Heart Failure Patients' Illness Representations and Attitudes towards Medication in a Specialist Nursing Intervention

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Thesis submitted to the University of Leicester, School of Psychology, Clinical Section, Faculty of Medicine and Biological Sciences in partial fulfilment of the degree of Doctorate in Clinical Psychology.

October 2004

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Acknowledgements

The help of the following people enabled the completion of this thesis.

I would like to thank Dr Noelle Robertson for her consistent support and guidance throughout the project. Her insightful comments in the early and later stages in particular, were invaluable.

My sincere thanks go to Dr Iain Squire for his clear-sighted advice and willingness to share his knowledge at the design stages of the project. I would also like to extend my gratitude to Dr Kamlesh Khunti for his support and encouragement at the planning stages of the study.

I am indebted to all the specialist heart failure nurses who I relied upon for the recruitment of all participants and whose advice and co-operation was essential.

My thanks also go to all the heart failure patients who kindly participated in the project. Their openness and warmth made the data collection process an enjoyable and enlightening experience.

Finally I would like to thank my family and friends who have supported me throughout the research process. In particular my mother, father and brother whose love and humour enabled me to overcome all obstacles and complete the study.

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1.0 Abstract

Objectives: To examine the impact of a specialist nursing intervention upon the illness representations, self-reported medication adherence, attitudes towards medication and psychological morbidity of heart failure patients.
Design: A study following a cohort of community based participants receiving a specialist nursing intervention, who had been previously hospitalised with heart failure over a three month time interval.
Method: A total of 28 heart failure patients participated in the study. Participants completed a demographic questionnaire, the Illness Perception Questionnaire (assessing construction of illness), the Medication Adherence Report Scale (measuring adherence), the Beliefs About Medicines Questionnaire – General Version (assessing general beliefs about medicines), the Beliefs About Medicines Questionnaire – Specific Version (measuring specific ideas about medicines), the Hospital Anxiety and Depression Scale (measuring anxiety and depression) and the Significant Others Scale – Form B (exploring levels of social support) at two interviews. Comparisons of data within the group at the two time points were undertaken.
Results: Analysis revealed no statistically significant differences within the group from time one to time two of the nursing intervention in illness representation, self reported medication adherence, attitudes towards medication or psychological morbidity. The exception to this was a significant difference on the BMQ-S subscale, "necessity". Between time one and time two participants' beliefs in the necessity of their medication had significantly reduced.
Conclusions: No significant psychological impact of this programme was detected. The potential reasons for the lack of significant results as well as the clinical implications of the findings are explored. The value of routine assessment of psychological morbidity in this population is discussed.

2.0 Introduction

Coronary Heart Disease (CHD) presents one of the most significant health challenges in the developed world. The health problems engendered by CHD prompted the UK government to produce a strategy to tackle and reduce it (National Service Framework for Coronary Heart Disease, 2000). The resultant paper highlighted the extent of cardiac diseases, 1.4 million people suffer from angina and 300,000 have myocardial infarctions (MIs, also known as heart attacks) annually. It also articulated a strategy to address and improve the provision of care for the condition of heart failure, an end stage of all cardiac diseases.

Heart failure has traditionally received less overt attention in the wider media than myocardial infarction or angina. However it is a significant health problem both in terms of morbidity and mortality rates in the population, and the economic burden it places upon the National Health Service (NHS). The need to improve detection, diagnosis and management of this complex condition has been reflected in the publication of a national clinical guideline for its diagnosis and management in both primary and secondary care by the National Institute for Clinical Excellence (2003). Petersen, Rayner and Wolstenholme (2002) estimate that heart failure costs approximately 1.8% of the NHS budget. 70% of this expenditure is accounted for through hospitalisation of patients. Patients experiencing heart failure occupy 2% of all NHS inpatient bed days and comprise 5% of all emergency admissions to hospital. Yet heart failure has economic and clinical significance at all levels of care in the NHS. Cowie, Wood, Coats, Thompson, Poole-Wilson, Suresh and Sutton (1999) have calculated that the cost to primary care exceeds £45 million

annually with an additional £35 million for referrals to outpatient clinics. Community based drug therapy costs an extra £129 million per year.

McMurray and Stewart (2000) point out that the pressure placed upon the NHS is likely to increase in the future, due to the increase in an ageing population where the incidence of CHD and hypertension is the highest; and also due to improvements in the survival of those with coronary artery disease. Based on projections carried out in the Netherlands and Australia which have comparable levels of industrialisation and disease rates, the prevalence of heart failure caused by coronary heart disease will have risen by around 70% over the period of 1985 to 2010 (Bonneux, Barendregt & Meeter, 1994).

2.1 Definition of Heart Failure

Denolin, Kuhn, Krayenbuehl, Loogen and Reale (1983) define heart failure as "the state of any heart disease in which, despite adequate ventricular filling, the heart's output is decreased or in which the heart is unable to pump blood at a rate adequate for satisfying the requirements of the tissues with function parameters remaining within normal limits (p446)." Consonant with this the Coronary Heart Disease NSF (2000) describes heart failure as a clinical syndrome, which is caused by a reduction in the heart's ability to pump blood around the body. Heart failure is not in itself a diagnosis, and the underlying cause(s) must be detected in people presenting with the condition (SIGN 35, 1999). This is essential to determine the type of treatment offered, which will vary according to the aetiology of the condition. The common symptoms of heart failure (although this list is not exhaustive) are breathlessness (or dyspnoea), fatigue, fluid retention (oedema) in the ankles and feet (if right

ventricular dysfunction) or lungs (if left ventricular dysfunction) and a nocturnal cough. The term congestive heart failure refers to a classic presentation of heart failure where an individual experiences florid symptoms of heart failure (previously described) and their system is congested by fluid retention. This differs from the term heart failure that describes the syndrome itself where congestive symptoms may not be present in an individual.

The heart's reduced output is commonly caused (though not always) when "the left ventricle cannot develop enough power to eject blood into the aorta (p5)" (Jackson, 1993), known as Left Ventricular Systolic Dysfunction (LVSD). Systole is the period of time during which the heart pumps (contracts) whereas the period of relaxation is diastole (Allan & Sheidt, 1996). LVSD damage is most commonly caused by an MI. However, about one third of the cases of heart failure result from hypertensive disease (Cowie, Mosterd, Wood, Deckers, Poole-Wilson, Sutton & Grobbee, 1997). Other common routes include cardiomyopathy (damage to heart muscle), diseases of the mitral and/or aortic valves, cardiac arrhythmias or electrical conduction disorders such as atrial fibrillation (McMurray & Stewart, 2000). Less commonly other dysfunctions of the heart muscle via pericarditis or rheumatic fever may engender heart failure and the condition may occur as a consequence of one or more of these problems, illustrating the complexity of this condition.

2.1.1 Prevalence and Incidence of Heart Failure

Petersen and colleagues (2002) have calculated that approximately 900 000 people in the UK are living with symptomatic heart failure, with almost a million other individuals asymptomatic. Prevalence of heart failure increases with age with between three and 20 cases per 1000 population in younger adults but this rises to more than 100 per 1000 population in those aged 65 years or over (McMurray & Stewart, 2000). Variability in prevalence estimates arise from difficulties defining heart failure, whether asymptomatic versus symptomatic or due to LVSD or other causes (McMurray & Stewart, 2000). Different population characteristics in the studies (age, geographic location, socio-economic status) and the investigative methods used to identify heart failure magnify variations in prevalence estimates. There are also differences in study design, some being cross sectional involving screening participants for heart failure (Royal College of General Practitioners, 1995), or focussing upon identified patients (Clarke, Gray & Hampton, 1995), whereas others are longitudinal (McKee, Castelli, McNamara & Kannel, 1971).

McMurray and Stewart (2000) emphasise that determining the incidence of heart failure in the population is more difficult than approximating prevalence rates. The Framingham study longitudinal study which began in 1946 (Ho, Pinsky, Kannel & Levy, 1993, McKee et al. 1971) still has the most detailed data concerning incidence. The researchers found that there were about 2 new cases per 1000 in people aged 45-54 years and this increased to 40 new cases per 1000 in men aged 85-94 years. Cowie et al. (1999), have carried out the most up to date UK study and calculated that the annual incidence in 150 000 people was 1.85 per 1000

population. The average age of a person to be first diagnosed with Heart Failure is 76 years (Cowie et al. 1999).

2.1.2 Gender and Ethnicity

Whilst prevalence estimates remain uncertain, gender ratios are better defined: the male to female ratio being two to one (NSF, 2000). However, women's symptoms appear less obvious to clinicians and are therefore under diagnosed. Some evidence has revealed that men have a higher risk of developing heart failure, but due to women's increased longevity as many women are diagnosed with heart failure as men (McMurray et al 2000). Research remains sparse on whether disease progression, treatment and prognosis of heart failure differs between genders (SIGN 35, 1999).

Additionally, there is a lack of data about the rates of heart failure in different ethnic groups (NICE, 2003). There is also suggestion that non-white populations arrive at the same cardiovascular endpoint (heart failure) through different underlying causes. However, this remains speculative in the absence of research on disease development in diverse ethnic groups (NICE, 2003).

2.1.3 Diagnosis of Heart Failure

Heart failure is a condition with a complex aetiology causing considerable difficulties in reaching an accurate diagnosis. Accurate diagnosis is problematic for several reasons. Signs and symptoms of heart failure are often non-specific and are similar to those indicating other conditions such as obesity, chest disease and venous insufficiency in the lower limbs (NICE, 2003). There is no singular clinical

investigation which can confirm the presence of heart failure, and until recently there has been a lack of provision of facilities to send people suspected of having the condition to have accurate clinical tests such as echocardiography. Finally, heart failure can have an insidious development and those who are asymptomatic may be more difficult to diagnose. Guideline development was initiated due to the need for a framework setting out standards for an accurate diagnosis of heart failure. For further details of clinical investigation for diagnosis refer to Appendix 1. For an extensive review refer to NICE Guidelines (2003).

2.1.4 Mortality Rates

Mortality rates for heart failure are high with a figure of 80% of men dying within six years of diagnosis (SIGN 35, 1999). Approximately 40% of patients diagnosed with heart failure die within a year. After this time the mortality rates decline to 10% per year (Cowie, Wood, Coats, Thompson, Suresh, Poole-Wilson & Sutton, 2000). These are comparable to mortality rates for cancer of the colon and reflect a poorer prognosis than for prostate and breast cancers (Quinn, Babb, Brock, Kirby & Jones, 2001). Psychological morbidity such as anxiety and depression are widely acknowledged to be a common problem with people with a range of chronic medical illnesses, such as diabetes, cancer and renal disease. There is some evidence to suggest that depression can affect the outcome of chronic illness and their mortality and quality of life (Rodin, Craven and Littlefield, 1991).
An important aspect of morbidity in this condition is psychological morbidity, which will be discussed in relation to heart failure in the next section.

2.2 Psychological Morbidity in Heart Failure

In a recent review of the literature in this area, Profant and Dimsdale (2000) point out that behavioural medicine investigators have focussed a lot of attention upon psychological factors in related heart conditions such as coronary artery disease, myocardial infarction and hypertension and yet heart failure has remained a curiously neglected condition. This fact is surprising and puzzling, considering that heart failure is a common condition with an increasing prevalence rate. Perhaps as a result of the paucity of literature concerning this topic there are also very few statistics about the occurrence of depression or anxiety in the heart failure population. Profant et al (2000) clearly summarise the state of the literature concerning psychological factors and heart failure, and emphasise the caveats and gaps in the research. They point to the fact that much of the previous research has not exclusively focussed upon psychological variables and heart failure, but rather this has been included as an adjunct to other research issues. This tends to have resulted in nebulous research hypotheses concerning psychological factors and the use of quality of life scales, which do not specifically measure these factors. The researchers also highlight the difficulty of measuring psychosocial variables and speculate that this adds to the reasons for a dearth of research. Profant et al (2000) have drawn out four main areas of interest that studies have attempted to address: psychiatric comorbidity in heart failure, psychological precipitants of heart failure, psychosocial consequences of heart failure and possible physiological mechanisms that link these factors and may account for any relationship between factors.

2.2.1 Prevalence of Depression in Heart Failure

The point prevalence of depression in people recovering from an acute MI tends to be between 15-23% (Carney, Freedland, Sheline, and Weiss, 1997). Freedland, Rich, Skala, Carney, Davila-Roman and Jaffe (2003) state that the majority of the small amount of research has investigated depression in outpatients as opposed to hospitalised patients, and has used instruments with cut off scores as opposed to utilising the criteria of the Diagnostic and Statistical Manual for Mental Disorders (1994) (DSM IV). Based on the results from these studies depression in the heart failure population would be estimated up to 42%. This number is not based upon large-scale investigations with a strict criteria for depression such as the DSM IV.

Two recent studies have cross-sectionally examined prevalence rates of depression in heart failure populations (Freedland et al. 2003, Turvey et al 2002). Freedland et al (2003) found that of 682 patients interviewed using the Diagnostic Interview Schedule (DIS) following DSM IV criteria 20% of the sample met the criteria for major depression, 16% for minor depression and 51% scored >10 on the BDI. Turvey et al (2002) found depression to be less prevalent occurring in one in 10 people. Depression was classified as syndromal rather than clinical and debate remains over classification in clinical practice. Differences in the prevalence rate of the studies could be due to different samples, hospitalised versus community and assessment instruments used. Further research is required to ascertain the prognostic importance and treatment of co-morbid depression.

2.2.2 Definition of Depression

DSM IV indicates that depression is a mood (affective) disorder varying in duration and severity. Major depressive disorder is characterised by five or more symptoms out of nine that have been present in the same two-week period and are a change in previous functioning. At least one of these symptoms must be depressed mood, loss or interest or pleasure. Alongside major depressive disorder, people can experience different forms of depression such as minor depressive disorder and dysthymia, which is a milder more chronic form of depression than major depressive disorder.

Potential reasons for the variety of estimates and inaccuracy are due to the overlap of somatic symptoms of depression (e.g. low appetite and low energy) with physical consequences of heat failure (Profant et al 2000, Turkey, Schultz, Arrant, Wallace & Herzog, 2002). Very few scales have been designed to measure depression in populations were people have comorbid conditions, which may mask depression. Many standardised scales such as the Beck Depression Inventory (BDI) create difficulties because they include somatic symptoms of depression, which could be due to physical illness.

2.2.3 Treatment for Depression in Heart Failure

Pharmacological therapy for depression (i.e. antidepressants) can lead to complications such as fluid retention, hypertension and arrhythmias and so their use is restricted. The lack of alternative interventions such as psychological therapies and minimal evidence base for them is of some concern for patients, considering that depression can have a negative and profound impact upon quality of life and mortality (NICE, 2003, Frasure-Smith, Lesperance & Talajic, 1993). Depression

can affect other aspects of the heart failure patient including medical morbidity, functional impairment, occupational disability and decreased adherence to medications (Freedland et al 2003). Depression has profound implications for patient and health professional in terms of the low mood itself and its effect on health outcomes and coping in the patient (SIGN 1999, NICE, 2003).

Anxiety is the other psychological factor that can be important in influencing outcomes for people with chronic medical illness. No studies were found which examined possible causality of anxiety in heart failure or its comorbidity, influence upon quality of life or mortality.

2.2.4 Depression as a Risk Factor in Heart Failure

Williams, Kasl, Heiat, Abramson, Krumholtz and Vaccarino (2002) investigated depression as a risk factor for heart failure. This is the only prospective study of its type, designed to investigate the influence of depression as a risk factor for the development of heart failure. 1000 men and 1500 women of diverse ethnic origin, aged 65 or more were followed up for 14 years from 1982-1996. The Centre for Epidemiological Studies Depression Scale (CES-D) was used to assess participants for depression (a score of 21 between 0-60 was met this criteria). Depression was a statistically significant risk factor for women but not men. The disparity across genders was attributed to a relatively small sample of men in the study. The study highlights a potentially important gender difference which requires further investigation.

2.2.5 Mechanisms of Action of Depression in Heart Failure

Researchers have developed a number of theories to account for physiological mechanisms that may link depression and heart failure. One theory is that depression increases the activity of the renin-angiotensin aldosterone pathway, mimicking the action of heart failure itself. An alternative hypothesis it that psychological stress affects left ventricular functioning predisposing the development of heart failure. A third possibility is that increased activation of the sympathetic (sympathoadrenal) system increases the risk of heart failure. It is likely that depression and heart failure may interact to exacerbate the effects of each. Depression also affects individuals' behaviour in the form of reducing adherent behaviour as a result of low mood (Profant et al 2000, Williams et al 2002).

In summary, there is a dearth of literature surrounding psychosocial and psychological factors and their relationship to heart failure. In particular there is no recent research concerning anxiety or other psychological factors upon heart failure. There had been more research dedicated to depression and its role in heart failure, however, there is not sufficient literature to conclude how whether depression can cause heart failure and if it can what the mechanism of action is. There is also little research about the consequences of developing depression when a person has heart failure (by examining health outcomes longitudinally) and there is no research concerning the effect of having heart failure when a person is depressed. The differences in the risk factor of developing heart failure when depressed for men and women emphasises the importance of the need for further research surrounding gender differences.

A factor which may influence many outcomes for heart failure patients including hospital readmissions, morbidity and medication adherence is social support. It remains a neglected area of research and its mechanisms of action are unknown. Recent research will be reviewed in the next section.

2.3 Social Support and Heart Failure

Social support is a term commonly used to describe the structure and function of an individual's social environment. Structure tends to include the size and stability of an individual's family, friends, colleagues, health professionals and community resources (Shumaker & Czajkowski, 1994). The functional component of social support comprises an individual's perception of its availability (Shumaker & Czajkowski,1994). Research has identified that reduced social support predicts increased risk of readmission to hospital, alongside medication adherence (Moser & Mann, 2002, Vinson et al 1990). Social support is also suggested to play a role in determining patients' levels of self care, the more social support an individual has the greater their level of self care (Reigel & Carlson, 2002). However the mechanism of action of social support and influence on readmission, mortality rates and morbidity remains speculative due to the dearth of rigorous research in this area. Anecdotally heart failure patients have highlighted the importance of social support and their fear of becoming socially isolated (Murray, Boyd, Kendall, Worth, Benton & Clausen 2002).

Murberg & Bru (2001) have conducted the only recent study to focus upon social support. They investigated the association between social relationships and mortality in heart failure patients over a two year period. Social support was

explored by measuring perceived social support and social isolation, with findings showing significant associations between social isolation and mortality. However, the researchers were unable to conclude the mechanism of action responsible for such association. Two difficulties have amplified the limitations of research to date, nebulous definitions of social support and a lack of validated standardised measures of the construct (Victor, Henderson & Lamping, 1999, Shumaker & Czajkowski, 1994). Further work is required to reduce these problems to enable greater understanding of the influence of social support in heart failure outcomes.

2.4 Treatment of Heart Failure

Despite high mortality and morbidity rates, heart failure is a treatable if not curable condition (SIGN 35, 1999). Initial treatment options for heart failure patients with LSVD are lifestyle management and pharmacological therapy. Invasive procedures such as surgery may also be considered if they can improve long term outcomes for patients (NICE, 2003). Lifestyle management is likely to comprise participation in a cardiac rehabilitation programme, exercise training and advice in the reduction of lifestyle risk factors. Other elements of non-pharmacological treatment that are important consist of: helping individuals to pace their activities of daily living to maintain functioning and reduce levels of fatigue. This treatment also includes advice about regulating mood in terms of managing anxiety (using relaxation techniques) and depression. Such support may involve helping individuals to schedule activities to lift mood and improve functioning (Stewart and Blue, 2004).

2.4.1 Pharmacological Treatment

Pharmacological treatment is also key for the majority of patients with this condition. As a result of numerous large scale randomised controlled trials of such medications in the UK and US, there is now a substantial evidence base for the effectiveness of the medications often recommended for patients (Cowley, Stainer, Wynne, Rowley & Hampton, 1986).

Studies examining the efficacy of the various pharmacological therapies tend to investigate whether they reduce symptoms and morbidity, and improve quality of life (in enabling people to carry out more activities of daily living and increase mobility). In comparison to placebos, Angiotensin-Converting Enzyme (ACE) Inhibitors have been found to increase life expectancies improve symptoms, and reduce the risk of hospitalisation of people with asymptomatic heart failure due to LVSD (Neal, MacMahon, Chapman, & Blood, 2000, Centre for Health Services Research University of Newcastle upon Tyne, 2001, Lubsen, Chadha, Yotof & Swedberg, 1996). Similarly beta-blockers can also improve life expectancy (Bouzamando, Hulot, Sanchez, Cucherat & Lechat, 2001, Bonet, Augusti, Arnau, Vidal, Diogene, Galve & Laporte 2000, Packer, Coats, Fowler, Katus, Krum, Mohasci, Rouleau, Tendera, Castaigne, Roecker, Shultz & DeMets, 2001). Pharmacological treatment is complex and is tailored to the individual needs of the patient.

