

MOTIVATION IN PULMONARY REHABILITATION

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Abstract

Background

Pulmonary rehabilitation is a highly evidenced intervention used in the management of patients with chronic obstructive pulmonary disease. Both patients and healthcare professionals have anecdotally acknowledged motivation as a key element in a programme. It has been suggested by some authors that motivation should be a prerequisite to entry, yet there is no evidence to support this suggestion. The purpose of this study therefore, was to provide some theory about the role of motivation in pulmonary rehabilitation and to produce a measurement instrument to enable further quantitative study.

Methods

A qualitative, exploratory investigation using focus groups and face-to-face interviews with patients undergoing a pulmonary rehabilitation programme was undertaken to generate data around factors influencing motivation. Results were used to develop a 43 item self-report questionnaire. The questionnaire was administered to 77 patients before and after a pulmonary rehabilitation programme along with other health status measures. The questionnaire was tested for reliability and validity. Item reduction was performed using factor analysis.

Results

Motivation within the context of a PR programme was shown to consist of a number of psychological, social and circumstantial variables that fell into 3 broad dimensions: Essential motivation, external motivation and functional outcome. A key finding was that attending pulmonary rehabilitation had an enormous positive influence on the patients' essential motivation. The questionnaire was reduced to 21 items and principal components analysis demonstrated 9 factors within the questionnaire. These were function, self-efficacy, effort, optimism, tenacity, self worth, isolation, ability and achievement. The questionnaire was named the Malvern pulmonary rehabilitation motivation questionnaire (MPMQ) for identification. The MPMQ was shown to be reliable with internal consistency, reproducibility on test-retest and sensitivity to change. Correlations were found between the MPMQ and health related quality of life, anxiety and depression, breathlessness, exercise capacity and hospital admissions during the previous 12 months. Motivation score was significantly lower in patients

who dropped out of the programme and was significantly higher at the end than the start of a programme.

Conclusion

The MPMQ has been shown to be a reliable tool with sound evidence of validity that can be used to objectively assess patients' motivation within the context of a pulmonary rehabilitation programme. These findings need to be supported with further evidence for the validity and reliability of the questionnaire. Further investigation of the association of MPMQ score and adherence in pulmonary rehabilitation is needed along with further exploration of the determinants of motivation. This would enable specialist staff to identify patients who are likely to have adherence problems and channel efforts into effective cognitive-behavioural interventions in the ongoing effort to establish the optimum pulmonary rehabilitation programme.

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CHAPTER 1 – BACKGROUND

This chapter presents the background to the research undertaken within this thesis, along with an explanation of the purpose, scope and multidisciplinary context of the research. The majority of the patients within this study have the condition; chronic obstructive pulmonary disease (COPD) and this chapter contains a definition and explanation of the condition and its' management. The political, physiological and psycho-social issues surrounding COPD are discussed in detail below, along with the impetus for the research. An explanation and detailed description of pulmonary rehabilitation, a healthcare intervention for people with COPD, is also included. The aim of the chapter is to 'set the scene' for the reader to enable a better understanding of the reasons behind this enquiry.

1.1 Purpose and scope of the research

The overall purpose of the research project described in this thesis was to develop and validate a motivation measurement tool developed specifically for use within pulmonary rehabilitation (PR) programmes. A PR programme is a therapeutic intervention delivered to patients with mainly chronic obstructive pulmonary disease (COPD) and both PR and COPD are described in detail later in this chapter. The measurement tool took the form of a self-report questionnaire and its' purpose is to provide an objective reflection of patients' motivation before and after a PR programme. The existence of a purpose – designed motivation measure will enable further study about the role of motivation within a PR programme. The tool can be used to establish any associations between the patient's motivation and adherence to a PR programme. The measurement tool has been designed so that it can be administered easily to patients by staff running PR programmes, usually physiotherapists and nurses. In order to develop the motivation questionnaire, it was necessary to collect data about factors associated with motivation within the context of a PR programme. Although this data has potential theoretical implications, the purpose of the data collection was to develop items for the questionnaire and not to provide a new model of motivation. Theoretical models and frameworks of motivation already exist and those will be discussed in chapter 2. The focus of the research was to develop the motivation questionnaire rather than to build theory.

1.1.1 The interdisciplinary nature of the research

Although the professional background of the author is nursing, the research had to be of an interdisciplinary nature and there are 2 reasons for this. The first is that PR by definition is a multidisciplinary intervention with most programmes in the UK being led by both physiotherapists and nurses in the main, with usually a lesser input from others, such as dieticians, occupational therapists and doctors. In our own local PR programme, it is our experience that members of the multidisciplinary team work very generically. Delivery of a PR programme often employs some unique clinical skills and knowledge that are not routinely used in the day – to – day clinical practice of either the nurse or physiotherapist. A good example of this is being able to lead a group of patients. Skill, knowledge and experience are needed in order to elicit the most effective outcome for the majority of the group. In our experience, group leadership is not the remit of one particular professional group, rather it is about who possesses that particular skill and how through peer review the different disciplines can develop their skills as a team. Measuring motivation within a PR programme is relevant to the entire multidisciplinary team delivering a programme, as success is based on the outcome for the patient as a result of a team intervention.

The second reason for the interdisciplinary focus of the research is that the field of enquiry (motivation) traditionally lies within the domain of health psychology. In the process of questionnaire development, as motivation is cognitive rather than biological, it was necessary to review research and literature from the science of psychology. Although nursing requires an understanding of psycho-biological mechanisms, this is not at the same advanced scientific level as the discipline of psychology. Therefore, study of the psychology literature was challenging, since the language and approach was very different to biomedical research papers. Within the UK many PR programmes are delivered without the input of a clinical psychologist. Nurses and physiotherapists running programmes often have to address psychological issues, such as motivation, with no training or guidance. PR staff have the benefit of the practical experience of delivering a programme and our experience is that some psychology skills develop as a result of reflective clinical practice, despite the lack of theoretical underpinnings. It became evident during the review of the literature on motivation that there is a great deal of theory that could be applied from the science of health psychology to PR programmes in order to enhance their effectiveness.

However, it was also evident that there exists a theory- practice gap and that it would benefit patients if both PR clinicians and health psychology academics could take steps towards more partnership working. In this instance, although the study of motivation has mainly been made within the domain of psychology, the practical application within PR is made by physiotherapists and nurses. Therefore a more unified approach should be sought.

Managing the interdisciplinary approach to this research required consideration of the language and levels of theory of different disciplines, particularly that of health psychology. This involved an advancement of knowledge about cognitive – behavioural theory and the language of health psychology on the part of the author. The nature of COPD is that it is a bio- psycho-social condition which responds to a variety of medical, therapeutic, social and psychological interventions, many of which are delivered during a PR programme. For this reason PR staff need a ‘toolbox’ of interventions that can be easily accessed and applied to practice. The challenge was to produce a measurement instrument that enabled the application of a psychological concept to clinical practice in a ‘user- friendly’ format that was acceptable to the PR team. The way the interdisciplinary approach was managed was that the research had methodological quality, with clearly stated scope and objectives and the correct research method to fulfil those objectives. It was more important that the research was scientifically robust than the professional background of the author. A further measure taken to bridge the multidisciplinary focus was to include members of other professional groups in the planning of the research. The research team included a consultant physician, a health psychologist and a physiotherapist in order to achieve an interdisciplinary approach to the research.

1.1.2 The nursing context of the research

Although PR is a multidisciplinary intervention, and often the team operates generically, the nursing profession can provide unique skills that can complement the skills of the other disciplines and enhance a programme. As will be discussed later in this chapter, COPD not only has pathological and physiological effects, but also impacts on patient’s psychological and social status. For this reason patients require a holistic approach to their management, which is part of the ethos of nursing. The Royal College of Nursing (2003) defines nursing as:

The use of clinical judgement in the provision of care to enable people to improve, maintain or recover health, to cope with health problems and to achieve the best possible quality of life whatever their disease or disability until death.

The definition of nursing focuses on improving health and quality of life, which are also the overall aims of a PR programme. Much has been documented about what constitutes the essence of nursing, but theorists suggest that it is the 'use of self' in attending the psycho-social needs of patients during illness (Dingwall and Allen 2001). This 'emotion work' and the holistic approach taken towards patients' is arguably what differentiates nurses from other professional groups. What also makes nursing distinctive from other professions, is the close therapeutic relationship with the patient (Salvage 1992). Using a holistic approach, utilising emotion and by building therapeutic relationships with patients nurses can therefore have an important role within a PR programme. Particularly with respect of dealing with the psychosocial needs of these patients such as building motivation. Using their unique skills, nurses can assist with the practical application of health psychology theory within a PR programme which will in turn enhance the benefit of programmes for patients.

1.2 Policy context of chronic obstructive pulmonary disease

Within the UK, the current government has endeavoured to reform the National Health Service in order to provide more modern and appropriately delivered healthcare. The Department of Health outlines 6 main objectives (Department of Health (DOH) 2006a), one of which is supporting people with long term conditions to lead healthy lives. Government policy is aimed at empowering patients in order that they take some responsibility for managing their condition and leading a healthy lifestyle (DOH 2006b). In the policy for long- term conditions, the emphasis is placed on preventative interventions such as rehabilitation, multidisciplinary care and increasing patient self-management (DOH 2005). The government advocates that healthcare professionals work in partnership with patients, carers and other organisations in order to achieve healthcare that is directed at the needs of patients (DOH 2004). In addition, there is a move to empower the patient with more choice about their healthcare provider, in order to increase their independence (DOH 2006c)

Historically, COPD has had a low profile within the NHS, with little funding or political interest. Recently, COPD has moved to the top of the health care agenda becoming an NHS priority. This is due to a number of events within the UK that have contributed to the significant increase in the profile of COPD. With an ever-increasing need to tackle financial problems in the NHS, the government have set 2 priorities that are particularly relevant to COPD. These are the move to reducing emergency admissions to hospital and chronic disease management.

A large proportion of COPD costs to the NHS can be attributed to hospital admissions, with 40 – 50% of patients discharged from hospital with an exacerbation of COPD being admitted during the following year (Osman et al 1997 and Connors et al 1996). It is clear that reducing the patient's need for hospital care could greatly reduce COPD costs within the NHS. However, in order to do this, improvements in COPD management by healthcare professionals in primary care is needed. Earlier diagnosis and the use of interventions aimed at preventing exacerbations and delaying the progression of disease would reduce associated costs (Britton 2003). Added to the recognition of the cost of the condition is the fact that there have been recent publications of national guidelines for COPD (National Institute for Clinical Excellence /British Thoracic Society 2004 and Rabe et al - Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2007). With NHS trusts now under obligation to provide evidence based healthcare, these guidelines have given health care professionals a tool to use when negotiating for additional COPD funding. Furthermore the guidelines will facilitate better and more evidence based care for people with COPD. Finally, political and public campaigning by the British Lung Foundation (BLF) charity in particular has contributed towards raising awareness of COPD throughout the UK.

1.3 Overview of Chronic Obstructive Pulmonary Disease

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) (Rabe et al 2007) defines COPD as:

A preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is

characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases.

The ATS/ERS task force (Celli et al 2004) have a very similar definition, also acknowledging the role of inflammation in COPD. Because of the impairment of airflow as a result of lung damage, the patient is rendered breathless (Calverey 2003). The airflow obstruction is progressive, not fully reversible and does not change markedly over several months (British Thoracic Society (BTS) 2004). COPD is the now preferred term for the conditions emphysema, chronic bronchitis and a subset of asthma and it can combine all three (Mannino 2002). It is classified by severity (mild, moderate or severe) based on the degree of airflow obstruction (McBride and Milne 1999), although the GOLD COPD strategy (Rabe et al 2007) describes a fourth classification of 'very severe'. COPD is mainly caused by cigarette smoking (Doll et al 1994), but can occur occasionally in non-smokers (BTS 1997). Exacerbations of the condition, caused usually by respiratory infection, result in increased healthcare costs and decline in health related quality of life (Turnock et al 2005).

COPD is believed to affect around 900,000 people in the UK, with half as many again having the condition but being undiagnosed (BTS 2004). The UK has one of the highest death rates for COPD in Europe, with around 27,000 deaths per year (Calverey 2002). Worldwide, COPD is steadily increasing in prevalence. In 2000, COPD was the fourth leading cause of mortality worldwide (Murray et al 2001). It is predicted that by 2020, COPD will rise to be the third leading cause of death (Murray and Lopez 1997) and the fifth leading cause of disability adjusted life years (DALY's) (Mannino 2002).

Patients with COPD are known to be a considerable health burden (McBride and Milne 1999). Morbidity is high with the direct costs to the NHS in the UK estimated at being almost £500 million per year (BTS 2004). It is thought that up to 1 in 8 emergency admissions in the UK are from COPD and that those admissions have a mean length of stay of 9.1 days (Office for National Statistics 2000). In addition to NHS costs, the disease causes around 21.9 million lost working days (Britton 2003).

Other common chronic diseases in the UK are declining, however the prevalence of COPD is steadily increasing (Office for National Statistics 2000). This fact, coupled with increased life expectancy magnifies the impact of COPD on the aging population (Ries et al 1997).

Because of the insidious nature of COPD and the large pulmonary reserve, COPD is not generally recognised until late in its course (Celli et al 2004 and Kaplan et al 1998). Patients initially often attribute early respiratory symptoms to the effects of cigarette smoke. The airflow impairment that is characteristic of COPD leads to breathlessness on exertion. The patient then limits their physical activity in response to their increasing breathlessness thus leading to physical de-conditioning and consequent disability. The disability is accompanied by an impaired mood state, including anxiety and depression (McBride and Milne 1999). Patients become frustrated with their condition and self-esteem is often low as a result of feeling embarrassed by the antisocial symptoms of COPD (MacCathie et al 2002).

Breathlessness produces fear and distress and panic attacks are common. Nutritional deficiencies are present in many of these patients. It is clear that much of the disability in COPD is due to the secondary effects of the disease rather than the original respiratory impairment (Rabe et al 2007 and Morgan 1999).

1.4 Outline of management strategies in chronic obstructive pulmonary disease

It is known that there exists a matrix of relationships between both physical and psychosocial variables in COPD (Jones 1995 and McCathie et al 2002).

Relationships of varying degrees exist between breathlessness, nutritional status, exercise capacity, anxiety, depression, quality of life, functional ability, degree of airways obstruction and uptake on healthcare resources (Osmon et al 1997). Good COPD management therefore addresses the patient holistically, taking into consideration the patient's disability as well as the physiological impact of the condition. In moderate and severe COPD management strategies as suggested within the national and international COPD guidelines (Celli et al 2004, Rabe et al 2007 and BTS 2004) fall into 3 broad categories: (1) Pharmaceutical treatment primarily aimed at a physiological improvement, (2) non-pharmaceutical interventions primarily aimed at improving health related quality of life and (3) hospital admission /

exacerbation prevention interventions, aimed at reducing healthcare costs as well as improving quality of life.

Pharmacological management of COPD has long been the mainstay of treatment. At its simplest it includes the use of inhaled bronchodilators, corticosteroids and theophylline to reduce airway obstruction, antibiotics to treat respiratory infection, mucolytics to assist mucus clearance and long or short-term oxygen to correct any abnormal arterial blood gas pressures. Pharmacological interventions are primarily aimed at optimising lung function (Mahler et al 1999) and reducing the amount of exacerbations (Pool and Black 2003 and Singh et al 2002), although many treatments have the ‘spin off’ of improving quality of life (Jones and Bosh 1997).

In addition to improving the patient’s quality of life, COPD management also includes interventions that demonstrate a saving in healthcare resources. Some of the interventions outlined above not only improve lung function along with health status, but often have a positive resource saving outcome. It is known that people with COPD who have a poorer health status are more likely to be admitted to hospital (Osman et al 1997), so in theory, interventions that improve health status should also reduce risk of hospital admission. This is apparent in the Bourbeau study (2003) and Farrero study (2001), where COPD patients who were case managed at home showed a reduction in hospital admissions of 40% and 60% respectively. Likewise, pharmaceutical interventions aimed at a physiological response often have the additional benefit of reducing use of NHS resources. For example, the drug - carbocysteine (a mucolytic) has been shown to reduce exacerbations by 40% (Gerrits et al, 2003). Recently, there has been an increase in research into management strategies that have the specific aim of reducing the healthcare resource burden of COPD. These are schemes where patients with exacerbation of COPD are managed at home as an alternative to hospital admission. Such services include early discharge support (Skwarska et al 2000), ‘hospital at home’ (Davies et al 2000) and admission prevention schemes (Hernandez et al 2003). These interventions have been shown to be extremely cost effective as well as safe and satisfactory for the patients.

The importance and effectiveness of treating the disability displayed in COPD has become more apparent in recent years (Calverey 2003 and Jones 1995). Hence, there

has been a dramatic increase in research and development undertaken into non-pharmaceutical COPD management strategies. Such interventions include: home case management (Bourbeau et al 2003 and Farrero et al 2001), patient education and action plans (Turnock et al 2005), pulmonary rehabilitation (PR) (Ries et al 2007 and Lacasse et al 2006) and early community pulmonary rehabilitation following acute exacerbations (Mann et al 2004). Outcomes of these interventions are focused on improving the quality of life and functional status of these patients. There is increasing recognition that behaviour modification within this patient group is a crucial element in the management of their condition. It is clear that lifestyle changes made by the patient in areas such as cigarette smoking, exercise, nutrition, sputum clearance and exacerbation management have an enormous impact on health outcomes. Current evidence supports the view that COPD patients should be assisted to develop self-management skills in order to deal with exacerbations and make lifestyle choices more effectively (Monninkof et al 2003, Snider 2004, Martin et al 2004, Dowson et al 2004, Bourbeau 2004 and Taylor et al 2005). Although it is clear that self-management should be promoted with patients with COPD, what is unclear are the methods that should be used to facilitate self-management behaviour. Whilst results of some trials of interventions to enhance self-management outside of a PR programme have shown success (Bourbeau et al 2003), others have failed to show positive effects (Monninkof et al 2003). These differing results may be the methods of delivery of the intervention itself rather than concluding that self-management is not effective.

No-where is the principle of self-management in COPD more intensely delivered than within a PR programme (described below), during which lifestyle choices are addressed and patients need to change their behaviour in order to achieve success on a programme. The American Thoracic Society and European Respiratory Society (ATS/ERS) statement on PR (Nici et al 2006) suggests that the most adherence-enhancing interventions are designed to improve self-management capabilities. The authors promote the notion of partnership working between the patient and healthcare provider as enhancing patient adherence. PR is also presented as a method of strengthening the partnership

1.5 Outline of Pulmonary Rehabilitation

The development of pulmonary rehabilitation (PR) programmes in the UK over the past 15 years has revolutionised the treatment of people with COPD. A PR programme consists of a group of patients with mainly COPD meeting twice a week for around 8 weeks at either a hospital or community venue for exercise and education about how they can manage their condition. The team providing the programme is multidisciplinary, mainly consisting of physiotherapists and nurses. The ATS/ERS (Nici 2006) statement on pulmonary rehabilitation (PR) defines it as:

An evidence based, multidisciplinary and comprehensive intervention for patients with chronic respiratory disease who are symptomatic and often have decreased life activities. Integrated into the individualised treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimise functional status, increase participation and reduce healthcare costs through stabilising or reversing systemic manifestations of the disease.

The majority of patients referred for a PR programme will have COPD. However it is recommended that patients with other chronic respiratory diseases who have a diminished functional capacity or quality of life would benefit from attending a programme (Nici et al 2006). When a patient is referred for PR an initial assessment is made, usually by a member of the team, of their suitability for the programme. Patients attend the venue at least twice a week for around 8 weeks for sessions that last around 2 hours. The minimum recommended supervised sessions for PR is 2 sessions per week (Nici et al 2006) and these guidelines present the evidence that the longer the duration of the programme, the better and longer lasting are the outcomes. Most PR programmes are delivered on an out patient basis either at a hospital or at a community setting. PR can also be effectively delivered on an individual basis in a home setting (Stribos et al 1996). There is no standardised method of programme delivery as its structure is designed to fit the healthcare needs of each location. A typical programme consists of patient assessment, exercise training, education, nutritional intervention and psychosocial support (Ries et al 2007). A typical session in the UK consists of a physical exercise session that will include warm up and stretching, cardiovascular exercises, weight training exercises and cool down. Exercises are individualised, based on the patients' functional ability and

breathlessness. Patients are monitored closely and prescribed oxygen where needed during exercise. Some programmes include a relaxation activity. Then this is followed by an education session designed to increase self- management of the condition. Education sessions cover aspects of COPD where patients can improve their self- management skills, for example, medication, exacerbation management and sputum clearance. It is essential to audit the effectiveness of programmes and it is recommended that assessment of symptoms, functional ability, exercise capacity, and health related quality of life should be an integral part of PR (Nici et al 2006).

The definition of PR (Nici et al 2006) contains the words ‘multidisciplinary’ and ‘comprehensive’. There are many facets to PR programmes producing a number of positive outcomes for the patient but overall the aims are about reducing the impact of COPD on the patient’s bio-psycho-social status. Current guidelines (Nici et al 2006 and Ries et al 2007) present the aims of a programme as follows:

- Increase physical endurance
- Increase muscle strength and muscle mass
- Enhance patient self-management skills
- Enhance patient self-management skills in the prevention and early treatment of exacerbation
- Correct exercise induced hypoxemia
- Improve dyspnea
- Improve health related quality of life.
- Reduce number of hospital days and other measures of healthcare utilisation..
- Patient management of energy conservation.
- Correct nutritional abnormalities.
- Improve exercise performance.
- Improve ability to perform activities of daily living.
- Restore a positive outlook in patients.
- Improve emotional status.

There is a tremendous amount of evidence to support PR as an effective intervention for people with COPD. A systematic review of PR was undertaken by Lacasse et al

(2006). The study included 31 randomised controlled trials of PR where quality of life and exercise tolerance were evaluated before and after a programme. The authors found statistically significant improvements for all outcomes and concluded that PR relieves dyspnea and fatigue, improves emotional function and enhances the patient's perception of control over their condition. McBride and Milne (1999) conducted a report that identified thirty-nine randomised controlled trials (RCT's) examining the benefits of PR. Within this report are presented two systematic reviews of PR. The first systematically reviewed the literature assessing the effectiveness of PR on exercise capacity and health related quality of life in patients with COPD (Lacasse et al 1996). Fourteen RCTs were reviewed and it was concluded that a PR programme including at least 4 weeks of exercise training improves breathlessness, exercise capacity, COPD control and health related quality of life. The second systematic review explored trials of the contribution of various PR components to the improvement of exercise capacity and quality of life in patients with COPD (Lacasse et al 1997). The review presented sound evidence for the exercise components, but was unable to assess the contribution of education. Psychosocial support had a positive effect on dyspnoea, compliance with exercise and quality of life.

Another frequently cited report was conducted by the American College of Chest Physicians and the American Association of Cardiovascular and Pulmonary Rehabilitation (Ries et al 1997). The components of PR were reviewed individually, enabling the panel to provide guidelines about what should be included in a PR programme. Components included lower extremity training, upper extremity training, ventilatory muscle training, and psychosocial / behavioural interventions. The panel also examined the evidence regarding health outcome topics including psychosocial and behavioural measures, dyspnea, quality of life, healthcare utilisation and survival. Another review of the PR literature (British Thoracic Society 2001) explored the evidence to support the various dimensions of PR. From this the committee were able to recommend which components should constitute a programme. Another important UK study examined the effect of PR on utilization of health care services (Griffiths et al 2000). This study demonstrated that patients who had undertaken PR spent significantly less time in hospital as an in-patient than those who had not had the intervention.

Over the past 10 - 15 years, PR programmes have been introduced into many NHS centres in the UK. Uptake has been slow as NHS funding for COPD services in the past has not been easy to obtain. Indeed, many people with COPD still do not have access to a programme, despite unequivocal evidence of its benefits and the fact it is recommended in the UK national guideline (National Institute for Clinical Excellence /British Thoracic Society 2004), the European and American thoracic society COPD guideline (Celli 2004) and the worldwide COPD guideline (Rabe 2007). A joint UK survey conducted in 2002 by the British Thoracic Society (BTS) and British Lung Foundation (BLF) (BTS/BLF 2002) demonstrated that only 1.7% of patients diagnosed with COPD had access to pulmonary rehabilitation each year. The same survey also showed that only 57% of all hospitals providing a programme had secure funding and one third of programmes do not provide an adequate number of sessions.

Locally, in the county of Worcestershire, a PR programme has been running for around 14 years. The programme had no secure funding at the time of the research. The programme operates at 2 rural community hospitals and 1 acute hospital and is run by the same multidisciplinary team but with additional input from staff based at each locality. The programmes are modelled on standard guidelines (Nici et al 2006) with an 8-week programme of exercise, education and lifestyle advice. In addition, a maintenance group is in operation at one locality in Worcestershire. This is a weekly group where post-programme participants can attend as desired for an exercise session, followed by refreshments and informal education or discussion. There is also a local 'Breathe Easy' patient support group. Breathe Easy is a national patient support organisation which is attached to the British Lung Foundation. The local PR programme links closely with the Breathe Easy club. These local PR programmes, maintenance group and Breathe easy group provided the setting for the research presented within this thesis.

1.6 Adherence, drop-out and maintenance in pulmonary rehabilitation

During a PR programme the principles and effectiveness of self-management, behaviour modification and lifestyle change are intensely delivered to patients. Within a programme, the patient is advised and encouraged to self – manage their condition and make lifestyle choices known to elicit improvements in people with

COPD. One of the most documented behavioural components in PR is exercise and there is overwhelming evidence that this component produces tremendous benefits for the patient (Kaptein and Dekker 2000, Lacasse et al 2004 and Troosters et al 2005). In a local PR programme it is not unusual for patients to describe their experience of attending a PR programme as a life-changing event.

Despite these documented and anecdotal benefits, it is known that exercise adherence in COPD patients is poor (Garcia-Aymerich et al 2003, Cockram et al 2006, Troosters et al 2000, Rabinowitz 1999 and Young et al 1999). Studies have shown that a substantial proportion of otherwise eligible patients refuse to participate in, or fail to complete, a PR programme (Young et al 1999). Consequently, non-adherence to a PR programme, whether it is through the patient dropping out of a programme, or declining to participate in one, is preventing the patient from attaining these potential benefits (Puhan et al 2008, ZuWallack 2007 and Fischer et al 2007). Furthermore, it is an inefficient use of precious resources if uptake of PR is poor, so clearly it is essential to try and improve adherence to PR. This is a view that is also strongly supported in the literature (Garrod et al 2006, Davis et al 2007 and Dodd et al 2001). In addition to adherence during a programme, maintenance of regular exercise following a PR programme has also been acknowledged as a problem (Ries et al 2003, Donesky et al 2007, and Nici et al 2005). There is little reference in the literature about maintaining lifestyle changes beyond the PR programme and PR teams anecdotally report maintenance of exercise plans as a difficulty. It has been shown that the benefits of PR can start to tail off after around 12 months (Ries et al 1995) and long-term maintenance of an exercise programme is difficult even with initial motivation (Kaplan et al 1998).

The American thoracic Society and European Respiratory Society (ATS/ERS) have acknowledged the problem of adherence within PR programmes and have recommended more research about this topic (Nici et al 2006). However, there is no consensus within the literature about what constitutes adherence to a PR programme. Practical experience and informal observation within a local PR programme highlights the complexity of the issue of adherence. For example, a patient may be considered 'adherent' by PR staff if they attend every session in a programme. But the patient may not follow their exercise plan outside of PR sessions and this

occasionally becomes evident when the patient 'admits' that they find it difficult to exercise alone at home. Often, they may still show an improvement in outcome measures, but this may be more as a result of increased confidence and positive attitude rather than physiological reasons. The ATS/ERS statement on pulmonary rehabilitation (Nici et al 2006) have adopted the World Health Organisation definition of adherence which is:

'The extent to which the person's behaviour corresponds with agreed- on recommendations by the healthcare provider'.

Within a PR there are a number of 'agreed on recommendations' about exercise. For example, they are prescribed a variety of exercises for different muscle groups, a certain level of intensity at which to exercise, an amount of time for each session of exercise and the number of times per week that they should exercise for. They are also instructed to warm up, cool down and to stretch. Some are instructed additionally to use oxygen during exercise. In the light of this definition the patient's exercise behaviour needs to 'correspond' to all of these instructions to theoretically be 100% adherent. However in the study by Young (1999), adherence is defined as non-completion of a PR programme, regardless of whether the patients continued to exercise away from the PR group. Clearer distinctions need to be made within the literature about whether adherence is to programme attendance or to performing the exercise plan. It is suggested that if a study is exploring 'drop out' this may be better termed completion or non-completion of a programme rather than adherence.

Only one study was found that addressed adherence to the required level of exercise intensity following a PR programme (Donesky et al 2007). This study found that although consistent adherence to exercise was related to better physical benefits, flexibility within an exercise programme led to better mental health scores. This supports the idea that 100% adherence may not be essential in order to benefit from a PR programme. Dropout, which has been cited in the PR literature as being consistent with non-adherence (Garrod et al 2006 and Young 1999), may not be a good determinant. In support of this view, a study by Oldridge and Spencer (1985) showed that in a cardiac rehabilitation programme, 50% of patients who had 'dropped out' of a structured programme were continuing to exercise alone at home on a regular basis 12 months later. It may be the case that patients who drop out of PR are wrongly dismissed as a failure. For example Morgan (1999) suggests that

dropouts from a PR programme, although inevitable, are wasteful of resources. This comment is making an assumption that people who drop out of a PR programme have not gained an improvement in outcome. This may not always be the case.

A number of authors have responded to the problem of adherence in PR and have tried to establish reasons for non-participation in a programme (Taylor et al 2007, Garrod et al 2006, Ries et al 2003, Cote and Celli 2005, Young et al 1999 and Donesky et al 2007). However the majority of these studies have examined predominantly physical variables as predictors of non-adherence within PR. For example, the study by Garrod et al (2006) was conducted in order to examine the relationship between COPD variables and success or failure in a PR programme. A feature of this study was that it also determined predictors of drop out. The authors concluded that there was a relationship between depression, lower quadriceps strength, smoking history and drop out from a PR programme. In another study, Young et al (1999), acknowledging the lack of research into compliance and drop out in PR, identified predictors of non-adherence to PR programmes. In this study, 91 patients who were referred for a PR programme were assessed for a range of psychosocial, demographic and physiological factors prior to programme commencement. These factors were previously shown to be related to adherence to health behaviour in COPD (Turner et al 1995). Thirty-six out of the 91 patients either did not complete, or declined to participate in the programme. These non-adherent patients were more likely than the adherent group to be divorced, live alone, smoke and less likely to use inhaled cortico-steroids. No differences were found between the adherent and non-adherent groups in physiological parameters or health status measures. Again, this study focused on non-cognitive variables and neither of these studies examined motivation as a predictor of drop out. The problem with demographic and physiological variables is that they would be difficult to manipulate in order to improve adherence. Whereas if motivation was found to be associated with adherence to PR, this would potentially open up much opportunity to support the use of cognitive-behavioural interventions within programmes. Motivation has previously been demonstrated as the best predictor of adherence to exercise within cardiac rehabilitation (Dishman et al 1980) and has been described as the crux of health behaviour performance (Plonczynski 2000). It is possible therefore that motivation is associated with adherence in PR.

1.7 The potential role of motivation in adherence in PR programmes

Motivation has been presented in the PR literature and even guidelines as a prerequisite for entry into a PR programme (Nici et al 2006, Troosters et al 2005, Morgan 1999 and Donner and Muir 1997). Within the ATS/ERS statement on PR (Nici et al 2006) it is recommended that motivation should be assessed within a psychosocial evaluation prior to the commencement of a programme. The paper indicates that patients should be allowed to express their concerns about adjustment to their disease by the interviewer asking questions about the patient's perceptions of motivation. However, the paper does not elaborate further on what the healthcare professional conducting the assessment should do with this information. There is also no further explanation about the meaning of motivation and how to interpret what the patient says in response to questioning on their perception of motivation. It is possible that these authors have made the assumption that motivated patients will have better adherence than un-motivated patients. However, where motivation is recommended as an entry criterion, there appears to be no scientific basis for making this recommendation.

It is surprising that there is a lack of research into what motivates people with COPD to continue to exercise either during or following a PR programme. Given the benefits gained by the patient from adherence to exercise both during and after a PR programme it would be valuable to identify the role of motivation where patients either drop out of PR, decline the offer to take part in a programme or fail to maintain their exercise prescription following PR. Some authors have evaluated interventions that aim to maintain adherence to exercise beyond a PR programme. For example Ries et al (2003) explored the use of post-PR telephone contact plus monthly 'reinforcement' sessions. This intervention had a modest effect in maintaining the benefits of PR. The study measured a variety of factors that may be related to adherence but these were mainly physiological variables such as breathlessness and lung function. The only cognitive variable explored was self-efficacy, and the authors found no difference in measurement between the control and intervention groups. Physiological variables are difficult to manipulate and change in order to elicit improved adherence. The authors of this appeared disappointed by the only modest improvements of the intervention group. It is a possibility that within the intervention

group, some patients were less motivated than others, and that the telephone contact and monthly reinforcement sessions were not enough to build the patients' motivation to adhere to exercise. The inclusion of the measurement of motivation within studies such as these would potentially offer a further dimension to knowledge within this field.

During local PR programmes in Worcestershire, the majority of patients that report difficulty in adherence to lifestyle change particularly exercise, blame it on poor motivation. Many patients communicate to us that their own motivation is crucial to achieving behaviour modification in respect of exercise and that they feel unable to make or continue this lifestyle change unless they have the 'motivation to do so'. During group discussions motivation is often cited as the precursor to adherence. Discussions about circumstances that adversely affect motivation are common. Patients report that the exercises are easy to maintain within the group setting, but when the programme ends motivation is lost and physical activity declines. For the person with COPD the lifestyle changes advocated within PR can often be very radical, given the enormous amount of physical de-conditioning that has normally occurred by the time they are referred for a programme. Patients have often spent several years avoiding activity on an increasing scale, as they fear the breathlessness that accompanies it. In the space of a PR programme, this behaviour and belief must be reversed in order for them to start increasing exercise tolerance. Although PR staff locally have no formal psychology skills or training, we continually educate and discuss with the patients the reasons why breathlessness on activity is not dangerous. It is our experience that patients appear to gain faith and trust in the PR staff and their confidence grows in their own ability to exercise. The patients' behaviour changes and they start to follow their exercise plan and their belief has changed because they realise that exercise is not actually bad for them but it is in fact very effective. Anecdotally patients and staff report this process as related to the patients' motivation. Their perception of this concept appears to be that motivation is about having an impetus to exercise and attend PR.

Patient comments about the importance of motivation are made far too frequently to ignore the possibility that motivation plays a key role in achieving lifestyle change in COPD. It is clearly also the opinion of COPD experts that this is the case. In order to

establish an optimum method of facilitating behaviour change within a PR programme it is important to understand factors associated with uptake, adherence and maintenance of the health behaviours advocated within a programme. If PR staff had a better understanding of factors that influence motivation, and the role of motivation within a programme, then this would potentially enable us to develop interventions that increase exercise adherence. Motivation may be an important factor in patient adherence within a PR programme and this notion provided the impetus for this research project.

1.8 Summary

This chapter has described the purpose, scope and context of the research and an overview of COPD and its management. An outline description of pulmonary rehabilitation was given and how it has been shown to have significant benefits to both the patient's health status and use of NHS resources. The problem of adherence in pulmonary rehabilitation was also discussed, along with how patients often refer to motivation as a big problem during and after a PR programme. The frequent reference to motivation by PR participants and seemingly lack of information about this topic provided the impetus to explore the role of motivation in PR.

CHAPTER 2 - LITERATURE REVIEW.

The previous chapter concluded that adherence is an important issue within pulmonary rehabilitation (PR) and that motivation may be an important factor that contributes and impacts on a patient's ability to adhere. The purpose of this chapter is to further explore this issue using the available literature relevant to motivation within the context of a PR programme. An exploration of the meaning of motivation within the health psychology literature is made, describing the social-cognition models and the exploration of motivation as part of a process. Research that has already been undertaken within the field of PR is discussed, along with the emerging recognition of a theory – practice gap between health psychology research and current clinical practice. Finally an argument is also made for a new motivation measurement tool for use in PR programmes.

2.1 Defining motivation

A review of the literature in pursuit of the meaning of motivation reveals many differing explanations of the concept of motivation, but not one unifying definition. It is evident within the huge body of literature about motivation that there are different approaches, interpretations and levels of understanding across the various disciplines and specialities. This was also the finding of Plonczynski (2000) when conducting a systematic literature review of the measurement of motivation for exercise. This literature review arrived at no interdisciplinary consensus as to the meaning of motivation. The author goes on to argue that the lack of a single definition of motivation slows progress in the field of exercise motivation in general. Many authors from different professional groups provide their own descriptions of motivation that have been arrived at from the author's own interpretation of the literature. For example, Davies (2007) describes motivation within the context of health behaviour change as a person's 'intrinsic determination or self-motivation'. A similar view is taken by Gifford and Groessi (2002) who present motivation as 'the readiness to change and maintain behaviour'. A unique interpretation of the meaning of motivation is presented by Plonczynski (2000), who defines motivation as the intrinsic determination towards goal attainment. The literature has been interpreted differently by Davies (2007), who argues that goal setting is merely one component of motivation. It is possible therefore, that the meaning of motivation is contextual and

within each speciality where motivation is important, a unique interpretation and application of the concept may be required.

2.1.1 Understanding motivation: What can be learnt from health psychology?

In an effort to understand the meaning of motivation within the context of PR, it is necessary to explore the wider picture of human health behaviour. It is argued that in order to understand health behaviour, we need to examine what underpins it (Forshaw 2002) and this is addressed within the science of health psychology. Fundamental to health psychology, is the person's perception of illness and health (Marks et al 2005). Health psychology is about the understanding of relationships between mind and body, behaviour, life experience and the social and circumstantial context of the person's life (Forshaw 2002). It is possibly an assumption that health psychology is an exclusive science, mainly accessed and contributed to by the psychology profession. However, because the science encompasses physical, cognitive, social and circumstantial factors, an interdisciplinary approach is required (Marks et al 2005). The authors promote this in their working definition of health psychology as follows:

“An interdisciplinary field concerned with the application of psychological knowledge and techniques to health, illness and healthcare”.

Because health psychology explores the complex relationships between mind, body and the context of the person's life, the science may offer further understanding of motivation within a PR programme.

Important historical models of motivation have been frequently used as frameworks for understanding the underpinnings of health behaviour. They are known as social cognition models (Marks et al 2005) and can be broadly summarized as presenting motivation as a collection of attitudes, beliefs and self-confidence. Whereas there still exists no universal definition of motivation, the theoretical frameworks, and subsequent adaptations of them, have been used in order to describe and explain its attributes. The social cognition models have been shown in a limited way, to denote the degree to which the person would adhere to the behaviour change. They have been applied across a range of specialities with some success (Armitage and Conner

2001), but also with some failure (Kaplan et al 1998). The main social-cognition models include: The Theory of Planned Behaviour (Ajzen 1985 and Ajzen 1991), the Health Belief Model (Becker 1974), Social – Cognitive theory (or Self-Efficacy theory) (Bandura 1977 and 1986), the Self-Regulatory model (Leventhal et al 1980) and the Stages of Change model (Prochaska and DiClemente 1983).

The Health Belief Model

The Health Belief Model (HBM) (Becker 1974) is believed to be one of the most important bodies of work in this area (Forshaw 2002). The HBM purports to predict the likelihood that a person will engage in a health behaviour according to their perception of 6 themes. These themes are: The costs and benefits of the behaviour, the severity of the threat posed to health by not undertaking the behaviour, their susceptibility to the threat and any internal or external cues to action. A further development of the HBM is the protection motivation theory (Rogers 1975). This model presents the theory that people are motivated to protect themselves by acting to preserve health. The person evaluates the health threat using 3 factors: fear, perceived severity of the threat and perceived vulnerability to the threat, and also their own ability to cope with the threat (self efficacy and response efficacy). The HBM has been revised over time with other variables added to the model (Marks et al 2005). There is mixed evidence about the ability of the HBM and PMT to predict health behaviour. In a study by Kanvil and Umeh (2000), the health cognition factors presented in the HBM and PMT only explained 3% of intention to smoke cigarettes. Yet when past behaviour was added to the regression model, this increased to 70%. Therefore past behaviour is possibly a component of motivation which is not encompassed by the HBM. An argument in support of the view that these 2 models are not providing a comprehensive framework of motivation is made by Forshaw (2002).

The Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) (Ajzen 1985) is an adaptation of the theory of reasoned action (Ajzen and Fishbein 1980). It presents the notion that perceived behavioural control affects behavioural intentions, moderated by a person's subjective norms and attitudes (Forshaw 2002 and Marks et al 2005). There has been criticism of the TPB that like the HBM, it over-emphasizes cognitive factors within the model

(Marks et al 2005). When authors have added additional variables to the model such as behavioural control (Godin 1994) and anticipated regret (Abraham and Sheeran 2004), the predictive power of the model was increased. Again this is indicative that the illness perceptions presented within the original framework provide a component of motivation rather than a comprehensive explanation of the concept.

Social –Cognitive Theory

Bandura's social – cognitive theory (Bandura 1986) is one of the most commonly – used theories to explore behaviour change in physical exercise (Umstattd et al 2006). This theory focuses on self-efficacy and presents the argument that the person's perceived mastery over a behaviour determines adherence to that behaviour (Marks et al 2005). The theory explains the interactions between behaviour, intrapersonal factors and the context of the environment (Bandura 1986). It has been described as the primary mediator of behaviour change through cognition (Plonezynski 2000) and it is widely supported that self – efficacy contributes towards sustaining motivation (Bandura 2001 and Vittorio and Steca 2006), as people do not undertake behaviour they feel they are incapable or that they do not think will produce results. This is observed informally within clinical practice, where many patients entering PR initially believe that breathlessness caused by exercise occurs as a result of their lung damage and it is bad for them. During the process of rehabilitation the participant comes to realise that the breathlessness during exercise is a natural, normal physiological response that is within their control. This change in the perception of breathlessness appears to elicit an increased zeal for exercise and a more optimistic view towards their condition as they realise improvements can be achieved. There is evidence within the literature that self- efficacy plays a significant role in both exercise and physical activity in general (Rimel 2001 and Sallis et al 1988). It has been shown to predict adherence to physical activity in cardiac rehabilitation (Luszczynska and Sutton 2006) and be determinant of exercise behaviour in the elderly (Resnick and Spellbring 2000).

Within PR, there is a growing interest into the role of self- efficacy, as self-efficacy is becoming more recognised as an essential part of the management of patients with COPD (Bourbeau 2007). In recognition of its' importance, Wigal et al (1991) previously developed a disease-specific COPD self-efficacy scale. Furthermore, in

the ATS / ERS statement on PR (Nici 2006), the importance of self- efficacy is promoted within programmes. Authors are increasingly exploring self-efficacy within studies. For example, a study by Arnold et al (2005) demonstrated a relationship between self-efficacy and physical functioning in COPD. Another series of studies demonstrated that self-efficacy increased in COPD patients attending PR (Scherer and Schmieder 1996 and 1997 and Scherer et al 1998). However, self- efficacy alone may not represent motivation per se within the context of a PR programme. In support of this is a study by Ries et al (2003) which explored the effectiveness of a post PR maintenance intervention aimed at maintaining the benefits of PR. The intervention group showed a modest success at maintaining the benefits of PR compared to the control group. Self- efficacy was measured during this study and there were no differences in change between the intervention group and control group. In another study, self – efficacy was not found to be a predictor of drop out from a PR programme (Garrod et al 2006). It could be argued therefore that there are other cognitive components in addition to self –efficacy that moderate the effectiveness of interventions that enhance adherence to exercise. It is possible that self-efficacy does not define motivation, but that it is a single component of motivation.

Self-Regulation

The self-regulatory model (Leventhal et al 1980) is concerned with beliefs about illness and it has undergone an amount of elaboration and development over the years (Marks et al 2005). Compared to Bandura’s social – cognition theory (Bandura 1986), self-regulation has received very little study (Umstattd 2006). Some authors have interpreted motivation as synonymous with self-regulatory behaviour (Caprar and Steca 2006) and Bandura (1986) describes self-regulation as the personal regulation of goal directed behaviour. The Self – Regulatory model describes how a person adjusts dynamically to the new situation of illness by using problem solving (Marks et al 2005). The information (or givens) that the person uses to convert into solutions have been classified by the authors into: (1) identity (or diagnosis of illness), (2) perceived cause, (3) time line (or prognosis), (4) consequences of the illness, (5) control and cure of the illness. The first stage of the model is the interpretation of the given information by the person and the emotional response evoked, which in turn feeds back into the interpretation (Forshaw 2002). This emotional response may cause the person to adjust and modify their original interpretation of the information

given about their condition. An example of this in COPD is when patients reach a point where they require oxygen for ambulatory purposes. This often evokes fear in patients and this emotional response causes them to amend their original cognitions about the disease time line. This is demonstrated when many patients announce that they believe oxygen is the 'end of the line' or the 'beginning of the end'. Many fail to see that the oxygen will actually enable them to improve their functional capacity, and consequently their quality of life. The second stage of the model is concerned with the actual behaviour change itself. The third part of the self- regulation model is appraisal of the behaviour change, where the person maintains or changes the behaviour in response to the perceived impact it has made.

Umstatted et al (2006) highlighted the fact that previous studies showing self- regulation as a predictor of physical activity had only been undertaken in middle aged and young populations. The authors undertook a study examining correlates of self- regulation in older adults. They studied a convenience sample of 296 older adults on a generic 'active for life' programme. This was a fitness programme for adults over the age of 50 years. A series of self-report measures were used that quantified self- regulation, self-efficacy, social support and physical activity. Data was also collected on sociodemographic and health related characteristics. Correlation and regression analyses were used to explore relationships between variables. The results demonstrated relationship between self-regulation and education, income, BMI, health status, self-efficacy, social support and physical activity. The authors suggest that although constructs such as self-efficacy can influence the decision to participate in exercise, self-regulation is necessary for the decision to be made.

Transtheoretical model of change

The Transtheoretical model of change (or stages of change model) was originally developed by Prochaska and DiClemente (1983 and 1984) in order to explain smoking cessation behaviour. The Stages of Change Model went a step further than previous social cognitive models. This model went on to present behaviour change as much more of a process, where decision- making links the motivation to the behaviour change. Aspects of the model have been used as a basis for motivational interviewing (Hettema et al 2005, Rollnick et al 2000 and Miller et al 2003), where motivation is presented very simply as a person's 'readiness for change'. Although

the model was developed to explore smoking cessation behaviour, it has shown some utility within a PR programme. A study by Yang and Chen (2005) successfully investigated the use of the Stages of Change model (Prochaska and DiClemente 1983) to help with PR programme planning. By assessing at which stage of change the patient was (i.e. contemplation, pre-contemplation, readiness) the authors found they were able to prescribe a more appropriate level of physical exercise.

Applicability of the social cognition models to PR

Although the social cognition models described above are able to explain some of the behaviour modification within a PR programme, they may not be comprehensive enough to provide an adequate framework to describe motivation in its' entirety. It has been argued that these models of motivation contain only a component, but not the overall conceptualisation of motivation (Plonczynski 2000). The models tend to focus on cognitions and do not consider the domestic, social or circumstantial contexts in which illness beliefs are expressed (Marks 2005). In PR programmes, patients often refer to external factors that they feel influence their cognitions related to exercise. Problems such as car parking, other group members and lack of spouse encouragement are some of the factors cited as causing a reduction in motivation. Alternatively, factors such as likeability of PR staff, the weather and seeing others with more severe disease have been presented as causing an increase in motivation. Supporting evidence of this is found in a study by Taylor et al (2007). The authors were investigating the reasons for poor recruitment of patients asked to take part in a PR study. They interviewed a sample of the 120 patients out of 297 suitable patients who declined to participate in a previous study. The findings were that despite a negativity associated with a lack of understanding of the research itself, factors such as travel to and location of the programme, and competing commitments were significant in the lack of participation. It could be argued that such factors are barriers to compliance rather than cognitive components of motivation. However, in practice, PR patients consistently describe how these practical issues affecting their motivation. Therefore they cannot be discounted as a possible facet of motivation within the context of PR. The problem with the social cognition models is that although many of the cognitive processes described appear to be applicable to a PR programme, there are many non-cognitive variables, unique to this group of patients, examples of which are given above, that may be missed. The predictive value of these models within PR

may not be strong as only a limited amount of the variance would be explained. This would possibly compromise sensitivity to change, an essential component of any exploration of motivation in the context of PR.

Motivation as part of a behaviour change process

One of the features of the social-cognition models is that they have a common theme that remains current. That is, motivation is a process interrelated with many variables that contribute to a person's personality. Therefore, motivation cannot be explained in a concise definition. It emerged from some of the literature that current thinking within health psychology study is that motivation is not the immediate precursor to behaviour change (Sniehotta et al 2006). It is suggested within the literature that health behaviour change is a process of which motivation is a part (Annesi 2002). Three components within this process were identified. The process begins with a cognitive status (often described as intention), moving through action control and then on to self-regulation in order to achieve the behaviour. An example of this is Sniehotta et al (2006), who argues that the social cognitive models do not elaborate on the post – intentional phase of the change process. In other words, there is no link between intention and action. The authors suggest that adding post intentional constructs will improve the predictive power of these models and that research should focus on mechanisms which occur following a behavioural intention. Sniehotta et al (2006) collectively describe these mechanisms as action-control. In this paper a study was conducted that explored the interplay of behavioural intentions, action control and adherence to exercise in 122 cardiac patients for the first two months following discharge from a cardiac rehabilitation programme. The authors found that action control was pivotal in predicting changes in both behavioural intentions and physical exercise changes. This emerging link between motivation (intention) and action is supported by other authors. Social Cognition theory (or self- efficacy theory) (Bandura 1986) presents cognition as the start of a process that facilitates and motivates people to make health behaviour change. Appropriate goal setting is a key component of Social Cognition Theory, and is associated with people achieving their specified goals (Davis, 2007). The process continues with attainment of goals providing further motivation to continue with the health behaviour that has led to success.

Motivation emerges therefore the precursor to action control. Although health psychology research is now clearly focussing on action control and self-regulatory mechanisms, motivation still remains important. Sniehotta et al (2006) found using regression analysis, that action-control predicted exercise behaviour over and above behavioural intention. This possibly supports the notion that behaviour change research is better focused on action control rather than initial motivation status. However, the authors go on to argue that behavioural intention is crucial for the self-regulation of behaviour.

This process of motivation, followed by action control and then goal attainment may actually operate as a cycle in PR, with goal attainment having an impact on initial motivation. Within clinical practice, patients describe their motivation as being very dynamic, for example affected by the weather or their degree of breathlessness. They also describe how when they start to notice improvements in functional ability this 'motivates' them to exercise more. We observe that patients who have little motivation at the outset of a PR programme often build motivation as the programme progresses. Self-regulatory theory gives this notion theoretical support. In self-regulatory behaviour, an aspect of the theory is that adherence to a health behaviour is influenced by the perception of the impact of this behaviour. Patients see that the exercise programme is having a positive effect on their health and this encourages them to continue to exercise

2.2 Motivation may be a factor in adherence to a PR programme

The motivation process of intention, self-regulation and goal attainment described within health psychology literature appears to give a theoretical explanation to the behaviour observed within PR. It also supports the view that motivation has a significant role in PR and may be a factor in patient adherence.

There does exist an amount of research within the specialist field of COPD, about motivation and factors that are related to motivation, that strengthen the argument that motivation is related to uptake, adherence and maintenance of exercise in PR. For example, a study by Cuenco (2003) examined adherence to exercise in patients with COPD, although this was not within the context of a PR programme. The findings of the study were that motivation predicted adherence, and that the more adherent the

patients were to the exercise programme, the better the benefits of exercise were. From this finding a reasonable assumption can be made that motivation would also be able to predict adherence within a PR programme.

The findings of a number of other studies support the significance of motivation within a PR programme (Davis 2007, Davis et al 2007, Arnold et al 2006, Fisher et al 2007, Kaplan et al 1998, Young et al 1999, Scherer and Shmeider 1997, Breukink 1998 and Yang and Chen 2005). Although none of these studies have explored motivation per se, each have explored factors that are possibly related to motivation. In these studies the authors appear to have made a slightly different interpretation of the concept of motivation according to the aims of the study. An example of this is the qualitative study by Fischer et al (2007). In this study, the patients' perspective of participation and drop out in PR was analysed. Semi-structured interviews were conducted with 12 patients in their home prior to the rehabilitation programme. Patients were asked about their beliefs regarding a PR programme and about what goals they hoped to achieve. They were also asked about what circumstances would make it difficult to complete a programme. Results showed there were four key attitudes towards participation in a PR programme: (1): optimistic, (2): 'wait and see', (3): pessimistic and (4): sceptic. There were 2 patients who 'dropped out' of the PR programme, and these patients were the only 2 who had been categorised as 'sceptic' towards participation. A limitation of this study is the sampling strategy. Only 12 patients were interviewed and these were consecutive referrals to the PR programme. Although the author gave details of disease severity that appears to be across the spectrum, there is no information about other variables that may affect attitudes and beliefs about drop out. For example, oxygen therapy may pose a barrier to attendance, or demographic variables. It is difficult to accept that a sample of 12 would be enough to capture the spectrum of data. Interviews were only conducted prior to PR and then 3 months following the programme. Data about patients' feelings towards drop out during a programme was not collected. Variables such as exercise intensity, which impacts most prominently during the programme itself, may have affected patients' attitudes and beliefs. It is therefore possible that the data does not reflect the comprehensive picture of patients' perspectives. It is possible that if interviews had been conducted at different stages during the PR programme this would have added to the reliability of the results. The authors admit that purposeful

sampling may have increased reliability, but also argue that the sample has more clinical validity since it reflects a real PR group. An important aspect of this study is that the data about influences on adherence has been extracted from the patients themselves, rather than applying theory from an existing generic motivation framework.

Another element of motivation that has been studied in the PR literature is goal-setting. Davies (2007) suggests that because a key function of exercise adherence is for people to improve their function within their everyday life, goal-setting may be an important determinant of exercise motivation. . It is evident that if goal setting is appropriate, realistic and purposeful then this will enhance motivation (Gifford and Groessi, 2002), but if goals are unrealistic or poorly defined, then motivation weakens (Resnick, 2002). Davis (2007) undertook a study to determine the relationship between motivation and goal orientation in people with COPD and also to explore their goal-setting behaviour. This was a prospective, cross-sectional study using a convenience sample of 14 people with COPD. Patient's motivation was measured along with their goal orientation. Participants were also interviewed about their exercise and activity goals using semi-structured questions. The results of this study showed that there was a relationship between motivation and goal orientation scores, with a higher motivation associated with a greater goal orientation score. It is of note that the interviews showed that patients were able to describe readily their activity goals, yet participants had difficulty identifying clear exercise goals. This calls into question the validity of the measure used in this study as goal orientation was measured as high in this sample when the participants were clearly not completely goal orientated during interview. The study demonstrated that even with a very small sample size that there is a relationship between motivation and goal-orientation in people with COPD. The author has hypothesised, based on the theoretical framework of Bandura's Social-Cognitive Model (Bandura 1986), that goal-orientation will be related to motivation in patients with COPD. Therefore, interview questions were structured to elicit information from the patients specifically about goal setting. However, patients with COPD have their own unique problems to face in maintaining exercise and goal setting may not be the only factor in motivation within this patient group. The interviews did not allow for the capturing of data regarding additional

influences on motivation, therefore this study may not give a comprehensive reflection of motivation.

2.2.1 The Theory-Practice gap

The evidence suggests that motivation is an important factor in a PR programme, and guidelines and COPD specialists recommend that it should comprise a PR assessment. However there is very little guidance or information about how staff can apply this to clinical practice and facilitate motivation with the patients. Added to this is the lack of consensus about the meaning of motivation. Most PR programmes are co-ordinated by physiotherapists or nurses, who generally have not had any psychology training. Furthermore, if motivation is to be included as part of a PR assessment, there is no indication of whether there are levels of motivation and 'how motivated' exactly does the patient need to be in order to gain entry to a programme? If PR staff had a better understanding of motivation in patients undergoing a PR programme, it may be possible to manipulate motivation to elicit improved outcomes. There is very little information available to show how PR staff can promote behaviour change. A paper by Rollnick et al (1993) discusses how healthcare practitioners generally receive very little or no training in this skill. Godin (1994) has previously acknowledged this problem and argues that in order to optimise a PR programme it is imperative that staff have an understanding of the factors underlying exercise and lifestyle behaviour. In some areas of the UK clinical psychologists are involved with PR programmes and can provide expert assessment and building of motivation (Personal communication, Plymouth PR team 2001). Employing psychologists as part of the PR multidisciplinary team to facilitate the application of behavioural research to clinical practice is costly. Many rehabilitation programmes have previously struggled to secure funding for even the most basic team. Many PR programmes in the UK are not funded at all (BTS/BLF 2002) and are not privy to psychology input. Instead they rely on the expertise of the remaining PR team, who may have very limited knowledge of psychological issues.

Within PR programmes in the UK, development of a cognitive-behavioural component appears to be slow in progression. It is possible that PR practitioners, with poor experience of health psychology language or the study of cognitive processes, fail to see the practical application of theory to clinical practice. For example, in a

paper by Caprara and Steca (2006) which studies self-regulatory efficacy beliefs, the authors refer to:

“self-referent processes that arrest to the functioning of an integrated self-system capable of conferring unity, coherence , continuity, and directedness to the individuals’ actions and behaviours....”

Arguably, such language is alien to everyday PR staff and is possibly a barrier to applying the psychology research to practice. The health psychology literature on health behaviour change appears far more academically advanced than presentation of the topic within respiratory medicine literature. Another example of the language barrier is illustrated clearly in the following papers. In a social psychology journal, Sniehotta et al (2006, p89) describes health behaviour change as:

‘an interplay of awareness of standards, self-monitoring and self-regulatory effort partly mediating the influence of intentions, action planning and self-efficacy’.

Whereas Davis (2007), in a nursing rehabilitation journal, when discussing adherence suggests simply that:

‘motivation is an important factor that can enhance exercise adherence’.

This example demonstrates a clear difference in the levels of understanding of motivation between the 2 disciplines and this would possibly prevent important research findings being applied to practice. It is acknowledged that there is a gap between research findings within the health psychology literature and clinical practice in general (Prohaska et al 2003).

Prohaska et al (2003) have looked at this problem and make a number of suggestions in order to bridge the gap between behavioural research and clinical practice. These include teaching health psychology researchers to write up their research for consumption by clinicians and increasing the publication of research findings in journals read by practitioners. Some health psychology academics have made an effort to bridge the gap between the research and clinical practice. Rollnick et al

(2000) have taken the theoretical underpinnings of health behaviour change and presented the theory in a way that healthcare professionals can make a practical application of the knowledge within a clinical setting. The practical guide that has been produced by these authors is the result of collaborative working between a clinical psychologist, a GP and a nurse. Health psychology is advocated as an interdisciplinary science (Marks et al 2005) and there is also a desperate need within PR to use the findings of behavioural research to develop and enhance programmes. It is clear therefore that there needs to be further integration and understanding of health psychology within the field of PR and a more continual 'feedback loop' between research and practice (Prohaska et al 2003). Additionally, it would be helpful in the future to arrive at a unifying theoretical framework for use in exercise motivation (Plonczynski 2000) in order to reduce the theory – practice gap.

2.3 Why do we need a measure of motivation in pulmonary rehabilitation?

It is the opinion of experts within COPD that motivation is important and should be assessed within a PR programme (Nici et al 2006, Morgan 1995 and 2005). However, no objective direction is given within any of the international guidelines about what methods should be used to assess motivation or how the concept should be defined. In PR programmes, patients' attitudes, beliefs and goal-setting behaviour have been shown to be important (Arnold et al 2006 and Fischer et al 2007). Being able to quantify and measure these components of motivation within the context of a programme would enable the advancement of our knowledge of this topic. Yet where papers have examined drop out or adherence in PR, motivation specifically has not been explored (Garrod et al 2006, Cote and Celli 2006 and Young et al 1999). Motivation may be easier to manipulate than physical and demographic predictors of adherence in PR. Therefore, if we have a better understanding of its' role within a PR programme this may enhance our ability to elicit better patient adherence (Fischer et al 2007). It is possible that motivation has previously not been readily explored because there does not exist a measure that has been designed specifically for use in a PR programme. It is possible that the reason self-efficacy has been explored in PR programmes (Garrod 2006 and Arnold 2005) proportionately more than other cognitive variables is that there exists an 'off the shelf' disease specific measure of this concept. Whereas the reason motivation has not been explored so readily is

possibly that there is no such disease specific measure to date. Indeed it has been demonstrated that in exercise motivation on the whole there is a lack of psychometric reporting (Plonezynski 2000). If it was possible to objectively measure motivation within the context of a PR programme then this would enable quantitative study of motivation and any associations with uptake, adherence and maintenance within PR programmes.

2.3.1 The need for a new, disease-specific measure of motivation

Existing measures of motivation may not be the most appropriate for use in a PR programme, firstly because of issues with validity and reliability and secondly because a context-specific measure may be more appropriate. Plonezynski (2000) undertook a systematic literature review of measures of motivation to exercise. Inclusion criteria were papers that studied a population of healthy adults and studies that utilised a motivation measurement tool. A total of 22 studies met the inclusion criteria. Out of these 22 studies, the author shows that only four measurement tools demonstrated both reliability and validity and suggests that based on these results, current knowledge of exercise motivation is underdeveloped. Generic motivation measures (Sackett and Haynes 1976, Oldridge and Streiner 1990, Wallston et al 1978) that may be good for general use may present problems for specific populations (Forshaw 2002). Health status measures that are developed for a specific purpose have been shown to be more sensitive and responsive than generic measures (Moretti et al 2005, Anderson et al 1997 and Ware et al 1998). No measures were found that have been specifically developed for use within a PR programme. The comprehensive review of motivation exercise tools by Plonczynski (2000) demonstrated that many measures are not operationally linked to concepts, so any new measure of motivation, therefore, must be linked a theoretical framework.

People with COPD attending a PR programme may experience different factors affecting motivation and self-regulation in exercise adherence than other populations. For example, breathlessness during activity, oxygen usage and respiratory symptoms such as coughing may add a different dimension to other populations. This is a view supported by Davis et al (2007) who found patients with COPD had unique problems compared to different populations in the study of exercise adherence. Whereas other

studies of older adults (Resnick and Jenkins 2000 and McAuley 1992) showed that factors such as 'interest' or 'dislike of the activity programme' were significant, Davis et al (2007) found that COPD patients did not share these concerns. Indeed, the COPD patients in that study had unique problems, which included breathlessness, oxygen usage and money worries. The authors suggest that individual self-regulatory efficacy may vary across health conditions and depend on the nature of the difficulties presented by a condition. This is supported by Ware et al (1998). In this study, 18 asthma- specific and generic quality of life scales were tested in order to evaluate their validity in relation to changes in asthma severity and treatment impact among adult patients. Although they found that both sets of measures produced reliable and valid results, the disease specific measure was more sensitive and responsive than the generic measures. In order to evaluate any change in motivation during the PR process, a measure would need to have the sensitivity to detect small changes. It is possible that existing measures would underestimate any change due to a lack of responsiveness, whereas a measure developed specifically around a PR programme may encompass domains that would be missed in generic measures. This view is also supported by other authors (Kaplan et al 1998 and Lareau et al, 1994).

In further support of developing a new specific motivation measure, is the fact that some disease specific physiological factors may either affect, or partly comprise the motivation of the patient attending a PR programme. Such factors may be disease severity and breathlessness. Disease severity in COPD is classified using the measurement of forced expiratory volume in 1 second (FEV1) (Rabe et al 2007). An example that motivation in PR may be affected by these unique factors can be found in a study by Breukink et al (1998). This study concerned physical activity rather than exercise. The study demonstrated a relationship between the dimensions of subjective fatigue and physiological variables including FEV1. Fatigue was measured using the Multidimensional Fatigue Inventory (MFI) 20, (Smets et al 1995), which includes 5 subscale dimensions: general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue. The dimensions of reduced activity and reduced motivation showed a significant correlation with FEV1 ($r = -0.62$. $r = -0.55$ respectively). The authors of this study suggest that the debilitating cycle in patients with COPD of impaired lung function, activity limitation and fatigue may have a negative impact on the motivation to carry out daily activities. In the same study,

motivation did not correlate with respiratory muscle function, exercise capacity or skeletal muscle strength. Likewise, breathlessness, occurring as a result of a reduced lung function, may also be related to motivation in PR. Within the study previously described (Breukink et al 1998), a relationship was found between the motivation component of the MFI20 and breathlessness during exercise in COPD patients. The authors suggested that motivation to carry out life activities may have been reduced because of the associated symptom of breathlessness. Also, less motivated patients may have an increased sensation of breathlessness during exercise. The suggestion that there is an association between breathlessness and motivation is also supported by Scherer and Schneider (1997). They examined the effect of PR on self-efficacy, dyspnea perception and physical endurance in patients with COPD. One of the findings of the study was that there was a correlation between self-efficacy and dyspnea, and self-efficacy and exercise endurance. The authors suggest that improvement in self-efficacy may decrease the patient's perception of breathlessness and increase exercise endurance. Additionally, Morgan et al (1983) found that subjective perception of exertion was correlated with exercise tolerance.

There has recently been developed a COPD motivation measurement tool although this was not developed within the context of a PR programme. Davis et al (2007) developed and validated a 16-item Exercise Self-Regulatory Efficacy Scale (Ex-SRES) for people with COPD. Items for the scale were extracted from interviews conducted with COPD patients who were asked to identify factors influencing their adherence to exercise. The questionnaire was administered to 109 patients with COPD. The questionnaire showed high internal consistency with a Cronbach's coefficient alpha score of 0.917 and evidence of validity as the Ex-SRES correlated with a quality of life measure and exercise behaviour. There are a number of limitations of the Ex-SRES that potentially make it not a good choice for using it during a PR programme. First, test-retest and sensitivity to change was not explored in the reliability testing of the Ex-SRES (Davis et al 2007). In a measure to be used within a PR programme, it is essential that an instrument must be demonstrated to be sensitive to change in order to detect any changes in motivation before and after PR. Furthermore, the effect of completing the questionnaire itself may change the phenomena being measured, which is a well known problem in social science (Frankfort-Nachmias and Nachmias 1996). Secondly, the Ex-SRES can only be

generalised to people with COPD, since it was from this population that the questionnaire items were developed. In PR, although the majority of patients have COPD, patients with other chronic lung conditions are also integrated. Therefore, a measure needs to be developed where data has been obtained from the population of patients who attend PR. These may include pulmonary fibrosis or even lung cancer. Just as patients with COPD have their own unique problems which impact on motivation, patients with COPD who attend a PR programme also may have specific problems. For example, the notion of being in a group, travel to the programme and the effort involved in attending the sessions may adversely affect motivation. Many patients complain verbally about the de-motivating effects of the winter months, when exacerbations of their condition are rife. If so, these specific factors would not be taken into consideration in a more general self-regulatory measure, making it a less sensitive measure. A new measure is needed therefore, linked to the specific and unique problems of people undergoing a PR programme.

2.4 Chapter summary.

The literature supports the view that motivation is a multifaceted, dynamic, bio-psycho-social and contextual concept that has been interpreted in a number of different ways. Motivation is the first stage in a health behaviour change process that may be a cycle. There is a theory –gap between the health psychology research findings and clinical practice and more knowledge of motivation is needed in the field of PR. In order to further investigate the role of motivation within PR a measure of motivation is required. Since there is no universal definition of motivation, and that patients attending PR programmes have unique problems that may affect their motivation, it is appropriate to develop a new measure. Such a measure must be linked to factors perceived to influence their motivation in the context of PR.

CHAPTER 3 – IDENTIFICATION OF FACTORS
AFFECTING MOTIVATION

This chapter describes the first study in a series designed to explore motivation within the context of pulmonary rehabilitation (PR). The design, methods and results are presented, along with a discussion of the findings.

3.1 Background

The literature review provided some information about the role of motivation in pulmonary rehabilitation (PR) programmes. Yet a number of questions remain about the importance and contribution of motivation to outcome and adherence within a programme. It was demonstrated that since many patients either decline or drop out of a PR programme, and that it has been shown to be such an effective intervention, this problem needs to be addressed. A better understanding of motivation, which both patients and PR staff believe locally to be such an important component, may help to make PR programmes more effective. For example, if we knew that motivation at the outset of a PR programme was related to drop out, then this would help to identify patients who are likely to drop out and enable staff to put increased effort into building their motivation. Likewise, if we knew that motivation increased during PR and was also related to other important variables, then motivation could be manipulated to improve outcome. In order to explore any of these ideas it is necessary to produce a context – specific motivation measure that is theoretically underpinned. In the literature review an argument was made for developing a new, specific measure for use in PR programmes. It was shown how patients attending PR programmes may have unique issues which may be pertinent to their motivation. It was argued that a measure that is developed using data specific to that population would be more sensitive to change. Since its' main purpose would be to measure motivation before and after a programme then sensitivity to change is an essential requirement.

The literature review also demonstrated that there are some generic facets of the available motivation theories that can help us to understand motivation within a PR programme. However these may not encompass all the components of motivation within the context of PR, as they tend to focus on mainly cognitive constructs. As discussed in the previous chapter, in our experience, patients talk about specific practical and physical issues that impact on their motivation, and these are not

encompassed within the social-cognitive theories. It was decided that the best source for gathering data about motivation in the context of a PR programme was from the patients who had actually had this experience. Data was needed from the patients regarding their views and beliefs about motivation in the light of their personal experience of PR. Evidence of collecting data directly from the study population is found within other studies where measures of health status for COPD were constructed (Davis et al 2007, Garrod et al 2000 and Jones et al 1991). In these studies, the perceptions, attitudes, beliefs and experiences of the patient group under study were used to construct valid questionnaires pertaining to health status. Collecting data from the participants themselves would ensure that the final measurement tool was based on their perceptions of motivation and therefore add to the validity of the instrument.

The results of this preliminary study would be used to generate the semi-structured questions for the patient interviews to be conducted in the subsequent research. The social-cognitive models of motivation previously developed and discussed in the previous chapter provide some theoretical explanations of processes occurring within motivation. Within the capacity of this study, the intention was not to develop a new model, but to provide some data about factors relating to motivation in PR from the point of view of the patients who had been privy to that experience. In order to provide such data, it needed to be extracted from patient's own experiences and attitudes to ensure that any final measure would be a valid one. A study was therefore designed on the basis of these ideas with the overall aim of developing a motivation measurement instrument specific to PR. The objective of this study is as follows:

To explore COPD patient's beliefs, interpretations, norms, ideas and understandings about motivation within the context of PR and also their experiences of factors which have influenced their own motivation either positively or negatively.

3.2 Research Design

In order to fulfil the research objective, the research design needed to be exploratory, or inductive, in its approach. The objective was concerned with generating rich data, rather than testing a hypothesis. Hence, a qualitative, rather than quantitative design

was selected for the study (Frankfort – Nachmias and Nachmias 1996). Human behaviour, which incorporates motivation, is a highly complex topic. Motivation in the context of a PR programme was considered by the author to be classified as a phenomenon that needed to be understood in more detail to inform the construction of a measurement tool. The approach to this study that was therefore chosen was phenomenology (Heidegger 1962, cited in Darbyshire et al 1999 and Koch 1995). The purpose of phenomenology is to uncover the essence of a phenomenon as experienced by a sample of people (Polit and Hungler 1996). It aims to reveal the phenomenon to which meaning is being attached (Wimpenny and Gass 2000) by exploring the lived experiences of people and the perceptions to which those experiences give rise, based on the person's own interpretation of those experiences (Polit and Hungler 1996). Phenomenology therefore appears to be an appropriate research approach for studying patients' contextual experiences of motivation, since patients would be able to discuss their own perceptions of the meaning of motivation within the context of their experience of PR

Some authors have raised concerns about the use of phenomenology in nursing research, claiming it has lacked consistency therefore leading to a lack of research rigor (Crotty 1996 and May 1991). Although the views of Crotty are refuted by Darbyshire et al (1999). Concerns have generally arisen because of a number of different methodological interpretations of phenomenology (Paley 1997). However, where there appears to be consensus is that there are 4 steps to a phenomenological study, although in other papers the process is described in only 3 stages (Maggs – Rapport 2000). For the purposes of this study, the 4 steps used were taken from Polit and Hungler (1996). The first step, *bracketing*, is about the researcher acknowledging and putting to one side any preconceptions or opinions about the phenomenon in an attempt to not bias the data. Secondly, *intuiting* is about having a common understanding of the phenomenon arising from creative examination of the data until the meaning emerges. Thirdly, *analysis* refers to the coding and categorising of the data in order to make sense of the phenomenon. Finally, *describing* is concerned with understanding and defining the phenomenon and communicating this in written form. The phenomenological approach has been deemed as useful when the phenomenon is poorly defined. Although motivation has been conceptualised within the health psychology literature, as discussed in the literature review patients attending PR may

have unique issues which are not covered by existing theory. Motivation also emerged as a contextual concept. The approach taken in this study, therefore, was not to create a new theory of motivation, but to simply explore the phenomenon in the context of a PR programme.

3.3 Methods

3.3.1. Using focus groups

There is a selection of methods for extracting data about peoples' perceptions in the context of their experiences. One of the most favoured is the in-depth semi-structured individual interview (Rubin and Rubin 1995). There are also other avenues of inquiry, such as questionnaires, surveys and literature review, which can provide equally as effective access to people's experiences and perceptions at less cost (Seidman 1998). Another favoured method of qualitative data collection is the focus group method (Wilkinson 1999). Focus groups have been used as a method of qualitative data collection in a number of studies (Nicolson and Anderson 2003, Toms and Harris 2002, Lambert and 'Louiselle 2008, Twinn 1998 and Obrien 1993) including questionnaire development (Powell et al 1996). They have also been used in combination with individual patient interviews to collect qualitative data (Lambert and 'Louiselle 2008). Focus groups are described as a form of group interview that capitalizes on the communication and spontaneity between participants (Kitzinger 1995). Participants create an audience for each other allowing them to express points of view and exchange anecdotes pertaining to their experiences. The participants are given the opportunity to provide an account of their beliefs, along with their interpretations and thoughts of their accounts, based on their own experiences.

Advocates of the focus group method suggest that focus groups provide an added depth to data collection that cannot be captured in individual interviews (Powell et al 1996 and Lambert and 'Louiselle 2008). These authors claim that when they have been used in combination with individual interviews this provides an initial conceptualisation of a phenomenon which informs the direction of the patient interviews. Focus groups have been used previously in COPD to explore issues relating to quality of life (Nicolson and Anderson 2003) and the effect of PR on living

with COPD (Toms and Harrison 2002). By using the focus group method, the authors of these papers claimed that the studies shed light on the impact of COPD on patients' quality of life, and enabled patients to describe factors they believed were associated with some health behaviours. The results of these 2 studies did provide some meaningful data. However there is no evidence to suggest that the results would have been any different by using individual interviews. Issues have also been raised about the analysis and interpretation of focus group data and its' impact on validity (Reed and Payton 1997). Additionally, it is possible that some patients may not feel comfortable expressing their beliefs and attitudes in a group situation and may feel more at ease in a face- to- face interview. In a study by Powell et al (1996) the authors observed four focus groups conducted between service users and providers within the NHS. The authors concluded that focus groups enhanced the validity of existing questionnaires by highlighting concerns of users and providers that would otherwise have been neglected. However, the same results again may have been obtained using interviews. The literature to date does not contain any head-to-head comparisons between focus groups and interviews. Therefore there is no theoretical evidence that either method is more effective than the other.

Despite the lack of theoretical evidence for the use of focus groups, a decision was made to use this method as there were practical advantages. In the need to collect some baseline themes about patient perceptions of motivation within the context of PR, it was considered that focus groups would enable the collection of a large amount of data conveniently in a short space of time. PR groups and the local 'Breathe easy' club were naturally occurring focus groups that could easily be accessed. Since these groups already existed it would save the patients making additional journeys to participate in the research. This may encourage participation, as the patients would feel they were not making any additional effort. Additionally, the patients within these existing groups were used to having group discussions as part of their therapy. It was possible that because they knew each other and felt comfortable as a group, this would make it easier for the patients to discuss their thoughts without fear of embarrassment. It was thought that the concept of motivation may be at times difficult to describe for the patients since there is no universal definition. Within the group dynamics it was projected that participants would assist each other in a

problem-solving way. This would possibly enable the collection of richer and more detailed data.

Random sampling was not appropriate for the focus group study because there was no hypothesis to be tested and generalisation was not the primary issue (Holloway and Wheeler 1996). The aim of the research was to gather in-depth information about patient's experiences of motivation within the context of PR. Therefore, patients who were on, or who had undergone a programme comprised the study population. A sample was needed that was representative of the study population so it was decided that a purposeful sampling (Frankfort – Nachmias and Nachmias 1996) strategy would be the most appropriate method. The decision was taken to use a 'naturalistic' sample consisting of patients who were currently undertaking a PR programme and also a group consisting of patients who had been through the programme in the past. This was because the experience of motivation may possibly have changed over time as patients frequently report that their motivation falls in the months following PR. Furthermore, it was decided to use patients who attended programmes at two venues in Worcestershire, as there may have been differences in the venues affecting motivation. For example, the population at one of the venue locations is far more 'affluent' than the other, and this may have an impact on influences on their motivational status. The other reason for using already established PR groups was because these groups of patients had already built up trusting relationships with each other and may therefore find it easier to discuss sensitive issues than with a group of strangers. In our experience, as each PR group progresses, patients lose many inhibitions as they get to know each other. Alternatively, it was possible that some may have felt constrained and not able to talk openly about sensitive issues as there was no anonymity. Finally, by inviting entire groups to attend, selection bias was avoided, as the researcher had 'no choice' about which patients comprised each group. The ideas and information collected from the focus group discourse would form the baseline for the next study.

3.3.2 Participants

A purposeful sampling method (Frankfort-Nachmias and Nachmias 1996) was used by selecting established pulmonary rehabilitation (PR) groups containing between 7 and 10 patients. The PR groups were selected from local programmes in South

Worcestershire. Groups were selected that were either in the process of a PR programme, or who had completed a programme within the previous 12 months (post PR). The sample was also a convenience sample, as groups were selected that were in progress at the time of the research. For the group of post PR patients, members of the local (Malvern and Worcester) 'Breathe Easy Club' (patient support group) were approached. These patients had all attended PR in the past and they were all familiar with each other.

The number of focus groups held was determined by data saturation (Rubin & Rubin 1995). This was the point that occurred when no new information was being collected through the focus groups. With regard to the number of patients within each focus group, consideration was given to having enough patients to create good group dynamics and varied opinions, but not making the group too large to effectively moderate (Kruegar 1994). Since this is the same issue that influences the number of participants recruited into a PR group, it was decided that using naturally occurring PR groups would automatically result in an acceptable number.

For the 'post PR' focus groups, an appeal for help with the research was made at a Breathe Easy club meeting, which was met with enthusiasm from the group. Patients who had been at the meeting were then approached by a telephone call from the researcher to invite them to participate. Consideration was given to the fact that patients may have felt under pressure to come out of a sense of duty, so every effort was made to explain to the patients that attendance was optional and the opportunity to decline was given. Patients attending current PR programmes were spoken to by the researcher at the outset about the focus groups. They were asked if they would be willing to take part and opportunity was given to patients to decline to participate. The whole process of the focus group was explained to them so that they were clear about what was entailed, including the fact that group conversation would be recorded by audio-tape.

Ethical approval was obtained from the local ethical approval committee (See appendix 3.1). Each patient taking part in the focus groups was given an information leaflet (Appendix 3.2) about the study and all patients signed a consent form (Appendix 3.3). Patients were told that they did not have to participate in any part of

the conversation they did not want to and that they could withdraw from the study at any time. The data held on each patient was stored in a locked notes cabinet in a locked office. Research data was not used for any other purpose except for the research project. Patients were reassured that confidentiality would be maintained and focus group audio-tapes would be destroyed following transcription. They were also reassured that names would be changed during the writing up of the research. At the beginning of each focus group, the moderator discussed issues of confidentiality and respect for others in the group.

