UNIVERSITY OF SOUTHAMPTON

Adherence to Treatment in Adolescents with Cystic Fibrosis: The Role of Illness Perceptions and Treatment Beliefs

Katharine Sarah Hawkins

This thesis is submitted in partial fulfilment
of the degree of Doctor of Clinical Psychology

Department of Psychology
Faculty of Social Sciences

July 2002

Word count: 19,709

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General Abstract

Cystic fibrosis (CF) is a chronic, progressive disease which affects multiple organ systems and ultimately results in premature death. There is currently no cure for the disease and, in order to maintain optimal health, patients are required to follow a complex, demanding treatment regimen. Whilst adherence to this regimen is associated with improved health status and longevity, rates of non-adherence are high and tend to peak during adolescence. Identifying the factors associated with adherence in adolescents is, therefore, crucial to CF care.

The review paper critically examines the existing CF adherence literature, highlighting the need for theoretically-based studies. The Self-Regulatory Model (SRM) of adherence is introduced and evidence for the utility of the approach in other illness groups is discussed. The potential application of the model to CF patients is explored, providing a rationale for the investigation of the SRM's key constructs, namely *illness perceptions* and *treatment beliefs*, in adolescents with CF.

The empirical study explores the illness perceptions and treatment beliefs held by adolescents with CF and examines the relationships between these variables and reported adherence to treatment. The findings provide preliminary support for the utility of the SRM as an explanatory model for adherence in CF adolescents. The clinical implications of the findings are discussed, focusing on the potential to identify patients at risk of non-adherence and, subsequently, develop strategies to enhance adherence.

Acknowledgements

I would like to thank Sandra Horn and Romola Bucks for their invaluable supervision and support. I would also like to thank Tony Roberts for his guidance with the statistical analyses and Rob Horne at the Centre for Health Care Research, University of Brighton, for his input regarding the measures used. For all their help in identifying participants, I would like to thank Dr. Keith Foote and Beverley Murray at the Royal Hampshire County Hospital, Winchester; Dr. Paul Seddon and his colleagues at the Royal Alexandra Hospital for Sick Children, Hove; Dr. Gary Connett and Judy Madison at Southampton General Hospital; Dr. Sheila Peters and her colleagues at St. Mary's Hospital, Portsmouth; and Dr. Anne Dewar at Poole General Hospital. Finally, and most importantly, I would like to thank the young people who gave their time to take part.

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Treatment Adherence in Adolescents with Cystic Fibrosis: A Review of the Literature

Katharine Sarah Hawkins
University of Southampton

Correspondence regarding this article should be addressed to Kate Hawkins, Doctoral Programme in Clinical Psychology, Shackleton Building (44), University of Southampton, Highfield, Southampton. SO17 1BJ.

*Prepared as if for submission to the British Journal of Health Psychology (see Appendix 1 for Notes for Contributors)

Treatment Adherence in Adolescents with Cystic Fibrosis: A Review of the Literature

Abstract

The medical management of cystic fibrosis (CF) requires patients to follow a time-consuming, multi-component treatment regimen. Adherence to this regimen retards disease progression and significantly improves the quality and longevity of patients' lives. However, research has shown that adherence to some aspects of treatment is poor and that non-adherence peaks during adolescence. In order to develop strategies to enhance adherence, researchers have begun to investigate the factors that are associated with adherence to treatment in individuals with CF. However, as this review highlights, few studies have specifically examined the determinants of adherence in adolescents and existing research in adult and paediatric populations has been flawed by the lack of a common, guiding, theoretical base. Drawing on the literature in other illness groups, Leventhal's Self-Regulatory Model is proposed as a possible framework for investigating adherence behaviour in adolescents with CF. This model, which has recently been revised, posits that patients' decisions about whether or not to adhere to treatment are guided by their cognitive and emotional interpretations of the illness (*illness perceptions* and *emotional representations*) and their personal ideas about treatment (*treatment beliefs*). The clinical implications of using this approach with adolescents with CF are discussed and ideas for future research suggested.

Introduction

Cystic fibrosis (CF) is the most common, lethal, genetically-inherited disease of the Caucasian population and the number one genetic killer of children (Orenstein & Wachnowsky, 1985). It affects multiple organ systems and ultimately results in premature death, usually from respiratory failure. There is currently no cure for CF and, thus, medical interventions seek to retard disease progression and increase longevity (Anthony, Paxton, Bines & Phelan, 1999). The prescribed treatment regimen for CF is multi-faceted, time-consuming and largely home-based, leaving patients and their caregivers responsible for daily interventions. Evidence suggests that adherence to this self-care regimen is associated with improved health status and survival (Brown, Rowley & Helms, 1994; Desmond, Schwenk, Thomas, Beaudry & Coates, 1983; Drotar, 1995; Patterson, Budd, Goetz & Warwick, 1993; Thomas, Cook & Brooks, 1995). However, reported non-adherence to some aspects of treatment is high (Abbott, Dodd, Bilton & Webb, 1994), and research indicates that non-adherence may peak during adolescence (Gudas, Koocher & Wypij, 1991; Hamlett, Murphy, Hayes & Doershuk, 1996; Ricker, Delamater & Hsu, 1998). Given the severity of the disease and the potential consequences of non-adherence, researchers have begun to investigate the factors that influence adherence to treatment in patients with CF (Koocher, McGrath & Gudas, 1990). However, much of the research to date has been criticised on the grounds that it is methodologically inconsistent, limited in scope and largely conducted outside a theoretical framework (Miller, Jelalian & Stark, 1999).

A recent approach to understanding treatment adherence within the context of chronic illness is Leventhal's Self-Regulatory Model (SRM; Leventhal, 1993; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Zimmerman & Gutmann, 1984). This model posits that, in response to illness, people develop parallel cognitive and emotional representations which help them make sense of their experience and provide a basis for their coping behaviour. These constructs, termed *illness perceptions* and *emotional representations*, influence whether or not individuals adhere to their treatment. The SRM has recently been expanded to incorporate patients' beliefs about treatment (*treatment beliefs*). Thus, the revised model proposes that adherence behaviour is guided not only by patients' interpretations of their illness, but also by their theories about the treatments prescribed to manage it.

Whilst research based on the SRM is still in its infancy, there is growing empirical support for the utility of the model in explaining treatment adherence in a range of illness populations. These include: diabetes (Griva, Myers & Newman, 2000); asthma (Horne & Weinman, 2001); hypertension (Meyer, Leventhal & Gutmann, 1985); and cardiac disease (Cooper, Lloyd, Weinman & Jackson, 1999; Petrie, Weinman, Sharpe & Buckley, 1996). To date, the SRM has not been applied to individuals with CF.

This paper will outline the nature and incidence of CF and briefly describe the various components of the treatment regimen. The current literature regarding adherence to treatment in individuals with CF will then be critically reviewed. Issues surrounding the concept and measurement of adherence will be discussed, and the factors associated with adherence examined. Particular attention will be paid to the salient issues for adolescents. Research investigating the validity of the SRM as a means of explaining treatment adherence will then be explored. The paper will end with a discussion of the model's potential utility in CF populations and suggest some areas for future research.

The Nature and Incidence of CF

CF is a disorder of the exocrine system that affects the respiratory, pancreatic, hepatic, gastro-intestinal and reproductive systems (Miller et al., 1999). A thick, viscous mucus accumulates in the affected organs, resulting in the progressive scarring and destruction of excretory ducts. The most serious manifestations of the disease are pancreatic insufficiency and chronic, progressive lung disease. Over 90 per cent of CF deaths are caused by respiratory failure (Mischler, 1985).

CF occurs in an estimated 1:2000 live Caucasian births and 1:17 000 live Afro-Caribbean births (Matthews & Drotar, 1984). It affects equal numbers of males and females and is typically diagnosed within the first six months of life (Cloutier, 1997). Genetic studies indicate that CF is transmitted via an autosomal recessive gene mechanism (Miller et al., 1999). The median survival age for individuals with CF doubled from 14 to 28 years between 1969 and 1990 (Fitzsimmons, 1993), and children born with the disease in 1990 have a median projected life expectancy of 40 years (Elborn, Shale & Britton, 1991). This improved prognosis has been attributed to a number of factors including; earlier diagnosis, the development of a new generation of antibiotics, routine physiotherapy, better pancreatic enzyme supplementation and dietary management, and the emergence of specialist treatment centres (Czajkowski & Koocher, 1987; Drotar, 1995; Orenstein & Wachnowsky, 1985).

The CF Treatment Regimen

Advances in the medical management of CF have dramatically improved the longevity of patients' lives (Orenstein & Wachnowsky, 1985). However, in order to maintain optimal health, individuals with CF have to employ a lifelong, complex, time-consuming treatment regimen. The major components of this regimen are chest physiotherapy (CPT), antibiotic therapy, pancreatic enzyme supplementation and dietary management.

The most time-consuming aspect of treatment is CPT (Miller et al., 1999). It is prescribed up to four times daily for 20-30 minutes per session and is employed as a prophylactic measure in all patients, regardless of disease status or symptomatology (Koocher, Gudas & McGrath, 1992). CPT involves a range of different techniques including; postural drainage, breathing exercises, voluntary coughing, and chest percussion (clapping on the patient's back whilst he or she assumes different positions). Although the assistance of a trained family member is generally required for young children, mechanical devices now permit adolescent patients to complete their CPT independently (Koocher et al., 1992). Research has shown that continued use of CPT is associated with better pulmonary function and that poor adherence adversely affects prognosis (Desmond et al., 1983; Patterson et al., 1993; Thomas et al., 1995).

Antibiotic therapy is crucial for the management of the chest infections associated with CF (Orenstein & Wachnowsky, 1985). Acute infections are typically treated in hospital using high doses of intravenous antibiotics. In addition, long courses of oral or nebulised antibiotics are prescribed in between admissions as a prophylactic measure to retard lung damage (Koocher et al., 1992).

The vast majority of people with CF suffer from pancreatic insufficiency and cannot digest fat, fat-soluble vitamins or protein (Fitzsimmons, 1993). As such, pancreatic enzyme supplements (ES) are prescribed with all meals and snacks to promote the absorption of these nutrients. The correct dose of ES has to be calculated on a meal-by-meal basis depending on the amount and type of food being ingested (Orenstein & Wachnowsky, 1985). Taking ES with food prevents stomach pains, bloating and bulky stools. Thus, the treatment has a direct impact on patients' symptomatology and well-being (Koocher et al., 1992).

Despite the use of ES, some individuals with CF continue to experience malabsorption (Abbott, Conway, Etherington, Fitzjohn, Gee, Morton, Musson & Webb, 2000). This places them at risk of malnourishment and dietary management is, therefore, a key component of their care. Such patients are encouraged to consume between 120 and 150 per cent of the recommended daily allowance of calories for healthy individuals, with as much as 35-40% of the energy provided by fat (MacDonald, Holden & Harris, 1991). Nutritional supplements, such as vitamins and minerals, are also prescribed and, for patients who become undernourished, overnight feeding through a gastrostomy tube may be required (Abbott et al., 2000). The associations between adherence to dietary requirements, nutritional status and pulmonary function are well-established (Durie & Pencharz, 1989; Elborn & Bell, 1996).

This brief review demonstrates that treatment for CF is complex, multi-faceted and time-consuming. The regimen is largely home-based, and patients and their families are, therefore, responsible for carrying out daily interventions. Adherence to treatment is associated with improved pulmonary status and longevity (Brown et al., 1994; Desmond et al., 1983; Durie & Pencharz, 1989; Elborn & Bell, 1996; Patterson et al., 1993; Thomas et al., 1995). However, as there is no cure for CF and treatment is only partially effective in retarding disease progression, even complete adherence does not guarantee good health. For individuals with CF, therefore, decisions about whether or not to adhere to treatment are made in the knowledge that the long term prognosis is, at best, uncertain (Koocher et al., 1992).

Conceptualising Adherence

In much of the literature to date, the term 'compliance' has been used to describe the process of following treatment advice (Myers & Midence, 1998). More recently, however, this term has been criticised on the grounds that it has unfavourable connotations for the clinician-patient relationship (Horne, 2000). It seems to denote a relationship in which the role of the clinician is to decide an appropriate treatment and the role of the patient is passively to submit to instructions (Horne, 1998). The term 'adherence' has, therefore, been adopted as an alternative to compliance. Adherence implies a more active role for patients, emphasising that individuals are free to decide whether or not to follow treatment advice (Horne, 2000). This conceptual shift constitutes an important step in recognising the independent, self-regulatory activity of patients (Leventhal, 1993), and acknowledges that poor adherence may be the result of a rational decision-making process (Koocher et al., 1990).

The Measurement of Adherence

Measures of adherence may be divided into two categories depending on whether the assessment is direct or indirect (Horne, 2000). Direct measures involve either observing prescribed treatments being carried out or detecting the presence of medication in body fluids. Indirect measures, on the other hand, infer that prescribed treatments have been carried out on the basis of alternative evidence, such as self-report. The strengths and weaknesses of these two approaches are discussed below.

Direct measures are typically regarded as the most objective and quantifiable methods of assessing adherence (Riekert & Drotar, 2000). However, these techniques are fraught with problems (Bryon, 1998; Horne, 1998). Firstly, practical issues, such as cost, often prohibit their systematic use in research and clinical practice. Secondly, with regard to drug assays, the relationship between the amount of medication taken and the concentration found in body fluids is, at best, precarious (Horne, 2000). There is often considerable individual variation in the absorption, metabolism and elimination of medication and, thus, the results obtained may not accurately reflect adherence behaviour (Bryon, 1998). Moreover, valid assays are available for only a limited number of drug therapies (Horne, 2000). Direct measures are also prone to the effects of social desirability, or self-presentational bias. Thus, in order to fulfil the perceived expectations of the clinician, individuals may increase their level of adherence during periods of observation or immediately prior to drug testing.

In summary, the major limitations of direct methods are that they are invasive, costly, prone to self-presentational bias, and of questionable reliability (Horne, 2000). Only a handful of studies has employed direct measures to assess adherence to the CF treatment regimen. These have typically used drug assays to measure adherence to antibiotic therapy (Meyers, Dolan & Mueller, 1975). As noted by Passero et al. (1981), almost no objective data are available for other aspects of CF treatment (Passero, Remor & Salomon, 1981).

Indirect measures of treatment adherence include self-reports, parent ratings and clinician estimates. In contrast to direct methods, these measures are frequently used in research and clinical practice as they are cost-effective and relatively easy to obtain. They are not without their limitations, however (Riekert & Drotar, 2000). Firstly, evidence from a range of chronic illness groups suggests that clinician estimates are highly inaccurate (Horne, 2000; Rand & Wise, 1994). With regard to CF patients, in particular, these ratings have been shown to reflect clinical markers, such as lung capacity and growth, rather than actual adherence (Sanders, Gravestock, Wanstall & Dunne, 1991). The validity of parent assessments has also been questioned. Specifically, research indicates that parents may over-estimate their child's level of adherence in comparison to more objective measures of adherence (Horne, 1998; Meyers et al., 1975). Nonetheless, for practical reasons, parent reports remain the most widely used means of assessment for children with CF (Anthony et al., 1999; Passero et al., 1981). The method is used less frequently with adolescents, however, due to ethical concerns about the risk of compromising family relationships (Horne, 2000).

The vast majority of studies assessing adherence to treatment in individuals with CF have used self-report methodology (Abbott & Gee, 1998). This approach is highly sensitive to social desirability effects, however (Rapoff, 1999), and there is evidence that patients are biased towards over-reporting adherence (Epstein & Cluss, 1982; Ley, 1982). Nonetheless, research demonstrates that those who do report non-adherence rarely lie (Epstein & Cluss, 1982; Horne, 2000). Thus, whilst there is a need to be mindful of inflated adherence rates, reports of non-adherence may be regarded as broadly accurate (Abbott & Gee, 1998).

Recently, a number of ways to enhance the validity of self-reported adherence have been proposed (Riekert & Drotar, 2000). Firstly, Rand and Wise (1994) suggest that phrasing questions in a non-threatening manner and assuring patients that their responses are both anonymous and confidential increases the accuracy of self-reports. Secondly, using a neutral researcher to question patients, rather than a clinician involved in their care, may also reduce patients' tendency to over-estimate adherence (Horne, 2000). Moreover, asking patients to report the frequency of non-adherent behaviour, as opposed to adherent behaviour, may normalise the process of omitting treatment and, thereby, increase the accuracy of self-reports (Kravitz, Hays, Sherbourne, DiMatteo, Rogers, Ordway & Greenfield, 1993; Rand & Wise, 1994). Finally, evidence suggests that more accurate self-reports may be obtained by presenting patients with a range of responses, for instance, from 0 (*I never take my medication*) to 5 (*I always take my medication as prescribed*), rather than a simple Yes or No dichotomy (Haynes, Taylor, Sackett, Gibson, Bernholtz & Mukherjee, 1980).

A number of self-report questionnaires designed to measure treatment adherence in patients with chronic illness have now been developed (Czajkowski & Koocher, 1986; Horne & Hankins, in press). Moreover, researchers have begun to design measures that specifically assess adherence to treatment in individuals with CF (Abbott et al., 1994; Horn, Myers & Abbott, in preparation). These measures have not been widely used to date, however, and the validity of the questionnaires has not been assessed using more objective measures. Given the lack of a well-validated, CF-specific measure of adherence, a wide variety of different self-report methodologies have been used in the literature. These include: Likert scales (Gudas et al., 1991); 24-hour recall (Ricker et al., 1998); and diary records (Anthony et al., 1999). The use of such diverse techniques poses problems for the comparison of data between studies (Bryon, 1998).

It is apparent that measuring adherence to treatment in individuals with CF is a complex task. Treatment for CF has many components and, consequently, assessing adherence to the CF treatment regimen involves monitoring a number of different self-care behaviours. At present, no reliable, objective measures of adherence to the different aspects of treatment have been developed. As such, researchers tend to rely on self-reports. A range of different self-report methodologies has been used in the literature and it is, therefore, difficult to compare data across studies. Moreover, self-reports have been shown to over-estimate adherence (Horne, 1998). Thus, researchers are advised to take steps to reduce self-presentational bias and, where possible, employ more than one measure to assess the reliability of patients' reports (Horne, 2000).

Rates of Adherence to the CF Treatment Regimen

Research has demonstrated that non-adherence to prescribed treatment is a significant problem across a range of different illness groups (Sackett & Snow, 1979). However, adherence to the CF treatment regimen is generally considered to be good (Miller et al., 1999; Orenstein & Wachnowsky, 1985), and CF patients have been cited as the most adherent of all chronic illness populations (Zeltzer, Ellenberger & Rigler, 1980). For instance, Czajkowski and Koocher (1987) found that, of their sample of 40 CF patients aged between 13 and 23 years, only 14 (35%) adhered poorly to their treatment regimen. This figure compares quite favourably with the rate of 50% reported for other chronic conditions, such as asthma and diabetes (Rapoff, 1999).