2.4.2 Invasive Procedures

Invasive procedures that may also be considered in the management of heart failure include coronary revascularisation (such as a Coronary Artery Bypass Graft

(CABG)) or cardiac transplantation. No randomised controlled studies evaluating outcomes of this procedure currently exist as the procedure is uncommon and patients must fulfil certain criteria for eligibility. More common invasive procedures undertaken are improving the contraction of the left ventricle (fitting a Ventricular Assist Device (VADs)), improving the electrical activation of ventricular contraction (via cardiac resynchronisation therapy) and reducing the irregularity of heart beats characterised by arrhythmia (fitting a Implantable Cardioverter Defibrillators (ICDs)). These methods have undergone evaluations regarding their clinical and cost effectiveness and impact upon patients' lives and symptoms (NICE, 2003).

Despite improved treatment with drugs such as ACE Inhibitors, and more standardised national guidelines for health professionals managing heart failure, there are high readmission rates of patients and the NSF (2000) states that they can be as high as 50% over three months. Cowie, Mosterd et al. (1997) and the SIGN (1999) guidelines report that half of these costly (in terms of NHS expenditure) admissions are preventable. Stewart and Blue (2001) have found evidence to suggest that an important factor responsible for readmission rates is a consequence of sub optimal pharmacological and non-pharmacological adherence. There are different reasons for lack of adherence and this can be intentional or non-intentional. Whilst the element of non-adherence is seen to be important in heart failure, there has been little exploration of this process with the population and the majority of evidence has been inferred from other chronic conditions. A recent development in service provision has been devised to improve long term prognosis, improve quality of life and also help to reduce hospital readmissions and improve adherence to

medication. This involves employing heart failure specialist nurses to provide a variety of health interventions with patients with heart failure and improve liaison between primary and secondary care. The next section will describe and evaluate this role in greater detail.

2.5 Role of the Specialist Nurse in Heart Failure

The following section will describe and discuss the reasons for the development of the specialist nurse role, the settings where it has been applied and the evidence for its effectiveness. Areas of the research literature where there is a paucity of evidence will be highlighted, in particular the psychological impact of this service for patients.

Developing services for heart failure (2003) is a new NHS guideline which includes local strategies for improving heart failure services, and also discusses important resources which need to be utilised to improve the care of heart failure patients. Key to this is the specialist nurse, whose role includes the following components:

- Monitoring patients' status to assess whether hospital readmission is absolutely necessary or medications need to be changed.
- Advising on lifestyle changes (particularly related to diet and exercise) which can improve quality of life.
- Providing emotional support to cope with a terminal condition and diminishing quality of life.

2.5.1 The Impact of the Specialist Heart Failure Nurse in Reducing Readmissions

Whilst the need for specialist nursing interventions has been observed and developed in other chronic conditions (Cooper & Mitchell, 2004), this is a very recent innovation in health care delivery for heart failure. The impetus to reduce rates of readmission prompted research in the USA, Australia and Europe. Many hospitalisations of heart failure patients result from lack of adherence to medications regimens (Dracup, Baker, Dunbar, Dacey, Brooks, Johnson, Oken & Massie,1994, Ghali, Kadakia, Cooper & Ferlinz,1988). Cumulative findings of research suggested that rates of dietary and medication non adherence vary from 20-58% in heart failure populations, with 27% of hospital readmissions attributed to reduced adherence to these health recommendations (Michalsen, Konig & Thimme, 1998, Vinson, Rich, Sperry, Shah & McNamara, 1990, Fletcher, Pappius & Harper, 1979, Hulka, Cassel, Kupper & Burdettte, 1976).

However, whilst research indicates non-adherence is a significant problem, little focus has been placed upon identifying the reasons for this and isolating specific influencing factors. Ley (1988) has conducted more in depth research in this area. He found that several factors are important in improving adherence to health advice and in particular adherence to medication. These were simplicity and brevity of messages and individuals' belief in the message (Ley, 1998). Additionally his research revealed that individuals tend to be more adherent if they have stored health information in their memory. Information presented to individuals first is more likely to be stored in their memory and they are thus susceptible to primacy effects (Ley, 1972). Whilst patient education and counselling are acknowledged to

be important in determining adherence, other factors may enhance this process such as a strong patient-practitioner relationship (Dracup et al 1994).

In the 1990s several large-scale randomised controlled studies were conducted to examine the efficacy of nurse-led multidisciplinary heart failure management programmes in improving outcomes for this population. Rich, Beckham, Wittenburg, Leven, Freedland and Carney (1995) conducted a prospective study examining the effect of a nurse-directed multidisciplinary intervention on rates of readmission within 90 days of discharge for high risk patients aged 70 or over who had been hospitalised with heart failure. The primary end point of the study was survival without readmission during the 90 days after discharge. However, other outcomes such as quality of life for patients and cost of care were also evaluated. Results showed that there was a trend towards non-significance between the two groups in terms of survival without readmission. However, there was a significant difference between the two groups in the number of readmissions in the follow up period ($p=0.03$). There was also a significant difference in the quality of life reported by the two groups, with participants in the treatment group producing higher quality of life scores ($p=0.001$). Rich et al (1995) acknowledged that their results did not have a high degree of generalisability to other heart failure patient populations, due to selective sampling of high-risk patients. The circumscribed follow up period and multidisciplinary nature of the intervention resulted in difficulties in concluding which elements of the intervention had been effective in improving patient outcomes.

In Australia, Stewart, Vandenbroek, Pearson and Horowitz, (1999) examined the effect of a single, home-based visit by a nurse and a pharmacist, one week after patients had been discharged. They advised patients on medication management, identified early signs of clinical deterioration and intensified medical follow up and caregiver support if appropriate. The follow up period was for 18 months and the primary end point was frequency of unplanned readmissions. The researchers found that there was a significant difference between the two groups where the intervention group had less readmissions. However, the study did not reveal significant cost savings or improved survival, which the researchers attributed to a small sample size. The intervention might have been too short to have a significant impact upon these variables. A similar study was conducted in Sweden where patients attended a nurse led outpatient clinic for one year. Results indicated that time to first readmission was significantly longer for the intervention group. However, unlike Rich et al. (1995) there was no significant difference between the groups at the beginning of the study or at one year follow up (Cline, Israelsson, Willenheimer, Broms & Erdhardt, 1998).

Although there are positive results from all three trials in terms of reducing readmission rates, and an improvement in quality of life in two of the trials, there was no significant improvement in survival in any study. It is difficult to determine why this is so. Reasons could include the baseline characteristics of the sample used (for example older patients who are more likely to die) or the fact the study sample size was not large enough, so a Type II statistical error was committed. However, McMurray and Stewart (1998) rightly question whether a reduction in mortality is an appropriate aim for this population. Whilst these studies have

similar aims, the interventions differed in setting, length of follow up and mode of delivery, thus restricting the generalisability of the results. The quality of life measures used are seldom validated and sparsely described making it difficult to assess what dimensions had improved.

The follow up times in these studies did not enable any investigation of medium or long term effects of such interventions (McMurray et al. 1998). The effects of the psychoeducational aspects of the intervention were not evaluated in these trials in terms of any positive influence upon psychological processes of patients. However, it is acknowledged such factors can precipitate positive change (Dracup et al 1994).

Later studies of home-based nurse-led management of heart failure programmes with longer follow up times have also produced some positive results for this type of intervention. Stewart and Horowitz (2002) conducted a follow up study to examine the longer term outcomes for the two groups of home-based intervention and control participants who had been involved in their previous two studies. Both groups in both studies (total n=297) were followed up for an average of 4.2 years with limited participant attrition. Intervention groups reported better rehospitalization, survival and cost outcomes compared to the usual care group. Mortality rates diminished with median survival of the intervention group of 40 months compared to 22 months in usual care group. These findings appear as powerful as the use of beta-blocker medication in people with heart failure (Moser & Mann, 2002). However, Moser et al (2002) comment upon a scarcity of evidence to show what type of nurse-led intervention is more effective and how these can be tailored to subgroups of heart failure patients.

Blue, Lang, McMurray, Davie, McDonagh, Murdoch, Petrie, Connolly, Norrie, Round, Ford and Morrison (2001) conducted a pioneering randomised controlled trial of a specialist nursing intervention in Scotland. The study design was similar to that of earlier studies but the specialist intervention was more clearly described in this instance. The intervention consisted of education, facilitation of self-management skills and psychological support after discharge. The nurses followed patients for 1 year via home visits and telephone contacts. Primary end point was death from all cause mortality or hospital admission for heart failure. The results revealed that there was a statistical difference between the two groups in terms of fewer readmissions for any reason and fewer admissions for heart failure. There was no significant difference in mortality rates but Blue at al (2001) attribute this to the relatively short length of follow up in the study.

The study has similar results to others in this field. These results are positive and important at a national level as it is one of the few RCTs conducted in the UK where the results have greater generalisability. A limitation common to all the reviewed studies is the focus upon high risk heart failure patients for inclusion in studies and the lack of a precise definition of this patient type (Blue et al 2001, Stewart et al, 1999, Rich et al, 1995).

2.5.2 Duties of a Heart Failure Specialist Nurse

The duties of a specialist nurse vary across countries. However, Stewart and Blue (2001) outline the key components of the role of the nurse generally used in the UK and adopted in the current study. This includes:

- Identifying and continuously monitoring high risk patients
- Optimising pharmacological therapy
- Providing individualised health care
- Providing care for the carers of the heart failure patient
- Facilitation of patient self management
- Education
- Psychosocial support
- Reducing hospital admissions
- Detecting clinical deterioration

The importance of psychological interventions (such as education and support of patients and carers) and their effects on underlying psychological processes are stated by researchers (Stewart and Blue, 2001). However very little research has been conducted to examine these processes in a systematic, in-depth way. Stewart and Blue (2001) state that "although the effectiveness of psychosocial support is difficult to measure and therefore hard to justify, it represents one of the cornerstones of any intervention of this type (p117)". They go on to recommend that anxiety, depression and quality of life should be assessed routinely in patients Yet in all the trials reviewed, anxiety and depression were not assessed and quality of life only included in some trials using less well validated instruments. The role of the nurse and home based interventions is to improve medication adherence. However, the level of adherence was not assessed in studies via self report, pill counts or patients' knowledge. No formal investigation of the psychological aspects of impact of the specialist nurse have been undertaken to date and published, yet there is a need for this information to further develop and improve the role.

There are no suitable paradigms for understanding the impact of psychological processes upon the health behaviour of heart failure patients in the nursing or medical literature. However, there are a number of models in health psychology, which have been specifically developed to understand individuals' responses to illnesses, (cognitively, emotionally and behaviourally). They have been applied to a range of illness populations but have not been widely used with heart failure populations. These will be considered in the next section.

2.6 Illness Representations

In the field of health psychology in the last 30 years researchers have developed Social Cognition Models (SCMs) such as the Health Belief Model (Rosenstock, 1974), the Theory of Reasoned Action (TRA), (Ajzen and Fishbein, 1980), and the Self-Regulation Model (SRM) (Leventhal, Nerenz and Steele, 1984) to try to explain how people understand and manage health threats or illnesses they may experience.

One such model was developed by Leventhal and colleagues (1984) called the Self-Regulatory Model (SRM) of Illness Cognition. Leventhal, Diefenbach and Leventhal (1992) theorise that individuals are active problem solvers who make sense of an illness or health threat by forming their own cognitive representation of the threat, called an illness representation. An illness representation is "personal understanding of the salient features of an illness" (Fox, 2000). This can determine how they respond to and manage the threat. Leventhal et al. (1992) state the SRM differs from other models by "its focus on proximal targets for self regulation. (p150)". The individual attends to ongoing indicators such as symptoms to act as

targets for interpretation, and for the evaluation of self-regulatory processes such as adherence or coping activities, in an ongoing dynamic process. The SRM also integrates factors from the wider social and cultural context with the intra-psychic process of understanding, distinguishing it from other models. The SRM is a parallel-processing model which incorporates two systems operating together. One is a psychologically objective representation with coping procedures and appraisal of the outcomes and the other is a subjective system which has emotions and coping procedures and appraisals of outcomes. The two sections together create the self-regulatory model.

There are three central assumptions which are fundamental to the Self-Regulatory Model: (1) the patient is an active problem solver motivated to test hypotheses about the meaning of symptoms and physical condition. (2) The illness representation is the central cognitive construct that guides the procedures chosen to cope with a health threat and appraisal of the outcomes of coping procedures. (3) Illness representations are individualised and may differ to the health care provider's representation of a health threat.

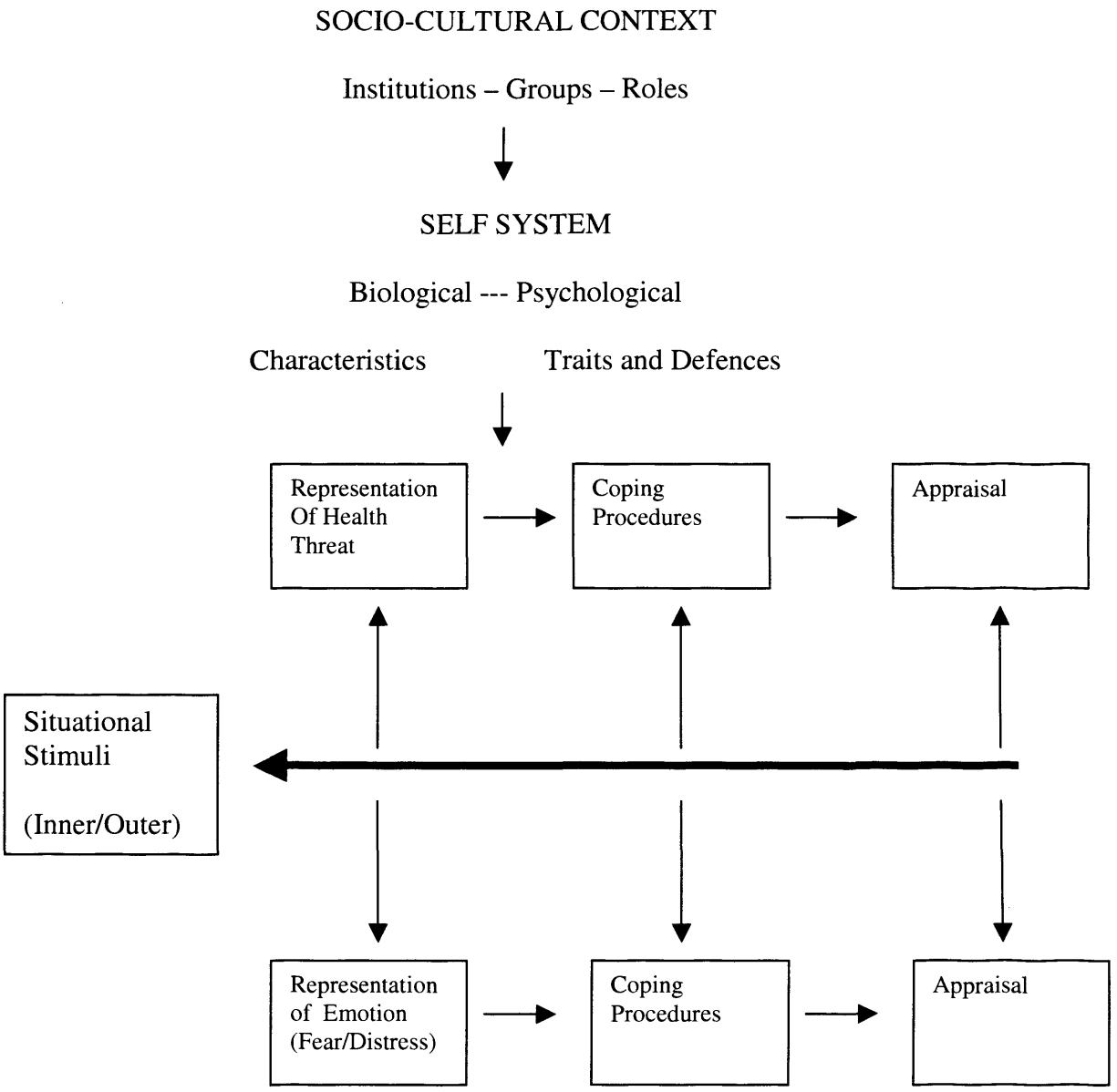

Figure 1: The Self Regulation Model

Leventhal, Nerenz and Steele (1984) developed this model by studying the impact of fear messages on the decision to take preventative action against lung cancer and tetanus. They discovered the four dimensions of identity, timeline, causes and consequences. Further research by Lau, Bernard, and Hartman (1989) isolated a fifth dimension of cure/control of an illness. Subsequent researchers using different methodologies in different populations have consistently identified these

dimensions to individual illness representations, thus providing additional validity for the model (Baumann, Cameron, Zimmerman & Leventhal, 1989, Bishop, 1987, and Lau, Bernard and Hartman, 1989).

Researchers have consistently found five themes or dimensions forming part of an illness representation, in different chronic illnesses such as cancer, rheumatoid arthritis and diabetes (Buick, 1997, Pimm & Weinman, 1998, Griva , Myers & Newman, 2000). (1) Identity is concerned with patients' ideas about the label of their condition and the link to symptoms. (2) Timeline reveals perceptions about the duration of the problem – acute, chronic or cyclical. (3) Cause is focused upon the cause of their condition (e.g. genetic, stress, chance). (4) Consequence consists of the individual's belief about illness severity and impact upon psychological, social, physical and economic functioning. (5) Cure/control is the dimension which examines to what extent the person think is their condition is curable or controllable.

Quantitative measures of illness representations have been developed, such as the Implicit Models of Illness Questionnaire (IMIQ) by Turk, Rudy and Salovey (1986). Whilst some researchers have found this to be a valid measure for assessing illness cognitions, (Schiaffino & Cea, 1995) other researchers have suggested that data from the IMIQ was not consistent with the SRM (Weinman et al 1996).
Probably the most widely known measures are the Illness Perception Questionnaire (IPQ) developed by Weinman, Petrie, Moss-Morris and Horne, (1996) and the Revised Illness Perception Questionnaire (IPQ-R) by Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick, (2002). The IPQ was specifically designed to

measure the cognitive components of the SRM. It has also has been widely used in a variety of illness populations, including heart failure (Fox, 2000) myocardial infarction, rheumatoid arthritis (Murphy, Dickens, Creed and Bernstein, 1999), diabetes (Griva, Myers, and Newman, 2000), and chronic fatigue syndrome (Heijmans, 1998). Moss-Morris et al. (2002) state that there is a substantial evidence base for the structural relations between the five components of illness representations and the predicted links between this and psychological outcomes of mood (Fortune, Richards, Main and Griffiths, 2000), functional adaptation (Heijmans, 1998) and adherence to medical recommendations (Cooper et al 1999). Initially when the IPQ was developed, it was tested with seven illness groups, including asthma, renal, diabetes and rheumatoid arthritis, totalling 848 participants. The measure was found to have acceptable levels of test retest reliability, concurrent, discriminant and predictive validity. Both the IPQ and the IPQ-R are the most widely used and have been validated with a variety of illness populations (Hagger & Orbell, 2003).

2.6.1 Inter-relationships between Dimensions of Illness Representations

Further studies have been conducted with the aims of exploring the inter-relationships between the five different components of illness representations. Heijmans (1999) points out "it is likely that a combination of illness beliefs is more important in determining coping and adaptive outcome than the individual illness dimensions (p142)". Studies with Myocardial Infarction (MI), Irritable Bowel Syndrome (IBS) and Addison's disease populations have all found that individuals with a strong illness identity (experience more symptoms) had stronger perceptions of chronicity, predicted graver consequences of their condition and had a reduced

perception of control over their condition (Heijmans, 1998, 1999, Moss-Morris, Petrie & Weinman, 1996, Rutter and Rutter, 2002). Strong illness identity correlates with stronger timeline, consequences and weaker perceptions of control or curability. Hagger et al (2003) conducted a meta-analysis of studies using Leventhal's model and confirmed the validity of the illness representation components and their inter-relationships.

2.6.2 Further Exploration of the SRM Model – Relationships between Illness Representation, Coping and Appraisal Outcomes.

Apart from investigating the inter-relationships between the different aspects of illness representations, recent research literature has concentrated on examining the assumptions of Leventhal's model. In particular the central prediction that a person's illness representation will guide their methods of coping about their condition and the coping methods will also mediate outcomes and appraisal of them (Heijmans and de Ridder, 1998). It is likely that coping methods exert some influence upon illness outcomes and appraisal, however, objective evidence for this has been somewhat limited. This is partly due to the lack of generic and validated measures developed for assessing coping. Additionally, some coping behaviours which are important in determining illness outcomes may not be related to illness representations and are therefore under-researched. An example of this would be seeking social support, which has been found to be unrelated to illness cognitions (Hagger and Orbell, 2003), yet is important in influencing outcomes and should be investigated. It has been hypothesised that social support may be affected by different cognitions and social context (Hagger and Orbell, 2003). The evidence

for this aspect of Leventhal's model has thus produced a mixture of results, not all of which confirm this prediction of the links of understandings of illness to coping and coping to outcome and their appraisals (Moss-Morris, Petrie and Weinman, 1996). Other researchers have also elaborated on these hypotheses and examined how appraisal outcomes can then influence an individual's original understanding of their illness and interpretation of their symptoms.

