THE INFLUENCE OF ILLNESS AND PSYCHOLOGICAL FACTORS ON PATIENT AND CAREGIVER OUTCOMES IN HEART FAILURE

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to Mark

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ABSTRACT

Heart Failure (HF) is a syndrome in which the heart is chronically unable to pump blood at a rate adequate for the needs of the body. Exercise intolerance, fatigue, breathlessness and oedema are the main symptoms. Despite advancements in the pharmacological treatment of HF, quality of life in HF patients remains low, and risk of hospitalisation and death high. Very few studies have addressed the influence of illness and psychological factors on patient psychological and clinical outcomes, and on caregiver distress. Therefore, the overall aim of this study was to extend current research on late life family illness by investigating outcomes for a large group of patients with HF and their caregivers. The focus of the research was to identify predictors of patient and caregiver distress using a longitudinal design and quantitative data.

An existing model of late family illness which emphasises the dynamic nature of caregiving for an elderly relative with a chronic illness provides a starting point for the current research (Young, 1994). However, Young's model is too simple and broad-ranging to allow specific hypotheses to be made. The first objective of the thesis was therefore to develop a theoretical framework in which specific hypotheses could be tested. As yet, few empirical studies have investigated the nature of the family illness situation in heart failure, and so a consideration of qualitative studies of patient experience of HF aimed to translate identified 'themes' into well-defined concepts within a health psychology framework. Thus identifying 'measurable' concepts which characterise patient experience of the illness situation, allows development of a framework within which specific hypotheses can be made.

The nature and symptoms of HF are presented to illustrate the demands that the illness puts on both patient and caregiver, and to familiarise the reader with concepts of illness severity and key objective and subjective indices of severity, duration and illness outcome.

A critical review of the small number of studies of the caregiving experience in HF, with an emphasis on methodological problems in current caregiving research, addresses the second objective; to identify major factors in the prediction of patient and caregiver distress, and to compare their predictive value. Hypotheses are made with respect to HF caregiving and care-receiving, and a simple model is proposed. Key failures of previous studies have been not to utilise designs or analyses in which the relative strength of different predictors could be compared, and also to neglect the role of patient and caregiver personality in predicting distress, which may act as a moderator or suppressor of various predictors. These flaws are both addressed by the current study.

A third objective, given the lack of studies in which empirical and validated measures have been employed, was to investigate the validity of a measure of HF knowledge, using a pilot study. Choice of measures for the main study are also discussed. In the current thesis, patient and caregiver outcome measures were not seen as global concepts, but rather they were conceptualised as measures *specific* to the caregiving – care-receiving situation (negative reactions to receiving care and carer distress) and measures *non-specific* to the caregiving – care-receiving situation (depression and anxiety).

Patients and caregivers were tested on two occasions. The tests and interviews took place approximately six months apart. 100 patients and 53 caregivers were interviewed at phase 1; 64 patients and 36 caregivers were interviewed at phase 2. The main cause of attrition was patient death.

The key findings were (i) that it was correct to conceptualise patient distress and caregiver distress as non-specific and specific to the caregiving – care-receiving situation, as the predictor variables accounting for the maximum variance differed for each aspect of patient and carer distress, (ii) severity of illness was predictive of patient psychological and clinical outcomes and carer distress, (iii) patient neuroticism was an important predictor of patient outcomes and carer distress and was a strong moderator of the associations between illness, patient and caregiver characteristics and patient outcomes, (iv) caregiver neuroticism directly affected carer distress and was a strong moderator of the associations between illness, patient and caregiver characteristics and caregiver outcomes, (v) contrary to the hypothesis, low patient specific knowledge of HF *per se* did not negatively affect patient outcomes, but patient level of self-care affected both patient and carer outcomes, (vi) patient coping style affected both patient and carer outcomes, (vii) for both patients and caregivers satisfaction with social support was a better predictor of distress than a global measure of social support, (viii) patient psychological status at phase 1 influenced patient morbidity in the follow up period, but not patient mortality, (ix) as proposed by Young's (1994) model, patient and caregiver outcomes influenced each other; specifically highly anxious patients increased their caregivers' anxiety and patients of highly anxious caregivers tended to be hospitalised more often in the follow-up period and to stay longer in hospital when admitted. To summarise, although the main predictors of patient outcomes are illness and patient characteristics, patient characteristics also consistently predict carer distress.

It is concluded that an "all-encompassing" model of caregiving–care-receiving is not appropriate giving the dynamic and unpredictable nature of HF. Therefore, a revised simplified model of caregiving – care-receiving in HF, which emphasises the critical role of patient and caregiver personality is presented.

THESIS RELATED PUBLICATIONS

Loftus, L, and Davies, ADM. Reactions to giving and receiving care in a heart failure sample. Abstract presented to the British Psychological Society's Annual Conference, London, March 2004.

Davies, ADM, Loftus, L, King, D and Ludgate, V. An evaluation of a hospital based heart failure education class. *Age and Ageing*, May 2004, 33(1) i6.

Davies, ADM and Loftus, L. The role of psychology in care for the heart failure patient: a research update. Presentation for the Second Wirral Heart Failure Seminar, Arrowe Park Hospital, September 2003.

Davies, ADM, Whitehead, DL, Loftus L, Cousins, R, Turnbull, CJ and Playfer, JR. Distress in Parkinson's Disease and Heart Failure Caregiving. Presentation at the British Psychological Society's Annual Conference, Bournemouth, March 2003

L.Loftus, ADM Davies and D King. Negative reactions to being cared-for in heart failure patients. Abstract presented to the British Psychological Society's Annual Conference, Bournemouth, March 2003.

Loftus L, Davies ADM , King D . The role of knowledge of heart failure on patients' mood states and illness uncertainty. Abstract presented to the British Psychological Society's Annual Conference (Division of Health Psychology), Annual Conference, Sheffield, September 2002.

Loftus L, Davies ADM, King D . The role of education in the management of heart failure: a review. Presentation at the British Psychological Society's Annual Conference, Blackpool, March 2002.

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CHAPTER 0

OVERVIEW OF CONTENT OF THESIS AND STRATEGY OF ANALYSIS

The aim of this study is two-fold. Firstly, the consequences *for the patient* of living with heart failure (HF) and receiving care are described. Secondly, the consequences for the *primary caregiver* of taking on the role of looking after someone who has HF are investigated. The ultimate goal of the research was to extend current models of late life family illness by conceptualising caregiving and care-receiving as a interpersonal dynamic process whose success depends on the interpersonal style and beliefs of both caregiver and recipient.

The approach has been to consider that whilst much of the existing caregiving research views the care-recipient as a potential stressor and the caregiver is seen in terms of his or her *negative outcomes*, the care-recipient and his or her perspectives and outcomes are vastly underemphasized. Therefore, in this study both the caregiver and the care-receiver are considered with the aim of developing a model of caregiving - care-receiving in a HF population. Moreover, outcomes for both members of the dyad are separated into those *specific* to the caregiving – care-receiving situation (such as negative reactions to receiving care, carer distress and satisfaction with role as caregiver) and overall, *non-specific* measures of mental well-being (such as anxiety and depression).

The scarcity of literature addressing psychological aspects of HF *in general* and caregiving and care-receiving in HF *in special* presented difficulties for the present study, in that a theoretical and methodological framework within which the study could be based was not in place. Therefore, in chapter one, a simple model of late life family illness - stressing the interaction between patient and caregiver - is presented as a methodological basis for the study. A review of qualitative studies of living with HF is then undertaken, in order to provide a theoretical framework for the study.

In chapter two, a review of the nature of HF includes information that is relevant to both patient and caregiver. An outline of the difficulties in defining and diagnosing HF is included in order to present how patients and their carers are sometime not told about diagnosis, therefore having little insight into the condition. The epidemiology of HF is presented to demonstrate the extent of caregiving – care-receiving required. An overview of the pharmacological and non-pharmacological treatment is included to stress the complexity of managing HF. Heart failure's poor prognosis is presented in order to make the reader aware that life expectancy of HF patients is worse than many forms of cancer (Stewart et al., 2001). A brief review of the high risk of re-hospitalisation of HF patients is included to emphasise the substantial impact of HF on the health services. The clinical presentation of HF is presented to illustrate the *physical problems* faced by patients and caregivers. Thus, chapter two gives the reader an overview of HF illness situation faced by the patient and their caregiver.

In chapter three, a review of cognitive change associated with HF is presented, alongside studies of patient knowledge of HF and psychological characteristics of the care-recipient. Studies investigating psychological outcomes in HF are also reviewed, in order to justify their use in the present research.

In chapter four, a brief review of the current state of caregiving research is undertaken, pointing out a number of methodological problems. At the end of chapter four, a summary of the hypotheses to be tested in the present study is presented, alongside a simple HF caregiving – care-receiving model.

Chapter 5 provides an overview of a pilot study carried out before the main study with the aim of validating a HF knowledge questionnaire developed for the present study. The choice of tests is also discussed in chapter 5, followed by details of the design and procedure.

Phase 1 results are presented in chapters six and seven, and phase 2 results are presented in chapter 8. The approach has been to consider that, as measures of distress are known to be influenced by how "neurotic" or emotional the participant is by temperament (Costa and McCrae, 1984), there is a need to control for these differences in patient and carer neuroticism. Therefore, throughout the results chapters patient and caregiver neuroticism are statistically controlled in relevant correlations between illness, patient and caregiver factors <u>and</u> patient and carer outcomes in order to interpret the "true" relationship between these variables, <u>independently</u> of patient or caregiver neuroticism.

Chapter nine presents a discussion of the results in chapters six, seven and eight with regard to the hypotheses and the relevant literature.

CHAPTER 1

HEART FAILURE AS A FAMILY ILLNESS SITUATION

1.1 HF as a family illness situation - conceptual framework

Long-standing illness and associated limitations in activities of daily living are common among older people (Bridgwood et al., 2000; Ayis et al; 2003). By the age of 80, 70% of people report some levels of disability in the UK, of which musculo-skeletal and cardiovascular disease are two major predictors (Martin et al., 1988). The preponderance of disability in the elderly suggests that caregiving for elderly relatives is widespread, and this was confirmed by research that identified families as the main source of aid to elders (Chappel, 1991). In the UK, the National Strategy for Carers (Department of Health, 1999) showed that Britain has an estimated 5.7 million carers, one in six households (17%) containing a carer. Moreover, one half of all carers look after someone aged over 75 years. The high proportion of health problems among the elderly combined with the dependence on their families to provide support suggests a complex family-illness "intermesh" (Young, 1983; Young, 1994). Illness affects the older patient and the family alike and in turn the way family reacts to illness influences the situation, suggesting a two-way, or reciprocal interaction.

This thesis is primarily concerned with describing the effects that a serious and an increasing progressing illness - heart failure (HF) - has on patient and caregiver outcomes in a family illness situation framework.

