TREATMENT ADHERENCE IN ADULTS WITH CYSTIC FIBROSIS: AN EXPLORATORY STUDY OF THE INFLUENCE OF SELF-EFFICACY, SELF-ESTEEM AND PSYCHOLOGICAL MORBIDITY

& RESEARCH PORTFOLIO

PART ONE

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For Anna, Kate and Susie-Beth

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PART TWO (separately bound copy; numbered from page 1)

CHAPTER 1: SMALL SCALE SERVICE EVALUATION PROJECT

Referrer awareness, utilisation and satisfaction with a dedicated Clinical Psychology service in a General Hospital nineteen months after its introduction.

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Abstract

Objective: To examine referrer awareness, utilisation and satisfaction with a dedicated General Medicine Clinical Psychology service 19 months after its introduction in a local hospital.

Design: Questionnaire survey with background information obtained from the departmental database.

Subjects & Settings: Sixty-two medical Consultants based within a General Hospital in Scotland.

Results: Forty-seven Consultants (75.8%) responded with a single reminder to the postal questionnaire. Overall, referrers were satisfied with the service, but were notably dissatisfied with the current length of the waiting list. Unfortunately, the survey revealed that the majority of Consultants (55.6%) were unaware of the service before this contact. Nevertheless, respondents were very positive about the potential usefulness of a range of psychological interventions and there was overall support for further contact and/or information from the service.

Conclusion: The survey demonstrated that Consultants at this local hospital have an awareness of the role of psychology in health, and an encouraging degree of enthusiasm for the application of the skills of Clinical Psychologists in their speciality. However, results suggest that Psychologists working within General Medicine must regularly review and audit their services in order to ensure that all potential referrers are aware of them. Moreover, further specialisation may be required within these services in order to meet the demands of individual medical departments.

Introduction

Traditionally, Clinical Psychologists spend most of their time working with clients referred to them by General Practitioners or by Psychiatrists within hospital settings. However, over the last two decades, increased numbers of Clinical Psychologists have begun working alongside a wide range of medical specialists. Their involvement has been encouraged by research revealing the important contribution psychological factors can play in mediating health outcomes and, concurrently, the usefulness of psychological therapies within medical settings[1,2]. This work has evolved within the rapidly growing field of health psychology, where psychological theory and practice are applied to physical health problems[3].

The Cambridge Handbook of Psychology, Health and Medicine[1] examines psychological theory relevant to 138 different medical conditions, investigations, treatments and prophylaxes. Research has indicated that psychological problems may present as physical disease[4], may be secondary to physical disease[5], may exacerbate existing disease processes[6], and/or may cause physical disease[7]. Psychological problems may also prevent patients from either accepting or complying with medical treatment[8]. Psychological interventions can therefore be used to increase the effectiveness of conventional treatment, to modify the negative psychosocial effects associated with some conditions and/or as an alternative to more traditional kinds of therapy[2]. Psychologists have, for example, made significant contributions in the medical fields of cancer and cardiac disease - two of the leading causes of death today. Psychological interventions with cancer patients have been shown to effectively reduce the distress associated with diagnosis[9] and treatment[10], facilitate effective methods of coping[11] and improve the quality of life of patients with disseminated disease[12]. Similarly, psychological interventions have been shown to effectively reduce the behavioural risk factors in both pre-MI[13] and post-MI populations[14], and reduce the distress associated with an acute cardiac event[15] and with cardiac surgery[16]. Importantly, these psychological interventions are also cost effective, for example, by reducing length of hospital stay[17].

Thus, in terms of the established levels of need and documented efficacy the case for services specialising in psychological care for patients in general hospitals is very strong. However, Psychologists are dependent on the medical Consultants, and other allied professions who are in charge of patient care, to provide appropriate referrals to their services. Therefore, their specific areas of expertise must first be recognised by these professionals. Moreover, the significance of psychological variables in the development, maintenance, and treatment of certain medical illnesses must also be considered by all those involved in the medical care of physically ill individuals.

Unfortunately previous research has shown that whilst professions allied to medicine i.e. speech therapy, physiotherapy, dietetics and occupational therapy, consider psychology services as relevant to their own work, some medical Consultants are ambivalent about this type of service[18]. A recent study in the UK revealed that Consultants within adult specialities of a large teaching hospital were both aware of, and positive about, psychological interventions offered by the local department of Clinical and Health Psychology[19]. However, despite their enthusiasm, 61% of the respondents in that survey had not made a referral to the department in the previous year. Respondents also frequently indicated that they “didn’t know” whether interventions would be useful or not to patient care. For example, 69% of respondents chose this option when asked about psychological interventions used to improve adherence with medical regimes. Yet patient non-adherence with medical regimes is well recognised, and in this area psychological interventions have been shown to improve outcomes[20]. Overall, it appears that more detailed information is still needed regarding health care professionals' beliefs and knowledge of psychological services. Without their awareness and endorsement of such services, patient involvement will be minimal.

The current study focuses on a dedicated Clinical Psychology service to a local general hospital. This service has been operating for nineteen months. It offers four sessions per week, aiming to deal with 30 new patients per year. When the service was established the service Psychologist wrote to the hospital's speciality advisors to notify them of its availability. These Consultants were asked to circulate a specially designed information sheet to the other Consultants for dissemination to their staff. The Psychologist also contacted the Clinical Nurse Managers for outpatients and both medical and surgical in-patient departments to inform them and their staff of the service. In addition to meeting with several Consultants, the Psychologist also addressed a group of senior nursing staff (including cancer and stoma care) about the nature of the service.

The providers of this service are now keen to establish the level of awareness amongst hospital Consultants and satisfaction with the service provided to date. There is the potential for further investigating perceptions of usefulness of psychological interventions within general medicine.

Methods

Aims

The main aims of the study were to assess awareness, utilisation and satisfaction with the service provided to date. In addition, limitations of the current service and methods by which further information could be provided were also examined. A secondary aim was to examine Consultants' perception of usefulness of various psychological interventions.

Design

Demographic information was obtained from the departmental database in order to provide background data to the study. Case notes were examined if additional information was required. A postal questionnaire was designed to achieve the other main aims and sent to Consultants from all medical departments within the hospital.

Measures

As noted, a two part postal questionnaire was designed (Appendix 1.2). In order to maximise return rate the questionnaire was kept short. Part one focused on the assessment of satisfaction with the service and was based on “The Patient Satisfaction Questionnaire" [21]. Questions that the service Psychologist felt important to address were also included. Consultants were asked to complete this section only if they had made a referral. Part 2 focused on the other main research questions with all Consultants asked to complete it. The item focusing on “perception of usefulness” was based on discussion with the service Psychologist and information gathered from previous research[19]. A list of possible Clinical Psychology interventions was presented, and for each one the Consultant was asked to rate whether they agreed or disagreed that it would be useful in their area of work. They were given the option to respond that they would require more information before being able to make a decision. This option was used as an alternative to "don't know". A final option of "not applicable" was also offered.

Not all patients referred to the service will be seen during their hospital admission. Consultants were asked to indicate the impact of this factor on the usefulness of the service. Consultants were also asked if they would welcome further information about the service. They were required to rank on the questionnaire their first and second preferences from a list of possible methods of providing information defined by the service Psychologist.

Procedure

Sixty-two Consultants were identified from the hospital telephone directory and checked with the secretaries of each medical department. The questionnaire was sent to them with a letter of explanation and a return envelope. Each questionnaire was coded so that feedback could be provided if requested. This code was also used to identify non-responders. A second questionnaire and encouraging letter was sent out after a time delay of one month to all non-responders. Consultants were aware that the information provided was confidential, although due to the coding system, not anonymous.

Results

I. Utilisation of the service (Information from database)

In the designated period, forty-two referrals were made to the psychology service from departments based within the hospital. A further five referrals were passed on to the service from other sources outside of the hospital. These are not considered in further analysis because they are not relevant to awareness and utilisation of the within-hospital General Medicine service.

Although there are 16 medical specialities within the hospital, most of the referrals came from Physicians, Geriatricians and Orthopaedic Surgeons (Table 1). Moreover, referrals came from only 14 Consultants, or members of their teams, out of a potential 62. Two of these Consultants have since retired. Thus, three Physicians, two Geriatricians and three Orthopaedic Surgeons account for 80.5% of the referrals from within the hospital i.e. 12.9% of potential referrers are currently providing the bulk of patients to the service.

INSERT TABLE 1 HERE

Analysis of demographic information revealed that twenty-six (55.3%) males and 21 (44.7%) females, aged between 21 and 83 (mean = 48.88, SD = 16.10), were referred. It is departmental policy to attribute either one or two broad formulations, using the Effective Purchasing Providing in the Community (EEPIC) system[22], to each patient from their referral letters. This system describes problems or disorders in psychological terms that relate closely to definitions within DSM IV[23]. Forty-one patients had one EPPIC code, 17 had two (total 58). Information for one patient was missing. Using this system, it appears that the most common reason for referral was difficulties adjusting to illness/disability (Table 2). Emotional problems, psychobiological functioning (e.g. pain) and cognitive functioning were also common reasons for referral.

INSERT TABLE 2 HERE

Information was gathered about treatment offered and/or received. The service operates an opt in system whereby patients are approached as they reach the top of the waiting list and asked if they still wish an appointment. There was a good up-take rate for this service with 76.3% of patients attending their first appointment (Table 3). Patients waited between two and 22 weeks for an appointment (mean = 10.29, SD = 5.22). The first appointment was conducted whilst six (15.7%) were in-patients. The remaining thirty-two (84.3%) were seen, or offered an appointment, in the psychology department on an outpatient basis.

INSERT TABLE 3 HERE

I. Awareness of the service (PART 1 of questionnaire)

Of the sixty-two Consultants identified, forty-seven replied to the questionnaire (a response rate of 75.8%). With the exception of Oral Surgery at least reply one was received from each department. However, thirteen were returned without appropriate data or left blank.

The remaining 34 questionnaires were either fully or mostly complete. Fifteen Consultants (44.4%) were previously aware of the Clinical Psychology service, of which ten had made a referral. Thus, the majority (66.6%) of those who were aware of the service had made a referral.

II. Satisfaction with service

Referrers were generally positive about the service, with only two out of ten responding that they were dissatisfied. However, although all were satisfied with communication between themselves and the service, seven out of ten responded that they were dissatisfied with the length of time patients had to wait to be seen (Table 4).

INSERT TABLE 4 HERE

Referrers were also positive about the type of service they had received. They perceived benefits to their patients and reported that it was likely that they would continue to make referrals (Table 5). Although two Consultants felt that they had not received the type of service they wanted they reported that the contact had been beneficial to their patient and that they would refer again in the future.

INSERT TABLE 5 HERE

Consultants were asked if there were any aspects of the service that they would like changed. Only two did so, both indicating their desire to have a shorter waiting time (Appendix 1.3).

III. Perception of usefulness (PART 2 of questionnaire)

All Consultants were asked to rate their perception of the usefulness of a range of psychological interventions. Response rates vary as some responders did not provide a rating for every intervention. The majority of interventions were endorsed as being both useful and applicable (Table 6). However, for most of the interventions a significant minority felt that they needed to know more about the potential benefits.

INSERT TABLE 6 HERE

Comparisons were made between referrers and non-referrers regarding the perception of usefulness of each intervention. Chi-squared analysis was conducted but no significant differences were found between the two groups (Appendix 1.4). Visual inspection of the results reveals that in general the referrers rated the interventions as more useful than the non-referrers, however there was little difference between the two groups (Figure 1). These results suggest that lack of awareness rather than perception of usefulness may be a more important factor influencing referral patterns to date.

INSERT FIGURE 1 HERE

IV. In-patient services

Thirty-three responses were given in response to the question of whether the service is only of use if patients can be seen during their medical admission. The majority (69.7%) of responders indicated that the service remains useful even if the patient cannot be seen whilst still in hospital.

V. Provision of further information

In respect to provision of further information, thirty-two responses were analysed. Twenty-five Consultants (78.1%) indicated that they would appreciate further information about the service, however, it appeared that there was little consensus over the best way to provide this. Similar numbers of Consultants indicated that they would appreciate either formal or informal presentations. Moreover, whilst some requested only written information a similar number requested more detailed case discussion (Table 7).

INSERT TABLE 7 HERE

Consultants were asked for any other comments. In general comments involved a request for further information and/or input from the service but one Consultant expressed concerns about his perceived difficulty of obtaining an urgent appointment (Appendix 1.5).

Discussion

Given the many demands on the Consultants' time, the response rate to the postal questionnaire compares favourably to previous research[19]. Responses indicate that, in general, the level and format of service provision is being well received. If there is a response bias it is small, as the majority of actual referrers replied to the survey. Consultants were, however, notably dissatisfied with the waiting list. In part, this may reflect the nature of the reason for referral. A two-month wait may not be a problem if the patient's difficulty is long-standing, however if it were an acute event then this delay in responding would be unsatisfactory. The potential length of the wait may then be deterring some Consultants from making a referral, although psychological input could improve patient care. Nevertheless, given the current limits on the service it is encouraging to note that the majority of Consultants indicated that the service is still of value even if the patient can not be seen as an in-patient.

In the first nineteen months just under the proposed number of referrals (42/47) were received from a range of different medical specialities within the hospital. Acceptance of five referrals from other sources outside of the local hospital makes up the quota. Results indicate that if Consultants are aware of the availability of the service they will refer, even if only occasionally. It is therefore perhaps unfortunate, but not surprising given the referral pattern, that over half the Consultants who responded to the survey were unaware of the service before this contact. This is disappointing given the service Psychologist’s attempts at publicising it. A future target may be to explore different methods of increasing awareness of the service, thereby increasing both the number and diversity of referrals. However, given that the service is already meeting its patient number targets, it may not be possible to effectively accommodate this increase whilst maintaining the current level of satisfaction.

Approximately one quarter of patients referred either did not opt in to treatment or failed to attend their first appointment. This rate is no higher than the general departmental opt-in rate. However, some patients who did attend the service commented that they were unaware of the referral by their doctor. Improved communication between the doctors and their patients regarding the reason for referral and the benefits that they may gain from attending a Psychologist may facilitate an increased up-take rate of the service. Nevertheless, research indicates that many patients do not understand or remember what they are told during a medical consultation[24], therefore, the provision of written information for patients about the service may also be required.

The results of this survey indicate a very positive view of potential usefulness of a wide range of interventions offered by Clinical Psychologists. There was considerable support for interventions associated with emotional problems, pain management, and adjustment to illness/disability. These are currently the most common reasons for referral. Consultants may have learnt through experience that these interventions are suitable for their patients. However, both those who had referred and those who had not were very positive, so it is difficult to assess what referrers have actually learned from the service. Moreover, there was also considerable support for interventions not used to date e.g. counselling for terminally ill patients. Staff support was also seen as important, as was staff education/training, but the service does not currently provide this.

Very few areas received negative ratings, although the respondents were clearly undecided about the possible benefits of neuropsychological assessment, psychological input to rehabilitation and psychological preparation for medical/surgical intervention. Given the quantity of research evidence indicating that psychological preparation for surgery can result in better outcomes[25] it is surprising that the latter was rated as the least useful. However, this appears to reflect a lack of knowledge about its possible benefits rather than a dismissal of its usefulness per se. It possibly also indicates that surgical specialities require a more on-call type of service.

Overall, the number of Consultants who indicated that they would require more information before being able to make a judgement about usefulness was noteworthy, ranging from 16.7% to 51.9% over the various interventions. Thus, it appears that there is scope for providing Consultants with more detailed information about the benefits of psychological interventions either through written material and/or by meeting with Consultants on a departmental or individual basis. In fact, the majority of Consultants indicated that they would welcome further information and/or contact. In future, this may facilitate an increased understanding of the potential benefits of the service to both patients and staff.

Conclusion

Although there appears to be a growing appreciation of the possible contributions of Clinical Psychology to health care by medical Consultants, it appears that the Psychologists involved must regularly review and audit their services in order to promote them. However, they must also have the resources available to them to be able to deal effectively with the number of referrals they could receive if their efforts are successful. Moreover, in order to meet the individual demands of different medical departments, some specialisation may be required by Psychologists working within this field.

Service recommendations

1. To explore different methods of promoting awareness of the service within the hospital, this may be achieved by providing Consultants with more detailed information about the service, as they have requested.
2. To examine the feasibility of providing staff training and support within the hospital.

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Table 1.Number (percentage) of department from which referrals were received.