Hagger and Orbell's (2003) meta-analysis is the widest review of the literature to date. In total 23 illness populations were included in the analysis, the majority being chronic conditions whose causes were not easily identified such as Multiple Sclerosis and IBS. However, other less researched populations (acute conditions) were also included such as people with the common cold. There is some evidence to suggest that illness cognitions are related to coping mechanisms and influence the method of coping that people utilise from studies with CFS, arthritis and diabetes (Heijmans, & de Ridder, 1999, Schiaffino, Sharwaryn & Blum, 1998, Hampson, Glasgow & Foster, 1995). The individual's perception of the controllability of their condition affects their method of coping – which is likely to be active if the condition is thought to be controllable. However, other studies have found that illness representations may be more closely related to outcomes than coping (Heijmans, 1999 and Steed, Newman & Hardman, 1999). Both studies used multiple regression analysis and found that coping methods accounted for very little of the variance for coping outcomes, such as physical functioning and psychological well-being.

There are different potential explanations for the different findings regarding the influence of coping on outcomes in the literature. One possible reason is the way that coping has been measured in many studies. Many instruments assessing coping in studies have been generic in nature so coping strategies used by patients in diverse populations may not be assessed due to the limitations of the tool. Very few objective measures of coping are used, such as help seeking behaviour to health care providers. The majority of studies are cross sectional and so the causality of influence of different aspects of the model and their dynamics cannot be accurately studied without longitudinal research. Methods of analysis tend to be correlational so whilst associations between factors can be detected (increased perception of control is associated with active coping) it cannot be concluded that one factor may influence another.

2.6.3 Illness Representations and Health Outcome

Cooper, Lloyd, Weinman & Jackson, (1999) and Weinman, Petrie, Sharpe & Walker, (2000) have prospectively examined the influence of illness representations upon health behaviours and outcomes in cardiac populations. Participants were followed up for 6 months in both studies. Cooper et al. (1999) investigated the illness representations of two groups of patients and the extent to which this could predict their attendance at a cardiac rehabilitation course 6 months later. One group had had MIs and the other had all had Coronary Artery Bypass Grafts (CABG). Patients who showed a stronger belief in control over their condition attended, whereas people with less strong beliefs did not. The researchers rightly pointed out that if people's illness representations and any misconstrued ideas about their condition were identified at an early stage of care, interventions could be tailored to

explore and alter these ideas so individuals could manage their own care more confidently and effectively. Weinman et al. (2000) investigated how people attributed the cause of an MI and whether these related to changes (or the lack of them) in lifestyle 6 months later. It was revealed that the individuals who made the largest numbers of positive lifestyle changes such as taking up vigorous exercise, were those who attributed their MI to poor lifestyle habits such as eating unhealthy food. Weinman et al (2000) also found that congruence of spousal attributions with patients' ideas were associated with greater improvements in lifestyle with the patients. These findings reveal how casual attribution and perception of control can influence behavioural outcomes of illnesses.

2.6.4 Influence of Health Professionals upon Illness Representations of Patients

Few studies have investigated the "issue of fit" between the illness representations of patients in relation to health professionals and the influence of this upon health behaviour (Martin, Rothrock, Leventhal & Leventhal, 2003 in Suls & Wallston, 2003). However, those that have, have found that a mismatch of ideas can be negative for the patients. Cohen, Tripp-Reimer, Smith, Sorofman and Lively (1994) found that diabetes patients who had a better relationship with their health care provider had better regulated serum glucose levels. Research in heart failure is sparse however it may be key to determining health outcomes as many patients experience difficulty in labelling and interpreting symptoms of heart failure (which can be routine and slow to change) so the condition can be unmanaged. A care provider with awareness of the individual's illness representation may help to

improve patients' difficulties in cognitive or physical monitoring (Martin at el 2003 in Suls & Wallston, 2003).

A congruence of illness representations between patient and health care provider may have more positive health outcomes for the patient but little research has explored the mechanisms of action of this process.

2.6.5 Influence of Significant Others upon Illness Representations

Leventhal, Diefenbach and Leventhal (1992) also highlight that an under researched area of the literature is the influence of significant others upon the illness representations and self-regulatory behaviour of patients. Weinman et al (2000) identified that congruence of spousal attributions with patients' representations were associated with greater improvements in lifestyle. Fox (2000) echoed these findings in relation to influence upon adherence behaviour in heart failure patients. Further research is required to understand the influence of the congruence of illness representation upon health behaviours and outcomes of patients in relation to health care providers and spouses and partners. A significant other version of the IPQ has been developed to assess these factors (Weinman et al 1996).

2.6.6 Amenability of Illness Representations to Change

Recent research has begun to look at whether illness representations might be amenable to change via health care interventions. Petrie, Cameron, Ellis, Buick and Weinman (2002) carried out a prospective randomised controlled trial to determine if MI patients' illness representations would alter as a result of a psychological

intervention versus normal care. A statistically significant difference was found between the intervention and usual care group in the perception of control they had and lower levels of belief in serious consequences. Further research needs to verify these findings. However, this work has significant clinical relevance, for if people's illness representations can be altered to be more accurate which influences their behaviour and health outcomes, this could improve patient's management of their conditions and quality and length of life. As Weinman and Petrie (1997) point out many health care interventions such as pain management and cardiac rehabilitation are not based on " a sound theoretical understanding of psychological processes" of the patient. However, the illness representations of a patient can be a key factor in hindering or promoting adjustment to illness and productive behaviours associated with that.

2.7 Medication Adherence

Social cognition models have also been applied to this area to try to understand individuals' adherence to treatment recommended by health professionals such as exercise, dietary changes and medication adherence. No model fully accounts for the reasons why individuals or groups of patients are adherent or not.

Myers and Midence (1998) discuss the difficulties of defining the term "adherence". Despite a significant body of research exploring adherence, it is not clearly defined by researchers. An additional complication arises from the use of the term "compliance" which is applied interchangeably with adherence. Compliance is a related but separate construct and does not necessarily refer to behaviour in the same context adding to confusion. Leventhal (1993) distinguishes the difference

between the two as a conceptual shift whereby the patient is seen as independent or self-regulatory (in relation to adherence) whereas they are seen as obedient in relation to compliance.

Both Myers et al (1998) and Fox (2000) refer to Hayne's (1979) definition of adherence as the most appropriate. This is "the extent to which a person's behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice. (p5)" This definition will be applied in the current study. Concordance is another term used in adherence literature which differs from both adherence and compliance. Horne (2000) defines concordance as a shared understanding between patient and practitioner as a result of a consultation. It is not the same as adherence, which is the patient's behaviour in relation to advice given by a health professional.

There is also a requirement to determine what is meant by non-adherence. With similar problems in trying to define the concept. For example, is a person non-adherent when they miss taking one quantity of medication or when a certain amount of medication is missed? (Myers et al 1998). There is no widely agreed definition of non-adherence and generally non-adherence is partial so that poor or incomplete adherence are more correct descriptions (Royal Pharmaceutical Society of Great Britain, Merck, Sharpe & Dohme, 1996). Further work needs to be undertaken between researchers to agree coherent definitions of these constructs.

2.7.1 Measuring Medication Adherence

A variety of methods can be used to assess whether an individual is adherent to their medication with no method being optimal. A range of methods have thus been deployed (Myers et al 1998), self-report, using health care professional's judgement, objective measures, checking prescriptions, outcome measures, direct methods and observation.

Self-report is the most commonly used method because of ease of measurement. Accuracy levels vary: people tend to be more accurate when they report their non-adherence rather than adherence. Variation of accuracy is a likely consequence of social desirability bias. Researchers have found that asking patients simply and directly about their adherence to medication produces the most accurate self-report responses (Kaplan & Simon, 1990, Morsiky, 1986).

Another method utilised is to seek opinions of health care professionals, particularly the medical profession. However, research has shown that doctors' judgements are not necessarily accurate and they over estimate adherence (Brody, 1980). Objective measures such as pill counts are widely used but are flawed since there is no objective assurance as to whether people have actually taken their medication, resulting in the over estimation of adherence (Ley, 1988). Monitoring of prescriptions can also be used but this only provides information about the dispensing of medication and not its ingestion. Invasive methods such as concentrations of drug in blood or urine levels can be utilised but are more intrusive for the patient, potentially reducing study participation. Furthermore such methods

are subject to individual differences in drug metabolism and may not assess patients' ability to be continually adherent (Ley, 1988).

In summary all methods of adherence measurement have limits and the most effective way of ascertaining adherence is by using a variety of methods from different sources, ensuring triangulation. This is acknowledged to be a more difficult process to undertake, as it is more complex, intrusive and time consuming for both researchers and participants.

2.7.2 Application of Social Cognition Models to Medication Adherence

Johnson (2002) has reviewed the Social Cognition Models applied to predict medication adherence. The Health Belief Model (HBM) was the earliest model designed to examine preventative health behaviours, particular relating to immunisations. Individuals took action based upon four perceptions (1) personal susceptibility (2) severity of threat (3) actions would be beneficial (4) intervention has minimal barriers. The application of the model has produced mixed results. Some researchers have found differences between adherent and non-adherent individuals according to their perceptions (Richardson, Simons-Morton & Annegers, 1993) other have not (Cronin, 1986). Generally researchers have concluded that the concepts in the HBM are correlated with health behaviours but they do not detect differences in beliefs in relation to medication adherence (Conner & Norman, 1996, Harrison, Mullen & Green, 1992). The Theory of Reasoned Action (TRA) (Ajzen et al 1980) attempts to predict the extent to which intention predicts action. The model has been effective in predicting certain behaviours

(becoming sexually active) but has been less successful in predicting intention to adhere to health behaviours and medication adherence (Miller, Wikoff and Hiatt, 1992). The Self Regulation Model (SRM) (Leventhal, 1983) has also been used to try to predict adherence behaviours (including medication adherence). The SRM has been previously discussed and will not be repeated here. Johnson (2002) states the SRM has extended the understanding of individual's responses to illness by theorising that their illness representations are influenced by past experiences and hypothesising that such representations are flexible which can alter in response to new information. It has been more successfully applied to illness populations to predict adherence behaviour (Brewer, Gretchen, Chapman, Brownlee & Leventhal, 2002, Horne & Weinman, 2002, Horne, Weinman & Hankins, 1999). However, the SRM does have some limitations in its application to this area, it does not explain adherence behaviours when disease or health threats are low or acute. Elements of all the models have been confirmed by empirical evidence, no one model comprehensively accounts for adherence to medication. This is unsurprising given the vast range of health threats that occur. None of the models were specifically designed to explain medical adherence and this might be mediated by cognitive factors in a different way.

2.7.3 Use of the Self Regulation Model in Predicting Medication Adherence

Horne et al (1999) have suggested that the SRM could be extended to explore beliefs about medication and their connection to adherence behaviour. Horne (1998) in Myers and Midence (1998) hypothesises that beliefs about medication may be organised cognitively in a similar manner to illness representations, with certain core dimensions. Individuals' decisions to adhere to medication could be

influenced by general and specific beliefs about medications. Other professionals support this view (Royal Pharmaceutical Society of Great Britain, 1997). Further exploration of these ideas has been limited (until recently) to the lack of quantitative measures available to assess medication beliefs.

2.7.4 Quantitative Measurement of Attitudes towards Medication

Horne et al (1999) have developed a quantitative tool for assessing beliefs about medication called the Beliefs About Medicines Questionnaire (BMQ) to address the gaps in the literature. There are two versions of the BMQ, a general version for beliefs about medicines generally and a specific version for prescribed medication for a condition. The measure was developed with 500 people experiencing a variety of chronic illnesses. Two themes underpin the general version, general harm (beliefs about medicines being addictive and poisonous) and general overuse (prescribed by doctors). Self reported adherence to medication was assessed and it was found that beliefs about specific medicines were more strongly predictive of adherence than general beliefs about medicines. Horne and colleagues also found that when people reported higher levels of concern about medicines they reported lower adherence to medicines but interestingly were not necessarily less adherent to other recommended treatment such as dietary recommendations or fluid intake. There is a dearth of studies which have examined the relationship between medication beliefs and behaviour and their interrelationship. Linked to this there is a lack of standardised quantitative measures applied across different illness groups to ascertain whether medication beliefs differ according to condition if there are common beliefs which are not condition specific. Theoretical models developed

specifically to look at medication adherence seem largely absent and deserve further focussed attention.

2.7.5 Medication Adherence in Chronic Illness Populations

The ability to adhere to medication is a significant issue for all populations of people who are managing a diagnosed condition. Exploration of adherence behaviour has received particular attention in chronic conditions. This may have resulted from a variety of reasons, the most obvious one that serious consequences of morbidity and mortality if medication is utilised sub-optimally. Specific conditions where this has been investigated are asthma (Horne and Weinman, 2002), hypercholesterolaemia, (Brewer et al. 2002) and diabetes (Horne,1997). Although heart failure is also a chronic and serious condition and lack of medication adherence is a known preventable factor in causing readmission rates to hospital and negative outcomes generally, adherence has been little examined.

Horne and Weinman's (2002) study involved 100 asthma suffers (average age 22 years) in the community and examined whether individuals' beliefs about their condition and medication influenced their adherence to preventer asthma medication. The researchers tested an extension of the SRM, which included treatment beliefs as an influencing factor for adherence. Three measures were used, the Illness Perception Questionnaire (IPQ), The Beliefs About Medicines Questionnaire (BMQ) and the Medication Adherence Report Scale (MARS). The MARS is a self-report questionnaire measuring adherence. The researchers undertook inter-correlations and regression analysis. Findings were that people who had strong beliefs about the necessity of medication were more adherent than those

with weaker necessity beliefs. People who had strong concerns about their medication were less adherent to their medication. They also found that when people had stronger beliefs about the seriousness of their asthma they were significantly correlated with stronger beliefs that their medication was necessary. A further (non-significant) result was that individuals' beliefs about necessity overrode their concerns of taking prescribed medication due to their perceived increase in risk of serious consequences. Illness perceptions and their treatment beliefs accounted for a proportion of the variance associated with reported adherence (13 and 17% for the necessity and concerns scales and 30% from the consequences dimension of the IPQ).

Adherence to cholesterol medication in people with hypercholesteraemia (a condition which can predispose individuals to coronary heart disease) was investigated by Brewer et al (2002). The researchers hypothesised that if people constructed illness representations which formed a "mental model" similar to that of an expert, they would be more adherent to their medication. In effect they would view their condition as an asymptomatic disease which required medication adherence and appropriate diet and exercise to control it. Adherence was measured both by self-reported pill taking and by the researchers calculating a person's low-density lipid (LDL) levels, an indicator of cholesterol control. Individuals' illness representations were not assessed using a set of survey questions designed to examine the five dimensions of illness representation along a five point likert scale. 169 people participated and their average age was 67. Correlations revealed that people presented with better cholesterol control when they had stronger beliefs that their condition caused symptoms they experienced, and when they believed the

consequences of lack of adherence resulted in the development of a serious condition (CHD). Greater adherence correlated with increased seriousness of consequences. Greater adherence was also associated with adoption of an "expert" mental model. It is important to note that correlations do not provide evidence of causal relationships between variables.

Both studies demonstrate that illness beliefs can contribute to self-reported medication adherence. Horne et al (2002) provided some preliminary evidence that individuals' beliefs about their treatment can also influence their adherence to medication. However, their data needs to be replicated in asthma and other illness populations before treatment beliefs can be seen as a legitimate extension of the SRM. The studies had large samples of participants which increases the generalisability of the findings. Brewer et al's (2002) study had utilised a comprehensive methodology to assess adherence. As both studies were cross sectional the authors were unable to conclude the direction of influence between illness representations and medication adherence. Longitudinal studies are required to explore these relationships.

2.7.6 Medication Adherence and Heart Failure

Despite the evidence that many hospital readmissions and poor outcomes are due to a lack of adherence to medication or other recommendations, there are surprisingly few studies which have exclusively examined medication adherence in people with heart failure, apart from those conducted by Fox (unpublished doctoral thesis, 2000) and Evangelista (unpublished doctoral thesis, 2000).

Fox (2000) conducted a study investigating whether the congruence of heart failure patients' and their spouses' representations of their illness affected their adherence behaviour. The study did not specifically examine medication adherence; rather it examined self-reported adherence to range of heart failure treatments such as dietary modification, and exercise. The sample comprised of 60 people in the cross sectional study. All the individuals were non-hospitalised heart failure patients aged 60 or more. They completed the IPQ (Weinman et al, 1996) and the Adherence Estimation Questionnaire (AEQ) (Higgins, 1995). The AEQ did not have information regarding its psychometric properties, but it was selected because its therapeutic recommendations for hypertension control and overall cardiovascular risk were reflective of those for management of heart failure. Spouses completed the IPQ for significant others and a version of the AEQ modified for significant others. Correlations and hierarchical multiple regression analysis were conducted on the data. The regression analysis revealed that after controlling for patients' illness perceptions, 52% of the variance in adherence behaviour could be accounted for by partners/spouses' representation of their illness. This reflects the importance that others can have upon adherence behaviour. Interestingly no statistically significant relationship was found between patients' adherence behaviour and their perception of the cause of their heart failure. This contrasts with Weinman et al's (2000) findings in post MI patients, who found that people who attributed their heart attack to their own behaviour were more likely to go to cardiac rehabilitation classes. It is likely that individuals' locus of control was internal rather than external.

Evengelista (2000) conducted a series of studies looking at determinants of re-hospitalisation in heart failure patients, including levels of adherence to medication. She was also interested in investigating which variables influenced patient adherence and how these influenced health outcomes. The study revealed high levels of non-adherence in the heart failure sample (64% for medication, 71.5% for smoking reduction, 69.5% alcohol rate). Lack of adherence to smoking and alcohol recommendations were independent predictors of hospital readmisisons.

Both of the studies reviewed (Fox, 2000, Evangelista, 2000) have begun to explore important issues in heart failure and adherence. However, there are significant gaps in the research. Neither study exclusively focused upon medication adherence or explored the cognitive factors which may account for adherence behaviour. Both researchers acknowledged the need for further research to be conducted on heterogeneous populations to increase generalisability of findings in heart failure populations.

In summary, the area of literature concerning medication adherence is complex, with researchers struggling to produce a clear definition of adherence and non-adherence. There are different types of adherence behaviours, medication, dietary modifications and exercise. There are also different ways of measuring adherence such as self report (most commonly used), pill counts, direct measures (blood tests), direct observation and judgement of health care professionals. All of these methods have significant advantages and disadvantages. Researchers have found evidence in the areas of asthma and hypercholesterolaemia that illness representations can influence adherence, and in the case of asthma, that beliefs about medications can

also influence adherence. Medication adherence is an under-researched area of the literature in heart failure, which is surprising given the evidence that sub optimal medcation adherence increases hospital readmissions. No research has exclusively examined the role of illness representations upon medication adherence longitudinally. Additionally no studies have investigated heart failure patients' beliefs about their medications and their associated self reported adherence.

2.8 Summary

Heart failure is a highly prevalent and serious condition. It is the process by which there is a reduction in the heart's ability to pump blood around the body to supply the tissues with adequate oxygen. As the end stage of all cardiac diseases, the condition has a high mortality rate, illustrated by the fact that 80% of all men will die within 6 years of diagnosis. It is a serious burden upon the NHS accounting for many inpatient days due to the high level of readmissions to hospital. Research has shown that approximately half of all readmissions are due to preventable factors. One prominent reason is that patients with heart failure adhere to medication and health recommendations at sub optimal levels. The role of the specialist heart failure nurse has evolved as key in service provision to reduce hospital readmissions and improve health care for individuals. The main duties of the specialist nurse are to: monitor a patient's status to assess whether a hospital readmission is necessary, provide advice about lifestyle changes and emotional support. Whilst trials investigating the effect of the nursing role have shown a reduction in hospital readmissions and other positive outcomes (improvements in survival rates and quality of life), research has not yet identified the mechanisms which are effective

in precipitating this change. Additionally, the psychological effects of a specialist nursing intervention have not been investigated, or the effects upon adherence to medication regimens as a possible mediating factor.

The self-regulation model is a way of understanding how people make sense of and react to an illness or health threat. The model maintains that individuals form an illness representation of their condition that comprises of five dimensions: identity, cause, timeline, consequences and cure/control. This has been confirmed in a number of chronic illnesses. The model also theorises that illness representations affect people's appraisal of outcomes and coping behaviour and that this is an ongoing bi-directional process. There has been very little longitudinal research to investigate these theories more fully in the form of follow up studies. Although the self-regulation model has been applied to people with heart failure, it similarly has not been investigated longitudinally with this population. This is a gap in the literature considering that the role of the heart failure specialist nurse is partly designed to help people form accurate ideas about their condition and manage it themselves.

Models of health behaviour such as the SRM have been used to explore the area of adherence behaviour in illness populations. There is no comprehensive theory currently to account for adherence to medication or other health recommendations. Very little research in the heart failure population has explored people's attitudes towards medication and their adherence. This is surprising given the consequences of the lack of adherence in this population. Studies have examined the influence of significant others in the development of illness representations and adherence

behaviour, but not the influence exerted by health professionals. As with most of the areas of literature discussed there is a lack of research about illness representations and medication, which can elucidate more about the relationship between these factors and their influence over each other over time.

2.9 Aims of the Current Study

As a result of the gaps that have been identified in the current literature in heart failure, the current study was an attempt to explore concepts that previously have not been given attention. It was an investigation to explore the effect of a specialist nursing intervention upon the illness representations and attitudes towards medication of heart failure patients over a three month period. A group of heart failure patients who had just been referred to a heart failure specialist nurse were followed up for 3 months. The group of patients had symptomatic heart failure and had been referred to the specialist heart failure nurse after being discharged from a hospital admission relating to heart failure (secondary care).