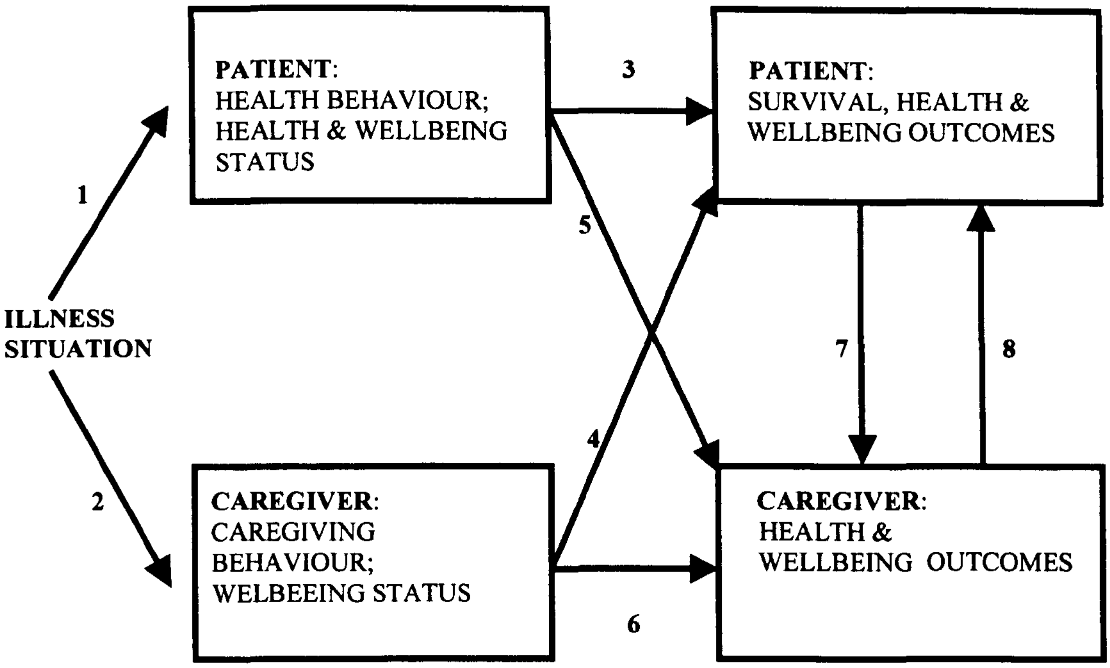
HF is the final common pathway for many and diverse cardiac pathologies, the most common of which is coronary artery disease (CAD) and hypertension (Cowie et al, 1999; Cowie et al., 2000). In patients diagnosed with HF the heart is unable to pump enough oxygen-rich blood to meet the body's needs and often a decreased heart function is accompanied by a build-up of body fluid in the lungs and elsewhere. As a consequence, the primary symptom of HF is dyspnoea or breathlessness. Moreover, a decreased cardiac output translates into unrelenting fatigue and difficulties in performing physical activities. Breathlessness, fatigue and exercise intolerance result in increased patient disability and poor quality of life. HF is a common clinical problem of the elderly and very elderly, on average patients presenting for the first time with clinical HF have a median age of 76 years. HF has been shown to be " more malignant" than cancer (Stewart et al., 2001), a quarter of HF patients dying within three months, over a third by one year and nearly one in two patients are dead by two years (Wood, 2002). Moreover, HF is the most common reason for hospitalisation in the Western world, representing a substantial societal burden (Rich, 2001).

1.2 Young's model of late life family illness

The major aim of this thesis is to describe the effects that HF has on patient and caregiver outcomes in a late life family illness situation framework. According to Lazarus and Folkman (1984), illness models are valuable explanatory tools in revealing the processes affecting individuals in stressful situations and their outcomes. In order to establish the framework within which this thesis was conceptualised, a model of late life family illness proposed by Young (1994) is firstly analysed.

Young (1994) proposed that the consequences of illness in the family should be conceptualised as a mutual encounter: illness affects both the patient and the caregiver, and their response to the illness situation in turn affects the situation. Moreover, her model shows that although the illness situation has a separate effect on the patient and the caregiver, their resulting behaviours affect each other's outcomes, the crucial implication being that the model is interactive (see Fig. 1.2.1, below).

Fig 1.2.1 Late life family illness: Patient-caregiver Interaction model (from Young, 1994)



1.2.1 Impact of illness situation on patient

One of the strengths of Young's model is its simplicity, which permits generalisation. As indicated by link 1, the illness constitutes a basic threat to life, quality of life and emotional well being of the sufferer. This is true for HF, as for myocardial infarction (MI), the illness situation Young used to explain her model. As will be further explored in the following chapters, a diagnosis of HF is highly traumatic to the patient; the quality of life of HF patients (both physical and emotional) is worse than most other chronic conditions, and levels of anxiety and depression are high. Moreover, as Hickey (1984) stated, there is an important physical-mental interface at later life because disease states reduce physical capacity and increase the need for assistance, which can result in fear of dependency. This is certainly true for HF patients whose breathlessness and physical effort intolerance are highly disabling.

1.2.2 Impact of illness situation on caregiver

Link 2 two indicates the effects of the illness situation on the caregiver. Typically, a decline in health is the starting point in a multi-faceted caregiver – care-receiver relationship (Miller et al., 1991). This relationship was argued to be the most prototypical dyadic relationship revolving around late-life dependency (Kahana and Young, 1990). Most caregivers are members of the patient's immediate family (Liwak et al., 1990; Larragy 1993; Tennstedt et al., 1993; Doty et al., 1998), most often spouses or daughters (Stoller et Earl, 1983). Of course, the caregiver enters the caregiving situation with their own health and well-being and their personal characteristics. Essentially, research has shown that caregiving is characterised by a great deal of individual variation in that caregivers react quite differently to similar situations (Zarit and Edwards, 1996). As will be reviewed in chapter four, very little research has been conducted on the effects that caring for a HF sufferer has on the carer.

1.2.3 Patients and caregiver response to illness and association with outcomes

Links 3-8 address the response of patients and caregiver to the demands of illness and ways in which these responses can influence the illness outcomes. Positive illness outcomes such as functional independence and recovery depend on many factors, not only the person's ability to heal and the underlying severity of the problem, but also medical treatment and psychosocial factors.

Young notes that the biopsychosocial model of recovery is increasingly recognised for its relevance to understanding good health. Undoubtedly the biopsychosocial model of recovery is at the core of health psychology, and encompasses domains such as effects of psychological and social factors on disease risk, prevention, treatment compliance, morbidity, quality of life and survival (Lutgendorf and Costanzo, 2003). Briefly, the biopsychosocial model was proposed by Engel in 1977, when he published a landmark article in *Science* in which he argued that biological factors such as genetics do not account for *all* health outcomes; rather, a proper understanding of the aetiology and progression of disease must take into account the interactions of psychological and social factors along with biological processes (Engel, 1977). Therefore, patient outcomes cannot be understood from indices of illness severity alone. Their "resources" such as coping abilities and social support must also be considered. Similarly, caregiver outcomes can also be viewed in the context of the biopsychosocial model. What the caregiver brings to the caregiving situation (such as personal characteristics) can help them to deal with the stress of caregiving and tip the balance in favour of good outcomes, such as psychological well-being and maintenance of health.

1.2.3.1 The influence of patient characteristics on patient outcomes

Crucial for Young's model is the fact that both patient and caregiver are viewed as having *some control* over outcomes for both themselves and the other constituent of the dyad. Without a doubt, as indicated by link 3, people are directly responsible for their actions and health behaviours. Physicians prescribe medications, advise on life change modifications such as diet and smoking instructions and schedule follow-up visits with the expectation that they will be followed, but the responsibility for following the treatment plan stays with the patient. This point is extremely relevant for the HF patients, who besides adhering to a complex medication treatment, are also expected to implement significant changes to their everyday life, such as modification of diet, limiting of their alcohol intake especially and liquid intake generally, keeping their weight under control and self-monitoring of HF through daily weighing and oedema observation. Medication adherence is particularly important for HF patients because their very lives can depend on medication that is taken correctly. Nevertheless, medication non-compliance is often reported in HF patients and is a major cause of unplanned hospital admissions (Ghali et al., 1988; Monane et al., 1994; Happ et al., 1997; Bennett et al., 1998).

1.2.3.2 The influence of caregiver characteristics and actions on patient outcomes

The value of family-based care has been increasingly recognised over the last quarter century (Litman, 1974; Shanas 1979). Particularly, caregiver's actions are essential components of recovery (link 4). Administering medication properly, ensuring that the patient has an adequate diet and avoids over-exertion were found to have direct health benefits. Moreover, caregiver attitudes, such as moral support and encouragement may also have an beneficial effect on the patient. This certainly seems to be true for HF patients. The absence of emotional support measured *before* hospital admission was found to be a strong independent predictor of the occurrence of fatal and non-fatal events in the year after admission (Krumholz et al., 1998). However, the way in which the caregiver reacts to the caregiver role can also be harmful to the care-receiver. Resentfulness and dislike of the caregiving role, low morale and depression and feelings of burden can create a poor emotional climate that negatively influences the care-receiver's mental health (Kahana and Young, 1990). Although the last decades have seen a mushrooming of caregiver research, paradoxically the effects of caregiving on *the care-receiver* have been neglected (Gaugler et al., 2002). To date, no research has been published regarding the effects that caregiving has on HF care-recipients.

1.2.3.3 The influence of patient actions and attitudes on caregiver outcomes

Link 5 shows that the patient's actions and attitudes affect caregiver's outcomes. Caring for patients who are very sick can be very demanding and stressful for the caregiver (Miler et al., 1991), especially if the patient's emotional state is affected. Caring for depressed elders has been shown to be especially demanding (Leinonen et al., 2001) and this could be the case for caregivers of HF patients, as HF is often associated with depression and low mood (Koenig et al., 1998; Havraneck et al., 1999; Turvey et al., 2002). Caregiving studies have shown that caregiver well-being is often affected as a result of providing care and this can take the form of physical, mental and /or social morbidity (Poulschock and Deimling, 1984; Pruchno and Resch, 1989; Miller et al., 1991).

1.2.3.4 The influence of caregiver behaviour and attitudes on their outcomes

Link 6 in the Young's (1994) model shows that caregiver behaviour and attitudes may exert considerable influence over his/her outcomes. Studies using stress and coping models have consistently demonstrated that much of the observed variability in caregiving outcomes can be attributed to caregiver's personal characteristics and resources, especially the *degree of emotionality or neuroticism* (Pearlin et al., 1990; Reis et al,1994; Schulz et al., 1995; Hooker et al., 1998; Patrick and Hayden, 1999; Gallant and Connel, 2003). However, the few studies investigating caregiving for HF patients consistently failed to take into account carer neuroticism when linking possible predictors to carer distress.

1.2.3.5 The interaction between patient and carer outcomes

Links 7 and 8 emphasise the relationship of patient and caregiver outcomes. On one hand, patient recovery or non-recovery directly affects the caregiver (link 7). Long-term care of a patient whose health is declining has been shown to be more stressful than similar care of a stable patient (Schultz, 1990). This is certainly true for HF patients whose health rarely improves. On the other hand, the way in which caregivers react to the illness situation can also directly impact care-recipient outcomes (link 8). Caregiver deterioration of his/hers physical or mental health as a consequence of caregiving can directly impact patient health status in that it may limit their desire or ability to care at home, resulting in extreme cases in institutional placement (Zarit et al., 1986).