Department	Number	%
Medicine	17	40.5
Medicine for the Elderly	8	19.0
Orthopaedic Surgery	8	19.0
General Surgery	3	7.1
Dermatology	2	4.8
Gynaecology	1	2.4
Neurology	1	2.4
Rheumatology	1	2.4
Urology	1	2.4

Table 2. Number (percentage) of referral EPPIC Broad Formulations

	Number	%
Adjustment of physical illness/disability	21	36.2
Emotional problems (anxiety &/or depression)	14	24.1
Psychobiological e.g. pain management	10	17.2
Cognitive functioning / psychometric testing	7	12.1
Behaviour/Conduct	2	3.4
Social Adjustment / relationships	1	1.7
Habit/dependency	1	1.7
Sexual Functioning	1	1.7
Bereavement	1	1.7

Table 3. Number (percentage) of patients categorised by treatment offered or received (excluding 4 on the waiting list)

Treatment offered or received	Number	%
Patient decided not to opt in to the service	4	10.5
Patient decided to opt in to the service		
Still in treatment	4	10.5
Did not attend or cancelled first appointment	5	13.2
Discharged following assessment and/or treatment	21	55.3
Patient died whilst in treatment	4	10.5

Table 4. Number of responses by question and category (sample number in brackets).

	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
General Satisfaction (n=10)	3	5	1	1
Waiting list (n=10)	0	3	3	4
Communication (n=10)	4	6	0	0

Table 5. Number of responses by question and category (sample number in brackets).

	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
Service wanted (n=9)	3	4	1	1
Beneficial to patient (n=9)	3	6	0	0
Future referral (n=9)	6	3	0	0

Table 6. Percentage of respondents rating intervention as useful, not useful, need more information and not applicable (valid percent in brackets).

	Yes	No	Need to know more	n/a
Psychological help for emotional problems (n=33)	69.7 (76.7)	6.1 (6.7)	15.2 (16.7)	9.1
Pain management (n=34)	64.7 (71.0)	0 (0)	26.5 (29.0)	8.8
Counselling relatives of the dying (n=32)	62.5 (76.9)	3.1 (3.8)	15.6 (19.3)	18.8
Staff education/training (n=31)	61.3 (70.4)	0 (0)	25.8 (29.6)	12.9
Adjustment to illness/disability (n=33)	60.6 (74.1)	3.0 (3.7)	18.2 (22.2)	18.2
Counselling the dying (n=33)	60.6 (76.9)	3.0 (3.8)	15.2 (19.2)	21.2
Staff support (n=30)	60.0 (69.2)	3.3 (3.8)	23.3 (26.9)	13.3
Counselling relatives for adjustment (n=32)	56.3 (69.2)	6.3 (7.7)	18.8 (23.1)	18.8
Adherence to treatment (n=30)	50.0 (65.2)	3.3 (4.3)	23.3 (30.4)	23.3
Eating and smoking disorders (n=32)	50.0 (66.7)	3.1 (4.1)	21.9 (29.2)	25.0
PTSD (n=31)	45.2 (63.6)	6.5 (9.1)	19.4 (27.3)	29.0
Neuropsychological assessment (n=32)	37.5 (52.2)	3.1 (4.3)	31.3 (43.5)	28.1
Rehabilitation (n=31)	38.7 (52.2)	9.7 (13.0)	25.8 (34.8)	25.8
Psychological preparation for medical/surgical intervention (n=34)	26.5 (33.3)	11.8 (14.8)	41.2 (51.9)	20.6

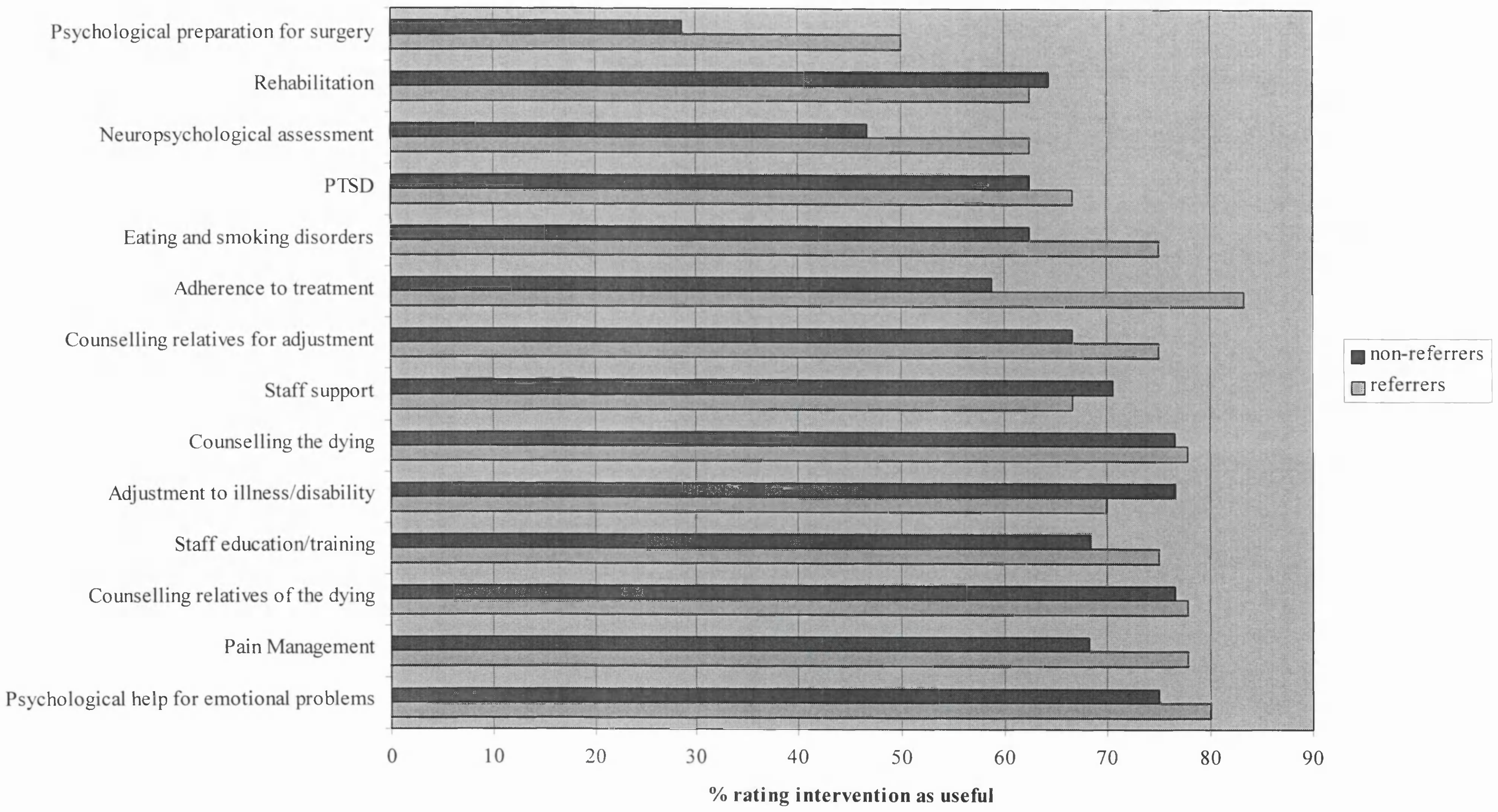
* valid percent = percentage calculated after removing not applicable responses.

Table 7. First and second choices for provision of further information.

	Frequency of response	
	1st Choice	2nd Choice*
Formal presentation to group of staff	7	5
Written information	7	5
Informal visit to their department	5	4
Case discussion	6	4

* Not all Consultants made use of the second choice option

Figure 1. Valid percentage of referrers and non-referrers who perceive each intervention as useful



CHAPTER 2: MAJOR RESEARCH PROJECT LITERATURE REVIEW

Treatment adherence in adults with Cystic Fibrosis: a discussion of contemporary research findings.

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Abstract

Advances in the care of patients with Cystic Fibrosis have led to the majority surviving into adulthood. However, the daily treatment routine involves a complex, time-consuming and expensive range of treatments and studies have consistently revealed variable rates of adherence. Non-adherence has a number of negative implications for both the individual and healthcare providers. Researchers in this field hope to be able to both identify patients at risk of non-adherence and to develop strategies aimed at improving adherence. A variety of demographic, clinical and psychological variables have been explored as potential predictors of non-adherence, but the literature in the adult population is limited. Future research will explore how these factors interact and impact upon the individual's ability to self-manage their illness.

Word count 121

Key phrases: Cystic Fibrosis, Adherence, Psychological Morbidity, Self-efficacy

Introduction

Cystic Fibrosis (CF) is the most common fatal hereditary disease in the Caucasian population; 4-5% carry the recessive gene and 1:2000 live births are affected (Lewiston, 1985; Mathews & Drotar, 1984). Whilst once considered a disease of childhood, advances in the management and care of patients with CF has led to the majority of patients surviving into adulthood (Elborn, 1998). The current median survival for patients with CF is approximately 30 years, compared with 5-6 years in the 1950's (Elborn, 1991). Understanding the psychological, social and vocational functioning of these adults is a new area of both clinical interest and research effort. Research in other chronic illness populations has revealed the important role that psychological factors can play in mediating health outcomes (Baum, Newman, Weinman, West, & McManus, 1997) and it is expected that as the literature in this field grows, similar findings will also be reported. The focus of this review is the examination of psychological factors that may influence treatment adherence in adult CF patients.

The self-management of Cystic Fibrosis

CF is a complex autosomal recessive disease affecting the exocrine glands in several major organ systems, including respiratory, digestive, and reproductive. The course of CF is extremely variable with respect to both the organs that are involved and its clinical severity. People with CF range from being asymptomatic with no outward appearance of ill health to having symptoms of chronic cough productive of large amounts of sputum, wheezing, dysponea and limited exercise tolerance. Patients with CF generally experience a slow deterioration in pulmonary function over time, but there is much variability within each person as well as between people with CF. Some of this variability may be attributable to the specific gene mutations (Kerem, Reisman, Corey, Canny, & Levison, 1990), but environmental factors and treatment strategies also play a large role. Assessment of the efficacy and effectiveness of any therapy in CF takes a long time because of this slow and variable progression.

Although there have been significant advances in understanding the genetic and basic defect in CF patients, cure is still not available (Collins, 1992). Therefore, the treatment of CF is actually the prevention and treatment of its complications. In the lungs, abnormal mucus production impedes the normal clearing mechanism. The mucus accumulates in the bronchi and bronchioles, leading to obstruction and infection from an early age (Oppenheimer & Easterly, 1995). Over time this process permanently damages the lungs and results in respiratory insufficiency. For example, cardio-respiratory factors were responsible for 78.1% of deaths in CF patients in North America in 1991 (FitzSimmons, 1993). General measures to minimise the extent and effect of chest infection include early diagnosis, good nutrition, minimising exposure to colds and acute viral respiratory infections, adequate immunisation, avoidance of smoking and "second hand" smoking. In addition, chest physiotherapy is an integral part of the management of cystic fibrosis. It aims to reduce airway obstruction by improving the clearance of secretions, to reduce the severity of the infection by clearing infected material and the maintenance of optimal respiratory function and exercise tolerance (Moss, 1995; Ramsey, 1996, Webber & Pryer, 2000). Exercise has also been advocated as an alternative or supplement to physiotherapy as it may loosen mucus from the lungs (Orenstein, Henke, & Cherny, 1983; Webber & Dodd, 2000). CF patients are also susceptible to bacterial infection, which is typically combated by antibiotic treatment administered orally, intravenously or through use of aerosols. Antibiotics can be prescribed prophylactically or following detection of infection (Hodson, 2000).

The secretion of digestive juice from the pancreas is also severely reduced in most CF patients from an early age and, unless treated with pancreatic extract, the digestion and absorption of food is severely impaired (Borowitz, 1994). Inadequate absorption of food from the bowel will lead to unpleasant digestive symptoms, malnutrition, poor growth and specific deficiencies of fat soluble vitamins A, D and E (Littlewood & Wolfe, 1994). There is evidence that well nourished patients have a better prognosis (Corey, McLaughlin, Williams, & Levison, 1988; Elborn & Bell, 1996). It is, therefore, essential that CF patients have an adequate energy intake, effective pancreatic supplements and a supplement of fat-soluble vitamins (Littlewood & MacDonald, 1987; Littlewood & Wolfe, 1994).

The negative implications of poor adherence

Good self-management involves the individual adjusting their daily routine and resources around their medical treatments. Patients must also routinely monitor their symptoms and interpret changes as a basis for modifying the frequency and type of therapy. Finally, they must know how to contact and communicate effectively with their health care providers regarding changes in symptoms or conditions. To maintain good self-management is a challenge for most patients as they attempt to balance their social and medical needs. Given these demands, some degree of non-adherence is unsurprising. In particular, adherence to chest physiotherapy, diet and exercise prescriptions are often cited as problematic (Abbott, Dodd, Bilton, & Webb, 1994; FitzSimmons, 1993; Shepherd, Hovel, & Harwood, 1990; Stark, Miller, Plienis, & Drabman, 1987).

Poor adherence over a sustained period of time has a number of negative implications. For the patient it may lead to increased infective exacerbations and faster disease progression; possibly causing lost time in education or work and further distress about health status (Patterson, Budd, Goetz, & Warick, 1993). For the health care provider it can result in wasted resources e.g. unused medications, an increased demand in outpatient visits, and inpatient stays (Abbott & Gee, 1998). In addition, non-adherence may interfere with research trials monitoring the effectiveness of new forms of treatment. It is therefore a major concern for not only the patient and their family, but also the medical team in charge of their care, National Health Service Trust purchasers and pharmaceutical companies.

Factors influencing adherence

Non-adherence to medical treatments is not a problem unique to CF. It is estimated that rates of non-adherence vary from a low of 15% for short-term regimens taken in episodes of acute illness to as high as 93% for longer-term regimens requiring changes in life-style (Kaplan & Simon, 1990). Moreover, research suggests that many patients fail to either correctly follow medication instructions and or to complete prescribed courses of treatment, potentially endangering their health and wasting health resources (Haynes, 1982). In order to address the negative implications of non-adherence investigators have attempted to both identify patients at risk of non-adherence and to develop strategies aimed at improving adherence. There is an extensive research literature examining the value of range of factors in predicting non-adherence (Conner & Norman, 1996; Edelmann, 2000). Early research tended to be atheoretical and focused mainly on examining the role of patient characteristics, clinical factors, provider characteristics and the interaction between patients and health care staff (Table 1). Searching for factors that identify the "non-adherent" patient is limited by findings that demonstrate that patients are inconsistent in their adherence behaviour; within the same individual adherence rates often vary between treatment types and over time. In recent years research has become more theory driven and models of health behaviour e.g. social cognition and self-regulatory models of illness have been applied to the understanding of patients' adherence to treatment regimens (Conner & Norman, 1996). Research using these models has broadened our understanding of the cognitive, behavioural and emotional factors that may influence adherence and the dynamic way in which these factors may interact. Findings have demonstrated that adherence may be influenced by patients' beliefs about their illness, their treatment and/or their ability to manage their health care. Therefore, at times, non-adherence can be viewed as the intentional result of patients' decision making about their health rather than the unintentional consequences of their personal characteristics, their health status, or the health care that they have received.

As in other areas, investigators hope to be able to identify factors that place CF patients at risk of non-adherence and to develop strategies aimed at improving adherence. Investigators have attempted to identify high-risk groups within the CF population by relating both demographic variables e.g. age, gender, socio-economic status etc. and clinical variables e.g. illness severity, age at diagnosis etc., to adherence. In addition, they have attempted to link variables such as psychological morbidity and level of knowledge to adherence in an attempt to produce a theoretical basis for designing interventions. This latter area of research has gained little attention to date in the adult population, however, based on research findings a number of interventions have been designed and applied successfully in the paediatric population (Maxwell & Stone, 1992; Stark et al., 1987; Steinberg, Taylor, Lemming & Simmons, 1992).

Demographic & Clinical predictors of non-adherence

Most studies of adults have failed to identify differences in adherence on the basis of demographic factors such as employment and socio-economic status (Abbott et al., 1994). In contrast, there is evidence to suggest that both age and gender are influential. Consistent with findings in other chronic illness groups (e.g. Korsch, Fine, & Negrete, 1978) adherence has been shown to be negatively affected during adolescence with female patients reported to be less adherent than their male counterparts (Czajkowski & Koocher, 1986; Ricker, Delamater, & Hsu, 1998). Moreover, there is some evidence to suggest that following adolescence adherence will improve again (Hamlett, Murphy, Haynes, & Doershuk, 1996). However, other studies have failed to confirm these findings (Abbott et al., 1994; Abbott & Gee, 1998) suggesting that there is not a straightforward relationship between demographic factors and treatment adherence.