3.3.3 Focus group process

The focus groups were moderated by the author, except one that was moderated by an independent academic from the local university, with experience of qualitative research methods. This was done in order to increase reliability (Seidman 1998). As the researcher was known to the patients already in the capacity of their PR nurse, this may have caused bias in the focus group discourse. Therefore the purpose of having a second moderator was to see if topics were discussed differently. Focus group procedure was the same for both moderators. The venues used for the focus groups were the same venues that the groups used for their PR sessions. This was to establish a naturalistic setting where the patients would feel comfortable with as little intimidation as possible because they were in familiar surroundings.

Patients were positioned in a circle and attention was paid to ensure privacy and minimal distractions for the group. A poster was displayed throughout the session in clear view of all group members. The poster displayed the following 2 questions:

- ◆ *How would you define motivation?*
- ◆ *What things motivate or de-motivate you in pulmonary rehabilitation?*

The purpose of this poster was to help to keep conversation focussed on the topic and to also act as a 'prompt' for the participants (Siedman 1998). It was envisaged that the displayed questions would stimulate personal reflection within participants and facilitate a better discourse. A short introductory explanation was given by the moderator explaining the aims of the focus group and rules for the session. An initial 'voice check' was made using the tape recorder to ensure it would pick up all of the voices. Furthermore this would enable the transcriber to identify which person was

talking. Everyone in turn said their name into the tape recorder and this was checked before the group officially started.

The length of time for the focus group session was decided during planning stages and was set for around 30 minutes. This would allow the moderator to hone their skills by working within a set amount of time (Siedman 1998). Focus group conversation was recorded on a tape recorder. The moderator also made hand written notes of any key comments, or items of particular interest. Participants were encouraged to discuss and debate the issue of motivation, based on their own experiences. During the focus group conversation the moderator maintained as discrete a role as possible, only intervening if conversation moved away from the topic or if there were any long silences. The moderator did not join in with the conversation so as not to bias the results, but made non-verbal gestures where appropriate to stimulate and facilitate discussion.

Immediately following each focus group the moderator reflected and made notes about the focus group discourse to establish first impressions, key issues raised and the overall 'picture' of motivation painted by the participants using both memory and hand written notes made during the group session. The entire focus group conversation was transcribed including silences, laughter and inaudible discourse.

3.3.4 Data analysis

Data analysis was undertaken in accordance with the stages of phenomenology described in Polit and Hungler (2006). The data was analysed by the author. The author firstly undertook intuiting – or becoming immersed in the data until understanding emerged, proceeding on to the analysis stage. Each transcript was read through by the researcher several times to ensure a working knowledge of the context surrounding the individual statements (intuiting). Any reflective thoughts made by the researcher were made in a notebook to assist the analytical process. Basic content analysis (Crabtree and Miller 1992) was applied to the discourse. This is where only the content of the conversation was analysed. (This is opposed to discourse analysis, where the way the conversation was executed is also analysed, i.e. body language, group interaction etc.). The author 'dwelt' on the descriptive data, until common

themes began to emerge (Shepard et al 1993), with consideration being constantly given to the research questions and study objectives.

Initially, each focus group was analysed separately using the same standard method. The text was reduced by deleting any data which was irrelevant or inaudible. The remaining statements were examined for emerging themes, patterns of data and data of special interest (Sapsford and Jupp 1996) and sense was made of the essential meanings of the phenomenon (Polit and Hungler 1996). Analytic induction was used by the investigator to group statements together where they were related to form themes (Seidman 1998). Any 'one off' statements were reviewed for categorisation. Themes were merged where appropriate as analysis progressed. Each theme was then labelled as a single category. The text was reduced further to make statements concise and eventually text was deleted leaving 1 – 2 statements to support each category. Progressive elaboration of categories enabled the formation of sub-categories in a similar structure as chapter headings and subheadings.

The final stage of the phenomenology process is description (Polit and Hungler 1996). In this stage firstly descriptive statistics were used to describe the group's characteristics. Then a table was constructed in order to demonstrate the categories and subcategories that emerged from the data.

3.3.5 Increasing validity

A number of steps were taken to ensure the method produced as valid results as possible. For each focus group it was ensured that exactly the same procedure was used and that the moderator did not influence the discussion. Attention was paid prior to the focus groups on the skills of the moderator which include many basic interviewing skills such as facilitating conversation, stimulating discussion, facilitating turn taking and ensuring conversation remains focused on the topic. Because one of the moderators had extensive experience of interviewing for research, and the other used the same skills for conducting group discussions during PR sessions a pilot focus group was not undertaken. However, during focus group 1, the 2nd moderator observed the technique of the primary moderator and gave critical feedback on technique following the session. The moderators' input was made as standard as possible to increase the reliability of the research, although this had to be

balanced with pursuing any interesting thoughts and opinions expressed by participants. The 2nd moderator facilitated one of the focus groups independently as a reliability check. Because the patients were familiar with the 1st moderator through the pulmonary rehabilitation sessions it was a concern that discussion may be biased, in that the patients may not want to say anything that caused offence.

During analysis one of the focus groups was also analysed independently by an investigator with a psychology background. The transcript was analysed into themes and results compared to the researcher's as a reliability check. Where possible comparisons were made between motivation research findings from the literature and categories of data to triangulate results to support validity.

3.4 Results

3.4.1 Sample

Three focus groups were moderated before the point of data saturation occurred. Group 1 consisted patients who had received PR within the past 12 months, group 2 consisted of patients who were in the process of a PR programme at a community venue and group 3 consisted of patients who were in the process of a PR programme at a hospital venue. Group characteristics are tabled below in table 3.1.

3.4.2 Discourse analysis

Emergent categories fell into 2 distinct and fairly discreet units. The first unit consisted of patients' descriptions of motivation as a cognitive, attitudinal or emotional entity. The second unit consisted of factors that had an influence on motivation, some of which were able to move motivational status backwards and forwards between motivated and de-motivated status. The first unit was labelled 'essential motivation' and is concerned with the persons' self. The second unit was labelled 'external motivational factors' and is concerned with elements of the person's life and environment that influence how motivated they feel. Table 3.2 presents the results of the analysis with the emergent themes and sub-themes and related motivation theory. Detailed explanation of these findings is presented in sections 3.4.3 – 4.4.4.

Table 3.1. Characteristics of focus group participants

	<i>Group 1 (N = 7)</i>	Group 2 (N =5)	Group 3 (N=6)
Gender	M – 2 F – 5	M – 5 F – 0	M – 2 F – 4
Venue	Community hall	Community hall	Acute hospital
PR stage	Past PR participants	Current patients	Current patients
Mean age	65 (Range 52 – 77)	70 (Range 69 – 81)	68 (Range 48 – 86)
Disease severity (Measured in mean % FEV1¹)	44% (Range 18% - 78%)	35% (Range 21% - 48%)	32% (Range 19% - 61%)
Receiving long term oxygen therapy	N = 2 (1 of these on nocturnal non- invasive ventilation)	N = 1	N = 3
Mean exercise tolerance (measured in shuttle walking test distance)	177 meters (Range = 90m – 280m)	162 meters (Range = 30m – 190m)	177 meters (Range = 20m – 310m)
Respiratory diagnosis	COPD – N=6 Asthma – N=1	COPD – N=5	COPD – N= 5 Pleural mesothelioma N=1
Health related quality of life (Measured in mean SGRQ² score)	55 (Range 37 – 71)	48 (Range 37 – 69)	44 (Range 34 – 55)

1. Forced expiratory volume in 1 second presented as percentage of predicted value. 2. St. Georges Respiratory questionnaire – quantifies quality of life in COPD – the higher the score, the worse the quality of life.

Table 3.2. Results of focus group content analysis

Category	Sub-categories with supporting statements. Positive aspects	Sub-categories with supporting statements. Negative aspects
<i>Essential motivation</i> Attitude	<ul style="list-style-type: none"> ◆ Making yourself do it ◆ Drive ◆ Willpower ◆ Determination. ◆ Optimism ◆ Get up and go ◆ Taking life as it comes 	<ul style="list-style-type: none"> ◆ Giving in ◆ Not being bothered ◆ Feeling depressed
<i>Essential motivation</i> Incentive	<ul style="list-style-type: none"> ◆ Wanting to live longer ◆ Better quality of life ◆ To have a reason for living 	<ul style="list-style-type: none"> ◆ Going to waste
<i>Essential motivation</i> Tenacity	<ul style="list-style-type: none"> ◆ Being alert. ◆ Motivation means being active ◆ Just do it ◆ To keep going. ◆ To have the ability to do things ◆ To try ◆ Live life to the full 	<ul style="list-style-type: none"> ◆ Not wanting to do anything
<i>External motivation</i> Family support	<ul style="list-style-type: none"> ◆ Not wanting to be a burden ◆ Grandchildren ◆ Having a supportive spouse ◆ Being alone with no-one to depend on 	<ul style="list-style-type: none"> ◆ Nagging' spouse ◆ Being alone
<i>External motivation</i> Perceived effectiveness of therapy	<ul style="list-style-type: none"> ◆ Being in need ◆ Believing therapy will work ◆ Experiencing improvement ◆ Hope of improvement ◆ Fear of deterioration in condition 	<ul style="list-style-type: none"> ◆ Realising how unfit you are ◆ Knowing there is no cure
<i>External motivation</i> Goal setting	<ul style="list-style-type: none"> ◆ Increasing exercise intensity in stages ◆ Setting weight loss targets ◆ Having an exercise plan ◆ Having an exercise 'schedule' ◆ Being told to exercise ◆ Exercising to music 	
<i>External motivation</i> Recreational activities	<ul style="list-style-type: none"> ◆ Dog walking ◆ Golf ◆ Holidays ◆ Going for walks ◆ Gardening ◆ Pets 	
<i>External motivation</i> Attending a PR programme	<ul style="list-style-type: none"> ◆ Feeling privileged to have opportunity to attend ◆ Receiving more information about condition ◆ Support of healthcare professionals ◆ Being part of a group ◆ Not wanting to 'look a fool' ◆ Competition with other patients 	<ul style="list-style-type: none"> ◆ Lack of interest from healthcare professionals.
<i>External motivation</i> Fear of deterioration	<ul style="list-style-type: none"> ◆ Not wanting condition to deteriorate ◆ Seeing people with more severe disease 	
<i>External motivation</i> Coping skills	<ul style="list-style-type: none"> ◆ Having illness for a long time ◆ Feeling in control ◆ Feeling confident 	Fear of breathlessness during activity
<i>External motivation</i> Symptom variability		<ul style="list-style-type: none"> ◆ The weather / seasons ◆ Having 'off days'

3.4.3 Essential motivation

Attitude

The first category within essential motivation was labelled ‘attitude.’ This interpretation was made from comments such as

“Motivation is a state of mind”

“drive” and “determination”

Some patients felt that the key to remaining motivated was the attitude of the person. Many expressed that this positive ‘state of mind’ was what they had experienced during a PR programme. One patient said:

“It’s what actually gets you to do the exercises”.

It was clear during the focus group discourse that patients often viewed motivation as synonymous with other positive emotional feelings. For example, when asked what they thought defined motivation, one patient replied:

“Since coming to class, I feel more confident in myself”.

Participants also discussed how there was an opposite ‘state of mind’ to the positive elements in this category. One patient described this:

“and you don’t want to do anything, you can’t be bothered to do anything”.

A word that was frequently used to encompass these negative aspects of attitude was ‘giving in’.

“It’s so easy with chest problems to give in; it’s very, very easy to give in. Because you’re really easier if you’re doing nothing – you’re sat down – but it’s not always the right thing to do.”

Another negative element that was discussed with particular emphasis was anxiety and depression.

“Anxiety. I think that’s one of the worse things for people that are complaining of short of breath. And they see all the time that I find myself really er struggling. For instance, my wife, she has rheumatoid arthritis. Somedays she’s very ill, and I can feel the anxiety and shortening my breath. But then again, mentally, we have to have the motivation to take over, because you have to do for her what she can’t do for herself. I lost my brother 2 years ago. Great anxiety stress over that.”

Incentive

The next emergent category within the dimension of essential motivation was labelled ‘incentive’. Patients described how they often had a reason to make the lifestyle change. This reason or incentive they associated with motivation. For example one patient found his motivation increased from seeing people older than him who were fitter.

“Seeing an older person than you overtake you when you’re walking up the road. Motivates people to go faster. An old dear passed me and I’m only 56, I think ‘God almighty!’ It makes me want to, you know, say ‘come on’, you know ‘get going’, you know, back to what you was like.”

Another patient stated

“it’s what actually gets you to do the exercises. You’ve got some incentive to try.”

Patients also described how they were motivated as they wanted to live longer or improve the life they had. One person said:

“What we are trying to achieve is trying to improve our quality of life – I suppose, with the exercises”.

The opposite end of the spectrum to this was described as

“Going to waste”.

Going to waste was discussed as a negative motivational state where people felt they had no incentive to improve their prognosis or quality of life.

Tenacity (Stamina)

The third category within essential motivation was labelled as tenacity – or stamina. Comments within this category were related by the inference that one element of motivation is about ‘carrying out’, ‘doing’ or ‘having the ability to carry out the lifestyle change’. One person described this as

“Living, moving, exercising, walking”.

Comments such as these were interpreted as the physical act of ‘doing’. Patients appeared to associate ‘being motivated’ with an ability to execute a lifestyle change. One patient reported:

“The need is that you have just got to keep going. Mainly if you are on your own, the fear of drying up and not being able to do things, makes you do them even on days when you perhaps would rather not.”

Another stated:

“Yeah, like being able to walk up the town, you know being able to walk”.

Subjects also discussed the negative side of tenacity that was described as

“Not wanting to do anything”.

Being inactive was considered to be associated with a lack of motivation. In this category, the patients discussed tenacity as a behaviour rather than an attitude.

3.4.4 External motivation

Family support

Patients described a variety of domestic circumstances that appeared to affect motivation in diverse ways. These experiences were grouped together under the category of ‘family support’. A number of patients had very supportive spouses and reported how this factor helped them maintain their motivation. One person described how his wife motivated him continually.

“The wife is always getting me motivated – come on do something you know, get out and do something, which is what I do. She has got to really shout, at me sort of thing.”

Others had less supportive spouses which they described as having the opposite effect and reduced motivation. One gentleman even discussed how the continuing nagging of his wife *stripped his motivation completely*. He said:

“But I think I’d rather be on my own than have a wife nagging me. I’m less likely to do things then”.

Living alone affected some patient’s motivation negatively, and some positively. One patient reported how being alone had a positive effect on motivation,

“when you have no-one else to rely on you have to do it yourself, and that what motivates me”.

Another said:

“Loneliness is a big thing, you can’t depend on anyone else, you have to do it or you just go down don’t you”.

Others described being alone as having a negative influence on motivation:

“When you’re by yourself you don’t have much motivation to do anything. It makes it much worse.”

Grandchildren (which are very common to this patient group) featured quite prominently as a motivating factor, as patients felt they had a very positive effect on their attitudes. One patient said:

“They keep you more active. They come and visit you and drag you by the hand and before you know it you’re doing things you were doing 50 years ago. So young children can make you motivated.”

Another described her grandchild’s affect on motivation:

“Then I’ve got my little granddaughter, she keeps me on my toes”.

Perceived effectiveness of therapy

Perceived effectiveness of therapy emerged as a discrete category. Many patients described how their motivation increased dramatically when they experienced improvements from the exercises. This was confirmation for them that PR was effective and this motivated them to continue. For example one patient said:

“Once you had started doing the exercises, in fairness some of them actually did help, not all of them, you know you found which ones helped you most”.

Another who had completed a PR programme was impressed with the result. He said:

“My breathing is much better than what it was.”

At the negative end of the spectrum patients described how their motivation was reduced when they felt nothing could be done to help them. Prior to PR one patient had been told there was nothing that could be done to help her condition. She told of the impact this had had on her motivation:

“they said ‘there is nothing that we can do’. And that must be horrible to have that said to you, knowing, you know there is no cure but it must give you some go. That is de-motivation”.

The importance to motivation of believing the exercises were going to be beneficial was reinforced in a strangely negative way by the poignant comments of one patient. This patient, who was in the process of a PR programme, actually had lung cancer rather than COPD, which is quite an unusual occurrence for a PR group. Obviously, the comments this patient made cannot be generalised to the rest of the PR population as his attitudes and beliefs were very different. However it was very interesting that this patient commented that it was difficult to be motivated when you knew you were not going to live. He said:

“But it takes a hit when you know that you’re not going to get any fitter. It doesn’t matter how much I exercise even if I exercise as much as possible, I know I am not going to get any fitter than I am now.”

Goal setting

Many patients spoke about planning their exercise regime so that they had achievable targets. This category was labelled goal setting. One patient described how his motivation increased by following a plan:

“I think you have to have goals, don’t you? You have to set yourself a goal each day er, to walk a bit further - do a few press ups”.

Other patients also described how they had devised an exercise plan for themselves and this had a positive influence on their motivation.

“I try to do them all in 3 stages, I don’t do them all at the same time”. “I do some in the morning, some after lunch and again in the evening”.

Others found that having goals was easier when the plan was devised by the rehabilitation staff. They discussed that being told when and how often to exercise increased their motivation. For example, one person stated:

“I think the important thing is having a routine and being given the exercises and having something positive and definite to do. Not only the exercises but everything else we love as well”.

Other patients felt that simply exercising to music influenced their motivation.

“Keeping up with music”

“You know, you are supposed to have done this by the time that piece finishes, so get on with it”.

Recreational activity

Many patients associated the undertaking of regular recreational activity with motivation. A variety of these were discussed, such as holidays, gardening and walking for leisure.

“As long as I have got a bit of garden I’m motivated – I am in and out the whole time”

said one. Pets seemed to be a very positive influential factor on motivation, in particular dogs.

“I tell you what can be a good motivator, is a pet. You have to do things for them, they make you do things”.

Many patients described how dogs by their nature require regular walking and therefore there was no choice than to go for a walk. For example when one group was discussing the effects of rain on motivation one patient said:

“Well actually you see that is the advantage of dogs because they don’t care if its raining or not, they want to go out”.

This, they pointed out, was a great way to stay motivated.

Attending a PR programme

A lot of discussion focussed around the positive impact on motivation of attending a PR programme and being in a group. There were a variety of issues around the effect of a group.

“You see other people doing it [exercising] and you think, well if they can do it, I can”.

Discussion also revolved around the fact that there was sometimes competition between the members of the group and this increased motivation.

“Well I, er, think that motivation really is created by contest.”

said one patient. Another said:

“Fear has a lot to do with it because you don’t want to, well lets put it this way, you don’t want to be left at the starting gate and you don’t want to be made to look a fool”.

A crucial influencing factor on motivation appeared to be the attitude of the healthcare staff during a PR programme. One patient was discussing her respiratory physician and she stated:

“I can talk to him [her consultant] and you can laugh with him and he doesn’t talk down to you, he talks to you and that makes you feel, I am somebody special. That’s the way I feel anyway, he makes you feel as if you are special”.

The patients discussed how they would feel a negative influence on motivation if staff were not dedicated.

“If you have got somebody who just does it as a job, and puts in the effort but has no personal interest.”

Some patients also highlighted that they felt they 'owed' it to the healthcare staff to work hard at their exercises and that this was a motivational factor. One patient said:

“Well yes, that’s right. If someone has gone to the trouble of organising this and giving their time, you feel that it is up to you to make use of it and not just sort of stay at home and say I can’t be bothered”.

Fear of deterioration of condition

One patient discussed that they did not want to lose the benefits they had gained from the PR programme that they had attended.

“I think the fear of losing what you have got, going backwards, is one big reason to keep going”.

What was often discussed was how patients had often noted others who were in a worse situation than themselves. This factor motivated them because they did not want to deteriorate into a similar condition.

“I’ve found these classes very helpful, because, in a mental way, because I’ve seen people here much worse than myself. That, in fact drives you on to know that, well thank goodness, you know, my limitations are far greater, there are people who are not here today, who are in wheelchairs and have oxygen cylinders, and thank God that we round here don’t have to do that. And that is really the encouragement.”

Coping skills

Many participants talked about motivation being associated with being able to cope with their condition. One lady said:

“As long as you can go on coping, well the way I thought was that as long as I can go on coping”.

Another patient who had suffered with a lung condition since childhood felt that he had learnt to cope over the years which had a positive motivational effect. He said:

‘Having had chest problems since being a small boy, I probably can control and motivate myself better than most people after 71 years. You get used to how much you can do, how far you can go.’

Patients discussed how their confidence had increased as a result of PR and that this made them more motivated.

“I think it gives you so much confidence. I was really depressed and I couldn’t get out and about. Since coming to class, I feel more confident in myself”,

said one. A lack of confidence and fear of the breathlessness during exercise was associated with a lack of motivation.

Symptom variability

The final emergent category was labelled symptom variability. This was because patients described the fact that their symptoms varied on a day-to-day basis and that this negatively affected their motivation. For example one patient said:

“There are some days I must admit, when I’m not feeling too good, when I have missed doing things.”

Patients reported that the weather throughout the seasons was a big influential factor on their motivation. One patient reported:

“It’s the seasons, because in the winter you get less motivated, come to the spring and that’s when you starting feeling motivated”.

3.5 Discussion

This study has produced some baseline data about motivation within the context of PR. It was demonstrated that patient’s experiences of motivation consist of many diverse elements and interpretation of these experiences have enabled the generation of some initial ideas about patients’ perceptions of factors related to motivation. The

study has found that motivation within PR was influenced by a set of circumstances that are unique to each individual participant. It is interesting that during the focus groups far more discourse was based around the positive aspects of motivation rather than negative aspects. The results contain limited information about de-motivating factors in relation to the positive influences.

During analysis there seemed to be a clear distinction between being a motivated person (essential motivation) and events or circumstances that motivate the patient (external factors). In previous years there have been a number of papers written about the notion of intrinsic and extrinsic motivation (Fox 1997). Some authors interpret motivation as a concept intrinsic to that person (Davis 2007, Gifford and Groessi 2002, Plonczynski 2000, Marin 1990 and Dishman 1991). The patients used words to describe motivation such as 'drive', 'determination' and 'willpower' which suggests that motivation comes 'from within' the person themselves rather than an external influence. Indeed, the classic social-cognition motivation models focus around cognitive factors, suggesting an 'intrinsic' focus (see Marks et al 2005 and Forshaw 2002). Our patients additionally described external factors as affecting their motivation, which suggests that the traditional generic motivation models do not encompass motivation comprehensively. This is supported by a study by Kanvil and Umeh (2000) where the addition of an external influence to a regression model dramatically increased the ability of the health belief model (Becker 1974) to predict health behaviour.

The findings of the study were similar to the results of other research. For example, some of the factors associated with enhanced motivation were very similar to the findings of a study that examined the effect of PR on the patient (Toms and Harrison, 2002). This was also a focus group study, where patients with chronic lung disease who had been on a PR course were asked to describe what it was like to live with the disease and the effect PR had on that. The key findings were that before PR patients felt frustration at the disability, but after a PR programme patients gained confidence and had a new-found functional ability. Three of the 'after PR' categories developed by the authors of that study were ability, stamina and increased control and one of the 'before PR' sub-categories was fear. These relate to our categories of coping skills, fear and tenacity and the sub-category, ability. It is a possibility that because all of

our focus group patients had been through the experience of PR, what they were actually describing were the positive feelings they had gained from the programme, rather than motivation itself.

The results showed that the patients at times described the onset of a more positive disposition rather than specifically describing motivation. Alternatively, it is possible that motivation is so closely linked with other positive feelings. The patients in the Toms and Harrison study (2002) may have been describing an increase in motivation without realising it. If this is true then this adds weight to the argument that motivation is gained throughout attendance at a programme. Whatever the explanation is for this similarity in findings, it is important that in later parts of the research, patients should be interviewed who have not yet attended the PR programme. This would ensure that descriptions of motivation are included from those who have not had the benefit of the positive feelings induced by attending a PR programme.

The essential motivation described in this study consisted of 3 categories. These were attitude, incentive and tenacity. These were interpreted as dimensions of a person's 'inner' motivational status. This finding is supported by the literature relating to motivational theory. Attitude for example, relates to components of the classic social cognition models. Attitude is an element of the Theory of Planned Behaviour (Ajzen 1991). This theory is based on the assumption that what a person intends to do is the most important influence on that person's behaviour. One of the elements affecting intention is the person's attitude towards performing the behaviour. In our study, anxiety and depression came under the category 'attitude' but it had a negative affect on motivation. Elements of motivation grouped under the heading 'incentive' relate to self-regulation theory (Leventhal et al 1980) and to Bandura's social-cognitive theory (1977) where goal setting is an essential part of regulating the health behaviour. Theoretical support is also found in the Theory of planned behaviour (Ajzen 1991) where the degree to which other significant individuals view the importance of the behaviour influences the intention. Additionally, within the Readiness to Change Model (Rollnick et al 1999) there are similarities. In this model, confidence along with the degree of importance the patient relates to the change bring about readiness. In the readiness to change model, importance is presented as

personal values and expectations – ‘why should I change?’ This relates directly to having an incentive. Again, the Theory of Planned Behaviour (Ajzen 1991) is related to incentive, as part of this theory assumes that the degree to which other significant individuals view the importance of the behaviour influences the intention.

The category ‘tenacity’ was perceived to refer to the patients’ functional ability to actually carry out behaviour. Many patients viewed adherence to their exercise programme as ‘part and parcel’ of being motivated and a significant amount of emphasis was put on this issue. Thematical analysis of this discourse was difficult, as ‘motivation’ and ‘adherence’ are seemingly different concepts. The definition of adherence within the context of PR guidelines (Nici 2006) is as follows:

‘The extent to which the person’s behaviour corresponds with agreed- on recommendations by the healthcare provider’.

This definition is focussed on health behaviour, which from the literature review emerged as the final stage in the *process* of health behaviour change and is different from initial motivation or *intention*. However, it was clear during the data analysis that the patients perceived that people who adhere to a healthy lifestyle choice as consistent with a motivated person. The patients were seemingly describing the self-regulatory phase of behaviour change. It is possible that patients do not disentangle the stages within the motivation process, they perceive all stages, including the behaviour itself, as part of motivation. This demonstrates that perceptions and interpretations of motivation may be contextual. Perceptions of the meaning of motivation by elite athletes may render different results. It is notable that these findings are similar to another study about motivation within a different rehabilitation context (Resnick and Spellbring 2000) where patients described their functional ability as being the opposite to being lazy. Again, in that context patients did not appear to disentangle health behaviour from motivation, they viewed it all as part of the same concept. Sniehotta et al (2006) describes this process of linking intention with the health behaviour itself as ‘action control’. It was argued in the literature review that motivation may be the precursor to action control and then self-regulation of behaviour. It appears that the patients’ perception within this study is that the entire process of health behaviour change is encompassed by the term motivation.

The findings of this study found that perceived external motivation consisted of the constructs family support, effectiveness of therapy, goal setting, recreational activity, attending a PR group, fear of deterioration, coping and symptom variability. Patients found that these things had an influence on their motivation. Many of the dimensions of external motivation that were found are supported by the findings of other studies. The coping dimension can be linked to self-efficacy theory (Bandura 1986, Bandura 2001 and Vittorio and Steca 2006). It is known that there is a relationship between self-efficacy and exercise behaviour (Rimmel 2001, Luszczynska and Sutton 2006 and Salis et al 1988). For example, patients described how they were frightened of being breathless during exercise. This relates to Bandura's theory of self-efficacy (1977) which presents self-efficacy as the individuals' confidence that they can follow the behaviour which will provide the outcome. The theory also explains that where unpleasant feelings are associated with exercise then motivation is decreased. Likewise, in the theory of planned behaviour (Ajzen 1985) the degree of perceived behavioural control again has an influence on intention.

Eakin and Glasgow (1997) found that fear of breathlessness often prevents patients with chronic lung disease from performing physical activity. The readiness to change model (Rollnick et al, 1999) also supports this category because of the emphasis it puts on the individuals confidence that they can execute the behaviour. Decreased control and the loss of 'self' have been found to be an integral part of the experience of living with a chronic lung disease (Toms and Harrison 2002). Fear of breathlessness and lack of control clearly impact on the motivation of patients undergoing PR and many patients report the increased confidence they feel following a programme. This suggests that as confidence increases during PR then so does motivation. A patient in one of the focus groups talked about how he had been living with a lung condition since he was a boy. He had a high amount of self-efficacy which he believed contributed to high level of motivation. Comments such as these, supported by the literature, support the possibility that self efficacy is closely related to motivation in PR.

The category 'effectiveness of therapy' emerged as one of the key categories. Patients frequently discussed how motivated they felt when they saw the exercises

really worked. The final component of the self-regulatory model (Leventhal 1980) describes how a person appraises the effect of the behaviour change in terms of impact. In this model, the person either maintains or changes the behaviour according to effectiveness. This process relates to our study. It was clear that patients must be sure that exercise is effective for them to gain the motivation to actually adhere to an exercise programme. It is possible that prior to a programme the PR team can influence this decision-making process by reinforcing the effectiveness of a rehabilitation programme. The health belief model (Becker 1974) also presents perceived response to the health behaviour as having an influence on a person's intention to continue with the behaviour. Our patients described this process from their own experiences of seeing their functional capacity improve as a result of the exercises within the PR programme.

The other components of external motivation are also supported by other research findings. Family support has been shown to affect both motivation and adherence in other areas of rehabilitation (Rejeski and Hobson 1994 and Duncan and McAuley 1993). Likewise goal setting has also been shown to increase motivation (McClellan et al 2000b) and is a construct of self-regulation theory (Leventhal et al 1980). Both effectiveness of therapy and fear of deterioration is supported again by self-regulatory theory and by Bandura's self efficacy theory (1977) where an individual who believes that a behaviour will lead to a positive outcome, is more motivated to carry out that behaviour.

3.5.1 Study strengths and limitations

Because the focus group enabled patients to interact with each other, this appeared to stimulate the 'baring of souls' possibly much more than in one to one interviews. Participants told the audience their own 'stories' of their experiences and this seemed to stimulate much emotion and consequent reflection within the group. A similar phenomenon occurs within PR groups themselves, with some of the success of the programme attributable to group interaction – the sharing of knowledge and being understood (Toms and Harrison 2002). During observation of the focus groups, it was noted that the group discussion appeared to be a positive, helpful – almost therapeutic experience in itself. This in turn seemed to stimulate focus upon the

discussion of positive issues rather than negative, as is illustrated by the results. It is possible that during one to one patient interviews, with the absence of the therapeutic experience, more emphasis may be put onto de-motivating influences and dispositions. There is a good argument therefore, for combining focus group research with other methods to ensure all perspectives are explored.

The 'post PR' patients were recruited from the local support group, 'Breathe easy'. It is possible that these patients were more motivated since they regularly attend the support group, which takes a degree of motivation in itself. Therefore a more positive view of motivation may have been collected.

During the focus group process two questions were prominently displayed to keep the participants 'focussed' on the topic. These questions were: *How would you define motivation?* and *What things motivate or de-motivate you in pulmonary rehabilitation?* This was done as the literature about conducting a focus group had suggested such methods (Kitzinger 1995). The displayed questions were informed by the previous literature review that demonstrated intrinsic and extrinsic motivation. In retrospect it was not altogether necessary to have the two questions for discussion displayed and just the words 'motivation in pulmonary rehabilitation' would have sufficed. It could be argued that by displaying the 2 questions response bias was immediately introduced by suggesting to the participants that motivation does fall into the categories of intrinsic and extrinsic factors. In observation of the focus groups, the discussion developed in such a way that it was clear that the concept of essential and external motivation would have emerged without influence. It was obvious that the questions were being used as intended – a prompt for discussion.

One difficulty with data analysis was determining which themes were more important or relevant than others. Concerns about analysis and interpretation of focus group research have previously been raised by other authors (Reed and Payton 1997). Initially, the amount of statements related to each emergent theme was counted, as a possible way of ranking them into order of importance. However, (Kruegar 1994) suggests caution in assuming that frequency or extensiveness of reference to a theme is indicative of its' importance. Kruegar also suggests that the most importance should be placed on responses that are based on actual personal experience rather than a

persons ideas. It was on this basis that decisions were made about levels of importance of data.

Another issue of reliability is that the researcher also provided clinical input into the PR programme. There was a possibility that preconceived ideas may influence focus group facilitation or discourse analysis. This would compromise the resulting theory, making the results unreliable (Frankfort-Nachmias and Nachmias 1996). In addition, it was possible that patients may have 'tailored' their experiences because of their relationship with the moderator. For example some negative points of view may have been modified or suppressed if the participant did not want to cause offence to the moderator. During data collection and analysis a large amount of attention was paid to this issue. Every effort was made by the researcher to remain open minded and not to influence the data in any way. To check for reliability, an independent investigator observed focus group 1 and moderated focus group 2 to check the moderator's technique and to see if there were differences in the type of data collected. The researcher left the room during focus group 2. There were strong similarities between data from focus groups 1 and 2, suggesting the methods used were reliable.

During analysis there was also the danger that the researcher could influence the results by making assumptions without being open-minded. An example of this is as follows. In focus group 1 a small amount of conversation took place pertaining to a patient who had been told by his doctor that there was nothing further that could be done for him and the anger felt by him at being told this. At the time, the impression taken by the investigator was that the conversation had 'drifted off course' at this point, with the patients taking the opportunity to get some of their complaints 'off their chest'. Therefore during analysis, these few statements were deleted as irrelevant discourse. Subsequently, during focus group 3, a patient who had lung cancer with a very poor prognosis talked about how his motivation was low because he knew there was no cure for him. The piece of discourse from focus group 1 which was deemed as irrelevant was clearly related to the above statement of there being 'no hope' and had been wrongly deleted. A vital piece of data could have been left out. Following this incident all the transcripts were re-read at the end of analysis to ensure no data had been left out. This example illustrates how easy it is for the researcher's opinions to unwittingly be applied detrimentally to qualitative data analysis. It would

be advantageous to keep any statements that at first seem obviously irrelevant in a 'miscellaneous' category until the end of the process when a theme may have emerged where they may be appropriately included. Rigour must be consistently applied at all stages to ensure reliability. In other studies concerns have been raised regarding issues of validity (Reed and Payton 1997) particularly pertaining to analysis and interpretation of data. The themes that were developed from focus group 1 analysis by the independent investigator were compared to those of the researcher. The themes were identical suggesting reliability of analysis methods.

A limitation of this study is that a focus group was not conducted with patients who had declined to participate in PR or who had dropped out of a programme. In retrospect such a group may have added another dimension to the data on motivation and such a group should be incorporated into future research. The participants in this study consisted of people who either were attending PR or who had attended in the past. The sampling method was chosen on the basis that it was representative of the study population – people on PR programmes, past or present. When suitable patients are referred for PR, there are a certain number who either decline the treatment at assessment, or drop out in the initial weeks of the programme. The opinions and feelings of these may have been important but were excluded from the data. It could be suggested that this compromised the validity of the data analysis as the sample was not representative. Patients who had declined or dropped out of PR would possibly have added an important dimension and would have been useful group participants. It is therefore imperative that future sampling with the patient interviews within this project needs to include representatives from this group.

3.6 Conclusions

Focus groups as a research method provided an enormous amount of data that was based upon patients' own experiences. Extensive rigour must be applied to this method but any compromise in reliability has to be balanced against the richness and quality of the data collected.

One of the prominent and consistent reported influential factors in motivation was the patients' involvement in a PR programme, with particular reference to the

motivational qualities of being in a group and the support of healthcare professionals. This brings into question the inclusion of motivation as an entrance requirement to the programme since patients clearly appear to have acquired motivation during the rehabilitation process. Further research is needed to examine the role of motivation in PR programmes. These initial findings suggest that there may be relationships between motivation and psychosocial variables relevant to COPD. Future research needs to be aimed at further exploration of the relationships between motivation and these variables.

3.7 Chapter summary

This chapter has described an exploration of factors perceived by patients to have an influence on motivation in PR programmes. The design was a qualitative, exploratory, focus group study using a phenomenological approach. The methods and procedures used were explained, along with details of the results. The findings were discussed and some suggestions made for future research.

CHAPTER 4 –PATIENT INTERVIEWS

This chapter describes a further investigation of motivation within a pulmonary rehabilitation (PR) programme in which more data is collected about factors related to motivation as perceived by the programme participants. The rationale, methods, procedures and results of the study are presented and findings are discussed along with inferences and suggestions for changes in practice.

4.1 Background

In the previous focus group study some preliminary baseline ideas about motivation within the context of PR have been generated. The purpose of the study described in this chapter was to build on that baseline theory and increase the detail and richness of data. Further exploration of patient's experiences of motivation was needed in order to present an understanding and description of the phenomenon that can be communicated to others with an interest in this speciality. It was envisaged that having 2 different approaches to the qualitative data collection would add to its richness and quality. Using both focus groups and interviews in combination has previously been shown to be a successful method of qualitative data collection (Lambert and 'Louiselle 2008). It is possible that patients may sometimes discuss things on a one to one basis that they may not wish to discuss in a group. Alternatively, having a group may stimulate thoughts that may have been forgotten in a one to one interview. It was believed that using both approaches enabled us to capture a wider range of data than just one approach. The themes identified within the focus group study described in the previous chapter were converted in semi-structured questions for use in the study described in this chapter (Appendix 4.4). Data collected within this study would then form the basis of a motivation measurement tool. The objectives of this study were as follows:

- To explore COPD patient's beliefs, interpretations, norms, ideas and understandings about motivation within the context of PR and also their experiences of factors which have influenced their own motivation either positively or negatively.
- From this data to produce a conceptual explanation of factors found to relate to motivation within the context of a PR programme.

4.2. Study design

As for the focus group study, a qualitative design using a phenomenological approach (Polit and Hungler 1996) was used. A description of phenomenology and its' application within this research project is given in chapter 3. Face-to-face interviews were employed using semi-structured questions developed from focus group results. Interviews were undertaken with patients participating in sections of the PR process. Data was collected around patient's beliefs, attitudes and experiences within the phenomenon of motivation in the context of a PR programme. The process of phenomenology was used throughout the study, to include the intuiting, analysis and describing stages.

4.3 Methods

4.3.1 Patient interviews

There are generally 2 types of interview that are used in research (Oppenheim, 1992). The first is an exploratory interview. This is a 'free-style' interview, where the interviewer is able to explore a topic further based on the responses of the interviewee. The second type is a standardised interview. This is where the interviewer has fixed questions and is commonly used in opinion polls, market research etc. Standardised interviews are concerned with mass data collection in large-scale surveys (Oppenheim 1996). The type of interview that was selected for this study was an exploratory, semi-structured interview, since it is more amenable to the phenomenological approach used (Polit and Hungler 1996). The research objective was to collect rich data about the phenomenon of motivation. Since motivation may be unique to each individual, the interview needed to be flexible enough to encompass unique, individual interpretations. Having a semi-structured design allowed the interviewer to pursue any interesting avenues and also be better placed to capture information about attitudes and perceptions. If the study had been focussed on collecting factual information, where often there is a definite answer (for example, what car do you drive?) then a standardised interview would be sufficient. However, as the study was concerned with attitudes, feelings and belief, where there is often not a straight- forward answer, then a semi-structured interview allowed the interviewee to express their feelings. Other researchers have used successfully used patient interviews to develop instruments to measure psychosocial variables (Davis et

al 2007, Lareau et al 1994, Jones et al 1991 and Garrod et al 2000). In these studies interviews have successfully contributed to the development of a valid measure.

Planning and practice was undertaken prior to the interviews. It is known that interviewing for research takes planning and skill (Mason 1996 and Polit and Hungler 1996) in order to generate sufficient data, so a great deal of consideration was given to developing the skills of the interviewers. Interviewers have to consider how the questions are phrased, what words to use and in what manner they should be asked, demeanour and approach should also be considered (Oppenheim 1996). The interviewer should be able to 'think on their feet' and often needs to formulate questions on the spot (Mason 1996). Interview skills were rehearsed and used by the interviewers. The skills required for successful interviewing that were adopted by the interviewers are presented in Mason 1996.

4.3.2 Sample

In this study, there was not the testing of a hypothesis, rather the objective was to gather in-depth data about patients' experiences, attitudes and beliefs. For this reason a random sample was not necessary, however the sample needed to have a relationship with the population (Mason 1996). Patients were chosen who were either in the PR process, or who had completed a programme previously. It would have been very easy without the need for randomisation to simply select the patients who were 'favourites' amongst the PR staff. Therefore a method of selection was used to ensure that the patients for interview were not 'hand-picked, and this is described below. There came a point however, where in order to fulfil the purposeful sampling criteria, patients with specific characteristics had to be chosen. A purposeful sampling (Patton 1989 and Polit and Hungler 1996) method was used because it was anticipated that with potentially very few patients being interviewed this would be a better way of producing rich, high quality data. The purposeful sampling technique used was maximum variation sampling (Patton 1989 and Tagg 1985). Maximum variation sampling enables the type of people and sites selected to be representative of the larger population. For this, the maximum range of sites and patients that constitute the population would be chosen for the sample and this is illustrated in table 4.1.

