ASSESSING COPING BELIEFS IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE

NICHOLAS AMBLER

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Critical Review: Addressing The Sexual Difficulties of Patients In Pain Management Programmes

Pain management programmes have expanded rapidly through the 1990's, partly driven by a clinical standards advisory group report in 1994 setting the target of one becoming available in every NHS general hospital. PMPs follow broadly similar protocols. Very few refer to help for the impact of chronic pain on sex life despite the importance of this issue to individuals and the indications of chronic
pain frequently having a disruptive effect on sex. The purposes of this critical review are to evaluate the findings in the literature representing the effects of chronic pain on sex life and draw guidance from this about how PMPs may be able to tackle the topic with their patients.

There is a relatively small literature. The majority of reports are of cross-sectional surveys and many have methodological flaws that undermine their applicability. The review will give particular emphasis to a survey undertaken by the author and 3 other clinical psychologists in 3 different pain management programmes that was designed to avoid the shortcomings of previous studies. The findings of this survey are being submitted to the Clinical Journal of Pain. The critical review covers some of the ground of the paper being submitted but is separate to this survey and will be solely the work of the author. The discussion will consider the practice implications of the findings of previous studies and the priorities for further research.

**Critical Review 2: The Psychological Care of Adults with Severe Burns**

The purpose of this critical review is to consider the background and current practice of the psychological care of burns, emphasizing the acute hospital phase of care.

The psychological care of burns was first reported in depth in the wake of a fire disaster in Boston, USA in 1942. The review will begin with the findings of this case series and follows the development of knowledge about the effects of burns. It will give particular emphasis to a major review reported in 1993, to the new directions that have followed since then, and to the very limited examples of treatment evaluations. A critique will be presented of the quality of the evidence and conclusions will be drawn about the practice implications and the likely directions of future research.
The author has worked in a regional burns service on a sessional basis since 1987. This work has led to the establishment of the first specialist disfigurement unit in the NHS, brought close involvement with the charity Changing Faces and the Centre for Appearance Research at the University of the West of England, with the establishment of a national Disfigurement Interest Group and publication of the text 'Visibly Different'. The review will draw on these sources. At present the British Burn Association have formed an advisory working party to review evidence and opinion for the future organisation of burn care in the NHS. The remit of this group includes gathering information about the psychological care and rehabilitation that is currently provided through burns units, any shortfalls in provision, and future needs. This critical review will support the opinion I have been asked to provide to the BBA panel for the purposes of their report.
The North Bristol NHS Trust Pain Management Programme: A Service Evaluation

The North Bristol pain management programme was set up in 1989 as a joint venture between two general hospital pain clinics. It has grown steadily over this period, expanding patient throughput, engaging in research trials, and diversifying its work. From the outset the PMP team have followed a formal plan of evaluation using assessment methods that have remained consistent for more than 10 years. This service evaluation report will describe the background and changes that have taken place over a decade which includes the amalgamation of the two organisations originally involved, the expansion, and the shift towards user-involvement. The convoluted issue of interpreting outcome data will be discussed.

The data will make comparisons over an unusually long period for a service of this sort from which long term trends may be evident. Shortcomings in the format of evaluation will be considered, especially the previous lack of formalised standards that could be audited. The discussion will consider the changes suggested by the evaluation in the light of the NHS modernization agenda.
The Assessment of Coping Beliefs in Chronic Obstructive Pulmonary Disease

The human toll of Chronic Obstructive Pulmonary Disease (COPD) is rising. It is now the UK's 4th biggest killer and the prevalence is increasing worldwide. The main characteristic is breathing difficulty. This restricts a person's physical capabilities. The disease usually progresses slowly, gradually curbing independence, social involvement, and self-confidence, whilst increasing dependence on support from medical services as well as carers. There is a constant risk of chest infection that can be life-threatening and often leads to hospitalisation. There is no medical cure however and professional help is focused on treating infections and providing symptom relief. There is also growing investment in rehabilitation for COPD. This began as exercise training and education about the illness. More recently the emphasis has shifted to psychological adaptation. It is noted that disease severity does not predict dysfunction, i.e. some people with severe COPD symptoms still maintain independence whilst others with a comparatively less severe disease state nevertheless appear more limited in their walking distance, avoid going out, and become depressed in reaction to their predicament. Raising confidence and adaptation are the new goals of COPD rehabilitation.

With the rising numbers of specialist COPD rehabilitation teams national bodies in the UK and USA have sought to standardise the treatment and the way this is evaluated. Scales reflecting exercise performance, emotional distress, and quality of life have been developed for this purpose. There exists a gap however. Few measures have been standardised for the evaluation of coping beliefs in COPD. The health psychology literature indicates that coping beliefs play a crucial role in successful adaptation to chronic illness and that assessment of this feature has direct relevance for rehabilitation. The role of self-efficacy
expectancies and fear-avoidance beliefs have proved to have particular significance elsewhere.

This research study will seek to develop a disease specific self-efficacy and fear-avoidance measure that has robust practical characteristics for use in the rehabilitation of severe COPD. The researcher began work on this in 1997 having joined the clinical team of a COPD rehabilitation programme known as LEEP (lung exercise and education programme). This is a research-based service and a measure of coping beliefs was felt to be needed for the purposes of a clinical trial. The best option of a published measure in the clinical literature was found to be impractical so it was agreed to include the development and standardisation of a new measure within the LEEP research trial. The design is to carry this out in three stages. The first is a pilot in which the clinical team will generate questionnaire items and a small group of COPD patients, complete these, and provide feedback. In the second stage a revised questionnaire will be completed by a larger sample. An item analysis will be undertaken with preliminary validity and reliability tests. Feedback will be taken and further revisions and a reduction of the measure completed. In the final stage respondents will complete the revised short-form scale both before and after rehabilitation treatment. Exploratory factor analysis will consider the structure of the scale. Separate factors of self-efficacy and fear-avoidance are expected. The measure will be considered for it's validity as a measure of change with COPD rehabilitation. The validity of the measure will also be considered by comparison with data from the same subjects on other standard measures used in the evaluation of COPD rehabilitation.

It is hoped that this study will produce a measure of coping beliefs that are relevant to COPD rehabilitation, that has sound psychometric properties, and that is easy to administer and analyse. The study report will place this in the context of the relevant literature and future research directions.
RESEARCH DOSSIER:

ASSESSING COPING BELIEFS IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE

ABSTRACT

The rehabilitation of chronic obstructive pulmonary disease (COPD) aims to raise participants' adaptation to an illness that is incurable and which causes an insidious decline of health and quality of life. Treatment educates patients about the disease, improves their physical fitness despite breathlessness, and raises their confidence and morale.

Robust COPD-specific measures have been developed to evaluate each of the main treatment goals above except confidence, i.e. coping beliefs. This study concerns the development of a COPD coping beliefs measure addressing, in particular, self-efficacy and fear-avoidance beliefs, because of the significance of these elsewhere in the literature on the self-management of chronic illness. A clinical team of a physician, physiotherapists, nurses, and a psychologist, who all specialize in pulmonary rehabilitation, generated a set of questions they deemed most relevant for coping with COPD and the goals of rehabilitation. Feedback on the questionnaire was obtained from twelve patients. 65 people then completed the modified version prior to their rehabilitation. Additional feedback, item
analysis, and test-retest data led to further revisions, shortening the questionnaire. This was then completed by a new sample of 121 people with severe COPD before and after their rehabilitation.

Statistical analysis suggested a 2-factor structure reflecting self-efficacy and fear-avoidance beliefs, comprising 7 and 4 items respectively. These had acceptable psychometric properties including internal consistency and retest reliability. The 2-factor structure was stable on post-treatment reassessment. Comparison of total scores for each of the 2 factors suggests the measure is sensitive to change with treatment. This revised measure appears useful and relevant for the evaluation of COPD rehabilitation. It is straightforward to administer and analyse. Further standardization is needed for the 11-item version to validate a threshold of clinically meaningful change. The measure is recommended as part of the framework for evaluating COPD rehabilitation but the need for a clearer definition of this treatment is also discussed.
INTRODUCTION

Overview

Chronic obstructive pulmonary disease (COPD) is a class of illness characterised by constricted breathing. The incidence of COPD is increasing worldwide and it has become the fourth leading cause of death in the UK, accounting for 240,000 UK hospital admissions, 24 million working days lost, and 26,000 deaths each year. It affects roughly 5% of the UK population. Medical therapies can provide temporary amelioration of the symptoms but there is no cure.

The symptoms of COPD cause physical impairment because of the build-up of breathlessness, fatigue, and sometimes unsteadiness and chest pain. As the disease progresses sufferers experience increasing limitation of their mobility, loss of fitness for work, and other losses of roles, social life and leisure interests. Many also react with psychological distress. Adaptation to the illness varies considerably from one individual to the next. Some people manage their symptoms effectively, making accurate judgements of what they are capable of doing and running their lives accordingly. For others the adjustment is less successful. They may become over-cautious in what they do, leading to a disproportionate impact on mobility and other activities. Others may over-reach the limitations created by the illness, worsening the long-term oxygen starvation of their bodies or triggering frequent breathlessness attacks.

Rehabilitation treatments have been developed to help sufferers raise their adaptation to COPD. These treatments address physical fitness, confidence for walking and other activities, and impart a good working knowledge about the nature and self-management of COPD. Further advancement of COPD rehabilitation relies on the availability of valid and sensitive forms of
measurement to evaluate treatment process and outcome. There are standardised assessments of lung capacity, airflow restriction, oxygen saturation levels in the blood, and maximal exercise tolerance, which reflect disease severity. The reversal of the disease is not however a target of rehabilitation. Instead it is the issue of coping that is the main focus. There have been developments in the standardisation of exercise performance and disease-specific quality of life measures but there are comparatively few procedures for evaluating coping beliefs in COPD and all of these methods have drawbacks.

The following sections describe the nature of COPD and its management. This includes an outline of the progression of the disease with some comment about the experiences and perspectives of sufferers. The accumulated experience of COPD symptoms and the guidance provided by rehabilitation programmes are each held to influence the attributions an individual makes about COPD and hence their coping responses. Links are identified in the literature with the psychological care of other chronic illnesses. The role of performance expectancies (self efficacy), along with the amelioration of fears in relation to breathing difficulties, are postulated as being central to the process of rehabilitation. The need for a standardised assessment measure of coping beliefs in COPD is set out, for use in understanding the processes and evaluating outcomes of rehabilitative treatment.

**What Is COPD?**

There have been a number of different definitions of COPD. The GOLD (global initiative for chronic obstructive lung disease) definition has been regarded as the international standard (e.g. Mannino, 2001). It defines COPD as,
“a disease state characterised by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases.”

This was updated in 2003 and the National Institute for Clinical Excellence (NICE), published a framework for diagnosis and clinical management (MacNee, 2004) with the definition:

“COPD is characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months The disease is predominantly caused by smoking”.

There are two main underlying disease processes, emphysema and chronic bronchitis. Both these conditions narrow or obstruct the airways and are progressive and debilitating.

The first noticeable effect of COPD is usually a cough or wheeze but this may only have become noticeable some time after the disease has set in. What draws attention to it is the failure to recover and then the insidious worsening of the initial symptoms. The principle sign of COPD is however breathlessness which is disproportionate to activity, formally described as dyspnoea. This is characterised as the sense of increasing effort to breathe, “feeling hungry for air”, gasping for breath, or a sense of heaviness with breathing. Discreet episodes of dyspnoea arise in reaction to physical exertion and are described as breathlessness attacks. This experience most often occurs in later stages of the illness however. COPD predominantly affects people in late middle age or older.

The underlying biological changes taking place involve a narrowing of the tubular passages of the lungs because of infection or inflammation. Irritation also leads to an over-production of mucus from the lining of the bronchi. In the longer term this
thickens the walls of the bronchi and further narrows the airways. Some can become completely blocked. This is chronic bronchitis. Alternatively emphysema involves damage in the walls of the alveoli. Air spaces in the membrane become enlarged, breaking down the functioning of the tissue and reducing the effective area for oxygen exchange between the lungs and the blood in the capillaries. These disease processes are distinct from asthma that involves an intermittent narrowing of the airways followed by remission. Although the pathologies are distinct, comorbidities of bronchitis, emphysema, and asthma occur frequently.

There is considerable variation of individuals' reactions to breathlessness in COPD. The onset is gradual and if the sufferer initially interprets it as a sign of normal ageing and makes lifestyle changes, reducing their activities, the symptoms may still go unrecognised as being a sign of an illness. Smokers may initially dismiss the problems of wheezing and breathlessness as a "smoker's cough".

Alternatively some people become highly sensitised to their symptoms. Qualitative studies such as Simon et al (1990) report frequently used adjectives such as tightness, heaviness and suffocation, that reflect a fearful overtone in describing the experience of the illness. In a study of the language used to describe breathlessness in clinical populations Skevington et al (1996) reviewed evidence demonstrating that the presence and intensity of breathlessness is not simply determined by effort and disease status. For example, some people can become intensely breathless when at rest. There is evidence that psychological factors such as anxiety explain some of the variance but individual differences in the intensity of breathlessness are yet fully understood.

What Are The Risks For COPD?

It is estimated that one in ten of the over-forties UK population has COPD. It affects 5% of the population, more than two million people, Moore and McQuay
The mortality rate is rising, closing the gap on the now falling mortality rates for heart disease and cancer.

As stated in the new NICE definition the principal known cause is tobacco smoking. Fifteen percent of smokers will eventually develop the disease and the overwhelming majority of COPD sufferers are, or have been, smokers. Atmospheric/environmental pollution is another known risk factor. After these factors are accounted for, the respective risks to men and women are roughly equal. The roles of genetic factors, infections, and enzyme deficiency have not yet been clarified. In most people the symptoms become apparent in the sixth or seventh decade of life.

**Accessing Medical Care and Diagnosis**

As the condition gradually worsens the sufferer will be increasingly aware of breathing difficulty, wheezing, and sputum production. By this stage the sufferer has usually recognised the significance of these symptoms and has sought medical help. They may start to experience breathlessness attacks. These occur when a period of over-exertion has produced an oxygen debt. The sufferer may then try to recover composure by stopping what they were doing and focussing inwards on their breathing. Despite the attempt to settle the episode a recovery does not begin straight away. The lack of response to these efforts can be alarming with the attack feeling like suffocation. The situation is then confounded by rising anxiety. Tension in the chest muscles generates a greater sense of breathing restriction aggravating the psychological impact of the attack, with the potential then for a cycle of escalation. This can be an extremely frightening experience that is vividly remembered. If there has previously been no medical investigation this will then become a turning point in seeking medical help.

The first contact with a doctor regarding COPD is rarely an emergency however. Referral to a specialist team will often only take place when symptoms have
deteriorated to a moderate or severe level. The central investigative procedure for COPD, spirometry, is the measurement of lung function. The subject is asked to exhale as quickly as possible and the forced expiratory volume (litres) in one second from the start is recorded as the FEV1. It is compared with reference data in a healthy population for height, age and sex, predicting the total volume of air that the individual can exhale after inhaling as deeply as possible, labelled as the forced vital capacity (FVC). The ratio of FEV1 to FVC is expressed as a percentage. It is used to categorise the severity of COPD and stages of the illness. The NICE definition criterion of airflow limitation for COPD diagnosis is FEV1 less than 80% predicted and the FEV1/FVC ratio being less than 0.7. The stages according to NICE are:

- I: FEV1 50-80% predicted, ‘Mild’
- II: FEV1 30-49% predicted, ‘Moderate’
- III: FEV1 less than 30% predicted, ‘Severe’

There are few symptoms in stage I. The condition will usually have had sufficient impact in stage II for triggering both GP care and hospital investigations. The morbidity and the mortality rate in stage III are conspicuous. More recently the thresholds shown above have been modified to separate the moderate grade into two categories with the ‘potential for severe exacerbations’ as the dividing criterion. It is noteworthy that, in a large US survey (Mannino et al 2000), 44% of people with FEV1 less than 50% predicted still did not complain of symptoms.

In summary then COPD symptoms develop slowly and the timing of diagnosis varies considerably from one person to the next. This variation is influenced by differences in usual activity levels, by the timing of minor chest infections, by the weather, by the presence of irritants in the air, and by the appraisal an individual makes of their emerging difficulties with breathing.
Medical Treatments

In addition to advice about stopping smoking, COPD patients are usually provided with bronchodilator drugs as a method of symptom reduction. These are usually taken through an inhaler that sufferers will continue to use thereafter. The same drugs can be administered through a nebuliser. This is a means of administering a drug using a compressor to vaporise it in air that is then inhaled. This has the advantage of enabling larger doses to be given with more reliable control of uptake compared to an inhaler. It is nevertheless a more cumbersome and expensive method and is usually reserved for acute exacerbations of breathlessness treated in hospital.

Patients can misjudge the potency of a nebuliser, feeling that it gives a greater degree of breathing control and mistakenly believing its use was a main influence in their recovery from an exacerbation when other treatments had a more substantial role. In fact there is little objective evidence of a distinction between the benefits of nebulisers as opposed to other methods for relieving airways restriction in an acute episode.

The other measures usually taken during an exacerbation include the use of corticosteroids that are used to combat inflammation when this is worsening the constriction of the airways. These can be taken orally but this is not generally continued as a long-term prescription. Inhaled corticosteroids may however be continued over a longer period. Similarly, temporary prescriptions of antibiotics are used to combat respiratory infections. Although usually only a minor problem in others, for someone with COPD a chest infection may become life-threatening.

When the COPD has reached the severe stage then the sufferer will have ongoing contact with a specialist respiratory team. There is a 95% mortality rate over ten years for people whose FEV1 is less than 0.751 and in the latter stages of the illness sufferers can become permanently hypoxic, i.e. when there is
inadequate tissue oxygen supply. This greatly increases fatigue and may impact on cognitive functioning. The development of hypoxia is perceived by many as signalling the end-stage of the disease. It is treated with Long Term Oxygen Therapy (LTOT). This can appear to patients and carers as an indication that the terminal phase of the illness has started. By this stage of COPD progression a person's life expectancy is less than three years (Shee, 1995). However, LTOT is an established palliative treatment that can extend survival. Two trials (Nocturnal Oxygen Therapy Trial Group 1980, Medical Research Council, 1981) demonstrated increased life expectancy although the latter study showed no notable benefit for quality of life. This treatment requires wearing nasal cannulae for at least fifteen hours a day including overnight. The supply of artificial oxygen from a tank in this way is aimed to redress the tissue oxygen insufficiency and as a result to reduce fatigue, to improve concentration and to protect the heart and other vital organs from the damaging effects of the otherwise permanently low levels of oxygen in the blood.

Another form of oxygen therapy is the use of a portable supply that is then used during periods of increased breathlessness. Unlike LTOT there is no convincing evidence of improvement in oxygen saturation levels or endurance of physical activity from this. It gives some reassurance to COPD patients but with the big disadvantage of needing to carry an oxygen supply wherever a person goes. This places a great restraint on movement away from the home. It can generate an inordinate fear of being separated from the oxygen should there be an acute attack of breathlessness. This perceived dependency therefore diminishes mobility and quality of life.

Professional support for severe pulmonary disease is provided by specialist respiratory nurses and physiotherapists, often organised as domiciliary teams linked to the hospital-based specialists. Their role is broadly one of information
and support with a preventative focus. During the late stages of the course of COPD there is typically a pattern of recurring crisis episodes. Exacerbations, chest infections, and respiratory failure can trigger admission to hospital. Here the medical care will probably involve the use of antibiotics, corticosteroids, a nebuliser and other various means for moderating the worsened airways obstruction. This may be on a general medical ward or in a specialist respiratory unit. The pulmonary specialist teams try to avert these episodes but when they do occur they usually track their patients through their stay in hospital. It is a time of great fear for patients and relatives since they are aware that an acute exacerbation is the most likely circumstance of eventual death from the disease. The support from the respiratory team at this time can be particularly valuable in as much as they are familiar and trusted care workers who can advise on the best means of recuperation, instilling confidence for overcoming the crisis phase. This will often be a recap on work done at an earlier time on preventing and coping with exacerbations. This has usually been undertaken either on a one-to-one basis, or in a formal rehabilitation programme.

**COPD Rehabilitation.**

There has been a steady increase in the number of pulmonary rehabilitation programmes during the past thirty years. These began as courses providing information, support, and supervised exercise training. Psychological therapy was then added and multi-disciplinary teams formed. US centres have set the pace for this both in the development of services and in defining the underpinning principles.

In 1974 the American Thoracic Society (ATS) published a definition of pulmonary rehabilitation in which the stated purpose of treatment is that it:

"stabilizes or reverses both the physio- and the psychopathology of pulmonary diseases and attempts to return the patient to the highest possible
functional capacity allowed by his pulmonary handicap and overall life situation.” (Morgan and Singh, 1997).

This was revised by the same group in 1994, describing the purpose as having:

"the goal of achieving and maintaining the individual's maximum level of independence and functioning in the community". (Morgan and Singh, 1997)

A further revision, ATS (1999) stated,

"Pulmonary rehabilitation is a multi-disciplinary program of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise physical and social performance and autonomy" and that it, " reduces symptoms, increases functional ability, and improves quality of life in individuals with chronic respiratory disease, even in the face of irreversible abnormalities of lung architecture".

These statements reflect an overall aim of improving quality of life. It assumes that an effective adjustment to COPD does not take place automatically. No details of therapeutic process are currently being specified.

The experience of taking part in a COPD rehabilitation programme varies considerably from one service to the next. The ATS definition describes the treatment as a multi-disciplinary approach. Rehabilitation is therefore a composite, not solely concerned with one area such as exercise or information-giving, but rather, a combination of these and other components. It may be delivered in a specialist centre or at home, it may be undertaken individually or in a group. The duration varies but usually spans at least four weeks, with two or more contacts a week. Partners may or may not be included.
Descriptions of pulmonary rehabilitation treatments have been detailed by a number of authors, (e.g. Petty, 1993; Morgan and Singh, 1997). The exercise component of rehabilitation treatment is usually formed around the rationale that a decline in physical performance has occurred in association with the illness. Fatigue and breathlessness is presumed to lead to reduced activity levels the consequences of which are a loss of muscle tone, increased fatigue and loss of endurance during exertion, and lost flexibility of movement. Any or all of these might affect steadiness and confidence for walking and other activities. The summary term applied to this is 'deconditioning'. A schedule of daily exercise is set up to redress this physical decline in gradual increments over the individual's initial baseline. A further principle of exercise is that by adopting a plan of regular exercise patients will stave off deconditioning in the future. The intention is that they should adopt the exercise routine on a permanent basis. There is also training and guidance about controlled breathing methods for tackling breathlessness attacks.

Undertaking exercise under the close supervision of a specialist physiotherapist and the watchful eye of other COPD sufferers is said to restore confidence for physical exertion. This is intended to replace any previous inhibitions arising from the fear of a breathlessness attack or the belief a person had that he or she would not be able to finish what they were considering doing. In this sense physical exercise provides a mastery experience aimed at producing a more generalised psychological change.

The educational content of rehabilitation treatment covers the structure and functioning of the lungs, disease processes, medical investigations and treatments, the importance of diet, the theory of the effects of smoking and the value of stopping smoking after the disease has developed, the effects of other environmental factors such as pollution, altitude, and weather change, and what is happening biologically during exercise and during a breathlessness attack.
This is not simply information-giving but rather, it provides the basis for an attitudinal shift necessary for reaching the main goals of treatment. If someone believes that exertion will trigger breathlessness, or even an exacerbation, and that the only way to manage this is with oxygen or an inhaler, then supervised exercise in a hospital setting cannot be expected to generalise to something which will continue in future, whilst alone at home. Conversely, if patients are persuaded that they can safely extend themselves further, that risks are less than they previously believed, and that regaining composure from breathlessness is in their own hands, then this new and more confident attitude will enable them to try more activities. There are assumed to be links here between a more informed understanding of the illness, a change of beliefs especially about the personal control of symptoms, raised confidence, and changed behaviour.

Most programmes include stress management. This places an understanding of the stress response in the context of breathlessness attacks as well as overall health. The stress response is viewed as an intermediary between the pressures of life circumstances (including the impact of chronic disease) and illness variables such as levels of fatigue and immune system responsiveness. Patients learn methods of identifying personal stress and how to achieve better control over it. This is an example of how programmes seek to engender a sense of mastery over COPD symptoms and effects.

Since it is recognised that psychological distress is closely linked to COPD there are components of rehabilitation programmes that address depressive reactions. A goal-setting approach is used to help patients regain social activities and through this restore a source of enjoyment and engagement, to build self-esteem and social support. Another example is the application of cognitive therapy principles to tackle systematically negative thinking. The objective is to lift low mood that may in itself have been a barrier to regaining activities.
Do COPD Rehabilitation Programmes Work?

For someone considering joining a COPD programme it is understandable that they would want to know if the commitment is worth making. Equally, health commissioners need evidence to compare an investment in this kind of intervention with other potential uses of finite resources. There have been attempts to review research findings and answer these two questions but there are problems with this, not least when the different components of rehabilitation are considered separately.

The evidence base regarding the rationale for exercise is not as clear-cut as might have been expected. Exercise tolerance is reduced in COPD patients, a fact that is widely regarded as the consequence of no longer being able to escalate the ventilation of the lungs in line with the increasing respiratory demands of physical exertion. However, there is only a weak association between lung function, dyspnoea and exercise capacity (Shee 1995, Jones 1995). There is also no evidence of gain in FEV1 as a result of exercise training. Benefit from exercise does emerge from outcome studies using exercise testing as an outcome criterion but this positive finding may be tied up in other factors such as increased confidence for exertion that was previously undermined by fears of breathlessness. If a person better understands their capacity for exercise and how to recuperate afterwards they are likely to perform better on retesting at the end of rehabilitation without necessarily being physically fitter or having better respiratory function.

The 1997 US report of evidence-based guidelines for COPD rehabilitation (ACCP/AACVPR Pulmonary rehabilitation guidelines panel, 1997) discussed the range of individual components and objectives that have been embraced by different rehabilitation programmes. These included upper extremity training, lower extremity training, ventilatory muscle training, education, psychosocial, and
behavioural interventions. The authors concluded that, in particular, dyspnoea and exercise tolerance (from lower extremity training) are improved by pulmonary rehabilitation. They found no evidence for the effectiveness of psychosocial interventions as a single modality intervention. The drawback with this review is in the division of the different aspects of a composite approach to treatment when the question to consider first is whether or not the intervention works as a whole. Furthermore there is no standard for outcome assessment. The overarching aim of rehabilitation is to improve quality of life but no measure of this was being consistently applied.

In a more recent meta-analysis of the effectiveness of COPD rehabilitation Lacasse et al (1996, updated 2002 and 2003) identified 301 relevant publications within which 81 potentially eligible papers were found. Only fourteen trials fulfilled qualifying criteria of rigour in design. Twelve of these fourteen randomised trials had addressed coping and quality of life as an outcome measure but using ten different methods. Only two of these ten employed published standardised measures.

The problem for reviewers is that the evidence to date is both crude and generalised. There are, as stated above, differences between the length of programmes, the settings, the numbers of participants, the composition of therapy, and who provides this. No consideration has been made in the available literature about the differences of ethos that exist between programmes. For example the self-management literature distinguishes an approach that is seen as a means of engendering responsibility and control in the individual, (hence the term ‘self-management’). This is in contrast to the usual of style of provision of health care that is seen as a paternalistic bio-medical approach prescribing a set of activities (e.g. exercise) in such a way that it engenders passivity and dependency. There is as yet too little evidence about COPD rehabilitation to dismantle the components for separate consideration. For example although
dyspnoea can be improved through exercise there was no evidence available about the relative efficacy of multi-disciplinary rehabilitation compared to exercise training. The most positive finding is of some limited evidence in the Lacasse (1996) review supporting the overall effectiveness of pulmonary rehabilitation as a composite treatment process where participants learn self-management of a chronic illness.

Much more data is needed about outcomes and the processes involved. Patients and commissioners are presently forced to make their decisions without the information they need. An individual with COPD might seek to join a rehabilitation programme as a best bet but without strong evidence or knowing what characteristics to look for in making a particular choice from the current range of services. A health commissioner on the other hand might prefer to withhold any financial commitment until the case is more convincing.

A format for evaluating COPD rehabilitation.

A criticism of the evidence gathered to date is the lack of comparability between trials.

The further evaluation of COPD rehabilitation requires an agreed format to allow reasonable comparison and the potential to combine data for meta analysis. A structure for evaluation can be drawn from elsewhere in the literature. A leading example of the development of interventions to improve coping in response to chronic illness is the work of Lorig and colleagues with the Arthritis Self-Management Programme, (Lorig et al, 1986, Holman and Lorig, 1992). This approach, developed in the US, has been to harness the knowledge and experience of sufferers, who have themselves achieved a good adaptation, to lead groups for people who are coping less well with the same condition. Interest at governmental level in the UK has led to the 'Expert Patient' movement. This
comprises a national panel whose role has been to interpret and develop the
rationale for the NHS, regional officers, and primary care workers. There is a lead
report of the same title (2001), and a structured and funded protocol of
developments based in primary care trusts. Compared to COPD there is a more
comprehensive evidence base regarding improved coping with arthritis, cost
effectiveness, and reproducibility across different cultures and health
organisations e.g. Lorig et al (1999) and Barlow and Wright (2000). In a review of
self-management methods applied across different illness conditions Barlow et al
(2002) identified 1129 publications that reduced to 145 reports for consideration.
There were 28 different conditions but arthritis, asthma, and diabetes accounted
for seventy percent of the reports. The authors singled out Lorig’s work because it
is well supported by evidence from across different settings.

In these trials the format of evaluation covered measures of exercise
performance, mood, self-efficacy, use of medications and other healthcare
resources, and health-related quality of life. The evidence is therefore multi-
factorial and was gathered using standardised methods.

The outcome evaluation of COPD programmes requires the same multi-factorial
method using standardised measures that are sensitive to change and that
directly relate to the goals of treatment. Therefore, in respect of COPD
rehabilitation, the format of evaluation should cover exercise performance, mood
state, beliefs about the illness and coping, and quality of life, using methods that
are geared to the impact of COPD and the impact of the intervention. Biomedical
data is required to compare subject populations and adds to the independent
variables but is not part of the outcome. The methods available in each of these
domains are considered below.
Measuring Physical Performance/Exercise

It was acknowledged in the early stages of developing performance measures that there is a considerable gap between the maximum capabilities of COPD sufferers and observed performance on exercise testing. Researchers have made inroads in controlling the various known sources of error in these assessment procedures. Attention has been given to the assessment environment, the instructions given and the intended targets of measurement in the design and modification of assessment procedures. For example, Guyatt et al. (1984) demonstrated that a change of instructions could produce a 30m increase in tested walking distance.

The development of standardised methods for exercise testing in COPD has been discussed by Revill et al. (1999) and by Rejeski et al. (2000). The best-developed standard methods including a timed paced shuttle walk are now widely adopted by rehabilitation programmes. However, they recognise that ultimately, observed exercise performance will not directly reflect the disease state and that unexplained individual differences affect performance profiles. Improved exercise performance is an objective of rehabilitation but can only reflect what is done in a clinical setting under the supervision of a therapist. It is of greater importance for performance gains in the hospital gym to be generalised to everyday life activities. Exercise testing does not measure this more critical outcome.

Quality of Life (QOL) measures in COPD

There is a long-standing philosophical debate concerning what is meant by the term 'quality of life'. Quality can be held either as a descriptor, as in the quality of a good wine, or as a comparator, for example when considering the quality of driving in London and in Paris (McCall, 1975). The goal of improving quality of life is widely adopted in the health care evaluation literature but the lack of a clear
definition has confounded approaches to measurement. Expressions of life satisfaction, i.e. the individual's own feelings about how life is, are distinguished from profiles of functioning. The former cannot easily be scored and pooled, whilst there continues to be an enigma in cross cultural comparisons where those with worse circumstances have expressed higher levels of life satisfaction, (McCall, 1975). The latter approach of profiling the disruptive effects of symptoms on functioning is seemingly more objective and quantifiable but nevertheless usually relies on self-assessment rather than observation and arguably misses the point about determining the level of enjoyment of life. These difficulties are discussed by Kaplan (1985) and Hyland (2003). Despite the confusion of meanings it is the functional profiling approach that has gained acceptance in health care evaluation.

Two types of quality of life measures have emerged. Generic scales that can be used to compare different patient groups and disease-specific measures which are attuned to the particular characteristic consequences of a single condition. The best-known and most widely used example of a generic measure is the Sickness Impact Profile, (SIP), (Bergner et al 1981). This covers impairments of mobility and restriction in activities of daily living, effects on mood, family roles, work-fitness, social and leisure activities. There are twelve subscales and a total of 138 items, separate domain measures of physical and psychosocial disturbance, along with an overall disability score. This could be separately standardised for use with COPD patients but this would not resolve the main objection to its use. It has not been designed to be sensitive to the impact of COPD on quality of life nor the areas where treatment can make a difference, (Jones, 1988,1991). The same criticism applies to the other most widely used generic scale, the medical outcomes study short form (SF)-36(Ware and Sherbourne, 1992) which has also been validated for use with COPD (Mahler et al 1995).
The first standardised multi-factorial measure of the impact of COPD on quality of life, the chronic respiratory questionnaire (CRQ) was published by Guyatt et al (1987). This was developed from the comments patients made about the consequences of the disease in their everyday lives. There were 4 subscales: dyspnoea, emotion, mastery, and fatigue. The first of these was a non-standardised subjective appraisal. Respondents decide on the most important activities that are disrupted by breathing difficulty and then apply ratings. Whilst there are justifications for this individualised content, the data from this subscale cannot be quantitatively compared between different people. There have since been revisions to redress this criticism (e.g. Schunemann et al 2003) and a parallel development that is more easily processed Shin-Ping et al (1997).

In a parallel development the assessment of quality of life in COPD has been taken up by Jones (1988, 1992 and 1995). In these papers he described the development of a disease-specific questionnaire for evaluating quality of life in COPD, the St George's Respiratory Questionnaire (SGRQ). In the process of validating the measure he demonstrated that indicators of disease severity did not predict quality of life as measured by the SGRQ. He found a rank order relationship between change in the pre- to post-intervention SGRQ scores and patients' perceptions of the success of their rehabilitation treatment. In her review of health-related quality of life measures Ware (1995) also noted surprisingly weak correlations between measures of pulmonary function and quality of life.

A further scale was developed by Hyland et al (1994), the Breathing Problems Questionnaire BPQ which addresses functional limitations and emotional impact provoked by COPD. A future measure is a pulmonary disease module attaching to the world health organisation quality of life measure due to be published soon, (WHO-QOL). This will combine a generic component with condition-specific items.
Singh et al (2001) compared the above measures for sensitivity to change, defining a minimum clinically important difference. All three disease-specific measures were found to have sufficient sensitivity to pick up changes achieved by patients who attended a seven-week course of pulmonary rehabilitation. The CRQ was found to have greatest sensitivity.

In his discussion of the issue of selecting a QOL measure for COPD assessment Hyland (2003) categorised types of scale according to their most appropriate use and dismissed the idea of there being a single ideal QOL measure. He divided those best suited to longitudinal use, for clinical and audit purposes, from those more suited to cross-sectional studies. For clinical and audit applications he emphasised the need for short measures that avoid floor and ceiling effects on individual items with extended response options as opposed to a two-category response type. He concludes that there is a sufficient range of measures with sufficiently good psychometric properties to suit most purposes and a rationale is presented which guides this choice.

A case exists for quality of life measurement being the most important dimension of outcome evaluation in COPD rehabilitation. The contents of the above disease-specific measures have been validated as directly relevant to the aims of treatment, the scales are reliable and sensitive to change. The scales comprised factors relating to symptoms, impairment, mood, and functioning as set out in the discussion of an assessment format above. There remains a further issue for assessment however. There is a weak link between health-related-QOL scores and the bio-medical profile data. The lack of correspondence in such data comparing, for example, FEV\textsubscript{1} and the SGRQ quality of life scores reported by Jones (1995), points to a gap in the understanding the process of adaptation to COPD. There remains at least one explanatory factor missing that is of major
importance to rehabilitation. What is it about some individuals that enables them to adapt better than others with COPD?

Self-Efficacy In COPD Rehabilitation

A potential explanatory variable is self-efficacy beliefs. This relates to coping beliefs, the missing category of the set discussed for the assessment format. Self-efficacy is also the theoretical base applied by Lorig, (e.g. Holman and Lorig, 1992), in the development of the self-management approach to chronic illness. This derives from the social cognitive theory of Bandura (1986). The underlying principle of the theory is described as follows:

"People’s level of motivation, affective states and behaviour are based more on what they believe than what is objectively the case" and "perceived self efficacy refers to people’s beliefs in their capabilities to organise and execute the courses of action required to deal with prospective situations". (Bandura, 1997b).

The confidence a person has for, say, being able to successfully climb fifteen steps, will determine whether or not they attempt to do this. These coping beliefs are influenced by four sources of information:

- Performance accomplishments
- Vicarious experience
- Verbal or social persuasion
- Emotional arousal

Bandura (1997a)

The relevance of this for COPD rehabilitation was discussed by Toshima et al (1992). Where patients successfully extend their exercise performance under the supervision of a specialist physiotherapist and see others achieving the same thing then at least the first three of these factors are in play. The educational
component of rehabilitation is a form of verbal persuasion as described earlier. Linking the contemplation of increased exercise, activities and social engagement with more positive emotional states, encouraged by those parts of a programme that address stress management and depression rehabilitation, satisfies the fourth factor.

This theory might be held as the unifying theme of the COPD rehabilitation process. All of the activities embraced by the treatment can be accounted for in terms of self-efficacy theory. This was observed by Barlow et al (2002) and Wright et al (2003) who described the self-management programmes they reviewed as following cognitive behavioural principles but usually constructed around self-efficacy theory. This model has been demonstrated to predict motivation for treatment, performance levels, and treatment success (e.g. Walker J, 2001 or Bandura, 1997). Kohler et al (2002) in a review of the links between self-efficacy beliefs and quality of life in COPD presented some evidence supporting the proposition, after Bandura (1997a), that self-efficacy is the mediating variable in adaptation to the illness.

**The measurement of self-efficacy**

Research trials in COPD rehabilitation have employed questionnaires to assess changes in self-efficacy beliefs. Toshima et al (1992) surveyed expectancies relating to lifting, climbing, pushing, walking, general exertion, and tolerance of stress and of anger arousal. The content was constructed from the advice of experienced practitioners. The authors validated their measure by comparison with other standardised methods and in terms of changes before and after treatment. For example they found close association between initial self-efficacy scores and treadmill walking and then small associations between repeated measures of these where the latter was regarded as an index of gain after treatment. However, other basic psychometric characteristics were not included
and this scale was not sufficiently standardised in terms of validity and reliability for its wider use.