Similarly, results from studies examining the influence of disease severity on adherence have been equivocal. Whilst some have reported that more severely ill patients are less likely to be adherent (Abbott, Dodd, & Webb, 1995; Gudas, Koocher, & Wypij, 1991), others have failed to confirm this finding (Abbott et al, 1994; Abbott, Dodd & Webb, 1996; Conway, Pond, Hamnett & Watson, 1996). Research in other chronic illness groups (Hartmen & Becker, 1978; Kirscht & Rosenstock, 1977) suggests that it is the perception of disease severity, not the actual disease severity, which predicts treatment adherence. This matter deserves further consideration in the adult CF population (Sawyer, Rosier, Phelan & Bowes, 1995).

Psychological morbidity and adherence

In recent years, investigators have devoted considerable attention to the role that psychological variables play in mediating self-management and health status in chronic illness patients. It is likely that the relationship between these variables is complex, and it is difficult to establish causality in the absence of longitudinal studies. However, in general, investigators have hypothesised that psychological variables have an indirect impact on health status through their impact on self-management behaviours including adherence to medical treatments (Newburgh, Simpkins, & Maurer, 1985; Peyrot, 1985; Schafer, Glasgow, McCaul, & Dreher, 1983). This hypothesised relationship is based on two assumptions: adherence directly influences health status, and psychological variables have a direct effect on adherence.

The bulk of literature in this area relates to metabolic control with diabetes patients. Studies have revealed that emotional difficulties e.g. anxiety, depression, low self-esteem, can have a negative impact of the individual's ability to manage their illness, which may lead to non-adherence (Littlefield, Craven, Rodin, Danenon, Murray, & Rydall, 1991; Warren & Hixenbaugh, 1996) and poor metabolic control (Mazze, Lucido, & Shamoon, 1994). In particular, research suggests that female patients tend to be at a greater risk of developing eating disorders and having poor metabolic control in their adolescent years in comparison with their male counterparts (Hamburg & Inoff, 1982; Kaar, Akerblom, Huttunen, Knip, & Sakkinen, 1984; Steel, Young, Llyod, & McIntyre, 1987). Research in other chronic illness populations is less extensive, however, similar findings have been reported. For example, Bosley and colleagues (Bosley, Fosbury, & Cochrane, 1995) reported a link between depressive symptomatology and poor adherence in adult patients with asthma. In addition, studies have reported a link between poor self-esteem and non-adherence in renal transplant patients (Korsch et al., 1978), adolescents with rheumatoid arthritis (Litt, Cuskey, & Rosenburg, 1982) and individuals with epilepsy (Friedman, Litt, & King, 1986).

CF, like other chronic diseases, can have a major impact on the individual's psychosocial status. The extraordinary effort required for self-care as well as the ever-present possibility of developing further complications may present psychological and social stresses. There is a small, but growing literature, examining the psychological functioning of adult CF patients. In general, investigators have concluded that CF patients are a well adjusted group (Anderson, Flume, & Hardy, 2001; Blair, Cull, & Freeman, 1994; De Jong, Kaptein, & VanderSchans, 1997). However, some studies have reported that adult patients frequently experience emotional difficulties, eating disorders and social isolation (Boyle, di Sant'Agnese, & Sack, 1976; Sawyer et al., 1995; Strauss & Wellish, 1981). It is possible that the inconsistent findings reported are a result of the variety of methodologies used in this research. Primarily, a variety of diagnostic and self-report measures have been applied, not all of which are standardised for use in chronic illness groups. Secondly, some studies have failed to use control groups either of well subjects or of families coping with other illnesses. Finally, even when control groups have been employed they have not always been well matched to the CF group (e.g. Blair et al., 1994). It is also possible that, given the rapidly improving prognosis of this disease, older studies may not generalise to today's adult CF patients.

However, it remains possible that some patients will experience psychological difficulties, either related to their illness or other life events. In addition, there is some evidence to suggest that adolescent CF patients are at increased risk of developing psychological difficulties (Boyle et al., 1976; Coffman et al., 1984; Sinnema, Bonarius, Von der Laag, & Stoop, 1988). Moreover, that adolescent females may experience more emotional difficulties than their male counterparts (Bywater, 1981; Coffman et al., 1984; Sawyer et al., 1995). Therefore, it is important to understand the possible impact psychological difficulties may have on adherence and, potentially, on health status.

Unfortunately, in comparison to other chronic illness groups, few studies have been published to date examining the impact of psychological adjustment on adherence in adult CF patients. In contrast, a number of studies have examined how the psychological status of parents of children with CF may impact on their ability to manage their children's illness (e.g. Geiss, Hobbs, Hannersley-Maercklein, Kramer, & Henley, 1992). In one of the few studies using older patients Ricker et al. (1998) revealed that self-esteem predicted adherence, but this study was limited by its small sample size. Thus, it appears that this is an area that requires further research. Given that research indicates that adolescent patients may be at risk of both poor adherence and increased levels of psychological morbidity there are a number of areas that merit particular attention when examining the relationship between psychological factors, adherence and health status.

Firstly, an adolescent's desire to conform to their peer group and to be independent of their parents may lead them to deny their illness and/ or to neglect their medical regimen (Heisler & Friedman, 1981; Sawyer et al., 1995; Tatersall & Lowe, 1981). Secondly, concerns about body image during adolescence may hinder good adherence. Research in diabetes has indicated that females' concerns about body image can interfere with their use of medication to control blood sugar levels (Polonsky, 1994). It is possible that similar concerns may lead female CF patients to be less adherent to their prescribed pancreatic enzyme medication and recommended calorific intake (Smrekar, Ellenmunter, Rothner, & Bonan, 1992). For example, it has been noted that young females with CF are often quite comfortable with a low body mass index because their shape and size conforms with their perception of normal body image for their sex (Elborn, 1998). Non-adherence in this area has potentially very negative implications as nutritional status is related to the clinical course for patients with CF (Elborn & Bell, 1996; Kerem et al., 1992). Finally, the chronic and incurable nature of CF may become more salient and discouraging during adolescence and the impact this has on adherence requires consideration.

Knowledge, Self-efficacy and adherence

Koocher, McGrath and Gudas (1990) hypothesised that inadequate knowledge due to either a lack of information or misinterpretation of information provided may influence treatment adherence. This hypothesis has good face validity: the management of CF requires extensive information about the condition and the skills required to monitor and manage its symptoms e.g. how chest physiotherapy should be performed, when enzymes should be taken etc. A number of studies have examined both patients' and caregivers' knowledge about CF and demonstrated that, in general, they are a well informed population (Conway, Pond, Hamnett, & Watson, 1996; Hames, Beesley, & Nelson, 1991; Henley & Hill, 1990; Nolan, Desmond, Herlich, & Hardy, 1986). Researchers have also attempted to examine whether knowledge is predictive of adherence. Unfortunately, as with much of the research in this field, findings have been equivocal. Whilst some studies have reported a positive relationship between knowledge and adherence (Czajkowski & Koocher, 1986; Giess et al., 1992), others have failed to find a significant relationship between these variables (Conway et al., 1996).

This has led some investigators to conclude that whilst patients should obviously be made aware of the various aspects and consequences of their illness, education alone will not be effective in improving adherence (Parcel, Swank, Mariotto, Bartholomew, Czyzowski, Sockrider, & Selheimer, 1994). Moreover, it has been proposed that efforts should be made to investigate other factors that may be important determinants of adherence. In particular, the role that self-efficacy and outcome expectations may play has been highlighted as an area of future research. Although the demanding nature of the CF treatment regimen is well recognised, little attention has been paid to patients' beliefs about their ability to perform the complex tasks necessary to be adherent, and the benefit of doing so. According to social cognitive theory (Bandura, 1986), individuals with knowledge of what to do and how to do it (behavioural capability), confidence in being able to perform the behaviours (self-efficacy) and belief that their behaviour will result in some favourable outcome (outcome expectation) will be more likely to perform the specified behaviour.

As with other areas of interest, research examining the relationship between adherence and self-efficacy has been limited to paediatric samples (Czajkowski & Koocher, 1986; Ricker et al., 1998). For example, Parcel et al. (1994) examined the role of self-efficacy in parents' management of their child's medical regime. Controlling for the effects of all other variables, including demographic, they concluded that self-efficacy was the most important educational factor predicting self-management behaviour for monitoring and treating respiratory problems. Therefore, because it is possible to enhance a person's self-efficacy in order to improve adherence (Kaplan, Atkins, & Reinsch, 1984) this is an area of potential future research in the adult CF population.

Research limitations

The research literature concerned with the examination of predictors of treatment adherence in adults with CF is small in comparison to other chronic illness groups. Moreover, it is unfortunate that studies to date have often yielded inconclusive or contradictory results. It has been suggested that these inconsistencies reflect the variety of methodologies employed to assess adherence (Abbott & Gee, 1998). The assessment of adherence is a complex task, but little empirical attention has been paid to the development of standardised methods of assessment. Although direct measures of medication adherence e.g. analyses of blood and urine samples, are more objective, they are difficult and expensive to obtain. Therefore, studies have generally used indirect methods e.g. diaries, self-report questionnaires and medical staff reports. Authors have suggested that self-report measures are invalid as they can be biased by factors such as a patient's desire to appear socially acceptable (Moise, Drotar, Doershuk, & Stern, 1987), and it has been suggested that they overestimate adherence by up to 20% (Haynes, 1982). Nonetheless this method has the advantage of being least expensive and valuable to the extent that those who report non-adherence rarely lie (Litt & Cuskey, 1980). In addition, it has been proposed that medical staff are also poor judges of patient adherence (Conway et al., 1996; Litt & Cuskey, 1980). For example, Roth (1987) reported that doctors overestimated patients' intake of medication by 50%. There are various reasons for their possible overestimation: they may believe that patients automatically follow their recommendations, or simply lack reliable information about their patients' behaviour.

Insensitive scoring systems have also been problematic in the assessment of adherence. Some studies have assessed several treatment components but then combined data to provide an overall adherence score (e.g. Czajkowski & Koocher, 1986; Patterson, 1985; Strauss & Wellisch, 1981). However, the validity of a combined score may be poor because patients are often adherent to one aspect of their treatment but not to others (Abbott et al., 1994; Conway et al., 1996; Passero, Remor, & Salomon, 1981; Pownceby, 1996).

In addition to the difficulty of accurately assessing adherence, many published studies appear to lack statistical power or are over-inclusive in terms of age range. For example, Czajkowski and Koocher (1986) combined school aged children as young as thirteen and patients in their early twenties, when examining psychological functioning in 'adolescent' CF patients. Moreover, children (some with parental reporting) and adults have been combined in data analyses (Meyers, Dolan, & Mueller, 1975; Passero et al., 1981; Patterson, 1985) yet reports of patient and parent are not necessarily similar, and neither are reports of children and adults. These problems probably reflect the difficulties in recruiting adequate sample sizes from within one medical centre. Unfortunately, this means that extrapolations regarding particular findings may be unwise. Similarly, most studies have been cross-sectional and it would be useful to have more longitudinal data so that adaptation to CF can be explored through developmental transitions.

A self-selection process may also be operating, with the more vulnerable or maladjusted patients not volunteering to participate in research studies. In addition, patients participating in research studies examining treatment adherence may either consciously or unconsciously try to portray themselves in the best possible light for fear of being criticised by medical staff. Therefore, when possible, research should be conducted by individuals who are independent of the medical team responsible for the patient care.

Finally, a major problem that arrives from gaining samples from medical centres is that health professionals may be reluctant to either engage in research or to allow access to their patient group. This reluctance may arise from genuine concerns regarding patients' rights to privacy, demands being placed on unwell patients and/or the quality of the therapeutic relationship between staff and patients being damaged. For example, medical staff may be concerned that patients will find the experience so aversive that they fail to attend subsequent appointments. Staff may also be concerned that the outcome of any research may reflect negatively on their practice. In addition, staff may be reluctant for researchers to 'take up' patients' time during busy clinic visits when they may have to see all members of a team (doctor, physiotherapist, nurse, dietician, psychologist) and under-go routine health checks. As with the other methodological limitations already noted, these factors highlight the difficulty of conducting good theoretically driven investigations (which may require large sample sizes and a wide range of lengthy and/or possibly intrusive measures) in hospital settings where the primary focus should always be the rights and needs of the patient.

Conclusion

Given the complexity, demanding nature and expense of treatment, combined with the negative effects of non-adherence, research evaluating self-management in CF has been surprisingly limited in its scope and sophistication. Understandably, most studies to date have concentrated on examining correlates of regimen adherence in children with CF. However, as the life expectancy of the CF population increases it is important to understand factors that may influence adherence in this condition. To date, findings suggest that some patients, in particular adolescent females, are at risk of experiencing psychological difficulties. Future research will determine how this impacts upon the self-management of their illness and health status.

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Table 1. A selection of factors that have been examined as potential predictors of treatment adherence.

- ***Patient Characteristics***

Demographic factors e.g. age, gender, ethnicity, level of education, socio-economic status, marital status, living situation etc.

Personality traits

Past behaviour in relation to treatment regimens

Level of social support and family functioning

Knowledge about disease and treatment regimen

Understanding and recall of treatment regimen information

Negative beliefs about medical treatments

Satisfaction with health care

- ***Clinical (disease/ treatment) variables***

Illness severity

Length of time since diagnosis

Complexity and type of treatment regimen (e.g. medication Vs exercise)

Side effects of treatment

Duration of treatment regimen

- ***Provider characteristics and interaction between patients and providers***

Communication style of health care staff and clarity of information provided

Empathy and understanding of health care staff

Health care staffs' satisfaction with in their job

Frequency, length and accessibility of consultations

- ***Factors associated with models of health behaviour***

Beliefs about illness e.g. symptoms, severity, cause, prognosis etc.

Beliefs about the benefits of treatment adherence

Beliefs about barriers to treatment adherence

Beliefs about the views of significant others (e.g. family, friends, doctors etc.)

Emotional adjustment

Self-efficacy and outcome expectancies

Coping style

Locus of control

(Litt & Cuskey, 1980; Conner & Norman, 1996; Edelmann, 2000)

CHAPTER 3: MAJOR RESEARCH PROJECT PROPOSAL

Treatment adherence in adults with Cystic Fibrosis: an exploratory study of the influence of self-efficacy, self-esteem and psychological morbidity

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Word Count 2452

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Title

Treatment adherence in adults with Cystic Fibrosis: an exploratory study of the influence of self-efficacy, self-esteem and psychological morbidity.

Summary

The daily medical regime for patients with CF involves a complex and time-consuming range of treatments. Poor adherence is a common problem within this population and is a major concern for the various groups involved in patient care. There is a growing literature on adherence within this population but to date only a few studies using paediatric samples have examined the influence of psychological factors on treatment adherence. Self-efficacy, along with self-esteem and psychological well-being, have been shown to be predictors of adherence in other chronic illness patient groups and

research indicates that they may also be of importance within the adult CF population. The objective of this study is to examine the inter-relationship between treatment adherence, self-efficacy, self-esteem and psychological morbidity. A minimum of sixty-six patients will be recruited from the West of Scotland Adult Cystic Fibrosis Centre based in Gartnavel General Hospital. Participants will be asked to complete a set of relevant questionnaires. Additional information will be obtained from patient records. It is hoped that the findings of this study may be used to help identify individuals who are at risk of having difficulty adhering to their medical regime as a result of psychological factors.

Introduction

Cystic Fibrosis (CF) is the most common fatal hereditary disease in the Caucasian population; 4-5% carry the recessive gene and 1:2000 live births are affected. It is a chronic illness that affects multiple organ systems and ultimately results in premature death. However, advances in the management and care of patients with CF have led to the majority surviving into adulthood (Elborn, 1998). This improved survival rate has been attributed to earlier diagnosis, multidisciplinary specialist care and more effective methods of treatment.