However, recent studies suggest that adherence rates vary greatly for different aspects of the CF treatment regimen. Whilst consistently high rates of adherence have been reported for ES and antibiotics, adherence to CPT and dietary requirements is often found to be problematic (Miller et al., 1999). For instance, in a sample of 80 CF patients aged between 14 and 40 years, Conway et al. (1996) found self-reported adherence rates of 85% for ES, 83% for oral antibiotics, 41% for CPT and 50% for dietary supplements (Conway, Pond, Hamnett & Watson, 1996). These findings are comparable with the results of a similar self-report study carried out by Abbott et al. (1994). Of their sample of 60 patients aged between 16 and 44 years, 83% reported adhering to their ES, 53% to their CPT and 46% to their vitamin supplements. Adherence to antibiotics was not assessed in this study. Finally, in a mixed sample of 58 paediatric and adult patients which included young children, Passero et al. (1981) reported adherence rates of 93% for antibiotics, 23% for CPT, 90% for vitamin supplements and 30% for calorie intake. Adherence to ES was not assessed.

These findings raise two important issues for the measurement of treatment adherence in individuals with CF. The first relates to the use of composite scores. The above results demonstrate that adherence is highly treatment-specific in CF. However, many studies, like the one carried out by Czajkowski and Koocher (1987), have assessed adherence to different components of treatment and subsequently combined the data to provide an overall score, thereby losing specific treatment data (Abbott & Gee, 1998). Such a score masks the potential disparities between adherence to different aspects of treatment. Thus, individual, treatment-specific measures are required (Miller et al., 1999).

The second point concerns the comparison of data between studies. The findings show that adherence rates for different aspects of treatment vary greatly between studies. For instance, adherence to vitamin supplements was markedly higher in Passero et al.'s study (1981) compared to the other studies. This may reflect the use of different assessment techniques, as discussed earlier. However, it also seems likely that the age of participants influenced the findings. It is widely acknowledged that the measurement of adherence in young children is confounded by the fact that parents contribute heavily to the administration of treatment (Koocher et al., 1992; Strauss & Wellisch, 1981). Thus, Passero et al.'s (1981) findings may reflect the fact that parents were overseeing the use of vitamin supplements in young patients. When comparing data across studies, therefore, it is important to consider the age of participants as well as the method of assessment used.

Factors Influencing Adherence to Treatment in CF Patients

The survival of patients with CF beyond childhood has only occurred since the 1970's (Drotar, 1995; Matthews & Drotar, 1984). As such, the opportunity to study patients' coping abilities and responses to treatment at different ages, or stages of development, has not previously existed (Gudas et al., 1991). The literature concerning adherence to treatment in adolescents is, therefore, quite limited. Furthermore, the studies that have been carried out have tended to group adolescents together with either young children or adults, failing to recognise that specific issues may exist for people at different stages of development. Thus, the evidence reviewed here draws upon research carried out in both paediatric and adult settings. A range of potential determinants of adherence has been investigated. For clarity, these factors have been divided into clinical and demographic variables, knowledge, cognitive variables, family factors and support, and characteristics of the treatment regimen.

Clinical and Demographic Variables

A number of studies have investigated the relationships between treatment adherence and clinical and demographic variables, such as disease severity, age, gender, and socio-economic status. On the whole, this research has produced inconclusive findings (Bryon, 1998; Koocher et al., 1992; Miller et al., 1999). For instance, it was originally assumed that greater disease severity would be associated with better adherence to treatment (Abbott & Gee, 1998). However, research using a variety of measures of severity, such as frequency of hospital admissions, forced expiratory volume, and height and weight percentiles, has shown that CF disease status and adherence are not related (Abbott et al., 1994; Conway et al., 1996; Gudas et al., 1991; Passero et al., 1981; Ricker et al., 1998; Shepherd, Hovel & Harwood, 1990). Nonetheless, as research has tended to be cross-sectional in nature, it is not clear how, or whether, this relationship varies over the course of the illness.

Studies investigating the relationship between gender and treatment adherence have produced conflicting findings. Whilst females were found to be less adherent than males in one study (Czajkowski & Koocher, 1987), another study demonstrated the opposite finding (Patterson et al., 1993). The majority of research, however, reports no differences between the sexes (Abbott et al., 1994; Conway et al., 1996; Passero et al., 1981; Ricker et al., 1998). Similarly, socio-economic status has not generally been found to influence adherence to treatment in CF patients (Abbott & Gee, 1998; Bryon, 1998). Nonetheless, one study demonstrated that children and adolescents in lower socio-economic groups were at greater risk of poor adherence (Gudas et al., 1991).

More consistent findings have been reported by studies investigating the relationship between age and adherence. For instance, studies that have focused on children and adolescents have generally demonstrated that increasing age is associated with poorer adherence (Czajkowski & Koocher, 1987; Patterson, 1985; Ricker et al., 1998), although Gudas et al. (1991) found that this relationship existed for oral medication only, not for CPT or diet. In contrast, studies that have been carried out in predominantly adult samples have tended to report no association between age and adherence (Abbott et al., 1994; Conway et al., 1996). In view of these findings, it has been suggested that, consistent with other illness groups, age and adherence are related in a U-shaped fashion in CF patients (Abbott & Gee, 1998; Bryon, 1998). Thus, adherence is highest during childhood and adulthood and poorest during adolescence. Two further studies provide support for this proposal.

Hamlett et al. (1996) carried out a retrospective study investigating the transition from parental control of treatment to self-management in 75 individuals with CF. Participants were asked to rate their current level of adherence and estimate how adherent they were when they first assumed responsibility for their treatment. Whilst the age at which individuals first became responsible for treatment varied for different aspects of the regimen, it always occurred during adolescence. For instance, the mean reported age for taking responsibility for treatment was 13 years for oral medication, 17 years for CPT and dietary requirements, and 18 years for making clinic appointments. Participants unanimously reported that adherence was poorest when they first became responsible for treatment. Thus, the transition from parental responsibility for treatment to independent control appears to be marked by poor adherence. This may help to explain why Gudas et al. (1991) found that increasing age was associated with poorer adherence to oral medication, but not to CPT or diet. The adherence ratings for CPT and diet may have been confounded by the fact that the participants' parents were still overseeing the administration of these treatments.

A second retrospective study has provided further evidence that treatment adherence is poorest during adolescence (Johannesson, Carlson, Brucefors & Hjelte, 1998). Semi-structured interviews were carried out with 14 females aged between 22 and 34 years to investigate their feelings about CF and elicit how they coped with their illness at different stages of their lives. The women recalled that they found CF hardest to manage during adolescence. They remembered feeling acutely different from their peers at this time and stated that they tried to hide their illness in case other people found out. They also remembered becoming aware during adolescence that they would die young and noted that this prompted self-destructive behaviour, such as avoiding treatment and smoking.

These studies provide some insight into the reasons why treatment adherence may be particularly problematic for adolescent patients. Adolescence is a time of rapid physical and social change and is associated with increasing independence and greater integration into peer culture (Chigier, 1997; Liakopoulou, 1999). One function of this developmental stage is to achieve successful separation from one's parents in order to become a self-sufficient adult (Bryon, 1998). Thus, during adolescence, treatment administration shifts from being primarily controlled by parents to becoming the responsibility of individual patients (Hamlett et al., 1996). Abbott and Gee (1998) suggest that this may lead to poor adherence as many adolescents do not share the long-term view of illness management held by their parents and health professionals and, therefore, may be reluctant to engage in time-consuming procedures for which they perceive no immediate benefit. Adolescents may also view treatment as a constraint on their autonomy and non-adherence may result (Ricker et al., 1998; Seiffge-Krenke, 1998). Furthermore, during adolescence, patients become aware that they are going to die young and, consequently, may engage in risky, non-adherent behaviour (Johannesson et al., 1998). Finally, for individuals with CF, the intensive treatment regimen serves as a daily reminder of being different from their peers (Abbott & Gee, 1998). Given the importance of peer integration during adolescence, young people with CF may, therefore, choose to neglect their treatment in order to fit in (Johannesson et al., 1998; Seiffge-Krenke, 1998).

Knowledge

Early research investigating 'compliance' with treatment tended to assume that greater knowledge about an illness and its treatment would enhance adherence and, consequently, that non-adherence could be avoided simply by giving patients more information (Abbott & Gee, 1998; Horne, 2000). More recently, however, studies have shown that the relationship between knowledge and adherence is not straightforward.

As expected, some studies have demonstrated that better factual understanding about CF and its treatment is associated with improved adherence (Anthony et al., 1999; Czajkowski & Koocher, 1986; Geiss, Hobbs, Hannersley-Maercklein, Kramer & Henley, 1992; Gudas et al., 1991; Ievers, Brown, Drotar, Caplan, Pishevar & Lambert, 1999). However, these studies have typically found that knowledge accounts for a relatively small amount of variance in comparison to other factors (Czajkowski & Koocher, 1986; Geiss et al., 1992; Gudas et al., 1991). Furthermore, one study has reported a virtually zero correlation between knowledge and reported adherence in CF patients (Conway et al., 1996). Thus, it cannot be assumed that patients with good knowledge will adhere to treatment. Whilst a basic understanding of treatment is essential, knowledge alone does not guarantee adherence (Horne, 2000).

Cognitive Variables

Recognising that individuals with a high level of knowledge do not always adhere to treatment has stimulated research to investigate the potential psychosocial determinants of adherence. Work in the field of Health Psychology has provided some insight into the range of cognitive variables that may influence adherence to treatment (Bandura, 1997; Connor & Norman, 1995; Sheeran & Abraham, 1995; Wallston, Stein & Smith, 1994; Wallston & Wallston, 1978). For instance, evidence suggests that two concepts derived from Social Learning Theory may affect patients' decisions about whether or not to follow treatment advice (Bandura, 1997). The first, health locus of control, concerns the extent to which individuals attribute their state of health to internal factors, such as their own actions, or to external factors, such as the actions of powerful others or chance. In CF patients, research has consistently shown that good adherence is related to external control. Specifically, individuals who have strong beliefs in the abilities of their doctors and other influential people, such as clinicians, family and friends, are more likely to follow their treatment instructions (Abbott, Dodd & Webb, 1996; Myers & Myers, 1999; Ricker et al., 1998).

The second concept, self-efficacy, relates to individuals' beliefs in their ability to perform specific actions. Whilst there is little agreement in the literature about how this concept should be operationalised, studies have consistently shown that having stronger beliefs in one's own abilities is associated with better adherence (Czajkowski & Koocher, 1987; Ricker et al., 1998).

The role of patients' perceptions of the severity of their illness has also been examined in relation to adherence behaviour. Research from a range of different illness groups, including diabetes and hypertension, has consistently shown that greater perceived severity is associated with better adherence (Bryon, 1998; Hartman & Becker, 1978; Kirscht & Rosenstock, 1977). However, two studies carried out in the CF literature indicate that the relationship between perceived illness severity and adherence may be quite complex in this population. For instance, Gudas et al. (1991) found that greater perceived severity was associated with lower adherence to CPT, but was not related to adherence to oral medication or diet. Additionally, Abbott et al. (1994) found no associations between adherence and patients' perceptions of past, current or future disease severity. One possible explanation for these findings is that, in CF, perceptions of disease severity are related to adherence in an inverted U-shaped fashion (Abbott & Gee, 1998). Thus, treatment adherence is poorest when severity is perceived to be very high or very low and greatest when it is considered to be moderate. For instance, it has been hypothesised that individuals who believe their illness is very severe may be prone to feelings of helplessness and, consequently, neglect their treatment. Moreover, those who consider their illness to be least severe may not regard prescribed treatments as necessary for them (Champion, 1985). At present, however, there is little empirical data to support these hypotheses.

Research has also examined the relationship between optimism and adherence. Higher optimism, defined as the expectation that good rather than bad events will occur (Koocher et al., 1992), has been shown to correlate significantly with improved adherence in CF patients (Abbott, Dodd, Gee & Webb, 2001; Czajkowski & Koocher, 1987; Gudas et al., 1991). Moreover, Gudas et al. (1991) found that the effects of optimism interacted with the effects of age in their study. Thus, higher optimism yielded better adherence with oral medication in older patients. Although adolescents tended to have lower medication adherence than younger children, those who were more optimistic adhered quite well with this aspect of treatment. These findings indicate that general optimism about life is associated with better adherence.

Several studies have investigated the relationship between coping and treatment adherence in individuals with CF. However, the results of this research depend heavily on how coping has been measured and, as with self-efficacy, there appears to be little consistency in how this construct has been operationalised in the literature (Abbott & Gee, 1998; Bryon, 1998). Csajkowski and Koocher (1987) identified several coping behaviours which were associated with greater adherence to treatment including; being open with peers about the illness, active participation in school, and taking a responsible attitude towards self-care. However, both coping and adherence were assessed by physicians in this study and it can clearly be seen how the two measures may have been confounded. More recently, Abbott et al. (2001) developed a questionnaire to assess coping behaviour in adults with CF. Using this measure, they demonstrated that passive strategies, such as avoidance and trying to put problems out of mind, were associated with poorer adherence. In contrast, strategies such as putting problems into perspective and trying to do something positive, termed optimistic acceptance, were associated with better adherence.

Family Factors and Support

As parents contribute heavily to the administration of treatment in children with CF, it has been suggested that family factors might influence adherence to treatment in this population (Bryon, 1998). However, only a small number of studies have investigated whether any aspects of family functioning facilitate or impede treatment adherence in paediatric patients. Geiss et al. (1992) examined the relationships between maternal adjustment and treatment adherence in 24 patients aged between 6 months and 17 years and found that higher levels of adherence were associated with lower levels of marital satisfaction and less contact with other adults. The results of another study suggest that family factors may be less important influences on adherence behaviour than demographic and cognitive variables. Ricker et al. (1998) examined the relationships between reported adherence and a range of demographic and psychosocial variables in 50 children and adolescents aged between 9 and 18 years. They found that, whilst family cohesiveness and adaptability were positively related to treatment adherence at a univariate level, these factors did not account for a significant proportion of the variance when entered alongside age, locus of control beliefs and self-competence in a multiple linear regression analysis.

Few studies have investigated whether receiving support with treatment influences adherence behaviour in individuals with CF. It has already been noted that rates of adherence in paediatric populations are often confounded by the fact that parents help with the administration of treatment. However, only one study has assessed the influence of instrumental support in older adolescents and adults. This study demonstrated that patients who received support with CPT from family members were more adherent with this aspect of treatment (Abbott et al., 1994).

Characteristics of the Treatment Regimen

There is now substantial evidence that rates of adherence vary greatly for different aspects of the CF treatment regimen (Abbott et al., 1994; Conway et al., 1996; Passero et al., 1981). There may be a number of possible reasons for this. Firstly, the different treatment components vary enormously in terms of the behaviours, skills and time they require (Meichenbaum & Turk, 1987). Research from a range of chronic illness groups suggests that, in any regimen consisting of multiple health care tasks, adherence tends to be lowest for the components that are complex, time-consuming, and interfere most with patients' lifestyles (Bryon, 1998; LaGreca, 1990; Riekert & Drotar, 2000). This may account for the comparatively poor adherence rates reported for CPT and diet. Furthermore, many aspects of the CF treatment regimen, such as CPT, are prescribed prophylactically and do not provide any obvious benefit in terms of symptomatic relief or improved health status. Thus, they are not inherently reinforcing (Bartholomew, Parcel, Swank & Czyzewski, 1993; Miller et al., 1999). With the exception of ES which have short-term benefits, there may be little motivation to perform treatments for purely long-term gains (Abbott & Gee, 1998).

There is growing empirical evidence that reasons for non-adherence vary for different aspects of the CF treatment regimen. When patients are asked directly, consistent reasons for neglecting certain treatments have emerged from separate studies (Abbott et al., 1994; Conway et al., 1996). With regards to CPT, the most commonly cited reasons for non-adherence were not having enough time for treatment, interference with social life, feeling well without it, and perceiving that it makes no difference to health status (Abbott et al., 1994; Conway et al., 1996). In contrast, the predominant reason for failing to take ES, oral antibiotics and vitamin supplements, was forgetting (Abbott et al., 1994; Conway et al., 1996). Furthermore, feeling embarrassed about taking ES in public and not being bothered to take vitamin supplements were also cited as reasons for non-adherence (Abbott et al., 1994; Conway et al., 1996). With regards to diet, the most commonly cited reasons for non-adherence related to the time and effort required to follow clinicians' recommendations (Conway et al., 1996).

A qualitative study carried out by Foster et al. (2001) provides some support for the notion that reasons for non-adherence vary for different components of treatment (Foster, Eiser, Oades, Sheldon, Tripp, Goldman, Rice & Trott, 2001). Separate semi-structured interviews were carried out with eight CF patients aged 10-18 years and their parents. The interviews focused on the difficulties patients and their families encountered with the treatment regimen. Thematic analysis of the interview transcripts revealed that non-adherent behaviours fell into three distinct categories. The first, unintentional non-adherence, was defined as accidental non-fulfilment of treatment demands. This referred to instances of forgetting and was most commonly reported for ES and oral antibiotics. In contrast, unintentional non-adherence was rarely given as a reason for missing CPT.

The second category of non-adherence was termed intentional non-adherence and referred to deliberate non-fulfilment of treatment. This included deciding not to bother with treatment and choosing to do something else instead, such as watching television. CPT and nebulised medication, the most time-consuming elements of treatment, were typically neglected for this reason. Furthermore, participants stated that they could get away without doing these treatments for substantial periods of time before they noticed an increase in symptoms. Incidents of intentional non-adherence were most commonly reported by older adolescents.

The final type of non-adherence was termed imposed non-adherence. This was defined as non-adherence due to external forces, such as practical constraints or perceived social pressure. Whilst Foster et al. (2001) acknowledged that this form of non-adherence was intentional to some degree, they argued that patients had less control over the decision to neglect treatment due to external pressures. Examples of this type of non-adherence were not having time to do CPT in the morning due to the demands of getting ready for school and neglecting to take ES in public due to feelings of embarrassment.

This evidence suggests that, whilst the most demanding aspects of treatment may be neglected due to time pressures or because patients perceive little symptomatic benefit, treatments that are less time-consuming and have a greater cause-and-effect impact on symptomatology are typically neglected due to forgetting.