A more detailed standardisation of a COPD self-efficacy measure was undertaken by Wigal et al (1991). From a pool of 250 people, 102 (54 men and 48 women) completed a 34-item questionnaire in which they made confidence judgements about controlling breathing difficulties across a range of challenging situations. These were rated on a 5-category ordinal scale between 'very confident' and 'not at all confident'. Factor analysis identified a 5-factor structure. These were labelled as negative affect, intense emotional arousal, physical exertion, weather/environment, and behavioural risk. They reported acceptable test-retest reliability (Pearson's product-moment correlations for retesting at 2 weeks) and internal consistency, (Cronbach's alpha). They advocated the resulting 34-item measure be used to identify problem areas that might then become a focus for rehabilitation. For example, raised emotional arousal could be treated with a stress management intervention.

Following this publication a small number of studies reported use of this measure, e.g. Scherer (1996, 1997). These each revealed a significant role of self-efficacy beliefs in the adjustment of patients to COPD during rehabilitation treatment. On the face of it this was an important development for COPD evaluation. However, this measure has not been adopted more widely for the evaluation of COPD rehabilitation. There are several drawbacks with the instrument that may explain this. Firstly, there are concerns with the standardisation. The factor analysis employed a varimax rotation where, in view of the relatedness of the data, an oblique rotation was the appropriate method. No confirmatory factor analysis is reported. There was also no cross-validation with other scales. In particular, in consideration of the strong influence of mood state evident in the first two emergent factors, a comparison with a measure such as the Beck Depression Inventory was needed. No item analysis was reported and no data was presented
on the responsiveness of the measure to the changes witnessed in patients as a result of rehabilitation. Secondly, there is a conceptual objection. A number of items had low face validity. Coping with the symptom of breathlessness is adopted as the sole emphasis of the measure. The reference for every item was control of breathing difficulty. Whilst this is the principle symptom, rehabilitation aims for a broad restoration of confidence and functioning. This warrants the inclusion of items where the wording reflects efficacy beliefs for completing a task without reference to breathing difficulty. However, the third objection, a practical concern, is perhaps the main drawback. Personal accounts from practitioners describing the measure as difficult to administer to their patients raises some doubt about the capacity or willingness of respondents to complete the measure. No data on this is reported. Scoring the measure, having a 5-factor structure, can give some practical difficulty in longitudinal uses of the type described by Hyland (2003). The scale is suggested as a means of identifying problems rather than as a way of monitoring change as a result of an intervention. It is therefore better suited to cross-sectional use in studies but still requires further standardisation.

No other self-efficacy measures for COPD are reported in the literature. The evidence to date points to self-efficacy beliefs being central to the adaptation of people with COPD. There remains a need for the development of an instrument which has a wider utility than the Wigal scale, which can in particular, address self-efficacy beliefs in outcome studies and for audit purposes.

The role of fear in COPD.

Self-efficacy theory has provided the main focus in small range of studies of coping beliefs in COPD. However, elsewhere in the literature on coping with chronic conditions there are consistent findings reflecting a role of negative cognitions having a key role in adaptive processes, e.g. Jenson, (1991) and Boothby et al (1999), that are particularly associated with fear. There is a prima...
facae link between at least three of the five factors identified by Wigal (1991), negative affect, extreme emotional arousal and behavioural risk. This might be described as anxiety/fear of triggering more severe symptoms. The description of the progression of the illness above points to two types of fear. The first might arise because of the constant risk of an exacerbation, e.g. through a chest infection, leading to admission to hospital. This is a genuine threat and many sufferers are mindful that this is likely, at some time in the future, to lead to a terminal decline of the illness and ultimately their death. Hence it is understandable that COPD sufferers should fear the development of an exacerbation and seek all possible means of avoiding anything they perceive as a risk. This may present a constant and long-term anxiety or a reaction provoked in particular circumstances. The second source of fear is more acute and concerns breathlessness attacks. These were described earlier as a suffocating and extremely frightening experience. It can provoke a cycle of escalating breathlessness and panic as described by Kaplan et al (1993) who summarised evidence of a high prevalence of anxiety symptoms amongst COPD patients. A person might fear triggering an attack, perhaps through over-exertion, and feel unable to bring it under control, perceiving this as an immediate life-threat. This impacts on the person's willingness to physically exert him/herself. Pulmonary specialists often refer to the 'fear/dyspnoea cycle'. The attack escalates because the anxiety it provokes raises the individual's level of arousal, autonomic activity, respiratory demand, and tightens the muscles in the throat and chest. This increases the sense of breathing difficulty which then further increases anxiety. Negative experiences of this sort can then mean that the individual learns to avoid the perceived triggers. This description aligns with behavioural theory applied to illness, e.g. Fordyce (1976).

The above conception of fear in COPD might be viewed as the opposite of competency beliefs, the negative pole of self-efficacy expectancies. However, researchers in the field of coping with another chronic incapacitating condition,
chronic pain, have differentiated fear cognitions from self-efficacy beliefs and sought to identify avoidance behaviours linked to the fears, e.g. Philips (1987). A parallel is drawn between chronic pain and chronic fear that leads to avoidance behaviour. This then has a negative impact on the level of coping of the individual. This is derived from Lethem et al (1983) who described a fear-avoidance model in chronic pain.

The measurement of fear-avoidance

Following these principles Vlaeyen (1995) developed a cognitive-behavioural model of maladaptive reactions to injury that leads to chronic pain. In this he emphasized the influence of negative attributions, especially 'catastrophizing', (beliefs of exaggerated and extremely negative consequences of an event, Rosenstiel and Keefe, 1983) leading to avoidance of activity, then to disuse-deconditioning, depression, and disability, as illustrated in figure 1(a). This subsequently became the basis for an intervention involving the systematic desensitisation of the fear of pain as part of chronic pain rehabilitation. The model also led to the development of fear-avoidance assessment methods in chronic pain (Waddell et al 1993 and Vlaeyen et al 1995).
Figure 1(a): Fear-Avoidance In Chronic Pain

- Depression
- Disuse
- Disability
- Avoidance
- Hypervigilance
- Pain-related fear
- Pain catastrophizing
- Negative affectivity
- Threatening illness information
- Pain experience
- Recovery
- Confrontation
- No fear
- Injury
Figure 1(b): Fear-Avoidance in COPD
The same disuse-deconditioning model has been described above in the
development of exercise principles for COPD. The outline shown in Fig. 1(b) has
been adapted for COPD by substituting the term 'injury' with 'pulmonary disease'
and 'painful experiences' with 'experiences of increased breathlessness'. The
adaptive route through the model via the confrontation of feared situations leads
to better coping rather than 'recovery'.

Given the descriptions of fear in the experience of COPD and the adoption of
fear-alleviating methods by therapists in COPD rehabilitation, there is an implicit
need to assess fear-avoidance beliefs as a feature of sufferers' cognitive
appraisals about this illness. To date however there is no literature concerning
the evaluation of fear-avoidance beliefs in COPD.

**Summary: the need for a new measure of coping beliefs in COPD.**

Rehabilitation programmes for COPD focus attention on the understanding and
control of breathing difficulties, the restoration of confidence for exertion and
changed attitudes about self-care in relation to the illness. Through this patients
are expected to achieve increased levels of activity, social engagement, and
improved morale. The content of treatment programmes has developed
empirically but the evidence of effectiveness, whilst broadly positive, is flawed by
inadequate methods of evaluation and only limited use of standardised
measures. In a position statement following up the review of pulmonary
rehabilitation the American Thoracic Society (ATS, 1999) criticised existing
measures as often being, "long, difficult to administer, or complex to score" and
called for the development of simpler methods that nevertheless maintain their
capacity to discriminate between individuals and to remain sensitive to change.
Specialist COPD rehabilitation programmes have probably reached a crossroads. Not enough is known about the true level of treatment success from a sound evidence base. This is a vulnerable position at a time when all forms of health care are under scrutiny regarding evidence and costs. There are now sufficiently well standardised instruments for evaluating exercise functioning and attributes of quality of life. The main area of need is for measures addressing coping beliefs. In particular, self-efficacy beliefs and fear-avoidance beliefs are strongly implicated as influencing the level of adaptation to chronic illness. This measure is required for audit and longitudinal research purposes. There are practical considerations in its development. It should be easily administered, possible therefore to fit this alongside other scales for a standard format of evaluation.

**Aims and Criteria.**

The main aim of this study is to develop a measure of self-efficacy and fear-avoidance in COPD, following a rational course from the identification of the main concerns of sufferers through to the standardisation of a short-form measure. The main use will be for the evaluation of COPD rehabilitation and the measure will therefore address the patient population referred for this treatment in the UK. The measure will satisfy psychometric requirements of validity and reliability; it will be straightforward and brief to administer and analyse. The development of the measure will therefore be undertaken in stages.

The criteria that should apply to the development of a robust psychometric instrument with high clinical utility are described by Anastasi (1990). For the purposes of the present study the new measure of coping beliefs in COPD will need to fulfil the following criteria:

1. The measure will have demonstrable construct validity.
2 The measure will have a high internal consistency.

3 All items included in the measure will show a high level of stability on re-test.

4 All items included in the measure will have demonstrable sensitivity.

5 The measure will have demonstrable validity and sensitivity for detecting change resulting from COPD rehabilitation.

6 The measure will only contain items relating to the constructs it seeks to measure.

7 The measure will be in a format that enables completion of all items by at least 90% of respondents from a representative sample of the target group, i.e. patients with COPD producing severe incapacity and undergoing rehabilitation.
METHOD

The development of the self-efficacy/fear avoidance coping beliefs measure was planned as a three-stage process. First was a consultation phase in which clinicians and patients attending the pulmonary rehabilitation programme were consulted about the contents of the measure. Secondly, a revised form of questionnaire was administered to a larger sample for further refinement of the items. Thirdly, the largest pool of subjects completed the refined version both prior to, and then after participation on the LEEP rehabilitation course. This was to address the process of change of beliefs in response to treatment.

The Setting

This study was undertaken within the pulmonary medicine specialty of the Department of Medicine, Frenchay Healthcare (NHS) Trust between 1995 and 1999. It was attached to the Lung Exercise and Education Programme (LEEP). The clinical team comprised two chest physicians, two physiotherapists, two nurses and a clinical psychologist who all specialised in COPD rehabilitation. This treatment programme was set up in 1994 and had both clinical and research components. At that time the status of the service was that of a project. The continuation of the treatment in the future was to be heavily influenced by the audit findings. The patients attending LEEP had all formally consented to participate in the project. There was no control group for the project at that time. Their participation in the research and audit being undertaken by the team involved the completion of assessment procedures and measures.
Participants

The 198 participants were all drawn from those attending LEEP. Three separate groups contributed in the different stages of this project. There were 12 in the first stage, 121 in the second, and 65 in the final stage. Their demographic and clinical details are discussed separately below. There was no overlap of participants between the three stages of the project.

All patients in the LEEP service were previously diagnosed as having COPD which in half of the sample was moderate or severe with pronounced incapacity as a result. The diagnosis was made during their attendance at the respiratory medicine department as hospital out-patients. Onward referral to the LEEP team was made where it was felt that the individual concerned could improve their adaptation to breathlessness and other symptoms and involved their formal consent. There was some co-morbidity with other chronic conditions such as heart disease and osteoarthritis but COPD was always both the principal diagnosis and the main cause of incapacity. This patient population is predominantly elderly, the average age being sixty five, but spanning a wide range, from people in their thirties to their eighties. The diagnosis of COPD was made by a consultant physician after investigations including spirometry.

Consent

As stated above, all the patients included in the study consented to participate as research subjects in a larger evaluation/audit of the LEEP service that embraced the development of a coping beliefs measure. Formal approval was confirmed by the Frenchay Healthcare (NHS) Trust Research Ethics Committee, code 97/53. The self-efficacy and fear-avoidance questions were included as part of the set of self-assessment measures being routinely administered in the project. Participants were aware that the development of a measure was a component of this evaluation. Informed consent was negotiated before any discussion took
place regarding the development of the measure. Consent was to the larger study but included written and spoken information about the development of the measure. This was in accordance with the main protocol for the LEEP project.

The LEEP course.

The treatment programme was delivered in a group format for between eight and fifteen participants at a time. The fourteen programme meetings took place twice weekly for seven weeks, each meeting lasting two hours. Relatives were also encouraged to participate.

The course was of a standard format as described by Morgan and Singh (1997), including a supervised exercise regime, information, and psychological support. The exercise content was constructed around a prior individual assessment of baseline exercise capacity. It introduced the idea of paced exertion and controlled breathing. Patients learned their exercise limits without triggering severe breathlessness, aiming to cautiously extend performance if assessed as under-functioning, curbing their usual activity level if assessed as repeatedly over-exerting to a severely breathless state.

The information aspect of the programme followed a psycho-educational format. Topics covered the biological basis of COPD, medical investigations and treatments; the causes and management of stress; the role of diet; depressed mood and its links to activity, social contacts and negative thoughts and beliefs. One of the team would present each topic and would encourage group discussion. This was aimed to draw out the different attitudes and beliefs of participants in respect of coping with COPD, encouraging them to try out changes based on what they had learned. The timetabling of breaks allowed for considerable informal mixing of those attending in order to build mutual support. Social contact between participants outside the course meetings was also

**Measures**

Assessment for LEEP involved completing a standardised six-minute shuttle walk, Singh et al (1992) and the evaluation of perceived breathlessness during walking exercise testing using the modified Borg Scale (1982). In this respondents rate their level of breathlessness on a scale of 1 to 10 between the descriptors 'nothing at all' and 'maximal' at successive stages of the exercise test. They also completed two self-assessment questionnaires, the Chronic Respiratory Disease Questionnaire, CRDQ, Guyatt et al (1987); and the Hospital Anxiety and Depression Scale, HADS, Zigmond and Snaith (1983).

**Statistical Analysis**

The data compiled for the study was analysed using the Statistical Package for the Social Sciences, SPSS for Windows version 12, supported by discussion of SPSS procedures in Brace et al (2000). Statistical tests were two-tailed adopting \( p<0.05 \) as the criterion of statistical significance. Correlation analyses were carried out using Pearson's \( r \) statistic. Internal consistency was analysed using Cronbach's alpha statistic with an adopted criterion of 0.7.

**Procedure for the development of the questionnaire**

This divided into three stages as follows:

**Stage 1(a): Item Generation**

The aim of this stage was to identify suitable items for the measurement of coping beliefs through consultations with pulmonary rehabilitation professionals
and patients. This also involved observing practical constraints on the length of
the procedure and the acceptability of individual items.

The generation of coping belief statements related to COPD could potentially
have led to several hundred items about everyday life activities as reflected in the
broad scope of quality of life measures. However, a basic principle was to ensure
that the practical administration did not become exhausting for respondents and
also that the validity of items incorporated the aims of COPD rehabilitation. This
is because the main intended use of the measure was for evaluating this
treatment, the longitudinal application described by Hyland (2003). This is a more
focussed perspective and does not require a comprehensive profile of all the
attitudes and beliefs associated with COPD. The initial set of theoretically
relevant items were planned to be reduced down to a small sample which would
nevertheless validly reflect both individual differences in coping beliefs and also
the change that takes place with these as a result of the treatment.

It was decided to initially consult the therapists involved in COPD rehabilitation to
identify those coping beliefs that they target during the treatment process. LEEP
patients were then consulted about these items and any additional coping beliefs
they considered important. The other source was to include topics covered by the
two previously standardised measures of coping beliefs, the Mastery subscale of
the CRQ (Guyatt 1987) and the COPD Self-Efficacy Scale, COPD-SES, (Wigal et
al, 1991). The wording of the Mastery subscale is framed in a form of words that
is not sufficiently specific to reflect self-efficacy statements according to the
principles set out by Bandura (1997a) but nevertheless the topic areas were
considered to be entirely relevant. Fear-avoidance items would be generated
based on the interpretation of items from the work of Waddell (1993) and Vlaeyen
(1995). Some items generated by the team as being important coping beliefs did
not closely fit the frame of either self-efficacy or fear-avoidance beliefs but were
nevertheless included for their face validity.
Inevitably the aim of identifying fear-avoidance beliefs meant that the contents of the COPD-SES would be insufficient on its own but it was decided to include this scale in full alongside newly generated items. This was to consider the possibility of further standardising this measure, adding catastrophising cognitions and avoidance behaviours as items, to form the new scale, rather than generating an entirely new item set. However, based on the earlier difficulties the team had experienced with using this scale, there were doubts about this succeeding. The researcher agreed with the clinical team on forming a second separate questionnaire in parallel, including items suggested by the COPD-SES, should this latter scale be found to be a less practical measure.

The researcher and the respiratory team who were responsible for LEEP all contributed to the generation of items. The team consulted therefore included the lead consultant who is a respiratory physician, a specialist nurse, a respiratory physiotherapist as well as the clinical psychologist-researcher. Their focus was to consider beliefs that reflected adaptation to COPD and that were encompassed by the LEEP intervention. Their choice of topics included the following:

*Controlling a breathlessness attack ......*

When exhausted  
Feeling stressed  
In a smokey or polluted atmosphere  
Feeling angry  
Climbing stairs  
During a chest infection  
When alone  
Going from warmth into cold  
Walking  
When lifting  
During physical exertion  
When sexually aroused  
Around traffic fumes  
When lying down  
In windy weather
In wet and humid conditions
When resting
Travel away from home
When physically exerting
After eating too much
When using a vacuum cleaner.

**Attitudes, having fears about, or avoiding…**

All activity that causes breathlessness
Shopping
Being away from medical help
Housework
Going on holiday
Travelling away from home
Being unable to go out
Feeling upset
Being unable to socialise with friends
Being able to lead a normal life
Embarrassment because of breathlessness
Being unable to socialise with friends
Belief that physical activity will make the condition worse in the longer term
Belief in staying active despite the condition
Weighing the fear of breathlessness when deciding to start an activity
Weighing the fear of breathlessness during physical exertion
Weighing the fear of breathlessness occurring during sleep

Where some uncertainty existed about the wording of a question two forms of words were included. In some cases a topic was presented as a self-efficacy item and also a fear avoidance item, such as confidence for managing the household shopping and then avoiding going shopping. Questions relating to self-efficacy were worded as a judgement of confidence in being able to manage breathing difficulties in the given set of circumstances, for example, 'when becoming stressed or upset'.

A 5-point Likert numerical rating scale was adopted. This drew a rating for self-efficacy items between 'Not at all confident' at one pole and 'Very confident' at the other. The fear-avoidance items were also rated against a 5-point scale, for example 'I always need someone with me in case I have an attack of
breathlessness'. Participants were asked to rate this between 'Strongly agree' at one pole and 'Strongly disagree' at the other. There were 43 questions in all matching the themes listed above. This followed the self-efficacy reference framework of confidence for 'controlling breathing difficulties' employed in the COPD-SES but differed in that it excluded several issues: denial of illness; sexual inadequacy/impotence; drinking alcohol; not following a proper diet; loss of a valued object or loved one; overeating; feeling helpless; feeling detached; feeling frustrated; feeling incompetent; and feeling persecuted. This was because of concerns about the face validity of these items as being clear, specific, and reflecting an important efficacy belief. For example the item: (rate confidence for managing breathing difficulties....) 'When I begin to feel someone is out to get me'. The team considered that this more likely addressed paranoid ideation rather than control of breathlessness. There was overlap of topics for the other COPD-SES items but the wording was often different because of concerns raised by the team about how it would be interpreted. For example 'when I yell or scream' in the COPD-SES was reinterpreted as, 'When I am angry' in the new questionnaire.

Stage 1(b): Consultation with COPD Rehabilitation Patients

Twelve members of one LEEP course agreed to complete the new questionnaire along with the COPD-SES. They were approached at the halfway stage of attending the course. No names or other personal or clinical data were compiled. Volunteers were requested to complete the questionnaires and give verbal feedback to the administrator who was one of the team running the LEEP course. All the attendees who were approached agreed to provide this feedback. No data analysis was intended for this stage. This was because the rationale of this consultation was to consider the validity of the items and the practicalities of administration. The respondents were asked for their reactions to the two measures, to comment on the relevance of the questions, any problems that may have arisen with the construction or wording of the questions, any practical
difficulties, or to point out any items that they regarded as particularly inappropriate. The questionnaires were administered face to face by the LEEP staff. The participants also discussed the questionnaires and the broad topic of coping beliefs in a group feedback session with one of the administrators after the individual consultations were completed.

The researcher then reviewed the feedback with the other administrators. This drew attention to the wording of several items that had caused confusion to respondents. Another frequent point made in the feedback referred to those items that appeared to be a simple repetition of each other. Although such pairs were knowingly included at the start the effect was to antagonise some respondents.

The staff noted that many of the respondents had baulked at several questions included in the COPD-SES and that overall, despite it being only 32 items, it had often taken more then 15 minutes to administer. Several respondents had also elected not to answer the item about sexual activity in the new questionnaire. Still more refused to respond to the item about feeling 'sexually inadequate or impotent' in the COPD-SES.

Following the review of this feedback between the researcher and the clinical team, changes were made to the wording of the items in the new questionnaire. Several of the difficulties with the COPD-SES were considered as possibly arising from cultural-language differences between the US participants in whom it was developed and this UK sample. The decision was taken to drop the COPD-SES because of the extent of problems that this consultation had revealed. There was debate about whether or not to drop the item on sexual activity in the new questionnaire. This was because of the number of non-responses on the one hand against which two members of the clinical team firmly believed that this topic is nevertheless of considerable importance regarding adaptive coping. It
was decided to keep this item and draw further data in the second phase of developing the measure before deciding whether or not to omit it. The example item in the instructions, a global reflection of confidence for controlling breathing difficulties, was observed as having good face validity for inclusion. This was circled on the form as an example of how to record a response but some respondents had wanted to mark a different rating. It was decided to remove the circle and, as part of the written instructions and spoken explanation, to present this as a first item. The administrator would, if necessary, prompt respondents to answer circling the number that best fits their own belief. This response would also then be included in the analysis.

Stage 2: The Pilot Sample

Having determined use of a single questionnaire with altered wording the next stage was the administration of the new questionnaire to a new and larger pilot sample.

The aims of this phase were:

1. To further check the acceptability of the wording of each of the individual items;
2. To check the sensitivity of the 5-point ratings with each item to identify any pronounced floor or ceiling effects in the range of responses.
3. To consider any new items for inclusion based on feedback;
4. To consider test-retest reliability in a sub sample.

It was anticipated that there would be further revision and removal of items that had incomplete responses or were unsatisfactory in other respects.
Sixty-five participants completed the revised questionnaire. This group comprised 41 males and 24 females, mean age 67, ranging from 49 to 83 years old. All the questionnaires were administered and checked one-to-one by a member of the team. The forms were then scored and encoded by the researcher and a psychology assistant. The semantics of five agreement/disagreement items required a mirrored reversal of the score before encoding, (see appendix 1). After this reversal a higher score (ranging 0-4) reflected a more positive coping belief on every item.

**Response omissions**

The total of non-responses against each item ranged from 0 to 3 with the single exception of the question about sex life. This was preceded by ‘As a result of my lung condition I am either unable to, or always avoid:’ and the item read as, ‘Engaging in sexual activity’. Fifteen of the sixty-five respondents (23%) omitted this item. This reaffirmed the feedback received at the first stage and therefore, despite concerns about the clinical importance of this topic, this non-response rate led to the item being removed.

All but one subject responded to the question concerning efficacy for managing breathing difficulties when angry. However, this raised concerns amongst the team administering the questionnaire because so many respondents had to be coaxed to answer. They indicated that many did not regard themselves as inclined to getting angry.

The other items in the self-efficacy section that also provoked difficulties with administration were: ‘When I have a chest infection’ that led to comments relating to how severe the infection is; and ‘when weather could affect my condition’ that led to objections that this is not specific and that all weather affects COPD one way or another. These items were therefore removed.
Item analysis

The first analysis of the data by item was a Pearson's r correlation to check for any perfect correlations between any pairs of items. None were found.

The next step was concerned with the response range on each item, sifting for possible floor/ceiling effects in the data. Responses were scored in a 0-4 range. Some respondents marked the form between two integers on the scale, e.g. at a notional 3.5 which is halfway between the integers 3 and 4. There were 8 examples of this accumulated in the data from the 1950 responses overall, (65 respondents by 30 items). This might have led to a small distortion of the scores overall (4 points in a total pool of data, 1950 responses multiplied by a score of 0-4, which could therefore range from 0-7800). There were no examples of this occurring more than once on any single variable. It was therefore assumed as not having an important effect and was handled by rounding the figure to the nearest integer, as judged by the data processor. Also, the low frequency of this procedural error did not lead to any revision of the questionnaire instructions other than to prompt the team to check for this at the time of administration.

The construction of the scale did not involve either criterion testing or an assumed normal distribution of answers for each item as discussed by Anastasi (1990). There was nevertheless a requirement that each item showed sensitivity in discriminating a spread of ratings amongst the respondents. The topic label of each item and histograms of the responses are shown in appendix 2. For the majority of items there is an evident spread of responses across the five response categories. The adoption of a 5-point scale was therefore judged successful. However, four profiles were identified where less than 10% of responses were recorded against either the first two or the last two points on the scale. The relevant data are shown in table 1 below:
<table>
<thead>
<tr>
<th>Item label</th>
<th>Responders</th>
<th>Non-Score Responders</th>
<th>Category (% Subjects)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controlling attack</td>
<td>63</td>
<td>2</td>
<td>0  1  2  3  4</td>
</tr>
<tr>
<td>Socialising</td>
<td>65</td>
<td>0</td>
<td>0  1  2  3  4</td>
</tr>
<tr>
<td>Resting</td>
<td>63</td>
<td>2</td>
<td>0  1  2  3  4</td>
</tr>
<tr>
<td>Constant attendance</td>
<td>63</td>
<td>2</td>
<td>0  1  2  3  4</td>
</tr>
</tbody>
</table>

**Table 1: Floor/Ceiling Effects**
Profiles identified where the combined first/last two categories have less than 10% of responses.

The data shows that for three of these questions the responses were spread more evenly between three other score categories. These items were therefore retained for the third stage. In the case of the fourth, a question referring to controlling breathlessness during rest, 90% of responses attached to a score of 3 or 4. The clinical team also reflected on some dissatisfaction with this item regarding its relevance for coping with COPD. This item was therefore omitted.
The final criticism to emerge in this stage was that the questions about activity such as walking and climbing stairs were not sufficiently specific. Therefore four new items were added: "confidence for controlling breathlessness when:"

- Walking for 5 minutes (at your own pace)
- Walking for 15 minutes (at your own pace)
- Climbing a flight of five steps
- Climbing a flight of 12 steps

These two pairs were nested variables. Success at walking 15 minutes always implies success at walking for 5 minutes. One or other in each pair would therefore be removed at the third stage depending on their relative sensitivity.

**Test-retest reliability**

A sub-group of 27 respondents agreed to repeat the questionnaire to check the stability of the items in the measure. This interval had to be short both because of fluctuations of other factors such as symptom severity (which are in turn influenced by weather conditions) and mood, that may be found to affect test scores. Also, the participants were undertaking a rehabilitation course where change in these factors was expected. The lag between the two administrations ranged from three hours to three days. Pearson's r correlation coefficients for each item, first-to-second administration, are shown in table 1 of appendix 3.

Twenty-one of the thirty pairs of scores (same item, first and second administration) were correlated at a statistically significant level ($p < 0.05$). Five
other non-significant pairings had a coefficient that was below 0.3. The small sample size meant a likelihood of some weak correlations and this was not therefore regarded as an absolute basis for excluding these items. This was however taken into account when the team reviewed all the findings of the second stage, adding weight to any other objections against these items, in determining the revisions of the questionnaire.

The Revised Questionnaire

After the alterations described above the questionnaire comprised twenty-nine remaining items. (This includes the global question at the beginning of the form). The resulting questionnaire is included in appendix 1.

There were eleven self-efficacy items, the first being the confidence for bringing a breathlessness attack under control, the next six framed as confidence for managing breathing difficulties when stressed or upset, in a smokey or polluted atmosphere, when physically exerting, when socialising with friends or family, when alone, and when in a hurry or under pressure. The remaining 4 were the nested items about walking and climbing steps. All the items after this were rated according to agreement/disagreement with each successive statement. The next 12 items addressed respondents' beliefs: that despite the condition I (the respondent) can lead a normal life; that because something causes breathlessness does not mean it is harmful; that physical activity will make the condition worse in the longer term; in staying active despite the condition; in always needing someone with me in case of having a breathlessness attack; in preventing the condition worsening by avoiding activities that cause breathlessness; in avoiding anything that causes breathlessness; that I can't do a lot of things normal people do because it's too easy to lose control of my breathing; that I would not be embarrassed if I became breathless in the company of friends; that I would not be embarrassed if I became breathless whilst out shopping; that I would not start something if there was a chance that I
would have to stop before finishing it; and that I am fearful about becoming breathless when asleep. The remaining 6 items were framed, "As a result of my lung condition I am either unable to, or always avoid:" going out; doing housework; going shopping; being away from easy access to medical help; socialising with friends; and, travelling away from home for more than one day.

**Stage 3: The Main Sample**

The largest survey was undertaken with a further sample group drawn from the LEEP service. Participants completed the questionnaire before entering the treatment programme and then again during their individual clinical assessment after the end of the course. The aims of this stage were:

1. To compare the questionnaire data with the other demographic and clinical details gathered by the service.

2. To repeat an item analysis for the removal of two nested variables and to further consider the sensitivity of those items where concerns were identified at stage two.

3. To compile additional feedback on any difficulties with administration.

4. To analyse the questionnaire data for internal consistency. This involved Cronbach's alpha statistic. A criterion alpha of 0.7 was adopted since the measure was being developed primarily for longitudinal use in clinical audit. If it were to be applied to clinical decision making in individual cases then an alpha value of 0.95 or above is required.

(6) To conduct a confirmatory analysis of any emergent factor structure and consider the internal consistency of these.

(7) To consider the re-test reliability of any emergent factor structure.

(8) To consider the stability of any emergent factor structure in COPD sufferers who have completed their rehabilitation treatment.

(9) To consider the external validity of the any derived indices of coping beliefs against the other assessment measures included in the study.

(10) To consider the sensitivity of any indices of coping beliefs to the changes resulting from rehabilitation treatment. This would involve an item analysis. It was anticipated that people who had completed their rehabilitation would raise their coping beliefs towards the positive pole of the questionnaire ratings where these were evenly spread prior to treatment. If so a ceiling effect might arise and some of the sensitivity of the measure would be lost as a result. A useful degree of sensitivity would need to be maintained. The analysis would then move to the computation of change scores for self-efficacy and fear-avoidance factors and comparison of these with the other outcome measures used by the LEEP team.

These aims formed the main standardisation of the coping beliefs measure.
RESULTS

Participants and handling of missing data

In total 121 participants agreed to complete the 29-item questionnaire as part of their assessment for the LEEP course. To protect confidentiality the research data was compiled on a separate database to the main records for the LEEP clinic. The questionnaires were returned named but with no other information. Clinical details were added later from the separate clinical database. However, there were a substantial number of missing details that only became apparent when merging the data at the stage of final data processing. When the two sets of data were compared details of age, sex, FEV₁, shuttle walk test, and HADS scores were incomplete. This arose mainly because of the day-to-day practical and administrative demands of compiling data from a busy NHS clinic. A correction was possible by a thorough review of all the individual medical records but constraints on resources prevented this. Two returned questionnaires had no name and could not be paired with any clinical/demographic data. These cases were excluded from the analysis. The data processing of the remaining 119 cases, complete for questionnaire data, nevertheless had a diminished sample size in those instances where only partial clinical data was available. For this reason the data presented below shows a varying sample size where clinical details are compared with the questionnaire data.

There were 75 men and 39 women, (5 missing values), a ratio of 2:1. Their ages ranged from 37 to 82 years with a mean age of 65. The profile of age is shown in figure 2.
The information on breathing restriction was complete for 57 of the sample. They had a mean FEV₁ of 40.1% predicted. This ranged from 12 to 110 as summarised in figure 3. Almost three quarters of the sample was in the moderate or severe range. There was one outlier, a respondent with FEV₁ 110% of predicted level, i.e. better than the average for the same age and sex. This was a male with breathing difficulties associated with a diagnosis of chronic fibrosing alveolitis. This is a serious respiratory condition with impairment of functioning but one that does not produce deficits with FEV₁ measurement. In all other respects the condition gives rise to the same needs as those of other participants in LEEP and it was for this reason that he was included in the treatment programme. If this case is removed the mean is reduced to 39.9% predicted and this does not skew the data substantially. No other aspect of this case produced outlying data and the case was retained.
Exercise testing

The six-minute walk test profile is shown in figure 4. Overall, data for 85 respondents produced a mean distance of 251 metres (SD 141m) that ranged from 20 to 910 metres.
Figure 4: Six-Minute Shuttle Walk
Anxiety and depression symptoms

The scores derived from the HADS are shown in figure 5, grouped according to the suggested categories for the measure. This shows high levels of anxiety with a quarter of the sample having case-level symptoms and a further quarter at a borderline level. There is a lesser degree of depressive symptoms. A fifth of the sample were borderline or above but only one in twenty five showed as case-level depression.
Figure 5(a) and (b): Hospital Anxiety and Depression Scale: Main Sample

Scores are categorised according to the cut offs for the scale: caseness (11+); borderline (8-10); normal (0-7).
**Completion of the 29-Item Measure**

All 119 questionnaires were administered by a team member, checked and returned complete. The questionnaire took most respondents between five and ten minutes to complete.

**Item analysis**

Following the same filtering method as in stage 2 for identifying floor or ceiling effects, there were no individual items in which the first or last two points on the response scale were endorsed by less than 10% of the respondents. The three retained items where this occurred from the second stage all had a more balanced spread of responses. There were therefore no grounds for removing any more individual items because of a lack of sensitivity at first administration.

The two pairs of nested self-efficacy items inserted at stage 2, (walking and climbing steps) were compared for their sensitivity as shown in table 2 below.

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<thead>
<tr>
<th>Descriptor</th>
<th>Score Category (%) of responders</th>
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<tr>
<td>Walking-5 minutes</td>
<td>6</td>
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<tr>
<td>Walking-15 minutes</td>
<td>18</td>
</tr>
<tr>
<td>Climb-5 steps</td>
<td>4</td>
</tr>
<tr>
<td>Climb-12 steps</td>
<td>11</td>
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</table>

**Table 2: Comparison of responses for nested items**

The data shows an acceptable spread of responses in each form with the 15-minute walk and the 12 step climb showing the most even spread. The 5-minute walk and the 5-step climb were therefore excluded from further analysis.
Additional Feedback

Four items were identified as having caused particular administrative difficulties. These were as follows:

'I can prevent my condition from worsening by avoiding activities that make me breathless'.

Respondents frequently asked questions about the meaning of this statement. This had appeared to be an acceptable item when developed amongst the pilot sample who were midway through their rehabilitation treatment and were familiar with the discussion of fear in relation to activity. The problem for those administering the measure in this third stage was that it was more difficult to explain this item to a group who were not familiar with this idea.

The item, 'Just because something makes me breathless does not mean it is harmful' was reported to be provoking the same problem. Respondents often did not understand the idea of 'harm' and the explanation was difficult for the administrator.

The item 'Despite my condition I can lead a normal life' was reported to have occasionally drawn comments about poor use of the language and that it should read, 'I can lead a normal life despite my condition'. This was therefore considered for exclusion from the analysis. The team felt that the idea being presented was, in retrospect, unacceptably vague and that the range of interpretations of what is meant by a normal life was too broad, raising doubts about the validity of the item.

Coinciding with the third stage, discussions took place with other COPD rehabilitation research groups in New Zealand and Australia where the
questionnaire was being administered in two other trials. No data was made available from these but a firm opinion was expressed by these groups about the item concerning housework. A substantial number of male respondents in both of these trials were reported to have been unable to complete this item on the grounds that they were not, and had never been, responsible for housework. The team discussed this in respect of their experience with this UK sample. They reported their impression that respondents seemed to interpret what is meant by the word 'housework' at very different levels of implied activity. It was accepted that this feedback represented an important objection.

It was decided that all of the 4 items above should be excluded from further analysis.

Reliability

The Cronbach’s alpha statistic was calculated for the scale in its revised form. The alpha = 0.892 reflected acceptable internal consistency.

Exploratory factor analysis

Factor analysis involved Pearson's Product-Moment statistic with extraction using alpha factoring, examination of the scree plot to identify a factor structure, following Kaiser's criterion in extracting factors that have Eigen values greater than 1, with an oblique rotation because of an assumed relatedness of factors.

Initially the factorability of the data set was assessed. A correlation matrix showed many intercorrelations greater than 0.3. An anti-image correlation matrix confirmed that values on the off-diagonal were approaching zero. The Kaiser-Meyer-Olkin test of sampling adequacy was computed. This gave a value of
0.824 which, held against a criterion of greater than 0.6, indicated a high degree of common variance. The details of these are included in appendix 4. The data was therefore deemed suitable for factor analysis, using oblique rotation, extracting Eigen values greater than 1 and delta set at 0. Cases were excluded list-wise and absolute values less than 0.3 were suppressed for ease of analysis.

### Pattern Matrix(a)

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a Rotation converged in 11 iterations.

**Table 3: Exploratory Factor Analysis Pattern Matrix**

Six components were extracted that had an Eigen value greater than 1, each explaining at least 4.8% of the variance. Examination of the pattern matrix (table
3) showed no items with a high loading (greater than 0.4) on more than one item. Examination of the data and the scree plot (figure 6) suggested that either a two-factor or a three-factor model should be extracted. Factors IV to VI emerged as almost level in the scree plot. The conceptual links between the variables on each of these factors were weak and the number of attaching variables was small.
Figure 6: Scree Plot
The factor structure was discussed by the researcher and two representatives of the clinical team, (consultant physician and lead physiotherapist). The first factor entirely comprised self-efficacy items and accounted for 31.3% of the variance. The variables were efficacy for controlling a breathlessness attack; for managing breathing difficulties when upset, when in a smokey or polluted atmosphere, when physically exerting, when socialising with friends or family, when alone, and when in a hurry or under pressure.

The second factor comprised four fear-avoidance items: the level of agreement with the statement "As a result of my lung condition I am either unable to, or always avoid:" going out, shopping, being away from easy access to medical help, and socialising with friends. This accounted for 10.3% of the variance. The theme of these appeared to be avoidance of certain 'out of the house' activities but these were considered to be distinct. The loadings ranged from 0.55 to 0.76.

The third factor explained 7.8% of the variance. It comprised three variables with only one of these, (avoiding starting certain activities that might have to stop because of breathlessness), loading above an absolute value of 0.5. The second highest loading variable (-0.44), 'I avoid anything that might cause breathlessness' was semantically very close to the first. It was considered that including this third factor would add little either in terms of the statistical robustness of the model or the conceptual value. It was therefore agreed that a two-factor model be adopted for the next stage of the analysis. The first was of seven items and the second, four items. These two factors in combination accounted for 41.5% of the variance. This interpretation fitted with the theoretical prediction of a two-factor model but comprised fewer items than anticipated. In particular it was expected that the two items about self-efficacy for walking for 15 minutes and for climbing 12 steps would both attach to Factor I.
Confirmatory factor analysis.

