A Qualitative Investigation of the Treatment Goals of Adult Asthmatics

M.Sc. Thesis

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Declaration

I hereby declare that the contents of this thesis represent work undertaken entirely by myself, except insofar as is detailed in the acknowledgements section.

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Abstract

Background

Asthma is a common disease with significant morbidity and mortality. The British Thoracic Society (BTS) guidelines inform its management in the UK. Although, these guidelines have clear goals for asthma treatment, little is known about the goals of people with asthma. Therefore, it was decided to interview people with asthma to ascertain their goals.

Method

Setting: A general practice of six thousand patients living mainly in owner occupied accommodation in the suburbs of Glasgow.

Sample: 23 adults aged 20-49 with asthma diagnosed for at least 2 years, on steps 2-4 of the BTS guidelines, with no significant co-morbidity.

Data collection: a semi-structured interview survey.

Analysis: the interviews were tape-recorded, transcribed verbatim and the transcripts analysed using the "Framework" model for qualitative data

Results

Seven people declined to participate. Of the remainder, seven had asthma goals and sixteen did not. The goals can be categorised as "cure" and "control". The reasons given for not having asthma goals are that asthma is of insufficient importance, the outcome of asthma is impossible to influence, asthma is already carefully controlled and that people have competing priorities.

People's evaluation of asthma explains the presence or absence of goals. All of the respondents would value being cured of asthma. The evaluation of

symptoms is based on past and present experience and on the perceived consequences of asthma. Comparisons are made to others with asthma, to healthy peers, and to other illnesses. Some people are highly concerned about asthma treatment but others are not. The reasons for high concern are that the medications symbolise the disease, are unnatural, are potentially harmful, are addictive, are unpleasant to take and are expensive. Commonly people are equally concerned about inhaled steroids and inhaled bronchodilators. If a difference in risk is perceived then it is always inhaled steroids which cause more concern. The reasons for low concern about medication are that the inhalers are perceived to be mild, essential, normal, convenient to use, worth taking compared to the perceived consequences of stopping and the person is following medical advice.

There is no evidence of people with asthma being directed towards goals by health professionals. Some people divide complex goals into sub-goals. Commitment to goals, self-efficacy and perceived goal difficulty varies. Past success in achieving an asthma goal can encourage people to persist with their goals in the face of set-backs. However, past failure to achieve an asthma goal does not necessarily prevent further goal setting. There was evidence of some goal conflict.

Discussion

Qualitative research methods were used to study the treatment goals of adults with asthma in depth and in their social context and because patient asthma goals have not been extensively investigated. The author's role as a general practitioner may have affected the accounts given.

As goals were not a dominant theme the hypotheses related to goals are discussed only briefly before concentrating on the reasons for having goals and for not having goals and the relationship of both states to the goals of the British Thoracic Society Guidelines. The implications of the study for asthma management are also discussed.

Goals, motivation and behaviour form a rational framework but there are many barriers to goal formation. People are motivated to change their asthma management behaviour if they become aware that asthma is affecting their life. There are six influences on motivation. They are the effect of asthma on self-image, the value of the life experience affected, the experience of symptoms, the attitude to medication, the acceptance of the diagnosis of asthma and the perceived consequences of asthma. An asthma treatment goal will result if change is perceived to be possible. Behavioural change will occur unless there are practical difficulties or the person forgets.

The relationship between patient goals, motivation and behaviour and the medical model is as follows. The goals of the British Thoracic Society (BTS) Guidelines are in concordance with the asthma management of some people without goals and with some people's goals. The reasons for concordance are an acceptance of both asthma and its treatment, coincidence, a shared concern about severe attacks, a shared estimation of the value of work and a shared view of the importance of controlling both symptoms and the use of medication. Lack of concordance with the goals of the BTS guidelines occurs because of differences in the estimation of the importance of asthma and a belief that it is possible to cure oneself of asthma.

The literature review and the findings of the study discussed in this thesis have implications for the measures of quality proposed for use in asthma care, compliance as a model for asthma management behaviour, the potential for using goals in asthma care and the development and use of guidelines in asthma. Quality measures are based on the goals of the BTS guidelines rather than on patient goals. Compliance does not seem to be a useful model for asthma management behaviour because it does not take in to account the preferences or the experience of the individual or the dynamic nature of the disease. The evidence for increasing patient participation in health care using methods such as goals is as yet equivocal. At the moment, the importance of continuing to research the inclusion of the patient perspective into health care is based on the

philosophy that it is the right thing to do. The development of the BTS guidelines has been limited by the relative lack of research evidence on patient goals, by the difficulty of appraising the quality of qualitative research using the existing criteria and by the use of "clinical" judgement rather than a consensus view of all stakeholders to inform the guidelines. The application of the BTS guidelines is also limited. Guidelines relate to the average person not the individual.

Conclusion

There is evidence of differences between the perspective of the person with asthma and the prevailing guidelines for the management of asthma. Consideration should be given to including the perspective of individuals with asthma in the consultation and in the development and implementation of guidelines.

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Illustrations

1. Introduction

Asthma is a common and chronic inflammatory disease of the airways which affects about 5% of adults in the UK (Action Asthma, 1990). Around 50% of patients with asthma do not take their treatment as prescribed (Rand, C.S. et al, 1992; Mawhinney, H. et al, 1991; Bosely, C.M., Pary, D.T. & Cochrane G.M., 1994). This poor compliance may be costly to both the individual in terms of avoidable continuing illness and premature death and to society in terms of economic loss and increased health service expenditure.

The Treatment of Asthma

Asthma is commonly treated with inhaled therapies (inhalers) which are either anti-inflammatory or bronchodilator. The former are also are also known as "preventers" because of their purpose of preventing symptoms. They are of two types: sodium cromoglycate and steroids. Sodium cromoglycate is of limited efficacy in adults and is rarely used in that age group. Examples of inhaled steroids are beclomethasone, pulmicort and flixotide. Bronchodilators are also known as "relievers" because they are used to relieve acute symptoms. Examples are salbutamol and ipratropium bromide.

The British Thoracic Society (BTS) guidelines form a framework for health professionals to manage asthma (The British Thoracic Society et al, 1997). They advise that inhalers be increased or decreased in a stepwise fashion according to symptoms. (Table 1)

Table 1: Recommended therapy by BTS step

Step on British Thoracic Society Guidelines	Therapy
1	inhaled bronchodilator alone (<1/day)
2	low dose inhaled steroid
3	high dose inhaled steroid
4	high dose inhaled steroid + long-acting bronchodilator OR + oral theophylline
5	oral steroids

Asthma may be reviewed in primary care during the routine consultation or in asthma clinics run by a general practitioner or, more commonly, a nurse. The purpose of these clinics is to monitor the effectiveness of therapy and to educate people in the management of their asthma. A review of asthma education concludes that it has not been found to improve health outcomes in adults (Gibson, P.G. et al, 1997a).

Self-management plans have been advocated to improve the outcome of asthma care. They are written advice, prescribed by a health professional, on the management of asthma when the patient is well and during deteriorations. They document the symptoms or peak flow signs of worsening asthma. Based on this information, they recommend the appropriate action: to double the dose of the inhaled steroid, to start oral steroids or to seek medical assistance. A review of their efficacy concludes that peak flow or symptom-based self-monitoring, along with regular medical review and a written action plan can improve health outcomes in asthma (Gibson P.G. et al, 1997). Self-management plans tend to be prescribed for, and adopted by, people who will benefit the most from their use (Hayward, S.A & Levy M.; 1990; Charlton, I. et al, 1990).

Compliance and Concordance

Concerns have been expressed about avoidable death and morbidity in asthma. This is thought to be due in part to a failure of the patient to adhere to their treatment plan. Compliance has been defined as "the extent to which a person's behaviour [in taking medications, following diets, or exacting lifestyle changes] coincides with medical or health advice" (Haynes,R.B., 1979). More recently a new term, "concordance", has been defined as a negotiated agreement on treatment between patient and professional (Royal Pharmaceutical Society, 1997).

There is an extensive literature on compliance. The Medline database contains 15821 references on patient compliance from 1966 to date. Some of the interest in compliance is attributed to the increase in effective drugs. Haynes, McKibbon & Kanani (1996) state "effective ways to help people follow medical treatments would have far larger effects on health than any treatment itself." Other authors believe that non-compliance is perceived by physicians to be a challenge to their authority and a sign of rising consumerism in health care (Trostle, JA, 1988).

The earlier compliance literature concentrates on attempting to identify patient characteristics associated with non-compliance. However no consistent associations were found for socio-economic status, education, age, sex or religion (Haynes, R.B., 1976). Research then turned to the drug, the regimen and the patient-doctor interaction.

Multiple drugs and complex regimes have been associated with non-compliance (Davis, M.S., 1966). Once daily dosing may increase compliance (Baird, M.G. et al, 1984). Medication cost may inhibit compliance (Brand, F.N., Smith R.T. & Brand P.A., 1977).

In Garrity's (1981) review of the literature, he identifies four ways the clinician-patient relationship may influence compliance. Firstly, the clarity of oral and written explanation given by the clinician has been thought to increase

compliance. However, although Ley and colleagues (1976) have demonstrated that teaching physicians to give advice increased patient recall of information, comprehension and compliance were not improved. Patient comprehension before and after the intervention were associated with compliance. Secondly, mutual agreement of expectations of the clinician-patient encounter may increase compliance. Francis, Korsch and Morris (1969) tape-recorded acute consultations in a paediatric out-patient setting. When parental expectations are met they report increased compliance. This agrees with interviewer judgements of compliance. Thirdly, "activating" the patient may increase compliance. Roter (1977) found that encouragement from a health educator to ask questions improves compliance with appointment keeping in an out-patient setting. Kaplan and colleagues (1989) in separate studies on diabetes, hypertension and peptic ulcer showed that increasing patients' involvement in the consultation produces improvements not only in physiological measures such as glycosylated haemoglobin but also in patients' perceived health. The fourth aspect on the clinician-patient relationship which may improve compliance is the affective tone, that is expressions of friendliness, joking, agreement and support. Freemon and colleagues (1971) found that compliance is associated with the affective tone of the clinical encounter in a paediatric out-patient setting. The Bales interaction process was used to measure the affective tone of 285 first visits to the clinic (Bales, R., 1951). It may be difficult to distinguish which aspect of the consultation is influenced by interventions designed to improve compliance. For example Inui, Yourtree and Williamson (1976) taught a group of physicians to discuss attitudes to medication taking with a group of hypertensive patients. Compliance with medication, but not appointment-keeping or diet, improved. This may have been due to improving the pedagogical technique of the physicians, negotiating any differences in expectation, activating the patients or enhancing the affective tone of the encounter.

Terminology has proved to be troublesome in compliance research. Concerns that patients were being "blamed" for non-compliance led to the definition of a new term "adherence" (Rosenberg, S.G., 1976). However this came to be used

interchangeably with compliance. Both terms may evoke an image of a paternalistic encounter between clinician and patient in which the doctor's duties are to give advice clearly and in the best interests of the patient. The patient's duties are to ensure he understands and follows instructions.

Social scientists have challenged this model by studying the patient's perspective of medication taking behaviour. Stimpson (1974) argues that patients choose whether or not to take medications on rational grounds. They take advice on health matters from many sources other than the doctor and critically evaluate the doctor's actions. Arluke (1980) found that patients define the efficacy of their drugs for rheumatoid arthritis in terms of the achievement of individual outcomes and test the ability of the drugs to achieve these outcomes. In Conrad's (1985) study of people with epilepsy, controlling medication taking behaviour symbolises mastery over the disease and the control of stigma. Additionally, people may test to ensure they still require medication and alter the dose of their medication to fit in with their other social roles. The last theme was also found to be important by Hunt and colleagues (1989) who found that people describe taking medication in terms of controlling symptoms in everyday life.

The Royal Pharmaceutical Society (RPS) recently reviewed compliance and medication taking behaviour in order to examine the types and causes of difficulty in obtaining the greatest benefit from medicines (Royal Pharmaceutical Society, 1997). They also reviewed attempts to modify medication taking behaviour. They conclude by proposing the term concordance to indicate that the views of the patient and of the health professional have equal value. Furthermore, they suggest that medication taking behaviour be negotiated in order to form a therapeutic alliance. In this model of the clinical encounter, the patient's task is to relate their health beliefs to the doctor. The doctor's task is to facilitate the communication. The desired outcome is to have an informed patient, competent to assess the diagnosis and treatment options. The patient and doctor will together form a "therapeutic alliance". "Although reciprocal,

this is an alliance in which the most important determinations are agreed to be those that are made by the patient."

Concordance in Asthma

Patients' attitudes towards asthma and its treatment have been found to be different from those of health professionals. Patients may not accept that they have asthma and reject asthma treatment (Adams, S, Pill R. & Jones, A., 1997). Adams and colleagues categorised people with asthma according to their beliefs about the nature of their illness. The "deniers" did not accept the diagnosis of asthma or prophylactic inhalers; the "accepters" did. "Pragmatists" were an intermediate group who acknowledged that they had a certain type of asthma and took prophylactic medication as they felt appropriate. Osman and colleagues (1993) suggest that both asthma and its treatment can be perceived to interfere with public and private life. Some perceive that treatment is ineffective (Tettersell, M.J., 1993). They distrust long-term medication because of fears of dependency and side effects (Harding, J.M. & Modell M., 1985). Some are reluctant to seek medical attention even during a severe asthma exacerbation (Tettersell, M.J., 1993). Bosley and colleagues (1996) have identified lack of perceived support from chest clinic staff and wishing to ignore chest disease as factors in adherence in chronic obstructive airways disease.

The health beliefs of at least one of the groups involved in asthma care, general practitioners, have been shown to be different from those of people with asthma (St Claire L, Watkins, C.J. & Billinghurst, B., 1996). Perhaps unsurprisingly the general practitioners focused on health as being the absence of disease (the "medical model") whereas asthmatics focused more on "ability". These different attitudes and beliefs may result in different goals for patient and professional.

Goal Theory

Lee, Locke and Latham (1989) define a goal as "that which one wants to accomplish; it concerns a valued future end state." Goal setting is based on

Bandura's Social Learning Theory and applies to purposeful behaviour (Bandura, A., 1977). The adoption and achievement of goals depends on efficacy expectations, outcome expectations, goal content and goal commitment (Lee et al, 1989; Strecher et al, 1986). Self-efficacy is the belief that one can accomplish a specific behaviour in a specific context. Outcome expectations consist of beliefs of whether a given behaviour will lead to a given outcome; efficacy expectations are beliefs about how *capable* one is of performing a given behaviour. Thus the perception of one's capabilities, and the perceived link between behaviour and outcome, influence behaviour rather than one's "true" capabilities. Goal content influences goal achievement as specific difficult goals are more likely to be realised than general "do your best" goals. Goal commitment depends on self-efficacy and perceived importance of the goal.

Goals in Asthma

The goals in The British Thoracic Society Guidelines in adults include: a) correct diagnosis: b) abolition of symptoms; c) restoration and maintenance of the best possible lung function; d) reduction of risk of severe attacks; and e) minimum absenteeism from the workplace (The British Thoracic Society et al, 1997). A review of the Medline and Embase databases using the terms motivation, self-care, patient-centred care, patient education and then searching the references of the resulting papers found two papers on patient treatment goals for asthma (Partridge, M., 1994; Folden, S.L. 1993). The first is written by a health professional and contains no data derived directly from patients. The second explores the goals of patients with chronic respiratory disease entering a pulmonary rehabilitation programme. The sample does not reflect the wider population of people with asthma nor their broader goals.

Current Methods of Chronic Disease Management

In asthma, educational strategies have been found to improve knowledge but not to change behaviour (Steckel, S.B. & Swain, M.A., 1977). Self-management shows promise but studies are confounded by enthusiast bias

(Beasley, R., Cushley, M., & Holgate, S.T., 1989). Currently self-management plans are prescribed by the physician or asthma nurse.

Setting goals to motivate people may be helpful in the management of chronic disease. Blood pressure control can improve by setting goals and contracting with patients to achieve the goals (Inui, T.S., Yourtree, E.L. & Williamson, J.W., 1976). A review of a self-management programme for arthritis after twelve years explored the role of self-efficacy in education in chronic illness (Lorig, K. & Holman, H., 1993). The first study showed that health related behaviours and health status improved after the self-management programme. However, in common with findings for other chronic illnesses, it failed to demonstrate a close association between health behaviour and health status. Subsequent studies showed an association between the programme, increased self-efficacy and health status. People who believed in their ability to manage their illness reported an improved health status. In asthma, a questionnaire survey failed to show an association between self-efficacy and projected adequate self-management behaviour (Van Der Palen, J., Klein J.J. & Seydel, E.R., 1997). This may have been due to the method of testing using hypothetical situations.

Goal attainment scaling can be used to ensure that treatment is goal-directed and to provide feedback to participants which can increase motivation to pursue treatment goals and for outcome evaluation. It was originally developed by Kiresuk and Sherman (1968) as a tool for programme evaluation in mental health settings. Goal attainment scaling has been studied in a range of settings and populations in mental health (Woodward, C.A. et al, 1978; Peckham R.H., 1977; Stanley, B., 1984). In addition Carr (1979) has found it to be a reliable and valid method for assessing the outcome of special education and initial reports of experience with the method in rehabilitation settings have been positive (Rockwood, K., Stolee, P. & Fox, R.A., 1993; Malec, J.F., Smigielski, J.S. & DePompolo, R.W., 1991). Goal attainment scaling is a standardised procedure which accommodates multiple individualised patient outcomes yet retains mathematical properties allowing comparisons between patients. Heavlin

and colleagues (1982) describe goal attainment scaling as being designed to measure outcomes which are abstract, global and idiosyncratic to the individual case. It has been suggested that a standard measure of outcome be included as well as goal attainment scaling when it is being used to evaluate a programme.

The Experience of Chronic Illness

In his review of the literature, Bury (1991) describes chronic illness as a biographical disruption. He contrasts the classic description of the phases of illness being dependency, regression and recovery with chronic illness. In the latter, people do not recover completely and the disease evolves and interacts with the person's life course. Bury categorises the phases of chronic illness as onset, explanation and legitimation, and adaptation. In his qualitative study of seven people with asthma, Snadden (1992) found a biographical adjustment over time. Fear of asthma decreases as people move from asthma being in control to feeling in control of asthma. The study is limited by its small numbers and retrospective accounts of adjustment to asthma. However, Hewett (1994) found that the biographical model of illness did not seem to apply to asthma. He proposed that the early onset and the nature of the disease led to it becoming a predictable part of life. As asthma does not usually get worse over the years its management becomes routine and habitual.

Gerhardt (1990) states that the increasing number of available treatments may have increased the prevalence of chronic illness. Also, in chronic illness treatments may be palliative rather than curative. They may have adverse effects as well as beneficial effects. Therefore, treatments and symptoms may affect quality of life. Bury (1991) reviews the impact of treatment regimes on chronic illness. From the literature, people try to weigh up the costs and benefits of treatments. This may be intuitive as well as cognitive. Bury also discusses the effects of treatments on daily life and the trade-offs that people may make. He sees the concept of "compliance" as being largely unhelpful in chronic illness. This term implies a clear outcome which will be attained if "doctor's orders are

followed. However, "neither the doctor or the patient have complete knowledge or answers."