1.2.4 Summary

In section 1.2 a model of late life family illness was presented in order to set out a framework for the current research. Young's (1994) model expands the theoretical base beyond approaches that unidirectionally portrays families *as responders.* It recognises that the family-illness interface is multidimensional and driven by the concept of mutuality. As the elder and his/her family are affected by late life illness, they respond to the illness situation in ways that influences the situation and can impact on both care-receiver and caregiver outcomes. Furthermore, Young stresses that outcomes may be beneficial as well as harmful.

The present research is concerned with defining more elaborately the nature of links 1-8 in Young's (1994) model of late life family illness, as applied to elderly HF patients and their caregivers. Although Young's model is theoretically useful, it is too general to allow specific predictions. Based on current literature, this study aims to extend Young's model to allow testing of hypotheses *specific* to the HF illness situation. The question posed is *which aspects of patient health status and behaviour and which aspects of caregiver characteristics and behaviour are most pertinent to patient and caregiver health and well-being outcomes?*

The next section depicts links 1 and 2, by reviewing *qualitative* studies of the effects of HF illness situation on the patient and caregiver. Chapter two and three presents patient characteristics and outcomes (links 3, 4 and 8) and chapter four presents HF illness situation from the carer point of view (links 5,6 and 7).

1.3 Qualitative reports of HF as a family illness situation

Qualitative reports use personal narratives to identify themes. Essentially exploratory in nature, qualitative studies are not set up specifically to test hypotheses or models, but rather are valuable in identifying themes that could then be addressed as part of a model. Given the scarcity of literature on caregiving in HF, in this section qualitative studies addressing the illness situation as experienced by patients and their carers is reviewed, with the aim of identifying concepts and defining research questions.

In 1999, Stull et al. published a qualitative study aimed at gaining a better understanding of the process of becoming a patient with HF. A total of 21 patients (17 male and 4 female) of an average

age of 61 years (range 29-79 years) diagnosed with HF were interviewed in the examining room as part of a regularly scheduled visit with their cardiologist. The authors found that the process of becoming a patient with HF involves a gradual and multiphasic process of taking a new identity. Five distinctive phases of this process of identity formation become apparent: a crisis event, the diagnosis, the patient's and family's response to the diagnosis, their acceptance and adjustment to life with the condition and making the decision to get on with life. Patients started the process of becoming a patient with HF with a crisis event, such as becoming very breathless and/or losing of energy that required a visit to the emergency room. Comments from the patients such as *"I couldn't breathe, like I had to sit up to sleep and anything. They got 31 pounds of fluid off me in the first 2 days"* (p 287) are typical of a first episode of HF and also of HF decompensation. Getting diagnosed was conceptualised as the beginning of the process of attaching meaning to the symptoms in order to make sense of the condition. Being diagnosed with HF had a different effect on the patient's ability of sense making according to previous heart problems. On one hand, for those patients who had a history of heart problems (such as a heart attack) the diagnosis of HF, although upsetting, had a pre-existing context, in that the patient and their family were aware and have had experience with heart or other cardiovascular problems. On the other hand, the diagnosis of HF for patients who reported no history of heart problems was much harder to accept because they lacked prior experience with similar situations. Words such as "scared", "nervous" and "worried" were commonly used to describe patients and family member's reactions to the diagnosis. For many patients the very term of heart failure brought up images of impending death or of only a short time to live. Uncertainty and lack of information overwhelmed other patients so they were not sure what to think, how to feel or how to act. For younger patients not being able to go back to work was often the most devastating aspect of the diagnosis. The forth phase of the process, acceptance and adjustment, was characterised by patients' efforts to adjust their lifestyle to the condition and realisation that they would have to modify their expectations about life. For many patients there was a settling-in period after the diagnosis, in which medications, diet and lifestyle are attuned in order to achieve a balance between minimising the patient's HF episodes whilst maintaining ability to perform every day activities. The final phase in the process of taking on the new identity of a patient with HF was summarised as a point in the process when a patient makes a decision about the course of his or her life. As one patient put it "*You need to maintain that quality of life that you had before*" (p 289). This study emphasises the need of HF patients and their families for information about illness and the normality of emotions, behaviours and changes in family life. Adequate information was deemed as essential if the patients were to establish new identities and to actively participate in the management of their illness.

Stull et al., (1999) study is valuable because it allows a glimpse into the psychosocial experience of the early phases of the condition. However, the study was based on relatively young patients and only four women, thus not permitting observation of possible gender differences in responses to HF. Two studies have reported gender differences in meaning and life situation in HF patients and will be summarised below.

Martensson et al., (1997; 1998) has carried out two separate studies in Sweden that explore the differences in how male (n=12; age from 48 to 80 years) and female (n=12; age from 65 to 83 years) HF patients conceive their life situation. Participants were recruited from a secondary care outpatient unit and the interviews were conducted in the informants' own home. Both studies used semi-structured interviews designed to focus on five dimensions: the biophysical, the socio-cultural, the emotional, the intellectual and the spiritual-existential. For males (Martersson et al., 1997) six categories emerged: feeling a belief in the future; gaining awareness; feeling support from the environment; feeling limitation; feeling a lack of energy and feeling resignation. Mental and physical fatigue experienced by male HF patients adversely influenced their ability to work and to participate in social activities. These limitations caused patients to believe that neither they nor the environment can influence their life situation and thus they were at risk of becoming "resigned" and without hope for the future. For female HF patients (Martensson et al., 1998) five themes emerged, namely feeling content, feeling a sense of support, feeling a sense of limitation, feeling anxiety and feeling powerless. As opposed to male patients, women experienced anxiety because they could not help those around them as much as they used to. Loss of their "nurturing role" made them insecure about themselves and in relation to their surroundings, prompting feelings of worthlessness and of being a burden to others. Similarly to Stull et al.'s (1999) recommendations, the need for educational nursing interventions directed to both patient and the family were viewed as essential in helping both male and female HF patients to maintain a hopeful perspective and a sense of control, competence and self-esteem.

More recently, Evangelista at al., (2001) conducted a study to determine whether gender differences exist in health perceptions, psychosocial adjustments to illness and concerns related to illness in patients with HF. Participants were a convenience sample of 32 (16 men, mean age 48 years and 16 women, mean age 56 years) patients diagnosed with HF and recruited from a single outpatients HF clinic. Face-to-face interviews were conducted in the participants' own homes. The interview involved a mixture of quantitative and qualitative methods, participants being asked to complete standardised tools to assess health perceptions and psychosocial adjustment to illness as well as answering two open-ended questions.

Women HF patients were found to have better health perceptions than men did and also demonstrated better psychological adjustment to illness. Four major themes emerged from the data analysis of the first open question, which asked participants to describe the impact that HF had on their lives: physical impairment, role limitations, loss and emotional burden (see fig 3.1, below).

Fig 1.3.2 Patients' perceptions regarding the impact of HF on their lives (adapted from Evangelista et al., 2001)

PHYSICAL IMPAIRMENT
-Decreased functional ability
-Decreased vitality
-Symptom distress
-Side effects of treatment

ROLE LIMITATIONS
-Unable to work
-Unable to meet family roles
-Poor self-concept
-Social limitations

LOSS
-Loss of independence
-Loss of health
-Financial loss
-Loss of control

EMOTIONAL BURDEN
-Fear/uncertainty
-Hopelessness
-Depression, anger, anxiety

The second open question asked patients to described how they felt about their illness. Patients described both positive meaning (illness as a challenge and as a value) and negative meaning (illness as a weakness and as an enemy). Men described greater negative feelings related to their illness than women did, whereas women were more likely to express acceptance of their condition and also described ways in which they learn to deal with HF. Moreover, gender differences were also evident in patients' coping strategies: men used coping strategies that were more emotion-focused, fatalistic and evasive, whereas women used more optimistic coping strategies. This study stresses the importance of gender differences in health perceptions related to HF and draws attention to the need to tailor education and counselling to address the gender-specific concerns of men and women with HF in order to improve outcomes.

Buetow and Coster (2001) and Buentow et al., (2001) also published two papers, which described the results from a qualitative study involving 62 patients diagnosed with HF (mean age 71 years) who received GP-care in 30 practices across central Auckland, New Zealand. The first paper examined whether patients with HF in general practice understood the nature and seriousness of their condition and whether they wanted more or better information about their condition and the second paper explored coping strategies in the self-management of heart failure with the aim of empowering GPs to facilitate patient self-care.

The first study found that approximately 40% of the patients appeared not to understand the nature and seriousness of their HF; two patients accidentally discovered the diagnosis from inappropriate sources and 11 patients (18%) expressed desire for improved information for their condition. The authors did not ask patients if they wanted to know information relating to the seriousness of their HF in order to "avoid harm". As will be further discussed in chapter 3, research has shown that health care professionals are often reluctant to discuss prognosis with HF patients.

In the second study, Buetow et al., (2001) found that overall, patients with HF used four different approaches of *emotional-focused coping*: *avoidance*, *disavowal*, *denial* and *acceptance*. These coping strategies were not mutually exclusive, although one usually was used preponderantly. *Avoidance* was characterised by deliberately avoiding information, especially if it may be unfavourable. Although avoidance may serve the role of "minimisation to reduce emotional arousal" (p 119) resulting in reduced anxiety which can aid recovery during *acute* HF, it can also leave patients maladaptive in the long term by preventing active involvement in decision making and affecting adherence to treatments. It could be added that, as educating HF patients about their condition has been consistently judged as essential to successful management of HF, the process should involve assessing patients' *desire for knowledge* in order to design an intervention that is tailored to the patient's individual needs, in order to improve outcomes.

The study found that *disavowal* or *healthy denial* was a distinct coping strategy in this sample, which was little influenced by patients' age, duration and severity of HF or gender. Authors noted that patients' who engage in this pre-conscious process basically understand the threat to their life situation, but in order to reduce the emotional strain it produces they seek to dissociate that awareness from its personal impact. These patients were described as "positively reconstructing" the personal meaning or significance of their diagnosis of HF. The third coping strategy, *denial* was reported as uncommon in this sample. The researchers stressed that the colloquial meaning of denial (refusal to believe or accept something) differs from its scientific meaning (a mechanism of defence against external reality, which operates unconsciously to prevent the patient from knowing the truth). Conceptualising denial in its scientific form, the authors reported that it was uncommon and they detected no one who clearly used it as a coping mechanism.

Finally, patients' using *acceptance* were described as those who consciously acknowledged the validity of their received diagnosis of HF without attempting to positively reconstruct its meaning or personal significance. Older patients who were diagnosed with HF at least 3 years previously and had suffered recent limitations in their physical function mainly used this coping strategy. Some "accepting" patients had a fatalistic attitude of coping through acceptance of man's mortality, "*What will be will be*"(p 121), whereas others, although admitting to dread the perceived inevitability of their premature death, nevertheless tried to make the best of it by using mechanisms such as humour, support from family and friends and distracting activities such as music and gardening.

To summarise, Buetow et al., (2001) suggested a framework for understanding how HF patients cope mentally with living with their condition. *Healthy denial* was extensively used by HF patients, but *avoidance* and *acceptance* was also commonly used by older patients. The authors suggested a number of strategies (affective, cognitive, behavioural, affiliative and temporal) that GPs can used to promote hope if HF patients.