After extracting the items that comprised the two-factor model a further factor analysis was undertaken, (see appendix 5). This involved analysis of the 11 items using maximum likelihood method generating a chi-squared analysis to consider goodness of fit. This confirmed the presence of two distinct factors that together accounted for 64% of the variance in the data. The chi square value and degrees of freedom were 74.8 and 34 respectively, close to but satisfying the criterion of $\chi^2<2df$. The correlation between the two factors was 0.39.

The Reliability of the two factors.

The Cronbach’s alpha statistic was calculated for each of the two factors. The values of $\alpha=0.91$ for the seven self-efficacy items and secondly, $\alpha=0.80$ for the four item fear-avoidance factor, both reflected a satisfactory level of internal consistency.

All eleven items that comprised the two factors were part of the questionnaire administered in the earlier test-retest sub-sample of 27 respondents. A Pearson’s $r$ correlation analysis was therefore computed for each of these two factors between test and re-test. This produced a correlation coefficient of 0.86 for factor I (self-efficacy) and 0.74 for factor II (fear-avoidance), reflecting an acceptable level of re-test reliability.

External Validity

A summed-total score was calculated for each subject for each of the two factors. This enabled a comparison to be made between these and other measures. The correlations with other measures are shown in table 4. Statistically significant
associations emerged between both factors and three of the four other measures. FEV₁ was not linked with either. Fear-avoidance was associated with anxiety but not depression from the HAD scale. None of these correlations were high, the highest being a coefficient of -0.59 between self-efficacy and HAD-anxiety.

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<td></td>
<td>(23)</td>
<td>(23)</td>
</tr>
<tr>
<td>Shuttle</td>
<td>0.06</td>
<td>-0.25</td>
</tr>
<tr>
<td></td>
<td>(39)</td>
<td>(53)</td>
</tr>
<tr>
<td>S-E</td>
<td>0.04</td>
<td>0.59*</td>
</tr>
<tr>
<td></td>
<td>(50)</td>
<td>(63)</td>
</tr>
<tr>
<td>F-A</td>
<td>0.05</td>
<td>-0.39*</td>
</tr>
<tr>
<td></td>
<td>(46)</td>
<td>(63)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FEV</th>
<th>HAD-A</th>
<th>HAD-D</th>
<th>Shuttle</th>
<th>S-E</th>
</tr>
</thead>
</table>

Pearson’s r (N), significant p<0.05*

Key
FEV = Forced Expiratory Volume
HAD-A = Hospital Anxiety and Depression scale for Anxiety
HAD-D = Hospital Anxiety and Depression Scale for Depression
Shuttle = 6 Minute shuttle walk distance (metres) factor I
SE = Self efficacy (Factor I)
FA = Fear Avoidance (Factor II)

Table 4: Correlation Coefficients between factors I and II, disease, distress, and performance measures

The 2-factor scale as a measure of change.

The next stage in the analysis was a comparison made between data gathered from two separate administrations of the questionnaire, before and after the
LEEP treatment, using the two total scores for the self-efficacy (S-E) and fear-avoidance (F-A) factors. The scoring range was 0-28 and 0-16 respectively. There were 23 cases where the respondent either did not finish the LEEP course or did not complete the questionnaire, leaving 94 people for whom there was complete data before and after treatment.

A further exploratory factor analysis was undertaken to consider the stability of the two-factor model in the questionnaire responses of people who have completed their rehabilitation treatment. The same method of exploratory factor analysis was employed as above with extraction by alpha factoring for the 11 variables derived as previously. The pattern matrix is shown in table 5 and the other SPSS output data is included in appendix 6. The two-factor structure was replicated, with these accounting for 63.4% of the variance.

Table 5: Exploratory Factor Analysis Of Post-Treatment Questionnaire (N= 94)

Pattern Matrix(a)

<table>
<thead>
<tr>
<th>Factor</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>segencn2</td>
<td>.794</td>
<td></td>
</tr>
<tr>
<td>seupset2</td>
<td>.870</td>
<td></td>
</tr>
<tr>
<td>sesmoke2</td>
<td>.723</td>
<td></td>
</tr>
<tr>
<td>seexert2</td>
<td>.658</td>
<td></td>
</tr>
<tr>
<td>sesocia2</td>
<td>.626</td>
<td></td>
</tr>
<tr>
<td>sealone2</td>
<td>.621</td>
<td></td>
</tr>
<tr>
<td>sehurry2</td>
<td>.803</td>
<td></td>
</tr>
<tr>
<td>bagoout2</td>
<td></td>
<td>.816</td>
</tr>
<tr>
<td>bashop2</td>
<td></td>
<td>.661</td>
</tr>
<tr>
<td>baacmed2</td>
<td></td>
<td>.619</td>
</tr>
<tr>
<td>basocia2</td>
<td></td>
<td>.703</td>
</tr>
</tbody>
</table>


a Rotation converged in 5 iterations.
An item analysis of the responses to the 11 items was then completed, (see appendix 7). This was to explore for possible ceiling effects and loss of sensitivity of individual items in the responses of people who have completed rehabilitation. There were further examples of responses being marked between the integers on the rating scale for these items, 32 out of 1034 responses, 27 of these being between a score of 3 and 4, but no more than 4 on any one item. These have been excluded from the histograms for ease of presentation. These show a shift towards the positive pole (higher scores) for each item as expected. However, there were no pronounced ceiling effects. There was a small reduction in variance at reassessment compared to pre-treatment as shown in table 6. The data nevertheless indicates that each item has preserved sensitivity post-treatment. This suggests that the summation of scores produces an index that will have discriminant validity, i.e. it might be used to reliably differentiate between groups of people who could be categorised as effective or ineffective copers. This would however require further standardisation.

<table>
<thead>
<tr>
<th>Item Label</th>
<th>Pre-LEEP</th>
<th>Post-LEEP</th>
<th>Pre-LEEP</th>
<th>Post-LEEP</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEGEN</td>
<td>2.6</td>
<td>3.1</td>
<td>1.1</td>
<td>0.8</td>
</tr>
<tr>
<td>SEUPSET</td>
<td>2.4</td>
<td>3.1</td>
<td>1.1</td>
<td>0.8</td>
</tr>
<tr>
<td>SESMOKE</td>
<td>2.0</td>
<td>2.4</td>
<td>1.2</td>
<td>1.2</td>
</tr>
<tr>
<td>SEEXERT</td>
<td>1.9</td>
<td>2.6</td>
<td>1.1</td>
<td>0.9</td>
</tr>
<tr>
<td>SESOCIAL</td>
<td>2.8</td>
<td>3.1</td>
<td>0.9</td>
<td>0.8</td>
</tr>
<tr>
<td>SEALONE</td>
<td>2.6</td>
<td>3.1</td>
<td>1.2</td>
<td>0.8</td>
</tr>
<tr>
<td>SEHURRY</td>
<td>1.6</td>
<td>2.4</td>
<td>1.2</td>
<td>1.0</td>
</tr>
<tr>
<td>BAGOOUT</td>
<td>3.1</td>
<td>3.4</td>
<td>1.1</td>
<td>0.9</td>
</tr>
<tr>
<td>BASHOP</td>
<td>2.6</td>
<td>3.2</td>
<td>1.3</td>
<td>1.0</td>
</tr>
<tr>
<td>BAMED</td>
<td>2.7</td>
<td>3.2</td>
<td>1.3</td>
<td>1.0</td>
</tr>
<tr>
<td>BASOCIAL</td>
<td>3.0</td>
<td>3.3</td>
<td>1.2</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Table 6: Item score Means and Variances for Pre- and Post-Treatment Questionnaires

Change scores for the self-efficacy and fear-avoidance factors were then calculated by adding the item scores. Histograms of the total scores before and after treatment are shown in figures 7(a) and (b), divided into six and four categories respectively for the purpose of presentation. The distributions show a shift towards greater self-efficacy and reduced fear-avoidance post-treatment. A paired-samples T test comparison of means (table 7) produced a statistically significant result (p< 0.001) supporting this observed difference. Substantial changes occurred on both factors by the end of the treatment.
Figure 7(a): Self Efficacy (factor I) Scores Pre- and Post-Treatment

Figure 7(b): Fear Avoidance (factor II) Scores Pre- and Post-Treatment

n.b. High scores reflect more intense fear-avoidance
Table 7 'T-Test comparison of means before and after treatment for self-efficacy (SE) and fear-avoidance (FA) scores.'

<table>
<thead>
<tr>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>df</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE1</td>
<td>15.7</td>
<td>6.3</td>
<td></td>
<td>-7.5 100 p&lt;0.001</td>
</tr>
<tr>
<td>SE2</td>
<td>19.8</td>
<td>4.7</td>
<td></td>
<td>-4.8 100 p&lt;0.001</td>
</tr>
<tr>
<td>FA1</td>
<td>11.4</td>
<td>3.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA2</td>
<td>12.9</td>
<td>3.1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Next a change score was computed for each of the variables: HADS-anxiety, HADS-depression, and shuttle walk distance. FEV₁ was excluded since no change is expected post-treatment. These change scores were the calculated difference between pre- and post-treatment assessment totals for each variable. A positive value indicated improvement post-treatment on all variables except HADS scores where a reduced score reflected reduced distress. This score was therefore reversed before further analysis. Correlation coefficients were calculated (Pearson's r) between all possible change scores, (table 8). The results show that the closest correlations were three-way, between shuttle walk, depression, and self-efficacy. There was therefore evidence of post-treatment improvement on each of the outcome measures that was correlated closely enough to suggest that the rehabilitation is helpful across all variables but that
these correlations were not so close as to suggest that there is a single global process of benefit, something closely equating between all the outcome measures.

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|}
\hline
 & HAD-A & HAD-D & Shuttle & SE & F-A \\
\hline
HAD-A & 0.29* & & & & \\
(62) & & & & & \\
HAD-D & & 0.50*** & & & \\
(50) & & (50) & & & \\
Shuttle & 0.22 & 0.36** & 0.38** & & \\
(55) & (54) & (63) & & & \\
S-E & 0.24 & & & & \\
(55) & & & & & \\
F-A & 0.13 & 0.22 & 0.19 & 0.22* & \\
(60) & (59) & (63) & (101) & & \\
\hline
\end{tabular}
\caption{Correlation matrix of computed change scores: Pearson’s r 2-tailed}
\end{table}

*\(p<0.05\), **\(p<0.01\), ***\(p<0.001\)

Key
HAD-A = Hospital Anxiety and Depression scale for Anxiety
HAD-D = Hospital Anxiety and Depression Scale for Depression
Shuttle = 6-Minute shuttle walk distance (metres) factor I
SE = Self-efficacy (Factor I)
FA = Fear-Avoidance (Factor II)

Table 8: Correlation matrix of computed change scores: Pearson’s r 2-tailed

The above method of comparing changes in raw scores between different measures is potentially misleading. Inherent differences may exist between the separate scales in respect of measurement error. A less precise scale will sometimes produce larger change scores by chance. This then suggests a greater degree of real change has taken place, a type I error, or that the measure has greater sensitivity when this has instead arisen because the measure is imprecise in describing real change. One method of addressing this is to
incorporate the standard deviation into the calculation of change values. This method is discussed by Lunnen and Ogles (1998) regarding an interpretation of clinically significant change. In applying this to the present data a change of one standard deviation as derived from the initial assessment data was adopted as a criterion. Hence, for the HAD-Anxiety scale the criterion was 4.3 and for the Self-Efficacy subscale it was 5.3. A change score exceeding this was considered to be a 'major change' and taken as clinically significant, for better or worse, depending on the direction of the shift. Adopting this method for a comparatively small sample size producing a larger standard deviation demands a sizeable treatment effect. One consequence of categorising the data in this way is to create the impression that proportionately few people derive treatment benefits, simply because the criterion is set high. The advantages however are firstly that a more useful comparison can be made between measures and secondly that it also clearly reveals the distinction between positive and negative effects on each measure. A null hypothesis of any major changes occurring randomly predicts equal proportions of positive and negative change.
There were 41 respondents for whom there was complete data, i.e. across all measures before and after treatment. The proportions of change against each measure, using the above method, are shown in figure 8. All show that a small number of participants experienced a negative shift on each scale, i.e. towards worse depression or lower self-efficacy beliefs, except for the shuttle walk where there was none. This proportion was roughly equal between each of the other four measures at approximately 5%. There were however notable differences
between the measures in respect of the degree of positive change. Also, comparing the positive and negative categories of 'major change' in Figure 8 illustrates the degree to which these findings differ from the null hypothesis that any change occurs randomly and not as a result of the treatment. The scales all reflected 20% or more of the respondents showing gains. Although this was a demanding criterion of change a substantial degree of clinically significant benefit is evident. Furthermore, compared to other standard measures that are accepted as demonstrating useful treatment effects the self-efficacy scale had the largest proportion of overall 'major change' with 46% of the sample showing a gain greater than one standard deviation. The self-efficacy scale appears to have good sensitivity to the changes associated with COPD rehabilitation compared to these other standard outcome measures.
DISCUSSION

The overall aim of this study was to develop a coping beliefs scale relevant to the rehabilitation of COPD that can be used as a measure of treatment outcome. To summarise the process, this involved drawing on the opinions of both patients and professionals involved in COPD rehabilitation. The literature indicated that two styles of coping beliefs would be of particular relevance. These were competency judgements that individuals make of themselves, described as self-efficacy beliefs, and specific fears that lead individuals to decide to avoid certain circumstances, described as fear-avoidance beliefs. Consultation and the conceptual analysis of coping challenges and the goals of rehabilitation led to the generation of a set of items for a new scale. Existing measures were included for comparison and validation. The process of standardisation involved the removal of items that caused difficulties during administration or where doubts were identified about the validity of the item. Attempts to modify the COPD-SES, an existing coping beliefs measure were abandoned because of problems with its administration. The items were reduced to 22. Responses against these were analysed for structure. Two factors emerged matching the self-efficacy and fear-avoidance constructs. These comprised 7 and 4 items respectively. This 2-factor structure was confirmed in reassessment data gathered at the end of treatment. There was evidence of internal consistency and re-test reliability of these two factors. There were positive indications of their sensitivity in measuring the changes associated with rehabilitation treatment.

The summary above suggests that the 7 aims of the project were fulfilled. However, there were some difficulties encountered with the completion of the project and several questions remain about the conclusiveness of the findings. These are considered below.
The Validity of Self-Efficacy Measurement.

In a discussion of the development of self-efficacy scales Bandura (1997a) commented that competency beliefs have many levels and that there is no single global dimension of self-efficacy. He advised on the inclusion of sufficient numbers of items so as to ensure that all the separate dimensions are covered that are key to the target of interest. It might be held that although the generation of items followed exactly the process he had advised the subsequent reductions removed too many items for the eventual scale to truly reflect the constructs as originally conceived. That is to say that the final set of items might no longer adequately mirror the range of coping beliefs associated with COPD, the processes of rehabilitation, or the various changes that occur for individuals as a result of treatment. Having sought to identify those items with a high level of correspondence with each other the exclusions have meant there is no longer any reference for example to managing breathing difficulties in bad weather, to the belief that challenging the limits of exertion could be harmful, and that fears about breathlessness during sleep or with sexual activity can be intense and inhibiting. Feedback from the clinicians both in LEEP and from the two groups in Australia and New Zealand was of reluctance amongst therapists to omit the other items included in the 29-item form from the second stage because too much interesting information was being sacrificed. Cursory analysis of the items included in the third stage but not included in factor analysis suggested that these too showed sensitivity to change post-treatment. Correlation data on those items that were analysed but that did not attach to the two emergent factors showed close associations between the two items reflecting embarrassment about symptoms and the pair of items on walking and climbing steps. It might be held that had more such items been included at the outset then additional factors would have been found in the data. Differing types of self-efficacy clusters might then have been described rather than a single factor. Furthermore, Bandura remarked (1997, chapter 2 page 45) that, "Restricting items to those that correlate highly with one another results in a self-efficacy scale that measures
redundantly only a segment of perceived efficacy”. If so this contradicts the aims of the study by raising doubts about the validity of the single factor 7-item measurement being sufficiently representative and suitable for evaluating COPD rehabilitation.

The appropriate means for addressing this criticism of the self-efficacy component of the questionnaire is to refer back to the model of intervention being examined in the development of the scale. COPD rehabilitation treatment focuses particularly on the control of breathlessness, particularly for managing physical exertion. Information is presented as a foundation to ensure that inaccurate beliefs about the disease are corrected and that the rationale of treatment is clear. The other components are the experience of supervised exercise, goal setting for behaviour change practiced between meetings, drawing on the support of other COPD sufferers whilst also witnessing their successes, and gaining confidence for managing the distress associated with the illness. These reflect the four characteristics of performance experience, vicarious learning, persuasion, and emotional arousal described by Bandura as the determinants of change of self-efficacy beliefs. This was the basis for adopting a self-efficacy perspective in the construction of the measure but it now raises the question of whether or not the range and accuracy of the final self-efficacy items still reflect this treatment model.

The seven residual self-efficacy items refer firstly to confidence for control of a breathlessness attack, (global item); and then to subjective confidence for the control of breathlessness:

- when feeling stressed or upset;
- when in smokey or polluted air;
- during physical exertion;
- when socialising;
when alone;
and, when in a hurry.

These are all less specific than the walking and climbing steps items. They relate only to confidence for controlling breathing difficulties and not other symptoms such as managing fatigue or confidence in memory and reasoning. However, the latter symptoms do not feature prominently in rehabilitation treatment. Furthermore, the seven items are representative of the main goals of COPD rehabilitation as it is presently described in the literature and by practicing COPD specialists. That is, managing breathing difficulties in challenging everyday life circumstances to achieve a better quality of life.

Bandura (1997a) refers to dimensions of generality, strength, and level, for the development of self-efficacy scales where generality reflects the degree of stability of self-efficacy beliefs across different modalities. It is implicit in this that there are higher order self-efficacy beliefs. An example is the level of confidence an individual has for maintaining emotional composure. This could be expressed consistently across different items such as controlling angry feelings when making a complaint in a shop or giving a speech at a wedding. In describing the generality notion Bandura comments that assessments linked to different activity domains, situational contexts, and social characteristics, can reveal a patterning and hence a degree of generality of efficacy beliefs. The notion of generality differs from a theory of personality because in spite of there being a consistency shown by an individual in reaction to different situations it does not imply constancy over time. He described the most fundamental self-efficacy beliefs as those around which people structure their lives. This has similarity for example with the construct of ‘core beliefs’ in Beck’s theory of cognitive therapy (Beck, 1976) and the basic set of ‘irrational beliefs’ in Ellis’ Rational Emotive Therapy, (Ellis, 1977). It follows that whilst different domains of functioning require different assessments there is nevertheless an underlying set of self-efficacy
items that will be found to be highly intercorrelated. In this study the reduction of items through factor analysis can be argued to have revealed a set of items reflecting efficacy for coping with COPD that possess generality.

The purpose of the measure was to sample self-efficacy beliefs, rather than capture a full spectrum, and through this produce a valid and reliable scale that reflects the impact of treatment. It is not possible at this stage to dismiss the criticism that 7 items, all intercorrelated, might be failing to capture a sufficient range of such coping beliefs, but this is not a fatal flaw. There is both a theoretical justification and evidence to support the alternative interpretation, that the measure has sampled a generality of self-efficacy beliefs that do represent coping variables addressed by rehabilitation.

One risk in reducing the measure to a small range of self-efficacy items was that a large proportion of respondents' ratings would cluster too closely, leaving only small numbers of people with high or low scores. For example if there was close adherence to a generality of self efficacy and variation around the mean for each item occurred randomly then adding together the initial scores would have neutralised the variation between individuals. Alternatively, if treatment had a simple effect on generality of self efficacy then the variability seen between the summed scores for individuals would be lost in the post-treatment assessments as the respondents all reached the same finishing position. If so the measure would be a blunt instrument, failing to reflect the differences seen between individual patients both before and after their rehabilitation. Its practical value would have been completely undermined. This did not turn out to be the case. Instead, the summation of responses from the 7 self-efficacy items demonstrated a sensitivity to individual differences that was stable on re-test and yet responsive in relation to treatment effects. This finding therefore adds further support against the criticism that the range of items that eventually formed the measure was too
narrow. A narrow measure of self-efficacy would not be expected to demonstrate characteristics of discriminant validity both before and after rehabilitation.

**The Validity of Fear-Avoidance Measurement.**

The reduction of the original fear-avoidance items through factor analysis was even greater than for self-efficacy, leaving only four items linked by the analysis that reflected the theme. These all followed the semantic of a category of activity avoided because of the problem of breathlessness and did not include for example fears about how the illness could be made worse. The treatment model considers how a coping style of avoiding activities that COPD sufferers believe will aggravate their condition leads them into following an over-cautious lifestyle with the loss of activities and social contacts, and consequential declines of physical and psychological well-being. The treatment seeks to correct catastrophising beliefs of this sort, to reduce fear through repeated success experience when confronting the feared circumstances, so that the decline is reversed with improved physical condition, increased social contacts, and emotional support. Measurement was intended to sample the catastrophising beliefs and the avoidance strategy. A substantial number of items were generated which reflected these beliefs and avoidance behaviours in relation to breathlessness, each with individual construct validity based on consultations with patients and therapists. Many of the individual items had the sought-after properties of reliability and sensitivity both to individual differences and to treatment effects. However, only avoidance items, the coping strategy that assumedly results from catastrophising cognitions, emerged as linked. Responses on the other items were evidently independent of each other.

It might be argued that there is a close correspondence between self-efficacy and fear, possibly that these are differing facets of a single dimension construct such as confidence for coping. This might then have been evident in the exploratory
factory factor analysis with an overlap of variables that reflected either self-efficacy or fear-avoidance within a single factor. Also there might have been close correlations between the fear-avoidance and self-efficacy change scores or between the latter and the change score for the HAD anxiety subscale change score. In fact none of these associations were evident to any statistically significant degree in the data. The exploratory factor analysis showed a notable distinctiveness between these categories of variable within the emergent factors and the only correlating change score arose as a negative correlation, between higher anxiety and greater confidence/self-efficacy, i.e. against prediction if there were close correspondence. On this basis it was concluded that the fear-avoidance and self-efficacy constructs could be regarded as distinct.

The lack of correspondence between catastrophising beliefs and avoidance in the findings of the present study does raise doubts about the validity of the fear-avoidance model for respiratory disease. It may be that avoidance behaviour is determined in some way other than through fear of what might happen.

The inclusion of fear-avoidance items was based mainly on findings from the chronic pain rehabilitation literature. Unlike the self-efficacy model, there is no evidence from previous studies of coping with COPD to substantiate links between catastrophising beliefs, avoidance behaviour, and poor coping. A conceptual review of the content of COPD treatment and reflection on the patient experience did nevertheless indicate an important role of fear. The method in this study was to use consultation of those involved in COPD rehabilitation for generating items that reflected fear-avoidance. The theme was therefore predetermined. A more thorough approach to this might have been to draw together characteristic coping beliefs that had been uncovered through qualitative study of coping with COPD, but no examples of this were revealed in the literature review undertaken prior to the study. More recently Nicholson and Anderson (2003) sought the themes of coping and adjustment in reaction to this
illness through a formal qualitative procedure, running 4 focus groups with 20 participants with chronic bronchitis. Their method was of thematic and conceptual analysis following a symbolic interactionist framework. In their discussion of their findings they comment that there were three dominant themes, (1) the physical effects of the disease, (2) the effects on family and social relationships, and (3) emotional reactions, life disruption, and loss of self esteem. They described these as,

"Interlinked around the experience of the disease. That is, the breathing problems which affect basic physical function, but are also linked to fear and anxiety, particularly about exacerbation and the related issue of physical and psychological dependency on medication".

Whilst this does not mirror exactly the assumed processes in the model of fear-avoidance, their interpretation of their findings is a very close fit. The main domains of reaction and adjustment appear to be a function of perceived breathing difficulty, the fear of this, and of future exacerbations. Other symptoms such as fatigue were not raised to the same level of importance. Fear had a mediating role. This is quite different to the previous literature such as the review by Kaplan et al (1993) that conceptualised fear and anxiety as a related disorder, the presence or absence of which was regarded as an outcome rather than a mediating variable in adjusting to COPD.

If the above is taken as further evidence supporting the broad construct validity of fear-avoidance in COPD then other interpretations are needed for the absence of links between catastrophising cognitions and avoidance behaviours in the present study. It is possible that the specific items reflecting catastrophising did not match the individual avoidance items closely enough to produce links in the pattern of responses. Alternatively it is possible that fear-avoidance beliefs that are assessed through a questionnaire measure are less accessible, that the phenomenon is one of disintegrated cognitions producing a more closely linked
pattern of avoidance behaviours, or that the overall influence of fear cognitions is weaker than was expected. The psychometric considerations are discussed further below. The more detailed consideration of the implicit process links within the fear-avoidance model and its relevance for COPD requires further study. The findings of this study, with a pronounced avoidance factor having emerged from the analysis, combined with the pointers from conceptual review both here and elsewhere in the literature, would support further research on the role of fear-avoidance in COPD.

**The Completeness of Standardisation.**

It is raised above that a lack of strength of influence of fear-avoidance beliefs in relation to each other may have led to the absence of wider intercorrelations between these items in the analysis of the questionnaire data. One hundred and nineteen people took part in the third and main stage in the survey when a residual twenty-two items were analysed. In a discussion of the subject numbers required for the statistical methods employed in the present study Tabachnick and Fidell (1996) recommend at least 5 subjects per item. The ratio in this study was better than five to one but nevertheless arguably lacks sufficient power to identify firm but subtle links that may exist in the data.

The next concern regarding the standardisation relates to the loss of clinical details for many of the 119 people in the third stage. The details of FEV₁, shuttle walk, and Hospital Anxiety and Depression Scale scores were only available in roughly half of the sample. This was arguably sufficient to reflect the characteristics of this group of COPD rehabilitation patients and a basic correlation analysis with the other measures. The smaller sample was potentially biased however, the exact reasons for missing data not being known. This also prevented any detailed consideration of the associations between the two coping belief factors and these other clinical variables. It is possible that there are important distinctions to be found between the coping beliefs associated with
varying severity of illness. Another shortcoming was that there was no separate analysis of data for the sexes and no consideration of possible age cohort effects in patterns of coping beliefs. The Cronbach’s alpha analysis showed a satisfactory level of internal consistency for the final shortened measure but a larger sample might have provided a coefficient above 9 that would have supported the use of the 2-factor measure at an individual level as well as for groups of COPD patients. For example the scores for a person could be considered sufficiently robust to be taken into consideration when planning their individual care. Indeed, high scores for fear-avoidance beliefs amongst chronic pain sufferers, where this measurement has been developed, have led to treatment innovations for sub-groups of patients based on their comparatively high scores on a fear-avoidance measure, (Vlaeyen et al, 1995). The measure would, through this stronger standardisation, have achieved a greater degree of clinical usefulness.

The test-retest data in the present study concerned only a small sub-sample and although this produced a positive finding the measure would require a larger sample to support its use for service evaluation. There was no control group of COPD patients in the standardisation who were not receiving rehabilitation. The patients who took part received help from the same therapists who readministered the questionnaires at the end of their treatment. There was therefore no control for the possibility of a social evaluative factor generating a distortion of the improvements that were considered to have been reflected in the post-treatment assessment scores. Respondents may well have sought to amplify the beneficial effects of the treatment in what is seen by them to be a direct and personal form of feedback to those who had been trying to help them. A further step would be to gather the questionnaires with greater anonymity using code numbers for identification and an investigator with whom there has been no therapy contact, as well as comparing this to a control group. In discussing this Bandura (1997a) reviews evidence that demonstrates that experimental effects of
this sort are minimal and do not significantly distort self-efficacy assessment scale results.

COPD symptoms are notoriously variable in their intensity and intrusiveness with, for example, small changes in the weather triggering exacerbations. The stability or variability of coping belief scores through these episodes needs to be taken into account for any further standardisation. Models of self-efficacy and fear-avoidance predict that patterns of coping beliefs would remain stable despite brief symptom flare-ups. Severity of disease does not predict other variables of function or emotional state but this has not been established regarding the coping beliefs data. If an opposite finding emerged, that coping beliefs were led by the severity of the symptoms from one day to the next, then this would have important implications for these models as they apply to COPD rehabilitation treatment.

A more critical issue for the future use of this measure is the definition of clinically meaningful change. The approach adopted in the analysis was to use a standard deviation derived from the initial administration of the measure as a benchmark of clinical significance for the reassessment data. This procedure was discussed by Lunnen and Ogle (1998) following Jacobson and Truax (1991) who recommended that two standard deviations be used as the criterion. Had this been applied in the present study this would have portrayed very few of the participants as having achieved a useful gain on any of the variables, something that is arguably more rigorous but that did not square with clinical experience. The use of one standard deviation allowed a standardised method of comparison between different measures that matched the informally expressed views of patients and therapists about the success of the rehabilitation. This is nevertheless an arbitrary criterion, acceptable if, at the same time, it is accepted that substantial changes are genuinely resulting from the treatment and that this effect is evident on the other outcome measures to a similar degree using the
same criterion. An alternative position is that the consistent sizeable changes seen in the coping beliefs data is no more than a meaningless artefact, perhaps a sense of having had a nice time attending the treatment sessions but no more than this, and that parallel changes on other measures merely reflect the same thing. A more thorough approach would involve patients and therapists separately making quantitative judgements of changes in themselves that have resulted from treatment and then calculating cross-correlations between these and changes in the self-efficacy and fear-avoidance factors and other outcome measures. This would include the quality of life measures discussed in the introduction but not included in the battery of measures in the present study. A different option would be to identify a group of individuals who are agreed by all to have adapted to COPD very successfully. This would provide benchmark scores for successful treatment.

A further issue for standardisation is the maintenance of gains through a follow-up period. The new coping beliefs measure should demonstrate that any longer term changes after the end of treatment are accurately reflected. This is differentiated from other potentially distorting factors such as respondents' drive to be consistent in their responses when completing the questionnaire based on their memory of previous answers rather than reporting their present state. However, the current level of evaluative evidence regarding the impact of COPD rehabilitation and the use of other standardised outcome measures does not include long-term follow-up data.

At the present stage this measure of coping beliefs has considerable shortcomings. The refinements suggested above to complete the standardisation could be expected to produce a more robust measure. To put this in perspective however no other scale reviewed in the introduction to this study, including those recommended by the British and American Thoracic Societies, has been taken to a level of standardisation that includes, for example, breakdown by gender,
sensitivity to treatment effects, and validation against a criterion of clinically meaningful change.

Concluding Comments

The present study concerned the development and standardisation of a coping beliefs measure in COPD. It produced a set of 11 items dividing between self-efficacy and avoidance factors. These have characteristics of validity, reliability, sensitivity to treatment effects, and practical utility, that support the future use of the measure for evaluation purposes. In view of some remaining concerns about standardisation a final stage is now needed in the development of this measure using the 11 items only in the questionnaire, surveying a larger sample, compiling more complete clinical and demographic data for the analysis of sub-samples, including the validation of clinically meaningful change, a control sample for the validation of change, and longer-term follow-up. Although the seven criteria for the study have been achieved this final stage would consolidate the scale for wider use in the evaluation of COPD rehabilitation.

In the wider context of the further development of COPD services this study raises another important issue. This concerns a lack of clarity about the treatment itself. The reports of both the British and the American Thoracic Societies have produced descriptions of rehabilitation treatment and recommended the adoption of a standardised set of outcome measures for evaluating different treatment centres and different treatment processes. It was hoped that this new measure would contribute to this, alongside scales addressing quality of life and exercise performance. This study focussed on coping beliefs because the descriptions of treatment reflected this component but did not include it in outcome evaluation. It was however surprising that there was no unified treatment model to refer to. One potential future step would be to expand the range of coping belief items for the evaluation of the treatment. It might then be possible through regression or path analysis to construct a beliefs model for the process of adaptation to COPD.
To date, the content of rehabilitation has been developing empirically. It has its roots in exercise training. It is frequently represented in the clinical literature as an amalgam of discrete components of exercise, education and support. It might be held that the treatment is unified by biopsychosocial themes but there is no explicit adherence to any psychological model.

The literature has repeatedly demonstrated that biological markers do not predict adaptation to chronic and incapacitating illnesses, (e.g. Rejeski et al 2000, regarding COPD). Browne (1990) went further in demonstrating how, across different conditions, service utilisation including hospitalisation was more strongly linked to psychosocial variables than disease severity or prognosis. Health psychology has embraced the development of theory that seeks to integrate and explain these variables. The description of COPD rehabilitation reflects psychological themes of threat, disruption, and loss in relation to chronic illness; individual differences in knowledge, appraisal, motivation, behavioural responses, and emotional distress; the processes of learning, reappraisal, restoration of confidence, and perceived control, during therapy; and the outcome aims of improved morale and functioning. These might be interpreted through one or several of the broad-base models of health psychology. Self-efficacy theory occupies a corner amongst a group of theories of social cognition such as the Transactional Model of Stress and Coping set out by Lazarus and Folkman (1984), Leventhal's Self Regulation Theory (1980), the Health Belief Model (Becker, 1974), Health Locus of Control (Walleston and Walleston, 1984), and Readiness for Change (DiClemente and Prochaska 1998). Each of these models is reflected in some way in the given descriptions of COPD rehabilitation. These can be distinguished from one another in terms of the predictions they make for the processes and outcomes of intervention. They offer a means of clarifying an overall model of COPD rehabilitation.
Returning to the role of evaluation, in a critique of assessment measures Williams (1996) pointedly comments that an assessment tool must directly address the goals of the treatment, otherwise it is of no practical use, no matter how reliable and how widely-used. At present the treatment goals of COPD rehabilitation are not clearly defined under a single integrated model of care. In the push to establish a single agreed set of outcome measures for COPD rehabilitation it is conceivable that the result will be a patchwork of different scales drawn together to reflect different treatment components. This is not a flaw in the measurement tools however. These can no more than correspond with the patchwork protocol of treatment that currently prevails. If patchwork evaluation is the result then this will do little to help advance the understanding of the treatment process. There remains a strong case for completing the final steps in developing this measure. Robust measurement of coping beliefs in COPD is needed, but this would be at the risk of putting the cart before the horse. There is a more important priority. A clearer definition of COPD rehabilitation, based on psychological models of adaptation, should be the lead.
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APPENDICES

Appendix 1: the questionnaire

The raw scores for questions 14, 15, 17, 22, 23, are reversed.
The coding label is noted against each question.
COPD ATTITUDES SURVEY

Frenchay Hospital

Bristol
Name: _______________________

These questions are about everyday life effects that sometimes occur with lung disease. Please try to answer all the following questions by placing a circle around a number on the scale.

In general how confident are you to bring a breathlessness attack under control?

0 1 2 3 4
Not at all confident Very confident

Now try the following by considering how you have been feeling over the last week:

At the moment, how confident are you that you can manage breathing difficulties:

1. When becoming stressed or upset.

0 1 2 3 4
Not at all confident Very confident

2. When in a smokey or polluted atmosphere e.g. traffic fumes.

0 1 2 3 4
Not at all confident Very confident

3. When physically exerting myself.

0 1 2 3 4
Not at all confident Very confident

4. When socialising with friends or family.

0 1 2 3 4
Not at all confident Very confident

5. When alone.

0 1 2 3 4
Not at all confident Very confident

6. When in a hurry or under pressure.

0 1 2 3 4
Not at all confident Very confident
Now indicate how confident you would be about managing the following:

7. How confident are you that you can walk for a full 5 minutes at your own pace?
   
   0 1 2 3 4
   Not at all Very confident
   confident

8. How confident are you that you can walk for a full 15 minutes at your own pace?
   
   0 1 2 3 4
   Not at all Very confident
   confident

9. How confident are you that you can successfully climb 5 steps?
   
   0 1 2 3 4
   Not at all Very confident
   confident

10. How confident are you that you can successfully climb a flight of stairs (that is a minimum of 12 steps) ?
    
    0 1 2 3 4
    Not at all Very confident
    confident

Now indicate how much you agree with each of the following statements:

11. Despite my condition I can lead a normal life.
    
    0 1 2 3 4
    Strongly Agree
    Strongly
    Disagree

12. Just because something makes me breathless does not mean it is harmful.
    
    0 1 2 3 4
    Strongly Agree
    Strongly
    Disagree

13. Physical activity will make my condition get worse in the longer term.
    
    0 1 2 3 4
    Strongly Agree
    Strongly
    Disagree

    
    0 1 2 3 4
    Strongly Agree
    Strongly
    Disagree
15. I always need someone with me in case I have an attack of breathlessness.

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16. I can prevent my condition from worsening by avoiding activities that make me breathless.

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17. I avoid anything which might cause an attack of breathlessness.

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18. I can’t do a lot of the things normal people do because it’s too easy to lose control of my breathing.

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19. I would **not** be embarrassed if I became breathless in the company of friends.

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20. I would **not** be embarrassed if I became breathless whilst out shopping.

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21. I would not start something if there was a chance that I would have to stop before finishing it because of breathlessness.

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22. I am fearful about becoming breathless when asleep.

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</table>
As a result of my lung condition I am either unable to, or always avoid:

23. Going out.

0 1 2 3 4
Strongly Agree

24. Doing housework.

0 1 2 3 4
Strongly Agree

25. Going shopping.

0 1 2 3 4
Strongly Agree

26. Being away from easy access to medical help.

0 1 2 3 4
Strongly Agree

27. Socialising with friends.

0 1 2 3 4
Strongly Agree

28. Travelling away from home for more than a day.

0 1 2 3 4
Strongly Agree
Appendix 2: Item analysis histograms

SEGENCN2

SEUPSET2

SESMOKE2

SEANGRY2

SEEXERT2

SESOCIA2

117
CAHARM2

Frequency

0.00 1.00 2.00 3.00 4.00

CAMAJNT2

.00 1.00 1.50 2.00 3.00 4.00

CALONGE2

Frequency

0.00 1.00 1.50 2.00 3.00 4.00

CAWITHM2

2.00 3.00 3.50

CAAVOID2

.00 1.00

CAMIGHT2

2.00 3.00 3.50

119
### Appendix 3: Test-Retest Reliability of Individual Items

Pearson’s r correlation coefficient matrix (N=27)

|        | Segencn2 | Seupset2 | Sesmoke2 | Seangry2 | Seexert2 | Sesocia2 | Serest2 | Seweath2 | Seinfec2 | Sealone2 | Sehurry2 | Canorma2 | Cailong2 | Caharm32 | Camaint2 | Cawithm2 | Canvoid2 | Canight2 |
|--------|----------|----------|----------|----------|----------|----------|---------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|
| Segencn2 | .77 *     |          |          |          |          |          |         |          |          |          |          |          |          |          |          |          | .50      |          |
| Seupset2 |          | .82 *    |          |          |          |          |         |          |          |          |          |          |          |          |          |          |          |          |
| Sesmoke2 |          |          | .82 *    |          |          |          |         |          |          |          |          |          |          |          |          |          |          |          |
| Seangry2 |          |          |          | .66 *    |          |          |         |          |          |          |          |          |          |          |          |          |          |          |
| Seexert2 |          |          |          |          | .67 *    |          |         |          |          |          |          |          |          |          |          |          |          |          |
| Sesocia2 |          |          |          |          |          | .55 *    |         |          |          |          |          |          |          |          |          |          |          |          |
| Serest2  |          |          |          |          |          |         | .60 *   |          |          |          |          |          |          |          |          |          |          |          |
| Seweath2 |          |          |          |          |          |          |         | .75 *    |          |          |          |          |          |          |          |          |          |          |
| Seinfec2 |          |          |          |          |          |          |         |          | .61 *    |          |          |          |          |          |          |          |          |          |
| Sealone2 |          |          |          |          |          |          |         |          |          | .74 *    |          |          |          |          |          |          |          |          |
| Sehurry2 |          |          |          |          |          |          |         |          |          |          | .57 *    |          |          |          |          |          |          |          |          |
| Canorma2 |          |          |          |          |          |          |         |          |          |          |          | .12      |          |          |          |          |          |          |          |

* Denotes statistical significance at the .05 level.
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Appendix 4: Exploratory Factor Analysis

Communalities

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Extraction Method: Alpha Factoring.
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Extraction Method: Alpha Factoring.
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Extraction Method: Alpha Factoring.
a Attempted to extract 6 factors. More than 25 iterations required. (Convergence=.002). Extraction was terminated.
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# Factor Correlation Matrix

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### Appendix 5: Confirmatory Factor Analysis

#### Communalities

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Extraction Method: Maximum Likelihood.
## Total Variance Explained

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Extraction Method: Maximum Likelihood.