Table 4.1 Dimensions of sample

Dimension	
Temporal	Before, during, after and dropped out from a PR programme
Spatial (geographic)	Worcester PR programme Malvern PR programme
Physiological	Mild / Moderate and Severe COPD Receiving long term oxygen therapy / Not on oxygen therapy
Psychosocial	Lives alone / with carer Depressed / not depressed Smoker / non-smoker

The number of patients for interview was not established at the beginning of the process, since scope was needed to be able to add patients if new dimensions emerge through the earlier interviews (Rubin & Rubin 1995). Two criterion were however applied to the sample size. The first is sufficiency of patients to be representative of the population. The second is data saturation (Rubin & Rubin 1995), a point in the study that occurred when no new information is being collected through the interviews.

Although the study sample did not need to be random, care was taken that the sampling frame was not selected in a biased way. A research assistant selected every third patient from the database of patients in the PR process. These patients were past, present, dropped out or who had had an assessment but were still on the waiting list for PR. This left a sampling frame of 73 patients. The patients were then contacted by a letter (Appendix 4.1) inviting them to take part in the research and sent a self addressed, stamped envelope to assist in the response. Seventy – three letters were sent out. There were 29 positive responses and 7 negative responses. Thirty-seven did not respond in any way. Patients were then selected purposefully by the author to meet the maximum variation sampling as described above. When needed, patients outside of the sampling frame were added to the sampling frame in order to

capture specific variations. Table 4.2 shows the characteristics of the interview sample.

Table 4.2. Characteristics of interview sample

Gender	Male: n = 9 Female: n = 9
Disease severity	Mild: n = 0 Moderate: n = 5 Severe: n = 13
Receiving oxygen therapy	Not on oxygen: n = 11 Receiving oxygen at home: n = 7
Anxiety and depression	Depressed: n = 8 Not depressed = 10 (As defined by HAD, Zigmond and Snaith 1983)
Domestic situation	Living alone: n = 4 Living with carer: n = 14
Smoking	Smokers: n = 1
Place of PR programme	Attending rural community programme: n = 3 Attending city hospital programme: n = 15

4.3.3 Ethical considerations

Ethical approval was obtained from the local ethical approval committee (see appendix 4.1). Each patient was given an information sheet (Appendix 4.2) about the study and gave informed consent (Appendix 4.3). Written and recorded data pertaining to the patients was stored in a locked cabinet inside a locked office and the information was only used for the research. Patients were reassured that confidentiality would be maintained, audio-tapes would be destroyed following transcription and names would be changed during the writing up of the research. A

copy of the signed consent form was placed in the patient's notes and a second copy stored within the research department.

4.3.4. Procedures

Focus group results were used to create a series of semi-structured questions for interview (Appendix 4.4). Care was taken with the wording, content and order of the questions to ensure response bias was not introduced (Oppenheim 1996). The questions were typed onto an A4 sheet of paper held on a clipboard by the interviewer enabling them to make brief notes during the interviews. The interviews were face to face with the patient and the dialogue was recorded on audio-tape. The interviews were conducted by either the author or a research assistant. The interview skills of the research assistant were observed and critiqued by the author prior to conducting interviews alone. In order to develop interview skills the author and research assistant 'practiced' interviews with work colleagues. 2 pilot interviews were also undertaken with patients and were peer observed. This enabled feedback regarding interviewing skills and question difficulty or ambiguity. The 2 pilot interviews demonstrated that some of the initial questions needed to be reviewed as they introduced response bias. Also the question format was changed to enable the interview to 'flow' in a more logical way. Interviews took place either at a PR venue, before during or after a PR session, or at the patient's home. A standardised time of 30 minutes was used for each interview enabling the interviewer to hone their skills by working within a set amount of time (Siedman 1998). The research assistant, who conducted some of the interviews, was not experienced in interviewing for research but had many years developing skills in taking a medical history from patients with chronic illnesses. Many of the skills required for interviewing for research are the same as taking a history from a patient. The second interviewer initially 'practiced' her skills by interviewing nursing colleagues and was given feedback about their performance. Then, she performed 2 observed interviews, again with feedback from the observer. At this point, the second interviewer was deemed competent enough to interview without observation.

The interviews began with questions that put the interviewee at ease before moving to the more searching questions. Patients were given the opportunity to provide an account of their motivation, along with their interpretations and thoughts of their

accounts, based on their own experience of PR. In the case of patients on the waiting list who had not yet been on a PR programme, their account was based on their experience of facing the challenge of making a lifestyle change. If patients found difficulty providing explanations the interviewer prompted the patient making every attempt not to influence their answers. The interviewer probed the patient further if interesting avenues of data emerged. As new dimensions emerged through earlier interviews, appropriate patients were added to the sample to enrich the data and the semi-structured questions were modified.

4.3.5 Data analysis

Data was analysed following the phenomenological approach described in Polit and Hungler (1996). The recorded interviews were listened to by the researcher in the intuiting stage of the process. The researcher became immersed in the data and creatively varied it until understanding emerged. Then analysis was conducted directly from the audiotapes using basic content analysis of the interview discourse (Crabtree and Miller 1992). Irrelevant discourse was discarded and only relevant discourse was transcribed. The data was then grouped into the coded categories originally generated by focus groups. During analysis, categories were modified or transformed as new concepts emerged. New emerging themes were labelled and categorised. Initial categorised data was then further broken down and coded into sub-categories. Three of the interviews were analysed by the research assistant, blind to the researcher to check reliability of methods.

Further intuiting and analysis was applied by the researcher to make sense of the meanings behind the phenomenon of motivation. Finally, a distinct and critical description of the findings was communicated to the reader in a visual form.

4.4 Results

In total, 18 patients were interviewed. Analysis of the discourse revealed 3 essential motivation categories, 4 external motivation categories and an additional category labelled 'behaviour' which was a stand-alone category. The results built on the analysis of the data collected from the focus groups and provided the formation of

new categories and the modification of old ones. The categories and sub-categories are presented in table 4.3.

Functional ability

Many of the patients interviewed associated motivation with consistently behaving, and having the ability to behave, in a ‘physically active’ way. This category was labelled tenacity because of the way patients described undertaking activity and exercise on a regular basis, overcoming external circumstances that may cause a less motivated person to discontinue. Tenacity was labelled as an essential motivation variable as it was part of the patient’s internal status. One patient seemed to encapsulate tenacity in a sentence. He said:

“You force yourself to do it – my wife will say I’ll do that, and I say no, I must do it. Might only be going to make a cup of tea or something like that but you get up and do it whether you want to or not that’s part of the secret – People give up too easily I think.”

Descriptions of adhering to physically active behaviour were also supported by comments such as:

“I keep on going and get out and about, getting out of the house, I find something to do all the time.”

“I never stop, always doing something.”

Table 4.3 Results of interview analysis.

Category	<i>Positive sub-categories</i>	<i>Negative sub-categories</i>
Functional ability <i>Behaviour</i>	Exercise routinely Regular recreational activity Making an effort to do things Having the ability to maintain activity	Can't stick to exercise regime Poor recreational activity Laziness Giving up Co-morbidity restricts activity Find activity an effort
Attitude. <i>Essential motivation</i>	Drive and determination To try to do your best Willpower Optimism Knowing there's always someone worse off Happy disposition	Lack of will power Not being bothered to do things Pessimism Depression
Self-efficacy <i>Essential motivation</i>	Confidence Independence Coping Disease self management	Fear of breathlessness Lack of belief in ability Lack of independence Unable to cope
Self esteem <i>Essential motivation</i>	Positive Body image Feeling valued	Feeling embarrassed Body image Feeling worthless
Life experiences <i>External motivation</i>	Encouraged to work hard in childhood / adolescence. Led hardworking and active life before illness.	
Impetus. <i>External motivation</i>	To be as well as possible To improve quality of life To prove I can do it. Not wanting condition to deteriorate Believing the exercises are effective / seeing the benefit Goal setting	Condition is getting worse Going onto oxygen No set exercise routine
Human interaction <i>External motivation</i>	Supportive Spouse Encouragement from spouse Need spouse for company Encouragement from family Having good social life (friends) Support from HCP's Being in a PR group. Being with people who are in the same situation Exercising with other people Motivation of going to a group	Unsupportive spouse Living alone Bereavement Lack of social life (friends) Poor support from HCP's Unable to exercise alone Not going to the group Reaction of other people
Symptom variability <i>External motivation</i>	Motivated even on bad days Good weather Feeling well	Having "off" days The weather Exacerbations

This consistency seemed to be important when it was under difficult circumstances.

One lady said:

“If I have a bad day I’ll do what I can.”

Consistency seemed to be the key in this category, for example one patient explained:

“I only miss coming here every week if I’m away or have got another medical appointment.”

Interviewees associated undertaking plenty of recreational activity with being motivated. Many patients talked about hobbies and interests such as travel and gardening as a motivating factor. Supporting statements included:

“When I get depressed or lethargic I try to read uplifting things.”

“I go out to the greenhouse.”

“I love my fishing.”

“I’ve got lots of hobbies, I write and I lecture……. I never stop. Photography motivates me to get out and about.”

There was an opposite side of tenacity, which appeared to be an inability to be consistent with exercise, activity or recreation. One patient described this as laziness. This was associated with de-motivation. Comments supporting this were:

“When I was young I used to dig the garden, but I don’t do it now I can’t.”

“ Everything was such an effort, I was always so tired.”

“ I can’t do it.”

“ I won’t attempt a hill.”

Patients described how they viewed not maintaining consistent activity and exercise would have a detrimental effect on them:

“A little step forward is better than slipping back.”

“It’s very easy to slip back – you know when you don’t do things, it’s very insidious.”

Attitude

Interviewees frequently presented motivation as an attitude taken by a person and hence, the category was thus labelled. The attitude of a person towards behaviour was viewed by many patients as an essential component of motivation. They associated positive attitudinal qualities with motivation and negative attitudes with demotivation. One patient, when discussing how the PR group had a motivational effect, was asked *“What motivates you if you don’t go to the group?”* and they replied:

“It’s just something inside me.”

Another patient, when asked what motivation meant to him said:

“It’s a frame of mind, you put yourself into a frame of mind.”

A number of words and short descriptive statements were used to describe a motivated attitude. These included: *Drive and determination, willpower, optimism, trying to do your best, go for it, get going, to pick yourself up, optimism, to try.* One lady said:

“I am determined to do it – I’m that breathless when I finish but it doesn’t stop me doing it again.”

A ‘happy’ disposition and an optimistic view of life seemed to be another positive facet of attitude. Supporting comments for this included:

“I try not to get myself down. – I try to look on the bright side all the time.”

“I’m quite a happy person – I don’t normally get up in a grumpy mood.”

There was an opposite side to a motivated attitude that was described by the patients. They discussed negative states of mind such as, depression, pessimism and lack of will power as being associated with de-motivation. The term ‘to give up’ was frequently used to describe an attitude associated with an unmotivated individual. Other statements similarly coded were:

“Why didn’t they let me die?”

“I don’t want to do it.”

“I have no will power.”

Some people talked about depression synonymously with de-motivation. Supporting statements were:

“I get depressed and lethargic – when everything’s a terrible effort.”

“There are days when I’m really low – then I don’t do a darn thing.”

Self efficacy

This emerged as an independent category that included variables such as confidence, independence, coping and disease self-management. People associated being motivated with these variables. There were a large number of supporting statements for this category and the following are the most representative.

“By the end of pulmonary I was confident.”

“You think ‘I can do it’ and you do it.”

“I am very independent.”

At the opposite end of the spectrum, patients described an inability to cope, fear of breathlessness and lack of independence as associated with de-motivation. For example:

“I’m frightened when I am on my own – I’ve lost the nerve to go out.”

“When I get out of breath I panic like hell.”

Self esteem

Interviewees talked about a positive self-image and a feeling of self-worth being a facet of motivation and a negative view of themselves as something they associated with de-motivation. This group of statements were labelled ‘self esteem’. Positive key statements included:

“ We’re still worth something / worth a million.”

“You feel attractive.”

Negative body image statements included:

“People look at you.”

“Feeling like I am on the scrap heap.”

“Feeling worthless.”

A lot of emphasis was put on how the patients believed they were viewed by others. One man described how this concern prevented him from going out of doors. He said:

“I don’t like anybody seeing me, I won’t walk out where there’s people. Which I know I should do but I just can’t.”

Another said they felt embarrassed about their condition. One lady even described how she no longer saw her friends, as she did not want them to see her as she was with COPD.

Life experiences

A small proportion of patients discussed how their life experiences during youth and middle age had had an influence on their motivation. Descriptions ranged from the motivational influence of prominent adults during childhood to employment experience. One patient described how she was brought up by a very strict aunt, who used to say:

“Come on Maggie, backbone.”

She explained how this had stayed with her all her life and whenever she lacked motivation she would say to herself *“backbone Maggie”* like her aunt and immediately this would restore her determination. Another patient described how he had been influenced by his father.

“My father was a fairly determined person. I came from a background where you had to work to get anywhere. Medical school was a struggle, even though I was determined to be a doctor.”

Others talked about how a hardworking lifestyle in middle age influenced their current attitudes. One patient said:

“we were in the pub game for 30 odd years and it was never easy, and regardless of how you felt, when you got up in the morning you’d got a day’s work in front of you. You couldn’t mollycoddle yourself. You just got stuck in. You forget your aches and pains”. Another said “I was a very active person”, and another reported “I was in management and every job was a challenge. So you were motivated all the time in your work.”

A small number of the interview sample had been diagnosed with their lung condition at a very young age. These patients made additional comments suggesting they had a better coping strategy as a result and consequently were able to motivate themselves

more successfully than patients who had been diagnosed in later years. One such person who had had their condition since childhood said:

“The motivation has always been there - but on the quiet. I never made my condition public.”

Another who had been diagnosed in their teens said:

“I’ve learnt to cope over the years”.

There were no negative comments in this category.

Impetus

The majority of patients interviewed discussed the fact that they had either one or more specific goals that they wanted to achieve and this assisted their motivational status. The incentives were very varied and unique to each person. This category was labelled impetus. Some incentives were very specific. For example:

“My grand-daughter’s wedding.”

“Going on holiday.”

“I wanted to do swimming again.”

“I wanted to get up top of garden and back without stopping.”

Some incentives were less specific:

“I would like to get better.”

“To want to live.”

One lady talked about how she wanted to prove to others that she could do things and that was her incentive. A number of people described how their grandchildren provided an incentive:

“My main reason is my Grandchildren – I haven’t been able to enjoy myself with them”

“ We look after my grandson on a Saturday, and that’s my only goal in life to be fit for Saturdays”.

A small number of interviewees described how not having a routine to follow caused them to be de-motivated. One lady described how she planned her housework and usually had a routine. But when she didn’t get out of bed at her usual time her routine seemed to ‘go to pot’ and her motivation reduced. She said:

“If I’m late that’s a problem – what I don’t do in the morning I don’t seem to do at all.”

Another, when discussing things that reduced their motivation said:

“ Not having a set day a week for my fitness club. I know that I’m slipping up on that one.”

A particular incentive that was described by a large proportion of patients interviewed was the perceived effectiveness of a PR programme. The belief that PR was an effective therapy gave the patients an incentive thereby increasing motivation.

Supporting statements were as follows:

“I found I was getting more and more energy and I started to do things.”

“ I knew it was working – I felt better.”

People also described how their motivation grew as they started seeing the results of the exercise. For example:

“The first 2 weeks it was really hard work, then, one Saturday morning, I was doing my housework and I noticed I was less breathless and you suddenly realise – yes, she was right, the exercise is good for you – and then you look forward to going. Suddenly you were getting improvement which you didn’t expect.”

It was apparent that not only was the patient’s own improvement motivational but also when improvements in other people were observed:

“ Seeing other people walking when at the start they couldn’t move.”

“Seeing yourself improve and seeing other people improve was a great boost.”

Attending a PR programme had made many interviewees more aware of other people with COPD who were physiologically and functionally worse than them. Seeing other patients with more severe disability seemed to provide the impetus for the interviewees to do anything possible to prevent them deteriorating to a similar level. Other patients interviewed were simply aware of the fact their condition could deteriorate and this motivated them to do their exercises. Supporting statements were:

“I’m not going to let it beat me.”

“If you give up, you’re going to be in a wheelchair and that’s it.”

“I’ve seen others in the group and I consider myself very healthy compared to some of them – it’s putting off that day when that’s going to be my future.”

“I know it’s not going to get better but I don’t want it to get worse.”

In contrast, a smaller number of patients felt that their condition was deteriorating and that this made them de-motivated. Again, commencement on oxygen was a significant factor. Supporting statements were:

“There’s nothing the doctors can do for me I’ve been chucked on the scrap heap.”

“Knowing that I’m getting worse makes me worse.”

Where patients saw others on oxygen therapy this either had a positive or negative impact on their motivation. For example, the motivation of some patients increased as seeing others on oxygen gave them the incentive to modify their behaviour to prevent themselves becoming oxygen dependant. For example, one lady said:

“I don’t fancy walking around with an oxygen tank. So if exercise is going to put that off, then it’s exercise every time, isn’t it?”

Others found it decreased motivation as they viewed oxygen therapy as an inevitable stage of their demise in health. One lady described this:

“I was a little depressed at first, because when I saw those other ladies with portable oxygen on I thought ‘Oh God! Is this going to be me’”

Oxygen, or at least the thought of starting it, seemed to instil a real fear in the patients. Patients interviewed who were oxygen dependent viewed this as almost the beginning of the end and it certainly contributed to a reduction in motivation. One man said:

“When I started this oxygen, I thought well that’s the end of me”

One patient commented on the plight of another and told how she felt as if oxygen was a failure. He said:

“A lady on the course tried so hard. But she was admitted to hospital and they told her she needed oxygen and she was devastated because she tried so hard”.

Human interaction

A considerable amount of discourse revolved around the importance of human interaction in increasing motivation. It emerged as a key category since patients comments about its’ importance were heavily weighted. Human interaction ranged

from the other members of a PR group, to healthcare professionals and to family and friends. There were strong positive and negative aspects to this theme.

Most patients reported the motivational benefits of actually attending a PR group.

Key statements included:

“ Coming to PR gave me the willpower I was lacking.”

“You’re with people that understand what you are going through.”

“The group motivates me, it’s nice to have someone different to talk to, to share their experiences.”

A number of different reasons were given as to why the group situation was motivational:

“You were with people in the same situation as yourself. You enjoyed the company and you learnt a lot.”

“You see people that’s worse off than yourself.”

Some found group competitiveness motivating:

“Being in the group motivated me – you know in a group you can always beat someone else doing it.”

There was a strong feeling that contact with supportive healthcare professionals either during PR or at other times instilled motivation. Some described how they were trying to do well to please their Consultant and specialist nurse and that to not follow their exercise programme would be letting them down. One lady described a period where she had not been exercising:

“I can go a little time without seeing you (the interviewer) or the consultant, but I think of you and I think – they wouldn’t like it if they saw me like this.”

Another patient said:

“I owe you my life.”

And another said:

“If I think ‘I’ve had enough now I’m giving up’ I’d be letting you and the consultant down because I was giving up.”

Patients clearly valued encouragement from healthcare professionals involved in their care:

“The healthcare team has given me new life – in what you say to us and what you do.”

A particularly strong theme within this category was that motivation is increased by having a supportive family. In particular, a supportive spouse. One man explained:

“My wife is very understanding – she’ll join in the exercises and go for a walk with me – she’s really my right hand person, you know. If I’m feeling a bit down or a bit sluggish she’ll give me that push ‘come on you’ve got to do it.’”

Other comments included:

“My son and his wife are all into exercises and all that and they keep onto me - have I done any exercises? She says ‘come on. It’s good for you.’”

Having positive social interactions with other people was associated with motivation. This seemed to mean more than simply having a supporting spouse. It was more about actively engaging in social interaction. Patients often made reference to having light-hearted, friendly conversation with other people, either friends or strangers. Supporting statements for this included:

“Getting ready to meet Emma (my friend), just that, meeting someone face to face, a real person.”

“What will do it is having someone come and talk, you know, or seeing a friend. Going out with a friend or to see a friend.”

There was a negative side to the human interaction category. Negative experiences included unsupportive spouses, living alone, bereavement, a lack of a social life, poor support from healthcare professionals, not being in a PR group and a negative reaction from others. Patients explained how these negative aspects of human interaction reduced their motivation.

Some patients described how either an unsupportive or an overprotective spouse could de-motivate them. One lady explained about her husband:

“He babied me – everything was done for my convenience.”

She described how this de-motivated her as she lost her independence. Another lady told how her husband stopped her from following the advice given in pulmonary rehabilitation to be as active as possible.

“He says - don’t do that because you’re breathless.”

This de-motivated her. One gentleman described how his wife had no time for him with his illness and this de-motivated him. He said:

“If my wife was different I would feel more motivated – like walking about more and not being so selfish. It’s her attitude.”

A similar experience was described by a lady whose husband frequently ridiculed her when she did her pulmonary rehabilitation exercises. She explained:

“I don’t exercise when my husband is there, because if he sees me he says ‘what you doing that for?’ Once he’s out the way I can get on with it.”

Another man described how his wife almost ridiculed him for his illness. He said:

“She encouraged me too much when I knew I couldn’t do it. She used to walk fast and I couldn’t catch up.”

All of the patients who had experienced this type of unconstructive response from their spouses described how this had negatively influenced their motivation.

Another negative side of the human interaction category was the de-motivating effect of having no family / spouse at all. Some patients discussed how living alone without a family made them de-motivated and sometimes depressed. Some interviewees also told how having a lack of social interaction with others made them lose motivation. Supporting statements for this category were:

“When you are on your own, I suppose you loose a bit of the motivation”

“Nobody is there to see you”.

“ I had no friends left.”

Symptom variability

Patients told of how the characteristic ‘good days and bad days’ experienced in COPD had a significant positive or negative impact on their motivation. Additionally, factors affecting COPD symptoms, in particular the weather or COPD exacerbation, had an effect on motivation. Some patients remained motivated even there was a worsening of symptoms. Supporting statements were as follows:

“I try not to let the breathless days affect my motivation, I am a bit slower doing my exercises but I still try to do them all the way through.”

“My motivation is absolute – even when I am breathless.”

“A good sunny day I’m happy – I can’t wait to get up and get out.”

“With these tablets I’ve been on, they’ve made me that breathless, I’ve done more sitting down than ever before.”

“The weather doesn’t help – in the hot weather your breathing’s difficult, and in the cold and damp your arthritis is worse.”

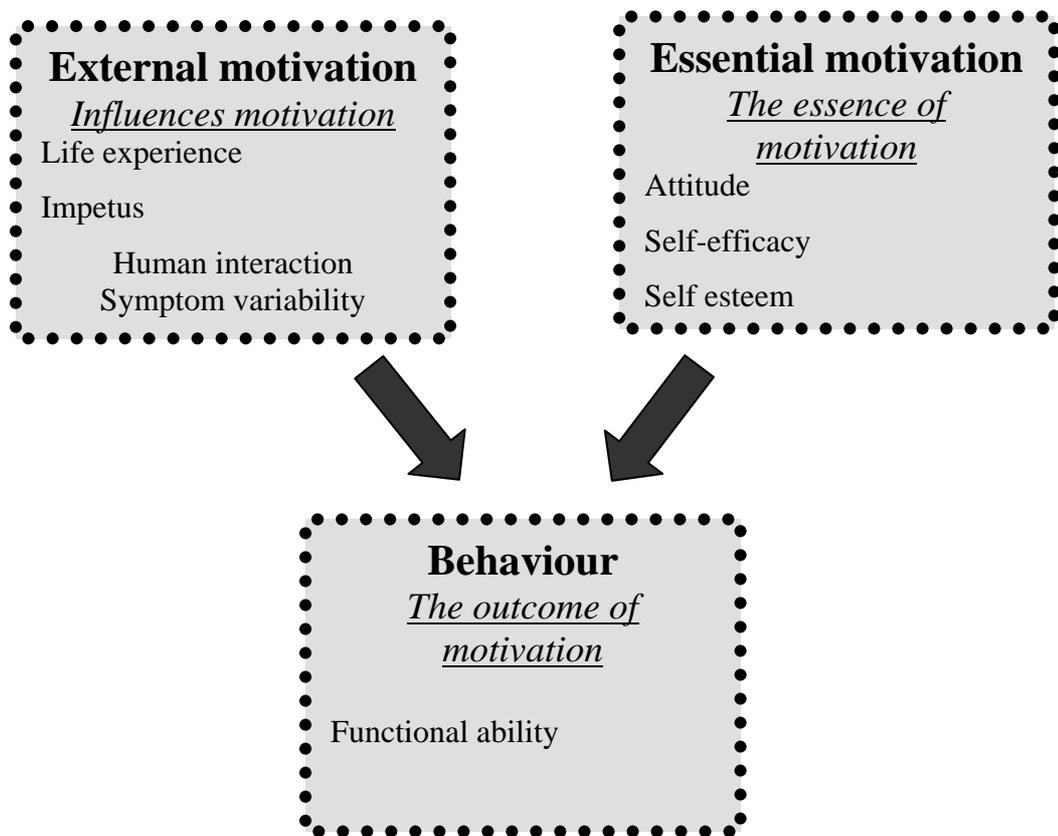
4.4.1 Description of the phenomenon of motivation

Motivation within the context of PR emerged as a group of components, most of which had both a positive and negative element. Each component was allocated to one of 3 dimensions: essential motivation, external motivation and behaviour. Essential motivation consisted of attitudes and behaviour that patients associated with a motivated person. These attitudes and beliefs reflected the essence of what motivation is within the context of PR. External motivation consisted of the components that indirectly had an influence on the patients’ motivational status. These components influenced essential motivation components that in turn increased or decreased motivation. Motivation then influenced behaviour. This dimension consisted of only one component and reflected how a motivated person behaves. Figure 4.1 illustrates the 3 dimensions.

The categories life experience, impetus, human interaction and symptom variability came within the dimension of external motivation. The positive and negative elements within these categories similarly influenced the patients’ motivation. These categories were dynamic and it emerged that they altered during a change in circumstances. The life experience category consisted of the patients’ upbringing as a child and their employment history. This category indirectly affected motivation via attitude. For example, where patients had had an upbringing where they were encouraged to work hard, apply themselves and persevere, this brought about a very positive attitude, thus making them a more motivated person. Impetus was a critical component that influenced motivation. One of the main incentives in this category was to maintain or improve health. This sub-category was closely related to another sub-category – believing that the exercise would work. This was the catalyst that enabled the incentive of improving health. Patients at the very least hoped the

treatment would work before they could use the goal of improving their condition. Their hope and belief in the effectiveness of exercise perpetuated as they progressed through the programme and they saw visible proof. This linked to the human support category, in particular healthcare professionals. Belief in exercise efficacy was increased when it was advocated by healthcare professionals. Where patients perceived their condition as deteriorating and did not feel that the PR programme could benefit them, this had an extremely negative affect on motivation. Human support affected all the essential motivation components by increasing self esteem and self-efficacy and improving attitude. This took place by either the active support of others (encouragement, praise, education, practical support, counselling etc), or passive support when patients saw others more severely ill and re-evaluated their own situation. The final external influence was symptom variability. This was induced by situations such as exacerbation, the weather or the day-to-day symptom variability characteristic of COPD. This affected attitude either positively or negatively, which in turn increased or decreased motivation.

Figure 4.1 The 3 dimensions of motivation in PR.



The categories self-efficacy, self-esteem and attitude comprised the essential motivation dimension. Patients associated positive attributes of these categories with a motivated person, and negative attributes with a de-motivated person. Essential motivation could fluctuate across a spectrum between positive and negative as a result of changes in the external dimension. For example, one lady's husband had died a year prior to her interview. He had always encouraged and helped her to maintain her independence. She described how this bereavement (categorised under human support, external motivation) had affected her attitude and independence (self-efficacy) negatively, thus reducing her motivation.

It emerged that the manifestation of a motivated person is one who is physically active, gets 'out and about' on a regular basis and generally leads a full and active life. The opposite was associated with a de-motivated person. Patients viewed physical activity, or functional ability, in COPD as an outward expression of their internal motivational status. This dimension was labelled behaviour and is the outcome of external and essential motivation – the end product. The figure 4.2 below conceptualises the relationships between the categories, subcategories, dimensions and motivation.

Analysis of the data further demonstrated how theoretically a PR programme is a process which builds motivation. This emerged as a cyclical process, from when a patient first enters a programme, to their completion. At the beginning of a programme patients agreed to attend with the goal (impetus) of improving their health. At this point essential motivation was often low. There was often scepticism about the efficacy of exercise, fear of breathlessness, poor self-esteem and a lack of belief in their ability to undertake an exercise programme. At this point the external motivation dimension needs to be at its most positive, where this can be manipulated. It is impossible to change the patients' upbringing, for example, but human support can be adjusted in order to influence essential motivation. Education, encouragement and practical help from healthcare professionals can help increase self-efficacy and facilitate a positive attitude. Likewise, encouragement and support from family can help with exercise compliance and attitude. As the patient progresses through the programme and starts to experience the benefits from both exercise and the group support, essential motivation components move to the more positive end of the

spectrum. Motivation is perpetuated and the influence of external motivation factors is lessened. For example, an unsupportive spouse does not exert as much negative influence when a patient has undertaken a PR programme. This is conceptualised in figure 4.3.

Figure 4.2 Patient perceptions of motivation in a pulmonary rehabilitation programme.

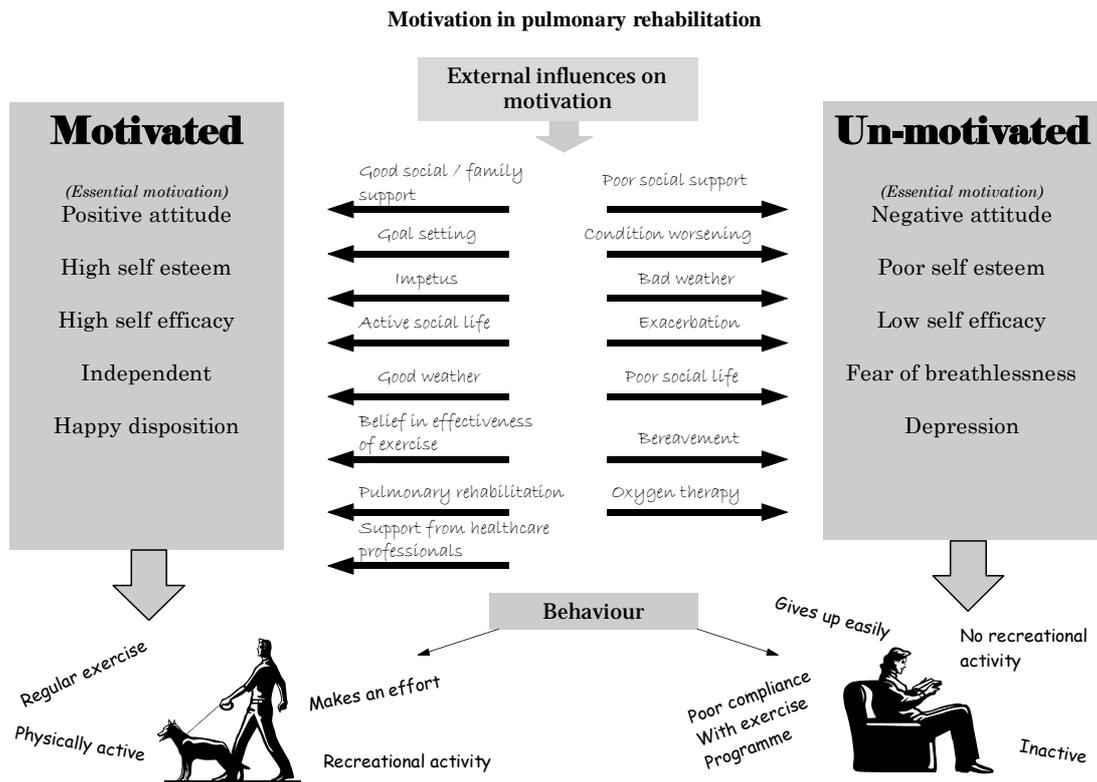
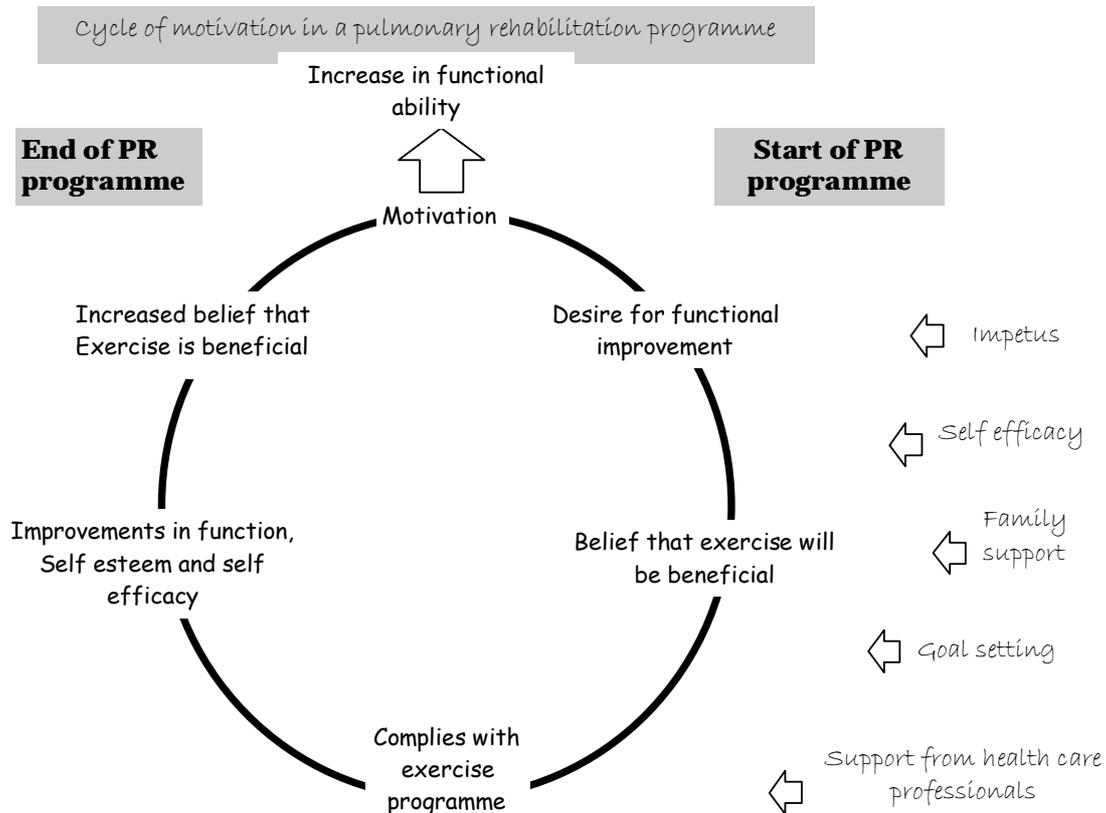


Figure 4.3 Cycle of motivation in a PR programme.



4.5 Discussion

This study has explored the experiences of motivation in COPD patients during the PR process and has demonstrated that motivation is a multi-dimensional concept with psychological, social, physical, circumstantial and behavioural components. This is evident in the theoretical models of motivation, where factors relating to the environment, personality, behaviour, attitudes, beliefs and norms of the individual interact with each other and determine health behaviour (Ajzen 1977, Bandura 1977, Prochaska and Diclemente 1994, Maehr and Braskamp 1986, Becker 1974 and Leventhal et al 1980). The experience of each patient who was interviewed was unique. However, data analysis demonstrated patterns and relationships between these unique experiences, enabling the data to be organised into a visual description of motivation in PR.

4.5.1 Essential motivation

Three constructs were found to constitute essential motivation. These were attitude, self-efficacy and self-esteem. The positive aspects of these constructs were associated with a motivated person and seemed to represent the very essence of motivation. These findings added detail to the original data collected in the previous study where the concept of having an 'internal' motivation was discussed.

Attitude

Attitude has been previously presented as a determinant of behaviour and has also been shown to predict exercise tolerance (Morgan et al 1983). In Ajzen's theory of planned behaviour (1985), attitude is shown to influence intention, which in turn predicts behaviour (Bozionelos and Bennett 1999). This study showed that the feeling of depression was associated with not being motivated. This finding is supported in other studies where it is argued that having a high self-motivation may include characteristics related to the control of anxiety and depression as well (Heiby 1987). The notion of optimism, which was described by the patients in this study, has been presented as playing a role in the self-regulation of behaviour (Carver and Scheier 2001).

Self esteem

In this study, self-esteem was shown to be a component of essential motivation. COPD has been shown to have a negative impact on self-esteem (Nicolson and Anderson 2003). Toms and Harrison (2002) found that patients with COPD felt a loss of self, role and identity as one of the effects of the illness. This was mainly due to the stigma of a 'self-inflicted' illness and the anti-social symptoms. The authors found that one of the key effects of a PR programme was that patients developed a positive self-image and gained redefinition of role and identity. These echo the findings of our study where patients discussed similar feelings of 'uselessness'. However in this study, the patients related these feelings to having a negative effect on motivation. Self-esteem has been shown to be a determinant of motivation in other studies (Fox 1997). It is also known that physical activity has a positive impact on self-esteem (Marsh 1986). These findings from other studies support the idea that the cycle of motivation in a PR programme includes an increase in self-esteem, brought about by an increase in physical activity, thus increasing motivation.

Self efficacy

Similar to the findings of the previous study, coping and confidence were frequently presented by patients as aspects of motivation, as was fear of breathlessness in the negative dimension. This category, labelled self–efficacy, was found to be a component of essential motivation. Other conceptual models of motivation support these findings. For example, in his social-cognitive theory, Bandura presents self efficacy as a predictor of behaviour (1977). In the theory of planned behaviour (Ajzen 1985), the person’s confidence in their ability to carry out the behaviour will influence their intention to do so. Bandura (1977) defines self-efficacy as a person’s perception that he or she is capable of performing a given behaviour successfully to produce a certain outcome. It has been argued that if individuals attribute health to factors beyond their control, it is unlikely they would attempt to control these factors (Heiby et al 1987).

On its own, self–efficacy has been shown to be an important element in patients with COPD (Scherer and Shimmel 1996, Zimmerman et al 1996, Scherer et al 1997) and it has been measured using the *COPD self-efficacy scale (CSES)* (Wigal et al 1991). Other studies have found that an increase in self – efficacy has led to an increase in physical activity in COPD (Gormley et al 1993 and Kaplan et al 1984). Toms and Harrison (2002) found that the perceived overall effect of a PR programme was that of confidence. This was supported by Zimmerman et al (1996) who found that self-efficacy was increased following a self-management programme for people with COPD.

In the social-cognitive theory (Bandura 1977), unpleasant sensations experienced during exercise affect self-efficacy expectations and decrease motivation. An informal observation of patients undergoing PR is that they often report that exercise ‘does not feel so bad’ when it is undertaken within a group than alone. Patients also anecdotally report that they can cope with a harder level of exercise within the PR group than at home alone. It is possible that the camaraderie of the other patients and presence of healthcare professionals decrease fear of breathless, thus increasing efficacy and motivation.

A study by Wedzicha et al (1998) supports this idea. In that study, patients reported that they were housebound using the MRC dyspnoea scale and yet achieved shuttle-walking distances in excess of 100 meters. This disproportionate self-perception of disability may be related to self-efficacy. At home fear of breathlessness probably existed preventing activity, however undertaking an exercise test in the presence of a healthcare professional may have made these patients feel safer, thereby increasing exercise tolerance. In a study by Stribos et al (1996) which compared the effectiveness of home and hospital PR programmes, it was observed that the breathing exercises given to the patients desensitised them to breathlessness. This in turn gave the patients control over their fear of breathlessness during exercise, allowing them to aim for a higher exercise intensity. Other studies also report a disproportionate improvement in breathlessness following a PR programme, which cannot be entirely explained by an increase in exercise tolerance (Reardon et al 1994 and Scherer and Shmeider 1997). It is clear from this and other studies that a dynamic interaction of cognitive processes occur during a PR programme which are over and above the effects of exercise alone.