Ekman et al., (1999, 2000) also conducted two separate qualitative studies that aimed to elucidate the meaning of the experience of care received in the hospital and the meaning of living with severe HF, respectively.

The first study involved in depth interviews with twelve elderly patients (5 women and 7 men, mean age 83, age range from 76 to 94 years) who were hospitalised with moderate to severe HF on at least two occasions in a Swedish hospital. Patients were asked to describe their experiences of hospital care. Overall the study found that patients experienced the care as *unpredictable*. This essential theme encompassed the divergent descriptions of two sub-themes: care was perceived as being either *confident but incomprehensible* or *non-confident and incomprehensible*. When the patients sought care, it was as though they were launching themselves into the unknown, because they knew that many experiences would be unpredictable. This finding is particularly relevant to HF and may explain the tendency of elderly patients with HF to remain at home too long with grave symptoms of deterioration before they seek hospital care, thus increasing their morbidity and mortality risk (Friedman , 1997; Evangelista et al., 2000). Therefore, patients may avoid exposing themselves to the unpredictable care in the hospital, no matter how medically skilful and well meaning. A shift of health care delivery from *doing for* (the patient) to *presence with* (the patient) was suggested by the authors as a way to offer a safe, calm and intelligible hospital care for elderly patients with HF.

In their second study Ekman et al., (2000) described the meaning of elderly patients' experiences of living with HF via narrative interviews. Ten elderly (4 women and 6 men, age from 75 to 94 years) patients with severe to moderate HF were interviewed in their own home where they lived supported by caregivers. The interviews began with the question "Could you please tell me what you think about when you think of your illness?" (p 131) and continued with follow-up questions. Two themes were identified: *feeling imprisoned in illness* and *feeling free despite the illness*. Three sub-themes were further identified for each of the main two themes (see Fig 1.3.3).

Fig1.3.3 Themes and sub-themes of meaning of living with severe HF in elderly people (adapted from Ekman et al., 2000)

Sub-themes	Themes
Feeling hindered from being of use	Feeling imprisoned by illness
Difficulty in trusting others	
Not being ready for death	
Transcending illness	Feeling free despite the illness
Confiding	
Being ready for death	

The two main themes uncovered describe variations in the awareness of the relationship between the self and the body. In the theme *feeling imprisoned by illness* the patient's body illness and disability was conceived as deterring the patients from being themselves, whereas in the second theme, *feeling free despite the illness* patient's disability was viewed as being part of patient's self and therefore not limiting. The authors suggest that patients' understanding of illness must be interpreted by the caregiver (here the term is used in sense of *health* caregiver rather than member of the patient-caregiver dyad) who also must be aware of different models of communicating feelings about the illness. In other words, the health care professionals should listen to the patient's narrative in order to gain an understanding of his or her experience of the illness situation and should assess whether he patient has any significant other person (e.g. family member) who is willing and able to support and promote a sense of wholeness and meaning in the patient. Of course, professionals cannot replace family members' support, but they can help the family system achieve a new balance by providing them with relevant illness information (Lidell, 2002).

Mahoney (2001) conducted an ethnographic study aimed at understanding the illness experience of patients with HF and their family members. Twenty-eight informants (16 patients age 50 years or older and 12 family members) were recruited from specialist outpatient facilities in Texas, USA. The interviews were conducted either in clinical sites or more often in the informant's home. The participants were informed that they were viewed as experts about what is like to live with this condition and were asked to teach the investigator about their experiences. Typical questions included in the interview were 'How does HF work in your body?' and 'What is your chief concern about having HF?' (p 431). The study showed that patients with HF and their family members experience a process of *disruption*, *incoherence* and *reconciling*. *Disruption* was defined as one or more interruptions in the normal course of life, causing disorder and ranging from having a lack of clarity about what to call the illness to feeling like drowning. *Incoherence* was conceptualised as the lack of congruence when an event does not make sense. *Reconciling* was defined as the attempts one makes to resolve a disruption or an incoherence to create order, coherence or sense. It emerged as the salient experience described by informants and was manifested as *struggling, participating in partnership, finding purpose and meaning in the illness experiences* and *surrendering.*

Struggling was conceptualised as working to make sense of the illness experience through 'trial and error' and applied to both patients and their families. On one hand, patients tried to understand and adapt to their symptoms and medications. On the other hand, husbands, wives and daughters described struggling to control symptoms by systematically observing their sick family member and trying to meet their physical needs by changing dietary habits, testing recipes and even knitting 'stockings without elastic so his legs won't swell so much' (p 432).

Participating in the partnership emerged as a way for informants to reconcile their HF experience, and many referred to God's role while others talked about doctor-patients relationship and family relationships in this context. *Finding purpose and meaning in the illness experience* was another way in which the participants reconciled their illness. Again, religion was often used by patients to understand their illness. The finding that patients refer to God's role when they became very ill is interesting and seems to signify a shift of health locus of control from *internal* (patients themselves) to *powerful- others* (God). Of course, it could be that people who refer to the role of God when they are ill may have always believed that God "is in charge" of their health. However, a recent study with HF patients (Dracup et al., 2003) has shown that patients with high perceived control were less distressed and could walk longer than patients with low perceived control when demographic and clinical characteristics were controlled. It also could be that turning to religion is one way of coping with a stressful situation. Koenig (2002) reported that religious activities (especially religious attendance) were widespread in patients hospitalised with HF or Chronic Pulmonary Disease (CPD) and were associated with greater social support, but were only weakly related to less depression.

Caregivers also reported finding purpose and meaning in illness. For example, the wife of a HF patient was very ill with hepatitis C before her husband was diagnosed with HF. However, after her husband was diagnosed she found the motivation and the energy to go and see him in hospital everyday, and to start cooking healthily in order to help him. This point is relevant to the current study, because caregivers of elderly HF patients are often themselves elderly and suffering from health problems. Nevertheless, many find purpose and meaning in being able to care for the loved ones. Finally, *surrendering* was described as another way of reconciling one's illness by accepting it. Mahoney's (2001) study reinforces Stull et al.'s (1999) findings that becoming a patient with HF is a process that starts with a crisis, continues with a period of adaptation in which the patient and their family try to make sense of the illness situation, and ends up with acceptance and decision to get on with life.

Murray et al., (2002) published a paper in the British Medical Journal comparing the trajectories, needs and service use of patients with advanced lung cancer and those with advanced cardiac failure living in Scotland. In this qualitative study, in-depth interviews were carried out at three monthly intervals for up to a year with 20 terminal lung cancer patients (average age 65 years) and 20 patients with HF (average age 74 years) and their main informal carer in the patient's home. The interviewee asked patients and their carers to talk about the main issues they were facing and their views about the care they were receiving. After each interview the professional carer identified by the patient as being most important to their care was also interviewed.

The study found that lung cancer patients often perceived diagnosis as delayed, however they clearly understood what it entails once it has been made. By comparison, cardiac failure was a chronic illness with episodes of acute deterioration that often resulted in emergency admissions to an acute hospital, marking an overall progressive decline with an unpredictable terminal phase.

Lung cancer patients had access to good quality and accessible information, which they understood. Although many patients appreciated honesty regarding prognosis, a few patients, carers and professionals colluded to avoid issues relating to dying. By contrast, HF patients had a poor understanding of their condition despite professionals' efforts to provide information using complex strategies. Moreover, in the absence of chest pain they did not associate symptoms such as breathlessness and oedema to their heart. Furthermore, the study found that prognosis in HF was rarely discussed and patients had little acknowledgement that end stage cardiac failure is a terminal illness.

For patients with lung cancer and their carers the prospect of death was found to be a constant threat. Carers worried about upsetting the patient and whether they will know what to do when the death did occur, whereas the patients worried more about how carers would cope rather than their imminent death. By contrast, HF patients and their caregivers were found to be less preoccupied with the idea of death and more with the declining quality of their lives. Losses of autonomy and self-esteem were reported as resulting from struggles with the daily frustrations of a progressive chronic illness: '*You can't do what you did before, things you took for granted are now an impossible dream, I feel useless*' (patient 9, p 931). Feelings of uncertainty about how the patient will feel from one day to another were also reported: '*One day I'll be on top, the next day back under again*' (patient 10, p 931). The authors identified social isolation, comorbidity and increasing disability as key issues. For carers, social isolation was found to be distressing: '*I feel like I am in prison in here with him and each days just like the last*' (carer 11, p 931). Moreover, difficulties in balancing and monitoring complex and frequently changing medication regimens and their side effects were frequently reported. Patients and carers identified the side-effects of the water tablets (frequent urination) as the most limiting: '*...I can't really go anywhere away from the house... you see, I've got to know where every toilet is wherever I go*' (patient 10, p 931). The authors concluded the summary of living with HF with two telling sentences of how patients viewed their quality of life: '*I was sitting in a chair all night...I would be screaming for air ...very, very frightening...I suppose is like drowning really*' (patient 9, p 931). '*It's a life but is not much of a life. I'm ready for the knacker's yard*' (patient 15, p 931).

One important finding of the study is the marked difference in the service provision between the two illness groups. Whereas patients with terminal lung cancer had access to adequate hospital care and comprehensive information, heart failure patients had to face poorly co-ordinated hospital care, lack of care continuity and little planned community support.

Zambroski (2003) recently described a naturalistic study which was aimed at describing the problems, challenges and processes of living with HF and identifying strategies and tactics adults use to live with HF in Louisville, USA. Eleven informants (5 men and 6 women, mean age 67 years, age range from 50 to 81 years) were interviewed in their own home, using a semi-structured interview. Examples of questions asked were ' Tell me about what it was like when you were first diagnosed with heart failure' and 'Tell me how your daily life has changed since you became aware of your heart problem' (p 34). Data analysis resulted in three key categories representing the experience of living with HF: *experiencing turbulence*, *navigating* and *finding safe harbour*.

Experiencing turbulence was associated with terms such as "turmoil", "commotion", "excitability" and "storm" and reflected the intensity of patients' symptoms. Three sub-categories of turbulence were identified: physical, emotional and social. *Physical turbulence* encompassed problems of increased fluid retention and difficulty breathing. Similar to Murray et al.'s (2002) study, patients used analogies to drowning to describe episodes of HF experience: '*When you can't breathe and you wonder what the hell, what do you mean I can't breathe?...And the feeling is ...like being under water and you can't breathe*' (p 35). Experiencing *emotional turbulence* was defined as intense emotions brought up by living with HF. Feelings of fear, boredom, frustration, impatience, depression, guilt and jealousy were related with the inability to "do" as patients had in the past and with experiencing emergent events. Experiencing *social turbulence* was conceptualised as having to make changes to their social and work lives as well as affecting patients' ability to "play". Not being able to perform activities once highly valued, such as going to church, grocery shopping and socialising with family and friends were found to be associated with a great deal of loss and grief. Similarly to Murray et al.'s (2002) findings, diuretic medication severely affected patients' ability to participate in social activities. However, patients appreciated the beneficial effect of diuretic therapy: ' *I would much rather go to the bathroom 40 to 50 times a day than I would [have trouble] trying to breathe*' (male patient, p 36).