- When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.
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Extraction Method: Maximum Likelihood.

a 2 factors extracted. 4 iterations required.

### Goodness-of-fit Test

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a Rotation converged in 4 iterations.

### Structure Matrix

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Appendix 6: Factor Analysis: the Post-Treatment Questionnaire Data
(N=94)

KMO and Bartlett's Test

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Communalities

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Extraction Method: Alpha Factoring.
### Total Variance Explained

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Extraction Method: Alpha Factoring.

a When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.
Appendix 7: Item Analysis Of Post Treatment Questionnaires

![Graphs showing item analysis results for different categories]

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PROFESSIONAL DOSSIER

Curriculum Vitae: Nicholas Ambler

Current NHS Post:

Head of Service, Clinical Health Psychology, (Critical Care and Surgery Directorates)
Frenchay Hospital,
North Bristol NHS Trust,
Bristol BS16 1LE

Main areas of clinical practice:

The organisation and provision of inter-disciplinary pain management programmes, psychological assessment and intervention in physical trauma (mainly burns and orthopaedic injury), specialty lead for cancer care (mainly supporting surgery and palliative care services).

Qualifications:

M.Sc. Clinical Psychology, University of Newcastle upon Tyne, 1983
B.Sc. (Hon.s) Psychology, University of Newcastle upon Tyne, 1977

Membership of Professional and other relevant organisations:

British Psychological Society, (Chartered Clinical Psychologist)
Division of Clinical Psychology
Division of Health Psychology

Member of the Pain Society, British and Irish Chapter
Member of the International Association for the Study of Pain (IASP)

Member of British Burn Association (BBA)
Summary of Previous Posts

1989 - current post as above, B Grade Clinical Psychologist, North Bristol NHS Trust

1987 - 1989 Principal Clinical Psychologist, Glenside Hospital, Frenchay District Health Authority

1986 - 1987 Senior Grade Clinical Psychologist, Glenside Hospital, Frenchay District Health Authority

1985 - 1986 Senior Clinical Psychologist, Nottingham Health Authority

1983 - 1985 Basic Grade Clinical Psychologist, Nottingham Health Authority

1981 - 1983 Probationer Clinical Psychologist, Northern Regional Health Authority

1978 - 1981 Graduate Research Worker, South East Kent Health District

1977 - 1978 Research Assistant, University of Newcastle upon Tyne

Summary of Post-Qualification Clinical Experience

During the first 3 years I held a post in the Nottingham clinical psychology department headed by Professor David Smail. The main areas of experience were in working in one of the first community psychiatric teams to be established nationally and then developing a similar protocol for a new sector team serving Nottingham North. I undertook training in the Nottingham Psychotherapy Unit (Director: Dr Mark Aveline). I undertook teaching and provided supervision for the trainees of the Leicester University clinical psychology training course.
My first post in Bristol in 1986 comprised sessions in 3 GP health Centres serving a 30,000 catchment, supporting an acute psychiatric admission unit, and a psychotherapy day hospital. The main role however was to develop clinical psychology in Frenchay General Hospital one day a week. This developed in 2 main areas, the pain clinic and the regional burns and plastics unit. It led to the full time establishment of my post in Frenchay in 1989. I was also able to negotiate the establishment of a pain management programme in 1989 that was amongst the earliest examples in the NHS.

In 1992/3 a Winston Churchill Fellowship enabled me to undertake a series of visits to burns units and pain management centres in the USA. In 1994 I was able to negotiate a three-fold expansion of the PMP at Frenchay. I also joined James Partridge and Nichola Rumsey in helping to set up a specialist disfigurement support unit at Frenchay Hospital funded initially by Changing Faces. In 1997/8 successful completion of this project led to NHS funding of a service that became known as Outlook. During this period I became involved in a number of service innovations in the treatment of breast cancer including the development of a ‘one-stop clinic’ and a new role for breast care nurse specialists. The role of specialist nurses has been a continuing interest and has led to posts developing in the adult burns unit and more recently in the intensive care unit. I am currently involved in supervising nurse specialists in each of the services above and in developing and coordinating supervision for nurses in palliative care and site-specific cancer teams.

More recently I have been involved in supporting a pulmonary rehabilitation team who have transferred their service to my department base. The pain management programme has extended to community bases, to providing secondary preventive treatment for people with recurrent acute back pain, and in setting up a multi-agency service helping chronic pain sufferers return to work, funded by the Department of Work and Pensions. I have also been closely involved in the establishment of a clinical coordinating network for the treatment of chronic fatigue/ ME as part of a Department of Health initiative.
This has involved joint working with other local stakeholder groups including PCTs, paediatrics, Action for ME/Westcare, and the ME Association.

I currently manage a department comprising psychologists, physiotherapists, occupational therapists, and support staff, numbering more than 20 people.
Summary of Academic/Research Background. (Post Graduation)

Research Assistant (1977 - 78), Evaluation of Proprioceptive Disturbance in Parkinson's Disease.
Dept of psychology, Univ Newcastle Upon Tyne

Graduate Research Worker and Honorary Researcher, Health Services Research Unit, University of Kent and Canterbury (1978 - 81). A Randomised Control Trial Evaluation of Stroke Rehabilitation comparing a specialised Stroke Unit with usual care in District General Hospitals. This project also included published research on a district register of stroke: incidence and mortality. Funding was from a SE Thames Region locally organised research scheme (LORS) grant. The findings were published in two reports in Age and Ageing in 1982 and 83 and as a chapter in the book “Recent Advances in Stroke Research, Vol II”.

Honorary Lecturer, the Professorial Unit, Department of Psychiatry, University of Nottingham Medical School, Mapperly Hospital, Nottingham. This post involved clinical psychology modules to third and fourth year medical students and supporting research projects in the unit.

Honorary Lecturer, Dept Psychology, University West of England (1988 - )

Joint lead investigator with Nicola Rumsey in a 2 year sponsored comparison of an advocacy role vs supportive counselling provided by breast care nurse specialists to women at the time of breast cancer diagnosis. (Publ. Journal of Advanced Nursing 29 (2) pp 445-53.

Winston Churchill Trust Fellow (1993) Awarded WCT fellowship to study pain management in specialist US centres. This was presented to the 2nd National Conference on Pain Management Programmes, Univ of London, 1994
Joint Coordinator of Research Project: "Evaluation of a One-Stop Breast Lump Clinic: A Randomised Controlled trial". (Publ. The Breast 7(6) pp 314-19). This three-year project was funded by a regional research and development grant 1994-97.

Clinical lead in the evaluation of a specialist disfigurement support unit, 1994-7, sponsored by the Nuffield Hospitals Foundation and 'Changing Faces'. This was published as a Nuffield Foundation report in 1998.

Joint PhD supervisor to a research trial conducted by Diana Harcourt evaluating the illness representations of women undergoing breast reconstruction following mastectomy. (Publ. Psychology, Health and Medicine (1999) 4(1) pp 57-71)

Second centre coordinator in a 2-centre trial of the effectiveness of a combined pain management programme and vocational guidance course in returning back pain sufferers into work and training. This project was led by Paul Watson, Dept of Behavioural Medicine, Salford Royal Hospitals Trust, sponsored by the National Disability Development Initiative and published in 2000.

Currently Member of a Project Team for a Randomised Controlled Trial Evaluation of Out-patient cognitive behavioural treatment for chronic fatigue syndrome (2000 - 2003). This is funded by the NHS Health Technology Assessment Programme. The final report will be published in 2004.
Service Appraisal:

The North Bristol NHS Trust Pain Management Programme

This report concerns the care provided in the Pain Management Centre for patients who are suffering with chronic pain conditions. This service is part of North Bristol NHS Trust and the majority of work is undertaken with patients referred by the Pain Clinics at Frenchay and Southmead Hospitals. The purposes of this appraisal are to consider the characteristics of patients being referred, the uptake of treatment and attrition, the effectiveness of interventions, and indicators of patient satisfaction. The findings are discussed in relation to NHS priorities and the implications for future audit of the service.
**Background and Milestones**

The emergence of a psychologically based rehabilitative treatment for chronic pain sufferers has its origins in the United States and in particular the work of Wilbert Fordyce, (eg Fordyce 1968) in Seattle. The outline of this was set down in the late 1960's but it was not until the 1980's that there was a wide scale development of treatment centres in the US. These were funded mainly by worker compensation insurance. A comparable development of U.K. National Health Service based pain management programmes (PMPs) then took off in the mid-1990s. When it did so this was with the emphasis on restoring functional capabilities and confidence for coping rather than return to work. These programmes were attached to general hospital pain relief clinics. They were also often linked to orthopaedic surgery departments.

PMPs aim to help people to accept and to effectively self-manage a chronic condition, bringing an end to a cycle of fruitless specialist investigations and treatments. It became possible to agree a discharge from specialist care with people who still had chronic pain. Previously patients were often left feeling dissatisfied with the outcome of no cure. They would then look for other sources of help elsewhere. At the end of PMP treatment the pain is still present but patients felt better equipped to cope and get on with life despite the pain. For this reason the level of satisfaction patients feel with their treatment is a particularly important aspect of the outcome of care.

During the past 15 years there has been an increasing evidence base supporting the effectiveness of PMP treatment. Systematic reviews, (e.g. Flor et al, 1992, Morley et al 1999) have added weight to this. Department of Health sponsored reports e.g. the Clinical Standards Advisory Group Reports in 1994 and 1999, have recommended that access to PMPs should be available to NHS patients through every general hospital and access should be timely, before an ineffective coping response becomes entrenched.
The development of a PMP in North Bristol began in 1989 with an agreement between Southmead and Frenchay Healthcare Trusts to set up a joint service. Patients were referred to the psychologist in one of the respective Pain Clinics in each hospital. If deemed suitable they would take part in an out-patient programme run by the two psychologists, a physiotherapist and an occupational therapist.

The format was for eight patients to participate in a course running for three hours, once a week for eight consecutive weeks. This was always preceded by an assessment process of roughly four hours that was repeated at the end of each course. Sixty percent were deemed suitable for the PMP. Funding permitted three courses to run in a year. There was very limited scope for individual psychological intervention and no individual physiotherapy.

Following the publication of the CSAG Back Pain Report (1994) Avon Health Authority commissioned an expansion of this PMP. The same format continued for nine courses instead of three and the patient capacity rose from approximately 50 to approximately 150 referrals a year. Three teams were established to run group courses. The service also diversified. A new course was set up which took referrals directly from G.P.s. This was aimed at the secondary prevention of chronic low back pain for patients believed to be at high risk. This became known as Back Pack. The expansion of the service also permitted individual help to be provided for people unable or unsuitable to join a group course. More recently a further waiting list initiative enabled a fourth PMP team to be established.
The Current Service

The core activity is of the PMP is to provide comprehensive pain management assessments and group treatment programmes. Supplementing this there are individual treatments, preventative group treatment known as Backpack, research projects, and joint assessment clinics with the pain consultants. There are now 21 members of clinical and administrative staff.

The majority of referrals come from the Southmead and Frenchay Pain Clinics with a third now coming from G.P.s and the extended scope practitioner (ESP) physiotherapists working in orthopaedics and neurosciences. PMP psychologists now run joint sessions with the pain consultants for patients explicitly referred to the pain service for the PMP. Joint consultations have helped both to rationalise and to speed up the management of patients following this pathway.

The PMP has reached its fourteenth year. It has developed far beyond the original small team that ran three groups a year. Where previously the title The Pain Management Programme meant only the group courses, this now refers to all the activities carried out by the team. Someone being referred to the PMP can now expect a more flexible and sophisticated package of care where previously there was a single track. In the past assessments revolved around the decision of whether or not a person was suitable for a group. There was usually a ten to twelve month wait before assessment and then only one treatment option to consider at one venue. There are several different care pathways that they might follow. Patients receive written information at successive stages and they have the opportunity to attend open meetings about treatment being offered to help their decision about whether or not to participate.

The Care Pathway

The pathway through to a PMP group is shown in Fig 1. If, in the judgement of the pain clinic consultant, a person with intractable pain is a suitable candidate
for the PMP they will refer. They select those people who are inordinately distressed or fearful, who have been unable to adapt in everyday life, or who have adopted self-defeating reactions to chronic pain, for example, repeatedly provoking flare-ups through over-exertion. Other selection characteristics are over-dependence on drugs and an adjudged failure to remobilise, perhaps unnecessarily relying on a wheelchair or crutches.

There is then an individual meeting with a psychologist. This usually lasts about an hour and a half, leading to a provisional decision about treatment. If this decision is to prepare for a PMP group the next step is to attend a meeting where the treatment is explained in more detail. This is called an opt-in meeting because at the end each person will decide if they would like to join a group course. If they decide in favour then there is further assessment with the PMP team. A final decision is then taken during a case review meeting.
Fig. 1: The Referral Pathway to the Pain Management Programme
What happens in a PMP group?

Between 8 and 12 people start each course. They plan specific changes they would like to make. These are to improve how they cope with their pain in everyday life, perhaps increasing how far they can walk or increasing their role in the running of the household or rebuilding an aspect of social life and leisure interests. The process of setting realistic goals and then solving the problems thrown up when trying to achieve these takes up a substantial proportion of the timetable. There is an exercise and stretch programme. This is conducted for the group as a whole but is worked out for each person separately, taking account of the profile that was built up during the individual assessment appointments. This part of the course aims to improve fitness, range of movement, posture and physical endurance as well as raise confidence for physical exertion.

Participants build up a better knowledge of the different effects of chronic pain, how decline can occur, how to combat the disruption of sleep and the effects on mood, temperament and self-confidence. Stress and depression often arise as effects of living with pain. They learn how to reduce the risks of a pain flare-up and better ways of coping when these do occur. The medical management of chronic pain is discussed with one of the pain clinic consultants. This covers the reasoning behind nerve blocks and surgery. The limitations of scans and X Ray investigations are explained as well as the reasons for the different types of medication used for relieving chronic pain. Prescribed drugs present a dilemma because many chronic pain sufferers resent having to rely on these but nevertheless regard them as a valuable means of controlling their symptoms. Only a few people decide to stop their drugs altogether but many try to cut these back during the course.

Relationships with health professionals, personal relationships and sexual difficulties related to the pain are also covered. This latter issue is particularly sensitive and is usually discussed individually with those who request help. Each course includes two separate meetings for partners to inform them about
pain management, and to address their own concerns about living with chronic pain.

Meetings take place following the original format of once a week for three hours over eight weeks. By the end of the course the expectation is that those who complete it will have grown in confidence for coping with their condition, that they will be less reliant on medical help, that they will move more freely and, by judging their limitations better, will have improved their quality of life. Each person completes an individual reassessment.

There is then a follow-up meeting 6 months later when some of the assessment measures are repeated. This is the stage when most patients are discharged, having also covered how and when to make contact with the PMP again should this be needed.
Evaluation

The purpose of this evaluation is to examine PMP group treatment. An evaluation of the secondary prevention programme known as Backpack is not dealt with in this report, nor is the range of individual treatments. The demand, the objectives, the components of treatment, and patients' satisfaction with care are each examined. Some comparisons are made with data for an earlier stage in the development of the service, from 1994-7.

Measurement

The methods used to evaluate the outcomes of PMP treatment comprise self-assessment measures and observed functional assessment, all of which are standardised and widely used in other pain centres. The range of measures is shown by category in Fig. 3. A pain intensity measure is included as a monitor of an important variable but this is not expected to change significantly. The main targets of the treatment are pain-related beliefs, functioning, pain-related distress, and the effects of pain on quality of life. The only health care resource effect to be included is the use of prescribed medications. These measures are initially administered individually by qualified assessors before the start of the course, secondly within three weeks of completion, and finally at a six month follow-up.
Figure 3 - The PMP Evaluation Plan

**PAIN LEVEL**
Visual Analogue Scales

**SELF CONFIDENCE FOR COPING WITH PAIN**
Pain Self-Efficacy Questionnaire (Nicholas, 1989)
Tampa Scale Of Kinesiophobia (Koo, Miller & Todd, 1992)

**PSYCHOLOGICAL DISTRESS**
Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

**PHYSICAL PERFORMANCE**
Chronic Pain Assessment Procedure (Harding et al, 1994)

**USE OF MEDICATIONS**

**QUALITY OF LIFE**
Sickness Impact Profile (Bergner et al, 1981)

**SATISFACTION WITH TREATMENT**

**SPECIFIC COMPONENT OUTCOME MEASURES**
Findings

There are four aspects to the data:

- A headcount of people going through the service
- Their background characteristics
- The changes that take place through treatment
- The views expressed by patients about their experience of the service.

The data reflects what has happened between 1st October 1997 and 31st March 2002. It can be compared with previous data for the period 1994-7. Notable differences are discussed as they arise. The main findings are summarised below with reference to a more detailed summary of the data included in appendix 1.

How many people are referred and what happens afterwards?

Overall the two pain clinics have sent 680 referrals over 4 ½ years. This is a rate of approx. 150 people a year. The attendance rate at the first appointment is 91%. The throughput after the first appointment is shown in Fig. 4. Nearly two thirds went on to join a PMP group. There are 23% who were treated individually and most of the remainder decide against further treatment because it is felt not to be needed, or is not at the right point in time for them, (many defer to a later date).

There are trends that underlie this. The number of referrals has risen steeply in the last two years and now stands at 200 per annum. Also, the proportion of referrals for individual therapy has risen and now stands at 33%, probably because of the increased availability of physiotherapy. There has therefore been a drop in the proportion going into a PMP group. A commentary on the throughput with additional data is included in appendix 1.
What are the characteristics of the patients?

The gender ratio is 42% male to 58% female. The age range is shown in Fig. 5. The average age is 46 years. Three quarters live with a partner, much the same as in general population. On average the people joining the groups have been suffering with pain for 8 ½ years, one in four having had the problem for more than a decade.
Other findings from the initial assessment show that only 4% do not take medication whilst more than half are taking at least three different kinds of prescribed drug in relation to their pain (Fig. 6). In a five-minute walking test the average distance covered by patients in their assessment was 150 metres. A standardised measure of distress, the Hospital Anxiety and Depression Scale, (HADS), indicated that 45% were clinically depressed and 58% had serious anxiety symptoms. Although these data resemble the previous findings for patients referred between 1994 and '97 there is a difference in the severity of symptoms. Patients referred '97-'02 were in greater difficulties. The proportion categorised by HADS as having clinically significant symptoms in the earlier sample was 28% for depression and 41% for anxiety. For the worst category of self-efficacy beliefs, (a score in the range 0-9), the proportion was only 5% 1994-7, but almost 25% for '97-02. This is illustrated in the appendix 1(c) figure 7 and is discussed further under the outcomes section below.
Figure 6: Number of pain related medications taken by PMP group participants at assessment
October 1997 – March 2002 n=369

Figure 7: Attendance at PMP groups: October 1997 – March 2002 n=369.
Completion of the PMP groups

The data for attendance over the eight meetings of each course show that only 4% drop out at the beginning. Many have to miss a meeting for various reasons but eight out of ten managed to attend at least six of the eight sessions (Fig. 7). This is an improvement on the previous three years' data when 75% of people completed at least six sessions but roughly 20% failed to complete more than three sessions, a figure which is now less than one in ten.

What are the outcomes of PMP groups?

The outcome data covers only those people who completed an individual assessment both before and after their treatment. This number, roughly 275 people, varies a little from one measure to the next because the data was collected in clinics where patients occasionally have to miss out part of the assessment for practical reasons such as the timing of their transport arrangements. The main questions are considered below with additional data presented in appendix 1.

Does the pain change?

The PMP therapists repeatedly remind patients that they do not expect a change of pain intensity as a result of the treatment. When patients were reassessed and asked to reflect on this (Fig. 8) there appears to have been a very small improvement in the average of pain ratings. It is in the nature of chronic pain that the intensity will often vary from one day to the next. The physical demands of the course can aggravate pain but on the other hand if the objective of improving the pacing of activities is successful then there would be fewer pain flare-ups and we would expect a lower average pain rating. Looking into the data in more detail we found that one in ten patients indicated a substantial* deterioration, one in five a substantial improvement of their pain.
Figure 8: Mean change in pain rating following a PMP group: October 1997-March 2002 n=260.

Overall, has your pain changed?

- a substantial change defined as 0 – 33 or 67 – 100 ratings on a 0 – 100 scale where 50 = no change.

Do patients reduce the amount of drugs they are taking?

The assessing clinicians were asked to make an overall judgement about whether medications had reduced, stayed the same, or increased by the end of the programme (Fig. 9). This takes account of the strength of the drug and encompassed several different kinds of drug including for example, analgesics and anti-depressants, as long as the prescription related to the chronic pain. Six out of ten people were adjudged to have made a reduction; only one in 33 increased their drugs. Combining this finding with the pain ratings it appears that it is possible to achieve an overall net reduction of medications without the pain getting worse as a result.
Figure 9: Prescribed medication change after treatment: October 1997 – March 2002 n=246.

Is there evidence of improved confidence for coping with chronic pain?

The beliefs and fears a person has about coping with their pain are a main concern of the therapists. They aim to build a greater sense confidence and independence. The measures that assess this are the pain self-efficacy questionnaire (PSEQ) and a scale of fears about exertion, the Tampa Scale of Kinesiophobia (TSK). The data for these measures is shown in Figs. 10 & 11. High PSEQ scores (40 or more), reflect a high level of coping. The proportion of people in this high level category rises from 6% before treatment to almost 35% afterwards. The TSK reflects a specific aspect of coping beliefs, the fear that physically trying to do more will cause worse pain, an idea that the treatment tries to expel. Lower scores on this measure depict better coping. Again, there has been a conspicuous shift to the lowest fear category by the end of the treatment.
Therefore, by the end of treatment, participants see themselves as coping far better with their pain.

Figure 10: Pain Self-Efficacy Questionnaire scores before and after PMP groups: October 1997 – March 2002 n=276. (Higher scores reflect better coping)
Figure 11: Tampa Scale of Kinesiophobia scores before and after PMP groups: October 1997 – March 2002 n=273. (Higher scores reflect increased fear of exertion)

Are people less distressed?

Improved confidence for coping with pain should relieve psychological distress. The measure used to assess this is the Hospital Anxiety and Depression Scale (HADS, Figs. 12 & 13). This sets out three categories with cut-off scores to reflect clinical caseness. By the end of the treatment the number of people categorised as clinically depressed has more than halved, dropping from 46% to 21%, whilst for clinical anxiety it is reduced from 58% to 33% of the sample.
Figure 12: HADS Depression Scale scores before and after PMP groups:
October 1997 - March 2002 n=277

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<td>20%</td>
</tr>
<tr>
<td>8-10 (borderline)</td>
<td>40%</td>
<td>50%</td>
</tr>
<tr>
<td>11= (caseness)</td>
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% of Patients
Figure 13: HADS Anxiety Scale scores before and after PMP groups: October 1997 – March 2002 n=277.

Do patients show change on the physical performance measures?

The data shows there to be an increased level of performance on each of four measures of timed observed activity, (Figs. 14-17). Unfortunately this aspect of the assessment may be misleading. In every group there are some people who are fearful about movement. They lack fitness and it is hoped that by the end of the treatment they will have increased what they are physically able and prepared to do. On the other hand there are some patients who habitually over-exert themselves, running the risk of a pain flare-up. The aim for them is to learn to restrain this tendency. For them the retest scores on physical performance measures should be lower rather than higher. Unfortunately the data cannot be divided between these separate groups. The data nevertheless shows increased performance of the four tasks.
Figure 14: Mean duration of arm raise before and after PMP groups: October 1997 – March 2003 n=289.

Figure 15: Mean number of 'sit-to-stands' in one minute before and after PMP groups: October 1997 – March 2003 n=287.
Figure 16: Mean number of 'step-ups' in one minute before and after PMP groups: October 1997 – March 2003 n=278.

Figure 17: Mean distance walked in 5 minutes before and after PMP groups: October 1997 – March 2003 n=279.
**Does the treatment improve quality of life?**

The measure chosen to reflect the range of consequences that chronic pain has on everyday life activities is the Sickness Impact Profile (SIP). It comprises 137 items in 12 subscales. These cover for example, mobility, independence in self-care, alertness, strain in relationships, social/leisure activities and effects on work. There is a single global disability score on this measure (Fig. 18) that again shows a notable improvement by the end of treatment. A more detailed breakdown of all SIP subscale scores is included in appendix 2. This also includes a comparison of all the mean scores for each measure before and after treatment.

**Figure 18: Sickness Impact Profile mean total score before and after PMP groups:** October 1997 – March 2003 n=285. (Higher scores reflect increased disability).
How significant are these differences?

Each of the measures shows a difference by the end of the treatment but how can these findings be interpreted? Statistical analysis considers the possibility that the results have occurred purely by chance. The findings summarised in appendix 1 table 1 show statistically significant differences (t test, p<0.001) between pre- and post treatment mean scores on each of the variables included in the outcome variables. These results also replicate the previous findings for the 1994-97 data.

A statistically significant improvement is not necessarily one that a patient or a practitioner would regard as worthwhile. Another more stringent method used to consider clinical significance is to calculate how many people change by at least one standard deviation, as derived from the pool of assessment data for each measure. Using this criterion the number of people who improved, deteriorated, or stayed the same against each measure is shown in Fig. 19. With the exception of the five minute walk, between a third and half of patients achieved this degree of improvement or better on each measure. There were a number who deteriorated on each measure as well, but this proportion was negligible.

As noted earlier, the data for the five-minute walk includes a group for whom a reduced score at the reassessment is seen as a good outcome. This is a potential explanation for the different balance of proportions on this measure.
Figure 19: Percentage of PMP group patients whose performance changes by a standard deviation on outcome measures: October 1997 – March 2002.

Do people who have finished a PMP group feel satisfied with their care?

There are a number of criticisms that are levelled at ratings of patient satisfaction. People are generally reluctant to criticise their NHS carers and may sometimes express satisfaction even when no useful change has been achieved by a treatment (e.g. Picker Institute, 2002). Also, there are no measures of satisfaction that have been standardised for use in the care of chronic pain. Nevertheless, a high degree of user-satisfaction with care is a main objective of the treatment, particularly in view of the frustrations many have experienced with their previous treatments that failed to achieve a cure for their pain. The method adopted here for reviewing patient satisfaction has been to ask questions about the different components of the experience of care and the impact this may or may not have had. This draws out specific feedback and also brings to mind the full scope of
the course for the four global questions about satisfaction with care at the end of the questionnaire (Fig. 20). The full questionnaire data is included in appendix 2. As can be seen in the overview ratings patients’ satisfaction with care appears to be high.
Figure 20: PMP group patient satisfaction. October 1997 – March 2002.

Overall, have you found the Pain Management Programme helpful?

Looking back, do you feel the programme:

Overall, how satisfied are you with the way in which you have been treated in the pain management programme?

Overall, were the therapists encouraging?
Are the benefits of this treatment sustained?

The follow-up meeting for a PMP group takes place roughly six months after the end of the weekly sequence of eight meetings. This is used as an update on progress reflecting on each person's long-term goals as well as discussing any new problems. Two of the brief assessment measures are completed again, the Pain Self Efficacy Questionnaire and the Hospital Anxiety and Depression Scale.

Approximately 60% of people completed this follow up assessment and the findings are shown in Figs 21 & 22. Some fallback from the original gains can be seen but the data still shows a significant improvement sustained at the follow up stage when compared with pre-treatment scores.

![Graph showing changes in Pain Self Efficacy Questionnaire mean scores over time.](image)

**Figure 21:** Pain Self Efficacy Questionnaire mean scores before and after PMP groups and at 6 month follow up: October 1997 – March 2002 n=156.
How do these outcomes compare with the previous findings?

As noted earlier the level of problems portrayed through these assessment measures has been greater for this cohort compared to 1994-7. Despite this the outcomes are closely similar. Mean scores comparing the two data sets are illustrated in table 5 of appendix 1(c). Figures 5, 6 and 7, show how the proportion in the worst scoring category of the distress and pain beliefs measures reflects a greater degree of improvement in the 1997-02 cohort. Using the same method for calculating ‘clinically significant’ change as above the two sets of outcome data are compared in fig 23 below. The self-efficacy measure scores show slightly greater gain for the 1994-7 cohort but on all other measures the ’97-’02 gains are greater. This suggests that the PMP groups have been achieving greater benefit for patients as time has passed.
Figure 23: Comparison of clinically significant change on outcome measures: 1994-7 and 1997-2002 cohorts

Change of one standard deviation

0% 20% 40% 60% 80% 100%

- Improvement
- No Change
- Worse
Discussion

The original reasons for compiling these data were to monitor demand, to form a profile of patient characteristics, and to consider evidence for the effectiveness of the treatment. The data for the PMP groups is detailed. It is closely comparable to previous data for an earlier period in the development of the service. Nevertheless, this has taken a large investment of time and there is no control data to show what would have happened if patients had not had PMP treatment.

Further support for the above findings can be found in the literature. A randomised controlled trial, (Williams et al 1995) carried out in a very similar NHS setting using a closely similar model of treatment and outcome measures, produced very similar results both in terms of the characteristics of the patient group and the outcomes of treatment. Meta-analyses (Flor et al, 1992, Morley et al 1999) and an International Association for the Study of Pain (IASP) review, (Mitchell, 1996) have broadly supported the effectiveness of PMP treatment. A recent review report from the Cochrane Institute (Guzman et al, 2003) concluded that, “Intensive multidisciplinary bio-psycho-social rehabilitation with a functional restoration approach improves pain and function”.

The success of the treatment in North Bristol Trust has been sustained over time for the PMP groups despite all the effects of expansion, diversification, staff turnover, and major changes to the host organisation. Patients have consistently reported high levels of satisfaction with their treatment. There are indications in this analysis that the people referred to the PMP groups were in greater difficulties than a 3-year cohort evaluated in 1998. PMP treatment has achieved a larger net gain with this most recent cohort.

The PMP groups broadly set out to improve coping with a persistent pain condition. All indications in this evaluation are that they successfully achieve this.
One important criticism that can be levelled at this evaluation is that it has not been part of a thorough process of clinical governance, making use of feedback to guide service revisions, the so-called audit cycle (National Institute for Clinical Excellence 2002). There are no examples to report where specific findings have been used to alter service delivery except in respect of non-attendance rates. Therefore, following on from this evaluation, the next steps are to refine the methods of gathering information in the light of issues which emerged about these, to set standards, to attempt improvements, and then to evaluate these.

**Improving Information**

To date the information that has been gathered has concentrated exclusively on the evaluation of group treatments. It is gathered only from those who complete the treatment. It is limited to self-assessment measures and observed function. The processes of clinical audit and user involvement in the service both require a more comprehensive method of drawing feedback.

Feedback will in future be gathered from a range of other sources. Focus groups of former users, an independent support group, and staff groups will each contribute to this process. Details relating to patient-centred care will be collated by a service users/staff group known as the SUS (Service Users Satisfaction) group. This will draw together the different sources of feedback to form a balanced perspective on service issues, make relevant recommendations, and initiate further evaluations.

Furthermore, little has been compiled about individual treatment. The number of people involved was originally too small and the treatments too varied for a standardised assessment process to be worthwhile. The numbers have since grown to a level where brief measurement is practicable for both physiotherapy and psychology interventions. Revisions will be made to the feedback questionnaire so that it can be completed by all patients across all treatments provided by the PMP service. The questions will in future include more detail
about the quality of information provided to service users and how well any special needs they had were dealt with by the team.
Figure 24: The structure of consultation for the audit of patient-centred care

- Clinical Governance Directorate NBT
- Patient Advice and Liaison (PALS) NBT
- Department of Health Guidance
- Patient Focus Group
- Audit Projects
- PMP Staff Group
- User Satisfaction Survey
- Uni-professional Groups
- Patient Support Group
**Aims and Standards**

"The public's top concern about the NHS is waiting for treatment". (NHS Plan 2000, chapter 12, section 1).

The reduction of waiting times for treatment is now a major priority for the NHS with a series of targets having been set within the framework of a national patient access initiative. In common with many other programmes elsewhere in the UK the PMP service has at times had a one year waiting list for an assessment appointment. The PMP service has always looked for ways to improve this situation. However, this issue has now become a main priority. The NHS plan (2000) states that it will, "deliver the most sustained assault on waiting the NHS has ever seen". Funding has been made available to help remedy this problem within the PMP service. Therefore:

*The aim of the PMP service is to achieve a substantial improvement with access. This is in terms of waiting times, equity of access, and the physical suitability of venues. This is to be achieved without provoking a significant loss of treatment effectiveness.*

Several modifications in respect of this have been described above. A new patient booking system ensures that assessment appointments are now offered straightaway. This has meant that anyone not suited to treatment finds out more quickly. This conforms with specified objectives of the NHS Plan (10.6 and 12.16).

The introduction of opt-in meetings has been aimed towards greater patient-centred care, improving the sense of involvement and choice in treatment decisions. Those people who have reservations about undertaking PMP treatment can raise these before they find themselves committed to an assessment process. This should lead to a higher attendance rate for individual appointments and a lower overall drop-out rate from the time of referral. This conforms with NHS Plan objectives 10.2 and 10.4. Improved efficiency then enables speedier access to the service.

The first standards for access to the service are that:
Patients will promptly receive an offer of an appointment at each successive stage in their care pathway.

Criteria:

- Patients who are newly referred will be sent an acknowledgement letter in no more than five working days seeking confirmation to proceed.
- A first booked appointment will be offered in no more than eight weeks from the time of their confirmation to proceed.
- All patients being referred to a group course will be offered an opt-in meeting within 10 weeks.
- All patients who opt for assessment and then are included in a course will always be informed, within five working days, of their next appointment.

Exceptions:

The only exceptions with the above will be where an offer of an appointment is turned down by a patient in preference for a later date.

The combined effect is aimed to ensure that no patient waits any longer than 3 months at any stage in their treatment pathway, in accordance with the NHS Plan (12.21).

It is possible that asking patients to attend a large 'opt-in' meeting will put some off coming before there has been a chance to describe the help available. The next evaluation report will consider the impact that the opt-in meetings have had on speed of access and drop-out rates.

Another access issue has been difficulty attending Frenchay Hospital where the PMP groups run. One of the PMP teams now provides courses in community settings. This is intended to make it easier for patients to travel to course meetings and also to build a closer liaison with GPs. Through this we would hope to improve the longer-term clinical management that is followed through by GPs. They should have better information from the PMP team and be better able to encourage a self-management approach to chronic pain by their patients. This conforms with NHS
Plan objective 12.7. We will monitor attendance rates to compare these with courses based at Frenchay Hospital, checking that places are taken up largely by people living locally to each venue. This may also have an effect on re-referral rates in the long term.

Another access issue under scrutiny concerns those patients who depend on hospital transport. Previous attempts to include those who attend by ambulance have foundered because their arrival and pick-up times were unreliable. The PMP service will make a further attempt to overcome this by adapting the timetabling of PMP group and monitoring the attendance and success of this.

There remain a series of other standards and related criteria defined for the service that will be included in the next audit round. These are listed in appendix 3.

The PMP group evaluation database extends to 13 years. Several of the measures are used in other centres. There is no agreed set of outcome criteria although the Pain Society special interest group for PMPs is pursuing a consensus for an evaluation package. Our service is collaborating with this and it will lead to an eventual alteration of the measures used. The benefit will be the comparison with other centres. Health commissioners will be able to set quality criteria within their contracts and PMP teams will use the data to find new ways of improving outcomes.

Although the main thrust of this audit concerns patient-centred care, the above evaluation did highlight three clinical issues that need to be addressed. The first is regarding physical performance measures. These are not a test of a person's fitness but, rather, are a reflection of how they personally react to the demand of exercise. The PMP group data has been confounded by mixing those people who need to build confidence for exertion with those who tend to over-exert. Physiotherapy assessment will in future attempt to differentiate between these two characteristics for the purposes of evaluation. This will be based on TSK score and clinical opinion.

The second issue arises from the feedback questionnaire. According to this data the most notable current shortcoming of PMP group treatment concerns sexual
adaptation to chronic pain. No useful gains are being reported by patients. An improved protocol for this aspect of the PMP groups is being developed. The initial standard will be:

**The PMP group courses will include screening to identify those seeking help with sexual adjustment to chronic pain, provide an intervention, and evaluate it's impact.**

Criteria:

- to achieve a 10% gain or better on the mean outcome score for a measure of sexual adjustment to chronic pain.

Exceptions: Those people who identify this as a problem but decline help.

At the time of writing most of these changes are underway. New information will soon be available to assist us in further improving the PMP service. A report on service standards will in future partner the review of clinical outcome data as presented in this report.

This evaluation of the Pain Management Programme has demonstrated wide-ranging benefits for patients. Whilst the team of staff can rightly derive a sense of achievement from the findings of this report there is much to be done in terms of successful modernisation. The service is building a closer partnership with its users. Steps have been taken to improve the way care is delivered. There are already indications that our response to the national challenge in the NHS Plan to improve access and efficiency is succeeding. We look forward to the next evaluation expecting that through these efforts we will soon know more about the processes of treatment, what methods work best for whom, and still better ways to deliver this service.
References


Picker Institute Europe, Problems with patient satisfaction surveys. World wide web accessed 19.11.02 http://www.pickereurope.org


APPENDIX

Glossary of Abbreviations

List of Appendices

Appendix 1a: Commentary on attendance at the first PMP assessment
Appendix 1b: PMP group outcome measures not reported in main body of text.

Appendix 1c: Tables of mean PMP group outcome measures at assessment and re-assessment and statistical significance of differences.

Appendix 2: Full user satisfaction questionnaire outcomes and commentary.