Potential Contribution of Proposed Study to Asthma Research

Green and Britten (1998) have recently stated that qualitative methods can broaden the scope of evidence based medicine in diseases such as asthma. For example, it is important to study patients' perceptions of their treatment goals and priorities in the everyday context of competing imperatives such as family and work. This is more valid than asking people to rate their priorities in hypothetical situations. Additionally, the study will allow insights into influences on goals such as asthmatics' interpretation of their illness and the perceived costs and benefits of the disease and its treatment. It will also investigate how asthma fits into the life process. Furthermore, it is vital that the different perspectives of doctor and patient in relation to goal setting and attainment are understood. Kleinman (1974) describes the patient and doctor as being from two different cultures. In depth interviews will elicit patients' view of their asthma goals in the context of their experience.

The purpose of the present study is to explore the treatment goals of adults with asthma. This will allow a deeper understanding of their priorities in treatment and identification of the most useful questions to quickly elicit treatment goals. This may be used to develop a tool to identify treatment goals in the routine asthma consultation. This tool may be used in future studies of goal attainment scaling in asthma. The purpose of studying goal attainment scaling in asthma is to put patients' priorities and values clearly and explicitly at the centre of the asthma consultation by encouraging them to set goals in partnership with the health professional. Patient and professional will be able to consider areas of agreement and disagreement in care during the consultation. Negotiation may increase adherence to the management plan. Inui and colleagues (1976) improved the control of blood pressure by giving physicians a tutorial on the barriers to compliance and how to take patients ideas on treatment into account. Kaplan and colleagues (1989) in separate studies on diabetes, hypertension and peptic ulcer showed that increasing patients' involvement in the consultation

produced improvements not only in physiological measures such as glycosylated haemoglobin but also in patients' perceived health. Three other studies show an association between physician-patient agreement about a problem and health outcomes (Starfield, B. et al, 1981; Stewart, M., 1984; Bass, M.J. et al, 1986). New approaches are required as we move from a culture of compliance to one of concordance (Royal Pharmaceutical Society, 1997).

This research was conducted during the author's attachment as a Higher Professional Training Fellow in General Practice to the University Department of General Practice in Glasgow, from August 1996 to July 1998.

2. Aims and Hypotheses

Aims

1. To explore the outcomes adult asthmatics hope to achieve from the management of their disease by investigating their treatment goals.
2. To explore these treatment goals in the context of their life goals.

Hypotheses

1. Patients have their own goals for the management of their asthma.
2. Patients are directed towards goals by others.
3. Patients divide complex goals into sub-goals.
4. Patients have different degrees of commitment to their goals.
5. Patients have different degrees of self-belief in their ability to achieve their goals.
6. Patients perceive goals as being of different degrees of difficulty.
7. Past success or failure in setting and achieving goals influences present attitudes.
8. Patients have goals that conflict with each other.
9. Patients openly communicate their goals to the primary health care team.
10. Patients' goals form a rational framework although this may not fit a medical model.

3. Method

Setting

A single general practice of six thousand patients living mainly in owner occupied accommodation in the suburbs of Glasgow. The author worked in the practice on a sessional basis as a general practitioner during the time of the study. This aided access to the study population.

Population

All adults on the practice list aged 20-49 with a current diagnosis of asthma but no current significant physical or psychological co-morbidity, on grades 2-4 of the BTS guidelines and diagnosed at least two years previously were identified.

Sample

From this population, 23 adults with asthma aged 20-49 were selected. Purposive sampling was used to ensure approximately equal proportions of males and females as asthma in this age group affects equal proportions of each gender. The sample was chosen from three age bands in case goals change with age. Only people on steps 2-4 of the BTS guidelines were included in order to control for disease severity. People whose asthma had been diagnosed for less than 2 years were excluded. This was a pragmatic choice based on the assumption that people would require time to form goals. Subjects with a current significant physical or psychological disease were also excluded: physical diseases such as cardiovascular disease because it may be difficult to distinguish their symptoms from those of asthma; psychotic or severe neurotic mental illness because it might interfere with interviews.

Patients were identified by computer and case record search. A written invitation from the author to participate in the study was issued. It was followed up by a telephone call to arrange an interview time. The invitation introduced the researcher as both a doctor working in the practice and a researcher. The initial invitations contained a reply slip asking the person to indicate whether or

not they would be able to participate in the study. This produced a disappointing response rate: four responses to twelve invitations; one of whom declined to participate. These people were interviewed as a pilot. The reply slip was modified so that a response was only required if the person did not wish to take part. This produced a response rate of 23 out of 30.

Table 2. Sample Characteristics

Respondent	Age	Gender	Family Status	Employment	Current Smoking Status
1	29	F	married, 1child	secretary	no
2	41	F	married, 2 children	drama teacher	no
3	23	F	single, no children	office management	no
4	47	M	married, 2 children from first marriage	self-employed driving instructor	yes
5	25	M	single, no children	chartered accountant	no
6	41	M	married, one child	postman	ex
7	39	M	married, two children	software engineer	no
8	32	M	single, no children	unemployed barman	yes
9	42	M	separated, no children	engineer	ex
10	36	F	married, 2 children	telephone financial services	ex
11	39	F	married, 2 children	housewife	no
12	40	M	married, 2 children	engineering inspector	no
13	38	M	married, 2 children	salesman	no
14	35	M	married, 2 children	engineer	no
15	25	F	single, one child	student	no
16	24	F	single, no children	wages clerk	yes
17	22	M	single, no children	telephone operator	no
18	39	F	married, 2 children	self employed building business	yes
19	32	F	co-habiting, no children	computer operator	no
20	36	F	married, 2 children	post-office manager	no
21	20	M	single, no children	telephone operator	no
22	47	F	married, 2 children	secretary	ex
23	42	M	married, 2 children	car mechanic	no

Patients were interviewed in depth in their own home or a place of their choosing by the author. Two people chose to be interviewed in the general practice surgery. The interviews were in depth, based on a topic guide. The topic guide was devised in collaboration with a general practitioner and a social scientist experienced in asthma research, with reference to the literature on goal setting and revised according to the emerging themes in the three pilot interviews. The data from the three pilot interviews were not included in the analysis. All interviews were tape-recorded and transcribed verbatim by a single secretary experienced in the transcription of qualitative data, except for four interviews where recording failed. In these cases, the interview was written up from notes taken during the interview. The author, an academic general practitioner and a social scientist read the transcripts and identified the key themes. Coding categories were developed for each theme and applied to four transcripts. The coding categories were then revised and applied to a further four transcripts. This process continued until all three analysts regarded the coding categories as complete. Thereafter, the completed coding system was applied to all the transcripts. The data were then entered into the "Framework" model devised by Social and Community Planning Research (Ritchie J, 1994).

The most important code developed was that of the "asthma goal". To recap, a goal is defined as "that which one wants to accomplish; it concerns a valued future end state" (Lee, Locke and Latham, 1989). Therefore, to identify goals evidence was sought that the respondent would like to achieve a change in their asthma management *and* that efforts were being made towards that change *unless* it was inappropriate for the respondent to be actively pursuing his/her goals. For example, two women had goals related to pregnancy but were not pregnant at the time of interview.

After entering the data into "Framework" hypotheses were generated and the data explored for disconfirming cases. The hypotheses were revised as appropriate and the revised hypotheses applied to the data. This process

continued until all disconfirming cases were accounted for. In particular the links between goals, motivation and behaviour were explored. Both data collection and analysis were based on grounded theory (Strauss, 1990).

4. Results

The first part of this chapter presents the response rate to the study. Next the results related to each hypothesis will be presented in turn.

4.1 Response Rate

Eleven females and 12 males were recruited. It proved difficult to recruit older women because of physical and psychological co-morbidity.

4.2 Hypothesis one: patients have their own goals for the management of their asthma.

The first hypothesis concerns the presence or absence of asthma goals. In addition to the number of respondents with goals, the nature of the asthma goals are described and the reasons for having or not having goals.

Seven of the 23 respondents had goals related to asthma of whom 5 were striving towards their goal at the time of interview. In both cases where goals were not actively being pursued at the time of interview the goals related to pregnancy. Both women were planning a pregnancy but were not pregnant at the time of interview.

4.2.1 Type of goal

Asthma goals could be categorised as "cure" and "control". Cure was universally defined as having no symptoms and no need for medication. Control was expressed in terms of the management of symptoms and the management of inhalers.

Cure

Three respondents were attempting to cure themselves of asthma through exercise. For example:

To go back to a question you asked earlier on, 'what's your goals?'. I suppose yes, to get off it (medication). To get off it, slowly. Obviously it's not going to change overnight. But maybe over the next couple of years then if I can take it (the medication) down slowly, it'll take it (the asthma) away completely.

[Respondent 8]

One respondent had experienced a recent deterioration in his asthma symptoms and an increased requirement for medication after a prolonged period free of inhalers. He attributed his past good control to having taken regular exercise. Conversely his present poor control was attributed to gaining weight and taking less exercise. He believed that by taking inhalers temporarily, his ability to exercise would improve. This would increase his fitness and thereafter he could control his asthma by exercise alone.

The second respondent did not believe her attempts to cure asthma by delaying or omitting taking inhalers during exercise would be successful but the process of trying was beneficial:

Even if I don't improve, the thought that I'm actually trying and not just sitting back and letting it happen makes me feel better about it.

[Respondent 16]

The third respondent was gradually reducing his inhalers in the hope of being able to stop them without his symptoms returning. Again, he did not expect success; it addressed his need to "fight" asthma.

What does that mean for you, when do you feel as if (your asthma's) in control?
When I don't have to... I feel when it's in control when I can use my Becotide in the morning and at night without having any kind of inclination to use the Ventolin at all. If I can do that then I'm quite happy.
Why does that make you feel happy?
Because I'm doing without the Ventolin.
Uh huh.

And once I've done that, if I can take the Becotide in the morning and not bother with it at night.

Right.

That's another step forward, then maybe in months to come if I can maybe just take one skoosh, like a slow process forward.

Right.

Until I haven't got it at all but I don't think that'll happen. I don't think, it's not a negative view I've got.

Mmm mm.

A more realist view I don't think that'll happen. I'll always have to take something. I'm not giving into it.

No.

I will keep trying, I will do without that Ventolin.

Uh huh.

And once I can, once I've proved that I can do it then maybe I'll go onto to do without the Becotide.

[Respondent 8]

Control

One respondent's goal was to keep her peak flow around 450:

When you are looking after your asthma what are your main aims?

Well if the peak flow is not very high my main aim is to increase my dosage... I don't think it matters really how many puffs you take as long as up to about 450 again.

[Respondent 20]

This was based on the advice of the asthma nurse and in order to control symptoms by motivating herself to take medication. She valued having few symptoms as this enabled her to work full time while looking after two young children. However she was afraid of developing osteoporosis from prolonged use of inhaled steroids and had found the diagnosis of asthma and the need for

regular treatment difficult to accept. The peak flow meter provided feedback on her condition which motivated her to continue to take inhaled steroids.

One respondent had managed to control his symptoms by using inhalers regularly. He was now keen to limit his use of inhalers by trying to establish the cause of his asthma. This might allow him to avoid trigger factors. As the inhalers were not curative he felt that taking them was "the easy life" and "was papering over the cracks" instead of tackling the underlying cause of asthma.

4.2.3 The reasons for having no asthma goals

16 of the 23 respondents had no asthma goals. The reasons for the absence of asthma goals may be summarised as follows.

(i) asthma of insufficient importance

> *Do you have an idea where asthma fits into your priorities?*
> It's not something I'm conscious of at all. I don't make a conscious decision one way or the other to do something or not to do something because of asthma.
>
> *Right and does it have any impact on your life do you think having asthma?*
> No, not at all. As I say the only thing I would think of is if I was going into a strangers house and there was a cat. That's the only thing that I would have to think well this is going to be uncomfortable but I wouldn't not go into somebody's house in case they had a cat
>
> [Respondent 2]

asthma can even become such a "part of me", that its effects are not noticed and it is not seen as amenable for goal setting

> I've never really been affected by it badly and I don't look upon it as an illness, it's just part of me.
>
> [Respondent 5]

(ii) perceived impossibility of influencing the outcome

Right and I mean do you then have to plan ahead with your asthma?

Not really because my asthma, as I say, is that brittle it's really pointless. There is nothing that I can say or do today that will make me okay for Saturday / Sunday or a week on Saturday or Sunday, you know, I could go from here to next Friday night okay and arrange to do something on Saturday and end up in hospital on the Friday night. *Right.* There is no point in really trying to do anything because nothing is going to stop it happening, as I say, that's not like my mother. My mother can feel it coming on and get antibiotics or something like that, it just doesn't happen with me, as I say if I've got them all there. If I catch a cold or something, I know that I've really got to do something there and then to try and prevent it getting any worse but as for preventing an actual asthma attack, no, mine's goes from quite good to the bin very quickly.

[Respondent 9]

(iii) goals not required as asthma always carefully controlled :

Well the fact that now I take the inhalers daily. If I wasn't taking anything on a daily basis, yes I would. I could see scenarios where I would take them prior to maybe some sort of event but it's lately, it's at least a year that I've been taking them every day so I don't take them for any particular event I just take them daily anyway.

[Respondent 12]

(iv) competing priorities

Yes I always...Yes, every time I go to the doctors I think I'll ask. But there are that many different things going on in my head that I forget and I had a leaflet with an address to write to but I lost the leaflet. I would like to know a lot more about it because I don't really understand it.

[Respondent 15]

4.3 Hypothesis two: patients are directed towards goals by others

Respondents showed no evidence of being directed towards goals by health professionals. However, some sought help to realise their goals, sometimes successfully. For example, one respondent's goal was to improve his performance at work by reducing nocturnal cough and improving his sleep. He consulted the primary care asthma nurse for advice and was motivated to use regular inhaled steroids:

> Certainly (my asthma) has improved remarkably since I started attending the asthma clinic and getting regular advice and top-ups from (the asthma nurse). Harassing me to take my inhalers.
>
> [Respondent 7]

Both respondents wishing to control asthma during pregnancy, did not succeed in communicating their goals to primary care. Despite consulting for the specific purpose of planning their asthma management during pregnancy, neither had a strategy.

Two respondents striving for a cure, had devised their strategies alone. They felt that primary care over-emphasised the importance of inhalers over other management strategies. The respondent aiming for a cure through the short-term use of inhaled steroids had rejected these drugs on two previous occasions. He did not follow advice until he considered it would fulfil a personal goal.

4.4 Hypothesis three: patients divide complex goals into sub-goals

Two respondents had asthma goals which they divided into sub-goals. One wished to be cured eventually. He was using inhalers temporarily to increase his exercise capacity. He believed that exercise alone would later control his asthma:

> I'd rather maybe try and control my asthma by getting a bit fitter, than the full use of my inhalers but I realise that I have to use my inhalers until I build up a bit of fitness.
>
> [Respondent 17]

The second respondent was using steroid inhalers to reduce his requirement for bronchodilators. Eventually, he hoped to stop all inhalers without his symptoms returning.

4.5 Hypothesis four: patients have different degrees of commitment to their goals

Three of the respondents showed evidence of consistent goal commitment. For example, respondent 17, a 22 year old single man, had given up socialising with friends, his second job in a night club and had started exercising five times per week in order to cure his asthma.

One other respondent showed intermittent commitment to her goal of delaying or omitting inhalers. When she suffered acute exacerbations she became frightened and took her inhalers more rigorously.

It was not possible to assess the commitment of the remaining three respondents. The two with goals related to pregnancy were not pregnant at the time of interview. The other respondent had only recently decided to reduce his inhalers. As he aged, health was becoming a higher priority and he was becoming increasingly concerned about using medications. Although he valued symptom control he was starting to investigate alternatives to inhalers.

4.6 Hypothesis five: patients have different degrees of self-belief in their ability to achieve their goals

Self-efficacy varied within the group. Two respondents were confident in their ability to achieve their asthma goal. For example:

> Obviously my ultimate goal probably is the asthma, to get rid of it totally the inhalers or at least being able to control it with the minimum help.
>
> *Yes. And do you think you will be able to get to that point, I mean how confident do you feel about that?*
>
> I think I will be, in the next six to eight months I'll be at a stage where I'm really starting to drastically reduce what inhalers I'm taking, if not the frequency, the dosage maybe.
>
> [Respondent 17]

Four were not confident. For example:

> *Okay, do you think you will be able to... you said you wanted to go to the gym and do different things without using inhalers. How confident do you think you'll be able to do that?*
> I can't see it. I can't see it at all. Yeah I mean I'd be fitter and stronger and everything but when it comes to the breathing side of it I don't see it helping that much, you know.
> It's not, I mean, I've not really looked much into it but I don't think that it's really that much to do with your level of fitness, I mean, you have asthma.
>
> [Respondent 16]

One felt he did not have enough information to judge his ability because he had only recently started to pursue his goal.

4.7 Hypothesis six: patients perceive goals as being of different degrees of difficulty

Two respondents regarded their goals as easy to achieve, four difficult and one was uncertain. People who regarded asthma as being under their control felt their goals were easily achievable. Two of the people who regarded their goal as difficult based their opinion on previous experience of failure to achieve their goal. The other two accepted that a diagnosis of asthma meant cure was impossible. The person who was uncertain had just started to pursue his goal. No-one had more than one asthma goal.

4.8 Hypothesis seven: past success or failure in setting and achieving goals influences present attitudes

Respondent 17 has successfully controlled his asthma using exercise alone in the past. This encourages him that he will succeed in his goal to do so again. Despite many set-backs due to asthma such as admissions to hospital, being unable to work and having a restricted social life he is still motivated to pursue his goal.

> As I say I was fairly fit through high school and I was weighing three or four stones off of what I am now. I never had to use it (my inhaler), I don't know maybe it's some of the extra weight I'm carrying about or whatever. I would generally say that fitness is better at controlling asthma than inhalers...

... First of all I think it was my gran, my gran didn't like me taking anything at all. So she encouraged me to cycle and run everywhere when I was younger. And that seemed to help me.

Do you find it worked in the past?

Oh yes, definitely.

[Respondent 17]

Respondent 11 has failed to avoid using oral steroids in a previous pregnancy to control asthma but is still motivated to try again. She is determined to protect her unborn child from the potential adverse effects of oral steroids. She believes oral steroids represent poor asthma control. She is normally able to control her asthma by herself using inhaled steroids but these measures do not work for her in pregnancy. She believes that if she can persuade the medical profession to help her to take better care of her asthma during pregnancy she will not require oral steroids.

There are no examples of people who have been put off setting goals in future because of failing to achieve a goal. People who have achieved a goal were content at the time of interview and therefore not motivated to set any further goals.

4.9 Hypothesis eight: patients have goals that conflict with each other

Respondent 22 had conflicting goals of symptom suppression and minimising inhalers. Therefore, she used a peak flow meter to provide feedback on disease severity which motivated her to use regular inhalers. Respondent 19 tolerated asthma symptoms in the summer in order to avoid using steroid inhalers. In her experience, failure to use steroid inhalers in the winter led to time off work. Therefore, she limited taking steroid inhalers to winter, when they were felt to be most necessary.

4.10 Hypothesis nine: patients openly communicate their goals to the primary health care team

As can be seen in hypothesis 2, some people communicate their goals but others do not. Of those who do seek help from primary care some are successful, others are not.

4.11 Hypothesis ten: (i) patient goals, motivation and behaviour form a rational frame work

Tables 1 and 2 in appendix A summarise patient goals, motivation and behaviour. Table 1 describes the asthma goals, motivation and behaviour of the seven respondents with asthma goals. Table 2 describes the motivation and behaviour of the remaining sixteen respondents who have no asthma goals.