Without a cure, medical treatment targets only the symptoms of the disease in order to increase life span. The daily treatment routine involves a complex, time-consuming and expensive range of treatments including physiotherapy; nebulised, oral and intravenous drugs; exercise and nutritional supplements. Adherence to such a treatment while living a busy school, work and social life is extremely difficult for most patients. In particular, adherence to chest physiotherapy, diet and exercise prescriptions are often cited as problematic. For example, whilst physiotherapy is crucial in preventing the onset of pulmonary disease, which is responsible for 78% of CF deaths (FitzSimmons, 1993), studies consistently reveal that approximately half of patients do not regularly adhere to this form of treatment (Stark et al., 1987; Shepherd et al., 1990; Abbott et al., 1994). Non-adherence may not only cause accelerated disease, but also leads to wasted resources, increased outpatient visits, and more admissions to hospital. In addition, non-adherence may interfere with research trials monitoring the effectiveness of new forms of treatment. It is therefore a major concern for not only the patient and their family, but also the medical team in charge of their care, National Health Service (NHS) Trust purchasers and pharmaceutical companies.

It is hoped that research investigating the determinants of adherence will help identify those at risk and be used to help design interventions for improving adherence. Understandably, most studies to date have concentrated on examining correlates of regimen adherence in children with CF. However, it is difficult to generalise findings to the adult patients, as it is the parents, and not the children themselves, who are generally responsible for implementing the medical recommendations. Based on research studies conducted in other chronic illness groups, a number of factors have been identified as potentially important predictors of non-adherence and have guided research to date.

Demographic factors

Research has suggested that during adolescence, rates of non-adherence increase (Gudas et al., 1991; Ricker et al., 1998). Research also suggests that gender may influence adherence during adolescence, with females reported to be less adherent than their male counterparts (Czajkowski & Koocher, 1987). However, other studies have failed to confirm these findings (Abbott et al., 1994), suggesting that there is not a straightforward relationship between demographic factors and treatment adherence.

Clinical factors

Similarly, results from studies examining the influence of disease severity on adherence have been equivocal. Whilst some have reported that more severely ill patients are less likely to be adherent (Gudas et al., 1991; Abbott et al., 1995), others have failed to confirm this finding (Conway et al., 1996; Abbott et al., 1994; Abbott et al., 1996). Research in other chronic illness groups (Hartmen & Becker, 1978; Kirscht & Rosenstock, 1977) suggests that it is the perception of disease severity, not the actual disease severity that predicts treatment adherence. This matter deserves further consideration in the adult CF population (Sawyer et al., 1995).

Psychological factors

Research in other chronic illness groups has suggested that psychological morbidity influences treatment adherence (e.g. Richardson et al., 1988). Although research indicates that in general adult CF patients are psychologically well adjusted (Blair et al., 1994), it appears that particular groups within this population are more vulnerable to psychological difficulties. Consistent with research in other chronic illness populations, studies have revealed that adolescent patients report higher levels of psychological morbidity and lower self-esteem when compared to their healthy peers (Seigel et al., 1990; Sinnema et al., 1988). A few studies have also indicated that females experience more difficulties than their male counterparts (Coffman et al., 1984; Cowen et al., 1984; Simmons et al., 1985). It is therefore of interest to examine how psychological morbidity affects treatment adherence in the adult CF population. In addition, it is of interest to examine further how these psychological factors relate to demographic factors.

Despite the demanding nature of the CF treatment regime, little attention has been paid to patients' beliefs about their capability to perform the complex tasks necessary to be adherent and the benefit of doing so. Perceived self-efficacy is thought to influence how a person feels, thinks and acts (Bandura, 1977, 1994). Individuals with high-perceived self-efficacy, it is proposed, will approach difficult tasks with a more competitive sense toward mastery, invest more effort and persist longer than those with low self-efficacy. In relation to a difficult medical regime, low self-efficacy beliefs may prevent the patient from investing the required amount of effort and persistence needed to adhere fully to all the recommended treatments.

Individually these psychological factors may all influence a patient's ability to be adherent to their medical regimen. It is also likely that they influence each other. A perceived inability to be adherent along with negative feedback from carers and medical staff may have a detrimental effect on the individual's self-esteem and psychological well being. Conversely, decreased self-esteem and psychological morbidity may maintain low self-efficacy.

As noted, the bulk of research to date has focused on examining correlates of adherence in children with CF. However, as the life-expectancy of the CF population increases it is important to understand non-adherence in both adolescents and adults. A review of the current literature indicates that the above factors merit further investigation.

Research Aim & Hypotheses

The main aim of the present study is to examine how psychological factors (self-efficacy, self-esteem and psychological morbidity) relate to treatment adherence in the adult CF population. There is little published research investigating psychological factors in this group but, as treatable causes of non-adherence, they have important implications. A secondary aim is to examine how these psychological factors inter-relate with demographic and clinical factors.

1) It is hypothesised that treatment adherence will be related to psychological factors. It is expected that those who have higher self-esteem and lower levels of psychological morbidity will be more adherent.

2) It is hypothesised that treatment adherence will be related to self-efficacy and outcome expectations. It is expected that patients with low self-efficacy and outcome expectation beliefs will be less adherent.

3) It is hypothesised that self-efficacy will be related to self-esteem and psychological morbidity. It is expected that patients with low self-efficacy will have poorer self-esteem and greater psychological morbidity.

4) It is hypothesised that demographic factors will interact with treatment adherence and psychological factors.

Plan of investigation

Subjects

Patients will be recruited from the West of Scotland Adult Cystic Fibrosis Centre based in Gartnavel General Hospital. Participants should be aged ≥ 16 and be responsible for the management of their CF treatment.

Measures

Information will be obtained directly from patients, from the staff involved in their care and from their medical records.

From patients - Basic demographic information and subjective reports of symptom severity will be obtained from all patients. Two visual analogue scales will be used to assess patients' subjective views on their health status. They will be asked to rate the severity of their illness and perception of their health in comparison to other individuals with CF (Appendix 3.2). A higher score on each reflects a perception of being in better health. The scales were anchored in this manner in order to mirror FEV_1 ratings.

In addition, they will be asked to complete the following questionnaires.

1. The Manchester Adult Cystic Fibrosis Compliance Questionnaire (Abbott et al., 1994). This questionnaire was developed to measure the rates of adherence, patients' perception of adherence and reasons for non-adherence (Appendix 3.3). It assesses adherence to physiotherapy, exercise, pancreatic enzymes and vitamin prescriptions.

2. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). This scale is a 14 item self-rating questionnaire designed to screen for anxiety and depression in patients with physical illness. It contains depression and anxiety subscales scoring from 0-21, where a score of ≥ 11 indicates probable disorder.

3. The Rosenberg Self-Esteem Scale (Rosenberg, 1965, 1989). This is a ten-item scale that assesses the strength of an individual's perceived self-worth. Possible scores range from 0 to 10, where a score of >6 indicates low self-esteem.

4. The CF Self-efficacy Instrument for Adolescents (SE) and the Outcome Expectation Instrument for CF (OE) (Bartholomew et al., 1993) will be used to examine patients attitudes towards treatment self-management (Appendix 3.4 & 3.5). The first scale assesses patients' feelings of self-efficacy i.e. their confidence in being able to manage their illness. The scale contains 14 items that assess four factors of treatment management (1) communication with the health care team, (2) acceptance and coping (3) medical judgement and communication and (4) adherence to medical treatment. Possible scores range from 0-70, with high scores indicating high treatment management self-efficacy. The second scale assesses outcome expectations i.e. patients' beliefs about the effect of self-management on disease process and quality of life. It contains 8 items; Possible scores range from 0-40 with high scores indicating high outcome expectations. The questions relating to medical treatment will be modified in order to reflect the range of treatments under consideration.

These measures were chosen from a range of potential measures that have been used in similar research. Measures that may have provided additional information relating to patients' beliefs about their health status and coping stype include the Illness Perception Questionnaire (Weinman et al, 1996), the Multi-dimensional Health Locus of Control Scales (Wallston et al, 1978), and the Ways of Coping Scale (Lazarus & Folkman, 1984). Following discussion with the unit team these measures were excluded due to concerns about the length of time it may take patients to participate in the study and about the potential negative connotations created by the wording of some of the questionnaire items.

From medical records - Information about the patients' prescribed medical regime will be obtained in order to help validate the self-report measure of adherence. Basic information regarding their previous medical history and treatment will be gathered as general measures of illness severity. Forced expiratory volume (FEV_1), a measure of pulmonary function, will be taken as a specific measure of illness severity.

From health professionals - The medical professionals involved in the patients' care will be asked to rate how adherent they believe the patients to be.

Design

The Manchester Compliance Questionnaire allows patients to be divided into two groups based on their responses (fully adherent and partially adherent/non-adherent). Previous studies have generally examined several different components of treatment e.g. physiotherapy, diet, exercise, etc., and then combined the data to provide an overall adherence score. Unfortunately, this type of score fails to recognise that patients commonly adhere to one aspect of their treatment but not to others (Shepherd et al., 1990; Abbott et al., 1994; Conway et al., 1996). Therefore, adherence to the individual treatment components will be considered. In addition, it has been suggested that self-report measures of adherence may have poor validity because they can be biased by factors such as the patients' desire to appear socially acceptable. Therefore, although patients will be divided into groups based on their self-report adherence, the validity of this will be confirmed through comparison with the medical team's reports/opinions.

The independent variables are self-efficacy, self-esteem and psychological morbidity (anxiety and depression scores). Demographic factors e.g. age, gender, living situation, marital status, and Clinical factors e.g. disease severity, symptom severity, frequency of clinic visit, will also be considered.

It is expected that data analysis will involve an examination of the relationships between the dependent and independent using a combination of descriptive and inferential statistics.

A literature search revealed no published studies examining the relationship between treatment adherence and self-esteem (as measured by the RSE) or psychological morbidity (as measured by the HADS) in the adult CF patients. Therefore, similar research conducted in children with CF and adults in other chronic illness populations was used to guide the power calculation. Two relevant papers were identified. Littlefield et al. (1991) examined psychological correlates of regimen adherence in adolescents with diabetes. Results indicated that patients who reported lower adherence tended to report lower self-efficacy ($r = 0.57$, $p<0.001$), lower self-esteem ($r = 0.45$, $p<0.001$) and higher levels of depressive symptomatology ($r = -0.51$, $p<0.001$). Ricker et al. (1998), when examining correlates of regimen adherence in children with CF, reported that patients who scored more highly on a measure of self-worth were more adherent ($r = 0.52$, $p <0.002$). These studies indicate that there is a robust relationship between psychological factors and regimen adherence in similar populations. Assuming a significance level of 0.05 and a power of 0.80, sixty-six subjects would enable an effect size of 0.40 to be detected between adherence and the psychological factors chosen (calculated using G*POWER).

Settings and equipment

Questionnaire booklets for this study will be produced and compiled using materials and equipment housed within the Department of Psychological Medicine. Data analysis will also be conducted on computers based within the department.

A room will be required within the out-patient clinic of the CF unit to conduct the interviews. The main researcher will also require access to a telephone.

Procedures

Patients who regularly attend out-patient clinic appointments will be provided with information about the study (Appendix 3.6). They will be requested to contact the main researcher should they wish to participate in the study. In addition to being able to discuss the research project, they will be given an information sheet and a consent form (Appendix 3.7). If the patient consents to participating in the study, they will be given the option of either: -

a. completing the questionnaires whilst present in the clinic,
b. making an appointment with the researcher to complete the questionnaires with them at a more convenient time e.g. at home, by telephone, during their next clinic visit etc.

Data Analysis

Data from the questionnaires and other information gathered will be stored in a lockable filing cabinet in the Department of Psychological Medicine. Data will be entered anonymously onto a database. The Statistical Package for Social Science (SPSS for Windows) will be used to analyse the data.

Descriptive statistics will initially be undertaken. It is expected that tests of difference (t-tests), association (Chi-square, correlation, kappa statistic) and analysis of variance will be used to explore the relationships between the dependent and independent variables. Further inferential statistics may be conducted depending on the results of the initial planned analysis. The qualitative data obtained from the interviews will also be examined.

Practical Applications

Psychological interventions have been effectively used to improve adherence to treatment in a number of chronic illness populations e.g. cancer, diabetes (Anderson & Golden-Kreutz, 1997; Bradley, 1997). It is hoped that the results of this study will reveal a relationship between psychological factors and treatment adherence in adult CF patients. Thus, the findings could be used to help identify individuals who are at risk of having difficulty adhering to their medical regime as a result of psychological factors. Moreover, as potentially treatable factors of non-adherence, the findings may indicate an increased role for Clinical and Health Psychology in the medical care of the adult CF patient.

Timescale

The proposed starting date would be June 2000. The project would run for 14 months.

Ethical approval

A submission will be made to the appropriate ethics committee (Appendix 3.8).

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Amendment to proposal

The following statement explains the discrepancies between the major research project proposal and the major research project paper.

Originally it had been planned to examine adherence to four components of the patients' treatment regimen – physiotherapy, exercise, pancreatic enzymes and vitamins. However, the physiotherapist attached to the unit advised that exercise is prescribed to only a few patients who attend the clinic. Therefore, it was decided not to analyse the data relating to exercise as part of the write-up of this paper.

The planned statistical analysis was altered following consultation with Dr James Currall (medical statistician). ANOVA was not used as the number of potential variables involved in the analysis would not have allowed for an accurate interpretation of interactions.

CHAPTER 4: MAJOR RESEARCH PROJECT PAPER

Treatment adherence in adults with Cystic Fibrosis: an exploratory study of the influence of self-efficacy, self-esteem and psychological morbidity

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Abstract

The aim of the present study was to examine how psychological factors, shown to be relevant in the self-management of other chronic illnesses, relate to adherence to treatment in the adult CF population. Sixty-nine participants completed a set of questionnaires assessing treatment adherence, psychological morbidity, self-esteem and beliefs about treatment self-management. In agreement with previous research, results from this study demonstrate that approximately half of adult patients are not fully adherent to their prescribed medical regimen and that adherence may vary between treatment components. Participants reported low levels of psychological morbidity and, contrary to predictions psychological well-being was not related to adherence. Beliefs about health status and self-management were predictive of adherence, suggesting that these are possible targets for psychological intervention.

Word count 121

Key Words: Cystic Fibrosis, Adherence, Psychological Morbidity, Health Beliefs

Introduction

Cystic Fibrosis (CF) is the most common fatal hereditary disease in the Caucasian population. Whilst once considered a disease of childhood, advances in the management and care of patients has led to the majority of individuals with CF surviving into adulthood (Elborn, 1998). This improved survival rate has been attributed to earlier diagnosis, multidisciplinary specialist care and more effective methods of treatment. However, it is likely that the prognosis of CF patients is determined not only by objective pathophysiological factors, but also by patients' psychological reactions to aspects of their disease and its management. Although research examining this issue has been limited, it is hypothesised that psychological variables influence health status through their impact on self-management behaviours (Bartholomew, Parcel, Seilheimer, Czyzewski, Spinelii, & Congdon, 1991; Brown, Rowlet, & Helms, 1994; Caine, Sharples, Smyth, Scott, Hathaway, & Higginbottom, 1991).

Without a cure, medical treatment targets only the symptoms of the disease. The daily medical regime for patients with CF involves a complex and time-consuming range of treatments. Poor adherence is a common problem within this population and is a major concern for the various groups involved in patient care (Abbott & Gee, 1998). Researchers in this field hope to be able to both identify patients at risk of non-adherence and to develop strategies aimed at improving adherence. Understandably, most studies to date have concentrated on examining predictors of adherence in children with CF. This research, along with that conducted in other chronic illness populations, has identified a number of psychological factors that may prove predictive of adherence in adult CF patients.

Firstly, studies have revealed that emotional difficulties can have a negative impact on patients' ability to self-manage their illness (Bosley, Fosbury, & Cochrane, 1995; Friedman, Litt, & King, 1986; Littlefield, Craven, Rodin, Danenon, Murray, & Rydall, 1991; Litt, Cuskey, & Rosenburg, 1982; Mazze, Lucido, & Shamoon, 1994; Warren & Hixenbaugh, 1996). Recent research has revealed that adult CF patients are a well adjusted group (Anderson, Flume, & Hardy, 2001; Blair, Cull, & Freeman, 1994; De Jong, Kaptein, & VanderSchans, 1997). However, this does not exclude the possibility that some patients will experience psychological difficulties. In addition, there is some evidence to suggest that adolescent females experience greater psychological difficulties than their male counterparts (Coffman, Levine, Althof, & Stern, 1984; Cowen, Corey, Simmons, Keenan, Robertson, & Levison, 1984; Sawyer, Rosier, Phelan, & Bowes, 1995; Simmons, Corey, Cowen, Keenan, Robertson, & Lewison, 1985). Concurrently, these females are less likely to be adherent (Czajkowski & Koocher, 1987; Gudas, Koocher, & Wypij, 1991; Ricker, Delamater, & Hsu, 1998) and to have a poorer prognosis (Kerem, Reisman, Corey, Canny, & Levison, 1992). Little is known about the interaction of these clinical, demographic and psychological factors. It is possible that the poorer health status of females reflects not only pathophysiological aspects of the disease, but also poor adherence and psychological adjustment. Which, in turn, may also be inter-related.