Appendix 3: Standards of service for the Pain Management Programme (PMP)
**Glossary of Abbreviations**

HADS  Hospital Anxiety and Depression Scale

PSEQ  Pain Self Efficacy Questionnaire

SIP    Sickness Impact Profile (Bergner 1981)

TSK    Tampa Scale of Kinesiophobia

VAS    Visual Analogue Scale
Appendix 1a: Commentary on attendance at the first PMP assessment

Some people drop out without ever having been seen by a member of the team. Just less than 10% either cancel or fail to show up for their first appointment. There were 630 people for whom we have good information. That left 50 “unknown” cases, mainly those people who have been referred to the service but who had not been seen at the time of processing the data. This was either because the referral was so recent or because they have asked to defer the assessment appointment.

Of those who did attend the assessment, two thirds were referred to a chronic pain group programme. This proportion is falling. Between 1997 and 1999 this was 65%. In the most recent year the proportion was only 56%. The main reason for this appears to be the rise in the number of individual treatments offered. Up to the end of 1999 15% were being referred for individual psychological treatment. This proportion has now risen to 20%. An additional 13% are currently being referred for individual physiotherapy treatment. Therefore, at the present time a third of our patients are now assigned for individual help, just over half join a group.

What happens to the rest?

In fact 16% reached a decision with the psychologist not to go forward for any treatment. This proportion is consistent with the data for '94 – '97. This is often because a person feels that, despite the offer of treatment, they don't need it or they are not ready. This could be because they are too distressed or are intent on pursuing surgery or further investigations. A number of people accept the offer of treatment but request a later course, sometimes deferring for as long as 12 months.
Appendix 1b: PMP data not reported in main body of text

Fig. 1 Duration of pain of PMP group patients \( n=369 \)

Mean = 8.5 years, Median = 6 years

Fig. 2 Gender of PMP group patients \( n=369 \)
Fig. 3 Relationship status of PMP group patients n=369

No Partner
25%

Partner
75%

Figure 4 Mean TSK score before and after PMP group n=292
(higher scores indicate greater fear of movement.)
Figure 5: Comparison of percentage of patients in HADS anxiety caseness category before and after PMP group.

Figure 6: Comparison of percentage of patients in HADS depression caseness category before and after PMP group.
Figure 7: Comparison of percentage of patients with PSEQ score of 0-9 before and after PMP group.

![Bar chart showing percentage of patients with PSEQ score of 0-9 before and after PMP group.](chart.png)
Appendix 1c: Tables of mean PMP outcome measures at assessment and re-assessment and statistical significance of differences

Table 1: Mean physical measure scores at assessment and reassessment and t-tests for significant differences

<table>
<thead>
<tr>
<th>Physical measure</th>
<th>N</th>
<th>Mean assessment score (sd)</th>
<th>Mean reassessment score (sd)</th>
<th>t value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arm raise / seconds</td>
<td>289</td>
<td>49.1 (36.7)</td>
<td>53.9 (38.1)</td>
<td>3.17*</td>
</tr>
<tr>
<td>Sit to stands (in 1 minute)</td>
<td>287</td>
<td>12.1 (10.2)</td>
<td>14.8 (11.0)</td>
<td>5.42**</td>
</tr>
<tr>
<td>Step ups (in 1 minute)</td>
<td>278</td>
<td>18.4 (14.6)</td>
<td>20.2 (14.1)</td>
<td>3.03*</td>
</tr>
<tr>
<td>Walking distance (in 5 minutes) / metres</td>
<td>279</td>
<td>153 (95.3)</td>
<td>181 (109)</td>
<td>6.19**</td>
</tr>
</tbody>
</table>

*p<0.01 (2-tailed), **p<0.001 (2-tailed)

Table 2: Mean Sickness Impact Profile scores at assessment and reassessment and t-tests for significant differences (n = 285 in all cases)

<table>
<thead>
<tr>
<th>SIP category</th>
<th>Mean assessment score (sd)</th>
<th>Mean re-assessment score (sd)</th>
<th>t value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulation</td>
<td>29.6 (16.1)</td>
<td>24.1 (16.5)</td>
<td>7.96**</td>
</tr>
<tr>
<td>Body Care</td>
<td>27.2 (16.5)</td>
<td>22.1 (15.4)</td>
<td>7.49**</td>
</tr>
<tr>
<td>Mobility</td>
<td>22.2 (17.8)</td>
<td>16.5 (16.2)</td>
<td>6.02**</td>
</tr>
<tr>
<td>Social Interaction</td>
<td>33.5 (19.5)</td>
<td>21.5 (18.9)</td>
<td>11.8**</td>
</tr>
<tr>
<td>Alertness</td>
<td>37.4 (30.5)</td>
<td>29.3 (35.5)</td>
<td>4.16**</td>
</tr>
<tr>
<td>Emotional Behaviour</td>
<td>46.9 (24.1)</td>
<td>33.7 (24.4)</td>
<td>10.0**</td>
</tr>
<tr>
<td>Work</td>
<td>56.0 (26.5)</td>
<td>45.5 (31.7)</td>
<td>6.08**</td>
</tr>
<tr>
<td>Rest</td>
<td>35.6 (23.5)</td>
<td>22.4 (21.0)</td>
<td>10.1**</td>
</tr>
<tr>
<td>Home Management</td>
<td>41.0 (21.1)</td>
<td>32.1 (20.9)</td>
<td>7.52**</td>
</tr>
<tr>
<td>Recreational Activity</td>
<td>47.8 (21.3)</td>
<td>31.9 (24.9)</td>
<td>9.98**</td>
</tr>
<tr>
<td>Psychosocial Subscale</td>
<td>30.3 (16.1)</td>
<td>21.0 (15.8)</td>
<td>12.2**</td>
</tr>
<tr>
<td>Physical Subscale</td>
<td>27.6 (15.1)</td>
<td>22.1 (14.4)</td>
<td>9.71**</td>
</tr>
<tr>
<td>**Total</td>
<td>29.5 (11.8)</td>
<td>21.9 (12.0)</td>
<td>13.8**</td>
</tr>
</tbody>
</table>

** p<0.001 (2-tailed)
Table 3: Mean psychometric outcome measure scores at assessment and reassessment and t-tests for significant differences

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>N</th>
<th>Mean assessment score (sd)</th>
<th>Mean reassessment score (sd)</th>
<th>T value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS – Anxiety</td>
<td>299</td>
<td>11.5 (4.41)</td>
<td>9.24 (4.40)</td>
<td>10.0**</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>299</td>
<td>10.0 (4.02)</td>
<td>7.20 (4.39)</td>
<td>12.7**</td>
</tr>
<tr>
<td>PSEQ</td>
<td>298</td>
<td>22.6 (11.0)</td>
<td>33.1 (12.5)</td>
<td>17.3**</td>
</tr>
<tr>
<td>TSK</td>
<td>292</td>
<td>41.0 (8.49)</td>
<td>35.2 (8.86)</td>
<td>13.0**</td>
</tr>
</tbody>
</table>

** p<0.001 (2-tailed)
### Table 4: Mean Hospital Anxiety & Depression Scale (HADS) and Pain Self-Efficacy Questionnaire (PSEQ) scores at assessment and 6 month follow up and t-tests for significant differences

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>N</th>
<th>Mean assessment score (sd)</th>
<th>Mean 6 month follow up score (sd)</th>
<th>t value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS – Anxiety</td>
<td>189</td>
<td>11.2 (4.32)</td>
<td>9.47 (4.09)</td>
<td>6.23**</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>190</td>
<td>9.83 (3.9)</td>
<td>7.64 (4.11)</td>
<td>7.65**</td>
</tr>
<tr>
<td>PSEQ</td>
<td>182</td>
<td>22.9 (10.9)</td>
<td>29.7 (13.3)</td>
<td>7.10**</td>
</tr>
</tbody>
</table>

**p<0.001 (2-tailed)**


<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score Before (sd)</td>
<td>Mean Score After (sd)</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>10.6 (4.3)</td>
<td>8.7 (4.2)</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>8.4 (3.6)</td>
<td>5.9 (3.5)</td>
</tr>
<tr>
<td>PSEQ</td>
<td>24.7(9.1)</td>
<td>35.3 (10.9)</td>
</tr>
<tr>
<td>SIP Physical</td>
<td>24.9 (13.5)</td>
<td>21.0 (13.3)</td>
</tr>
<tr>
<td>SIP Total</td>
<td>26.3 (9.2)</td>
<td>20.3 (9.6)</td>
</tr>
<tr>
<td>Sit to Stand</td>
<td>14.9 (10.4)</td>
<td>18.9 (11.2)</td>
</tr>
<tr>
<td>Step Ups</td>
<td>18.1 (12.7)</td>
<td>22.1 (13.4)</td>
</tr>
<tr>
<td>Five Minute Walk</td>
<td>165.4 (102.6)</td>
<td>195.0 (113.1)</td>
</tr>
<tr>
<td>Has you pain changed?</td>
<td>N/A</td>
<td>48.42 (15.55)</td>
</tr>
<tr>
<td>How helpful have you found PMP?</td>
<td>N/A</td>
<td>85.67 (15.75)</td>
</tr>
<tr>
<td>How satisfied are you with the treatment you have received?</td>
<td>N/A</td>
<td>90.49 (10.05)</td>
</tr>
</tbody>
</table>
Appendix 2: Full user satisfaction questionnaire outcomes and commentary. (See also figure 20 of the main text)

Each response is a rating on a 10 cm line and the mean score for the global satisfaction ratings are summarised in fig 20 in the main text. Question 23 (How satisfied are you with the way you have been treated on the Pain Management Programme?) shows a mean of 90, close to the “very satisfied”, pole a high overall rating of patient satisfaction. Only 5 people (1.9%) indicated any degree of relative dissatisfaction (i.e. a score of less than 50). This item, the question about how helpful the treatment had been (q 22) and the rating of how encouraging the therapists were (q 24) produced the 3 most positive scores overall. The one area of concern was the feedback on sexual activity (q 14). This shows no change resulting from the course.
Patient Feedback Questionnaire
Visual Analogue Scale Mean Rating
n = 260 in all questions

Q1: Have you changed how much you try to do, in spite of the pain?

Q2: Do you feel that the talk on medical aspects of pain was useful?

Q3: Do you feel it was useful to talk to other pain sufferers?

Q4: Has your ability to rest, unwind and relax changed at all?
Patient Feedback Questionnaire
Visual Analogue Scale Mean Rating

Q5: Was the discussion on sleep useful?

Q6: Was the discussion on stress and pain useful?

Q7: Have your relationships with other people changed?

Q8: Has what you have learnt about the ways in which you think when you are in pain been useful?
Patient Feedback Questionnaire
Visual Analogue Scale Mean Rating

Q9: Are you now coping better emotionally?

Q10: Were the discussions on medication useful?

Q11: Do you now know more about how to pace yourself in your activities?

Q12: Has your self confidence changed?

[Bar charts showing responses to the questions with ratings from Much Worse to Much Better.]
Q13: Do you now feel more confident about the way in which you sit in chairs, lie in bed, lift and generally move around?

Q14: Has your sexual activity changed at all?

Q15: Were the printed handouts useful?

Q16: Are you visiting people, or simply going out more often now?
Patient Feedback Questionnaire
Visual Analogue Scale Mean Rating

Q17: Did you find the physical exercises useful?

Q18: Has your understanding of doctors and their work increased?

Q19: Overall, has your pain changed?

Q20: Do you feel better informed about pain and its effects?
Patient Feedback Questionnaire

Visual Analogue Scale Mean Rating

Q21: Do you feel that, in general, your ability to cope with pain has changed?

Q22: Overall, have you found the pain management programme helpful?

Q23: Overall, how satisfied are you with the way in which you have been treated in the pain management programme?

Q24: Overall, were the therapists encouraging?
Patient Feedback Questionnaire
Visual Analogue Scale Mean Rating

Q25: Looking back, do you feel the programme:

- Did not push you enough
- Pushed you too hard
Appendix 3: Standards of service for the pain management programme

During a three-year period from 2000 – 03 the staff team of the PMP has undertaken a major review of the service, modernising the way it is organised and delivered, making improvements in access and comfort, building better ways of communicating with service users and acting on the feedback that is received. Through this we have set down a series of standards concerning the way in which the PMP is achieved. These standards will be monitored and publicised. They are in addition to both professional practice standards and the organisational standards of North Bristol NHS Trust. These are a framework against which our performance can be assessed and future improvements in service will be targeted.

This first statement of standards is derived from the work of the Chartermark steering group, from advice received in user Focus Groups carried out 2001-2 and from a workshop undertaken by the staff team in February 2002.

The Pain Management Programme aims to provide a service for people suffering with complex and long term pain conditions helping them to achieve a better adaptation. Core characteristics of this service are that it is demonstrably effective, efficient and patient-centred. In future the service will be monitored and developed in partnership with those people whom it serves.
STANDARD: Users of the Pain Management Programme will be seen by staff who have appropriate qualifications and training, experience, and supervision.

<table>
<thead>
<tr>
<th>CRITERIA</th>
<th>MEASUREMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The staffing of the PMP will be in accordance with the guidelines of the Pain Society and the International Association for the Study of Pain (IASP)</td>
<td>Criteria included in Appendix.</td>
</tr>
<tr>
<td>2. Each member of the team will participate in peer supervision</td>
<td>Supervision dates recorded and included in performance review.</td>
</tr>
<tr>
<td>3. All PMP staff will undertake continuing training and professional development to update their skills and knowledge in relation to pain management.</td>
<td>Each member of staff will maintain a log of training activities which is recorded in performance review.</td>
</tr>
<tr>
<td>4. All PMP staff will have appropriate professional registration</td>
<td>Confirmed at appointment. Annual updates logged by professional line manager.</td>
</tr>
<tr>
<td>5. The PMP will maintain a process of induction training for new staff to ensure consistency of practice.</td>
<td>Induction to be supervised by professional line Manager making use of an induction pack for the PMP.</td>
</tr>
<tr>
<td>6. Trainees will only work face to face with patients when clear supervision arrangements are in place and with the agreement of the patients that they see.</td>
<td>Training records will log the supervision. Badges will state the training status of the trainee. Reports and letters will include the supervisors name as well as the trainees name.</td>
</tr>
</tbody>
</table>
STANDARD: The Pain Management Programme will strive to ensure that the service is fully accessible to users, that it is delivered fairly, promptly, and in an environment that accommodates any special needs.

<table>
<thead>
<tr>
<th>CRITERIA</th>
<th>MEASUREMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The facilities of the PMP are set up to support the needs of users with sensory impairments and problems with mobility.</td>
<td>The views of all service users will be sought concerning these issues and the findings will be audited. The Pain Management Programme will maintain level access to the building, disabled parking and set-down areas within 100 metres, adapted toilet facilities, varied seating, a loop system for the hard of hearing and well-lit treatment areas.</td>
</tr>
<tr>
<td>2. The PMP will seek to remove unfair discrimination in the selection of patients for treatment.</td>
<td>Personal and demographic profiles of service users will be compared with the same data for the source population to ensure close comparability. Any signs of difference in terms of e.g. age, sex or ethnic background will be taken up with referrers to the service.</td>
</tr>
<tr>
<td>3. The PMP will provide advice and practical help for those patients having difficulties finding transport for attending the Centre.</td>
<td>Details of bus timetables, taxi companies and financial support for those in receipt of benefits will be displayed in Reception. Administration staff will provide telephone advice for enquiries about this. Details about transport and parking will be included in appointment letters and information leaflets.</td>
</tr>
</tbody>
</table>

- The PMP will provide a translator service if needed by service users unable to follow in spoken English.
- The PMP will provide adapted materials where handout information cannot be read or understood by a service user.
STANDARD: The Pain Management Programme will provide patient-centred care ensuring confidentiality, and informed patient involvement in care planning decisions. It will be delivered in a way that is welcoming and respectful of each individual.

<table>
<thead>
<tr>
<th>CRITERIA</th>
<th>MEASUREMENT</th>
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<tbody>
<tr>
<td>1. All patients who attend the PMP will receive a personal greeting from the Receptionist and offered seating and a hot drink.</td>
<td>Specific feedback about this will be sought from all service users.</td>
</tr>
<tr>
<td>2. All individual consultations will take place in private areas of the centre behind closed doors.</td>
<td></td>
</tr>
<tr>
<td>3. Explicit rules of confidentiality will be discussed and agreed with all participants in group meetings before any discussion of personal information takes place.</td>
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<tr>
<td>4. Users who may be taking part in a group programme will receive a detailed explanation of the nature of these courses and will be able to ask questions about this before a decision is reached about proceeding.</td>
<td>The PMP will run a schedule of open meetings for patients who have been referred to explain the treatment before agreeing to participate.</td>
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STANDARD: The Pain Management Programme will ensure clear and prompt communication with all patients referred to the service, with the referrers, and with the patient's general practitioner.

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<tr>
<td>1. When a new referral is received by the PMP confirmation of this will be posted to the patient within five working days of receipt asking for confirmation to proceed.</td>
<td>The receipt and response dates will be monitored.</td>
</tr>
<tr>
<td>2. On receipt of confirmation the PMP Receptionist will offer a time and date for a first assessment appointment. This will be within eight weeks but can be altered to fit with patients' preferences.</td>
<td>The time lag to the offer of first appointment will be audited to check for 100% compliance with the eight-week target.</td>
</tr>
<tr>
<td>3. The PMP Administrator/Receptionist will run a logging system of enquiries and messages to ensure that these are dealt with promptly and appropriately.</td>
<td>Response times in the log to be audited.</td>
</tr>
<tr>
<td></td>
<td>All patient and referrer enquiries to be responded to within one working day with the enquirer being advised or attended to by another member of staff if the relevant team member is unavailable in that timescale.</td>
</tr>
<tr>
<td></td>
<td>Enquiries will be possible face-to-face 9.00 a.m.–5.00 p.m. weekdays, by telephone or fax and by e-mail.</td>
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</tbody>
</table>
STANDARD: The Pain Management Programme will through a variety of means consult with users about the service it provides and involve them in the modernisation of the service.

<table>
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<tr>
<th>CRITERIA</th>
<th>MEASUREMENT</th>
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<tbody>
<tr>
<td>1. Every patient seen in the PMP will be asked to complete a feedback form at the end of their treatment concerning the care they have received.</td>
<td>Audit of this information will be reported to the SUS group and summary data will be made available to users.</td>
</tr>
<tr>
<td>2. The PMP will run a users' Focus Group to gain additional feedback and to address specific topics of concern as directed by the steering group.</td>
<td>Focus Groups to be convened on a four monthly basis with a summary of findings reported after each meeting.</td>
</tr>
<tr>
<td>3. A Service User Satisfaction (SUS) Group will fulfil a steering role drawing information from Focus Groups, individual patient feedback, from the independent patient support group (Pacing Forward), from other written feedback including a Suggestions Box and a Comments Book, from the Patient Advice and Liaison Service (PALS), and from the Trust Complaints' Manager.</td>
<td>The Service Users Group will meet on a six monthly basis reporting on how it has collated information and on its specific recommendations for the modernisation of the PMP.</td>
</tr>
</tbody>
</table>
The stated aims of treatment in pain management programmes (PMPs) embraces concepts of adjustment, adaptation, and restoring confidence and functioning. This is meant to be a broad-based intervention tackling the full range of disruption caused by chronic pain, flexible enough to take on the specific issues of any individual, whilst covering all the main themes of coping such as pacing of activities, depression, and sleep disturbance. The timetables of different programmes reflect this despite their variable settings, referral patterns, and staffing.

One of the common themes that would be expected to be included is sex life. After all, both individuals and society place considerable value on sexual functioning. It is considered an important domain of quality of life (Fallowfield, 1990) and it is vulnerable to disruption, through illness and injury, including chronic pain (Roy, 1986, Payne and Norfleet, 1986). Surveys of chronic pain sufferers have pointed to a high prevalence of difficulties with sex life, (e.g. Monga et al, 1998).

If chronic pain undermines fitness, confidence, and interest in sex, then this straightforwardly fits in with the PMP treatment framework for restoring these. However, the indications are that comparatively few PMPs tackle this. The topic does not usually appear on treatment timetables. Whilst there are a number of surveys of sexual difficulties in the scientific and professional literature there is a dearth of information about methods of helping. The Pain Society special interest group series of national conferences for PMP practitioners has included only one
presentation on this issue since it was founded in 1993. In one of the first detailed
descriptions about the organisation and provision of multi-disciplinary treatment
for chronic pain following a model of cognitive-behavioural group interventions,
Turner and Romano, (1989) commented that,

"It is very common for patients to report a decrease in level of [sexual] interest or
activity following the onset of pain"

and recommended that the issue be explored. This is presented as a topic for
assessment but they did not make any further reference to it when discussing
different aspects of treatment. The same gap is evident in an up-to-date and
otherwise comprehensive description of the format of National Health Service
PMPs, (Main and Spanswick, 2000).

It seems that there is an acknowledgement amongst those involved in the care of
people with chronic pain that sexual difficulties are a concern but there is a lack
of understanding about how to approach it. This review explores the literature
relating to sexual difficulties with chronic pain. This includes a discussion of the
particular obstacles that exist for finding true prevalence rates, the different ways
that sexual difficulties may develop, and the issues facing PMP therapists in
tackling this with their patients. The literature is reviewed with particular reference
to a survey carried out between three UK pain management programmes.
Conclusions are drawn about future directions for both research and clinical
practice.

Problems with researching the topic.

There are inherent difficulties for research that is aimed to make sense of the way
chronic pain affects sex life. Firstly, a substantial proportion of chronic pain
sufferers have an injury or disease that might have disrupted the biology of
sexual response. Spinal cord injury and surgery for intervertebral disc disease
are examples of this. Slight damage to the nerve tracts either as part of the condition or as a result of surgery can cause erectile dysfunction.

There may be a direct influence of prescribed medication on sexual response. The principle group of pain relief drugs, the opiates, is linked to loss of sexual desire, as are the benzodiazepines that are frequently prescribed as muscle relaxants and for insomnia (Parkinson and Bateman, 1994). The effects are idiosyncratic however, affecting some people but not others. Also some other prescribed drugs such as certain tricyclic antidepressants, are known to occasionally heighten sexual response. Another related problem is the use of drugs prescribed for other conditions that may have negative side effects, for example with the treatment of hypertension often provoking male impotence. Therefore, with such drug effects being unpredictable for individuals and sometimes the combination of drugs having a confounding effect, this factor cannot be statistically controlled in the analysis of research data.

Sexual difficulties may also predate the onset of pain. This was pointed out by Turner and Romano (1989) as an example of how detailed questioning can shed new light on something that was initially believed to be a consequence of chronic pain. A couple whose relationship was at a low ebb before pain started may nevertheless attribute current difficulties entirely to the pain condition.

Another issue that frequently pre-dates the pain condition is the proportion of people who have experienced sexual abuse. There are some indications that this has occurred in a particularly large number of people with chronic pain. In a survey of women with chronic pelvic pain Toomey et al (1993) described 19 of their sample of 36 respondents reported previous abuse. Linton (1997) reported a comparison between samples from a population survey and a clinical sample of chronic pain sufferers. Twenty three percent of 209 women in a 'no pain' group reported sexual abuse whilst this was disclosed by forty six percent of 136
women in a ‘pronounced pain’ group. The proportions were eleven percent and thirteen percent respectively for the corresponding samples of men. The implication of this data is that there is a strong link between chronic pain and previous experience of sexual abuse amongst women and, furthermore, that this may be involved in the transition of an acute condition to chronic pain.

A further problem for researchers is that this topic is personal and highly sensitive. There is an understandable reluctance of some individuals to participate in research. There is no reliable source of normative data with which to compare research findings from chronic pain sufferers. Many published surveys of sexual behaviour report a low proportion of subjects agreeing to take part. If recruitment to a survey or trial is hampered by a substantial drop-out rate, then this causes problems for the interpretation and extrapolation of results. There is no way of examining possible selection bias in the data. Sensitivity about the topic also has a cultural constraints dimension with some groups more open to discussing it than others. Research ethics committees can take a particularly cautious view and sometimes there is also a political obstacle for researchers to negotiate. The 1994 survey of sexual behaviour in Britain, (Wellings et al) the largest to be carried out in the UK, having passed through the usual processes of approval, was interrupted by a cabinet committee review. It then hit an indeterminate delay subsequently reported to have been directed by the Prime Minister of that time Margaret Thatcher, (Sunday Times, 1989). This was unconfirmed but the delay imposed on the research team was later described in the research report as an example of “Scientific decisions being made on political grounds”.

Researchers aiming to describe sexual activity amongst the general population therefore face the problem of designing a method that is not so intrusive in its content that it puts off potential subjects and others who must approve it, but one which nevertheless uncovers useful information.
The findings of previous surveys.

Despite the obstacles described above, several studies have been published on this topic which despite the concerns about sampling do give pointers to the scale and nature of the effects of chronic pain on sex. A consistent finding, irrespective of the group surveyed, the setting, or the different methodologies, has been that all of these reported a high prevalence of difficulties with sex life. This is of the order of two out of three or more reporting problems. Maruta et al (1978) interviewed 50 chronic pain sufferers and their spouses, of whom 78% of the pain sufferers and 84% of partners described deterioration, including cessation, of their sex life. In a further study (Maruta et al, 1981), of 66 married patients, two thirds reported a decline in sexual activity and 30% reported deterioration of the marital relationship. In another survey of back pain patients referred to a rehabilitation service (Sjogren, 1981), half the sample of 35 men and 25 women with low back pain reported decreased frequency of sex since the onset of chronic pain. This was associated with physical limitations, fatigue, and loss of sexual satisfaction. Women reported more difficulties than men.

Flor and Turk (1987) sampled 58 male patients and their spouses who were attending a chronic pain management programme: 77% had reduced the frequency of sexual activity and 42% stopped completely. Two thirds were dissatisfied with their sexual relationship, and this was correlated with pain intensity, whereas marital dissatisfaction was associated not with pain intensity but with cognitive appraisal and coping variables.

A qualitative study in which 28 women of childbearing age were interviewed, in community and clinic settings, found that the sense of a lack of understanding was a predominant issue in the way sex life had been affected. Added to this there was a perceived loss of physical closeness and the fear of exacerbating
pain, both for the women and their partners (Schlesinger, 1996). Two of the 28 attributed the loss of a sexual partner to their pain problem.

A survey by Monga et al (1998) used a standardised measure (the Derogatis Inventory of Sexual Functioning, DISF(1990)) to address sexual expression in more detail. This method was notably thorough because the use of this measure permitted comparison with standardization data. One third of a sample of patients attending a chronic pain programme, 62 men and 8 women, completed the questionnaire: 53% of the men were no longer sexually active by the criterion minimum frequency of once per month, and on the DISF, 71% scored at least one standard deviation below the mean, and 56% more than two standard deviations below. An association was found between DISF scores and measures of depression, catastrophizing, and passive coping style. Patients with high levels of general activity were more satisfied with their level of sexual function. It seems from these studies that chronic pain has a devastating effect on the sex lives of the majority of sufferers.

The consistency of results across these studies to some extent mitigates the shortcomings of small sample sizes, low response rates, and the lack of separate analysis of male and female subjects or preponderance of male responders. However, there are other methodological problems with these studies. They have mostly made an assumption of, or have made restriction to, heterosexual relationships. The emphasis in most studies is typically on intercourse as the defining sexual activity. Chronic pain sufferers will often complain of physical over-exertion being the main cause of flare-up of symptoms and sexual activity therefore threatens pain exacerbation. Alternatively the frequent associated psychological effects of pain such as loss of family or bread-winner role, diminished self esteem, depression and relationship strain are all recognised as factors in loss of sex drive. Information is still lacking from these studies on the extent to which such physical and psychological characteristics of chronic pain
are the attributed cause of sexual difficulties. There are distinctions that needed to be drawn between sexual desire, performance and satisfaction, in understanding the nature of the difficulty when a problem with sex is being highlighted. The above studies have not sought to incorporate the effects of prescribed drugs on sexual responses in the analysis of their findings. Although these factors cannot easily be isolated in survey research it is nevertheless possible to consider the strength of association say between quantified physical dysfunction, psychological distress, and perceived limitations of sexual activity.

The Bristol-London-Gloucester survey.

The methodological problem of defining valid criteria of what is, or is not, sexual activity, or what constitutes a problem with sex, and what was the cause, can each be negotiated by focusing on subjects' own judgements of this. A survey of attributions amongst a clinical sample can clarify what this group believe to be the nature of their difficulties and what help they would like whilst avoiding some of the assumptions inherent in the above studies.

This method was adopted by Ambler et al (2001) who drew together a range of features of sexual activity and difficulties that were based on both the previous literature and on the authors' experiences of the concerns raised by chronic pain patients during CBT-based rehabilitation. This was carried out in three separate centres and involved 327 consecutive attendees. Demographic and clinical information was available on non-responders to consider the issue of representativeness and sampling bias. The format of the survey was such that those people not currently in a relationship might still complete the questionnaire and the wording did not assume heterosexual relations or intercourse. There was a comparatively high response rate (72%) Respondents were asked to indicate their frequency of sex, their satisfaction with this, and the degree to which they believed it had been affected by their pain condition. They were then asked to rate the degree to which they believed each of a range of factors was
interfering with their sex life. These factors included fears of exacerbating pain through the exertions of sexual activity, the influence of other problems in the relationship with their partner, difficulties with arousal, or finding a comfortable position, anxiety about performance, loss of enjoyment of sex and the effects of overall loss of confidence. This was compared with data on general functional impairment, psychological distress and their use of prescribed drugs.

The data from this clinical sample replicated the previous findings of a high prevalence of perceived difficulties in that 73% of the respondents had pain-related problems with sexual activity. There were no pointers in the data to any large-scale difference between responders and non-responders further supporting the validity of this consistently high prevalence rate. A recent survey carried out in the UK involving 1768 members of the general public (Dunn et al, 1998) showed a substantially lower rate, roughly half the rate in the chronic pain sample, with 34% of men and 41% of women expressing a problem with sex life. Similar proportions emerged from a comparable US survey (Laumann et al, 1999). A simple head count categorising the presence or absence of a problem can be misleading however. When this chronic pain sample were asked how they felt about the situation 28% felt ‘very concerned’ whilst 30% described themselves as ‘a little concerned’. Here then is an indication that although this is a frequent problem there is not an equivalent degree of desperation about it as might have been assumed from previous studies. That a third of people feel ‘very concerned’ is nevertheless an important finding.

The profile of the causes of difficulty in this study did not show any one dominant factor. It might have been expected that worry over the exertions of sex or, alternatively, loss of interest, was seen as paramount. Instead the majority of people regarded the disruption of their sex lives as being a combination of factors. The most frequent was a combination of all of the factors, a profile endorsed by a quarter of the sample.
The identification of sexual difficulties does not necessarily imply the perceived wish to access help. This study was the first to survey patients' perceived need for professional help and their preferences concerning its delivery. This question was included in one of the three centres, a sub-sample of 68, comprising 30 men and 38 women. They were asked whether or not they would like support and given the options of information only, single-sex, or mixed-sex group discussion, or one-to-one counselling. Half this sample (47%) opted for information, a quarter (27%) sought discussion whilst 22% asked for both. Half of the people who opted for discussion preferred this to be on an individual basis, the remainder dividing equally between a preference for single-sex or mixed group discussion. There was no notable distinction to be found between the balance of preferences expressed by men compared to women in this sample.

There were a number of shortcomings with this study. It failed to derive conclusive data about the effects of prescribed drugs on sex life because in so many cases the hypothetical effects of different medications were confounded. For example, whilst a person might have been taking an analgesic that is known to impair sexual responsiveness it may at the same time have provided sufficient pain relief for freedom of movement to engage in sex which otherwise would have been avoided. This study also failed to shed light on the role of psychological distress, an issue which remains equivocal. Previous findings of Tan et al (1998) had shown a statistically significant association between measures of depression and sexual difficulties. This was contradicted however by the results of the Monga study (1998) where no such link emerged. The influence of both distress and drugs need clarification through further research. A main theme of the Bristol-London-Gloucester survey had been to provide useful data for practitioners. Although succeeding with this in some respects the number of people surveyed about their preferences for help was small. Also, a concern for pain management programmes is to understand the role of past sexual abuse in the expression of sexual concerns amongst this clinical sample. The previous
findings of Linton et al (1997) had indicated a notably high prevalence but this survey did not explore this issue further.

**Barriers to providing help.**

The earliest study covered in this review was carried out by Maruta (1978). During the 25 years since this was published there is a theme of repeated surveys highlighting the significance of sexual difficulties amongst chronic pain sufferers. Most then recommend the development of treatments but there has been no follow-through of reports of new interventions and their evaluation. Why is this?

One clear barrier is that, despite the surveys, there is no evidence-based model of the aetiology from which to design an intervention. Uncertainty still prevails. The Bristol-London-Gloucester findings were that chronic pain patients see the roots of their difficulties with sex as being interwoven. This is problematic when trying to work out an intervention strategy. Therapists cannot be sure where to start and what to emphasize. If the prospect of aggravating the pain had been behind diminished sex life then treatment would focus on improving flexibility, endurance for exercise, understanding of posture and movement particularly range of movement of the lower back and pelvic rotation. This would then be the domain of PMP physiotherapists. If loss of independence, loss of role such as those of bread-winner or home-maker, relationship strain, lower self esteem and depression, were found to be causing a loss of libido then this would point to a different type of intervention, one for the PMP psychologists. Instead these different factors appear to be equally implicated.

If the side effects of prescribed drugs had emerged as a main explanation then this would again give a different pointer for care. The clinical management to improve sex life would be through further medical supervision. Lastly, if the
research on past sexual abuse is taken into account as a suspected major contributor in the disruption of sex then this could put a block on help. PMP therapists might justifiably feel that the topic falls outside their remit. It is arguably inappropriate to embark on treatment that would often lead into a level of therapeutic work that in the short term risks provoking greater distress in their patients, where they could not offer sufficient help in the longer term.

Another barrier related to the lack of clarity about cause is that the topic of sex is not assigned to any one of the pain management professions. Individual therapists may feel that this aspect of care is not particularly their own professional domain and that training did not prepare them for this component of chronic pain care. It may be further reflected in the lack of access to supervision about this. Without a sense of training and support therapists may feel that they are instead forced to draw heavily on their own personal experience to discuss sex life with patients. This amounts to a form of personal disclosure and many will feel uncomfortable about this.

There are practical constraints on therapists such as the time-pressure to complete those aspects of pain programmes that clearly are their remit. There is the consideration of ensuring an even greater degree of confidentiality and sensitivity for this topic which may conflict with the facilities in which many NHS pain services are provided.

Another problem is to decide whether or not to directly involve partners in covering sexual adjustment. They are obviously the subject of much of what will be covered but not every patient wishing to discuss this has a partner. Including them could have a divisive effect. This dilemma is reflected in the literature where some surveys included partners and some did not.
These considerations when present could explain what appears to be a professional resistance to discussing sexual concerns in pain management programmes. It leads to what has been described by Seymour (1998) as, “Professional neglect of sexual issues”. In her qualitative study of 24 men and women with spinal cord injuries she described how respondents repeatedly condemned health workers for this neglect and for, “the sexism embedded in their advice on the rare occasions that it is given”.

The professionals appeared to be making an assumption of asexuality in their patients. She cites examples where written information is used to bypass any direct discussion of sex; of how the rehabilitation literature is dominated by reproductive issues for women and mechanical aspects, particularly erection, for men; and a constant stereotyped emphasis on the “active male, passive female [in] the choreography of heterosexual interrelationships”. Her respondents had all undertaken extensive rehabilitation yet in retrospect they felt that the best help came through what they could glean from fellow patients, not from the professionals.

**Overcoming the barriers.**

A summary of the barriers above might be: ‘uncertainty about cause, no specific training, lack of a professional remit, inadequate support, tight time constraints, and poor facilities’. Most PMP organisers who have set up a new service within the NHS would recognise these as the same barriers that they overcame in establishing a PMP. The success of a PMP has depended on different professions combining to form an interdisciplinary method without definite boundaries for each professional role. A pragmatic problem-solving approach is adopted with patients in circumstances where the pain aetiology was still a puzzle. The interventions were usually patient-led, which meant that individuals would negotiate their own set of goals with the PMP team, omitting those aspects of the timetable that are not a priority or which they prefer to avoid. These same
overall principles can be applied to the barriers above in order to develop interventions for better sexual adjustment to chronic pain. A development like this can proceed in spite of constraints and uncertainties.

Sexual difficulties need to be tackled directly rather than indirectly. PMP treatment already addresses physical reconditioning, restoration of mood, self-confidence, and relationships, as well as the rationalising of prescribed drugs. These have each been postulated as contributing to sexual difficulties. However, an example of audit (Ambler, 2004), has demonstrated substantial improvements in each of these areas but the same data shows no improvement in sexual adjustment. The lead from PMP patients through the surveys reviewed above is that they believe this area of difficulty is strongly associated with their pain and they would like specific help with it.

The following is a series of steps, based on the above review, which a PMP team could take to provide this help.

**Prepare and establish support for the PMP therapists.**

There is still seemingly a barrier for therapists to overcome with their collective resistance to this work. Any initiative will need to address this. Preparation involves drawing together those who would be willing to tackle this topic, then forming an overview of what is known through their collective experience. A team can map out the scope of this new component of their PMP in terms of the time and facilities they could assign to it. They can also resolve strategic issues. For example, there is a decision to be made about whether or not to involve partners. Different teams are likely to take differing views about this as they have for including relatives in other aspects of their courses.

Establishing a timetable for mutual supervision will enable therapists to learn through practice. Following the principles of reflective practice will draw out
concerns about boundaries of content in therapy and elements of implicit personal disclosure. They will need a forum in which to consider the influence of their own sexual preferences on their work with patients. A formal structure of staff support can therefore be a means of resolving professional resistance.

**Set clear limits for the intervention.**

Time constraints and the professional limits of PMP therapists will usually mean that help regarding sexual adjustment will be brief. Given the overall remit for PMPs this should emphasize the effects of chronic pain and demands that therapists think through the extent to which they will engage related territory such as emergent relationship problems which are deeper than the effects of pain. This can then become part of the 'ground rules' worked out with participants at the start. The mode of delivery, through individual, couple, or group discussion, the setting, and the time made available, will all influence a person's decision about whether or not to access the help being offered. Where it is clear that an individual or couple need additional help beyond the scope of what is being offered in the PMP then the therapists should be prepared with a knowledge of where and how to arrange this help.

**Identify those seeking help.**

The published surveys recognise the sensitivity of the topic and that some people will be unwilling to discuss this. An optional session in a PMP timetable or a confidential survey of the type employed in the Bristol-London-Gloucester study allows PMP patients to sub-divide according to their wishes.

**Compile resource materials and local contacts.**

Written information has been available for some time. Herbert (1987) has published a booklet and videotape for back pain sufferers. Ritchie and Daines
(1992) and Weiss and Harner (1982) have also set out information for this purpose, although these are subject to the same criticisms conveyed by Seymour (1998). Jordan and Keefe (1988) give a descriptive summary of frequent themes such as the way relationships can alter with the development of chronic pain. Beyond the specifics of the effects of chronic pain there are numerous contemporary resource materials geared to helping people with their sex lives that can be used as hand-out information and to support therapists who are building a knowledge base. National and local contacts can support this work. Local links are vital particularly when past sexual abuse is disclosed and it is apparent that further help for this is needed. Otherwise the World Wide Web has well-developed routes of support such as through the Sexual Health Network, (2003), where it is possible to consult for expert advice on-line; SPOD (2003) (The association to aid the personal and sexual relationships of people with a disability) provides advice, support, materials, and training; REGARD (2003) is a national organisation of disabled lesbians, gay men and bisexuals; and RESPOND (2003) is a help line supporting professionals and carers regarding sexual abuse, offending, and identity issues.