Interim Summary

A key finding of this review of factors is that failures to follow treatment advice do not all stem from a common aetiology (Koocher et al., 1990). There appear to be numerous determinants of non-adherence including; age, knowledge, cognitive variables, family factors, support, and treatment characteristics. However, as yet, no consistent single reason or set of predictor variables has emerged (Myers & Myers, 1999). To date, the literature has been flawed by a number of methodological and theoretical weaknesses. For instance, data have been almost exclusively cross-sectional in nature and there has been little consistency between studies in how adherence and other key variables have been measured (Abbott & Gee, 1998). Moreover, the research has lacked a common, guiding, theoretical framework and, thus, studies have tended to focus on different variables, or combinations of variables, in isolation. It is, therefore, difficult to make cross-study comparisons and draw firm conclusions about the relative importance of different factors.

The Self-Regulatory Model

A recent approach to understanding treatment adherence within the context of chronic illness is Leventhal's Self-Regulatory Model (SRM) (Leventhal, 1993; Leventhal et al., 1984, 1992). The SRM describes how individuals make sense of and respond to illness, and incorporates many of the cognitive variables suggested by previous work in the field of Health Psychology. Within this framework, patients are viewed as active problem solvers whose decisions to follow or reject treatment advice are governed by whether or not it makes sense in the light of their own cognitive and emotional interpretations of the illness. The model posits that patients actively construct their own theories or representations of their illness based on past experience, abstract disease knowledge and concrete perceptual information, such as symptoms. Decisions about whether or not to follow treatment advice are guided by these schema, or *illness perceptions*. Once a decision has been implemented, the patient evaluates the effectiveness of the behaviour (e.g. adhering to treatment) against specific criteria, such as symptom experience. If the behaviour is perceived as being ineffective, the patient may adopt an alternative strategy (e.g. neglecting treatment advice) or modify their representation of the illness. As such, illness perceptions are constantly being up-dated in the light of new evidence.

In this way, the SRM proposes that adherence behaviour is regulated by the dynamic interactions between three stages, or sets of variables: cognitive representations; coping behaviour; and appraisal. In addition, the model posits that emotional reactions may be provoked at any of the three stages and that additional coping plans and appraisals may be generated to control them (Leventhal & Cameron, 1987). Whilst these *emotional representations* are often parallel to, and partially independent of, the cognitive processes, research suggests that the two systems generally interact (Leventhal & Cameron, 1987; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997). Thus, emotional states may alter the interpretation of symptoms so that they are perceived as either catastrophic or benign and, subsequently, influence the decision about whether or not to adhere to treatment advice (Leventhal et al., 1992).

The cognitive and emotional response systems are viewed as self-regulatory in that they both impinge upon, and are influenced by, individuals' self-representations (Weinman & Petrie, 1997). Thus, a patient's self-concept may be shaped by their cognitive and emotional interpretations of the illness and, likewise, their illness perceptions and emotional representations may be moderated by individual characteristics, such as optimism, attributional style and age (Leventhal et al., 1997; Nerenz & Leventhal, 1983; Weinman & Petrie, 1997). In addition, Leventhal (1993) postulates that the emotional and cognitive processing systems may be influenced by contextual factors, such as socio-cultural background.

Leventhal (1993) emphasises the role of concrete symptoms in forming illness perceptions and guiding the appraisal of coping behaviours. He argues that the dynamic interactions between representations, coping and appraisal are guided by the individual's need to maintain *coherence* between these processes. Within this framework, adherence will be more likely if it makes common-sense in light of the patient's own views about the illness and their experience of symptoms. Thus, from the patient's perspective, non-adherence may be the intentional result of a lack of coherence between their cognitive and emotional representations of the illness, their experience of symptoms, and the instruction to perform treatment. For instance, it is argued that a patient who does not feel ill or who feels worse when they follow treatment advice, may be less likely to adhere to their prescribed regimen (Horne, 1997, 1998; Leventhal, 1993).

Research using a variety of different methodologies and incorporating samples from both healthy and clinical populations has consistently demonstrated that illness perceptions are structured around five key components. The first, *identity*, relates to the label attached to the disease and any symptoms that are associated with it. The second, termed *time-line*, concerns the individual's expectations about the duration of the disease and its characteristic course. For instance, whether the illness is deemed to be acute, chronic or cyclical. Thirdly, illness perceptions incorporate beliefs about the likely *cause(s)* of the disease and any changes in symptomatology. These attributions may be categorised as psychological (e.g. related to the patient's emotional state), risk factors (e.g. heredity), immunity (e.g. a germ or virus) or chance (e.g. an accident) (Moss-

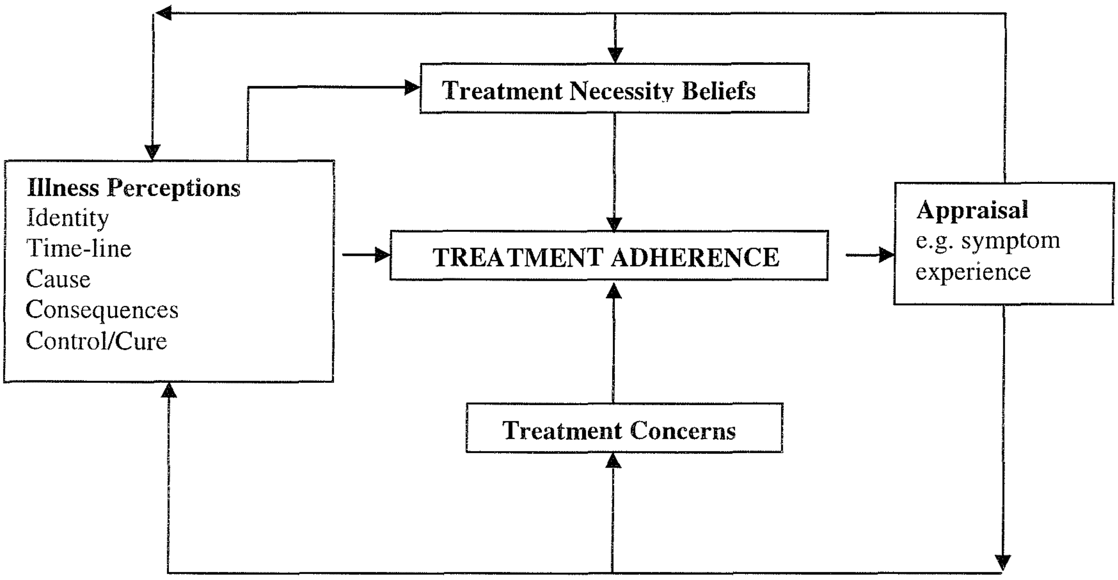
Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). The fourth dimension concerns the individual's beliefs about the possible *consequences* of their illness in terms of its impact on personal, social and financial domains. Finally, illness perceptions incorporate ideas about how amenable the disease is to *control* or *cure* in terms of the extent to which patients themselves, or the providers of their medical care, can exert an influence over the course of the illness.

Incorporating the Role of Treatment Beliefs

A recent development in the adherence literature has seen greater emphasis placed on individuals' beliefs about their treatment. This work, largely conducted by Horne and Weinman, has demonstrated that patients form coherent beliefs about prescribed treatments (*treatment beliefs*) which influence adherence (Horne, 1997, 1998; Horne & Weinman, 1995, 1999; Horne, Weinman & Hankins, 1999). In a series of studies involving over 500 patients from a range of different chronic illness groups, the researchers found that beliefs about treatment are structured around two key concepts: patients' perceptions of the *necessity* of their treatment for maintaining or improving health and their *concerns* about the potential adverse consequences of the treatment in terms of the side effects or disruption caused. These constructs are consistent across illness groups and relate to adherence in a logically consistent way. Thus, patients with strong concerns about treatment tend to report low adherence rates, whilst those with strong beliefs in the necessity of treatment tend to report high adherence rates (Horne, 1997; Horne & Weinman, 1999). Specifically, Horne (1997) suggests that adherence decisions may be influenced by a cost-benefit analysis in which patients' perceptions of the necessity of treatment are weighed against their concerns about its potential adverse consequences. Thus, patients who believe that the benefits of treatment outweigh the costs are more likely to adhere to the regimen, whilst those who perceive that the costs outweigh the benefits are less likely to follow treatment advice.

Based on this evidence, Horne (1997) proposes that the explanatory power of the SRM as a model of adherence may be enhanced by the inclusion of treatment beliefs. He argues that, in addition to having personal ideas about their illness, self-regulating patients will also have their own theories about prescribed treatments. Thus, adherence decisions will be influenced by patients' views about the necessity and possible negative consequences of treatment, as well as their ideas about the identity, time-line, cause, consequences and controllability of the illness. The proposed model is presented in Figure 1 below (Horne, 1997).

Figure 1. Augmented Self-Regulatory Model (Horne, 1997).



Thus, it is suggested that patients' beliefs about the necessity of a prescribed treatment are shaped by their illness perceptions. As such, the model proposes that illness perceptions exert both a direct and an indirect influence on adherence behaviour (Horne, 1997).

In summary, it has been suggested that the SRM provides a useful framework in which to conceptualise patients' motivation to follow or reject treatment advice. Leventhal's (1993) original model emphasised the role of illness perceptions and emotional representations in guiding adherence behaviour. The model has recently been expanded to include treatment beliefs. It is argued that, when deciding whether or not to follow treatment advice, individuals draw upon; i) their expectations and beliefs about the necessity and potential negative consequences of treatment, and ii) their cognitive and emotional representations of the illness. Consistent with the original model, Horne's (1997) augmented version highlights the importance of patients' concrete symptoms in shaping their beliefs about the illness and its treatment, and in guiding their appraisal of coping behaviour.

Measuring the Key Constructs of the SRM

The above discussion of the SRM demonstrates that the approach has a number of strengths as a framework for understanding decisions to follow or reject treatment advice. The model conceptualises adherence behaviour as a dynamic process, rather than the product of a static, one-off decision, and acknowledges that patients' beliefs, emotions, coping behaviours and appraisals are all influenced by individual characteristics and socio-cultural context (Horne, 1998). Whilst this complexity adds to the validity of the SRM as a framework for explaining adherence, the model is difficult to operationalise in its entirety in research. Furthermore, empirical testing of the model has been hampered by the lack of any standardised assessments designed to measure the key constructs. As such, a number of different methodologies have been used in the literature and it has been difficult to make systematic comparisons between studies.

More recently, evaluation of the SRM has been aided by the development of two theoretically-based measures specifically designed to assess the constructs outlined in the model. The first, the Illness Perception Questionnaire (IPQ), provides a validated, quantitative assessment of the five components of illness perceptions described in Leventhal's model (Weinman, Petrie, Moss-Morris & Horne, 1996). It is a flexible measure, purposely devised so that it may be adapted for use with a range of different illness groups. Thus, researchers are encouraged to add specific items that are particularly salient to the group being studied. The measure has recently been revised to incorporate two additional scales: *emotional representations* (patients' emotional responses to their illness) and *coherence* (the extent to which patients' believe their illness perceptions provide a coherent account of the illness) (Moss-Morris et al., 2002). This revised version, the IPQ-R, constitutes a more comprehensive measure of Leventhal's original model than the IPQ and has been shown to have superior psychometric properties.

The second theoretically-derived measure available in the literature concerns patients' beliefs about prescribed treatments. The Beliefs about Medicines Questionnaire - Specific (BMQ-Specific; Horne & Weinman, 1995; Horne et al., 1999) was devised to assess the two dimensions of treatment representations identified in Horne and Weinman's research (Horne, 1997; Horne & Weinman, 1995, 1999; Horne et al., 1999). The questionnaire was originally developed to measure perceived necessity and concerns about medication. However, it is sufficiently flexible to be adapted for use with a range of different treatment types and components of a regimen (Horne et al., 1999). Furthermore, the measure may be used to calculate the balance between patients' necessity and concerns scores, akin to the cost-benefit analyses of treatment outlined in the augmented SRM.

The SRM and Treatment Adherence

The recent development of two theoretically-derived questionnaires designed to measure patients' cognitive and emotional representations of their illness and beliefs about treatment has facilitated evaluation of the SRM as an explanatory framework for adherence. These measures, the IPQ-R and the BMQ, are psychometrically sound, flexible and have the advantage of being available in the public domain. However, as they have only been published for a short length of time, few studies have benefited from their use. Thus, the majority of research has independently evaluated the role of illness perceptions and treatment beliefs as determinants of adherence, and only a small body of literature has investigated the interactions between these two sets of beliefs or explored their combined influence on adherence. Furthermore, data concerning the relationships between emotional representations and adherence is particularly scarce. In the absence of a full validation of the SRM, therefore, the utility of the approach must be judged on the basis of studies that have assessed key constructs or tenets of the model. This research will be examined here.

In an early study pre-dating the development of the IPQ, Meyer et al. (1985) used structured interviews to elicit the illness perceptions of different groups of patients attending a hypertension clinic: 50 people who had been in *continuous* treatment for at least three months and 65 patients who were *newly* *diagnosed* and were attending the clinic for the first time. For both groups of patients, adherence to treatment was related to time-line and control beliefs. Specifically, continuous treatment patients who held a chronic view of their hypertension were less likely to report regular omissions of treatment than patients with either cyclical or acute views of their illness. Furthermore, those who perceived their symptoms to be amenable to treatment control had higher rates of adherence than those who considered their symptoms to be uncontrollable. For the newly diagnosed group, time-line and control beliefs elicited during the initial appointment predicted drop-out from treatment at six-month follow-up. Patients who perceived their problem to be a chronic condition were less likely to discontinue treatment than those who considered hypertension to be cyclical. In turn, those with a cyclical view of the problem had lower drop-out rates than those with an acute view of their condition. Furthermore, patients who interpreted their symptoms as indicating that treatment could not control their condition were more likely to drop out of treatment during the six-month period.

Control beliefs have also been shown to relate to treatment adherence in individuals with insulin-dependent diabetes mellitus (IDDM). In their sample of 64 patients aged between 15 and 25 years, Griva et al. (2000) found that perceived control, as measured by the IPQ, was positively related to self-reported adherence to four aspects of treatment: insulin administration; blood-glucose monitoring; diet; and exercise. Moreover, control beliefs accounted for the largest proportion of variance in total adherence (39%) when entered into a multiple linear regression analysis alongside demographic variables, self-efficacy beliefs and the other dimensions of illness perceptions. The data also revealed that self-reported adherence to dietary recommendations was related to illness identity. Patients who experienced fewer diabetes-related symptoms reported being most adherent with their dietary regimen. As the study was cross-sectional in nature, however, the direction of causality could not be determined.

In a prospective study carried out by Petrie et al. (1996), illness perceptions were found to predict adherence to medical recommendations to attend rehabilitation classes following a first myocardial infarction (MI). The results demonstrated that attendance at the rehabilitation programme was predicted by IPQ control beliefs and perceived consequences elicited during hospital convalescence. Patients who failed to attend had significantly lower expectations that their illness could be controlled or cured and considered the consequences of their illness to be significantly less serious than those who attended the course.

In a similar prospective study, a combined group of 137 patients who had either suffered an acute MI or undergone coronary artery bypass surgery completed the IPQ whilst recovering in hospital (Cooper et al., 1999). As with the previous study, the perceived control and consequences dimensions predicted future attendance at a cardiac rehabilitation programme. Patients with stronger beliefs in the controllability of their condition were more likely to attend as were individuals who perceived their condition to have the most serious impact on their lives. This study also demonstrated that patients who attributed their heart condition to their own lifestyle had higher rates of rehabilitation attendance. Thus, the authors concluded that ascribing the heart condition to something internal yet changeable increased patients' commitment to alter their behaviour.

With regard to treatment beliefs, reported non-adherence has been shown to relate to doubts about the necessity of prescribed treatment and concerns about potential adverse consequences in a range of different illness groups including;

asthma, renal dialysis, cardiac disease and cancer (Horne & Weinman, 1999). In particular, the study demonstrated that the interaction between patients' BMQ necessity and concerns scores (the necessity-concerns differential) was more strongly related to adherence than either construct alone. When entered into a step-wise multiple linear regression analysis alongside demographic and clinical variables, the necessity-concerns differential was found to be the strongest predictor of variance in reported adherence (Horne & Weinman, 1999). Thus, patients whose concerns about treatment outweighed their beliefs about its necessity were significantly less adherent than those whose perceptions of treatment necessity outweighed their concerns. These findings are consistent with the cost-benefit analysis of treatment beliefs proposed by Horne (1997).

A small number of studies have investigated the relationships between illness perceptions, treatment beliefs and self-reported adherence. In a sample of 99 patients with IDDM, Horne (1997) found that patients with strong illness identities, chronic time-line beliefs and high perceived consequences were more likely to adhere to treatment. Moreover, identity and time-line beliefs were related to perceptions of treatment necessity. Thus, individuals who experienced a high number of symptoms and those who considered their illness to be a chronic condition had strong beliefs in the necessity of treatment to maintain or improve health. In turn, perceived treatment necessity was positively related to adherence. Concerns about treatment, in contrast, were not related to any of the five dimensions of illness perceptions and were negatively correlated with adherence. Thus, the study provides some support for the interactions outlined in Horne's (1997) augmented SRM.

The relationships between illness perceptions, treatment beliefs and reported adherence have also been explored using structural equation modelling (Horne & Weinman, 2001). In a sample of 100 asthma patients aged between 16 and 84 years, self-reported non-adherence to preventative medication was found to correlate significantly with both illness perceptions and treatment beliefs. The strongest correlations were obtained for treatment beliefs. Specifically, reported non-adherence was associated with doubts about the necessity of treatment and concerns about its potential adverse effects. Of the five components of illness perceptions, only the perceived consequences dimension was directly related to adherence. Indeed, the model demonstrated that the influence of illness perceptions was largely mediated by patients' beliefs about the necessity of treatment. Thus, patients who viewed their asthma as a chronic condition with severe consequences were more likely to consider their preventative medication to be necessary. As predicted by the revised SRM, in contrast, patients' concerns about treatment were not related to illness perceptions. In a multiple linear regression analysis, IPQ consequences, BMQ necessity and BMQ concerns jointly predicted 26% of the variance in reported non-adherence.

The evidence reviewed provides preliminary support for the validity of the SRM as an explanatory framework for adherence. A key finding of the research is that illness perceptions, treatment beliefs and adherence appear to be related in a logical way. Patients' beliefs about the necessity of prescribed treatments are shaped by their theories about their illness and, along with concerns about treatment, these beliefs influence adherence. Furthermore, patients' representations of their illness and its treatment may not be consistent with medical views (Horne, 1997, 1998; Horne & Weinman, 1999). Thus, perceptions of hypertension as an acute condition and doubts about the necessity of preventative medication for asthma may both result in poor adherence, even though these beliefs contradict medical opinion (Horne & Weinman, 2001; Meyer et al., 1985). It has been noted, however, that relatively few studies have investigated the role of self-regulatory processes as determinants of adherence (Horne & Weinman, 2001) and that existing research has tended to report quite modest correlation coefficients (Horne, 1998). Thus, only tentative conclusions can be drawn from the findings.