Self-efficacy may mediate the effect of exercise intensity on motivation. Perceived exertion during exercise seemed to be negatively related to participation (Dishman 1994c). Morgan et al (1983) showed that fear of exercise was related to exercise tolerance. However, little is known about what effect types and intensity of exercise within a PR programme has on motivation or compliance. During interviews, patients did not present this as a determinant of motivation, and we do not know if it impacts on compliance. The study by Scherer and Shmieder (1997) examined the effect of PR on self-efficacy, perception of dyspnea and physical endurance. The authors found that at the end of a PR programme there had been an increase in these 3 outcome measures and that there were correlations between self-efficacy and both dyspnea and physical endurance. This seems to support our qualitative data collected in this study. However, what remains unknown is the causal relationships between these constructs. In other words, what comes first during a PR programme? Is it the increase in self efficacy which then leads to a desensitisation in dyspnoea which then enables the patient to increase their walking distance, or does self-efficacy increase in parallel with the other constructs? Some may question whether it matters at all as long as patients get an increased function at the end of a PR programme. Yet within the

speciality of PR, the emphasis is currently defining the optimum programme, in which case understanding the role of self-regulation will help us to maximise its' effectiveness.

4.5.2 External motivation

Life experience

The finding that past life experience influenced current health behaviour is supported by the findings of Resnick and Spellbring (2000). They found that older adults who had never exercised were less likely to exercise. However another finding in the same study was that some adults who had exercised in the past failed to see the benefits now that they were older adults. Little is known about how motivation changes with increasing age. Dishman (1994) suggests that the presentation of exercise programmes for older adults may affect their motivation, since the concept of appropriate physical activity may differ in older persons from younger people. Further retrospective study would be useful to explore in greater depth the activity and motivation history of patients and its' impact on motivation and activity in older adulthood.

A small number of the interview sample had been diagnosed with their lung condition at a very young age. These patients made additional comments suggesting they had a better coping strategy as a result and consequently were able to motivate themselves more successfully than patients who had been diagnosed in later years. These comments were straddled between both life experience and self-efficacy. A study by Morgan et al (1983) showed that exercise tolerance was predicted by attitude, mood and beliefs. Young (1999) suggests that the patient's perception of their illness and its' management may have an effect on the need for PR. It is possible that people whose respiratory condition has existed for a longer time than usual may have a higher internal motivation.

Human support

Support from others as an influential motivational factor was described in the form of spouse, family and healthcare professionals. Experiences of the effect of social support on motivation was very varied and at times contradictory. For example, some

patients found living alone a demotivating factor and some found living alone increased their motivation as they had no choice to be independent.

There is a strong relationship between social support and physical activity in other studies (Rejeski and Hobson 1994 and Duncan and McAuley 1993) although the relationship between social support from family and friends and social-cognitive determinants of physical activity has not been examined (Dishman 1994c). In a study by Young et al (1999) patients who were widowed or lived alone were less likely to adhere to a PR programme. Many of the patients discussed having over-protective spouses which caused a reduction in motivation. This finding is comparable to a study by Thompson et al (1989) which looked at recovery following stroke. The authors found a statistically significant correlation between low motivation and carer overprotection.

Patients told how the support from healthcare professionals was at its' most pertinent during the PR process. Clearly PR staff have a major role to play in motivating patients. Rollnick et al (2000) argue that simple advice giving or health education is not effective enough on its own to bring about behaviour change and that patients' individual needs depend on where they are in the stages of change cycle (Prochaska and Diclemente 1983). Dishman (1994) further promotes the importance of the facilitative role of the healthcare provider in encouraging patients in their decision making, programme maintenance and adherence and prevention of relapse. Young et al (1999) found that a lack of disease-specific social support predicted non-adherence to a PR programme, whilst a lack of general social support did not. This supports patients' comments that it is the influence of specialist, rather than generic healthcare professionals, that is the key to their motivational status. Rollnick et al (1993) discuss the dangers of patient resistance to unsolicited advice from healthcare practitioners. It may be possible to enhance patient compliance with behavioural change by positively influencing their attitude and intentions. Ajzen (1985) found that the views of other significant individuals influenced health behaviour in the theory of planned behaviour. This suggests that it is important for all healthcare professionals coming into contact with the patient to promote the importance and benefits of adhering to the PR programme. Miller and Rollnick (1991) found that it is also possible for the healthcare practitioner, in the way that they speak to the patient, to cause them to be

resistance to change. The implication for PR programmes is that staff running programmes need to possess motivational skills. Additionally, it is clear that encouragement from other healthcare professionals dealing with the patient is important.

Impetus

Numerous incentives were discussed as determinants of motivation. These ranged from specific functional goals, through to belief in the efficacy of PR. Goal identification has been shown to be an important motivating factor in other studies (Resnick and Spellbring 2000 and Dzewaltowski 1994).

Many patients described their shock, when beginning a PR programme, that there were other patients with the same condition who were more severely ill than they were. In particular, one finding of the study was the negative perception of oxygen therapy and its' impact on motivation. Many patients viewed the need for oxygen in both themselves and others as 'the end of the line' and it was always viewed as a label of severe disease and disability. When patients saw others in a PR group who were more severely ill than themselves, this produced a real fear of deterioration and provided the impetus to prevent this happening to them. Another reaction to more severely ill patients was the realisation that there were others 'worse off'. This feeling stimulated motivation.

The impetus to stop or reverse disease progression is supported by other authors. Morgan et al (1999) suggest that PR would be inappropriate in patients who have only minor disability symptoms, as in order to gain benefit, patients need to be aware of their disability. There may be an issue here about motivation. i.e. perhaps the more severe the disability, the more the patient views the importance of PR. This concept is evident in the theory of planned behaviour (Ajzen 1985). In contrast, a study by Wedzicha et al (1998) showed no improvements following PR in severely breathless patients compared to significant changes in outcome in moderately breathless patients. However, these results are questionable as variables between the two groups were not entirely controlled. The severely breathless patients were treated at home and the moderate group treated in hospital, therefore the lack of improvement may have been due to the fact the rehabilitation was not performed in a group, rather than

the degree of disease severity. Another study indicates that PR benefit is unrelated to initial disease severity (Niederman et al 1991), although ZuWallack et al (1991) found that patients with a lower FEV1 seemed to have increased benefits.

This study showed how motivation is increased when patients start to see the benefits of the PR programme for themselves. This reinforced their belief in the effectiveness in the therapy. This is comparable again to self-regulatory theory (Leventhal 1980) and the health belief model (Becker 1974) where the impact of the health behaviour influences the decision making process about whether to continue or change the behaviour. This process of self-reinforcement of the effectiveness of exercise has been discussed by other authors (Heiby et al 1987 and Dishman 1982) and has been related to exercise adherence (Dishman and Gettman 1980). Impetus relates to the theory of planned behaviour (Ajzen 1985). In that theory the person makes a value judgement about a behaviour such as exercise. They evaluate the consequences of carrying out or not carrying out the behaviour in order to come to a decision about their intention. This study showed similarly that patients believe that PR is going to help them, which increases their motivation to carry out the exercise. Rollnick et al (2000) claim that anything a patient does which enhances their perception of the importance of the behaviour change, or their confidence in their ability to successfully make the change will increase their motivation.

Another finding of this study was the positive motivating effect of seeing others exercising who were either at the same or worse level of disability. This seemed to provide a good incentive – almost a competitiveness. Although in this model this concept was categorised under ‘incentive’, it links with self-efficacy. Bandura (1977) describes one of the constructs of self-efficacy as being vicarious experience. One of the examples of vicarious experience is where patients are exposed to others of similar disability who have successfully performed a given behaviour.

Symptom variability

A surprising finding was the very strong emphasis patients put on seasonal weather variations as a determinant of motivation. One finding was the effect of the weather on motivation. Many of the patients interviewed described how seasonal extremes of weather, particularly the winter, were de-motivational factors. There has been a

recent increase in interest into the effects of temperature on patients with COPD and cold weather has been shown to reduce exercise capacity in patients with COPD (Koskela et al 1998). In that investigation, it was found that it was the increase in cold related dyspnea that was responsible for the reduced exercise capacity. A recent unpublished study (Singh et al 2005) examined the seasonal effects on COPD outcomes. The authors demonstrated that patients with COPD were more active and had better scores of exercise tolerance, quality of life and anxiety and depression in the summer than the winter. The only outcome that did not change significantly was FEV1. The difference between mean scores for summer and winter were quite startling. For example, the mean daily step count for the summer was 3 times higher than the winter.

During qualitative data collection in our interview study patients described their motivation levels as lower during bad weather, which seems to relate to the results of the seasonal effects study. It would be interesting to know if it is the lack of motivation that had an effect on the sensation of breathlessness and caused the reduction of winter activity or if the lack of activity was caused by another factor, i.e. too cold to walk outside, which in turn led to a reduction in motivational status. This has implications for the time that the PR programme takes place. For example, patients who report difficulty coping during the winter months may be better having their PR programme targeted at that time of year.

An additional seasonal problem is that during the winter, exacerbations are 50% more likely to occur (Donaldson and Wedzicha 2006), and yet more go unreported than in the summer (Miravittles 2004). It was interesting that, given patients accounts of the detrimental effect of the weather on motivation, only a minority of patients considered exacerbations to be a de-motivating factor. Instead, the majority of patients described how symptom variability, so characteristic of COPD, was a major factor affecting motivation. Exacerbation is a common problem in COPD and has a negative effect on health status (Spencer and Jones 2003 and Seemungal et al 1998) so it is surprising that it did not feature more significantly during the interviews and focus groups. A large proportion of the study sample were patients who suffer frequent exacerbations and one of the semi-structured questions gave them the opening to discuss this factor so there was certainly opportunity to capture any data pertaining to the effects of

exacerbation. One explanation for this may be that very few patients were actually experiencing an acute exacerbation at the time of interview. It may be therefore the case that reflecting on circumstances associated with exacerbation, for example the winter, brings about de-motivation rather than the actual exacerbation itself. It is also possible that patients accept that exacerbations are an ongoing part of their condition and just accept their presence.

4.5.3 Functional outcome

The patients' collective view of motivation seemed as much about constructs that they associated with being motivated, and the tangible manifestations of motivation, as the factors that influence it. The study results showed that many patients felt that having ample social interaction was associated with motivation. For example, one lady said:

“I was meeting people and getting out of the house”

She was describing a time that she was very motivated. It appears that it was the motivation that had caused her to meet people rather than the social interaction to cause the motivation. Likewise, another person said:

“The motivation is to help me to make friends, be friendly towards people and have people friendly towards me”.

Again it was the motivation that caused the social interaction in this instance. These examples were not unique during interviews. When freely discussing the meaning of motivation within their experiences patients described variables that influenced motivation along with variables that were influenced by motivation. It seemed irrelevant to the interviewees whether it was motivation or another variable that pre-existed, as long as outcome was positive. The study showed that patients appeared to view motivation as a positive outcome of PR in its own right and frequently described the effect of a PR programme on their motivation. The theme of functional outcome is supported by other studies (Resnick and Spellbring 2000 and Resnick, 1998) where patients described themselves as determined to keep moving and to exercise in contrast to being lazy.

4.5.4 Influence of pulmonary rehabilitation on motivation

This study showed that motivation within PR is a dynamic process, with the outcome being a part of that process. Patients reported the motivational benefits of the group environment. The benefits of the group environment were also reported as a finding in a focus group study by Toms and Harrison (2002). In that study, PR instilled an overall feeling of confidence, culminating in a redefinition through new roles and re-established identity.

When discussing exercising in the group environment, many patients commented on how they enjoyed coming to the group and this motivated them. One lady said that it was fun, but serious as well. During local programmes, from where the sample was selected, PR staff try and make the groups an enjoyable experience for the patients. The mood at each session is lively, positive, encouraging and energetic, mainly due to the personality of the staff. There is often lots of laughter and joking, mixed with the seriousness message we are trying to give to participants. Patients who attend the sessions are always happy and relaxed during the sessions. It seems reasonable to suggest that the enjoyment they experience during the sessions is an influencing factor on their motivation as it gives them a desire to attend. There is support for this argument within the literature with a number of studies which demonstrate that enjoyment of exercise has a relationship with constructs of motivation (Bray et al 2007, Raedeke 2007 and Vlachopoulos and Karageorghias 2005). The study by Bray et al (2007) found a relationship between intention to exercise and an exercise instructor style that is motivationally enriched as opposed to bland. Patients commented during interviews on how the PR team leader was enthusiastic and that this 'motivated' the group. This suggests implications for selection of staff for PR programmes, in that personality and charisma maybe important attributes for consideration during selection.

The effect of the setting of a PR programme is currently under-investigated. The assumption that a group setting is more motivational may be a misconception. The literature contains contrasting evidence for individual home PR versus a group setting. A study by Wedzicha et al (1998) reports no improvement in exercise performance in severely dyspnoeic patients receiving PR at home compared to the significant improvements in the moderately breathless patients receiving PR at a hospital setting.

This brings into question whether patients receiving domiciliary PR are not as motivated as a result of the lack of peer support. However the Wedizicha study did not compare similar disease severities, as the patients receiving PR at home were more breathless. This may have compromised the results. In contrast, Strijbos et al (1996) found that compliance with exercise at 18 months post programme was better maintained with home-based, rather than hospital-based programmes. The patients exercising at home additionally strengthened the exercise improvement over the 18 months. This calls into question the validity of our patients' self-reports of the motivational influence of being in a group. One difference of note between the home and hospital PR programmes in the Strijbos study is that the patients who had home PR received home visits from a nurse. One of the nurse's interventions was to motivate the patient to continue exercising. This input may have made a difference to the results. Patients in the study by Strijbos et al (1996) managed to maintain their exercise tolerance improvements for a maximum of 6 months.

It is possible that patients may become dependent on the peer support gained from a group PR programme and when that support is withdrawn at the end of a programme their essential motivation drops. Home programmes may build essential motivation within the patient, so their need for external influences are lessened. Interestingly, Rabinowitz (1999) studied 8 patients who had completed an 8 week in-patient PR programme found that non-adherence following discharge home was the norm in these patients. The study went on to show that that the most significant barrier to compliance was fear of breathlessness. The patients perceived exercise as dangerous. It is possible that in a hospital environment with health staff supervision there was less fear of the dangers of exercise. However it is clear that the patients self efficacy remained low, as at discharge there was no improvement in fear of breathlessness. It may be more effective for patients long term compliance to have an exercise setting that is more orientated to their home environment. This view has been supported by Garrod (1998) who argues that programmes designed around the patient's home environment may lead to longer term lifestyle changes.

During a PR programme we informally observe patients' motivation increasing as they progress further along the PR process. Other research shows how PR impacts on determinants of motivation. For example, it has been demonstrated that exercise itself

strengthens efficacy beliefs (Kaplan et al 1984 and McAuley et al 1995) and it is also known that physical activity has a positive impact on self-esteem (Marsh 1986). A study by Kersten (1990) demonstrated that self-concept significantly increased during a PR programme. This strengthens the validity of the PR cycle of motivation described in this study. As patients start to obtain benefits from their exercise, their essential motivation increases. It is possible that with their increased confidence, patients then exercise at a higher, even more beneficial level. Interestingly, in the study by Kersten (1990) Men showed a higher change in self-concept than women during PR, but this dropped significantly after the programme had finished. This brings into question gender differences in motivation. In future research, consideration should be given to the moderating effect of gender on motivation.

It has been suggested that behavioural strategies could be incorporated into the psychosocial component of PR in order to reinforce positive health behaviours (Ries et al 1997). A study was conducted in 1984 that evaluated the benefits of a behavioural and cognitive-behavioural intervention to increase adherence to exercise in patients with COPD (Atkins et al 1984). The authors of this study reported at the time a lack of research into interventions enhancing exercise compliance in COPD. It seems that little has changed in the present day. Scherer and Schmeider (1997) found that an effect of a PR programme was an increase in self-efficacy. Dishman (1994) promotes the use of a behaviour modification model to foster participation in physical exercise. This model includes sensible goal setting, commitment from the individual and feedback and rewards. In the literature referring to PR programmes, lifestyle change is discussed, with very little reference to methods that help patients achieve this lifestyle change. Theory needs to be extended to give guidance to PR staff about helping the patient with behaviour change.

4.5.5 Motivational status of interviewees

Most patients surprisingly described themselves as motivated – even the ones thought by the pulmonary rehabilitation staff not to be. One possibility for this is that patients may have over-reported their own motivation during interview in an attempt to ‘please’ the interviewer. This is one of the hazards of patient self-assessment in behavioural medicine (Frankfort – Nachmias and Nachmias 1996 and Dishman, 1994). However, if this was the case, the results of this study would not have been

affected since the motivational status of the patients interviewed was not actually being assessed. The study aim was to explore their views and experiences of motivation. Another explanation for seemingly poorly motivated patients declaring they were quite motivated is that there may be a lack of ability of healthcare professionals to objectively assess a patient's motivational status. It is possible that the negative attitudes associated with COPD (McCathie et al 2002) are mistaken for a lack of motivation. Often it is to the great surprise of PR staff that patients who it is believed are not particularly positive about PR turn out to be extremely motivated during the programme. Where there is no clinical psychologist attached to PR programmes, healthcare professionals need to be better equipped with psychology skills in order to differentiate between psychological constructs.

Another interesting finding was that many patients had gained improvements following a PR programme that the healthcare team were unaware of. Following a PR programme many patients eventually start to lose the benefits gained and they deteriorate (Ketelaars et al 1998 and Ries et al 1995). Some of our patients talked about further increases in functional ability following cessation of their PR programme, which were both pleasing and surprising. Such patients appeared to have high essential motivation and self efficacy which in turn seemed to enable them to be very self-directing in terms of exercise. It would be useful to be able to identify these patients using a measurement tool in order to direct post PR support where it is most needed.

4.5.6 Study limitations

It was clear that by using the interview method, some patients at times used this as an opportunity to talk about their feelings in general about the impact of COPD on their life. There is little doubt that most of the patients found the experience quite therapeutic. Local observation is that patients are rarely, if ever, given the chance to discuss their 'innermost' feelings with a healthcare specialist on a one to one basis for any length of time. A large proportion of the patients expressed the fact that they had really enjoyed the experience of being interviewed. Yet the downside of this is that a proportion of the data was not specifically related to motivation – it was expressions of the general impact of COPD on the patient's life. Indeed some of the data was similar to the findings of Toms and Harrison (2002). That study explored generally

the effect of a PR programme on patients' lives. This problem was anticipated at the beginning of the study and was planned for. During the interviews, at the first sign that the patient was deviating from the focus of motivation the interviewer immediately but sensitively re-focused the conversation. Additionally, during analysis, any discourse that was clearly not focussed on motivation was excluded.

Very few patients were interviewed who had either dropped out of a PR programme or declined to participate from the outset. This was a result of ethical approval requirements for recruitment. In research involving patients, the procedure often employed is to ask for volunteers either by advert or letter. It would be rational to assume that this requires a certain degree of motivation from the patient in order to respond. It was important in this research study to make an effort to capture some patients who were not motivated in the samples for all 3 studies. This proved very difficult because of ethical requirements, as getting de-motivated people to participate would have required a degree of persuasion. This may have been viewed as an unethical approach as patients may have felt under pressure to participate. This was easier to overcome in the previous focus group study, as patients were approached in a group situation, where a de-motivated patient may have felt more positive about participating. Initially, the plan was to approach patients for interview by telephone, in order to capture some de-motivated patients or patients who had dropped out of a programme. However, the local research ethics committee would only give approval of the patients being invited to participate by letter. As expected, the most motivated patients responded and only 1 patient who had dropped out of a programme. It may be for this reason that results from the focus groups and interviews were heavily weighted to the more positive aspects of motivation.

It could be argued that validity is questionable for the reasons above, however there did emerge a large amount of data surrounding the negative aspects of motivation. Interviews were continued until no new information appeared to be emerging (data saturation), either negative or positive aspects of motivation. It is also interesting that the established theoretical motivation models found in the psychology literature appear to be also weighted positively. It is possible that because 'motivation' was therefore being the focus of study is a positive concept and thus results will be weighted towards the positive aspects of the concept. Furthermore a rational

assumption is that motivation and de-motivation are at opposite ends of the same spectrum and when a person is de-motivated they will not answer positively to the questionnaire items.

Intention is a construct featuring strongly in other models of motivation (Dishman 1994c) but did not emerge as a separate entity in this study. For example, in the theory of planned behaviour, Ajzen (1985) presents the intention of a person as a predictor of health behaviour. Ajzen demonstrates that intention is influenced by attitude, views of other significant individuals about the importance of the behaviour and the degree of perceived behavioural control. These 3 factors were associated with motivation in our study. Intention to carry out a health behaviour did feature within the interviews but were coded as attitude. For example, discourse such as

“you have to just do it”,

and

“I don’t need a motivator – I just takes it into my head to say: well, I’ve got to do this and I’ve got to do that – but I get on and do things”.

Could have been labelled under a category of intention. The main theoretical models of motivation available in the literature were designed to explore predictors and determinants of adherence to health behaviour. In this case the label intention is more appropriate as it is a cognitive- behavioural process under study. Whereas our study was intended only to examine the concept of motivation so therefore it was more appropriate to categorise discourse pertaining to intention as attitude.

Because of the specific aims of this study, it was only possible to explore the emergent variables at face value only. Limitations in time restricted further in-depth exploration of interesting themes. It would have been valuable to gather more data about how for example, partner support moderates the impact that social-cognitive variables have on behaviour. Similarly, rich data emerged about the moderating effect of PR programme on motivation, but there was no time to explore this further.

Further study is required examining the complex interactions between the emergent variables to add validity to the motivation model and its underlying constructs.

4.6 Conclusions

This study has illuminated the many factors that patients perceive to have an influence over their motivation within a PR programme. Motivation within the context of PR consisted of an essential motivation that was influenced by external factors. The manifestation of motivation was the patients' behaviour, or function. A PR programme increased the patients' essential motivation in a circular way. At the beginning of a programme external factors are more important to sustain motivation until essential motivation is increased. At the end of the programme it is the patients' own essential motivation that maintains behaviour.

Many of the variables making up essential and external motivation could possibly be changed or influenced by the way a PR programme is delivered. Cognitive-behavioural interventions could be incorporated into PR to enhance the patients' motivation and although a small amount of investigation has been undertaken, more work is needed to identify the optimum PR programme.

Motivation appears to increase during a PR programme, which suggests it should not be used as an entry criterion to a PR programme. Furthermore PR staff are not able to objectively measure motivation. Development of a measurement instrument is needed to allow further quantitative study and exploration of the effect of PR on motivation.

Key healthcare professionals were identified by patients as a crucial element of instilling motivation. When appointing a PR team it is clear that disposition and enthusiasm are essential qualities to be considered. Managers and programme leads should either consider education for PR staff around appropriate elements of psychology or acquire some input to the programme from a clinical psychologist. It would be valuable to explore motivational methods that can easily be applied by a standard PR team. For example, motivational interviewing was a method designed by Rollnick and Miller (1995). Motivational interviewing is aimed at raising the level of

the patients' motivational status in the context of behaviour change (Rollnick 2000). Building the patients confidence through reassurance, encouragement and praise is clearly a crucial part of the role of PR staff.

Self- efficacy has been demonstrated as a key component of motivation that clearly is positively manipulated by a PR programme. Since a valid measurement tool exists for this construct (Wigal et al 1995), it would be a valuable outcome measure for a PR programme. More study needs to be undertaken about the role of self-efficacy within COPD and PR.

Continuation of lifestyle change beyond a PR programme is an area in great need of research. Clearly the longer the benefits of PR are maintained, the more cost-effective an intervention it is. Presently, there is not enough data relating to a programme design that produces optimum long-term motivation and compliance. Longitudinal studies are needed of the effects of motivational status, PR setting and exercise type and intensity on compliance and outcome measures following PR. Such studies should include examination of the reasons for programme drop out, declination of participation and post PR discontinuation of exercise.

4.7 Chapter summary

This chapter has described a study that built upon the basic information created in the focus group study surrounding motivation in PR. A description of patients' perceptions of motivation within the context of PR has been made. The design was a qualitative piece of research, using semi-structured interviews to generate data using a phenomenological approach. The methods and procedures used were explained, along with a presentation of the results and the theoretical model. The findings of the study along with the limitations were discussed and some suggestions made for future research and clinical practice. The results of this qualitative study were then used for development of a measurement instrument described in the subsequent chapters.

CHAPTER 5 – DEVELOPING THE MALVERN
PULMONARY REHABILITATION MOTIVATION
QUESTIONNAIRE (MPMQ)

The previous studies collected qualitative data about factors perceived by the patients to have an influence on motivation in the context of PR. This data was collected in order to underpin a context specific motivation measure. This chapter presents the method used to develop a measurement instrument that would be able to quantify the concept of motivation. The purpose of this was to show that the instrument was developed following theoretical guidelines and that careful consideration was given to the reliability and validity of the measure. The chosen instrument was a self-report questionnaire. The rationale for the questionnaire type is given, along with the methods of question construction. This chapter also describes a test of patient acceptability.

5.1 Background

In the previous chapters, the need to quantify psychosocial variables in COPD has been discussed. The ability to measure variables such as health related quality of life (Jones et al 1991 and Guyatt et al 1987), breathlessness (Garrod et al 2000), anxiety and depression (Zigmond et al 1983), and self efficacy (Wigal et al 1991) has enabled a more comprehensive management approach to COPD. This has undoubtedly led to an improvement in the lives of people with COPD.

There would be a number of benefits to being able to measure the concept of motivation. These benefits would be to both local practice and also others running pulmonary rehabilitation (PR) programmes. First, PR staff with no psychology training would be able to undertake an objective measurement of a patient's motivational status. Secondly, factors associated with motivation could be identified, enabling staff to know which cognitive – behavioural interventions are likely to be the most effective in a PR programme. Thirdly, investigators would be able to establish whether motivation is related to uptake, adherence and maintenance of exercise beyond a PR programme. This knowledge would enable healthcare professionals to identify which patients need extra support.

5.2 The objectives of a measurement instrument

In designing a measurement tool, it was important to establish its' objectives (Oppenheim 1992), as a tool should be designed to collect information which can be subjected to statistical analysis procedures (Denscombe 2003). This would affect the type of instrument selected and its design. The objective of the measurement instrument was to assess the motivational status of patients before, during and after the PR process. It would be aimed primarily at patients who are referred for PR, the majority of which will have COPD. However, it should also be suitable for a minority of patients with other conditions such as bronchiectasis and pulmonary fibrosis. These patients, although in a minority, are also referred for a programme. For this reason the measurement items within the instrument could not be disease specific. However, as the processes of disability are the same in most chronic lung conditions (i.e., breathlessness causes activity avoidance which causes physical and psychological deconditioning), generic measurement items relating to disability could be included.

The instrument needed to be able to identify a change in the patient's motivation in order to evaluate any improvement during a PR programme. Therefore it needed to have the sensitivity to detect change (Field 2005). This requirement would influence the type of measurement tool selected, along with the scale of measurement.

5.3 Choice of measurement instrument

A self – report questionnaire was selected as the measurement instrument. There were a number of reasons for this. Firstly, motivation is a psychological construct, where the information needed to be collected consists of attitudes, beliefs and feelings. Therefore, the person best placed to evaluate it would be the patient themselves, the direct source. In other words, the data is collected 'straight from the horse's mouth' (Denscombe 2003). The method of self-report also ensures a good response rate and reduces the risk of interviewer bias (Oppenheim 1996). Secondly, as the measurement of motivation is to be made within the PR process, a self-report questionnaire was the most practical instrument to be used. During a programme, a small number of staff are often dealing with a whole group of patients who need a range of assessment procedures. Measures are needed that are quick and easy to

administer. Patients attending a PR programme are familiar with self-report questionnaires as a number of outcome measures are collected using this method. For example questionnaires pertaining to quality of life, breathlessness and anxiety. A number of patients anecdotally report that they enjoy filling out self-report questionnaires about their health. They describe the experience as therapeutic as it makes them think about and re-evaluate their situation. Some report that this has added to their motivation to 'do something about' their condition.

5.4 Scoring the questionnaire

A Likert scaling method was chosen for the questionnaire as opposed to other methods such as multiple-choice or closed ended questions. One of the reasons for not using a multiple-choice questionnaire is that it may force the respondent into a choice. This would be more appropriate for factual questions where the answers are straight-forward. However, with a measure motivation, where beliefs, feelings and attitudes are being assessed, the respondent may only partially identify with a status. Furthermore there is evidence that the position of an item on a list has a significant impact on it being chosen (Frankfort-Nachmias and Nachmias 1996). Respondents most often choose items that appear first. As the questionnaire would be mainly measuring attitude rather than factual constructs, a multiple choice questionnaire may be more open to response bias, and closed ended questions were also not used as they may introduce bias (Oppenheim 1996). Closed ended questions may be either forcing the respondent to choose from alternatives given or by offering alternatives that may not have come to mind otherwise. Again, because of the nature of the construct being measured by the questionnaire, closed questions may have been more open to bias.

A Likert rating scale would reflect the intensity of the attitude. This was believed to be the most unbiased way of scaling the level of motivation. Also, this method would be the most sensitive to minor changes in motivational status (Field 2005). There are limitations to the Likert method of scaling, however. Distances between the ratings may not be equal, they are only higher or lower. Therefore measurements collected from the questionnaire would be ordinal and require the use of non-parametric statistical analysis. Another drawback is that when people are asked for a numerical estimate, they tend to choose a figure near the average or the middle of a series. This

is known as ordinal bias (Oppenheim 1996). A 'don't know' answer category was included in the response section. It could be argued that this may pose a problem. Some people may respond 'don't know' when they do not want to commit themselves to an answer. However, having this response category prevents patients from being forced into an answer that is not completely reflective of their actual opinion.

A decision was made to score the questionnaire so that the lower the score, the lower the patients' motivation and the higher the score the better the patients' motivation. Scores for each item ranged from 1 for the response associated with the least motivation to a score of 5 for the most motivated response. The choice of responses was: 'Strongly disagree', 'disagree', 'don't know', 'agree', 'strongly agree'. Ranking in this way unfortunately does not provide information about the distance between the ranks (Frankfort-Nachmias and Nachmias 1996). To obtain a total score for the questionnaire, the scores indicated by the patients' response for each item were added together.

5.5 Objective of the questionnaire

Denscombe (2003) suggests that there is no 'golden formula' in developing a questionnaire and that much is left to the author's discretion and judgement. The questionnaire must motivate the respondent to provide the required information (Oppenheim 1996). Therefore, much consideration was given to the content, structure, format and sequence of the questions to ensure that the questionnaire would collect the optimum amount of reliable data. There were to be both factual items and subjective experience (involving beliefs, attitudes, feelings and opinions) items, as both constituted motivation as described in the previous chapter. There were many factors considered during the design of the motivation questionnaire that may have had an effect on the patients' responses to the questions. These considerations are outlined below.

Method of approach to respondents

Consideration was given to the context and environment in which the questionnaire would be completed. During assessment sessions, staff would not have a great length of time to spend with patients explaining the questionnaire and how to fill it in.

Therefore the questionnaire had to be structured and worded very simply with clear instructions to prevent confusion. The length of the questionnaire and the amount of time it took to fill in were also considered. Patients in practice would be filling in the motivation questionnaire along with at least 2 other health status questionnaires as part of the assessment procedure for a PR programme. It was important to look at the questionnaire length in context with the other standard questionnaires administered. Although the questionnaire could theoretically have been made a lot longer, many questions were removed during development that were deemed to replicate other questions. However, the topic of motivation is very relevant to patients on a PR programme, so it was assumed that they would find the questionnaire interesting which would encourage response. The questionnaire would also have to reassure the patient that their responses would remain confidential. Failure to do this may result in biased responses.

Appearance of the questionnaire

The layout and appearance of a questionnaire is an important factor in encouraging respondents to fill it out in a reliable way (Oppenheim 1996). The questionnaire was designed so that the patient is not asked for a great number of demographic details. This can be off-putting (Oppenheim 1996). The respondent is simply instructed to fill in their name and the date. Care was taken to ensure the questionnaire looked as conservative as possible in an effort not to distract the respondent. White, size A4 paper with black type in 'Times New Roman' font was used for the questionnaire. The layout was neat and orderly to ensure it was easy to read. Care was taken with the size of the text. It needed to be big enough for the patients to read clearly, but not so big that the respondents felt patronised. Finally, consideration was given to the length of the questionnaire. One deterrent to questionnaire completion is the sheer size (Denscombe 2003). There needed to be enough items in the questionnaire to represent all the dimensions of motivation, without including duplicate questions which were unnecessary.

5.6 Increasing validity and reliability

Answers to attitude questions are more sensitive to changes in wording, emphasis and sequence than factual questions (Oppenheim 1996). The score of a questionnaire may

be affected by a variety of things, for example if the patient does not understand the questions. It is important to reduce this risk of errors in order to increase the reliability of the questionnaire (Salkind 2004). Therefore a great deal of attention was given to these issues during development in order to elicit the most reliable responses from the patients. Because attitudes are being measured rather than facts, sets of questions relating to the same attitude are more reliable than a single opinion (Oppenheim 1996). For example 'How motivated do you feel?' would not elicit very reliable responses. However, constructing the questionnaire by using a set of items drawn from the findings of the previous chapter was deemed to be a far more reliable method. In the previous study, motivation was shown to comprise of a number of variables, so this needed to be reflected in the measurement tool.

Question sequence

Research shows that the order in which the questions are presented in a questionnaire affects the type of response (Salkind 2004). Answers to attitude questions can vary depending on the preceding item in the questionnaire (Frankfort – Nachmias and Nachmias 1996). Therefore, in order to increase the reliability of the responses, the sequence of the items in the questionnaire was selected from 2 types: The funnel sequence, where questions are more general at first and then become more and more specific, and the inverted funnel sequence, where questions begin by being very specific and become more general (Oppenheim 1996). Consideration was also given to the context sequence of the questions to ensure the previous question did not produce a response bias. The developed questionnaire contained statements that if put into a particular sequence, may have produced a bias. For example, response bias might have occurred if the statement '*I believe that exercise is very good for me*' had preceded the statement '*Exercise is part of my normal routine*'. If patients answered 'strongly agree' to the fact they believe exercise was good for them, but actually did not exercise regularly, these 2 responses in a way are contradictory. Therefore, the respondent may be tempted to give an inaccurate response to the second question in order to support their response to the first question. So during development of the questionnaire, the context of the questions was examined carefully to minimise the risk of bias.

An effort was also made to avoid a response set. This is where a set of questions related to the same topic are presented together with the same response format (Salkind 2004). To help prevent this order effect, the response category was varied throughout the questionnaire. For example positive statements about motivation were interdispersed with negative statements to ensure the respondent maintained their concentration during questionnaire completion. The initial items in the questionnaire were designed to put respondents at ease and motivate them to continue completing the questionnaire. These questions were made as easy, interesting and non-controversial as possible.

Wording of the statements

Within the motivation questionnaire, statements were used and respondents were invited to select the response that most closely related to them. For example, one of the statements was worded: *'I always try to do my best'*. The patient then is invited to indicate which response most closely fits their life ranging from 'strongly disagree' to 'strongly agree'. The statements were kept as simple, short and straightforward as possible because it was essential that questions were easily understood, to avoid response bias. Words that were open to interpretation were avoided, along with leading questions (where the question suggests what the answer should be). Double barrelled questions were avoided (i.e., Do you regularly do cardiovascular or weight training exercise?), along with double negatives (i.e., I don't believe there is very little that can be done for my condition). It was ensured that the questionnaire statements were balanced, not too patronising, but also not containing difficult terminology.

Consideration was given to the phrasing and language used so that none of the questions came across as rude or intrusive. An effort was made to phrase questions politely and respectfully to encourage an honest response. Questions were worded so that they did not make the respondent feel wrong. For example, respondents tend to agree with statements that are accepted social norms or socially desirable things (social desirability bias) (Oppenheim 1996). This was difficult in questions relating to activity levels. During PR programmes staff constantly encourage and motivate patients to maintain their exercises. In completing the questionnaire patients may not want to be entirely truthful in their response to a question regarding how much they exercise, producing a bias. In order to avoid this as much as possible, the wording

and sequence of the questions were constructed so that there was no suggestion that not exercising was unacceptable. For example, this statement was worded:

“Despite my condition, I try to remain as active as possible”.

This was felt to be the best way of wording the question to promote an honest as possible response. The use of loaded words was avoided – for example, *unfaithful*, *modern*. .

5.7 The Process of the development of the questionnaire

The factors relating to motivation demonstrated that the concept consisted of a perceived interrelationship of those factors. It was therefore challenging to create concise questions that represented a synopsis of the attitudes and beliefs of an individual person. For this reason, one single question was not relied upon to measure each group of factors. Instead, by using several attitude statements, the strength of the respondents attitude is more accurately ascertained (Frankfort-Nachmias and Nachmias 1996) and reliability is increased.

The author and the research nurse together constructed the items for the questionnaire. The aim of the item construction was to represent each category of factors relating to motivation with several attitude and factual statements. The statements were constructed to interpret the meaning of the sub-categories, as perceived by the researchers. A process was used to arrive at the resultant statement for each sub-category. Firstly, each subcategory was examined and an interpretation of its' meaning arrived at. Then, a statement was constructed which both researchers agreed best illustrated the meaning. The statement was reflected upon and compared with the original category. Revision was made where appropriate. During construction of the questionnaire items, the 2 researchers used reflection, discussion critical evaluation and inductive skills to arrive at the final statement. Sometimes during the process it was necessary to revisit the original interview notes to examine again the data analysis to ensure the correct perception of the meaning of each factor. One of the possible limitations of using this method is that the interpretations made of the meaning of the data by the researchers may be biased. The researchers may make

their own interpretations of the data based on their own attitudes or experiences. For this reason 2 independent judges were used as a reliability to check to examine the data and resultant questionnaire items to ensure they were representative. The 2 independent judges had an interest in the research but had not been involved in the original item construction. One was an academic and one a healthcare professional. Items for the questionnaire were extracted from the categorised groups of statements recorded from the patient interviews. Table 5.1 shows which questionnaire items were constructed from which motivation factors. Many of the statements were combined into 1 item as they had the same meaning but the patients had used different words of expression during interview. For example:

“I was determined to do what I was told”.

“I do my best, try hard”.

Both of these statements had the same meaning. These, and other similar statements were grouped into the item: *I always try to do my best*. Similarly, often patients had described different experiences but were explaining the same concept. For example:

“With these tablets I’ve been on, they’ve made me that breathless, I’ve done more sitting down than ever before”.

“When I was put onto oxygen I did think well that’s the end of me”.

These statements had the same meaning and were encapsulated in the questionnaire item: *‘My treatment gets me down’*.

At times the ‘rules’ about developing questions were deliberately broken and words were included that were open to the individual interpretation. For example, because of the wide ranging viewpoints of what denotes an active individual, the questions had to be worded in a way that encompassed this variety. One person may class themselves as an ‘active’ person if they exercise 7 days a week. Another may see themselves as active if they are housebound but walk around the house. Although these would be entirely different levels of activity, both people may view their own

level as being consistent with a motivated individual. Therefore, lifestyle questions were worded thus:

“I regularly socialise with friends”.

“I regularly get out and about”.

The unspecific word ‘regularly’ was deliberately used in order to incorporate different interpretations of its meaning. If the amount of activity or socialisation had been quantified, then it would have been impossible to standardise the questionnaire for the statistical procedures for which it was designed.

Table 5.1. Extraction of items from sub-categories of motivation factors.

Category	<i>Positive sub-categories</i>	<i>Negative sub-categories</i>	<i>Associated questionnaire items</i>
Functional ability <i>Behaviour</i>	Exercise routinely Regular recreational activity Making an effort to do things Having the ability to maintain activity	Can’t stick to exercise regime Poor recreational activity Laziness Giving up Multipathology restricts activity Find activity an effort	<ul style="list-style-type: none"> • I regularly get out and about. • Despite my condition, I try to remain as active as possible. • When I am having a bad day I tend to give up. • Exercise is part of my normal routine • I find activity too much effort. • I always make an effort to things • I tend to give up easily
Attitude. <i>Essential motivation</i>	Drive and determination To try to do your best Willpower Optimism Knowing there’s always someone worse off Happy disposition	Lack of will power Not being bothered to do things Pessimism Depression	<ul style="list-style-type: none"> • I find it difficult to stick to an exercise regime • I have a lot of drive and determination. • I lack willpower • I always try to do my best. • Because of my health I tend to feel that I can’t be bothered to do things • I am an optimistic person. • I feel depressed • I have a happy disposition • I feel there are many people worse off than me.