Navigating, the second category representing the experience of living with HF refers to the variety of strategies and tactics that patients develop in order to enhance their ability to deal with the conditions of turbulence in their lives. Patients engaged in both positive self-care behaviours (such as taking medications as directed, making appointments with their doctor, weighing daily and refraining from smoking) as well as negative self-care behaviours, such as smoking or binge eating.

The final category, *finding safe harbour*, refers to patients' desire of regaining a feeling of calm in their psychical health, emotional health and social relationships. Similarly to Ekman et al.'s (1999) study, Zambroski acknowledged that although health providers may consider hospitalisation as a source of safe harbour, several of her study participants did not always associate the hospital with being either calm or safe. The importance of family members as 'navigational aids' towards a safe harbour is also stressed. She gives an example of a man who needs to rely on his family to decide when to ask for help: '*I'm dumb. I have to wait for my wife to tell me, or my daughter who is a* *nurse...I mean I will sit there and die...Till somebody told me, look you are dying...And I just, I guess I'm thankful that I've got other people that kind of keep an eye on me because...in my home we never went to a doctor until we were sick' (p 38).*

Zambroski's (2003) study, used a novel way of looking at living with HF (navigating to safe harbour) and confirmed findings reported by previous studies that HF is a process of adaptation and acceptance.

The eleven studies summarised above were all qualitative studies, which provided general information about how HF patients and their caregivers react to the illness situation. There have been a number of other qualitative studies reported that focused upon examining certain *specific* aspects of the condition, such as patients knowledge of their illness and communication difficulties (Rogers et al., 2000, 2002), facilitators and barriers to self-care in HF patients (Riegel and Carlson, 2002; Horowitz et al., 2004), patients' conception of their sleep situation (Bostrom et al., 2001), the effects of HF on patients' sexuality (Jaarsma et al, 1996; Westlake et al, 1999) and patients' perceptions of physical fitness (Oka et al., 1999). Some of these studies will be reviewed in relevant sections in chapter 2 and 3.

1.3.1 Summary

Qualitative studies which investigated how HF patients and their families react to the illness situation reached similar conclusions, despite using different approaches (descriptive, naturalistic, comparative, ethnographic, phenomenological hermeneutic and metaphorical). Becoming a patient with HF was reported as a process of searching for a meaning to this condition and a process of taking on a new identity and appropriate role behaviours. Women were described as better adjusting to illness and using positive coping strategies, although feelings of worthlessness and being a burden to others were common. Men were more likely to become "resigned" and use coping strategies that were more emotion-focused, fatalistic and evasive. Not being the person “one used to be” was found to be particularly distressing for the male HF patients. Carers of HF patients struggled to control illness symptoms by systematically observing the patient, helping with dietary changes and encouraging the patient to see professional help when symptoms deteriorated. Many caregivers found purpose and meaning in being able to help for the loved ones, however caring for patients with severe HF was reported to be stressful to the caregiver. All studies suggested that providing accurate information and educating the patients and their caregiver about self-care is essential to the successful management of the illness. It was also stressed that patients should be educated to recognise worsening symptoms of HF and to go to hospital or see their health care provider when this occurs. However, research has also shown that some *patients do not want information* about their illness, suggesting that patient's desire for illness knowledge should be assessed in order to develop interventions that are targeted to each patient's individual needs. Moreover, research has shown that, although health care professionals may regard the hospital as a ”safe harbour” for the HF patient, many patients perceived the hospital care as unpredictable, thus avoiding going to hospital until they become very ill. Table 1.3.1, below presents a summary of the qualitative studies reviewed and the major themes identified by each study.

Table 1.3.1 Summary of qualitative studies of subjective experiences of heart failure

Study	**Location, Informants, age range**	**Main themes**
Martensson et al.,1997	Sweden 12 males 48-80 years	Mental and physical fatigue, Loss of role (work and social), Resignation, Loss of hope, Support from others
Martensson et al.,1998	Sweden 12 females 65-83 years	Support from others, Role limitations (not being able to help others), Anxiety, Feelings of being a burden to others, Powerlessness
Stull et al., 1999	USA 17 males, 4 females 29-79 years	Illness as a process, Breathlessness, Lack of information, Uncertainty, Anxiety, Inability to work, Acceptance
Ekman et al., 1999	Sweden 7 males, 5 females 76-94 years	Patients perceived hospital care as incompressible. Uncertainty about what to expect in hospital
Ekman et al., 2000	Sweden 6 males, 4 female 75-94 years	Feelings of being imprisoned in illness and feelings of being free despite the illness. Health care professionals as providers of information and assessors of family support
Buetow and Coster, 2001	New Zealand 36 males, 26 females 64-86 years	Low illness knowledge. Reluctance of health care professionals to discuss severity of illness and prognosis
Buetow et al., 2001	New Zealand 36 males, 26 females 64-86 years	Use of emotional-focused coping (avoidance, disavowal, denial and acceptance). Use of humour, family support and hobbies to "accept" illness
Evangelista et al., 2001	USA 16 males, 16 females 40-64 years	Physical impairment. Role limitations. Loss. Emotional burden (fear/ uncertainty, hopelessness; depression, anxiety, anger). Different coping strategies according to gender. Women had better health perceptions than men
Mahoney, 2001	USA 16 patients and 12 relatives 50+ years	Illness situation as a process. Making sense of illness through "trial and error". Turning to religion. Caregivers finding meaning in being able to care for the loved ones
Murray et al., 2002	Glasgow 20 patients and their carers Mean age 74 years	Poor understanding of HF. Prognosis rarely discussed. Complex medical regimens and medication side effects. Patients did not associate breathlessness and oedema with HF. Preoccupation with declining quality of life. Loss of autonomy and self-esteem. Social isolation. Uncertainty. Poorly co-ordinated hospital care. Lack of care continuity. Little planned community support.
Zambroski et al., 2003	USA 5 males, 6 females 50-81 years	Physical turbulence (breathlessness, oedema). Emotional turbulence (fear, boredom, frustration, impatience, depression). Social turbulence (unable to work, social limitations).

The major themes identified in the qualitative studies of the experience of living with HF can be grouped into five main domains (see Table 1.3.2, below). These concepts will be further investigated in chapters 2,3 and 4 and the specific hypotheses to be tested in the present study will be summarised at the end of chapter 5.

Table 1.3.2 Summary of the main themes identified in qualitative studies of living with HF (adapted from Bosworth et al., 2004)

Domains	Attributes
Symptoms	Physical symptoms (breathlessness, oedema, fatigue)
	Medication side-effects
	Co-morbidities
	Prognosis and trajectory unpredictable
Role loss	Participation in normal activities/Loss of independence
	Loss of social role
	Loss of work roles
	Loss of family roles
Affective responses	Depression
	Hopelessness
	Loss of control
	Emotional strain
	Burden
	Anticipatory fear
	Self-worth
	Denial
	Guilt
	Anxiety
Coping and compensation	Positive self care (medication, diet, weight monitoring)
	Negative self-care (smoking, binge eating)
	Emotional-focused coping
	Knowledge of disease
	Turning to religion
	Use of humour
Social support	Informational support
	Tangible support
	Emotional support

CHAPTER 2

THE NATURE OF HEART FAILURE

2.0 Introduction

In this chapter heart failure definition, aetiology and epidemiology are firstly reviewed in order to give an insight into the extent of the problem. Secondly, an overview of the pharmacological and non-pharmacological management of HF is presented. Thirdly, clinical features of HF are reviewed and measures of HF severity are discussed alongside prognosis and specific hypotheses to be tested in the present study are formulated.

2.1 Heart Failure: historical perspective, definition and aetiology

Heart failure was described as early as ancient Egypt, Greece and India, although the nature of the condition is unlikely to have been understood before William Harvey's description of circulation in 1628 (Davis at al, 2000). Momentous discoveries in medical science, such as Roentgen's X-rays, Einhoven's electrocardiography in 1890s and more recently echocardiography, cardiac catheterisation and nuclear medicine have further improved the diagnosis and management of HF. Early treatment for HF included blood letting and leeches and the Romans were known to use foxglove to treat HF, although the first published document on the benefits of digitalis was that of William Withering in 1785. In the 19th century and early 20th century, fluid retention caused by HF was treated by means of mechanical devices (Southey's tubes), which were replaced with diuretics in the 20th century. Vasodilatators began to be used in the treatment of HF after the development of angiotensin converting enzyme inhibitors (ACE-I) in the 1970s.

Despite of the recent advancements in the diagnosis and treatment of HF, there is no universally agreed definition of it as a disease (Denolin et al, 1983). The first attempt at defining HF belongs to Sir Thomas Lewis, in 1933 who described it as "*a condition in which the heart fails to discharge its contents adequately*"; he also stressed the importance and complexity of early diagnosis in his statement that "*The very essence of cardiovascular practice is the early detection of heart failure*" (Thomas Lewis 1933, cited in Davis et al, 2000). Over the years, numerous definitions have been proposed (see Table 2.1.1.) but none have been granted unanimous recognition.

Table 2.1.1 Some definitions of HF (adapted from Davis et al, 2000, p 39)

" A state in which the heart fails to maintain an adequate circulation for the needs of the body despite a satisfactory feeling pressure" (Paul Wood, 1950)
"A pathophysiological state in which an abnormality of cardiac function is responsible for the failure of the heart to pump blood at a rate commensurate with the requirements of the metabolising tissues (E Braunward, 1980)
" Heart failure is the state of any heart disease in which, despite adequate ventricular feeling, 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" (Denolin et al, 1983)
" A clinical syndrome caused by an abnormality of the heart and recognised by a characteristic pattern of hemodynamic, renal, neutral and hormonal responses" (Philip Poole-Wilson, 1985)
"[A] syndrome...which arises when the heart is chronically unable to maintain an appropriate blood pressure without support" (Peter Harris, 1987)
"A syndrome in which cardiac dysfunction is associated with reduced exercise tolerance, a high incidence of ventricular arrhythmias and shortened life expectancy" (Jay Cohn, 1988)
" Abnormal functioning of the heart causing a limitation of exercise capacity" or " ventricular dysfunction with symptoms" (anonymous and pragmatic)
" Symptoms of heart failure, objective evidence of cardiac dysfunction and response to treatment directed towards heart failure" (Task Force of the European Society of Cardiology, 1995)

The controversy surrounding what constitutes a good definition of HF is still very much alive. Recently the editors of *Cardiovascular Research* asked Journal's reviewers to define HF in less than 150 words (Coronel et al., 2001). Out of 2238 reviewers, 130 gave a definition of HF. Although these definitions could be broadly classified as "clinical" or "pathophysiological", not a single definition was the same as another, with the exception of three cases in which HF was defined as " failure of the heart".

The Task Force of the European Society of Cardiology definition of HF recently updated their definition of HF (Remme and Swedberg, 2001) (see table 2.1.2, below).

Table 2.1.2 Definition of heart failure. Criteria 1 and 2 should be fulfilled in all cases (adapted from Remme and Swedberg, 2001, p 1528)

Symptoms of heart failure (at rest or during exercise)
and
Objective evidence of cardiac dysfunction (at rest)
and
(in cases where the diagnosis is in doubt)
Response to treatment directed towards heart failure

The large variability in the definition of HF is ultimately caused by its complex aetiology. HF is the "the end stage of all diseases of the heart" (Davies et al, 2000). Table 2.1.3, below presents a list of HF causes.

