Behavioural Disengagement scale's alpha coefficient failed to exceed .60. This exploratory study suggests the shortened measure is suitable for use with chronically ill individuals and may become a useful research tool. Further research is clearly required to determine whether it can also differentially predict adaptive and maladaptive outcomes of chronically ill individuals.

6.5.1 Methodological issues

Several issues arise regarding the sample of study 4. Firstly, the response rate of 25.5% from the university sample clearly reflects a rather biased sample. However, it must be borne in mind that the questionnaire was sent to a random selection of university staff with no means of assessing whether they had suffered from an appreciable illness in recent months or from a more chronic complaint. Thus a low response rate was to be expected. Secondly, a larger sample size would ideally have been obtained to maximise the reliability of the factor analysis. Guides to acceptable sample sizes for using factor analysis vary widely; sample sizes of around 200 are generally viewed as acceptable but clearly the larger the sample size and the subject: variable ratio the better (Kline, 1994). However, the similarity between the underlying factor solution of Study 4 and previous studies suggests that the solution was reliable enough to produce a basis from which to develop the short form COPE.

6.5.2 Conclusions

Overall, the underlying similarities in the factor structure of the current study to previous studies and the acceptable internal reliabilities of the subscales suggest that the COPE is applicable for use with people coping with illness. Moreover, the development of a shorter but psychometrically rigorous coping measure is clearly of value to researchers investigating people's responses to chronic illness. Indeed, its development was driven by the pressing need for a suitable measure of coping in the study reported in the next chapter. This final empirical study (Study 6) will also enable further exploration of the discriminative properties of the 32 item COPE. Ultimately the most salient question regarding a measure of this kind is whether it is able to differentiate between clinical groups on the basis of outcome measures (e.g. functioning and well being).

CHAPTER 7

The self-regulatory model in chronic illness: The case of diabetes and hypertension

7.1 Introduction to study 6

The primary aim of this final empirical study was to assess the sufficiency of the self-regulatory model in predicting adherence (depicted as a coping response) and functioning in people with chronic illness. As discussed in the previous chapter, the study of a chronic patient sample enabled a more thorough investigation of the relationship between the different levels of the model (i.e. between patients' illness representations, coping strategies and appraisal of functioning). Indeed, the self-regulatory model lends itself particularly well to the understanding of chronic complaints where self- management of illness is frequently the key to successful adaptation. In the current study, diabetes and hypertension were specifically selected because "sufferers" are typically required to engage in a complex regimen to manage their condition and prevent complications. As outlined below, the treatment regime generally requires lifestyle changes such as regulating diet and undertaking exercise in addition to daily medication. Such patients therefore exert considerable control over the management of their illness; indeed their treatment regime typifies an active process of self-regulation. Previous studies have indicated the importance of beliefs in directing self-management for both conditions (e.g. Meyer et al., 1985; Gonder-Frederick & Cox, 1991; Hampson, 1996). This clearly has implications for both the disease process (i.e. control of the medical condition and of disease-related complications) and for the quality of life of patients undergoing long-term treatment. The self-regulatory model suggests that an understanding of the relationship between people's perceptions of their illness, how they manage the demands of chronic illness and how they appraise their condition is crucial to the development of better self-management.

Before examining the specific aims of the current study, some background is provided on the nature and treatment of hypertension and diabetes.

7.1.1 Hypertension

Hypertension (sustained elevation of blood pressure) affects around 20% of the adult population in the UK and other western countries (WHO, 1996). It is increasingly viewed as posing a serious health threat since it is a major risk factor for other diseases, particularly cardiovascular disorders (Weiss, Anderson, & Weiss, 1991). Ninety percent of cases are defined as essential or primary hypertension, having no identifiable disease cause. Although there is no clear consensus as to the causes of hypertension, heredity is "the best single predictor of individual pressures in industrialized populations" (Hart, 1993). Hypertension is also associated with obesity, heavy drinking, high sodium intake, high levels of stress, lack of physical fitness and socio-economic status.

Hypertension is due to raised arteriolar resistance and is clinically assessed on the basis of diastolic or systolic blood pressure. Classification systems vary, but generally a systolic blood pressure greater than 140 mmHg or diastolic pressure greater than 90mmHg indicates mild hypertension. Severe hypertension is diagnosed as a systolic pressure greater than 160 mmHg and diastolic greater than 115 mmHg (Phillips, 1998).

Disease-related complications

There appears to be a linear relationship between blood pressure and risk of complications: the higher the pressure, the greater the risk of complications (Kaplan, 1982). Hypertension is associated with increased susceptibility to following conditions:

- *Coronary thrombosis/myocardial infarction*: the most frequent outcome of hypertension and rarely preventable. However, risk is significantly increased in combination with other risk factors such as smoking (Strasser, 1992).
- *Angina*: common with long-term hypertension and usually improved with lowering of blood pressure.
- *Stroke*: the risk of stroke can be reduced with the lowering of blood pressure. It has been estimated that 40% of all strokes in the U.K result from systolic pressures of 140 mmHg or higher (Marmot & Poulter, 1992).
- *Brain haemorrhages*: risk increased by severe hypertension.
- *Eye damage*: increased risk at all levels of high blood pressure, but particularly at the higher levels.
- *Kidney damage*: rarely caused principally by high blood pressure, but control of blood pressure can preserve renal function and delay end-stage failure.
- *Impotence:* associated with hypertension medication.

Treatment

Hypertension is controlled with a variety of treatments aiming to reduce blood pressure and risk of disease-related complications, although increasing emphasis is being placed on the importance of lifestyle factors in managing hypertension (Joint National Committee on the Prevention, Detection, Evaluation, and Treatment of Hypertension, 1998).

1. **Medication:** generally prescribed when systolic pressure is sustained at 140 over 90 mmHg (diastolic) or higher, although lifestyle modifications may be the most appropriate treatment for mild hypertension.
2. **Diet**: hypertensives are advised to increase potassium uptake by following a diet high in vegetable fibre and low in meat, cholesterol and saturated fat. Low sodium diets are also a widely used and popular intervention for reducing blood pressure, but evidence regarding the efficacy of a sodium restricted diet remains inconclusive. The American Heart Association (AHA, 1998) recommend such dietary changes to lower the blood pressure significantly. Weight loss through diet can also be effective in lowering blood pressure in obese patients, although it appears to be most effective for those under 40 years with severe hypertension (Hart, 1993). However, even moderate amounts of weight loss in obese patients can reduce blood pressure considerably (Rosenfield & Shotat, 1983).
3. **Exercise:** appears to lower the risk of cardiovascular disease as well as aiding blood pressure control (Siegal & Blumenthal, 1991). The benefits of even moderate levels of exercise may, however, be due to psychological rather than direct physiological processes, through increasing self esteem and buffering stress and inducing positive mood states (Appel, 1986; Phillips, 1998).

Relaxation training and stress management techniques have also been shown to reduce blood pressure and improve overall health as well as being associated with a reduced risk for coronary heart disease (Johnston, 1991; Patel et al, 1985).

The asymptomatic nature of hypertension combined with the need for lifestyle changes makes it particularly difficult to manage well, with high rates of non-adherence to treatment regimens and drop-out from treatment programmes.

7.1.2 Diabetes

It is estimated that approximately 3% of the population (1.4 million people) suffer from diabetes in the UK (British Diabetic Society, 1996). Diabetes is a metabolic disorder resulting from either insufficient production of insulin or complete failure of the pancreas to produce insulin. There is a strong hereditary component in the aetiology of both Type I and Type II diabetes, although it is particularly implicated in the latter. Type I diabetes appears to involve a combination of genetic factors, viral damage, and autoimmune dysfunction, whilst environmental factors, such as inadequate diet and exercise are implicated in Type II diabetes (Cox, Gonder-Frederick, Pohl, & Pennebaker, 1986; Cox, Gonder-Frederick, & Saunders 1991; Taylor, 1991). A high percentage (around 80%) of Type II patients are obese (Cox et al, 1986).

Disease-related complications

Hypoglycaemia, or low blood glucose, occurs when there is too much insulin and not enough glucose supplied to the brain. This may happen as frequently as once a month in 50% of Type I patients (Goldgewicht et al., 1983). Moreover. the incidence of hypoglycaemia has increased with the greater emphasis on attaining normoglycaemia; at least 10% of Type I patients will have one severe episode of hypoglycaemia per year (Cryer et al., 1989). In Type II patients, hypoglycaemia occurs when insulin stimulating tablets are taken and not followed by a meal. Hyperglycemia occurs less frequently, often when a patient is unwell and stops injecting insulin. Without sufficient insulin to break down the glucose present in the body, levels of blood glucose rise together with an accumulation of ketones, which can result in diabetic ketoacidosis and lead to life-threatening coma.

Diabetics are also at risk of a number of more long-term complications (Lewin and Seymour, 1992). The Oxford community survey found that 80% of patients over 60 (N=193) had complications (Neil Thompson, Thorogood, Fowler, & Mann, 1989).

- *Cardiovascular disease:* the incidence is three times higher in diabetics compared with non-diabetics. Cardiovascular disease is the principal cause of death in diabetics, accounting for 40-60% of Type I deaths.
- *Hypertension:* not strictly a complication of diabetes but an associated problem. A prospective study of Type II diabetics found that half of newly diagnosed patients were hypertensive (Turner, 1985).
- *Nephropathy (renal disease):* a common complication of diabetes and a major cause of morbidity and mortality. Approximately 40% of Type I diabetics who have had the disease for ten years develop renal impairment, and up to 50% of patients on renal replacement therapy have Type II diabetes.
- *Neuropathy:* either: a) damage to the nerve fibres of the peripheral nerves which makes diabetics less aware of sensation in the legs and feet and more susceptible to infection or b) damage to the autonomic nervous system which may affect blood pressure and bladder control, sometimes causing impotence.
- *Foot problems:* remain the commonest cause of hospital admission amongst diabetics. Diabetics most at risk are those with peripheral neuropathy, previous foot ulceration or other diabetic

complications. The risk of foot complications can be dramatically reduced by effective education leading to self-care.

- *Amputation:* diabetics with neuropathy and peripheral vascular disease have a fifteen-fold higher risk of developing gangrene and having lower limb amputation.
- *Impotence:* experienced by 50% of men over 40 with Type I diabetes.
- *Retinopathy:* leads to impaired vision and sometimes blindness. There is a ten-fold higher risk of blindness in diabetics than non-diabetics, but serious visual impairment can be prevented with regular screening.

Treatment

There are five main components to the treatment regime (for both Type I and Type II diabetics), although there is considerable individual variation:

1. **Insulin injections:** injections are an essential component of Type I diabetes and are also required by approximately 20% of Type II diabetics. Insulin is injected between one and four times per day and normally administered by the patient 15-20 minutes before eating. There are three basic types of insulin used which differ in the time they take to work and how long they remain active in the body.
2. **Tablets:** approximately 50% of Type II patients require tablets to control their diabetes. They are prescribed in conjunction with a diet and taken prior to meals. There are two main types of tablet which either stimulate the production of insulin (sulphonylureas) or increase the up-take of glucose by the tissues (biguanides).
3. **Diet:** dietary recommendations involve reducing fat intake, particularly saturated fat and increasing fibre content together with monitoring of calorie/energy intake. Type I patients must balance the energy content of their meals with insulin dosage and energy expenditure. Most patients cannot achieve good glycemic control without adherence to their diet plan, i.e. management of diet is a necessary but not sufficient basis for glycemic control. Christensen, Terry, Wyatt, Pichert, and Lorenz (1984) found an association between metabolic control and deviations from dietary recommendations. For Type II patients the diet is usually directed at weight loss so that naturally produced insulin can utilize the food as energy.
4. **Exercise:** aids utilization of blood glucose (Feinglos & Surwit, 1988, cited in Taylor, 1991; DiPietro, Seeman, Stachenfeld, Katz, & Nadel, 1998), as well as weight loss for obese Type II patients. For some Type II diabetics, a combination of diet and exercise is sufficient to maintain blood glucose control.

5. **Monitoring of blood glucose (BG):** self-testing of blood and/or urine samples is necessary to balance food intake, physical activity and insulin requirement. Patients injecting insulin are typically recommended to test BG four times per day, but few appear to do so (Cox et al., 1986). Yet, regular testing is essential for monitoring the success of their self-management for both Type I and II diabetics.

The goal of treatment is to maintain blood glucose levels within an acceptable range and thereby reduce the risk of complications. Long-term studies such as the Diabetes Control and Complications Trial (DCCT, 1993) have demonstrated that good control of glucose levels can prevent or significantly delay the onset of diabetic complications. However, the complex nature of the diabetic treatment regime means that maintaining acceptable levels of glycaemia is restricting and disruptive for diabetics. According to Lewin and Seymour (1992) treatment has two aims: firstly to minimize acute and long-term complications, and secondly to allow as normal a daily life as possible without symptoms. In order to achieve this balance and facilitate successful management of diabetes, it is therefore essential that we view it from the *patient's* perspective. Indeed, the health beliefs of diabetics may be better predictors of blood glucose control than adherence itself (Harris & Linn, 1985). There is increasing concern about the health risk posed by diabetes; a recent study estimated that nearly 6% of the US population have diabetes, the highest level ever recorded (Disease Control & Prevention, 1997). It is the fourth leading cause of death in developed countries (Kings Fund, 1996). The concomitant financial costs are also high, consuming an estimated 8% of NHS funds in the UK (Kings Fund, 1996).

7.1.3 The current study

Many earlier studies with hypertensive and especially diabetic patients have tended to involve small, non-random or biased samples. Additionally, few studies with diabetics have investigated the impact of beliefs on behaviour for both Type I and Type II diabetics simultaneously. Whilst it is important to distinguish between these two groups of diabetics since they differ in terms of treatment and age of onset, both involve complex regimes and lifestyle changes. It is therefore of interest to compare systematically the beliefs of these two clinical groups with their concomitant implications for adaptation to the illness.

The self regulatory approach is gradually being applied to clinical populations (see Petrie & Weinman, 1997 for examples), but the lack of standardized measures to assess illness representations has proved problematic and has been identified as a deficiency and barrier to the utilization of the self-regulatory model. The recent development of the IPQ (Illness Perception Questionnaire: Weinman, Petrie, Moss-Morris & Horne, 1996) has attempted to address this problem, thus enabling patients' illness representations to be measured more systematically using quantitative analysis. Its use also enables direct comparison with findings from other studies examining the role of illness representations in various chronic illness groups. The current study thus contributes to this body of research by: a) providing normative data for hypertensives and diabetics, b) comparing patients' perceptions of two chronic illnesses which depend on self-management, and c) exploring the relationship between illness representations, coping and functioning in these two samples.

Of particular interest was the potentially direct pathway between illness representations and functioning. Although the original formulation of the self-regulatory model proposed that coping behaviour served as a mediator between perceptions and appraisal, several subsequent studies have found that patients' representations of their illness are more powerful predictors of adaptation and disability than coping per se (Earll, 1994; Heijmans, 1998; Moss-Morris et al., 1996;). Thus, Leventhal's model may require some reformulation to account for such findings (Johnston, 1996, 1997). However, most previous studies demonstrating this "direct" relationship have been with uncontrollable illnesses such as chronic fatigue syndrome (Heijmans, 1998; Moss-Morris et. al, 1996) and MS (Earll, 1994). The current study therefore sought to determine: a) whether coping was predictive of functional status in two controllable illnesses, and b) whether patients' illness perceptions predicted functioning when controlling for the effect of coping. In addition, this enabled further exploration of the validity of the 32-item COPE developed in the previous study (Cartwright & Lamb, 1996). Whilst the shortened version demonstrated construct validity with the longer version, only the investigation of associations between the COPE subscales and functional status will indicate whether it is sufficiently discriminative to predict adaptive and maladaptive outcomes.

This final study also extends previous work on the self-regulatory model in several ways. Leventhal's model essentially provides a framework for understanding the pathway between people's representations of illness and the manner in which they respond to and appraise their condition. It is therefore particularly amenable to addition from other existing models (Leventhal & Cameron, 1987). Study 3 (Chapter 5) suggested that the costs and particularly the benefits of treatment, components of the Health Belief Model (HBM), were important in predicting adherence to treatment. This is consistent with a variety of previous studies (e.g. Glasgow et al., 1986;

Pennings-Van der Eerden, 1990). When viewed within the framework of the self-regulatory model, the perceived costs and benefits of treatment can be conceptualized as aspects of the appraisal process in which an individual decides whether to adhere to medical recommendations. Perceptions of illness severity and vulnerability can be conceptualized as components of the representation of the health threat. To explore this relationship further, factors from the HBM were therefore incorporated into the present study to determine whether they would enhance the predictive power of the self-regulatory model in explaining adherence.

As discussed in chapter 1, the self-regulatory model distinguishes between abstract representations (general beliefs about one's illness) and concrete representations (beliefs about one's own condition). However, these have not been explicitly examined in previous studies, despite evidence that discrepancies between patients' general beliefs and those they have about their own condition can have an impact on adherence to treatment (Meyer et al., 1985). For example, patients may be aware that hypertension is asymptomatic (abstract representation), but they also experience symptoms which they associate with increased blood pressure (concrete representation)[1]. The model suggests that people are likely to regulate their treatment according to their concrete symptom feedback, rather than their abstract view of hypertension as asymptomatic. In the current study, the IPQ (Illness Perception Questionnaire) was adapted to assess abstract illness perceptions (as well as concrete representations) and thereby enable the comparison of patients' abstract and concrete beliefs. Patients' concrete representations were expected to demonstrate a stronger relationship with adherence than their abstract representations.

Study 3 found that satisfaction with medical care at follow-up was associated with higher levels of adherence. Other studies with chronic illness have also found satisfaction to be a predictive factor of adherence and functioning (e.g. Sherbourne et al., 1992). The current study therefore measured satisfaction with both general care and with information in order to explore its relationship with both adherence and functioning.

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[1] Although the majority of hypertensive patients in study 2 (N = 13) perceived their condition as asymptomatic. It is therefore interesting to investigate whether this finding is replicated in the much larger sample of hypertensive patients' participating in the current study.

7.2 Summary of aims and hypotheses

The study can be divided into five main sections:

Content of illness representations[2]

Aims:

- To explore the content of chronic patients' illness representations and the relationship between the components of illness representations for hypertensive and diabetic patients.
- To assess the internal reliability of the Illness Perception Questionnaire (IPQ).

Adherence

In addition to assessing the extent of adherence to treatment regimes, it is hypothesized that:

- Patients' concrete representations will demonstrate a stronger relationship than abstract representations with their self-reported adherence to: a) medication, b) dietary recommendations, c) exercise recommendations, and d) blood glucose testing (for diabetics only).
- Illness representations (concrete) will explain a significant amount of the variance in self-reported adherence to the four aspects of the treatment regimen.
- The inclusion of variables from the Health Belief Model will account for a significant amount of additional variance in self-reported adherence to the four aspects of the treatment regimen.

Coping

Aims:

- To assess the internal reliability of the short-form COPE.
- To investigate the relationship between patients' illness representations and coping strategies. It is hypothesized that a strong illness identity and perceptions of serious consequences will be associated with avoidant and emotion-focused strategies.

Functioning

It is hypothesized that:

- Coping will explain a significant amount of the variance in functioning (for the eight SF-36 scales).
- Illness representations will account for a significant amount of variance in functioning beyond that explained by coping (for the eight SF-36 scales).

Satisfaction

- Satisfaction will demonstrate positive relationships with a) self-reported adherence and b) functioning.

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[2] The terms illness representations and illness perceptions are used interchangeably.

7.3 Method

A pilot study was conducted in a single Oxfordshire practice to assess comprehensibility and adequacy of response rate. One hundred and ten patients (30 diabetics and 80 hypertensives) were sent the questionnaires (see below). Overall response rate for the first questionnaire was 65% (61% for hypertensives and 76% for diabetics). Seventy eight percent of respondents consented to further participation in the study, of which 82% returned the second questionnaire (79% and 82% respectively).

No changes were made to the questionnaires as a result of the pilot study. The data from the pilot were therefore combined with that of the main study.

7.3.1 Participants

Nine hundred and twelve patients with diabetes (Type I and Type II) and hypertension were identified from the registers of five regional general practices (including the pilot). Patients were excluded if they were identified by their GP as having emotional problems or medical complications. Questionnaires were sent to 460 diabetic patients and 452 hypertensive patients; 62% returned the first questionnaire (299 diabetics and 270 hypertensives). Fifty five percent of participants were male (N=303). Eighty five percent of these respondents consented to a second questionnaire, and 78% of these returned the questionnaire (N=362). Twenty questionnaires were excluded because at least 20% of the questionnaire was incomplete.

The final sample (those who had completed both questionnaires) was thus composed of 186 diabetics (72 Type I and 110 Type II) and 176 hypertensives. Of these, 203 (56%) were male and 159 (44%) were female. The sample was primarily Caucasian (94%) and the majority (74%) of participants were married. Ages ranged from 14 to 91 years, with a mean age of 59 years (SD=13.7). Almost half (49%) of the sample were in employment, 35% were retired and 13% housewives. Mean level of education was 17 years (SD=4.2). The self-reported mean duration of participants' illness was 11 years (SD=9.7). To evaluate potential selection biases, t-tests were conducted to compare participants who completed the second questionnaire with those who did not respond or declined further participation. There were no significant differences in age, level of education or illness duration. For the categorical data (sex, marital status, occupation and ethnic group), chi square analyses were performed to compare the two groups. Non-responders differed only in terms of their ethnic status and were more likely to be either Black or Asian ($\chi^2 = 16.37$, df = 2, p <.001).

There were, however, some notable differences between the samples. Hypertensive participants were significantly older than the diabetics (62 vs. 56 years; $t = -5.32$, $df = 530$, $p<0.001$) and were more likely to be female (52% and 38%; $\chi^2=11.12$, df=1, $p<0.001$). Comparing Type I and Type II diabetics, the latter were significantly older (61 vs. 48 years; $t=-6.79$, df=167, $p<0.001$) and have had diabetes for a shorter duration than their Type I counterparts (7 vs. 16 years; $t=7.23$, df=138, $p<0.001$). Type I diabetics had spent more time in formal education than had Type II participants (leaving age 19 vs. 16 years; $t=3.88$, df=121, $p<0.001$).

7.3.2 Measures

Time 1 (See Appendix 15, p.A43[3])

- **Demographic details**: sex, age, marital status, education, occupation, ethnic group, duration of illness, and family history of hypertension/diabetes. Diabetic patients were also asked whether they were insulin-dependent.
- **Abstract illness perception questionnaire (AIPQ):** a modified version of the IPQ (see below) which asked about participants' *general* beliefs about diabetes/hypertension. The AIPQ measured patients' beliefs about four components of illness representations: cause, time-line, consequences and cure/controllability.

  Symptom monitoring: beliefs about the relationship between symptoms and health status are central to the self-regulatory approach and are particularly important in understanding diseases such as hypertension and diabetes. Since the original formulation of the IPQ did not include explicit questions pertaining to people's beliefs and confidence in symptom monitoring, this was added in the current questionnaire. Hypertensives were asked to rate a single question ("can people usually tell when their blood pressure is high?) on a 5-point scale ranging from "never" to "all of the time". In the same manner, diabetics were asked two questions; the first about monitoring high BG, the second, low BG.

Time 2 (See Appendix 16, p.A47)

- **IPQ:** consists of five scales measuring the components underlying illness representations. The IPQ demonstrates satisfactory reliability and validity with a range of chronic illnesses (Weinman et al., 1996). Identity is assessed by asking how often the patient experiences a number of symptoms on a four-point scale ranging from "never" to "all of the time". The list of symptoms was derived from previous work with diabetic and myocardial infarction /atrial fibrillation patients (Weinman, personal correspondence 1997). There was a range of 20 symptoms for diabetics and 17 for hypertensives. The causal component consisted of 10

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[3] Only the diabetic questionnaire is provided in the Appendix since the questionnaire is the same for the two samples with the exception of an additional monitoring question for diabetics (see p.188 for details).

possible causal factors for diabetes and nine for hypertension. The cause component and the remaining three scales (time line: three items, consequences: seven items, cure: six items) are rated on a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5)[4]. Higher scores on the latter three scales indicate a belief that the illness will last a long time, have serious consequences, and can be controlled or cured.

Symptom monitoring: As with the AIPQ, additional questions were added pertaining to patients' beliefs about their ability to monitor blood pressure ("can you tell when your blood pressure is high?") and BG ("can you tell when your blood sugar is high/low?").

- **SF-36** (UK version): assesses eight health concepts relevant to functional status and well-being: 1) physical functioning; 2) role limitations due to physical health problems; 3) bodily pain; 4) general health; 5) vitality (energy/fatigue); 6) social functioning; 7) role limitations due to emotional problems; and 8) mental health. The SF-36 is a comprehensive short-form survey with good reliability and validity in both US and UK studies (e.g. Ware, 1993; Jenkinson, Coulter, & Wright, 1993). It has also been used extensively with diabetic and hypertensive patients.
- **32-item COPE:** consists of seven subscales: active coping (eight items), emotion-focused coping (six items), positive reinterpretation & growth (four items), alcohol/drug use (four items), acceptance (four items), denial (four items) and behavioural disengagement (two items). Study 5 (chapter 6) suggested that this shorter version demonstrates good internal reliability and construct validity.
- **Self-Management Questionnaire:** focuses on self-care activities in four areas: medication, diet, exercise, and BG testing (for diabetics only). Each scale consists of two 5-point Likert scales ranging from "never" to "all of the time", with the exception of the dietary scale which contains six items. Each section also contains an open-ended question to elicit common reasons for non-adherence. Health beliefs are measured with 10 items pertaining to the costs and benefits of treatment, rated on a 5-point scale (5 = strongly agree to 1 = strongly disagree) and nine items (eight for hypertensives) measuring perceived susceptibility to complications (the likelihood of developing each complication is rated from 1 = "very unlikely" to 5 = "extremely likely", and 6 = "I already have this problem"). Satisfaction with medical care is measured with two 5-point Likert scales ("1 = "not at all satisfied" to 5 = "extremely satisfied") and an open-ended question asking how current care might be improved. See below for details regarding the design of this questionnaire.

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[4] Scoring was reversed from the original questionnaire so that ratings of 5 indicated strong agreement rather than strong disagreement.

7.3.3 Questionnaire design

The Self-Management Questionnaire assessed adherence, health beliefs, and satisfaction with care. The questionnaire was developed from relevant literature on diabetes and hypertension, since no currently available measures could be applied to both diabetics and hypertensives. However, disease-specific measures were used as a guide in the development of the current questionnaire (e.g. Toobert & Glasgow, 1994; for overview of diabetes-specific measures see Bradley, 1994). The questionnaire can be divided into the following categories:

Adherence/self-management

In line with previous research, adherence to four aspects of the treatment regime was measured: medication, diet, exercise and BG testing (for the diabetic sample only); each section included questions both about general adherence (e.g. "In general, how often are you able to take the medication exactly as suggested by the doctor/nurse?") and behaviour over the previous two weeks (e.g. "In the past two weeks, how many times have you missed taking your medication?"). Although no objective measure of prescribed regime was available, participants were asked to compare their behaviour with their own representation of the recommended treatment. This is consistent with previous studies (Wilson, Ary, Biglan, Glasgow, Toobert, & Campbell 1986) and with the recommendations outlined by Leventhal et al. (1984). An additional question was included to assess whether patients had sought any additional treatments to help manage their illness, since such decisions are likely to be governed by patients' illness representations (Chrisman, 1977; Kleinman, 1980).

Health Beliefs

To assess components of the Health Belief Model, questions on benefits and barriers to treatment and vulnerability to complications were modified from an existing diabetic-specific measure (Lewis & Bradley, 1995) so as to be applicable to both diabetics and hypertensives. Perceptions of illness severity were measured by the IPQ (consequences) so no additional questions were included.

Satisfaction with care

Participants were asked to rate their satisfaction with a) their general medical care and b) the information they had received about their condition. Dissatisfaction with the amount of information provided by health professionals has been found in many studies (e.g. Hall & Dornan, 1988, Williams et al., 1995). In addition, an open-ended question was included to elicit patients' views about how their care might be improved.

7.3.4 Procedure

1. Patients were sent an invitation letter together with Questionnaire 1 (demographic details and Abstract Representation Questionnaire). They were asked to complete a consent slip if they were willing to complete a further questionnaire.
2. Consenting patients were sent a questionnaire booklet containing the IPQ, 32-item COPE, SF-36 and Self-management Questionnaire. A two-week interval was left between receiving the first questionnaire and sending out the second questionnaire.
3. Patients who had failed to return the second questionnaire after a period of 2 weeks were sent a reminder together with another questionnaire.

7.4 RESULTS

7.4.1 Content of illness representations of hypertensive and diabetic patients

An exploration of the content of patients' illness representations (abstract and concrete) using the IPQ was the primary aim of this first section. Although monitoring beliefs were not assessed in the IPQ they are included here since they are particularly pertinent to people's perceptions of illness such as diabetes and hypertension. Higher scores indicate greater confidence in detecting changes in blood pressure/blood glucose. The IPQ was scored in accordance with recommendations (Weinman et al., 1996). The identity component was scored by summing symptoms endorsed at "occasionally" or greater, scores therefore ranged from 0 to 20 for diabetics and 0 to 17 for hypertensives. Patients scoring highly perceived more symptoms. The remaining scales consisted of mean scores (range = 1 to 5). Higher scores indicate perceptions of one's illness as having serious consequences, long duration and as controllable or curable.

Mean scores for patients' abstract (AIPQ) and concrete representations (IPQ) are presented in Table 7.4.1.1. Abstract scores are based on the 549 respondents who completed the first questionnaire (291 diabetics and 258 hypertensives) and concrete scores on the 359 respondents (186 diabetics and 176 hypertensives) who completed the second questionnaire. All analyses are two-tailed unless otherwise stated.

Comparing concrete and abstract representations : Paired t-tests to compare patients' abstract and concrete representations indicated that disease (i.e. hypertension or diabetes) in the abstract was perceived to have more severe consequences ($t = 12.4$, $df = 324$, $p <.0001$) but to have greater controllability ($t = 8.2$, $df = 331$, $p <.0001$). Patients' also felt less confident in their own symptom monitoring skills compared with people in general ($t = 7.8$, $df = 350$, $p <.0001$). There was no significant variation in the perceived duration of the illness (t = .66). Comparing abstract and concrete representations for diabetics and hypertensives separately produced the same results.