Summary and Conclusions

CF is a chronic, progressive disease for which there is currently no cure. It is managed by a comprehensive, invasive treatment regimen which is largely prophylactic in nature and carried out in the patient's home. Despite the health advantages of good self-management, research has shown that non-adherence to certain aspects of CF treatment is high and peaks during adolescence (Abbott et al., 1994; Conway et al., 1996; Hamlett et al., 1996). In view of these findings, identifying the factors associated with adherence in adolescents constitutes a key area of CF research. There have been numerous attempts to account for adherence behaviour in CF patients (Abbott et al., 2001). However, the existing research has been flawed by a number of methodological and theoretical weaknesses. Adolescents have typically been grouped together with either adults or young children and, thus, little is known about the specific concomitants of adherence in this population. Furthermore, studies have tended to explore different factors, or sets of factors, in isolation, without reference to a shared, theoretical framework and without consistent operationalisation of variables. As such, it is difficult to draw firm conclusions from the findings.

CF and the SRM

In recent years, Leventhal's SRM (Leventhal, 1993; Leventhal et al., 1984, 1992) has been used to explain and predict treatment adherence in a variety of different illness groups (Cooper et al., 1999; Griva et al., 2000; Horne & Weinman, 2001; Meyer et al., 1985; Petrie et al., 1996). It is envisaged that the model may provide a useful framework in which to conceptualise adherence to treatment in CF patients. The SRM, which has recently been revised (Horne, 1997), proposes that adherence is influenced by three sets of variables: illness perceptions; emotional representations; and treatment beliefs. Although these constructs have not been systematically explored in individuals with CF, evidence suggests that they may be important determinants of adherence in these patients. For instance, it has been demonstrated that adherence to the CF treatment regimen is influenced by some of the factors incorporated in illness perceptions, such as locus of control beliefs (the *cure/control* dimension) and perceived disease severity (the *identity* and *consequences* dimensions) (Gudas et al., 1991; Myers & Myers, 1999; Ricker et al., 1998). Furthermore, in relation to treatment beliefs, research has shown that adherence may be affected by patients' perceptions of the *necessity* of treatment in terms of health status and *concerns* about its potential negative effects. For instance, studies have demonstrated that CPT may be missed if patients perceive that it makes no difference to their health or consider that it interferes with social activities (Abbott et al., 1994; Conway et al., 1996).

The SRM emphasises the importance of concrete symptoms in shaping patients' illness and treatment representations and in guiding their appraisal of coping behaviours (Leventhal, 1993). This tenet of the model may be particularly important in explaining adherence to treatment in CF patients. Many aspects of the

CF treatment regimen are prescribed prophylactically and, consequently, provide very little in the way of concrete symptomatic benefit. For CF patients, therefore, the association between adhering to treatment and perceived health status is quite tenuous. Moreover, with regard to CPT, treatment itself may be a source of unpleasant symptoms, such as coughing. According to the SRM, this lack of *coherence* between performing a treatment and perceived well-being is likely to reduce the motivation to adhere to the regimen.

Clinical Implications

Using the SRM as a framework for understanding adherence to treatment in CF patients has a number of potential implications for clinical practice. Research in other illness groups has demonstrated that adherence to treatment is influenced by patients' representations of their illness and their perceptions of prescribed treatment. Furthermore, it has been observed that these beliefs do not always correspond with medical views (Horne & Weinman, 2001; Meyer et al., 1985). As such, more detailed information about individuals' own theories about their illness and its treatment may enable health professionals to identify patients at risk of non-adherence (Scharloo & Kaptein, 1997). Furthermore, having identified the specific beliefs which are associated with poor adherence, clinicians may be able to develop appropriate, patient-centred interventions to enhance adherence.

There is growing empirical evidence that illness perceptions may be amenable to change. For instance, research has shown that cognitive-behavioural techniques may be used to modify the unhelpful, or catastrophic, illness perceptions associated with poor adjustment in a range of clinical populations, including CF (Fisher & Johnston, 1996; Hains, Davies, Behrens & Biller, 1997;

Hains, Davies, Behrens, Freeman & Biller, 2001; Kemp, Morley & Anderson, 1999; Leventhal et al., 1997). However, the possibility of using these techniques to alter the inaccurate illness perceptions or treatment beliefs associated with poor adherence has not yet been explored.

Future Research

It has been argued that exploring the illness perceptions and treatment beliefs held by CF patients might usefully account for differences in adherence both between individuals and between different aspects of the treatment regimen. Systematic research is required to test these hypotheses. Firstly, the relationships between adherence to different components of the CF treatment regimen, illness perceptions, emotional representations and treatment beliefs need to be investigated. To enable data to be compared between studies, the same, standardised measures should be used. Thus, illness perceptions, emotional representations and treatment beliefs should be assessed using the IPQ-R and BMQ as these measures were specifically designed to tap the constructs outlined in the SRM. Furthermore, the same measures of adherence should be used across studies. Finally, where possible, adherence should be assessed using more than one measure in order to verify the reliability of patients' reports (Horne, 2000).

If preliminary, cross-sectional studies demonstrate that illness perceptions, emotional representations and treatment beliefs are related to adherence, later research will need to use longitudinal designs to clarify the direction of causality. The SRM conceptualises decisions to follow or reject treatment advice as the product of dynamic interactions between patients' representations of their illness and treatment, their behaviour (e.g. following treatment advice) and subsequent appraisals of outcome (e.g. did the behaviour reduce symptoms?). Thus, longitudinal studies are required to assess changes in representations and/or adherence behaviour over time.

Finally, if research indicates that patients' illness perceptions and treatment beliefs are important determinants of adherence, the next challenge will be to demonstrate that interventions devised to change these representations impact positively on outcome (Weinman & Petrie, 1997). Thus, having identified the beliefs that are associated with poor adherence, it should be possible to devise interventions to modify these beliefs. The final test of the model will then be to demonstrate that these interventions successfully alter the targeted beliefs and improve adherence.

Conclusion

In conclusion, research has shown that adherence to the CF treatment regimen is influenced by a range of factors. To date, however, the literature has been flawed by the lack of a common, guiding, theoretical framework in which to conceptualise adherence behaviour. One model that has been used to understand adherence behaviour in other illness groups is Leventhal's SRM (Leventhal, 1993; Leventhal et al., 1984, 1992). This model postulates that treatment adherence is influenced by patients' theories about their illness and their emotional reactions to it. It has recently been extended to include patients' beliefs about their treatment (Horne, 1997). At present, few studies have investigated illness perceptions, emotional representations and treatment beliefs in individuals with CF, and no work has explicitly applied the SRM to this group of patients. It is argued that research investigating patients' beliefs about CF and its treatment may enable clinicians to identify those at risk of non-adherence and, thereby, develop patient-centred interventions to enhance adherence.

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EMPIRICAL PAPER*

Running head: TREATMENT ADHERENCE IN CYSTIC FIBROSIS

Adherence to Treatment in Adolescents with Cystic Fibrosis: The Role of Illness Perceptions and Treatment Beliefs

Katharine Sarah Hawkins
University of Southampton

Correspondence regarding this article should be addressed to Kate Hawkins, Doctoral Programme in Clinical Psychology, Shackleton Building (44), University of Southampton, Highfield, Southampton. SO17 1BJ.

*Prepared as if for submission to the British Journal of Health Psychology (see Appendix 1 for Notes for Contributors)

Adherence to treatment in adolescents with cystic fibrosis: the role of illness perceptions and treatment beliefs

Abstract

Objectives. This study was conducted to explore the relationships between illness perceptions, emotional representations, treatment beliefs and reported adherence in adolescents with cystic fibrosis (CF).

Design and Method. Using a cross-sectional design, 38 adolescents, aged 11-17 years, completed questionnaires assessing their perceptions of CF, beliefs about prescribed treatments and reported adherence to chest physiotherapy, enzyme supplements and antibiotics.

Results. Reported non-adherence to chest physiotherapy was associated with having stronger concerns about the treatment relative to beliefs about its benefits, having strong doubts about the necessity of chest physiotherapy and viewing CF as a short-term problem. Reported non-adherence to antibiotics was related to doubts about the necessity of antibiotics, believing that CF is not amenable to treatment control and perceiving CF as an acute condition. Reported non-adherence to enzyme supplements was not associated with illness perceptions or treatment beliefs.

Conclusions. The findings provide preliminary support for the utility of the self-regulatory model in explaining adherence to treatment in adolescents with CF. The clinical implications of the findings are discussed.

Introduction

Cystic fibrosis (CF) is the most common, fatal, hereditary disease of childhood (Orenstein & Wachnowsky, 1985). It occurs in an estimated 1 in 2000 live Caucasian births and 1 in 17 000 live Afro-Caribbean births (Matthews & Drotar, 1984). The disease affects multiple organ systems, primarily the lungs and pancreas, and ultimately results in premature death, usually from progressive respiratory failure (Miller, Jelalian & Stark, 1999). Recent advances in the medical management of the disease have dramatically improved the survival statistics (Elborn, Shale & Britton, 1991; Fitzsimmons, 1993). However, there is currently no cure for CF and, in order to maintain optimal health, patients are required to follow a lifelong, multi-component treatment regimen (Drotar, 1995; Orenstein & Wachnowsky, 1985). The three main aspects of treatment are: chest physiotherapy (CPT), carried out up to four times daily for 20-30 minutes each session; pancreatic enzyme supplements (ES), taken with all meals and snacks; and routine courses of oral or nebulised antibiotics. These treatments differ both in terms of their impact on symptoms and the time and effort they require (Miller et al., 1999). Whilst CPT and antibiotics are typically prescribed prophylactically and, therefore, provide very little in the way of symptomatic benefit, taking ES with food prevents stomach pains, bloating and bulky stools (Koocher, Gudas & McGrath, 1992). Moreover, CPT, which is the most time-consuming and tiring aspect of treatment, may itself lead to unpleasant symptoms, such as coughing.

Research has shown that adherence to the CF treatment regimen is associated with improved pulmonary status and increased longevity (Desmond, Schwenk, Thomas, Beaudry & Coates, 1983; Elborn & Bell, 1996; Patterson, Budd, Goetz & Warwick, 1993; Thomas, Cook & Brooks, 1995). However, non-adherence to certain aspects of treatment, especially CPT, is a significant problem, particularly during adolescence when the responsibility for performing treatment transfers to the patient (Abbott, Dodd, Bilton & Webb, 1994; Conway, Pond, Hamnett & Watson, 1996; Hamlett, Murphy, Hayes & Doershuk, 1996). Thus, many adolescents with CF are placing themselves at risk of accelerated disease progression and reduced life expectancy.

Identifying the factors associated with poor adherence in adolescents is, therefore, crucial to CF care. However, few studies have specifically investigated adherence to treatment in adolescents with CF. Existing work has tended to group adolescents together with either young children or adults and, consequently, little is known about the specific determinants of adherence in this group. Research carried out in adult and paediatric populations has identified a number of possible influences. These include: knowledge about the disease (Ievers, Brown, Drotar, Caplan, Pishevar & Lambert, 1999); locus of control beliefs (Myers & Myers, 1999; Ricker, Delamater & Hsu, 1998); self-efficacy (Czajkowski & Koocher, 1987; Ricker et al., 1998); perceived illness severity (Gudas, Koocher & Wypij, 1991); optimism (Czajkowski & Koocher, 1987; Gudas et al., 1991); coping style (Abbott, Dodd, Gee &Webb, 2001); family factors (Geiss, Hobbs, Hannersley-Maercklein, Kramer & Henley, 1992; Ricker et al., 1998); support (Abbott et al., 1994); and characteristics of the treatment regimen (Abbott et al., 1994; Conway et al., 1996). Unfortunately, this research has largely been conducted outside a theoretical framework and without consistent means of assessing key variables, such as adherence. As such, it is difficult to make cross-study comparisons and draw firm conclusions about the relative importance of different factors.

One theory that has been used to explain and predict adherence behaviour in other illness groups is Leventhal's Self-Regulatory Model (SRM; Leventhal, 1993; Leventhal, Diefenbach & Leventhal, 1992; Leventhal, Zimmerman & Gutmann, 1984). This model posits that patients' decisions to adhere to or reject treatment advice are governed by their individual cognitive and emotional interpretations of the illness (*illness perceptions* and *emotional representations*), and their personal theories about treatment (*treatment beliefs*). Continuation of the behaviour (e.g. adhering to treatment) depends upon an appraisal of whether or not it has worked (e.g. have my symptoms been reduced?). If a behaviour is deemed to be ineffective, patients may alter their representations of the illness and its treatment and/or adopt an alternative strategy (e.g. not adhering to treatment). Thus, according to the model, non-adherence may be the intentional result of a lack of *coherence* between patients' individual beliefs about the illness and its treatment, their concrete experience of symptoms and the recommendation to perform treatment.

Illness perceptions and treatment beliefs are ascribed a key role in guiding adherence behaviour and the question of how these representations are structured is central to the SRM (Horne & Weinman, 2001). Research has consistently shown that illness perceptions lie across five, broad dimensions: beliefs about the nature of the illness (*identity*); expectations about its likely course (*time-line*); attributions about aetiology (*cause*); perceptions of the impact of the illness on patients' lives (*consequences*); and expectations about how amenable it is to control or cure (*cure/control*) (Leventhal, Meyer & Nerenz, 1980; Scharloo & Kaptein, 1997). Treatment beliefs are structured around two components: perceptions of the *necessity* of a prescribed treatment for maintaining or improving health and *concerns* about its potential adverse effects (Horne & Weinman, 1999). The SRM proposes that illness perceptions and treatment beliefs are related in a logical way, such that patients' theories about their illness influence their beliefs about the *necessity* of a prescribed treatment, but not their *concerns* about its potential negative consequences (Horne, 1997).

There is growing empirical support for the utility of the SRM as an explanatory framework for adherence. To date, however, the majority of studies have evaluated the roles of illness perceptions and treatment beliefs separately and research investigating emotional representations is scant. Nonetheless, illness perceptions have been found to relate to treatment adherence in patients with hypertension (Meyer, Leventhal & Gutmann, 1985); diabetes (Griva, Myers & Newman, 2000); and asthma (Horne & Weinman, 2001); and to predict adherence to recommendations to attend rehabilitation classes in patients with cardiac disease (Cooper, Lloyd, Weinman & Jackson, 1999; Petrie, Weinman, Sharpe & Buckley, 1996). Specifically, good adherence has been shown to correlate with perceptions of a chronic *time-line*, high perceived *consequences* and expectations that the illness is amenable to *control*. With regard to treatment beliefs, it has been demonstrated that poor adherence is related to doubts about the *necessity* of treatment to maintain or improve health and *concerns* about its potential adverse effects (Horne & Weinman, 1999). In particular, evidence suggests that adherence decisions are influenced by a cost-benefit analysis in which the perceived advantages of a prescribed treatment (*necessity* beliefs) are weighed against the perceived barriers (*concerns*) (Horne & Weinman, 1999, 2001). Using hierarchical multiple linear regression, one study has examined the combined roles of illness perceptions and treatment beliefs in explaining reported adherence to treatment in asthma (Horne & Weinman, 2001). Illness perceptions and treatment beliefs were found to add significantly to the amount of variance explained by clinical and demographic variables. Furthermore, using structural equation modelling, the study demonstrated that treatment beliefs were the strongest predictors of reported adherence, and that the contribution of illness perceptions was largely moderated by treatment *necessity* beliefs.

The SRM has not previously been applied to individuals with CF. Thus, the purpose of this research was to explore the illness perceptions, emotional representations and treatment beliefs held by adolescents with CF, and examine the associations between these variables and reported adherence to the three principal forms of treatment: CPT, ES and antibiotics. It was envisaged that more specific information about how adolescents view their CF and its treatment would facilitate the development of appropriate interventions to enhance adherence. Furthermore, the study would begin the empirical testing of the SRM as an explanatory framework for adherence in adolescents with CF.

As CPT, ES and antibiotics place different demands on patients in terms of the time and effort required and are associated with varying levels of symptomatic benefit, it was deemed important to explore how the relationships between illness perceptions, emotional representations, treatment beliefs and adherence might differ for each aspect of treatment. From the current literature, however, it was not possible to make specific predictions about the different treatments and, thus, the hypotheses were general.

Based on studies in other illness populations, it was anticipated that adherence to CPT, ES and antibiotics would be associated with perceptions of the *necessity* of the treatment to maintain health and *concerns* about its potential adverse effects. Regarding illness perceptions, it was expected that adherence to each component of treatment would be associated with illness *identity* (e.g. the number of symptoms attributed to CF), *time-line* beliefs, *causal attributions*, perceived *consequences* and beliefs about the extent to which CF is amenable to *control.* Finally, as predicted by the SRM, it was anticipated that adherence to the three treatments would be related to *emotional representations.*

Method

Design

A cross-sectional design was used to investigate the relationships between illness perceptions, emotional representations, treatment beliefs and reported adherence in adolescents with CF.

Participants

Participants were recruited from the paediatric outpatient departments of five hospitals in the South of England: the Royal Alexandra Hospital for Sick Children, Hove; St. Mary's Hospital, Portsmouth; the Royal Hampshire County Hospital, Winchester; Southampton General Hospital, Southampton; and Poole General Hospital, Poole. All adolescents with CF aged between 11 and 17 years inclusive who were known to the services were considered for participation. Potential participants were excluded if they were receiving in-patient care during the period of data collection as this has been shown to confound adherence rates (Abbott & Gee, 1998).

Fifty-two adolescents were approached to participate in the study. One was excluded as she was receiving in-patient care during the period of data collection and twelve declined to take part. Of the remaining 39 adolescents who gave their consent, one died before any data had been collected. Thus, 38 participants completed the study. This figure represents 73% of the people approached (see flow diagram in Appendix 2).

The sample consisted of 20 females (Age: M = 13.1 years, SD = 2.3) and 18 males (Age: M = 14.1 years, SD = 1.7). This gender split is comparable to the CF population as a whole (Cloutier, 1997). The mean age overall was 13.6 years (SD = 2.1). Differences between the participants (N = 38) and those who refused consent or were unable to take part (N = 14) were explored using chi-square analysis for gender and an independent sample t test for age. No statistically significant differences were found between the two groups (Gender: $\chi^2(1) = .39$; Age: $t(50) = 0.36$).

Measures

Participants completed the following four measures. (These are given in Appendix 3. Details of the development and psychometric properties of the scales are given in Appendix 4).

The Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002).