Table 2.1. 3 Causes of heart failure (adapted from Lip et al., 2000)

- Coronary artery disease (CHD)
- Hypertension
- Cardiomyopathy
- Valvar and congenital heart disease
- Arrhythmias
- Alcohol and drugs
- "High output" failure
- Pericardial disease
- Primary right heart failure

The aetiology of HF varies somewhat around the world, but the most common cause of HF in the Western countries is CHD (Lip et al., 2000). Moreover, risk factors associated with the development of HF show significant differences between sexes: hypertension and diabetes are stronger risk factors in women than in men (Levy et al., 2002), whereas prior MI due to CHD is a stronger risk factor in men than in women (Hope and Hermann, 2003).

From the patient and caregiver point of view, the difficulties in diagnosing and defining HF have dire consequences. The term "heart failure" is a misnomer in itself because it implies the heart has stopped. When a doctor says someone is suffering with HF the patient and family's first reaction is to assume the worst (Cleland, 2001). As a consequence health care professionals (HCPs) are often reluctant to use the term HF (Mair et al., 2000; Buetow and Coster, 2001) resulting in patients not knowing they have HF and having very little insight into their condition (Cowie, 2002). Therefore, knowledge of diagnosis and level of knowledge of illness may have implications for patients' experience of disease. A review of studies investigating illness knowledge in HF is presented in chapter 3.

2.2 Epidemiology, pathology and treatment of heart failure

2.2.1 Epidemiology

2.2.1.1 Prevalence

Studies of the epidemiology of HF have been complicated by the lack of universal agreement on a definition of HF (Davis et al., 2000). Studies of HF *prevalence* can be broadly grouped into three categories: prevalence according to physician records and prescriptions of diuretics; population studies based on clinical criteria and finally, prevalence of left ventricular systolic dysfunction based on echocardiographic surveys (see Table 2.2.1.1.1, below).

Table 2.2.1.1.1. Prevalence of HF (adapted and updated from McMurray et al., 1998)

Study	**Country**	**Year of publication**	**Prevalence rate**	
			Whole population	**Persons > 65 years**
Physician records/prescriptions of diuretics[1]				
RCGP*, Logan and Cushion, 1958	UK	1958	3/1000	
Gibson et al., 1966	USA	1966	9-10/1000	65/1000
Parameshwar et al., 1992	UK	1992	4/1000	28/1000
Mair et al., 1996	UK	1996	15/1000	80/1000
RCGP, 1988	UK	1986	11/1000	-
RCGP,1995	UK	1995	9/1000	74/1000
Clarke et al., 1995	UK	1995	8-16/1000	40-60/1000
Lip et al., 1997	UK	1997	24/1000	-
Rodeheffer et al., 1993	USA	1993	3/1000	
Clinical criteria				
Droller and Pemberton, 1953	UK	1953	-	30-50/1000
Garrison et al., 1966	USA	1966	21/1000	35/1000
Framingham study (McKee et al., 1971; Ho et al., 1993)	USA	1971	3/1000	23/1000
Eriksson et al., 1989	Sweden	1989	-	130/1000
Landahl et al., 1984	Sweden	1984	-	80-170/1000
Schocken et al., 1992	USA	1992	20/1000	-
Echocardiography (prevalence of left ventricular systolic dysfunction)				
McDonagh et al, 1997	Scotland	1997	15/1000	-
Mosterd et al., 1997	Netherlands	1997	15/1000	-
Davis et al., 2002	UK	2002	6-13/1000	-
Raymond et al., 2003	Denmark	2003	5/1000	-

*Royal College of General Practitioners

It can be seen from Table 2.2.1.1.1, above, that studies of HF prevalence in the UK based on physician prescriptions of diuretics suggest that there may be a north-south gradient: the prevalence of HF in Liverpool (Mair et al., 1994) and Midlands (Clarke et al., 1995; Lip et al., 1997) was found to be much higher than that in London (Parameswar et al., 1992). Recent data confirms this. A HF Audit in Primary Care carried out before December 2003 in the population from which this study's participants were drawn (Wirral NHS Trust) identified 1364 cases of HF in a practice population of 90870, indicating a prevalence of 15/1000 (Mantgani, 2003). 53% of patients were female, showing that HF prevalence rates are similar in men and women (Davis et al., 2000).

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[1] One criticism of using prescription data for loop diuretics as a method of determining the prevalence of HF is that it may exclude individuals with mild HF who are not prescribed diuretics and include patients on diuretics who do not have HF (Cowie et al., 1997; Davis et al., 2000).

To summarise, the crude HF prevalence (unadjusted for age) ranges from 3 to 20 individuals per 1000, which increases to 30 to 130 individuals per 1000 for those aged over 65 years. The broad range in prevalence estimates is likely to reflect methodological and timing differences, rather than true population differences (Cowie et al., 1997).

2.2.1.2 Incidence

The Hillingdon study (Cowie et al., 1999) examined the incidence of HF on the bases of clinical and radiographic findings with electrocardiography from a population of 151000 served by 82 general practitioners in West London. The HF diagnosis was determined by cardiologists. The mean age of presentation was 76 years. The crude incidence rate was 1.3 cases per 1000 population per year for those aged 25 years or older. The incidence rate increased from 0.02 cases per 1000 population per year in those aged 25-34 years to 11.6 in those aged 85 years. The incidence was higher in male than females (age-adjusted incidence ration 1.75{95% confidence interval 1.34 –2.29, $p< 0.0001$).

However, in the UK most patients with HF are cared by general practitioners and only rarely by cardiologists (Wheeldon et al., 1993). Johansson et al., (2001) estimated the incidence of HF in general population based on data derived from the UK General Practice Research Database (final source population 689,467 individuals). The diagnosis was mainly based on the clinical judgement of the GP. The mean age of presentation was 72 years. The annual incidence rate was 4.2 per 1000-person years, corresponding to an incidence of 4.4 in men and 3.9 in women. The incidence rate increased significantly with age in both sexes, but in all age groups women showed a lower incidence rate as compared with men.

HF incidence rate in Johansson's study was higher than that detected by Cowie et al., (1999), but this may be explained by the criteria for case definition used in the two studies.

To summarise, both studies found that HF incidence rate increased with age and in all studied age groups the incidence rate was higher in males than in women. Survival in the women is generally better than in the men, leading to the same point prevalence as reported above (Davis et al., 2000). These results confirm previous findings (Remes et al., 1992; Ho et al., 1993; Chen et al., 1999).

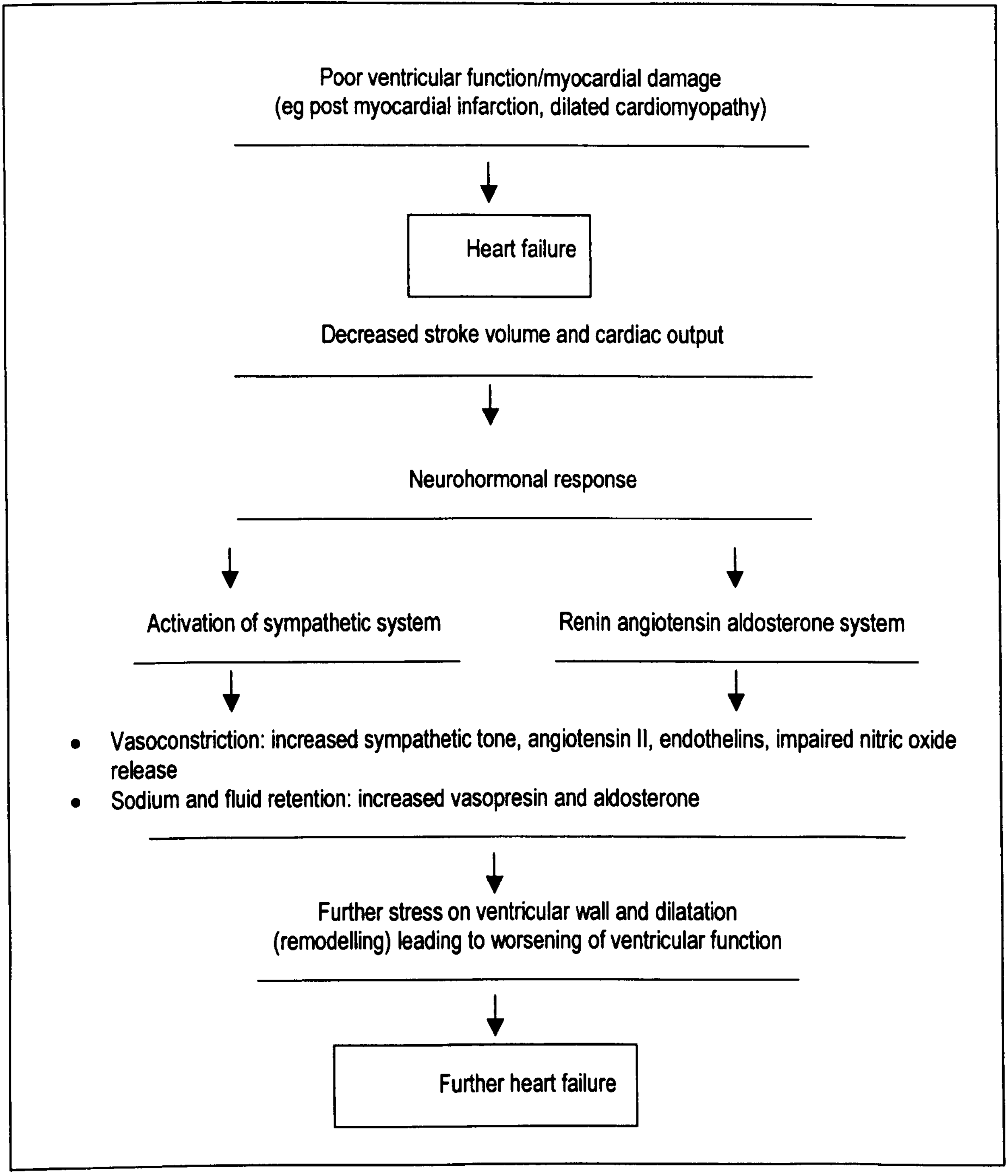
Over the last 50 years the incidence of HF has declined among women, but not among men, whilst survival after onset of HF has improved in both sexes (The Framingham study, Levy et al., 2002). A reduction in the risk of developing HF after myocardial infarction due to advances in treatment was cited as responsible for the decrease in HF incidence (Hellermann et al., 2003). However, others argue that improvements in the treatment of hypertension and myocardial infarction only *delay* the onset of HF and ultimately may increase HF incidence further (Cleland et al., 2001).

2.2.2 Pathology

The pathophysiologyy of HF is complex, involving abnormalities of cardiac, skeletal muscle and renal function, stimulation of the sympathetic nervous system and an array of neurohormonal changes (Jackson et al, 2000).

The key abnormality in non-valvular HF is left ventricular systolic dysfunction (or LVSD) resulting in a reduction in cardiac output, which trigger several neurohormonal compensatory mechanisms that work together to improve the mechanical environment of the heart (See Fig. 2.2.2.1, below).