2.9.1 Research Questions and Hypotheses

The current study aimed to answer the following research questions:

Q1. What is the effect of a specialist nursing intervention upon the illness representations of heart failure patients?

H1. There is a significant effect of a specialist nursing intervention upon the illness representations of heart failure patients.

Q2. What is the effect of a specialist nursing intervention upon the self reported medication adherence of heart failure patients?

H2. There is a significant increase in the self-reported medication adherence of heart failure patients as a result of a specialist nursing intervention.

Q3. What is the effect of a specialist nursing intervention upon attitudes towards prescribed medication of heart failure patients?

H3a. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards medicines in general.

H3b. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards their prescribed medication.

Q4. What is the effect of a specialist nursing intervention upon the psychological morbidity of heart failure patients?

H4. There is a significant decrease in the psychological morbidity of heart failure patients as a result of a specialist nursing intervention.

3.0 Method

3.1 Design

The present study was designed to explore any effect that a specialist nursing intervention might have upon the illness representations, attitudes towards medication and psychological morbidity within each individual in two groups of heart failure patients over a three month time period, from the first contact until three months later. Due to the time constraints of the study a three month follow up period was selected to make data collection possible whilst retaining a minimal time interval to detect any psychological change. Whilst this time frame was shorter than similar studies (Blue et al. 2001, Stewart et al. 1999), it has been used by other researchers, during which significant changes have been detected (Rich et al. 1995).

3.2 Participants

The participants in the study were recruited by two groups of specialist heart failure nurses. The participants were symptomatic heart failure patients who had recently been hospitalised for their condition (in secondary care) and upon being discharged had been referred to the specialist heart failure nurse. They had had at least one episode of congestive heart failure.

Individuals were excluded from the study on the basis of the following criteria:

1. The person has a condition which renders them unable to provide informed consent and participate fully in the study (e.g. dementia).
2. The person's heart failure is considered to be too severe to enable them to participate (following advice from an appropriate health professional).

3. The person does not have sufficient fluency in English precluding interview or completion of questionnaires.

3.3 Procedure

At first face to face contact following referral, the specialist nurse introduced the study and gave participants an information sheet (see Appendix 2) about the study. Following any expression of interest from participants, the nurse obtained verbal consent from the individual for their name and telephone details to be passed to the researcher. The researcher contacted the individual by telephone, discussed the project and arranged a meeting with the patient as soon as possible. The researcher visited individuals at home unless they stated they were unhappy with this arrangement. At the first meeting written consent to participate in the study was obtained from patients (see Appendix 3). Subject to individuals' consent, an information letter regarding the study was sent to participant's GPs (see Appendix 4), with a copy of the signed consent form.

At the first meeting individuals were asked the demographic questionnaire by the researcher to gain an accurate view of their cardiac history. The participant then completed all other questionnaires. At the end of the first visit, a second meeting was arranged three months later. In the intervening time the participant was sent a copy of their consent form and a reminder slip with the second appointment listed. Prior to the second meeting the researcher contacted the participant's nurse to check there was no deterioration in their health status. During the second visit the participant completed the questionnaires for a second time. (Please refer to Appendix 5 for a diagram of the recruitment process.)

Ethical approval for the study was gained from the relevant local ethics committee in December 2003 for the study to be carried out (Please refer to Appendix 6 for details).

Details of Nursing Intervention

During the three month period, participants would receive a tailored nursing intervention which consisted of: education about the participant's cause of heart failure using diagrams and models, assessment, monitoring and alteration of heart failure medication after discharge from hospital to obtain optimal regime, regular monitoring of weight, assessment of lifestyle and associated psychoeducation to improve mobility and quality of life (advice regarding activity levels and exercise), dietary advice and ongoing assessment and monitoring of psychological status in relation to acceptance of condition and morbidity.

A power analysis was conducted prior to the study to ascertain the necessary sample size required to achieve a certain level of power. The analysis was undertaken for the main statistical test (a t test) using a software package and data from a previous study that had used the IPQ (Fox, 2000). Taking a medium effect size of 0.5 on a two tailed paired t-test, in order to reach an acceptable level of power of 0.8 (Cohen, 1988) a sample of 27 was required in each of the two groups.

3.4 Pilot Study

A pilot study was undertaken with two patients who had been contacted by the specialist nurses and had expressed an interest in the study. The aim of the pilot

study was to check that all the measures used in the study were clear and understandable and that the interview format for gathering demographic information was appropriate. This process also allowed the opportunity for the researcher to assess the logistics of home visits and duration of meeting times.

As a result of the pilot study, one question on the demographic questionnaire was altered to include a "retired" option for employment status which had been omitted. Patients stated that they had found the questionnaires straight forward in nature and easy to complete. They stated they had enjoyed the opportunity to discuss their cardiac history. The duration of the meeting varied between 30 and 75 minutes.

3.5 Measures

3.5.1 Background Questionnaire

Participants completed a questionnaire designed by the researcher to obtain demographic data. This consisted of questions about age, ethnicity, reasons for diagnosis of heart failure, length of time of diagnosis, co-morbid health conditions and the medication people were currently taking (please refer to Appendix 7).

3.5.2 Illness Representations

The Illness Perception Questionnaire (IPQ)Weinman, Petrie, Moss-Morris and Horne (1996)

The IPQ was developed to produce a quantitative assessment of the five components of illness representation based on Leventhal's self-regulation model of illness. The measure has been widely used and has been found to have acceptable levels of test retest reliability, concurrent, discriminant and predictive validity. The first section of the IPQ is an identity scale, which allows individuals to state whether they experience any of 12 core symptoms related to their illness (these are items that are thought to occur in many conditions). Weinman et al (1996) have suggested that researchers investigating specific conditions are welcome to add Taking all these factors into account the researcher chose to use the IPQ in the current study (please refer to Appendix 8 for details).

The first section of the IPQ is an identity scale, which allows individuals to state whether they experience any of 12 core symptoms related to their illness (these are items that are thought to occur in many conditions). Weinman et al (1996) have suggested that researchers investigating specific conditions are welcome to add extra symptoms relevant to the illness population completing the questionnaire. Individuals state whether they experience any of these symptoms "all of the time", "frequently", "occasionally" or "never". Items are scored 1 if a person states occasionally or more and 0 for the never. Total score for the subscale with only core items range from 0 to 12. In the current study the researcher added six additional symptoms pertinent to heart failure which had been utilised by Fox (2000) and were developed by Tresch (1997). The symptoms were: "difficulty lying in bed" "dry hacking cough when lying down" "confusion" "difficulty concentrating" "swollen feet/ankles/legs" and "weight gain of several pounds in one week". The researcher verified that these were appropriate supplementary items

with a cardiologist before inclusion on the scale. The internal reliability of this scale of the IPQ revealed $\alpha = 0.82$.

The other four sections of the IPQ are structured in the same manner. They comprise a list of statements about different aspects of illness and assess their perceptions by examining the extent of respondents' agreement. The answers consist of a five point Likert scale ranging from "strongly agree, agree, neither agree nor disagree, disagree, strongly disagree." The scoring for each item is one to five (1=strongly disagree, 5=strongly agree). Occasionally some items are reverse scored. Apart from the cause subscale, all other subscales are scored by adding the totals for each item and dividing this by the total number of items for the scale. The tem "my illness" used on the four original IPQ subscales was substituted with the term "my heart failure" to tailor the measure to the current study.

The second scale of the IPQ assesses individuals' perceptions of causes of their condition. There are ten items where the person indicates to what extent they agree a factor caused their condition. It is not appropriate to sum all of the items as each one represents a specific causal belief (Weinman et al 1996). However, the authors have suggested that it can be useful to combine items into internal/psychological or external causes.

The third section of the IPQ is the timeline section that explores how long people think their illness will last, whether it is acute, chronic or cyclical. Internal consistency was found to be $\alpha = 0.73$.

The fourth section of the IPQ is the consequences section. This consists of seven items and one item is reversed scored. It explores the impact the condition has had upon an individual's life. Internal consistency was found by Weinman et al (1996) to be $\alpha = 0.82$.

The fifth section of the IPQ is the cure/control section. It examines individuals' beliefs about the extent to which their condition can be cured or controlled. Internal consistency for this scale is $\alpha = 0.73$.

3.6 Medication Adherence Measures

Medication adherence can be measured in a variety of ways, as noted in the introduction. There are merits and disadvantages inherent in all methods. Self-report questionnaires were used in the current study to measure attitudes towards medication and adherence.

3.6.1 The Medication Adherence Report Scale (MARS) Horne and Hankins (2004)

Many studies investigating self-reported adherence tend to devise measures specific to the population and medication particular to the research (Brewer et al 2002, Horne et al 1999). Hence there is a scarcity of standardised, validated questionnaires examining medication adherence. Fox (2000) used the Adherence Estimation Questionnaire (AEQ) by Higgins (1995) in her study with heart failure patients, but this is a more generic measure investigating adherence to a range of health recommendations such as diet, work and medication. As a result of these

different factors the MARS was chosen for the current study because it was a short, accessible and easy to use instrument for participants, which reduces the pressure of social desirability as it phrases questions in a non-threatening way. (Please refer to Appendix 9 for details).

The MARS was constructed to facilitate reports of non-adherence, an approach that has been validated in other research (Kravitz, Hays, Sherbourne, DiMatteo, Rogers, Ordway & Greenfield, 1993 and Rand and Wise, 1994). Adherence is measured on a continuous scale rather than seen as a dichotomous construct with people being either adherent or non-adherent (Oppenheim, 1992).

The MARS has been used in different research populations and a paper describing validity and reliability is in press. It comprises a five item scale which requests respondents to rate the frequency with which they engage in five aspects of non adherent behaviour. This is rated on a five point scale, where 5=never, 4=rarely, 3=sometimes, 2=often, 1-very often. Scores of each of the five items are summed to give a scale score ranging from five to 25 where higher score indicates a higher level of reported adherence.

The MARS has been utilised in published research studies with illness populations, such as asthma (Horne and Weinman, 2002). The majority of reliability and validity tests were performed on data from three illness populations, diabetes, hypertension and asthma. The internal reliability of items in the scale was $\alpha = 0.83$. Principal component analysis revealed that all items loaded on to one factor. Test – retest reliability for the MARS was found to be acceptable when taken at two time

points and the Pearson correlation scores were high $r=0.97$ ($p<0.001$). Horne et al (2004) also conducted analyses to assess whether the MARS had convergent validity with other indicators of adherence such as clinical outcomes. Assessed in a hypertensive population, by examining blood pressure readings in relation to participants' answers on the MARS, 63% of people classified as adherent by the MARS had blood pressure within recommended range, and 61% of people classified as non-adherent had a blood pressure out of range. Using a chi square test this association reached statistical significance ($\chi^2= 4.4$ df = 1, $p<0.05$). Convergent validity was examined in the asthma sample, revealing a weaker association.

3.6.2 Beliefs about Medicines Questionnaire (BMQ) Horne, Weinman and Hankins (1999)

The measure was designed to gain a greater understanding about key issues of self reported adherence. Horne (2000) points out there has been much interest in why patients do not adhere to medication. However, there are few measures that have been created to quantitatively assess medication beliefs and behaviours, which are psychometrically sound and provide data that can be reliably compared across different illness populations. Woller, Kruse, Winter and Mans (1993) and Echabe, Guillen, Ozamiz (1992) have constructed quantitative questionnaires examining beliefs but have tended to do this within a wider context of medical practice. There are thus no standardised quantitative questionnaires to assess medication beliefs for researchers to use. Other prior research in this area has been qualitative in nature, examining either views about medicines in general (Britten, 1994) or about medicines relating to specific illnesses such as epilepsy (Conrad, 1985).

Two versions of the BMQ have been developed. The BMQ – General (BMQ-G) explores beliefs about medicines in general. The second version, the BMQ – Specific (BMQ-S) examines beliefs about medicines prescribed for a specific condition. The two measures consist of a five point Likert scale. Patients rate to what extent they agree with each item (5) strongly agree, (4) agree, (3) uncertain, (2) disagree, (1) strongly disagree. The scores for each sub scale are then summed to give a total score. Both versions of the BMQ were used in the current study. (Please refer to Appendices 10 and 11 for details).

3.6.2.1 Beliefs about Medicines Questionnaire – General Version (BMQ-G)

This scale is comprised of three subscales, benefit (four items), harm (five items), and overuse (three items). The higher the score the stronger belief in the particular theme of the scale (e.g. that generally medicines benefit people). The range of scores for each subscale are: benefit, 4-20, harm 5-25 and overuse 3-15. Tests for validity and reliability were conducted in the development of this scale upon data from 524 people from 6 illness groups (asthmatic, diabetic, psychiatric, cardiac, general medical and renal). Exploratory principal components analysis revealed that the scale comprised of two factors general-harm and general-overuse. A benefit component was also identified. Tests of internal consistency for all subscales was 0.70 or above, apart from the general-overuse subscale. This had internal consistency scores of less then 0.70 for some populations. The authors hypothesised that this subscale was generally weak as no "rogue" item could be identified for the lower scores. The scale has an acceptable level of test-retest

reliability (Pearson correlation of 0.60). There was no data for predictive validity of the scale, this was currently being assessed by the researchers.

3.6.2.2 Beliefs about Medicines Questionnaire – Specific Version (BMQ-S)

This version of the BMQ is to assess people's beliefs about a specific medication they are taking for an illness or a series of medicines for one condition. It consists of two subscales, necessity (five items) and concerns (six items). It examines a person's positive and negative attitudes towards medicines. A high score on any sub scale indicates a stronger belief in that dimension. Scores on the necessity scales range from 5-25 and the concerns scale range from 5-30. Principal component analysis revealed two core themes of necessity and concerns of this scale taken from 524 people in six illness populations. Internal consistency was generally $\alpha = 0.70$ or greater for both subscales. However internal consistency of the necessity subscale was lower for renal and psychiatric populations. Test retest reliability was above 0.70 (using Pearson correlations) for both sub scales, which is within acceptable limits.

Horne et al (2004) also completed some exploratory analyses to examine the relationship between health beliefs and self reported adherence in six illness samples (HIV, asthma (hospital), Ulcerative colitis, Crohn's disease, Diabetes, asthma (community) and warfarin dependent individuals), in terms of correlations between the MARS and health belief scale the Beliefs About Medicines Questionnaire (BMQ-S). The BMQ-S consists of two subscales, necessity and concerns about medicines. In all six samples the direction of correlations between

scales was borne out by the data. That is the BMQ-S concerns scale was negatively correlated with the MARS (i.e. the more concerned a person is about their medication the less adherent they will be) and was positively correlated with the necessity scale (i.e. the more necessary a person believes the medication to be the more adherent they report to be). The correlations were significant for BMQ-S concerns and MARS in all samples except the asthma hospital and warfarin samples. All correlations were significant for the BMQ-S necessity scales and MARS except the HIV, diabetes and warfarin sample.

3.7 The Hospital Anxiety and Depression Scale (HADS) Zigmond and Snaith (1983)

The HADS is a 14 item self-report questionnaire designed to detect anxious and depressive states. It was initially created for use with medical outpatient populations and does not rely on symptoms, such as weight loss or pain, which might occur in physical illness. It is therefore particularly appropriate to use with heart failure patients where physical symptoms are prevalent. Participants choose one option from four in each item indicating how frequently or intensely they experience each symptom. The HADS consists of two subcales, Anxiety (A-scale) and Depression (D-scale) and two scores result from the administration of the scale. Scores from each of the seven items are summed to gain a total for each subscale and the higher the score on either scale indicates a "greater number of symptoms and a greater severity of emotional state (p18)." Scores can be interpreted as follows: 0-7 = normal, 8-10 = mild, 11-14 = moderate, 15-21 = severe. Bjelland, Dahl, Haug and Neckelmann (2002) reviewed the sensitivity of the HADS in

detecting cases of Anxiety and Depression. It was concluded that the scale was appropriately sensitive and specific when clinical "caseness" was taken as a score of 8 or above. (Please refer to Appendix 12 for details).

Moorey, Greer and Watson (1991) completed a factor analysis upon the HADS using data from 568 cancer patients. Two factors explained 53% of the variance. The items split into the two factors as expected apart from one item. Different factor analyses have revealed that the HADS could be composed of between two and four factors (Andersson, 1993, Dunbar, Ford, Hunt & Der, 2000). However, Bjelland et al (2002) reviewed a large number of studies and found evidence that the HADS consisted of two factors of anxiety and depression as orginally intended. Internal consistency from the reviewed studies was $\alpha = 0.68\text{-}0.93$ for the A-subscale and from $\alpha = 0.67\text{-}0.90$ for the D- subscale which is within acceptable limits.

The HADS was chosen in this study because it is easy to complete, has evidence to suggest reliability and validity and most importantly does not include physiological items to detect depression and anxiety. Other measures which could have been used were the Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961), Beck Anxiety Inventory (Beck, Epstein, Brown & Steer, 1988), or the Hamilton Anxiety and Depression Scales (Hamilton, 1959, 1960). However, these scales tend to include physiological symptoms in scales and were considered to be less appropriate. The Geriatric Depression Scale (Yesavage, Brink & Rose, 1983) was also a feasible alternative, given that many people with heart failure are in the

elderly population. However, some patients can be younger than this and so it was appropriate to use a scale with a wide range of application.

3.8 The Significant Others Scale - Form B (SOS(B)) Power, Champion and Aris (1988)

This scale assesses emotional and practical support across four items. The participant is requested to list up to seven key people and rate the level of support across four items using a seven point rating scale where 1=never and 7=always. The raw scores are then summed for each of the two scales (emotional and practical support) and divided by the number of individuals rated to give a mean score for each type of support. (Please refer to Appendix 13 for details).

Power at al (1988) conducted validity and reliability assessments upon the instrument and found it to be satisfactory. The measure was selected by the researcher for the current study as previous research has shown that social support can be an influential factor in determining readmissions for heart failure patients as well as longer-term outcomes. It was felt it would be useful to explore this aspect with participants. The SOS B was used as it distinguishes between different types of social support people can receive from important individuals and allows participants to select people who were important in their lives.

4.0 Results

Prior to conducting any statistical analysis the data were explored to ascertain whether conditions for parametric analysis were met. The usual conditions for parametric analysis are that the dependent variables are measured using a continuous scale from an interval or ratio scale, thus providing continuous data. In psychological research it is considered acceptable to relax this rule if the data are ordinal in nature but have an adequate number of items to allow analysis (Clark-Carter, 1997). The data should also be independent of each other, so participants have not influenced each other's scores. The main assumptions are that the data is normally distributed and that scores from the sample have the same variance as the data from the population it was taken, known as homogeneity of variance (Pallant, 2001).

The distribution of the data were visually explored using histograms prior to analysis. It was found that 21 dependent variables were normally distributed. Three variables were not normally distributed. The first variable was the HADS depression follow up scores at time two. This is a common occurrence as low levels of anxiety or depression are often reported and distribution is positively skewed (Pallant, 2001). The data from the current study followed this distribution. The MARS adherence scale scores at time one and time two were not normally distributed and were negatively skewed, indicating high scores and a consistently high level of reported adherence on both occasions.

4.1 Choice of Statistical Test

Paired samples t-tests were used to assess whether there was a statistically significant effect of the nursing intervention upon all the variables measured in the study between time one and time two three months later. The dimensions of illness representations (identity, cause, timeline, consequences and cure control), the medication adherence report scale, the dimensions of the BMQ-G, overuse, harm and benefit, the BMQ-S dimensions of necessity and concerns and the HADS were all analysed using this test.

The paired sample t-test was appropriate to use as the aim of the study was to detect any difference within participants on any of the variables measured on two separate occasions, as a result of the independent variable of the nursing intervention. The test compares the mean scores of both samples to determine whether they are statistically significantly different between the two occasions thus measuring the level of any change that has occurred. An additional assumption of paired samples t-tests is that the difference between the two scores collected for each participant are normally distributed (Pallant, 2001). The distribution of the change in scores for all variables was visually scanned using a histogram prior to undertaking any analysis ensure appropriate application of the statistical test.

Although three dependent variables appeared to have data that were not normally distributed taken from time 1 or time 2, distribution of the change in scores was also displayed as a histogram to examine whether it was normal in shape. The change in score data for all variables was found to be normally distributed, and thus met the

requirement for the parametric analysis. The paired samples t-test was then employed to analyse all variables.

Statistical significance level was set at 0.05, the value conventionally used in psychological research (Clark-Carter, 1997).

All of the statistical analyses were carried out using Statistics Package for the Social Sciences (SPSS) for Windows version 11.5.

4.2 Reliability Analysis of Measures

The internal consistency (reliability) was analysed for all scales used in the current study. An acceptable indicator of internal consistency is usually considered to be a Cronbach's α of 0.70 or higher (Pallant, 2001). Shorter scales (containing five items or fewer) can produce lower α results, of 0.50 or less. It has been suggested that reporting the mean inter-item correlation may have more relevance (Briggs and Cheek, 1986). The appropriate range for this calculation is considered to be 0.20-0.40.