The motivation of people with asthma can be understood by examining their evaluation of their illness. People may be motivated to set goals and change their behaviour if they regard it to be important to achieve a cure, resolve symptoms or change their medication. The findings related to the value of a cure, the experience of symptoms and the experience of asthma treatment are presented in the following section.

4.11.1 Evaluating Asthma

4.11.1.1 The value of a cure

All subjects valued a cure for asthma i.e. no symptoms and no inhalers. However, the strength of the desire for cure varied widely. It might be a wish to help others, a gift that would be appreciated if offered, a fervent hope that a cure would be found through research.

> I'd like to see somebody obviously come up for a cure for it because I know a lot of kids on the television it's quite unpleasant watching them gasping for breath.
>
> [Respondent 4]

> I wouldn't mind not having asthma, so you wouldn't have to worry about it at all but...But it's there so I just make sure I take my inhalers in the morning so that I don't have to think about it for the rest of the day.
>
> [Respondent 5]

> I give quite a lot to asthma research hoping somebody comes up with some miracle.
>
> [Respondent 9]

4.11.1.2 Evaluating Symptoms

The Experience of Asthma Symptoms

This section describes the symptom experience of people with asthma. The extent to which chronic symptoms become normalised may vary from person to person. It may be regarded as normal to have mild symptoms, infrequent symptoms, symptoms occurring in response to known triggers or sometimes only complete freedom from symptoms is regarded as normal. As the treatment of asthma is influenced by the
personal experience of symptoms and their presentation to the health service an understanding of the subjective symptom experience is important.

Asthma severity can be difficult for the individual to assess because:

> What you are is what you are really so you don't really know what you would be like without (asthma).
>
> [Respondent 13]

Several were keen to know how severe their asthma was and some took the opportunity to ask the author. Symptom severity is described in terms of the perceived severity of the current asthma symptoms compared to the past experience of asthma symptoms and a judgement of one's own function against others with asthma and against healthy peers. It is also described in terms of the degree of unpleasantness of the symptoms. Asthma symptom severity is set in

the context of the experience of other illnesses and the perceived potential consequences of asthma.

The impact of asthma symptoms may depend not only on symptom severity but also on symptom frequency, the adjustment to symptoms over time, the value of activities affected by the symptoms and the predictability of the onset and resolution of asthma symptoms.

Asthma Symptom Severity

Individuals assess the severity of their asthma symptoms by comparison to their own past experience of symptoms, to others with asthma and to healthy peers. Additionally, the degree to which symptoms are experienced as unpleasant varies. For some people symptoms are a mild irritation; for others an extreme annoyance. All symptoms such as cough, wheeze, shortness of breath etc. may be of equal value or one symptom may be felt as particularly annoying.

Past experience of asthma

If asthma had improved with time, then even limitations which appeared significant to an observer may have been perceived to have minimal impact.

> I have to admit that my asthma is not as bad really as, I mean it's not chronic, it's no where near anything like that at all. It's not half as bad as it used to be, it was worse when I was a child.
>
> [Respondent 4]

Symptoms may only be noticed when they deteriorate or deviate from what is normal for that person. People speak of asthma "coming on" at times:

> I don't know, I think my aims are just the same I think of anyone else who has got asthma, just to be free of it and more than just having to rely on something. Just to be able to, I mean, I am a normal person just like everyone else, it's just occasionally the asthma comes on. But I just feel like I wish it just never happened, I just wish it would go away sometimes and it does interfere, it annoys me more than anything, I think why me why have I got this?
>
> [Respondent 16]

This may make asthma appear to be an episodic condition whereas health professionals regard it as a chronic condition.

Comparison to others with asthma

In only one case did a respondent view his asthma as more severe than most others with asthma. He perceived that, unlike others with asthma, he was unable to take part in normal physical activities even with the help of the standard dose of salbutamol and he could not identify with the common asthma triggers:

> To me there are a lot of people say they've got asthma and they've had asthma attacks and fair enough they might have a bit of wheeziness which I suppose is asthma but people say they've had an asthma attack and next day you see them running for a bus now that to me is somebody who hasn't got asthma, they've got a wheezy chest.
>
> I know for a fact that if they had asthma, the fright of the first attack would probably kill them anyway because they really don't know what they are talking about. If you can run for a bus you've not go asthma. People say they take two puffs of their inhaler and then play a game of football. They've not got asthma, definitely not, as I say, I know where I'm coming from here, I've played football, five-a-side, rugby, everything as I told you but once this started I couldn't do it so if somebody can do it, I wish whatever they where taking, they would give to me. As I say, I just hope that some day they find out because there must be something, cause there are more and more people seem to be suffering from some sort of chest infection or something, whether it's asthma or related to whatever I don't know because I was told when I first had it that I shouldn't work in dirty, dusty places and all that. Well in my work it's been dirty and dusty since the day I ever went in there and when my asthma is good it doesn't bother me at all.
>
> So I don't know as you say, pollen, a lot of people with asthma, on the news you hear it in the morning, especially coming in at this time of year, they say oh asthma sufferers you are in for a hard time. The pollen count is away up, doesn't bother me. You asked again about cold, a lot of people say oh if it's really cold air or something my asthma is away, well I've just been away ----- myself in 30 below for 6-8 hours a day. It never bothered me. I would just like to know where all this information comes from and who starts the rumours.
>
> [Respondent 9]

The others compared themselves to the worst case of asthma they had ever heard about and regarded their own asthma as comparatively mild:

> I've always felt as though, you know, that asthma there is serious cases of that and I've felt that that must be an awful sort of thing, you know. This is why I never class myself as having asthma really because I'm not really like that. I just have an odd wheeze or a catch in the back of my throat. It's never like a panic attack or something like that you know.
>
> [Respondent 13]

Comparison to healthy peers

Some people are content if their asthma is better than before or better than others. However some will not accept anything less than complete freedom from asthma symptoms like their healthy peers.

Respondent 6 is proud that he feels fitter than most men his age and visits the doctor only once a year for his asthma review. He attributes this to a strict regime of inhalers, rest, diet and exercise. He describes a childhood when due to "weak lungs" he was always last in running races "along with the fat boys". He was inspired by a friend who overcame a badly injured leg through exercise and his general practitioner who:

> "was quite cheeky. He told me I could run a marathon if I took the inhalers".
>
> [Respondent 6]

Present symptom experience

The similarity of the symptoms of asthma to other conditions such as the common cold may lead to a delay or even a failure to recognise asthma symptoms.

> Sometimes you don't even know if it's a cold I've got. Only if it keeps...it only unfurls eventually that that was a cold, initially it's very similar sort of symptoms in many ways.
>
> [Respondent 12]

Recognition of symptoms may be avoided in order to avoid asthma treatment:

> Well I think it's more controlled now, I think the last time I really wasn't paying attention to the symptoms and I was coming down to yourselves at the surgery and I'd think there was something completely different wrong with me but deep down I thought is this this asthma thing again and it was, it was just a failure to really acknowledge that I would have to take the inhalers every day.
>
> [Respondent 20]

Asthma symptoms are often described as mild and not particularly burdensome. Language such as "only" or "a wee bit" is used to signify this.

> I can cough up a little bit of phlegm but nothing sort of, nothing grotty. Some mornings but no I don't have a cough.
>
> [Respondent 4]

> I just was getting a slight wheeze at times, at night really.
>
> [Respondent 13]

Some people do find symptoms unpleasant.

> Well as I say if I don't take these inhalers, it's very wearying. There was one day that they were getting quite low and maybe have to wait a day or two before we get a repeat prescription and these couple of days in between are very unpleasant I mean I just can't.... I'm just sitting sneezing all the time, my eyes are heavy. It grinds you down quite a bit, you know.
>
> [Respondent 12]

Some symptoms are perceived to be worse than others:

> As long as I've not got a cough I'll say that I'm OK. The wheeze doesn't bother me, because the wheeze I'm quite used to but the cough definitely annoys me, definitely.
>
> [Respondent 1]

Asthma symptoms may be acute in which case they are described as an asthma attack. These are different to everyday asthma symptoms in that the onset may be more sudden and the symptoms feel frightening and life-threatening.

> I've seen me with two bad attacks, two frightening attacks in 10 years and...And the worst, maybe 1 or 2 others but 2 sort of ones that looking back, none of the other ones came anywhere near. So I'd say I've only really had 2 severe attacks to the frightening level...They two in particular were down, I had the second one about 2/3 years ago and I found that one extremely worrying because I just couldn't get a breath but luckily the doctor did come out quickly and within minutes of this injection I could feel my breath coming back. But *that* one there was worrying, the rest is just the sneezing non-stop, you don't .... You don't feel sort of life threatening with it or anything like that so it's never really been a worry as such. There's only been a few occasions when it's been a worry and that's over 10/11 years so then taking the inhalers I've never really came across anything like these two.
>
> [Respondent 12]

Asthma Severity Compared To Other Illnesses

All of the above measures of asthma severity relate to how severe one's own asthma is on a scale from very mild to very severe. Asthma may also be seen in the context of other illnesses. People find it difficult to compare asthma to illnesses suffered by others. They may be particularly aware of this because of the failure of non-sufferers to understand asthma:

> I've had a couple of people say to me there is nothing wrong with you. They look at me and say there is nothing wrong with you, why have you got all these inhalers, why have you got these tablets, why have you got this and that, you know?
>
> [Respondent 16]

Asthma may be regarded as better or worse than other illnesses according to the experience of symptoms, its effects on life, its response to treatment, how serious it is perceived to be and how permanent it is seen to be.

(i) Symptom Experience

In the following case the respondent used to suffer from hayfever but is not a current sufferer. She regards hayfever symptoms as being more uncomfortable than asthma symptoms:

> I think that is the worse. I would hate to be a hayfever sufferer and I mean, I now have sympathy for hayfever sufferers and I never thought...
> *It sounds so trivial but it's meant to be awful.*
> I never thought twice about it before but I now have the utmost sympathy for hayfever sufferers because I just thought it's something and nothing but I now know how they suffer. The nipping eyes, the runny nose and they must be miserable when the sun shines.

[Respondent 18]

(ii) Effects on life

Respondent 21, who suffers from asthma alone, argues with his friend, who suffers from hayfever alone, as to which is the worse illness. Respondent 21 argues that asthma is worse because it can interfere with an activity they value, smoking cannabis. His friend feels that the symptoms of hayfever are more uncomfortable.

(iii) Response to treatment

In the following case asthma symptoms seem to resolve rapidly when salbutamol is used whereas hayfever symptoms are thought to require prevention because they are not easily relieved:

> I like to try and control the hayfever because although the asthma can be distressing sometimes I know if it's coming on, I've got something that can prevent it or can calm it down whereas with the hayfever, if that happens. If I'm getting my watery eyes and I'm sneezing and that. By the time that happens it's too late to take the tablets, it's too late to take the eyedrops because it's already happened as with the hayfever, as long as I take the tablets and my nasal sprays and all that. I know my nose won't get blocked, I know it won't affect me. So that's why in the summer I tend to get my hayfever stuff as well. So as long as I've got my inhaler I know I should be okay.

[Respondent 16]

(iv) Seriousness

In the following case the man's wife has a serious illness, muscular dystrophy, which is causing a progressive decline in function and therefore inhibits future planning:

> I don't have any long term ambition other than see this house paid off, which won't take that long anyway and then I don't know what will happen after that, it might, I don't know when I'll retire but when I do, whether we stay here or live somewhere else I don't know but I always wanted to move into the country anyway. My wife likes that idea too but she's got muscular dystrophy and she's retired now so, most long-term plans are really a sort of... I haven't really got any long term plans, you know, nothing really for the future, you know...
> ...I mean my wife has got more problems than I have, well, you know, health wise she's got a lot more, you know, it doesn't hold her back, she's very determined. Very positive. My mother said to me the other day, how she never hears Sandra complain about things, you know, about her health. She complains about her knees and that sort of thing and the cold weather and her back can be sore at times, shoulders get sore but she doesn't complain so I don't complain either.
>
> [Respondent 4]

(v) Permanence

In the following case, hayfever is perceived as an illness which may go away with age, unlike asthma. The respondent is happier to treat hayfever because she perceives that treatment will not be required "forever". Adverse affects of treatment are perceived to be more likely with increasing duration of treatment:

> I don't know if I'd ever be without the asthma, I really can't see me being without the asthma. Forget it. Although I've only got it the last few years I don't think I'll grow out of it. I just cannot get it into my head that I've got this for life. I don't want to think I've got it for life whereas hayfever, I at least think there is a possibility that I'll grow out of that, so just treat it now and hopefully it will go away, you know, like a cold it'll go away.
>
> [Respondent 16]

Consequences of asthma

Asthma severity is also seen in the context of the potential consequences of asthma. Some people thought asthma had potentially serious consequences but others did not:

> To be cured would be quite good but it really, it's not life-threatening. It doesn't harm any organs in your body, your heart or your liver or anything like that. It doesn't attack them like a bacteria or anything like so, it's a condition really isn't it. So it doesn't bother me. If I've got it until then so be it, you know, I'm not going to worry about it. But if somebody said to me listen this will cure you, do you want it. I'd say yes please.
>
> [Respondent 8]

Some recognised that asthma *could* be serious but it was not serious for them:

> *What do you mean healthy?*
> Well I'm very rarely off my work and I can get up and about and do things. I'm not ill. I'm very rarely... I've not had anything serious wrong with me. I feel fine, I may be unfit but I feel healthy.
> I wouldn't like to think that (asthma) would affect me if I wanted to pick a, any job I would pick. I don't think it would affect me anyway but I wouldn't like to think it would stop me doing what I wanted in life. I mean I've never thought that it would. I'm like it'll never happen to me but nobody thinks it'll happen to them I suppose...it is a life threatening disease or whatever but I don't think of it as that I just think of it as asthma. It's just something I've got, it doesn't affect me, it won't affect me. That's not to say it won't that's just the way I feel about it just now. Ask me in five years time and I might be better, I might be worse. I think because I'm all right just now...
>
> [Respondent 1]

The impact of symptoms

As previously discussed, it is difficult for people with asthma to judge how severe their symptoms are. Therefore they refer to their own past experience, their experience of asthma in others and their abilities compared to healthy peers. In addition, symptoms are regarded as severe if they have a large impact on life. Even mild symptoms may have a large impact on life if they are frequent,

interfere with a valued activity or are unpredictable in onset or in response to treatment. The impact of symptoms on life may also be modified by "getting used" to the symptoms and their effects over time.

Symptom frequency

If asthma symptoms are experienced infrequently their impact on life is perceived to be small.

> I don't really, I don't have a bad case of asthma, so I don't really tend to suffer too much. Occasionally just out of breath if I'm doing exercise or whatever but no real problems.
>
> [Respondent 2]

The value of the activities affected

If asthma symptoms affect important activities such as work their impact is perceived to be greater than if they hinder less vital activities. The impact can be mitigated if the activity can be completed albeit more slowly or to a lower standard than could be achieved by someone without asthma. However some people cannot except a lower standard than their healthy peers. "Not allowing" asthma to affect activities was a recurrent theme which represented "fighting against" the illness rather than "giving in".

In the following example inability to take part in much loved sporting activities and demotion to a less physically demanding job have been attributed to asthma:

> Asthma's had a big impact in my life, yeah. It's really stopped me doing just about everything that I've ever done because I say the sport and all that went quite quickly and now the job that I've always done, I served my time in engineering and worked all my life and then I'm out it. I just can't do it because there was a lot of physical work involved what I was doing and it just can't be done anymore.
>
> [Respondent 9]

Predictability of the onset and resolution of symptoms

A predictable response of asthma to triggers may give a feeling of control over events. It may be possible to avoid the trigger in future or at least appraise the risk of exposing oneself to the trigger more accurately. The fear of the unknown may be reduced which can increase self-efficacy.

In the following case the respondent is confident of his ability to manage asthma because of the infrequency and predictability of the onset of asthma attacks:

> I don't regard (asthma) as an issue, it's not something that's a priority or a concern on a daily basis. The one and only flare up that I did have, I just regarded that as a flare up. I knew what triggered it.
>
> [Respondent 14]

If symptoms respond predictably to treatment then their impact is diminished. The confidence to tackle activities may be increased if treating any symptoms which might arise is straightforward.

> I don't really consider myself as an asthma sufferer. It's more just a tendency if you like... you hear about people who are dead low that take a lot of time off their work etc. But that doesn't happen to me. It's a very mild form. I'm just on the fringes.
>
> *Yes, it doesn't effect you or anything a great deal.*
>
> It doesn't stop me doing anything, you know, and I know that if I do something and it does trigger any symptoms I know that one puff of a ventolin inhaler is enough.
>
> [Respondent 14]

The adjustment to symptoms and their effects over time

Becoming accustomed to chronic symptoms may reduce their perceived impact. Symptoms may worry friends and family more than the sufferer and they may encourage the sufferer to seek medical attention.

Certainly it upsets my wife because she thinks I'm not well again and she give me ...So it seems to effect the people around me but I suppose after 30 years I've got a bit used to it. I know how I feel in myself, whether I'm actually ill or not -- -- --- --- to other people it does make them worried that I'm not very well.

[Respondent 7]

4.11.1.3 Evaluating Inhalers

Low Concern About The Use of Inhalers

Inhalers were valued for their ability to minimise symptoms even though they are not curative. They became a part of "normal" life. The reasons given for being prepared to take medications even in the absence of symptoms were:

(i) the inhalers taken are mild

I don't really have any worries about taking (inhalers). I think if it got worse and I had to take more steroids I'd like to know a bit more about it. I mean you hear all sorts of things about steroids and things like that but at the moment I'm not too worried about it because I know it takes it away and I know it's quite a low dose, so...

[Respondent 3]

(ii) the inhalers taken are essential

There's not a lot I can do about (taking inhaled steroids), you know, likes of the (oral) steroids, that they give me when I'm not well. There is, you can have the course and you know if you had another course you might get better a bit quicker but you know that once the first course is past, fair enough, it's going to take a couple of weeks but you can off them. The things that I'm on permanent are the only things that are keeping me alive at the moment so you learn to live with these things. When they first told me that I'd have to take inhalers, they never said for the rest of your life but for the foreseeable future. It took me a long, long time to come to terms with that but you have got to do it.

[Respondent 9]

(iii) inhalers are "normal" and therefore not noticed

I just accept it, I just accept that I have to take inhalers in the morning and I don't tend to worry about things like that or .... I just carry on with them.

[Respondent 5]

(iv) it is not worth the consequences of stopping inhalers

> Whether my asthma is getting better I don't know. I'm still on the inhalers which are stopping it. I think the only way to do that would be to come off the inhalers and see how bad it was but I don't know if I want to do that."
>
> [Respondent 3]

(v) the inhalers are convenient to take

> You just take one puff and that's it, yeah that's fine. As I say I don't really think of these things anymore, they are more inconvenient than getting up in the morning and cleaning your teeth and shaving, you know. It takes five seconds.
>
> [Respondent 4]

(vi) they have been advised not to discontinue their inhalers

> I used to stop my inhalers in the summer when I felt OK but (my GP) gave me a row for it. He said "You never stop your inhalers."
>
> [Respondent 6]

High Concern About The Use of Inhalers

Inhalers were devalued because they were not seen as curative. Their disadvantages were weighed against their ability to control symptoms, the effects of asthma symptoms and the availability of other strategies for symptom control. People could feel vulnerable in situations where inhalers are unavailable or faulty, if inhalers were their only method of symptom control. Deciding how much treatment and of what kind to take may increase feelings of control over asthma.