Secondly, research in other chronic illness groups has revealed that patients who perceive their health to be under threat are more likely to be adherent (Hartmen & Becker, 1978; Kirscht & Rosenstock, 1977). Results from studies examining the relationship between illness severity and adherence with adult CF patients have been equivocal (Abbott, Dodd, & Webb, 1996; Conway, Pond, Hamnett, & Watson, 1996, Gudas et al., 1991). However, since CF patients' beliefs about their health status may not match objective measures of disease severity (Abbott, Dodd, & Webber, 1995) it is important to understand how both perceived and actual illness severity relate to adherence in this group.

Finally, it has been demonstrated that in paediatric CF samples parents who have confidence in their ability to manage their child's illness and who appraise the outcome of their actions as being beneficial are more likely to be adherent (Parcel, Swank, Mariotto, Bartholomew, Czyzowski, Sockrider, & Selheimer, 1994). How self-efficacy and outcome expectations relate to adherence in the adult CF population requires further consideration.

Whilst individually these psychological factors may all influence a patient's ability to be adherent to their medical regimen, it is also likely that they influence each other. A perceived inability to be adherent along with negative feedback from carers and medical staff may have a detrimental effect on the individual's self-esteem and psychological well being. Conversely, decreased self-esteem and psychological morbidity may maintain low self-efficacy.

Therefore, the aim of this study is to examine how psychological adjustment, beliefs about health status and self-management affect treatment adherence in the adult CF population. Moreover, to examine how these psychological factors relate to each other, to demographic factors and to clinical factors. The findings of this study may be used to help design interventions aimed at facilitating improved adherence.

Method

Participants

Consecutive patients attending a local adult Cystic Fibrosis Centre were invited to take part in the study. Ninety-seven patients were approached to take part in the study. Eleven refused and 86 consented to participate.

Procedure

A brief interview was conducted with each participant. To minimise the "faking of good effect," interviews were conducted away from the treatment area by a researcher not directly involved in patient care. The importance of confidentiality was emphasised. The study questionnaire (made up of the measures below) was explained and left with patients to be completed alone. Patients returned the questionnaire either at the end of the clinic or by post. If the questionnaire had not been returned within two weeks a reminder letter was sent.

Measures

1. The Manchester Adult Cystic Fibrosis Compliance Questionnaire (MCFCQ: Abbott, Dodd, Bilton, & Webb, 1994). This questionnaire was developed to measure the rates of adherence, patients' perception of adherence and reasons for non-adherence (Appendix 3.3). Three treatment areas were considered - physiotherapy, pancreatic enzymes and vitamin supplements. The MCFCQ allows patients to be divided into fully adherent and non-adherent groups for each treatment component.

2. The Hospital Anxiety and Depression Scale (HAD: Zigmond & Snaith, 1983). This scale is a 14 item self-rating questionnaire designed to screen for anxiety and depression

in patients with physical illness. It contains depression (HAD-D) and anxiety (HAD-A) subscales scoring from 0-21, where a score of ≥11 indicates probable disorder.

3. The Rosenberg Self-Esteem Scale (RSE: Rosenberg, 1965, 1989). This ten-item scale assesses the strength of an individual's perceived self-worth. Possible scores range from 0 to 10, where a score of >6 indicates low self-esteem.

4. The CF Self-efficacy Instrument for Adolescents (SE) and the Outcome Expectation Instrument for CF (OE) (Bartholomew, Parcel, Swank, & Czyzewski, 1993) were used to examine patients' beliefs about treatment self-management (Appendix 3.4 & 3.5). The first scale assesses patients' confidence in being able to manage their illness. Possible scores range from 0-70, with high scores indicating high treatment management self-efficacy. The second scale assesses patients' beliefs about the effect of self-management on disease process and quality of life. It contains 8 items; Possible scores range from 0-40 with high scores indicating high outcome expectations. Following data collection, reliability analysis was performed on both scales as they had been slightly modified for the purpose of this study. Reliability coefficients (Cronbach's alpha) of 0.92 for the SE scale and 0.76 for the OE scale reflected adequate internal consistency for both.

5. Subjective illness severity. Two visual analogue scales were used to assess patients' subjective views on their health status (Appendix 3.2). They were asked to rate the severity of their illness (PIS) and perception of their health in comparison to other individuals with CF (PHC). A higher score on each reflected a perception of being in better health. The scales were anchored in this manner in order to mirror FEV_1 ratings.

6. Objective illness severity. Disease severity of participants was categorised using spirometric determination of lung function. FEV_1, the volume of air exhaled during the first second of forced exhalation was measured. FEV_1 is analysed as the percentage predicted based on an individual's height, age and gender (Knudson, Lebowitz, Holberg, & Burrows, 1983). The normal range is 80-100% of predicted FEV_1. Mild pulmonary disease is 60-80% of predicted FEV_1, moderate is 40-60%, and severe is below 40%.

The health professionals involved in the patients' care also provided ratings of adherence. Research has suggested that health professionals are more accurate if they rate the element of treatment they have the most involvement in (Conway et al., 1996). Therefore, the physiotherapist was asked to rate adherence to physiotherapy, the dietician to rate adherence to pancreatic enzymes and the nurse to rate adherence to vitamin therapy.

Data analysis

A number of studies in this area have assessed several treatment components and then combined data to provide an overall adherence score. However, this may fail to reflect that patients can adhere to one aspect of their treatment but not to others. Therefore, to prevent loss of information specific to each treatment component, data relating to physiotherapy, pancreatic enzymes and vitamins were analysed separately.

The main aim of the study was to consider the potential value of certain demographic, clinical and psychological factors for predicting treatment adherence. Model building techniques e.g. linear regression, are often employed to answer this type of question. The aim of these techniques is to find the best fitting and most parsimonious model to describe the relationship between an outcome i.e. dependent variable and a set of variables i.e. independent variables (Hosmer & Lemeshow, 1995). For this study, logistic regression is the most appropriate method of analysis as adherence was measured as a discrete (adherent/ non-adherent) outcome variable. Initially, the relations between the independent variables were examined using Pearson correlation coefficients. Secondly, in order to select potential predictor values to be entered into the logistic regression analysis, univariate analysis of each independent variable was conducted. Differences between adherent and non-adherent patients were investigated using independent *t*-tests and chi-square analysis. Kolmogorov-Smirnov and Levene's tests were applied to the data to assess normality of the distribution and equality of variances respectively, with results indicating that parametric statistics were appropriate. Predictors were selected if they met recommended criterion of $p < 0.25$ and a model was prepared for each treatment component using a forward procedure. The significance of the variables in the models are examined by comparison to a model fit with the constant term only (constant only model).

All analyses were performed using the Statistical Package for Social Sciences (SPSS Version 9.0 for Windows). Given the number of planned comparisons a conservative alpha level of $p < 0.01$ was set for *t*-tests in order to minimise the chance of a Type 1 error.

Results

Sixty-nine adults returned completed questionnaires, a response rate of 80.23%. The demographic and clinical pattern of the sample (Table 1) is consistent with recent surveys of the adult CF population (Walters, 2000; Walters, Britton, & Hudson, 1993).

INSERT TABLE 1

In general, the non-responders were a younger and healthier sample. However, no significant differences were revealed between the groups in relation to gender ($\chi^2 = 1.80$, p = 0.26), age ($t = 1.18$, p = 0.06) or lung function ($t = -2.01$, p = 0.05).

Distribution of adherence

Only physiotherapy had been prescribed to all patients, the majority (n = 46: 66.7%) of whom had been advised to perform it twice daily. Fifty-eight (84.1%) patients were prescribed pancreatic enzymes to be taken with meals and snacks and sixty-two (89.9%) were prescribed daily vitamins. In accordance with previous research, rates of adherence varied amongst the treatment components. Approximately one half of patients (n = 36, 52.2%) were classified as fully adherent to physiotherapy, 46.6% (n = 27) were adherent to their pancreatic enzymes and 61.8% (n = 38) were adherent to vitamins. One quarter of patients (n = 17, 24.6%) rated themselves fully adherent to all their prescribed treatments, 52.2% (n = 36) were adherent to some components but not to others, and the remaining 23.3% (n = 16) did not adhere to any component of treatment.

Reasons given for non-adherence

Patients were asked to provide common reasons for missing therapies. Respondents could give more than one reason for non-adherence. Reasons given appear to be related to the perception that treatment is not required if the patient is in good health, a lack of commitment required in terms of time and effort and a natural tendency to forget (Table 2).

INSERT TABLE 2

Comparison with health professionals' ratings of adherence

The physiotherapist felt unable to provide ratings for fourteen patients because he met with them infrequently. For similar reasons the dietician rated adherence for 48 patients and the nurse rated adherence for 58 of the patients. There was a modest ($\kappa = 0.40$, $p = 0.02$) level of agreement between patient and physiotherapist's ratings of adherence (Table 3). There was poorer agreement between the patients and dietician in relation to enzyme intake ($\kappa = -0.03$, $p = 0.75$) (Table 4) and between patients and nurse in relation to vitamin intake ($\kappa = -0.04$, $p = 0.78$) (Table 5).

INSERT TABLES 3-5

This unexpected level of discordance led to an exploratory analysis comparing cases where there was agreement between the patient and the health professional to cases where there was disagreement. Responses were divided into two groups (agreed or disagreed on level of adherence) for each treatment component and discordance examined in relation to the patients' demographic factors, health status (objective and subjective), emotional adjustment and beliefs about self-management. Unfortunately, no statistical differences were revealed between groups in any treatment component (Appendix 4.1). For vitamin adherence the analysis relating to age approached significance ($p = 0.05$), with better agreement found between nurse and patients when the patients were older.

Psychological adjustment

Overall, levels of depressive symptoms were low within the sample (Mean HAD-D score = 2.56, SD = 2.27), the majority of patients falling within the normal range (n = 65, 94.2%). It is notable that no patients scored within the morbid range for depression. Although a greater number of anxiety symptoms were reported (Mean HAD-A score = 6.38, SD = 3.18), the majority of patients again scored within the normal range (n = 46, 66.7%). Similarly, the majority (n=54, 78.3%) of patients scored within the high self-esteem range of the RSE (Mean score = 1.79, SD = 2.20). Contrary to predictions there were no significant differences between males and females or between younger and older patients when compared on measures of psychological adjustment (Appendix 4.2).

Correlations between independent variables

Table 6 shows the Pearson correlations coefficients between the independent variables.

INSERT TABLE 6

I. Demographic measures

Age was not significantly associated with either health status (objective and subjective) or measures of psychological adjustment. However, there was a significant association between age and outcome expectancy scores ($p = 0.04$) with older patients reporting higher levels of beliefs in the benefits of self-management activities.

II. Health status

There was a significant association between lung function and both perception of illness severity ($p = 0.04$) and health in comparison to others ($p < 0.01$). However, correlational analysis fails to reflect that patients appear to be consistently underestimating the severity of their lung disease. The majority of patients (79.7%) fell within the moderate and severe categories of pulmonary disease, yet 61.8% rated themselves towards the mild end of the subjective illness severity scale (score ≥ 60).

III. Psychological adjustment, self-efficacy and outcome expectations

As expected, patients with lower levels of psychological morbidity had higher levels of self-efficacy. Both measures of anxiety ($p = 0.02$) and self-esteem ($p = 0.01$) were significantly associated with self-efficacy. The relationship between outcome expectancy scores and psychological measures was more variable. However, there was a trend for higher levels of expectancies to be associated with higher self-esteem ($p = 0.08$).

In relation to measures of health status, there was a significant association between lung function and depression scores ($p = 0.03$), patients with poorer lung function reporting a greater number of symptoms. Similarly, trends were revealed between level of depression and both perception of illness severity ($p = 0.07$) and perception of health in comparison to others ($p = 0.08$), again with patients who perceived themselves to be more unwell reporting a greater number of depression symptoms. The relationship between objective and subjective measures of health status, anxiety, self-esteem and self-efficacy was more variable. However, perception of illness severity was significantly associated with outcome expectation score ($p < 0.001$). Patients who perceived themselves to be more ill had higher expectations about the benefits of good self-management.

Selection of potential predictors of non-adherence

In order to aid selection of potential predictors of non-adherence planned univariate analysis was conducted for each treatment component. It is recommended that any variable whose univariate test has a $p < 0.25$ should be considered as a candidate for the multivariate model (Hosmer & Lemeshow, 1995).

I. Demographic measures

Previous research has suggested that adherence varies with age and gender. Results revealed that for enzymes female patients were less adherent than male patients, this difference meeting the criteria for inclusion in the logistic regression ($\chi^2 = 8.39$, $p < 0.01$). For vitamins the adherent patients were older than non-adherent patients, this difference meeting criteria for inclusion in the regression analysis ($t = 2.30$, $p = 0.02$). No other differences met the criterion.

II. Health status

The relationship between health status and adherence varied between treatment components. For physiotherapy, both objective and subjective measures of health status met criteria for inclusion in the logistic regression analysis, with the non-adherent appearing to be in better health than the adherent patients (Table 7). For enzymes, perception of illness severity met criteria for inclusion in regression analysis (Table 8), again with the non-adherent patients perceiving themselves to be in better health than the adherent patients. No health status factors met criterion for inclusion in the analysis related to vitamins (Table 9).

INSERT TABLES 7-9

III. Psychological adjustment, self-efficacy and outcome expectancies

Contrary to predictions there was not a strong association between adherence and measures of psychological adjustment. However, the difference in self-esteem score reached criterion for inclusion in the regression analysis for both physiotherapy and vitamins (Table 7&9). In both cases non-adherent patients had lower self-esteem scores than adherent patients. In addition, the difference in depression score reached criterion for inclusion in the regression analysis for vitamins, with the non-adherent patients reporting a higher level of symptoms (Table 9).

In contrast, stronger associations were demonstrated between adherence and beliefs about self-management. The group differences for self-efficacy and outcome expectation scores for both physiotherapy and vitamins met criterion for inclusion in regression analysis (Tables 7&9). Similarly, the group difference for self-efficacy score met criterion for inclusion in the regression analysis for enzymes. In all cases the non-adherent patients reported poorer self-efficacy and outcome expectancies than the fully adherent patients.

Logistic regression

In summary, based on the results of the *t*-tests potential predictors were selected for initial inclusion in the regression analysis for each treatment component. For physiotherapy, FEV_1, perception of illness severity, health in comparison to others, self-esteem score, self-efficacy and outcome expectation scores were selected. For enzymes, gender, perception of illness severity and outcome expectation scores were selected. For vitamins, age, depression, self-esteem, self-efficacy and outcome expectation scores were selected.

A model was then built for each treatment component to establish the combination of variables that best predicted adherence. Variables were removed if they contributed no additional explanatory variance (*R*) to the prediction of adherence. Table 10 shows regression coefficients, odds ratios and other relevant statistics for predictor variables in each treatment component.

INSERT TABLE 10

For physiotherapy, a model comprised of perception health in comparison to others and outcome expectancy scores was found to be the best predictor of adherence. The model correctly identified 68% of the fully adherent patients and 69.23% of the non-adherent patients and was significant ($\chi^2 = 16.03$, $p < 0.01$) when tested against a constant only model. For enzymes, a model comprised of gender and perception of illness severity was found to be the best predictor of adherence. The model correctly identified 70.8% of adherent patients and 75.9% of non-adherent patients and was significant ($\chi^2 = 11.90$, $p < 0.01$) when tested against a constant only model. For vitamins, a model comprised of age and outcome expectation scores was found to be the best predictor of adherence. The model correctly identified 78.6% of the fully adherent patients but only 45% of non-adherent patients. A test of the model with these predictors against a constant only model was significant ($\chi^2 = 8.98$, $p = 0.01$).

Discussion

It may be unrealistic to expect adults with CF to strictly follow treatment advice as they attempt to strike a balance between their psychosocial needs and medical demands. However, it remains important to identify and address psychological factors that may negatively affect self-management. Results from this study suggest that psychological adjustment is not predictive of adherence. In contrast, demographic factors, beliefs about health status and self-management behaviours are influential, although this varies between treatment components.