Comparing hypertensives and diabetics: Although diabetics reported more symptoms (identity component) than hypertensives,[5] the latter also associated a high number of symptoms with their condition, considering that hypertension is an "asymptomatic" disease. Whilst it is possible that these symptoms may actually be related to other concurrent illnesses, patients appeared to link their symptoms with hypertension. Diabetics perceived their condition to have more severe personal consequences and to have a longer duration than the hypertensive patients. Interestingly, diabetics were less confident about detecting fluctuations in their BG levels compared with hypertensives (confidence in monitoring BP levels), despite their presumably greater awareness of bodily changes through formal BG testing. Patients with hypertension also expressed greater confidence in the controllability of their condition.

Table 7.4.1.1: AIPQ and IPQ mean scores (SD) for combined sample, diabetics and hypertensives, with t-tests comparing the hypertensive and diabetic samples on each subscale

Scale	*Combined*	*Hypertension*	*Diabetes*	*t*
Abstract (AIPQ)				
Consequences	3.11 (0.60)	2.96 (0.58)	3.24 (0.60)	5.33***
Control/Cure	3.58 (0.48)	3.75 (0.44)	3.43 (0.46)	-8.35***
Timeline	4.11 (0.75)	3.76 (0.71)	4.41 (0.64)	11.01***
Monitor	3.17 (0.89)	2.92 (0.84)	3.39 (0.88)[a]	6.28***
Concrete (IPQ)				
Identity[b]	9.01 (4.74)	7.65 (2.67)	10.32 (4.64)	
Consequences	2.70 (0.63)	2.50 (0.58)	2.88 (0.62)	5.75***
Control/Cure	3.35 (0.50)	3.42 (0.57)	3.28 (0.41)	-2.88**
Timeline	4.15 (0.81)	3.84 (0.81)	4.44 (0.70)	7.40***
Monitor	2.74 (1.11)	3.10 (1.08)	2.36 (1.02)[a]	6.58***

**p<.01, ***p<.001

[a] mean score for both monitoring questions

[b] Frequency of symptoms (20 symptoms listed for diabetics, 17 for hypertensives).

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[5] It should be noted that diabetics were given a list of 20 illnesses compared with the 17 presented to hypertensives.

7.4.1.1 Diabetes

Identity

The symptoms associated with diabetes are shown in Table 7.4.1.2. As indicated earlier, the identity component is composed of the sum of symptoms perceived to be associated with the illness. This includes symptoms which are experienced only "occasionally" as well as those experienced "frequently" and "all of the time". It might be assumed, however, that a relatively high number of symptoms will be experienced on an occasional basis whereas it is the number of symptoms experienced more frequently that have greater impact on one's perception of illness. For this reason percentages are given both for the standard scoring system (i.e. symptoms endorsed at "occasionally" or greater) and for those symptoms only experienced more frequently (in brackets). Thus, although the listed symptoms were reported by a high percentage of diabetics on an occasional basis, this declines substantially when we consider only symptoms reported as being more frequently experienced. The implications of this large differential will be discussed in the concluding section. The major symptoms associated with diabetes were: frequent passing of water, tiredness, sleep difficulties, tingling feelings in the feet, and irritability.

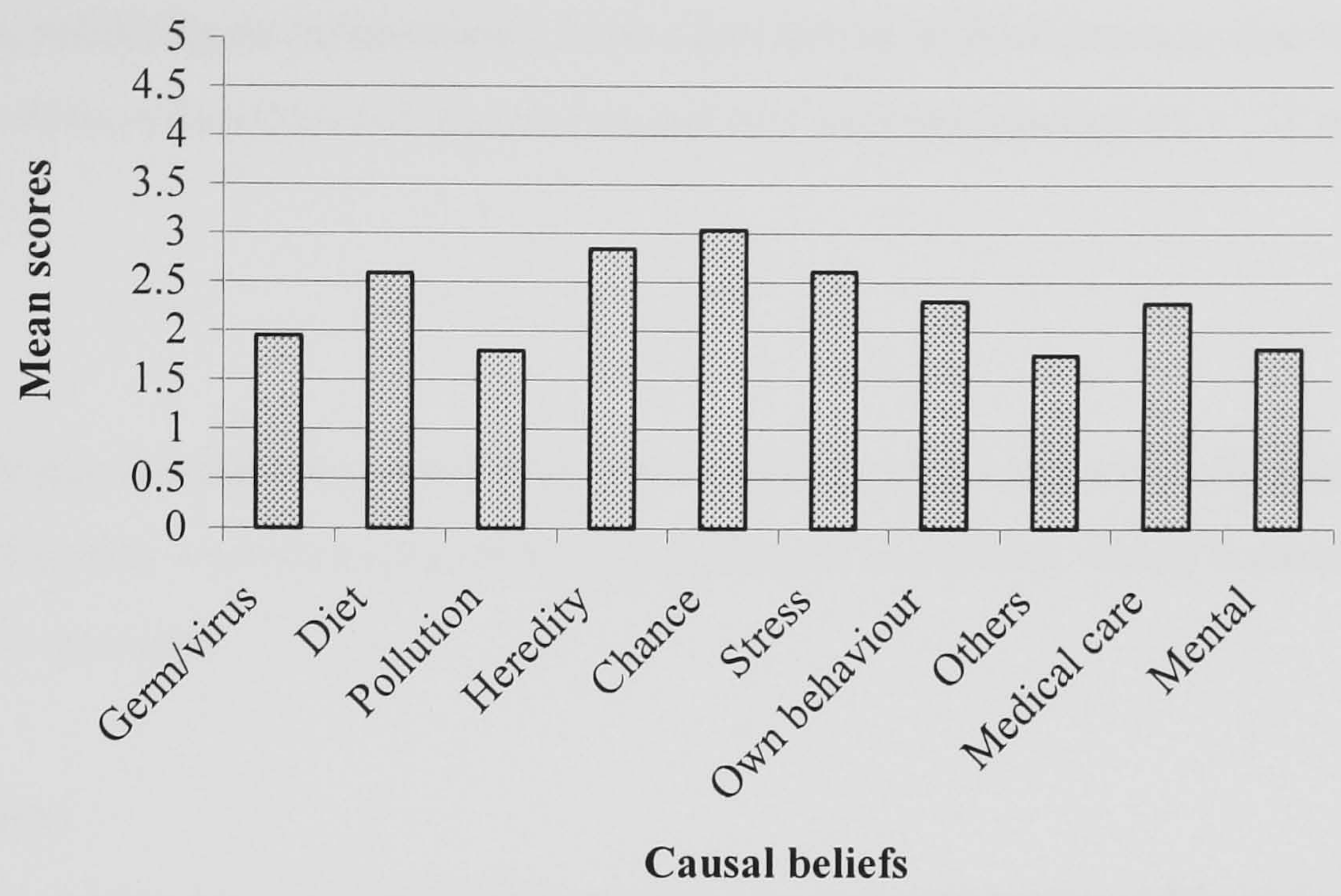
Table 7.4.1.2: Percentage of diabetic participants reporting symptoms "occasionally" or greater *("frequently" or greater)*

Pain	44.7 *(12.3)*	Depression	55.6 *(13.7)*	Sleep difficulties	55.6 *(20.5)*
Nausea	32.5 *(5.3)*	Sore eyes	49.7 *(12.5)*	Feeling hungry	59.3 *(13.2)*
Weight loss	31.3 *(4.4)*	Tiredness	86.9 *(31.4)*	Blurred vision	55.2 *(8.1)*
Loss of strength	64.2 *(12.1)*	Headaches	47.9 *(10.3)*	Chest pain	26.6 *(4.1)*
Breathlessness	47.0 *(11.3)*	Weight gain	57.7 *(16.1)*	Thirst	54.7 *(8.8)*
Freq. urination	83.4 *(33.2)*	Tingling feet	57.8 *(19.9)*	Dizziness	40.2 *(3.0)*
Irritability	76.2 *(19.2)*	Upset stomach	41.7 *(8.3)*		

Causal beliefs

The means for the causal scale for both Type I and II diabetics are shown in Figure 7.4.1.1, and are comparable to those reported by Weinman et al. (1996). Participants were most likely to agree that their diabetes was a result of heredity, chance, diet, and stress. Not surprisingly, diabetes was significantly more likely to be attributed to hereditary factors when family members were also diabetics (t = 11.68, df = 163, p <.0001). The only significant differences between Type I and II diabetics were that Type II diabetics were more likely to attribute their condition to their own behaviour (t = -3.56, p<.0001) and to diet (t = -3.45, p<.001). This is consistent with medical opinion.

Figure 7.4.1.1: Causal beliefs (mean scores) of diabetics



To investigate underlying patterns in patients' causal attributions, principal components analysis (with varimax rotation) was conducted with the causal items of the IPQ. Three factors were extracted, accounting for 60.8% of the total variance (see Table 7.4.1.3).

Table 7.4.1.3: Factor structure of the IPQ cause component for the diabetic sample with loadings for each factor

Causal belief	*Factor 1 (30.8%)*	*Factor 2 (16.4%)*	*Factor 3 (13.6%)*
Germ/virus	**.55**	-.26	-.46
Pollution	**.72**	.15	-.24
Stress	**.52**	.35	.13
Other people	**.70**	.01	.37
Medical care	**.78**	.08	.04
State of mind	**.61**	.44	.15
Diet	.03	**.83**	.01
Own behaviour	.22	**.88**	.08
Heredity	.15	-.09	**.75**

The factor structure indicates a relatively clear pattern of causal attributions, with factor one composed of items which are *uncontrollable*, and factor 2 consisting of behaviours over which the individual can exert control *(controllable)*. State of mind appears to bridge these two factors with loadings above .40 on both factors. The final factor is composed solely of the *heredity* explanation, reflecting its independence from other causal attributions (see also table 7.4.1.6). Cronbach's alpha reliabilities for factors one and two were satisfactory ($\alpha = .73$ and $\alpha = .76$ respectively).

Time line

Not surprisingly, participants agreed that their condition would last a long time (mean = 4.57), reflecting diabetics' awareness that diabetes is a chronic complaint, which is permanent rather than temporary or transient.

Consequences

The diabetic participants perceived their condition as serious (mean = 3.86) and one that had major consequences on their lives (mean = 3.18), although it was less likely to be viewed as affecting the way they saw themselves (mean = 2.74) or the way others viewed them (mean = 2.42). Similarly, the mean score for perceived financial consequences was low (mean = 2.57).

Cure

Participants' expressed a strong belief in their personal control over the disease (mean = 3.96) and its symptoms (mean = 4.10). Consistent with this belief of control, they disagreed that there was little that could be done to improve their diabetes (mean = 2.32), or that recovery was dependent on chance or fate (mean = 2.04). They were also realistic about the long-term prognosis i.e. about their diabetes improving in time (mean = 2.14) and the possibility of cure with treatment (mean = 1.78).

Comparing the illness representations of Type I and Type II diabetics: Mean scores of illness perceptions for Type I and II diabetics are presented in Table 7.4.1.4. Type I diabetics perceived their condition as having more serious consequences and as lasting longer. Type I diabetics were also more confident about their ability to predict high and low BG. This appeared partly to reflect Type Is' greater familiarity with the formal testing procedure, since Type I diabetics tested more frequently than Type IIs (see p.202), and this was significantly correlated with monitoring confidence ($r = .22$; $p<.01$). Monitoring confidence was also related to duration of illness ($r = .27$, p<.001), with Type Is having had diabetes for longer than Type IIs. The previous finding that diabetics were less confident in their monitoring skills compared with hypertensives (Table 7.4.1.1) reflects the lower confidence of Type IIs rather than diabetics in general.

Table 7.4.1.4: AIPQ and IPQ scale mean scores (SD) for Type I and Type II diabetics, with t-tests comparing the two samples on each subscale

Scale	*Type I*	*Type II*	*t*
Abstract			
Consequences	3.25 (0.60)	2.96 (0.58)	1.93 n.s
Control/Cure	3.44 (0.46)	3.75 (0.44)	-3.49**
Timeline	1.41 (0.64)	3.76 (0.71)	4.95***
Monitor	3.74 (0.68)	3.13 (0.90)	6.40***
Concrete			
Identity	10.32 (4.64)	7.65 (2.67)	-0.73 n.s
Consequences	2.88 (0.62)	2.50 (0.58)	3.56***
Control/Cure	3.28 (0.41)	3.45 (0.57)	-1.80 n.s
Timeline	4.44 (0.70)	3.84 (0.81)	3.93***
Monitor	3.59 (0.81)	2.75 (1.10)	5.94***

*p<.05, **p<.01, ***p<.001

7.4.1.2 Hypertension

Identity

The main symptoms associated with hypertension were: stiff joints, sleep difficulties, weight gain, fatigue, breathlessness and irritability.

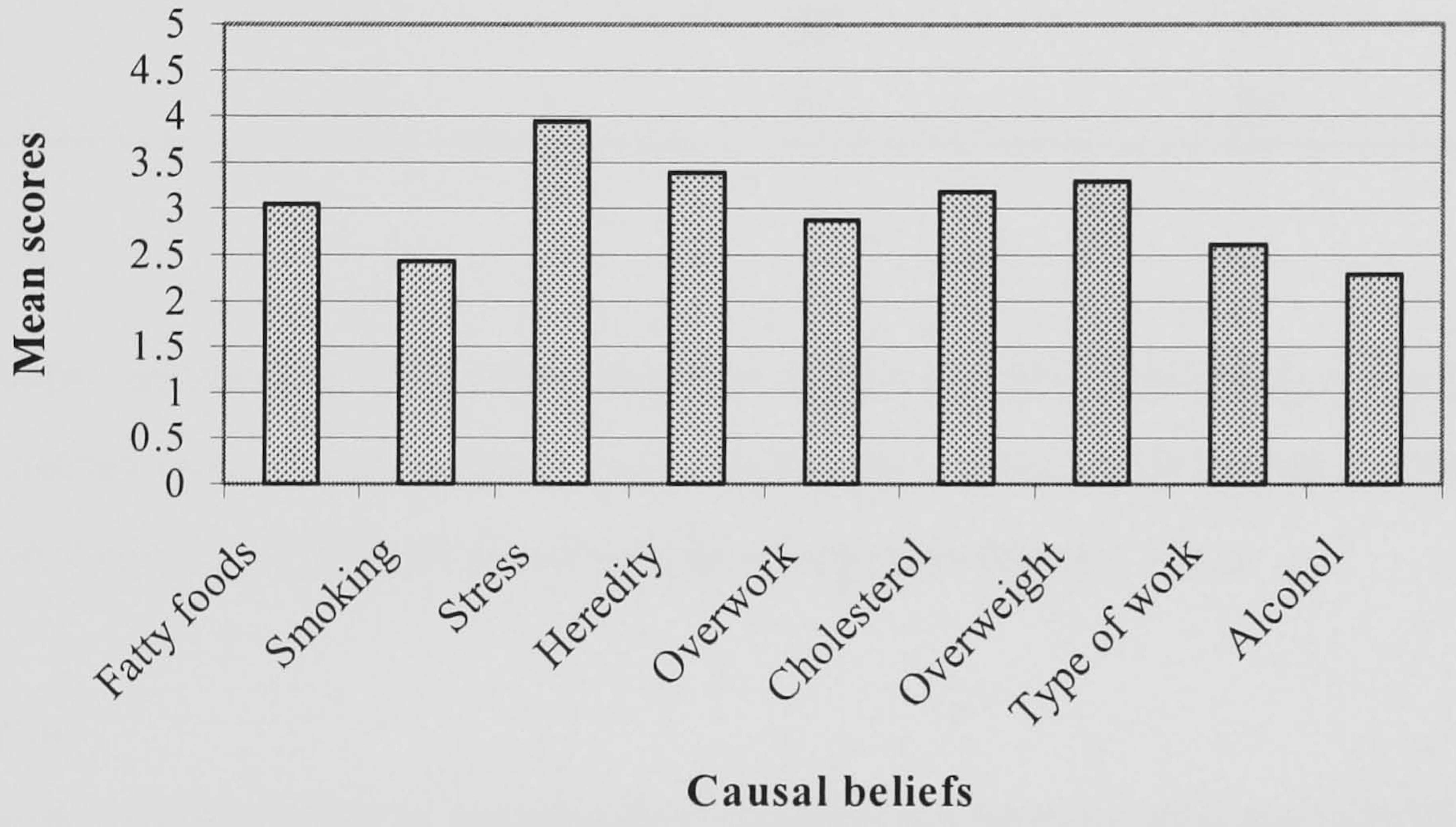
Table 7.4.1.5: Percentage of hypertensive participants reporting symptoms "occasionally" or greater *("frequently" or greater)*

Chest pain	35.5 *(4.8)*	Stiff joints	57.1 *(23.9)*	Weight gain	46.9 *(17.9)*
Nausea	22.1 *(2.5)*	Headaches	54.3 *(12.8)*	Fatigue-walking	52.1 *(13.2)*
Breathlessness	63.1 *(14.9)*	Upset stomach	35.8 *(8.6)*	Palpitations	37.8 *(7.3)*
Weight loss	14.1 *(3.1)*	Sleep difficulties	60.7 *(20.2)*	Irritability	58.8 *(15.8)*
Fatigue	70.9 *(15.8)*	Dizziness	41.0 *(2.4)*	Difficulty concentrating	50.0 *(7.9)*
Sore eyes	38.0 *(8.0)*	Loss of strength	46.3 *(8.1)*		

Cause

Participants' causal beliefs reflected both lay and medical perspectives (See Figure 7.4.1.2). The most commonly endorsed item was the belief that hypertension was caused by stress or worry, consistent with the notion of hyper-tension (Blumenhagen, 1980). Dietary factors were also favoured, specifically being overweight, having high cholesterol, and eating fatty foods. In common with diabetes, heredity was a popular causal explanation. This was more marked among those with hypertensive family members (t = 5.52, df = 156, p <.0001).

Figure 7.4.1.2: Causal beliefs (mean scores) of hypertensives



As with the diabetic sample, principal components analysis was conducted to investigate causal patterns. Similarly, three factors were extracted accounting for 69% of the variance (see Table 7.4.1.6). Although the IPQ contained different causal factors for the two samples, the factor structures show underlying similarities (compare with Table 7.4.1.5). Factor 1 contains dietary/lifestyle factors under the individual's control, whilst factor 2 is largely composed of (external) stressors. Once again, heredity alone forms the final factor. Cronbach's alpha reliabilities for factors one and two were high (α = .85 and α = .78 respectively).

Table 7.4.1.6: Factor structure of the IPQ cause component for hypertensives with loadings for each factor

Causal beliefs	*Factor 1 (44.0%)*	*Factor 2 (13.5%)*	*Factor 3 (11.6%)*
Smoking	**.82**	.20	.03
Alcohol	**.79**	.20	-.05
Fatty foods	**.79**	.18	.09
Overweight	**.72**	.14	-.03
Cholesterol	**.68**	.24	-.07
Overwork	.20	**.87**	.10
Type of work	.26	**.85**	.13
Stress	.23	**.66**	-.24
Heredity	.02	.01	**.97**

Timeline

Whilst diabetics appeared to accept the chronicity of their condition, acceptance was lower amongst hypertensives. However, scores indicate that most participants agreed that their condition was permanent (mean = 3.85) and would last for a long time (mean = 3.71).

Consequences

Hypertensives were less likely to perceive their condition as serious compared with diabetics (mean = 3.40). This is likely to reflect differences in the nature of the two conditions, in which hypertension is a "silent disease" without obvious symptomatology and having less direct impact on daily life. Thus, hypertensives did not perceive their condition as being incumbent on their lives (mean = 2.55), as having an impact on how they saw themselves (mean = 2.44) or how others saw them (mean = 2.02).

Cure

Like the diabetic sample, hypertensives reported strong beliefs concerning their personal control over their condition (mean = 3.92). They felt that there was a lot they could do to control their symptoms (mean = 3.8), and disagreed that little could be done to improve their condition (2.2). Interestingly however, the role of chance/fate in recovery was lent some support (3.46). In terms of disease progression, hypertension was not perceived as improving with time (mean = 2.67), or being cured with treatment (mean = 2.54).

7.4.1.3 Relationships between the components

The relationships between the different components of illness representations for both the abstract and concrete scales are shown in Table 7.4.1.7. Intercorrelations between abstract and concrete scales were highly significant in all cases (see figures in bold). When considering relationships between the IPQ scales, the findings demonstrated face validity and were largely consistent with previous work (e.g. Petrie et al, 1996; Weinman et al., 1996). Experiencing more symptoms (strong illness identity) and perceiving one's illness as long-term (strong time line) were associated with greater perceived consequences. Perceiving one's illness as more controllable[6] was associated with fewer consequences and a shorter illness duration. When looking at diabetics and hypertensives separately, the findings were broadly comparable although beliefs about illness controllability were not significantly associated with illness duration for the hypertensive sample (see Appendix 17, p.A61).

Table 7.4.1.7: Intercorrelations between AIPQ and IPQ scales for total sample

Scale	*Abstract*			*Concrete*		
	Conseq.	*Cure*	*Time*	*Identity*	*Conseq.*	*Cure*
Abstract						
Cure	-.18**					
Time	.12**	-.27**				
Concrete						
Identity	.18**	-.11*	.11			
Conseq.	**.56****	-026**	.17**	.35**		
Cure	.05	**.43****	-.26**	-.06	-.14*	
Time	.02	-.22**	**.53****	.08	.21**	-.33**

*p<.05, **p<.01

7.4.1.4 Reliability of the IPQ and AIPQ

Internal reliability for both the AIPQ and IPQ scales were moderate to good (ranging from .63 for time line to .90 for identity), with the exception of the control/cure scale which was unacceptably low for the diabetic sample (see Table 7.4.1.8). The fact that this scale demonstrated acceptable internal consistency in the hypertensive sample suggests that this finding is disease-specific. Indeed other studies with diabetics have also found low alpha reliability for this scale (Weinman,

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[6] To clarify, controllability is assessed by the cure/controllability scale which is labelled as "cure" in the tables.

1998: personal correspondence). This lack of internal consistency is not surprising when we consider the individual items within the control/cure scale. It can be viewed as containing two potentially independent components, namely beliefs in personal control (e.g. "there is a lot I can do to control my symptoms") and beliefs in treatment (e.g. "My treatment will be effective in curing my diabetes"). This distinction between control and cure is clearly an important one for diabetics, since whilst diabetes can be managed with treatment it cannot be cured. Indeed, when the scale is separated on this basis, alpha reliability rises to .58 for the treatment component and .49 for personal control. Clearly however, this scale is problematic and will therefore be excluded in further analyses conducted with the diabetic sample.

Table 7.4.1.8: Cronbach's alpha reliability for the AIPQ and IPQ scales

Scale	*Diabetes*	*Hypertension*	*All*
Abstract (AIPQ)			
Consequences	.72	.74	.74
Control/Cure	.26	.53	.41
Timeline	.65	.78	.76
Concrete (IPQ)			
Identity	.83	.90	.83
Consequences	.69	.70	.70
Control/Cure	.10	.67	.45
Timeline	.63	.80	.76

7.4.1.5 Health Belief variables

Diabetics perceived both more benefits (t = 3.64, df = 349, p <.001) and costs of treatment (t = 3.43, df = 349, p <.001) than hypertensives, but both samples viewed the benefits of treatment as substantially higher than the costs (perceived cost-effectiveness = 9.81 and 10.00 for diabetics and hypertensives respectively). Both samples placed most importance on taking medication as prescribed (mean = 4.65) and controlling their disease to avoid complications (mean = 4.39). Diet (mean = 3.6) and exercise (mean = 3.9) were perceived as least important, but as incurring the most costs (2.24 and 2.44 for diet and exercise respectively).

Not surprisingly, diabetics also perceived themselves as more susceptible to disease-related complications compared with hypertensives (3.51 vs. 2.86, t = 5.33, p <.001). Specifically, diabetics felt most vulnerable to impaired vision, heart problems, hypertension, foot problems, and numbness in feet/legs. Hypertensives felt most susceptible to angina, impaired vision, heart problems and stroke.

7.4.2 ADHERENCE

7.4.2.1 Incidence of adherence

Adherence or self-management of four areas of the treatment regimen was explored: medication (tablets/insulin), diet, exercise, and blood glucose testing (diabetics only). Ratings ranged from 1 to 5, with a high score indicating greater self-reported adherence. Mean scores for each of the adherence scales are presented in Table 7.4.2.1. Consistent with previous findings, self-reported adherence to medication was higher than to aspects of the treatment regime requiring more substantial life-style changes.

Eighty four percent of diabetics and 91% of hypertensives reported taking medication for their condition. Diabetics reported taking significantly more medication than hypertensives (means = 3.2 and 2.2, $t = 4.5$, $df = 293$, $p<.001$). Consistent with previous findings (e.g. Ley, 1988), the number of prescribed drugs was inversely related to adherence ($r = -.12$, $p <.05$), providing a possible explanation for differences between the two samples (mean adherence = 4.78 for hypertensives and 4.53 for diabetics).

A substantially higher percentage of diabetics than hypertensives reported having dietary recommendations either to control their diabetes (76% vs. 37%) and/or to control their weight (59% vs. 41%). The significantly higher adherence scores of diabetics (3.57 vs. 3.30) suggest that they perceived diet as more central to their treatment regime compared with hypertensives. Indeed, diabetics were more likely to perceive diet as helpful in controlling their condition compared with hypertensives (means = 3.96 and 3.30 respectively; $t = 6.5$, $df = 346$, $p<.001$).

Only 41% of diabetics and 40% of hypertensives reported that exercise was part of their recommended treatment regime. As found in previous studies (e.g. Ary, Toobert, Wilson, & Glasgow 1986; Surwit, Scovern, & Feinglos, 1982), adherence to such regimes was low with no significant differences between the two patient groups.

Monitoring of blood glucose (using BG tests) also proved problematic for diabetics. Patients' level of BG testing was below the recommended level (Cox et al., 1986), with only 29% of Type I diabetics reporting three or more tests per day. However, Type I diabetics tested more frequently than their Type II counterparts (means of 12.8 and 4.3 tests per week respectively, t = 6.3, df=108, p<.0001). Patients' open-ended responses revealed that many were unaware that they were testing below recommended levels and felt that they were adhering to recommendations either by testing infrequently or under special circumstances. For example, some patients reported obtaining detailed profiles at regular intervals e.g. for clinic records, but did not test regularly outside profiling. Others reported increasing the number of tests during illness or when results were higher/lower than normal. Indeed no clear guidelines appeared to exist as to what the recommended level of testing is, particularly for Type II diabetes.

Table 7.4.2.1: Mean adherence scores (SD) for all participants, hypertensives and diabetics, with t-tests comparing the two samples on each subscale

Scale	*All*	*N*	*Hypertension*	*N*	*Diabetes*	*N*	*t*
Drugs	4.65 (0.54)	300	4.78 (0.43)	147	4.53 (0.60)	153	-4.28***
Diet	3.57 (0.56)	224	3.30 (0.54)	81	3.72 (0.52)	143	5.62***
Exercise	3.33 (1.13)	170	3.45 (1.13)	77	3.23 (1.13)	93	-1.25 ns
BG tests	-		-		3.64 (1.13)	155	

*p<.05, **p<.01, ***p<.001

There were no significant differences between Type I and Type II diabetics on any of the remaining scales. Gender comparisons were also conducted for each of the adherence scales, but revealed no differences for either the hypertensive or diabetic sample.

7.4.2.2 Scale intercorrelations

Whilst rates of adherence varied considerably for different aspects of the treatment regime, Table 7.4.2.2 indicates that there were significant correlations between the scales. Not surprisingly, the strongest relationship was found between diet and exercise since both entail considerable life-style changes. However, adherence to dietary recommendations also demonstrated a positive relationship with adherence to both medication and BG monitoring.

Table 7.4.2.2: Intercorrelations between adherence scales for total sample

Scale	*Drugs*	*Diet*	*Exercise*
Drugs			
Diet	.35***		
Exercise	.13	.58***	
BG tests	.18*	.34***	.19

7.4.2.3 Illness representations, health beliefs and adherence

There were three hypotheses relating to adherence. The first suggested that patients' concrete representations would demonstrate a stronger relationship with adherence than abstract representations. In order to explore the relationships between illness representations and adherence, Pearson's correlation coefficients were calculated (for total, hypertensive and diabetic sample[7]). Contrary to expectations, neither abstract nor concrete representations were strongly correlated with adherence. Indeed, there were no significant relationships for the hypertensive sample, and only the perception of serious consequences (concrete) was significantly associated with exercising for diabetics ($r = -.22$, $p < .05$). When the two illnesses were combined, beliefs about illness duration demonstrated a positive relationship with dietary adherence i.e. perceptions of illness as chronic were associated with higher levels of adherence. This applied to both concrete and abstract representations ($r = .26$ and .22 respectively, $p < .01$). Correlation coefficients were also calculated to investigate the relationship between people's causal beliefs[8] and adherence. However, no significant relationships were found for any of the adherence scales.

This clearly has implications for the remaining two hypotheses, namely that a) illness representations will explain a significant amount of the variance in self-reported adherence (for the 4 scales) and b) Health Belief variables will significantly add to this predictive model. Correlations were computed to explore the relationship between the Health Belief variables and adherence. Beliefs about the costs and benefits of treatment were significantly correlated with adherence for both samples, particularly for diet and exercise (with costs ranging from -.22 ($p < .05$) to -.46 ($p < .01$) and benefits ranging from .22 ($p < .05$) to .38 ($p < .01$). Perceptions of susceptibility to complications and perceptions of seriousness were not significantly related to adherence for either sample.

In order to control for the effect of demographic factors, correlation coefficients were calculated between the four adherence scales and demographic variables (age, duration of condition and educational level). Only age was significantly correlated with adherence to all four aspects of the treatment regimen ($p < .05$).

A series of hierarchical multiple regressions were conducted for each adherence scale, with age entered at the first step. For adherence to medication and BG testing, two-level regressions were

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[7] Due to the low reliability of the control/cure component for the diabetic sample, this component was not included in any analysis involving the diabetic sample.

[8] Using factor mean scores.

conducted: a) age, b) costs and benefits. For diet and exercise, 3-level regression analyses were conducted to include illness representations at the second step. For diet: a) age, b) timeline, c) costs and benefits. For exercise: a) age, b) consequences, c) costs and benefits. The analyses were performed with listwise deletion of missing variables. Prior to analysis, the data were checked for evaluation of assumptions leading to the reflection and logarithmic transformation of the drug adherence scale which was negatively skewed prior to transformation (Tabachnick & Fidell, 1996). The results are summarized in Table 7.4.2.3.