> "I don't like taking (my inhaler) anyway, no. I know I've got to, I know there is times I've got to take it because if I don't take it I'm unwell but I still don't like taking, I don't like the thought of taking something forever you know I just feel...I keep thinking I can cut it back but I can't cut it back it's something that

you have got to live with. I keep thinking I can cut it back and I'm all right and then three months down the line I'm not all right and I need to take this inhaler again and I just feel as if it's something I've got to take all the time and I just don't like that idea. I feel maybe, I don't know, maybe it's I suppose something I've got. I've not really sat and thought about oh I've got asthma, this is going to affect the rest of my life or this is going...I don't like anything to effect me and I feel as if I don't like something to take control of my life, you know it's like I'll control you and you can't, you can't control it.

[Respondent 1]

Medications may also serve as a reminder of chronic illness:

I don't know, maybe it's denial. Maybe it's you don't want to admit the fact that you've got something wrong with you that you can't kind of fix. You know, it's not like a broken arm that once you have got the plaster off it's mended, it's fine, it's something that you have got to take forever or whatever.

[Respondent 10]

Some objections to asthma medications applied to all medications; others were specific asthma medications.

General objections:

(i) they are "unnatural"

I don't know how much it costs but I know my sister she used homeopathic for medicines for certain things and it always sounds that expensive for certain things I'm always put off. Next month I keep promising myself and I've never changed my diet or anything but I would consider, if I thought cutting out something would make me feel better then I would because I'd rather change my diet than take medicines.

What is it that appeals to you about homeopathic medicines?

I don't know I suppose it's all natural stuff, that appeals to me as opposed to the inhalers being steroids."

[Respondent 1]

(ii) it is difficult to remember to take medications when asymptomatic

You were saying that you feel that as you start to get better sometimes you forget to take the Becotide, is that right?

I think whenever I feel well, there's certainly no motivation and if you are feeling okay and you are in a rush in the morning, the last thing you are going to do is to habituate that. Try and make it part of your routine when there is nothing wrong with you but I understand from (the asthma nurse) that's told me that an important part of it is to build up the amount of becotide and then there's an accumulative effect but that really doesn't seem to....

How are you finding trying to get into the habit of taking it.

I think it's difficult, I mean I go through periods where I'm quite studious I think and then think back I didn't actually take any on Tuesday or Wednesday so I haven't been studious but I certainly thought I was.

[Respondent 7]

Specific objections to asthma medications:

(i) the potential for harm due to long term use

I think the word steroid, I think that's all and I've had it explained to me that there are minute steroids in it. And that I would have to be on it for so many times so many you know before there was any damage done or anything like that but I always think if you are taking something over a long term there must be something, it must be doing something to you. And I've got this thing in the back of mind that maybe it's actually weakening instead of building up your lungs, it's maybe weakening the lungs and you are having to depend, the more you take, you are having to depend more on it.

[Respondent 18]

(ii) addiction

I know that things can get addictive and I don't want to have to rely on them all the time. I'd rather something more natural... I don't know, I've just got it into my head that's like depending on something, like somebody has to take drugs or something and you feel as if you can't survive without it. I don't like that feeling, I prefer when they used to be there just in case.

[Respondent 15]

(iii) high doses being seen as a marker of more severe asthma

> The more inhalers I've got the more dosage I've got to take, it means my, I'm not dealing with it very well so the least I can take or the less I can take, the more confident I get.
>
> [Respondent 8]

(vii) inhalers being unpleasant to use because of taste or side-effects

> *Is there anything that you particularly don't like about the inhalers?*
> The taste.
> *Taste?*
> It's disgusting."
>
> [Respondent 15]

> when I take the tablets as I say I get a shaking sensation. I don't like the side effects either. The other thing that I get when I was taking them regular, my voice, I have a deep voice anyway but with the tablets it was really deep and I find now when I talk for any length of time my voice totally disappears.
>
> [Respondent 10]

(viii) the cost of inhalers being resented as they are essential to people with asthma.

> But have to constantly throughout the year pay for different medications I don't think that's right, you know, if it's an ongoing thing and it's not preventable or it's not basically my fault or anything then I don't see why I should have to pay for it if I pay my taxes."
>
> [Respondent 16]

Inhaled Steroids Versus Inhaled Bronchodilators

Some people distinguish between their inhalers; others have equally positive or negative reactions to inhalers whether bronchodilator and steroid. If a

distinction is made, bronchodilators are always favoured over inhaled steroids because:

(i) the benefits of inhaled steroids are not immediate

> Even if you don't feel any symptoms, it still gives you a wee bit of relief if you know what I mean. It's still doing something, whereas the brown one is not doing anything so that's why it's always been the blue one.
>
> [Respondent 14]

(ii) the risks of inhaled steroids are perceived to be greater

> *Do you worry about building up a dependency on Becotide... ?*
> Yes.
> *... Ventolin or both?*
> It's the Becotide more than the Ventolin. I see that as more of a high risk.
> *Why is that?*
> I've no idea, it's just something the way I see but I feel my Ventolin gives me better results for what I take of it, I don't know it that's just all in my mind.
> *Yes.*
> I know that the Becotide is probably doing it some good but the effects of it isn't noticeable.
>
> [Respondent 17]

(iii) inhaled steroids may not make bronchodilators completely unnecessary and one inhaler is preferred to two (for reasons of cost, convenience, minimising medications)

> I think even if I did take my Becotide first thing in the morning and last thing at night, when it came to going to the gym or something like that I think I would still need to have my salbutamol with me anyway.
>
> [Respondent 16]

5. Discussion

In the first part of this chapter, the reasons for choosing the study methodology will be outlined. Thereafter, the other hypotheses will be discussed in turn. Firstly, the treatment goals of the sample, which were described in detail in the results section, will be briefly summarised. Next, issues related to the goals such as who sets goals, sub goals, self-efficacy, perceived goal difficulty and goal conflict will be outlined. Hypothesis ten will then be discussed in some detail. Using grounded theory, it emerged that goals were not a dominant theme for the respondents. However, it was noted that some respondents with no goals were motivated to change their behaviour in relation to asthma. This prompted an analysis of patient motivation and behaviour and the reasons for having no asthma goals. Therefore, hypothesis ten has been modified to "patient goals, (motivation and behaviour) form a rational framework although this may not fit into a medical model". It will include a discussion of the reasons for having no asthma goals and how this fits with the medical model. Finally the implications of the findings for asthma management will be discussed.

5.1 The Use of Qualitative Research Methods To Study The Treatment Goals of Adults With Asthma

Qualitative research methods have a long history in the study of the experience of chronic illness. Gerhardt (1990) states that we are in an era of "treatable long-term sickness with relatively minor effects on physical capacity and lifestyle". It is therefore important to understand the effects of illness and its treatment on life. Qualitative methods allow an insight into the perspective of the sufferer. It is as common to decline to use treatments for asthma as it is to use them. Therefore, it is important to understand the goals of asthma management from the perspective of the person with asthma. The reasons why people have treatment goals can be illuminated. Studying asthma goals in the context of other arenas of everyday life and priorities helps to avoid the findings overstating the importance of asthma goals.

Qualitative methodology is also recommended when a topic has not yet been extensively investigated or is poorly understood (Britten, N. et al, 1995). In these circumstances, the inductive techniques used in qualitative research are more appropriate than the deductive techniques of quantitative research. Lack of information hampers the construction of an adequate hypothesis to be tested by quantitative methods. The literature review described in the introduction found only two papers on patient treatment goals for asthma neither of which reflect the wider population of people with asthma nor their wider goals (Partridge, M., 1994; Folden, S.L., 1993).

In the study discussed in this thesis, the sample is drawn from a single general practice population. All the subjects had been offered a prescription for inhaled steroids. Therefore, the sample represents a subset of the asthma population who have consulted with symptoms and been offered treatment. People with a similar degree of symptoms who did not consult primary care will not have been identified. People whose symptoms were not recognised by their general practitioner or whose general practitioner did not offer them treatment will have been missed. It is unknown if primary care influences patients' treatment goals. Further studies in different practices would illuminate this.

The data were collected by in depth interview. The author introduced herself as a general practitioner and a researcher. Hoddinott and Pill (1997) found no clear answer from the literature as to the influence of knowledge that the interviewer was a doctor. She found that some subjects guessed she was a doctor and she felt uncomfortable that she was not telling respondents the whole truth. The author decided to reveal she was a doctor for the practical reason that she was working in the practice although she had not been involved in the care of the people interviewed. In addition, she preferred to be honest with the respondents as they were being asked to provide full and frank accounts. People seemed keen to tell their views of their illness and volunteered potentially sensitive information such as that they did not always take their medication as advised and that they smoked cannabis. Only respondent 2 showed evidence of changing her account. She condemned inhaled steroids on the telephone when the

interview was being arranged but moderated her view at interview. It is possible that other respondents chose not to declare some information to a doctor. The interview was an interactive process which allowed questions and concepts to be framed in the language of the respondent. The interview was flexible enough to allow subjects' ideas to be pursued while still addressing the research question. Respondents were interviewed on one occasion. Therefore the evolving nature of goals could not be studied and the data is in the form of retrospective accounts.

The data were analysed using the Framework method devised by Social and Community Planning Research (Ritchie, J. & Spencer, L., 1994). This allows data to be systematically categorised and coded but avoids the danger of "shattering" the data identified by Conrad (1990). Framework allows both within case and between case analysis. Some other methods separate the coded data from the context and from the individual. To gain another perspective, the author discussed the analysis at all stages with a social scientist to try to avoid viewing the data only through the medical gaze.

5.2 Hypothesis one: patients have their own goals for the management of their asthma

To recap, only a minority of respondents have asthma treatment goals. These goals can be categorised as "cure" or "control". The former are described as being the absence of both inhalers and symptoms. The latter refer to the management of inhalers, symptoms and function. As new properties were still emerging, it seems that the theme of asthma goals has not been saturated. However, as goals were not a dominant theme for respondents, motivation in general and the reasons for having no goals were pursued.

5.3 Hypothesis two: patients are directed towards goals by others

Goals appeared to be self-set. This may be because of the discord between people with asthma and health professionals. People with asthma were more interested in non-medical strategies to control asthma and the dominant aim of treatment was to achieve a balance between medication, symptoms and other

priorities in life. The medical view is to abolish symptoms completely. The respondents aiming to control asthma were more likely to accept advice on devising and implementing strategies than those aiming for cure. This may also be due to discord with the medical view of cure being impossible or the desire to "fight" illness may be incompatible with accepting assistance.

5.4 Hypothesis three: patients divide complex goals into sub-goals

Only two respondents had sub-goals. From the limited data on sub-goals, it is difficult to assess what people with sub-goals in asthma have in common. Further studies of people with asthma goals would be required.

5.5 Hypothesis four: patients have different degrees of commitment to their goals

It is difficult to assess goal commitment because respondents were interviewed on only one occasion. Some respondents showed evidence of making significant changes to their life in order to achieve their goal. If people suffer an acute asthma attack it can set them back from pursuing their goal.

5.6 Hypothesis five: patients have different degrees of self-belief in their ability to achieve their goals

Self-efficacy varied within the group. Past experience of successfully achieving a goal can lead to high self-efficacy. The perception that a goal is impossible to achieve can lead to low self-efficacy. Goals are perceived to be impossible if they are not seen to be under the subject's control. For example, exercise was thought to be able to improve fitness but not to alter the underlying disease process.

5.7 Hypothesis six: patients perceive goals as being of different degrees of difficulty

In some cases, the perception of goal difficulty is based on previous experience. Past failure to achieve a goal may lead to the goal being seen as difficult and vice versa. In other cases, goals are perceived to be difficult because the outcome is not perceived to be under the individual's control. Difficult goals can

motivate people to strive for better asthma self-care even if they do not believe they will achieve the goal. The purpose of the goal is to keep the person fighting rather than giving in.

5.8 Hypothesis seven: past success or failure in setting and achieving goals influence present attitudes

Past success in achieving an asthma goal can encourage people to persist with their goals in the face of set-backs. However, past failure to achieve an asthma goal does not necessarily prevent further goal setting. It might be expected that failure to achieve a goal would discourage further goal setting. This may not be true of individuals because although people who have failed to achieve a goal will be *less likely* to set goals in future some individuals may persevere.

5.9 Hypothesis eight: patients have goals that conflict with each other

Goal conflict arose when people who wished to limit both asthma treatment and symptoms were unable to achieve both at the same time. Imaginative strategies were used to reach the best compromise between symptoms and treatment. The desire to limit treatment before symptom control is reached, discords with the aims of the British Thoracic Society Guidelines. This is discussed more fully in section 5.12.1.2.

5.10 Hypothesis nine: patients openly communicate their goals to the primary health care team?

See hypothesis 2.

5.11 Hypothesis ten: (i) patient goals, motivation and behaviour form a rational framework

5.11.1 The route to behavioural change

Figure 1

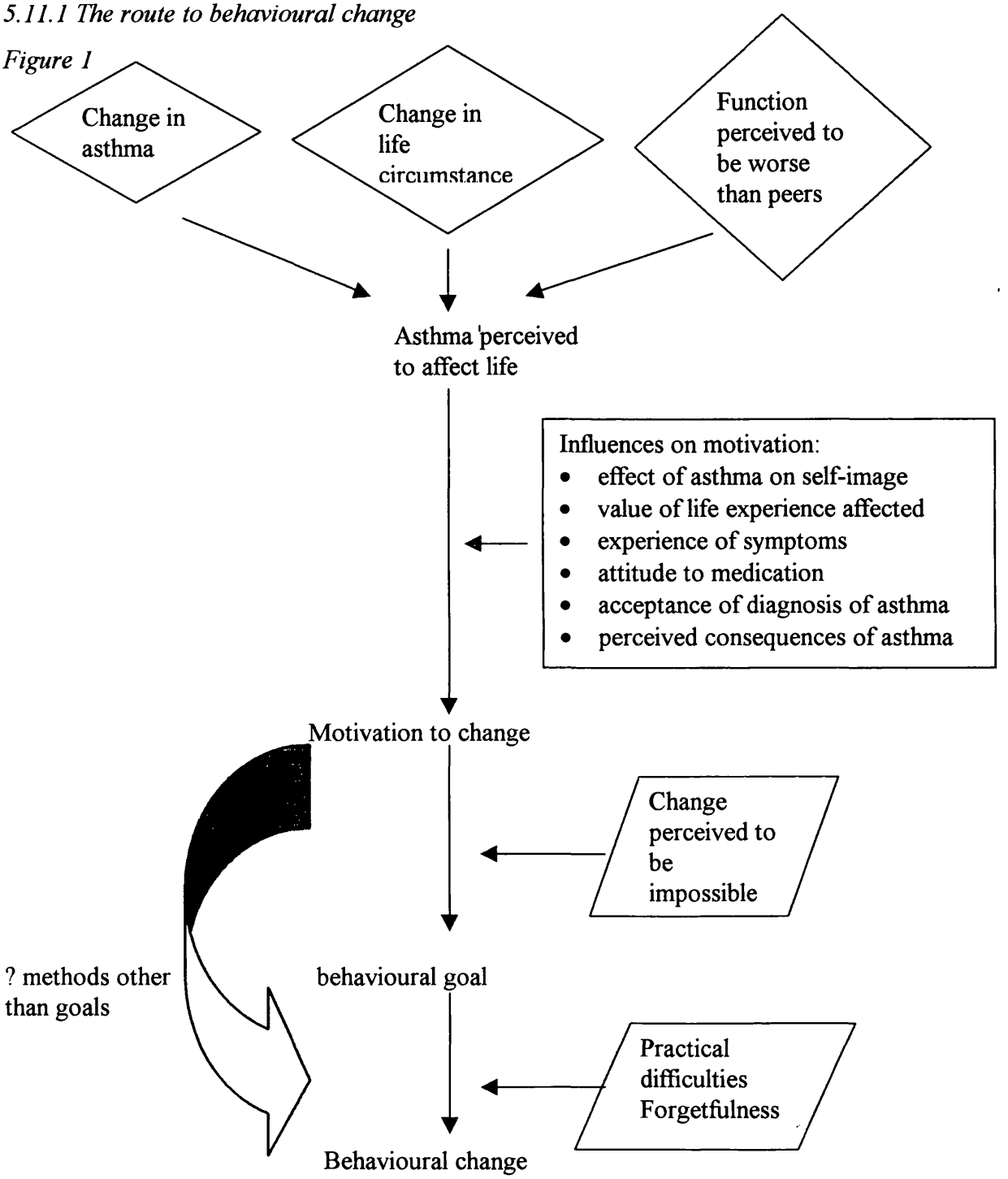


Figure 1 illustrates the route to behavioural change described by the respondents. It is a hypothetical model based on the results of one study. It requires further testing before it can be accepted as valid or generalisable. The

model demonstrates that once asthma is perceived to affect life, people may be motivated to change their behaviour. They may set goals and achieve behavioural change. The section of the model that illustrates the influences on motivation is better developed than the section illustrating goals because motivation was more common than goals in the study discussed in this thesis.

Three stimuli were found to cause people with asthma to notice its effect on their lives. A change in asthma symptoms or treatment, a change in life circumstances or an incident which highlights the inability to keep up with one's peers may bring asthma to the attention. Conversely, becoming accustomed to the effects of asthma may reduce the motivation to change.

Several factors may influence motivation to change asthma behaviour. Lack of acceptance of the diagnosis of asthma may lead to attempts to avoid or limit the use of anti-asthma medication because the medication symbolises the disease. Asthma may damage the individual's self-image leading to attempts to control asthma. A trade off between the value of the life experience affected, the experience of asthma symptoms, the perceived consequences of asthma and the person's attitude towards medications may motivate a change of behaviour. Each factor has the potential to increase or decrease motivation to change.

Three barriers to behavioural change were found. If change is perceived to be impossible, motivated individuals may not set goals. Goals may not be achieved due to practical difficulties in executing plans and forgetfulness. Some people describe changes in behaviour in terms of goals, others do not. It may be that behavioural change occurs without goals being set. The act of the interviewer asking why one behaved in a certain way may lead to it being described in terms of purpose. However, the person may in fact have acted without much forethought or planning.

5.11.1.1 Factors which stimulate people with asthma to notice its effects

Changes in the experience of asthma

Changes in the experience of asthma may alter the perception of the effect of asthma on life. For example, when respondent 21 perceived that asthma had started to impair his ability to inhale cannabis he consulted his general practitioner for advice to improve his asthma. Others do not notice the effects of asthma because their asthma responds predictably to routine inhaled therapy. Some "step down" treatment once symptoms are controlled. Others persist taking inhalers in the absence of symptoms to make absolutely sure that no symptoms return.

Changes in life circumstances

Changes in life circumstances can also alter the perception of the effect of asthma on life. For example, on becoming a mother, health became a higher priority for respondent 15. In order to improve her health, she had changed her diet and had tried to do more exercise. However, she found that asthma limited her ability to exercise. Other life changes such as pregnancy can cause people to review their asthma management because the potential effects of symptoms and treatments on the unborn child are considered. Awareness of ageing may also lead to a reconsideration of asthma management. Health may become a higher priority as people contemplate their mortality and begin to notice a physical deterioration. This may increase the value of low dose inhalers because of fears of long term adverse effects. Perhaps inhalers were taken with impunity when young with no thought for tomorrow. Alternatively, a more rigorous treatment regime may be started as this may be perceived to be necessary to permit physical exercise. Following a prescribed treatment regime may be viewed in the same way as following a healthy diet or an exercise plan: difficult in the short term but ultimately worthwhile.