Figure 2.2.2.1 Neurohormonal mechanisms and compensatory mechanisms in heart failure. (Adapted from Jackson et al, 2000)



In normal physiological circumstances, the compensatory neurohormonal mechanisms presented in Figure 2.2.1.1 are indispensable resources, which allow the heart to function adequately. However, in long term these mechanisms contribute to the development and progression of chronic heart failure (CHF).

CHF is further aided by significant alterations in cardiovascular structure and function caused by the aging process, such as impaired left ventricular filing due to changes in relaxation and compliance which predispose older individuals to the development of CHF. An important characteristic that separates CHF in the elderly from CHF in middle-aged individuals is a significant increase in the proportions of cases of diastolic heart failure, in which the left ventricular systolic function is normal or near normal. Diastolic HF was found to account for less than 10% of CHF cases in persons under age 65, but more than 50% of cases after age 75. Moreover, diastolic HF is more common in women than men, being the cause of approximately two thirds of all HF case in women over age 80 (Vasan et al, 1999; Gottdiener et al, 2000; Kitzman et al, 2000, Wong et al, 1989). All these factors contributed to scientists labelling heart failure a " cardiogeriatric syndrome" (Rich, 2001).

2.2.3 Treatment

2.2.3.1 Pharmacological treatment

In contrast to the preceding 20 years, in recent times there have been many developments in therapies for HF mainly due to increased understanding about the pathophysiology of heart failure (Krum and Liew, 2003). The pharmacological treatment of HF is extremely complex and aims to improve patient quality of life and help reduce morbidity and mortality. A detailed review of the pharmacological treatment of HF is beyond the scope of this study. For reference, a number of comprehensive reviews of the pharmacological treatment of HF have been recently published (Cotter et al., 2002;Abdelhafiz, 2002; Krum and Liew, 2003; Klein et al, 2003; Jessup and Brozena, 2003). Table 2.2.3.1.1, below lists the main groups of drugs recommended for HF and their effects and side-effects.

Table 2.2.3.1.1 HF medication (adapted from NSF, 2000 and Cleland, 2001)

Class of drug	Example of drug	Purpose and comments	Possible side effects for class of drug
ACE-I*	Captopril Enalapril Lisinopril	First-line treatment which prolongs life, delays progression and improves symptoms	Persistent dry cough, dizziness
Angiotensin II blokers	Losartan Candesartan	To try to prevent worsening HF (less evidence than for ACE-I)	Headache, dizziness (not associated with cough)
Diuretics	Frusemide Bumetanide Spironalactone	Force the kidneys to get rid of salt and water and can provide rapid symptomatic relief.	Gout, dramatic increase in urine production, can lead to urine retention in men with an enlarged prostate
Beta-blockers	Bisoprolol Carvedilol Metoprolol	In people with controlled HF Beta-blockers can reduce mortality when used with other treatments	Tiredness, lethargy, cold hands, nightmares
Cardiac glycosides	Digoxin	Regulates heart rate. Does not reduce mortality but may reduce symptoms and un-planned hospital admissions	Excess can lead to nausea, vomiting and confusion
Nitrates and nitrate-like medicines	Glyceryl Trinitrate (GTN), Nicorandil	Relieve angina, reduce blood pressure (BP)	Faintness, throbbing headaches, dizziness, flushing, ankle swelling, constipation
Calcium channel blockers	Amlodipine, Felodipine, Verapamil	Relieve angina, reduce BP	Headache, dizziness, vomiting
Alpha-blockers	Doxazosin Indoramin	Reduce BP	Fainting, fluid retention
Antiplatelets	Aspirin Clopidogrel Dipyridamole	Thin blood	Gastric upset
Anticoagulants	Heparin Warfarin	Prevent blood cloths forming in the circulation	Possible interactions with other medications

* Angiotensin-converting enzyme inhibitors

It can be seen from Table 2.2.3.1.1 above that the pharmacological treatment of HF is complex. As the burden of HF falls disproportionately on elderly people, HF patients are also likely to suffer from other chronic illnesses, such as diabetes (Bauters et al., 2003; Domanski et al., 2003), renal disease (Hillege et al., 2000; Ruilope et al., 2001) and anaemia (Kosiborod et al., 2003). These co-morbidities further intensify the medical management and corresponding pharmaceutical regimen of HF patients. The term *polypharmacy* is often used to describe this complex situation (Trupp et al., 2003). Polypharmacy has been shown to be associated with episodes of acute HF decompensation[1] (Vinson et al., 1990) and to medication non-compliance, which has been implicated as a cause of up to 50% of hospitalisations for HF (Vinson et al., 1990; Monane et al., 1994).

2.2.3.2 Non-pharmacological treatment

Notwithstanding the great importance of drug therapy, as the severity of HF increases so do the importance of non-pharmacological[2] approaches to patient care (Uretsky et al., 1998). In recent years, educating HF patients and their families about the condition and ways in which they can help themselves have been recognized as important strategies to improve clinical and psychological outcomes:

> *" In selecting the correct treatment it is important that patients also manage the condition as best they can. In other words they should feel empowered through being given full information about their condition and how it is being managed (Cowie, 2002, p 21)"*

There are a wealth of guidelines concerning the type and amount of information to be given to HF patients and their families both internationally and nationally. In the US, the Agency for Health Care

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[1] The word "decompensation" signifies an imbalance in patient's neurohormonal and compensatory mechanisms. Typically, patients retain fluid, became extremely breathless and are taken to hospital with "acute HF decompensation". In the hospital they are given intravenous diuretics to eliminate the excess fluid and medication is "attuned" to reach a new balance and "stabilise" the patient.

[2] Non - pharmacological aspects of HF care include both "low-tech" but indispensable educational, social and medical services and "high-tech" devices capable of sustaining the heart and circulation, such as intra-aortic balloon pump, left ventricular assist devices or the total implantable heart (Uretsky et al., 1998; Trupp et al., 2003). Mechanical devices for the treatment of HF are beyond the scope of this study and will not be covered in this section.

Policy and Research (AHCPR) published the first guidelines for the treatment of HF in 1994 (Konstam et al, 1994). A second set of US guidelines was prepared in 1995 by a joint task force of the American College of Cardiology and the American Heart Association (ACC/AHA). The 1995 guidelines were revised and published in 2001 (Hunt at al, 2001) and a paper presenting the relevance of these guidelines to geriatric patients was published recently (Ahmed A, 2003).

The first European Guidelines for the diagnosis and treatment of heart failure were published in 1995 and 1997 respectively. The two documents were combined, reviewed and published in 2001 (Remme and Swedberg, 2001) and a comprehensive summary of the guidelines was made available in 2002 (Remme and Swedberg, 2002). In the UK, the National Service Framework (NFS) for Coronary Heart Disease, published by the Department of Health in 2000 allocates chapter six to

" set out how the NHS and others can

- Help people with heart failure to live longer and achieve a better quality of life
- Help people with unresponsive heart failure an other malignant presentations of coronary heart disease receive appropriate palliative care support" (NFS, chapter 6, p 3)"

The National Institute for Clinical Excellence (NICE) published the most recent guidelines regarding the management of CHF in July 2003.

Table 2.2.3.2.1, below presents the types of information the guidelines suggest it should be given to patients and their families.

Table 2.2.3.2.1 Suggested education topics for the HF patient and their families (adapted from US, European and UK guidelines for the management of HF)

Topic	Information
General advice	What is HF? Self-monitoring with daily weights Explanation of treatment/care plan Advise on pharmacological treatment Clarifications of patients' responsibilities Importance of stopping smoking/tobacco use Role of family members or other caregivers in the care plan Availability and value of qualified local support groups Importance of vaccinations against influenza and pneumonia Compliance with the treatment plan
Dietary Recommendations	Balanced diet Sodium restriction

	Fluid restrictions Alcohol restrictions
Activity	Leisure and activities Travelling Sexual activities Driving regulations
Prognosis	

To conclude, the management of HF is extremely complex. Patients have a complicated medical regimen, which is further complicated by co-morbidities, and they have to assimilate a large amount of information in order to self-manage.

2.2.3.3 Who manages the HF patient?

In Europe, patients with HF are managed mostly in the community primary-care physicians (Cleland et al., 2002). There is some controversy regarding the issue of whom may be the best provider of care for HF patients: many studies have found that cardiologists provide better HF care than general practitioners (Philbin et al., 1999; Davie and McMurray, 1999; Bello et al., 1999; Baker et al., 1999; Reis et al., 1997; Chin et al; 1997; Jong et al., 2003), whereas others found that *collaboration* between GPs and cardiologists was associated with better outcomes for HF patients (Ahmed et al., 2003; Indridason et al., 2003).

The National Service Framework for CHD advises that care of HF patients should multidisciplinary (NFS, 2000, p 8). In multidisciplinary models of disease management a team of health specialists (nurses, physicians, pharmacists, dieticians, social workers and others) work together to deliver a holistic approach to care. The goal is that each patient's multi-faceted circumstances (medical, psychosocial, behavioural and financial) are taken into account (Rich, 1999). There is universal agreement that the HF specialist nurse plays a central role in multidisciplinary interventions, he/she being the main source of contact to the patient, being responsible for patient assessment and education and dealing with clinical deterioration and assessment of the need for change in therapy (Ryder et al, 2003). Moreover, there is extensive evidence that multidisciplinary interventions in HF management produce dramatic results, especially in reducing re-hospitalisations and improving quality of life (Rich et al., 1995, 1999; Ahmed 2002; Gattis et al., 1999; Holst et al., 2001;Blue et al., 2001; Whellan et al., 2001; Doughty al., 2002; McDonald et al. 2001, 2002).

Although trials have shown consistently the benefits of multidisciplinary interventions, translation of these benefits into routine HF community is still a major problem because of the underdevelopment of the necessary care structures to implement these changes (Ryder et al., 2003). As a consequence, two distinct populations of HF patients have emerged: a trial population showing better outcomes due to improved therapy and the much larger community population, where therapy is ineffectively prescribed, patient knowledge is poor and follow-up unstructured (Horan et al., 2000). Moreover, despite the fact that HF is a disease of old age clinical trials often consist of predominantly male and overall younger patients questioning the applicability of findings in older population (De Geest et al., 2003).

2.3 Prognosis and clinical outcomes

2.3.1 Mortality

HF has a poor prognosis. Most long term (more than 10 years of follow up) longitudinal studies of HF, including the Framingham heart study (1971) were carried out before the widespread use of ACE-I. In the Framingham study the overall survival at eight years for all NYHA classes was 30% compared with one-year mortality in classes III and IV of 34% and a one-year mortality in class IV of over 60%. Recent studies of cardiac mortality in placebo controlled HF trials ranged from 17 – 38% in HF patients treated with ACE – I (see Table 2.3.1.1, below).

Table 2.3.1.1. Cardiac mortality in placebo controlled HF trials (adapted from Watson et al, 2000).