The results of the analyses indicated that, of the illness representation variables, only timeline accounted for a significant amount of variance (for diet). As hypothesized, health beliefs variables accounted for a significant amount of further variance in this equation (i.e. diet). The perceived costs and benefits of treatment were moderately successful in predicting adherence to diet and exercise recommendations, particularly for diabetics, but were poor predictors of both medication and BG tests. Older patients were more likely to follow recommendations for medication, diet, and BG testing (diabetics only).

Medication: The regressions were able to explain only 3-9% of the variance in adherence to medication. This is likely to reflect, in part, the low variability in this scale with 98% of patients reporting adhering to their regime "most of the time" (34%) or "all of the time" (64%). Age was the primary predictor of medication. Beliefs only accounted for 3% of the variance (combined sample) with the perceived costs of treatment being negatively associated with taking medication.

Diet: Time line (i.e. perceiving one's illness as chronic) accounted for only 4% of the variance in the diabetic sample (11% in the combined sample). Health beliefs accounted for a further 21% of the variance in dietary adherence for diabetics. In contrast, age was the sole predictor for the hypertensive group (11%). Although bivariate correlations indicated that both costs and benefits were significantly related to reports of dietary adherence ($r = -.22$ and $r = .22$, $p < .05$ respectively), neither significantly added to the variance already explained by age in the regression analysis. When comparing the differential effects for the diabetic and hypertensive samples, it is interesting to note that diabetics rated diet as more important in controlling their condition than hypertensives (means 3.96 and 3.30; $t = 6.55$, $df = 346$, $p<.0001$).

Table 7.4.2.3: Results of hierarchical regression to predict adherence to medication, diet, exercise and blood glucose monitoring

Variables	Combined Multiple R	Combined Beta	Combined sr^2	Hypertension Multiple R	Hypertension Beta	Hypertension sr^2	Diabetes Multiple R	Diabetes Beta	Diabetes sr^2
Drugs									
1. Age	.27	$.27^a$	.07***	.25	$.25^a$	.6**	.20	$.20^a$	.04*
2. Costs	.31	$-.16^a$	.03**						
	Adj R^2 = .09	F (2,289) =	15.58***	**Adj R^2 = .06**	F (1,139) =	9.45**	**Adj R^2 = .03**	F (1,149) =	6.12*
Diet									
1. Age	.20	.20	.04**	.34	.34	.11**	.25	.25	.06**
2. Time line	.39	.34	.11***	.38	.07	.03 ns	.32.	.21	.04*
3. Benefits	.52	.35	.12***				.53	.43	.18***
Costs							.56	-.19	.03*
	Adj R^2 = .26	**F (3,209) =**	**26.03*** **	**Adj R^2 = .12**	**F (1,77) =**	**6.41*** **	**Adj R^2 = .31**	**F (4,131) =**	**14.10*** **
Exercise									
1. Age	.14	.14	.02 ns	.21	.21	.05 ns	.07	.07	.01 ns
2. Costs	.42	-.40	.15***	.44	-.39	.15***	.40	-.39	.15***
Benefits	.46	.21	.04**						
	Adj R^2 = .20	**F (3,154) =**	**13.45*** **	**Adj R^2 = .17**	**F (2,72) =**	**8.47*** **	**Adj R^2 = .14**	**F (2,81) =**	**7.34*** **
BG Tests									
1. Age							.21	.21	.05**
2. Benefits							.27	.17	.03*
							Adj R^2 = .06	**F (2, 149) =**	**5.67*** **

*p<.05, ** p<.01, *** p<.00

[a] Although the drug scale has been reflected and logarithmically transformed (to correct negative skewness), the Beta coefficients have been reversed for ease of interpretation to reflect their true relationship with the independent variables.

Exercise: The perceived cost of treatment was the sole predictor of exercise for diabetics and hypertensives, accounting for 15% of the variance in both analyses. The importance of patients' beliefs about costs is particularly highlighted when the relationship between specific costs and exercise adherence is explored. The item "I find exercising inconvenient" correlates at -.6 and above ($p<.0001$) for both samples (for diabetics, $r = -.62$; for hypertensives, $r = -.60$). When the exercise-specific costs and benefits are entered into a regression analysis, the predictive power is increased substantially to explain 42% of the variance ($F (3,161) = 40.45$, $p<.0001$), of which 35% is due to perceived costs.

BG Testing: Like adherence to medication, health beliefs exerted minimal impact on testing for blood glucose, accounting for only 3% of the explained variance over and above age.

7.4.2.4 Open-ended responses

In addition to the Likert response scales, participants were asked to describe reasons for not following the recommended treatment for each aspect of self-care in order to explore motivational factors underlying adherence. Content analysis of responses yielded similar results for both the diabetic and hypertensive samples. To assess the reliability of the coding scheme, 30 randomly selected questionnaires (15 diabetic and 15 hypertensive) were coded by an independent researcher blind to the aims of the study. The researcher was given a list of categories for each aspect of self care: medication (3), diet (5), exercise (5), and BG tests (8)[9]. These categories are described in detail below. Two additional categories were provided for a) miscellaneous responses and b) no response (i.e. when the participant did not respond to the question). Inter-rater reliability exceeded 90% for all four self-care activities: medication (97%), diet (90%), exercise (93%), and BG tests (100%).

Medication

It was clear that the majority of participants recognized the importance of medication in controlling their condition[10], and that non-adherence was largely accidental rather than volitional. Indeed, the link between medication and avoiding complications was often a motivating factor:

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[9] For diabetic questionnaires only.

[10] This finding mirrored participants' agreement with the Health Belief item "It is important to take all my medication at the times recommended by the doctor if I am to achieve good control of my diabetes/hypertension" (mean = 4.7).

> *"The main method by which I convince myself to continue to monitor/treat etc my diabetes is by persuading myself that I will prevent these conditions (complications) occurring"* (Patient 315: male 57 years; Type I diabetic).

Similarly,

> *"The thought of a CVA makes me very compliant, and family history"* (Patient 587: male 50 years; hypertensive).

The main reasons cited for departures from the regime were occasional forgetfulness (20% of hypertensives and 27% of diabetics) and disruption to one's routine (22% and 17% respectively). A minority of diabetics (5%) stated that they modified the timing of injections but did not miss the medication itself.

Diet

Social pressures and eating away from home were the main reasons cited for departing from dietary recommendations (15% of hypertensives and 22% of diabetics)[11]. Indeed social events are a means by which the disease aspect of the self is emphasized and some patients expressed the need to deviate from their dietary regimen in order to feel "normal".

> *"Christmas is particularly difficult as one's peers are busy tucking into the forbidden foods. Embarrassment - not wishing to draw attention to oneself"* (Patient 250: male 40 years; Type I diabetes).

Other reasons largely revolved around the monotony of the diet itself, such as liking food, particularly forbidden foods (7% of hypertensives and 16% of diabetics), boredom (6% and 11% respectively), lack of self-discipline (11% and 6% respectively), and occasional indulgence, especially in sweet foods (12% and 11% respectively).

However, several patients spoke of the importance of balancing dietary requirements with overall quality of life, favoring moderation over rigid dietary adherence:

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[11] However, participants agreement with the health belief statement "sticking to a diet interferes with my social life" was low (mean = 2.3).

> *"I do not intend to live the rest of my life depriving myself of everything I like to eat and drink because I am a diabetic* (Patient 51: male; Type II diabetic).

> *"I don't feel ill if I deviate a little"* (Patient 443: male 66 years; Type II diabetic).

Exercise

The most common reasons cited for not exercising as recommended were: lack of time (25% of hypertensives and 24% of diabetics), lack of self-discipline (13% and 15% respectively), and physical limitations (22% and 8% respectively). Other respondents stated that factors such as bad weather (8% for both samples) and fatigue (8% and 6% respectively) were responsible.

BG Tests

A number of different explanations were proffered for failing to test BG levels, which may explain the poor predictive power of the regression model. For some diabetics, BG tests had either not been recommended (9%), or no specific number had been advised (3%). A further 8% relied on the tests given by health professionals. In common with medication adherence, some reported simply forgetting (6%) or being out/too busy (12%).

Consistent with previous findings (Hampson, Glasgow & Toobert, 1990) some diabetics relied on their subjective interpretations of symptoms to assess their BG levels (7%):

> *"I seem to know if it is high or low by my temper"* (Patient 130: male 59 years; Type II diabetes).

Others used symptoms as prompts to BG testing, or tested only when they anticipated fluctuations (8%):

> *"It's to do with the "feel good factor" - if I feel OK I don't check them. However, sometimes I don't feel 100% and use the meter to check them"* (No. 34, male: 52 yrs; Type II diabetes).

Although such biased testing can result in inaccurate perceptions of the link between symptomatology and BG, validation of subjective perceptions with BG tests may also lead to accurate interpretation. Systematic feedback to improve judgements of covariation between symptoms and BG has been used successfully in training programs (Gonder-Frederick & Cox, 1991).

> *"When I know what my blood sugar is I sometimes check it with Medisense tests and it's nearly always within 1 digit of the reading (45 years experience!)"* (Patient 377: female 54 years; Type I diabetes).

Although regular testing of BG is important in managing diabetes effectively and avoiding complications, 7% of patients mention the difficulties and unpleasantness associated with testing, as illustrated by the following explanation of why BG tests are not carried out:

> *"because I am lazy, because it hurts, because my fingers become like pin cushions and as I have a dirty job the pin pricks become full of grime. I have been told to get blood from my ear lobes, it is very difficult. Have you tried?"* (Patient 64: male 55 years; Type I)

On a more positive note, monitoring blood glucose can also provide a sense of control over one's illness:

> *"Close personal monitoring can relieve the unpleasant effects of the illness and allow a relatively good quality of life"* (Patient 266: male 62 years; Type I diabetic).

7.4.3. COPING

A further aim of the study was to: a) assess the internal reliability of the short-form COPE that was developed in the previous study, and b) to investigate the relationship between patients' illness representations and coping strategies.

7.4.3.1 Internal reliability and scale intercorrelations

Cronbach alpha reliability coefficients for the seven COPE scales established in Studies 4 and 5 are presented in Table 7.4.3.1. All scales exceeded the basic criteria of .6 with the exception of the denial scale for the diabetic (and combined) sample. The internal consistency of the six remaining scales was higher than in the previous study, exceeding .7 for those scales with four or more items.

Table 7.4.3.1: Cronbach's alpha reliabilities for the COPE scales

COPE scales	Combined	Hypertension	Diabetes
Active	.87	.90	.83[a]
Emotion-focused	.82	.85	.82[b]
Positive reinterpretation	.77	.80	.72
Drug use	.91	.90	.92
Denial	.57	.60	.54
Acceptance	.81	.79	.81
Behavioural disengagement	.67	.68	.66[c]

Note: Range of possible values is 4-16, with the following exceptions:
[a] 8-32 (8 items)
[b] 6-24 (6 items)
[c] 2-8 (2 items).

Correlations among the COPE subscales are presented in Table 7.4.3. Active coping, emotion-focused coping, growth and acceptance all demonstrated positive relationships with each other. Behavioural disengagement, alcohol/drug use and denial, strategies of questionable adaptive value, were also intercorrelated. Consistent with previous findings (e.g. Carver et al., 1989), emotion-focused coping was strongly correlated with scales conventionally seen as adaptive (e.g. active growth and acceptance) and non-adaptive (drug use and behavioural disengagement). Whether it acts as an adaptive tool therefore appears to depend on the other strategies employed in conjunction with emotional outlet.

Table 7.4.3.2: Correlations among COPE scales

Scales	1	2	3	4	5	6
1. Active						
2. Emotion	.48***					
3. Growth	.59***	.41***				
4. Drug use	.01	.22***	.04			
5. Denial	-.08	.08	.06	.17*		
6. Accept	.39***	.15**	.48***	.00	-.01	
7. B.D	.10	.34***	.12*	.37***	.38***	.04

*p<.05, **p<.01, ***p<.001

7.4.3.2 Means of the short-form COPE

The means for each of the short-form COPE subscales are presented in Table 7.4.3.3. A comparison with Study 5 indicates that the individual coping strategies were employed less frequently in the current study (i.e. mean scores were lower than in the previous study; see Table 6.4.1, p.175), particularly active and emotion-focused coping.

ANOVAs were conducted by gender and illness. Diabetics scored significantly higher on active coping (F = 4.16, df= 1/334, p <.05), emotion-focused coping (F = 6.14, df= 1/342, p <.01), positive reinterpretation and growth (F = 12.10, df= 1/333, p <.001), acceptance (F = 11.34, df = 1/344, p <.001) and behavioural disengagement (F = 4.82, df= 1/347, p <.05). Females were significantly more likely to use emotion-focused coping than males (means = 10.67 vs 9.62; F = 8.42, df= 1/342, p <.01), but were less likely to engage in drug/alcohol use (means = 4.56 vs 5.01; F = 3.25, df= 1/348, p <.07). There were no significant interactions between illness and gender.

Table 7.4.3.3: COPE mean scores (SD) for combined, hypertensive, and diabetic sample

COPE scale	Combined	Hypertension	Diabetes
Active	17.12 (6.20)	16.50 (6.62)	17.70 (5.74)
Emotion-focused	10.06 (3.92)	9.63 (3.88)	10.46 (3.92)
Positive reinterpretation	8.86 (3.36)	8.17 (3.42)	9.50 (3.18)
Drug use	4.82 (2.18)	4.74 (2.00)	4.89 (2.34)
Denial	5.88 (2.32)	5.96 (2.43)	5.80 (2.21)
Acceptance	12.70 (3.43)	12.00 (3.52)	13.35 (3.21)
Behavioural disengagement	2.96 (1.43)	2.80 (1.37)	3.11 (1.49)

7.4.3.3 Relationship between illness representations and coping

The relationship between patients' illness representations and their use of coping strategies was examined using Pearson's correlations which are presented in Table 7.4.3.4. As hypothesized, a strong illness identity was associated with emotion-focused coping and avoidant strategies (drug use, denial and behavioural disengagement). In contrast, perceiving illness as having serious consequences was associated with adaptive and maladaptive strategies including active coping, emotion-focused coping, positive reinterpretation and growth, drug/alcohol use and behavioural disengagement[12]. Beliefs about the illness lasting a long time were related to acceptance and

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[12] It was hypothesized that perceptions of serious consequences would be associated with avoidant and emotion-focused coping strategies.

positive reinterpretation and growth. Belief in one's ability to monitor blood pressure or blood glucose levels was significantly associated with all the COPE's subscales with the exception of denial. Of course, monitoring confidence may itself form an important coping strategy by which people resume control over their physiological condition.

Table 7.4.3.4: Correlations between illness representations and the COPE scales

Scale	Active	Emotion	Growth	Drugs	Denial	Accept	BD
Identity	.09	.32***	.10	.34***	.19***	-.01	.45***
Conseq.	.21***	.36***	.23***	.28***	.09	.09	.35***
Time	.10	.03	.15**	.05	-.08	.31***	.02
Monitor	.18**	.22***	.35***	.18***	-.03	.17***	.13**

*p<.05, **p<.01, ***p<.001

7.4.4 FUNCTIONING

The SF-36 was scored according to the recommendations of standardization in the SF-36 manual (Ware, 1993). Higher scores indicate a better health state.

7.4.4.1 Internal reliability of the SF-36

Alpha coefficients for the SF-36 scales were good, ranging from .70 to .92 (see table 7.4.4.1) and were comparable with previous UK psychometric studies (Brazier, Harper, Jones, et al., 1992; Jenkinson, Coulter & Wright, 1993; Garratt, Ruta, Abdalla, et al., 1993).

Table 7.4.4.1: Cronbach's alpha reliability for the SF-36 scales

Scale	Combined	Hypertension	Diabetes
Physical functioning	.91	.90	.92
Role-physical	.88	.91	.86
Bodily pain	.90	.90	.90
General health	.73	.70	.74
Vitality	.84	.84	.83
Social functioning	.79	.85	.75
Role-emotion	.82	.87	.78
Mental health	.82	.82	.83

7.4.4.2 Mean scores for the subscales of the SF-36

Means scores for each of the SF-36 scales are presented in Table 7.4.4.2. Comparison with the normative data for both hypertensives and diabetics provided in the manual (Ware, 1993) indicate comparable scores, although physical role functioning was higher for both samples in the current study.

Two-way ANOVAs were conducted by illness and gender. Consistent with previous findings (e.g. Brazier et al., 1992) females reported lower perceptions of health than males (see Fig 7.4.4.2). Female scores were significantly lower on the following dimensions: physical functioning ($F = 4.81$, df= 1/358, $p < .05$), role-physical ($F = 5.05$, df= 1/348, $p < .05$), bodily pain ($F = 4.34$, df= 1/358, $p < .05$), vitality ($F = 9.41$, df= 1/354, $p < .01$), and mental health ($F = 5.11$, df= 1/354, $p < .05$). Diabetics reported significantly lower scores for bodily pain ($F = 12.40$, df= 1/358, $p < .001$), general health ($F = 17.44$, df= 1/358, $p < .001$), vitality ($F = 8.45$, df= 1/358, $p < .01$), and social functioning ($F = 6.17$, df= 1/358, $p < .05$). There were no interactions between gender and illness. T-tests revealed no significant differences between Type I and Type II diabetics.

Table 7.4.4.2: Mean scores (SD) on the eight SF-36 dimensions for combined sample, hypertensives and diabetics

Scale	Combined	Hypertension	Diabetes
Physical functioning	76.61 (23.47)	77.55 (22.11)	75.70 (24.72)
Role-physical	73.04 (37.96)	76.01 (37.68)	70.16 (38.10)
Bodily pain	73.44 (24.45)	77.58 (22.36)	69.47 (25.74)
General health	64.75 (18.64)	68.80 (17.18)	60.76 (19.20)
Vitality	57.67 (20.27)	60.22 (19.61)	55.20 (20.65)
Social functioning	84.05 (22.79)	86.79 (21.96)	81.41 (23.32)
Role-emotion	80.29 (33.98)	83.14 (33.14)	77.53 (34.64)
Mental health	74.71 (17.63)	75.61 (17.87)	73.83 (17.39)

7.4.4.3 Functioning and the self-regulatory model

The principal aim was to explore the relationship between patients' illness representations, coping responses and their self-reported functioning. This was explored through a series of regression analyses. Correlation tables are presented in Appendix 18 (p.A62) to illustrate the relationships between the eight SF-36 scales, and subscales of the IPQ and short-form COPE for both the hypertensive and diabetic samples (Appendix 18: Table 1 and 2 respectively).

There were two primary hypotheses: a) that coping would explain a significant amount of the variance in functioning (for the eight SF-36 scales), and b) illness representations would account for a significant amount of variance over and above that explained by coping. A series of hierarchical regression analyses were conducted to test these hypotheses. Age was entered in the first block, once again acting as a control variable. Coping styles (active, emotion-focused, drug use, positive reinterpretation and growth, acceptance, behavioural disengagement, and denial) were entered in the second block, followed by illness representations variables (identity, time line, consequences, plus the additional monitoring scale)[13] in the third step. If illness representations have a direct impact on functioning as suggested by previous findings (e.g. Moss-Morris et al, 1994; Earll, 1994), then the representational components will continue to add to the prediction of functioning over and above the coping strategies employed. A summary of the analyses is presented in Table 7.4.4.3.

The regression models accounted for between 14% and 50% of the variance in functioning. More variance was explained in the hypertensive sample (26-50%) compared with diabetics (14-39%). Age was a significant predictor of physical functioning (accounting for 8%-9% of the variance) and mental health (5%-11%) in both samples, and social functioning for diabetics (4%). Whilst age, not surprisingly, demonstrated an inverse relationship with physical functioning, it was positively associated with both mental health and social functioning.

As hypothesized, coping strategies significantly predicted functioning although there was considerable variation between the eight scales, with coping strategies accounting for between 6% and 41% of the variance beyond that explained by age. Although the majority of coping strategies selected by the regression were inversely related to functioning (i.e. avoidant and emotion-focused strategies were associated with poorer functioning) for both hypertensives and diabetics, there were some differences between the two samples. For hypertensives, behavioural disengagement was the main strategy associated with poorer functioning for *all* of the SF-36 scales and was the sole predictor (in block 2) for physical functioning (18% of the variance), physical role limitations (26%), and bodily pain (6%). For diabetics on the other hand, emotion-focused coping rather than behavioural disengagement was a better predictor of physical and social functioning (7% and 15%

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[13] The control/cure component was omitted from all analyses due to its low internal reliability in the diabetic sample and non-significant correlation with all functioning scales for the hypertensive sample.

Table 7.4.4.3: Summary of hierarchical multiple regression predicting functioning by coping and illness representations

	Combined		Hypertension		Diabetes	
Variables	**Beta**	sr^2	**Beta**	sr^2	**Beta**	sr^2
PF scale						
1. Age	-.28	.08***	-.30	.09***	-.29	.08***
2. B.D	-.28	.08***	-.43	.18***		
Emotion	-.18	.03**			-.27	.07***
3. Identity	-.30	.07***	-.22	.04**	-.40	.08***
Conseq.	-.15	.02*	-.29	.07***		
		Adj R^2=.26		**Adj R^2=.36**		**Adj R^2=.22**
RP scale						
1. Age	-.09	.01 ns	-.13	.02 ns	-.08	.01 ns
2. B.D	-.35	.12***	-.51	.26***		
Drug use	-.18	.03**			-.26	.07**
Growth	-.14	.02**	-.18	.03*		
Emotion					-.23	.05**
3. Identity	-.32	.08***	-.35	.09***	-.25	.05***
		Adj R^2=.25		**Adj R^2=.38**		**Adj R^2=.14**
BP scale						
1. Age	-.04	0	-.10	.01 ns	.07	.01 ns
2. B.D	-.33	.11***	-.40	.06***		
Emotion	-.21	.03***			-.34	.11***
3. Identity	-.35	.10***	-.39	.12***	-.29	.07***
		Adj R^2=.24		**Adj R^2=.27**		**Adj R^2=.17**
GH scale						
1. Age	-.13	.02*	.14	.02 ns	.06	0
2. B.D	-.38	.15***	-.41	.16***	-.34	.12***
Drug use	-.20	.03***	-.21	.04**	-.21	.04**
Emotion	-.13	.01*				
3. Identity	-.34	.09***	-.28	.07***	-.36	.11***
Conseq.	-.15	.02**			-.17	.02**
		Adj R^2=.30		**Adj R^2=.26**		**Adj R^2=.27**
VT scale						
1. Age	.06	0 ns	.15	.02 ns	-.04	0
2. B.D	-.39	.16***	-.50	.25***	-.27	.08***
Emotion	-.19	.03***	-.24	.05**	-.28	.06**
Growth	.17	.02**			.26	.07***
3. Identity	-.46	.16***	-.41	.13***	-.43	.15***
		Adj R^2=.36		**Adj R^2=.43**		**Adj R^2=.32**
SF scale						
1. Age	.15	.02*	.02	0	.21	.04**
2. B.D	-.43	.18***	-.55	.30***		
Emotion	-.26	.05***	-.26	.02*	-.39	.15***
Drug use	-.20	.03***	-.26	.05***	-.25	.06***
Accept					.15	.02*
3. Identity	-.28	.07***	-.28	.06***	-.36	.10***
Conseq.	-.16	.02**			-.21	.04***
		Adj R^2=.36		**Adj R^2=.39**		**Adj R^2=.38**
RE scale						
1. Age	.08	.01 ns	.15	.02	.01	0
2. B.D	-.50	.25***	-.55	.30***	-.44	.19***
Emotion	-.27	.06***	-.30	.07***	-.24	.05**
Drug use	-.24	.05***	-.22	.04**	-.25	.06**
Growth					.16	.02*
3. Identity	-.18	.02***	-.17	.02*	-.17	.02**
		Adj R^2=.37		**Adj R^2=.44**		**Adj R^2=.31**
MH scale						
1. Age	.27	.07***	.33	.11***	.22	.05**
2. B.D	-.44	.19***	-.50	.24***	-.38	.15***
Emotion	-.27	.06***	-.27	.06***	-.28	.06***
Growth	.20	.03***			.30	.08***
Drug use	-.18	.03***	-.21	.03**	-.17	.03*
Accept	.11	.01*	.13	.02*		
3. Identity	-.28	.06***	-.28	.05***	-.28	.06***
		Adj R^2=.44		**Adj R^2=.50**		**Adj R^2=.39**

(PF = physical functioning, RP = role limitations-physical, BP = bodily pain, GH = general health, VT = vitality, SF = social functioning, RE = role limitations-emotional, MH = mental health).

respectively), physical role limitations (5%), and pain (11%). However, behavioural disengagement also accounted for the majority of the variance (from block 2) in the remaining four SF-36 scales (accounting for between 8% and 19% of the variance).

Whilst behavioural disengagement and emotion-focused coping were the principal predictor variables (from block 2), several other strategies were also selected by the regression equation. Use of drugs or alcohol was associated with greater physical (diabetes only) and emotional role limitations, and poorer general health, social functioning, and mental health. However, it accounted for only 3-7% of the total variance. Only acceptance and positive reinterpretation & growth were positively related to functioning, although there was some variation between the two samples. Positive reinterpretation & growth was associated with vitality (7%), mental health (8%) and fewer emotional role limitations (2%) for the diabetic sample. For hypertensives on the other hand, positive reinterpretation was negatively associated with physical role limitations (i.e. was associated with poorer functioning) although accounting for only 2% of the total variance[14]. Acceptance was, however, positively related to the mental health scale for hypertensives, but added only 2% to the explanatory equation.

Illness representations (identity and consequences) continued to contribute significantly to the regression model for all the SF-36 scales, but had relatively low explanatory power above that of age and coping (2% to 16%). Their contribution was most notable for vitality (13-16%). Identity accounted for the majority of the variance and was the sole variable selected (in block 3) for five of the eight scales.

The results of the hierarchical regressions demonstrated that: a) coping strategies alone explained moderate amounts of the variance in functioning (6%-41%), and b) illness representations exerted a small, but significant effect beyond that explained by coping. These findings support the hypotheses. In addition, they suggest that coping may act as a mediator between illness representations and functioning, as proposed by the self-regulatory model. Further regression analyses (stepwise) were also conducted to examine the independent effect of illness representations on the eight SF-36 scales[15]. These are described below and summarised in Table 7.4.4.4.

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[14] Pearson correlations for the remaining scales supported this trend, with significant inverse correlations for both social functioning ($r = -.17$, $p < .05$) and emotional role limitations ($r = -.24$, $P < .001$).

[15] To test whether the relationships between illness representations and the scales of the SF-36 were stronger than the relationships when coping had already been partialled out as in the analysis above).

Illness perceptions and functioning

Illness representations alone predicted between 14% and 36% of the variance in functioning. Consistent with the previous analyses, illness representations were most predictive of the social and well-being scales, namely mental health, vitality and social functioning as compared with the physical limitations caused by illness.

Table 7.4.4.4: Summary of multiple regression predicting functioning by illness representations

	Combined		Hypertension		Diabetes	
Variables	Beta	Adj. R^2	Beta	Adj. R^2	Beta	Adj. R^2
PF scale						
Identity	-.39	**.15**	-.41	.16	-.39	.15
Conseq.			-.22	**.20**		
Monitor					.18	**.17**
RP scale						
Identity	-.44	.19	-.55	.30	-.35	.11
Conseq.	-.16	**.21**	-.16	**.32**	-.20	**.14**
BP scale						
Identity	-.44	.19	-.48	**.23**	-.36	.13
Conseq.	-.17	**.21**			-.19	**.15**
GH scale						
Identity	-.49	.24	-.43	.18	-.49	.23
Conseq.	-.24	.28	-.20	.21	-.25	**.28**
Time	-.11	**.29**	-.15	**.23**		
VT scale						
Identity	-.54	**.29**	-.61	**.36**	-.47	.21
Monitor					.16	.24
Conseq.					-.20	**.26**
SF scale						
Identity	-.45	.20	-.50	.24	-.49	.23
Conseq.	-.29	**.27**	-.18	**.27**	-.22	**.27**
RE scale						
Identity	-.40	.16	-.45	.19	-.24	.18
Conseq.	-.21	**.19**	-.16	**.21**	-.38	**.14**
MH scale						
Identity	-.48	.23	-.50	.24	-.48	.23
Conseq.	-.18	.26	-.21	.28	-.20	**.25**
Time	.11	**.26**	-.15	**.29**		

Note: total amount of variance explained by each regression is shown in bold for ease of interpretation.

(PF = physical functioning, RP = role limitations-physical, BP = bodily pain, GH = general health, VT = vitality, SF = social functioning, RE = role limitations-emotional, MH = mental health).

A strong illness identity and a belief in the serious consequences of the illness were the primary predictors of poorer functioning for both samples, although the regressions accounted for a greater percentage of variance in hypertensive compared with diabetic patients (20%-36% compared with

14%-28%). Only on the general health scale did diabetics' beliefs account for a greater percentage of the variance compared with hypertensives (28% vs. 23%). Perceptions of a chronic time line were also associated with poorer general health and mental health for the hypertensive and combined sample, although its contribution to both equations was minimal. Confidence in one's ability to monitor blood glucose levels was positively related to physical functioning and vitality for diabetics, although adding only 2% and 3% to each regression equation respectively. However, whilst "monitor" was not selected as a predictor variable in the remaining analyses, its relationship to functioning was generally a negative one. This was particularly the case for hypertensives, for whom perceptions of monitoring ability were significantly correlated with poorer functioning on all of the SF-36 scales (ranging from -.16 to -.32, p < .05; see Appendix 18, p.A62) with the exception of bodily pain. Thus, there appears to be a difference between the two samples as to the role of beliefs about monitoring ability, whereby it was negatively associated with functioning only for hypertensives.

Taken together with the results of the previous hierarchical regressions, the findings demonstrate that coping accounts for the majority of the variance in functioning which illness representations account for when coping is omitted. This provides strong support for the proposed role of coping as a mediator between illness representations and functioning.

7.4.4.3.1 Causal beliefs and functioning: Pearson's correlations were computed to investigate the relationship between causal beliefs and functioning. For diabetics, Factor 1 (uncontrollable causal factors) was associated with poorer physical functioning (r = -.20, p<.01), social functioning (r = -.15, p<.05), mental health (r = -.20, p<.01) and greater emotional role limitations (r = -.22, p<.01). Factor 2 (controllable factors) was negatively associated with mental health (r = -.15, p<.05) and emotional role limitations (r = -.24, p<.01) whilst Factor 3 (heredity) was significantly related to physical functioning (r = -.19, p<.01) and general health (r = -.17, p<.05).