Incidents which lead to function being perceived to be worse than peers

Some people do not perceive that asthma has much effect on their lives because they are able to complete their every day activities. Sometimes an incident

occurs which makes them realise they are unable to keep up with their peers. For example, respondent 20 had been trying not to admit she needed regular treatment for asthma until she joined an aerobic class where she was unable to keep up with her peers. Some people describe noticing the effect of asthma only transiently. For example, respondent 10 seems to notice the effects of asthma anew each time she tries to join in family walks. Between walks the effects of asthma fade from her mind and she does not sustain motivation to make any changes to her asthma management.

5.11.1.2 Influences on motivation to change asthma management behaviour

Acceptance of the diagnosis of asthma

Some people accept that they have asthma and expect to have symptoms. This reduces their motivation to find better treatment. Conversely, some respondents who reject the diagnosis of asthma avoid using medication because it symbolises the disease.

The effect of asthma on self-image

Damage to the self-image due to asthma can motivate attempts to control the disease.

For example, respondent 16 sees asthma as a fault and attempts to minimise her use of medication which symbolises disease. In his review of the literature on chronic illness, Bury (1991) comments on the predominance of research into the difficulties people experience rather than their competencies and ability to mobilise resources. For example, Charmaz (1983) identifies "loss of self" as a form of suffering in the chronically ill. As a result of chronic illness, people lose their self-image and it is not replaced with a valued new one. Loss of self is due to being unable to take a full part in life, being socially isolated, being devalued and being dependent. Bury's own work (1982) sees chronic illness in terms of biographical disruption. He describes chronic illness as a "critical situation" which evolves to disrupt life in three ways. First, it disrupts previously held certainties and abilities. Second, the person's self-concept and future are reconsidered. Third, resources are assembled to cope with the disruption.

However, Gerhardt observes that the treatment of renal failure has improved to the extent that people can lead normal lives.

In the asthma literature stigma and "loss of self" are not predominant findings. In Adams and colleagues (1997) study of asthma and identity, "loss of self" occurs in some cases when asthma conflicts with other social identities and therefore with personal identity. In other cases, asthma is accepted into the person's personal identity and does not cause a "diminished self'. Hewett (1994) found neither a diminished sense of self nor a biographical disruption due to asthma. He hypothesises that asthma is accepted because of its onset early in life. He also notes the difference between asthma and other chronic illnesses in that there is no "trajectory" of increasing symptoms and declining function. In addition, the symptoms of asthma may only be manifest during physical activity. Therefore, they can be avoided and may be explained to others as a common cold or being unfit. Another explanation for increasing numbers of people with chronic diseases being able to lead a normal life is improvements in treatment. Gerhardt noticed this phenomenon in renal failure and it also seems to hold true for the study discussed in this thesis. In this study, all but one respondent feel able to lead a normal life. The exception is a man who has been demoted and is unable to join in with his peers or to plan activities due to asthma. Despite high dose treatment he suffers significant impairment of function. All the others report only minimal difficulties due to asthma or are able to overcome problems by various strategies. Asthma may be mild in nature and may respond well to treatment. However, even impairment of lung function may be compatible with a normal career, family and social life.

Perceiving asthma to be an integral part of one's self-image may lead to a lack of motivation. Asthma is not thought of in terms of goals because it cannot be separated from one's identity. Hewett (1994) and Adams and colleagues (1997) also found evidence of asthma becoming integrated into the individual's identity. If this happens then disability and potential for change may not be recognised. Therefore, people are unable to articulate goals. Accepting what cannot be

changed can be a useful strategy to cope with chronic illness. However, it may blind one to new developments in treatment or a slow deterioration in function.

The value of the life experience affected

If asthma affects activities important to the individual then it is more likely to motivate change. Despite feeling motivated to stay healthy because of a sense of responsibility to her son, respondent 15 had taken no action to improve her asthma. Her reasons were that she currently had competing priorities of caring for her son and studying for a college degree. In contrast, when asthma was perceived as preventing respondent 19 from working he restarted his inhalers after a break of several years because the value he attached to symptoms and treatment changed. The effects of the symptoms outweighed his dislike of feeling dependent on inhalers. Therefore, asthma is more likely to motivate change if it is perceived to limit a valued life experience. Asthma may be perceived to be severe but not to interfere with any valued life experiences. In those circumstances, no action may be taken unless asthma is seen to be of relatively high priority. Against work, family and social life asthma may be of low priority. For example, respondent 23 feels her requirement for asthma treatment, which she dislikes, would decrease if she got rid of her dog. As it is an old dog with not much longer to live, she is prepared to wait until it dies of natural causes. This relationship is illustrated in figure 2.

Figure 2. The effect on motivation of perceived asthma severity and perceived limitation of activity due to asthma

		Asthma perceived to be severe	
		yes	no
Asthma perceived to limit a valued activity	yes	Motivation high	Motivation high
	no	Motivation variable – depends on competing priorities	Motivation low

Symptom experience

Asthma symptoms are more likely to motivate change if they are severe, frequent and unpredictable in onset and response to treatment. Symptoms are not generally regarded as severe because they are perceived to have improved with time, to be better than others with asthma, not to limit ability or to be less severe than other illnesses.

Symptom severity may improve with time, perhaps due to improvements in asthma therapy. Indeed some respondents comment that therapy has greatly improved since their childhood. Alternatively, chronic symptoms may become normalised over time. Activities which provoke asthma may be avoided and strategies such as pacing used to complete tasks. Pacing involves doing an activity at one's one rate. People with asthma describe completing tasks by going more slowly and taking rests. The adaptation does not appear to be conscious. However, some people have a low tolerance for symptoms even after many years. Some people tolerate all symptoms equally; others feel that some symptoms are worse than others. Acute, frightening symptoms which are perceived as life threatening are termed an asthma attack. These are usually described in vivid language and are felt to be serious.

Normalisation is explored in a qualitative study of 30 women with rheumatoid arthritis (Shaul, M.P., 1995). Three stages are described in the evolution of the disease: "becoming aware", "learning to live with it" and "mastery". The third stage, mastery, "involved learning how to reset goals and expectations, how to ask for and receive help from others, how to marshal and maintain one's energy, how to maintain connections with family and community without becoming depleted, and how to work with the physician in managing medical routines." It was compared to normalisation, where the illness and illness-related coping strategies become an integral part of daily life. Normality is redefined and the long term nature of the disease is accepted.

No relationship could be found between perceived severity of asthma compared to others and the presence of goals because all but one of the respondents feel

they have relatively mild asthma. Asthma is regarded as comparatively mild because people measure themselves against the worst case of asthma they have ever encountered. This may be because of the stereotypical media portrayal of "an asthma epidemic" and "asthma sufferers" combined with images of people with asthma wearing oxygen masks. Comparison with the worst case may also enable people to retain a self-concept of being a healthy individual and guard against stigma. The one person who feels worse than average is unable to identify with others with asthma. He feels more physically limited, cannot identify with any of the common asthma triggers and his symptoms do not respond to the standard asthma therapies.

Two other qualitative studies also find that people with asthma regard their condition to be mild compared to others "worse off" (Adams, S. et al, 1997; Hewett, G., 1994). Even one man who had been hospitalised with asthma in the latter study felt fortunate compared to the man in the next bed. Hewett (1994) explains these findings as a mechanism for coping with the impact of asthma.

Some people feel their ability is not limited by asthma compared to normal peers. Others feel they are limited but accept this as a normal consequence of having asthma. Only a few feel limited due to asthma and perceive that they should be able to keep up with healthy peers.

Asthma may be perceived to be mild because it is compared to other illnesses. For example, respondent 4 feels his asthma is mild compared to the muscular dystrophy suffered by his wife. Not all the respondents have experience of illnesses other than asthma so the data on the reasons for judging the comparative severity of different conditions cannot be regarded as complete. The criteria given for judging the relative severity of asthma were the symptom experience, the effects on life, the response to treatment, the consequences and the permanence of the two illnesses. Unsurprisingly these criteria form a sub-set of the criteria used to judge the severity and impact of asthma symptoms and treatment. In a larger sample, all of the criteria used to assess the severity and impact of asthma might be cited.

If symptoms are predictable in their onset and response to treatment this reduces their impact on life in a least two ways. Firstly, it is easier to anticipate asthma exacerbations and treat them effectively. Secondly, the consequent successful self-management may lead to increased self-efficacy. For example, respondent 14 does not regard a recent asthma exacerbation as serious despite requiring treatment with oral steroids because he feels he knows its cause and would be able to avoid it in future (he had been steam-cleaning carpets). He declines to use the inhaled steroids prescribed by his general practitioner to help prevent future attacks as he does not regard them to be necessary.

Attitude towards inhalers

People with asthma can be described as exhibiting high or low concern about their inhalers. Some of the explanations given for the degree of concern are the same in each group. For example, people in both groups give the degree of difficulty of incorporating inhalers into a daily routine as an explanation for their inhaler use. Some find it as easy as brushing one's teeth, others as impossibly difficult. People who have low concern about inhalers might voice a few minor concerns about cost or side-effects when questioned. They then state that they had not given these points much thought until the interview. Therefore, the overall concern about inhalers may represent a considered view of the pros and cons of inhalers versus the perceived effects of the illness with and without treatment. People may prefer not to consider the potential problems of inhalers if they regard them as essential to control their symptoms.

Low Concern about Inhaler Use

Some people are not concerned about their inhalers and some even regard them as a normal part of life. One explanation given is that they believe their inhalers to be mild. However, someone with a high concern about inhalers may regard the same dose of inhaler to be strong. People may have different tolerances for risk or different attitudes towards medication. Some view inhalers as a benign treatment compared to "tablets" or "drugs". Another qualitative study of 54 adults with arthritis analysed in-depth interviews and tape-recorded

consultations in a rheumatology out-patient clinic. (Donovan, J.L. & Blake, D.R., 1992) It found that relying on drugs was seen as a sign of weakness. Dowell and Hudson (1997) found that people could overcome this barrier to taking drugs if they were able to regard the drugs as trivial or harmless. Weaker drugs were seen as safer and not as a sign of illness.

Inhalers may be viewed as essential. For example, people with asthma may be seen as requiring inhalers. Consequently a strong desire not to be seen as an "asthmatic" may lead to a rejection of asthma medication. Adams and colleagues (1997) also found an association between the acceptance of the diagnosis of asthma and the acceptance of prophylactic medication. In addition, Dowell and Hudson (1997) found an association between accepting a diagnosis and accepting the need to use medication.

The acceptance of the diagnosis of asthma may lead to the acceptance of inhalers. However, inhalers may be accepted but the diagnosis of asthma rejected and vice versa. The former may occur when inhalers are seen as a valuable therapy even though the diagnosis is disputed. Some respondents, did not think of themselves as "asthmatic" or as having "proper" asthma. Nevertheless, they believe that taking inhalers improves their symptoms.

Although the diagnosis of asthma is not accepted the use of inhalers may become normalised. The prolonged use of inhalers may lead to them being regarded as normal or not as "strong" medicines. Britten's (1994) qualitative study, set in general practice, of patients' views of medications found that the negative attributes of medications were described in much more detail than the positive. She postulates that this is due to the benefits of medications being "taken for granted". If medication taken routinely for a chronic condition is unproblematic then it is not mentioned. The chance of inhalers becoming an insignificant part of the daily routine may increase if they are convenient to take. It has been found that compliance improves with once daily treatment regimes. (Baird, M.G. et al, 1984) This may be due to the minimal disruption of routine.

In contrast inhalers may be rejected although the diagnosis of asthma is accepted because inhalers are seen as ineffective, or too costly in terms of money, time, side-effects or harm. Some people seem to follow advice more passively than others. This conforms to the model of a patriarchal doctor-patient relationship. The disadvantage may be a blind adherence to instructions even if circumstances change or the instructions are misguided. The nature of asthma as an illness which fluctuates in severity may necessitate treatment decisions to be taken every day (Harding, J.M. & Modell, M., 1985). Neville (1996) states that the purpose of self-management plans is to guide these decisions. This approach will overcome some of the difficulties of guiding people through changing circumstances. However, the current use of the term "self-management plan" may be a misnomer. It may refer to a way of translating the medical view into every day use rather than as a more holistic approach to enabling people to manage their disease to their own satisfaction.

High concern about inhaler use

The ability of inhalers to control but not cure asthma may lead people to seek alternative ways of managing their illness. Choosing the best method of asthma management may increase feelings of mastery over the illness. Many authors have found that people alter their treatment regimes to enhance feelings of control over the illness (Cassileth, B.R. et al, 1980; Bury, M., 1991; Hunt, L.M. et al, 1989; Hayes-Bautista, D.E., 1976; Conrad, P., 1985). Relying on inhalers may also make people feel vulnerable in situations where inhalers are faulty or unavailable. In addition, medications may serve as an unwelcome reminder of chronic illness.

Some objections to inhalers are expressed as part of a more general objection to all medications. Firstly, medications may be seen as "unnatural". Britten (1994) also found that medications were criticised as being "unnatural" in two senses. First, in the sense of being chemically synthesised rather than found in nature and second in the sense of being a compound foreign to the body. Regarding a drug as "unnatural" may be particularly important when the medication is not

curative. It may be seen as worthwhile to take a substance however unnatural if it produces a cure.

The second general objection to drugs, is the difficulty of remembering to take long-term medications if not prompted by symptoms. However, some people find the routine use of inhalers as easy as the routine of brushing one's teeth. Several authors cite practical difficulties related to the daily routine as being a cause of not taking medication as prescribed (Adams, S. et al, 1997; Dowell, J. & Hudson H., 1997; Hewett, G., 1994). Dowell and Hudson (1997) view practical difficulties as a "late obstacle". They are only taken into account when earlier obstacles to accepting treatment such as accepting the diagnosis have been overcome. However, goal theory stresses the importance of feedback if goals are to be achieved. The presence of symptoms may act as a prompt to the use of medication, a reduction of symptoms may act as positive feedback to reinforce the use of medication but the complete absence of symptoms may provide negative feedback which reduces the use of medication until symptoms re-emerge.

Some objections expressed as specific to asthma medications include the perception of potential harm due to long term use, the perceived problem of addiction, the perceived association between high dose inhalers and disease severity, the side-effects and the cost of inhalers. Some people believe that although they take a low dose inhaler, there is a potential for a cumulative effect. That is, the drug or its effects can build up in the body over many years like a slow poison. Some people also understand the concept that trials showing no evidence of harm are not the same as proof of safety. In a pilot interview, a woman compared the dangers of the long-term use of inhalers to the dangers of Bovine Spongieform Encephalopathy (BSE). In her view, BSE was thought to be harmless to humans in the past until increasing research began to suggest the opposite.

Taking a medication every day was felt to have connotations of "addiction" and "weakness". This theme is well recognised in the literature on attitudes to

medications and compliance (Britten, N., 1994; Dowell, J. & Hudson H., 1997; Greenfield, S. et al, 1988). It may reflect a societal belief that drugs create dependence and that it is better not to be on medicines.

People may view taking increasing doses of inhalers as a marker of their inability to control their disease. This may sap confidence. People may prefer to "fight" symptoms through other means. Again, this has been found in Conrad's study (1988) of people with epilepsy. He postulates that people notice that doctors prescribe increased doses of medication when they complain of increased symptoms. High doses of medication come to symbolise more severe disease and vice versa.

Short-term side-effects of inhalers may lead to their rejection. In particular the benefits of steroids are long term so immediate side-effects may be regarded as more important. Similarly the cost of payment for a prescription for inhalers may be more important than benefits which will not be felt immediately.

Inhaled Steroids Versus Inhaled Bronchodilators

Despite reports in the literature of "steroid phobia", some people in the study to which this thesis refers had equally positive or negative attitudes to their bronchodilator and steroid inhalers. (Price, D., 1994) Of those who did make a distinction, bronchodilators were always preferred. The explanations given were that bronchodilators were of more immediate benefit, the risks of steroids were greater and that it was possible to manage without a steroid inhaler but not a bronchodilator.

People may regard steroid inhalers as ineffective if they are not warned of the delay in onset of action. However, even with this knowledge, some think the costs of taking an inhaler every day outweigh the long term benefits. Asthma is an unpredictable, episodic condition. A medication taken to decrease the frequency and severity of exacerbations may be perceived to be ineffective in the absence of feedback. The value of a future benefit may be discounted compared to the value of an immediate benefit.

People have heard of steroids both in the context of illnesses such as asthma and also their illegal use in bodybuilding. The steroids used in asthma are largely differentiated from the other uses of steroids. However the word steroid may still carry negative connotations sufficient to cause unease and caution in their use.

Some people wish to reduce their total use of inhalers. They may feel able to avoid using steroids but not bronchodilators because even on large doses of inhaled steroid they may require to use some bronchodilator for acute symptoms. In contrast, one respondent who wished to reduce his total inhaler intake did so by using steroids alone. This enabled him to virtually discontinue his bronchodilator. Thus the total number of puffs of inhaler used per day decreased. Steroid inhalers may be devalued because they do not completely obviate the need for bronchodilators. Using two inhalers may be regarded as being more costly in terms of money or inconvenience and therefore bronchodilators alone selected.

Adams and colleagues (1997) found evidence of "steroid phobia": their group of "deniers" was unable to accept preventative treatment. Rejection of the diagnosis of asthma because of an inability to reconcile it with social identity led to a rejection of preventer inhalers. Relievers were accepted as they were believed to help those with "bad chests" as well as people with asthma. In the study discussed in this thesis, acceptance of preventers was not always associated with acceptance of "proper" asthma. Some people who felt they did not really have asthma, accepted steroid inhalers because of their perceived alleviation of symptoms.

Perceived consequences of asthma

Believing that asthma will not have serious consequences may reduce the motivation to control symptoms. If asthma is not considered to have serious consequences, the decision to control asthma is more likely to be based on the current symptom experience. In common with the findings of a qualitative study

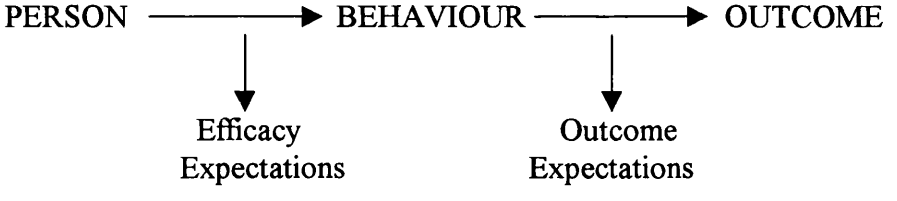
on diabetes, also using in depth interviews, the perceived seriousness of each illness is complex. People with asthma or diabetes may believe that they are serious conditions but are not "serious for me". (Murphy, E. & Kinmonth, A.L., 1995) People with asthma estimate risk based on their recent personal experience of asthma attacks or admissions to hospital. These events are infrequent for any given individual. For people with asthma, the impact of an exacerbation fades with time. This may be due in part to denial being used to cope with the fear caused by an asthma exacerbation. The impact of an asthma exacerbation is also mitigated, if its cause is known, due to the potential to avoid the trigger in future and a reduction in fear of the unknown.

5.11.1.3 Translating motivation into goals

Change perceived to be impossible

One person had set no goals because he regarded his asthma as so unpredictable that planning was impossible. This relates to Bandura's social learning theory (1977), illustrated in figure 3, which states that in order to perform a behaviour a person must believe that he is capable of performing the behaviour and that the behaviour will result in a desired outcome. In this case the subject felt capable of using medication and modifying his behaviour as recommended but did not believe this would produce the desired result of fewer symptoms and increased ability.