Self-efficacy <i>Essential motivation</i>	Confidence Independence Coping Disease self management	Fear of breathlessness Lack of belief in ability Lack of independence Unable to cope	<ul style="list-style-type: none"> • I feel I know a lot about my lung condition. • I am frightened to do things because of breathlessness • I am an independent person. • I am usually in control • I tend to panic when I am breathless
Self esteem <i>Essential motivation</i>	Positive Body image Feeling valued	Feeling embarrassed Body image Feeling worthless	<ul style="list-style-type: none"> • I am self conscious about my condition • I tend to get embarrassed about my condition • I feel useless because of my lung condition
Life experiences <i>External motivation</i>	Encouraged to work hard in childhood / adolescence. Led hardworking and active life before illness.		<ul style="list-style-type: none"> • In the past I have led a very active life. • I was encouraged to work hard as a child
Impetus. <i>External motivation</i>	To be as well as possible To improve quality of life To prove I can do it. Not wanting condition to deteriorate Believing the exercises are effective / seeing the benefit Goal setting	Condition is getting worse Going onto oxygen No set exercise routine	<ul style="list-style-type: none"> • I believe that exercise is very good for me. • I want to do everything I can to stop my condition getting worse. • I want to do everything I can to improve my quality of life. • My medical treatment gets me down. • I try to prove I can still do things. • I believe there is little that can be done to help my condition.
Human interaction <i>External motivation</i>	Supportive Spouse Encouragement from spouse Need spouse for company Encouragement from family Having good social life (friends) Support from HCP's Being in a PR group. Being with people who are in the same situation Exercising with other people Motivation of going to a group	Unsupportive spouse Living alone Bereavement Lack of social life (friends) Poor support from HCP's Unable to exercise alone Not going to the group Reaction of other people	<ul style="list-style-type: none"> • I have lots of support from healthcare professionals. • I am able to talk to people in a similar situation to me. • I regularly attend an exercise group or other support group • I have a supportive family. • I regularly socialise with friends • My family encourage me. • I feel lonely

Symptom variability <i>External motivation</i>	Motivated even on bad days Good weather Feeling well	Having “off” days The weather Exacerbations	<ul style="list-style-type: none"> • My health prevents me from being active • I still try to exercise even when I’m having a bad day. • My condition is currently a lot worse than normal. • At the moment the weather is making my condition worse.
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During questionnaire construction each statement was carefully reflected upon by the author to ensure it fitted the ‘good practice’ guidelines discussed above. The process used was construction, revision then refinement. The questionnaire was read through several times by a number of healthcare professionals to ensure that it ‘flowed’ and that the questions were in a logical sequence. Changes were made to wording, sequence and appearance where problems were identified.

The resulting measurement tool was a 43 item, self-report questionnaire (Appendix 5.1a). Responses were indicated on a Likert scale, scored 1 – 5. Responses ranged from strongly agree, to strongly disagree, with a higher score representing a higher motivational status. Items had either a negative or positive statement and had to be appropriately scored so that the scoring remained consistent.

In other questionnaire development studies, the items were initially divided into their relevant components, thus creating ‘sections’ within the questionnaire (see Jones et al 1991 and Garrod et al 2000). This was not done for the new motivation questionnaire for 2 reasons. Firstly, the questions were sequenced in a way that would elicit the most honest response. Having sections would require a change in question order. Secondly, the questionnaire appeared to ‘flow’ logically. But if acceptability testing showed otherwise, the questionnaire could be changed into sections. Thirdly, there seemed no good reason to divide the questionnaire into sections at this stage.

5.8 Acceptability testing

In order to pilot the questionnaire prior to formal tests of reliability and validity, a small test of acceptability was undertaken with a convenience sample of patients. The

patients used for this test were a group of 9 patients attending a post PR maintenance group. The group was asked if it would take part in the pilot during the previous week. All patients taking part in the test were given an information sheet (Appendix 5.2) and signed a consent form (appendix 5.3). Ethical approval was given by the local research ethics committee (see appendix 4.1). It was explained to the patients that the focus of the test was the acceptability of the questionnaire rather than their particular answers to the questions. The group were administered the questionnaire and were asked to complete it, making notes of any arising problems. To assist them to do this, each patient was given a list of things to consider when filling in the questionnaire (See Appendix 5.4). They were asked to take note of any questions that seemed difficult to answer, or could have been better worded. Also, they were asked to consider the layout of the questionnaire and to comment on anything that they found confusing. When all patients had completed the questionnaire, verbal feedback was obtained by the researcher in an informal discussion.

Patients completed the questionnaire in the group room all at the same time. No discussion occurred between patients during completion. Only one patient asked for clarification of one of the questions, otherwise patients appeared to complete the questionnaire easily without help. Each patient was asked individually and privately for comments and then a group discussion was held.

Response to the questionnaire completion was very positive. Patients reported that instructions on how to complete the questionnaire were clear and the questionnaire itself was easy to complete. Most patients also commented without prompting that it was almost of positive therapeutic value since it made them reflect on their motivational status. Many of the patients felt that some of the questions were almost the same but just worded differently and one patient felt these were 'trick' questions. No-one felt that any questions were rude or over - intrusive. The answer format was deemed acceptable and easily understood. One patient felt, however, that when questions 'switched' from a positive to a negative mode, patients had to think carefully about the direction of positive in the answer format. This may cause mistakes, although others felt it was not a significant problem. For example, the question 'I tend to give up easily' is followed by 'I always try to do my best'. The

patient initially had mistakenly answered 'agree' for both, and then realised that the same answer format was applicable to both positive and negative questions.

One question was found to have a grammatical error and 6 questions were identified as difficult to understand by individual patients. The rest of the group did not have a problem understanding these questions, but agreed on the suggested alternative wording. These questions were as follows:

The questions: *'I find activity too much effort'*, *'My health prevents me from being active'*, *'I feel I know a lot about my lung condition'*, *'my medical treatment gets me down'* and *'my condition is currently a lot worse than normal'*. One patient for each of these felt the wording needed to be more specific. The question: *'as a child I was encouraged to do my best'* was not understood by one patient although the other patients felt it was very clear. On discussion, the patients agreed that slight alterations to the wording of the questions: *'I feel I know a lot about my lung condition'*, *'my medical treatment gets me down'* and *'my condition is currently a lot worse than normal'*. would make these clearer to the respondent. However, it was agreed that the other questions could not really be any more specific and the group felt these questions did not pose a significant problem on the whole.

The group suggested that the questionnaire could easily be divided into sections as many of the questions related to each other. They felt that doing so would make respondents focus on specific issues and in doing so give more precise answers. The patient who had found difficulty moving between positively and negatively directed questions felt that dividing the questionnaire would help with this issue too. The respondent would stay more alert during completion than answering a long battery of questions.

As a result of acceptability testing, a grammatical error in one question was corrected. The wording to 3 of the questions was changed as discussed above to make them more specific. The other 3 questions that single individuals had found difficult to answer were not changed. The decision was made to retain these items for the time being for 3 reasons. Firstly, the majority of respondents had not had a problem with the items highlighted. Secondly, as the questionnaire would be later tested on a larger population for reliability, any problems with these items would be mathematically

revealed. Thirdly, making the questions more specific would then not encompass a variety of life situations. The questionnaire was divided into sections as suggested by a number of the patients. However, it was possible that the original 43 items may be reduced during the subsequent reliability and validity tests. If a large number of items remained on the questionnaire after statistical testing then consideration would be given to maintaining the divisions within the questionnaire. Finally the answer response 'don't know' was changed to 'neither agree or disagree'. Although this was not discussed with the patients, after much reflection it was felt that there was no category that was in-between agree and disagree to allow this response. Whereas 'don't know' really relates rather to a misunderstanding of what is being asked rather than a measure of the degree to which the person agrees or disagrees. The questionnaire was therefore changed as indicated above (appendix 5.1b) and subsequently this new version was used for further study.

5.9 Conclusions

The objective of the pilot work that was undertaken in order to produce the final 43 item questionnaire was to ensure response bias was kept at a minimum. The literature provided some guidance on how elements of a questionnaire, such as length, wording, question sequence and layout, could affect the response. The literature used in order to guide the method of the development of the questionnaire included: Oppenheim (1996), Denscombe (2003), Field (2005), Frankfort- Nachmias and Nachmias (1996) and Salkind (2004). The approach to questionnaire development provided within these texts were followed in order that the resulting questionnaire was as reliable as possible. Although every effort was made to minimise the risk of response bias, there is no guarantee that it can truly be completely eliminated. Hence, the added importance of reliability testing which was subsequently carried out. The importance of validity testing is also pertinent in measuring motivation as the questionnaire is not a true level of motivation but only a reflection of that level (Denscombe 2003).

The acceptability test was undertaken in a very informal way by the author of the questionnaire. It is possible that patients may thus have responded in a more positive way as they did not want to cause offence to the researcher. However, the very enthusiastic way that the patients responded seemed to indicate their positive

comments were genuine. In addition, as the questionnaire would be subjected to validity testing, this would illuminate questions where there were problems.

During the acceptability test, the patients only filled out the motivation questionnaire so they did not perceive that the 43 items was too long. In the reality situation of a PR assessment session, patients would have 3 additional health status questionnaires to complete. In this situation, a 43-item questionnaire along with the other questionnaires would probably be too long. It was clear that if possible, a shorter questionnaire would be far more practical. The feasibility of reducing the item pool was to be explored in the subsequence validation study.

5.10. Chapter summary

Using the findings of the previous qualitative research studies about motivation in PR, a measurement instrument was developed in order to quantify this concept. This would enable further quantitative investigation into the role of motivation in PR programmes. The measurement tool that was deemed to be the most appropriate for this purpose was a self – report questionnaire with a Likert scale response method. The resulting questionnaire had 43 items and was developed following theoretical guidelines about questionnaire development in order to increase reliability and validity. The questionnaire was tested for acceptability with a group of patients and was deemed to be ready for larger scale validation studies.

CHAPTER 6 – VALIDATING THE MALVERN
PULMONARY REHABILITATION MOTIVATION
QUESTIONNAIRE (MPMQ)

This chapter presents the tests of reliability and validity of the motivation questionnaire that was described in chapter 5. The objectives, methods, and findings are described. A discussion of the study and its' findings is also demonstrated along with implications for practice.

6.1 Background

There is little information to date about the effect of PR on motivation and its relationships with other key variables measured in PR. No studies exist where motivation has been measured as a discrete construct within a PR programme. Previous motivation measures have been designed for lifestyle changes and other medical conditions that are not appropriate for patients undertaking a PR programme.

A motivation measurement tool had been designed, based on the qualitative data about factors relating to motivation from the previous study. The results of the previous qualitative studies identified factors perceived by patients to influence motivation within the context of a PR programme. From these results 43 items were extracted to form a motivation measure that was identified as the Malvern Pulmonary Rehabilitation Motivation Questionnaire (MPMQ). The resulting measure was a self-report questionnaire. The previous chapter described the construction of the questionnaire and the pilot work undertaken in order to obtain a measure that was ready for statistical testing. In order to be used as a quantitative measure in future research studies it is necessary for a measure to be tested for validity and reliability.

Validity

Validity does not refer to the instrument itself but to whether the interpretations of the scores are related to the construct that the instrument is designed to measure. Validity refers to the degree to which the instrument measures what it is intended to measure (Polit and Hungler 1999). An instrument is not simply either valid or invalid, but has a degree of validity related to the purpose for which it was intended (Greenhalgh 2006). Validity cannot be established completely in one study, but is established over time as the instrument is used in different study populations. There are a number of ways evidence can be gathered to support the validity of a measurement instrument

and types of validity have been identified, but there is variation between descriptions of validity types (Anthony 1999).

Content validity refers to the degree to which the components of an instrument are linked to the construct it is measuring. The components of the instrument are examined to see if they are relevant to the construct. This is often done by referring to the literature or previous studies (Anthony 1999). The components of the MPMQ were underpinned by the actual experiences, beliefs and attitudes of the population for which the questionnaire was intended. Because of this, it could be argued that there is no need to establish content validity, as it already exists. Alternatively, if the questionnaire items had been developed from literature review, content validity would not have been so clear.

Concurrent validity refers to whether instrument is measuring what it claims to measure (Greenhalgh 2006). Because the measure of motivation was developed as a self-report questionnaire, it is not actually directly measuring motivation itself. The MPMQ is measuring what the patient chooses to say about their motivation. The more the questionnaire score reflects the patients' actual motivation, then the more valid the measure is. In order to establish the extent to which the information reported on the questionnaire is related to the patients' actual motivation is established by examining the relationship of the measure with a related variable (Bryman and Cramer 1994). For example in the literature review it was shown that anxiety and depression may be related to motivation. Therefore if the motivation tool has concurrent validity, its' scores will correlate to some extent with measures of anxiety and depression. Criterion validity is another dimension of validity. A criterion is a 'gold standard' measure of the same variable to which the results of the new measure can be compared (Oppenheim 1996). However, since no such criterion existed, this was unable to be tested.

Finally, responsiveness to change is another aspect of validity that can add support to the evidence for a new measure (Bryman and Cramer 1994). This is where respondents are subjected to a treatment or situation where their scores are expected to change. Pre and post treatment scores on the instrument under study are tested for differences in means. If the change in mean is significant then this shows the

instrument measures a change in the underlying construct. In the case of motivation, it would be reasonable to assume that this will increase during a PR programme. Hence, the research design included this test of validity.

Reliability

The reliability of an instrument is the extent to which it produces consistent and repeatable estimates of the true measure (Oppenheim 1996 and Field 2005). Demonstrating that the motivation measure was reliable was an essential part of this research. If the measure was to be used in subsequent quantitative studies in PR programmes, an unreliable tool would invalidate such research. One of the tests that examines reliability is called test-retest reliability. This examines the extent to which an instrument produces the same scores on two successive occasions providing the construct that is being measured has not changed in-between testing (Anthony 1999). Internal consistency reliability refers to the components of an instrument are all measuring the same construct (Salkind 2004). Again, this test was important in the development of a motivation questionnaire to ensure all the components were actually measuring motivation. In order to test for this, the degree of inter-correlation of the components is measured statistically. A high correlation can be interpreted as a reliable tool because the components are measuring the same or closely related constructs (Field 2005). The reliability coefficients described above are classical coefficients which are derived from generalizability statistics and should always be provided when a new instrument is developed (Field 2005).

Testing

It is possible that the process of completing a questionnaire itself might change the patients' motivation status. It is a well known problem in social science research that the effect of being pre-tested may sensitise patients and improve their scoring on the post-test (Frankfort – Nachmias and Nachmias 1996). By repeated testing, patients might learn the socially accepted responses to the questions and an improvement in motivation scores may occur when there has been no change in the patient's actual motivation. For this reason, it was important to perform a test-retest on the questionnaire to ensure similar scores were being obtained from the questionnaire on repeat testing.

The reliability and validity of the MPMQ needed to be supported prior to its' use in further research of motivation in PR, which was the overall aim. There were a number of objectives of this study. These were:

- To test the questionnaire for reliability.
- To test the questionnaire for validity.
- To investigate any change in motivation following PR in the context of evaluation of the measurement tool.
- To explore any differences in patients who did not complete the PR programme.
- To explore possible relationships between motivation and other outcome measures of a PR programme.
- To reduce the item pool into a more 'user-friendly' questionnaire.
- To explore the relationships between the questionnaire items and identify clusters.
- To identify any relationship between motivation at the outset of PR and improvement in outcome measures following a programme.

6.2 Methods

6.2.1 Study design

This was a prospective study using a single-group, pre-test and post-test design to investigate the validity, reliability and relationship to other PR outcome measures of the new 43 – item PR motivation questionnaire (MPMQ).

6.2.2 Patients

Patients for this study were recruited from out-patient PR programmes, PR maintenance group and the local Breathe Easy group in 4 sites across South Worcestershire between November 2005 and April 2006. The criteria for inclusion was that patients had to either be embarking on an initial PR programme, or who had completed a PR programme and were attending either the local maintenance group or Breathe Easy club. Most patients had a diagnosis of COPD. A small number of

participants had other disabling lung conditions such as bronchiectasis or pulmonary fibrosis, but had very similar functional problems to the patients with COPD.

The way the patients were approached to participate in the study was dependent on which environment they were being recruited from. The patients who were recruited from PR programmes were given an explanation of the study along with an information sheet (Appendix 6.1) when they had their initial one-to-one assessment for the programme. They were then approached at the first session of the PR programme by a research nurse and invited to participate in the study. The research nurse was not a member of the PR team, but was an experienced respiratory nurse who was familiar with COPD patients and PR. If the patients agreed to participate they signed a consent form (appendix 6.2) which was copied into their notes and also into the research site file. The maintenance group and Breathe easy group were spoken to as a group at one of their sessions by the research nurse who gave a detailed explanation of the research project and its purpose. Patients were asked to talk to the research nurse and author following the session if they wished to participate. All patients who volunteered to take part gave informed consent, signed a consent form and were given an information leaflet. Surprisingly, all patients from all of the groups that were asked if they wanted to participate readily volunteered. Not one patient declined to participate. Ethical approval was given by Hereford and Worcester Research Ethics Committee (see appendix 4.1).

6.2.3 Procedures

The motivation questionnaire was administered to a sample of patients within the PR process across 4 sites. The version of the MPMQ that was used throughout the entire study was version 4 (appendix 5.1b). Two of the sites were community hospitals, 1 was an acute hospital and 1 was a maintenance group held in a community hall. The PR process begins at referral, encompasses the duration of a PR programme and the maintenance period following a programme when the patient is in the care of the PR team. Patients who had given informed consent to participate in the study were given the MPMQ by the research nurse. Instructions were given on how to fill it in and not to take too long over thinking about the answers. Wherever possible each patient completed all questionnaires in the same environment – usually the PR venue.

However 4 patients, for reasons such as not having brought their reading glasses with them completed it at home.

These patients also completed the standard PR outcome measures and PR programme. Standard measures consisted of: The St George's Respiratory Questionnaire (SGRQ), the Hospital Anxiety and Depression Scale (HAD), the six minute walking distance (6MWD), the London Chest activity of daily living scale (LCADL), body mass index (BMI) and forced expiratory volume in 1 second (FEV1). Data was also collected about numbers of hospital admissions and acute exacerbations in the previous 12 months, smoking status, oxygen usage and whether the patient lived alone. Operational definitions of measures are presented below.

PR programme

Patients attended an 8-week programme of exercise and education at either a district or community hospital. Each programme was delivered by a multidisciplinary team. Patients attended 2 sessions per week, which consisted of a physical training session, relaxation or walking and an education session. The exercise workout consisted of a combination of cardiovascular and weight training exercises lasting around 45 minutes. Patients were also given a programme of home exercises and structured walking which they were advised to undertake 3 times a week at home in addition to the PR sessions. Relaxation consisted of either progressive muscle relaxation or visualisation. The education sessions included the topics: management of breathlessness, exacerbation, medication, anxiety, panic and nutrition and understanding COPD.

St George's Respiratory Questionnaire (SGRQ)

The SGRQ is a validated questionnaire which measures health related quality of life (HRQL) in patients with COPD (Jones et al 1991). The questionnaire is self-administered and contains 50 items with multiple-choice responses. These responses are weighted and have to be added together to give a total HRQL score. There are 3 dimensions to the total HRQL score, these are: symptoms, activity and impacts.

Six minute walking Distance (6MWD)

This is a test designed to measure the exercise capacity of patients with COPD (Enright 2003) and is commonly used as an outcome measure in PR. The patient has to walk on a flat surface for a total of 6 minutes. The object of the measure is for the patient to cover as much distance as possible in the allotted time. They can take rests when needed and walk at a pace of their choice. Patients completed one practice walk prior to their first walk. The member of staff directing the test only walked with the patient if they had portable oxygen that needed to be carried. Instructions and encouragement phrases were standardised. After each minute the patient was told how much time has passed and a short encouraging phrase was said, such as 'well done, you are doing very well'. The minimal clinically important difference in the test is estimated at 54 meters (Redelmeier et al 1997).

London Chest Activity of Daily Living Scale (LCADL)

This is a validated questionnaire that measures dyspnoea during activities of daily living in patients with COPD (Garrod et al 2000). It is a supervised questionnaire and contains 15 items of daily activity. Each item refers to a basic functional requirement and the patient is asked to select one of 6 responses indicating the degree of breathlessness associated with each activity.

Hospital anxiety and depression scale (HAD)

This is a validated measure of anxiety and depression (Zigmond and Snaith 1983) that measures distress in physically ill subjects. It is a 14 item self-report questionnaire with multiple-choice answers and is commonly used as an outcome measure in pulmonary rehabilitation programmes. A combined score of > 11 represents a clinical state of anxiety and depression. If depression is taken individually, then a score of <8 is normal, 8 – 10 is considered borderline and above 10 indicates referral for further assessment is needed.

Forced Expiratory Volume in 1 second (FEV1)

The measurement of FEV1 is obtained by performing a spirometry test on the patient. A spirometer is an instrument that measures the volume and flow of the air expired by a patient. Patients are asked to blow into a spirometer using a forced manoeuvre. The spirometer calculates the volume of air that the patient has expired forcibly in the first

second of their expiration, this is known as the FEV1. Normal values are determined by age, sex, race and height (Nolan et al 1999). Vitalograph spirometers were used for the tests which were performed by a cardiopulmonary technician. Patients were asked not to take their inhaled bronchodilators from 4 hours prior to the test. All patients were seated for the test. They all performed 2 slow expiratory manoeuvres and 3 forced expiratory manoeuvres. The spirometer machine then calculates the best of these readings and gives a printout of the results.

Body Mass Index (BMI)

BMI is a measure of nutritional status (Landbo et al 1999). It is calculated from the height and weight of the patient. Patients were weighed in kgs in day clothes without shoes or coats / jackets and their height was measured in cms without shoes. BMI score was calculated by dividing the patient's weight by their (height in meters)².

Living alone

Patients were classified as living alone where for the majority of their time they did not share their living space with anyone else.

Smoking

Non-smokers were defined as not having had a cigarette within the previous 3 months.

Acute exacerbation

The definition of an exacerbation was taken from the National Institute of Clinical Excellence / British Thoracic Society COPD guidelines (2004, p.131) which reads as follows:

An exacerbation is a sustained worsening of the patient's symptoms from his or her usual stable state that is beyond normal day-to-day variations, and is acute in onset. Commonly reported symptoms are worsening breathlessness, cough, increased sputum production and change in sputum colour. The change in these symptoms often necessitates a change in medication.

Hospital admissions

This was deemed to be where the patient had been admitted to an acute hospital bed with a first diagnosis of an acute exacerbation of COPD. This data was collected from the local hospital computerised database.

6.2.4 Data analysis

Collected data was computed and analysed using SPSS for windows versions 11.5 and 14.0. Motivation scores were considered to be an ordinal level of measurement. A probability (p) value of < 0.05 was considered statistically significant. A summary of the statistical analyses conducted are presented in table 6.1. Descriptive statistics were used to describe the group's characteristics.

Table 6.1 Summary of statistical analyses

Analysis	Method	Statistical test
Relationship between MPMQ score and number of co-morbidities	Bivariate correlation	Spearman's Rho coefficient
Differences in MPMQ scores at different stages of the PR process	Analyse statistical differences in mean scores	One way ANOVA F-ratio
Differences in MPMQ score in PR 'completers' and 'non-completers'.	Compare mean scores	t-test
Discriminative properties of the MPMQ	Compare mean MPMQ scores within classifications of disease severity	t-test
Concurrent validity	Questionnaire correlated with other health status measures.	Spearman's Rho coefficient
Sensitivity to change	Comparison of mean scores before and after PR	Wilcoxon signed – rank test
Ability of standard health status variables to predict MPMQ score	Correlations among health status variables	Multiple linear regression
Post-PR change in health status measures.	Compare health status means pre and post PR	Paired samples t-tests
Exploration of any relationships between Post PR change in MPMQ score and other health status variables	Correlations of health status variables	Spearman's Rho coefficient
Exploration of any	Correlations of health status	Spearman's Rho

relationships between Post PR change in health status variables and MPMQ score	variables	coefficient
Factor analysis	Correlation of items and calculation of eigenvalues.	Principle components analysis with varimax rotation
Test re-test reliability	Correlation of scores between 2 completed questionnaires 1 –2 weeks apart.	Kendall's tau-b coefficient
Internal reliability	Inter-correlation of questionnaire items	Chronbach's alpha coefficient

Concurrent validity

Spearman's Rho coefficient was used to establish any correlations between the motivation questionnaire and other measures of health status taken during routine assessment of patients undergoing a PR programme. Mean improvements in PR outcome measures were compared to motivation score at the outset of the programme using Spearman's Rho correlation coefficient.

Sensitivity to change

Sensitivity to change was established with the Wilcoxon signed – rank test (Wilcoxon 1945). Total motivation scores from before and after a PR programme were tested. This test is the non-parametric equivalent of the dependent *t*-test, so was more appropriate for the data.

Discriminative properties of MPRMQ

The discriminative properties of the MPRMQ between disease severity was explored. COPD severity was classified into mild, moderate, severe and very severe using the criteria in the GOLD guidelines (Rabe et al 2006).

Factor analysis

The first objective of factor analysis was to reduce the size of the item pool statistically and to enable an informed decision about items to be removed from the

questionnaire. The second objective was to examine underlying factors within the questionnaire and the relationship of items to those factors (Bryman and Cramer 2001).

Initial data screening was undertaken in order to exclude any items in the questionnaire that showed obvious poor consistency, discriminatory ability or were unrelated to any other items. A poor question will produce a narrow range of responses or will be misunderstood by part of the sample (Oppenheim 1992). The criteria for item exclusion was where: (1) The item had a standard deviation and variance of less than 0.9 (this would ensure that items were retained where responses were spread across the scale and reflected adequate variance (McDonald 1994), (2) The test-retest reliability of the item was poor ($p > 0.05$), (3) There were no significant correlations between the item and any other items using Spearman's Rho (Field 2005). Any items fulfilling the criteria were removed and the remaining items were analysed further.

Principal components analysis was the factor analysis method selected, as this is a psychometrically sound procedure and is one of the easiest factor analysis methods to understand (Field 2005). During this statistical procedure a correlation matrix of all the questionnaire variables was computed. The linear components (or factors) were then calculated by determining the eigenvalues of the matrix. Subsequently the analysis produced a matrix displaying the loading of a particular variable onto a particular component (or factor). Kaiser's criterion (Anthony 1999) was used to retain components where the Eigenvalue was more than 1, as these components will explain the majority of the variance in the questionnaire. To improve interpretation, factor rotation was performed using Varimax (Bryman and Cramer 2001). This method of orthogonal rotation is recommended if underlying factors may not be related (Field 2005).

The rotated component score correlation matrix was examined by the researcher. Questionnaire items that showed a high loading factor (> 0.4) onto their associated component were retained, as recommended by Field (2005). Items that loaded highly onto 2 or more components were excluded. The items that loaded onto each

component were examined by the researcher for a related underlying concept. A subjective decision was then made about the title of the factor.

Test- retest

To establish repeatability, test re-test reliability was examined by administering an identical motivation questionnaire between 1 and 2 weeks following completion of the first questionnaire. Scores from all the questionnaire items from the first test were correlated with scores from the second test using Kendall's tau-b (Field 2005 and Anthony 1999).

Internal reliability

Internal reliability of the questionnaire consistency was tested using Chronbach's alpha coefficient (Field 2005). This was performed on the questionnaire following item reduction. The test examines scores between 2 halves of the questionnaire. Chronbach's alpha calculates the average of all possible split half reliability coefficients. A score of over 0.8 is generally accepted as showing internal reliability (Bryman and Cramer 1999).

6.3 Results

A total of 77 patients entered the study, 51 of which were embarking on a PR programme. The other 26 had attended a PR programme previously and were now either attending the maintenance group (n = 21) or the local Breathe easy club (n=5). Out of the 51 patients embarking on a PR programme, 41 patients completed and 10 of the patients failed to complete. Two of the PR completers were unable to attend their final assessment session due to illness, hence there are only 39 completed data sets for the end of PR outcome measures. In addition to this 9 of these 39 were unable to perform a second 6-minute walking test as they had symptoms of exacerbation on the final assessment day.

All 77 patients completed an initial motivation questionnaire on recruitment to the study and they also completed a second, identical questionnaire, no less than 1 week and no more than 2 weeks, following the first completion. The version of the questionnaire that was used for the entire study was version 4 (Appendix 5.1b). At

the same time of the initial completion of motivation questionnaire, 76 of the patients completed the other health status questionnaires (HAD, LCADL and SGRQ) and 57 patients completed the 6MWD. 39 patients out of the 41 patients who had completed a PR programme completed the motivation questionnaire (version 4 appendix 5.1b) along with all other health status measures at the end of their PR programme.

Demographics of sample

There was a wide range of health status, exacerbation and hospital admission frequency represented within the sample. 6 patients were smokers and 68 were non – smokers. 24 patients lived alone and 53 lived with at least one other person. The majority of the patients - 70 in total had COPD, 6 patients had bronchiectasis and 1 patient had pulmonary fibrosis. Patients had a range of co-morbidities. The mean number of co-morbidities was 1.48. Descriptive statistics of health status and demographic variables are presented in table 6.2.

Table 6.2: Health status and demographic variables of sample.

	N	Minimum	Maximum	Mean	Std. Deviation
MPMQ score	77	108.00	213.00	156.7532	19.13330
SGRQ	76	13.00	91.00	55.1263	14.88970
HAD	76	2.00	29.00	12.4868	5.84578
LCADL	76	3.000	71.000	29.92105	13.092250
BMI	72	17.00	45.70	27.9333	5.65304
6MWD	57	60.00	504.00	286.2456	104.80378
Exacerbations last 12 months	62	.00	20.00	3.5323	3.38133
Number of admissions previous 12 months	68	.000	4.000	.52941	.837027
FEV1%	65	17.00	77.00	43.3462	14.47922
Number of co-morbidities	64	0.00	7.00	1.48	1.47994

SGRQ = St George’s Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale. LCADL = London Chest Activity of Daily Living Scale.

Co-morbidities

Data on co-morbidity was available on 64 patients. Co-existing cardiac conditions were common amongst the sample. Details of co-morbidities are represented in table 6.3. There were no significant relationships between motivation score and number of co-morbidities.

Table 6.3: Co-morbidities. (N = 64)

Cardiovascular conditions	N = 21
Diabetes	N = 10
Musculo-skeletal conditions	N = 25
Ear, nose and throat	N = 5
Gastrointestinal conditions	N = 17
Other respiratory conditions	N = 4
Obesity	N = 6
Cardiac conditions	N = 40

Stages of rehabilitation process

The patients within the sample were at 4 different stages along the PR process and this is represented, along with descriptive statistics of mean MPMQ (appendix 6b, version 4) scores for each stage in table 6.4.

Table 6.4: Mean motivation scores (MPMQ) at different stages of the PR process. (n = 77)

	N	Minimum	Maximum	Mean	Std. Deviation
Start of a PR programme	51	108.00	182.00	151.6471	17.22187
Maintenance group	21	125.00	213.00	163.4762	18.24450
End of a PR programme	39	135.00	201.00	164.1538	17.54024
Breathe Easy Group	5	165.00	210.00	180.6000	17.41551

The lowest mean MPMQ score was found in the patients starting a PR programme and the highest mean MPMQ score was found in Breathe Easy attendees. In-between, mean MPMQ score for end of PR programme was slightly higher than the maintenance group. A one-way analysis of variance (ANOVA) explored the significance of differences between the mean MPMQ scores for maintenance group

attendees, Breathe easy club attendees, patients who would go on to complete a PR programme and patients who would not complete a PR programme. Results showed a significant difference between these groups, with an F -ratio of 7.379 ($p = 0.000$). This is demonstrated in table 6.5.

Table 6.5. Analysis of variance between stages of the PR process.

ANOVA

Total M score

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	6473.682	3	2157.894	7.379	.000
Within Groups	21348.630	73	292.447		
Total	27822.312	76			

Non-completers of PR programmes

Out of the 51 patients undertaking a PR programme, 10 patients did not complete the programme and are referred to as programme ‘drop outs’. Nine of the drop outs were from the group based at the acute hospital and 1 from a community hall programme. This is presented in table 6.6.

Table 6.6: Details of patients who failed to complete PR programme.

Locality of subjects	N	N of patients failing to complete programme
Worcester pulmonary rehabilitation programme	N = 25	N = 9
Malvern pulmonary rehabilitation programme	N = 17	N = 1
Evesham pulmonary rehabilitation programme	N = 9	N = 0
Maintenance group	N = 21	NA
Worcester and Malvern Breathe easy group	N = 5	NA

Descriptive statistics for mean MPMQ scores shown in table 6.7, show the differences in motivation (MPMQ, appendix 5.1b) and other health status measures, between patients who completed a PR programme and patients who did not complete. Patients

who had dropped out of a PR programme had a lower mean motivation, worse quality of life and breathlessness scores, higher anxiety and depression scores, lower exercise capacity, were more likely not to live alone and to be a smoker, have more exacerbations and hospital admissions and a poorer lung function than programme completers.

Table 6.7. Descriptive Statistics of ‘completers’ and ‘non-completers’ of PR programmes

	N	Mean score for completers	Mean score for non-completers
Total MPMQ score	50	155.12	139.70
SGRQ	49	54.85	66.40
HAD	49	12.97	14.30
LCADL	49	30	35.10
BMI	49	27.82	27.04
6MWD	41	276	230.60
FEV1%	50	43.69	41.1
	N	Total number for completers (Percentage)	Total number for non-completers (Percentage)
lives alone	50	Yes – 15 (37.5%) No – 25 (62.5%)	Yes – 1 (10%) No – 9 (90%)
Smoker	50	Yes – 3 (7.5%) No – 36 (90%)	Yes – 3 (30%) No – 7 (70%)
Exacerbations last 12 months	42	111 (N = 38)	23 (N = 4)
Number of admissions previous 12 months	45	17 (N = 39)	5 (N = 6)

SGRQ = St George’s Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale. LCADL = London Chest Activity of Daily Living Scale.

There was a statistical difference ($p = 0.010$) in motivation score between non-completers and completers of PR (see table 6.8). MPMQ score was more likely to be lower in non-completers than completers.

Table 6.8: Differences in MPMQ score between drop outs and completers.

t-test for Equality of Means						
	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Motivation score	48	.010	15.42500	5.71285	3.93855	26.91145

Discriminative properties of MPMQ

In examination of the ability of the MPMQ to discriminate between classifications of disease severity (GOLD guidelines, Rabe et al 2006) there was found to be a statistically significant difference in motivation score only between 'severe' and 'very severe' COPD ($p = 0.46$) (Table 6.9). Mean MPMQ score was found to be lowest in the 'very severe' patients and highest in the 'severe' patients. No patients with mild disease took part in the study.

Table 6.9: Mean motivation score by COPD severity.

COPD severity	N	Mean	Std. Deviation	Std. Error Mean
Severe	30	156.5000	15.65963	2.85904
very severe	12	144.6667	19.60210	5.65864
Moderate	23	154.2609	17.45961	3.64058

When mean MPMQ score of 'very severe' patients was compared to the combined mean score of all the other severities, mean motivation score in the very severe category was significantly lower than the combined other classifications of disease severity ($p = 0.049$). This is illustrated in table 6.10.

Table 6.10: Mean MPMQ score of 'very severe' COPD compared to mean motivation score of other categories combined.

	COPD Severity	N	Mean	Std. Deviation	Std. Error Mean
Total M score	Other severities	53	155.5283	16.33967	2.24443
	Very severe	12	144.6667	19.60210	5.65864

Concurrent validity

There was a clear, strong negative correlation between MPMQ scores and HAD and SGRQ scores and a strong positive correlation between MPMQ scores and 6MWD (see graph 6.1). The higher the motivation score, then the lower the HAD and SGRQ scores were. The lower the SGRQ score, the worse the patient's quality of life and the lower the HAD score, the more anxious and depressed they are. Also, the higher the MPMQ score, the higher the 6MWD was, showing that the further the patient could walk, the higher their motivation score is likely to be. There was also a

significant correlation between MPMQ score and LCADL score and also a significant correlation between MPMQ score and hospital admissions over the previous 12 months. MPMQ scores did not correlate with lung function, exacerbations within previous 12 months or body mass index. Table 6.11 lists the individual variables, their co-efficient score and p values.

Table 6.11: Inter-correlations of MPMQ and other health status measures.

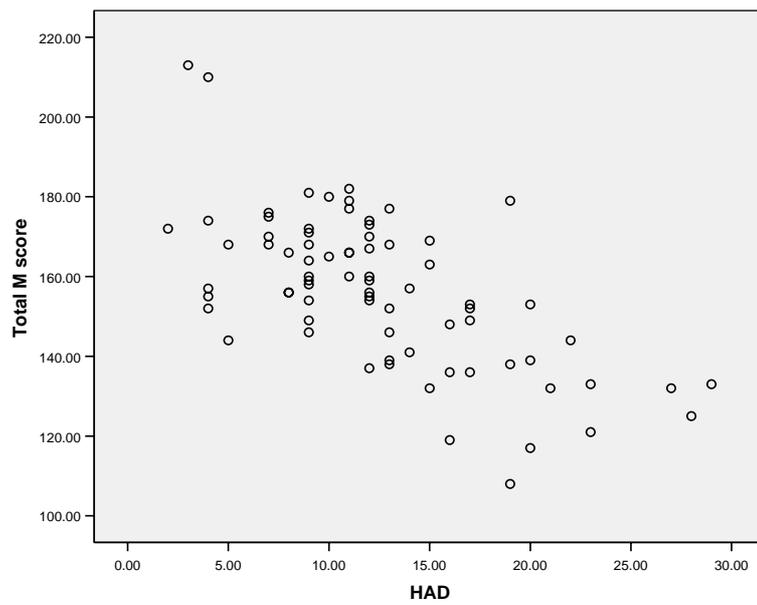
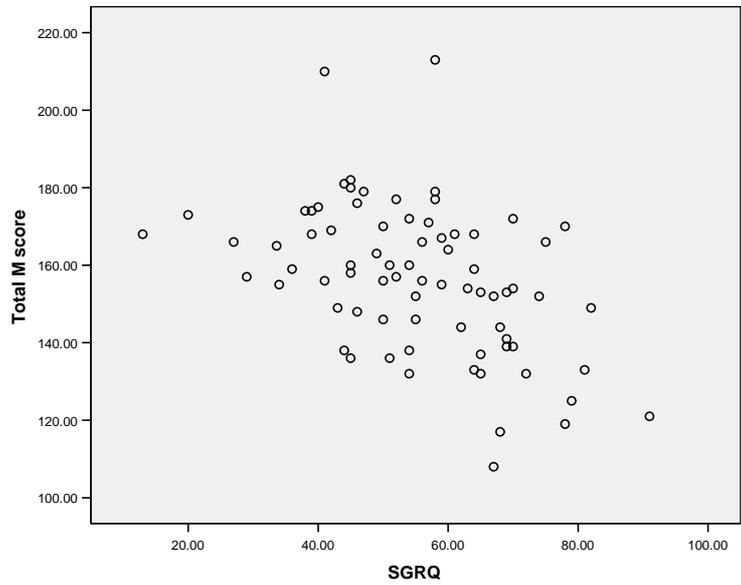
Variable	Spearman's Rho	P value	N
HAD	-0.610	0.000*	76
SGRQ	-0.476	0.000*	76
6MWD	0.413	0.001*	57
LCADL	0.298	0.009*	76
Hospital admissions last 12 months	0.274	0.024*	68
FEV1	0.172	171	65
BMI	-0.001	0.993	72
Exacerbations in previous 12 months	0.105	0.418	62

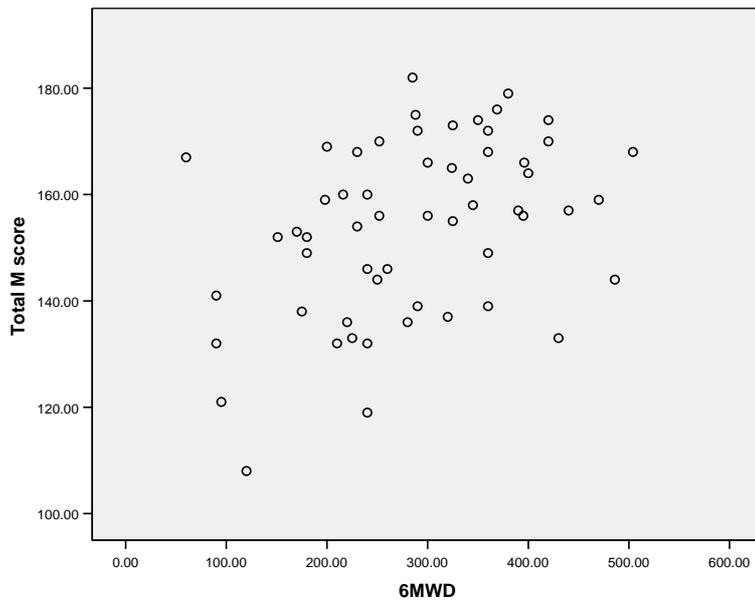
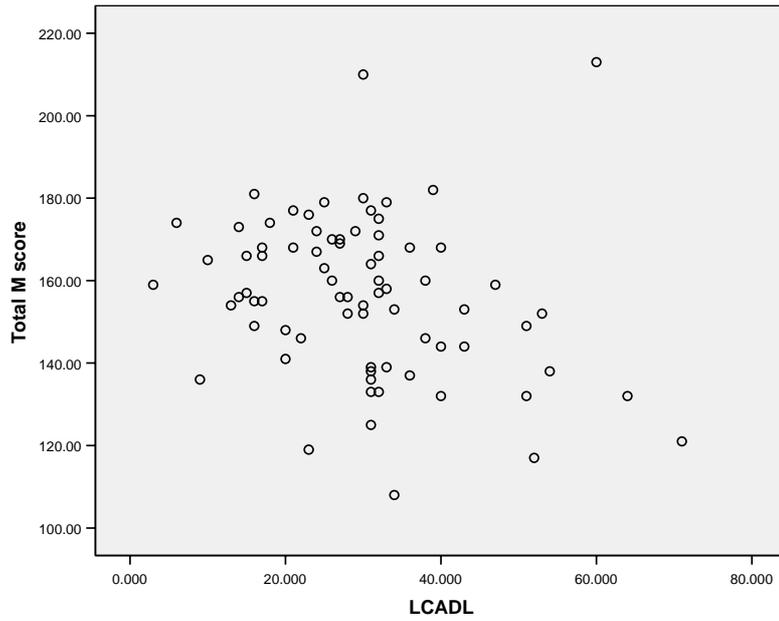
* = Significant correlation.