In the hypertensive sample, Factor 2 (work and stress) demonstrated the strongest relationship with functioning, with significant correlations with physical role functioning (r = -.20, p <.05), vitality (r = -.25, p <.01), social functioning (r = -.16, p <.05), emotional role limitations (r = -.34, p <.001), and mental health (r = -.30, p <.001). Factor 1 (lifestyle) was correlated only with emotional role limitations (r = -.19, p <.05). Factor 3 (heredity) was not significantly associated with any of the functioning scales.

7.4.4.4 Relationship between adherence and functioning

Pearson correlations were calculated to investigate the relationship between adherence and functioning. Since hypertensives and diabetics reported quite different responses to the exercise and diet aspects of their regimes, separate computations were calculated for each sample. For diabetics, adherence to medication was negatively related to physical functioning ($r = -.21$, $p < .05$). Similarly, regular testing of BG was associated with poorer physical functioning ($r = -.18$, $p < .05$) and greater physical role limitations ($r = -.26$, $p < .001$). Following dietary and exercise recommendations were, however, associated with higher levels of functioning in terms of general health ($r = .28$, $p < .01$ for both), vitality ($r = .33$, $p < .01$ for both), mental health ($r = .31$ & $.32$ respectively, $p < .01$), emotional role limitations ($r = .22$, $p < .01$ and $r = .21$, $p = <.05$ respectively), and social functioning ($r = .22$, $p < .01$ and $r = .25$, $p < .05$ respectively).

For hypertensives, exercise but not diet was positively correlated with general health ($r = .25$, $p < .05$), vitality ($r = .27$, $p < .05$), and mental health ($r = .23$, $p < .05$).

7.4.5 SATISFACTION

7.4.5.1 Satisfaction with medical care

There were no significant differences between diabetics and hypertensives in reported levels of satisfaction with care, but participants felt more satisfied with their general medical care than with the amount of information received (mean = 4.4 & 3.8, $t = 10.48$, $df = 354$, $p < .0001$).

The desire for more information was also reflected in patients' open-ended responses. The type of information patients requested was varied, but largely centred around information regarding the disease, its aetiology, prognosis and treatment.

> *"I did not receive enough information about the complications of diabetes when I was first diagnosed, and it came as quite a shock when I did"* (Patient 87: male 54 years; Type II diabetic).
>
> *"I would like something to read about hypertension to explain it and explain how the pills work - physiology is interesting"* (Patient 785: female 85 years; hypertensive).

Several patients also requested help with problems associated with the disease and more detailed information regarding its management, particularly diet and exercise. A related issue was the request for a more holistic approach to treatment to recognize the complexity of the illness and its treatment.

> *"Whilst I am receiving exemplary treatment for individual disorders, I have the strong impression that each is being treated in isolation. Is it not possible that a whole person approach can be emphasized to better examine the interactions that are occurring between disorders and so improve their understanding and treatment?"* (Patient 394: female 52 years; Type II diabetic).
>
> *"It has to be treated holistically by reference to lifestyle, and medication if necessary"* (Patient 799: male 66 years; hypertensive).

Use of alternative therapies has been associated with perceived deficiencies in orthodox medicine in providing holistic care (e.g. Vincent & Furnham, 1997). Although there was no significant relationship between satisfaction and use of complementary medicine in the current study, dissatisfied patients were more likely to have used other treatments to help manage their condition ($t = 2.0$, $df = 234$, $p < .05$)[16].

7.4.5.2 Relationship of satisfaction with adherence and functioning

It was hypothesized that satisfaction would demonstrate a positive relationship with adherence and functioning. For hypertensives, satisfaction (using a composite score) was positively correlated with adherence to medication ($r = .23$, $p < .01$). In the diabetic sample, satisfaction demonstrated a positive relationship with adherence to both dietary and exercise recommendations ($r = .26$ & $.27$ respectively, $p <.01$), and satisfaction with medical care was significantly correlated with medication adherence ($r = .16$, $p <.05$).

Satisfaction was also significantly correlated with six of the eight SF-36 dimensions for the combined sample, especially those assessing well-being i.e. vitality ($r = .20$, $p <.001$) and mental health ($r = .23$, $p <.001$). However, there was no significant relationship with either physical or social functioning.

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[16] "Do you use any other treatment (e.g. alternative medicine, home remedies) to help manage your condition?" (1 = never to 5 = all of the time). "If so, what do you use?"

7.5 DISCUSSION

The primary aims of Study 6 were to assess the sufficiency of the self-regulatory model in predicting a) adherence and b) functioning in diabetic and hypertensive patients. Illness representations were not strong predictors of adherence, which was more strongly associated with components of the HBM, most notably the costs and benefits of treatment (for diet and exercise only). This suggests that the incorporation of additional models has the potential to improve the self-regulatory model's predictive power. As hypothesized, Study 6 demonstrated that coping strategies significantly predicted functioning for both diabetic and hypertensive patients. Consistent with the self-regulatory model, the findings also suggested that coping played a mediatory role between patients' illness representations and their appraisal of functioning. Illness representations did, however, exert a small direct effect on functioning beyond that explained by coping.

7.5.1 Content of illness representations

The preliminary aim of Study 6 was to explore the illness representations of hypertensives and diabetics and to assess interrelationships between the components of illness representations. Not surprisingly, there were differences between diabetics and hypertensives in terms of their representations of illness, with diabetics scoring higher on the identity and consequences components. Diabetics thus perceived their illness as having a wider range of symptoms and greater impact on their lives. This accurately reflects the medical model. Diabetics also perceived their condition as more chronic, whereas hypertensives were more confident than diabetics that their condition could be cured/controlled. This suggests that diabetics actually had more realistic beliefs about the chronicity of their condition and the limitations of treatment as a cure.

The exploration of relationships between the components of illness representations demonstrated logical associations. Indeed, Leventhal, Benyamini, Brownlee, et al. (1997) stress that the components are not individual entities but "are organised and function as sets". In the current study, the strongest relationship was found between identity and consequences, both of which were strong predictors of functioning. Consistent with Hampson (1997), consequences and time line also demonstrated strong associations. Such findings are also consistent with studies 1 and 2, which revealed strong interrelationships between components, despite using a very different methodological approach.

A secondary aim was to assess the internal reliability of the IPQ. This is discussed in section 7.5.5 (methodological implications).

7.5.2 Adherence

Consistent with previous research, self-reported adherence to different aspects of the treatment regimen varied considerably, with high rates for medication usage compared with diet, exercise and BG testing.

There were three hypotheses relating to adherence. The first predicted that patients' concrete representations would demonstrate a stronger relationship than their abstract beliefs with adherence. However, neither concrete nor abstract illness perceptions demonstrated strong relationships with adherence[17]. This had direct implications for the second and third hypotheses which stated that a) concrete beliefs would explain a significant amount of variance in adherence to the four aspects of the regime and b) the inclusion of health belief variables would account for a significant amount of additional variance in adherence. Whilst perceiving one's illness as chronic accounted for a small percentage of variance in dietary adherence (4-11%), the perceived costs and benefits of treatment (HBM) were most predictive of adherence, but only for diet and exercise.

It is perhaps not surprising that beliefs about the costs and benefits of *treatment* were more predictive of adherence than patients' representations about their *illness*. Indeed previous studies have found that the more specific the beliefs assessed, the better their predictive power (Glasgow et al., 1986; Horne, 1997). The distinction between volitional and non-volitional adherence is pertinent here in understanding the factors underlying adherence. Patients' open-ended responses revealed that non-adherence was generally not perceived as a means of assuming control over one's condition as found in some previous studies (e.g. Conrad, 1985). Rather it reflected forgetfulness (medication), changes in routine (diet and medication), social and lifestyle pressures (diet, exercise and BG testing), and lack of self-discipline (diet, exercise and BG testing) i.e. costs or barriers as opposed to more general beliefs about illness. It is increasingly recognized that adherence must be viewed within the patient's perspective which may involve a balancing of the medical benefits of following treatment recommendations alongside the difficulties associated with life-style changes. For example:

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[17] Perceptions of a chronic time line, both abstract and concrete, were significantly associated with adherence (diet), whilst concrete beliefs regarding the consequences of illness were associated with diet, but only for diabetics.

> *"I feel that whilst diabetes is a chronic condition, and one respects that, it should not "rule" one's life"* (Patient 377: female 54 years; Type I diabetic).

That components of the HBM were most predictive of exercise and dietary behaviour seems to support this perspective, with patients appearing to balance the costs and benefits accrued by following medical advice. Hampson (1997) also found that beliefs about treatment effectiveness were the most important predictors of self-management of diet and exercise in NIDDM patients, but did not predict either medication or BG testing. In the current study, benefits were most salient in predicting dietary adherence (for diabetics) whereas costs weighed most heavily in determining exercise. This may reflect the perspectives of both patient and doctor, since diet is more central to the treatment regime from a medical perspective (particularly for diabetics) and patients viewed it as important in helping to control their condition.

Taking the diabetic and hypertensive sample separately, it is evident that diet played a more important role for diabetics. Seventy seven percent of diabetics were aware that they should follow a specialist diet either to control their diabetes and/or to lose weight, compared with only 46% of hypertensives. Additionally, whilst benefits and costs were the main predictors of dietary adherence for diabetics, age was the only predictor selected for hypertensives (accounting for 10% of the variance), with older patients reporting a more rigorous adherence to dietary advice. Older diabetic patients were also more adherent (accounting for 6% of the variance), but health beliefs accounted for an additional 21% of the variance (over and above age and time line (4%).

For diabetics, testing of BG levels proved problematic. There seemed little consensus as to how often patients felt they should test their blood glucose, despite recommendations of three or more tests per day (Cox, 1991). Patients in this sample were certainly testing well below these levels although many still felt that they were adhering to recommendations. This variability in what is perceived as "adherent behaviour" is likely to be influencing the motivational factors underlying BG testing. Thus, beliefs underlying infrequent testing may be very different from those associated with testing three or four times a day. For example, the perceived costs in terms of discomfort and inconvenience are much higher for frequent testers. On the other hand, the benefits of BG tests may also be more apparent to regular testers as a means of monitoring and exerting control over their condition. Interestingly, BG testing was most strongly correlated with dietary adherence ($r = .34$, $p<.001$) suggesting that both behaviours may be associated with a greater concern about taking control of one's condition. Comparing frequent (three or more times per day) and non-frequent BG testers, only the former demonstrated a significant relationship between test adherence and perceived benefits (r = .25, p<.05) suggesting that for frequent testers, the potential benefits of testing act as a motivating force.

7.5.3 The self-regulatory model: relationships between illness representations, coping and functioning

7.5.3.1 Coping

There were two main aims specifically relating to coping. The first was to assess the internal reliability of the short-form COPE; this will be discussed in section 7.5.5 (methodological implications). The second aim was to explore the relationship between patients' illness representations and coping strategies. Illness representations were related to coping strategies in conceptually logical ways consistent with previous findings (e.g. Petrie et al., 1996; Moss-Morris et al., 1996). As hypothesized, representations which are likely to cause greater emotional threat, such as having a strong illness identity and believing that one's illness has serious consequences were associated with emotion-focused and avoidant strategies. Interestingly however, perceptions of serious consequences were also associated with adaptive coping strategies such as active coping and positive reinterpretation and growth. In the current study, however, these strategies did not demonstrate a positive relationship with functioning. Nevertheless, this suggests that patients who perceive their illness as impinging considerably on their lives may well employ a wider variety of coping strategies to deal with their condition. Indeed, diabetics (who perceived more serious consequences) reported higher employment of coping strategies (both active and emotion-focused) than their hypertensive counterparts. Believing the illness has a chronic time line was associated with acceptance and positive reinterpretation and growth, adaptive strategies suggesting the integration of a long-term illness into the patient's life. Although the control/cure component lacked internal reliability for the diabetic sample, belief in illness controllability was associated with using active coping and reinterpreting the situation for hypertensives.

7.5.3.2 Functioning

As hypothesized, coping strategies significantly predicted functioning, accounting for between 6% and 41% of variance beyond age. Consistent with previous findings, emotion-focused and disengagement strategies were more important in predicting functioning than adaptive strategies (Carver et al., 1993; Dunkel-Schetter et al., 1982; Moss-Morris et al., 1996). There were however, some differences between the two samples in the primary coping strategies associated with functioning. For hypertensives, behavioural disengagement was the main predictor of all the functioning scales, whereas for diabetics, emotion-focused coping was more central to physical and social functioning, physical role limitations and pain. These differences aside, it was those coping strategies of questionable adaptive value that were most strongly associated with functioning for both samples, particularly for those scales assessing social and psychological status.

The second hypothesis was in response to previous findings suggesting that illness representations have a direct effect on appraisal of functioning without the mediating effect of coping (e.g. Earll, 1994; Moss-Morris, 1996). It received partial support in the current study, with illness perceptions predicting between 2% and 16% of the variance beyond that of coping (on all eight scales). Illness representations accounted for moderate amounts of variance beyond that explained by coping on outcomes such as vitality and bodily pain, but only had a very small effect on others such as emotional role limitations and social functioning. Whether the relationship was a causal one was beyond the scope of this investigation.

The coherent relationships between illness representations and coping described in the previous section suggest that patients' beliefs about their illness and how they cope were related in logical ways. Further analysis to investigate their independent relationship with functioning yielded findings of both theoretical and practical interest. Illness representations alone accounted for moderate percentages of variance in functioning (14% - 36%) for all eight of the SF-36 scales (see Table 7.4.4.4, p.219), but particularly for those scales assessing social and psychological status. The strong relationships between illness representations and coping together with the finding that the independent effects of illness representations on functioning were largely partialled out when coping was included in the regression before illness representations strongly suggest that coping served a mediatory function between illness representations and functioning. This is consistent with the proposed stages of the self regulatory model.

The identity and consequences demonstrated the strongest relationships with functioning. That these components were negatively related to all functioning scales is consistent with their association with emotion-focused and avoidant coping strategies. The self-regulatory model places considerable importance on the role of symptom beliefs in understanding and interpreting an illness experience. People's beliefs about symptoms are frequently found to be stronger predictors of functioning than objective measures of disease severity (Lacroix, 1991). It is also not surprising that perceiving illness to have serious consequences was associated with poorer functioning, although causality cannot be assumed. Whilst such beliefs may result in greater perceived physical, social and psychological limitations, it is equally plausible that poorer functioning will lead to increased perceptions of disease impact.

Comparing the diabetic and hypertensive samples, the former reported poorer functioning than their hypertensive counterparts which is likely to reflect the more visible impact of diabetes on physiology and daily functioning. However, despite the differing aetiology and impact of the two diseases, perceptions of serious consequences and a strong illness identity consistently predicted functioning for both samples. Thus, although there were some differences between the samples, the pattern of results was broadly the same for both chronic conditions. One difference is however notable. Confidence in one's ability to monitor symptoms and recognize fluctuations in blood glucose or blood pressure was significantly related to poorer functioning for hypertensives (on seven of the eight SF-36 scales), but not diabetics. This is likely to reflect differences in the nature of the two conditions. For hypertensives, monitoring confidence reflects the *inaccurate* belief that their condition is symptomatic. Indeed, patients certainly viewed their hypertension as symptomatic, associating an average of eight symptoms with their condition. Diabetics, on the other hand, are often encouraged to monitor their symptoms for early detection of hypo- and hyper-glycemic episodes whilst additionally carrying out objective tests of blood glucose. Thus, a belief in one's ability to monitor BG may serve an *adaptive* function which is congruent with medical advice. This therefore supports previous findings regarding the importance of emphasizing to newly diagnosed and continuing patients the asymptomatic nature of hypertension.

Causal beliefs were also related to functioning in logical ways. For both hypertensive and diabetics' uncontrollable or external causal attributions demonstrated the strongest relationships with impaired physical and mental functioning. In particular, state of mind demonstrated significant associations with five of the SF-36 scales for the diabetic sample, which is consistent with previous findings linking emotional attributions with poorer psychological adjustment (Moss-Morris et al, 1994). For hypertensives, attributions of stress and overwork were the primary attributions associated with poorer functioning. Such beliefs appear to reflect the folk model of "hyper-tension" (Blumenhagen, 1980).

7.5.4 Satisfaction

Consistent with Studies 4 and 5, patients were relatively satisfied with their overall care, but the amount and quality of information was less satisfactory. Patients required more elaborate information, particularly with regard to their treatment. This has ramifications for both adherence and well-being since, as hypothesized, satisfaction was related to self-reports of adherence (medication, diet and exercise) and functioning. Whilst satisfaction with care may promote psychological well-being through its supportive function, it may equally be the case that those patients who are better adapted and have fewer difficulties are more satisfied and less demanding of their care. Nevertheless, diabetic and hypertensive patients do appear to adopt a critical approach to their medical care which is related to their reports of adherence and functioning. Health professionals should therefore continue to monitor and evaluate the services they provide, taking into account patients' expectations, particularly with regard to treatment information.

7.5.5 Methodological implications: Use of the IPQ and short-form COPE

The IPQ has undoubtedly advanced the utilization of the self regulatory model by making it more amenable to quantitative measurement (see Petrie & Weinman, 1997, for a collection of recent studies). Findings from the current study do, however, point to the need for its further development and refinement. The internal reliability problems associated with the cure/control scale for diabetics may in part be disease-specific, since similar problems have been reported elsewhere with diabetic patients (Weinman, 1998, personal correspondence). This may, however, reflect more general problems with a scale that incorporates two distinct concepts, namely that of personal control over the illness course and cure or treatment of the illness. Clearly, such a distinction is particularly relevant for diseases such as diabetes, which may be managed but not cured.

An additional issue involves the scoring of the identity component. It is argued that the incorporation of symptoms experienced "occasionally", "frequently", or "all of the time" is an overly broad classification, since symptoms will inevitably have a differing impact according to their perceived frequency. Clearly, the identity component is adequately discriminative in that it was the component accounting for the most variance in functioning. However, when identity is scored by summing only those items endorsed at "frequently" or "all of the time", its discriminatory power is significantly improved. Indeed, it accounts for between 27% and 50% of the variance in functioning for hypertensives (compared with 20% - 36% using the current scoring system) and between 21% and 37% in diabetics (compared with 14% - 28%). Thus, some refinement of the scoring of this scale is desirable.

The current study was also concerned with evaluating the reliability and discriminatory power of the 32-item COPE developed in Studies 4 and 5. The internal reliability for the seven scales was higher than in the previous study for all scales except Denial, which fell below .60 for the diabetic sample. The shorter measure also successfully discriminated between different groups (male/female, diabetic/hypertensive) and different functional outcomes. Consistent with previous findings (Carver et al., 1992, 1993: Felton et al., 1994; Moss-Morris et al., 1996), behavioural disengagement proved to be an important predictive tool for maladaptive outcomes and should therefore be retained in the measure despite only including 2 items. Indeed, it may be advisable to include further items to this scale to increase its reliability. Overall, these exploratory findings suggest that the short-form COPE may indeed be a useful research tool for clinical populations, although further psychometric testing is clearly required.

7.5.6 Practical implications

The current study has highlighted a number of issues that should be addressed by health professionals, many of which pertain to health education. Whilst the majority of diabetic patients were aware of the importance of following a diet either to control their diabetes directly or to lose weight, few hypertensives appeared to view diet as part of their treatment or as important in controlling their condition. For those patients who reported dietary recommendations, adherence was low. This therefore suggests two related issues. Firstly, patients (particularly those with hypertension) need to be more fully informed about the importance of adhering to a healthy diet. Secondly, patients need to be given more specific dietary advice. Many were aware that they had originally been supplied with dietary advice when newly diagnosed (often many years previously), but were unclear about the exact content of the recommended diet or desired a dietary plan tailored to their own needs.

Similarly, only 41% of diabetics and 40% of hypertensives reported being recommended exercise as part of their treatment regimen, yet there is considerable evidence that exercise improves health and well being (Appel, 1986; Burton, 1998) in addition to preventing disease-related complications (Siegal & Blumenthal, 1983). Indeed, following both dietary and exercise recommendations was associated with higher social and psychological functioning in the current study. Interestingly, both diabetic and hypertensive patients felt that exercise was helpful in the management of their condition (mean = 3.9), although adherence rates appeared to reflect the logistical problems of actually implementing good intentions. Thus, inconvenience accounted for 35% of the variance in self-reported exercise. However, recent evidence suggests that general practitioners can increase the activity of their patients by spending a few minutes providing advice and discussion (Bull, Schipper, Jamrozik, & Blanksby, 1998). Whilst hypertensives and diabetics may be given information about the role of diet and exercise in controlling their illness when first diagnosed, these recommendations need to be repeated over the course of the illness. Indeed simple health education with specific dietary/exercise recommendations can significantly improve blood glucose control (Burton et al, 1998).

Clearer guidelines as to suitable levels of blood glucose testing are also required, since patients' perceptions regarding recommended levels are hugely divergent. Obviously, this may in part reflect differences among patients such as type and severity of diabetes, but even withstanding individual differences there appears to lack any consensus as to "standard recommendations". It is difficult to assess and attempt to predict adherence when medical agreement as to desirable levels of behaviour is lacking, or is not being communicated to patients.

The strong relationships between appraisals of functioning and patients' illness perceptions and coping also highlights the importance of taking patients' perspectives into account when considering their overall well-being. In particular it is important to address patients' beliefs about the symptoms associated with their condition, especially for hypertensives, and also their concerns about the consequences of illness on everyday life and functioning. The provision of concrete information may be a method of discouraging emotion-focused and disengagement strategies and thereby improving patient functioning.

Most practices already run specialist clinics to deal most effectively with patients' needs and increase health behaviour, but it is important that all diabetic and hypertensive patients receive appropriate and updated behavioural advice, information and support. The difficulties of meeting patients' individual needs are perhaps best met through clinics which provide up-to-date medical advice and also enable patients to meet others facing similar difficulties. This is illustrated by one diabetic (Type II) patient:

> *"I should have wished to attend a clinic with other non insulin diabetics in order to find out first hand what they feel, how they suffer, how they cope. Doctors/nurses are busy people and one feels that you are impinging on their time, when other people with more serious problems need them"* (Patient 45: male 62 years)

7.5.7 Theoretical implications

The present findings have several implications for the development and application of the self-regulatory model. Firstly, the utility of incorporating relevant concepts from other complementary or overlapping models. This was clearly demonstrated in the prediction of adherence, where components of the Health Belief Model demonstrated a stronger relationship with self-reported adherence than patients' perceptions about their illness. This suggests that they constitute an important addition to the self-regulatory model when considering decisions about treatment. Indeed their incorporation is entirely consistent with the overall framework of the *regulatory* model in which patients evaluate the utility of adopting particular coping strategies or behaviours. It also highlights the importance of assessing beliefs relevant to specific behaviours. Thus, illness perceptions may provide a useful framework for understanding people's conceptualization of their experience, but additional components may be necessary to adequately explain specific behaviours such as adherence.

The present study's investigation of the relationship between illness representations, coping and functioning in two distinct samples makes a valuable contribution to research investigating the applicability of the self-regulatory model to understanding and predicting behaviour. Although Leventhal's model is becoming increasingly popular in health psychology, relatively few studies have investigated the relationship between the different levels of the model. The current study clearly demonstrated the strong relationship between people's representations of their illness, their choice of coping strategies, and their appraisal of functioning. Indeed, the patterns of findings were broadly consistent across both samples lending support to the generalizability of these observations. The study also provided support for the mediatory role of coping in the process of self-regulation. That illness perceptions continued to exert a small effect on functioning beyond that explained by coping, also lends some support to the suggestion that illness perceptions may have a direct impact on adjustment (Earll & Johnston, 1993).

However, it must be borne in mind that the study was cross-sectional and therefore cause-effect relations cannot be established. Thus, it is unclear whether perceptions concerning symptomatology and the consequences of illness result in poorer functioning, or whether poorer functioning leads to more negative perceptions of illness (or whether they are both the result of a third variable such as personality). In reality, the two processes are likely to operate together. Whilst our beliefs influence how we respond and cope with illness and thereby influence our adjustment to disease, so too does the appraisal of our relative success in this process cause a reassessment of our original perceptions and coping choices. Self-regulation is by definition a dynamic process.

It would therefore be of both practical and theoretical interest to explore adaptation to chronic complaints longitudinally to assess the role of self-regulation from initial diagnosis through to long-term adjustment to illness. This would allow an exploration of how people's perceptions of illness change over time and how they adjust their coping strategies to deal with the ongoing demands of illness.

CHAPTER 8

General discussion and implications

This thesis has focused on the role of illness representations in classifying and responding to illness. It began from a conceptual basis, looking at the classification of illnesses by lay people (Study 1) and went on to look at patients' representations of their own illness and role in their evaluation of medical care (Studies 2 and 3). Studies 4 and 5 paved the way for the final empirical study by producing a shortened version of the COPE suitable for using with clinical populations. Finally, Study 6 explored the relationship between patients' illness representations, the coping strategies they employ in dealing with chronic illness and their appraisal of their physical and psychological functioning.

8.1 Illness representations: their content and structure

People's perceptions about illness have constituted the underlying thread of this thesis. Moreover, the measurement of these perceptions has taken various forms throughout the course of the research. Study 1 examined *lay* representations of a variety of different illnesses using questionnaires to assess people's *abstract* perceptions of illness. It explored how illnesses were conceptually clustered together on the basis of the components of illness representations. The remaining studies focused on *patients'* perceptions of their own illnesses. Study 2 used interviews to explore patients' *concrete* representations of their illness when visiting the GP and related these to outcomes such as satisfaction. Study 3 was a follow-up postal questionnaire study which evaluated changes in beliefs over time in addition to assessing outcomes such as satisfaction and adherence. Finally, study 6 assessed the illness perceptions of diabetic and hypertensive patients using a standardized questionnaire (Illness Perception Questionnaire, Weinman et al., 1996).

8.1.1 Lay representations

Study 1 provided a systematic description of lay people's *abstract* representations of 37 different illnesses, which was more extensive than any previous research. Moreover it also assessed people's perceptions about the typical sufferer of each illness, which had previously been found to be a significant component of people's beliefs when classifying illness (Lalljee et al, 1993). Indeed, the study showed that people had clear ideas about the sort of person that typically contracted each illness and these were closely linked with the other components originally proposed by Leventhal and colleagues, particularly causal attributions and beliefs about how the illness could be treated. Such interrelationship between the components supports Leventhal's assertion that illness representations are relatively integrated schemas and that the components can be clustered together in logical ways.

The main focus of Study 1 was to assess which of the components were most relevant to the categorization of illness. It was particularly interested in identifying the components that were most relevant in *discriminating* between clusters of illnesses, whereas previous studies had focused on *similarities* (Lalljee et al., 1993). It found that beliefs about the symptoms, typical sufferer and cure/treatment of illnesses were most effective in differentiating between illnesses. Time line was the least useful both in terms of discriminating between illnesses and as a means of linking illnesses within a particular cluster. Whilst symptomatology was the most accurate classifier of illnesses, it was also a principal means of interconfusability, as in the case of lung cancer and bronchitis, meningitis and flu. Indeed, attempts to avoid such misclassification have recently been a target for health prevention campaigns directed towards early detection of meningitis. Providing people with information relating to each component of people's representations in addition to symptom information (particularly who is likely to contract it and what can be done to treat it) will facilitate the development of more accurate and cohesive illness prototypes thereby having the potential to reduce delays in seeking care (see also Horne et al., 1999 in relation to early detection of MI).

8.1.2 Patients' illness representations

Study 1 indicated that lay people had quite comprehensive representations of a range of illnesses although they were more complete for those illnesses with which participants presumably had greater familiarity. Thus, it is not surprising that the majority of patients in Study 2 had relatively well-developed representations when they were seeking medical care for their own condition. Moreover, the similarity in the representations held by lay people and patients in Studies 1 and 2 (i.e abstract and concrete representations for the same illnesses) supports the validity of the findings in Study 1.

Study 2 also focused specifically on discrepancies between doctor and patient regarding the illness label and treatment. Indeed, this is a relatively neglected area in the literature and yet Study 2 indicated that: a) doctors and patients sometimes differed in their perceptions of the illness being assessed and b) this was the only factor associated with patients' satisfaction. This suggests that future work should focus on an investigation of doctor-patient discrepancies for each of the components of illness representations, and relating these to outcomes such as satisfaction.

The follow up (Study 3) found that there were minimal changes in patients' perceptions of their illness over time, indicating that patients' beliefs were relatively stable over the two week period following the consultation. Consistent with previous findings (e.g. Hunt et al, 1989), patients very rarely discarded their original beliefs altogether but rather integrated new information into existing perceptions. However, it is interesting to reflect on the finding that patients who refined their original perceptions by integrating additional information and those who maintained their original beliefs when discrepant from those of the doctor were less likely to feel satisfied with the consultation. Clearly, these subgroups were very small (11% and 9% respectively), but it does suggest that particular attention needs to be given in the consultation to those patients who have discrepant views from those of the doctor.

Study 6 described the illness perceptions of diabetics and hypertensives. The use of the IPQ allowed a quantitative exploration of the interrelationships between the components of patients' representations. Although it employed a different methodological approach from studies 1 and 2, the findings of study 6 also demonstrated logical relationships between the individual components which were consistent with previous findings (Hampson, 1997; Petrie et al, 1996). Taking the three studies together, they support Leventhal et al's (1997) assertion the individual components of people's illness representations are logically related to and influence each other.

8.2 <u>Satisfaction</u>

8.2.1 Are patients satisfied with their care?

Three studies assessed patient satisfaction (Studies 2, 3 and 6). All three assessed the extent to which patients' felt satisfied with their care and asked patients which aspects of care could be improved. Consistent with previous studies, reports of satisfaction immediately following the consultation were high, with 84% of patients reporting complete satisfaction (Study 2). Two weeks after the consultation this was reduced significantly to 70% (Study 3). Several explanations were proffered for this difference: a) effects of the environment (home vs medical), b) temporal effects (patients had the opportunity to re-evaluate their consultation over the time interval), c) the impact of lay consultation (half the patients had discussed their consultation with others) and finally, d) the impact of subsequent experience (such as whether the condition had improved as a result of treatment). It is likely that a combination of these factors contributed to the increase in dissatisfaction compared with the original consultation.