**Follow-up and evaluation.**

The success or otherwise of attempts to develop an intervention can only be guided by feedback from the service users at the end of treatment. This will enable therapists to work out the helpful and unhelpful aspects of what they try to do. There is a need to understand the competencies required of professionals for this area of work and one purpose of audit will be to clarify these.

There are very few standardised measures that can be used for evaluation. The DISF used by Monga et al (1998) is arguably the best example but it is lengthy to administer and unnecessarily intrusive in the coverage of details of sexual expression. Instead a brief measure focussing on quality and satisfaction with
sex life would be sufficient for an audit of interventions. The development of such a measure is one area where further research is needed.

Other research directions.

The purpose of this review was to derive some guidance from the relevant literature that can be applied to the care of people with chronic pain. The Bristol-London-Gloucester study has taken this forward from a measure of prevalence to a description of patients' perceptions about pain and sex life. One constructive observation from that study was that there is a small proportion who despite their pain have a sex life they feel entirely happy with. Qualitative research methods could shed light on how this is achieved in ways that would have direct relevance for patient care. A recent example of this is Regan and Rowley (2001) who focussed on patients' experiences and wishes.

Several other threads for further work have been described above. Linton et al (1997) have identified a likely influence of past sexual abuse in the development of chronic pain. The scale of this was striking and if replicated then a further exploration of this is likely to influence the future delivery of help for sexual adjustment to chronic pain.

The relative influence of physical impairment and psychological distress remains uncertain. This could be pursued through further research. However, for reasons described above, the absence of any strong trend in the surveys reviewed means it probably has little to contribute to methods for resolving them. The role of prescribed drugs was still not clear from the Bristol-London-Gloucester survey but, similarly, there was no conspicuous trend to pursue.

The over-riding priority at this point is for the development of intervention protocols that can then be evaluated through research. Jordan and Keefe (1988) reached much the same conclusion 15 years ago. The position seems static
despite the clearly expressed needs and wishes of people with chronic pain. If this remains the same in the future then research will instead need to address the processes that have maintained it.
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CRITICAL REVIEW 2

The Psychological Needs Of Adults With Severe Burns

Sometimes it is a tragedy that triggers a leap forward in applied psychology. A well-known example is the murder of Kitty Genovese in 1964. There were at least 38 witnesses to her protracted death but no one went to her aid. This led to a surge of investment in social psychology research to try to explain the inaction of on-lookers (e.g. Cialdi, 1980). The psychology of burn care is another example. On 28th November 1942 Coconut Grove, a large nightclub situated in the centre of Boston, Massachusetts, was crowded to capacity with Saturday night revellers. At about 10.10 p.m. a fire started. It spread rapidly and became an inferno. Many of the emergency exits were locked or blocked. The building was gutted. 492 people were killed, 142 were injured. The city's hospitals and mortuaries were overwhelmed, unable to manage the scale of the disaster.

A car park and a pizza take-away are now the replacements where the club had once stood. There is no commemorative notice, even though the fire remains on record as the worst disaster in Boston's history. At that time severe burn injuries were almost always fatal and only a small proportion of those rescued who were severely burned managed to survive the following days. It was the challenge of how to look after those who did survive that has turned out to be the main legacy of the Coconut Grove fire disaster. Boston now has one of the most advanced burns units in the world. The fire also led to a landmark study of the experiences of forty-six people survivors. This was the first case series describing the psychological effects of burns, (Adler, 1943).

The aim of this critical review is to consider how the understanding of the psychological needs of burns patients has developed since Adler's paper. This focuses on psychological reactions of severely burned adults during their hospital stay in the immediate aftermath of the injury but with reference to findings concerning the longer-term impact of burns. The discussion considers clinical
implications and future research directions for psychologists working in this specialty.

**Background: The Emergency Care of Burn Injuries**

Small burns or scalds are a common minor injury, rarely needing any special medical attention. An area of the epidermis is damaged, it is usually reddened, it perhaps swells a little, and it is painful. Recovery is typically complete within two weeks. This is categorised as a first-degree burn. There is no reliable estimate of the number that occur each year. Moving along the scale of injury a second-degree burn is deeper, affecting both the dermis and epidermis. There is usually blistering, pain, and discolouration. This is also known as a partial thickness burn. According to figures summarised in the National Burn Care Review (2001) a quarter of a million people receive community-based treatment for burns in the UK each year and the majority of these are partial-thickness, affecting a small area. Recovery takes longer and may leave scarring. This level of injury is also heavily represented amongst the additional 190,000 people who attend accident and emergency departments and the 16,100 who are admitted to hospital each year. The wider area, as well as the depth of the injury, dictate the increased seriousness.

Where the dermis is completely penetrated this is categorised as a third degree or full-thickness burn. Nerve endings are often destroyed. As a result areas of full thickness injury can feel less painful but the skin does not recover from this depth of injury and grafting is needed. Extensive full thickness burns are often fatal. The age of the victim is another main determinant of survival. Until quite recently if the figure for the percentage total body surface area affected by the burn (TBSA) added to the age of the patient was greater than 90 there was little chance of survival.
Emergency care involves the restoration and close monitoring of fluid levels, maintaining effective kidney functioning, treatment of the wounds, and pain relief. If there is any injury from inhaling fumes then swelling is likely to develop as a result, compromising the airway, so the patient will be intubated to protect respiration. Over subsequent days the prevention of infection is a major concern and requires the removal of areas of dead tissue and the earliest possible replacement of skin. This may be harvested from sites such as the thighs. Alternatively, donated cadaver skin or artificial skin may be used, these methods being credited for the recent improvement in survival rates. Some patients need multiple organ support and/or ventilation. The amputation of fingers or limbs is sometimes necessary because of infection or loss of effective blood supply.

As the crisis of survival subsides there is continuing concern about pain relief, infection control, and nutrition. There are frequent changes of the wound dressings. Therapists set up regimes of exercises and stretches, often using splints and aids, for the restoration of function and the prevention of contractures. These procedures are all usually painful. Pressure garments and moulded masks are used to prevent hypertrophic scars developing. Itching of healing wounds, exposure to sunlight, or to chemical irritants, can each complicate the recovery.

The relative infrequency of severe burns and the complex nature of this work has meant that severe burns are treated in regional centres with dedicated specialist teams. Patients often experience extreme suffering, their lives are often under threat, and there is considerable emotional strain for family members and the professional staff who provide care.

**Uncovering the Psychological Issues**

The findings presented by Adler in her 1943 case series described two categories of long-term psychological effect. First was a group who were fatigued, irritable
and had disturbed sleep. Second was a group with uncontrollable fear that she described as anxiety neurosis reactions. As the first study that portrayed clear-cut psychological reactions to burns this was a breakthrough paper. However, the sample was small, the selection of the respondents was not systematic, and although there was a process of follow-up this was not organised as a longitudinal study. Two generations of surveys have followed, some with larger sample sizes, but which were otherwise affected by the same shortcomings. Hamburg et al (1953) addressed reactions during hospitalisation drawing attention to pain, forced dependency, prolonged monotony, anger and hostility. Korloff, (1966) described subsequent loss of jobs and marital break-ups in a questionnaire survey of 138 people. Williams, (1969) described diminished social life amongst a sample of 42 males. McGregor (1974) coined the phrase “Social death” to reflect the isolation seen in the longer term amongst people facially disfigured by burns.

There is considerable evidence concerning the pre-disposition of burn-injured patients. Andreasen et al (1972) identified pre-burn psychological problems amongst a sub-group of their sample of 32 who fared comparatively poorly in their longer-term adjustment. Kolman (1983) concluded from a review that there is a higher incidence of pre-existing psychological symptoms amongst burns patients. Williams and Griffiths (1991) similarly found that a third of their sample of 23 people (from a consecutive series of 55) had characteristics that they considered predisposing to the burn injury. Powers et al (2000) found evidence of more preventable injuries and more emergent psychiatric problems amongst the one-third of their sample who had a pre-burn psychiatric disorder. In a series of 100 people 83 injuries were evaluated as avoidable, most often the result of what was termed 'misjudgement'. This encompassed errors in technique in managing dangerous equipment or materials, but also deliberate self-emoliation in 6 people, and 3 people who were victims of assault/abuse, (considered a 'misjudgement by others'). Of those with a previous psychiatric history 41% had a new psychiatric
diagnosis following injury as opposed to 29% of the group who had no previous history. However, this paper arguably overstates the pre-disposition factor. Two thirds of the group with a previous history were known to have a problem with substance abuse. A frequent post-burn diagnosis was substance withdrawal, something that is hard to avoid for an addict who is faced with a prolonged stay in hospital.

In respect of consequential psychological problems Wallace and Lees (1988) found a prevalent depressed reaction to burn injury that increased rather than abated during the course of their study. A 31% prevalence at the time of discharge rose to 38% at six months and 40% at two years. A main shortcoming of this survey was their reliance on a brief self-assessment measure, the Hospital Anxiety and Depression Scale, (Zigmond and Snaith, 1983) for identifying caseness without any other source of supporting data. Altier et al (2002) surveyed 121 people who had suffered severe burns, (mean TBSA 35%) an average of 5 years after the burn, comparing them with an uninjured control group matched for age, sex, and education level. They found a 25% prevalence of various clinically significant psychological problems that was double that of the control group, but a measure of quality of life reflecting functional capabilities and life satisfaction showed no notable difference between the groups. This study is likely to have produced an underestimate of post burn long-term psychological morbidity because the researchers excluded individuals with any prior history of psychological problems.

Anxiety disorders, especially Post Traumatic Stress Disorder, (PTSD), have also been prominent in surveys of the effects of burns. Perry et al (1987) found 41% of a sample of 104 met formal criteria for PTSD. The presence of PTSD symptoms was seen in 63% of a series of 54 people consecutively admitted with burns conducted by Patterson et al (1990) but only 30% met formal diagnostic criteria. This was resolved by the time of discharge with no new occurrences seen in the
follow-up. However, in a further longitudinal study, (Perry et al, 1992), following 51 people, found a 35% prevalence of PTSD two months after injury, 40% at six months, and 45% at twelve months, reflecting a progressive worsening with the passage of time rather than recovery. Ehde et al (2003) followed-up 172 people at 24 hours, a month, and a year after injury. They found that more than half of their sample had intrusive recollections throughout the follow-up period and that persistent sleep disturbance and other anxiety symptoms were also common, although many were regarded as 'sub-clinical' in terms of the range and severity of the symptoms. The size of the injury did not predict these symptoms but PTSD symptoms present at 1 month was predictive of the outcome at a year post-injury. A longitudinal study of nightmares in 166 people who received treatment in a Swedish burns unit (Low et al, 2003) found these were occurring ‘frequently’ in 9% and ‘sometimes/seldom’ in a further 34%, an average of 11 years after the injury had occurred. Regression analysis revealed some association between burn size and the long-term risk of nightmares.

**Modeling Individual Psychological Reactions**

Review reports of the above studies provide the basis for models of the psychological impact of burns. Malt (1980) concluded that there was clear evidence of anxious and depressive reactions, effects on social life especially in respect of scarred appearance, and speculated about the effects of intense fear and threat to life as having an effect that is independent of the level of burn injury. The authors also speculated about the possibility of a 'psychosyndrome', a burn-specific condition developed as a long-term reaction. The evidence regarding PTSD has been reviewed by Baur et al, (1998) who confirmed varying but high levels of chronic symptoms. They concluded that the evidence for the influence of the severity of injury predicting long-term outcome was, at best, equivocal.

Bernstein (1976) referred to psychodynamic theory in describing a stage-based overview of the psychological response to burns. His model was based on
detailed and long-term casework rather than survey evaluation. The notion of a sequence of stages was taken up by Bereni-Marzouk et al (1981), by Watkins et al (1988), and by Roberts and Appleton (1989). These papers each set out their own descriptions of stages of psychological reaction, differing in terms of the concepts used and their timing. However, this kind of model was dismissed by Patterson et al (1993) on the grounds that they could find no supporting evidence of a sequence of psychological stages in their extensive literature review. Instead these authors introduced a pragmatic division of the evidence between successive stages of care. They addressed pre-burn psychopathology; critical care i.e. when survival is threatened and many patients need respiratory support; acute care when much of the skin grafting is undertaken; and lastly the post-discharge long-term effects. This review gave new emphasis to two issues with particular significance during hospitalisation. Firstly they referred to the phenomenon of delirium following burn injury that is sometimes labelled 'ITU (intensive treatment unit) syndrome'. This had been noted by Kolman (1983) and is described in more detail elsewhere e.g. Granberg et al (1996). Disorientation, confusion, hallucinations and other psychotic symptoms are said to result from the combination of the sensory bombardment of pain and constant noise from monitoring equipment, the sensory deprivation of an environment that lacks day/night differences, whilst also being unable to move, and having had high levels of opiate medication. Secondly, evidence was presented indicating that pain from therapeutic procedures such as dressing changes is even more distressing for patients than the pain of the burn injuries. They reaffirmed that there is an above-average level of pre-existing psychological problems amongst burns patients and evidence of diminished social involvement in the long term. They found no indication of any neuropsychological deficits resulting directly from burns. Evidence of prevalent anxious reactions (including PTSD) and depression showed overlap from hospital care into their longer-term category of burn effects but mainly in the first year after discharge. In their conclusions the authors argued for a shift of emphasis, away from post-burn psychopathology, concentrating
instead on positive coping reactions. They reviewed evidence of maintained self-esteem and quality of life, the beneficial effects of social support, their own findings of recovery from PTSD during hospital stay, and a consistent finding in most studies that, despite methods that focussed on psychopathology, a majority of respondents adjusted well in the longer term.

Tarrier (1995) in his review of the psychological sequelae covered the same evidence base and reflected similar conclusions about the nature of both the initial and subsequent effects. He drew a distinction between evidence in studies of fire disasters from the reactions of people who suffered their burns in other ways. Citing studies of fire-fighters involved in a bush fire disaster in South Australia (McFarlane, 1988) he argued that disasters produce a higher incidence of PTSD. One other difference was that where Patterson et al (1993) had observed that many psychological reactions including PTSD seemed largely transient, Tarrier concluded that the evidence indicates between 30% and 40% of people suffer long-term psychological disorders and that in many cases these follow a transient remitting-recurring pattern.

**Interpersonal Factors In Burn Care**

The argument to shift away from a pathological focus in burns psychology is repeated in subsequent commentaries, (e.g. Partridge, 1999) but both Patterson et al (1993) and Tarrier (1995) nevertheless concentrated on the cognitive and emotional effects of burn injury. A criticism of these reviews, when attempting to derive a model of acute burn care, is that they were limited to a mainly intrapsychic perspective despite considerable evidence in the literature of the importance of social interaction factors with burns.

Erving Goffman's essay on stigma (1963) and the work of Frances Cooke Macgregor (1979 and 1990) have given lucid examples of the subjective experiences of being noticeably different in appearance. Since then the summary
of experimental work set out by Bull and Rumsey (1988); the personal account of James Partridge in his book 'Changing Faces' (1994) and his work in establishing the charity-based support organisation of the same name; and the combined work and experience of these and other authors in the book 'Visibly Different' (1997) sets out a clear position, that visible scarring from burns, particularly facial scars, has considerable impact on encounters with other people. This body of work reflects the often mutually negative expectancies of those with a disfigurement and the people they meet, lesser degrees of spontaneous closeness in social encounters, and accounts of hostility, bullying, and rejection. Disfigurement has been described by McGrouther (1997) as 'The last bastion of discrimination'. Each of these authors identifies competence in social skills as an important variable enabling individuals to adapt and cope in contrast with others who have reacted with social avoidance and in other unsuccessful ways, (also Clarke, 1999).

The importance of disfigurement at the acute stage of care is uncertain. On the one hand, disfigurement concern is not prominent in the literature surveying psychological reactions during hospitalisation. On the other hand clinicians describing psychological care of burns, (e.g. Gilboa, 2001, Ambler, 1997, Bergamasco et al, 2002) and personal accounts, (e.g. Partridge and Robinson, 1995; Afari-Mintu 1997) place considerable emphasis on the impact of seeing one's own facial scars for the first time and on how this is handled. Usually burns units do not allow easy access to mirrors, an attempt to actively manage this first encounter.

There are a number of reports describing the clinical role of psychologists and psychiatrists in adult burn care that have drawn attention to the needs of spouses and other relatives, e.g. Bernstein (1976 and 1988), Gilboa et al (1983), West and Spinks, (1988), Antebi (1993), Franulic (1996) and Gilboa (2001). There are few systematic studies however. Shelby et al (1992) found high levels of anxious
and depressive symptoms with diminished immune responsiveness in a longitudinal survey of a small group of spouses and parents assessed 72 hours after admission to hospital and then 2-5 weeks later. Cella et al (1988) followed up 48 close relatives of burns patients, recording high levels of distress in the acute phase of hospitalisation. A third had case-level depressive symptoms on a standard measure at that point. Most recovered by 6 months when only 5% of a diminished sample had an entrenched psychological reaction. Patterson et al, (2000) found strong evidence of social variables influencing outcome. They followed-up 295 adults at 6 months, 1 year and 2 years after the injury. The respondents reported more distress and poorer quality of life than a carefully selected comparator normative sample. The level of distress was predicted in a regression model through a combination of social support (e.g. living with another adult at the time of the injury), prior psychological difficulties (e.g. having had psychological treatment in the year prior to injury), and medical variables, (e.g. TBSA). The conclusiveness of this finding was hampered by the lack of a standard assessment of social support however.

The descriptive accounts of the work of burn teams listed above also refer to psychological processes amongst nursing and other professionals. Lewis et al (1990) linked high stress levels with the care of pain, the death of patients, the challenge of non-cooperative patients, and conflicts within staff teams. Similarly high levels of staff stress were reported by Alexander (1993), and Steenkamp et al (1998). Furthermore, the erroneous beliefs of burn staff may distort their sensitivities to patients' needs. For example Patterson et al (2000) referred to a persisting staff attitude that the extent of a burn (TBSA) is a main predictor of pain and distress despite evidence to the contrary. Important misjudgements of patients' distress by burn staff have been linked to their length of professional experience and seniority. Adcock et al (2000) surveyed 50 patients and 75 burns staff, (nurses, surgeons, and occupational therapists), comparing staff projections and patients' own ratings of distress using the Beck Depression Inventory (Beck
et al, 1961) and a series of Likert rating scales of anxiety, depression, general mood, optimism, physical and social discomfort, covering a time frame of the previous two days. The comparison revealed systematic over-estimates by staff of their patients' distress, especially depression, and the under-estimation of patient-optimism. This was more pronounced amongst the staff with the longest burns experience. This finding is consistent with the spinal cord injury literature (e.g. Cushman and Dijkers, 1990). The authors concluded that misjudged expectations by burns staff of their patients potentially has a distorting influence on the outcome of treatment.

Another error of staff judgement has been described in the management of burn pain. Choiniere et al (1990) compared the estimates made by nurses of their patients' current pain intensity with the patients' self-ratings using visual analogue scales. There were 42 patients and 42 nurses in the study. Again, there was a consistent misjudgement that was greater amongst the more senior members of the burns team, but this time the trend was of professionals underestimating patients' pain and overestimating the beneficial effects of pain relief medication. Perry (1984) and Melzack, (1990) had drawn attention to under-medication for pain relief. In a review of the treatment of burn pain Latarjet and Choiniere (1995) cited a fear of opiate dependency amongst burn staff as a contributory factor despite the lack of any evidence of risk of inducing such dependency. They presented evidence that, contrary to the beliefs of many caregivers, pain does not steadily diminish with the passage of time after the burn. They set out a rationale that distinguished between background pain, procedural pain, and neuropathic pain. The significance of these were that the latter is not usually responsive to opiates and may persist in the long term, whilst the acute pain of dressing changes and other procedures during hospital care can be remembered by patients as the worst aspect of the whole episode of their injury and treatment. Since then this has also been found to be associated with poorer long-term adjustment and PTSD, (Ptacek et al, 1998).
**Predicting Psychological Reactions**

The earlier surveys set out above established that there exists a degree of predisposition to post-burn psychological reactions. Patients in an albeit crude category of having received psychological treatment in the past are at greater risk of prolonged distress. Some of the above surveys noted a predictive role of the extent of injury, usually TBSA, although others found no evidence of this. Several studies have considered cognitive appraisals/attributions and coping strategies as predictive variables. Tedstone et al (1998) carried out a multiple regression analysis on data from 45 people followed-up to 3 months post-burn. They found no notable trend of injury severity affecting psychological outcome and pointed to a proportion who, with burns of less than 1%, still suffered serious psychological consequences. Higher levels of distress in the first fortnight post-burn were associated with a worse psychological outcome at 3 months. Higher levels of acceptance of the injury and more positive appraisals about how they saw 'things working out' appeared to have a protective effect, whilst active emotion-focussed coping and problem-focussed coping beliefs were both associated with a poorer outcome. The authors speculated that it was premature to be resorting to such coping beliefs in the first 2 weeks, possibly an effect of higher levels of distress amongst those that did so, leading to greater psychological distress in the longer-term. However, the small sample size precluded the formation of any clinically predictive models.

A larger sample was studied by Willebrande et al (2002). Their postal follow-up of 161 people, at an average of 11 years post-burn, segregated 3 groups using cluster analysis. These were described as extensive, adaptive, or avoidant copers. These 3 groups were not different on demographic or injury variables but differed considerably on the outcome self-ratings of health status, PTSD
symptoms, aggressiveness, and neuroticism. Adaptive copers fared best and avoidant copers the worst. This was not a longitudinal study however and the coping characteristics described could not therefore be interpreted as predictive when these were being identified at the same point in time as the symptoms of psychological distress. Lawrence et al (2003) combined a moderate sample size with a longitudinal method in their study of 94 adults followed at 1-month and 6-months post-discharge. Using a path analysis they hypothesized a model embracing neuroticism, extraversion, active coping, avoidant coping, and social support, to predict PTSD symptoms. The model explained 29% of variance of PTSD symptoms at 1 month. Overall, the best single predictor of PTSD at 6 months was PTSD symptoms during hospitalisation. Although the latter detail was not surprising in view of previous findings, this model, modified post-hoc, demonstrated sufficient predictive power to justify replication in further research as suggested by Patterson (2003), in a supporting editorial, who argued for the inclusion of the compensation claim variable as an additional factor.

**Treatment Studies**

Although there is a sizeable literature outlining psychological factors in burn care there is comparatively little concerning psychological interventions. This has been highlighted by Pruzinsky (1998) in respect of disfigurement, by Patterson et al (1997) in respect of pain control, emotional adjustment, and rehabilitation, and by Ehde et al (2003) in respect of PTSD. Patterson has described psychological methods of managing acute pain during procedures using hypnosis, (Patterson et al, 1989) and Hoffman (2000) using virtual reality distraction, but these employed small samples and therefore present limited evidence.

There are two important exceptions to the lack of treatment studies with adults. The first is a report on the secondary preventive treatment of PTSD by Bisson et al (1997). This group followed the critical incident debriefing model described by
Mitchel (1983) for counselling disaster victims and workers. Although widely adopted this model had not previously been systematically evaluated. They followed 104 people to one year post-burn, 57 of whom had been randomly allocated for psychological debriefing with 46 as no-intervention controls. The control group fared better with only 9% categorised as having PTSD at 1 year compared to 26% of the intervention group. This may have been because the intervention disrupted adaptive processes that would otherwise protect against PTSD but the authors did not explore this possibility. There are criticisms of the study in that the randomisation failed to evenly balance the groups. People in the intervention arm had more severe burn injuries, lower social support, experienced a worse financial impact, and attributed greater blame to others. The findings were nevertheless against expectations and showed a trend for people treated by trained professionals to fare worse than those debriefed by lay individuals under professional supervision. The legacy of this trial is that the possibility of debriefing causing psychological harm has made it unlikely that any replication will be carried out, yet the findings were not sufficiently convincing for debriefing protocols to be abandoned by major incident response planners. Nevertheless, the study showed a stark failure of this intervention to prevent PTSD amongst a group of burns patients.

The second exception to the dearth of treatment studies has been the evaluation of a social skills-based intervention developed by the charity Changing Faces (Rumsey et al, 1986; Robinson et al, 1996; Clarke, 1999, Rumsey and Harcourt, 2004) regarding coping with reactions to disfigurement. This group have also reported on the evaluation of the work of a specialist NHS disfigurement support unit, (Partridge et al, 1997). Benefits are reported for social confidence, lower distress, and increased social engagement. These studies focus on later stage reactions to disfigurement however, which has less direct bearing on the acute care of burns.
In other respects the evidence supporting psychological interventions for acute burn care with adults has to be drawn from elsewhere. For example the treatment of PTSD has been reported by Foa et al (1999) and measures to prevent delirium are set out by Dyer (1995 a and b).

**Conclusions**

Since the time of the Coconut Grove fire disaster much has been compiled about the psychological impact of severe burns and a first impression of this is that a great deal is now known about the dreadful impact these injuries have on sufferers. This is misleading. The main reasons are that the quality of information and the direction and emphasis adopted by researchers in their conclusions can be called into question. The reasons are as follows:

Comparison between the main studies above is confounded by important differences between them. Firstly, many of the earlier studies used poorly defined methods and small samples. Secondly, the sample sizes when quoted above are the numbers who have completed these studies. The dropout rates reported in most trials are typically a third or more of those originally approached for inclusion, a problem that has consistently hampered research with this patient population. This raises concern about how representative the findings are for all burns victims. The next issue concerns the clinical criteria applied to psychological reactions that have changed considerably over the past 60 years, not least in respect of PTSD. This diagnosis came into use at the halfway point in this timescale and has had a major influence on methods of case definition in burns studies since then. It changed again with updating revisions of the source definition in the Diagnostic and Statistical Manual with the current version, DSM-IV (American Psychiatric Association 1994) introducing more stringent criteria. Many of Adler’s 1943 series described as either ‘fatigued/irritable/sleep-disturbed’ or having ‘anxiety neurosis’ would now be combined as having PTSD symptoms.
and then differently segregated according to the extent and severity of these symptoms. The definition of depression has also undergone revisions. This creates further difficulties for generalising findings between studies.

Next there is a concern regarding the measurement of psychological outcome. Few standard measures were available for early studies. General measures such as the Sickness Impact Profile (Bergner, 1981) and the Medical Outcomes Study SF36 (Ware et al, 1992) do not address some of the main issues such as the interpersonal effects of disfigurement. Some directly relevant scales have been developed (e.g. Blades et al 1982, Kildal et al, 2001, Willebrand et al, 2001) but on the evidence of the literature researchers seem reluctant to adopt burn-specific standard outcome measures consistently between studies. This also makes it difficult to compare findings.

Several of the above problems were raised twenty years ago by Eyles et al (1984) but still stand as general criticisms in the present review. The above methodological issues therefore raise doubts about the available evidence from which a theory of the psychology of burns might be derived. In discussing this evidence the majority of reviewers have continued to focus on unravelling a psychopathology of burns, pursuing the nature and indicators of unsuccessful adjustment. This approach has provided some reasonably reliable answers to the main questions about psychological issues for the acute care of adult burn victims. These can be summed up as follows:

*What are the psychological effects of severe burns?*

During the acute phase many patients experience life-threat, raised arousal level, delirium, anxiety, sleep disturbance, intrusive re-experiencing of the injurious event, depression, the challenges of coping with pain from wounds and from medical procedures, seeing their disfiguring scars for the first time, the loss of fingers or limbs with loss of functional capabilities, bereavements relating to the
accident, high distress in family members, and difficulties with communicating pain and distress accurately to professional helpers. Any of these except delirium can persist in the longer term when the interpersonal impact of scarred appearance and social withdrawal can also become a serious problems. Each of the above is found amongst a significant minority of burn victims; estimates range up to 40%. The majority however do not develop these psychological reactions. No evidence-based model of psychological effects has been developed. The notion of a stage-based adjustment process adopted by some researchers, similar to descriptions of bereavement, is not supported by evidence from any formal evaluation.

None of the list of effects are found uniquely in burn injury and there is no evidence of a burns 'psychosyndrome' as suggested by Malt (1980). However, this conclusion risks minimising the psychological needs of burns victims during hospitalisation. In a survey comparing the long term outcomes of 91 burns patients with other medical patients having 41 different conditions Doctor et al (1997) showed that a comparatively good outcome is achieved one and then two years after the burn injury. They nevertheless drew attention to prevalent distress in the earlier stages pointing out that if this is evaluated using conventional DSM psychiatric criteria many would be regarded as 'subclinical' against any single diagnosis. The clustering together of different psychological symptoms in burns patients is significant. There is undeniable suffering for a majority of people in the acute phase that warrants specialist attention. There is also evidence that this can be systematically misjudged and mismanaged by professionals.

Is it possible to predict which people will develop adverse psychological reactions?
No. Contrary to a lay belief but in line with findings from elsewhere in health psychology most studies indicate that the extent of injury does not in itself predict the extent of psychological distress. Many people with small burns experience a
severe psychological reaction and many profoundly burned individuals fully adjust to their injuries. Pre-injury psychological problems and PTSD symptoms during hospitalisation are associated with poorer psychological outcome. Recent research findings are that a composite of injury, initial distress, attributions, and coping beliefs provides a risk model of long-term psychological adjustment but this has not yet been adequately validated.

Are there effective treatments for psychological reactions?
There are some but overall there is insufficient evidence to draw conclusions about this question. A widely used method intended to prevent PTSD in burn victims was found not to work in one trial. Small studies of psychological methods of acute pain management have demonstrated benefits. Social interaction skills training has been found to be helpful for coping with the interpersonal effects of facial scarring at a later stage after hospital care has ended. Psychological methods of treating PTSD evaluated for other settings have relevance for burn care as has the evidence for the management of delirium.

Is there a model of psychological care for specialist burns units?
There are several descriptive accounts in the literature noted above e.g. Gilboa (1983). These have now been superseded by a recent British Burn Association review report on the NHS treatment of burns (BBA, 2001). This proposed a national burns strategy with closer integration between specialist centres. This report incorporated a model of psychological care during hospitalisation with a set of associated standards. These were based on the evidence above and, if implemented, will provide a more solid foundation from which the future provision of care can be evaluated, with greater uniformity of selection, measurement, and clinical protocols.

Future psychological research is likely to focus on composite models of risk such as Lawrence et al (2003), outlined above, as a means of understanding individual
needs. The future practice issues that derive from this review mainly concern how
a psychologist in a burns team can best proceed when confronted by obvious
suffering but with so little solid evidence regarding interventions. For these
purposes the conclusion that there is no unique psychology of burns is helpful.
Treatments have been developed and evaluated elsewhere and can be applied in
respect of each of the main psychological issues that arise in burn care as
referenced above. In view of staff and other interpersonal issues highlighted
above there are also clear grounds for developing systemic interventions in this
setting. The main cautionary conclusions are firstly, that most people successfully
adjust, so their adaptive processes need to be supported rather than disrupted;
secondly, that there are some indications that professionals can lose sensitivities
to patients' pain and distress as they accumulate experience; and thirdly that
some psychological interventions may cause harm. The BBA report advocates
close clinical networking between centres in the future and if the facilities
materialise then working partnerships will replace the sense of professional
isolation that many burns specialists have experienced in their work. There is
also a new ethos of much closer involvement of users in service planning,
provision, and research. The role of Changing Faces is a prominent example of
this. Echoing Patterson (1993) who criticised the emphasis on psychopathology,
they have added weight to the demand for a different approach to care,
(Partridge, 1999). This is to uncover the essential characteristics of successful
adaptive reactions to severe burns, achieved by so many when the odds seem
stacked against them; understanding the nature of resilience and hardiness;
using these as the source of guidance for the next stage of development of
psychological methods of burn care.
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APPLYING THE COGNITIVE THEORY OF DEPRESSION
TO THE ELDERLY: THE VALIDITY AND UTILITY
OF COGNITIVE SELF-ASSESSMENT MEASURES

NICHOLAS AMBLER

Supervisors:
Dr. J.M.G. Williams
Ms. J. Wheatley

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University of Newcastle upon Tyne.

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ABSTRACT

Depression is a major clinical problem amongst the elderly. Discussions of its origins generally emphasize age-related changes. Strangely there is little recognition of the cognitive theory of depression in this context. This is despite the popularity of the theory as a model from which effective treatment strategies have been developed.

Cognitive self-assessment scales can be used to evaluate the appropriateness of the theory. However it is not known how valid or usable these measures are with elderly people. This study involved the development of five scales in this context and considered their validity. Modifications were described that increased their utility. Results indicated the need to standardize the scales for use with elderly respondents. Some evidence for the validity of the cognitive theory emerged. Discussion included the clinical and research implications of these findings.
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INTRODUCTION

The Prevalence and Aetiology of Depression in the Elderly: Some Remarks

The limitations and criticisms that have been levelled at the methods used in many research studies of the aging process are equally cogent for the foundation of knowledge concerning depression in this age-group. These methodological issues are reviewed at length by Kausler (1982) but in this context can be simplified as mainly concerning case finding methods, variations of the diagnostic and measurement methods, and in the definition of the disorder.

Studies that draw from the general population have invariably led to estimates of prevalence far in excess of those derived from head-counts of clinical populations. The inefficacy of a health service in reaching all of those who may be clinically depressed in its catchment population is an obvious source of error that will lead to underestimates of prevalence. However the use of symptom counts in general population surveys may have led to an overestimate of prevalence if somatic signs have been included as symptoms. These are arguably the simple result of declining health in later life in many cases, rather than the manifestation of a depressive illness, (Gurland 1976; Zemore and Eames 1979).

A further difficulty arises from the use of cross-sectional sampling method. Transient and mild episodes are reported to be common amongst the elderly, sometimes lasting only days, whilst persistent and more severe depressions are a much less frequent experience, (Pfeiffer 1977). Cross-sectional sampling without follow-up of cases would lead to an overestimate of prevalence. Also, the use of a milder level of intensity of depression as a criterion would have the same effect,
Reported figures for prevalence of depression in the over-sixty year olds, or the over sixty fives have ranged from 2% to 10% in European studies, and up to 65% in the United States, (Georgotas 1983). Although it is evident that more careful methods and analyses are required to give a more reliable estimate, it is also clear that depression is a prominent, arguably the most prevalent, health problem for the older age range of the adult population, (Georgotas 1983, Pfeiffer 1977, Williamson 1978).

The symptomatology of depressive illness in the elderly is usually described by dividing physical and psychological features. The former might comprise loss of appetite, loss of weight, sleep disturbance and fatigue, constipation, inactivity, and sometimes severe headache or other pain. Withdrawal, apathy, great sadness or flattening of affect, slowing of cognitive functioning, pessimism and lowered self esteem may each emerge in the psychological profile. All of these are also features of depressive illness in younger adults and comparisons between the age-groups have drawn some blurred distinctions. For example Goldstein (1979) described shallower symptoms with more chronicity amongst the aged, whilst others (e.g. Hussain 1981) assert that there is a more biological (somatic) involvement.

Even without recourse to models of biochemical or structural change during later-life development there is no shortage of very plausible psychological explanations for the etiology of depression in this age group. Most of these are formed around descriptions of personal and social change during this time of life. Pfeiffer (1977) summarizes depressions as 'basically pathological responses to loss.' This is certainly a main theme in the analysis of this
period of development. After retirement there are typically losses of income, lifestyle and standard-of-living, status and recognition. Apart from the possible death of a spouse, mortality amongst relatives and friends increases. Health and physical performance declines, sometimes leading to disability and consequential handicaps. These are often loss of mobility and independence leading to social isolation and loneliness. Decline of cognitive performance and the lowered expectations and prejudices of society, families and elderly people themselves are all types of loss. These may have led Lewinsohn and McPhillamy (1974) to draw direct comparison between the observed attributes of younger depressed adults and the behaviour of most elderly people.

If such severe and extensive losses are the ubiquitous experience of the elderly, depressive reactions are not. This fact forces a refinement of the model of loss to one of failure of adjustment. This can form an adequate (although simplistic) explanation of the clinical experience of many depressions occurring in this age-group (e.g. bereavement). However there are many other cases to which the model cannot be applied. Other behavioural interpretations have been proposed to explain depressions in the elderly. Burton (1979) and Simpson, Woods and Britton (1981) considered the model of engagement/disengagement that had been synthesized from models of 'inadequate reinforcers,' 'loss of reinforceable behaviour,' 'loss of reinforcer effectiveness,' and 'learned helplessness.' Whilst this had gained support elsewhere in the literature these authors found no relationship between disengagement and measures of depression. Instead they suggest that the way in which an individual construes a situation may be
more fundamental to the aetiology of depressions in the elderly.

Other such cognitive interpretations in this context are
difficult to find elsewhere in the literature. This observation
is also made by Leng (1982) in a recent review of behavioural
treatments applied to the elderly. When depression is discussed
it is generally from the premise that the experience in this
heterogeneous group is somehow inevitably different from the
clinical depressions experienced by individuals of a younger age.
Perhaps this has arisen from the evidence suggesting depression
is a more common condition amongst the elderly. Therefore
explanations are required for a relative difference of frequency
between age-groups. Perhaps it has arisen because interpretations
are very easy to form from the characteristic life experiences of
the elderly. However, even without such experiences depression
is a major clinical problem amongst younger adults. There is no
evidence or good reason to presume that the origins of these
depressions should not also apply to an older age group.

It is particularly surprising that the cognitive theory of
depression is conspicuous by its absence from discussions of the
condition amongst the elderly. Elsewhere this model has figured
prominently during the last decade. It has also formed the
theoretical basis from which a treatment approach has been developed.
Evaluations of this treatment indicate it to be successful in
alleviating clinical depression, (e.g. Hollon and Beck 1979,
Blackburn et al 1981). The therapy focusses on the hypothesized
functional components of depression which it is argued are evident
in the thoughts, statements and behaviour of the depressed patient.
All these attributes are amenable to assessment by standardized
methods.

Review of the literature that has developed around this theory has revealed only one reference to work with the elderly (Emery 1981) but no balanced discussion of the appropriateness of this model in this major clinical context. This project is intended as an initial step towards that end.

The means by which the appropriateness of the cognitive model can be evaluated with the elderly would seem to be found in the application of the standardized assessment measures used in the therapy. Before consideration of these a brief outline of the cognitive model is required.

The Cognitive Model Of Depression

The cognitive theory of depression has been described and developed principally by Beck (e.g. 1980). It is formed from recordings of the statements of depressed patients and describes cognitive dysfunctions.