Figure 3. The effect of efficacy expectations and outcome expectations on behavioural change



The expected level of physical ability varies. Some people expect that asthma will limit their physical abilities compared to healthy peers. Others are determined to be as physically able as their peers.

5.11.1.4 Translating goals into behavioural change

Practical difficulties

Practical difficulties may cause people to fail to achieve their intended behaviour. For example, respondent 3 aims to take sufficient medication to enable her to compete with her horse. However, she stays at friends' houses at least two nights per week. She can only fit one inhaler in her handbag and she needs her bronchodilator in case of acute symptoms. Therefore, she does not use her inhaled steroid when away from home.

Forgetfulness

Some people intend to use regular medication but forget to do so. People are more likely to forget medication when they are out of their usual routine or when they are asymptomatic. Some people find it more difficult to adopt asthma into their daily routine than others.

5.11.1.5 The reasons for having no asthma goals

Goals were not a dominant theme. People are either not motivated to change their behaviour or their motivation does not translate into goals. The reasons for this will be discussed in terms of the relationship between goals, motivation and behaviour illustrated in figure 1. First, the study took the form of a single interview with each respondent. Therefore, only a few respondents had experienced a recent change in their asthma, life circumstances or had had a recent incident which had demonstrated they were unable to keep up with their peers. Second, few people had a damaged self-image due to asthma or a need to fight asthma. This may be because of the length of time since diagnosis. People may have accepted the diagnosis of asthma and integrated it into their identity. Alternatively, people with a damaged self-image may have been less likely to wish to talk about their asthma and to participate in the study. Third, asthma was not thought to limit valued activities either because the activity was not affected by asthma or the activity could be completed using strategies such as pacing. Priorities in life tended to be family or work. People felt they could play

an active role in most family activities and could work despite asthma. This compares to Gerhardt's study (1990) of chronic renal failure where advances in therapy have meant that most people are able to have a normal social role. Fourth, symptoms are not generally regarded as severe because they are perceived to have improved with time, to be better than others with asthma and not to limit ability. Fifth, there are some negative attitudes towards medication. Medication may be perceived to symbolise the illness severity, be "unnatural", be intrusive into one's life, be harmful, be addictive and to have adverse effects. Finally, asthma is often perceived as not being "serious for me" because of the perception that one's asthma is relatively mild. Even if people are motivated to change their asthma, perceiving that change is impossible may lead to the status quo being maintained.

5.11.1.6 The reasons for having asthma goals

The reasons for having a "cure" goal seem different to having a "control" goal. The small numbers of people with goals may mean that the range and diversity of asthma goals and the reasons for having them have not been fully explored in this study. Also the apparent difference may only exist because of the small numbers involved.

The reasons for having a "cure" goal

The desire to obtain a cure appeared related to three factors. Firstly, a sense of a damaged self image resulting from having asthma:

> I try not to see myself as having (asthma) because... then I see it as almost like a fault.
>
> [Respondent 16]

Secondly, an inability to accept the diagnosis:

> If I can go without the ventolin then I don't need this ventolin anymore, I'm not asthmatic.
>
> [Respondent 8]

Thirdly, the adoption of a positive self-determined response, characterised by the sense of wanting to "fight back" against disease:

> Even if I don't improve, the thought that I'm actually trying and not just sitting back and letting it happen makes me feel better about it.
>
> [Respondent 16]

The reasons for having a "control" goal

People striving for control accepted they had asthma and tried to manage its symptoms and treatment. Control of asthma symptoms and treatments were thought to be important during pregnancy because of the potential for harm to the foetus. A "control" goal could also be used to resolve the conflicting values. For example, one respondent wished for low dose treatment and good symptom control. She had a goal of keeping her peak flow at least 450. This motivated her to use inhalers before her symptoms became out of control.

Adams and colleagues (1997) categorised people with asthma as "acceptors", "deniers" and "pragmatists". The reasons for having a "cure" goal are similar to themes amongst the "deniers". That is, failure to accept the diagnosis of asthma and a rejection of the identity of "asthmatic". People with a "control" goal had accepted the diagnosis of asthma, similar to the "acceptors". However, the attitudes towards medications of the people in the study discussed in this thesis seemed more complex than found in the study by Adams and colleagues. They found that acceptance of the diagnosis and acceptance of treatment were closely related. However, some people with a "cure" goal were prepared to use prophylactic medication. Some people with a "control" goal failed to accept regular medication. Therefore, acceptance of the diagnosis may not mean acceptance of treatment and vice versa.

5.11.1.7 Behaviour

Asthma management behaviours can be categorised as the use of medication, the use of various non-medical strategies, the monitoring of the condition and the avoidance of triggers. The aim of asthma management can be to have no symptoms or inhalers, to have the ability to function normally using minimal inhalers or to have no symptoms by using inhalers. Respondent 4 had no aim of his own. He managed his asthma as recommended by his GP. All the groups use other strategies such as relaxation, fresh air and physical exercise to reduce the need for medication. The use of trigger avoidance depends on the value of the trigger compared to the value of reducing symptoms or the need for inhalers.

Aim: no symptoms, no inhalers

The strategies used to achieve this aim ranged from only using inhalers when absolutely necessary to the use of a regular preventer to minimise the total dose of inhalers in the short term with the eventual aim of gradually reducing then stopping all medication. Inhalers are thought necessary during acute attacks and under some other circumstances. The influences on motivation already discussed affect the perceived need for inhalers. For example, respondent 17 is prepared to use medication temporarily to enable him to return to work but his eventual aim is to control his asthma through exercise alone.

Able to function normally, minimal inhalers

People in this group tailor their use of inhalers to the level of function required. They have different requirements for normal function depending on their lifestyle. For example, one keen horsewoman wants to be able to compete with her horse. Some continue to "test" their need for inhalers by stopping them when asymptomatic and restarting them when symptoms return. Others use medication regularly because they have learnt how much medication is required.

No symptoms through the use of inhalers

People in this group use regular medication to try to achieve complete resolution of symptoms. One respondent motivates herself to use inhalers by

measuring her peak flow. A normal peak flow acted as a reward for the regular use of inhalers. A reduced peak flow exposed the need to use more medication.

5.12 Hypothesis ten (ii) patient goals, motivation and behaviour may not fit with the medical model

5.12.1 Absence of goals and the medical model

The biomedical perspective sees asthma as important because it causes avoidable mortality and significant morbidity. It makes this judgement by looking at population statistics. For example, although asthma deaths are not common and may be decreasing (Bucknall, C.E. et al, 1999), this study agreed with the conclusions of an earlier confidential enquiry into asthma deaths that a considerable proportion of asthma deaths may be preventable (Mohan, 1996). The latter study found evidence of adverse social factors in 25 out of 34 deaths and adverse psychological factors in 23 out of 31 deaths where these could be assessed. The 1995 Health Survey for England found significant morbidity in adults (Joint Health Surveys Unit, 1995). Amongst adults who reported wheezing in the past 12 months, 19% experienced sleep disturbance once or more per week. This morbidity has social consequences, 17 million working days were lost in Great Britain due to asthma in 1994/5, an increase of almost 55% since 1991/92 (House of Commons Hansard, 1996).

To recap, the British Thoracic Society (BTS) Guidelines are widely used in the primary care management of asthma in the UK (The British Thoracic Society et al, 1997). The treatment goals of the BTS Guidelines are: a) abolition of symptoms; b) restoration and maintenance of the best possible lung function; c) reduction of risk of severe attacks; and d) minimum absenteeism from the workplace. They recommend taking sufficient treatment to suppress symptoms and to allow normal function.

In the study discussed in this thesis, some people feel no need to change their behaviour related to asthma. In some cases this would concord with health professionals adhering to the BTS guidelines. In the following section the

reasons for concordance with the goals of the BTS guidelines will be outlined. Next, the reasons for a lack of concordance with each goal of the BTS guidelines will be discussed in turn. The methodology of the study did not include a measure of actual lung function or best lung function. Therefore it is not possible to discuss concordance with the second goal of the BTS guidelines. Instead concordance with the aim of normal function (i.e. the same function as healthy peers) will be discussed.

5.12.1.1 Concordance with the British Thoracic Society Guidelines

Respondents 3, 5, 6, 9, 14 and 23 behave in concordance with the goals of the British Thoracic Society Guidelines. The behaviour is in concordance with the goals of the BTS guidelines because of acceptance of both asthma and its treatment, coincidence or a shared desire to avoid severe attacks.

Respondents 5, 6, 9 and 23 accept that they have asthma and that inhalers are essential to control their symptoms. The first three do not question the need for inhalers because they find it reasonable that as asthmatics they will need asthma medication. In an ideal world, they would prefer not to have asthma or need inhalers but they accept that it is not so and that nothing can be done to change things. Respondent 23 thinks she might be able to stop her inhaled steroid if she got rid of her dog but she is prepared to use medication temporarily until he dies. Therefore, the goals of the BTS guidelines coincide with respondent 23 but her asthma management strategy is less orientated towards the use of medication.

The goals of respondent 3 coincide with the goals of the BTS guidelines. She aims to take sufficient preventer medication to train and to compete with her horse. She put up with asthma symptoms in the past until they began to limit her ability to train and care for her horse. Therefore, although it suits respondent 3 at the moment to behave in concordance with the BTS guidelines her priorities may change in future.

Although respondents 2, 14 and 18 do not wish to experience severe attacks, they do not wish to use the strategy which been recommended to them i.e. inhaled steroids. None of the respondents believes that inhaled steroids are necessary for them. Respondent 2 only suffers occasional asthma symptoms on exposure to cat hair and only needs to use occasional relievers. She thinks that her GP and asthma nurse have recommended inhaled steroids because they are more concerned about the consequences of untreated asthma than she is. There is some doubt as to the veracity of her account because she condemned inhaled steroids on the telephone prior to the interview but retracted this at interview. She did say that she would be reluctant to increase her use of steroid inhalers, because of fears of adverse effects, even if her symptoms deteriorated.

Respondent 14 attributes a recent exacerbation to a trigger which he will be able to avoid in future. (steam-cleaning carpets) Respondent 18 attributes two recent exacerbations to "chest infections". Therefore, she believes that inhaled steroids will not prevent future exacerbations. Both respondents are able to lead full, active lives with very few symptoms between exacerbations. Therefore, they have infrequent symptoms or inability to function as they would like to prompt the use of regular inhalers.

The biomedical tendency is to use the population risk to estimate an individual's risk of a severe attack. A specific example is the Jones morbidity index illustrated in Figure 4 (Jones, K., Cleary, R. & Hyland, M., 1999).

During the past four weeks:

1. Have you been in a wheezy or asthmatic condition at least once a week?
2. Have you had time off work or school because of your asthma?
3. Have you suffered from attacks of wheezing during the night?

Figure 4. The Revised Jones Morbidity Index. Patients' responses are assessed as follows:

NO to all questions	= LOW morbidity
One YES answer	= MEDIUM morbidity
Two or three YES answers	= HIGH morbidity

Questions 1 and 3 can be answered "yes" or "no" by all respondents but question 2 will not apply to those who do not attend work or school. For the purposes of morbidity classification, a "not applicable" answer is treated as "no".

The authors recommend the morbidity index as a way of identifying those at greater risk of adverse events. Even in those classified as being of high morbidity using the Revised Jones Morbidity Index, the incidence of admission to hospital in one year is 13.2%, of being prescribed oral steroids is 47.3% and of experiencing an acute asthma attack is 38.1%. Therefore the majority of people, even if they are classified as having a high morbidity, will not experience the aforementioned adverse events in a given year. It may be useful to health professionals to identify this group as being of high morbidity as their relative risk of admission to hospital is 3.45, of oral steroids is 2.38 and of an acute attack is 2.88 compared to those of low morbidity. However, the individuals in this group may base their perception of risk on their recent personal experience of adverse events such as admission to hospital modified by factors such as feeling able to control the perceived trigger in future. As these events occur in fewer than half of people, the individual with asthma may feel less at risk than his clinician would estimate. It is unknown whether an understanding of medical view of risk would change the behaviour of people with asthma.

Respondents 2, 14 and 18 would be classified as low risk by Jones morbidity index. Respondent 2 does not feel at risk because she has very occasional symptoms. Respondent 14 sees his risk of another asthma attack as being low because he attributes his last attack to a preventable cause. Respondent 18 attributes the cause of her exacerbations to infection rather than asthma. Therefore anti-asthma treatments will not prevent them. It is important for the health professional and the person with asthma to understand the other's perspective of risk and causal attributions. They may then negotiate a long-term strategy to prevent acute attacks. If long-term prevention is the goal rather than the relief of symptoms or the enablement of people with asthma consideration

will have to be given to feedback and the setting of sub-goals. It is difficult to sustain motivation if people do not receive regular encouragement.

5.12.1.2 Lack of concordance with the goals of the British Thoracic Society Guidelines

a) Abolition of symptoms

Respondents 4, 15, 19 and 21 could be regarded as suffering from excessive symptoms using the British Thoracic Society Guidelines as a standard.

Although suffering frequent symptoms, Respondent 4 could complete all his necessary tasks by pacing himself. He regarded asthma as unimportant compared to his past history of severe depression and the health problems of his physically disabled wife. He attributed his symptoms to smoking rather than asthma. Similarly, respondent 15 could complete most of her desired activities. Although she regarded asthma as limiting some important activities she had not tackled it because of competing priorities.

Respondent 19 tolerated asthma symptoms in the summer in order to avoid using steroid inhalers. In her experience, failure to use steroid inhalers in the winter led to time off work. Therefore she limited her use of steroid inhalers by only using them when most necessary, that is in winter.

Respondent 21 suffered daily symptoms but they responded quickly to salbutamol. Using two inhalers was regarded as too expensive. He believed salbutamol was necessary before playing football even when using regular inhaled steroids. He felt able to play football normally using salbutamol.

Therefore, symptoms alone may not motivate a change in behaviour unless they interfere with a valued activity or fail to respond to "reliever" inhalers. For some people, the aims of British Thoracic Guideline to abolishing symptoms is too exacting. This can be explained by examining the effects of treatment on life and considering other priorities unrelated or only loosely related to health.

Drummond and Mason (1990) describe the illness constructs of people with diabetes living in a socially deprived area. They contrast this with the diabetics' interpretation of their doctors' views. The constructs of the people with diabetes were found to base normality on their symptom experience. Mild hyperglycaemia is asymptomatic but mild hypoglycaemia causes discomfort. Therefore, the people with diabetes preferred to have a higher blood sugar than recommended by their physician. Additionally, pressures related to family, emotional well-being and identity affected diabetic control. People with asthma and diabetes are influenced by many other variables in their lives rather than simply their illness.

b) Normal function

Respondents 7, 10 and 22 could be regarded as accepting a lower level of function than the British Thoracic Society Guidelines would suggest. Respondent 7 began to use his steroid inhaler regularly about a year prior to interview with a perceptible improvement in function. In particular, he felt his sleep improved leading to a better ability to work. At the time of interview, he still experienced some symptoms and found it difficult to exercise in order to lose weight. He believes that even stricter adherence to his steroid inhaler would improve his exercise capacity and symptom experience. However, as he feels his asthma has improved he is no longer motivated to improve it any further. His asthma is good enough to allow him to work but not perfect. He does not seek perfection.

Respondent 10 is unable to do housework or join in family walks because of breathlessness. She has adapted by seeking help from her family with housework and her lack of ability is only brought to mind once she starts the activity. Also, she does not regard herself as a "tablet taker". Therefore she tolerates being less physically able and only used her inhalers to relieve acute symptoms. She uses strategies other than inhalers to ensure that tasks were completed in order to avoid perceiving her identity as a healthy person being diminished.

Respondent 22 perceives and accepts that he is unable to run because of asthma. However, this is not currently a problem due to family commitments which are seen to limit the time available for vigorous exercise. It is uncertain if he will take any action to improve his asthma if he wishes to take more exercise.

c) Reduction of severe attacks

All respondents wish to avoid severe attacks. Severe attacks are perceived as frightening and to interfere with life.

d) Minimal absenteeism from work

There was no evidence of discord with the BTS goal of minimal absenteeism from work. No respondents prefer to stay off work rather than use medication for asthma. Instead, several respondents are motivated to use more medication than they would ideally like in order to work. Some respondents receive no sick pay or reduced pay when off work. Others fear redundancy or difficulty changing jobs if they have a poor record of sickness absence.

e) Failure to "step down"

The British Thoracic Society Guidelines now advocate "stepping down" asthma therapy if symptoms are abolished in order to avoid using excessive doses of treatment. In the light of this respondent 13 could be regarded as using excessive inhalers. He perceives the potential consequences of having symptoms as being too great to consider reducing his use of inhalers. He feels under such pressure at work that he cannot afford to be ill. The medical emphasis on "stepping down" has increased recently and may not yet be known to patients. Alternatively, people may not be prepared to take the risk of decreasing their asthma treatment if they have more pressing concerns in other areas of their lives.

5.12.2 Presence of goals and the medical model

Four people are striving to cure themselves of asthma i.e. to have no symptoms and no inhalers at the time of interview. The biomedical view is that cure is impossible except in cases of industrial asthma where the cause is detected early

in the disease process. Two of the three respondents also believed that cure was impossible to achieve but the process was valuable.

"Control" goals refer to the control of medication as well as symptoms. The traditional biomedical view emphasises the control of symptoms. However, the most recent guidelines from the BTS advise that medication should be reduced once symptoms are controlled. Respondents worry more about the side-effects of steroids than the current medical view in that they are prepared to reduce medication before symptoms are controlled. Attitudes towards inhalers have been discussed in section 5.11.1.2. A broader view of symptoms in relation to everyday life is taken than the narrower biomedical perspective. People weigh up the advantages and disadvantages of treatment versus non-treatment of symptoms. They wish for an acceptable level of symptoms at an acceptable level of treatment. Both symptoms and treatment of asthma may interfere with daily life. Trade-offs may have to be made between symptoms, treatment and other priorities.

5.13 The Implications of the Findings on Asthma Management

5.13.1 Measures of Quality Proposed for Use in Asthma Care

These findings have implications for the definition of quality in asthma care. Suggested quality measures include a prescribing ratio of 2:1 of inhaled steroids to bronchodilators (Shelley, M., 1996; Aveyard, P., 1997). However, people with asthma may define good asthma control as the ability to perform activities using an acceptable dose of medication. Provision of high quality asthma care might be said to be developing the knowledge, skills and attitudes of people with asthma such that they can assess risk and plan their asthma care accordingly.

5.13.2 Compliance

Compliance is defined as following medical advice. However, professional advice may not be central to asthma management. People with asthma may consider it alongside personal experience and information from other sources. Also, asthma management is a dynamic process over a lifetime responsive to changes in circumstances. The compliance model does not take in to account the preferences or the experience of the individual.