Reports of satisfaction with medical care and information were considerably lower for the chronic sample in Study 6. Overall, only 45% of patients were fully satisfied with their medical care and a mere 23% were fully satisfied with the information they were given about their condition. This indicates that there is considerable room for improvement in the care that is provided to chronically ill patients. The lack of satisfaction with information in Study 6 was indicative of the comments made by patients in all three studies regarding aspects of their care which could be improved. Thoroughness of care (typified by more information regarding the illness and its treatment) was the most frequently cited area for improvement. Other, less frequently mentioned aspects included logistic issues e.g. reduced waiting times, longer consultations (Study 2) and style of consultation (Study 2).

8.2.2 Predicting satisfaction

The main focus of Studies 2 and 3 was to assess which factors from a range of demographic, consultation and illness perception variables could best predict satisfaction. Particular focus was placed on the role of doctor-patient concordance regarding diagnosis and treatment beliefs. In Study 2, it was hypothesized that concordance would be the principal statistical predictor of satisfaction. This was supported by both the subjective and objective measures of concordance[1]. However, whilst concordance predicted initial reports of satisfaction, this effect did not withstand the test of time. When satisfaction was assessed two weeks after the consultation in Study 3, self-reported concordance was no longer significantly related to concordance at time 2 and certainly did not predict follow-up satisfaction as hypothesized. However, satisfaction assessed immediately following the consultation did predict later satisfaction. In addition, several other factors were related to satisfaction at follow-up: age (older patients being more satisfied), concern (lower concern following the consultation), positive evaluation of the doctor, and perceiving one's treatment as beneficial.

Taken together, the findings from Studies 2 and 3 suggest that a dual process may well be operating when patients evaluate their consultation. It is proposed that initially, doctor-patient

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[1] The subjective measure refers to patients' self-reported agreement (1-5). The objective measure refers to the comparison between patients' pre-consultation beliefs (about diagnosis and treatment) and the doctor's diagnosis and prescribed treatment. At time 1, objective concordance was associated with significantly higher self-reported agreement.

congruency is particularly salient in the evaluation process, but exerts a primarily indirect effect at subsequent stages (through the mediating variable of satisfaction). At later stages, patients' *affective* responses to the consultation (i.e. how the individual felt about the consultation) are more salient together with perceptions of subsequent experiences, such as whether the treatment was perceived as effective. This is congruent with the explanations proffered for the increase in dissatisfaction over the two week period after the consultation. Moreover, this interpretation is also supported by theories in social cognition and memory which postulate that initial cognitive representations (e.g. congruency) are subsequently translated into affective evaluations which determine subsequent judgments and memory for events (e.g. Srull & Wyer, 1989).

8.3 Adherence

The same three studies (2, 3 and 6) investigated patterns of adherence. Study 2 explored patients' *intentions* to follow treatment recommendations, but found very little variability in responses since most patients (95%) had the intention to adhere immediately following their consultation with the doctor. Contrary to predictions, neither satisfaction nor doctor-patient concordance were significantly related to intentions. Those who fully intended to adhere tended to be older and have a stronger belief in the biomedical model (as evidenced by lower favourability towards complementary medicine). However, despite such good intentions, there is considerable evidence demonstrating that around half of patients do not fully carry out the recommended treatment (e.g. DiMatteo et al, 1993; Turk & Meichenbaum, 1991) and that there is frequently a discrepancy between intentions and behaviour (Abraham & Sheeran, 1993; Sheppard, Hartwick, & Warshaw, 1988). Moreover, adherence may be differentiated into two quite distinct types of behaviour. With volitional non-adherence, an individual makes a conscious decision not to follow treatment recommendations (this is more in line with Leventhal's conceptualisation of adherence as a coping mechanism), whereas non-volitional non-adherence reflects a non-conscious or unintentional deviation from recommended behaviour (e.g.forgetting).

These issues were explored in Study 3, which followed-up a sub-sample of the patients interviewed in Study 2. Patients were categorized as adherent, volitional non-adherent, and non-volitional non-adherent. As expected, self-reports of adherence revealed that only 66% of patients fully adhered to their treatment regimen, indicating that there was a considerable discrepancy between intentions and actual behaviour. However, only 17% deliberately departed from the regime and this was related to initial intentions. As expected, volitional non-adherence was discriminated from the other two groups. Patients' beliefs about the benefits of their treatment emerged as the primary differentiating variable. Contrary to predictions, concordance and satisfaction (from Study 2) did not discriminate volitional non-adherers from the other two groups. However, satisfaction and adherence were significantly associated when measured concurrently[2]. Thus there appears to be a relationship between satisfaction and adherence but previous findings that satisfaction is a significant *antecedent* of adherence were not substantiated.

Study 6 used a much larger and more homogeneous sample of chronically ill patients (diabetics and hypertensives) enabling a more systematic investigation of adherence to different aspects of a treatment regime. Consistent with previous findings, adherence was highest for medication, but much lower for diet, exercise and BG testing. Indeed many patients appeared to be unaware that diet and exercise might form a component of their treatment regime. Additionally, there were large individual differences in diabetics' reports of the frequency with which they were instructed to test BG levels. Overall, BG testing was well below medical recommendations (Cox et al., 1991).

Within the self-regulatory framework, adherence is viewed as a potential coping mechanism. Since people's illness representations are viewed as an important means of directing coping, it might be expected that such perceptions would be strongly related to adherence patterns. However, illness representations demonstrated very few relationships with patients' self-reports of adherence. Consistent with the findings of Study 3, it was patients' health beliefs which were more salient in predicting adherence in Study 6. Beliefs about the costs and benefits of treatment were the primary predictors of adherence to diet (for diabetics) and exercise (for diabetics and hypertensives)). This is also consistent with previous findings (e.g. Hampson, 1997).

It is suggested that these findings reflect the relative specificity of the beliefs measured, since beliefs about the costs and benefits of treatment are more specific to the behaviour measured, i.e. adherence to treatment recommendations. This does not mean that illness representations are not playing any role in adherence. Representations were significantly related to patients' beliefs about the costs and benefits of treatment[3]. Rather, the suggestion is that we need to look at the

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[2] Study 6 also found a significant relationship between satisfaction and adherence measured at the same time point.

[3] Benefits were associated with perceptions of a longer illness duration and a stronger belief that the illness could be controlled. Costs were positively correlated with perceptions of serious consequences and negatively with beliefs that the illness was controllable. Both costs and benefits demonstrated positive relationships with illness identity.

intervening variables which have a direct impacting on adherence (e.g. beliefs about treatment efficacy). This is discussed further in section 8.3.1 and 8.6.

8.3.1 Adherence: implications

Taken together, the findings suggest several themes in the data which have implications both for the measurement and the enhancement of patient adherence.

a) *Specificity of beliefs:* Study 6 demonstrated the importance of assessing patients' specific beliefs about their treatment as opposed to their more general beliefs about illness (i.e. their illness representations). Moreover, patients' beliefs about the costs and benefits of treatment were also related to satisfaction in Study 3. These findings highlight the value of emphasizing the importance and relevance of treatment to patients in order to encourage adherence and to promote satisfaction.

b) *Provision of information:* patients' requests for more information across all three studies have already been discussed in the previous section (8.2). Its implications for adherence are considerable, particularly in light of the fairly limited awareness of the chronic patients in Study 6 regarding diet, exercise and particularly BG monitoring (for diabetics). Such difficulties are especially dramatic when we consider that these are patients who are receiving continual health education through specialist clinics. This certainly invites the question as to whether patients are receiving adequate and regularly up-dated information and reinforcement of appropriate behaviour, especially when it comes to difficult life style changes such as diet and exercise. Additionally, this makes the measurement of adherence problematic, since clear guidelines are lacking regarding the regime that patients are expected to follow. Despite improvements in health education it appears that a primary reason for non-adherence is that people are simply not aware of the full complexity of the treatment regime. This is discussed further in section 8.8.

c) *Logistical barriers to adherence:* several logistical problems were commonly reported by patients as reasons for not following treatment recommendations. Time restrictions and inconvenience were major perceived difficulties faced by patients, especially when it came to activities such as exercise. Indeed, these are problems faced by most health promotion experts in persuading people to adopt a healthier lifestyle (see also section 8.6).

8.4 Coping with illness

Studies 4 and 5 (reported in chapter 6) responded to the need for a suitable measure to assess coping in a clinical population. Although the COPE is a well-used, if relatively new measure, no previous studies had assessed its suitability for use in populations of people suffering from illness. Study 4 was therefore an exploratory study to examine the properties of the COPE in people suffering from illness and to develop a much shorter version which was suitable for using with patients. Although there were some differences in the factor structure of the COPE in study 4 compared with Carver et al.'s original study, the underlying similarities in structure suggested that the COPE was a suitable tool for using with illness populations. Study 5 indicated that the 32-item short-form COPE demonstrated construct validity with the longer version and had acceptable internal reliability. Study 6 investigated the discriminative power of this shorter measure in a second clinical population. This final study demonstrated that the 32-item COPE was able to discriminate between different sub-samples of patients and functional outcomes. This suggests that the shortened version may be a useful tool where time is restricted or a large number of psychological measures must be administered.

An additional point is relevant here. The behavioural disengagement scale was included in the short-form COPE for exploratory purposes only since it only included two items. However, since this demonstrated strong relationships with functioning in Study 6 (see section 8.5 below), it is recommended that additional items are included in the future to increase the reliability of this scale.

8.5 Illness representations, coping and functioning

The final empirical chapter (Study 6) enabled the self-regulatory model to be investigated more completely by exploring the relationships between illness representations, coping (including adherence as already discussed) and functioning. Although it was a cross-sectional study and therefore causal relationships cannot be assumed, logical relationships were found between each stage of the model. At the time the study was conducted, very few other studies had investigated these relationships[4] and none had also examined adherence. Moreover, Study 6 went beyond earlier studies by including two groups of patients with chronic illness (diabetics and hypertensives) which provided indications of trends across the data.

The identity and consequences components consistently demonstrated the strongest relationships with both coping and functioning for both hypertensives and diabetics. This is consistent with previous findings (e.g. Moss-Morris et al., 1996). As hypothesized, having a strong illness identity (i.e. perceiving a greater number of symptoms) and believing that diabetes or hypertension had

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[4] To my knowledge, only two other studies had specifically focused on the relationships between the different levels of the model and both with uncontrollable illnesses (Earll, 1994; Moss-Morris et al., 1996).

serious consequences were both associated with emotion-focused and avoidant strategies which are conventionally seen as less adaptive (Carver et al, 1989; Moss-Morris et al, 1994; White et al., 1992). Indeed, they were consistently associated with poorer functioning in Study 6. However, perceiving more serious consequences was also associated with problem-focused coping, although problem-focused strategies did not predict functioning. Consistent with previous findings (Carver et al., 1993; Dunkel-Schetter et al., 1982; Moss-Morris et al., 1996), Study 6 found that emotion-focused and avoidant strategies were more effective in predicting levels of functioning than problem-focused strategies. This suggests that the most important focus of health education in chronic illness is to: a) address patients' concerns about the consequences of illness for individuals and their health, and b) teach ways in which to deal with emotional difficulties and discourage avoidant behaviour.

Thus far we have seen that the individual elements of the self-regulatory model appear to demonstrate logical relationships with each other, consistent with predictions and previous research. A further question concerns the potentially direct effect of illness representations on functioning, by-passing the mediatory role of coping (Johnston, 1996, 1997). This was tested in a hierarchical regression analysis. After controlling for the effect of age and coping, illness representations (identity and consequences) accounted for moderate amounts of variance for some aspects of functioning (e.g. vitality and bodily pain), suggesting that there is a direct relationship (or rather one that is not mediated by coping) between illness perceptions and appraisals of functioning. However, the direction of that relationship remains untested; indeed it seems plausible that the relationship is a bi-directional one. Such findings suggest that this is an interesting area for future study and one that would lend itself to a longitudinal project.

8.6 Summary of theoretical implications

The studies described in this thesis have demonstrated the potential of the self-regulatory model in understanding people's responses to illness and the ways in which they adapt when faced with long-term illness. It is argued that the studies have contributed to existing research in four key ways, which are summarized below.

Content and organisation of illness representations

Illness representations continue to be the focus of the self-regulatory model (Leventhal, Leventhal & Contrada, 1998). The current studies have contributed to this body of research by investigating the content of representations in a lay non-patient sample (Study 1), in patients' visiting their GP

(Studies 2 and 3), and in patients with chronic illnesses (Study 6). Additionally, Study 1 demonstrated how illnesses were organised on the basis of the individual components of representations. It was the first of its kind to a) investigate the organisation of such a wide range of illnesses, and b) demonstrate the relative usefulness of the individual components in discriminating between different clusters of illness. The similarity in the content of illness representations in Studies 1 and 2 (i.e. abstract and concrete) suggest that such a classification is useful in understanding the kind of misclassifications that people make when diagnosing their own illnesses and also of diagnostic differences between patients and their doctors. This could not be systematically explored in Study 2 due to the small number of doctor-patient diagnosis discrepancies in the subgroup of patients presenting with illnesses investigated in Study 1. However, it is an area worthy of further research.

Discrepancies between patients' and doctors' illness representations

The current studies were also the first to explore the role of illness perceptions in the consultation and relate to outcomes such as satisfaction. In particular, Study 2 bridged the gap between Kleinman's explanatory model and Leventhal's self-regulatory model by focusing on the potential impact of doctor-patient discrepancies. The extension of such an approach could be an important means of addressing criticisms that the self-regulatory model remains too individualistic (Cohen et al, 1994; Ogden, 1995) as well as increasing the scope of the model.

The addition of health belief variables in predicting adherence

Few studies have investigated the relationship between the components of illness representations and adherence to treatment. This was explored in Study 3, and more systematically in Study 6. Both studies demonstrated that beliefs about the costs and benefits of treatment were more important predictors of adherence than illness representations. It is argued, therefore, that such constructs are valuable additions to the self-regulatory model in understanding why people do not follow treatment recommendations. Indeed, this is compatible with Leventhal's conceptualisation of the self-regulatory model as a *framework* for understanding the process by which people perceive illness and respond at various stages as the illness progresses. Thus it is a dynamic model which is amenable to additions from other existing models.

The inclusion of specific beliefs about treatment is one way forward suggested by the current studies. A related area is recent work on the relationship between medication beliefs and adherence (Horne, 1995, 1997). Consistent with the current studies, Horne's work suggests that illness representations have an indirect effect on adherence through the mediating effect of beliefs about one's medication. In addition, the current thesis' finding that a major obstacle to following dietary and exercise recommendations are factors such as inconvenience and time restraints suggests that Gollwitzer's (1993) work on implementation intentions may also be a valuable addition when attempting to increase participation to recommended treatment regimens.

Relationships between the stages of the model

Although the common-sense approach of the self-regulatory model lends itself to clinical application, few studies have investigated the relationships between the proposed stages of the model[5] in clinical populations. This was a principal focus of the final empirical study. Study 6 provided cross-sectional support for the proposed relationships between the stages of the self-regulatory model. Moreover, the pattern of relationships was found to be broadly consistent across both samples of chronically ill patients suggesting that they are generalizable to other chronic illness groups, at least those which are medically "controllable". Clearly it would be valuable to extend this to other clinical groups. Longitudinal studies would also enable the clarification of causal relationships between the various stages of the model. It is argued that the studies in this thesis have laid the foundations for such research and have also suggested ways in which the self-regulatory model might be extended to improve the prediction of outcomes such as patients' satisfaction and adherence.

Finally, it is acknowledged that the studies in this thesis have focused on people's cognitive representations of illness. A distinctive component of the self-regulatory model is its recognition of a dual processing system of both cognitive and emotional self-regulation. However, research to date has largely focused on the make-up and impact of cognitive representations. In order that the relationship between these two "partially independent processing systems" be fully explicated, further empirical research is clearly necessary.

8.7 Methodological issues

Various methodological limitations of the studies reported in this thesis have been highlighted in the individual chapters, but some general methodological issues will be discussed here.

All six studies constituting this thesis were conducted with either a lay sample (Studies 1 and 4) or a patient sample (Studies 2, 3, 5 and 6). In total, over 900 people with acute and chronic illness

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[5] I.e. between illness representations, coping and appraisal.

were included and were recruited from the community, from General Practices (11 in total) and from hospital settings. This suggests that the studies had high external validity, since in the majority of cases, participants were recruited from "natural" settings as opposed to artificial or laboratory ones. As a result, however, they were largely opportunistic in their selection.

Patient satisfaction was a major focus of Study 2, although a standardized measure was not used due to a) time limitations, and b) the focus on patients' perceptions of the consultation using a structured interview format. Thus, although specific dimensions of satisfaction were not assessed[6], the patient was given the opportunity to discuss aspects of the consultation which were either unsatisfactory or which could be improved. Indeed, a similar approach has been adopted previously (Pendleton, 1981). Moreover, the findings are consistent with previous studies, both in terms of levels of reported dissatisfaction and patients' requests for more elaborate information about their illness.

Adherence was assessed in Studies 3 and 6 using self-report. It is well documented that self-reports produce overestimates of adherence when compared with other more objective measures (Becker, 1985; Ley, 1988). Although the additional use of more objective measures might be desirable to enable comparison, the present studies were particularly interested in patients' perceptions of a) their treatment regime and b) whether they felt they adhered to this regime. It is all the more revealing, then, that reports of dietary and exercise adherence in Study 6 were low, even for those who perceived them as a part of their treatment regime.

Overall, the samples for each of the studies were relatively large and, in the case of Studies 2, 3 and 6, came from a number of different General Practices (although in the Oxfordshire region) which suggests that the results are generalizable. However, there were some exceptions. Study 3 was a follow-up of a proportion of the patients interviewed in Study 2, thus the sample was more limited (N = 92). This posed particular difficulty when assessing adherence since only a proportion of those patients had actually received treatment (N = 58). Despite such limitations, the results were compatible with Study 6, a much larger study which investigated adherence to different aspects of a treatment regime. The sample of Study 4 also had limitations in that it was a) potentially biased due to a low response rate and b) had a relatively low participant variable ratio for factor analysis. However, the results were broadly consistent with previous findings with larger samples suggesting that the results were reliable in spite of sampling limitations.

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[6] For example affective, cognitive and behavioural dimensions of satisfaction.

8.8 Practical implications

Whilst the practical implications of the individual studies have already been discussed, the findings from Studies 2, 3 and 6 suggest some general implications for doctor-patient communication and health education.

Consistent with previous findings, the current studies have shown that by the time people seek medical care, the majority have already consulted others and have developed relatively clear ideas about what is wrong with them and how it should be treated. The doctor's perspective is thus only one influence on how people make sense of and respond to their condition. It is not surprising then that discrepancies between the patient's and doctor's perspectives are a major factor in patient dissatisfaction. The current studies show how patients' beliefs (both illness representations and health beliefs) influence their evaluation of the consultation, whether they adhere to treatment recommendations and how they cope with their illness. It is essential then, that health professionals recognize the salience of these beliefs and address them either in the consultation or when they are developing health education programmes, as in the case of chronic illness. Indeed, "it is not so much a question of examining lay beliefs as just another set of facts but of recognizing the place they occupy in a patient's life and thoughts" (Williams & Wood, 1986).

The need for more information which addressed patients' questions about their illness and its treatment was reflected both in patients' suggestions regarding ways in which their care could be improved and also in the apparent lack of consensus regarding their treatment amongst patients with diabetes and hypertension[7]. Thus, there was huge variation regarding what the treatment entailed (e.g. whether it included a dietary component or how often diabetics should test their BG levels). Indeed, previous studies have found that even when patients are generally satisfied with their medical care, they desire more information (Hall & Dornan, 1988; Greenberg et al., 1984). This also has obvious implications for adherence. On the one hand, it suggests that patients should be provided with more information. Indeed, doctors spend only a small percentage of the consultation providing information. However, research also indicates that patients do not fully understand or forget much of the information that is presented in the consultation (Ley, 1988). The key to this apparent paradox therefore appears to lie in communicating effectively (e.g. using the guidelines outlined by Ley and others) and in providing information orientated towards the patients' needs. Evidence suggests that wide discrepancies exist between the information that doctors and patients regard as important (Berry et al., 1997). Consistent with previous research,

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[7] This is consistent with previous research indicating that both recall and adherence to different aspects of the regime are highly variable (Kravitz et al., 1993).

the current studies suggest that it is important for doctors to highlight the benefits of treatment but also to explain the potential side-effects of treatment. Clearly, this can be addressed in medical training. Indeed, increasing doctors' awareness of the difficulties associated with adherence and providing training on how to alter patients' beliefs can increase adherence and health outcomes (Innui et al., 1976).

A major retort by doctors to the suggestion that they elicit and take into account patients' beliefs and provide more elaborate information is the time restrictions they face. However, the teaching of good communication skills can result in doctors being able to elicit information more efficiently thereby requiring less time to give and receive information (Evans et al., 1991). Certainly the balance between good communication skills and provision of adequate information must necessarily be maintained. For example, an intervention in patient-centred care for nurses treating Type II diabetics resulted in reports of better communication, satisfaction and well-being, but lower knowledge scores i.e. "he communicates well but tells you nothing" (Kinmonth, Woodcock, Griffin et al., 1998).

The work constituting this thesis is consistent with the self-regulatory view of the patient as an active decision-maker. It suggests that in addition to the provision of adequate information and directions about how to best manage their illness, the active *involvement* of the patient in the management of their condition is a crucial step in facilitating successful care. Indeed, this emphasis is currently receiving particular recognition, as evidenced by a recent special edition of the British Medical Journal on patient participation (2000, 319; 7212). It is important to involve patients in the whole decision-making process by addressing their beliefs about their condition and by adapting the management of their condition to fit with external demands. This process may require delegation to other specialist health professionals such as dieticians. The active participation of patients in their own care can avoid discrepancies occurring between lay and medical models because it involves negotiated *agreement* during which inaccuracies or maladaptive components in the patients' model can be addressed.

8.9 Future directions

Several suggestions for future directions in developing the self-regulatory model have already been made, including the need for further longitudinal studies. However, several further areas worthy of investigation are suggested by the current research.

This thesis explored how people make sense of and respond to illness, but predominately focused on their perceptions once they had sought medical care. It was, however, evident that lay consultation played a role in the early interpretation stage for many patients. A related issue therefore, is the decision-making process undertaken prior to the seeking of medical advice, whereby people attend to, interpret and decide how to respond to somatic signs. It would be of interest to explore both the cognitive and emotional processes that underlie such decisions.

A further line of enquiry is the impact of disease on the individual's concept of self. Nerenz and Leventhal (1983) suggested three ways in which illness might be integrated into the self-system (total, encapsulated and at risk; see chapter 1, section 1.3.4), but little attention has since been placed on the impact of disease on self, although Leventhal Benyamini, Brownlee, et al. (1997) have recently discussed the overlap of representations of disease and self in enhancing health promotion behaviour. It seems that the relationship between disease and self has largely remained within the domain of clinical psychology, despite its direct relevance to individual patterns of adaptation and the self-regulation of illness. A qualitative study is therefore currently being undertaken to explore the impact of diabetics' beliefs about their illness on their concept of self. It is hoped that this exploratory study will suggest ways in which beliefs have an impact on the self-system, with implications for successful adaptation to long-term illness.

Finally, it is proposed that the extension of the conceptual underpinnings of the thesis to other cultures has considerable potential to aid the understanding of illness and to maximise the benefits of available health care. The conceptual overlap of the self-regulatory model with Kleinman's explanatory approach suggests that the self-regulatory framework would be applicable for use in other cultural settings. Indeed, Leventhal et al. (1997) suggest that whilst the content of people's representations may differ cross-culturally (e.g. causal attributions for pain may relate to a curse from a local witch doctor in one culture but overwork in another), the attributes themselves are unlikely to differ substantially although their significance may vary from culture to culture. In particular, it would be interesting to compare the illness representations and strategies of coping in a culture in which the biomedical model is not adopted as the cultural norm. In many cultures[8], two or more conflicting systems of medicine stand alongside each other with very different

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[8] For example, in Andean countries such as Bolivia, the belief systems underlying available systems of care are hugely divergent. According to indigenous Andean beliefs the health of the individual and the environment are inexorably linked and conventional western treatment frequently fails to a) identify the underlying problem and b) communicate with the patient in a manner which relates to these beliefs. Thus important services (such as re-hydration therapy for potentially fatal diarrhea) are under-utilized or the treatment is not followed correctly (Bastien, 1987).

underlying belief systems, creating considerable difficulties in communication between doctors and their patients and an under-utilization of medical care and treatment (Bastien, 1987; Bodelier, 1996; Kleinman, 1980). As previously discussed, the studies reported in this thesis have many potential practical applications, particularly with regard to communication and health education. However, the application of the self-regulatory framework to other cultures promises even greater potential.

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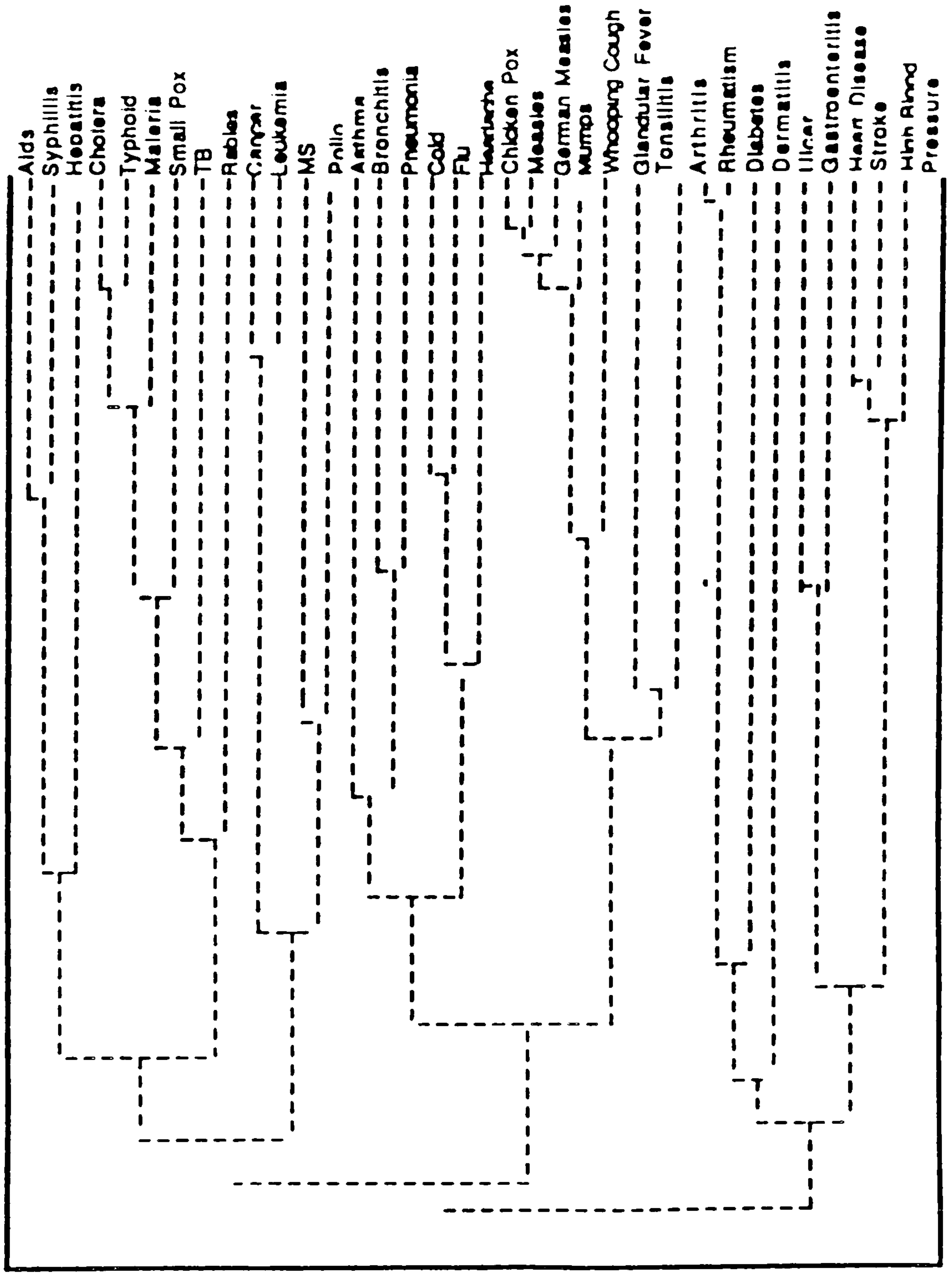
Appendix 1

Chapter 3: Average linkage cluster analysis of 35 illnesses (taken from Lalljee et al., 1993)

CYCLE	I	J	COEFF
1	2	28	130.000
2	6	22	129.000
3	6	13	124.000
4	7	34	119.000
5	6	24	110.333
6	5	20	109.000
7	16	30	109.000
8	7	21	99.500
9	16	18	91.500
10	8	19	88.000
11	1	31	87.000
12	6	35	83.500
13	4	25	83.000
14	7	29	64.333
15	11	12	63.000
16	8	15	60.000
17	14	32	57.000
18	23	26	54.000
19	7	33	52.250
20	6	14	50.500
21	3	4	45.000
22	7	27	40.400
23	1	17	37.500
24	3	8	29.000
25	5	23	28.750
26	2	10	26.500
27	11	16	22.833
28	3	6	22.143
29	1	7	20.333
30	2	9	19.333
31	2	11	16.850
32	1	5	15.056
33	1	3	11.024
34	1	2	7.470



Appendix 2

Chapter 3: Sample of questionnaire from study 1 (only one illness included here)

This study is concerned with people's ideas about illnesses, and the typical features people use in identifying different illnesses.

The questionnaire will take you a short time to complete. It has five pages (including this one) and asks you to consider four different illnesses.

Please answer **all** the questions for each of the four illnesses. The study is concerned with your beliefs about each illness, not with the correctness of your answers; so your replies should reflect what you believe.

Before you start please write your age, sex, occupation, nationality and ethnic group in the spaces below.

Thank you for your help.

AGE:

SEX:

OCCUPATION:

NATIONALITY:

ETHNIC GROUP:

RHEUMATISM

1. What are the typical symptoms of this illness?

2. What sort of person typically gets this illness?

3. Why/How does one typically get this illness?

4. How serious is this illness?

5. For how long does this illness typically last?

6. What might be done to treat this illness?

Appendix 3

Chapter 3: Content Analysis of Questionnaire (Study 1)

Below is an outline of the content analysis of respondents' responses to the six questions on the questionnaire. The 37 illnesses are grouped into the clusters identified by Lalljee et al. (1993) and the preliminary study described on p.73. Thirty participants responded to each illness. The numbers given after each feature indicate the number of participants citing this feature.