A depressed person is said to exhibit a cognitive triad, an unrealistically negative view of self, world and future. This is based on schemas which are inflexible general rules or assumptions. For example, "I must be good at my job to enjoy life." These schemas determine the way information and experience is screened and evaluated, and for the formation of judgements. The operation of these schemas brings about logical errors in thinking such as the misinterpretation of events which in turn reinforce the cognitive triad. Therefore the depressed individual exhibits rational responses (depressive behaviour) that are based on false information and processing. To extend the example above, if a minor part of job performance is criticized this may be attributed
unnatural importance. The schema then applied determines, "I am now no good at my job, therefore I do not enjoy life."

Several validation studies have demonstrated close correspondence between predictive features of this theory and the conduct and performance of depressed individuals, (e.g. Hammen & Krantz 1976; Beck, Kovacs & Weissman 1975; Loeb, Beck & Diggory 1971; Neuringer 1966).

The various therapeutic techniques that have developed around this theory involve the patient in the identification and testing-out of these dysfunctional cognitive systems. Severity of depression and change during therapy are usually measured by successive applications of the Beck Depression Inventory or other such instrument. Self assessment schedules are often used during treatment since they aid both the client and therapist in the identification of cognitive distortions and as evidence of change and of the achievement of therapeutic goals.

The Use Of Self Assessment Scales To Find Evidence Of Cognitive Dysfunction

Recent reviews of cognitive assessment methods (e.g. Kendall & Korgeski 1979; Rhem 1981; Shaw & Dobson 1981) illustrate a wide range of measures aimed at separate features of depression. To some extent these represent the various facets of the cognitive theory, e.g. a measure of hopelessness is aimed at the respondent's view of the future, part of the cognitive triad. However the components described in the cognitive theory are not entirely independent. Neither are the core constructs of the various assessment measures that are available. It is therefore not possible or appropriate to try to compile in piecemeal fashion a complete representation of the theory in the form of a battery of cognitive
measures. Instead it is possible to apply several such instruments, each used within the terms of their design to assess their individual validity and utility.

In a complete evaluation of cognitive therapy with depressed elderly people all available cognitive measures might be included. Such a large scale study is ill-advised however without prior research indications of appropriateness in a smaller project. Furthermore the applicability of this type of measure with elderly people also requires prior consideration.

**Age-Related Difficulties In Assessment**

It is a typical flaw of assessment instruments that they are not standardized for use with the whole adult age-range. It is usually assumed that the old are the same as the young yet research in cognitive development provides a great deal of evidence to the contrary. Sensory deterioration and changes in cognitive performance and some changing aspects of personality may all have a bearing on test results.

Sensory declines are extensively reviewed by Kausler (1982) and in Birren and Shaie (1977). These indicate age-related decrements in the perception of speech, and reduction of pupil size and loss of lens transparency which impair vision. The same authors draw evidence from many sources that indicate deficiencies in perceptual-manipulative skills, the processing of aurally presented information, and of short-term memory. Different test-taking motivation, an increased tendency to attempt to please the examiner, greater cautiousness, and susceptibility to distraction and fatigue are all highlighted.

These points all represent possible limitations in assessment.
They will not necessarily interfere with responding to cognitive assessment measures but their potential to do so requires practical consideration. On the other hand these limitations might represent an alternative explanation for the scarce evidence of cognitive treatment methods in use with the elderly. As already indicated cognitive therapy makes frequent use of self assessment scales. Difficulties in using these may have been regarded as a contra-indication for cognitive treatment.

Two phases are therefore required in this project. The first phase is a consideration of how usable self assessment scales of cognitive dysfunction are with a group of elderly people. Where practical problems are identified modifications will be considered with the aim of developing an operable method for the second part of the study.

This second phase will consider the validity and utility of these scales both as measures of severity and of cognitive dysfunction in elderly clinically depressed patients. Since many elements in these scales arguably reflect the results of age-related changes and not depression a control group is included. The results from these elderly non-depressed hospital patients will be used to consider the validity of both the overall scores derived from the scales and also their separate components.
PHASE 1

Aims

The identification of practical difficulties in the application of self assessment measures. Adaptation of format to facilitate completion of the scales. The development and refinement of methodology for phase 2 of the study.

Selection Of Scales

Six scales were selected for initial inclusion in the study. As already indicated these were not intended to cover all facets of the cognitive theory. However they do emphasise different areas. Each scale is briefly described and a copy included in the appendix.

The Beck Depression Inventory, B.D.I. (short form) Beck & Beck (1972)

This 13 item scale was derived from a multiple regression analysis of the original 21 item scale. Each item relates to a symptom of depression. The four response alternatives are scaled from 0 to 3. It was conceived as a rapid screening instrument for assessing severity of symptoms. Cut-off scores are suggested that categorise the total range of 0 to 39 into groups of none, mild, moderate and severe. There is a wealth of data concerning validity and reliability. The scale is extensively applied in research and clinical practice.


This 20 item scale was derived from the statements of patients who had made a recent suicide attempt. Each item is a statement, either optimistic or pessimistic, concerning attitude to the future. Respondents decide if they agree with each statement, 'true' or 'false.' The scale was designed to assess suicide risk
and cut-off scores are suggested that categorise this risk.

The face validity of this test must be questioned in this context compared to a younger age-group. The elderly realistically have much shorter lives ahead of them and therefore their attitudes towards the future might reasonably be expected to be different. This may or may not lessen the significance of what may seem to be hopelessness amongst the elderly depressed. Hence the importance of comparison with a control group.


This is a 25 item scale in which respondents compare themselves with others for each of a set of constructs concerning abilities, appearance, and personality, (e.g. "good natured"). There are five response choices for each item. These range from, "less (or worse) than anyone else I know," to, "more (or better) than anyone else I know." These are scored -2 through to +2 and can be summed to give a single 'self concept score.' The test is conceived to be sensitive to an unrealistically negative view of self in depression. An alternative summary score is in the addition of only those responses on the negative pole for any item.


This scale is made up of thoughts 'that pop into people's heads' during episodes of depression. The items are made up of those thoughts that best discriminated between depressed and non-depressed subjects. The respondent is required to describe how frequently, if at all, each negative thought occurs. These are categorised, "not at all," "sometimes," "moderately often," "often," or, "all the time." These are scored 0 to 4. These automatic thoughts, beliefs, or self-talk are conceptualised as dysfunctional and negatively
reinforcing in the cognitive model of depression. These can be considered as specific targets for 'testing-out' in therapy. Also the number of negative thoughts can be summed as a measure of depression.


This test is aimed to assess attributional style. Each of 30 cameos describes an experience that might occur in everyday life. The respondent is first required to imagine this event and then to select one of four different interpretations. This response is scored in the range 0 to 3, a low score for a positive interpretation, a high score for a negative one. The 30 items cover events related to self, world and future, (10 items each). These are each further divided into 5 which are mildly pleasant and 5 mildly unpleasant. The responses represent a range from strong internal to strong external attribution. The cognitive model predicts that a depressed individual would make strong self attributions for unpleasant events and strong external distancing attributions for pleasant events. As an example, an item categorised as pleasant and relating to self:

A Person That You Admire Tells You That He/She Likes People Like You.

(a) That's a nice thing to say.
(b) I'm not sure he/she really means it.
(c) He/she must like me a lot.
(d) I wonder if he/she is being sarcastic?

Response (c) is an internal interpretation and positive for this item. Response (d) represents a distancing of positive information regarding self and a negative interpretation. This latter choice
is therefore indicative of a depressogenic cognitive system of attributions. Mean scores presented with the test illustrate broad distinctions between the summed scores of depressed patients and other groups.

The original paper suggests that the 30 cameos should reflect everyday life situations. Several of these refer to work, driving, or aspects of social life that it was felt are outside the normal experience of most elderly people. Small alterations were therefore made to these items. Where possible the central theme was maintained. The original and adapted forms can be compared in the appendix.

The Dysfunctional Attitude Scale, D.A.S, Weissman & Beck (1978)
This 100 item scale is aimed to describe the link between certain attitudes and the tendency to become depressed. These are theoretically established in those vulnerable to depression as well as the depressed. Each item is a statement to which the respondent indicates degree of agreement/disagreement on a seven-point scale. A total score is summed from these responses.

Subjects
Five volunteer helpers from Age Concern, Newcastle, and one patient with a main diagnosis of depression from Newcastle General Hospital agreed to take part. Three were male, three female. All were aged between sixty and eighty five.

Procedure
Subjects were asked if they would be willing to take part in the study after a brief explanation of its aims. The usual considerations
and conditions required for testing were observed. Although not all of the subjects undertook all six measures each attempted at least three. Initially the scales were administered in their original paper and pencil format. Subjects were closely observed whilst completing the tests. All errors, difficulties, questions and objections were recorded. Modifications to improve the ease of administration were made throughout this part of the study rather than at its end. For this reason, and because no two subjects completed the same set of measures in the same order only a summarized analysis of the practical difficulties is presented.

Summary Of Findings And Modifications

The usual testing requirements of a quiet well-lit room proved of great importance because of hearing and eyesight difficulties. Two subjects were still unable to read the typescript. Reading out each item to the subject did not easily solve the problem. For example with the B.D.I. having listened to the end of the range of response choices these subjects had forgotten the first part. It was decided to reproduce the scales in large print and to routinely read aloud each item.

The instructions for each test were not easily understood. This problem was improved considerably by the addition of an example item at the start of each test.

Some subjects displayed what appeared to be a poor memory for the test instructions. This created a vicious circle in which the subject would then re-read the instructions and lose track of the current item or choice of response. Furthermore, some subjects
often announced a decision and then continued to the next item without recording the response. Some other items, and in one case a complete page, were accidentally overlooked. It was decided to print each item on a separate card and to control presentation so that only one item at a time was visible. This removed the distraction of adjacent items. The choice of response could then either be recorded by the experimenter or sorted by the subject against response headings also written on cards. In this form instructions also became more self-explicit and less of a demand on memory.

Difficulties with specific measures were greatest in the case of the D.A.S. Problems with its complexity might have been overcome but it proved far too long to administer. After three consecutive failures it was discarded from the method.

Considerable difficulties also arose with the A.T.Q. Subjects struggled to grasp both the choice of responses and the transformation of these into a numbered scale. This was tackled by dividing the decision into two parts. Firstly subjects sorted the thoughts according to whether or not they ever occurred, 'true' or 'false.' They then re-sorted the 'true' thoughts into the four categories of frequency. By writing these categories on separate 'heading' cards the numbered scale was no longer required.

In the writing of cards for response headings for the B.S.C.T. two types of phrasing for these had to be reduced to one type. This forced some alteration of the wording of items. These changes can be examined by comparison of the original and modified forms in the appendix.

Some difficulties arose with the content of the measures. Firstly, two subjects repeatedly remarked that they did not think
ahead to the future when completing the H.S. Another difficulty arose with the adapted cognitive style test (A.C.S.T.). Two subjects had difficulty with several items because the situations were outside their experience and they were unable to imagine them, (e.g. serving on a stall in a church fête). Similarly in the B.C.S.T. one subject felt unable to make judgements about himself relative to others. This might be regarded as a problem of abstraction. There were no apparent practical solutions to these problems. Rather, they were regarded as related to the content of the measures and are considered in the second phase of the project. Finally two items in the B.S.C.T. were rejected or objected to as inappropriate by all the subjects that undertook the test. These were "sex appeal" and "athletic." It was decided to exclude these from the scale.

Comment

Except for the D.A.S., modifications of format overcame the practical difficulties that were identified. There was no evidence of fatigue. The time taken to complete a scale appeared to be related to its difficulty for each subject. It was therefore decided to include this variable as part of the evaluation of the scales.

Subjects tended to verbalize their reasoning whilst undertaking the assessments. As well as providing some additional insight this presented an opportunity to check that responses were correctly sorted. This cross-checking was therefore incorporated into the method.
PHASE 2

Aims
To consider the validity of the cognitive theory of depression in the elderly using a set of cognitive self-assessment procedures.
The evaluation of individual scales as measures of depression.
The evaluation of individual scales in the identification of cognitive distortions.

Subjects
Consultant and nursing approval was obtained to approach patients attending Brighton Clinic psychogeriatric day unit for the depressed group and the Wingrove Clinic day unit for the control group. Both are part of Newcastle General Hospital. The normal assessment procedure in both of these clinics includes screening for the full range of possible medical and psychiatric conditions. This would normally exclude very severely depressed or suicidal patients who would receive treatment elsewhere. However the project was approved on the understanding that should an assessment reveal a very severe or suicidal profile then this fact would be immediately referred to the medical and senior nursing staff.

The Depressed Group
These patients had a main diagnosis of depression which was not complicated by any functional, organic or mentally handicapping condition. Diagnosis in settings such as this is notoriously unreliable, (e.g. Hoffman 1982). However the principal error associated with depressive pseudo-dementia does not affect the study. Such errors might have led to some depressed patients not
being considered but would not lead to inappropriate inclusions. Furthermore the inclusion of a clinical psychologist's assessment in the diagnostic process in this clinic is likely to have enhanced its accuracy.

As an additional support to the project the Senior Registrar in the unit carried out a Hamilton Rating Scale (H.R.S.) assessment for depression (Hamilton 1960, 1967) for every patient in the unit during the period of study.

The Control Group
These patients were attending the Wingrove Clinic for non-psychiatric physical illnesses. Only those with no psychiatric history and no observed major cognitive impairment or signs of depression were approached to take part. These distinctions were made from medical notes, clinical assessment, and the observations and intuitions of the medical and nursing staff.

The experimenter did not contribute in the selection process for either group.

Procedure
Each of the subjects was asked if they would be willing to take part in a research project that would involve the completion of five questionnaires. No indication of the aim of the project was provided prior to testing. It was explained that some of the questions were, "very direct" and that there was no obligation to answer all of them. It was suggested to subjects that testing would probably take two sessions and that should they feel tired at any stage the session would be discontinued.
The scales were administered in the order: B.D.I.; A.T.Q.; B.S.C.T.; H.S.; a.C.S.T. Test times were recorded discretely. These included the instructions and example at the beginning of each assessment. Recording of the subject's responses was performed by the experimenter either during testing, (for B.D.I. and a.C.S.T.) or from the sorted piles of cards after the session was completed, (A.T.Q., B.S.C.T., H.S.). Questions, objections and difficulties were noted. Where the remarks made spontaneously by subjects did not agree with their sorted responses the experimenter drew attention to the discrepancy. A correction could then be made, and a record taken of the adjustment.
RESULTS

Altogether thirty-five people were asked to take part in the study. One person from the Wingrove Clinic refused leaving a total of thirty-four, seventeen in each group. Although there was no attempt to balance the two groups for the ratio of the sexes there were six males and eleven females in each. This also reflects the ratio of the sexes in this age-range of the general population. The age distributions were comparable as shown in fig.4 of the appendix. The mean age being slightly lower in the depressed group, 76 years as opposed to 81 years. The diagnosed illnesses of control group patients included heart disease, arthritis, Parkinson's disease, diabetes with decubitus ulcers, and combined causes of immobility.

In most cases testing was completed over two separate interviews, the first of these lasting up to an hour, the second up to forty minutes. Five subjects in each group completed all the tests in a single session, the fastest doing so in less than forty minutes. The first session was often ended because of the demands of the ambulance services and hospital meal times. Therefore only statistics regarding the duration of individual tests are considered. Analysis of overall duration of testing would be misleading.

One subject from the depressed group refused to complete two of the five scales (B.D.I., H.S.) because the experience proved to be too upsetting. One subject in the control group became very distressed whilst completing the first of the series, the B.D.I. The responses selected by this subject indicated a severe depression and produced the highest overall total for this
scale from either group. This was reported to the medical and
senior nursing staff and no further assessment of this subject
was undertaken. These two instances were exceptions however, and
subjects generally expressed interest after taking part in the
study.

Four other subjects, two from each group, did not complete
the full set of measures. (Two missed one scale, one subject
missed two, and one subject missed three). This was simply
because a second assessment session could not be arranged.

The results for each scale are presented separately. In
each case the discriminant validity of total scores is considered
first. The validity of individual items in forming a profile of
depression in this age-group is considered by examining item
selections in the control group, and then discrimination between
the groups for each item. The external validity of the scales
is considered by their intercorrelations with each other. In the
depressed group the Hamilton Rating Scale scores are also included.
These all have implications for the validity of the cognitive
theory with this age-group and this is considered in the discussion
section.

Two statistical tests are used frequently in the analysis.
These are the Wilcoxon Rank-Sum test and the Fisher Exact Test.
The method for these is described by Leach (1979). The value of
probability adopted as the criterion of statistical significance
for the rejection of the null hypothesis was \( p = 0.05 \).
THE BECK DEPRESSION INVENTORY, Short Form

Completion of the test

All subjects in both groups undertook this test. One depressed group subject was unable to complete six of the thirteen items and was therefore excluded from the analysis leaving sixteen depressed group and seventeen controls who completed the assessment.

Calculation of Test Scores

The four ordered response alternatives for each item were assigned a score from 0 to 3. These were summed to give a total score that could range from 0 to 39, higher scores indicating increasing severity of depression.

Group Comparison of Total Scores

The total scores in each group are shown in table 1 ordered by the categories suggested in the validation study for this scale. These results are also illustrated in fig.1.

Overall the scores ranged from 0 to 25. A difference can be seen between the two groups both in the raw data and in its form in fig.1. This is further supported after the application of the Wilcoxon Rank-Sum test. The null hypothesis is rejected with a criterion of $p < 0.05$. The clinically depressed group seem to be producing higher scores on the scale. There is considerable overlap however, and when the data are re-analysed by the suggested categories, also shown in table 1, (again using the Rank-Sum test) the null hypothesis can no longer be rejected. Half of the control group are categorised as at least mildly depressed. Even when the control
group subject who had the highest score of 25 (referred-on from this project) is excluded from this analysis the criterion of $p = 0.05$ is not reached.

Fig. 1: Cumulative Frequency Distributions Of B.D.I. Scores In Each Group
<table>
<thead>
<tr>
<th>Category</th>
<th>Score Range</th>
<th>Depressed Group</th>
<th>Control Group</th>
<th>N = 16</th>
<th>N = 17</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Individual Scores</td>
<td>Individual Scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Depressed</td>
<td>0 - 4</td>
<td>0,3,4,4</td>
<td>0,0,1,1,3,3,3,4</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Mildly Depressed</td>
<td>5 - 7</td>
<td>5,5,6,6,7</td>
<td>5,7</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Moderately Depressed</td>
<td>8 - 15</td>
<td>8,9,14,14,15</td>
<td>9,9,10,11,13</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Severely Depressed</td>
<td>16+</td>
<td>16,19</td>
<td>25</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1:
Beck Depression Inventory (Short Form) Scores In Each Group, Ordered By Test Score Category

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<th>10</th>
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<th>12</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sadness</td>
<td>Pessimism</td>
<td>Sense of Failure</td>
<td>Dissatisfaction</td>
<td>Guilt</td>
<td>Self Dislike</td>
<td>Harm</td>
<td>Social Withdrawal</td>
<td>Veness</td>
<td>Self Image</td>
<td>Difficulties</td>
<td>Change</td>
<td>Culty</td>
</tr>
<tr>
<td>Depressed (N=16)</td>
<td>9</td>
<td>10</td>
<td>1</td>
<td>13</td>
<td>4</td>
<td>9</td>
<td>4</td>
<td>7</td>
<td>6</td>
<td>4</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Control (N=17)</td>
<td>8</td>
<td>5</td>
<td>2</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>6</td>
<td>7</td>
<td>2</td>
<td>12</td>
<td>11</td>
</tr>
</tbody>
</table>

Table 2:
Beck Depression Inventory: Number In Each Group Selecting A Scoring (Depressive-Type) Response For Each Item
(* Fisher Exact Test  p < 0.05)
Comparison and Analysis if Single Items

By combining all responses that were not in the '0' rated category for each item the profile of responses in each group can be considered (see table 2). This shows the frequency of depressive signs in the control group. The specific items that best differentiate the two groups can also be distinguished.

Firstly in the control group nearly three-quarters noted "decline in ability to work" and "fatigue." For nine out of the thirteen items more than a quarter of the group gave a scoring response.

Secondly the largest differences in responding between the groups were for items 2, 4 and 6, namely 'pessimism,' 'dissatisfaction,' and 'self dislike.' When these are analysed using the Fisher Exact test only for the item 'dissatisfaction' can the null hypothesis be rejected. Responding on the other ten items in the scale was very similar between the groups.

This remains the case when the data is studied in the form of responding on the full range of response alternatives, 0 to 3, rather than the '0' or non 0' categories shown in table 2.

Ease Of Administration; Comment

Data concerning the time taken to complete the test is shown in table 3. There is no marked difference between the groups and the overall average of just over eight minutes reflects how straightforward the test was to administer. This is only slightly slower than the time suggested by Beck & Beck (1972) and is probably the result of both adding an example item and reading out the test to the subjects.
<table>
<thead>
<tr>
<th>Test</th>
<th>Depressed Group</th>
<th>Controls</th>
<th>Overall Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>Mean</td>
<td>Range</td>
<td>N</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------------</td>
<td>----------</td>
<td>--------------</td>
</tr>
<tr>
<td>Beck Depression Inventory (short form)</td>
<td>16   8m</td>
<td>16 (20-4)</td>
<td>17</td>
</tr>
<tr>
<td>Hopelessness Scale</td>
<td>15   8m</td>
<td>16 (20-4)</td>
<td>16</td>
</tr>
<tr>
<td>Automatic Thoughts Questionnaire</td>
<td>17   15m</td>
<td>20 (25-5)</td>
<td>15</td>
</tr>
<tr>
<td>Self Concept Test</td>
<td>15   12m</td>
<td>23 (30-7)</td>
<td>16</td>
</tr>
<tr>
<td>Cognitive Style Test (adapted)</td>
<td>14   20m</td>
<td>24 (36-12)</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 3:
Mean And Range Of Test Times (minutes) For The Depressed And Control Groups On Each Scale
Serious difficulties in administration arose for two of the thirty-four subjects. Both became distressed by the questions. One who completed produced the highest total score as mentioned earlier. The other who discontinued after answering seven out of the first nine items from these alone had a score of 18. Prorating suggests there might have been a score of 33. Rather than these simply being a problem in the form of the test administration it would seem that extreme depression was brought out by the test. In the case of the control subject this had hitherto gone unnoticed.

For the less extreme cases the B.D.I., on the evidence of these data, seems suspect. A large number of the control group fall into a 'depressed' category and a large proportion of the same group gave depressive-type responses to a majority of the test items, particularly the two somatic symptoms. In other words if it is assumed that the diagnostic distinction between the groups is correct then the measure tends to falsely indicate depression amongst non-depressed elderly people. Further comment on this appears later in the text.

THE HOPELESSNESS SCALE

Completion Of The Test

One subject in each group did not undertake the test. One of the depressed group rejected nine of the twenty items and was excluded from the analysis. One subject from the same group rejected a single item, and a control subject rejected two items. Neutral scores were assigned in each case. Hence totals were calculated for fifteen depressed group and sixteen control group subjects.
Calculation Of Test Scores

There was a simple true/false response alternative on this scale. 'Hopeless-type' answers scored 1 and neutral or positive attitude answers scored 0, giving a possible range of 0 to 20 for the total score.

Group Comparison Of Total Scores

These are shown in table 4. It seems on examination of the total scores that as a group the depressed subjects were producing higher scores than the controls. This is further illustrated in the cumulative frequency distribution in fig.2.

Analysis of the data using the Rank-Sum test indicates that the null hypothesis should be rejected (criterion p < 0.05). As with the B.D.I. there was considerable overlap between the groups. When analysed by the suggested categories (also shown in table 4)
Table 4: Hopelessness Scale Scores In Each Group Ordered By Category

<table>
<thead>
<tr>
<th>Category</th>
<th>Score Range</th>
<th>Depressed Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Individual Scores</td>
<td>Individual Scores</td>
</tr>
<tr>
<td>No Immediate Problem</td>
<td>0 - 10</td>
<td>0,4,5,6,9,9,9,9,10</td>
<td>1,3,3,3,3,4,5,5,6,6,7,8,9,9,10</td>
</tr>
<tr>
<td>Requires Monitoring</td>
<td>11 - 15</td>
<td>11,12,12,12,13,14</td>
<td>11</td>
</tr>
<tr>
<td>Definite Suicide Risk</td>
<td>16 - 20</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

N = 15

N = 16

Table 5: Hopelessness Scale: Number In Each Group Selecting A Scoring (Hopeless-Type) Response For Each Item

| ITEM NUMBER | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
|-------------|---|---|---|---|---|---|---|---|---|----|----|----|----|----|----|----|----|----|----|
| Depressed(N=15) | 4 | 7 | 3 | 13| 3 | 5 | 11| 6 | 7 | 4  | 4  | 10 | 5  | 12 | 4  | 8  | 10 | 13 | 4  | 7  |
| Control(N=16)  | 4 | 3 | 3 | 12| 2 | 2 | 6 | 9 | 6 | 0  | 1  | 7  | 3  | 9  | 2  | 4  | 5  | 7  | 1  | 7  |
using the Fisher Exact Test it is not possible to reject the null hypothesis. No subjects from either group were categorised as a definite suicide risk whilst only one of the controls and six of the depressed group made up the "requires monitoring" category. If however the criterion scores were adjusted from '0 to 10' down to '0 to 8' for the first of these categories the re-analysis would lead to the rejection of the null hypothesis.

Comparison And Analysis Of Single Items

The profile of scoring ('hopeless-type') responses of each group is shown in table 5. Scrutiny of the responses chosen by the control group shows that more than a quarter selected the negative pole for eleven of the twenty items. For three of these, namely item 4: "I can't imagine what my life will be like in ten years," item 8: "I expect to get more of the good things in life than the average person," and item 14: "Things just don't work out the way I want them to," more than half of the controls selected the negative pole.

The largest differences between the groups' selections were for items 7, 17 and 18. Analysis by the Fisher Exact Test did not allow the rejection of the null hypothesis for any of these.

Ease Of Administration; Comment

The data regarding test duration is shown in table 3. As with the B,D,I. the average time taken of only seven minutes reflects the straightforwardness of the test in its adapted form.

The subject who was unable to answer eleven items insisted that she did not think about the future and was therefore unable
to give a true or false answer to the items she rejected. This objection was previously raised for several items in this scale during the first phase of this study.

A further and specific problem occurred which concerned ambiguity of response to item 4 "I can't imagine what my life will be like in 10 years." Many of the twenty-five who responded 'true' remarked that they would probably be dead. Most of the six who responded 'false' said that they would certainly be dead. In other words, subjects who had the same belief were making opposite response choices. For an elderly person only further discussion of the item can reveal if this is a "realistic or hopeless-type" of belief. More importantly this suggests that any individual with suicide plans may respond 'false' believing they would carry out their wish and score '0.' This ambiguity is a serious flaw in a test aimed to assess suicide risk.

It was not surprising to find that no patients were categorised as a serious suicide risk. As already indicated such patients were unlikely to have entered the study as their treatment would take some other form. Furthermore the two most severely depressed subjects as indicated by the B.D.I. were not able to complete this scale. (One refused to do so and one was referred on).

When considered as an assessment tool to identify specific dysfunctional cognitions this test appears to be a fairly blunt instrument. A large proportion of the control group selected the negative pole for a large number of the test items. Also there were no major differences between groups for particular items. As a measure of the level of hopelessness, a feature of depression, the scale did discriminate between the groups. However, as with the
B.D.I. there was a tendency to portray the non-depressed elderly as more hopeless or depressed than would be expected. Although the score categories also appeared inappropriate it was suggested that an adjustment of these might improve their discriminative validity.

**THE BECK SELF CONCEPT TEST**

**Completion Of The Test**

Sixteen subjects in each group undertook the test. One of the depressed group could not respond to seventeen of the twenty-three items and was excluded from the analysis. Another from the same group was unable to sort the items whilst four other subjects, (one of the depressed group and three controls) each refused only one item. For these five subjects a neutral score (0) was assigned.

**Calculation Of Test Scores**

The first overall score worked out for each subject reflected the balance between responses on the positive pole and those sorted to the negative pole of each item. For each item scores ranged from -2 through to +2, with higher positive scores reflecting poor self concept (see table 6). The scoring range was therefore -46 through to 46.

A second total was calculated for each subject which was the sum of responses reflecting poor self concept only. Hence the range for this was 0 to 46, (see bracketed scoring key, table 7). These two summed scores were labelled SCt and SCn respectively.
Group Comparison Of Total Scores

The summed SCt and SCn scores are shown in tables 7 and 8 respectively. There was a tendency for the depressed group to have a poorer overall self concept as shown by the SCt scores in fig.3.

The picture for the SCn scores is more complicated, fig.4. Here two-thirds of the control group made a smaller number of negative self-evaluations than most of the depressed group. However one-third made a larger number than the depressed group. Analysis using the Rank-Sum Test did not produce a statistically significant result for either SCt or SCn scores. Therefore despite some difference in the appearance of the data there was no good evidence of a systematic distinction between the groups as measured by this scale.

Comparison And Analysis Of Single Items

Firstly amongst the controls half of the group made a negative self evaluation for the item "Ability at telling jokes." (See Table 9). A quarter made a negative self evaluation of "reading ability" and "hard working." Although these are not interpreted by the test as depressive signs, if it is assumed that the control group do not have a low self concept then these items might be regarded as unimportant to this age-group.

The largest single-item difference between the groups was for 'self conscious,' (7 depressed and 2 controls). The result of a Fisher Exact Test analysis was not statistically significant. Thus there were no particular aspects of this scale that notably distinguished between the two groups.
Fig. 3: Cumulative Frequency Distributions Of SCt Scores In Both Groups

Fig. 4: Cumulative Frequency Distributions Of SCn Scores In Both Groups
<table>
<thead>
<tr>
<th>More Than Nearly Anyone I Know</th>
<th>More Than Most People I Know</th>
<th>About The Same As Most People I Know</th>
<th>Less Than Most People I Know</th>
<th>Less Than Nearly Anyone I Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Self Concept</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0)</td>
<td></td>
<td>(0)</td>
<td>+1</td>
<td>+(2)</td>
</tr>
<tr>
<td>Poor Self Concept</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 6: Self Concept Test Scoring Key For SCT and (SCn)**

<table>
<thead>
<tr>
<th>GROUP</th>
<th>Good Self Concept</th>
<th>SCT Score</th>
<th>Poor Self Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed</td>
<td>-26 -15 -14 -13 -12 -10 -8 -7 -6 -5 -4 -3 -2 0</td>
<td>1 2 3 1</td>
<td>1 1 1 1</td>
</tr>
<tr>
<td>Control</td>
<td>1 1 2 1 3 1 1 1 2 2 1 1</td>
<td>1 2 2 1</td>
<td>1 1 1 1</td>
</tr>
<tr>
<td>N</td>
<td>15</td>
<td>16</td>
<td></td>
</tr>
</tbody>
</table>

**Table 7: The Self Concept Total Scores (SCT) In Each Group**

<table>
<thead>
<tr>
<th>GROUP</th>
<th>SCn Score: Increasingly Poorer Self Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed</td>
<td>0 1 2 3 4 5 6 7 8 10 11 13</td>
</tr>
<tr>
<td>Control</td>
<td>5 1 3 1 1</td>
</tr>
</tbody>
</table>

**Table 8: The Self Concept Negative Pole Scores (SCn) In Each Group**

31
<table>
<thead>
<tr>
<th>Item</th>
<th>Depressed</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Good Looks</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Greed ∗</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ability at Telling Jokes</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Intelligence</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Popular</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Tidy</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Successful</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Memory</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Kind</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Personality</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Lazy ∗</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Selfish ∗</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Reading Ability</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Nice Appearance</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Good Natured</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Independent</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Ability To Finish Things</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Self Conscious ∗</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Ability To Learn Things</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Jealous ∗</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Hard Working</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Cruel ∗</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 9: The Use Of The Negative Response Pole By Subjects In Each Group In The Self Concept Measure

* Negative/positive poles reversed in analysis
Ease Of Administration; Comment

The test times ranged from four minutes to half an hour, (see table 3), the latter time being taken up by a subject who had difficulty responding to several items. If this case were ignored the overall mean was ten minutes.

Of the items that caused difficulties 'reading ability,' was rejected by one subject who was virtually blind. Another subject rejected two items (17 and 20) on the grounds that these were, "for others to judge." Although no other items were refused for this reason it was a frequent objection that subjects made.

Finally item 4, "Ability At Telling Jokes" was rejected by three controls. Since this was also sorted to the negative pole by half of this group exclusion of this item would improve the ease of application of the test.

As an overview this test failed to identify any specific or systematic differences in the self concepts of patients between the two groups.
AUTOMATIC THOUGHTS QUESTIONNAIRE (A.T.Q.)

Completion Of The Test

All of the seventeen in the depressed group and fifteen controls undertook the test. There were no difficulties with particular items since rejection of inappropriate thoughts was part of the method itself.

Calculation Of Test Scores

Two types of total score were calculated for each subject. The first was the total number of negative thought items selected as "true" i.e. at some time occurring to the subject. This score could range from 0 to 30. The second score was summed from the scaled categories of thought frequency, 1 = "sometimes", 2 = "moderately often", 3 = "often", and 4 = "all the time." This could range from 0 to 120.

Group Comparison Of Total Scores

The distribution of these total scores in each group is shown in tables 10 and 11. The differences between the two groups for both types of score are easily observable and best illustrated by the cumulative frequency distributions, figs. 5 and 6.

Statistical comparison using the Rank-Sum Test allows the rejection of the null hypothesis at the $p =<0.05$ level for both sets of data. Almost all of the individuals in both groups selected some negative thoughts but as a group the depressed patients were selecting more. No categories are suggested for the test. However if scores were grouped as 0 to 9, or 10 to 30 for the simple sum of negative thoughts then this would segregate depressed and
Fig. 5: Cumulative Frequency Distributions Of A.T.Q. Score, (total negative thoughts)

Fig. 6: Cumulative Frequency Distributions Of A.T.Q. Thought/Frequency Scores
<table>
<thead>
<tr>
<th>Scoring Range</th>
<th>Depressed Group</th>
<th>Control Group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 9</td>
<td>1,2,3,5,6,</td>
<td>0,0,1,2,4,5,6,8,9</td>
<td>11</td>
</tr>
<tr>
<td>10 - 19</td>
<td>10,11,11,12,13,14,19</td>
<td>13,13,16</td>
<td>3</td>
</tr>
<tr>
<td>20 - 30</td>
<td>22,22,23,26,27</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15</td>
</tr>
</tbody>
</table>

Table 11: Automatic Thoughts Questionnaire: Total Number Of Negative Thoughts Of Each Subject In Each Group
Comparison And Analysis Of Single Items

Thirteen of the fifteen controls selected at least one negative thought (see table 12). The four most common were: "I can't get started," (selected by eight subjects), "Something has to change," (8 subjects), "What's wrong with me?" (7 subjects) and, "There must be something wrong with me," (7 subjects). Similar numbers of the depressed group also selected these.

A Fisher Exact Test was calculated for the numbers selecting each particular thought since the group difference was notable for a large number of items. Statistically significant results emerged for items 1, 4, 9, 10 and 29 (see table 12). In other words the larger number of depressed patients selecting these thoughts to an extent unlikely to have occurred by chance alone.

Ease of Administration

The test times for this measure are a direct function of the number of thoughts selected, since these are re-sorted. Hence the depressed group who selected more took longer on average to complete the test (see table 3). This adapted presentation of the original test caused no difficulties that hindered its completion.

Comment

Both scores derived from the test produced a very similar result. This method effectively differentiated between the two groups
Table 12: Automatic Thoughts Questionnaire: Item selections Depressed group D (N = 17) and Control Group C (N = 15). * - Fisher Exact Test $ p < 0.05$

<table>
<thead>
<tr>
<th>Item</th>
<th>GROUP: D C</th>
<th>Item</th>
<th>GROUP: D C</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I feel like I'm up against the world</td>
<td>10 1*</td>
<td>16 I can't get things together</td>
<td>8 5</td>
</tr>
<tr>
<td>2 I'm no good</td>
<td>6 1</td>
<td>17 I hate myself</td>
<td>2 0</td>
</tr>
<tr>
<td>3 Why can't I ever succeed?</td>
<td>10 4</td>
<td>18 I'm worthless</td>
<td>6 2</td>
</tr>
<tr>
<td>4 No-one understands me</td>
<td>7 0*</td>
<td>19 I wish I could just disappear</td>
<td>5 3</td>
</tr>
<tr>
<td>5 I've let people down</td>
<td>9 3</td>
<td>20 What's the matter with me</td>
<td>10 5</td>
</tr>
<tr>
<td>6 I don't think I can go on</td>
<td>7 2</td>
<td>21 I'm a loser</td>
<td>4 1</td>
</tr>
<tr>
<td>7 I wish I were a better person</td>
<td>13 6</td>
<td>22 My life is a mess</td>
<td>4 3</td>
</tr>
<tr>
<td>8 I'm so weak</td>
<td>6 4</td>
<td>23 I'm a failure</td>
<td>5 0</td>
</tr>
<tr>
<td>9 My life's not going the way I want it to</td>
<td>12 4*</td>
<td>24 I'll never make it</td>
<td>4 3</td>
</tr>
<tr>
<td>10 I'm so disappointed in myself</td>
<td>13 4*</td>
<td>25 I feel helpless</td>
<td>8 6</td>
</tr>
<tr>
<td>11 Nothing feels good any more</td>
<td>9 4</td>
<td>26 Something has to change</td>
<td>9 8</td>
</tr>
<tr>
<td>12 I can't stand this any more</td>
<td>7 2</td>
<td>27 There must be something wrong with me</td>
<td>8 7</td>
</tr>
<tr>
<td>13 I can't get started</td>
<td>9 8</td>
<td>28 My future is bleak</td>
<td>10 3</td>
</tr>
<tr>
<td>14 What's wrong with me</td>
<td>9 7</td>
<td>29 It's just not worth it</td>
<td>8 1*</td>
</tr>
<tr>
<td>15 I wish I were somewhere else</td>
<td>4 5</td>
<td>30 I can't finish anything</td>
<td>5 2</td>
</tr>
</tbody>
</table>
according to their diagnoses although there was some degree of overlap. As an instrument for the identification of dysfunctional cognitions there was a mixed picture. Clear differences emerged between the groups for several items. A large proportion of the controls selected other specific thoughts which could perhaps be regarded as relating to their age or physical condition rather than as depressive signs.

THE ADAPTED COGNITIVE STYLE TEST (ACST)

Completion Of The Test

Sixteen from the depressed group and fifteen controls undertook the test. Two of the depressed group were unable to complete it however, and in each case the attempt was abandoned after ten minutes. One control subject who did finish the test rejected seventeen of the thirty items and was therefore not included in the calculation of total scores. Two other subjects had difficulties, one in the depressed group rejected three items and one in the control group rejected a single item. For each of these the items were assigned an average score based on responses to the other items in that part of the test.

Hence, total scores were calculated for fourteen subjects in each group.

Calculation Of Total Scores

Three scores were computed for each individual according to the original design of the test. These were CSTp, cognitive style for pleasant items, CSTu, for unpleasant items, and CSTt, the sum of CSTp and CSTu. Each of the 30 items produced a score in the
range 0 to 3. Therefore the scoring range for CSTp and CSTu was 0 to 45 and the maximum possible for CSTt was 90. Higher scores are said to indicate a more dysfunctional cognitive style.