5.13.3 The Potential for Incorporating Patient Goals into the Primary Care Asthma Consultation

Patient goals may be used to determine the most appropriate asthma treatment for each individual in three ways. The health professional can base his or her recommendations for asthma management on each person's goals. Alternatively, the health professional and person with asthma can share information on their respective goals in order to reach a decision regarding medical treatment to which both parties agree. The latter negotiated agreement has been termed "concordance" (Royal Pharmaceutical Society, 1997). The process of reaching concordance has been called "shared decision-making" (Charles, C., Gafni, A. & Whelan, T., 1997). Elwyn and colleagues have recently set out the arguments for and against shared decision-making (1999). The third method is to provide the person with information and allow them to take a decision based on that evidence but without guidance. Once a decision has been reached, the treatment plan can involve setting goals, providing feedback and changing goals as appropriate to changing circumstances but this discussion will concentrate on the use of patient goals to decide on treatment. The use of patient goals to inform asthma management could be categorised as "patient-centred care" (Henbest, R.J. & Stewart, M., 1990). This is a philosophy that medical care should concentrate on people and their problems rather than disease and pathology. It can be defined as a consultation where the patient is able "to express all of his or her reasons for coming including: symptoms, thoughts, feelings and expectations" (Henbest, R.J. & Stewart, M., 1990).

In the following section, the reasons for incorporating patient goals into the primary care consultation, either by the health professional considering them alongside his or her own view, or by sharing decision-making, will be discussed. Firstly, there is the argument that it is "right" to base care on patient goals. Secondly, there is evidence that patients wish to participate more in the medical consultation and in decision-making. Thirdly, there is some evidence that shared decision making improves health outcomes. Finally, increased patient participation may strengthen the doctor-patient relationship. Next, the arguments against incorporating patient goals in the primary care consultation and against shared decision making will be considered. They are lack of time, the need for extra resources such as training, the difficulty of making informed choices due to a poor evidence base and problems communicating risk. Finally, the limitations of improving health through patient involvement in care will be discussed.

Patient-centred care as a philosophy

The philosophy of patient-centred care is that it is right that health professionals take the view of the individual into account alongside the medical view when decisions are made about that person's future. Chewning and Sleuth (1996) argue that the medical model bases treatment decisions on the clinical significance of symptoms and outcomes. Other authors comment that this devalues the psychological and social effects of illness and therapy (Ben-Sira, Z., 1990; Engel, G.L., 1977; Drummond, N. & Mason, C., 1990). The evidence that patients do not comply with medication because they feel it affects their quality of life supports the view that patients and doctors have different perspectives of the value of medication (Donovan, J.L. & Blake D.R., 1992; Hunt, L.M. et al, 1989; Stimson, G.V., 1974). Brody's review (1980) of the patient's role in clinical decision-making, reasons that the position of clinician authority is not tenable. He argues that many clinical decisions cannot be supported by evidence and that differences in clinical decisions may be associated with doctors' personality, social characteristics and clinical expertise. More recent studies support this hypothesis and suggest it may be true today. It

is estimated that there is evidence to sustain 10-30% of clinical decisions (Naylor, D.C., 1995). Furthermore, female doctors have been found to be more likely to be patient-centred than males in one study (Law, S.A.T. & Britten, N., 1995) but not in another (Kaplan, S.H. et al, 1995). Health professionals can influence patient choice without realising that they are doing so. For example, people attending a cardiovascular risk management clinic were more likely to choose sodium reduction from a range of options if they saw the nurse who had a special interest in sodium reduction (England, S.L. & Evans, J., 1992).

Patient preferences for participation in the medical consultation

The evidence of patient preferences for participation in the medical consultation and in treatment decisions has been reviewed by Deber (1994, 1995) and Guadagnoli (1998). The studies have been criticised on three grounds. Firstly, as most studies are North American their relevance to British primary care settings or to people with asthma is not known. It has been postulated that the predominantly private or fee-for-service health care system in North America may encourage consumerism in health care and a greater desire for participation in the consultation amongst patients (Coulter, A., 1997). Secondly, the validity of the studies has been questioned because they commonly assess patient preference using hypothetical scenarios which may not reflect real-life preferences or behaviours. For example, 64% of the public expected they would wish to choose their treatment if they had cancer but 59% of newly diagnosed cancer patients wanted physicians to make treatment decisions on their behalf (Degner, L.F. & Sloan J.A., 1992). Thirdly, it is difficult to compare the findings from different studies because they are based on surveys using different instruments.

The findings of the aforementioned studies are that patients' desire for information is stronger than their wish to participate in decisions. Two studies, one of adult cancer patients, the other of adults with hypertension, found a high level of desire to participate in treatment decisions especially in younger patients and an even higher desire for information on their illness (Cassileth, B.R. et al, 1980; Strull, W.M., Lo, B. & Charles, G., 1984). Another survey of primary

care patients found little desire to participate in treatment decisions but again patients wanted to be kept informed (Ende, J. et al, 1989). Illness severity and age were associated with less desire to participate in decisions. A survey of adults with asthma found a strong preference for information about asthma but a desire to make treatment decisions during exacerbations with a physician (Gibson, P.G., Talbot, P.I., Toneguzzi, R.C., 1995). The preference was for an equal say during mild exacerbations and for the physician to play a greater role during more severe exacerbations. Younger patients had a stronger preference for decision making. The preference for participation in decisions regarding the treatment of chronic symptoms was not assessed. All of these studies report their findings on participation as a dichotomy whereas it may be more appropriate to think of it as a continuum. People may wish to be involved in treatment decisions to a greater or lesser extent. The studies discussed find that some patients wish to participate in treatment decisions. These results are supported by a qualitative study using in-depth interviews which identifies three kinds of medication-user (Dowell, J. & Hudson H., 1997). It describes some people who passively follow treatment advice, some who determine how they wish to take the treatment and some who completely reject the medicine. It may be that different consultation techniques are required for different individuals.

The influence of patient-centred care on clinical outcome

The evidence that patient-centred care leads to better outcomes is conflicting. In sequential studies, Kaplan and colleagues (1989) found an association between teaching patients to participate more in the consultation and improved self-reported health outcomes and in objective measures of disease control. Starfield and colleagues (1981) found that patient-practitioner agreement as to what problems required follow-up was associated with improved health outcomes. Resolution of symptoms has been found to be associated with "patient-centred care" (Henbest, 1990). Two recent studies in the UK found an association between patient-centred care and satisfaction (Kinnersley, P. et al 1999; Kinmonth, A.L. et al, 1999). The former study found no association with clinical outcome for a range of conditions presenting to general practice. The latter found an association between patient-centred care and worse clinical

outcome in people with diabetes. The studies are difficult to compare because they use different instruments to measure patient-centred care. There are insufficient studies on patient-centred care using standardised instruments to make a definitive statement of its effect on clinical outcome. However, all the studies show improvements in patient defined outcomes such as satisfaction. Patient-centred outcomes may be the best judge of the success of patient-centred care. The clinical outcome may not reflect all the issues that are important to the person with the illness. If care is to be truly patient-centred, then patient-centred outcomes must prevail. In some cases, patient-centred care may result in worse clinical outcomes. For example, patient and practitioner may agree to a treatment plan that is less onerous than the physician would usually recommend. This could be illustrated by a young person with diabetes who prefers to have less strict diabetic control in order to avoid hypoglycaemia and to be able to drive and work with machinery. The clinical outcome would be worse but the patient as a whole would be better. In some cases, the clinical outcome would improve. For example anti-hypertensive medication may be completely rejected because of immediate side effects. A discussion of the value of long-term medication versus side-effects may encourage some people to tolerate the medication.

Even if patient-centred care does not improve clinical outcomes, it may focus the consultation on areas which are important to the person with the illness. The sharing of similarities and differences may strengthen the therapeutic relationship. The finding of increased satisfaction with patient-centred care compared to usual care (Kinnersley, P. et al, 1999; Kinmonth, A.L. et al, 1999) supports this hypothesis but it would need to be tested formally in clinical trials.

Lack of time has been cited as a barrier to increasing patient participation in the consultation. In the study discussed in this thesis, interviews lasted between 45 minutes and 90 minutes. General practice consultations are booked at 5-10 minute intervals. A survey, sent to all general practices in the UK with a response rate of 30.4%, found that practices reported spending an average of 22 minutes on the initial assessment of people with asthma and 13 minutes

thereafter (Barnes, G. & Partridge M.R., 1994). A North American study found that physicians were more likely to have a "participatory decision-making style" if they worked in a practice with a low volume of patients (Kaplan, S.H., et al, 1996). Howie (1997, 1998) has also found that longer consultations are associated with quality of care and facilitating patient understanding of, and ability to cope with, their illness. Therefore, it would seem that time is important to allow patient participation. If patient participation is thought to be worthwhile, consultation length may have to increase. However, more research is needed to discover if involving patients is more time-consuming and if longer initial consultations are followed by shorter follow-up consultations because of more effective communication. If the interview used in the study discussed in this thesis can be adapted to allow a brief intervention within the constraints of the primary care setting, it may allow better use of existing resources. At present only around half of people with asthma take their treatment as prescribed. At least some of them will never have discussed why. It may be that consultations which attempt to convince people of the medical viewpoint instead of trying to understand the person's view are an ineffective use of time.

Lack of training has been described as another potential barrier to increasing patient participation in the consultation (Elwyn, et al, 1999). Physicians have been found to underestimate patients' information needs (Strull, et al, 1984). In the study discussed in this thesis, people found it difficult to articulate asthma goals. This may be because asthma has become normalised and people are "unconsciously competent" at its management. Alternatively people may be "unconsciously incompetent". It may be that people are unused to thinking of asthma in terms of goals and outcomes due to lack of experience with this approach. Certainly, towards the end of the interview more goals were identified. It may be that health care professionals require training to elicit patient goals and to encourage them to participate in the consultation. The general practice registrars who participated in the study by Elwyn and colleagues (1999) felt that sharing decision-making was a new approach for which they felt inadequately prepared. This finding might not apply to more experienced general practitioners or other health professionals.

It has been proposed that patients may struggle to make an informed choice because of lack of evidence. While it is true that many clinical decisions are not evidence-based, the basis on which decisions are made could be shared with patients. This would allow them to share their perspective on the health professional's thought processes and contribute any other issues which they believe to be important. Indeed, Brody (1980) argued that lack of evidence gave even less justification for clinician authority. Elywn and colleagues (1999) found that many of the registrars in their study felt uncomfortable sharing decisions because of insufficient evidence for some decisions and a lack of faith in existing evidence. In contrast, the simulated patients felt they would be more committed to a decision if they understood the reasoning behind it. This preliminary study looked only at the clinical evidence for three conditions. Further studies in clinical settings might be useful to look at what patients can add to clinical decision-making.

Difficulties presenting risk so that it can be understood might limit the ability of patients to participate in the consultation. In another publication from the preliminary study of shared decision-making, GP registrars felt that a range of methods of communicating risk would be required to cope with the variety of people and their problems encountered in general practice (Edwards, A., Elwyn, G. & Gwyn R., 1999). Further studies would be required to see if risk can be communicated effectively to patients. If it cannot, then this would favour the consultation model of the doctor taking clinical decisions, informed by the patient's perspective rather than with the patient.

Attempts to improve health by studying the perspective of the person with a chronic illness and patient participation have two important limitations. Firstly, advocating a greater understanding of the patient perspective and more participation does not equate to agreeing to every patient demand. Marinker, one of the founders of concordance, states "Considerations of personal safety, harm to others, and public health will always set boundaries and limits to individual rights" (Royal Pharmaceutical Society, 1998-99). Secondly,

improvements in health as a result of a better understanding of the patient and increased participation are limited to outcomes which individuals can influence. For example, for some people the provision of free prescriptions may be the best way to improve access to medication and improve asthma treatment.

In conclusion, patient goals could be used to inform decisions about their care or patients could be involved in the decision-making process. There is a growing movement for increasing patient involvement in health care. There is evidence that people would like to be informed about their health care but less evidence that people wish to be involved in decisions. The preference for involvement in health care may vary from person to person along a continuum. There is some evidence that involving people in their care improves clinical outcomes and more evidence that patient-centred outcomes are improved. Time and training may be barriers to the implementation of methods of involving people in health care. When considering health improvements through involving people in care, the health of the population must be considered alongside the health of the individual and the outcome must be under individual control. The evidence for increasing patient participation in health care is as yet equivocal. At the moment, the importance of continuing to research including the patient perspective in health care is based on the philosophy that it is the right thing to do.

5.13.3 The Development and Use of Guidelines in Asthma

As previously discussed, the BTS Guidelines are widely used in the management of asthma in primary and secondary care in the UK. They are consensus guidelines devised by the British Thoracic Society, the National Asthma Campaign, The Royal College of Physicians of London in association with the General Practitioner in Asthma Group, The British Association of Accident and Emergency Medicine, the British Paediatric Respiratory Society and the Royal College of Paediatrics and Child Health. The National Asthma Campaign is a charity which has patient members. Thus, it could be said that patient representatives were able to contribute to the development of the guidelines.

Grimshaw and Russell (1993) discuss how to develop "scientifically valid guidelines". They recommend that guidelines should be based on the best available scientific evidence or, if absent, the best clinical judgement. In view of the literature review and the findings of the study discussed in this thesis, the development of the BTS guidelines has been limited in three ways. First, the research evidence related to asthma treatment goals is sparse. Second, guidelines appraise research findings according to the quality of the trial: randomised controlled trials are held to be the best. Qualitative research cannot be appraised by these criteria and may thus be devalued. Third, the use of "clinical" judgement to inform guidelines suggests listening to the prevailing biomedical viewpoint but there is evidence that patients have a different viewpoint. In contrast, the Royal Pharmaceutical Society (1997) conclude that "the clinical encounter is concerned with two sets of contrasted but equally cogent beliefs- that of the patient and that of the doctor". In order to come to a therapeutic alliance, they suggest that both sets of beliefs should be regarded as valid.

The application of the BTS guidelines is also limited. Guidelines relate to the average person not the individual. They are not sensitive to the perspective of the individual. It might be possible to use the British Thoracic Society guidelines as a summary of the medical perspective of asthma and use them alongside the patient perspective when making treatment decisions.

In conclusion, the currently recommended method of developing guidelines does not have clear mechanisms to incorporate patients' views. In addition, qualitative research methodology which is often used to explore the patient's experience is undervalued in the current method of grading research evidence. When guidelines are being used to plan the care of the individual it is important to remember to include the individual's perspective.

6. Conclusion

Although asthma is a common illness which has been extensively studied, the treatment goals of people with asthma have not often been explored. This study uses qualitative methods to gain an insider's view of treatment goals in asthma. Perhaps surprisingly, only a minority of people had treatment goals. Goals were present if symptoms had deteriorated; if the person wished to master the illness; if there was conflict between asthma symptoms, treatment and life goals; and if circumstances such as ageing or pregnancy changed priorities. Goals were absent if asthma had become assimilated into life, if it was regarded as unimportant, if people had other more pressing priorities and if change seemed impossible. The goals related to cure or control of the illness. To people with asthma, "control" had a broader definition than the biomedical one of minimising symptoms through the use of medications. Treatments, symptoms and exposure to activities could all be controlled. The priority given to each was individualised.

In order to understand the existence, nature and importance of asthma goals it is important to understand the experience of asthma symptoms and treatments. Misunderstandings between doctor and patient may arise if the impact of medication is not considered as well as the impact of symptoms.

The severity of symptoms is often judged in comparison to previous experience, to other people with asthma, to healthy peers and to other diseases. Some people find symptoms more unpleasant than others. The impact of symptoms depends not only on severity but also on frequency, the predictability of both the onset and resolution, on habituation and on the wider implications for valued activities. This makes it difficult for the "outsider" to understand the severity and impact of asthma. Adjustment to symptoms over time may make asthma easier to manage both physically and emotionally. As repetitive actions such as driving a car become habitual, the movements become unconscious and flow in a sequence. If being admitted to hospital becomes habitual, fear decreases. However, if symptoms and treatment become unconscious it may limit the

ability to make the most of new treatment innovations and people may be too easily satisfied with poor performance.

Some people are highly concerned about their medications; others are not. Some of the arguments for feeling concerned were also used to justify low concern. People are not concerned about taking inhalers if they regard them as mild, essential, normal, convenient to use, if they worry about the consequences of stopping inhalers or if a trusted person had advised them never to stop. People are concerned about inhalers if they regard them as unnatural, difficult to fit into a routine, potentially harmful, addictive, symbolic of severe asthma, unpleasant to use and expensive. Some think that inhaled steroids are less effective and riskier than bronchodilators. The perceived ineffectiveness may be due in part to ignorance of the delayed action of inhaled steroids. However, it also seemed to be due to delayed action being inherently less valuable than immediate action and steroids only *decreasing* rather than *preventing* the need for bronchodilators. The concerns expressed about medications are not exclusive to drugs used in asthma: they have been found in other studies of patients' beliefs about medicines. It would be interesting to study how attitudes and beliefs about medications form.

Goals were not a predominant finding. Even some of the goals present related to temporary changes of circumstance such as pregnancy. Afterwards, it is presumed that the previous equilibrium would be re-established.

There is an interaction between goals, motivation and behaviour. People are motivated to alter their asthma management by changes in life circumstance, by a perception that asthma interferes with a valued activity, to satisfy a need to take action against asthma and its treatment rather than accept it and because of concerns about losing control of asthma. In order for motivation to be translated into goals a change must be perceived to be possible or the process of goal setting perceived to be valuable, the person must be aware of the effects of asthma and its treatment on life and asthma must be a priority. Behaviour

depended on the attitudes and beliefs about inhalers and the symptom experience.

Patient goals are based on broader criteria than the goals of the British Thoracic Society Guidelines. Life events and priorities from areas of life other than health influenced asthma management. Minimising drug therapy might also be important. Consequently, most people had standards of symptom control and ability lower than those set by the British Thoracic Society Guidelines. One person used more inhalers than would be advised by these guidelines but again this was due to an imperative from another arena of life. Pressure at work made it important for him to avoid symptoms.

Individuals have different priorities for asthma management. It might be said that quality asthma care would *enable* people with asthma to assess risk and plan their care accordingly.

The management of asthma is a dynamic process which is not congruent with a model of compliance with "doctor's orders". There is evidence of some discord between the patient and the biomedical view. The concordance model may allow differences to be negotiated. This may motivate some people with asthma who have become accustomed to a level of disability and may help others to realise their goals. A fuller understanding of the person with asthma may reduce frustration for health professionals. The goals, motivation and behaviour of people with asthma may be better understood by health professionals when seen in the context of competing imperatives from other arenas of life.

The relative lack of research into patient's views may handicap the use of guidelines. Guidelines should represent the best available research evidence. The lack of research on patient views and the qualitative nature of the research will reduce its incorporation into guidelines.

Goal setting may be difficult to implement clinically if it is time-consuming and requires patients and professionals to interact differently. A trial would be

required to assess the costs and benefits of goal setting. However, it should not be forgotten that current chronic disease management is wasteful of resources.

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Appendix A

Hypothesis ten: (i) patient goals, motivation and behaviour form a rational frame work

1) Asthma goals present

Respondent	Asthma goals	Motivation	Behaviour
1	• to be able to detect worsening asthma in pregnancy	• fears both asthma symptoms and treatment (especially during pregnancy) • realises she has difficulty detecting worsening symptoms • accustomed to regular wheeze • finds the symptom of cough distressing	• Consulted her general practitioner for advice on the best management of asthma during future pregnancies. Failing to recognise her inability to detect worsening asthma he was unable to give her any useful strategies. • avoiding inhalers and hoping for the best re symptoms

8	• To maintain the present level of symptoms but without inhalers.	• Desires autonomy over asthma: avoiding inhalers symbolises a "fight back" against the disease.
		• Wishes to reduce his total dose of inhaler which symbolises less severe asthma to him. Perceives no difference in safety between his preventer and reliever.
		• Rejected a prescription for a preventer twice before because he perceived his asthma was not bad enough to require it.
			• Has started to usea regular preventer
			• Avoids using his reliever if possible:
			  • tries to relax to see if the symptoms subside spontaneously,
			  • ensures he always has access to his reliever to avoid panic which he perceives makes symptoms worse.