SGRQ = St George's Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale.
LCADL = London Chest Activity of Daily Living Scale.

Scatter plots showing relationships between the motivation questionnaire and with anxiety and depression (HAD), quality of life (SGRQ), breathlessness (LCADL) and exercise tolerance (6MWD) are illustrated in graph 6.1.

Graph 6.1: Scatterplots showing relationships between MPMQ scores and SGRQ, HAD and LCADL scores.





Regression analysis

Linear regression was performed to assess the ability of a combination of 6MWD, HAD, LCADL and SGRQ to predict post rehabilitation *change* in MPMQ score. No significant relationships were found. The ability of the same combination of variables to predict initial MPMQ score rather than the change in the score was again assessed using linear regression. It was found that HAD score and 6MWD were able to predict motivation ($p = .000$ and 0.22 respectively) with HAD score being the strongest predictor variable. This is represented in figure 6.1

Figure 6.1 Linear regression analysis. Predictors of MPMQ score.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.712(a)	.508	.469	12.10903

a Predictors: (Constant), 6MWD, HAD, LCADL, SGRQ

ANOVA(b)

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	7709.364	4	1927.341	13.144	.000(a)
	Residual	7478.065	51	146.629		
	Total	15187.429	55			

a Predictors: (Constant), 6MWD, HAD, LCADL, SGRQ

b Dependent Variable: Total M score

Coefficients(a)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	164.452	10.708		15.358	.000
	SGRQ	-.162	.141	-.157	-1.150	.255
	HAD	-1.450	.328	-.514	-4.415	.000
	LCADL	.095	.170	.074	.560	.578
	6MWD	.045	.019	.277	2.366	.022

a Dependent Variable: Total M score

Change in outcome measures post – PR.

A paired samples t – test on pre and post -PR outcome measures showed significant improvements in anxiety and depression scores and 6-minute walking distance scores, but not in SGRQ and LCADL scores. This is illustrated in tables 6.12 and 6.13.

There were no relationships between total motivation score (MPMQ version 4, appendix 5.1b) at outset of a PR programme and post PR changes in 6MWD, LCADL scale, SGRQ or HAD questionnaire values. Results are presented in table 6.14. Additionally, there were no relationships between changes in MPMQ scores and changes in the other health status measures following a programme (Table 6.15)

Table 6.12: Paired samples statistics. Pre and Post PR measures.

	Mean	N	Std. Deviation	Std. Error Mean
Pre – PR SGRQ	54.8462	39	11.91977	1.90869
Post – PR SGRQ	55.3846	39	15.20840	2.43529
Pre-PR HAD	12.9744	39	5.99775	.96041
Post – PR HAD	10.5128	39	4.96764	.79546
Pre-PR LCADL	30.00000	39	10.915947	1.747950
Post PR LCADL	30.5385	39	12.98348	2.07902
Pre- PR 6MWD	277.5000	30	93.71407	17.10977
Post PR 6MWD	353.3333	30	106.83804	19.50587

SGRQ = St George's Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale.
LCADL = London Chest Activity of Daily Living Scale.

Table 6.13: Paired Samples t- Test. Pre and Post PR measures

	Paired Differences					t	df	Sig. (2-tailed)
	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
				Lower	Upper			
SGRQ	-.53846	11.36672	1.82013	-4.22313	3.14620	-.296	38	.769
HAD	2.46154	4.75641	.76164	.91969	4.00339	3.232	38	.003
LCADL	-.538462	10.567692	1.692185	-3.964111	2.887188	-.318	38	.752
6MWD	-75.83333	64.31447	11.74216	-99.84875	-51.81792	-6.458	29	.000

SGRQ = St George's Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale.
LCADL = London Chest Activity of Daily Living Scale.

Table 6.14: Relationship of MPMQ score and post PR changes in health status measures.

Spearman's rho	Health status scores measured pre and post PR	Correlation coefficient	Sig. (2-tailed)	N
	Change in 6MWD	0.116	P = 0.541	30
	Change in LCADL score	-0.161	P = 0.327	39
	Change in SGRQ score	-0.141	P = 0.390	39
	Change in HAD score	-0.022	P = 0.894	39

SGRQ = St George's Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale. LCADL = London Chest Activity of Daily Living Scale.

Table 6.15: Correlations of change in motivation score and change in health status measures pre and post PR.

			Change in MPMQ score	Change in HAD score	Change in LCADL score	Change in SGRQ score	Change in 6MWD
Spearman's rho	Post PR change in Motivation score	Correlation Coefficient	1.000	-.310	.097	-.102	.303
		Sig. (2-tailed)	.	.070	.580	.559	.124
		N	36	35	35	35	27

SGRQ = St George's Respiratory Questionnaire. HAD = Hospital Anxiety and Depression Scale. LCADL = London Chest Activity of Daily Living Scale.

Sensitivity to change

A total of 39 patients completed the MPMQ (version 4, appendix 5.1b) before and after a PR programme. The Wilcoxon signed rank test showed a significant improvement in mean motivation scores after the programme. The number of negative ranks (where motivation score was higher prior to a PR programme) was 5, the number of positive ranks (where motivation was higher after PR) was 30 and that there were 4 ties (where the patient scored the same on both occasions). The z score was -3.875 which showed that there was a significant improvement in MPMQ scores

following PR programme. Results of the Wilcoxon signed ranks test are illustrated in table 6.16.

Table 6.16: Change in MPMQ scores following PR programme. (Wilcoxon signed ranks test).

	N	Mea	Std.	Minimu	Maximu
Total M	77	156.753	19.1333	108.0	213.0
Total M	39	164.153	17.5402	135.0	201.0

Ranks

	N	Mean Rank	Sum of Ranks
Total M score - Negative Ranks	5 ^a	15.70	78.50
Total M score Positive Ranks	30 ^b	18.38	551.50
Ties	4 ^c		
Total	39		

- a. Total M score < Total M score
- b. Total M score > Total M score
- c. Total M score = Total M score

Test Statistics(b)

	Total M score - Total M score
Z	-3.875(a)
Asymp. Sig. (2-tailed)	.000

- a Based on negative ranks.
- b Wilcoxon Signed Ranks Test

Median change in MPMQ score

The median change in MPMQ score following a PR programme, in the 39 patients whose data was available 11.5 points. Values are shown in table 6.17.

Table 6.17: Median change in motivation score following pulmonary rehabilitation.

	Total motivation score pre- PR	Total motivation score post - PR.
N	40	39
Valid		
Missing	0	1
Median	155.5000	166.0000

Factor analysis

The descriptive statistics for the motivation questionnaire items are displayed in appendix 7.3. Sixteen items were removed from the questionnaire on the basis that they showed poor discriminatory ability. Table 6.18 presents these items.

Table 6.18: Questionnaire items removed due to poor discriminatory ability

Item	Variance
"When I am having a bad day I tend to give up"	0.440
"I was encouraged to work hard as a child"	0.317
"I have a lot of drive and determination"	0.383
"I find it difficult to stick to an exercise routine"	0.566
"At the moment the weather is making my condition worse"	0.605
"I am self conscious about my condition"	0.422
"I am frightened to do things because of breathlessness"	0.440
"I am able to talk to people in a similar situation to me"	0.411
"My condition is currently a lot worse than normal"	0.693
"I want to do everything I can to improve my quality of life"	0.695
"I still try to exercise even when I'm having a bad day"	0.899
"I lack willpower"	0.765
"Because of my health I tend to feel that I can't be bothered to do things"	0.762
"I want to do everything I can to stop my condition getting worse"	0.753
"I regularly attend an exercise group or other support group"	0.881
"I am an independent person"	0.404

The correlation matrix showed that all items correlated significantly ($p < 0.05$) with at least 3 other variables so no further questions were excluded.

Principal components analysis was performed on the remaining 27 questionnaire items. Nine components were identified as having an Eigenvalue of greater than 1. Table 6.19 shows the Eigenvalues and % of variance of each component before and after rotation.

Table 6.19 Eigenvalues of each component before and after rotation

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
	1	6.671	24.709	24.709	6.671	24.709	24.709	2.915	10.797
2	2.635	9.758	34.467	2.635	9.758	34.467	2.657	9.840	20.638
3	2.364	8.756	43.223	2.364	8.756	43.223	2.424	8.978	29.616
4	1.821	6.745	49.969	1.821	6.745	49.969	2.331	8.633	38.249
5	1.431	5.301	55.269	1.431	5.301	55.269	2.244	8.310	46.558
6	1.332	4.932	60.201	1.332	4.932	60.201	1.959	7.256	53.814
7	1.188	4.401	64.603	1.188	4.401	64.603	1.877	6.952	60.765
8	1.111	4.116	68.719	1.111	4.116	68.719	1.807	6.693	67.459
9	1.043	3.862	72.581	1.043	3.862	72.581	1.383	5.122	72.581
10	.927	3.434	76.015						
11	.836	3.098	79.113						
12	.734	2.720	81.833						
13	.615	2.279	84.112						
14	.585	2.168	86.280						
15	.541	2.005	88.285						
16	.510	1.890	90.175						
17	.416	1.540	91.715						
18	.400	1.482	93.198						
19	.373	1.380	94.578						
20	.315	1.167	95.744						
21	.220	.814	96.559						
22	.197	.730	97.288						
23	.191	.706	97.994						
24	.184	.683	98.677						
25	.153	.568	99.245						
26	.109	.405	99.650						
27	.094	.350	100.000						

Extraction Method: Principal Component Analysis.

All items showed a high loading (>0.4) to a particular component. A table showing the rotated component matrix which contains the factor loadings of each variable (questionnaire item) onto each component can be seen in appendix 7.6.

Following examination of the component matrix, 6 items were removed on the basis that they loaded highly (> 0.4) onto more than one component: These are items are as follows:

- *“In the past I have lived a very active life”.*
- *“My medical treatment gets me down”.*
- *“I always try to do my best”*
- *“I regularly socialize with friends”*
- *“I feel I know a lot about my lung condition”*
- *“Exercise is part of my normal routine”*

It was felt that the items therefore could not be reliably attached to a single component and to avoid confusion they were excluded from the questionnaire. This left a total of 21 items.

The 9 factors were labeled effort, optimism, tenacity, self worth, isolation, ability, achievement, function and self- efficacy. These labels best represented the underlying concepts of the associated items. Table 6.20 shows the factors, labels and associated variables.

Test-retest

Test-retest of the remaining items of the MPMQ following item extraction using Kendall's tau-b (Field 2005) showed all of the questions that remained following item extraction correlated consistently ($p < 0.05$).

Internal reliability

Chronbach's alpha test on the remaining 21 items of the MPMQ showed a value of 0.8324. This demonstrated the questionnaire had a good internal reliability.

Table 6.20 Factor labels

Factor	Factor label	Items loaded to factor
1	Effort	I find activity too much effort I tend to give up easily I feel depressed
2	Optimism	I have a happy disposition I am an optimistic person
3	Tenacity	Despite my condition I try to remain as active as possible I believe that exercise is very good for me
4	Self worth	I tend to get embarrassed about my condition I have lots of support from healthcare professionals I always make an effort to do things I have a supportive family I feel there are many people worse off than me
5	Isolation	I tend to panic when I am breathless I feel lonely My family encourage me
6	Ability	I feel useless because of my lung condition I try to prove I can still do things
7	Achievement	I believe there is little that can be done to help my condition I regularly get out and about
8	Function	My health prevents me from being active
9	Self efficacy	I am usually in control of my breathlessness

6.4 Discussion

This study has shown that the Malvern Pulmonary Rehabilitation Motivation Questionnaire (MPMQ) is a reliable measurement with support for its validity. Factor analysis demonstrated that the 43 items could be reliably reduced to 21 and that there were 9 factors represented by the remaining items. The factors appear to support the findings of the qualitative study where motivation in PR had a number of components.

6.4.1 Reliability

Internal reliability testing of the MPMQ was made using Chronbach's alpha coefficient. The result demonstrated that the questionnaire was internally reliable. The MPMQ consists of a number of components which were shown to make up the

construct of motivation. Had the internal consistency coefficient been very high, this may have suggested that the instrument was measuring a very narrow dimension of motivation and was failing to assess adequately all of the dimensions (www.thoracic.org 1998). Internal reliability can be checked by asking the same question in a different way at a different point in the questionnaire. However this is difficult in attitude scales as they are far more sensitive to word changes than factual questions (Oppenheim 1996). Another test of reliability, parallel forms, was not used as this involves administering the questionnaire in a different format and correlating results of the 2 formats. This would not have been possible as many of the questions are attitude questions and the format is designed to elicit the most truthful response from the patient.

The test-retest of the questionnaire using Kendall's tau-b (Field 2005) was performed on the 21 items that remained following item reduction in the factor analysis. In this test the statistical programme produce a correlation matrix showing the coefficients of all the items across the 2 tests. All the correlation coefficients were of a significant value ($p < 0.05$). This showed that the MPMQ is reliable over time. It could be argued that completing the questionnaire within such a short space of time (1 – 2 weeks) may have produced a practice effect. However, given the dynamic nature of motivation, leaving a longer space of time before the re-test may have shown incorrect inconsistencies.

Mean MPMQ scores were compared before and after a PR programme to see if the questionnaire was sensitive to change. The qualitative work performed previously suggested that a PR programme may increase motivational status. The Wilcoxon signed rank test, which was used to calculate the change in mean scores, showed that there was a significant improvement in mean motivation scores after the programme compared to before the programme. This supports the findings of the qualitative study where patients reported how elements of a PR programme increased their motivation. An increase in motivation is another positive benefit of a PR programme that has previously been unreported. This adds more evidence to the effectiveness of PR in the treatment of COPD.

In the literature review an argument was made that there was no evidence to support the statements that motivation should be used as an entry criterion to a PR programme. This study has further demonstrated the lack of support for this idea. There were no relationships found between total motivation score at the beginning of a PR programme and post PR changes in health status measures. Neither was there a relationship between the degree of improvement in motivation score and the degree of improvement with the other outcome measures. Un-motivated patients should therefore be considered equally for referral to PR.

6.4.2 Tests of validity

Concurrent validity was tested by correlating the MPMQ with other health status measures using Spearman's Rho coefficient. Analysis showed high correlations with COPD health status measures and less correlation (but still significant) with admissions to hospital during previous 12 months. There was a strong negative correlation between motivation and anxiety and depression scores, motivation and quality of life scores and a positive correlation between walking distance and motivation. These findings support the concurrent validity of the MPMQ. Linear multiple regression showed that HAD and 6MWD predicted MPMQ score, best predictor was HAD score. It was also found that in the same regression model SGRQ and LCADL did not significantly predict MPMQ score. It is of interest that the SGRQ and LCADL did not significantly improve following PR. This may be due to the fact that only 41 patients completed a PR programme, so there may not have been enough numbers to demonstrate a difference in change in LCADL or SGRQ. If a post-PR improvement had been shown in these variables then this may have altered the regression result. Nevertheless, HAD scores were found to predict MPMQ scores. Garrod (2006) identified depression as a strong predictor of PR drop out. It is possible therefore that the motivation status of the drop outs in that study was low. Further regression analyses using larger numbers of patients would be valuable in the future to further explore any relationships between motivation and psycho-social and physical variable.

These correlations with health status measures were expected, as other studies have shown that self-efficacy is related to higher levels of depression, anxiety and lower quality of life levels, and positive social support are associated with lower levels of

anxiety and depression (McCathie et al 2002). Both of these were identified as factors that influenced motivation in the preceding qualitative studies. Failure of the questionnaire to correlate with FEV1 and BMI was expected since physiological measures in COPD have shown no relationship to adherence to PR programmes in previous studies (Young et al 1999). However, this is in contrast to the findings in a study by Breukink et al (1998). That study showed a relationship between the motivation dimension of the Multidimensional Fatigue Inventory (Smets et al, 1995) and FEV1. That questionnaire however was not disease specific and its purpose is to measure fatigue rather than motivation. This may explain the different results. The study did not have the ability to present the causal relationships between motivation and other health status variables. For example we know that motivation is related to anxiety and depression but we cannot tell if being depressed 'causes' a lack of motivation. Further study is needed to establish this level of relationships.

One unexpected finding of the study was the relationship between MPMQ score and hospital admissions during the previous 12 months. Furthermore there was no relationship between motivation and acute exacerbation within the previous 12 months. This supports the idea that psychological, as well physical factors are determinants of acute admission. Surprisingly, living alone and smoking did not correlate with MPMQ scores, whereas both of these variables predicted non-adherence to a PR programme in a previous study (Young et al 1999).

One of the limitations of this study is that the MPMQ was not compared to another validated generic measure of motivation. This would have enabled establishment of criterion-related validity. This is where a new instrument is compared to a well-validated older measure (Anthony 1999). Furthermore there exists no gold-standard measure that has been tested within the context of a PR so the decision was made to not make this comparison. The construct validity of the MPMQ is supported by the fact that the items were developed from interviews with patients who had experienced the PR process. The data underpinning the MPMQ had been extracted from its' actual source. Additionally, the fact that the questionnaire was internally reliable, and that factor analysis showed good relationships between the components further supports the construct validity.

6.4.3 Motivation pre and post a PR programme

The findings of this study showed a significant improvement in MPMQ scores following a PR programme. However, we cannot say that it was the PR programme that caused the improvement as there was no control group. Nevertheless, the improvement in motivation supports the findings of the interviews where patients discussed how attending a programme increased their motivation. Motivation was examined at 4 points along the PR process and scores were different at these points. The lowest mean motivation score was found in the patients starting a PR programme. This supports our own observations where patients are often sceptical and are not convinced the programme will have any benefit. The highest mean motivation score was found in Breathe Easy attendees. The patients run this group themselves. It is possible that because there is no external motivational influences from healthcare professionals, then those that attend naturally have more of the essential motivation traits (discussed in chapter 4). Therefore it is unsurprising that their motivation scores were the highest. Maintenance group had slightly lower motivation scores than those at the end of a PR programme. This may be because the patients who have just gone through a PR programme have had intense external motivation influence from healthcare professionals so would be at their 'optimum'. It is important to note that the maintenance group had higher motivation scores than patients at the beginning of a PR programme. It is unknown if the maintenance group is causing the increase in motivation or if the patients who attend just happen to have a higher motivation score by nature. What this study has not been able to show, is the clinical significance of a change in motivation score. For example, what difference does a change in total motivation score make to the patient themselves? In other research, the clinically significant change in score has been established by either using multivariate analysis to relate the score of the questionnaire under study to other disease related variables, or related the change in questionnaire score to the patient's view of change in that variable (Jones 1995). The issue of the clinical significance of a change in motivation score, along with the relationship and effect of motivation to adherence needs to be further explored.

The other pre and post programme outcome measures were presented in the results. The only statistically significant improvements shown in post programme measures were in 6MWD and HAD scores. This was unexpected, as LCADL and SGRQ were

slightly worse following the programme and usually in the local programmes under study there is an observed general improvement in these measures. It is possible that there were not enough patients to demonstrate an improvement in these measures. The PR was certainly effective as improvements were gained in exercise capacity. As the aim of this study was not to demonstrate the effectiveness of the PR programmes from where the sample was extracted it was not felt to be an issue.

6.4.4 Non-completers of the PR programme

A total of 10 patients out of 51 failed to complete the PR programme. Known reasons were that 2 patients had un-resolving acute exacerbations of their COPD and 1 patient was admitted to hospital. Unfortunately, the scope of the study did not allow us to interview patients for their reasons for non-completion. It is interesting that 9 out of the 10 non-completers were from the programme held at the acute hospital. Since this research project was completed, the acute hospital programme was moved to a community hall, the reason being that many patients complained that there were not enough disabled parking places. Parking at the hospital was always notoriously difficult and this may have contributed to some patients not completing the programme.

Patients who had ‘dropped out’ of PR showed differences in mean scores within all of the outcome measures made at the outset of the programme. Generally these patients had a poorer motivation, worse quality of life and more severe disease than the completers. Patients who dropped out had a higher mean anxiety and depression score than the completers. This was also the finding of Garrod (2006) who suggests that depression in PR participants may have a more profound effect on participation than previously thought. Although some of the data was not available, patients who did not complete the PR programme proportionately had much higher hospital admission and exacerbation rates than the programme completers. It is possible that lots of exacerbations with admissions could cause a reduction in motivation in these patients and consequently their ability to complete a PR programme may be reduced. However, with only a small amount of data on non-completers in this study a larger research project is warranted in order to explore relationships further.

Motivation at outset of a PR programme was shown to be statistically worse in patients who dropped out than completed. It is therefore possible that the MPMQ could be used to identify patients who are at risk of drop out in PR programmes. This would enable PR staff to channel their efforts into at risk patients in order to encourage and reinforce the benefits of exercise with them to try and increase their motivation.

6.4.5 Discriminative properties of MPMQ

Using GOLD guidelines (Rabe et al 2006) to classify disease severity it was found that the MPMQ scores in the 'very severe' classification of COPD (FEV1 < 30% of predicted or FEV1 < 50% predicted plus respiratory failure) were significantly lower than the other categories combined. Unexpectedly, MPMQ scores were higher in the 'severe' category than in the moderate category. There were no patients in the sample who were 'mild' disease severity. It would have been advantageous to examine differences in motivation using the BODE index (Celli et al 2004). The BODE index computes the patients body mass index, FEV1, MRC dyspnea scale and exercise capacity to achieve a numerical score which the authors found predicted risk of death more accurately than FEV1. Unfortunately MRC scores were not available for the sample so the BODE index was unable to be calculated. In future testing of the MPMQ it would be valuable to include the BODE score within the data collected to explore any relationships.

6.4.6 Dimensions found within the MPMQ

Factor analysis identified 9 underlying components within the questionnaire. The 9 factors were labeled effort, optimism, tenacity, self worth, isolation, ability, achievement, function and self- efficacy. These labels best represented the underlying concepts of the associated items. These were very closely related to the components found in the qualitative work done previously. Table 6.21 illustrates this close relationship.

It was expected that the components identified from the factor analysis would strongly relate to the themes identified from the findings of the qualitative interview study. This was because the questionnaire items themselves were constructed from these themes. It could be argued that there was no point in undertaking a factor analysis as

a similar outcome had been obtained qualitatively. However, the factor analysis has supported the validity of the qualitative research, and has mathematically supported the notion that these themes exist. There seem to be 2 exceptions to this. Life experience and symptom variability do not feature in the MPMQ, yet during interviews patients described these as factors related to motivation. This supports the fact that when exploring attitudes and beliefs, qualitative data is an important method of data collection and can capture information that may not emerge with quantitative, large-scale research studies.

Table 6.21 Comparison of components from MPMQ and factors identified in the qualitative study

Components of MPMQ	Related components identified qualitatively
Effort	Attitude
Optimism	Attitude
Tenacity	Function
Self worth Self efficacy	Self esteem
Isolation	Human support
Function Ability	Function
Achievement	Impetus
	Life experience
	Symptom variability

Factor 3 was labelled human support despite the fact that the item “I tend to panic when I am breathless” did not appear initially to fit this category. In reality, there is a link between loneliness and anxiety, so this may explain why this item loaded to this factor. Finding unifying ‘threads’ between variables loading to one particular factor has been shown to be a common problem (Anthony 1999).

Patients dropping out of programme.

6.4.7 Study limitations

It is possible that some of the improvement in motivation following the PR programme may have occurred simply as a result of the process of completing the questionnaire itself. It is a well known problem in social science research that the effect of being pre-tested may sensitise patients and improve their scoring on the post-test (Frankfort – Nachmias and Nachmias 1996). Because the study was not randomised, we are not able to conclude that the improvement was a result of completing a PR programme. The improvement may have occurred from the learning process of completing the questionnaire. However, the test-retest demonstrated that on the second completion of the questionnaire similar results were obtained to the initial completion so any effect of testing was minimal.

Because of limited time and staff available for the PR programme, only one practice walk was undertaken with each patient as opposed to the recommended 3 practice walks (Troosters 2005). Some of the improvements in 6MWD may therefore have come from a practice effect. However, this would not have affected the results of the study since the distances would have remained constant despite any practice effect.

The data analysis in this study did not identify any correlations between motivation and post PR changes in health status. Likewise, no significant relationships were found between change in motivation score and change in other health status scores before and after PR. It would be reasonable to expect that since there was a correlation between motivation and health status, if health status improved following PR, then so would motivation. It is possible that the reason for the insignificant results is that the sample size was too small. Again, due to limitations in time and resources, the sample size of patients who completed the MPMQ before and after a PR programme was limited to only 41. Further study of motivation before and after a PR programme using a larger sample size is needed to identify if any relationships exist.

Another limitation of this study is that the questionnaire was administered within a short space of time to the entire sample. Item reduction and reliability testing were then undertaken at the same time using the responses from the whole sample. In retrospect, it may have been a better method to complete the study in stages. Firstly,

to administer the questionnaire to a smaller sample and perform factor analysis, then, following item reduction, to review the questionnaire prior to performing tests of validity and reliability. It is known that in questionnaires, the order in which the questions are placed, and the nature of the preceding question, can affect responses (Oppenheim 1992). In effect, this means that the new 21-item MPMQ may elicit slightly different responses than the 43 items administered to the sample. It is clear that the new 21-item MPMQ needs further testing using a different population in clinical practice to further support validity and reliability.

Patients attending PR are often keen to show they are compliant with their prescribed exercise regime even when this may not be entirely the case. This is possibly because they want to 'please' the PR who have put in the effort to help them. This became apparent in the previous interviews as one motivational factor was that some patients did not want to let the healthcare team down. This fact may have caused response bias within the questionnaire, in that patients may have given more positively loaded answers than they should. Attempts to minimise this possibility was made by using a research nurse, who had very little or no involvement in the patients clinical management to administer the questionnaire. Nevertheless, in any future studies involving the MPMQ this issue should be considered.

6.5 Conclusion

This study has shown that the 21 item MPMQ is a reliable measurement instrument and also that there is evidence to support its' validity for use in assessing motivation in a PR programme. Analysis of the questionnaire uncovered 9 sub-components of motivation that confirmed the findings of the earlier qualitative study. It was found that motivation was related to measures of health status. Generally it appears that the worse the patient's quality of life, the poorer their motivation. There was a significant increase in mean motivation score after a PR programme, although the clinical significance of this remains unknown. In addition, motivation score at the outset of a PR programme was not related to the improvement in health status following a programme. An unexpected finding was that motivation was related to hospital admissions in the previous 12 months. An important finding was also that motivation was significantly lower in patients who did not complete the PR programme. The

questionnaire could be used during assessment for a programme to screen patients who are at risk of non-completion. Furthermore, as motivation improved during PR, this provides weight to the argument for the effectiveness of PR in reducing acute hospital admissions.

6.6 In summary

This chapter has presented a quantitative study investigating the reliability and validity of a motivation measurement instrument – the MPMQ. The tool was shown to be reliable and had construct validity. It was shown that further tests of reliability and validity are required to support the use of the questionnaire in clinical practice.

**CHAPTER 7: SYNTHESIS AND IMPLICATIONS
FOR CLINICAL PRACTICE**

This chapter provides a synthesis of the work, studies and findings described in the previous chapters. A discussion about the findings and their implications for clinical practice is presented along with suggestions for future research.

7.1 Summary of the research project

In the clinical management of patients with COPD, non-pharmaceutical interventions, aimed at treating disability are being increasingly employed within this speciality. The benefits of pulmonary rehabilitation (PR) in treating COPD disability are becoming increasingly apparent. Motivation is anecdotally acknowledged, by both patients and healthcare professionals, and features in PR literature, as a key element in a PR programme (Nici et al 2006). It has also been suggested that motivation should be a pre-requisite to entry to a PR programme (Troosters et al 2005, Morgan 1999 and Donner and Muir 1997). The literature review demonstrated that motivation is part of a process of behaviour self-regulation. There is substantial information available about motivation in the health psychology literature, but research into this subject within the PR literature is in its' infancy. A review of the literature also found that there was no suitable specific measure for use in a PR programme to explore the role of motivation in patient adherence to a programme. Therefore, the main aim of the research project was to develop and validate a motivation measure for specific use within a PR programme, underpinned with data about patient perceptions of factors relating to motivation from the own experiences of a PR programme.

A series of 3 studies were undertaken in order to fulfil these objectives. The first was a qualitative, exploratory focus group investigation designed to collect some initial data about the meaning of motivation for patients in the context of a PR programme. This initial data informed the construction of some semi-structured questions for the second study. The second study was also qualitative and consisted of face- to- face interviews. This enabled the collection of data about patient – perceived factors associated with motivation within a PR programme. From this data, items were extracted to form a self-report questionnaire designed to quantify the qualitative findings was developed. The third study was a quantitative, prospective pre and post-test investigation, where the questionnaire was tested for reliability and validity.

The 2 qualitative studies produced rich and informative data about the role of motivation in PR. It was found that patient's perceptions of motivation within PR consisted of a number of variables that made up an 'essential motivation' element and an 'external motivation' element. The manifestation of motivation was perceived to be the functional, or behavioural, outcome. One of the most prominent findings of the study was that attending a PR group seemed to have an enormous positive influence on the patients' essential motivation. In particular, the input of the specialist healthcare professionals involved in their care was perceived to have an enormous influence on the patients' motivation. Using this data, theoretical guidelines were then followed in order to construct a 43 item, self-report questionnaire designed to measure the motivational status of patients entering a PR programme. The questionnaire was identified as the Malvern Pulmonary Rehabilitation Motivation Questionnaire (MPMQ).

The 43 – item MPMQ questionnaire was administered to 77 patients initially and it underwent a variety of reliability and validity tests. Using factor analysis, the MPMQ was able to be reduced to 21 items and was shown to be a reliable measurement tool with evidence to support its' validity for use in assessing motivation in a PR programme. Analysis of the questionnaire uncovered 9 sub-components of motivation that supported the findings of the earlier qualitative study. It was found that MPMQ scores correlated with health related quality of life, anxiety and depression, breathlessness, exercise capacity and previous hospital admissions. Patients who dropped out of the PR programmes were found to have lower motivation scores than completers of the programme. There was also a significant increase in mean MPMQ scores after a PR programme and the motivation score at the outset was not related to the improvement in health status following a programme.

7.2 Motivation as a process.

Both the qualitative and quantitative data obtained from this research supports the notion that motivation within PR is a phenomenon determined by a number of physical, psychological and social variables that formed an interrelated network. Motivation was also shown to be a dynamic construct that was perceived by patients to increase during a PR programme. In describing their perceptions of the meaning of motivation, PR patients considered that the whole process of self-regulation fell under

the umbrella term of motivation. They did not disengage the concept of motivation from the actual self-regulation and goal attainment. This is in contrast to some of the health psychology literature where motivation precedes self-regulation in the process of health behaviour change (Caprara and Steca 2006, Sniehotta et al 2006 and Umstatted et al 2006). The study by Umstatted et al (2006) presents self-efficacy as the influencing factor on the decision to engage in physical exercise and self-regulation as the next stage in the process to operationalise the decision followed by participation in the behaviour itself. Sniehotta et al (2006) argue that there is another dimension to the process, which follows intention and precedes self-regulation. This is the construct 'action control'. The authors present action control as consisting of awareness of standards, self-monitoring and self-regulatory effort. Our patients clearly perceived the entire process of behaviour change as being part of the concept of motivation.

Although patient perceptions of motivation in the context of PR in our study did not aspire to the theoretical detail of the health psychology literature, the findings can be linked to the theory. Patients identified motivation factors in their experience of PR as their own intrinsic determination developed from life experiences, social and healthcare support, skills in carrying out physical exercise prescription and the actual adherence to the health behaviour. Our patients described a process of health behaviour change that is simpler in description, but similar to the process of intention, action control, self-regulation and carrying out of the behaviour. Patients also recognised that motivation consists of many factors, some of which are individual to the person and that motivation is also dynamic and can be manipulated by external factors. In PR this is an important issue. If we can manipulate motivation, which was demonstrated in this study to be lower in non-completers, then this may have an impact on adherence with a PR programme. What is also important is that our COPD patients have unique problems compared to the generic populations used in previous self-regulatory research (Umstatted et al 2006). Research is needed within the speciality of PR to explore and adapt health psychology theories to patient experiences of motivation. By further exploration of motivation and its determinants within a PR programme, the most powerful determinants could be identified, thus enabling us to channel efforts into the most effective cognitive-behavioural PR interventions.

7.3 Motivation and PR adherence.

American and European guidelines in PR (Nici et al 2006 and Dodd et al 2001) recommend more research into uptake, adherence and post programme maintenance of exercise in PR. In order to undertake such research, it is necessary initially to have a consensus about what constitutes 'uptake', 'adherence', 'drop-out' and 'maintenance' in PR. This issue was discussed in chapter 1. It is also necessary to understand determinants of these constructs in order to plan appropriate behavioural-cognitive techniques for use within a programme to enhance adherence. Knowing which patients are at risk of programme 'non-adherence' would enable PR staff to target those patients with appropriate adherence-enhancing strategies.

Although the focus of this study was not to explore PR 'drop-out', some data emerged about patients who did not complete the PR programmes. A finding of this study was that patients who did not complete a PR programme had statistically lower motivation scores than completers. Patients who had dropped out of a PR programme also tended to have, worse quality of life and breathlessness scores, higher anxiety and depression scores, lower exercise capacity, were more likely not to live alone and to be a smoker, have more exacerbations and hospital admissions and a poorer lung function than programme completers. These findings are similar to other studies in PR adherence (Donesky 2007 and Young 1999). For example, Garrod et al (2006) found that PR drop out patients were more likely to be depressed, although a different depression assessment tool was used to our study. Also, results are similar in that both studies found that non-completers were more likely to be smokers. Contrasting findings were found in breathlessness scores. Garrod et al (2006) found that severity of breathlessness was not associated with drop-out, whereas in our study, drop-outs tended to have higher breathlessness scores, both studies using the LCADL measurement tool. Drop out was not the primary focus of either this study or the Garrod (2006) study. More study is needed, both quantitative and qualitative, that explores the different aspects of adherence. In particular, there seems to be very little information in the PR literature on initial uptake of PR following referral in the first instance. Most studies appear to have explored drop out and maintenance following initial attendance (Taylor et al 2007, Garrod et al 2006, Ries et al 2003, Cote and

Celli 2005, Young et al 1999 and Donesky et al 2007). It is known in local clinical practice that a number of patients decline PR in the first place and it would be valuable to understand why this is the case in order to address this issue in practice. Assessment of the motivation of patients at referral would possibly highlight those who may decline a programme in the first place. This would enable the PR team to streamline their first consultation with these patients in order to manipulate their motivation to participate in the programme.

Although this study has demonstrated that mean MPMQ scores were poorer in patients who did not complete a PR programme, using motivational status as an entry criterion for a PR programme may not be satisfactory. We have shown that patient perception is that motivation increases during a programme and there was a significant increase in motivation score following PR, although as there was no control we are unable to claim that this was as a result of the programme itself. Nevertheless, the MPMQ has now provided an objective measure that PR staff can use to assess the patients' motivation, rather than it just being left to their judgement. Since patients with a poorer health status are more likely to drop out of PR, surely these are the one's who are in need of PR and it's life-changing benefits the most.

Rather than use the MPMQ to determine which patients to exclude, it is recommended that the tool be used to highlight patients who may struggle to adhere so that efforts can be channelled towards them to facilitate programme completion. During a PR group situation, it is often difficult to give a great deal of time to the needs of the individual. There is currently a danger that patients whose adherence starts to diminish are not recognised early and preventative measures taken. The findings of this study suggest that measuring patient's motivation at the outset of a programme may highlight which patients need additional support to enhance their essential motivation. Such support may be extra encouragement and individual discussion about the benefits of PR.

Continuation of lifestyle change beyond a PR programme is an area in great need of research. Clearly the longer the benefits of PR are maintained, the more cost-effective an intervention it is. Presently, there is not enough data relating to a programme design that produces optimum long-term motivation and adherence.

Initial attempts to examine ways of maintaining the effects of a PR programme have been made (Ries et al 2003 and Donesky et al 2007) but with only limited short-term effectiveness. Longitudinal studies are needed to examine any associations between motivation, PR setting, exercise intensity and self-regulation on maintenance of the prescribed exercises beyond a PR programme. The MPMQ facilitates such study.

The qualitative findings of this research showed the positive effect of a PR programme on a patient's motivation. The findings also show that patients with a higher essential motivation may continue their lifestyle changes more successfully than those with a lower essential motivation who may need additional external motivation enhancing interventions. It was interesting that patients attending the Breathe Easy club had the highest MPMQ scores in the PR process. The Breathe Easy club is orchestrated by the patients themselves and they do not have the benefit of external influences from PR staff to motivate them to attend. This supports the idea that a higher essential motivation may exist in these patients as they appear to not be dependent on external influences.

Previous studies have shown that a one-off PR programme may be unrealistic in its expectation of producing lifetime coping and health behaviours (Toms and Harrison 2002). The authors of this study present the hypothesis using Badura's self-efficacy theory (1977) that without group support the increase in effort related to managing COPD could gradually weaken individuals' perceived self-efficacy. Our study has shown that this may not be the case in every patient, as some have a higher essential motivation enabling them to continue to exercise at a sufficient effort level and maintain the benefits of PR independently. The standard model of a one-off, 6-8 week PR programme which has been so successful to date may now need to be reviewed in order to target individual needs to maintain lifelong support.

Studies appear to differ on how long following a PR programme improvements are maintained. For example Conner et al (2001) showed improvements in exercise tolerance following a PR programme were maintained at 1 year and yet Ketelaars et al (1998) found HRQL deteriorated 4 – 9 months following a programme. Although these 2 studies used different outcome measures. Differences may be attributed to standards of programme delivery. There is a growing interest within the speciality of

PR into cognitive behavioural interventions intended to enhance patient self-management, thus facilitating long term adherence to the principles of PR (Monninkof et al 2003, Snider 2004, Martin et al 2004, Dowson et al 2004, Bourbeau 2004 and Taylor et al 2005). It is now recommended in American and European guidelines that such strategies should be incorporated within a PR programme (Nici et al 2006).