Psychological adjustment

It is encouraging to find that the majority of patients in this sample were in good psychological health. Consistent with recent research that has reported little or no difference between the psychological adjustment of CF patients and normal controls (Anderson et al., 2001; Blair et al., 1994; De Jong et al., 1997), patients reported low levels of depressive symptomatology and high self-esteem. The greater frequency of anxiety symptoms reported is consistent with the clinical experience of mental health professionals working within CF services who have highlighted the need for basic anxiety management information/treatment to be provided to CF patients (Hains, Hobart Davies, Behrens, & Biller, 1997; Spirito, Russo, & Masek, 1984). In this sample, gender and age were not predictive of psychological adjustment.

Results from this study failed to demonstrate an association between measures of psychological adjustment and treatment adherence. This is perhaps related to the low levels of psychological morbidity within the sample, with comparative studies in other chronic illness groups reporting higher levels of both anxiety and depression (e.g. Bosley et al., 1995). Due to the self-selection of this sample it is possible that the least adherent and/or the most psychological maladjusted patients have either not been recruited to the study or have not returned questionnaires (Breetvelt & Van Dam, 1991). Alternatively, these results may highlight that the relationship between adherence and psychological adjustment is more complex in this patient group in comparison to other groups previously sampled.

Health beliefs, self-efficacy and outcome expectancies

The demands of the different treatments vary considerably, in terms of behaviours, skills and time requirements. It is therefore unlikely that a unitary explanation of non-adherence can be applied to all individuals and all treatment components. However, results suggest that beliefs about health status and self-management have some predictive power in determining risk of non-adherence. Firstly, a perception of poorer health was associated with better adherence to both physiotherapy and enzyme therapy. Thus, patients are more adherent to these forms of therapy if they perceive that their health status is compromised. Secondly, for both physiotherapy and vitamin therapy, patients' who appraised the outcome of self-management tasks as being beneficial to their health were more likely to be adherent. Moreover, greater confidence in the ability to adequately perform the tasks necessary to self-manage their illness was also related to better adherence.

The aim of this study was not to examine any one model of health behaviour, but to explore more generally psychological factors that may be related to non-adherence. However, both social cognition and self-regulatory models of illness advocate that cognitive variables can influence adherence to treatment regimens (Conner & Norman, 1995). The findings in this study are consistent with predictions made in a variety of models including The Health Belief Model (Rosenstock, 1974), the Theory of Planned

Behaviour (Ajzen 1985; Ajzen & Madden, 1986) and the Self-Regulatory Model of illness (Leventhal, Meyer, & Nerenz, 1980). These models predict that the likelihood of an action being performed is increased if the perceived threat of the disease is high. In addition, they predict that patients' beliefs about treatment self-management, which reflect evaluations of their ability to perform certain tasks and their appraisals of the outcome, will also influence adherence. Future research should expand upon the current findings, investigating the potential relevance of these models in more detail with a larger sample size.

Reasons given for non-adherence

The reasons given by patients for missing therapies highlights the different factors that affect adherence to each treatment component. Consistent with the data relating to health beliefs and previous research (Abbott et al., 1996, Conway et al., 1996), common reasons given for non-adherence to physiotherapy were that patients believed that they were well enough without it and that the severity of their disease was less than that of others. In addition, reasons reflected that it is a time-consuming and inconvenient task to perform. In comparison, reasons provided for non-adherence to the medications reflected practical issues e.g. not always having enzymes available when deciding to have a snack or simply forgetting.

The different reasons given for non-adherence to enzymes and vitamins compared with physiotherapy also highlight the fact that it is not only the physical demands of treatments but also the social implications of them that potentially influence adherence. Enzymes must be taken with all meals and snacks. This could prove inconvenient if individuals either do not wish to discuss their condition or do not want others to know about it. There is little published literature examining the potential impact of CF patients telling peers, employers etc. about their condition. However, surveys have shown that if patients reveal that they have CF at a job interview it reduces the likelihood of being employed (Walters et al., 1993) and/or that they may find it difficult to secure life insurance, loans and mortgages (Quin, 1992). It is unfortunate that some individuals may be allowing their health to be compromised because of the fear of negative evaluations by others.

In addition, a small number of patients, mainly female (4/5), admitted to not taking enzymes because it aided weight loss. Concurrently, results demonstrated that females are less adherent than their male counterparts to this form of treatment. Eating disorders are a recognised clinical problem within this population (Elborn, 1998) yet nutritional status is related to the clinical course of CF (Elborn & Bell, 1996; Kerem et al., 1992). It is a challenge for health professionals to encourage patients, in particular young females who are often quite comfortable with a low body mass index, to be adherent to this form of treatment.

Objective vs subjective measures of health status

Results suggest that patients' beliefs about the severity of their illness influences adherence. However, it is recognised that patients' subjective beliefs about their illness severity do not necessarily match objective measures and that CF patients under-report the severity of their illness in comparison to the health professionals involved in their care (Abbott et al., 1995; Pownceby, 1996). Results from this study revealed a significant association between patients' ratings of health and objective measures of health status. However, it appears that patients' reports are more optimistic than objective measures of health status. Denial, as a form of coping, has been reported in many chronic illness populations and is thought to facilitate emotional adjustment

(Edelmann, 2000). Unfortunately, coping mechanisms involving denial and minimisation have a negative impact on good treatment adherence as patients may fail to recognise and/or accept the severity of their condition. This poses a difficult dilemma: if patients use of denial is related to good psychological functioning then it should be accepted. However, if concurrently it impedes them from engaging in self-care behaviours, because they deem them only necessary when their health deteriorates, then these beliefs should be challenged. Prospective research is needed to explore the interactions of these factors over time.

Patients' vs health professionals' ratings of adherence

It is unfortunate that results revealed a poor level of agreement between health professionals' ratings of adherence and patients' ratings. Whether this relates to the validity of patients' self-ratings or the ability of the health professionals' to recognise non-adherent patients is open to debate. The patients in this study did not have any reason to lie, as the researcher was independent of the clinic and confidentiality was assured. Conversely, the health professionals involved have a high level of contact with these patients and only provided ratings on patients they felt they knew well enough.

Exploratory analysis of factors that may have been associated with discordance between patients' and staffs' reports failed to demonstrate any significant associations. These factors, however, related only to patient and clinical variables. Alternative factors such as the relationship between the patient and the health professional e.g. frequency of meetings, quality of relationship etc., may be more strongly associated with discrepancies in reports. Similarly, characteristics of the health professional e.g. number of years in practise, beliefs about non-adherence etc., may also be important.

Further research is required to help clarify this issue, as it is important that health professionals are able to identify patients at risk of non-adherence in order to provide support aimed at improving adherence. As part of this process the factors that lead to discordance in reports of adherence must also be understood.

Illness severity & psychological morbidity

Previous research within CF and other chronic illness groups has suggested that psychological well being is relatively independent of the severity of illness (Bradley, Dempster, Wallace, & Elborn, 1999; Cowen et al., 1984; Drotar, 1981; De Jong, et al. 1997; Moise, Drotar, Doershuk, & Stern, 1987; Stein & Jessop, 1984). However, in this study there was an association between level of depressive symptoms and both objective and subjective assessments of health status, with patients in poorer health reporting a greater number of depression symptoms. Correlations do not imply causation and it is impossible to determine if poor physical functioning leads to poor psychological functioning or vice versa. Prospective studies are needed to assess the interaction between disease severity (objective & subjective) and psychological adjustment.

Limitations

There are a number of limitations with the current study. Firstly, patients were recruited on the basis of their willingness to take part in the study, therefore, a selection bias cannot be excluded. Secondly, as noted, self-report measures of adherence can be unreliable because many patients misjudge their behaviour or deny non-adherence for fear of being criticised (Litt & Cuskey, 1980; Moise et al, 1987). Unfortunately, whilst direct measures of medication adherence e.g. analyses of blood and urine samples, are more objective, they are difficult and expensive to obtain. Thirdly, the anchoring used on the visual analogue scales assessing patients' beliefs about their health status may been confusing to some patients which, potentially, limits the validity of these measures. Whilst they correspond to the type of feedback patients may receive from medical staff regarding their health status, the anchoring is the reverse of what one might expect from a scale of this type. Fourthly, the correlational and cross-sectional nature of the present study does not allow precise determination of the direction of influence of the obtained relationships and further prospective studies are required. Finally, the predictive models generated in this study explained only a small amount of the variance. On the basis of statistical evidence the potential value of them for predicting adherence is limited. However, they are of clinical value when taken in context with the additional information provided by patients as to why they are non-adherent.

Clinical implications

Results suggest a number of possible avenues for interventions aimed at promoting good adherence in this population. Patients' self-efficacy beliefs and outcome expectations should be enhanced. In addition, their beliefs about their health status should be monitored. It is important that patients are aware that their actions in following prescribed treatments can make a difference, even if the benefits are not immediately apparent. Moreover, health professionals should monitor not simply whether patients are aware of what they should be doing, but also whether they feel that they are able to adequately perform these tasks. Close monitoring, extensive follow-up and adequate supervision should aid this process. Concurrently, staff must ensure good communication between themselves and patients, and attempt to foster an environment where patients feel comfortable in expressing their difficulties in being adherent and/or motivations for non-adherence. As part of the process of improving communication and acceptance between staff and patients and between patients and their peers/employers etc., support groups may provide a forum for patients to discuss the difficulties they face in attempting to manage their illness effectively. Patients may be able to support and advice each other on solutions/coping strategies useful in ameliorating some of these difficulties. Current practice in CF units limits socialisation between patients in order to reduce the risk of bacterial cross-infection, therefore, support groups of this type would need to be run on a remote basis e.g. by using the Internet.

Conclusion

Many aspects of the CF medical regimen are prescribed prophylactically, often do not provide obvious benefit in terms of symptomatic relief or improved health status, and are not inherently reinforcing. It is likely that a combination of factors predict non-adherence in this population, and that these factors vary in strength depending on the treatment component under consideration. Results from this study suggest that health beliefs and attitudes towards self-management are related to adherence and, therefore, may be incorporated into interventions aimed at improving adherence.

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Table 1. Characteristics of the study population*

Characteristics	Responders	Non-responders
Subjects		
Total	69	17
Male	40 (60%)	13 (76.5%)
Female	29 (42%)	4 (23.5%)
Age, yr		
Mean	25.78 (7.64)	22.00 (6.23)
Range	16-47	16-34
Median	24	20
FEV_1		
% predicted	44.45 (19.24)	54.85 (16.68)
< 40% predicted	33 (47.8%)	4 (23.5%)
40-60% predicted	22 (31.9%)	5 (29.4%)
> 60% predicted	14 (20.3%)	8 (47.1%)
Employment status		
Employed	28 (40.6%)	4 (23.5%)
Student	20 (30.0%)	8 (47.1%)
Unemployed	9 (13.0%)	2 (11.8%)
Housewife/carer	7 (10.1%)	2 (11.8%)
Unfit for work	5 (7.2%)	1 (5.9%)
Marital status		
Single	51 (73.9%)	15 (88.2%)
Married/ Cohabiting	18 (26.1%)	2 (11.8%)
Living arrangements		
Lives with family/partner	57 (82.6%)	16 (94.1%)
Lives alone	9 (13.0%)	
Lives with friends	3 (4.3%)	1 (5.9%)

* values given as means (SD) of patients, unless otherwise indicated.

Table 2. Reasons given for non-adherence

	No. of times given as a reason for non-adherence
Physiotherapy	
I feel well without treatment	31
I can't always be bothered	29
There isn't enough time	21
I simply forget	19
My CF isn't as serious as most of the other CF patients	19
It interferes with my social life	17
It's embarrassing	11
I resent having to do it	9
I do plenty of exercise, so I don't need to do it	8
It interferes with family routine commitments	4
It makes me feel worse	3
I have difficulty doing my own physiotherapy	3
I have to rely on someone to help me	2
I don't fully understand why I need to do it	1
I don't believe that it does me any good	1
Enzymes	
I simply forget	27
I don’t always carry them around with me	23
I am embarrassed to take them in front of other people	9
I don't want others to know that I have CF	6
If I don’t take them it helps me to lose weight/ stay slim	5
I only take enzymes when I feel unwell	4
My CF isn't as serious as most of the other CF patients	3
It interferes with my social life	3
I resent having to take them	2
My body occasionally needs a rest from medication	1
I have difficulty swallowing them	1
I have difficulty getting repeat prescriptions	1
Vitamins	
I simply forget	31
I don’t always carry them around with me	7
I can’t always be bothered	6
I only take them when they are given to me	4
I only take them when I feel unwell	3
I don't want people to know that I have CF	3
I don't believe they do me any good	3
I have too many treatments, and this is the least important	2
I take more than I am prescribed	1
My CF isn't as serious as most of the other CF patients	1
I resent having to take them	1
I have difficulty swallowing them	1
I have difficulty getting repeat prescriptions	1

Table 3. Agreement between patients' self-report of adherence and physiotherapists' ratings

Patient Physiotherapist	Non Adherent	Fully adherent	
Non-adherent	14	5	35.6%
Fully adherent	11	25	65.4%
	45.5%	54.5%	

Table 4. Agreement between patients' self-report of adherence and dieticians' ratings for enzymes

Patient	Non-adherent	Fully adherent	
Dietician			
Non-adherent	21	19	88.9%
Fully adherent	3	2	11.1%
	53.3%	46.7%	

Table 5. Agreement between patients' self-report of adherence and nurses' ratings for vitamins

Patient Nurse	Non Adherent	Fully adherent	
Non-adherent	12	21	56.9%
Fully adherent	10	15	43.1%
	38.0%	62.0%	

Table 6. Pearson correlations between independent variables

	AGE	FEV_1	PIS	PHC	HAD-A	HAD-D	RSE	SE
FEV_1	0.02							
PIS	-0.05	0.25*						
PHC	0.11	0.35**	0.75***					
HAD-A	0.01	0.07	-0.16	-0.15				
HAD-D	0.15	-0.26*	-0.23	-0.23	0.52***			
RSE	0.01	-0.07	-0.12	-0.17	0.26*	0.45***		
SE	0.21	-0.01	-0.15	0.01	-0.30*	-0.12	-0.33*	
OE	0.25*	0.12	-0.37**	-0.24	-0.22	-0.06	-0.24	0.77***

* $p < 0.05$, ** $p < 0.01$, ***$p < 0.001$

FEV_1 = Lung function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self efficacy, OE = Outcome expectations

Table 7. Means (SD) and *t*-test results for adherence to physiotherapy groups and independent variables

	df	Non-adherent	Fully adherent	*t*	p value
FEV_1	67	48.30 (16.59)	40.91(21.00)	-1.61	0.11
PIS	61	76.32 (16.49)	64.44 (24.26)	-2.27	0.03
PHC	61	79.19 (16.70)	63.62 (22.72)	-3.07	<0.01
HAD-A	67	6.61 (2.93)	6.17 (3.43)	-0.57	0.57
HAD-D	67	2.72 (2.38)	2.77 (2.38)	0.59	0.55
RSE	66	2.12 (2.48)	1.50 (1.89)	-1.18	0.24
SE	61	54.53 (10.74)	59.11 (8.50)	1.78	0.04
OE	61	31.52 (4.87)	35.44 (3.67)	3.40	<0.01

FEV_1 = Lung Function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self-efficacy, OE = Outcome expectations

Table 8. Means (SD) and *t*-test results for adherence to enzyme groups and independent variables

	df	Non-adherent	Fully adherent	*t*	p value
FEV_1	56	46.19 (18.59)	40.64 (21.19)	-1.06	0.29
PIS	51	72.96 (18.71)	61.71 (23.57)	-1.94	0.04
PHC	51	71.31 (22.01)	66.00 (20.54)	-0.90	0.37
HAD-A	56	6.32 (3.04)	6.44 (3.51)	0.14	0.89
HAD-D	56	2.51 (2.28)	2.44 (2.15)	-0.12	0.90
RSE	55	1.81 (2.30)	1.58 (1.86)	-0.41	0.68
SE	51	55.86 (9.68)	59.25 (10.36)	1.15	0.26
OE	51	32.93 (4.77)	34.84 (4.61)	1.36	0.18

FEV_1 = Lung Function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self-efficacy, OE = Outcome expectations

Table 9. Means (SD) and *t*-test results for adherence to vitamins groups and independent variables

	df	Non-adherent	Fully adherent	*t*	p value
FEV_1	60	45.38 (18.50)	42.99 (8.33)	-0.46	0.65
PIS	55	70.52 (21.99)	67.97 (22.02)	-0.42	0.68
PHC	55	70.31 (21.51)	67.50 (21.69)	-0.48	0.63
HAD-A	60	6.87 (3.34)	5.89 (3.16)	-1.16	0.25
HAD-D	60	3.12 (2.59)	2.08 (1.99)	-1.79	0.08
RSE	59	2.21 (2.56)	1.37 (1.72)	-1.55	0.13
SE	55	54.16 (8.67)	59.90 (9.93)	2.13	0.04
OE	55	32.25 (4.72)	35.15 (4.10)	2.29	0.03

FEV_1 = Lung Function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self-efficacy, OE = Outcome expectations

Table 10. Results of logistic regression analysis and the set of variables that best predict adherence for each treatment type

	B	SE	Wald	df	Significance	R	Odds Ratio Exp(B)
Physiotherapy							
PHC	0.04	0.02	5.04	1	0.02	0.20	1.04
OE	-0.19	0.08	6.08	1	0.01	-0.24	0.82
Enzymes							
Gender	-1.75	0.65	7.20	1	<0.01	-0.27	0.17
PIS	0.03	0.02	3.88	1	0.04	0.16	1.03
Vitamins							
Age	-0.11	0.06	2.84	1	0.09	0.11	0.90
OE	-0.12	0.07	2.55	1	0.11	0.09	0.89

PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, OE = Outcome expectations

CHAPTER 5: CLINICAL CASE RESEARCH STUDY

Night waking during infancy: an experimental investigation of the impact of withdrawal of parental presence at bedtime.