Measures	Cronbach's α
IPQ - Identity	0.88
IPQ - Cause	0.52
IPQ - Timeline	0.68
IPQ - Consequences	0.71
IPQ – Cure/Control	0.46
BMQ G - Overuse	0.74
BMQ G - Harm	0.35
BMQ G - Benefit	0.34
BMQ S - Necessity	0.76
BMQ S - Concerns	0.73
MARS - Adherence	0.37
HADS - Anxiety	0.84
HADS - Depression	0.78

Table 1: Summary of Reliability Analysis

The reliability analysis revealed that the internal consistency of scales were at an acceptable level of 0.70 or higher, with the exception of the IPQ timeline, cause and cure/control subscales, BMQ G harm and benefit subscales and the MARS, which did not meet the minimum level of acceptability. Both the MARS and the BMQ G benefit scale have low levels of reliability, a weakness that could be attributed to the shortness of the scales.

4.3 Demographic Data

In total 42 individuals were approached by the researcher to complete the study and 28 participants were recruited. There was no attrition of participants between time one and time two in this study. Eight people were approached by the specialist heart failure nurses and did not wish to be contacted by the researcher to participate in the study. Four people who initially consented to participate later declined. Reasons for refusal were: having too many health appointments already or lack of interest in the study. Two people consented to participate in the study but had to withdraw due to a hospital admission and a spouse becoming unwell.

The sample of participants had a large range of ages from 36 to 83, the extent of this range was increased by one very young participant. A large proportion of people did not have any comorbid conditions (42.9%) although over half of the sample had at least one other condition, most commonly insulin dependent diabetes. The New York Heart Association (NYHA) Class of heart failure is provided for the sample, as this classification indicates the severity of symptoms heart failure patients experience and is considered to be the most important factor in clinical history in determining prognosis (Stewart and Blue, 2004). The classes range from one, least severe to four, most severe (refer to Appendix 14 for further details). The majority of participants had class two or greater of heart failure symptoms, as expected for a sample of heart failure patients who have been hospitalised. During the follow up period 2/28 (7.1%) of participants were readmitted to hospital due to deterioration in their heart failure. The mortality rate over the same period was zero.

Tables 2 and 3 display the demographic and clinical characteristics of the participants.

Demographic variables	Heart Failure Participants (N=28)	Percentages (%)
Mean age (years) (SD)	69.5 (12	
Range	36-83	
Gender:		
Males	18	64.3
Females	10	35.7
Ethnicity:		
White	26	93
Asian	2	7
Living Arrangements:		
Spouse	11	39.3
Partner	3	10.7
Child	1	3.6
Alone	8	28.6
Family*	4	14.3
Other**	1	3.6
Employment Status:		
Employed	1	3.6
Unemployed	2	7.1
Unemployed due to illness	4	14.3
Retired	21	75

*= Participant lived with spouse/partner and at least one child

** = Participant lived with landlady

Table 2: Demographic Data

Clinical Data	Heart Failure Participants (N=28)	Percentages (%)
Mean length of time of diagnosis (years) (SD)	2.15 (3.21)	
Range	0.08-12.41	
Cause of heart failure:		
MI	5	17.9
MI & Ischeamic Heart Disease	7	25
Arrhythmia	3	10.7
Hypertension	2	7.1
Dilated Cardiomyopathy	2	7.1
Valvular Heart Disease	1	3.6
Ischeamic Heart Disease	7	25
Systemic Amyloidosis	1	3.6
Comorbidities:		
None	12	42.9
Diabetes	3	10.7
1 other comorbidity*	5	17.9
2 other comorbidities**	6	21.4
3 or more comorbidities***	2	7.1
Mean number of nurse visits (SD)	3.86 (1.84)	
Range	1-8	
New York Heart Association Class (NYHA)		
Class I	5	17.9
Class II	9	32.1
Class III	4	14.3
Class IV	5	17.9
Classes I-II	1	3.6
Classes II-III	3	10.7
Classes III-IV	1	3.6
Mean number of medications:		
Time 1	6 (1.56)	
Time 2	6 (1.80)	

* = Hypertension, Hypertension, Neuralgia, Osteoarthritis, Rheumatoid Arthritis.

** = Osteoarthritis & Stroke, Hernia & Rheumatoid Arthritis, Stroke & Kidney removed, Glaucoma & Osteoporosis, Diabetes & Hypertension, Diabetes and Chronic Arthritis.

*** = Diabetes (onset of blindsightedness), Neuropathy, Osteoarthritis of spine & Kidney problems. Thyroid problems, pernicious anaemia & colostomy bag from rectal cancer.

Table 3: Clinical Data

4.4 Research Questions and Hypotheses

4.4.1 *Q1: What is the effect of a specialist nursing intervention upon the illness representations of heart failure patients?*

H1: There is a significant effect of a specialist nursing intervention upon the illness representations of heart failure patients.

Paired sample t-tests were undertaken to detect whether there was a significant change along any of the illness representation dimensions of the participants between time one and time two. The analysis revealed that there were no statistically significant differences in the way people viewed their heart failure at the beginning of the nursing intervention and three months later, as displayed by the negligible change in the mean scores for all the dimensions. Table 4 displays the means scores and statistical results for all the IPQ dimensions.

Subscale	Scoring Range	Time 1 Mean (SD)	Time 2 Mean (SD)	T value	P value
Identity	0 – 18	9.05 (4.66)	9.05 (3.62)	0.00	1.00 (ns)
Timeline	1 – 5	3.82 (0.70)	3.66 (0.64)	1.69	0.10 (ns)
Consequences	1 – 5	3.26 (0.67)	3.29 (0.58)	-0.38	0.70 (ns)
Cure/control	1 – 5	3.20 (0.52)	3.02 (0.60)	1.76	0.08 (ns)
Cause					
Germ/virus	1 – 5	2.26 (0.98)	2.19 (0.68)	0.40	0.69 (ns)
Diet	1 – 5	2.36 (0.87)	2.71 (0.20)	-1.54	0.13 (ns)
Environment	1 – 5	2.19 (0.63)	2.04 (0.59)	1.16	0.25 (ns)
Hereditary	1 – 5	2.59 (1.18)	2.85 (1.26)	-1.09	0.28 (ns)
Chance	1 – 5	3.28 (1.24)	2.88 (1.05)	1.47	0.15 (ns)
Stress	1 – 5	3.26 (1.13)	2.89 (1.25)	1.62	0.11 (ns)
Own Beh	1 – 5	2.64 (1.31)	2.68 (1.24)	-0.19	0.84 (ns)
Others	1 – 5	2.04 (1.09)	2.00 (1.14)	0.17	0.86 (ns)
Medical Care	1 – 5	2.04 (0.85)	1.93 (0.82)	0.72	0.47 (ns)
Mind	1 - 5	2.00 (1.07)	2.15 (1.19)	-0.59	0.55 (ns)

Table 4: Mean scores and statistics for the IPQ

IPQ Identity

The results for the IPQ show that on both occasions participants had a relatively strong illness identity, and on average they experienced a high number of symptoms (nine of eighteen) which did not change over time. Figures 2 and 3 show the percentage of people who experienced each symptom at time one and time two. At time one the most frequently experienced symptoms were breathlessness (89%), fatigue (85%) and loss of strength (75%). These symptoms are also most frequently

experienced at time two but the percentages have increased to 100%, 96.4% and 85.7% respectively.

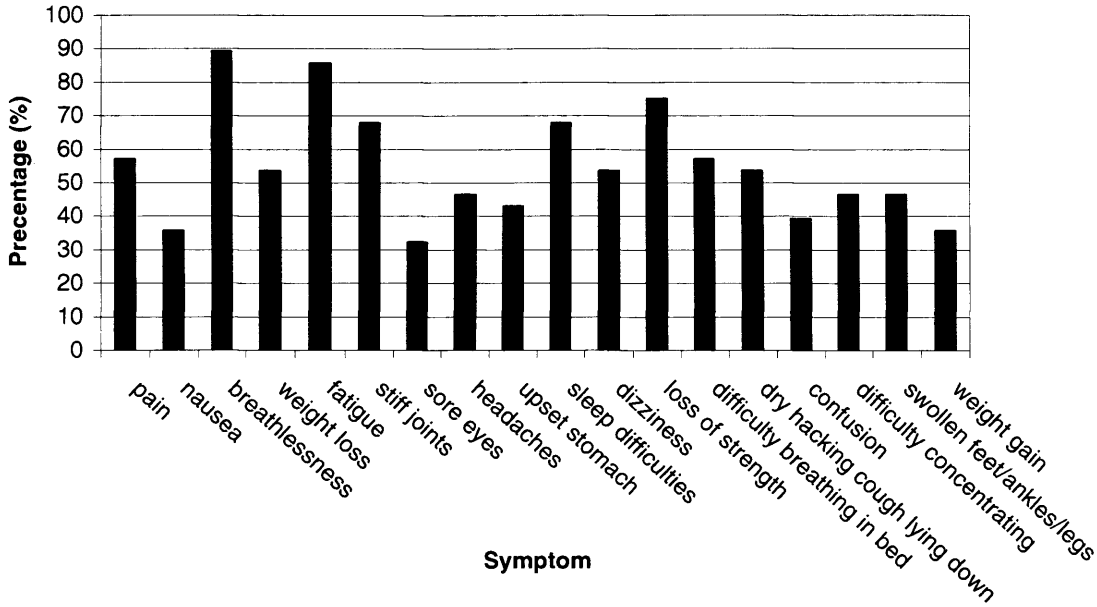

Figure 2: Percentage of symptoms experienced by participants at time 1

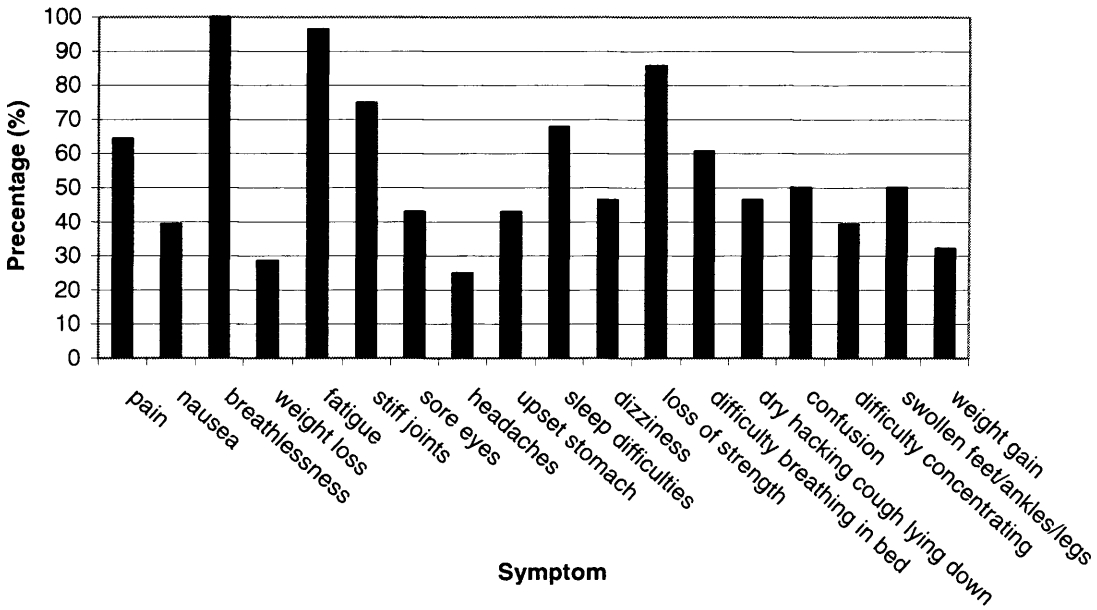

Figure 3: Percentage of symptoms experienced by participants at time 2

IPQ Timeline, Consequences and Cure/Control

The results from the timeline dimension show that people generally viewed their condition as chronic at the beginning of and later in the nursing intervention (as indicated by the relatively high mean score on both occasions). The consequences subscale mean was also stable over time and showed that people thought that there were serious implications of having heart failure. The relatively high mean scores for the cure/control dimension indicate that the heart failure was viewed as controllable (to some extent), this belief did not alter significantly over time.

IPQ Cause

There were no statistically significant differences between any of the attributions individuals made about the reasons for their heart failure between time one and time two of the intervention. Other researchers have split this subscale into internal and external causes. The results from the heart failure sample show that individuals' beliefs about the cause of their condition remained stable over time. The highest mean score in the subscale were derived from the causes of chance and stress (seen as external causes), indicating that people had stronger beliefs that these factors caused their heart failure. Figures four and five display the percentages of attribution of each cause at time one and time two. At time one the causes most frequently attributed to the development of heart failure (as measured by agreement or strong agreement on the IPQ) were chance 57.1% and stress 50%. These were both external causes. At time two these causes were also the most frequently listed as 42.8% and 39.3% respectively. However, the frequency of both had reduced. The causes of diet and heredity were 14.3% and 17.8% at time one and the

frequency had increased at time two to 32.2% and 35.7%. There was also an increase in the attribution of people's own behaviour from 28.6 to 32.1%.

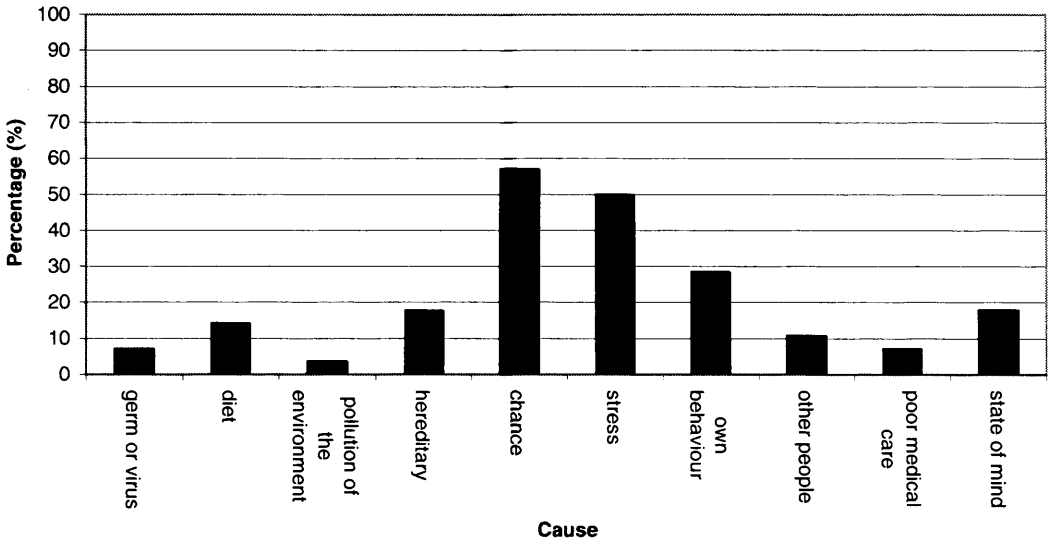

Figure 4: Percentage of participants' attributions of causes of their condition at time 1

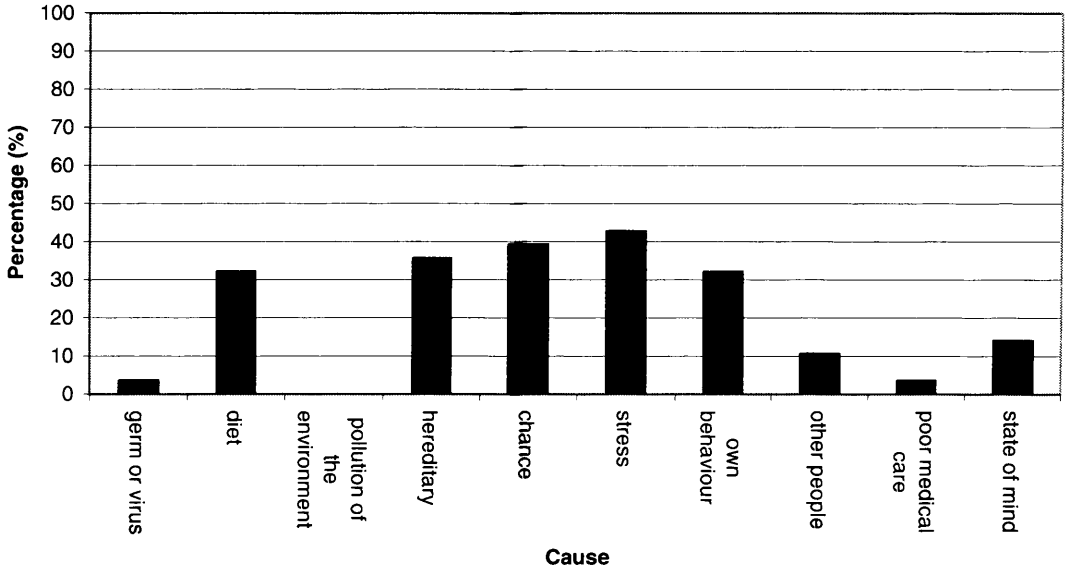

Figure 5: Percentage of participants' attributions of causes of their condition at time 2

4.4.2 *Q2. What is the effect of a specialist nursing intervention upon the self reported medication adherence of heart failure patients?*

H2. There is a significant increase in the self-reported medication adherence of heart failure patients as a result of a specialist nursing intervention.

The self report adherence data was analysed using paired sample t tests to ascertain whether any statistically significant change had occurred over the three month follow up period when people experienced the nursing intervention. No statistically significant increase in self reported adherence was found between time one and time two. The mean scores were very high at both time points (24.07 and 23.86 respectively) which show that participants consistently reported a high level of adherence to their heart failure medications. The mean score is slightly lower for adherence at time two, however this difference is neither statistically nor clinically significant. The results of the analysis are displayed in table 5.

Scale	**Scoring Range**	**Time 1 Mean (SD)**	**Time 2 Mean (SD)**	**T value**	**P value**
Adherence	5 - 25	24.07 (1.41)	23.86 (1.62)	0.92	0.36 (ns)

Table 5: Mean scores and statistics for the MARS

4.4.3 *Q3. What is the effect of a specialist nursing intervention upon attitudes towards prescribed medication of heart failure patients?*

H3a. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards medicines in general.

General Attitudes towards Medicine

Paired t tests were used to analyse whether there was any statistically significant change in participants' general attitudes between time one and time two of the nursing intervention on the BMQ-G. The results show that there were no significant differences in people's views regarding medication along any of the three dimensions of the questionnaire. People generally indicated that they felt medicines were overused in healthcare as shown by the high mean score of 8.74 and 9.00 at time one and time two and this view altered very little over time (there was a slight increase in this score at time two). Overall, the group had relatively lower average scores for the harm scale in comparison to the overuse scale, showing that they did not view medicines to be harmful generally. The highest mean scores were from the benefit scale (16.00 and 15.59) and reflect a strong belief in the potential benefits of medicines generally. Although people indicated that medicines were overused they also felt them to be beneficial. Table 6 displays the means scores and analysis results for the BMQ-G.

Subscale	Scoring Range	Time 1 Mean (SD)	Time 2 Mean (SD)	T value	P value
Overuse	3 - 15	8.74 (2.39)	9.00 (2.76)	-0.67	0.50 (ns)
Harm	5 - 25	13.11 (2.48)	13.18 (2.79)	-0.19	0.84 (ns)
Benefit	4 - 20	16.00 (1.54)	15.59 (1.69)	1.34	0.19 (ns)

Table 6: BMQ-G analysis results

4.4.4 *H3b. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards their prescribed medication.*

Specific Attitudes Towards Prescribed Medicine

The two subscales of the BMQ-S were analysed using a paired samples t test to ascertain whether there was any statistically significant difference in the scores for time one and time two in relation to participants' views about their prescribed medicines for heart failure. The analysis revealed that there was a statistically significant change in people's attitudes in terms of how necessary they thought their prescribed medicine was between time one and time two ($p<0.05$). At both time one and time two the results show that people had a relatively strong belief in the necessity of their medicine for maintaining their health, as reflected by the high mean score of 20.32 and 19.61. However, there was a significant reduction in the score of necessity at time two indicating people believed their medicine to be less necessary 3 months into the nursing intervention. Table 7 displays these results in full.

Subscale	Scoring Range	Time 1 Mean (SD)	Time 2 Mean (SD)	T value	P value
Necessity	5 - 25	20.32 (2.43)	19.61 (2.69)	2.07	0.048
Concerns	6 - 30	16.72 (3.93)	17.00 (3.80)	-0.418	0.68 (ns)

Table 7: Analysis results for BMQ-S

4.4.5 *Q4. What is the effect of a specialist nursing intervention upon the psychological morbidity of heart failure patients?*

H4. There is a significant decrease in the psychological morbidity of heart failure patients as a result of a specialist nursing intervention.

A paired sample t test was used to analyse whether there was any statistically significant difference in the psychological morbidity scores on the anxiety and depression subscales of the HADS between time one and time two. There was no significant reduction in either the anxiety or depression scores at time one and time two. The mean scores of anxiety for the heart failure patients were exactly the same at both time points. The average score was 6.89, which shows that anxiety levels were within what is considered normal range of mood. (Scores of 0 – 7 are considered to be normal level of anxiety and 8 or more show clinical caseness). The levels of anxiety of participants were stable over time. The mean scores for depression were 5.96 and 6.39 again indicating that individuals' levels of depression were within the normal range. Participants' depression scores did increase between time one and time two but this was not statistically significant and nor was it

clinically significant as all scores continued to remain within the normal range of mood. The results of the analysis are displayed in Table 8.