The IPQ-R is an extended version of the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996) which was designed to provide a quantitative assessment of the five components of illness perceptions outlined in the SRM (Leventhal et al., 1984; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997). In addition to demonstrating improved internal consistency, the IPQ-R incorporates two aspects of the SRM that were overlooked in the original IPQ. These are: *emotional representations* (respondents' emotional responses to their illness), and *coherence* (the extent to which participants believe their illness representations provide a coherent model of their illness). Furthermore, two of the original subscales were modified significantly in the development of the IPQ-R. The *time-line* dimension was divided into two subscales assessing: i) beliefs about illness *chronicity*, and ii) beliefs about the *cyclical* nature of illness. The *control/cure* dimension was also divided into two subscales. A principal components analysis revealed that items from the scale loaded onto two distinct factors: *personal control* (self-efficacy beliefs) and *treatment control* (outcome expectancies) (Moss-Morris et al., 2002). The measure has been used with a range of illness groups and demonstrates good psychometric properties.

The IPQ-R is divided into three sections. The *identity* scale is presented first and consists of 14 core symptoms: pain, nausea, breathlessness, weight change, fatigue, stiff joints, sore eyes, headaches, upset stomach, sleep difficulties, dizziness, loss of strength, sore throat, and wheeziness. Respondents are asked, firstly, to identify which symptoms they experience and, secondly, to rate which of these they believe are related to their illness. The total number of items that respondents consider to be associated with their illness forms the identity score. In addition to the 14 core symptoms used in the scale, researchers are encouraged to include items that are specific to the particular illness group being studied (Moss-Morris et al., 2002; Weinman et al., 1996). Thus, the following five, CF-specific symptoms were added after discussions with two paediatricians and a specialist nurse: coughing, blocked nose, bowel problems, loss of appetite, and production of sputum. A third paediatrician approved the list.

The second section comprises 38 statements assessing the *time-line*, *consequences*, *cure/control*, *emotional representations* and *coherence* dimensions of the IPQ-R. Items from these dimensions are presented in a mixed order to reduce the influence of ordering effects and rated on a five-point scale from strongly disagree (1) to strongly agree (5). Some items are reverse-scored. Scores above the mid-point of 3 indicate agreement with the concepts represented in the scale. To facilitate comparison between the scales, mean scores are computed by dividing the total scale score by the number of items in the scale, giving a range of 1 to 5 for each.

The *cause* dimension is presented in the final section and consists of 18 attributional items that respondents are asked to rate according to how much they consider each one to be a cause for their illness. Ratings are made using the same five-point scale described above. In this study, responses were re-coded according to whether or not each participant endorsed an item as a cause of their CF. Thus, strongly agree and agree were coded 1, and uncertain, disagree and strongly disagree were coded 0. It was, therefore, possible to determine which causal beliefs were endorsed by each participant and how many attributions each individual perceived (Horne & Weinman, 2001).

The Beliefs about Medicines Questionnaire-Specific (BMQ-Specific; Horne & Weinman, 1995; Horne, Weinman & Hankins, 1999).

The BMQ-Specific was developed to provide a flexible, quantitative assessment of patients' beliefs about prescribed treatment. The measure comprises two scales assessing respondents' beliefs about the *necessity* of a specific treatment and their *concerns* about the potential adverse consequences of using it. Each scale consists of five items which assess beliefs that have been found to be common across a range of chronic illness groups (Horne & Weinman, 1999). Furthermore, researchers are encouraged to add or adapt items in accordance with the specific treatment being studied (Horne et al., 1999). In this research, the measure was adapted to assess beliefs about CPT, ES and antibiotics. In the version adapted for CPT, two items from the *concerns* scale were changed: 'I sometimes worry about the long-term effects of my **treatment*' and 'I sometimes worry about becoming too dependent on my **treatment*' were replaced with 'My CPT is a hassle' and 'My CPT is difficult because I need help from others to do it properly'. In the ES and antibiotics versions, one item was added to the *concerns* scale: 'My ES/antibiotics give me unpleasant side effects'. These alterations were based on the clinical experiences and medical knowledge of one of the paediatric teams involved in the study and were subsequently approved by R. Horne (principal author of the BMQ). The questionnaire was renamed the Beliefs about Treatment Questionnaire (BTQ) for the purposes of this research.

As with the IPQ-R, items from the two subscales are presented in a mixed order and rated on a five-point scale from strongly disagree (1) to strongly agree (5). Scores for the individual items in each scale are summed and divided by the number of items in the scale to give a mean score. Again, the scales may be dichotomised at the mid-point as a means of categorising respondents according to the strength of their views about treatment. Furthermore, the difference between respondents' *necessity* and *concerns* scores may be calculated to provide individual cost-benefit analyses of treatment. A positive *necessity-concerns* differential indicates that the respondent perceives the benefits of treatment to outweigh the costs, whilst a negative differential demonstrates that the perceived costs outweigh the benefits.

The Medication Adherence Report Scale (MARS; Horne & Hankins, in press). Self-reported adherence to CPT, ES and antibiotics was assessed using the MARS. This measure comprises six statements about non-adherent behaviour that respondents are asked to rate according to how often they engage in each. Ratings are made on a five-point scale from never (1) to always (5). Scores for each item are summed and divided by six in order to obtain a mean score, with higher scores indicating poorer levels of reported adherence.

In accordance with the literature, the MARS attempts to diminish the social pressure on individuals to over-estimate adherence by normalising the process of adapting treatment to fit their lifestyles (Rand & Wise, 1994). Thus, the questionnaire is preceded by a statement assuring respondents that many people follow treatment in a way that suits them and that this may differ from the recommendations given by health professionals. Furthermore, the focus on *non-adherence* challenges participants to recall acts that obstruct their self-care, in contrast to focusing on *adherence* which emphasises compliance with practitioner instruction. This technique has been used in previous work and evidence suggests that it may further reduce patients' bias towards over-estimating adherence (Kravitz, Hays, Sherbourne, DiMatteo, Rogers, Ordway & Greenfield, 1993; Rand & Wise, 1994).

The Cystic Fibrosis Treatment Questionnaire (CFTQ).

The CFTQ was used in this study as an adjunct to the MARS. The literature recommends that more than one measure of adherence is used to assess the level of agreement between responses (Horne, 2000; Miller et al., 1999). The CFTQ was adapted from the Living with Cystic Fibrosis Questionnaire (LCF; Horn, Myers & Abbott, in preparation) which measures health perceptions and adherence behaviour in CF patients. The LCF was deemed too lengthy for the purposes of this study and, thus, only the questions assessing adherence to CPT, ES and antibiotics were included in the CFTQ.

Patients' are asked to rate their level of adherence to CPT, ES and antibiotics according to: i) how often they carry out the treatment as prescribed; ii) whether they see the treatment as part of their daily routine; and iii) how often they miss the treatment. Items relating to each aspect of treatment are summed to provide separate adherence scores for each component. As with the MARS, the CFTQ attempts to reduce patients' bias to over-report adherence by normalising the process of modifying treatment to suit their lifestyles. In addition, patients are assured that their responses are both anonymous and confidential (Rand & Wise, 1994).

Procedure

Approval for the study was granted by the relevant Local Research Ethics Committees and the Department of Psychology at Southampton University (see Appendix 5 for correspondence). In order to generate interest in the study, a presentation was made at the CF Society's Annual Branch meeting which was attended by the paediatric teams from the Royal Hampshire County Hospital and Southampton General Hospital.

Slightly different research protocols were agreed with the different paediatric departments involved in the study. At four of the hospitals (the Royal Alexandra Hospital for Sick Children, the Royal Hampshire County Hospital, St. Mary's Hospital and Southampton General Hospital), the author was invited to attend the outpatient clinics. Potential participants and their families were identified by a member of the paediatric team, usually the consultant paediatrician or specialist nurse, and given an information letter inviting them to participate in the study (see Appendix 6). Those who agreed to meet the author were encouraged to ask questions and discuss the study before completing a written consent form (see Appendix 7). Once written consent had been obtained from the participant (and from his or her parents, for those aged below 16), an individual appointment to administer the measures was arranged. In the majority of cases, this occurred in a quiet room at the clinic. If this was not convenient, however, the participant was visited at home.

At Poole General Hospital, the consultant paediatrician wrote a brief covering letter to potential participants (see Appendix 8), and sent it along with a stamped addressed envelope, consent form and information letter inviting them to take part. Those who gave their written consent were then contacted, and a suitable time to meet them at home was arranged.

In all cases, participants were assured that the study was independent of the hospital and that their responses were confidential and anonymous. It was hoped that this would encourage the adolescents to give their own views rather than those they considered to be socially desirable (Abraham & Hampson, 1996; Rand &

Wise, 1994). The measures were administered in the following order: CFTQ, IPQ-R, BTQ, MARS. The researcher sat with participants whilst they completed the questionnaires in order to answer any queries and reduce the risk of missing data.

Data Analysis

The data were analysed using SPSS 10.1 for Windows (2001). The nature of participants' illness perceptions, emotional representations and treatment beliefs was examined by exploring the distribution of scores on the IPQ-R and BTQ subscales. The internal consistency of each subscale was assessed using Cronbach's alpha. Kolmogorov-Smirnov tests for normality revealed that the pattern of scores for four questionnaire subscales deviated significantly from the normal distribution, namely IPQ-R *time-line chronicity*, BTQ *chest physiotherapy necessity*, MARS *antibiotics* adherence and CFTQ *antibiotics* adherence. These data were transformed using log transformations for BTQ *chest physiotherapy necessity* and MARS *antibiotics* and reflect and log transformations for IPQ-R *time-line chronicity* and CFTQ *antibiotics*. Parametric statistics were used for the subsequent analyses as these have greater statistical power than non-parametric statistics (Siegel & Castellan, 1998). The relationships between respondents' scores on the two measures of self-reported adherence were examined using Pearson Product Moment correlations. Similar correlations were used to explore the relationships between illness perceptions, emotional representations, treatment beliefs, age and reported adherence. Due to the number of comparisons carried out (11 for each aspect of treatment), there was a risk of Type I errors (Grove & Andreasen, 1982). The Bonferonni correction was not used, however, as the analyses were exploratory in nature and adopting a more conservative alpha level would have increased the risk of Type II errors (Altman, 1991; Howell, 1997). Moreover, as the sample size was small, the risk of failing to detect statistically significant correlations was already deemed to be high. Differences in reported adherence between patients who did and did not endorse specific *causes* for their CF were examined using independent sample t tests. Independent sample t tests were also used to investigate the relationships between gender and adherence. Finally, hierarchical multiple linear regression analyses were performed to identify the variables that best accounted for reported adherence. It has been argued that a minimum sample size of 50 participants is required for multiple linear regression analyses (Tabachnick & Fidell, 1996). However, as the number of independent variables was small and the data were normally distributed (following transformations for some variables), it was deemed appropriate to use the technique with this sample. Nonetheless, the results should be interpreted with caution. In keeping with the exploratory nature of the study, two-tailed tests were used throughout the analyses (Howell, 1997). A significance level of .05 was employed.

Results

Descriptive Statistics

The descriptive statistics and Cronbach alpha values for the IPQ-R, BTQ, MARS and CFTQ subscales are given in Table 1. With the exception of the IPQ-R *time-line cyclical* subscale, which was excluded from further analyses (α = .18), the internal consistency of each variable was considered to be within acceptable limits. Only three of the remaining subscales had alpha values below .65, namely BTQ *chest physiotherapy concerns* (α = .55), BTQ *antibiotics concerns* (α = .55) and

MARS *enzyme supplements* adherence ($\alpha = .51$). As the internal consistency of these variables could not be improved by the removal of any individual items, the scales were used in their entirety in the analyses.

Insert Table 1 about here

Illness Perceptions

Exploration of the IPQ-R data revealed that, in terms of illness *identity*, there was substantial individual variation in the number and type of symptoms attributed to CF. The number of symptoms ascribed to CF ranged from 1 to 13, with a mean of 5.2 (see Table 1). The most frequently reported symptoms were: coughing (endorsed by 61% of the sample); breathlessness (58%); production of sputum (53%); and wheeziness (50%).

The mean score for *time-line chronicity* (also given in Table 1) indicates that the sample, as a whole, perceived CF to be a chronic condition. There was little individual variation on this dimension, with 95% of participants scoring above the scale midpoint. Ratings for the *time-line cyclical* subscale suggest that, on the whole, respondents perceived their symptoms to come and go in cycles (58% of the sample scored above 3 on this dimension). However, given the poor internal reliability of this scale, the results should be interpreted cautiously. Examination of the distribution of scores for individual items on the scale revealed that there were considerable differences between items. Whilst 68% of the sample endorsed the statements; 'My symptoms come and go in cycles' and 'I go through cycles in which my CF gets better or worse', only 21% of participants agreed that

'The symptoms of my illness change a great deal from day to day'. Thus, patients may have perceived cycles of their illness to last longer than one day.

The descriptive statistics for the *consequences* subscale suggest that the participants had diverse views about the impact of their CF, with just over half scoring above the mid-point on this dimension. There were considerable differences between the scores for individual items in the scale, however. Whilst, 68% of respondents endorsed the view that 'My CF is a serious condition' and 53% agreed that 'My CF has major consequences on my life', only 13% and 18% of patients, respectively, endorsed the statements 'My CF strongly affects the way others see me' and 'My CF causes difficulties for those who are close to me'.

Respondents' ratings of control over their CF suggest that the sample had both a high sense of self-efficacy and strong beliefs in the effectiveness of their treatment. Ninety-seven per cent of participants perceived their CF to be relatively amenable to *personal control*, and 84% considered their *treatment* to be effective in controlling the condition.

The descriptive statistics for the *emotional representations* dimension indicate that, as a whole, the sample did not consider their CF to have serious consequences in terms of their affect. Only 29% of participants scored above the midpoint for this dimension. Examination of the individual items on the scale revealed that anger and worry were the most salient emotional responses to CF for these individuals, endorsed by 34% and 32% respectively. Anxiety and fear, on the other hand, were experienced by only 13% and 16% of respondents respectively.

There was little individual variation between scores on the *coherence* dimension, with 95% of participants considering their illness representations to provide a good account of their CF.

Table 1 indicates that the mean number of *causes* for CF endorsed by the sample was low. Examination of the individual items on the scale revealed that there was little variation in the attributions made. Ninety-five per cent of the [illegible]

sample was low. Examination of the individual items on the scale revealed that there was little variation in the attributions made. Ninety-five per cent of the [illegible]

were endorsed by a reasonable proportion of participants.

Treatment Beliefs

were endorsed by a reasonable proportion of participants.

The descriptive data for participants' beliefs about treatment are also given in Table 1. Whilst most respondents (76%) agreed that CPT was *necessary* for the maintenance of their physical health, 24% of the sample did not hold this view. In contrast, only 18% of participants had strong *concerns* about their CPT. However

Table 1. Whilst most respondents (76%) agreed that CPT was *necessary* for the maintenance of their physical health, 24% of the sample did not hold this view. In contrast, only 18% of participants had strong *concerns* about their CPT. However

sample. Seventy-one per cent of participants agreed that 'My CPT is a hassle' and 42% endorsed the view that 'My CPT disrupts my life'. Only 3 participants (8%) perceived that the costs of CPT outweighed the benefits.

There was little individual variation between respondents' beliefs about the use of ES. Ninety-two per cent considered ES to be *necessary*, and no-one had strong *concerns* about taking them. Inspection of the individual items in the *concerns* scale revealed that 'My ES disrupt my life' (endorsed by 16% of participants) was the only worry reported by more than 10% of the sample. No participants considered the costs of ES to outweigh the benefits.

A similar picture emerged for antibiotics. Eighty-nine per cent of the sample agreed that they were *necessary,* and no-one reported strong *concerns* about their use. However, examination of the individual items in the *concerns* scale revealed that three worries were particularly salient to this sample. Twenty-four per cent of participants agreed that 'My antibiotics disrupt my life' and 21% of the sample endorsed the statements 'I sometimes worry about the long-term effects of taking antibiotics' and 'My antibiotics give me unpleasant side effects'. In total, only one participant (3%) perceived that the costs of antibiotics outweighed the benefits.

Reported Adherence

There was considerable variation in respondents' self-reported adherence to CPT, as measured by the MARS (see Table 1). Table 2 shows the percentage of participants who reported engaging in each aspect of non-adherent behaviour tapped by the scale. Sixty-six per cent of the sample reported that they sometimes, often or always altered the way they did their CPT in comparison to how they were instructed to do it. Just less than half of the respondents also reported sometimes, often or always doing less than instructed (47%), avoiding it if they could (45%), missing out a session (45%) and forgetting it (45%).

Scores for the MARS-ES and MARS-antibiotics were both positively skewed, indicating low levels of reported non-adherence (see Table 1). With regard to ES, forgetting was the most frequently endorsed behaviour, reported by 39% of the sample (see Table 2). Altering the dose and deciding to miss out a dose were each endorsed by 13% of participants. In terms of antibiotic use, 26% of the sample reported forgetting to take their medication, and 21% and 13% respectively reported deciding to miss out a dose and stopping taking them for a while.

Insert Table 2 about here

Agreement Between Measures of Reported Adherence

The relationships between respondents' scores on the two measures of adherence were examined using Pearson correlations. Significant negative correlations were found for all three aspects of treatment assessed (CPT: $r = -.91$, $p < .001$; ES: $r = -.89$, $p < .001$; Antibiotics: $r = -.87$, $p < .001$), indicating that greater reported non-adherence on the MARS was associated with poorer reported adherence on the CFTQ. The level of agreement between the scales provides some support for the reliability of participants' responses.

Correlates of Reported Adherence

In order to examine the relationships between self-reported adherence, illness perceptions, emotional representations, treatment beliefs and age, two-tailed Pearson Product Moment correlations were carried out. The correlation coefficients are given in Table 3. Reported adherence to CPT was found to correlate significantly with the *necessity-concerns differential*, such that patients who perceived greater costs in comparison to benefits were more likely to report engaging in non-adherent behaviour; with *necessity* beliefs, such that stronger ratings of CPT necessity were related to lower reported non-adherence; with *age*, such that older respondents reported greater levels of non-adherence; and with *time-line chronicity*, such that perceptions of a longer time-line were associated with lower reported non-adherence. The correlation co-efficient for the *necessity-concerns differential* was particularly high (r = -.70), indicating that this variable accounted for 49% of the variance in CPT adherence.

Reported adherence to ES was not significantly correlated with any of the IPQ-R or BTQ subscales, or with age. Significant correlations were found between reported adherence to antibiotics and *treatment control*, such that stronger perceptions of the ability of treatment to control CF were related to lower reported non-adherence; with beliefs about the *necessity* of antibiotics, such that greater necessity was associated with lower reported non-adherence; with *time-line chronicity*, such that perceptions of greater chronicity were related to lower levels of reported non-adherence; and with *age*, such that older participants reported more non-adherent behaviours. Perceptions of *treatment control* were the strongest correlates of reported adherence to antibiotics (r = -.53), accounting for 28% of the variance.

Insert Table 3 about here

The Relationships Between Causal Attributions and Reported Adherence

In order to assess the relationships between adherence and the causal attributions of *heredity* and *chance or bad luck*, independent sample t tests were conducted.