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Prepared in accordance with guidelines for publication in the *Journal of Child Psychology and Psychiatry and Allied Disciplines* (Appendix 5.1)

Word Count 3802

Abstract

Sleep disorders are highly prevalent among young children and can be extremely disruptive to family life. It is proposed that the method by which parents manage their child's sleep difficulties may contribute to the maintenance of the problem. Behavioural models suggest that parental presence at bedtime may contribute to settling difficulties and night waking as it can impede the child's ability to develop appropriate discriminative stimuli to falling sleep. Using a multiple baseline design this study examined the impact of withdrawal of parental presence on bedtime disturbance and night waking in an 18-month-old boy. Results indicated that a modified graduated extinction procedure (gradually increasing the time before attending to the child's crying) resulted in reduction in these sleep problems. However, in this study increasing the child's opportunity to gain self-soothing skills at bedtime did not result in an immediate reduction in night waking. This highlights the role that excess parental attention during the night can play in contributing to the maintenance of this problem. It is concluded that chronic sleep problems in children may be amenable to behavioural intervention.

Word count = 176

Abbreviated Title: The impact of withdrawal of parental presence at bedtime on night waking during infancy.

APPENDICES

Appendix 1.1

Notes for Contributors

Papers, articles and other contributions should be sent to the Editor, *Health Bulletin*, Scottish Executive Health Department, Room IE05, St Andrew's House, Edinburgh EH1 3DE. They must be submitted exclusively for *Health Bulletin*. Acceptance is on the understanding that editorial revision may be necessary. All papers are reviewed by the Editor and by peer review, referees being drawn from a panel of appropriate professionals. No correspondence can be entered into in relation to articles found to be unsuitable and returned to authors.

Potential contributions can be submitted in two ways. Material submitted for publication must be typewritten on one side of the paper only, in double spacing and with adequate margins, and each page should be numbered. The top typed copy should be submitted, with four other copies. We are willing to receive one copy typewritten in the above format and accompanied by a disk (Microsoft Word version 98, Excel for tables and figures). All papers should be prefaced by a structured Abstract, of about 250 words in length. It should normally contain six clearly headed sections entitled Objective, Design, Setting, Subjects, Results and Conclusion. The name, appointment and place of work of the authors should be supplied on a separate title page. This same page should include the full postal address of one author, to whom correspondence and reprints will be directed. There should be adequate references to any relevant previous work on the subject; these references should appear at the end of the material on a separate page or pages, using the Vancouver style, which in the case of papers in journals includes:

Surname and initials of author(s)
Title of paper
Full name of journal
Year published
Volume number
Opening and closing page numbers

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Proofs

Contributors will receive one set of proofs. This should be read carefully for printer's errors, and any tables, figures and legends should be checked. Alterations should be kept to a minimum, and the proofs should be returned promptly. Ten reprints will be supplied free of charge.

Appendix 1.2

PSYCHOLOGY IN GENERAL MEDICINE QUESTIONNAIRE

Please help us to improve our service by answering the following questions. We are interested in your honest opinions, whether they are positive or negative. We also welcome your comments and suggestions.

Thank you very much, we appreciate your help.

PLEASE RETURN THIS QUESTIONNAIRE IN THE ENVELOPE PROVIDED

Clinical Psychology has been operating a small, dedicated service to general medicine for just over one year.

1. **Prior to *this* contact were you aware of this service ? yes/no**
2. **Have you made a referral to this service (or asked any member of your team to make a referral) ? yes/no**

If Yes please answer the following. If No please ignore Q. 2a-3, and go to question 4 overleaf.

2a. In an overall, general sense, how satisfied are you with the service?

Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
1	2	3	4

2b. Did you get the kind of service you wanted?

No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
4	3	2	1

2c. Do you think that the intervention was beneficial to your patient?

No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
4	3	2	1

2d. How satisfied are you with the length of time between your referral to the Psychology service and an appointment being available to your patient?

Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
1	2	3	4

2e. How satisfied are you with the communication between you and the Psychology service (telephone & written communication)?

Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
1	2	3	4

2f. Do you think that you will make more referrals in the future?

No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
4	3	2	1

3. Are there any aspects of the service that you would like changed? Please specify. (please continue on a separate sheet if necessary)

To be answered by all.

4. **For the following please indicate whether you agree or disagree that these psychological services would be useful to your patients. Alternatively you may be undecided because you require more information about, or evidence of, their potential benefits to your patients. If you feel that any are not applicable to your speciality please tick the final column.**

PLEASE TICK ONE COLUMN ONLY

	Agree-useful	Disagree-not useful	Need more information about service	Not applicable
Assessment				
Neuropsychological assessment				
Preparation				
Psychological preparation for medical/surgical intervention				
Management				
Psychological help with emotional problems				
Psychological approaches in pain management				
Psychological help with post-traumatic stress				
Problems with adherence to treatment				
Eating and smoking disorders				
Adjustment				
Psychological help for adjustment problems to chronic illness/disability				
Counselling relatives for adjustment				
Rehabilitation				
Involvement with rehabilitation				
Bereavement				
Counselling the dying				
Counselling relatives				
Staff				
Staff support e.g. bereavement support				
Staff education/training				

5. Is a Psychology service only of use to you if the referral can be responded to whilst the patient is in hospital ? yes/no

6. Would you like more contact with the Psychology service? yes/no

If yes, how would this contact be best provided (please rate your first and second choice):-

	Rating (1st & 2nd choice)
1. Formal presentation to group of staff	
2. Written information e.g. leaflet	
3. Informal visit to your department	
4. Case discussion	

7. Are there any other comments you would like to make ? (please continue on a separate sheet if necessary)

Appendix 1.3

Comments made by referrers when asked if there were aspects of the service that they would like changed.

“Opportunity for telephone referral”

“Rapid response time”

“Patients have to wait far too long, often the acute event has resolved making the referral irrelevant”

Appendix 1.4

Chi-square analysis of referrers' compared with non-referrers' perception of usefulness of psychological interventions.

	Chi-square	p
Psychological help for emotional problems	0.093	0.760
Pain management	0.285	0.593
Counselling relatives of the dying	0.006	0.940
Staff education/training	0.117	0.732
Adjustment to illness/disability	0.137	0.711
Counselling the dying	0.006	0.940
Staff support	0.042	0.837
Counselling relatives for adjustment	0.181	0.671
Adherence to treatment	1.174	0.278
Eating and smoking disorders	0.375	0.840
PTSD	0.033	0.856
Neuropsychological assessment	0.524	0.469
Rehabilitation	0.524	0.469
Psychological preparation for medical/surgical intervention	0.964	0.326

Appendix 1.5

Comments made by referrers when given the opportunity to provide additional feedback.

"I suspect there is a great unmet need for this service" (Medicine for the elderly)

"Is there any way waiting times for appointments (in any age group) can be reduced? They are totally unacceptable for anyone who needs to be seen urgently" (Medicine for the elderly)

"I have a special interest in menapouse/climacteric - input from Clinical Psychology is very relevant and any help would be greatly appreciated" (Gynaecology)

"I would rarely refer and even then act through the GP" (Opthamology)

"As a diabetes consultant the psychology service can be very useful. However, in practical terms I don't know much about the current service" (Medicine)

"I am interested to explore further the potential benefit of psychological therapy in the potential management of chronic pain syndromes" (Orthopaedic surgeon).

Appendix 2.1

Health Psychology

Manuscript Submission Guidelines

Submit two manuscript copies and a floppy disk with an electronic version of the paper (MS Word or Word Perfect word processing formats are fine) to:

Arthur A. Stone, PhD
Department of Psychiatry
Putnam Hall, South Campus
State University of New York
at Stony Brook
Stony Brook, NY 11794-8790

The preferred length of manuscripts is 25-30 double-spaced pages, including references, notes, tables, captions, and figures. All copies should be clear, readable, and on paper of good quality. A dot matrix or unusual typeface is acceptable only if it is clear and legible. In addition to addresses and phone numbers, authors should supply electronic mail addresses and fax numbers, if available, for potential use by the editorial office and later by the production office. Authors should keep a copy of the manuscript to guard against loss.

Authors may submit a list of suggested reviewers for the paper; suggested reviewers should not, of course, have any conflict of interest regarding the review. Masked review may be requested by the author. Authors requesting masked review should include a cover sheet, that shows the title of the manuscript, the authors' names and institutional affiliations, and the date the manuscript is submitted. The first page of the manuscript should omit the authors' names and affiliations but should include the title of the manuscript and the date it is submitted.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (4th ed.). Type all components of the manuscript double-spaced, including title page, abstract, text, quotes, references, appendixes, author note, footnotes, tables, and figure captions. All manuscripts must include an abstract containing a maximum of 960 characters and spaces (which is approximately 120 words). After the abstract include four to six key words or phrases. All manuscripts are copyedited for bias-free language (see chap. 2 of the *Publication Manual*). Original color figures can be printed in color provided the author agrees to pay half of the associated production costs.

Instructions for preparing abstracts, tables, figures, metrics, and references appear in the *Manual.* References should be cited in text as follows: "The results replicated those of a previous study (Knoth & Mair, 1991)," or "The procedure was a modification of Krettek and Price (1989) and Smith et al. (1977)." Multiple references should be cited in alphabetical order: Earlier investigations (Abbott, 1988; Hunt & Aggleton, 1983; Winocur, 1985). . . . Each listed reference should be cited in text, and each text citation should be listed in the reference section. Some examples of common types of references—a journal article, a book, and a book chapter—follow:

Barnett, R. C., Davidson, H., & Marshall, N. L. (1991). Physical symptoms and the interplay of work and family roles. *Health Psychology, 10,* 94–101.

Cohen, J., & Cohen, P. (1975). *Applied multiple regression/correlation analysis for the behavioral sciences.* Hillsdale, NJ: Erlbaum.

Haynes, S. G., Eaker, E. D., & Feinleib, M. (1984). The effect of employment, family, and job stress on coronary heart disease. In E. B. Gold (Ed.), *The changing risk of disease in women: An epidemiologic approach* (pp. 37–48). Lexington, MA: Heath.

Submission Letter

Authors are *required* to include the following in their submission letter:

1. a statement of compliance with APA ethical standards in the treatment of their sample, human or animal, or a description of the details of the treatment (see below);
2. a statement that the manuscript or data have not been published previously and that they are not under consideration for publication elsewhere;
3. a statement to reflect that all listed authors have contributed significantly to the manuscript and consent to their names on the manuscript; and

4. a brief statement of how the article content is relevant to the domain of *Health Psychology* as described in the journal inside cover (see Content).

Failure to include any of the requirements above may result in a delay of the review process.

Brief Reports

Health Psychology accepts Brief Reports of soundly designed research studies that are of specialized interest or limited importance—reports that cannot be accepted as regular articles due to lack of space. An author who submits a Brief Report must agree not to submit the full report to another journal. To ensure that a Brief Report does not exceed the available journal pages (approximately 4 pages), set your computer so that (a) the approximate number of characters per line is 65 (this can be achieved by using 12-point type with left and right margin widths of 1.0–1.5 in.), (b) the number of double-spaced lines per page is about 25, and (c) the total number of lines in the report is about 400. Count all lines, including headings and references but excluding title, author name(s), affiliation(s), and abstract; figure 27 lines for each 1/4 journal page required for tables and figures (visual estimation necessary).

Letters to the Editor

Health Psychology will now consider letters concerning papers previously published in the journal. Letters should be no more than 500 words in length and have a maximum of five references. Letters may be sent electronically to the journal's editorial assistant, Michelle McCarren, at mmccarren@mail.psychiatry.sunysb.edu. Authors will be notified of the decision to publish the letter and will be sent an edited version. Authors of the original article will be offered an opportunity to reply to the letter. No additional letters on the topic will be accepted.

Ethical Principles

Authors are required to obtain and provide to APA all necessary permissions to reproduce any copyrighted work, including, for example, test instruments and other test materials or portions thereof.

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications. In addition, it is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 6.24). As this journal is a primary journal that publishes original material only, APA policy prohibits as well publication of any manuscript that has already been published in whole or in substantial part elsewhere. Authors have an obligation to consult journal editors concerning prior publication of any data upon which their article depends.

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 6.25). APA expects authors submitting to this journal to adhere to these standards. Specifically, authors of manuscripts submitted to APA journals are expected to have available their data throughout the editorial review process and for at least 5 years after the date of publication. A copy of the APA Ethical Principles may be obtained by writing the APA Ethics Office, 750 First Street, NE, Washington, DC 20002-4242.

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test procedure, funding by pharmaceutical companies for drug research).

Production

Authors whose manuscripts have been accepted for publication are encouraged to submit their finalized manuscripts on computer disks. Manuscripts are copyedited and typeset directly from disks when possible. Authors receive edited manuscripts and page proofs for review.

Appendix 3.1 D.Clin.Psy guidelines for major research project proposal

1.1 Applicants - names and addresses including the names of co-workers and supervisor(s) if known.

1.2 Title - no more than 15 words.

1.3 Summary - No more than 300 words, including a reference to where the study will be carried out.

1.4 Introduction - of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.

1.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.

1.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.

1.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants.

1.6.2 Measures - a brief explanation of interviews/observations/ rating scales etc. to be employed, including references where appropriate.

1.6.3 Design and Procedure - a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements, etc. A summary chart may be helpful to explain the research process.

1.6.4 Settings and equipment - a statement on the location(s) to be used and resources or equipment which will be employed (if any).

1.6.5 Data analysis - a brief explanation of how data will be collated, stored and analysed.

1.7 Practical applications - the applicants should state the practical use to which the research findings could be put.

1.8 Timescales - the proposed starting date and duration of the project.

1.9 Ethical approval - stating whether this is necessary and, if so, whether it has been obtained.

Appendix 3.2

Visual Analogue Scales for the assessment of health status

1. Overall, how severe do you feel your illness is at this time? (please place a ✗ on the line)

0 **100**

Most severe rating **Mildest rating**

2. In comparison with other individuals with CF, how healthy do you think you are at this time? (please place a ✗ on the line)

0 **50** **100**

Sicker **About the same** **Healthier**

Appendix 3.3

The Manchester Cystic Fibrosis Compliance Questionnaire

The following questions ask you about your treatment. So that we can assess how effective your treatment is, please answer all the questions honestly.