Subscale	Scoring Range	Time 1 Mean (SD)	Time 2 Mean (SD)	T value	P value
Anxiety	0 - 21	6.89 (3.94)	6.89 (3.76)	0.00	1.00 (ns)
Depression	0 – 21	5.96 (4.01)	6.39 (4.00)	-0.84	0.40 (ns)

Table 8: Analysis results for HADS

4.5 Further Exploration of the HADS Data

Further analysis was undertaken on the HADS anxiety and depression subscale scores to assess any change in the proportion of participants' scores exceeding clinical caseness (defined as a score of eight or more) from the time one to time two three months later. McNemar's test of change was used which detects any statistically significant change in scores in two related samples of data. The results for both the anxiety and the depression subscales showed that there was no statistically significant change in the proportion of participants whose anxiety or depression exceeded clinical caseness between time one and time two. At time one 12 individuals (42.8%) had scores for anxiety at or exceeding caseness and time two there were 11 individuals (39.2%). At time one 11 individuals had scores for depression which reached or exceeded casesness (39.2%) and at time two ten individuals (35.7%) had equivalent scores. (please refer to Appendix 15 for details of frequency of scores according to HADS classification)

4.5.1 Participants' Changes in Anxiety Scores on the HADS

Participant no	Time 1	Time 2	Change in Score
1	3	5	2
2	7	7	0
3	9	6	-3
4	7	4	-3
5	2	5	3
6	12	9	-3
7	7	8	1
8	10	8	-2
9	12	15	3
10	6	3	-3
11	5	6	1
12	9	8	-1
13	3	0	-3
14	3	4	1
15	3	5	2
16	8	5	-3
17	2	5	3
18	12	7	-5
19	6	7	1
20	1	1	0
21	2	7	5
22	8	13	5
23	13	11	-2
24	14	10	-4
25	5	8	3
26	11	15	4
27	11	10	-1
28	2	1	-1

Table 9: Change in individuals' Anxiety Scores

Over the three month follow up period 13/28 participants had lower anxiety scores at time 2. Within this category three individuals shifted from a caseness level of anxiety to anxiety within normal range. It was found that 2/28 participants had the same score. Finally, 13/28 participants had higher anxiety scores at time 2. In this category two participants had levels of anxiety which reached a level of caseness having been within the normal range.

4.5.2 Participants' Changes in Depression Scores on the HADS

Participant no	Time 1	Time 2	Change in Score
1	3	3	0
2	8	5	-3
3	8	4	-4
4	3	5	2
5	3	3	0
6	5	9	4
7	3	5	2
8	10	11	1
9	10	15	5
10	0	2	2
11	0	2	2
12	12	6	-6
13	3	5	2
14	5	4	-1
15	9	4	-5
16	8	13	5
17	4	7	3
18	5	5	0
19	15	15	0
20	3	3	0
21	2	1	-1
22	12	10	-2
23	6	8	2
24	7	8	1
25	3	5	2
26	11	12	1
27	9	8	-1
28	0	1	1

Table 10: Change in individuals' Depression Scores

Over the follow up period 8/28 participants reported a reduction in their depression scores between time one and time two. Within this group four participants indicated a change in mood from a level of caseness to within normal range. In total 5/28 participants had scores which were unchanged. The remaining proportion of the sample reported a increase in their level of low mood (15/28). Of this sub group, three participants' mood levels shifted from the normal to caseness range.

4.6 Social Support Data

Social support was assessed at time one and time two of the study. The data has been used descriptively and no inferential analysis conducted. Individuals' levels of social support were stable over time and on average patients listed 4.29 (time one) and 4.18 (time two) individuals as providing important social support. Table 9 indicates the mean scores for individuals' support network.

	Minimum	Maximum	Mean	Standard Deviation
Time 1	1	7	4.29	1.74
Time 2	1	7	4.18	1.70

Table 11: Mean number of people in participants' support network

Levels of practical and emotional support were also calculated for this sample. The results are presented in table 10. Overall participants received more emotional support than practical support and both levels of support remained consistent over time. In relation to other populations where the measure has been used, the heart failure sample received much greater levels of both types of support. Non depressed individuals had emotional support scores of 4.2 and practical support scores of 4.4. Depressed individuals had scores of 4.3 (emotional support) and 4.5 for practical support. Individuals with Parkinson's disease had slightly higher scores for 6.0 (emotional support) and 5.8 (practical support).

Type of support	Mean time one (SD)	Mean time two (SD)	Minimum Score	Maximum Score
Emotional	12.82 (1.71)	12.82 (1.68)	7.50	14
Practical	10.96 (2.22)	10.88 (2.16)	7	14

Table 12: Emotional and practical support received by participants

Participants most commonly listed their spouse or partner, children and neighbours as providing social support. However, health professionals were occasionally included in the support network. Three participants listed the specialist heart failure nurse, two listed their GP, one their district nurse and a helpline.

5.0 Discussion

The results of statistical analysis will be considered in relation to the original hypotheses formulated at the beginning of this study. The remainder of this section will focus upon the clinical relevance of the findings and the methodological limitations of the study. Particular attention will be given to discussing methodological limitations of sample size and time intervals that have placed significant constraints upon the current study. Future avenues of research will be explored in relation to the findings and final conclusions will be drawn about the current study.

5.1 Research Questions and Hypotheses

5.1.1 *Q1. What is the effect of a specialist nursing intervention upon the illness representations of heart failure patients?*

H1. There is a significant effect of a specialist nursing intervention upon the illness representations of heart failure patients.

Analysis revealed that there were no statistically significant differences between the illness representations of the heart failure sample between time one and time two along the dimensions of identity, cause, timeline, consequences and cure/control. The illness identity of participants in this study was relatively strong and on average people experienced nine of 18 symptoms. Fox's (2000) results from a sample of heart failure patients using the same core and specific symptoms were lower, 7.8 indicating that that population had a less strong illness identity. Participants in this study also believed they had a chronic condition more strongly than other heart

failure populations, as the average score was 3.82 (time one) and 3.66 (time two) in this study as compared with a mean of 2.5 in Fox's study (2000). The strength of beliefs in serious consequences of the heart failure is comparable in the two studies (3.26 and 3.29 in this study, 3.3 in the Fox study). Fox's sample of patients have many similar clinical characteristics to individuals in the current study in terms of New York Heart Association (NYHA) class, length of time of diagnosis and age. The stronger illness identity (experience of symptoms) in this population could be due to the fact that this sample had been hospitalised for heart failure whereas people in Fox's study had not. This suggests that the sample in the current study had more severe heart failure which required hospital admission. The mean scores for this heart failure population along the IPQ dimensions are similar to those of other chronic illness populations, such as diabetes, rheumatoid arthritis, chronic fatigue syndrome and pain (Weinman et al 1996). However, it must be remembered that heart failure is a terminal condition (unlike some of the other diseases mentioned).

Although there were no significant difference between participants' overall mean scores in the different dimensions of their illness representations, there were changes in specific aspects of their perceptions of symptoms experienced, and their attributions of factors that caused their heart failure between time one and time two. At time one and time two the symptoms most frequently reported by participants were breathlessness, fatigue and loss of strength (classic heart failure symptoms). By time two the incidence of these symptoms had increased. The increase of reported symptoms could be due to the trajectory of heart failure, with the condition worsening in participants over time, consistent with medical evidence (Stewart et al

2004). The increased awareness of symptoms could be due to other factors. Individuals may have become more attentive to symptoms as a result of undergoing a nursing intervention or participating in research for the current study. Alternatively, a proportion of individuals who had been very recently diagnosed with heart failure as a result of a sudden cardiac event, may have become more aware of their symptoms after hospitalisation as part of a process of readjustment living with heart failure in the community.

Participants' attributions of reasons for aetiology of their conditions also altered between time one and time two. At both time points external causes of stress and chance were most frequently attributed to causing heart failure. However, at time two of the intervention the internal causes of diet and own behaviour were listed more frequently. Heredity also followed this trend. The changes in attribution of causes could suggest that individuals had gained a greater understanding of the variety of causal factors contributing to heart failure, resulting from education through the specialist nursing intervention. It is accepted in the literature that heart failure is often the end product of previous cardiac difficulties that are themselves influenced by poor diet, an unhealthy lifestyle and hereditary factors. The importance of attribution of causes of illness (also known as "control over cause cognitions") has been acknowledged by other researchers as being the most strongly predictive of health behaviour change. Consequently, behaviour can determine the extent of positive health outcomes in terms of attending cardiac rehabilitation programmes and making lifestyle changes (Cooper et al 1999 and Weinman et al 2000).

Whilst these changes are interesting, there were no significant differences between illness representations over time for a variety of possible reasons. Although there were no significant changes in illness representation between time one and time two this does not preclude the fact that individual's perceptions did not alter at all over time. It is likely that the length of follow up time was not sufficient for changes to be detected, but had the scope of the study been enlarged, changes in illness representations may have been detected at 6 month or annual follow ups. It should also be remembered that the self-regulation model consists of two pathways, cognitive and emotional representations of illness. They are theorised to operate in parallel. Emotional representations were not measured in this study since the IPQ was used, which does not explicitly explore emotional illness representations. Indeed in the wider literature emotional representations of many chronic illnesses have been less frequently investigated, partly due to the lack of standardised measures which can be utilised to do this (Moss-Morris et al 2002).

The IPQ –R (Moss-Morris et al 2002) is a very recently developed measure that assesses emotional representation. Emotional representations are also considered to be less accessible to both researchers and patients for exploration. There is thus a dearth of research surrounding these components, their alteration over time and effects upon coping, appraisal and health outcomes, and illness identity. The assessment of emotional representation may be key in the realm of heart failure as individuals enter a process of accepting they have an ultimately life threatening condition with much uncertainty attached to this. Further research is required to explore the importance of emotional illness constructs for people with heart failure. An important aspect of this work should focus upon the influence of emotional

representations upon coping behaviours and outcomes. Should such constructs be found to be influential, health professionals could develop ways of working clinically with these issues.

Other factors may account for the lack of significant change in illness representations during the three-month interval. The mean sample population was of older adults (mean age = 69 years) and less research has been directed towards exploring the illness representations of an elderly population. It may be that beliefs are less flexible in older people as an effect of age. The few studies which have shown illness representations to be flexible over time have been conducted in younger adults (Petrie et al 2002). The paucity of longitudinal research concerning illness representations restricts the possibility of placing findings from the current study into a wider theoretical context.

Whilst a significant proportion of individuals in the sample did not have other co-morbidities, there were a proportion of people who had other serious health problems such as diabetes or rheumatoid arthritis. Illness representations of participants' co-morbid conditions were not assessed. Individuals' cognitive representations of heart failure may have been influenced by constructs relating to other conditions. Although people were directed to think about their heart failure by the researcher, it is possible that individuals' responses on the IPQ referred to general beliefs about other conditions including heart failure. Other researchers in the condition of atrial fibrillation (Steed et al 1999) have highlighted this effect.

Other issues that need to be taken into account are the nature of the nursing intervention; the sample itself and the length of time of diagnosis. The nursing intervention is not standardised and the role of the nurse is to tailor the interventions to individuals, and this is a mark of the high level of expertise of the nurse. However, this means that not all participants will have received the education and support from the nurse in a standardised content or style. Therefore people's illness representations may not have altered depending upon the information they received. On average the nurse visited people four times in three months, which constitutes regular contact in comparison to other nursing intervention trials in this area. However, this is less intensive than an intervention such as a cardiac rehabilitation programme. It is likely that the magnitude of cognitive change experienced by participants would be limited by the frequency of contacts in this intervention.

5.1.2 *Q2. What is the effect of a specialist nursing intervention upon the self reported medication adherence of heart failure patients?*

H2. There is a significant increase in the self-reported medication adherence of heart failure patients as a result of a specialist nursing intervention.

Statistical analysis did not reveal any support for the above hypothesis as there was no significant increase in the adherence scores of the heart failure patients between time one and time two. High levels of adherence were reported at both time points and this is reflected in the mean scores of 24.07 and 23.86. The scores at both time points were negatively skewed, showing high levels of adherence. It seems that

these scores resulted from a ceiling effect on the MARS. This was a very short measure consisting of five items. Had more items exploring adherence been included there may have been a greater range of scores. Indeed when it has been used to measure adherence in other populations, the MARS has been lengthened to include additional items measuring adherence specific to the medication for the condition, for example asthma (Horne at al 1999). There may have been value in tailoring the MARS to ask specific questions about adherence to heart failure medication which would have explored adherence in more depth to give a broader picture of self reported adherence. The researcher met patients after the first contact with a nurse, the earliest possible time point where minimal change would have occurred in individuals' attitudes.

One possible explanation for the lack of significant change in scores of self reported adherence might have been the effect of patients' social support network, particularly their living arrangements. Anecdotally many participants reported that their partner or spouse helped them to remember their medication and ensured doses were never missed. Although individuals were genuine in their responses their adherence levels may have been increased by supportive living arrangements. There is anecdotal support for this possibility, as participants living alone reported they struggled to remember to take their medication consistently. The informal findings of this study highlight the importance of partners and spouses in determining adherence. It would be useful to explore partners' beliefs about medicines and adherence, to assess the effect of this upon patients' behaviour. Linked to this work, partners' representations of patients' illnesses could be explored with particular attention to controllability and consequences of heart

failure in relation to medication adherence. This would extend Fox's (2000) work which addressed adherence behaviour in a wider context.

The high level of self reported medication adherence in this heart failure sample is similar to the level of adherence found by Fox (2000). Participants in that study reported a high level of adherence to measures to manage heart failure on the Adherence Estimation Questionnaire. The content of this measure was wider than the MARS as it included other lifestyle measures such as adherence to dietary recommendations. Fox found that the levels of reported adherence were higher in her sample in comparison to that reported by other samples of the elderly population found by Ghali et al (1988) and Monane, Bohn, Gurwitz, Glynn and Avorn (1994). However, Rich, Gray, Beckham, Wittenburg and Luther (1996) obtained results consistent with Fox (2000) which concerned a heart failure population experiencing a multi disciplinary out patient management programme. Whilst considerable attention has been given to the effect of a specialist heart failure nursing intervention upon outcomes for heart failure patients (including improving adherence of patients), randomised controlled trials have not included adherence measures so there is no comparative research with the current study.

Other populations have reported lower levels of adherence on the MARS (such as asthma sufferers) (Horne et al 2002). The results of a high level of adherence in this sample may not reflect the heart failure population more generally and therefore any suggestion of generalisability of findings must be made with caution. Qualitative differences may exist within the heart failure differences between people who do or do not receive a specialist nursing service. The role of the specialist heart failure nurse is not widespread nationally and it is a pioneering intervention. A control

comparison group would have been important in examining levels of adherence in these populations. Regular contact with the nurse may increase patients' medication adherence, partly through increased support and education and via more precise monitoring of objective measures of adherence such as weight fluctuation. The individuals who refused to participate in the current study may have differed qualitatively to individuals who gave consent. Refusers may have been less adherent to medication that participants. Alternatively refusers and participants may have differed along other dimensions such as clinical, demographic or personality characteristics. Had such individuals participated in the study the results may have been different.

Social desirability was not controlled in this study and it may have affected individuals' responses to the MARS. Any effect of social desirability may have increased in potency, as individuals were required to report behaviour not only attitudes. Individuals may have felt a need to report greater adherence to increase credibility with the researcher.

5.1.3 *Q3. What is the effect of a specialist nursing intervention upon attitudes towards prescribed medication of heart failure patients?*

5.1.3.1 *H3a. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards medicines in general.*

General Attitudes towards Medicines

There was no statistically significant change in participants' beliefs about medicines in general between time one and time two of the nursing intervention and therefore the findings do not support the hypothesis. The scores on the subscales of overuse, harm and benefit were similar at both time points. It is possible that the stability of the beliefs could be an effect of the older age of the participants in this sample. People may well have had considerable experience of taking medications, before developing heart failure and so their cognitive representations of medicine are more firmly fixed. However, due to the paucity of literature concerning elderly patients' view about medicines in the literature these findings cannot be compared with other research. Overall, participants' scores at both time points reflected that they strongly believed medicines were overused (8.74 and 9.00 out of 15) but they also scored highly on the benefit subscale (16.00 and15.59 out of 20) and they had less strong beliefs that medicines were generally harmful (13.11 and 13.18 out of 25). In summary they believed medicines were a generally positive form of treatment which could be over-prescribed by the medical profession.

These themes have similarities to patients' specific views about their heart failure medicine in the current study, as they had strong beliefs in the necessity of the medication and less strong concerns. Researchers have found similar patterns of agreement between general and specific medication beliefs, however along a negative rather than positive continuum (Horne et al 2002) also echoed by Fallsberg (1991). The ideas regarding the current study are speculative, and no statistical analysis was undertaken to examine the concordance of relationships between the different subscales of the BMQ-G.

The generally positive view of medicines could also be linked to the high scores of self-reported medication adherence, but again no statistical analysis confirms a relationship. Anecdotally parity can be seen between positive views of medicines and the high level of reported adherence that may be due to an underlying positive cognitive representation of the treatment. Research in this area has focused upon the components of adherence and beliefs to find support for the self-regulation model in terms of beliefs about treatment influencing behaviour and outcomes just as the representation of an illness can guide coping and outcome appraisals.

It should be noted that when the BMQ-G was tested the benefit subscale did not emerge as a coherent separate construct to the dimension of harm and overuse. As this subscale is short, and has lower reliability any results from it should be viewed with some caution (Horne et al 1999).

5.1.3.2 *H3b. There is a significant effect of a specialist nursing intervention upon the attitudes of heart failure patients towards their prescribed medication.*

Specific Attitudes towards Medicines

No statistically significant differences were detected in participants' scores on the subscale of concerns on the BMQ-S scale between time one and time two of the nursing intervention. A significant difference was detected as a result of analysis on the necessity subscale of the BMQ-S ($p<0.05$). This difference was shown by a change in the mean scores that at time one had been 20.32 and time two were 19.61. The scores on the necessity subscale were high at both times indicating that people thought their heart failure medication was important. The concerns scores were

lower than the necessity scale but remained stable over time. Taking into account the results for both subscales it can be concluded that participants viewed the medication as necessary and they has less strong concerns about it. This attitude may concur with the self-reported high level of adherence to medication that people stated. It would seem logical that those patients who thought their medication was necessary and were less concerned about their effects would be more adherent and such a pattern has been confirmed with asthma population (Horne et al 2002).

The change in scores was not in the direction which would have been predicted. The results of the necessity scores show that participants viewed their medication as less necessary three months after experiencing the nursing intervention. It would be predicted that as a result of more education and information about their illness, patients' beliefs in the necessity of medication would be strengthened. It is possible that participants may have believed that it was less necessary to take certain medications further into the intervention. As the BMQ-S was not tailored to assess beliefs about a particular medication, participants' responses may have reflected a general view of all their heart medicines or focussed upon a specific medication. Participants may therefore have a variety of cognitive representations of their different heart failure medicines and their adherence to each varies accordingly. One limitation of the study was that the measure was not tailored to a specific medication although this was not done due to the complexity of participants' medication regimens. Typically heart failure patients have to take a range of medications to meet their individual requirements. It was beyond the remit of the study to individually tailor questionnaires for participants to complete due to the increase in interview time required.

Participants' slightly reduced belief in the necessity of their medicines could have reflected the reality of a change in medication regimens. Pharmacological protocols are frequently altered in this population where medications are reduced or discontinued in response to patients' health status. Another reason for the reduction in the view of necessity of medication could have been an effect of the nursing intervention. As people had the ongoing support of the nurse, their locus of control in adhering to the medication may have shifted. However this remains speculative, as there are a lack of comparative results from other studies. The result from the current study could be anomalous or an effect of interventions.

It would have been useful to examine participants' views of the necessity of other aspects of recommended treatment such as dietary or exercise advice, to assess whether these representations altered over time and in relation to medication beliefs. Positive health outcomes for heart failure patients are reliant upon adherence to other treatments such as dietary advice as well as medication. As patients' medical regimens stabilised they may have viewed the treatment as less necessary in relation to other health advice to which they had attended less in earlier stages of their condition. Horne (2000) comments that people may hold different ideas about the necessity of treatment adherence to various aspects of a treatment regimen. Whilst a person may adhere to one aspect they may not adhere to another. This is a complex area and requires further investigation. The effects of significant others should also be considered in relation to the patient's view regarding medication. If an individual's partner was heavily involved in helping them to adhere to their medication (anecdotally this situation occurred), the patient's locus of control may have shifted as a result of this help. As the partner took on more responsibility in

determining adherence, the patients may have felt less personal responsibility and control in managing their regimens. The alteration in locus of control of the patients may have been affected in a similar way by the nursing intervention. It must be remembered that although the finding is statistically significant the difference of one point on the necessity subcales total is not highly clinically significant. Both scores at the two time points indicate a strong belief in the necessity of medication and the change is not dramatic. It is possible that the significant result is an artefact of statistical analysis.