There were no significant differences in reported adherence to CPT, ES and antibiotics according to whether or not patients' endorsed either attribution as a cause for their CF (*CPT*: Heredity: $t(36) = -1.06$; Chance: $t(36) = -1.55$. *ES*: Heredity: $t(36) = 0.83$; Chance: $t(36) = -1.64$. *Antibiotics*: Heredity: $t(36) = -1.43$; Chance: $t(36) = -1.62$).

The Relationships Between Gender and Reported Adherence

Independent sample t tests were carried out to investigate the relationships between gender and adherence. There were no significant differences between the sexes in terms of reported non-adherence to CPT ($t(36) = 0.34$), ES ($t(36) = -0.69$) or antibiotics ($t(36) = -0.75$).

Exploratory Multiple Linear Regression Analyses

To identify the variables that best accounted for adherence to CPT and antibiotics, hierarchical multiple linear regression analyses were conducted. To control for the influence of participants' age, this variable was entered in Block 1 under forced entry criteria. The forward method was performed on Block 2 where treatment beliefs and illness perceptions were entered in order to avoid the problem of multicollinearity among variables (Tabachnick & Fidell, 1996). Only the variables that were found to correlate with reported adherence at a criterion level of $p < .05$ were included in the analysis for Block 2.

The regression model for CPT is given in Table 4. Reported non-adherence to CPT as measured by the MARS was entered as the dependent variable with the independent variables entered in the following steps: i) age; ii) BTQ *necessity-concerns differential*; BTQ *necessity*; and IPQ-R *time-line chronicity*. As can be seen from the model, age accounted for 16% of the variance in reported adherence to CPT. Of the psychological variables, only the BTQ *necessity-concerns differential* emerged as a significant predictor, contributing a further 42% to the variance in CPT adherence. In total, the model explained 58% of the variance.

Insert Table 4 about here

The regression model for antibiotics is given in Table 5. Reported non-adherence to antibiotics as measured by the MARS was entered as the dependent variable. The following independent variables were entered: i) age; ii) IPQ-R *treatment control;* BTQ *necessity*; and IPQ-R *time-line chronicity*. Participant age accounted for 13% of the variance in reported adherence to antibiotics. IPQ-R *treatment control* accounted for an additional 25% of the variance, increasing the total variance explained to 38%. IPQ-R *time-line chronicity* entered the equation last, increasing the total variance in adherence behaviour explained to 51%. BTQ *necessity* did not add significantly to the amount of variance explained by the model.

Insert Table 5 about here

Discussion

The principal aims of this study were, firstly, to explore the illness perceptions, emotional representations and treatment beliefs held by adolescents with CF and, secondly, to investigate the role of these variables in explaining reported adherence to CPT, ES and antibiotics. From the descriptive data, it was encouraging to note that, whilst the majority of patients viewed their CF as a *chronic* condition, a similar proportion felt that the illness was amenable to *control* in terms of both *personal* and *treatment control.* Thus, although patients seemed aware that there is no cure for CF, they had strong perceptions of their own self-efficacy and high expectations that the condition could be managed by their treatment. Less than a third of participants scored above the mid-point on the *emotional representations* subscale, indicating that, on the whole, they were not experiencing emotional distress as a result of their CF. Moreover, the respondents scored consistently highly on the *coherence* subscale, suggesting that they considered their illness perceptions to provide a coherent account of their condition. Finally, nearly all the participants were aware that CF is *hereditary.* Nearly half the respondents also considered *chance or bad luck* to be a cause for their illness. This may suggest that patients were aware that they had a one in four chance of developing CF given their parents' genetic make-up.

With regard to treatment beliefs, less than one tenth of respondents had strong doubts about the *necessity* of ES for maintaining health. The SRM emphasises the role of concrete symptoms in formulating patients' representations of their treatment (Horne, 1997). Failing to take ES with food typically results in stomach pains, bloating and bulky stools (Koocher et al., 1992). Thus, taking ES produces symptom relief which patients can clearly relate to the treatment. Eleven per cent of patients had strong doubts about the *necessity* of antibiotics. Whilst this treatment is often prescribed prophylactically, high doses of intra-venous antibiotics are also used to treat the recurrent chest infections associated with CF.

Thus, patients may also have perceived a direct link between treatment and symptom relief. In contrast, nearly a quarter of patients had strong doubts about the *necessity* of CPT. This aspect of treatment is always prescribed prophylactically and does not provide any symptomatic benefit. Furthermore, performing treatment may itself be a source of negative symptoms, such as coughing. Thus, it is, perhaps, not surprising that more patients had strong doubts about the benefits of CPT than the benefits of ES and antibiotics.

It was encouraging to note that no patients had strong *concerns* about the use of ES or antibiotics. In comparison, nearly two tenths of the sample had strong *concerns* about CPT. CPT is the most time-consuming and physically demanding aspect of the CF treatment regimen (Miller et al., 1999). Approximately twice as many patients considered CPT to be disruptive in comparison to ES and antibiotics. Furthermore, nearly three quarters of participants described CPT as a 'hassle', confirming that this item was a pertinent addition to the BTQ for this aspect of treatment. These findings are broadly consistent with previous studies which have shown that patients perceive CPT as a source of interference (Abbott et al., 1994; Conway et al., 1996).

The pattern of relationships between illness perceptions, treatment beliefs and reported adherence differed for each of the treatments assessed. Consistent with previous research, adherence to CPT was poorest in older adolescents (Foster, Eiser, Oades, Sheldon, Tripp, Goldman, Rice & Trott, 2001; Ricker et al., 1998). The strongest correlations, however, were obtained for treatment beliefs. Specifically, patients appeared to be influenced by a cost-benefit analysis in which their beliefs about the *necessity* of CPT were weighed against their *concerns* about its adverse effects (the *necessity-concerns differential*). Those who had stronger *concerns* in comparison to *necessity* beliefs reported more acts of non-adherence. At a univariate level, reported adherence to CPT was also significantly associated with beliefs about the *necessity* of CPT and perceptions of the *chronicity* of CF, such that patients who had greater doubts about the benefits of treatment and those who viewed their illness as a short-term condition were less likely to adhere to CPT. When entered into a hierarchical multiple linear regression analysis, however, only the *necessity-concerns differential* added significantly to the proportion of variance in adherence behaviour explained by age (16%). This belief alone accounted for 42% of the variance in reported non-adherence to CPT. Similar, albeit weaker, associations between the *necessity-concerns differential* and reported adherence have been found in other illness groups, such as asthma, renal dialysis, cardiac disease and cancer (Horne & Weinman, 1999). The findings indicate that non-adherence to CPT may be the result of a rational decision based on patients' individual beliefs about the treatment. Those who fail to adhere to CPT may be doing so because they perceive that the benefits of treatment do not justify the disruption caused. Thus, the results provide preliminary support for the explanatory role of treatment beliefs outlined in the SRM.

Reported adherence to antibiotics was also poorest in older adolescents. Nonetheless, the strongest correlates of adherence to this aspect of treatment were illness perceptions and treatment beliefs. Specifically, reported non-adherence was associated with lower expectations about the extent to which CF is amenable to *treatment control*, greater doubts about the *necessity* of antibiotics to maintain health and perceptions of a shorter *time-line* for CF. Hierarchical multiple linear regression analysis revealed that perceptions of *treatment control* and *time-line chronicity* explained an additional 38% of the variance in adherence behaviour after the effects of age (13%) had been taken into account. Beliefs about the *necessity* of antibiotics did not add significantly to the proportion of variance explained by the regression equation. These findings are consistent with research carried out in other illness groups which highlights the importance of perceived *control* and *time-line* beliefs in shaping adherence behaviour (Cardiac disease: Cooper et al., 1999; Petrie et al., 1996. Diabetes: Griva et al., 2000. Hypertension: Meyer et al., 1985). Thus, the results provide tentative empirical support for the role of illness perceptions posited by the SRM.

The absence of significant relationships between reported adherence to ES and the self-regulatory constructs suggests that other factors contribute to non-adherence to this aspect of treatment. Consistent with previous research, adherence to ES was high and acts of non-adherence were largely due to *forgetting* (Abbott et al., 1994; Conway et al., 1996). Thus, in contrast to CPT and antibiotics, failure to adhere to ES appears to be predominantly unintentional in nature. Therefore, patients may not be making rational decisions to neglect this aspect of treatment, but simply forget to follow their regimen from time to time. As such, their personal beliefs about CF and ES may not influence their adherence behaviour.

The present study provides important, preliminary information about the relationships between illness perceptions, treatment beliefs and reported adherence in adolescents with CF. Due to the cross-sectional nature of the study, however, it is not possible to infer causality. Thus, future, longitudinal research is required to clarify the direction of the relationships between variables. Moreover, using prospective designs would enable researchers to investigate changes in illness perceptions, treatment beliefs and adherence behaviour over time. The SRM posits that illness perceptions, treatment beliefs and decisions about whether or not to adhere to treatment are constantly being reviewed as patients appraise the effectiveness of their behaviour in terms of symptom relief (e.g. did adhering to treatment work?). Thus, full validation of the model requires longitudinal studies designed to assess how the relationships between variables change in response to symptom fluctuations.

Due to the relatively low prevalence of CF and the severity of its impact on patients' lives, it can be difficult to recruit large numbers of people to CF research (Anthony, Paxton, Bines & Phelan, 1999; Geiss et al., 1992). Within the time constraints of this study, a reasonable sample of 38 adolescents was obtained. The response rate was high (73%) and there were no differences between those who did and did not take part in terms of age or gender. Thus, it did not seem that the study was subject to sampling bias. Whilst this adds credence to the findings, it is important to interpret the results with caution given the absence of any corroborating evidence. Modest sample sizes increase the risk of Type II errors. Thus, although parametric statistics were used, it is possible that comparatively weak, but stable, relationships between the variables were not detected. Clearly, future research would benefit from using larger sample sizes to allow more confident interpretations of the findings. Furthermore, with larger sample sizes more sophisticated statistical techniques, such as structural equation modelling, could be used to explore the interactions between variables (Tabachnick & Fidell, 1996). This would enable the proposed mediating role of treatment *necessity* beliefs over illness perceptions to be investigated.

The measurement of treatment adherence is controversial and fraught with methodological problems (Horne, 2000; Riekert & Drotar, 2000). Whilst patients' self-reports are the most common means of assessing adherence in the literature (Horne & Weinman, 2001), evidence suggests that they are prone to self-presentational bias (Rapoff, 1999) and that patients may over-estimate their levels of adherence to please the assessor (Epstein & Cluss, 1982; Ley, 1982). Nonetheless, other, more direct measures of adherence, such as observation and drug assays, have been found to be no less problematic (Bryon, 1998; Horne, 1998, 2000; Passero, Remor & Salomon, 1981). In their favour, self-reports are the most patient-centred and convenient means of assessing adherence (Horne, 1998, 2000; Horne & Weinman, 2001). Furthermore, by taking steps to reduce the social pressure on patients to over-report adherence, the reliability of participants' reports may be substantially improved (Horne, 2000; Kravitz et al., 1993; Rand & Wise, 1994). As recommended in the literature, therefore, respondents were assured that their answers were confidential, data were collected using a neutral researcher (the author), and care was taken to normalise the process of omitting treatment. Analysis of patients' responses on the MARS revealed that the prevalence of non-adherence reported in this study was similar to the levels of non-adherence found in previous CF research (Abbott et al., 1994; Conway et al., 1996). Many patients freely admitted that they did not perform treatment in exactly the way they were instructed to by the professionals involved in their care. Furthermore, two measures of adherence were used and a high level of agreement between the two was found. Thus, there was no reason to believe that patients were under-reporting their levels of non-adherence in this study. Moreover, the high levels of non-adherence reported suggest that the presence of the researcher did not cause patients to give unrealistically positive reports.

It was notable that many of the illness perceptions and treatment beliefs dimensions, namely illness *identity*, perceived *consequences*, *causal attributions*, *emotional representations*, *coherence* and treatment *concerns*, were not related to reported adherence to any of the treatments studied. Whilst this may be an accurate reflection of the relationships between the variables, there are other possible reasons for these findings. As stated earlier, the lack of significant correlations may reflect the increased risk of Type II errors associated with small sample sizes. Alternatively, it is possible that the items included in the IPQ-R and BTQ are not especially pertinent to the beliefs held by adolescents with CF. Both the IPQ-R and the BTQ are newly developed questionnaires that have not previously been used with CF patients. Thus, although the measures demonstrate good psychometric properties in other illness groups (Horne & Weinman, 1995; Horne et al., 1999; Moss-Morris et al., 2002), little is known about the reliability and validity of the scales in CF populations. The measures were designed to be applicable to a diverse range of patient groups, however, and, as recommended by the questionnaires' authors, some CF-specific items were added. Furthermore, initial analysis of the internal consistency of the scales produced encouraging results. Thus, it is possible to be reasonably confident that the measures were relevant to the group being studied. Nonetheless, future research may seek to develop the questionnaires further so that they suit adolescents with CF better. Qualitative studies, in particular, may be helpful in identifying the most salient illness and treatment cognitions held by this patient group.

This study makes a new contribution to the CF adherence literature and has some important implications for clinical practice. The results suggest that the SRM may be a useful framework in which to explore the factors associated with adherence in adolescents with CF. Moreover, if the findings can be replicated in prospective studies, they suggest that assessing adolescents' perceptions of CF and its treatment may enable clinicians to identify patients at risk of non-adherence and, subsequently, develop appropriate strategies to enhance adherence in this patient group. With regard to CPT, the results suggest that patients will be more likely to adhere to treatment if they have stronger beliefs about the *necessity* of CPT in comparison to *concerns* about its adverse effects. To date, few intervention studies have assessed whether adherence may be enhanced by altering patients' beliefs about treatment. However, Horne (1998) suggests that encouraging an open dialogue between patients and practitioners may be one way to reassure patients about the need for treatment and allay their worries about its potential negative consequences. Thus, clinicians could provide patients with a clear rationale as to why CPT is *necessary* and give them the opportunity to express their *concerns* about its use.

Regarding antibiotics, the results indicate that adherence will be more likely if patients consider their CF to be amenable to *treatment control* and regard it as a *chronic* condition. Thus, increasing adolescents' expectations about the efficacy of treatment and fostering beliefs that CF is an ongoing illness may improve adherence. There is growing evidence that illness perceptions may be amenable to change using cognitive-behavioural techniques (Fisher & Johnston, 1996; Hains, Davies, Behrens & Biller, 1997; Hains, Davies, Behrens, Freeman & Biller, 2001; Kemp, Morley & Anderson, 1999). To date, however, the possibility of using such techniques to modify the beliefs associated with poor adherence has not been explicitly assessed.

Finally, with regard to ES, the findings suggest that interventions designed to enhance patients' ability to remember to take their supplements may improve adherence. For example, encouraging friends and family members to offer reminders might be a beneficial approach.

In sum, this study has provided valuable evidence regarding the nature of the illness perceptions, emotional representations and treatment beliefs held by adolescents with CF, and about the contribution of these variables to explaining reported adherence to CPT, ES and antibiotics. Longitudinal studies using larger sample sizes are now required to confirm the findings. These may help clinicians to develop strategies to enhance adherence and, subsequently, improve survival rates for adolescents with CF.

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List of Tables

Table 1. Descriptive Statistics and Internal Reliability Co-efficients (*N* = 38)

	Mean	(SD)	*N* (%) scoring above scale midpoint	Cronbach's α
Revised Illness Perception Questionnaire				
Identity	5.2	(3.1)	NA	.73
Time-line - chronicity	4.2	(0.6)	36 (95)	.81
Time-line - cyclical	3.2	(0.4)	22 (58)	.18
Consequences	3.0	(0.6)	20 (53)	.66
Personal control	3.8	(0.4)	37 (97)	.66
Treatment control	3.7	(0.6)	32 (84)	.72
Emotional representations	2.7	(0.7)	11 (29)	.84
Coherence	4.1	(0.5)	36 (95)	.87
Cause	1.4	(0.6)	NA	NA
Beliefs about Treatment Questionnaire				
Chest Physiotherapy				
Necessity	3.5	(0.7)	29 (76)	.90
Concerns	2.6	(0.6)	7 (18)	.55
Necessity -Concerns differential	0.9	(0.8)	3 (8)	NA
Enzyme Supplements				
Necessity	4.0	(0.5)	35 (92)	.81
Concerns	2.0	(0.5)	0	.76
Necessity-Concerns differential	2.1	(0.8)	0	NA
Antibiotics				
Necessity	3.9	(0.6)	34 (89)	.81
Concerns	2.2	(0.5)	0	.55
Necessity-Concerns differential	1.7	(0.9)	1 (3)	NA

Table 1 continued overleaf

Table 1 continued. Descriptive Statistics and Internal Reliability Co-efficients (*N* = 38).

	Mean	(SD)	*N* (%) scoring above scale midpoint	Cronbach's α
Medication Adherence Report Scale				
Chest Physiotherapy	2.6	(1.0)	10 (26)	.88
Enzyme Supplements	1.5	(0.3)	0	.51
Antibiotics	1.5	(0.5)	0	.75
CF Treatment Questionnaire				
Chest Physiotherapy	3.6	(0.8)	NA	.91
Enzyme Supplements	4.3	(0.6)	NA	.85
Antibiotics	4.5	(0.5)	NA	.69

Table 2. Responses to individual items on the MARS ($N = 38$)

Type of non-adherent behaviour	N (%) reporting engaging in each aspect of non-adherent behaviour (sometimes, often or always)
Chest Physiotherapy	
I alter the way I do it	25 (66)
I do less than instructed	18 (47)
I avoid doing it if I can	17 (45)
I decide to miss out a session	17 (45)
I forget to do it	17 (45)
I stop doing it for a while	8 (21)
Enzyme Supplements	
I forget to take them	15 (39)
I alter the dose	5 (13)
I decide to miss out a dose	5 (13)
I avoid using them if I can	1 (3)
I take fewer than instructed	1 (3)
I stop taking them for a while	0
Antibiotics	
I forget to take them	10 (26)
I decide to miss out a dose	8 (21)
I stop taking them for a while	5 (13)
I avoid using them if I can	4 (11)
I alter the dose	1 (3)
I take fewer than instructed	0

Table 3. Pearson correlations between illness perceptions (IPQ-R), treatment beliefs (BTQ) and reported adherence (MARS) (*N* = 38)

	Medication Adherence Report Scale		
	CPT	ES	Antibiotics
Demographics			
Age	.43**	-.11	.40*
Revised Illness Perception Questionnaire			
Identity	-.16	.11	-.10
Time-line - chronicity	.34*	.01	.46**
Consequences	-.26	.07	-.11
Personal control	-.01	.01	-.25
Treatment control	-.25	-.21	-.53**
Emotional representations	-.01	.14	-.08
Coherence	.14	.02	.18
Beliefs about Treatment Questionnaire			
Chest Physiotherapy			
Necessity	-.67***		
Concerns	.12		
Necessity-Concerns differential	-.70***		
Enzyme Supplements			
Necessity		-.03	
Concerns		.11	
Necessity-Concerns differential		-.09	
Antibiotics			
Necessity			-.49**
Concerns			-.02
Necessity-Concerns differential			-.32

*$p < .05$ (two-tailed); ** $p < .01$ (two-tailed); ***$p < .001$ (two-tailed)

Table 4. Hierarchical multiple linear regression model of predictors of reported adherence to MARS Chest Physiotherapy ($N = 38$)

Significant Predictors	β	t	Adjusted R^2	Increase in adjusted R^2
Age	.43	2.8**	.16	.16
BTQ Necessity-Concerns differential	-.65	-6.1***	.58	.42

$^{**}p < .01$; $^{***}p < .001$

Table 5. Hierarchical multiple linear regression model of predictors of reported adherence to MARS Antibiotics ($N = 38$)

Significant Predictors	β	t	Adjusted R^2	Increase in adjusted R^2
Age	.40	2.6*	.13	.13
IPQ-R Treatment control	-.50	-3.9***	.38	.25
IPQ-R Time-line - chronicity	.14	3.3**	.51	.13

$^*p < .05$; $^{**}p < .01$; $^{***}p < .001$

List of Appendices

Appendix 1: Notes for Contributors (Review Paper and Empirical Paper)

Notes for contributors

The aim of the *British Journal of Health Psychology* is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:
- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journals is worldwide. There is no restriction to British authors; papers are invited and encouraged from authors throughout the world.