1. SYMPTOMS

Primary Cluster 1

Primary Cluster 1a.

CYSTITIS: Pain or burning sensation on urinating 18, Frequent passing of urine 7, Discoloured/bloody urine 5, Inflammation of bladder 3, Fever/temperature 3, Miscellaneous 9, Don't know 5.

VENEREAL DISEASE: Genital sores/warts/rash 27, Discharge 13, Itching/irritation 12, soreness/pain 8, Inflammation 3, Pain or burning sensation on urinating 3, Fatigue 2, Misc. 14, Don't know 1.

Primary Cluster 1b.

MENINGITIS: Fever 12, Headache 11, Flu-like symptoms 7, Fatigue 5, Nausea 4, Photophobia 3, Sore throat 3, Cold/shivering 3, Inflammation 3, Aching joints 3, Cough 2, Misc. 11, Don't know 5.

Primary Cluster 1c.

LUNG CANCER: Breathlessness/breathing difficulties 16, Cough 14, Chest pain 10, Pain 7, Weight loss 4, Fatigue 2, Misc. 5, Don't know 2.

BREAST CANCER: Lump(s) in breast 28, Change in appearance of breast 9, Pain 3, Misc. 3.

Primary Cluster 2

Primary Cluster 2a.

ASTHMA: Breathing difficulties 9, Wheezing 9, Tight chest 3, Lung congestion 3, Cough 2, Misc. 1.

BRONCHITIS: Tight/congested chest 17, Breathing difficulties 17, Cough 19, Phlegm 6, Wheezing 4, Sore throat 3, Fever 4, Lung problems 4, Misc. 2.

PNEUMONIA: Breathing difficulties 13, Fever 13, Coughing 7, chest pain 7, lung problems 7, Cold-like symptoms 4, Cold/shivering 5, Fatigue 3, Misc. 6, Don't know 1.

Primary Cluster 2b.

COLD: Runny/blocked nose 28, Sore throat 19, Headaches 9, Sneezing 7, Fever 5, Cough 4, Ear ache 3, Watery/sore eyes 4, Cold/shivering 3, Misc. 7.

FLU: Fever 25, Headache 14, Aches and pains 13, Runny/blocked nose 11, Sore throat 7, fatigue 6, Cold/shivery 5, Malaise 3, Watery eyes 2, Misc. 6.

EAR INFECTION: Ear ache 26, Discharge 6, Loss of hearing 6, Fever 4, Dizziness 6, Irritability 2, Flushed 2, Nausea 2, Headaches 2, Misc. 9.

SINUSITIS: Sinus pain 19, Blocked/runny nose 15, Headaches 16, Cold-like symptoms 3, Breathing difficulties 3, Tender face 2, Misc. 4, Don't know 1.

LARYNGITIS: Sore throat 23, Voice loss/hoarseness 21, Swollen glands 6, Fever 3, Cough 2, Misc. 2.

MIGRAINE: Severe headaches 24, Nausea 12, Impaired/blurred vision 10, Photophobia 4, Dizziness 2, Misc. 8, Don't know 1.

Primary Cluster 3

MEASLES: Spots 25, Fever 18, Rash 8, Fatigue 3, Swollen glands 2, Malaise 2, Sore throat 2,

Photophobia 2, Misc. 5.
CHICKEN POX: Spots 7, Fever 12, Rash 7, Malaise 5, Sore throat 3, Misc. 6.
MUMPS: Swollen glands 28, Fever 7, Sore throat 7, Blotchy skin/bumps 4, Misc. 8.
GERMAN MEASLES: Spots 19, Rash 12, Fever 9, Nausea 3, Malaise 3, Sore throat 2, Appetite loss 2, Itching 2, Misc. 7 .
SHINGLES: Rash 13, Spots 7, Pain 5, Fever 3, Itching 4, Dry skin 3, Misc. 10, Don't know 4.
TONSILLITIS: Sore throat 26, Swollen tonsils/throat 13, Fever 9, Difficulty swallowing 6, Nausea 3, Fatigue 3, Malaise 3, Misc. 3, Don't know 1.
GLANDULAR FEVER: Swollen glands 27, Fever 14, Fatigue 14, Sore throat 8, Appetite loss 5, Malaise 3, Headaches 3, Flu-like 2, Misc. 10.

Primary Cluster 4

Primary Cluster 4a.
ARTHRITIS: Painful/aching joints 25, Stiff joints 13, Swollen joints 10, Restricted movement 7, Misc. 3.
RHEUMATISM: Painful/aching joints 22, Stiff joints 13, Pain 6, Swollen joints 4, Restricted movement 3, Misc. 8.
LUMBAGO: Back ache/pain 17, Pain in lower back 7, Painful/restricted movement 3 Joint pain 2, Misc. 7, Don't know 2.
SCIATICA: Back ache/pain 15, Limb pain/numbness 16, Muscular pain 5, Restricted movement 2, Don't know 7.
Primary Cluster 4b.
ANAEMIA: Fatigue 24, Pale complexion 16, Faintness 4, Misc. 9.
Primary Cluster 4c.
DERMATITIS: Dry/flaky skin 19, Itching skin 12, Rash 15, Sore/irritated skin 8, Spots 5, Misc. 5, Don't know 2.
ECZEMA: Dry/flaky skin 26, Itching skin 17, Rash 12, Sore/irritated skin 5, Scabs/blisters 3, Spots 2, Misc. 3, Don't know 1.

Primary Cluster 5

Primary Cluster 5a.
PEPTIC ULCER: Stomach pains 19, Indigestion 8, Abdominal pain 3, Nausea 3, Appetite loss 2, Misc. 6, Don't know 3.
GASTROENTERITIS: Sickness 21, Diarrhoea 18, Stomach pains 9, Fever 7, Stomach upset 4, Misc. 9, Don't know 2.
IRRITABLE BOWEL: Diarrhoea 15, Constipation 8, Painful/itchy anal region 6, Stomach pain 5, Stomach upset 3, Abdominal pain 2, Nausea 2, Misc. 4, Don't know 5.
APPENDICITIS: Abdominal pain 15, Stomach pain 8, Nausea 5, Pain on right side 5, Diarrhoea 2, Pain 2, Pain in side 2, Misc. 2.
CIRRHOSIS: Pain/malfunction in liver 10, Jaundice 7, Discoloured/bloody urine 3, Misc. 16, Don't know 7.
Primary Cluster 5b.
HEART DISEASE: Chest pains 19, Breathing difficulties 14, Limb pain 5, High B.P 3, Angina 4, Fatigue 3, Heart attack 2, Misc. 5, Don't know 1.
ANGINA: Chest pains 19, Breathing difficulties 10, Heart burn/pain 3, Fatigue 2, Hot flushes 2, Misc. 9, Don't know 2.
THROMBOSIS: Blood clot 9, Pain 5, Limb pain 5, Chest pain 4, Inflammation 4, Breathing difficulties 2, Misc. 8, Don't know 5.
HIGH B.P: Flushed 11, Headaches 10, Dizziness/balance loss 9, Swollen ankles/wrist 4, Fatigue 3, Sweating 2, None 2, Breathlessness 4, Heart palpitations/pain 4, Irritable 2, Visual disturbance 2, Misc. 7, Don't know 2.

2. PERSON

Primary Cluster 1

Primary Cluster 1a.

CYSTITIS: Female 20, Anyone 7, Sexually active 4, Older 2, Misc. 4, Don't know 4.

VENEREAL DISEASE: Sexually active/promiscuous 17 , Who has unprotected sex/sex with infected persons 12, Prostitutes 4, Anyone 5, Misc. 5.

Primary Cluster 1b.

MENINGITIS: Anyone 16, Children/Young 15, Rundown 2, Misc. 4, Don't know 2.

Primary Cluster 1c.

LUNG CANCER: Smoker 24, Older 7, Anyone 5, Passive smokers 4, Exposed to carcinogens/chemicals 3, Poor/dusty working conditions 4, Misc. 3.

BREAST CANCER: Women 14, Older women 14, Some men 4, Misc. 5, Don't know 1.

Primary Cluster 2

Primary Cluster 2a.

ASTHMA: Anybody 14, Allergy/hayfever/eczema sufferers 6, Genetically predisposed 4, Children 3, With chest/lung/respiratory problems 4, Weak 2, Misc. 5, Don't know 1.

BRONCHITIS: Smokers 17, Older 10, Anyone 5, Poor environment/working conditions 8, With chest/lung problems 6, Asthmatics 2, Misc. 8, Don't know 2.

PNEUMONIA: Elderly 18, Anybody 10, Young/kids 6, With chest weakness 5, With lowered immunity 9, Smokers 2, Exposed to cold conditions 2, Misc. 3, Don't know 1.

Primary Cluster 2b.

COLD: Anyone 24, Children 3, Rundown (incl. unhealthy) 5, With lowered immunity 3, Exposed to cold/damp 2, Misc. 3.

FLU: Anyone 17, Rundown 5, Elderly 4, Misc. 8, Don't know 1.

EAR INFECTION: Anyone 14, Children 13, Elderly 3, Misc. 6, Don't know 1.

SINUSITIS: Anyone 17, Adults 3, With lowered immunity 3, Misc. 3, Don't know 5.

LARYNGITIS: Anybody 17, Who uses voice a lot 11, Smokers 5, Children 2, Misc. 6.

MIGRAINE: Anyone 15, Female 5, Stressed 3, Misc. 6, Don't know 5.

Primary Cluster 3

MEASLES: Children 25, Anyone 5, Misc. 1.

CHICKEN POX: Children 29, Anyone 2, Misc. 1, Don't know 1.

MUMPS: Children 26, Sometimes adults 4, Anyone 2, Misc. 1, Don't know 1.

GERMAN MEASLES: Children 28, Anyone 4 Not immune 2, Misc. 6.

SHINGLES: Adults 8, Older 7, Elderly 4, Anyone 4, (Had chicken pox 4), Not immune 2, Misc. 5, Don't know 6.

TONSILLITIS: Anyone 13, Children/Young 15, Rundown 3, With tonsils 3, Who uses voice a lot 2, With lowered immunity 2, Misc. 3.

GLANDULAR FEVER: Teenagers/Young people 19, Rundown 5, Anyone 6, Stressed 3, Misc. 4, Don't know 2.

Primary Cluster 4

Primary Cluster 4a.

ARTHRITIS: Elderly 17, Older 9, Anybody 4, Active people 3, Misc. 2, Don't know 1

RHEUMATISM: Elderly 14, Anyone 10, Older/middle-aged 7, Active 2, Young 2, Misc. 6, Don't know 1.

LUMBAGO: Anyone 9, Older/middle-aged 6, Who strains their back/lifts a lot 5, Adults 4, Predominately male 3, Elderly 4, Misc. 2, Don't know 5.

SCIATICA: Older 10, With back injury 6, Elderly 5, Who strains their back/lifts a lot 6, Anyone 4, Pregnant women 2, Overweight 2, Inactive/unfit 2, Misc. 2, Don't know 7.

Primary Cluster 4b.

ANAEMIA: With poor diet 10, Women 12, Pregnant women 5, Anyone 7, Teenagers 3, Stressed 2, Children 2, Misc. 9, Don't know 2.

Primary Cluster 4c.

DERMATITIS: Anyone 13, With allergies/sensitive skin 4, Genetic predisposition 3, Nervous disposition 2, Exposed to oils, chemicals etc 3, Misc. 11, Don't know 3.

ECZEMA: Anyone 10, Children/young 9, Nervous disposition 5, With allergies, hayfever or eczema) 5, Teenagers 3, With genetic predisposition 3, Stressed 2 Misc. 3, Don't know 3.

Primary Cluster 5

Primary Cluster 5a.

PEPTIC ULCER: Stressed 9, With poor diet/eating habits 8, Anyone 5, Heavy drinker 4, Business person 4, Nervous disposition 3, Smoker 2, Male 2, Misc. 5, Don't know 6.

GASROENTERITIS: Anyone 17, With poor hygiene 4, Elderly 3, Contact with germ/infected person 3, With lowered immunity 2, Children 2, Misc. 8, Don't know 2.

IRRITABLE BOWEL: Anyone 7, Stressed 6, With poor diet 6, Nervous/tense 6, Older 3, Misc. 6, Don't know 7.

APPENDICITIS: Anyone 23, Children/Young 5, Misc. 1, Don't know 1.

CIRRHOSIS: Alcoholics/heavy drinkers 26, Men 4, Stressed 2, Anyone 2, Misc. 5.

Primary Cluster 5b.

HEART DISEASE: Smokers 13, Overweight 13, Older 14, Unfit 12, Heredity 7, With poor diet/high cholesterol 8, Stressed 6, With hypertension 4, Heavy drinkers 3, Men 2, Misc. 4.

ANGINA: Older 14, Elderly 8, Stressed 4, With heart problems 3, Overweight 3, Male 3, Smokers 3, With poor diet 3, Anybody 2, Unfit 2, Misc. 1, Don't know 1.

THROMBOSIS: Older 7, Anyone 5, Overweight 5, Smokers 5, Elderly 3, With poor circulation 3, Heavy drinkers 2, Unfit/inactive 2, Stressed 2, Misc. 8, Don't know 5.

HIGH B.P: Overweight 14, Stressed 9, Pregnant women 7, Inactive/unfit 6, Smokers 5, Anyone 4, Older 5, With poor diet 2, Misc. 6, Don't know 1.

3. CAUSE

Primary Cluster 1

Primary Cluster 1a.

CYSTITIS: Infection 11, Too much sex 4, Misc. 9, Don't know 13.

VENEREAL DISEASE: Sex (unprotected/with infected persons) 27, Sexual promiscuity 3, Misc. 3. ***Primary Cluster 1b.***

MENINGITIS: Contagion 1,1 Virus 8, Infection 4, Misc. 6, Don't know 8.

Primary Cluster 1c.

LUNG CANCER: Smoking 23, Harmful substances/pollution 7, Heredity 4, Misc. 7.

BREAST CANCER: Heredity 8 Spontaneous 6, Contraceptive pill 4 Unknown 4, Mutating cells 4, Smoking 3, Misc. 12.

Primary Cluster 2

Primary Cluster 2a.

ASTHMA: Heredity 15, Allergies 12, Pollution 3, Spontaneous 2, Misc. 9, Don't know 4.

BRONCHITIS: Infection 10, Smoking 5 Damp/poor environment 5, Rundown 5, Previous lung pathology 3, Pollution 2, Misc. 10, Don't know 6.

PNEUMONIA: Infection 12, Exposure to cold/wet 9, Rundown 7, Neglect/unhealthy 3, Virus 2, Contagion 2, Misc. 4, Don't know 4.

Primary Cluster 2b.

COLD: Contagion 26, Exposure to cold/wet 6, Infection 4, Rundown 2, Misc. 1, Don't know 1.

FLU: Contagion 21, Virus 7, Rundown 3, Infection 2, Exposure to cold/wet 3, Misc. 2.
EAR INFECTION: Infection 16, Virus 7, Exposure to cold/wet 2, Misc. 5, Don't know 6.
SINUSITIS: Infection 8, Infected sinus/catarrh 4, Allergy 2, Environment 2, Heredity 2, Virus 2, Misc. 13, Don't know 9.
LARYNGITIS: Voice/larynx strain 10, Infection 9 Contagion 7, Virus 4, Smoking 2, Misc. 3, Don't know 2.
MIGRAINE: Stress 13, Allergy (to foods) 11, Tiredness/fatigue 2, Diet 2, Misc. 13, Don't know 6.

Primary Cluster 3
MEASLES: Contagion 24, Infection 4, Virus 3, Don't know 1.
CHICKEN POX: Contagion 27, Virus 3, Infection 2, Misc. 2, Don't know 1.
MUMPS: Contagion 20, Virus 2, Misc. 3, Don't know 6 .
GERMAN MEASLES: Contagion 25, Virus 3, Misc. 2, Don't know 3.
SHINGLES: Contagion 11, Virus (chicken pox) 10, Rundown 3, No immunity (to chicken pox) 2, Misc. 8, Don't know 7.
TONSILLITIS: Infection 16 Contagion 7 Rundown 3, Misc. 9, Don't know 3.
GLANDULAR FEVER: Contagion 16, Stress 6, Virus 3, Infection 2 Poor diet 2, Opportunistic 2 Overwork 2, Misc. 1, Don't know 5.

Primary Cluster 4
Primary Cluster 4a.
ARTHRITIS: Wear & tear/joints worn out 9, Heredity 6, Age 5, Damp environment 2, Misc. 7, Don't know 8.
RHEUMATISM: Heredity 12, Wear and tear/joints worn out 7, Damp/cold environment 5, Age 3, Poor diet 3, Misc. 7, Don't know 5.
LUMBAGO: Heavy lifting/physical strain 12, Damp/cold environment 5, Age 3, Bad posture 2, Spontaneous 2, Misc. 4, Don't know 10.
SCIATICA: Heavy lifting/physical strain 12, Trapped nerve 6, Bad posture 3, Misc. 5, Don't know 9.
Primary Cluster 4b.
ANAEMIA: Poor diet 16, Iron deficiency 12, Poor health/neglect 3, Blood loss/menstruation 2, Pregnancy 2, Misc. 6, Don't know 3.
Primary Cluster 4c.
DERMATITIS: Allergy/sensitivity to substances 10, Heredity 8, Detergents/oils/chemicals 5, Spontaneous 3, Contagion 3, Neglect 2, Misc. 5, Don't know 7.
ECZEMA: Heredity 14, Allergy 7, Stress 7, Hormonal 2, Diet 2, Misc. 10, Don't know 5.

Primary Cluster 5
Primary Cluster 5a.
PEPTIC ULCER: Poor diet 15, Stress 13, Excess acid in stomach 6, Excess alcohol 5, Irregular/poor eating habits 3, Misc. 8, Don't know 7.
GASTROENTERITIS: Food poisoning (contaminated food) 17, Virus 10, Poor hygiene 5, Contagion 4, Poor diet 4, Contaminated water 2, Misc. 5, Don't know 2.
IRRITABLE BOWEL: Poor diet 9, Stress 9, Poor eating habits 2, Misc. 10, Don't know 8.
APPENDICITIS: Inflamed/infected/blocked appendix 14, Spontaneous 3, Misc. 4, Don't know 11.
CIRRHOSIS: Excess alcohol 25, Liver dysfunction 3, Poor diet 2, Overwork 2, Misc. 3, Don't know 4.
Primary Cluster 5b.
HEART DISEASE: Smoking 12, Lack of exercise 10, Poor diet 10, Heredity 8, High cholesterol 7, Stress 6, Overeating/overweight 6, Blocked coronary arteries 5, Excess alcohol 4, Age 2, Unhealthy lifestyle 2, Misc. 3.

ANGINA: Poor diet 8, Smoking 6, Heart disease 6, Unfit 4, Stress 4, Overweight 4, High cholesterol 4, Heredity 2, Over work 2, Excess alcohol 2, Spontaneous 2, Misc. 4, Don't know 7.
THROMBOSIS: Lack of exercise 4, Smoking 5, Poor diet 5, Stress 3, Injury 3, Spontaneous 3, Blood clotting 3, Bad circulation (varicose veins) 3, Blocked arteries 3, Contraceptive pill 2, Misc. 12, Don't know 6.
HIGH B.P.: Stress/pressure 16, Poor diet 12, Unfit/lack of exercise 10, Smoking 7, Overweight 5, Pregnancy 4, Heredity 4, Excess alcohol 3, Blocked arteries 3, Heart problems 2, Misc. 4, Don't know 3.

4. SERIOUSNESS

Primary Cluster 1
Primary Cluster 1a.
CYSTITIS: Not serious 16, Serious 6, Quite serious 2, Uncomfortable/unpleasant 2, Misc. 3, Don't know 5.
VENEREAL DISEASE: Very serious 10, Depends 5, Life threatening 7, Quite serious 4, Serious 2, Treatable 2, Not serious 2, Misc. 1, Don't know 2.
Primary Cluster 1b.
MENINGITIS: Very serious 20, Life threatening 12, Varies 2, Don't know 1.
Primary Cluster 1c.
LUNG CANCER: Very serious 14, Terminal/life threatening 15, Misc. 2.
BREAST CANCER: Very serious 22, Life threatening 11, Misc. 2.

Primary Cluster 2
Primary Cluster 2a.
ASTHMA: Very serious 1,1 Life threatening 12, Not serious 4, Serious 3, Varies 3, Misc. 2.
BRONCHITIS: Very serious 10, Serious 7, Serious in vulnerable groups 8, Life-threatening 4, Not serious 3, Quite serious 2, Misc. 3.
PNEUMONIA: Life threatening 13, Very serious 13, Very serious in vulnerable groups 3, Not serious 2, Misc. 3.
Primary Cluster 2b.
COLD: Not serious 27, Serious in vulnerable groups 5, Misc. 1.
FLU: Not serious 16, Serious (in vulnerable groups) 10, Life-threatening 3, Misc. 3.
EAR INFECTION: Not serious 15, Quite serious 6, Can -> deafness 5, Painful/debilitating 2, Depends 2, Misc. 1, Don't know 1.
SINUSITIS: Not serious 20, Painful 3, Misc. 3, Don't know 4.
LARYNGITIS: Not serious 20, Quite serious 4, Very serious 3, Misc. 3, Don't know 1.
MIGRAINE: Unpleasant/debilitating 11, Not serious 9, Not life threatening 4, Serious 3, Misc. 5, Don't know 2.

Primary Cluster 3
MEASLES: Not serious 17, Serious 4, Serious if pregnant 6, Can -> secondary problems 4, Life threatening for babies/foetus 3, Serious in adults 2, Misc. 3, Don't know 1.
CHICKEN POX: Not serious 20, Can -> secondary problems 5, Serious in adults 3, Serious in vulnerable groups 2, Quite serious 2, Misc. 3.
MUMPS: Not serious 14, Serious in adults 13, Quite serious 2, Very serious 2, Uncomfortable 2, Misc. 4, Don't know 1.
GERMAN MEASLES: Serious if pregnant 19, Not serious 19, Serious in adults 3, Misc. 3.
SHINGLES: Quite serious 8, Unpleasant/painful 7, Very serious 7, Not serious 3, Misc. 3, Don't know 5.
TONSILLITIS: Not very serious 15, Serious 4, Quite serious 4, Unpleasant/debilitating 3, Can

-> secondary infections/problems 2, Misc. 2, Don't know 1.

GLANDULAR FEVER: Quite serious 8, Not very serious 9, Very serious 6, Serious 5, Misc. 2, Don't know 1.

Primary Cluster 4

Primary Cluster 4a.

ARTHRITIS: Painful/debilitating 15, Very serious 7, Not very serious 4, Misc. 3.

RHEUMATISM: Painful/debilitating 13, Not life threatening 5, Very serious 4, Varies 4, Quite serious 3, Not serious 3, Serious ,2 Don't know 1.

LUMBAGO: Not serious 10 Painful/debilitating 5, Quite serious 4, Not life threatening 3, Very serious 2, Misc. 3, Don't know 5.

SCIATICA: Serious 9, Quite serious 4, Uncomfortable 5, Not serious 5, Don't know 8.

Primary Cluster 4b.

ANAEMIA: Not serious 7, Serious 6, Very serious 5, Debilitating 4, Quite serious 5, Don't know 4.

Primary Cluster 4c.

DERMATITIS: Not serious 13, Uncomfortable 5, Varies 4, Quite 3, Misc. 2, Don't know 3.

ECZEMA: Not serious 14, Uncomfortable/unpleasant 9, Disfiguring 3, Misc. 6, Don't know 2.

Primary Cluster 5

Primary Cluster 5a.

PEPTIC ULCER: Very serious 7, Quite serious 7, Not serious 5, Serious 5, Life threatening 3, Don't know 5.

GASTROENTERITIS: Very serious 10, Can be fatal 6, Quite serious 6, Not serious 4, Serious in vulnerable groups 2, Misc. 2, Don't know 1.

IRRITABLE BOWEL: Not serious 14, Not life threatening 5, Quite serious 5, Can -> secondary problems 3, Uncomfortable 2, Misc. 4, Don't know 5.

APPENDICITIS: Life-threatening 9, Serious 8, Very serious 6, Not serious (if treated) 5, Misc. 5.

CIRRHOSIS: Life threatening/fatal 1,1 Very serious 9, Quite serious 8, Misc. 2, Don't know 1.

Primary Cluster 5b.

HEART DISEASE: Very serious 21, Life threatening 9, Serious 2, Quite serious 2.

ANGINA: Very serious 11, Life threatening 8, Not very serious 6, Quite serious 5, Serious 1, Don't know 1.

THROMBOSIS: Very serious 10, Life threatening 12, Serious 2, Misc. 4, Don't know 3.

HIGH B.P: Very serious 18, Life threatening 9, Not serious 4, Quite 3, Serious 1, Don't know 1.

5. TIME LINE

Primary Cluster 1

Primary Cluster 1a.

CYSTITIS: < week 9, 1 week 3, Chronic/lifetime 4, Intermittent 2, Depends 2, Misc. 7, Don't know 7.

VENEREAL DISEASE: Until treated 13, Depends 4, Lifetime 4, 1 - 4 mths 3, Recurring 2, Misc. 2, Don't know 4.

Primary Cluster 1b.

MENINGITIS: Weeks 7, Up to 6 months 5, 4 - 8 weeks 2, Misc. 7, Don't know 10.

Primary Cluster 1c.

LUNG CANCER: Lifetime 8, Depends 6, Up to a year 6, Years 5, Until treated 4, Misc. 3, Don't know 2.

BREAST CANCER: Lifetime 7, Until cured/treated 8, Varies 6, Indefinitely 4, 1 - 5 years 2, Misc. 3, Don't know 3.

Primary Cluster 2

Primary Cluster 2a.

ASTHMA: Lifetime 20, Can be outgrown 8, Varies 5, Indefinitely 2, Misc. 1, Don't know 1.

BRONCHITIS: 2-3 weeks 10, Chronic 4, Varies 4, 1 - 3 weeks 4, Up to 6 months 2, 4-8 weeks 3, Misc. 3, Don't know 2.

PNEUMONIA: Few weeks (< 4 weeks) 13, Up to 6 months 5, Up to 6 months 4, Until treated 2, Depends 2, Misc. 3, Don't know 1.

Primary Cluster 2b.

COLD: Few days (< week) 16, Week 6, 1-2 weeks 4, Misc. 4.

FLU: Week 11, Few days (< week) 11, 1-2 weeks 6, Misc. 3, Don't know 1.

EAR INFECTION: Week 7, < week 6, Until treated 4, 1 - 2 weeks 4, Misc. 4, Don't know 5.

SINUSITIS: Several days 5, Lifetime 3, Reoccurring 3, 2 - 3 weeks 3, 1 week 2, Depends 2, Misc. 4, Don't know 11.

LARYNGITIS: Few days (< week) 12, 1-2 weeks 8, 2-4 weeks 5, Varies 2, Misc. 1, Don't know 2.

MIGRAINE: Lifetime/indefinitely 7, Hours 7, < 36 hours 6, Few days 6, Varies 2, Misc. 2, Don't know 2.

Primary Cluster 3

MEASLES: 2 weeks 10, 1-2 weeks 11, 2-3 weeks 7, Misc. 2.

CHICKEN POX: 1 - 2 weeks 11, 2 weeks 6, 2 - 3 weeks 4, 2 - 4 weeks 4, 6 weeks 2, Misc. 1, Don't know 1.

MUMPS: 2 weeks 9, 1 - 2 weeks 7, 2 - 3 weeks 5, 2 - 4 weeks 4, 6 weeks 2, Misc. 1, Don't know 2.

GERMAN MEASLES: 2 weeks 6, Week 6, 1-2 weeks 7, 2 - 3 weeks 3, 2 - 4 weeks 3, Weeks 2, Misc. 2, Don't know 1.

SHINGLES: Up to 6 months 4, 4 - 8 weeks 6, Years/indefinitely 3, 1 - 2 weeks 2, 2 - 3 weeks 2, Varies 2, Misc. 6, Don't know 5.

TONSILLITIS: 2-3 weeks 9, 1-2 weeks 7, Few days 4, Misc. 7, Don't know 4.

GLANDULAR FEVER: Reoccurring 5, 2 - 4 weeks 6, 4 - 8 weeks 4, Up to 6 months 4, 6 - 12 months 4, Varies 3, Indefinitely/years 2, Misc. 5, Don't know 1.

Primary Cluster 4

Primary Cluster 4a

ARTHRITIS: Lifetime 24, Years/indefinitely 5, Don't know 1.

RHEUMATISM: Lifetime 22, Years/indefinitely 7, Misc. 1, Don't know 1.

LUMBAGO: Varies 10, Lifetime/chronic 7, Misc. 6, Don't know 8.

SCIATICA: Lifetime 6, Varies 4, Indefinitely/years 5, Weeks 2, Misc. 5, Don't know 8.

Primary Cluster 4b.

ANAEMIA: Until treated 13, Years 4, Varies 3, Up to 6 months 2, Misc. 3, Don't know 6.

Primary Cluster 4c.

DEMATITIS: Lifetime 11, Varies 8, Until treated 2, Recurring 2, Misc. 4, Don't know 4.

ECZEMA: Years/indefinitely 11, Lifetime 9, Varies 5, Misc. 4, Don't know 4.

Primary Cluster 5

Primary Cluster 5a.

PEPTIC ULCER: Until treated 9, Lifetime 3, Indefinitely/years 4, 1-4 months 2, Misc. 4, Don't know 8.

GASTOENTERITIS: < week 12, 1 - 2 weeks 6, Few weeks 7, Until treated 2, Misc. 1, Don't know 2.

IRRITABLE BOWEL: Until treated 5, 1 - 4 months 4, Few weeks 3, Few days 3, Reoccurring 3, 1 week 2, Misc. 5, Don't know 9.

APPENDICITIS: Few days 6, Until treated 6, Up to a year 4, Sudden illness 5, Varies 4, Misc. 4, Don't know 5.

CIRRHOSIS: Lifetime 11, Years 5, Until change in lifestyle 2, Misc. 4, Don't know 9.

Primary Cluster 5b.

HEART DISEASE: Lifetime 17, Until treated 4, Varies 4, Indefinitely/years 3, Misc. 3, Don't know 3.

ANGINA: Lifetime 19, Years 4, Varies 2, Misc. 3, Don't know 2.

THROMBOSIS: Years/indefinitely 6, Varies 5, Until treated 4, Lifetime 5, Misc. 5, Don't know 9.

HIGH B.P: Lifetime 12, Indefinitely 4, Varies 3, Misc. 8, Don't know 4.