Beliefs about specific medication have been explored in other illness populations. Horne et al's (2002) study of an asthma population found that there was a significant intercorrelation between illness representations and beliefs about the "necessity" of taking medication. People who had a strong belief that their asthma was chronic also had strong beliefs in the necessity of taking medication. A significant correlation was also found between strong beliefs in the necessity of medication and greater self-reports of adherence. The limits of correlational analysis should be noted. Horne (2000) has also found that strong beliefs in necessity of medication do not preclude lower concerns populations have been found to have strong concerns and beliefs in necessity. The interrelationships and influences of medication beliefs are thus complex and require further investigation.

5.1.4 *Q4. What is the effect of a specialist nursing intervention upon the psychological morbidity of heart failure patients?*

H4. There is a significant decrease in the psychological morbidity of heart failure patients as a result of a specialist nursing intervention.

The statistical analysis carried out did not support the above hypothesis. No significant reduction was detected in participants' levels of depression and anxiety between time one and time two of the specialist nursing intervention. Both sets of scores on the HADS for anxiety and depression remained within the normal mood range at time one and time two (mean anxiety scores 6.89 at both time points, mean depression scores 5.96 and 6.39). The mean scores for depression for the group did increase slightly but this increase was not statistically significant. Nor could this change be considered to be clinically significant, as the increase did not precipitate recategorsiation of the group into a level of depression that reached caseness. The elevation of scores did not change over time, although there was a wide spread of data as indicated by standard deviations of three or four at both time points for anxiety and depression scores.

The lack of change over time in levels of depression and anxiety are encouraging as participants had low levels of psychological morbidity and remained stable over time. The presence of the specialist nurse and the effect of regular contact could have acted in a preventative way to stop individuals from becoming clincally anxious or depressed, keeping them on an "even keel" in psychological terms. The lack of change in terms of an improvement in psychological morbidity and lower scores could be a result of the fact that reducing psychological morbidity was not a focal point of the nursing intervention. The specialist nurses did not routinely screen for anxiety and depression and although it is part of their role to provide

"psychological support" to patients and carers, this aspect of clinical work is not clearly defined in the research literature or in clinical practice. The specialist heart failure nurse has a range of skills but is not specifically trained in psychological assessment or intervention techniques. This fact is surprising given the recommendations from NICE (2003) that the diagnosis of depression should be considered with all heart failure populations and psychological status should be monitored regularly.

Alternatively, the low scores for anxiety and depression could be an effect of individuals responding in a more socially desirable manner. It was made clear to all participants what the HADS measured and even though anonymity was assured people may have struggled to disclose their true feelings in order to present an image of being able to cope with their condition. Responses may have also been an effect of the older age of the sample. Elderly people may be less used to revealing their feelings due to growing up in a society where this was not encouraged. They may also conceptualise their feelings differently to younger adults, which results in a different pattern of responses.

Whilst the mean scores for the sample at both time points were low, there were still some higher scores of depression and anxiety from individual participants which would qualify as mild, moderate and occasionally severe levels of depression and anxiety (please refer to Appendix 15 for more details). There appears to be a general theme of overall low mean scores with more extreme scores in the sample. As depression and anxiety are known to negatively influence quality of life (and in the case of depression and heart failure can influence mortality, [Frasure-Smith,

Lesperance & Talajic, 1993]), the results of this study highlight the importance in screening all individuals and discussing appropriate interventions where necessary.

The scores on the HADS can be compared with results from other studies of depression in community samples of people with heart failure. The results from this sample seem to differ. In a cross sectional study Turvey et al (2002) found that 11% of a sample of 199 heart failure patients met the criteria for syndromal depression (using the Composite International Diagnostic Interview [CIDI]) compared with 4.8% of people with other heart conditions and 3.2% of elderly people with no heart conditions. The age of the community sample was 70 or over which is comparable with that in the current study. Higher levels of depression have been found in hospitalised heart failure patients (Koenig, 1998) however it may not be appropriate to compare these findings with that of the current study as the sample was based in the community. Nelson and Jordan (2001) found that 32 out of 54 participants with heart failure in the community scored positively for depression, using the Zung Depression Inventory (Zung, 1973).

There are several difficulties when comparing the results of psychological morbidity across studies in this population. Firstly, it is underresearched in this population (Profant and Dimsdale, 2000). Secondly, researchers tend to have used samples from different settings (for example community or hospital based). The nature of depression may differ according to populations and their environment and so results from either population type may not be generalisable to other. Thirdly, there is a lack of standardised measures of anxiety and depression that have been validated with this population and are widely used by researchers, enabling comparisons

across studies. This is reflected in the variety of measures used in studies reviewed here. Linked to this difficulty is the issue that some physical aspects of depression such as low energy, anhedonia and poor sleep (Turvey et al 2002) may be due to the effect of heart failure rather than depression. Indeed many standardised measures such as the Beck Depression Inventory include items with a focus upon physical symptoms. The instruments have been used with heart failure patients but may provide an inaccurate representation of depression as these effects coincide with medical illness. The HADS was specifically selected to overcome this problem but it has not to the researcher's knowledge been used by other researchers in heart failure populations. The low rates of depression and anxiety could be due to a characteristic of this particular study sample in that people were less anxious or depressed.

The paucity of research regarding the nature of depression and particularly anxiety, in which there is no research concerning prevalence or incidence, is suprising and disturbing. There is also a lack of research regarding different therapies that may alleviate depression in this population. It is suprising that psychological therapies have not received any attention, given that antidepressants may not be tolerated by patients due to pharmacological contraindications or increased age (NICE, 2003). In this context psychological therapies may be the most appropriate and effective treatment especially when depression may have been caused by the development of heart failure. Patients may experience difficulties accepting a diagnosis of heart failure and adjusting to a life with the condition. This is a considerable caveat in this area of healthcare theory and practice. This contrasts with the population of MI patients research where the potential links between psychological and physical

factors have been explored extensively. Quality of life has received more attention in the heart failure literature (Grady, Jalowiec, White-Williams, Pifarre, Kirklin, Bourge & Costanzo, 1995, Jaarsma, Dracup, Walden, Stevenson, 1996) and is often used as an outcome measure of interventions. It is probable that quality of life is no doubt influenced by psychological morbidity. The relationship is likely to be bi-directional with the two factors exercising influence over one another.

5.1.5 Social Support

Individuals in this sample scored very highly on levels of practical and emotional support. Their mean scores were high at both time one and time two, with people giving slightly lower ratings of practical support. It is difficult to identify why individuals from the sample had scores which were almost double those of individuals in illness and general populations. Patients rated their level of the support they received as 7, the maximum score possible. The high levels of social support may reflect the high level self reported adherence in this population. Individuals anecdotally reported that a partner maintained their adherence and partners or family members who lived with or visited individuals were often the first people listed in the support network. Patients perceived people as being highly supportive and examination of the high level of adherence suggests that partners were supportive a variety of ways, such as in planning regimes and reminding patients to take their medication.

5.2 Clinical Relevance of Study and Findings

Despite the lack of significant results from this study there are many aspects of it, which have clinical relevance for health care professionals. Some of the issues,

which have clinical relevance in a wider context, were identified through anecdotal evidence in the research process and do not rely entirely upon statistical results.

In the area of heart failure it is widely accepted that an important factor for precipitating readmission to hospital is lack of adherence by patients to recommended treatments, one of which is adherence to medication. Until this time there has not been significant exploration (with the exception of Fox, 2000) of the intrapsychic factors which may contribute to this process of non-adherence. Studies have generally been medically oriented with an emphasis on developing the role of the specialist heart failure nurse and comparing this intervention with "harder" outcomes such as reduction in readmission rates and improvement in mortality. It is essential that these factors are examined. Yet it is also important to understand the psychological processes which lead to such patterns of non-adherent behaviour and precipitate readmission. It seems greatly important to use a psychological perspective in this area as modern healthcare now places an emphasis on primary care, reducing the episodes of readmission and teaching people self management skills with support of professionals to allow greater autonomy of the patient. With these aims in mind it seems essential to explore people's cognitive and emotional representations of their illness to ascertain whether there may be any barriers to successful outcomes of people remaining physiologically stable in the community.

Whilst the measures used in the current study did not detect changes as a result of the nursing intervention, they did provide useful information about heart failure patients' perspectives about their condition. Using the IPQ (Weinman et al 1996) enables health professionals to explore a person's representation of their heart

failure along several key dimensions. This enables the specialist nurse to have a greater understanding of their patients' perceptions and increases rapport between the patient and practitioner. The information gained from exploring illness representations would also enable the nurse to understand how accurate the heart failure patient's views of their illness are and dispel any misconceptions they may have, for example, thinking heart failure will last a short time when it is permanent. Exploring such beliefs would help to maximise the effectiveness of the nursing intervention and increase its precision, as areas of need for health education could be quickly identified. This process has some similarity to the intervention designed by Petrie et al (2002) in targeting education for MI patients. If a nurse identifies that a heart failure patient attributes their heart failure to external causes such as chance, without accounting for other internal causes such as poor diet, smoking or lack of exercise, this would be identified through the IPQ. This would direct advice for self-management and lifestyle interventions. In the current study, heart failure patients reported that completing the IPQ helped them to think about their condition more widely and reflect upon their illness trajectory. People commented that often there was little time in hospital to ask questions about their condition, particularly when heart failure had developed from an acute cardiac event accompanied by a sudden deterioration in health status. Fox (2000) states that the use of the self regulation model via the IPQ in heart failure populations represents " a move away from the biomedical model which ignores patients' cognitive and emotional processes in adaptation to illness. (p104)."

The BMQ general and specific versions are also useful clinical tools with which health professionals can use to explore patients' views regarding medicines. This

may be of particular value considering the lack of accessible quantitative measures of adherence, and the well-documented adherence problems in this population. The general version of the BMQ may be useful when an individual has been prescribed new medication and the individual may not yet have developed beliefs about specific medications. This sometimes occurs with patients who find they suddenly have to take many medicines regularly. Using the general version of the BMQ may provide an indication of how predisposed a person is to taking medication. The BMQ general and specific versions and the MARS could all be used to assess beliefs about medicines, identify any concerns, misconceptions or gaps in patients' knowledge and guide education and the nurse's intervention. Horne (2000) also emphasises that this approach may help to develop concordance between patients and professionals. It could be predicted that greater concordance between professionals and patients might increase a patient's adherence thus dialogue regarding these issues is desirable.

Perhaps out of all the findings in the study the ones relating to the HADS have the most widespread clinical relevance in terms of encompassing professions other than nursing. Although the mean scores of anxiety and depression were generally within normal range, certain individuals had scores which reached and surpassed levels of caseness, when clinical interventions may be considered to be necessary. The NICE guidelines (2003) recommend that depression and anxiety should be routinely assessed in heart failure patients but whether this is carried out in practice and in what form this is done (i.e. via tools or a discussion with the patients) is not widely reported in the literature. The assessment of depression and anxiety via a standardised tool would help to identify people who were experiencing distress.

The combination of the nurse's clinical judgement with patient's self report could enable the nurse to direct patients towards a more specialised form of help for their psychological distress. In particular the role of the clinical psychologist in either directly providing this help to patients or in acting in a consultative or supervisory role to other professionals could be essential. Such help may improve individual's quality of life significantly and improve other aspects of treatment such as adherence.

There is a negligible body of literature concerning the role of the clinical psychologist in the area of heart failure service provision. This is also reflected in the very small numbers of clinical psychologists working clinically with patients. Although the results of the current study are not statistically significant it has nevertheless revealed aspects of valuable clinical work which a clinical psychologist could undertake, as a result of profession specific expertise. Whilst psychological morbidity was generally low in the sample, according to HADS scores, five sets of scores indicated individuals could be classified as severely depressed or anxious. During the study nurses stated that individuals had low mood and difficulties accepting the condition, and that this was difficult to address therapeutically. The clinical psychologist could play an important role in the form of consultation with other professionals or direct clinical work with patients. Such developments in service provision have not occurred and remain speculative.

5.3 Methodological Limitations of the Study

There are several significant limitations to the current study, which should be acknowledged and have been learned from.

Inclusion of a control group for the group of heart failure participants would have also been desirable. The control group could have comprised people with heart failure who did not receive a specialist heart failure nursing service. Until recently this reflected the uneven provision of heart failure nursing care in the area studied. However, this was not possible and due to ethical issues with inclusion of such controls. Although the results may have highlighted the importance of the role of the nurse, there may have been negative psychological effects on the control participants in the study. Individuals suitable for the control group are often not clearly informed that they have heart failure (it is often under diagnosed by GPs). It is likely that control participants would experience significant distress when asked to indicate their views about a condition they have previously been unaware of. This situation would also affect the researcher's position, as they would no longer be observing people but by discussing heart failure with participants they would have undertaken a more active role. It is questionable whether the group would constitute a true control if they were given information that would inevitably alter their cognitive representations of their health during the research process.

Nurses also informed the researcher that many people in this situation would be recruited by examining primary care heart failure registers. However, individuals are often miscoded as having heart failure when they do not have the condition. There would again be profound ethical ramifications of asking people to reflect on a condition that may not have been correctly diagnosed.

In the absence of constraints upon doctoral research, the recruitment process could have continued over a longer period and a larger sample collected, resulting in a

more substantive study. This may have produced more statistically significant and clinically relevant results than those gained in the current study. The length of follow up time for participants would have been extended to visits at six month and annual intervals in order to gain a more informed view of the process of change of illness representations and attitudes toward medication.

5.4 Measures

The IPQ was selected as an appropriately validated measure to assess illness representations. However, an alternative measure could have been used, the IPQ – R (Moss-Morris et al 2002). Use of this measure would have enabled the assessment of people's emotional representations and the illness coherence of their heart failure, thereby exploring a larger proportion of the self-regulation model than the IPQ. The IPQ – R was developed because later analysis of the IPQ revealed that the cure/control scale was composed of two separate factors, personal control and self-efficacy beliefs and secondly beliefs in recommended treatments. In the IPQ – R these factors have been included as separate scales. To some extent the IPQ – R could be viewed as an "improved version" of the IPQ although it deviates slightly more from the self regulation model then the IPQ and has been less well validated due to its more recent development.

Measures of self-reported medication adherence are notoriously rare and there is a paucity of standardised validated scales that can be used with a variety of illness populations (Horne et al 1999). Both versions of the BMQ and the MARS have been used with other populations, and have been designed in accordance with recommendations from researchers in this area. However, the MARS in particular

is a very short scale and has a lower level of internal consistency that is not ideal when it is the only measure of self reported adherence utilised in a study. Further tailoring of the questionnaire (which the authors encourage) to the heart failure population with additional items concerning adherence in relation to particular medications and symptoms of heart failure may have produced a more informed view of self reported medication adherence in this population. If items had been asked about common heart failure medications the results may have had an increased clinical application. Although the use of a combination of measures of adherence is not widely discussed in the adherence literature, a more accurate view of participants' adherence would have been gained by using a range of assessment methods. The findings of the current study may have had more clarity had several sources of adherence been used such as self report, pill counts and direct measures such as blood samples.

Heart failure patients usually have a range of health recommendations to follow such as diet alterations in the form of lowering sodium intake, as well as exercise. Although one of the focal points of this study was to examine medication adherence and attitudes it may have been beneficial to explore people's adherence attitudes to other treatments to understand more fully how people cognitively represent this guidance and adhere to it.

Further measures of outcome and other important factors would have also broadened the understanding of the heart failure patient more comprehensively had they been included in the current study. Social support is acknowledged to be an important factor in influencing readmission and outcomes for people with heart

failure. Although a measure of social support was included in this study its purpose was mainly descriptive. Social support is by its nature a less tangible construct to measure and this difficulty is coupled with a lack of standardised sophisticated measures. However it warrants further attention in many illness populations and particularly in relation to heart failure.

Quality of life is a factor which has been the focus of a larger amount of research in the heart failure literature and is often included as an outcome measure (Profant and Dimsdale, 2000). As psychological morbidity is often not exclusively assessed in the area of heart failure, quality of life measures may provide an indication of psychological well being in the absence of specific measures. Researchers have also highlighted that as mortality rates are often and inevitably high in this population due to irreversible heart damage, quality of life of patients is possibly the most important factor for clinicians to focus upon improving with patients (McMurray et al 1998). The Minnesota Living with Heart Failure Questionnaire (MLHF – Q) (Rector, Kubo & Cohn, 1987) is the most widely used and validated measure of quality of life in this population. Inclusion of this in the current study would have provided useful information in terms of an important outcome measure of the nursing intervention. Its wide application in other research (Rector & Cohn, 1992, Colucci, Packer & Bristow, 1996) would have enabled comparisons with the findings of other studies. Unfortunately it was not possible to use this measure at the time of data collection.

The method of visiting participants in their homes and having personal contact with may well have been a reason why there was no attrition of the sample between time

one and time two of the study. This approach also improved rapport with participants and enabled the researcher to gain a fuller understanding of heart failure and the meaning of living with a debilitating condition. However, such an approach may have meant that participants' responses were skewed by the need to increase social desirability with the researcher. Such a method of investigation could be classified as an intervention. It is possible that an anonymous postal questionnaire may have produced different results to the ones in the current study.

5.5 Recommendations for Future Research

There are a number of directions in which future research in the population of heart failure would be desirable. Firstly work should be undertaken to extend the current study and address technical flaws. Secondly heart failure is a growing problem and requires further exploration in a more general context.

Future work could focus more closely upon the area of illness representations and the self regulation model and explore the interrelationships between the dimensions of illness representations of identity, timeline, cause, consequences and cure/control between each other, as has been done in other populations (Hagger and Orbell, 2003, Vaughan et al, 2003). Specifically, how the strength of perceptions of cure and control relate to strength of illness identity, timeline and consequences. Such work would further investigate the Self Regulation Model, but it would also add to the literature concerning illness representations of heart failure patients.

Further examination of heart failure patients' attitudes towards medication and self reported adherence is indicated. Such work would provide further insight into the complex relationship between illness representations and medication adherence, and any links between cognitive representations of illness and attitudes towards medication. Further longitudinal work is required to understand the nature of the self-regulation model and additional components of the model such as attitudes towards treatment and consequent behaviour. The area of the literature is relatively new and the relationships between these cognitive and emotional factors are complex and warrant further investigation. Replicating some of Horne's work to look at the interrelationships between illness representation and attitudes towards medication adherence may contribute to the literature concerning the self-regulation model. A greater understanding of these components may also have significant implications for clinicians with heart failure patients, where adherence to medication and other health advice is problematic and there is not a full understanding of the causes of such difficulties.

An important aspect of the self-regulation model is the role coping plays in relation to illness representation and the appraisal of health outcomes and actual outcomes for patients. It is theorised that coping may mediate outcomes but research has not yet clarified how this process occurs. Coping is an important factor that was not examined in the current study. Future studies would be improved by investigating the role of coping and its role in the self-regulation model. The use of validated coping measures such as the COPE (Carver, Scheier and Weintraub, 1989) would be important to utilise to enable such investigations. Such research would also have clinical relevance, as methods of coping have not received wide attention in the area

of heart failure. However, the mechanisms of coping in this population may be key to long term outcomes and may influence medication adherence in this debilitating condition. Greater knowledge of adaptive and maladaptive methods of coping in this population may be of value for health professional. Heijmans et al (1998) have found evidence for a link between coping and social support. It would also be important to investigate this relationship in some depth with this population, when social support is known to affect illness outcomes for heart failure patients.

There is a body of literature developing concerning the role of both significant others and health professionals in influencing individuals' illness representations and subsequent behaviour. The self-regulation model includes both of these roles as being potentially highly significant in the construction of and response to a health threat. Fox's (2000) study examined the congruence of illness representations between patients and partners and the relationship to self reported adherence behaviour. Weinman et al (1996) have also highlighted the validity of exploring illness representations significant others hold about their partner's conditions. Additionally there is value in exploring a health professional's illness representation of a patient's condition and the congruence of these perceptions. Anecdotally the researcher found that significant others influenced adherence in this study. An important extension of this work would be to undertake a process of triangulation. The illness representations of patient, partner or carer and health professional (in this instance the heart failure specialist nurse) could be explored and followed overtime to ascertain levels of concordance and mutual influence of components. Such work could also be carried out in the realm of attitudes towards medication

that might help to develop satisfactory concordance between patients and health professionals, encouraging adherence to medication.

There is scope to explore many issues in heart failure in a qualitative manner. This method may be more appropriate to apply in certain topics due to the lack of any research and so the absence of theories, which can be tested by later research. Such areas are women with heart failure, people from ethnic minorities with heart failure and patients with asymptomatic heart failure. Exploration of illness representations and the meaning of the condition for these people may produce valuable information. One reason for this is that qualitative methods do not assume prior knowledge of the structure or content of research data.

5.6 Conclusion

Although the current study has a number of methodological limitations it is nonetheless an original addition to the literature. It is the first longitudinal study to examine the impact of a specialist nursing intervention upon the illness representations and attitudes towards medication of heart failure patients.

The current study has used the Self-Regulation Model to explore illness representations and self reported medication adherence. Although no significant results were found, the study used a follow up design with a community-based sample. Results drew attention to the importance of assessing psychological morbidity in this population. Very few studies have examined the psychological processes and outcomes of heart failure patients in relation to acknowledged clinical

problems. Heart failure is a growing health burden and further research is required. It is hoped that this study may provoke further interest in psychological processes in this illness population.