1) Asthma goals present (cont.)

Respondent	Asthma goals	Motivation	Behaviour

11	• to achieve better asthma control and avoid oral steroids in pregnancy	• accepts steroid inhalers because perceives they are essential to prevent asthma symptoms and permit normal function
		• fears oral steroids especially during pregnancy:
		  • perceived increased risk of harm compared to inhaled steroids to herself and the foetus
		  • they represent loss of control of asthma
		• poor asthma control in previous pregnancies led to the need to use oral steroids
		• Had failed to find a strategy to control asthma in pregnancy from the health service in previous pregnancies.
		• found asthma made it difficult to work
		• perceives antibiotics hasten recovery from asthma exacerbations
		• thinks too many antibiotics are harmful
			• uses preventers regularly and relievers as required
			• increases her steroid inhalers in response to deteriorating symptoms
			• ensures she has sufficient rest in order to control symptoms
			• took antibiotics to hasten recovery from asthma exacerbations when she worked as teacher, manages without them now she does not work outside the home

12	• to maintain the present level of symptoms but reduce the dose of his inhalers	• recent increase in interest in his health as he approaches middle age:
		  • he had previously accepted his inhalers because he found his symptoms impaired sleep and were uncomfortable without them
		  • now, he was becoming increasingly concerned about the side-effects and safety of inhalers particularly in the long term
		  • perceives that inhalers cover up the symptoms of asthma rather than tackling the root cause of the allergy
			• uses regular preventers and relievers (takes reliever routinely along with preventer as he perceives he has been instructed by his asthma nurse)
			• has not yet taken any action to find out more about alternative methods of asthma control

16	• To maintain the present level of symptoms but without inhalers.	• Desires autonomy over asthma: avoiding inhalers symbolises a "fight back" against the disease. • Does not value an activity performed with the help of inhalers because it is not "normal" compared to her healthy peers. • Takes hayfever treatment regularly because she perceives that there are no reliever treatments for hayfever. Uses preventer when using hayfever remedies as part of a routine.	• Uses preventer in hayfever season, avoids the rest of the year. • Tries to avoid using reliever: sometimes uses pacing to complete exercise routine.

1) Asthma goals present (cont.)

Respondent	Asthma goals	Motivation	Behaviour
17	• to return to work • to cure asthma using physical exercise	• has experienced a recent deterioration in asthma symptoms • this recent deterioration prevents him working • no sick pay • in danger of losing his job due to prolonged sick leave • suffering from chronic debilitating symptoms • 2 recent hospital admissions with acute asthma • fears dependency on inhalers • perceives physical fitness as being more effective than inhalers in controlling asthma symptoms	• using inhalers in the short term to enable him to go on holiday and return to work
20	• to keep her peak flow around 450	• perceives uncontrolled asthma would limit her ability to work full time while caring for two young children • finds asthma symptoms uncomfortable • wishes to change jobs • fears that steroid inhalers could cause osteoporosis • accepting inhalers has meant accepting having a chronic incurable illness • finds it difficult to motivate herself to take inhalers without the feedback of symptoms or abnormal peak flow	• uses regular preventers and occasional relievers • measures peak flow to give her feedback on her condition and enable her to change jobs, sustain her lifestyle and resolve her conflicting attitudes towards symptoms and inhalers

2) Asthma goals absent

Respondent	Motivation	Behaviour
2	• Able to work full-time (involves physical activity), does not currently exercise but anticipates no difficulty when she starts again • Only suffers occasional asthma symptoms on exposure to cat hair. • Wants to lose weight through exercise to be fit for a forthcoming operation (surgeon will not operate unless she does) • Has been prescribed inhaled steroids: thinks her GP and asthma nurse are more concerned than she is about the potential long-term consequences of asthma. • Fears the adverse effects of inhaled steroids. • Thinks inhaled steroids are "unnatural".	• Uses occasional inhaled bronchodilator. (some doubts of the veracity of this statement as she voiced a strong aversion to inhaled steroids on the telephone when the interview was being arranged but moderated her view at interview) • Normally she avoids taking inhaled steroids. • She would be prepared to use inhaled steroids temporarily if necessary in order to be fit for the operation.
3	• Able to work full-time (sedentary) and take strenuous exercise • She intends to take sufficient inhaled therapy to allow her to exercise. • Perceives her current dose of inhaled steroids to be low and "mild". • Can only fit one inhaler in her handbag on her weekly overnight stays with friends. • Chooses salbutamol because perceives it may be needed in emergencies.	• Takes sufficient steroids to be able to look after and compete with her horse. • tends to forget her inhaled steroid when asymptomatic and when staying away from home.
4	• able to work full-time (sedentary, self-employed), exercises only occasionally but able to do occasional heavy exercise with pacing • asthma is "part of me", not separate enough to set goals • attributes symptoms to smoking not asthma • asthma less severe now than in childhood • asthma less severe than others with asthma • would like to control asthma better, lose weight, stop smoking to ensure a healthy retirement but keeps putting it off • future uncertain because of wife's progressive ill health • has past history of severe mental illness which he attributes to worrying too much about the future • follows doctor's orders on medication • no fears of medication – effective, much better than in his younger days	• uses inhalers exactly as recommended by doctor • avoids smoky pubs • smokes cigarettes

2) Asthma goals absent cont.

Respondent	Motivation	Behaviour

5	• Able to work full-time (sedentary) and take strenuous exercise
	• Experiences only occasional mild asthma symptoms.
	• Severe symptoms on exposure to pets but not a pet-lover.
	• Socialises in pubs which may have smoky atmospheres.
	• Perceives inhalers to be simple to use.
	• Would prefer only one inhaler which did the work of two in order to reduce his feelings of dependency.
	• Does not worry about the potential adverse effects of inhalers because:
	  • he accepts they are necessary to prevent symptoms,
	  • he has never personally suffered any adverse effects nor has he read of any on the patient information leaflet included with the inhaler,
	  • regular inhaled steroids give him the confidence to leave his salbutamol at home and avoids the need to use salbutamol in public.
		• Uses preventer regularly.
		• Uses reliever prior to exercise.
		• Avoids households with pets as they provoked asthma symptoms.
		• Tolerates smoky atmospheres although they also cause symptoms.

6	• Able to work full-time (manual) and take strenuous exercise • Suffers no asthma symptoms. • Does not regard his inhalers as medicines because he is accustomed to them and feels they are essential to control his asthma symptoms. • His general practitioner has advised him never to stop his inhalers. • He feels as least as fit as his peers despite a childhood blighted by physically limiting asthma.	• Staying healthy involves, rest, good food and regular inhalers. • Takes his preventer twice daily, exactly 12 hours apart.
7	• Able to work full-time (sedentary) and play golf (other exercise too strenuous) • Suffers fewer asthma symptoms now than in past • Able to sleep with disturbance by asthma • Started regular steroid inhalers about a year ago because of disturbed sleep leading to reduced performance at work • Unable to keep up with peers • Regards some lung damage as irreversible • Attributes some symptoms to being overweight • Not as bad as others with asthma – does not suffer attacks • No fears of inhalers • Not motivated to take inhalers when asymptomatic	• Uses inhaled steroid regularly when symptomatic, forgets when asymptomatic • Uses peak flow meter to provide feedback to motivate the use of regular inhaled steroids • Uses inhaled bronchodilator as required • Avoids smoky atmospheres – gave up chess club • Wishes to lose weight but finds it difficult to sustain motivation

2) Asthma goals absent

Respondent	Motivation	Behaviour

9	• Attributes losing an enjoyable, well-paid, but physically demanding job to having severe asthma.
	• Perceives he has had to give up sport and socialising with peers due to asthma.
	• Suffers chronic debilitating symptoms.
	• Frequent hospital admissions due to acute asthma.
	• Feels incapable of improving his asthma:
	  • cannot identify with the common asthma triggers,
	  • common asthma treatments do not seem to be effective,
	  • if anything his condition had deteriorated since giving up smoking,
	  • has never been certain that smoking makes his asthma worse,
	  • advised by doctors to give up smoking,
	  • perceives he does not get sufficient warning of asthma exacerbations, despite measuring his peak flow, to allow him to increase his medications effectively.
	• Regards steroid inhalers as essential to keep him alive.
	• Fears side-effects of oral steroids.
		• Takes regular preventers and relievers inhalers.
		• Will start oral steroids as required but prefers to endure symptoms for a little longer than necessary than take a second course of oral steroids, if prescribed.
		• Recently gave up smoking.

10	• Sedentary occupation • Unable to do heavy housework because of asthma – paces herself, asks daughters to help • Asthma triggered by household cleaners and sprays especially the best ones • Important to have a clean house • Frustrated because unable to join in fully on family outings such as walks because of asthma • Attributes some symptoms to being overweight • Fears acute asthma • Not a tablet taker • Would only use regular inhalers if she thought asthma was life-threatening • Believes regular inhalers would decrease but not abolish symptoms • Employs strategies such as resting instead of using medications • No fears of inhalers • Dislikes side-effects of inhalers – husky voice • Takes her some time to get used to the idea of taking medications – tries to get by without them first • Smoke triggers asthma only in enclosed spaces	• Only uses inhalers during acute asthma attacks • Carries inhalers at all times as a precaution • Cannot lose weight because unable to exercise due to shortness of breath • Avoids household cleaners sometimes but uses them at others • Ex-smoker – gave up because of difficulty breathing during an asthma exacerbation • Avoids smoke in enclosed spaces but husband smokes

2) Asthma goals absent

Respondent	Motivation	Behaviour
13	• Due to a highly pressured job (sedentary) he feels he cannot afford to have symptoms or time off sick. • Perceives a temporary increase in dust during house renovations might exacerbate his asthma. • Experiences only occasional mild symptoms. • Regards inhalers as essential to control symptoms. • Finds inhalers easy to use. • Resents time spent ordering and collecting inhalers and on asthma reviews.	• Intends to stay with a relative for a few days if his house becomes too dusty. • Takes preventer regularly. Never uses a reliever (does not even possess one).
14	• Able to work full-time (sedentary), study for MBA, and take exercise (never takes strenuous exercise – has young family) • A recent asthma exacerbation was his first for many years, had not led to time off work and was due to a known, avoidable cause. Therefore not motivated to use the inhaled steroids his GP had recommended. He has nothing against inhaled steroids per se but regards them as unnecessary • He usually experiences only occasional mild asthma symptoms easily relieved by salbutamol.	• Uses preventer alone. • Had a recent asthma exacerbation which required oral steroids.

15	• Able to study fulltime and care for son
	• Perceives asthma to impair weight loss but not her ability to earn.
	• It is more important to study in order to become qualified for a well-paid job than to lose weight.
	• Feels ability to exercise is severely limited by asthma, making weight loss difficult.
	• Weight loss is motivated by health being of increased priority since becoming a mother.
	• Perceives her current symptom control to be unsatisfactory because:
	  • it limits her ability not only to exercise but also to do normal activities such as climbing stairs,
	  • it limits her abilities compared to her peer group
	  • she fears acute attacks.
	• Her symptom control was worse before her son's birth as socialising was a higher priority than health.
	• She fears becoming addicted to inhalers.
	• She wishes to know more about the benefits and adverse effects of inhalers and about alternative asthma management strategies, in particular allergen avoidance.
	• Feels she has limited time to spend on asthma because of competing priorities: son, studying, extended family, friends.
		• Takes preventer regularly and often needs reliever too.

2) Asthma goals absent

Respondent	Motivation	Behaviour
18	• Able to work full time (sedentary, self-employed), look after house and family, take regular strenuous exercise • Feather pillows trigger asthma • Symptoms virtually disappeared since started avoiding feather pillows • Only off work because of a few "chest infections", which need oral steroids, this is unavoidable • Strong household cleaners trigger asthma • Fears adverse effects of inhaled steroids • Fears dependency on steroids • Steroids do not cure "chest infections", antibiotics do • Fears acute asthma	• Uses inhaled steroids only during exacerbations • Uses inhaled bronchodilators as required • Carries bronchodilator everywhere • Avoids feather pillows and household cleaners
19	• Able to work full-time (sedentary) and take strenuous exercise • In the past, asthma exacerbations had led to unwanted absences from work in the winter months. • Fears the adverse effects of inhaled steroids particularly over the long term. • Wishes to minimise both the dose of inhaled steroid and time off work	• Only uses inhaled steroids in the winter months. Tolerates asthma symptoms in the summer months because they do not lead to time off work and they are preferable to using inhaled steroids throughout the year.
21	• Able to work full-time (sedentary) and take strenuous exercise • Not entitled to sick pay. • He has never had time off work due to asthma, • In the past, the belief that asthma was impairing his ability to inhale cannabis had motivated him to consult his general practitioner. He was prescribed two inhalers and a nasal spray which he finished. As he found three prescriptions too expensive, he only repeated his prescription for salbutamol. This was chosen because it was perceived to work immediately and to be required to prevent exercise induced asthma.	• Takes reliever only: prior to exercise and as required.

2) Asthma goals absent

Respondent	Motivation	Behaviour
22	• Able to work full-time (manual occupation) • Some symptoms if plays vigorously with children • Unable to run • Would like to know more about asthma and have more regular feedback on how is asthma is but will wait for routine appointment (does not want to bother nurse) • No worries about inhalers – needs them • Advised by asthma nurse not to use bronchodilator regularly, stopped it and used steroid only, symptoms returned so went back to old routine • Smoky atmospheres trigger asthma	• Uses inhaled steroids and bronchodilators twice daily • Avoids smoky atmospheres
23	• Able to work part-time (sedentary), care for house and children, take strenuous exercise • Gave up smoking because of a severe, acute asthma attack (feared she might die) • Symptoms much better since stopping smoking -no time off work, able to run • Asthma triggered by some household cleaners but can complete housework • Needs inhaled bronchodilator prior to exercise • Forgets steroids when asymptomatic • Would like to be off medication completely as this would symbolise good health. It might be possible if got rid of dog but dog old so will wait till he dies naturally • No worries about inhalers because feels they are essential	• Reduces inhaled steroids until symptoms appear then increases them (suffers increased symptoms for a few days) • Uses bronchodilator as required • Ex-smoker • Uses the household cleaners that work best even if they trigger asthma

Appendix B: The semi-structured interview

The semi-structured interview is based on a topic guide. This appendix contains the topic guide followed by an explanation of how the topic guide is used.

Topic Guide

Disease severity

In the past 6 months have you had any:

1. night-time wakening with asthma	0	1-5	>5 occasions
2. exercise induced asthma symptoms	0	1-5	>5 occasions
3. early morning symptoms	0	1-5	>5 occasions
4. days of work/school/college etc.	0	1-5	>5 occasions
5. courses of oral steroids	0	1-5	>5 occasions

General

Age

Occupation

Household

Smoking status

Age of onset

Management

Describe effect of asthma on life
How bad is it now compared to usual, compared to best ever
Describe any trigger factors

Any friends or family with asthma

Current asthma treatment
Do they have to alter their treatment at all

Do they have a self-management plan
Do they use it

Goals

Describe their goals in life
Does asthma affect their goals at all

Describe their priorities in life
How does asthma fit into their priorities

Describe the most recent event that they had to plan ahead for
Did they have to alter their asthma treatment at all
In what way
How did that work out

Do they have any events coming up that they have to plan for
How do they intend to do that

Describe their overall aim of asthma treatment, if any
Any other aims
Any short-term aims
How important is it to them to achieve their aims
Describe any barriers to achieving their aim

How difficult would it be to achieve their aim

Do they break down their aim?

Are their any changes they would like to make to their asthma treatment
Anything they can't do?

Does asthma hold them back at all? Compared to friends and family?

Self-Efficacy

Confidence in management of asthma

How do they compare with others

Anything that has happened to increase or decrease confidence

Contact with Primary Care

Is the asthma nurse/doctor aware of their aims?
Why not? / How and when did they tell them?

Using the Topic Guide

The purpose of the topic guide is to list the areas that the interview was to cover. The questions in it are not fixed. Therefore, the interviewer could develop the most useful form of questioning over the course of the study. Also, the questions could be tailored to the individual by, for example, phrasing them in the respondent's own language. It should not be implied that the topics were covered in the order that they are written down. Some respondents raised issues spontaneously. In other cases the interviewer chose to cover sensitive issues such as smoking towards the end of the interview.

The topic guide is divided in to six sections: disease severity, general, management, goals, self-efficacy and contact with primary care. The reasons for the inclusion of each section and the way each was used will be described in turn.

Disease severity

A measure of disease severity was included in order to set the subject's goals in the context of disease severity *measured from the perspective of the health professional.* It was thought that differences in perceived disease severity might explain differences in the goals of the person with asthma and the health professional. The measure is based on the one used by the asthma nurse in the practice in which the study took place.

General

The purpose of this section was to ascertain the social background of the subject (in terms of occupation and household composition) and the duration of their asthma. Subjects were not asked about their smoking habits unless they had not raised the issue spontaneously by the end of the interview.

Management

The aim of this section was to explore the subject's experience of asthma and its management. It was hypothesised that people who feel they can live their life "as well as the next man" or who have no problems with their asthma management would be less likely to have goals. The questions on the experience of asthma covered the effect of asthma on life, the subject's asthma triggers, a comparison of their present experience with their past experience and a comparison of their asthma to any friends and family with asthma. The questions on asthma management covered their compliance with medication and their use of self-management plans. It became apparent that some people use non-medical strategies to manage asthma and this issue was added to the topic guide in later interviews.

Goals

This section was concerned with identifying the person's goals in life and for their asthma. A goal was conceptualised as something one wanted "to work towards", "to achieve" or "to change". For example:

I mean is there any changes you would like to make to your asthma treatment?

To the treatment? Not really, no. I can't think of anything that I've heard of or read about that the consultant's at Stobhill haven't given me. I've got no bones with them, these guys up there are doing the best they can for me, it just doesn't seem to be working.

[Respondent 9]

Life goals were explored in order to set asthma goals in the context of other goals and priorities in life and to introduce the concept of goals. The reasons for the presence or absence of asthma goals were explored including the influence of the past success or failure of goal-setting. If the person had goals the aim was to find out about their commitment to the goal, the perceived goal difficulty, goal conflict

and sub-goals. Subjects were also asked to describe any aims they had for their asthma treatment. An aim differs from a goal because it describes the subject's objective of their current treatment rather than any changes they would like to make. However, given the similarity of the two concepts it is unsurprising that questioning respondents about their aims might result in a discussion of the reasons for the presence or absence of goals. For example:

Do you have an overall aim for your asthma treatment at all?

Not really, I know there is sort of talk about something coming onto the market which would be a cure for it, if a doctor said to me well your asthma is not that serious and I don't think this really would be good for you, I don't think you need this then I'll accept that. But if he said to me yes, I think you should take this then you know, I'll take it but no I don't... I do nothing that would deliberately sort of set me off on a bad attack but then it takes quite a lot to you know set me off on the first place. So as far as my asthma is concerned and it's treatment, well there is nothing I can do other than what I've been told to do and leave it at that.

[Respondent 4]

Self-efficacy

This section explores the respondent's confidence in managing their asthma because a lack of confidence might be thought to preclude goal setting.

Contact with Primary Care

The purpose of this section is to discover whether goals are perceived to be self-set or set by the health professional and to explore the communication of goals with the health professional.