6. TREATMENT

Primary Cluster 1

Primary Cluster 1a.

CYSTITIS: Medication 15, Drink fluids 5, Alternative medicine 2, Non-prescription medicine 4, Creams 3, Misc. 3, Don't know 8.

VENEREAL DISEASE: Medication 23, Creams 6, Pessaries 3, See Dr./clinic 2, Misc. 5, Don't know 3.

Primary Cluster 1b.

MENINGITIS: Medication 12, Hospitalisation 6, Surgery 2, Vaccination 2, Misc. 6, Don't know 10.

Primary Cluster 1c.

LUNG CANCER: Chemotherapy 15, Radiotherapy 14, Surgery 13, Medication 2, Painkillers 1, Misc. 6, Don't know 2.

BREAST CANCER: Surgery (remove lump) 19, Radiotherapy 17, Mastectomy 15, Chemotherapy 12, Medication 4, Misc. 1.

Primary Cluster 2

Primary Cluster 2a.

ASTHMA: Inhaler 24, Medication (inc. steroids/anti-histamines) 8, Alternative medicines 3, Avoid allergic substances/dust 2, Misc. 6, Don't know 2.

BRONCHITIS: Medication 21, Inhaler 5, Consult Dr./medical advice 6, Stop smoking 4, Rest 5, Improved living standards/healthier living 3, Oxygen treatment 2, Misc. 6, Don't know 3.

PNEUMONIA: Medication 21, Rest 4, Hospitalization 3, Oxygen treatment/breathing assistance 2, Hot drinks/food 3, Warmth 3, Misc. 5, Don't know 2.

Primary Cluster 2b.

COLD: Aspirin 18, Warm 7, Hot drinks 6, Rest 5, Medication 7, Vit. C 5, Complementary medicine 3, Nothing 6, Drink fluid 3, Don't know 1.

FLU: Rest 22, Medication 15, Drink fluids 6, Alternative medicine 3, Warmth 3, Hot drinks 2, Vitamin. C 3, Misc. 2, Don't know 1.

EAR INFECTION: Medication 19, Drops 10, Ears syringed 3, Cream 2, Operation 2, Misc. 6, Don't know 1.

SINUSITIS: Medication 15, Operation 12, Sprays/drops 4, Painkillers 3, Alternative medicine 2, Inhalation 2, Misc. 3, Don't know 6.

LARYNGITIS: Medication 22, Throat lozenges/syrups/gargling 10, Rest voice 6, Rest 5, Hot drinks 2, Paracetamol 2, Misc. 2, Don't know 1.

MIGRAINE: Pain killers 11, Medication 12, Rest 9, Relaxation 5, Change diet 4, Lifestyle changes 2, Misc. 6, Don't know 3.

Primary Cluster 3

MEASLES: Vaccination (prevention) 10, Rest 9, Medication 8, Lotion/cream 5, Drink fluids 3, Paracetamol/aspirin 2, Nothing 2, Misc. 3, Don't know 4.

CHICKEN POX: Lotions/creams 14, Rest 7, Paracetamol/aspirin 6, Medication 4, Consult Dr. 2, Vaccination 2, None 2, Misc. 2, Don't know 3.

MUMPS: Rest 6, Medication 9, Drink fluids 3, Vaccination 3, Consult Dr. 2, Nothing 2, Misc. 3, Don't know 7.

GERMAN MEASLES: Rest 7, Lotions/creams 6, Medication 6, Nothing 6, Vaccination 5, Drink fluids 3, Misc. 3, Don't know 3.

SHINGLES: Creams/ointments 8, Medication 8, Rest 4, Painkillers 2, Change diet 2, Nothing (time) 2, Misc. 5, Don't know 7.

TONSILLITIS: Medication 24, Operation (remove tonsils) 18, Rest 2, Aspirin/paracetamol 2, Hot drinks 2, Misc. 4, Don't know 1.

GLANDULAR FEVER: Rest 17, Medication 14, Drink fluids 3, Consult Dr. 2, Nothing 2, Misc. 5, Don't know 3.

Primary Cluster 4

Primary Cluster 4a.

ARTHRITIS: Medication 16, Painkillers 11, Surgery (joint replacements) 6, Alternative therapies 4, None 4, Diet 3, Physiotherapy 3, Exercise 2, Creams/ointments 2, Dietary supplements 2, Warmth 2, Misc. 5.

RHEUMATISM: Drugs 11, Painkillers 8, Physiotherapy/massage 6, Diet 4, Exercise 4, Dietary supplements 4, Warmth 3, None 2, Surgery (joint replacement) 2, Misc. 7, Don't know 3.

LUMBAGO: Rest 10, Painkillers 5, Physiotherapy/massage 5, Heat treatment 4, Medication 4, Surgery 3, Misc. 9, Don't know 8.

SCIATICA: Rest 9, Painkillers 7, Medication 8, Physiotherapy/massage 8, Surgery 5, Lifestyle changes 2, Correct posture 2, Misc. 8, Don't know 7.

Primary Cluster 4b.

ANAEMIA: Iron supplements/injections/increase 18, Improved diet 13 Medication 4, Dietary supplements 3, Blood transfusion 2, Misc. 3, Don't know 4.

Primary Cluster 4c.

DERMATITIS: Creams/lotions 24, Medication 7, Avoid irritating substances 3, Alternative medicine 2, Misc. 7, Don't know 3.

ECZEMA: Creams/lotions 20, Medication 6, Alternative medicine 5, Change diet 5, Avoid irritating substances 4, Hygiene 2, Misc. 7, Don't know 4 .

Primary Cluster 5

Primary Cluster 5a.

PEPTIC ULCER: Surgery 16, Diet change 14, Drugs 7, Relaxation/stress reduction 5, Weight loss/dieting 2, Misc. 5, Don't know 3.

GASTROENTERITIS: Drink fluids 16, Medication 10, Drink fluids 7, Consult Dr. 3, Rest 2, Non-prescription medicine 2, Misc. 7, Don't know 4.

IRRITABLE BOWEL: Change diet 12, Medication 10, Stress reduction/relaxation 7, Creams 2, Nothing 2, Misc. 4, Don't know 7.

APPENDICITIS: Surgery (removal) 29, Consult Dr. 1,

CIRRHOSIS: Stop drinking alcohol 18, Surgery 5, Change diet 3, Dialysis 2, Lifestyle changes 2, Medication , Misc. 6, Don't know 4.

Primary Cluster 5b.

HEART DISEASE: Exercise 15, Surgery 10, Change diet 10, Medication 6, Lifestyle changes 8, Reduce cholesterol 6, Stop smoking 7, Stress management/relaxation 3, Reduce alcohol intake 2, Weight loss 2, Misc. 6, Don't know 4.

ANGINA: Medication 22, Change diet 6, Lifestyle changes 5, Surgery 3, Stop smoking 3, Rest 3, Painkillers 2, Misc. 4, Don't know 2.
THROMBOSIS: Medication 9, Surgery 7, Anticoagulants/thinning of blood 8, Change diet 4, Exercise 3, Rest 3, Consult Dr. 2, Change lifestyle 2, Misc. 4, Don't know 6.
HIGH B.P: Medication 21, Change diet 11, Exercise 8, Lifestyle change 7, Rest 4, Stop smoking 4, Lose weight 4, Reduce stress/relaxation 6, Misc. 6, Don't know 2.

Appendix 4

Chapter 3: Categories entered into the discriminant analysis for each component (Study 1)

1. Symptoms

- Abdominal pains
- Aches and pains
- Back pain
- Breathing difficulties
- Blocked nose
- Blood clot
- Chest pain
- Congested chest
- Cough
- Diarrhoea
- Discharge
- Dry skin
- Earache
- Fatigue
- Fever
- Flushed
- Genital sores/rash
- Headache
- Itching
- Itchy skin
- Joint pain
- Joint stiffness
- Joint swelling
- Limb pain/numbness
- Liver pains
- Lump(s) in breast
- Nausea
- Pain on urination
- Pale complexion
- Rash
- Sinus pain
- Sore throat
- Spots
- Stomach pains
- Swollen glands
- Swollen tonsils
- Voice loss

2. Person

- Adults
- Anyone
- Children
- Drinker (alcohol)
- Elderly
- Female
- Older
- Older women
- Overweight
- Person who has unprotected sex
- Person who talks a lot
- Person with poor diet
- Promiscuous person
- Smoker
- Stressed person
- Unfit

3. Cause

- Alcohol (excess)
- Allergy
- Contagion
- Contaminated food
- Diet/dietary deficiencies
- Exercise (lack of)
- Exposure to cold/wet
- Heredity/genetic
- Infection
- Infected appendix
- Muscle strain
- Sexual intercourse
- Smoking
- Stress/worry
- Virus
- Voice strain
- Wear and tear

4. Seriousness

- Not serious
- Quite serious
- Serious
- Serious in adults
- Serious in pregnancy
- Very serious
- Life threatening
- Painful/debilitating

5. Time Line

- Less than 1 week
- 1 week
- 1-2 weeks
- 2 weeks
- 2-4 weeks
- 4-8 weeks
- Indefinitely/years
- Lifetime
- Until treated
- Variable

6. Treatment

- Alcohol cessation
- Aspirin
- Chemotherapy
- Creams
- Diet
- Dietary supplements
- Drinking fluids
- Drops/sprays
- Exercise
- Inhaler
- Lubricating medicine
- Medication/drugs
- Painkillers
- Radiotherapy
- Rest
- Surgery
- Vaccination

Appendix 5

Chapter 3: Discriminant analysis ~ Classification of illnesses into clusters (Study 1)

Table 1: Percentage accuracy of classification of illnesses into clusters on the basis of symptoms

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**80**	0	0	20	0
2	0	**100**	0	0	0
3	0	0	**86**	14	0
4	0	0	0	**100**	0
5	0	11	0	0	**89**

Correct classification = 92%

Table 2: Percentage accuracy of classification of illnesses into clusters on the basis of person information

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**80**	20	0	0	0
2	0	**89**	0	11	0
3	0	14	**86**	0	0
4	0	14	0	**86**	0
5	0	22	0	11	**67**

Correct classification = 82%

Table 3: Percentage accuracy of classification of illnesses into clusters on the basis of causal beliefs

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**80**	0	20	0	0
2	11	**67**	11	11	0
3	14	0	**86**	0	0
4	0	29	0	**71**	0
5	33	0	0	0	**67**

Correct classification = 73%

Table 4: Percentage accuracy of classification of illnesses into clusters on the basis of severity

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**60**	20	0	0	20
2	22	**56**	0	22	0
3	0	29	**57**	14	0
4	0	0	0	**100**	0
5	33	11	0	0	**56**

Correct classification = 65%

Table 5: Percentage accuracy of classification of illnesses into clusters on the basis of perceptions of time line

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**40**	40	0	20	0
2	11	**78**	0	11	0
3	0	0	**100**	0	0
4	29	14	0	**57**	0
5	33	11	0	44	**11**

Correct classification = 57%

Table 6: Percentage accuracy of classification of illnesses into clusters on the basis of treatment beliefs

Actual cluster	*Predicted Group membership*				
	1	*2*	*3*	*4*	*5*
1	**100**	0	0	0	0
2	11	**78**	0	11	0
3	14	0	**71**	14	0
4	0	0	0	**100**	0
5	0	0	0	0	**100**

Correct classification = 89%

Appendix 6

Chapter 4: Illnesses presented by patients in study 2

Minor illnesses	**No.**
Muscular strains/injury	32
Viral/infection	13
Ear infection/blockage/wax	18
Acute throat infections	10
Chest infection	10
Migraine/headache	7
Sinusitis	6
Backache	6
Eczema/dermatitis	8
Flu/cold	5
Urinary tract infection	3
Oesphagitis	5
Dyspepsia	2
Constipation	2
Piles	1
Allergies	5
Cysts	4
Acne	2
Athletes foot	2

Acute major illness	
Acute bronchitis	3
Appendicitis	1

Other	
No diagnosis	19
Nothing wrong	8
Iatrogenic	6
Miscellaneous	37
No report from doctor	2

Chronic illnesses		**No.**
Cardiovascular		
	Heart disease	4
	Hypertension	11
	Haematoma	2
Respiratory		
	Asthma	13
Central nervous system		
	Epilepsy	2
Gastrointestinal		
	Ulcers	3
	Irritable bowel syndrome	3
Endocrine		
	Thyroid disorders	1
Musculoskeletal		
	Arthritis/Rheumatism	8
Gynaecological		
	Menstrual problems	2
	Menopause	4
	Infection	5
	Miscellaneous	6
Psychological & psychosocial		
	Anxiety	10
	Depression	15
	Stress/psychosocial	8
	Alcoholism	5
Cancers		1

List of illnesses is based on the diagnoses provided by the doctor. Categorization of illnesses is based on Fry (1993) & Macleod (1977).

N.B Number of illnesses exceeds 304 since some patients presented with more than one illness.

Appendix 7a

Chapter 4: Demographic Questionnaire (Study 2)

Patient No: ....

Would you mind filling in the following details about yourself? Your answers are **anonymous**.

1. Sex: Male/Female

2. Age:

3. Marital status: Married
Single
Other (please state)

4. Occupation:

5. Occupation of spouse (if applicable):

6. At what point did you leave formal education?

7. To which of these groups do you belong? (Please tick):

White	White
	Irish
	Greek
	Turkish
	Other European
	Mixed White
Black-Caribbean	Black-Caribbean
	Caribbean Island, West Indies or Guyana (non-mixed origin)
	Other
Black-African	Black-African
	Other African countries (non-mixed origin)
	Other
Black-Other (Mixed origin)	British
	East African Asian or Indo-Caribbean
	Black/White
	Other Mixed
Asian	Indian
	Pakistani
	Bangledeshi
	Chinese
Other Asian	Indian Sub-continent
	East African Asian or Indo-Caribbean
	Other
Other	North African, Arab or Iranian
	Asian/White
	Other

Appendix 7b

Chapter 4: Doctor's report (Study 2)

Patient No: ....

DOCTOR'S REPORT

1. Patient's symptoms:

2. Diagnosis:

3. Prescribed treatment:

Appendix 8a

Chapter 4: Pre-Consultation interview schedule (Study 2)

Note: The additional questions which were only included in the extended interview (n=181) are written in italics for identification purposes.

Patient No.: ....

Pre-Consultation Interview

Have you read the information sheet? Do you want to ask any questions about the study?

I may ask you some questions which you already seem to have answered. However, it is necessary to ask each participant all the questions, so that all interviews follow the same format.

Do you understand that you are free to leave the interview at any point without having to give a reason for leaving and without affecting your medical care?

Would you mind if I tape-recorded this interview?

1. How do you decide whether to visit a doctor?

2. What do you think are the most important qualities of a good doctor?

3. Would you use any of the following types of treatment for any health problems?
If yes, for which problems?

Acupuncture
Aromatherapy
Chinese medicine
Chiropractor
Folk healing
Herbal remedies
Hypnotherapy
Massage
Osteopathy
Reflexology
Spiritualist
Other (please specify)

4. Under what circumstances do you use home remedies for ailments?

5. Have you used any treatment for your current problem prior to coming here?
If yes, what?

6. Have you seen Dr______ before? Approximately how many times?

7. Have you visited him/her previously about your current problem? How many times?

8. Generally how well do you get on with the doctor?

Very well	*Moderately well*	*Acceptably well*	*Moderately badly*	*Very badly*

9. How did you get to the surgery today, and approximately how long did it take you?

10. Could you describe your symptoms?

11. What do you think is wrong with you?

12. Have you talked to anyone else about your problem? Who?

13. What do they think is wrong with you?

14. Did anyone advise you to come to the doctor today? Who?

15. How long have you had this/these problem(s)?

16. What do you think has caused your problem(s)?

17. Why do you think it started when it did?

18. How concerned are you by this problem?

Extremely				*Not at all*
1	*2*	*3*	*4*	*5*

19. How serious do you think your condition is (on the following scale)?

Extremely serious	Serious	Not very serious	Not at all serious

20. To what extent does your problem interfere with your daily activities?

21. What kind of treatment do you expect to receive?

22. What benefits do you hope to receive from this treatment?

23. Apart from the treatment recommended by this doctor, what other kinds of treatment do you think could help you get better?

Appendix 8b

Chapter 4: Post-Consultation interview schedule (Study 2)

Note: The additional questions which were only included in the extended interview (n=181) are written in italics for identification purposes.

Patient No.: ....

Post-Consultation Interview

I would now like to ask you a few more questions. As with the previous interview, you will remain anonymous and you are free to stop the interview at any time.

1. Would you mind telling me what the doctor said was wrong with you?

2. To what extent did you agree with the doctor's diagnosis?

Completely Moderately Unsure Not very much Not at all

3. How concerned are you about your problem now?

Extremely *Not at all*

1 2 3 4 5

4. Is there anything about your condition that you would have liked to explore more fully in your consultation? If yes, can you say what?

5. Do you think that the doctor spent enough time with you?

6. How satisfied were you with the consultation?

Completely Moderately Unsure Not very much Not at all

7. What was good/bad about it?

8. Would you have liked it to be different in any way? How?

9. Would you have liked more information about anything?

10. What treatment did the doctor prescribe for you?

11. What instructions did he give you about taking the medicine?

12. Were the doctor's instructions:

Very clear Clear Neither Unclear Very unclear

13. How well do you think you remember his instructions?

Completely Moderately Unsure Not very much Not at all

14. How determined are you to follow the treatment prescribed by the doctor?

Definitely won't	Probably won't	Don't know	Probably will	Definitely will

15. Can you see any difficulties which might arise out of this treatment?

16. Do you intend to obtain any treatment for your condition elsewhere?

Thank you for your help. Would you mind if I asked Dr. ______ a few questions about his diagnosis of your condition? This will not involve the use of your name, as you will be identified solely by the number that you were given earlier. Your interview will not be discussed with the doctor.

Appendix 9a

Chapter 4: Content analysis categories for each component (Study 2)

Symptoms

- Breathing difficulties
- Blocked nose
- Chest pain
- Cough
- Earache
- Headache
- Hearing difficulties
- Joint pain
- Restricted movement
- Nausea
- No symptoms
- Numbness in limbs
- Pain
- Phlegm
- Rash
- Sinus pain
- Sore throat
- Stomach ache
- Tiredness
- Wheezing

Cause

- Ageing
- Allergy
- Diet
- Heredity
- Infection
- Overweight
- Pollution
- Rundown
- Smoking
- Stress
- Viral
- Wear & tear

Severity

- Not at all serious
- Not very serious
- Serious
- Extremely serious

Treatment

- Advice
- Alternative medicine
- Cream
- Diet
- Inhaler
- Medication
- Rest
- Tests

Appendix 9b

Chapter 4: Content analysis of patients beliefs about symptoms, cause, severity and treatment (Study 2)

Below is an outline of the content analysis of patients' responses to the interview questions regarding symptoms, perceptions of cause, seriousness and treatment. The illnesses are grouped into the clusters described on p.74. The numbers given in brackets after each illness indicate the number of patients reporting each illness. Similarly, the numbers given after each feature indicate the number of participants' citing this feature.

1. SYMPTOMS

CLUSTER 2
Subordinate cluster 2a
Asthma (13): Breathing difficulties 8, Wheezing 7, Cough 5.
Bronchitis (3): Cough 3, Tight chest 2, Phlegm 2.
Pneumonia (1): Breathing difficulties 1, Chest pain 1.
Subordinate cluster 2b
Cold (3): Runny nose 2, Cough 2, Sore throat 1, Ear pain 1, Blocked sinuses 1, Joint pain 1, Phlegm 1.
Flu (6): Joint pain 3, Cough 2, Sore throat 2, Runny nose 2, Headache 2, Chest pain 1, Phlegm 1, Blocked sinuses 1, Nausea 1, Tired 1, Breathlessness 1, Misc. 6.
Sinusitis (7): Blocked sinuses 4, Sore throat 2, Headache 2, Chest pain 1, Ear pain, Hearing problems 1, Runny nose 1, Cough 1, Phlegm 1, Tired 1, Misc. 3.
Migraine (5): Headache 3, Nausea 3, Pain 3, Disturbed vision 2, Misc. 2.
Ear infection (8): Ear pain 6, Hearing problems 3, Sore throat 1, Misc. 2.

CLUSTER 4
Subordinate cluster 4a
Arthritis (8): Joint pain/stiffness 7, Restricted movement 5.
Rheumatism (2): Joint pain/stiffness 2.
Rheumatoid arthritis (2): Joint pain/stiffness 2.
Subordinate cluster 4b
Anaemia (2): Nausea 2, Tiredness 1, Misc. 2.
Subordinate cluster 4c
Dermatitis (1): Skin rash/irritation 1.
Eczema (9): Skin rash/irritation 9.

CLUSTER 5
Subordinate cluster 5a
Ulcer (3): Stomach pain 3, Chest pain 1, Misc. 1.
Irritable bowel (3): Stomach pain 2, Misc. 4.
Appendicitis (1): Stomach pain 1, Nausea 1,
Subordinate cluster 5b
Heart Disease (6): Breathing difficulties 3, Chest pain 2, Restricted movement 1, Numbness in limbs 1, Misc. 2.
Angina (1): Misc. 1.
Hypertension (13): No symptoms 11, Tired 1, Numbness in limbs 1, Misc. 3.

2. CAUSE

CLUSTER 2
Subordinate cluster 2a
Asthma (13): Pollution 4, Allergies 4, Stress 3, Heredity 2, Smoking 1, Don't know 1.

Bronchitis (3): Smoking 2, Cold conditions 1.
Pneumonia (1): Run down 1.
Subordinate cluster 2b
Cold (3): Virus 3, Infection 1, Misc 1.
Flu (6): Virus 3, Infection 3, Run down 2, Stress 1, Don't know 1.
Sinusitis (7): Infection 3, Run down 2, Smoking 3, Pollution 1, Don't know 1.
Migraine (5): Stress 4, Allergies 1, Heredity 1, Misc 2, Don't know 1.
Ear infection (8): Infection 5, Virus 2, Misc. 1, Don't know 1.

CLUSTER 4
Subordinate cluster 4a
Arthritis (8): Ageing 3, Wear & tear 3, Misc. 1, Don't know 3.
Rheumatism (2): Heredity 1, Ageing 1, Misc. 1.
Rheumatoid arthritis (2): Don't know 2.
Subordinate cluster 4b
Anaemia (2): Stress 1, Misc 1, Don't know 1.
Subordinate cluster 4c
Dermatitis (1): Stress 1, Viral 1,
Eczema (9): Stress 5, Heredity 2, Viral 1, Allergy 1, Pollution 1, Misc. 1, Don't know 1.

CLUSTER 5
Subordinate cluster 5a
Ulcer (3): Diet 1, Misc 2.
Irritable bowel (3): Stress 2, Don't know 1.
Appendicitis (1): Stress 1,
Subordinate cluster 5b
Heart Disease (6): Smoking 4, Ageing 1, Diet 1, Stress 1, Misc. 2.
Angina (1): Stress 1.
Hypertension (13): Heredity 5, Overweight 4, Stress 4, Drinking 2, Smoking 2, Ageing 2, Diet 1, Don't know 3.

3. SERIOUSNESS

CLUSTER 2
Subordinate cluster 2a
Asthma (13): Not very serious 7, Not at all serious 3, Serious 2.
Bronchitis (3): Not very serious 3.
Pneumonia (1): Serious 1.
Subordinate cluster 2b
Cold (3): Not at all serious 1, Not very serious 2,
Flu (6): Not at all serious 2, Not very serious 2, Serious 1, Misc. 1.
Sinusitis (7): Not very serious 6, Not at all serious 1,
Migraine (5): Serious 3, Not very serious 2,
Ear infection (8): Not at all serious 4, Not very serious 4.

CLUSTER 4
Subordinate cluster 4a
Arthritis (8): Not very serious 4, Serious 4.
Rheumatism (2): Not very serious 1, Serious 1.
Rheumatoid arthritis (2): Serious 1, Extremely serious 1.
Subordinate cluster 4b
Anaemia (2): Not at all serious 1, Not very serious 1.
Subordinate cluster 4c
Dermatitis (1): Not at all serious 1.
Eczema (9): Not very serious 5, Not at all serious 4,

CLUSTER 5

Subordinate cluster 5a
Ulcer (3): Not very serious 2.
Irritable bowel (3): Not at all 1, Not very serious 1.
Appendicitis (1): Not very serious 1.
Subordinate cluster 5b
Heart Disease (6): Not very serious 3, Serious 2, Extremely serious 1.
Angina (1): Serious 1.
Hypertension (13): Not very serious 5, Not at all 3, Serious 5.

4. TREATMENT

CLUSTER 2

Subordinate cluster 2a
Asthma (13): Medication 11, Inhaler 6, Alternative medicine 1.
Bronchitis (3): Medication 2, Don't know 1, Quit smoking 1.
Pneumonia (1): Medication 1.
Subordinate cluster 2b
Cold (3): Medication 3, Rest 1.
Flu (6): Medication 3, Rest 3, Alternative medicine 1, Misc. 1, Don't know 1.
Sinusitis (7): Medication 4, Alternative medicine 3, Rest 1, Misc. 2, Don't know 1.
Migraine (5): Medication 3, Rest 2, Tests 1, Alternative medicine 1, Misc. 1
Ear infection (8): Medication 8, Alternative medicine 1.

CLUSTER 4

Subordinate cluster 4a
Arthritis (8): Medication 5, Alternative medicine 2, Misc. 2, Don't know 1.
Rheumatism (2): Medication 2, Diet 1.
Rheumatoid arthritis (2): Medication 2, Diet 1.
Subordinate cluster 4b
Anaemia (2): Misc. 1, Don't know 1.
Subordinate cluster 4c
Dermatitis (1): Cream 1.
Eczema (9): Cream 5, Medication 1, Alternative medicine 2, Don't know 2.

CLUSTER 5

Subordinate cluster 5a
Ulcer (3): Diet 2, Medication 1, Tests 1, Don't know 1.
Irritable bowel (3): Medication 1, Diet 1, Alternative medicine 1, Don't know 1.
Appendicitis (1): Tests 1.
Subordinate cluster 5b
Heart Disease (6): Medication 3, Advice 3, Rest 2, Tests 1, Misc. 1.
Angina (1): Advice 1.
Hypertension (13): Medication 11, Advice 2, Rest 1, Misc. 3.

Appendix 10

Chapter 5: Follow-up questionnaire (Study 3)

Patient No: .... **Date:** ....

This questionnaire is concerned with your thoughts and experiences since your visit to the doctor two weeks ago. Please answer all the questions which apply to you. Your responses are **confidential** - your answers will not be revealed to the doctor and your name will not be used in the study.

Thank you for your assistance.

Part A: General

1. What was the purpose of your visit to the doctor (when you were interviewed)?

2. What was wrong with you?

3. Could you describe your symptoms?

4. What do you think may have caused your problem(s)?

5. Has there been any change in your condition since you visited the doctor? (Please give details)

6. How concerned are you about your problem now? (Please circle appropriate answer)

Extremely				Not at all
1	2	3	4	5

7. Have your beliefs about what is/was wrong with you changed since your consultation?
   If so, what do you think now?

8. Have you been back to see the doctor since we last spoke? Yes/No

If yes:
Why did you go to see the doctor?

What did the doctor say about your condition?

9. Have you used anything to relieve your condition apart from what the doctor recommended? If yes, what have you used?

10. Have you been anywhere else for treatment? If yes, where?

11. Are you considering obtaining any treatment for your condition elsewhere? If yes, where?

Part B: Prescribed Treatment (If you did not receive any treatment from the doctor please go on to the next section).

12. What treatment were you given by the doctor?

13. What instructions were you given about it?

14. Do you think that these instructions were easy to understand and follow? Yes/No

If not, in what way were they unclear or confusing?

15. Would you have liked any more information about the treatment?

16. Did you agree with the treatment that the doctor gave you?

If no, why not?

17. Have you discussed your treatment with anyone else? Who?

If yes, what did they think about the treatment you were given?

18. Have you followed the treatment recommended by the doctor? Yes/No

If not, is there any particular reason why you didn't follow the treatment? (Please state reasons)

19. Did / have you come across any problems with the treatment? Yes/No

If you have encountered any problems, what were they?

20. Were there ever occasions when you didn't take the medicine as prescribed for any reason; e.g. forgot, lack of time, inconvenience, disruption etc? (Please state reasons)

21. Do you think the treatment has been beneficial to your condition? (Please circle)

Definitely   Moderately   Unsure   Not very much   Not at all

<u>Part C: The Consultation</u> (at time of interview)

22. Overall, how satisfied do you feel with the consultation now? (Please circle)

Completely   Moderately   Unsure   Not very much   Not at all

23. Was there anything the doctor said during the consultation that you did not really understand?

24. Is there any additional information or advice about your condition that you would have liked from the doctor?

25. Did you feel able to discuss everything that you wanted with the doctor? Yes/No

If no, why not?

26. To what extent do you agree with what the doctor said about your condition? (Please circle)

Completely Moderately Unsure Not very much Not at all

27. Please rate what you think of your doctor on the following scales (by circling the appropriate X):

Example:

Helpful Not helpful
X.............X.............X.............X.............X
Moderately Neither Not very

(If you think that your doctor was moderately helpful).

a) Understanding Not understanding
X.............X.............X.............X.............X

b) Sympathetic Unsympathetic
X.............X.............X.............X.............X

c) Cold Warm
X.............X.............X.............X.............X

d) Efficient Inefficient
X.............X.............X.............X.............X

e) Unfriendly Friendly
X.............X.............X.............X.............X

f) Unclear Clear
X.............X.............X.............X.............X

g) Approachable Unapproachable
X.............X.............X.............X.............X

h) Competent Incompetent
X.............X.............X.............X.............X

i) Impatient Patient
X.............X.............X.............X.............X

28. Since your visit to the doctor have you discussed your consultation with anyone? Yes/No

If yes, who have you spoken to? Did they express any opinion about the consultation?

29. Overall, to what extent do you think the consultation dealt with your concerns and expectations? (Please circle)

Completely				Not at all
1	2	3	4	5

30. Finally, is there anything else you would like to add about your experiences or any problems you have come across since your consultation?

Thank you for your help.