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Appendices

Appendix 1 – Diagnostic Tests for Heart Failure

Diagnostic Tests for Heart Failure

NICE (2003) states that the most accurate clinical finding for diagnosis is a displaced apex beat in the heart. This information needs to be balanced with the presence or absence of other features such as cardiac history (e.g. if person has had an MI) and current symptoms such as dsypnoea or a gallop rhythm of the heart. The key investigations recommended are:

- 12 lead Electrocardiogram (ECG) (heart failure unlikely if this is normal)
- and/or Natriuretic peptides (BNP or NTproBNP) – where available

- Echocardiogram

Other investigations such as iron test, chest X-ray, renal function, weight should be used where necessary.

Appendix 2 – Patient Information Sheet

SPECIAL NOTE

ITEM SCANNED AS SUPPLIED
PAGINATION IS AS SEEN

21/11/2003 Version 3

Patient Information Sheet

Comparison of illness representations and medication adherence in heart failure patients who have or have not been hospitalised who experience a specialist nursing intervention.

You are being asked to take part in a research study. Before you make this choice it is important for you to understand the reason why the research is being carried out and what it will involve. Please take time to read the following information sheet carefully and discuss it with the specialist nurse or researcher if you wish. Ask the specialist nurse if any of the information is unclear or if you have any queries not answered in the sheet. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

Heart failure is a common condition particularly in the elderly in the UK. One of the reasons heart failure patients may be readmitted to hospital can be because they struggle to follow (another word is adhere) recommended advice from health care professionals. Recent research in this area has found that people who receive care from a specialist heart failure nurse have fewer admissions to hospital. We are interested in looking at how a person's understanding of their condition, and their views about taking their medication can change as a result of having contact with a specialist heart failure nurse. This study may provide important information about how patients' understanding of their heart failure can be changed by a specialist nursing intervention. The researcher carrying out the study, Elizabeth Swain, is a trainee clinical psychologist. She has no clinical links with the specialist heart failure nurses and their interventions. The study will last approximately 9 months from October 2003 to June 2004.

Why have I been chosen?

You have been chosen because you have heart failure and you have been referred to a specialist heart failure nurse for treatment. All heart failure patients in Leicester who receive a nursing intervention are being invited to participate in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen if I take part?

If you take part the specialist nurse will pass your name and telephone number to the researcher with your consent. The researcher, Elizabeth Swain will then contact you to arrange a time to meet with you. This will happen within the next 2 weeks if possible. The meeting will take place at a venue you are happy to meet at. Any

travel expenses you have will be refunded to you. At this meeting the researcher will briefly explain the research and ask you to sign a consent form, agreeing to participate in the research. You will then be asked to complete 5 short questionnaires and a sheet of background information about yourself. The study has a follow up design. This means that the researcher is interested in measuring how things change for you over a period of time. You will meet with the researcher twice. Firstly at the beginning of the nursing intervention and then again 3 months later in the intervention. At the first meeting the researcher will arrange a time to meet again 3 months later. They will give you a card with the date and time. They will telephone you one week before this second meeting to check you are still willing and able to participate. At the second meeting you will be asked to complete 4 questionnaires again. This is your involvement in the research.

What do I have to do?

You will be asked to meet with the researcher twice in 3 months and answer 5 questionnaires at each meeting.

What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part could be that by answering the questionnaires this may draw more attention to your condition and you may feel upset or worried. In the unlikely event that this might happen you can contact the Department of Medical Psychology, University Hospitals of Leicester NHS Trust, Hadley House, Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW Tel No: 0116 258 4958 and you will have access to a clinical psychologist to discuss your concerns.

What are the possible benefits of taking part?

The information we get from this study will further professionals' understanding of patient's perspectives. The information we get from this study may help them to treat other heart failure patients better in the future.

What if new information becomes available?

Sometimes new information becomes available about the intervention that is being studied. If this happens you will be informed of the new information and you can decide to withdraw from the study if you wish.

What happens when the research study stops?

When the research stops this will not affect any ongoing contact you have with health care professionals or your treatment. You will be given feedback about the results of the study.

What if something goes wrong?

If you experience any harm by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's

negligence then you may have grounds for a legal action but you may have to pay for it. Regardless of this if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanism would be available to you.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you which the researcher leaves with will have your name and address removed so that you cannot be recognised from it.

The researcher must inform your GP in writing that you are participating in this research study. At the first meeting with the researcher they will ask for your consent for this to be done. At this meeting you will be asked to tell the researcher about any other health care professionals involved in your care (e.g. medical consultants). The researcher will ask for your consent to inform any other professional involved in your care that you are taking part in the study.

What will happen to the results of the research study?

The results of the research will be written up and submitted as part of a doctoral degree in clinical psychology. A shortened form of the results will be made available to all patients who were involved in the research in September or October 2004. The research may be published in a psychological or health related journal after this point. No participants will be identified in any way in these documents.

Who is organising and funding the research?

The Department of Clinical Psychology at the University of Leicester oversees the research study.

Who has reviewed the study?

All research that involves NHS patients of staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the Committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

The researcher's academic supervisor.
Research panel of academics from the School of Psychology – Clinical Section, the University of Leicester.
NHS Research Ethics Committee.

Contact for Further Information:

If you would like any further information please contact the lead researcher:

Elizabeth Swain
Trainee Clinical Psychologist
Department of Clinical Psychology
104 Regent Road
The University of Leicester
Leicester
LE1 7LT

0116 258 4958
0116 223 1648/9
ejs29@le.ac.uk

You can ask the specialist heart failure nurse who has given this sheet to you for more information.

If you choose to participate in the research study you will be given a patient information sheet along with a copy of your signed consent form to keep.

Thank you for reading this patient information sheet.

Appendix 3 – Consent Form

20/08/2003 Version 1

Consent Form

Comparison of illness representations and medication adherence in heart failure patients who have or have not been hospitalised who experience a specialist nursing intervention

Elizabeth Swain Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated..... version ..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that responsible individuals may look at my medical notes from my Primary Care Trust where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

4. I understand that the lead researcher Elizabeth Swain may contact the specialist nurse regarding my health status during the course of this study. I give my permission for this to happen. ☐

5. I agree to the named researcher Elizabeth Swain informing my GP and any other health care professionals involved in ongoing care of myself that I am participating in the above study. ☐

6. I agree to take part in the above study. ☐

Name of Patient Date Signature

Researcher Date Signature

1 for patient; 1 for researcher; 1 to be kept with notes

Appendix 4 – Information Letter to GP

Appendix 5 – Diagram of Recruitment Process

Date

University of Leicester

School of Psychology
Clinical Section

104 Regent Road
Leicester LE1 7LT · UK
Tel: +44 (0)116 223 1639
Fax: +44 (0)116 223 1650

Dear (GP / Consultant)

Re: Patient's name D.O.B
Address

Participation in research: Comparison of illness representations and medication adherence in heart failure patients who have or have not been hospitalised who experience a specialist nursing intervention.

I am writing to inform you that the above named person (your patient) has voluntarily consented to participate in this research project. The project is investigating whether the way heart failure patients understand and adhere to their medication is affected by the involvement of a specialist nurse in their care. The study runs from 1st October 2003 until the 30th June 2004 and is being undertaken for the completion of a Doctoral Degree in Clinical Psychology at Leicester University. I would be grateful if you could place the enclosed signed consent form in the patient's notes and record their participation in this study in their medical records. I will inform you if they withdraw their consent at any time prior to the full completion of the study.

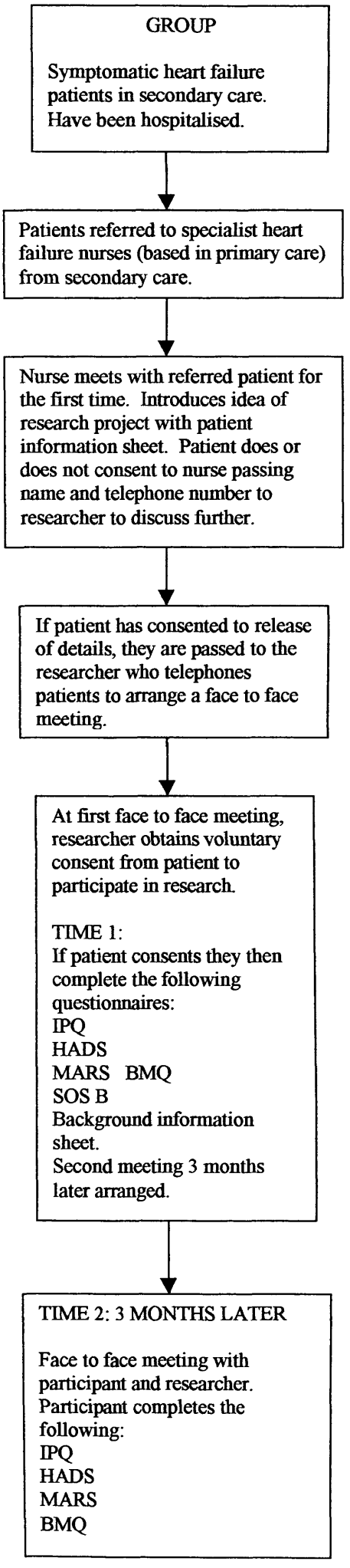
If you require any further information please do not hesitate to contact me at The Department of Clinical Psychology, 104 Regent Road, The University of Leicester, Leicester LE1 7LT Telephone number 0116 258 4958 email ejs29@le.ac.uk.

Thank you for your co-operation

Yours sincerely

Elizabeth Swain
Trainee Clinical Psychologist

THE QUEEN'S ANNIVERSARY PRIZES
1994 & 2002


GROUP
Symptomatic heart failure patients in secondary care. Have been hospitalised.
Patients referred to specialist heart failure nurses (based in primary care) from secondary care.
Nurse meets with referred patient for the first time. Introduces idea of research project with patient information sheet. Patient does or does not consent to nurse passing name and telephone number to researcher to discuss further.
If patient has consented to release of details, they are passed to the researcher who telephones patients to arrange a face to face meeting.
At first face to face meeting, researcher obtains voluntary consent from patient to participate in research.
TIME 1:
If patient consents they then complete the following questionnaires:
IPQ
HADS
MARS BMQ
SOS B
Background information sheet.
Second meeting 3 months later arranged.
TIME 2: 3 MONTHS LATER
Face to face meeting with participant and researcher. Participant completes the following:
IPQ
HADS
MARS
BMQ

Appendix 6 – Letter of Ethical Approval

NHS

Leicestershire Primary Care Research Alliance

Third Floor
Enkalon House
92 Regent Road
Leicester
LE1 7PE

Telephone: 0116 295 4080
Fax: 0116 295 4177

12 December 2003

Ref: RA2066

Ms Elizabeth Swain
Trainee Clinical Psychologist
The University of Leicester
School of Psychology
Astley Clarke Building
Leicester
LE1 7RH

Dear Liz

Comparison of illness representations and medication adherence in heart failure patients who have or have not been hospitalised who experience a specialist nursing intervention; Ethics Ref: 7159; LPCRA 0286

We are pleased to advise you that, under the authority delegated to us as a designated RM&G PCT (hosted by Eastern Leicester PCT) for the six PCTs in Leicester, Leicestershire and Rutland, PCT and Ethics approvals are now in place. We therefore advise that approval from the Leicestershire Primary Care Research Alliance to carry out your study within Leicester City West, Eastern Leicester PCT, Charnwood & Northwest Leicestershire, South Leicestershire, Hinckley & Bosworth and Melton, Rutland & Harborough PCTs.

Could you please ensure that any interim or final reports, protocol amendments or any document/s that requires submission to the LREC are channelled through this office. We will undertake to forward any documentation to the LREC as well as advise the relevant PCT/s in accordance with Research Governance requirements.

Please also be aware that, where required under NHS obligations, we will submit details of this study to the National Research Register to log the PCTs/PCT's involvement in this study. The Alliance is also currently implementing new systems for research governance on behalf of local PCTs so it will be subject to some follow up and/or auditing during its field work stage.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

Sue Palmer-Hill
Acting Research & Development Manager

Appendix 7 – Demographic Questionnaire

Background Information Sheet for Participants

1. Date of birth: ____ / _____ / ____

2. Age: _____

3. Gender: Male (1) ☐ Female (2) ☐

4. Ethnic background: (1) White
(2) Black
(3) Asian
(4) Other please specify: _____

5. With whom do you live?

(1) Spouse
(2) Partner
(3) Child
(4) Brother/sister
(5) Friend
(6) No one
(7) Other please specify:_____

6. Could you list the number of years you spent in full time education post 16:
_____

7. Please indicate you current employment status:
employed (1) ☐ unemployed (2) ☐ retired (3) ☐

8. In what year (approximately) were you diagnosed with your heart problem?
_____

9. Have you recently been hospitalised for your heart problem? Yes ☐ No ☐

If you have, please could you list the dates you were admitted and discharged from hospital: _____

10. Please list any other health problems you currently have:
_____
_____

11. Please list any medications you are currently taking:
_____
_____

12. Who (which professional) told you that you had heart failure?

_____

_____

What did you make of this?

_____

_____

13. Please list any other health professionals who you are seeing at the moment (e.g. medical consultant)

_____

_____

Appendix 8 – Copy of the IPQ

Illness Perception Questionnaire (IPQ)

Illness Identity (Core Symptom List)

Please indicate how frequently you experience the following symptoms as part of your heart failure:

Symptom	All of the time	Frequently	Occasionally	Never
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				
Difficulty breathing when lying in bed				
Dry hacking cough when lying down				
Confusion				
Difficulty concentrating				
Swollen feet/ankles/legs				
Weight gain				

Participant ID Code:

We are interested in your own personal views of how you now see your heart failure.

Please indicate how much you agree or disagree with the following statements about your illness.

Tick the box

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
A germ or virus caused my heart failure					
Diet played a major role in causing my heart failure					
Pollution of the environment caused my heart failure					
My heart failure is hereditary – it runs in my family					
It was just by chance that I became ill					
Stress was a major factor in causing my heart failure					
My heart failure is largely due to my own behaviour					
Other people played a large role in causing my illness					
My heart failure was caused by poor medical care in the past					
My state of mind played a major part in causing my heart failure					

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
My heart failure will last a short time					
My heart failure is likely to be permanent rather than temporary					
My heart failure will last for a long time					

Participant ID Code:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
My heart failure is a serious condition					
My heart failure has had major consequences on my life					
My heart failure has become easier to live with					
My heart failure has not had much effect on my life					
My heart failure has strongly affected the way others see me					
My heart failure has serious economic and financial consequences					
My heart failure has strongly affected the way I see myself as a person					

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
My heart failure will improve in time					
There is a lot which I can do to control my symptoms					
There is very little that can be done to improve my heart failure					
My treatment will be effective in curing my heart failure					
Recovery from my heart failure is largely dependent on chance or fate					
What I do can determine whether my heart failure gets better or worse					

Participant ID Code:

Appendix 9 – Copy of the MARS

QUESTIONS ABOUT USING YOUR MEDICINES

- **Many people find a way of using their medicines which suits them.**
- **This may differ from the instructions on the label or from what their doctor has said.**
- **We would like to ask you a few questions about how you use your medicines**

Here are some ways in which people have said that they use their medicines

For each of the statements, please tick the box which best applies to you

	Your own way of using your medicines	Always	Often	Sometimes	Rarely	Never
M1	I forget to take them					
M2	I alter the dose					
M3	I stop taking them for a while					
M4	I decide to miss out a dose					
M5	I take less than instructed					

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Appendix 10 – Copy of the BMQ-G

BMQ_General_12 Questionnaire number .....

YOUR VIEWS ABOUT

MEDICINES IN GENERAL

These are statements that other people have made about medicines in general.

Please show how much you agree or disagree with them by ticking the appropriate box.

There are no right and wrong answers.
We are interested in your personal views

	Views about MEDICINES IN GENERAL	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
O1	Doctors use too many medicines					
H1	People who take medicines should stop their treatment for a while every now and again					
B1	Medicines help many people to live better lives					
H2	Most medicines are addictive					
H3	Natural remedies are safer than medicines					
B2	In most cases the benefits of medicines outweigh the risks					
B3	In the future medicines will be developed to cure most diseases					
H4	Most medicines are poisons					
H5	Medicines do more harm than good					
B4	Medicines help many people to live longer					
O2	Doctors place too much trust on medicines					
O3	If doctors had more time with patients they would prescribe fewer medicines					

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Appendix 11 – Copy of the BMQ-S

BMQ-S11-singular

Project Number .....

YOUR VIEWS ABOUT THE
MEDICINE PRESCRIBED FOR YOU

- We would like to ask you about your personal views about the medicine prescribed for you.
- These are statements other people have made about this medicine.
- Please show how much you agree or disagree with them by ticking the appropriate box.

There are no right or wrong answers.
We are interested in your personal views

	Views about the MEDICINE PRESCRIBED FOR YOU:	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
N1	My health, at present, depends on this medicine					
C1	Having to take this medicine worries me					
N2	My life would be impossible without this medicine					
C2	I sometimes worry about long-term effects of this medicine					
N3	Without this medicine I would be very ill					
C3	This medicine is a mystery to me					
N4	My health in the future will depend on this medicine					
C4	This medicine disrupts my life					
C5	I sometimes worry about becoming too dependent on this medicine					
N5	This medicine protects me from becoming worse					
C6	This medicine give me unpleasant side effects					

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Appendix 12 – Copy of the HADS

Hospital Anxiety and Depression Scale (HADS)

Name: Date:

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A D

I feel tense or 'wound up'
- 3 Most of the time
- 2 A lot of the time
- 1 From time to time, occasionally
- 0 Not at all

I still enjoy the things I used to enjoy
- 0 Definitely as much
- 1 Not quite so much
- 2 Only a little
- 3 Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
- 3 Very definitely and quite badly
- 2 Yes, but not too badly
- 1 A little, but it doesn't worry me
- 0 Not at all

I can laugh and see the funny side of things
- 0 As much as I always could
- 1 Not quite as much now
- 2 Definitely not so much now
- 3 Not at all

Worrying thoughts go through my mind
- 3 A great deal of the time
- 2 A lot of the time
- 1 Not too often
- 0 Very little

I feel cheerful
- 3 Never
- 2 Not often
- 1 Sometimes
- 0 Most of the time

I can sit at ease and feel relaxed
- 0 Definitely
- 1 Usually
- 2 Not often
- 3 Not at all

I feel as if I am slowed down
- 3 Nearly all the time
- 2 Very often
- 1 Sometimes
- 0 Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach
- 0 Not at all
- 1 Occasionally
- 2 Quite often
- 3 Very often

I have lost interest in my appearance
- 3 Definitely
- 2 I don't take as much care as I should
- 1 I may not take quite as much care
- 0 I take just as much care as ever

I feel restless as if I have to be on the move
- 3 Very much indeed
- 2 Quite a lot
- 1 Not very much
- 0 Not at all

I look forward with enjoyment to things
- 0 As much as I ever did
- 1 Rather less than I used to
- 2 Definitely less than I used to
- 3 Hardly at all

I get sudden feelings of panic
- 3 Very often indeed
- 2 Quite often
- 1 Not very often
- 0 Not at all

I can enjoy a good book or radio or television programme
- 0 Often
- 1 Sometimes
- 2 Not often
- 3 Very seldom

Now check that you have answered all the questions.

A D

TOTAL

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Health & Social Care

Appendix 13 – Copy of the SOS B

SIGNIFICANT OTHERS SCALE (B)

Name: .....

Date: ..... **Record Number:** .....

Instructions

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

Person 1 –	*Never*		*Sometimes*				*Always*
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 2 –							
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 3 –							
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

Person 4 – .....

		Never			Sometimes			Always
1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 5 – .....

1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 6 – .....

1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 7 – .....

1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

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Appendix 14 - Table of NYHA Classification of Heart Failure

Class of Heart Failure	Symptoms
I – Asymptomatic	No limitation in physical activity despite presence of heart disease. This can be suspected only if there is a history of heart disease which is confirmed by investigation e.g. echocardiography
II – Mild	Slight limitation in physical activity. More strenuous activity causes shortness of breath-for example, walking on steep inclines and several flights of steps. Patients in this group can continue to have an almost normal lifestyle and employment.
III – Moderate	More marked limitation of activity which interferes with work. Walking on the flat produces symptoms.
IV - Severe	Unable to carry out any physical activity without symptoms. Patients are breathless at rest and mostly housebound.

New York Heart Association Classification of Heart Failure

Appendix 15 -Table of Clinical Classification of HADS Data at times one and two

	Time 1 Frequencies	Time 1 Percentages (%)	Time 2 Frequencies	Time 2 Percentages (%)
0-7 normal mood	16	57.1	17	60.7
8-10 mildly anxious	5	17.8	7	25
11-14 moderately anxious	7	25	2	7.1
15-21 severely anxious	0	0	2	7.1

Distribution of scores according to severity of Anxiety at time 1 and time 2

	Time 1 Frequencies	Time 1 Percentages (%)	Time 2 Frequencies	Time 2 Percentages (%)
0-7 normal mood	17	60.7	18	64.2
8-10 mildly depressed	7	25	5	17.8
11-14 moderately depressed	3	10.7	3	10.7
15-21 severely depressed	1	3.5	2	7.1

Distribution of scores according to severity of Depression at time 1 and time 2