7.4 Motivation, disease severity and hospital admissions.

The MPMQ correlated significantly with health related quality of life, anxiety and depression and breathlessness. This seems to be supported by other research where similar findings were apparent. For example, Breslin (1998) found that the multi-fatigue inventory (MFI) 20 subscale of motivation correlated significantly with the St George's Respiratory Questionnaire score, a measure of quality of life. Breukink et al (1998) also found that the motivation dimension in the MFI correlated with breathlessness and FEV1. The MPMQ score also correlated with breathlessness but not FEV1 in our study. There was an association found between quality of life and self-regulation in validation of the exercise self-regulatory efficacy scale for people with COPD (Davis et al 2006) which supports the findings of our study.

Another finding of this study was a significant correlation between MPMQ scores and the previous years' hospital admission, yet motivation did not correlate with exacerbation frequency. This is an important finding as COPD admissions to hospital are costly and a massive burden to the NHS (British Lung Foundation 2003). Since exacerbations increase the risk of admission to hospital (Garcia-Aymerich et al 2003) it is possible that a moderating factor of admission is motivation. We already know that other psychosocial variables are associated with increased risk of hospital admission, for example poor quality of life (Osman et al 1996) and low levels of physical activity (Garcia-Aymerich et al 2003). The hospital admission and exacerbation data was collected retrospectively in this study. It is unclear whether it is the poor motivation that has caused admissions or the admissions that have caused the poor motivation. A prospective study would now be useful in order to explore a causal relationship. Furthermore, our hospital admission data was collected as number of admissions. It would be more informative to record days spent in hospital to give a more precise result. If motivation was shown to be a factor in hospital

admission, this would add theoretical support to interventions designed around preventing readmission such as early PR following hospital admission (Man et al 2004). It is also of interest that patients who failed to complete the PR programme in this study tended to have higher previous hospital admissions. Further research exploring any relationships between MPMQ scores, admission and adherence to PR programmes would offer valuable information to underpin COPD management.

7.5 Increasing motivation within a PR programme.

The ATS / ERS pulmonary rehabilitation guidelines (Nici et al 2006) provide a limited amount of information suggesting strategies that aim to facilitate self-management in PR programmes. These strategies have been adapted from Bourbeau et al (2004) and include 'patient feedback and reinforcement', 'personal experience and practice' and 'analysis of causes of failure and vicarious experiences'. Nurses and physiotherapists running PR programmes have very little training in health psychology and would need additional training and support in order to undertake the application of such strategies. The guidelines do provide an argument for including a clinical psychologist on the PR team, however funding for PR programmes in the UK has traditionally been poor, and such input may be difficult to obtain.

Patients reported in this study that the weather, in particular the cold during the winter, had an effect on their motivation. Other authors have found that there is a seasonal effect on quality of life and anxiety and depression (Miravittles et al 2004) and FEV1 and number of acute exacerbations (Donaldson et al 1999), with worse scores in the winter. During validation of the MPMQ, a relationship between motivation score and anxiety and depression was observed. As anxiety and depression worsens during the winter, this indicates that there may be a complex sequence of psychological and behavioural events that are dynamic throughout the seasons. In contrast, a study by Spence et al (1993) showed that cold air actually reduced breathlessness, probably as a result of hypoventilation. However, this study was done using cycle ergometry in a clinical situation, not in an outdoor situation. It is possible that there are psychological as well as physical dynamics involved during the winter. The cold weather clearly has a significant impact on a number of parameters, physical, psychological and behaviour. It would be an interesting exercise to administer the MPMQ along with other health status measures throughout

the seasons and during health and exacerbation to establish any associations. Reduction of exacerbation is a target for patients with COPD (Donaldson and Wedzicha 2006). If a seasonal lack of motivation was identified as a factor contributing to the patient not undertaking exacerbation preventative measures, then it may be possible to manipulate their motivational status and improve outcomes.

Support from family, friends and healthcare professionals was discussed by the patients in the qualitative study as having an influence on motivation. However the quantitative data showed no relationship between living alone and motivation. There is therefore a need to explore further the relationship between social support and motivation using an objective measure which may differ from a self report social support may differ from an objective measure. It appears that there is not much research on affect of social support including family and peers on cognitive variables. Young et al, 1999 found that whilst general emotional support is obviously important, it was the disease specific specialist support that was the key to patients attending and adhering to a PR programme. Our study supports this finding as it was the support and encouragement of the specialist respiratory healthcare staff that was important to the patients' motivation. Maclean and Pound (2000) make a cautionary observation that practitioners must take care not to favouritise patients with a more motivational character (moralise), as those with a low motivation will be further disadvantaged. Since staff support is so important to the patients' motivation, consideration should be given when appointing PR staff to their personal qualities. Having the skills to encourage and motivate patients seems as important as clinical skills.

One outcome of the qualitative section of the research was that the patients thoroughly enjoyed the experience of the focus groups and interviews. Following these procedures patients made many comments about how enjoyable they had found these experiences. Many even said they were motivation enhancing in their own right and focus group participants even requested that they were incorporated into a PR programme as a therapeutic intervention! As discussed in previous chapters, most patients interviewed had never had the opportunity to talk in such depth at such length. These comments indicate that group discussion, using similar methods to focus group research, may be a useful cognitive-behaviour intervention within a PR programme.

7.6. Using the MPMQ in clinical practice

A potential practical problem in using the MPMQ as part of the assessment of patients for PR programmes is that they may end up with too many questionnaires to fill in. It is possible that monotony could set in with several self-report questionnaires which may reduce the reliability of the patients' responses. The MPMQ was not intended to be routinely used in PR programmes as a standard outcome measure. It was intended for use in research specifically concerned with factors of motivation and adherence. Because of the correlations between motivation and other outcome measures used in PR programmes, it could be suggested that it is not altogether necessary to know what the level of motivation is. If someone has a poor quality of life, is anxious and breathless during minimal activity we can take a good guess that they will not be motivated.

As discussed above, further study is needed to explore factors such as PR setting and exercise type and intensity on motivation and adherence. In chapter 4 the potential benefits of delivering PR in the patients home environment were discussed. There are often many differing findings about what is the optimum setting for PR and how long the benefits last. For example McBride and Milne (1999) claimed to have found little evidence to support a home- based PR programme in their systematic literature review. However, there are a number of studies, which have shown favourable results. For example, Strijbos et al (1996) showed that a home PR programme was very successful. Studies evaluating PR programmes are conducted in different rehabilitation settings, sometimes in different countries and programmes are not completely standardised. Therefore it is hardly surprising that researchers have conflicting findings. For example, a PR programme where improvements were still maintained at 12 months may be delivered by a far more experienced healthcare team than a programme where benefits are lost after 6 months. The optimum PR programme has still yet to be established (Troosters et al 2005) and even then some programmes will naturally get better results than others. So comparing the results of studies across different PR locations is always going to be difficult. There is a lack of research into the effect of the rehabilitation setting or exercise intensity on outcomes and long-term adherence with exercise. Longitudinal prospective studies are needed

to compare the effects of different rehabilitation settings and exercise intensity on motivation, adherence and outcome. It may be possible to increase essential motivation by combining an outpatient programme with home visits in order to ‘wean the patient off’ the group situation. This process could be compared to standard home and hospital PR programmes.

Allaker (1995), whilst discussing motivation in cardiac rehabilitation, suggests that introducing low level activity into the patients daily routine which becomes a lifelong habit may be far better than adhering to a supervised exercise programme which is discontinued once physiological targets have been reached. It is interesting that a study comparing out patient PR to a home PR programme found that although the outpatient group had a higher improvement in their outcomes, the home group maintained their improvements for longer (Wedzicha et al 1998). It has been suggested that outside of a PR group, patients are unlikely to exercise at the same level of intensity (Toms and Harrison 2002). But it is possible that patients may find adherence to exercise, which is specifically targeted at their own environment easier to incorporate into their daily routine than a generic exercise programme aimed at a group. Norweg et al (2005) investigated the effectiveness of different combinations of pulmonary rehabilitation programmes. A programme featuring a combination of exercise plus activity – specific training produced additional benefits in terms of dyspnoea, functional status and quality of life compared to an exercise and education programme, or exercise alone. Unfortunately, this study only examined outcomes up to 24 weeks following the programme. It would be valuable to use the MPMQ to measure motivation across different exercise intensities to establish differences in motivation scores. For example in local practice we are introducing a COPD walking group. It would be of interest to construct a research project to compare long term adherence and motivation scores between a walking group and the maintenance exercise group.

7.7 Study limitations

In the literature review presented in chapter 2 there was discussion about the theory – practice gap between the health psychology literature about motivation and clinical practice in the field of PR. The research was difficult as the health psychology

literature about motivation is far more advanced, detailed and analytic than the research in the PR literature. Whilst PR literature maintains the use of the classification of 'motivation', the health psychology literature uses far more contemporary theory, such as 'self-regulation'. Also this research study was performed in a nursing context and was focussed on a very specific population to fulfil a particular clinical need. This posed numerous problems in efforts to bridge the theory – practice gap. However, the MPMQ was constructed from the experiences of patients who underwent a PR programme, so it is very contextually specific. The patient's perceptions of motivation, although simplistic, related well to health psychology theories such as self-regulation (Leventhal et al 1980) and action control (Sniehotta et al 2006). The fact it has been constructed from data extracted from patients experience in simple language makes it easy to apply within the clinical area.

Another limitation of this study is that it cannot be concluded from the results that motivation increased as a result of a PR programme as there was no control group. Motivation scores did improve but this was only in the context of exploring the sensitivity of the questionnaire. It is possible that some of the increase in motivation scores was as a result of testing. In order to examine whether it was the PR that caused the motivation to increase the motivation questionnaire would need to be administered within a randomised controlled trial with a control group that were not receiving PR.

A limited number of PR 'non-completers' were included in the study. The reason for this is that only 41 patients were included who actually were commencing on a PR programme. Motivation scores in programme drop-outs were shown to be statistically lower than in completers. It would add weight to these results therefore, to measure motivation in a larger sample of patients entering a PR programme, in a study designed specifically to examine the ability of the MPMQ to predict non-adherence within a programme. The low amounts of subjects who actually completed the PR programme in the study may account for the lack of statistical improvement in the SGRQ and LCADL scores post – PR. Additionally, it would have been valuable to have included more patients within the qualitative studies who had dropped out of a PR programme. Possible a focus group would have been a good way to collect data as non-completers of PR would have added a more negative dimension to motivation.

It is recommended that further research is undertaken to collect data on factors associated with drop-out.

Only 30 patients completed a post-programme 6MWD test as the other patients were not well enough to do the test on the assessment day. Due to a lack of resources, it was not possible to undertake these tests at another time. It would have added to the power of the study if more patients were included in the 6MWD. Likewise, some of the data on co-morbidities was not available which limited the ability of the study to determine any relationships between co-morbidities and other variables.

One of the concerns of the focus group study was that it was possible that patients were describing the onset of a more positive disposition due to PR rather than specifically describing motivation. It is possible that motivation is so closely linked with other positive feelings, that it may be difficult to separate the components of the psychological improvements gained from a PR programme. This was one of the reasons why, during the second study, patients were interviewed who had not attended a PR programme. This was to ensure that descriptions of motivation are included from those who have not had the benefit of the positive feelings induced by attending a PR programme. Again, it would have been useful to have conducted a focus group on non-completers of PR to obtain a more negative description of motivation.

The MPMQ to date has only been tested for validity and reliability using the 43-item version prior to item reduction as informed by the factor analysis. The MPMQ was subsequently reduced to a 21-item questionnaire. Since this has changed the sequence of some of the questions, there is a possibility that this may have affected the reliability. It is known that the sequence of the questions in a questionnaire affects the type of response (Salkind 2004). Response to attitude questions can be dependent on the preceding item in the questionnaire (Frankfort – Nachmias and Nachmias 1996). Therefore, further reliability and validity testing needs to be carried out on the new 21-item questionnaire to ensure it remains a reliable tool.

In retrospect an alternative method to using the semi-structured questions in the patient interviews may have produced more robust results. The process of asking semi-structured questions may have biased the patients' responses. Being asked

questions from a list on a clipboard may have inhibited patients from discussing determinants of motivation that did not appear on the question list. They may have felt that the determinants of motivation were ‘cut and dried’ and that they were simply required to discuss their thoughts about these determinants. In addition, there were times when the interviewers could have explored an interesting thread of information further, but felt a little restricted by the semi-structured format. It is possible that a ‘free-form’ interview may have gleaned richer data by allowing the interviewer and interviewee more freedom to discuss individual idiosyncrasies. The downside of this is that not having an agenda may have caused interviews to lose focus and important data may too have not been captured.

The MPMQ developed in this project is a self – report questionnaire. Anecdotally healthcare professionals portray patients who are motivated about their treatments in a positive light. For this reason, patients may try to ‘please’ the PR team by answering the questionnaire more favourably than their true feelings warrant. This is known as social desirability bias (Fox 1997). Awareness of the possibility of this problem should be made if the questionnaire is to be used in any further studies. A way of reducing this risk would be to use a research assistant who is unknown to the patient and has not been involved in their clinical care.

On reflection, the quantitative method used in factor analysis appeared to be a mathematical way of repeating the qualitative method used to analyse the patient interviews previously. Both of these methods (qualitative thematic analysis and quantitative factor analysis) have the overall aim of making sense of the data by identifying the underlying concepts. Both methods involved the researcher making subjective decisions about underlying concepts within the data. Data was organised statistically in one method and manually in the other method. It could be argued that the statistical method is more trustworthy because there is no researcher bias during analysis. However, many of the items demonstrating poor discriminatory ability statistically, represented concepts that were deemed as very important by COPD patients during the interviews. For example, the question “*I have a lot of drive and determination*” represented a large amount of interview data where patients felt that drive and determination formed part of the essence of motivation. One explanation is that questions such as this were not well worded which is why there was not a good

spread of responses. Alternatively, it is possible that trying to represent the beliefs, experiences and behaviour of humans with a simplified measurement tool is not as valid as using a qualitative approach.

It would have been valuable to have measured self-efficacy as part of the validation of the MPMQ. Self efficacy was demonstrated to be a key component of motivation that clearly is positively manipulated by a PR programme. Since a valid measurement tool exists to measure self-efficacy (Wigal et al 1995), it would be valuable to correlate the MPMQ scores with self efficacy scores to supply further evidence regarding its' validity.

When the data from the focus groups was revisited it was apparent that the majority of data captured within the interviews already existed within the focus group results. One of the differences with the data analysis in the 2 studies was that analysis of focus group discourse was fairly descriptive. The discourse was simply categorised, resulting in a basic presentation of how patients viewed motivation in a PR programme. Whereas in the interview study, axial coding (Strauss and Corbin 1990) was applied to the data, which resulted in a far more analytical result. This gave much more informative results, allowing the emergence of richer data about motivation in PR. In retrospect, had the data from the focus group study been treated in a similar way, it is clear the results would have been virtually the same. It is possible that the inclusion of maybe 1 or 2 more focus groups, to ensure data saturation, would have prevented the perceived need for the interviews. This would have saved much time in the project. It is clear from this study that focus groups conducted to high standards, with meticulously executed analytical procedures, could provide an excellent method of investigation for future studies in COPD and PR.

The generalisability of the findings of this research are limited. The qualitative data collected about motivation and the MPMQ measurement tool have only been applied to patients who are undertaking a PR programme within this study. Many of the questions would not have the same meaning to a person who did not have a chronic lung disease. For example the question "*I am an independent person*" would not be appropriate to motivation in a person without a chronic disease. It is possible that the findings can be applied to patients outside of the context of a PR programme, since

the MPMQ does not actually have questions that specifically relate to a PR programme. The reliability of the questionnaire within another context would need to be tested prior to recommendation for its use outside of PR. The research was also undertaken using patients referred for a PR programme. In the main these were mainly patients with moderate to severe COPD who were experiencing a disability as a result of their symptoms. A small number of subjects had other disabling respiratory conditions such as pulmonary fibrosis or severe asthma. Again, the reliability of the MPMQ would be questionable in a population with a different level of disease severity. For example, patients with mild to moderate COPD who had little disability may have different determinants of motivation to those used in this study. Therefore, the results cannot be generalised to such populations without further research.

It should be noted that the tests of reliability and validity in this study are only preliminary and that further evidence for the validity of the instrument will need to be gathered from future studies in different patient populations. It would be important to also use a larger sample size to assess motivation before and after a PR programme. A possible weakness within the study is that a psychological construct

7.8 Conclusion

This research project has provided original information about the role of motivation within the context of a PR programme. More research is needed to provide additional evidence for the validity and reliability of the 21-item MPMQ, using a criterion such as the COPD self-efficacy scale (Wigel et al 1991). It is important that the relationship between the MPMQ and adherence to a PR programme is investigated to further determine the validity of the questionnaire and its relationships between the 2 constructs. More theory surrounding the relationships between motivation, adherence and PR outcome would enable us to more effectively hone in on appropriate cognitive-behavioural interventions to facilitate adherence within and after a PR programme. This would contribute to the development of guidelines for the optimum PR programme that produces lifelong, lifestyle change for patients. This study has reinforced the fact that a PR programme is 'more than just the sum of its' parts' and high standards of programme delivery should be maintained. In order to maximise

the effectiveness of PR, programmes should be led by specialist staff who not only are experts in COPD but who also have the knowledge, skill and experience to be able to successfully lead a group. With continued restrictions on NHS resources, specialists should ensure that managers understand that whilst PR is not an acute high tech intervention, financial restraints should not cause a drop in standards. High standards are essential in order to maximise the outcomes of the programme and maintain its' cost- effectiveness.

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Appendix 3.1 Correspondence with respect of ethical approval

Appendix 3.2 Information sheet, focus groups.

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith

Pulmonary Rehabilitation

Room 27
Worcester Royal Infirmary
Castle Street
Worcester
WR1 3AS
01905 760183

Patient Information

Focus group

Dear patient,

We are conducting some research into what motivates people to do their exercises in the pulmonary rehabilitation group. We are in the process of developing a motivation questionnaire in order to try and 'measure' motivation to follow an exercise programme.

Learning more about motivation to exercise will enable us to improve pulmonary rehabilitation programmes in the future. The results of this research may be published so that other people can learn from this work.

Thankyou to agreeing to participate in this focus group, you will be asked to sign a consent form. The purpose of the focus group is to discuss and debate the topic of motivation in pulmonary rehabilitation. The discussion will be moderated by Elaine Bevan-Smith and it will be recorded. You do not have to join in with any part of the discussion that you do not want to and you can withdraw from the group at any time without affecting any future treatment.

If you have any questions about the research please contact Elaine Bevan-Smith on the above number.

You can also contact your local Community health council if you have any concerns. Their address is:
Severn House, 10 The Moors, Worcester, WR1 3EE Tel: 01905 22715

Yours sincerely,

Elaine Bevan-Smith
Pulmonary rehabilitation specialist nurse.

Appendix 3.3 Consent form, focus groups.

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith

Pulmonary Rehabilitation

Spring Gardens Health Centre
Providence Street
Worcester
Phone: 01905 411452

CONSENT FORM

I.

OF:

.....

.....

I agree to participate in this focus group which is part of a motivation research study. The research has been explained to me by an appropriate person and I understand the reasons for the research. I understand that I can withdraw from the study at any time and this will not affect any future treatment that I may need.

Signature of patient:
.....

Name:..... Date:

Signature of staff member:

Name:..... Date:

Appendix 4.1 Letter inviting patients for interview.

Pulmonary Rehabilitation
Spring Gardens Health Centre
Providence Street
Worcester
WR1 2BS
Tel: (01905) 681452

DATE
Dear

I am conducting some research about the role of motivation in pulmonary rehabilitation (see attached information sheet). The next stage of the research is to 'interview' a small number of patients individually about their experience of motivation and the things that affect it. We need to talk to people who are currently attending a pulmonary rehabilitation programme, or have attended a programme in the past and people who are waiting to go on a programme, or have dropped out of a programme. All interviews will be conducted by a research nurse called Tracey Lucas. Tracey is an experienced respiratory nurse who has recently been employed at Worcestershire Acute Hospitals NHS Trust by Dr. S O'Hickey, respiratory consultant.

Your name has been selected from the pulmonary rehabilitation database as someone who we may possibly wish to interview at some point within the next few weeks. If you agree to be interviewed this would be arranged entirely at a time and place to suit you. For example, it could either be in your own home or at the hospital if you were attending a clinic appointment. **Please complete the slip attached and return in the enclosed pre paid envelope.**

What happens next.

If you agree for us to contact you, you may get a telephone call from Tracey Lucas to arrange an interview. Only a few patients will need to be interviewed – therefore you may not be contacted at all.

Yours sincerely

Elaine Bevan-Smith
Pulmonary Rehabilitation Specialist Nurse

Appendix 4.2 Patient information sheet, interviews.

Pulmonary Rehabilitation
Spring Gardens Health Centre
Providence Street
Worcester
WR1 2BS

Tel: (01905) 681452

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith

Patient Information

Interview

We are conducting some research into what motivates people to do their exercises in the pulmonary rehabilitation group. We want to try and identify what thoughts, beliefs and outside factors (such as family support) increase or decrease your motivation to follow an exercise programme.

Learning more about motivation to exercise will enable us to improve pulmonary rehabilitation programmes in the future. The results of this research may be published so that other people can learn from this work.

If you agree to being interviewed, you will be asked to sign a consent form. The interview will last about 20 minutes and any answers you give will be totally confidential. You will be given a code number so that no-one apart from myself and the person interviewing you will know who you are. The interview will be recorded. When the tape is transcribed, no names will be used and the tape will be deleted.

You will be asked questions about your attitude towards exercise and what things make you more (or less) motivated to perform the exercises. You do not have to answer any questions you do not want to and you can stop the interview and withdraw from it at any time without affecting any future treatment.

If you have any questions about the research please contact Elaine Bevan-Smith on the above number.

You can also contact your local Community health council if you have any concerns. Their address is:

Severn House, 10 The Moors, Worcester, WR1 3EE Tel: 01905 22715

Elaine Bevan-Smith
Pulmonary Rehabilitation Specialist Nurse

Appendix 4.3 Consent form, interviews.

Motivation in pulmonary rehabilitation research project

CONSENT FORM

Pulmonary rehabilitation
Spring Gardens Health Centre,
Providence Street,
Worcester.
WR1 2BS

01905 681452

I.

OF:

.....

.....

Consent to being interviewed about things that either motivate or demotivate me during the pulmonary rehabilitation programme. I do not have to answer any questions that I do not want to. The format of the interview has been explained to me by an appropriate person and I understand what will happen. I understand that I can withdraw from the interview at any time and this will not affect any future treatment that I may need.

Signature of patient:

Name: Date:

Signature of staff member:

Name: Date:

Appendix 4.4 Semi-structured interview questions

<p>You attended a pulmonary rehabilitation programme (PRP) at venue in month / year. How did you get on?</p> <p><i>Or:</i></p> <p><i>You are due to attend a PRP at venue in month / year. Are you looking forward to it?</i></p>
<p>How easy is it (will it be) to stick to your exercise regime?</p>
<p>Do you feel motivated at the moment?</p> <p>Describe those feelings.</p>
<p>In general would you say you are a naturally motivated person?</p> <p>Is there anything about your life in the past that you think has affected this – for example your upbringing as a child?</p>
<p>Do you (did you) have a reason for going to a PRP?</p> <p>Have you got something in mind that you want to achieve through exercise (or diet) and do you work towards that goal?</p> <p>How do you (will you) organise your exercise regime? Have you got a ‘master plan’?</p>
<p>Do you think that the PRP works (is going to work)?</p> <p>So does that make a difference to how motivated you feel?</p> <p><i>You know that you are always going to have this lung condition. And although there are lots of treatments available that can help your symptoms, the condition is unfortunately incurable. Does knowing this affect your motivation?</i></p>
<p>Did you find that being in a group helped your motivation?</p>
<p>Did / do you find the staff affect how motivated you feel?</p> <p>Why?</p>
<p>Do you live alone?</p> <p>Does this affect your motivation?</p>
<p>Do you have lots of friends or do you feel a bit lonely?</p>

Does this affect how motivated you feel?

Do you feel good about yourself?

Do you ever worry about what others think of you?

Does this affect your motivation?

Do you ever feel low or even depressed?

Does this affect how motivated you feel?

Have you any hobbies?

Do you think that helps (would help) your motivation?

Do you have any pets?

Do you think this helps (would help) your motivation?

Do you go on holiday nowadays?

Do you think this helps (would help) your motivation?

Do you worry about your condition getting worse?

Does this (will this) affect how motivated you are?

How do you feel about seeing people in a worse condition than you?

Does this affect your motivation?

How long have you had your condition?

Do you think you cope well with it?

Do these things affect your motivation?

Do you have good days and bad days?

How does this affect your motivation?

Are you worse at a certain time of the year- like in the winter?

Does this affect how you feel?

Is there anything else we haven't covered that you think is important?

Appendix 5.1a. 43 item motivation questionnaire prior to acceptability testing

1	I regularly get out and about.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
2	Despite my condition, I try to remain as active as possible.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
3	When I am having a bad day I tend to give up.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
4	Exercise is part of my normal routine.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
5	I find it difficult to stick to an exercise regime.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
6	I believe that exercise is very good for me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
7	My health prevents me from being active.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
8	In the past I have led a very active life.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
9	I was encouraged to work hard as a child.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
10	I find activity too much effort.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
11	I still try to exercise even when I'm having a bad day.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
12	My condition is currently a lot worse than normal.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
13	At the moment the weather is making my condition worse.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
14	I always make an effort to do things.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
15	I tend to give up easily.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
16	I have a lot of drive and determination.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	I lack willpower.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
18	I always try to do my best.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
19	Because of my health I tend to feel that I can't be bothered to do things.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
20	I am an optimistic person.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
21	I feel depressed.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
22	I have a happy disposition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
23	I want to do everything I can to stop my condition getting worse.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
24	I feel I know a lot about my lung condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
25	I want to do everything I can to improve my quality of life.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
26	I feel there are many people worse off than me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
27	I am self conscious about my condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
28	I am frightened to do things because of breathlessness.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
29	I am an independent person.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
30	I have lots of support from healthcare professionals.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
31	I am able to talk to people in a similar situation to me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
32	I am usually in control of my breathlessness.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

33	I tend to get embarrassed about my condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
34	I feel useless because of my lung condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
35	My medical treatment gets me down.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
36	I try to prove I can still do things.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
37	I believe there is little that can be done to help my condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
38	I regularly attend an exercise group or other support group.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
39	I have a supportive family.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
40	I regularly socialise with friends.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
41	My family encourage me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
42	I feel lonely.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
43	I tend to panic when I am breathless.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Appendix 5.1b Motivation questionnaire prior to validity testing

PULMONARY REHABILITATION MOTIVATION QUESTIONNAIRE (version 4)

Name.....

Date

This questionnaire is designed to assess how motivated you feel at the moment. It is very important to answer all the questions honestly. We appreciate your feelings may change regularly so please relate your answers to how you feel lately.

Read each statement carefully and indicate to what extent you agree or disagree with the statement by placing a tick in the appropriate box.

Please ask a member of staff if you are unsure about any of the questions.

Section 1:

This section is related to how active you have been *lately* in your everyday life.

1	I regularly get out and about.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
2	I find activity too much effort.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
3	I always make an effort to do things.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
4	I tend to give up easily.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
5	Despite my condition, I try to remain as active as possible.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
6	My health prevents me	Strongly	Disagree	Neither	Agree	Strongly

	from being active.	disagree <input type="checkbox"/>	<input type="checkbox"/>	agree or disagree <input type="checkbox"/>	<input type="checkbox"/>	Agree <input type="checkbox"/>
7	Exercise is part of my normal routine.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
8	I find it difficult to stick to an exercise regime.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Section 2:

This section is concerned with how you have been feeling *lately*.

9	I always try to do my best.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
10	I lack willpower.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
11	I have a lot of drive and determination.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
12	I have a happy disposition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
13	I am an optimistic person.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
14	I feel depressed.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
15	Because of my health I feel that I can't be	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

	bothered to do things.	<input type="checkbox"/>	<input type="checkbox"/>	disagree <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	I feel there are many people worse off than me.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Section 3:

These questions are about your life in the past.

17	In the past I have led a very active life.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
18	I was encouraged to work hard as a child.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Section 4:

This section focuses on how you feel you are coping *lately* with your condition.

19	I am an independent person.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
20	I am self conscious about my condition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
21	I feel useless because of my lung condition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
22	I tend to get embarrassed about my condition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
23	I am usually in control of my breathlessness.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	I am frightened to do things because of breathlessness.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
25	I have a good knowledge and understanding of my lung condition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
26	I tend to panic when I am breathless.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Section 5:

This section is about your own attitude towards your lung condition.

27	I want to do everything I can to stop my condition getting worse.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
28	I try to prove I can still do things.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
29	I want to do everything I can to improve my quality of life.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
30	My medical treatment gets me down. (i.e., medication, oxygen).	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
31	I believe that exercise is very good for me.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
32	I believe there is little that can be done to help my condition.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

--	--	--	--	--	--	--

Section 6:

This section is about what support you receive from others *lately*.

33	I have a supportive family.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
34	I am able to talk to people in a similar situation to me.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
35	I regularly attend an exercise group or other support group.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
36	I have lots of support from healthcare professionals.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
37	I regularly socialise with friends.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
38	My family encourage me.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
39	I feel lonely.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Section 7:

These questions are concerned with how your condition varies from day to day. Please relate your answers to how you are at the present time.

40	When I am having a bad day I tend to give up.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
41	I still try to exercise even when I'm having a bad day.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
42	My condition is currently a lot worse than it normally is.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
43	At the moment the weather is making my condition worse.	Strongly disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Neither agree or disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Thankyou for completing this questionnaire.

Please check back through and ensure you have answered all of the questions.

Appendix 5.2 Patient information sheet, questionnaire

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith
Pulmonary Rehabilitation
Spring Gardens Health Centre
Worcester
WR1 2BS
01905 681452

Patient Information

Motivation questionnaire

Dear patient,

We are conducting some research into what motivates people to do their exercises in the pulmonary rehabilitation group. We are in the process of developing a motivation questionnaire in order to try and ‘measure’ motivation to follow an exercise programme.

Learning more about motivation to exercise will enable us to improve pulmonary rehabilitation programmes in the future. The results of this research may be published so that other people can learn from this work.

Thankyou to agreeing to complete this questionnaire, you will be asked to sign a consent form. You will be given a code number so that no-one apart from the person administering the questionnaire will know who you are. You do not have to answer any questions you do not want to and you can withdraw from the study at any time without affecting any future treatment.

If you have any questions about the research please contact Elaine Bevan-Smith on the above number.

You can also contact your local Community health council if you have any concerns. Their address is:

Severn House, 10 The Moors, Worcester, WR1 3EE Tel: 01905 22715

Yours sincerely,

Elaine Bevan-Smith
Pulmonary rehabilitation specialist nurse.

Appendix 5.3 Consent form, questionnaire

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith
Pulmonary Rehabilitation
Spring Gardens Health Centre
Providence street
Worcester
WR1 2BS
01905 681452

CONSENT FORM

II.

OF:

.....

.....

I agree to fill in a questionnaire which is part of a motivation research study. The research has been explained to me by an appropriate person and I understand the reasons for the research. I understand that I can withdraw from the study at any time and this will not affect any future treatment that I may need.

Signature of patient:

.....

Name:..... Date:

Signature of staff member:

Name:..... Date:

Appendix 5.4 Handout for acceptability testing

When completing the questionnaire please consider the following things, making a note of any questions you feel were a problem:

Were there any questions you did not feel you wanted to answer honestly, or even did not want to answer at all? Were any too 'sensitive'.

Could any of the questions be worded better – were there any you found difficult to understand or too long?

Were there any questions you found difficult to give only one answer to, or were unclear about their meaning.

What about the question sequence – do you feel the order of the questions needs changing?

What about the answer format – was this easy to complete or not?

Would the questionnaire be better divided up into sections explaining what each section is measuring, or is it Ok as it is? (the final version of the questionnaire will be much shorter than this version).

Did the first couple of questions put you at ease or not?

Were any questions rude, intrusive or inconsiderate?

Were any questions patronising?

Did you feel if you gave negative answers you would not 'look good'?

Appendix 6.1 Information sheet, questionnaire validation study

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith
Pulmonary Rehabilitation
Spring Gardens Health Centre
Worcester
WR1 2BS
01905 681452

Patient Information

Motivation questionnaire

Dear patient,

We are conducting some research into what motivates people to do their exercises in the pulmonary rehabilitation group. We are in the process of developing a motivation questionnaire in order to try and 'measure' motivation to follow an exercise programme.

Learning more about motivation to exercise will enable us to improve pulmonary rehabilitation programmes in the future. The results of this research may be published so that other people can learn from this work.

Thankyou to agreeing to complete this questionnaire, you will be asked to sign a consent form. You will be given a code number so that no-one apart from the person administering the questionnaire will know who you are. You do not have to answer any questions you do not want to and you can withdraw from the study at any time without affecting any future treatment.

If you have any questions about the research please contact Elaine Bevan-Smith on the above number.

You can also contact your local Community health council if you have any concerns. Their address is:

Severn House, 10 The Moors, Worcester, WR1 3EE Tel: 01905 22715

Yours sincerely,

Elaine Bevan-Smith
Pulmonary rehabilitation specialist nurse.

Appendix 6.2 Consent form, questionnaire validation study

Motivation in pulmonary rehabilitation research project

Lead researcher: Elaine Bevan-Smith
Pulmonary Rehabilitation
Spring Gardens Health Centre
Providence street
Worcester
WR1 2BS
01905 681452

CONSENT FORM

III.

OF:

.....

.....

I agree to fill in a questionnaire which is part of a motivation research study. The research has been explained to me by an appropriate person and I understand the reasons for the research. I understand that I can withdraw from the study at any time and this will not affect any future treatment that I may need.

Signature of patient:

.....

Name:..... Date:

Signature of staff member:

Name:..... Date:

Appendix 6.3 Descriptive Statistics of motivation questionnaire items

	N	Mean	Std. Deviation	Variance
motivation q1	77	3.6883	1.15005	1.323
motivation q2	77	3.0390	1.14065	1.301
motivation q3	77	4.1429	.66321	.440
motivation q4	77	3.6494	1.03576	1.073
motivation q5	77	3.9870	.75208	.566
motivation q6	77	3.0000	1.18099	1.395
motivation q7	77	3.1818	1.23253	1.519
motivation q8	76	2.9868	1.07695	1.160
motivation q9	77	4.1558	.56347	.317
motivation q10	77	3.8182	.96963	.940
motivation q11	77	3.6104	.94807	.899
motivation q12	77	3.9351	.83252	.693
motivation q13	77	3.8831	.77755	.605
motivation q14	77	3.4935	1.20986	1.464
motivation q15	77	3.4286	.99245	.985
motivation q16	77	4.5455	.61869	.383
motivation q17	77	4.2987	.87457	.765
motivation q18	77	4.0390	.97928	.959
motivation q19	77	4.1169	.87320	.762
motivation q20	77	2.7532	1.12573	1.267
motivation q21	77	3.4026	1.12694	1.270
motivation q22	77	3.2078	1.17359	1.377
motivation q23	77	3.4935	.86790	.753
motivation q24	77	3.4026	1.00341	1.007
motivation q25	77	3.8312	.83355	.695
motivation q26	77	3.1818	1.07272	1.151
motivation q27	77	4.3766	.64968	.422
motivation q28	77	4.1429	.66321	.440
motivation q29	77	4.4156	.63558	.404
motivation q30	77	3.3247	1.17475	1.380
motivation q31	77	4.2727	.64147	.411
motivation q32	77	3.3117	1.00341	1.007
motivation q33	77	4.0779	1.04839	1.099
motivation q34	77	3.7532	1.02798	1.057
motivation q35	77	3.1558	1.33835	1.791
motivation q36	77	3.7662	1.03741	1.076
motivation q37	77	3.6883	1.02930	1.059
motivation q38	77	4.0130	.93883	.881
motivation q39	77	3.6883	1.06696	1.138
motivation q40	77	3.3506	1.21142	1.468
motivation q41	77	3.2987	1.13630	1.291
motivation q42	77	3.3377	1.08349	1.174
motivation q43	77	2.7922	1.20675	1.456
Valid N (listwise)	76			

Appendix 6.4 Factor loadings

Rotated Component Matrix(a)

	Component								
	1	2	3	4	5	6	7	8	9
motivation q10	.828	.108	.041	.118	.030	.242	-.166	.103	.159
motivation q4	.778	.023	.418	.144	-.089	-.085	.178	-.041	-.145
motivation q15	.633	.195	.338	.154	.074	.250	.322	.093	.034
motivation q24	.557	.464	.053	.084	.176	.088	.118	.141	.056
motivation q21	.445	.394	.293	.173	.261	-.120	.263	-.069	.391
motivation q22	.113	.830	.008	.182	.079	-.025	.118	.148	.044
motivation q20	.139	.745	.289	.163	-.005	-.052	.054	-.086	.019
motivation q6	.184	.233	.768	.039	-.040	-.094	.139	.100	.144
motivation q2	.291	.048	.713	.112	.069	.194	.068	.166	.036
motivation q33	.065	.015	-.072	.791	-.092	.037	.002	.049	.018
motivation q30	.082	.389	.140	.570	.089	-.108	.254	-.025	.130
motivation q14	.204	.266	.116	.550	.060	.261	.113	-.120	.075
motivation q39	.139	.316	.171	.548	-.222	.340	.285	-.154	-.106
motivation q26	.076	.336	.357	.414	.118	-.049	-.214	.172	.161
motivation q42	.064	.064	.085	-.042	.825	-.054	.146	-.182	.045
motivation q43	-.045	.263	-.143	-.049	.751	.101	-.204	.069	.068
motivation q40	.392	-.279	.116	.505	.519	-.016	.104	.205	-.109
motivation q41	.363	-.386	.080	.136	.517	-.012	.220	.313	-.081
motivation q18	.225	.183	-.416	.217	-.444	-.019	.370	.291	-.160
motivation q34	.090	.049	.012	.063	.030	.842	.164	.086	-.133
motivation q36	.231	-.264	.004	.132	-.007	.718	-.046	.236	.316
motivation q35	-.049	-.023	.356	-.012	.003	.479	.144	.338	-.478
motivation q37	.021	-.002	.011	.282	-.117	.103	.758	-.067	.253
motivation q1	.145	.228	.142	-.055	.185	.142	.645	.221	.003
motivation q7	.048	.004	.119	-.036	-.047	.182	.132	.886	.060
motivation q8	.241	.185	.480	.022	-.044	.160	-.146	.569	.098
motivation q32	.033	.092	.237	.072	.066	.033	.221	.149	.788

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 12 iterations.

Appendix 7.1 The Malvern Pulmonary Rehabilitation Motivation Questionnaire

This questionnaire is designed to assess how motivated you feel at the moment. It is very important to answer all the questions honestly. We appreciate your feelings may change regularly so please relate your answers to how you feel at the moment.

Read each statement carefully and indicate to what extent you agree or disagree with the statement by placing a tick in the appropriate box.

Please ask a member of staff if you are unsure about any of the questions.

1	I regularly get out and about.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
2	Despite my condition, I try to remain as active as possible.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
3	I believe that exercise is very good for me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
4	My health prevents me from being active.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
5	I find activity too much effort.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
6	I always make an effort to things.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
7	I tend to give up easily.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
8	I am an optimistic person.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
9	I feel depressed.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
10	I have a happy disposition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

11	I feel there are many people worse off than me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
12	I have lots of support from healthcare professionals.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
13	I am usually in control of my breathlessness.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
14	I tend to get embarrassed about my condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
15	I feel useless because of my lung condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
16	I try to prove I can still do things.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
17	I believe there is little that can be done to help my condition.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
18	I have a supportive family.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
19	My family encourage me.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
20	I feel lonely.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>
21	I tend to panic when I am breathless.	Strongly Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Don't Know <input type="checkbox"/>	Agree <input type="checkbox"/>	Strongly Agree <input type="checkbox"/>

Thankyou for completing this questionnaire.
Please check back through and ensure you have answered all of the questions.