2. Length

Pressure on Journal space is considerable and papers should be as short as is consistent with clear presentation of the subject matter. Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length.

3. Refereeing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page (and the text should be free of such clues as identifiable self-citations ('In our earlier work...')).

4. Submission requirements

(a) Four copies of the manuscript should be sent to the Editor (Professor Douglas Carroll, Journals Department, The British Psychological Society, St. Andrews House, 48 Princess Road East, Leicester, LE1 7DR, UK). Submission of a paper implies that it has not been published elsewhere and that it is not being considered for publication in another journal. Papers should be accompanied by a signed letter indicating that all named authors have agreed to the submission. One author should be identified as the correspondent and that person's title, name and address supplied.

(b) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.

(c) Tables should be typed in double spacing, each on a separate piece of paper with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locationsindicated in the text.

(d) Figures are usually produced direct from authors' originals and should be presented as good black or white images preferably on high contrast glossy paper, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Paper clips leave damaging indentations and should be avoided. Any necessary instructions should be written on an accompanying photocopy. Captions should be listed on a separate sheet.

(e) All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention and results or conclusions of the article.

(f) Bibliographic references in the text should quote the author's name and the date of publication thus: Smith (1994). Multiple citations should be given alphabetically rather than chronologically: (Jones, 1998; King, 1996; Parker, 1997). If a work has two authors, cite both names in the text throughout: Page and White (1995). In the case of reference to three or more authors, use all names on the first mention and et al. thereafter except in the reference list.

(g) References cited in the text must appear in the list at the end of the article. The list should be typed in double spacing in the following format: Herbert, M. (1993). *Working with children and the Children Act* (pp. 76-106). Leicester: The British Psychological Society. Kanvil, N., & Umeh, K.F. (2000). Lung cancer and cigarette use: Cognitive factors, protection motivation and past behaviour. *British Journal of Health Psychology*, 5, 235-248. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

(h) SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses (see The British Psychological Society *Style Guide* at: http://www.bps.org.uk/publications/jAuthor.cfm).

(i) Authors are requested to avoid the use of sexist language.

(j) Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

5. E-mail submissions

Manuscripts may be submitted via e-mail. The main text of the manuscript, including any tables or figures, should be saved as a Word 6.0/95 compatible file. The file must be sent as a MIME-compatible attachment. E-mails should be addressed to journals@bps.org.uk with 'Manuscript submission' in the subject line. The main body of the e-mail should include the following: title of journal to which the paper is being submitted; name, address and e-mail of the corresponding author; and a statement that the paper is not currently under consideration elsewhere. E-mail submissions will receive an e-mail acknowledgement of receipt, including a manuscript reference number.

6. Ethical considerations

The code of conduct of The British Psychological Society requires psychologists 'Not to allow their professional responsibilities or standards of practice to be diminished by consideration of religion, sex, race, age, nationality, party politics, social standing, class or other extraneous factors. The Society resolves to avoid all links with psychologists and psychological organizations and their formal representatives that do not affirm and adhere to the principles in the clause of its Code of Conduct. In cases of doubt, authors may be asked to sign a document confirming the adherence to these principles. Any study published in this journal must pay due respect to the well-being and dignity of research participants. The British Psychological Society's Ethical Guidelines on Conducting Research with Human Participants must be shown to have been scrupulously followed. These guidelines are available at http://www.bps.org.uk/about/rules5.cfm

7. Supplementary data

Supplementary data too expensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Proofs

Proofs are sent to authors for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the senior author, but further copies may be ordered on a form accompanying the proofs.

9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

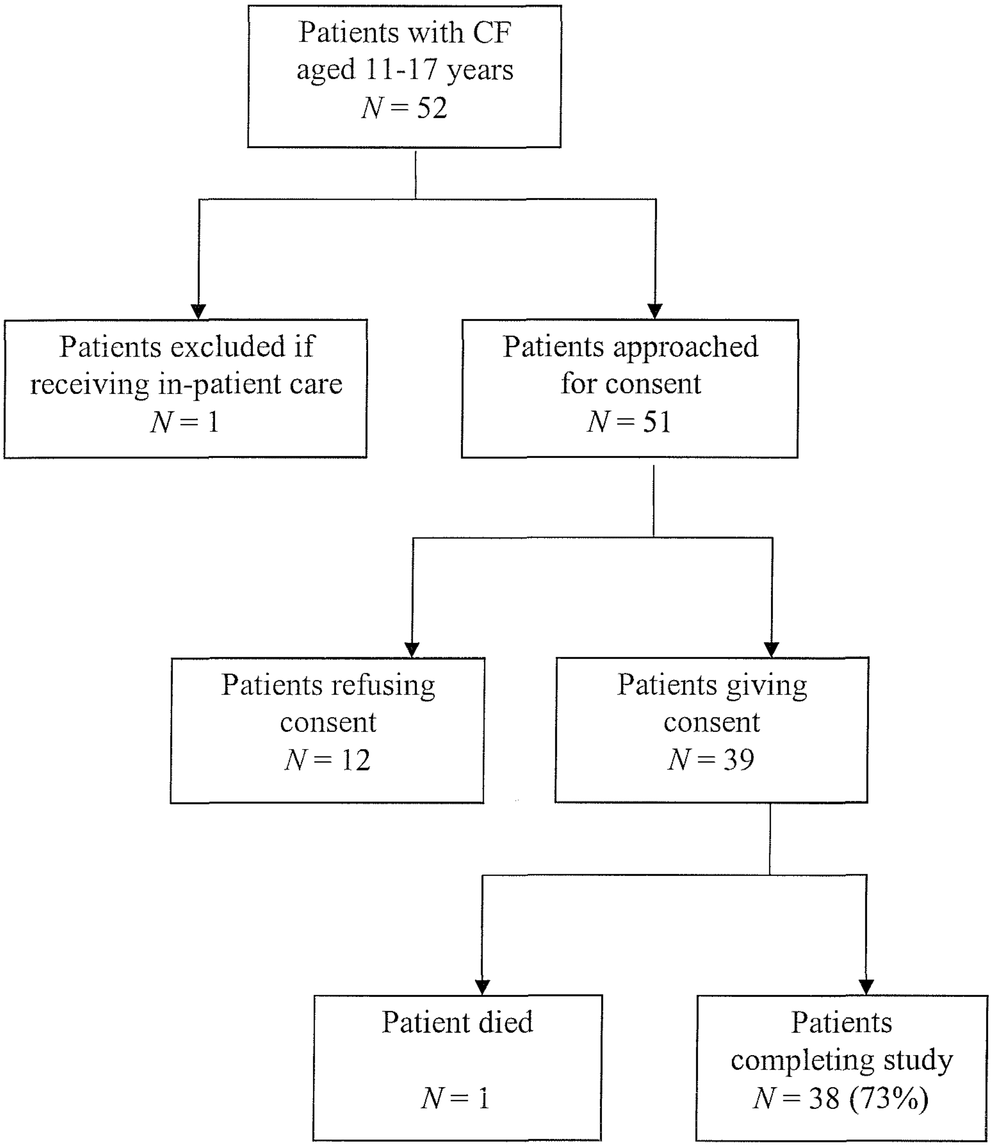
10. Checklist of requirements:

- A signed submission letter
- Correspondent's title/name/address
- A cover page with title/author(s)/affiliation
- Double spacing with wide margins
- Tables/figures at the end
- Complete reference list in APA format
- Four good copies of the manuscript (or an e-mail attachment)

Appendix 2: Flow Diagram of the Recruitment Process

Appendix 2

Flow Diagram of the Recruitment Process



Appendix 3: Measures - IPQ-R, BTQ, MARS and CFTQ

Illness Perception Questionnaire - Revised

Listed below are a number of symptoms.

Please indicate whether or not you have experienced each of the following symptoms recently by circling *Yes* or *No*.

For each symptom that you have experienced recently, please indicate whether or not you believe it is related to your cystic fibrosis.

	I have experienced this symptom recently		This symptom is related to my cystic fibrosis	
Pain	Yes	No	Yes	No
Sore throat	Yes	No	Yes	No
Nausea	Yes	No	Yes	No
Breathlessness	Yes	No	Yes	No
Weight change	Yes	No	Yes	No
Coughing	Yes	No	Yes	No
Stiff joints	Yes	No	Yes	No
Blocked nose	Yes	No	Yes	No
Wheeziness	Yes	No	Yes	No
Headaches	Yes	No	Yes	No
Upset stomach	Yes	No	Yes	No
Sleep difficulties	Yes	No	Yes	No
Dizziness	Yes	No	Yes	No
Production of sputum	Yes	No	Yes	No
Loss of appetite	Yes	No	Yes	No
Bowel problems	Yes	No	Yes	No
Sore eyes	Yes	No	Yes	No
Loss of strength	Yes	No	Yes	No
Fatigue	Yes	No	Yes	No

I am interested in *your own* personal views of how *you* currently see your cystic fibrosis.

These are statements other people have made about cystic fibrosis.

Please indicate how much you agree or disagree with each of the following statements by circling the appropriate number.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My CF will last a short time.	1	2	3	4	5
My CF is likely to be permanent rather than temporary.	1	2	3	4	5
My CF will last for a long time.	1	2	3	4	5
My CF will pass quickly.	1	2	3	4	5
I expect to have CF for the rest of my life.	1	2	3	4	5
My CF will improve in time.	1	2	3	4	5
My CF is a serious condition.	1	2	3	4	5
My CF has major consequences on my life.	1	2	3	4	5
My CF does not have much effect on my life.	1	2	3	4	5
My CF strongly affects the way others see me.	1	2	3	4	5
My CF causes difficulties for those who are close to me.	1	2	3	4	5
My CF has strongly affects the way I feel about myself.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
There is a lot which I can do to control my symptoms.	1	2	3	4	5
What I do can determine whether my CF gets better or worse.	1	2	3	4	5
The course of my CF depends on me.	1	2	3	4	5
Nothing I do will affect my CF.	1	2	3	4	5
I have the power to influence my CF.	1	2	3	4	5
My actions will have no effect on the outcome of my CF.	1	2	3	4	5
There is very little that can be done to improve my CF.	1	2	3	4	5
My treatment will be effective in controlling my CF.	1	2	3	4	5
The negative effects of my CF can be avoided by my treatment.	1	2	3	4	5
My treatment can control my CF.	1	2	3	4	5
There is nothing which can help my condition.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
The symptoms of my condition are puzzling to me.	1	2	3	4	5
My CF is a mystery to me.	1	2	3	4	5
I don't understand my CF.	1	2	3	4	5
My CF doesn't make any sense to me.	1	2	3	4	5
I have a clear understanding of my condition.	1	2	3	4	5
The symptoms of my illness change a great deal from day to day.	1	2	3	4	5
My symptoms come and go in cycles.	1	2	3	4	5
My CF is very unpredictable.	1	2	3	4	5
I go through cycles in which my CF gets better or worse.	1	2	3	4	5
I get depressed when I think about my CF.	1	2	3	4	5
When I think about my CF I get upset.	1	2	3	4	5
My CF makes me feel angry.	1	2	3	4	5
My CF does not worry me.	1	2	3	4	5
Having CF makes me feel anxious.	1	2	3	4	5
My CF makes me feel afraid.	1	2	3	4	5

I am interested in what *you* consider may have been the cause(s) of your CF. Below is a list of possible causes that other people have suggested. Please show how much you agree or disagree that they were causes for you by circling the appropriate number.

I am most interested in *your own* views about the cause(s) of your CF rather than what others, including your doctor or family, have suggested to you.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
Stress or worry.	1	2	3	4	5
Hereditary – in my genes	1	2	3	4	5
A germ or virus.	1	2	3	4	5
Diet or eating habits.	1	2	3	4	5
Chance or bad luck.	1	2	3	4	5
Poor medical care in my past.	1	2	3	4	5
Pollution in the environment.	1	2	3	4	5
My own behaviour.	1	2	3	4	5
My mental attitude e.g. thinking about life negatively.	1	2	3	4	5
Family problems or worries.	1	2	3	4	5
My emotional state e.g. feeling down, lonely, worried.	1	2	3	4	5
Smoking	1	2	3	4	5
Accident or injury	1	2	3	4	5
My personality	1	2	3	4	5
Overwork	1	2	3	4	5
Ageing	1	2	3	4	5
Alcohol	1	2	3	4	5
Altered immunity (ability to fight germs and infection)	1	2	3	4	5

Beliefs about Treatment Questionnaire

These are statements other people have made about their treatments.

Please indicate how much you agree or disagree with each of the statements by circling the appropriate number.

There are no right or wrong answers. I am interested in *your own* personal views.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My health at present depends on doing chest physiotherapy	1	2	3	4	5
Having to do chest physiotherapy worries me	1	2	3	4	5
My life would be impossible without my chest physiotherapy	1	2	3	4	5
Without my chest physiotherapy I would be very ill	1	2	3	4	5
My chest physiotherapy is a mystery to me	1	2	3	4	5
My health in the future will depend on doing chest physiotherapy	1	2	3	4	5
My chest physiotherapy disrupts my life	1	2	3	4	5
My chest physiotherapy protects me from becoming more ill	1	2	3	4	5
My chest physiotherapy is difficult because I need help from others to do it properly	1	2	3	4	5
My chest physiotherapy is a hassle	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My health at present depends on my enzyme supplements	1	2	3	4	5
Having to take enzyme supplements worries me	1	2	3	4	5
My life would be impossible without my enzyme supplements	1	2	3	4	5
I sometimes worry about the long-term effects of taking enzyme supplements	1	2	3	4	5
Without my enzyme supplements I would be very ill	1	2	3	4	5
My enzyme supplements are a mystery to me	1	2	3	4	5
My health in the future will depend on taking enzyme supplements	1	2	3	4	5
My enzyme supplements disrupt my life	1	2	3	4	5
I sometimes worry about becoming too dependent on my enzyme supplements	1	2	3	4	5
My enzyme supplements protect me from becoming more ill	1	2	3	4	5
My enzyme supplements give me unpleasant side effects	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
My health at present depends on my antibiotics	1	2	3	4	5
Having to take antibiotics worries me	1	2	3	4	5
My life would be impossible without my antibiotics	1	2	3	4	5
I sometimes worry about the long-term effects of taking antibiotics	1	2	3	4	5
Without my antibiotics I would be very ill	1	2	3	4	5
My antibiotics are a mystery to me	1	2	3	4	5
My health in the future will depend on taking antibiotics	1	2	3	4	5
My antibiotics disrupt my life	1	2	3	4	5
I sometimes worry about becoming too dependent on my antibiotics	1	2	3	4	5
My antibiotics protect me from becoming more ill	1	2	3	4	5
My antibiotics give me unpleasant side effects	1	2	3	4	5

Medication Adherence Report Scale

Many people find a way to carry out their treatment that suits them.

This may differ from the instructions given by their doctor.

I would like to ask you a few questions about how you carry out the treatments prescribed for your cystic fibrosis.

Here are some ways people have said they do their treatment.

For each of the statements please circle the number that best applies to you.

	Always	Often	Sometimes	Rarely	Never
I avoid doing my chest physiotherapy if I can	1	2	3	4	5
I forget to do my chest physiotherapy	1	2	3	4	5
I alter the way I do my chest physiotherapy	1	2	3	4	5
I stop doing chest physiotherapy for a while	1	2	3	4	5
I decide to miss out a session of my chest physiotherapy	1	2	3	4	5
I do less chest physiotherapy than instructed	1	2	3	4	5

	Always	Often	Sometimes	Rarely	Never
I avoid taking my enzyme supplements if I can	1	2	3	4	5
I forget to do take my enzyme supplements	1	2	3	4	5
I alter the dose of my enzyme supplements	1	2	3	4	5
I stop taking my enzyme supplements for a while	1	2	3	4	5
I decide to miss out a dose of my enzyme supplements	1	2	3	4	5
I take fewer enzyme supplements than instructed	1	2	3	4	5

	Always	Often	Sometimes	Rarely	Never
I avoid taking my antibiotics if I can	1	2	3	4	5
I forget to do take my antibiotics	1	2	3	4	5
I alter the dose of my antibiotics	1	2	3	4	5
I stop taking my antibiotics for a while	1	2	3	4	5
I decide to miss out a dose of my antibiotics	1	2	3	4	5
I take fewer antibiotics than instructed	1	2	3	4	5

Cystic Fibrosis Treatment Questionnaire.

Many people with CF find that the treatments they are prescribed are time-consuming and may interfere with their daily routine. To reduce this disruption, people often look after their CF in a way that suits them, rather than following the treatment recommendations of medical staff to the last detail.

It is important to try and find out which aspects of CF treatment are the most and least difficult for people to follow as prescribed and fit into their lifestyle. I am therefore interested in how *you* look after *your* CF and how *you* feel about your treatment. Your answers to this questionnaire are strictly confidential.

Please circle the answers that best describe you:

1) I carry out my chest physiotherapy as often as prescribed

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

2) I do my chest physiotherapy when I am well

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

3) Chest physiotherapy is part of my daily routine

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

4) Over the past month, how often have you done your chest physiotherapy?