Appendix 11

Chapter 6: Chronic and acute illnesses reported by respondents (Study 4)

Chronic Illnesses	*N*	*Acute conditions*	*N*
Psychological	17	Colds/flu	39
Chronic back pain/strain	17	Acute throat infections	6
Rheumatoid/arthrititic conditions	9	Injury	7
		Viral	4
Asthma	9	Appendicitis	3
Gynaecological	7	Gynaecological	3
Migraine/headaches	7	Psychological	2
Cancers	5	Chicken pox/shingles	2
Gastrointestinal	4	Acute bronchitis	1
Injury	4	Ear infection	1
Anaemia	3	Piles	1
Hernia	3	Pneumothorax	1
Epilepsy	2	Non-specific	2
Multiple sclerosis	2		
Diabetes	2		
Varicose veins	2		
Angina	2		
Eczema	2		
Chronic throat/ viral problems	2		
Duodenal ulcers	1		
Hypertension	1		
Liver failure	1		
Parkinson's	1		
Polio	1		
RSI	1		
Nonspecific	6		

Note. Illnesses were classified as chronic when they were: a) defined as medically chronic diseases (Fry, 1993), b) conditions from which the person had suffered for more than one year. The number of illnesses may exceed sample size where more than one illness was stated by respondents.

Appendix 12

Chapter 6: 60 item COPE (Study 4)

We are interested in how people respond when they are faced with illness. There are lots of ways to try to deal with illness. This questionnaire asks you to think of a debilitating illness you have had over the **PAST FEW MONTHS** or a **LONG-TERM** illness you are currently suffering from, and then to indicate what you did and how you felt when you were ill (or how you have been dealing with an illness you still have). You may feel that some of the items do not apply to your own condition, but please respond to ALL the following items on the questionnaire.

Please respond to each item by circling one number on your answer sheet, using the response choices listed below. Please think about each item **separately from each other item.** Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer **every** item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU - not what you think "most people" would say or do. Indicate what YOU did or are doing in response to your illness.

1 = I didn't do this at all /I haven't done this at all
2 = I did this a little bit /I have done this a little bit
3 = I did this a moderate amount /I have done this a moderate amount
4 = I did this a lot /I have done this a lot

Please fill in the following details about yourself. The questionnaire is anonymous.

Sex: Male Female

Age: ....years

What illness did you suffer from/are you suffering from?

....

For how long did you suffer/have you suffered from this complaint?

....

Have you sought medical help? YES NO

Have you taken time off from work/college? YES NO

Answer each item with these response choices:

1 = I didn't do this at all /I haven't done this at all
2 = I did this a little bit /I have done this a little bit
3 = I did this a moderate amount /I have done this a moderate amount
4 = I did this a lot /I have done this a lot

1. I tried to grow as a person as a result of the experience. 1 2 3 4

2. I turned to work or other substitute activities to take my mind off things. 1 2 3 4

3. I got upset and let my emotions out. 1 2 3 4

4. I tried to get advice from someone about what to do. 1 2 3 4

5. I concentrated my efforts on doing something about it. 1 2 3 4

6. I said to myself "this isn't real." 1 2 3 4

7. I put my faith in God. 1 2 3 4

8. I laughed about the situation. 1 2 3 4

9. I admitted to myself that I couldn't deal with it, and quit trying. 1 2 3 4

10. I restrained myself from doing anything too quickly. 1 2 3 4

11. I discussed my feelings with someone. 1 2 3 4

12. I used alcohol or drugs to make myself feel better. 1 2 3 4

13. I got used to the idea that it was happening. 1 2 3 4

14. I talked to someone to find out more about the situation. 1 2 3 4

15. I kept myself from getting distracted by other thoughts or activities. 1 2 3 4

16. I daydreamed about things other than this. 1 2 3 4

17. I got upset, and was really aware of it. 1 2 3 4

18. I sought God's help. 1 2 3 4

19. I made a plan of action. 1 2 3 4

20. I made jokes about it. 1 2 3 4

21. I accepted that this was happening and that it couldn't be changed. 1 2 3 4

Continue to answer each item with these response choices:

1 = I didn't do this at all /I haven't done this at all
2 = I did this a little bit /I have done this a little bit
3 = I did this a moderate amount /I have done this a moderate amount
4 = I did this a lot /I have done this a lot

22. I held off doing anything about it until the situation permitted.	1	2	3	4
23. I tried to get emotional support from friends.	1	2	3	4
24. I gave up trying to reach my goals.	1	2	3	4
25. I took additional action to try to get rid of the problem.	1	2	3	4
26. I tried to lose myself for a while by drinking alcohol or taking drugs.	1	2	3	4
27. I refused to believe that it was happening.	1	2	3	4
28. I let my feelings out.	1	2	3	4
29. I tried to see it in a different light, to make it seem more positive.	1	2	3	4
30. I talked to someone who could do something concrete about the problem.	1	2	3	4
31. I slept more than normal.	1	2	3	4
32. I tried to come up with a strategy about what to do.	1	2	3	4
33. I focused on dealing with the problem, and if necessary let other things slide a little.	1	2	3	4
34. I got sympathy and understanding from someone.	1	2	3	4
35. I drank alcohol or took drugs, in order to think about it less.	1	2	3	4
36. I kidded around about it.	1	2	3	4
37. I gave up the attempt to get what I wanted.	1	2	3	4
38. I looked for something good in what had happened.	1	2	3	4
39. I thought about how I might best handle the problem.	1	2	3	4
40. I pretended that it wasn't really happening.	1	2	3	4
41. I made sure not to make matters worse by acting too soon.	1	2	3	4
42. I tried hard to prevent other things from interfering with my efforts to deal with this.	1	2	3	4

Continue to answer each item with these response choices:

1 = I didn't do this at all /I haven't done this at all
2 = I did this a little bit /I have done this a little bit
3 = I did this a medium amount /I have done this a moderate amount
4 = I did this a lot /I have done this a lot

43. I went to the movies or watched TV, to think about it less.	1	2	3	4
44. I accepted the reality of the fact that it was happening.	1	2	3	4
45. I asked people who had had similar experiences what they had done.	1	2	3	4
46. I felt a lot of emotional distress and I found myself expressing these feelings a lot.	1	2	3	4
47. I took direct action to get around the problem.	1	2	3	4
48. I tried to find comfort in my religion.	1	2	3	4
49. I forced myself to wait for the right time to do something.	1	2	3	4
50. I made fun of the situation.	1	2	3	4
51. I reduced the amount of effort I put into solving the problem.	1	2	3	4
52. I talked to someone about how I felt.	1	2	3	4
53. I used alcohol or drugs to help me get through it.	1	2	3	4
54. I learnt to live with it.	1	2	3	4
55. I put aside other activities in order to concentrate on this.	1	2	3	4
56. I thought hard about what steps to take.	1	2	3	4
57. I acted as though it wasn't even happening.	1	2	3	4
58. I did what had to be done, one step at a time.	1	2	3	4
59. I learnt something from the experience.	1	2	3	4
60. I prayed more than usual.	1	2	3	4

Appendix 13

Chapter 6: Illnesses reported by respondents in Study 5

Illness	*N*
Cardiac	70
Respiratory	30
Renal disease	12
Diabetic	10
Rheumatic/arthritic conditions	10
Diseases of nervous system	8
Gastrointestinal	5
Cancers	5

Appendix 14

Chapter 6: Short-form COPE (Study 6)

We are interested in how people respond when they are faced with illness. There are lots of ways to try to deal with illness. This questionnaire asks you to indicate what you have done and how you feel about your illness.

Please respond to each of the following items by circling one number on your answer sheet, using the response choices listed below. Please think about each item **separately from each other item.** Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer **every** item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU - not what you think "most people" would say or do. Indicate what YOU have done in response to your illness.

Answer each item with these response choices:

1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

1. I have tried to grow as a person as a result of the experience.	1	2	3	4
2. I have got upset and let my emotions out.	1	2	3	4
3. I have tried to get advice from someone about what to do.	1	2	3	4
4. I have concentrated my efforts on doing something about it.	1	2	3	4
5. I have said to myself "this isn't real."	1	2	3	4
6. I have discussed my feelings with someone.	1	2	3	4
7. I have used alcohol or drugs to make myself feel better.	1	2	3	4
8. I have got used to the idea that it has happened.	1	2	3	4
9. I have talked to someone to find out more about the situation.	1	2	3	4
10. I have got upset, and have been really aware of it.	1	2	3	4
11. I have accepted that this has happened and that it can't be changed.	1	2	3	4
12. I have given up trying to reach my goals.	1	2	3	4
13. I have taken additional action to try to get rid of the problem.	1	2	3	4
14. I have tried to lose myself for a while by drinking alcohol or taking drugs.	1	2	3	4

Answer each item with these response choices:

1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

15. I have refused to believe that it has happened.	1	2	3	4
16. I have let my feelings out.	1	2	3	4
17. I have tried to see it in a different light, to make it seem more positive.	1	2	3	4
18. I have talked to someone who could do something concrete about the problem.	1	2	3	4
19. I have tried to come up with a strategy about what to do.	1	2	3	4
20. I have drunk alcohol or taken drugs, in order to think about it less.	1	2	3	4
21. I have pretended that it hasn't really happened.	1	2	3	4
22. I have given up the attempt to get what I want.	1	2	3	4
23. I have looked for something good in what has happened.	1	2	3	4
24. I have accepted the reality of the fact that it has happened.	1	2	3	4
25. I have felt a lot of emotional distress and I have found myself expressing these feelings a lot.	1	2	3	4
26. I have taken direct action to get around the problem.	1	2	3	4
27. I have talked to someone about how I feel.	1	2	3	4
28. I have used alcohol or drugs to help me get through it.	1	2	3	4
29. I have learnt to live with it.	1	2	3	4
30. I have thought hard about what steps to take.	1	2	3	4
31. I have acted as though it hasn't even happened.	1	2	3	4
32. I have learnt something from the experience.	1	2	3	4

Appendix 15

Chapter 7: Questionnaire sent at time 1 (Study 6)

Patient No. ______

Please fill out the following details about yourself. All information is *confidential.*
✓Tick the box where appropriate.

Sex: Male ☐ Female ☐

Age: ________ years

Marital status:

Married	Single	Separated/divorced	Cohabiting	Widowed
☐	☐	☐	☐	☐

Age at which you left education: ___________ years

Occupation: ____

Ethnic group:

White	☐	
Asian - Indian	☐	
- Pakistani	☐	
- Bangladeshi	☐	
- Chinese	☐	
- Other	☐	
Black - Caribbean	☐	
- African	☐	
- Other	☐	
Other (state)	☐	______________________

When was your diabetes first diagnosed? 19______

Do you have:	insulin-dependent diabetes	(Type I)	☐
	non-insulin-dependent diabetes	(Type II)	☐

Does anyone else in your family have diabetes? YES ☐ NO ☐

If yes, who: ____________________________________

This questionnaire is concerned with what you think about diabetes in general. **Please answer all the questions.** If you are not sure what you think, please give the response you feel is most appropriate.

Please indicate how much you agree or disagree with the following statements about diabetes, by circling the appropriate response:

1 = strongly agree
2 = agree
3 = neither agree nor disagree
4 = disagree
5 = strongly disagree

1. Diabetes is caused by a germ or virus.	1	2	3	4	5
2. Diet plays a major role in causing diabetes.	1	2	3	4	5
3. Pollution of the environment causes diabetes.	1	2	3	4	5
4. Diabetes is hereditary.	1	2	3	4	5
5. Diabetes occurs just by chance	1	2	3	4	5
6. Stress is a major factor in causing diabetes.	1	2	3	4	5
7. Diabetes is largely due to the individual's behaviour.	1	2	3	4	5
8. Other people play a large role in causing diabetes.	1	2	3	4	5
9. Diabetes is caused by poor medical care.	1	2	3	4	5
10. State of mind plays a major role in causing diabetes.	1	2	3	4	5
11. Diabetes lasts a short time.	1	2	3	4	5
12. Diabetes is temporary rather than permanent.	1	2	3	4	5
13. Diabetes lasts for a long time.	1	2	3	4	5
14. Diabetes is a serious condition.	1	2	3	4	5

Please indicate how much you agree or disagree with the following statements about diabetes, by circling the appropriate response:

1 = strongly agree
2 = agree
3 = neither agree nor disagree
4 = disagree
5 = strongly disagree

15. In time, diabetes becomes easier to deal with.	1	2	3	4	5
16. Diabetes strongly affects the way a person sees themselves.	1	2	3	4	5
17. Diabetes has major consequences on a person's life.	1	2	3	4	5
18. Diabetes strongly affects the way others see that person.	1	2	3	4	5
19. Diabetes has serious economic and financial consequences.	1	2	3	4	5
20. Diabetes does not have much effect on a person's life.	1	2	3	4	5
21. Diabetes improves in time.	1	2	3	4	5
22. A lot can be done to control the symptoms of diabetes.	1	2	3	4	5
23. There is very little that can be done to improve diabetes.	1	2	3	4	5
24. Treatment is effective in curing diabetes.	1	2	3	4	5
25. Recovery from diabetes is largely dependent on chance or fate.	1	2	3	4	5
26. What an individual does determines whether his/her diabetes gets better or worse.	1	2	3	4	5

Please answer the following questions according to what you think. There are no right or wrong answers.

27. Can people usually tell when their blood sugar is high?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

28. Can people usually tell when their blood sugar is low?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

29. Please list any other medical conditions which may come about as a result of having diabetes:

30. To what extent are such complications likely to develop in people with diabetes?

Very Unlikely	Not very likely	Moderately likely	Quite likely	Extremely likely
1	2	3	4	5

Thank you very much for your time and help. Please feel free to add any further comments.

Consent slip

✓Please tick the appropriate box.

I **am** willing to fill in another questionnaire ☐

I **am not** willing to fill in another questionnaire ☐

Appendix 16

Chapter 7: Questionnaire sent at time 2 (Study 6)

No. _____

This questionnaire is concerned with your experiences of diabetes and how you feel about your condition. The questionnaire consists of 4 sections. **Please answer all the questions in each section**. There are no right or wrong answers, so choose the most accurate answers for **YOU**.

All information is *confidential* and will not be discussed with your doctor.

SECTION 1: SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent 1

Very good 2

Good 3

Fair 4

Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago 1

Somewhat better now than one year ago 2

About the same as one year ago 3

Somewhat worse now than one year ago 4

Much worse now than one year ago 5

3. **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c) Lifting or carrying groceries	1	2	3
d) Climbing **several** flights of stairs	1	2	3
e) Climbing **one** flight of stairs	1	2	3
f) Bending, kneeling, or stooping	1	2	3
g) Walking **more than one mile**	1	2	3
h) Walking **half a mile**	1	2	3
i) Walking **one hundred yards**	1	2	3
j) Bathing or dressing yourself	1	2	3

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?**

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would you like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

(circle one)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

7. **How much bodily pain have you had during the past 4 weeks?**

(circle one)

None 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

(circle one)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> -

(circle one number one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives etc.)?

(circle one)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

11. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

SECTION 2: COPING WITH DIABETES

There are lots of ways to try to deal with illness. The following items ask you to indicate what you have done and how you feel about your diabetes.

Please respond to each of the items by circling one number, using the response choices listed below. Please think about each item **separately from each other item.** Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer **every** item.

Answer each item with these response choices:

1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

1. I have tried to grow as a person as a result of the experience.	1	2	3	4
2. I have got upset and let my emotions out.	1	2	3	4
3. I have tried to get advice from someone about what to do.	1	2	3	4
4. I have concentrated my efforts on doing something about it.	1	2	3	4
5. I have said to myself "this isn't real."	1	2	3	4
6. I have discussed my feelings with someone.	1	2	3	4
7. I have used alcohol or drugs to make myself feel better.	1	2	3	4
8. I have got used to the idea that it has happened.	1	2	3	4
9. I have talked to someone to find out more about the situation.	1	2	3	4
10. I have got upset, and have been really aware of it.	1	2	3	4
11. I have accepted that this has happened and that it can't be changed.	1	2	3	4
12. I have given up trying to reach my goals.	1	2	3	4
13. I have taken additional action to try to get rid of the problem.	1	2	3	4
14. I have tried to lose myself for a while by drinking alcohol or taking drugs.	1	2	3	4
15. I have refused to believe that it has happened.	1	2	3	4

Answer each item with these response choices:

1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

16. I have let my feelings out.	1	2	3	4
17. I have tried to see it in a different light, to make it seem more positive.	1	2	3	4
18. I have talked to someone who could do something concrete about the problem.	1	2	3	4
19. I have tried to come up with a strategy about what to do. about it less.	1	2	3	4
20. I have drunk alcohol or taken drugs, in order to think	1	2	3	4
21. I have pretended that it hasn't really happened.	1	2	3	4
22. I have given up the attempt to get what I want.	1	2	3	4
23. I have looked for something good in what has happened.	1	2	3	4
24. I have accepted the reality of the fact that it has happened.	1	2	3	4
25. I have felt a lot of emotional distress and I have found myself expressing these feelings a lot.	1	2	3	4
26. I have taken direct action to get around the problem.	1	2	3	4
27. I have talked to someone about how I feel.	1	2	3	4
28. I have used alcohol or drugs to help me get through it.	1	2	3	4
29. I have learnt to live with it.	1	2	3	4
30. I have thought hard about what steps to take.	1	2	3	4
31. I have acted as though it hasn't even happened.	1	2	3	4
32. I have learnt something from the experience.	1	2	3	4

SECTION 3: MANAGING YOUR DIABETES

We are interested in the sorts of difficulties people have with their treatment and the methods they use to make it easier to cope. For example, by adapting their treatment regime to fit with their daily schedules. Please complete the appropriate sections. **Please remember that all the information you give is confidential.**

1. Can you tell when your blood sugar is low?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

2. Can you tell when your blood sugar is high?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

Medication

✓Please tick whether you take:
a) insulin injections ☐
b) tablets ☐
c) neither ☐ *(Go to question 7)*

3. How many insulin injections/tablets do you take each day? ....

4. There are many reasons why people miss taking their medication, can you describe the main reasons why *you* have missed injections/tablets:

5. In general, how often are you able to take the medication exactly as suggested by the doctor/nurse ?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

6. <u>In the past 2 weeks</u>, how many times have you missed taking your medication?

Never	Rarely	Sometimes	Most of time	All of the time
1	2	3	4	5

Diet

7. Has your doctor recommended you follow a diet or meal plan to:

i) Control your diabetes?	Yes	☐	No	☐	Not sure	☐
ii) Lose weight?	Yes	☐	No	☐	Not sure	☐

(If no to both questions, go to question 11)

8. There are many reasons why people don't stick to their diet, can you briefly describe the main reasons why *you* don't follow your recommended diet:

9. In general, how often are you able to follow the diet recommended by the doctor/nurse?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

10. <u>In the past 2 weeks</u> how often did you:

	Never	Rarely	Sometimes	Most of the time	All of the time
a) Limit your calories	1	2	3	4	5
b) Eat high fibre foods (e.g. fresh fruit/vegetables, whole grain bread)	1	2	3	4	5
c) Eat high fat foods (e.g. butter, oil, deep-fried food, nuts, bacon & meat with fat/skin)	1	2	3	4	5
d) Eat sweets & desserts (non-diet) (e.g. cake, pie, jelly, soft drinks)	1	2	3	4	5
e) Eat regular meals	1	2	3	4	5

Exercise

11. Has your doctor recommended exercise as part of your diabetes programme?

Yes ☐ No ☐ *(Go to question 15)* Not sure ☐

12. There are many reasons why people don't stick to their exercise programme, can you describe the main reasons why *you* don't exercise:

13. In general, how often do you exercise the amount suggested by the doctor/nurse? (E.g. If your doctor recommended 20 mins of activity per day.)

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

14. <u>In the past 2 weeks</u>, how often have you followed the recommended exercise programme?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

<u>Other treatment</u>

15. Do you use any other treatment (e.g. alternative medicine, home remedies) to help you manage your diabetes?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

If so, what do you use?

....

<u>Glucose testing</u>

16. In general, how often do you check your blood glucose levels? .... per day/week (delete as appropriate)

17. There are many reasons why people don't test their glucose levels as often as recommended. Can you describe the main reasons why *you* don't test your glucose levels:

18. Generally, how often do you test your glucose as recommended?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

19. <u>In the past 2 weeks</u>, how many times have you missed a test?

Never	Rarely	Sometimes	Most of the time	All of the time
1	2	3	4	5

General Health

20. Please indicate how strongly you agree or disagree with each of the following statements, using these response choices:

1 = strongly disagree
2 = disagree
3 = neither agree nor disagree
4 = agree
5 = strongly agree

a) It is important to take all my medication at the times recommended by the doctor if I am to achieve good control of my diabetes.	1	2	3	4	5
b) Sticking to a diet interferes with my social life.	1	2	3	4	5
c) It is just not possible to manage my diabetes well and live in a way that is acceptable to me.	1	2	3	4	5
d) Regular exercise helps in the management of my diabetes.	1	2	3	4	5
e) Controlling my diabetes well interferes with my whole lifestyle.	1	2	3	4	5
f) I find that keeping to a diet is helpful in controlling my diabetes.	1	2	3	4	5
g) My medication has unpleasant side-effects.	1	2	3	4	5
h) I find exercising inconvenient	1	2	3	4	5
i) Good control of my diabetes reduces the risk of developing complications.	1	2	3	4	5
j) By careful planning of diet, exercise and medication, I can control my diabetes at least as well as other people with diabetes.	1	2	3	4	5

21. How satisfied do you feel with the medical care you receive for your diabetes?

Not at all satisfied	Not very satisfied	Neither satisfied nor dissatisfied	Quite satisfied	Extremely satisfied
1	2	3	4	5

22. Is there any aspect of your medical care which you would like to see improved? (please state)

23. How satisfied do you feel about the amount of information you have received about diabetes?

Not at all satisfied	Not very satisfied	Neither satisfied nor dissatisfied	Quite satisfied	Extremely satisfied
1	2	3	4	5

24. How frequently do you see a doctor/nurse about your diabetes care? .... per month/year

25. How likely do you feel you are to develop the following problems? If you already have any of these problems, please tick the appropriate box.

	Very Unlikely	Not very likely	Moderately likely	Quite likely	Extremely likely	I already have this problem
a) Cataracts	1	2	3	4	5	☐
b) Impaired vision	1	2	3	4	5	☐
c) Heart problems	1	2	3	4	5	☐
d) High blood pressure	1	2	3	4	5	☐
e) Kidney problems	1	2	3	4	5	☐
f) Skin problems	1	2	3	4	5	☐
g) Foot problems	1	2	3	4	5	☐
h) Sexual problems	1	2	3	4	5	☐
i) Pain or numbness in feet or legs	1	2	3	4	5	☐

✏**Please feel free to add any further comments:**

SECTION 4: YOUR VIEWS ABOUT YOUR DIABETES

We are interested in your own views and there are no correct answers to any of these questions.

✓Please tick how often you experience the following symptoms **as part of your diabetes**.

SYMPTOM	ALL OF THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Weight loss				
Loss of strength				
Breathlessness				
Frequent passing of water				
Feeling irritable				
Feeling depressed				
Sore eyes				
Tiredness				
Headaches				
Weight gain				
Tingling feeling in your feet				
Upset stomach				
Sleep difficulties				
Feeling very hungry				
Blurred vision				
Chest pain				
Feeling very thirsty all the time				
Dizziness				

Please indicate how much you agree or disagree with the following statements about your diabetes, by circling the appropriate response. <u>Please answer all the questions</u>.

1 = strongly agree
2 = agree
3 = neither agree nor disagree
4 = disagree
5 = strongly disagree

VIEWS ABOUT YOUR DIABETES

1. A germ or virus caused my diabetes.	1	2	3	4	5
2. Diet played a major role in causing my diabetes.	1	2	3	4	5
3. Pollution of the environment caused my diabetes.	1	2	3	4	5
4. My diabetes is hereditary - it runs in my family.	1	2	3	4	5
5. It was just by chance that I developed diabetes.	1	2	3	4	5
6. Stress was a major factor in causing my diabetes.	1	2	3	4	5
7. My diabetes is mainly due to my own behaviour.	1	2	3	4	5
8. Other people played a large role in causing my diabetes.	1	2	3	4	5
9. My diabetes was caused by poor medical care in the past.	1	2	3	4	5
10. My state of mind played a major part in causing my diabetes.	1	2	3	4	5
11. My diabetes will last a short time.	1	2	3	4	5
12. My diabetes is temporary, rather than permanent.	1	2	3	4	5
13. My diabetes will last for a long time.	1	2	3	4	5
14. My diabetes is a serious condition.	1	2	3	4	5

Please indicate how much you agree or disagree with the following statements about your diabetes, by circling the appropriate response.

1 = strongly agree
2 = agree
3 = neither agree nor disagree
4 = disagree
5 = strongly disagree

VIEWS ABOUT YOUR DIABETES

15. My diabetes has had major consequences on my life.	1	2	3	4	5
16. My diabetes has become easier to live with.	1	2	3	4	5
17. My diabetes has not had much effect on my life.	1	2	3	4	5
18. My diabetes has strongly affected the way others see me.	1	2	3	4	5
19. My diabetes has strongly affected the way I see myself.	1	2	3	4	5
20. My diabetes will improve in time.	1	2	3	4	5
21. My diabetes has serious economic and financial consequences.	1	2	3	4	5
22. There is a lot I can do to control my symptoms.	1	2	3	4	5
23. There is little that can be done to improve my diabetes.	1	2	3	4	5
24. My treatment will be effective in curing my diabetes.	1	2	3	4	5
25. Recovery from diabetes is largely dependent on chance or fate.	1	2	3	4	5
26. What I do can determine whether my diabetes gets better or worse.	1	2	3	4	5

MANY THANKS FOR YOUR TIME AND HELP

Appendix 17

Chapter 7: Intercorrelations between IPQ scales for diabetics and hypertensives (Study 6)

Table 1: Intercorrelations between IPQ scales for diabetic sample

Scale	*Abstract*		*Concrete*	
	Conseq.	*Time*	*Identity*	*Conseq.*
Abstract				
Time	.17**			
Concrete				
Identity	.28**	-.02		
Conseq.	**.62****	.15*	.42**	
Time	.10	**.46****	.13	.25**

*p<.05, **p<.01

Note: cure scale is excluded due to low reliability

Table 2: Intercorrelations between IPQ scales for hypertensive sample

Scale	*Abstract*			*Concrete*		
	Conseq.	*Cure*	*Time*	*Identity*	*Conseq.*	*Cure*
Abstract						
Cure	-.04					
Time	-.16*	-.18**				
Concrete						
Identity	.10	-.05	.08			
Conseq.	**.43****	-.16*	-.09	.35**		
Cure	.16	**.47****	-.29**	-.01	-.12	
Time	-.25**	-.13	**.42****	.02	-.02	-.45**

*p<.05, **p<.01

Appendix 18

Chapter 7: Correlations between SF-36, IPQ and COPE scales for hypertensives and diabetics (Study 6)

Table 1: Correlations between SF-36, IPQ and COPE scales for hypertensive sample

Scale	PF	RP	BP	GH	VT	SF	RE	MH
SF-36:								
RP scale	.66***							
BP scale	.62***	.61***						
GH scale	.47***	.45***	.49***					
VT scale	.49***	.58***	.53***	.55***				
SF scale	.50***	.66***	.54***	.50***	.60***			
RE scale	.23**	.52***	.38***	.31***	.61***	.61***		
MH scale	.21**	.42***	.30***	.50***	.67***	.58***	.66***	
IPQ:								
Identity	-.37***	-.52***	-.46***	-.39***	-.58***	-.47***	-.44***	-.48***
Conseq.	-.32***	-.33***	-.26***	-.33***	-.29***	-.33***	-.31***	-.34***
Cure	.14	.15	.09	.15	.13	.07	.10	.10
Time	-.10	-.07	-.03	-.17*	-.08	-.02	.06	.06
Monitor	-.16*	-.27***	-.14	-.17*	-.25***	-.32***	-.27***	-.31***
COPE:								
Active	-.07	-.21**	-.07	.01	-.08	-.18*	-.18*	-.06
Emotion	-.13	-.19*	-.15*	-.24**	-.33***	-.33***	-.38***	-.42***
Drug use	-.12	-.25**	-.17*	-.32***	-.24**	-.38***	-.46***	-.42***
Growth	-.15	-.25**	-.13	.00	-.10	-.17*	-.24**	-.12
Acceptance	-.09	-.20**	-.16*	-.06	-.07	-.13	-.05	.03
Denial	-.19*	-.28***	-.23**	-.10	-.18*	-.16*	-.24**	-.16*
Behav. disengage	-.39***	-.52***	-.34***	-.36***	-.49***	-.51***	-.52***	-.50***

*p<.05, **p<.01, ***p<.001

(PF = physical functioning, RP = role limitations-physical, BP = bodily pain, GH = general health, VT = vitality, SF = social functioning, RE = role limitations-emotional, MH = mental health).

Table 2: Correlations between SF-36, IPQ and COPE scales for diabetic sample

Scale	PF	RP	BP	GH	VT	SF	RE	MH
SF-36:								
RP scale	.66***							
BP scale	.49***	.62***						
GH scale	.37***	.39***	.45***					
VT scale	.55***	.57***	.56***	.44***				
SF scale	.48***	.53***	.58***	.44***	.49***			
RE scale	.37***	.47***	.48***	.33***	.45***	.55***		
MH scale	.32***	.39***	.43***	.40***	.60***	.57***	.52***	
IPQ:								
Identity	-.34***	-.30***	-.34***	-.49***	-.43***	-.35***	-.33***	-.46***
Conseq.	-.18**	-.29***	-.30***	-.42***	-.31***	-.47***	-.37***	-.34***
Cure	.03	.01	.07	.08	.03	.02	.04	-.08
Time	.12	.02	-.05	-.16*	.02	-.01	-.02	-.01
Monitor	.13	.04	-.02	-.13	-.07	-.11	-.02	-.05
COPE:								
Active	-.02	-.03	-.12	.10	-.01	-.11	-.06	-.01
Emotion	-.12	-.19*	-.29***	-.22**	-.16*	-.34***	-.33***	-.38***
Drug use	-.05	-.21**	-.10	-.29***	-.22**	-.32***	-.35***	-.33***
Growth	.02	-.05	-.11	-.01	-.24**	-.12*	.04	.12
Acceptance	.05	-.03	-.06	-.05	.12	.07	.07	.11
Denial	-.13	-.07	-.10	-.03	-.04	-.09	-.15*	-.10
Behav. disengage	-.14	-.22**	-.31***	-.35***	-.31***	-.35***	-.42***	-.37***

*p<.05, **p<.01, ***p<.001

(PF = physical functioning, RP = role limitations-physical, BP = bodily pain, GH = general health, VT = vitality, SF = social functioning, RE = role limitations-emotional, MH = mental health).