1. **How often do you attend the CF outpatient clinic?__________________per year**

   How often do you attend as an inpatient? ______________________per year

Physiotherapy

2. How many times each day has it been suggested that you should do physiotherapy? ______________________per day

3. Over the last three months, which of the following statements best describe you

Tick one box only

1.	I do my physiotherapy once or twice each day, every day	
2.	Occasionally I miss one or two days physiotherapy	
3.	I often miss one or two days physiotherapy	
4.	I often miss several days physiotherapy	
5.	The only time I do my physiotherapy is when I feel unwell	
6.	I never do my physiotherapy	

4. Please tick the boxes which best describe you. When I miss my physiotherapy it is usually because.

Tick as many boxes as you like

1.	I feel well without treatment	
2.	It interferes with my social life	
3.	There isn't enough time	
4.	I have to rely on someone to help me	
5.	I simply forget	
6.	My CF isn't as serious as most of the other CF patients	
7.	It interferes with family routine commitments	
8.	I can't always be bothered	
9.	I don't believe that it does me any good	
10.	I have to many different treatments to attend to, and physiotherapy is the least important of them	
11.	It makes me feel worse	
12.	I don't fully understand why I need to do physiotherapy	
13.	I do plenty of exercise, so I don't need to do physiotherapy	
14.	I don't know how to do it	
15.	I have difficulty doing my own physiotherapy	
16.	I resent having to do it	
17.	It's embarrassing	
18.	OTHER, please specify	

5. Do you think that the amount of physiotherapy you do is:
Tick one box only

About right	Not enough	Too much	Don't know

6. Do you have help with your physiotherapy? Yes No

If YES, please give details

7. What age were you when you started having physiotherapy? ________________

Do you know what made you start? ______________________ ________________

Exercise

8. Has it been suggested to you by the medical staff that you should do exercise?

Yes No

If YES how much ? __________________ per week

9. Do you do any exercise? Yes No

If YES, what do you do and how often? ________________per week I
______________________ e.g. play football, go to aerobics, go swimming.

11. If I don't exercise at all, or my usual exercise sessions lapse, it tends to be because:

Tick as many boxes as you like

1.	I don’t enjoy exercise	
2.	I simply forget	
3.	Most of the time I don't feel well enough to exercise	
4.	I resent having to exercise	
5.	I don't fully understand why I should exercise	
6.	I have too many different treatments to attend to, and exercise is the least important of them	
7.	I don't believe it does me any good	
8.	I haven't enough time	
9.	I don't want to lose weight	
10.	I can't always be bothered	
11.	Exercise makes me feel worse	
12.	It interferes with my social life	
13.	Exercise makes me too breathless	
14.	OTHER, please specify	

12. Do you think your present level of exercise is:

Tick one box only

About right	Not enough	Too much	Don't know

Pancreatic enzymes

13. Are you prescribed enzymes? Yes No

If YES, do you take your enzymes with a MAIN meal?

Tick one box only

Never	Occasionally	Usually	Always

14. How many do you usually take with a MAIN meal?________________________

15. With a MAIN meal do you take them:

Tick one box only

Throughout the meal	
Only at the beginning of the meal	
Only at the end of the meal	

16. Do you take them with snacks?

Tick one box only

Never	Occasionally	Usually	Always

17. If I don't take my enzymes it is usually because:

Tick as many boxes as you like

1.	I only take them when they are given to me	
2.	I am embarrassed to take them in front of other people	
3.	I don't like the taste	
4.	I have difficulty swallowing them	
5.	I have difficulty getting repeat prescriptions	
6.	I simply forget	
7.	My body occasionally needs a rest from medication, otherwise I may become immune to them, and they will not work when I really need them	
8.	I only take enzymes when I feel unwell	
9.	I resent having to take them	
10.	I don't want my friends/colleagues to know that I have CF	
11.	I don't fully understand why I need to take them	
12.	My CF isn't as serious as most of the other CF patients	
13.	I have too many different treatments to attend to, and this is the least important of them	
14.	I don't believe that they do me any good	
15.	They make me feel worse	
16.	It interferes with my social life	
17.	I don't always carry them around with me	
18.	If I don't take them it helps me to lose weight and/ or to stay slim	
19.	OTHER, please specify	

18. Do you think that your pancreatic enzyme intake is:
Tick one box only

About right	Not enough	Too much	Don't know

19. Do you eat whatever you like? Yes No
Do you eat a fat-free diet? Yes No
Do you eat a vegetarian diet? Yes No

Vitamins

20. Are you prescribed vitamins? Yes No

21. If YES, what has been prescribed, and how often should you take them?

____

____

22. How often do you actually take your vitamins?
Tick one box only

Never	Occasionally	Usually	Always

23. If I don't take my vitamins as prescribed it is usually because.
Tick as many boxes as you like

1.	I only take them when they are given to me	☐
2.	I don't like the taste	☐
3.	I have difficulty swallowing them	☐
4.	I take more than has been prescribed for me	☐
5.	I have difficulty getting repeat prescriptions	☐
6.	They make me feel worse	☐
7.	I simply forget	☐
8.	My body occasionally needs a rest from medication, otherwise I may become immune to them, and they will not work when I really need them	☐
9.	I only take vitamins when I feel unwell	☐
10.	I resent having to take them	☐
11.	I don't want my friends/colleagues to now that I have CF	☐
12.	I don't fully understand why I need to take them	☐
13.	My CF isn't as serious as most of the other CF patients	☐
14.	I have too many different treatments to attend to, and this is the least important of them	☐
15.	I don't believe that they dome nay good	☐
16.	I can't always be bothered	☐
17.	I don’t always carry them around with me	☐
18.	OTHER, please specify	☐

24. Do you think that your vitamin intake is:
Tick one box only

About right	Not enough	Too much	Don't know

Appendix 3.4

Self-efficacy Instrument for Adolescents

Here is a list of statements that relate to how you feel about yourself and your medical treatment. Please indicate how sure you are that you could do each of them.

Circle one number for every statement

	Not at all sure		Moderately sure		Very sure
Decide what you need to talk about with your doctor or nurse	1	2	3	4	5
Notice whether your doctor or nurse is understanding what you are saying	1	2	3	4	5
Identify feelings in yourself that you wish to discuss	1	2	3	4	5
Judge how the doctor or nurse will react when you talk about your feelings	1	2	3	4	5
Figure out several ways to solve a problem	1	2	3	4	5
Use several methods to make yourself feel better when you have a problem or are distressed.	1	2	3	4	5
Accept CF as your diagnosis	1	2	3	4	5
Accept that CF may present new problems to you and your family at any time	1	2	3	4	5
Accept that CF-related problems will demand that you and your family make changes and adjustments	1	2	3	4	5
Notice changes in cough, sputum, and shortness of breath that might indicate a chest infection.	1	2	3	4	5
Tell when symptoms mean that you have developed a chest infection	1	2	3	4	5
Ask other questions when you do not get an answer or do not understand an answer from your doctor or nurse	1	2	3	4	5
Use the right words when talking about your CF or describing your symptoms to your doctor or nurse	1	2	3	4	5
Do medical treatments as often as your doctor suggests*	1	2	3	4	5

* This question was modified from "do physiotherapy as often as your doctor suggests" in order to reflect multiple treatment components under consideration

Appendix 3.5

Outcome Expectation Instrument for Cystic Fibrosis

Please answer the following questions.

1. How sure are you that it is beneficial for your health to do the **medical treatments** that has been recommended to you?* ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

2. How sure are you that it is beneficial for your health to keep a close eye on **changes in your symptoms**? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

3. How sure are you that it is beneficial for your health to be able to decide **what to talk about** with your doctor/ nurse? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

4. How sure are you that it is beneficial for your health to be able to **understand** what your doctor/ nurse is telling you? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

5. How sure are you that it is beneficial for your health to talk with your **doctor/ nurse about how you are feeling**? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

6. How sure are you that it is beneficial for your health to be able to talk to your **friends and family about how you are feeling**? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

7. How sure are you that it is beneficial for your health to be good at **organising your time**? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

8. How sure are you that it is beneficial for your health to be good at **solving problems**? ***(Circle one number)***

Not at all sure		Moderately sure		Very sure
1	2	3	4	5

* This question was modified in order to reflect multiple treatment components under consideration.

Appendix 3.6

THIS SHEET HAS BEEN APPROVED BY THE WEST ETHICS COMMITTEE INFORMATION SHEET FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

Brief Title of Project

Treatment adherence in adults with Cystic Fibrosis: the influence of self-efficacy, self-esteem and psychological morbidity.

Patient's Summary (Purpose of study, nature of procedure, discomfort and possible risks in terms which the patient or volunteer can understand).

INTRODUCTION

You are invited to take part in a study of adherence to treatment of adults with Cystic Fibrosis.

WHAT IS THE PURPOSE OF THE STUDY?

This study will look at the difficulties people have following their prescribed treatments for Cystic Fibrosis. It will focus on how they feel about themselves and what they think about their prescribed treatments.

WHO IS ORGANISING THE STUDY?

The study has been organised by Laura Pettigrew, who is currently training in the Department of Psychological Medicine.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you decide to take part in this study, you will be asked to fill in a short questionnaire. You can do this either by yourself or, if you would like help, by discussing it with Ms Pettigrew. It will take approximately 30 minutes of your time to complete the questionnaire. You will not be asked to complete any further assessments.

WHAT ARE THE POSSIBLE RISKS?

There are no foreseeable risks involved in this project. Some people might feel a little bit uncomfortable talking about their concerns. If you feel too uncomfortable, you need not carry on filling out the questionnaires.

WHAT ARE THE POSSIBLE BENEFITS?

It is not anticipated that you will experience any direct benefit from participating in this study. It is hoped, however, that the information provided could be used in the development of treatment for the benefit of future patients.

WHO WILL KNOW WHAT I HAVE SAID?

Any information that you give will be treated in strict confidence and will be stored in a safe place. You will not be identified by name during the study and, if publication of the results follows, your anonymity will be assured.

Ms Pettigrew will have access only to parts of your medical records that are relevant to the study. Information will not be given to any other health professional unless they first gain your written permission. However, your family doctor will be informed that you are taking part.

WHAT WILL HAPPEN IF I DECIDE NOT TO PARTICPATE?

You are under no obligation to participate in this study and should feel completely free to decide not to take part. If you do agree to take part, you can withdraw from the study at any time without having to give an explanation. If you do not choose to participate or decide to withdraw, your care and treatment will not be affected in any way.

IF YOU HAVE ANY FURTHER QUESTIONS ABOUT THE STUDY PLEASE CONTACT ME ON: **0141 211 3920.** My name is Laura Pettigrew. I am based within the Department of Psychological Medicine, Gartnavel Royal Hospital. Glasgow. G12 0XH.

Appendix 3.6

WEST ETHICS COMMITTEE

FORM OF CONSENT FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

Title of Project :

Treatment adherence in adults with Cystic Fibrosis: the influence of self-efficacy, self-esteem and psychological morbidity.

By signing this form you give consent to your participation in the project whose title is at the top of this page. You should have been given a complete explanation of the project to your satisfaction and have been given the opportunity to ask questions. You should have been given a copy of the patient information sheet approved by the West Ethics Committee to read and to keep. Even though you have agreed to take part in the research procedures you may withdraw this consent at any time without the need to explain why and without any prejudice to your care.

Consent:

I,...(PRINT)

of...

give my consent to the research procedures above, the nature, purpose and possible consequences of which have been described to me

by...

Patient's signature...Date..................

Doctor's signature..

Appendix 3.7

West Glasgow Hospitals

PART OF THE NORTH GLASGOW UNIVERSITY HOSPITALS NHS TRUST

WEST ETHICS COMMITTEE
Western Infirmary
Dumbarton Road
Glasgow G11 6NT

Direct Line: 211 6238
Fax: 211 1920

Our Ref: AHT

Your Ref:

Please reply to: Mrs A H Torrie
SECRETARY - WEST ETHICS COMMITTEE

21 June, 2000

Ms Laura Pettigrew
Department of Psychological Medicine
Gartnavel Royal Hospital
Glasgow

Dear Ms Pettigrew,

00/85(2) Ms L Pettigrew - Treatment adherence in adults with Cystic Fibrosis; the influence of self-efficacy, self-esteem and chological morbidity.

The Committee at the meeting held on 20 June, 2000 discussed and approved the above study but required the undernoted minor amendment to the Patient Information Sheet:

Under Section "Who is organising the study" - the second sentence should be deleted. The Committee would also like sight the recruitment letter sent to patients.

The above should come back to me for checking and filing.

Please note that the approval contained in this letter is valid for all sites which form part of the North Glasgow Trust. If however, this research is to be carried out at sights within the North Glasgow Trust other than the one covered by this letter, then a covering letter signed by the person responsible for the research on that site should be sent listing names, titles and addresses of all collaborating researchers. A copy of this approval letter should also be passed to them.

It should be noted that although Ethics Committee approval has been granted, Trust Management approval is still required. This should be obtained through the Research & Development Office at Gartnavel General Hospital (Miss W Burton tel No. 0115).

Kind regards.

Yours sincerely,

Andrea H Torrie

Andrea H Torrie
SECRETARY - WEST ETHICS COMMITTEE

Appendix 4.1

Results of exploratory analysis examining factors that may impact on agreement between patients' and health professionals' ratings of adherence.

Means (SD) and *t*-test/ chi-square results for physiotherapy agreement/disagreement groups and independent variables

	df	Agreement between patient and staff	Disagreement between patient and staff	*t*	p-value
Gender	-	-	-	$\chi^2 = 0.58$	0.45
Age	53	25.69 (7.21)	25.88 (8.96)	-0.08	0.94
FEV_1	53	39.76 (18.59)	45.47 (20.92)	-0.99	0.32
PIS	49	70.00 (19.95)	71.93 (21.68)	-0.31	0.76
PHC	49	67.88 (22.23)	77.69 (16.02)	-1.58	0.12
HAD-A	53	6.46 (3.14)	6.31 (3.40)	0.16	0.88
HAD-D	53	2.87 (2.47)	2.37 (2.16)	0.70	0.49
RSE	52	1.50 (1.89)	2.12 (2.48)	-1.18	0.25
SE	49	56.42 (9.55)	60.80 (9.81)	-1.38	0.18
OE	49	33.83 (4.33)	34.10 (5.68)	-0.17	0.87

FEV_1 = Lung function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self efficacy, OE = Outcome expectations

Means (SD) and *t*-test/ chi square results for pancreatic enzyme agreement/disagreement groups and independent variables

	df	Agreement between patient and staff	Disagreement between patient and staff	*t*	p-value
Gender	-	-	-	$\chi^2 = 2.02$	0.16
Age	43	23.96 (5.78)	26.23 (8.26)	-1.07	0.29
FEV_1	38	45.22 (19.72)	43.69 (21.68)	0.25	0.80
PIS	38	73.40 (19.27)	64.85 (21.52)	1.32	0.19
PHC	43	70.65 (22.22)	70.25 (19.76)	0.06	0.95
HAD-A	43	6.22 (3.27)	6.82 (3.75)	-0.57	0.57
HAD-D	43	2.65 (2.48)	2.45 (2.04)	0.29	0.77
RSE	42	1.61 (2.29)	1.19 (1.72)	0.68	0.50
SE	38	56.44 (9.28)	60.61 (11.01)	-1.23	0.23
OE	38	33.37 (4.50)	35.13 (5.18)	-1.09	0.28

FEV_1 = Lung function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self efficacy, OE = Outcome expectations

Means (SD) and *t*-test/ chi square results for vitamin agreement/disagreement groups and independent variables

	df	Agreement between patient and staff	Disagreement between patient and staff	*t*	p-value
Gender	-	-	-	$\chi^2 = 0.01$	0.93
Age	56	27.22 (7.92)	23.22 (6.48)	2.11	0.05
FEV_1	56	43.26 (19.00)	44.31 (20.74)	-0.19	0.84
PIS	51	76.04 (15.51)	66.50 (22.50)	1.74	0.09
PHC	51	73.71 (17.67)	67.93 (22.54)	1.02	0.31
HAD-A	56	6.74 (3.41)	5.84 (3.12)	1.05	0.30
HAD-D	56	2.59 (2.36)	2.45 (2.23)	0.23	0.82
RSE	55	1.81 (2.00)	1.35 (1.94)	0.86	0.39
SE	51	58.21 (9.51)	58.18 (9.38)	0.01	0.99
OE	51	34.24 (4.43)	34.25 (4.34)	-0.01	0.99

FEV_1 = Lung function, PIS = perceived illness severity, PHC = perceived health in comparison to other CF patients, HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem, SE = Self efficacy, OE = Outcome expectations

Appendix 4.2

Results of multivariate analysis of age (median split groups) and gender by each measure of psychological adjustment.

Means (SD) for each group on each measure of psychological adjustment.

	Young males (n=19)	Young females (n=14)	Older males (n=21)	Older females (n=14)	F	P
HAD-A	5.42 (3.35)	5.71 (2.52)	6.81 (2.99)	7.29 (3.45)	0.01	0.90
HAD-D	2.37 (2.63)	1.57 (1.50)	2.03 (2.22)	3.50 (2.88)	2.04	0.16
RSE	1.89 (2.40)	1.78 (2.36)	1.76 (2.09)	1.71 (2.12)	0.03	0.96

HAD-A = Anxiety, HAD-D = Depression, RSE = Self-esteem