1. I haven't done any chest physiotherapy this month.
2. I often missed sessions of chest physiotherapy.
3. I missed about two sessions each week.
4. I only missed my chest physiotherapy once or twice this month.
5. I did all my sessions this month.

5) I take my enzyme supplements with meals

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

6) I take my enzyme supplements with snacks

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

7) Taking enzyme supplements is part of my daily routine

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

8) Over the past month, how often have you taken your enzyme supplements with meals?

1. I haven't taken any enzyme supplements with meals this month.
2. I often missed taking them with meals.
3. I missed taking them with about two meals each week.
4. I only missed taking them with meals once or twice this month.
5. I took them with all meals this month.

9) Over the past month, how often have you taken your enzyme supplements with snacks?

1. I haven't taken any enzyme supplements with snacks this month.
2. I often missed taking them with snacks.
3. I missed taking them with about two snacks each week.
4. I only missed taking them with snacks once or twice this month.
5. I took them with all snacks this month.

10) I take my antibiotics as prescribed by my doctor

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

11) I run out of my antibiotics

Always	Almost Always	Sometimes	Hardly Ever	Never
1	2	3	4	5

12) Taking antibiotics is part of my daily routine

Never	Hardly Ever	Sometimes	Almost Always	Always
1	2	3	4	5

13) Over the past month, how often have you taken your antibiotics?

1. I haven't taken any antibiotics this month.
2. I often missed taking them.
3. I missed taking them about twice each week.
4. I only missed taking them once or twice this month.
5. I took all my antibiotics this month.

Appendix 4: The Development and Psychometric Properties of the Measures

Appendix 4

The development and psychometric properties of the measures.

The IPQ-R

The IPQ-R was developed and validated on a sample of 711 patients from eight different illness groups; rheumatoid arthritis, type II diabetes, asthma, chronic pain, acute pain, multiple sclerosis (MS), myocardial infarction and HIV (Moss-Morris et al., 2002). Two principal components analyses (PCAs) were conducted on the data to validate the questionnaire's structure and determine item selection. All subscales of the IPQ-R have demonstrated good internal reliability, with Cronbach alpha values ranging from .79 to .89 (Moss-Morris et al., 2002). The dimensions also show satisfactory test-retest reliability over a three-week period, with Pearson correlations ranging from .46 to .88. Furthermore, the questionnaire has good convergent validity in relation to measures of perceived health status, locus of control and number of GP visits. Finally, evidence for the concurrent and predictive validity of the IPQ-R is indicated by its ability to distinguish between different illness groups and predict levels of disability, fatigue and emotional distress in people with MS.

The BMQ- Specific

The psychometric properties of the BMQ-Specific were evaluated on a sample of 524 patients with chronic illnesses, comprising asthmatic, diabetic and psychiatric out-patients and cardiac, general medical and renal dialysis in-patients. Cronbach alpha values for each diagnostic group ranged from .55 to .86, indicating that the measure has satisfactory internal consistency. The *necessity* score for renal dialysis in-patients was the only value to fall below .65. The test-retest reliability of the BMQ-Specific, measured by Pearson correlations, was also satisfactory when re-administered to the patient sample after a two-week interval (*necessity;* $r = .77, p < .001$; *concerns;* $r = .76, p < .001$). Evidence for the concurrent validity of the scale is indicated by its ability to distinguish between patients of different illness (and treatment) groups. Furthermore, there is growing evidence for the predictive validity of the BMQ-Specific in a range of illness groups. For instance, the measure has been shown to predict treatment adherence in patients with asthma, diabetes, cardiac disease and cancer (Horne & Weinman, 1999, 2001).

The MARS

The MARS was developed on a sample of 1541 individuals with chronic conditions who were taking regular, prescribed medication (Horne & Hankins, in press). It demonstrates both high internal consistency ($\alpha = .83$) and high test-retest reliability ($r = .97, p < .001$). Evidence for the convergent validity of the MARS is suggested by its relationships with treatment beliefs, as measured by the BMQ-Specific (Horne & Weinman, 2001). Multiple linear regression analyses have demonstrated that variance in MARS adherence is independently attributable both to treatment *necessity* and treatment *concerns* (Horne & Hankins, in press). The predictive validity of the MARS has been demonstrated by its ability to predict blood pressure in patients taking medication for hypertension (Horne & Hankins, in press).

The CFTQ

The CFTQ constitutes an abbreviated version of the Living with Cystic Fibrosis Questionnaire (LCF; Horn, Myers & Abbott, in preparation) which was designed to measure health perceptions and treatment adherence in patients with CF. The LCF was developed in two stages. The initial questions were generated with reference to the CF literature and on the basis of informal discussions with CF patients and their families. The questionnaire was then piloted on a group of 50 patients with CF and subsequently revised. The measure has recently been completed by over 500 patients with CF and appears to have good face validity (Horn, personal communication). However, as yet, there are no published data concerning the validity or reliability of the measure. The LCF provides a comprehensive measure of adherence behaviour and patients' perceptions of CF. It was deemed to lengthy for the purposes of this study and, thus, only the questions pertaining to CPT, ES and antibiotics were used.

Appendix 5: Ethics Committee Correspondence

From: **"AMANDA" <Amanda@psy.soton.ac.uk>**
Organization: **Psychology - University of Soton**
To: **dc4@soton.ac.uk**
Date sent: **Thu, 3 May 2001 09:54:21 +0000**
Subject: **Kate Hawkins** – RESEARCH DISSERTATION
Send reply to: **A.Josling@soton.ac.uk**
Priority: **normal**

To Denise

Can you let Kate Hawkins know that her ethical form has been approved.

Amanda

NORTH AND MID HAMPSHIRE
LOCAL RESEARCH ETHICS COMMITTEES
North and Mid Hampshire Health Authority
Harness House
Aldermaston Road, Basingstoke
Hampshire RG24 9NB
Tel: 01256 312248 Fax: 01256 312299
Email: sandra.tapping@nm-ha.nhs.uk
www.hants.gov.uk/nmhha/ethics.html

Chair of Biomedical Committee: ***Mrs Jane Ogden-Swift***
Chair of Qualitative and Non-invasive Committee: ***Rev'd Dr Rosemary Baker***
Ethics Committee Co-ordinator: ***Mrs Sandra Tapping***

Our ref: SKT/mk/321A/L4161

12th September 2001

Kate Hawkins
22 Wharf Hill
Winchester
Hants
SO23 9NQ

Dear Miss Hawkins

321/A - Correlates of treatment adherence in adolescents with cystic fibrosis : the role of illness perceptions and beliefs about treatment

Decision - Approval

Thank you for your email dated 7 September 2001 which because of problems with our server did not arrive until 11 September. I am satisfied with your response and am empowered to grant you full approval.

I must emphasise that whilst the committee look at work on ethical grounds, it is up to the Trust to finally sanction the work, taking into account financial and other implications.

To comply with good practice a list of members at the July meeting is enclosed.

The committee wish you every success with the study. The following conditions apply to all approvals:

(a) that you notify the LREC immediately of any information received or of which you become aware which would cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the LREC and/or which would raise questions about the safety and/or continued conduct of the research.

(b) you need to comply with the latest Data Protection Act and Caldicott Guardian issues.

(c) you need to comply throughout the conduct of the study, with good clinical research practice standards, including obtaining informed consent.

(d) you need to refer proposed amendments to the protocol to the LREC for further review and to obtain LREC approval thereto prior to implementation (except only in cases of emergency where the welfare of the subject is paramount).

(e) you must supply an annual summary of the progress of the research project and of the conclusion and outcome of the research project and inform the LREC should the research be discontinued.

(f) that satisfactory indemnity arrangements agreed with the Trust are in place before the study commences.

The committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely

Matthew Dryden
Vice Chair - Biomedical Committee

cc Maureen Larkin - RHCH

enc July meeting members

North and Mid Hampshire
Local Research Ethics
Committees

Isle of Wight, Portsmouth and
South East Hampshire
Health Authority

Finchdean House
Milton Road
Portsmouth PO3 6DP

Tel: 023 9283 8340
Fax: 023 9273 3292

Direct Line: 023 9283 5139
Fax: 023 9283 5073

Kate Hawkins
22 Wharf Hill
Winchester
Hampshire
S023 9NQ

31 August 2001

Dear Ms Hawkins

REC Prop No: **06/01/1193**
Title: **Correlates of treatment adherence in adolescents with cystic fibrosis: the role of illness perceptions and beliefs about treatment**

This is to inform you that the Chair of the Local Research Ethics Committee has approved the above study. Approval for the study is only granted until the end of **April 2002**. If your study continues after this date further Ethics Committee approval will be required.

The following documents were reviewed:

Protocol	not dated
Patient consent form	not dated
Patient information sheet	Version 2 - 10 August 2001
Paediatrician's letter	Version 1 - 13 August 2001
Questionnaires	not dated
Researcher's CV	Kate Hawkins

The Ethics Committee will require a copy of the completed study for its records, you are therefore requested to submit a copy of the completed study to the address above.

The Committee must be informed of any untoward or adverse events which occur during the course of the study.

Please inform the Committee if the study is withdrawn, or does not take place.

The Ethics Committee must also be informed of, and approve, any proposed amendments to your initial application.

Please note it is the policy of the Committee NOT to deal direct with sponsoring companies. All correspondence (including telephone enquiries) MUST be from the first named researcher. Enquiries from other sources will be refused.

Ethics Committee approval means that the proposal is ethically sound. It does not mean approval of resources, access to data or any other requirement relating to the project. These must be agreed with the organisation where the research / project is to take place.

If you have any further questions please do not hesitate to contact me quoting the Research Ethics Committee Proposal Number given above.

Yours sincerely

Anna Noble
Administrator to the Research Ethics Committee

E-mail: anna.noble@portsha.swest.nhs.uk

Poole Hospital NHS
NHS Trust

Longfleet Road
Poole
Dorset
BH15 2JB

Tel: 01202 665511
www.poolehos.org

Our Ref : SW/RCH/LREC 51/01/S

1 October 2001

Miss Kate Hawkins
Trainee Clinical Psychologist
22 Wharf Hill
Winchester
Hants SO23 9NQ

Dear Miss Hawkins

LREC NO. 51/01/S [must be quoted in all correspondence]
Correlates of treatment adherence in adolescents with cystic fibrosis: the role of illness perceptions and beliefs about treatment

The East Dorset Local Research Ethics Committee met on 27 September 2001 to further discuss this submission.

They received your letter dated 10 August 2001 which confirmed the alterations to the patient information sheet. The Committee agreed to the use of the letter format on this occasion.

Present at the meeting :

S Wheeler, Chairman
M Burrows
S Elliot
J Begley
G P Clein
R Day, Vice Chairman
B J Waltho
F Randall
G Roberts
T Hollingberry
T Hamblin
M Leggett
D Tory

In Attendance : R Hanson

Yours sincerely

RACHAEL HANSON
ADMINISTRATOR, EAST DORSET LOCAL RESEARCH ETHICS COMMITTEE

SOUTHAMPTON & SOUTH WEST HANTS
LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Dr A Kermode

Manager: Mrs Clair Wright
Trust Management Offices
Mailpoint 18
Southampton General Hospital
Tremona Road
Southampton
Hants
SO16 6YD

Tel: (023) 8079 4912
FAX: (023) 8079 8678

Ref CPW

2 October 2001

Miss K Hawkins
22 Wharf Hill
Winchester
Hants
SO23 9NQ

Dear Miss Hawkins

RE: 258/01 – Correlates of treatment adherence in adolescents with cystic fibrosis: the role of illness perceptions and beliefs about treatment.

The Ethics Committee considered your application for the above study at its recent meeting and I am pleased to inform you that **approval was given**.

May I draw your attention to the enclosed conditions of approval which **must be complied with.** In particular: it is mandatory that ALL correspondence, information sheets, consent forms, adverts etc, carry the LREC submission number. YOU SHOULD BE AWARE THAT A SUBSTANTIAL RANDOM PROPORTION OF RESEARCH PROJECTS ARE AUDITED ANNUALLY.

The data protection officer for the Trust/University is to be notified of the project.

This committee is compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

The composition of the committee is enclosed for your files and confirms which members were present at the meeting. Most pharmaceutical companies request this information and we would be grateful if you could forward this to them if appropriate.

Should any unforeseen problem of either an ethical or procedural nature arise during the course of this research and you feel the Joint Ethics Committee may be of assistance, please do not hesitate to contact us.

Yours sincerely,

CWright

Clair Wright
LREC Manager

East Sussex, Brighton and Hove NHS
Health Authority

17 October 2001

36-38 Friars Walk
Lewes
East Sussex
BN7 2PB

Direct Line: 01273 403540
Direct Fax: 01273 403505
🖂 kerryl@esbhhealth.cix.co.uk

Ms K Hawkins
22 Wharf Hill
WINCHESTER
SO23 9NQ

Ref: **(B) 01/70**

Dear Ms Hawkins

Study title: Correlates of Treatment Adherence in Adolescents with Cystic Fibrosis: The Role of Illness Perceptions and Treatment Beliefs

Thank you for your letter and enclosures of 11 October 2001.

I can confirm that the amended parent invitation to participate letter and questionnaires are now satisfactory and I am writing to inform you that Vice-Chairman's Action has been given to **approve** this study.

It would be appreciated if, on its conclusion, you could supply a brief report to the Committee of your findings and conclusions.

Yours sincerely

Kerry Longhurst (Mrs)
Research Ethics Committee Administrator

Appendix 6: Parent and Participant Information Letters

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

10 October 2001

Dear

Re: Research investigating individuals' thoughts and feelings about cystic fibrosis and its treatment.

Introduction
Your child is being invited to take part in a research study. Before you decide whether or not you want your child to participate, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with members of your family and your consultant if you wish. Do not hesitate to contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish your child to take part.

Background Information and Purpose of the study
It is understood that the treatments prescribed for people with cystic fibrosis are time-consuming and sometimes unpleasant. Thus, we feel that it is important to find out how young people with CF feel about their illness and the treatments that are prescribed for them. We hope that this will lead to better understanding in the health professions about how CF and its treatment affects individuals' lifestyles.

Procedure
We are asking all 11 to 18-year-olds with CF who receive treatment in Winchester, Southampton, Portsmouth, Poole and Brighton to take part. The study would involve me (Kate Hawkins – a Trainee Clinical Psychologist) interviewing participants for approximately 45 minutes about their thoughts and feelings regarding CF and its treatment. The interview would take place at the convenience of the individual and his or her family. The questions are not intended as a test for participants, but rather to help us with the care of young people with CF in the future. The questions focus on three main areas; 1) participants' beliefs about their illness, for instance how it affects their lifestyle; 2) participants' beliefs about their treatment, for instance how effective it is at controlling their symptoms; and 3) the extent to which participants feel able to carry out their treatment, for instance how often they do their physiotherapy.

Withdrawal from the study
It is entirely up to your child whether or not he or she wishes to take part. For individuals under the age of 16 years, parental consent for the interviews to take place will be sought. If your child decides to take part he or she will be given this information sheet to keep and be asked to sign a consent form. Even if your child decides to take part, he or she is still free to withdraw consent at any time without giving a reason. This will not affect the standard of care your child receives in the future.

Confidentiality
All information that is collected will be kept strictly confidential. Only I will look at the answers that are given. I am not permitted to disclose them to your child's consultant, physiotherapist, dietician, or anyone else.

Contacts
Please feel free to discuss any queries you may have with the consultant or myself. I can be reached on the above number. If your child would like to take part, please complete the consent form overleaf and return it to me or a member of the CF team.

Thank you for your time.

Kate Hawkins
Trainee Clinical Psychologist

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

10 August 2001

Dear

You are being invited to take part in a research study. Before you decide whether or not you want to participate, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with members of your family and your consultant if you wish. Do not hesitate to contact me if there is anything that is not clear or if you and your family would like more information. Take time to decide whether or not you wish to take part.

It is understood that the treatments prescribed for people with cystic fibrosis are time-consuming and sometimes unpleasant. Thus, we feel that it is important to find out how young people with CF feel about their illness and the treatments that are prescribed for them. We hope that this will lead to better understanding in the health professions about how CF and its treatment affects individuals' lifestyles.

We are asking all 11 to 18-year-olds with CF who receive treatment in Winchester, Southampton, Portsmouth, Poole and Brighton to take part. The study would involve me (Kate Hawkins – a Trainee Clinical Psychologist) interviewing participants for approximately 45 minutes about their thoughts and feelings regarding CF and its treatment. The interview would take place when it is convenient for you and your family. The questions are not intended as a test, but rather to help us with the care of young people with CF in the future. They will include requests for information about how difficult or easy you find it to cope with different aspects of your treatment.

It is entirely up to you to decide whether or not to take part. For individuals under the age of 16 years, parental consent for the interviews to take place will also be sought. If you or your family decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw your consent at any time without giving a reason. This will not affect the standard of care you receive in the future.

All information that is collected will be kept strictly confidential. Only I will look at the answers that you give. I am not permitted to disclose them to your consultant, physiotherapist, dietician, or anyone else.

Please feel free to discuss any queries you may have with your consultant or myself. I can be reached on the above number. If you would like to take part, please complete the consent form overleaf and return it to me or a member of the CF team.

Thank you for your time.

Kate Hawkins
Trainee Clinical Psychologist

Appendix 7: Consent Form

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

Thoughts and Feelings about Cystic Fibrosis and its Treatment.

CONSENT FORM

	Please delete as necessary
Have you read and understood the Patient Information Sheet?	Yes / No
Have you had an opportunity to ask questions and discuss the study?	Yes / No
Have you received satisfactory answers to all your questions?	Yes / No
Have you received enough information about the study?	Yes / No

To whom have you spoken? ....

Do you understand that you are free to withdraw from the study:	
At any time?	Yes / No
Without having to give a reason for withdrawing?	Yes / No
Without affecting your future medical care?	Yes / No
Do you agree to take part in this study?	Yes / No

Signed: .... Date: ....

Name in block letters: .... Date of birth: ....

Parent's/Guardian's signature (if under 16 years): ....

Name in block letters: .... Date:.......................

Contact details ('phone number or postal address): ....
....
....
....

Signed (researcher): .... Date: ....

Appendix 8: Covering Letter for Poole General Hospital

Dear

Kate Hawkins, Trainee Clinical Psychologist, is doing some research into how young people (aged 11-18) feel about having Cystic Fibrosis. The research consists of answering some questionnaires, which Kate will complete with you.

Attached is a letter giving more information about the study. Please read this letter carefully; it is yours to keep. If you would like to take part, please complete the consent form and send it back to me. Alternatively, if you would like to talk to me before making your decision, I am happy to discuss the study with you. You are free to take part, or not take part, as you choose. Your decision will not affect your health care.

Yours sincerely,

Dr Sheila Peters, MRCP FRCPCH
Consultant Paediatrician