**Group Comparison Of Total Scores**

The three sets of data shown in tables 13, 14 and 15 represent the scores for CSTt, CSTp and CSTu. Overall the mean scores are identical. The distributions when compared between groups for each of the three measures are also very similar. Statistical comparison gives no suggestion of any difference between the groups. There is no evident link between test scores and diagnostic group.

**Comparison And Analysis Of Single Items**

Scanning of the data indicates that although there was wide variation in the choice of response for most items there was no notable difference between the two groups in the profile of these choices.

**Ease Of Administration**

The mean test time for each group was similar and overall was 18 minutes. Individual times varied between nine and thirty-six minutes. In all, six items were rejected but none by more than one subject. The reason for rejection was the same in each case. The subject could not relate the situation described to his or her own experience. Neither were they able to imagine it. For example, one subject's reaction to item SU2, 'meeting someone on a street corner.' This subject never walked out from his home, and therefore felt unable to answer. This type of problem could be regarded as a failure of the test to describe
### Table 13: Adapted Cognitive Style Test: Total Sources, aCSTE

<table>
<thead>
<tr>
<th>Score</th>
<th>Depressed Group (N=14)</th>
<th>Control Group (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-29</td>
<td>26</td>
<td>28,28,28</td>
</tr>
<tr>
<td>30-39</td>
<td>32,33,33,35,36,37,37</td>
<td>30,33,33,35,39</td>
</tr>
<tr>
<td>40+</td>
<td>40,40,41,41,43,49</td>
<td>41,44,44,45,46,48</td>
</tr>
</tbody>
</table>

Rounded Mean : 37  

### Table 14: Adapted Cognitive Style Test Scores: Pleasant Items, aCSTp

<table>
<thead>
<tr>
<th>Score</th>
<th>Depressed Group (N=14)</th>
<th>Control Group (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>13,14,14,15,18,19,19,19</td>
<td>11,14,15,16,16,16,19,19</td>
</tr>
<tr>
<td>10-19</td>
<td>22,22,25,26,27</td>
<td>21,22,23,23,31</td>
</tr>
</tbody>
</table>

Rounded Mean : 19  

### Table 15: Adapted Cognitive Style Test Scores: Unpleasant Items, aCSTu

<table>
<thead>
<tr>
<th>Score</th>
<th>Depressed Group (N=14)</th>
<th>Control Group (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>13,14,15,15,16,18,18,18,19,19</td>
<td>13,13,14,14,14,17,18</td>
</tr>
<tr>
<td>10-19</td>
<td>21,21,22,22</td>
<td>20,20,22,22,25,28,28</td>
</tr>
</tbody>
</table>

Rounded Mean : 18  

Rounded Mean : 19
situations within everyday experience of all of the subjects. Alternatively however, it could be interpreted as an abstraction problem, as mentioned earlier. That is to say that a subject is only able to make decisions from real experience (concrete thinking) and not imagined experience (requiring abstract thinking).

Comment

Comparison between the mean scores produced by the two groups in this project with those published in the original publication of the test is shown in table 16.

<table>
<thead>
<tr>
<th>CSTt</th>
<th>CSTt*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed (N = 14)</td>
<td>Controls (N = 14)</td>
</tr>
<tr>
<td>Mean Score</td>
<td>37.3</td>
</tr>
</tbody>
</table>

Table 16: Comparison Of Group Means For Cognitive Style Test

* From Wilkinson and Blackburn 1981

These mean scores align closely to that for the 'normal' group in the original study. This suggests that if the test was a valid indicator of Cognitive Style amongst these elderly groups then the style of the depressed group was not of the form described as characteristic with depression. However as in the original validation study, a Pearson's product-moment correlation was calculated between CSTp and CSTu as an indicator of internal consistency. This was -0.08 indicating virtually no association between the two scales and suggesting that this test was not functioning as a measure of cognitive style with these groups.
Intercorrelations Between Measures

A Pearson's Product-Moment coefficient of correlation was calculated between the summed totals produced from each scale. These were worked out from complete pairs of data only. The results are intended to serve as an indicator of the external validity of these scales as measures of depression. Three matrices summarize the results shown in tables 17, 18 and 19.

The Hamilton Rating Scale scores (H.R.S.) have also been included. The raw data for these are shown in the appendix, table B. Only one of the two total scores derived from the A.T.Q. were included since these scales were closely equivalent. Intercorrelations between separate scales derived from the same assessment instruments are not included.

Since these instruments were designed for use with clinical populations it is anticipated that accuracy and sensitivity would be greater in assessing the depressed group. This is borne out when the results of the intercorrelations in the data are compared between the two groups, tables 17 and 18.

If each scale were a sensitive measure of depression with elderly subjects then statistically significant correlations would have been expected between each type of score, as modelled in fig.7(a). The actual results of this analysis for the depressed, control and combined groups are shown in figs.7(b) (c) and (d).

Intercorrelations arose only for those measures that had previously been found to demonstrate some degree of discriminant validity. The exceptions to this being the correlations between B.D.I. and SCn, and H.R.S. with BSCt.

The intercorrelations found between the B.D.I., H.S. and A.T.Q.
### Table 17
Inter correlations Between Scales: The Depressed Group

<table>
<thead>
<tr>
<th></th>
<th>sBDI</th>
<th>HS</th>
<th>ATQ</th>
<th>BSCT</th>
<th>SCn</th>
<th>aCSTt</th>
</tr>
</thead>
<tbody>
<tr>
<td>sBDI</td>
<td></td>
<td>0.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATQ</td>
<td>0.66*</td>
<td></td>
<td>0.54*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSCT</td>
<td>0.30</td>
<td>0.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCn</td>
<td>0.51*</td>
<td>-0.32</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>aCSTt</td>
<td>0.41</td>
<td>0.31</td>
<td>0.31</td>
<td>-0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRS</td>
<td>0.52*</td>
<td>0.26</td>
<td>0.30</td>
<td>0.49*</td>
<td>0.36</td>
<td>0.37</td>
</tr>
</tbody>
</table>

### Table 18
Inter correlations Between Measures: The Control Group

<table>
<thead>
<tr>
<th></th>
<th>sBDI</th>
<th>HS</th>
<th>ATQ</th>
<th>BSCT</th>
<th>SCn</th>
<th>aCSTt</th>
</tr>
</thead>
<tbody>
<tr>
<td>sBDI</td>
<td></td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS</td>
<td>0.30*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATQ</td>
<td>0.81**</td>
<td></td>
<td>0.33</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSCT</td>
<td>-0.13</td>
<td>-0.13</td>
<td>-0.33</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCn</td>
<td>0.25</td>
<td>0.31</td>
<td>0.13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>aCSTt</td>
<td>-0.04</td>
<td>-0.37</td>
<td>-0.05</td>
<td>-0.49*</td>
<td>-0.31</td>
<td></td>
</tr>
</tbody>
</table>

### Table 19
Inter correlations Between Measures: Combined Sample

<table>
<thead>
<tr>
<th></th>
<th>sBDI</th>
<th>HS</th>
<th>ATQ</th>
<th>BSCT</th>
<th>SCn</th>
<th>aCSTt</th>
</tr>
</thead>
<tbody>
<tr>
<td>sBDI</td>
<td></td>
<td>0.30*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS</td>
<td>0.81**</td>
<td></td>
<td>0.55**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATQ</td>
<td>0.18</td>
<td>0.11</td>
<td>0.01</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSCT</td>
<td>0.32*</td>
<td>0.07</td>
<td>0.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCn</td>
<td>-0.09</td>
<td>-0.14</td>
<td>-0.19</td>
<td>-0.31</td>
<td>-0.30</td>
<td></td>
</tr>
</tbody>
</table>

**Pearson's Correlation Coefficient Matrices**

- sBDI: Beck Depression Inventory
- HS: Hopelessness Scale
- ATQ: Automatic Thoughts Questionnaire
- BSCT: Beck Self Concept Test, total scores
- SCn: Self Concept, negative scores only
- aCSTt: Adapted Cognitive Style Test, totals
- HRS: Hamilton Rating Scale

* p < 0.05
** p < 0.001
Fig. 7: Intercorrelations Between Measures

An illustration of the hypothetical and actual links.
account for three of the six statistically significant links.

These scales were not designed to directly assess exactly the same condition but rather different facets of a single condition. Therefore extremely close correlations between them would be evidence against their individual construct validities. However the only strong values of correlation were between the B.D.I. and A.T.Q. and between the A.T.Q. and H.S. This finding is not in line with the close associations between the B.D.I., H.S. and H.R.S. reported elsewhere in the literature.
DISCUSSION

The general aim of this project was to begin an assessment of the validity of the cognitive theory as a model of depression in the elderly. In order to do this it was decided to use a range of cognitive assessment schedules intended to measure different facets of the theory. However in developing this as a method it has also been necessary to assess the practicalities of applying these techniques to elderly people. Hence three considerations evolved. Firstly the problems and modifications required to utilise certain cognitive assessment measures in this context; secondly the individual validity of each scale (as a measurement instrument and a screening device for cognitive distortions); and thirdly the validity of the cognitive theory reflected by combination of the results.

Before discussing the findings some important assumptions in the method are considered.

Methodological Assumptions

Firstly were the diagnoses accurate? For the selection of the depressed group great effort was taken to ensure that there were no inappropriate inclusions. Clinical judgements and assessments were supplemented by the use of the Hamilton Rating Scale. This produced a mean score for the group that is very similar to the means reported in other studies of comparable clinical groups, (e.g. Carroll et al 1973). These and the other data generated by this group did not suggest any non-depressed patients had been included.

There is less certainty regarding the control group. Selection
here was based on clinical assessment and intuition. Although staff were attuned to psychological problems amongst their patients the main emphasis in this clinic is on physical illness. The 'discovery' that one of the subjects selected for this group was severely depressed underlines the fact that the categorization of all of these subjects as non-depressed cannot have been wholly accurate. It is more reasonable to assume that most of these subjects were not depressed.

The next consideration is the extent to which the control group can be regarded as representing normal elderly people. It was decided to draw a control group from a hospital day unit setting to match as closely as possible the circumstances, anxieties and expectations of both groups during assessment. However, these people were all unwell enough, in some sense or other, to require hospital treatment. Most elderly people are not in the same predicament. This difference is important for the interpretation of parts of the data particularly regarding items relating to somatic signs of depression. It may be that amongst the general population the scales used in this study serve, in part at least, only to differentiate those who need help from those who don't, rather than the underlying causes. The requirement of differentiating depression from other conditions in hospital patients is a more severe test of the validity of these scales. This has been accounted for where the schedules have been standardized with younger groups but this specific feature may not remain valid for elderly subjects.
Findings Regarding The Practical Application Of The Scales

The schedules were not generally applicable in their original forms. This forced a rejection of one of the scales, (D.A.S.). To improve the others simple modifications of presentation were made. These accommodated for eyesight difficulties. A simplicity of layout and method of response recording compensated for difficulties in the understanding and memory of instructions, and the problem of distraction. These increased the range of convenience of each test enough to enable all subjects to attempt the scales without evident difficulties related to format.

As a result of these modifications the data derived here cannot be considered to be directly comparable to other data derived from the schedules in their original form. A separate study would be required to assess the effect of these practical adaptations on the content of responses.

The Validity And Utility Of Individual Tests

The scales generally demonstrated greater discriminant validity as measurement instruments as opposed to screening devices for specific cognitive distortions. There were few scale items that successfully segregated the groups. Only one item from the B.D.I. and five items from the A.T.Q. produced data that satisfied the criterion of statistical significance. This was largely because the control group were generating depressive signs, rather than the depressed group not doing so. This might have been improved had it been possible to ensure there were no depressed people in the control group.

The two scales that appeared least effective for use with
elderly subjects were the a.C.S.T. and the B.S.C.T. These were also the longest and most difficult to administer. Regarding the a.C.S.T. it is not possible to ascertain whether the depressed patients did not operate the predicted depressive style or alternatively that the technique failed to function as an indicator of cognitive style. The latter case seemed more likely as there was no evidence of internal consistency in individual response profiles. Any further attempt to develop this measure for use with the elderly will need to take account of the difficulties encountered here that were described as problems of abstraction. Judging from the self-talk of subjects in completing the a.C.S.T. their choices of response were generally drawn from past experience rather than the imagined situation. This tendency has been observed experimentally by Welford (1958). Abstraction difficulties may also have accounted for some of the comments made by subjects when completing the B.S.C.T. These people found it hard to compare themselves to others. The same problem did not arise when making self-referent statements in a different form for other scales. It is also possible that this scale failed to discriminate between the groups because the items that comprise it are not fundamental to the self-esteem of an elderly person, and hence could not be dysfunctional. Items such as 'sex appeal' and 'athletic' were rejected as irrelevant. This evidence indicates that future development of a self concept scale for use with elderly people would need to recognize age-differences in the components of self-esteem as well as the problem of assessment format.

These data indicated that the total scores calculated from the
B.D.I., H.S. and A.T.Q. all possessed discriminant validity. These were less clear-cut than in the original validation reports. If this were entirely due to some of the control subjects being depressed then it would be anticipated that the profile of 'depressive-type' response selections in the control group would be scattered. Instead the profiles show that these responses were concentrated over a few specific items. This is more suggestive of an age-related difference in responding rather than the inclusion of depressed people in the control group.

The categories suggested for the B.D.I. and H.S. did not discriminate between the groups although the data suggested that alteration of the cut-off levels might yield a more effective system of categorization.

The intercorrelations found between the B.D.I., H.S. and A.T.Q. provide additional evidence for the validity of the scales for use with the elderly. However, comparison between the results of this study and the original data related to a younger age-range strongly indicates that these scales need to be separately standardised for use with the elderly. Furthermore with the close similarity between the groups in this study for so many of the items a re-development of these scales seems a more appropriate course.

The Validity Of The Cognitive Theory
As already stated this study was an initial consideration rather than an evaluation of the cognitive theory in this context. One reason for this was that had no group differences emerged from the data it would not have been possible to determine if that was
because of flaws in the theory or in the assessment methods. The latter consideration has been investigated here and these findings would be of value in establishing a more thorough evaluation.

Group differences did emerge in the data however. These results, particularly from the A.T.Q., provide useful evidence of dysfunctional cognitive processes according to the theory. The principal reservation must be that no reliability data are available.

This theory of depression was evolved from research and clinical experience with younger depressed people and in the same way that some of the measures do not readily transfer to the elderly, neither might some facets of the theory. The hopelessness scale provides a good example in that it assumes the respondent has at least ten years of future living to plan for and speculate about. The experience of this project has been that elderly people are probably less concerned about the future. Instead they are noted for their reflectiveness towards the past. Pfeiffer (1977) describes the importance of an "evaluative backward glance," as a task in later life. Butler (1973) has described it as an "identity review." An example of dysfunctional thinking in this process can be drawn from a case description presented by Emery (1981). In this a client was found to have attached distorted importance to having once struck his wife. This cognition had led to a serious depression. However, it was against a background of evidence that he had been a loving and caring husband. His treatment was therefore aimed towards a more realistic appraisal of the evidence.

If evaluative reminiscence is both an important adaptive process in aging and occasionally a facet of dysfunctional
thinking then the cognitive theory might be extended to encompass this when considering elderly people. The cognitive triad (systematically negative cognitions related to self, world and future), would therefore have 'the past' added to it, perhaps with diminished importance attached to the future. Some scales have already been developed to assess the elderly person's perception of the past, e.g. Thurnher's (1973) 'Life Evaluation Chart.' An additional suggestion for further research would be the development of such scales to be incorporated into cognitive therapy for depression in the elderly.

Wider Research Implications
Apart from the suggestions already made, future research must now be directed towards a more thorough evaluation of the cognitive theory and therapy in the context of the elderly. This study has indicated that whilst the theory has some validity its various facets and manifestations are probably different in this age-group. This might therefore best be developed in the same way as the rest of the theory, from the experience and statements of elderly depressed people.

Clinical Implications
The totals derived from the self-rating depression scales used here are not reliably comparable between the young and old. Hence the norms for these scales are not applicable to elderly clients. Some responses of the depressive-type may not be valid indicators of a depressive symptom. It is therefore suggested that until there are separate standardizations of measures such as the B.D.I.
clinical assessors should seek the qualification of depressive-type responses from their elderly clients.

If the inability of some elderly people to complete self-assessment schedules has proved an obstacle in applying cognitive techniques then this can be successfully negotiated by simple modifications of schedule format. This study has provided evidence that the cognitive theory is an appropriate model of depression in elderly people. If applying the theory as a form of therapy presents idiosyncratic difficulties when working with elderly clients then this is a challenge to adapt therapeutic methods and not a contra-indication for treatment.
APPENDIX A

Tables
### Depressed Group (N = 17)  Control Group (N = 17)

<table>
<thead>
<tr>
<th>Range</th>
<th>Depressed Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69</td>
<td>62,64</td>
<td>68</td>
</tr>
<tr>
<td>70-79</td>
<td>70,72,72,73,75,75,77,77,78,78,79</td>
<td>71,71,73,77,79,79</td>
</tr>
<tr>
<td>80-</td>
<td>81,82,87,94</td>
<td>80,82,83,84,84,85,85,88,90,92</td>
</tr>
</tbody>
</table>

**Table A : The Age Distributions Of The Samples**

<table>
<thead>
<tr>
<th>Scoring Range</th>
<th>Individual Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 14</td>
<td>10,12,12,14,14</td>
</tr>
<tr>
<td>15 - 29</td>
<td>16,16,16,18,26,26</td>
</tr>
<tr>
<td>30+</td>
<td>30,32,32,32,36,46</td>
</tr>
</tbody>
</table>

**Table B : The Hamilton Rating Scale Scores Of Depressed Group Subjects**
APPENDIX B

Scales: Original Forms
INSTRUCTIONS: This is a questionnaire. On the questionnaire are groups of statements. Read the entire group of statements in each category. Then pick out the one statement in the group which best describes the way you feel today, that is, right now! Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally, circle each one.

Sure to read all the statements in each group before making your choice.

BECK DEPRESSION INVENTORY: SHORT FORM

I am so sad or unhappy that I can't stand it.
I am blue or sad all the time and I can't snap out of it.
I feel sad or blue.
I do not feel sad.

I feel that the future is hopeless and that things cannot improve.
I feel I have nothing to look forward to.
I feel discouraged about the future.
I am not particularly pessimistic or discouraged about the future.

I feel I am a complete failure as a person (parent, husband, wife).
I feel as though I am very bad or worthless.
I feel quite guilty.
I feel bad or unworthy a good part of the time.
I don't feel particularly guilty.

I hate myself.
I am disgusted with myself.
I am disappointed in myself.
I don't feel disappointed in myself.

I would kill myself if I had the chance.
I have definite plans about committing suicide.
I feel I would be better off dead.
I don't have thoughts of harming myself.

H.
3 I have lost all my interest in other people and don't care about them at all
2 I have lost most of my interest in other people and have little feeling for them
1 I am less interested in other people than I used to be.
0 I have not lost interest in other people.

I.
3 I can't make any decisions at all anymore.
2 I have great difficulty in making decisions.
1 I try to put off making decisions.
0 I make decisions about as well as ever.

J.
3 I feel that I am ugly or repulsive-looking.
2 I feel that there are permanent changes in my appearance and they make me look unattractive.
1 I am worried that I am looking old or unattractive.
0 I don't feel that I look any worse than I used to.

K.
3 I can't do any work at all.
2 I have to push myself very hard to do anything.
1 It takes extra effort to get started after doing something.
0 I can work about as well as before.

L.
3 I get too tired to do anything.
2 I get tired from doing anything.
1 I get tired more easily than I used to.
0 I don't get any more tired than usual.

M.
3 I have no appetite at all anymore.
2 My appetite is much worse now.
1 My appetite is not as good as it used to be.
0 My appetite is no worse than usual.
Here are some statements about the way you see the future. Read each statement carefully. If the statement describes how you think about the future, circle the word True at the side of the questionnaire. If it does not describe how you think about the future, circle the word False at the side of the questionnaire.

**HOPELESSNESS SCALE**

1. I look forward to the future with hope and enthusiasm. True False
2. I might as well give up because I can't make things better for myself. True False
3. When things are going badly I am helped by knowing that they can't stay that way forever. True False
4. I can't imagine what my life would be like in 10 years. True False
5. I have enough time to accomplish the things I most want to do. True False
6. In the future I expect to succeed in what concerns me most. True False
7. My future seems dark to me. True False
8. I expect to get more of the good things in life than the average person. True False
9. I just don't get the breaks, and there's no reason to believe I will in the future. True False
10. My past experiences have prepared me well for my future. True False
11. All I can see ahead of me is unpleasantness rather than pleasantness. True False
12. I don't expect to get what I really want. True False
13. When I look ahead to the future I expect that I will be happier than I am now. True False
14. Things just don't work out the way I want them to. True False
15. I have great faith in the future. True False
16. I never get what I want so it is foolish to want anything. True False
17. It is very unlikely that I will get any real satisfaction in the future. True False
18. The future seems vague and uncertain to me. True False
19. I can look forward to more good times than bad times. True False
20. There's no use in really trying to get something I want because I probably won't get it. True False
How are a variety of thoughts that pop into people's heads. Please read
right and indicate how frequently, if at all, the thought occurred to you
last week. Please read each item carefully and circle the appropriate
on the answer sheet in the following fashion (1 - "not at all", 2 - "some-
3 - "moderately often", 4 - "often" and 5 - "all the time").

<table>
<thead>
<tr>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) I feel like I'm up against the world.</td>
</tr>
<tr>
<td>2) I'm no good.</td>
</tr>
<tr>
<td>3) Why can't I ever succeed?</td>
</tr>
<tr>
<td>4) No one understands me.</td>
</tr>
<tr>
<td>5) I've let people down.</td>
</tr>
<tr>
<td>6) I don't think I can go on.</td>
</tr>
<tr>
<td>7) I wish I were a better person.</td>
</tr>
<tr>
<td>8) I'm so weak.</td>
</tr>
<tr>
<td>9) My life's not going the way I want it to.</td>
</tr>
<tr>
<td>10) I'm so disappointed in myself.</td>
</tr>
<tr>
<td>11) Nothing feels good anymore.</td>
</tr>
<tr>
<td>12) I can't stand this anymore.</td>
</tr>
<tr>
<td>13) I can't get started.</td>
</tr>
<tr>
<td>14) What's wrong with me?</td>
</tr>
<tr>
<td>15) I wish I were somewhere else...</td>
</tr>
<tr>
<td>16) I can't get things together.</td>
</tr>
<tr>
<td>17) I hate myself.</td>
</tr>
<tr>
<td>18) I'm worthless.</td>
</tr>
<tr>
<td>19) Wish I could just disappear.</td>
</tr>
<tr>
<td>20) What's the matter with me?</td>
</tr>
<tr>
<td>21) I'm a loser.</td>
</tr>
<tr>
<td>22) My life is a mess.</td>
</tr>
<tr>
<td>23) I'm a failure.</td>
</tr>
<tr>
<td>24) I'll never make it.</td>
</tr>
<tr>
<td>25) I feel so helpless.</td>
</tr>
<tr>
<td>26) Something has to change.</td>
</tr>
<tr>
<td>27) There must be something wrong with me.</td>
</tr>
<tr>
<td>28) My future is bleak.</td>
</tr>
<tr>
<td>29) It's just not worth it.</td>
</tr>
<tr>
<td>30) I can't finish anything.</td>
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SELF CONCEPT TEST

this page and the next are statements about various traits such as looks, honesty, and personality. For each trait, please rate yourself in relation to other people you know, circling the most accurate phrase.

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<th>Trait</th>
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On these cards are some descriptions of everyday events, some pleasant, some unpleasant. After each one there are four different ways of thinking about each event. What I would like you to do is to imagine these events are happening to you and then to choose which of the four thoughts you are most likely to have about the situation.

COGNITIVE STYLE TEST: ADAPTED FORM  (APPENDIX C)

SP1 You help a friend to serve on a stall in a church fete. Afterwards the friend thanks you loudly in front of some other people.

A) He/She was pleased with my help.
B) It's not worth mentioning.
C) I hope the others were pleased too.
D) He/She probably thinks I wasn't much help.

SP2 An old friend whom you used to be very close to, and whom you have not seen for a long time, visits you.

A) Will He/She still be the same?
B) It's good to see old friends.
C) I wonder if we still like each other?
D) He/She must like me a lot.

SP3 A person that you admire tells you that He/She likes people like you.

A) That's a nice thing to say.
B) I'm not sure He/She really means it.
C) He/She must like me a lot.
D) I wonder if He/She is being sarcastic?

SP4 You go to visit a new friend and you have a lovely time.

A) He/She was very friendly.
B) It was all because of Him/Her.
C) I was in a good mood.
D) He/She must like me.

SP5 You hear from a friend that your neighbour has been saying what a tremendous help you are.

A) I don't believe it.
B) It's best to forget it.
C) It may be true but lots of others are helpful too.
D) It's quite true really.
SU1 While shopping one morning you see a friend coming along the street, but he/she gives no sign of recognition and walks straight past you.

   A) He/She is probably in a bad mood with everyone.
   B) He/She really didn't see me at all.
   C) He/She doesn't really like me.
   D) He/She hasn't got time for me today.

SU2 You have arranged to meet someone at 3 o'clock on a street corner. By a quarter past three they have still not turned up.

   A) They should be along soon.
   B) They haven't bothered to come.
   C) They have probably forgotten.
   D) There could be all sorts of reasons.

SU3 You inquire after a friend's health. Later on you hear her saying 'I get fed up with people who pry into private matters'.

   A) She probably means me particularly.
   B) She probably means something completely different.
   C) She might mean me particularly.
   D) She probably means lots of people.

SU4 You go to visit a new friend. You do not really enjoy yourself as the atmosphere is a little strained.

   A) New situations are always difficult for everyone.
   B) He/She didn't like me.
   C) We were both too shy.
   D) I was too shy.

SU5 You find out through a friend that someone else you know has been saying nasty things about you.

   A) There may be some truth in it.
   B) I wonder what else people say?
   C) Everyone says bad things sometimes.
   D) It's not worth bothering about.
WP1 You receive two invitations to visit friends on the same day.

A) Which one will I enjoy visiting most?
B) I'll go to see both of them.
C) One of them is bound to be offended.
D) It's a shame to turn one down, but it can't be helped.

WP2 Without help you come up with a new idea for raising money for the church which saves everyone a lot of time and effort.

A) I've done a very good job.
B) I hope it doesn't all go wrong.
C) I'm glad to make things easier.
D) It's best to forget it and carry on.

WP3 You volunteer to be secretary of a local club and you spend quite a lot of your time making arrangements for the club. At the end of the year you think:

A) I've learned a lot in the year.
B) I won't do that again.
C) I did a good job.
D) The work is over.

WP4 You are asked by a neighbour to help with 'a little job'. He/She says you'll be able to do it easily.

A) I think I might be able to help.
B) I'm not sure.
C) I'll refuse in case I can't do it.
D) I'm fairly sure I can help.

WP5 Some friends come to visit you and want you to choose somewhere to go out for the day. You aren't sure what would please them so you take them to your favourite place.

A) They probably won't like my choice at all.
B) They trust my judgement.
C) I wish they could give some idea.
D) They will probably be easily pleased.
WU1 Some friends force you to join in a game that you are not very good at and don't much like.

A) I'll only spoil it for them.
B) I don't really mind.
C) I don't think I'll enjoy it much.
D) At least I'll learn how to play it properly.

WU2 You are working with several other people and make some stupid mistakes which create more work for everyone else.

A) I'll just forget it.
B) Everyone will now dislike me.
C) They won't like it but everyone makes mistakes.
D) They would probably be glad to get rid of me.

WU3 You are trying to arrange an outing with six other people but you can't seem to find a date when everyone can come.

A) It's unfortunate but these things happen.
B) I should have arranged it earlier.
C) At least I tried my best.
D) They probably won't want to come.

WU4 You are involved in a minor car accident which is only partially your fault.

A) I shall be more careful from now on.
B) These things are bound to happen occasionally.
C) I'm really just glad I'm not hurt.
D) I think I must have been really stupid.

WU5 You have been rearranging furniture when your grandchild nearly pulls a heavy piece on top of himself. Fortunately you were keeping an eye on him and manage to stop him just in time.

A) I nearly caused that child to have an accident.
B) The child should be more careful.
C) I must be more careful in future.
D) These things happen, I should just calm down.
FP1 You invite some new friends round to your home for tea. Looking ahead you think:

A) I hope they will like me.
B) I'll just wait and see what happens.
C) It should be good to get to know them.
D) It will be a pleasant afternoon.

FP2 It is your birthday next week. Looking ahead:

A) I look forward to it eagerly.
B) I don't think about it at all.
C) A few people will remember.
D) I suppose a few people might remember.

FP3 For the last year you've been wanting to visit a friend who has moved away. Looking forward you think:

A) I'll probably never really go.
B) I will go if I put some effort into it.
C) I will definitely do it some day.
D) I might go if my friend offers to take me in his car.

FP4 You discover that a forgotten insurance policy is due to mature soon bringing you a large amount of money. Looking ahead you think:

A) I'm quite pleased.
B) Something will go wrong before I receive it.
C) I won't think about it until I get it.
D) I am really pleased and very lucky.

FP5 You enter a competition and hear you have reached the finals. Looking ahead you think:

A) I won't bother since I'll never win.
B) It would be marvellous if I win.
C) I only have a very small chance.
D) I've done very well to get this far.
FU1 Your fridge breaks down, but you are very short of money. Looking ahead you think:

A) I'll leave it as it is for now.
B) I'll see if anyone knows a cheap repair man.
C) I'd better sell it before something else goes wrong.
D) I'll get it fixed and not worry.

FU2 You have been invited to attend the funeral of a close friend by his family. Looking ahead you think:

A) It's too upsetting to go.
B) It's good to say goodbye properly.
C) It's very upsetting but I ought to go.
D) It's difficult but I still want to go.

FU3 You are about to go into hospital for an operation on your back which has been giving you pain. Looking ahead you think:

A) The pain will soon be over.
B) It probably won't work.
C) It's fairly likely that it will work.
D) I'm not sure if it's the best thing or not.

FU4 You miscalculate your spending and find yourself unable to make certain payments without borrowing money. Looking ahead you think:

A) I'll have to be careful not to do that again.
B) I'll just have to be careful until it's paid back.
C) I'll borrow it and not worry.
D) I wonder if I've got anything else wrong.

FU5 You forget to pay your television licence and get summoned to court. Looking ahead:

A) I try not to think about it.
B) I worry in case I'm punished severely.
C) I don't bother about it.
D) I keep thinking about it.
APPENDIX C

Scales: Adaptations
Self Concept Test

On each of these cards there is a word or phrase that can be used to describe people, such as "looks," or "knowledge," or "greed."

What I would like you to do is to compare yourself with other people you know. You can do this by deciding which of these headings the card best fits:-

less than nearly anyone I know
less than most people I know
more than most people I know
more than nearly anyone I know

So, with this card as an example, (‘relaxed’) how relaxed are you compared to the other people you know?

1. Knowledge
2. Good Looks
3. Greed
4. Ability at Telling Jokes
5. Intelligence
6. Popular
7. Tidy
8. Successful
9. Memory
10. Kind
11. Personality
12. Lazy
13. Selfish
14. Reading Ability
15. Nice Appearance
16. Good Natured
17. Independent
18. Ability To Finish Things
19. Self Conscious
20. Ability To Learn Things
21. Jealous
22. Hard Working
23. Cruel

(‘Sex Appeal’ and ‘Athletic’ have been excluded)
Automatic Thoughts Questionnaire

On each of these cards are written some thoughts that might come to mind. What I would like you to do is to read each card through and then decide if the thought has recently occurred to you.

Either: TRUE
This thought has occurred to me for example, "I need a good rest."

or FALSE
This thought has not occurred to me

1. I feel like I'm up against the world
2. I'm no good
3. Why can't I ever succeed?
4. No-one understands me
5. I've let people down
6. I don't think I can go on
7. I wish I were a better person
8. I'm so weak
9. My life's not going the way I want it to
10. I'm so disappointed in myself
11. Nothing feels good any more
12. I can't stand this any more
13. I can't get started
14. What's wrong with me?
15. I wish I were someone else
16. I can't get things together
17. I hate myself
18. I'm worthless
19. I wish I could just disappear
20. What's the matter with me?
21. I'm a loser
22. My life is a mess
23. I'm a failure
24. I'll never make it
25. I feel so helpless
26. Something has to change
27. There must be something wrong with me
28. My future is bleak
29. It's just not worth it
30. I can't finish anything

Now (selecting the cards sorted as "true") I would like you to sort in rough each of these and decide just how much or how often each thought has occurred, either: 'Sometimes'; 'Moderately Often'; 'Often'; or 'All The Time.'
You help a friend to do his/her garden. The next time you visit, he/she thanks you loudly in front of some other people.

A - He/she is pleased with my work
B - It's not worth talking about
C - I hope the others like it too
D - He/she probably thinks I did a poor job

An old friend whom you used to be very close to, and whom you have not seen for a long time, visits you.

A - Will he/she still be the same?
B - It's good to see old friends
C - I wonder if we still like each other?
D - He/she must like me a lot

A person that you admire tells you that he/she likes people like you.

A - That's a nice thing to say
B - I'm not sure he/she really means it
C - He/she must like me a lot
D - I wonder if he/she is being sarcastic?

You go out socially with some new people that you have just met and have a marvellous time.

A - They were very friendly to me
B - It was all because of them
C - I was in a good mood
D - They must have liked me

You find out through a friend at work that your boss has been saying what a good worker you are.

A - I don't believe it
B - It's best to forget it
C - It may be true, but so are lots of others
D - He is quite right, really
SU1 While shopping one morning you see a friend coming along the street, but he gives no sign of recognition and walks straight past you.

A - He is probably in a bad mood with everyone
B - He really didn't see me at all
C - He doesn't really like me
D - He hasn't got time for me today

SU2 You have arranged to meet someone at six o'clock on a street corner. By quarter past six he has still not turned up.

A - He should be along soon
B - He hasn't bothered to come
C - He has probably forgotten
D - There could be all sorts of reasons

SU3 You ask a colleague to help you with some work. Later in the day you hear him saying "I get fed up with people who can't do a thing for themselves".

A - He probably means me particularly
B - He probably means something completely different
C - He might mean me particularly
D - He probably means lots of people

SU4 You go out socially with some people you have just met, but the evening is not very enjoyable as everyone seems rather nervous.

A - New situations are always difficult for everyone
B - They didn't like me
C - We were all too shy
D - I was too shy

SU5 You find out through a friend that someone else you know has been saying nasty things about you.

A - There may be some truth in it
B - I wonder what else people say?
C - Everyone says bad things sometimes
D - It's not worth bothering about
WP1 You receive two invitations to different parties on the same day.
   A - Which one will I enjoy most?
   B - I'll go to both of them
   C - One host is bound to be offended
   D - It's a shame to miss one of them, but it can't be helped.

WP2 Without help, you invent a new way of doing something at work that saves everybody time.
   A - I've done a very good job
   B - I hope it doesn't all go wrong
   C - I'm glad to make the work easier
   D - It's best to forget it and carry on

WP3 You volunteer to be secretary of a local club, and you spend quite a lot of your time making arrangements for the club. At the end of the year you think
   A - I've learned a lot in the year
   B - I won't do that again
   C - I did a good job
   D - The work is over

WP4 You are asked by a neighbour to help him with 'a little job'. He says that he thinks you could do it easily.
   A - I think I might be able to help
   B - I am not sure
   C - I refuse in case I can't do it
   D - I am fairly sure I can help

WP5 Some people arrive unexpectedly and make you choose somewhere to go out with them. You don't really know what they like, so you take them to your favourite place.
   A - They probably don't like my choice at all
   B - They trust my judgement
   C - I wish they could give some idea
   D - They are probably easy to please
WU1 Some friends force you to play a game that you are not very good at and don't like very much
A - I'll only spoil the game for them
B - I don't really mind
C - I don't think I'll enjoy it much
D - At least I'll learn how to play properly

WU2 You are working with several other people and make some stupid mistakes which create more work for everyone else.
A - I'll just forget it
B - Everyone will now dislike me
C - They won't like it but everyone makes mistakes
D - They would probably be glad to get rid of me

WU3 You are trying to arrange an outing with six other people but you can't seem to find a date that they can all make.
A - It's unfortunate but these things happen
B - I should have arranged it earlier
C - At least I tried my best
D - They probably don't want to come.

WU4 You are involved in a minor car accident which is only partially your fault.
A - I shall be more careful from now on
B - These things are bound to happen occasionally
C - I'm really just glad I'm not hurt
D - I think I must have been really stupid

WU5 While driving one day a child runs right out in front of you.
Fortunately you are driving slowly and you manage to stop just in time.
A - I nearly caused a child to die
B - The child should be more careful
C - I must be more careful in future
D - These things happen - I should just calm down
FP1 You invite some new friends round to your home for a meal. Looking ahead, you think:
A - I hope they will like me
B - I'll just wait and see what happens
C - It should be good to get to know them
D - It will be a good evening

FP2 It is your birthday next week. Looking ahead:
A - I look forward to it eagerly
B - I don't think about it at all
C - I think a few people will remember
D - I suppose a few people might remember

FP3 All your life you have wanted to make a trip round the world. Looking forward, you think:
A - I'll probably never really go
B - I will if I put some effort into it
C - I will definitely do it some day
D - I might if I come into some money

FP4 A distant relative who is very old tells you that he will leave you a large sum of money when he dies. Looking ahead you think.
A - I am secretly pleased
B - I think it's an awful way to get it
C - I wish he hadn't told me
D - I am very glad and tell him so

FP5 You enter a competition, and then hear that you have reached the finals. Looking ahead you think:
A - I won't bother since I'll never win
B - How great it would be if I won
C - I really only have a small chance
D - I've done very well to get this far
FU1 Your car breaks down, but you are very short of money. Looking ahead, you think:
   A - I'll leave it off the road for now
   B - I'll search around for somewhere cheap
   C - I'd better sell it before something else goes wrong
   D - I'll get it fixed and not worry

FU2 You have been invited to attend the funeral of a close friend by his family. Looking ahead, you think:
   A - It's too upsetting to go
   B - It's good to say goodbye properly
   C - It's very upsetting but I ought to go
   D - It's difficult, but I still want to go

FU3 You are about to go into hospital for an operation on your back which has been giving you pain. Looking ahead, you think:
   A - The pain will soon be over
   B - It probably won't work
   C - It's fairly likely that it will work
   D - I'm not sure if it's the best thing or not

FU4 You miscalculate your spending and find yourself unable to make certain payments without borrowing money. Looking ahead, you think:
   A - I'll have to be careful not to do that again
   B - I'll just be careful until it's paid back
   C - I'll borrow it and not worry
   D - I wonder if I've got anything else wrong

FU5 You have to go to court for a minor traffic offence. Looking ahead:
   A - I try not to think about it
   B - I worry in case I am punished severely
   C - I don't bother about it
   D - I keep thinking about it
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