Trial	**Patients' characteristics**	**IHD (%)***	**Treatment**	**Cardiovascular mortality**		**Follow up (years)**
				Treatment %	**Placebo %**	
CONSENSUS	NYHA IV (cardiomegaly)	73	Enalapril	38	54	1
SOLVD-P	Asymptomatic (EF<35%)	83	Enalapril	13	14	4
SOLVD-T	Symptomatic (EF<35%)	71	Enalapril	31	36	4
SAVE	Post MI (EF< 40%)	100	Captopril	17	21	4
V-HeFT I	NYHA II-III (EF<45%)	44	H-ISDN	37	41	5
V-HeFT-II	NYHA II-III (EF<45%)	52	Enalapril	28	34	5
PRAISE	NYHA III-IV (EF ,30%)	63	Amplodipine	28	33	1.2

* Ischaemic heart disease

Recently Blackledge et al., (2003) reported rates of HF prognosis in Leicestershire during 1993-2001, based on 12 220 individual patients newly hospitalised with HF. In this period the mean age of presentation increased for men from 74 years to 77 years, but not for women (80 years). Overall, one and five year mortality was 43% and 63% respectively. There was a 43-45% increase in risk of death for each decade of age at admission and a 14-17% increase associated with male sex. Mortality was higher for patients whose first admission was concomitant with acute MI and co-morbidity also affected outcomes. Similar findings were reported in the US (Vaccarini et al., 1999; Rich et al., 2001; Feinglass et al., 2002; Varadarajan et al., 2003; Baker et al., 2003), Canada (Jong et al., 2002) and Switzerland (Muntwyler et al., 2002).

An audit consisting of patients admitted to Arowe Park Hospital (APH is the hospital covering the population from which participants for the current study were recruited) with a primary discharge of HF from 1st of December 2001 and 28Th February 2002 reported a death rate of 16% within 30 days of admission compared to 26% in the previous audit (1999/2000). The mean age of those included in the audit was 78.3 years in 2001/2002 and 81 years in 1999/2000.

With the notable exception of lung cancer HF is as 'malignant' as many common types of cancer (Stewart et al., 2001). The overall population rate of expected life-years lost due to HF in men was reported to be 6.7 years /1000 and for women 5.1 years/1000. Unlike a diagnosis of cancer, however, it is difficult to specify a prognosis for people with HF as they have a 50% risk of sudden death rather than dying of progressive HF (Stevenson et al, 1993). Moreover, the model of care for cancer patients including palliative care is well developed, whereas HF patients have less access to services including specialist palliative care (Murray et al., 2002).

To summarise, annual mortality for HF patients ranges from 10% to 50% depending on age, gender, severity and co-morbidities. A number of psychological factors were found to predict HF mortality *independently* of clinical risk factors: marital quality (Coyne et al, 2001),personality (with low distress predicting better outcome, Bradwin et al., 2000), coping (behavioural disengagement was a significant mortality predictor, Murberg and Bru, 2001a) and social isolation (Murberg and Bru, 2001b). In chapter these factors are reviewed in detail.

2.3.2 Re-hospitalisations and impact on health services

In the UK 5% of general medical and geriatric admissions is accounted by HF and (Davis et al., 2000). The average length of hospitalisation for HF was estimated to be 11.4 days on the acute medical ward and 28.5 days on a geriatric ward in the UK in 1990 (McMurray et al., 1993) and similar findings were reported in the US (Gillum, 1993). However, while *admission* rates for HF have doubled in the past 10-15 years in the US (Haldeman et al., 1999; Ni et al., 1999), Australia (Roughead et al., 1998) and various European countries such as Sweden (Cline et al., 2002), Netherlands (Reitsma et al., 1996) and Scotland (Stewart et al, 2001), the average length of hospital stay has decreased in many countries over the last decade (Wright et al., 2002). For example the average length of stay in Scotland has decreased from up to 3 weeks in 1985 to approximately 1 week in 1995 (Stewart et al., 2001). This may not necessarily be beneficial to both the patient and the health services: it has been shown that short lengths of stay may be associated with a higher risk of readmissions (Cline et al, 1996), maybe due to inadequate time to stabilise patients and to prepare for adequate follow up after discharge (Cline et al., 2002). Moreover, decreased lengths of stay related to increased hospital efficiency shift the responsibility for patient care to spouses at an earlier point in the recovery process after a cardiac event (Stolarik et al., 2000).

Readmission rates are high, especially in the elderly where up to one-third of the patients may be readmitted within 1 year of discharge (McMurray and Stewart, 2000). Shorter-term readmissions rates can be even higher (see Table 2.3.2.1, below).

Table 2.3.2.1 Readmission rates for heart failure (adapted from Rich, 2002)

Authors	Age group	Timeframe	Readmission rate
Gooding, 1985	>= 65 years	6 months	36%
Rich et al., 1988	>= 70 years	3 months	29%
Vinson et al., 1990	>= 70 years	90 days	47%
Krumholtz et al., 1997	>= 65 years	6 months	44%
Philbin et al., 1999	Mean 76 years	6 months	46%

From a financial standpoint, HF readmissions are a significant outcome indicator because they involve returns for the most expensive type of health services, inpatient acute care (Walter, 1998). A study conducted in 1990/1991 estimated that HF accounted for 1.2% of the NHS expenditure in the UK (McMurray et al., 1993). Stewart et al., (2002) re-examined the cost of HF in the UK for the year 1995 and estimated that the direct cost of healthcare was £716 million, or 1.83% of the total expenditure; 69% of theses costs were accounted by hospitalisations. The authors estimated that by the year 2000 the total direct cost of HF to the NHS is likely to be higher again, 1.91% of the total expenditure.

Considering the significant economic burden that HF hospital admissions and readmissions exert on the health system, extensive research has been carried out to identify risk factors for hospital readmissions. Research has shown that up to 50% of HF readmissions may be preventable (Vinson et al, 1990; Michalsen et al., 1998). Table 2.3.2.2, below presents the main factors identified as predictors of HF readmissions.

Table 2.3.2.2 Risk factors for unplanned heart failure re-hospitalisation

Study	Location	N	% of patients readmitted	Risk factors of readmission
Vinson et al., 1990	US	98	-	Medication and dietary non-adherence
Berkman et al., 1991	US	628	28%	Non-married status ;Older age; Coping difficulties
Opasich et al., 1996*	Italy	304	-	Arrhythmias; Infections; Poor medication compliance; Angina; Iatrogenic factors
Bennett et al., 1997	USA	65	37% (6 months)	Worse baseline symptoms impact in the areas of emotional symptoms and deficits of attention and memory
Chin et al, 1997	USA	257	32% (2 months)	Single marital status; Comorbidity index; Admission BP; Absence of ST-T wave on ECG
Happ et al, 1997	USA	54	50%(6months)	Medication and dietary non-adherence
Bennett et al., 1998	USA	1992	75%	Sodium retention; Angina; Dysrhythmia; COPD; Hypertension; Infection
Michalsen et al, 1998*	Germany	179	-	Medication non-compliance; Coronary ischemia; Arrhythmias; Uncontrolled hypertension; Inadequate preadmission treatment
Marcantonio et al., 1999**	USA	154	11%(one month)	Age 80 years or older; Previous admission within 30 days; Four or more medical comorbidities; History of depression; Lack of documented patient or family education
Evanghelista et al., 2000	USA	753	29.2%(24 months)	Living alone; HF associated with ischemic aetiology; Higher NYHA class; Care by a primary care physician compared with a cardiologist; Current smoking; Current alcohol use
Krumholtz et al., 2000	USA	2176	50%(6 months)	Prior admission within 1 year; Prior HF; Diabetes; Creatinine level >2.5mg/dL
Kossovsky et al., 2000	Switzerland	442	48% (1 month)	Previous diagnosis of HF; Older age; History of cardiac revascularization; Readiness for discharge
Tsuchihashi et al., 2001	Japan	230	35%(one year)	Poor follow-up visits; Previous admission; No occupation; Longer hospital stay ; Hypertension
Mistry et al., 2001**	USA	123	55%(one year)	Social isolation; Anxiety; Subjective health
Stull et al., 2001	USA	6,797	-	Health related quality of life; Psychosocial quality of life
Polanczyk et al., 2001	USA	205	30%(3 months)	Low evaluation and treatment score
Kennedy et al., 2001	USA	2812	-	Poor self-rated health
Tsuyuki et al., 2001	Canada	768	50%(10months)	Non-compliance with salt restriction; Other noncardiac causes; Arrhythmias; Inappropriate reduction in CHF therapy
Schwarz et al., 2003	USA	156	44%(3 months)	Interaction of cardiac illness and functional status (patient); Interaction of caregiver stress and depression (caregiver)

* predictors of HF decompensation

** non-HF patients

To summarise, studies have shown that a large number of factors (clinical and psychological) can influence HF patient risk of hospital readmission. Illness severity and co-morbidities have a major role, however psychosocial factors such as self-care, coping difficulties and social support also affect the risk of readmission. One aim of the present study is to identify which clinical and psychological factors are best predictors of risk for hospital admission at six months follow up.

2.4 Clinical presentation

2.4.1 Symptoms

Four symptoms are cardinal to the diagnosis of HF in both younger and older age: dyspnoea, fatigue and lethargy, oedema and impaired exercise tolerance. However, these symptoms are non-specific to HF and further investigations are necessary to aid diagnosis (Rich, 2001; Watson et al 2000).

The term *dyspnoea* comes from Greek and means disordered (*dys-*) breathing *(-pnoea)* (Renwick, 2001). Dyspnoea or breathlessness is a frequent symptom of HF, although is also a frequent symptom in the general population, especially in patients with pulmonary disease (Watson et al, 2000). In HF, dyspnoea may present with progressively increasing severity as (i) exertional dyspnoea (shortness of breath upon activity), (ii) orthopnea (dyspnoea when lying down, usually worse at night), (iii) paroxysmal nocturnal dyspnoea (a gasping type of respiration with coughing and wheezing which is a classic sign of more advanced HF; patients often awake from sleep suddenly because of shortness of breath), (iv) dyspnoea at rest and (v) acute pulmonary oedema (Fujita et al., 2002). As the HF progresses the patient uses more pillows to sleep but still feels breathless. Sitting or standing help to reduce breathlessness; as a consequence, patients may feel more comfortable to sleep in a chair. Dyspnoea is one of the most anxiety producing symptoms of HF and anxious reactions to dyspnoea are more frequent in inpatients with HF who are depressed than in patients who are not depressed (Freedland and Carney, 2000; Ho et al., 2001).

Although *fatigue* is a prominent symptom in patients with HF, limiting physical activity and impairing quality of life (Drexler and Coats, 1996) it is still one of the least understood and investigated phenomenon in the cardiac population (Luchi et al., 1991; Senni and Redfield, 1999). A number of factors contribute to this circumstance. Firstly, fatigue is difficult to define. Ream and Richardson (1996) found that colloquial definitions of fatigue differ from scientific definitions and proposed a clarified definition based on the notion of concept analysis:

> *'Fatigue is a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition, which interferes with individuals' ability to function to their normal capacity.' (Ream and Richardson, 1996, p 520).*

Secondly, patients with chronic disease come to accept fatigue as a consequence of their illness, thus rarely reporting fatigue unless they are specifically asked to do so (Piper et al., 1988). In a descriptive study of 158 patients with severe HF, only four persons reported that HF was the primary cause of fatigue. "Old age" was another reason for fatigue and which was cited significantly more often by women than men (Ekman and Ehrenberg, 2002). Thirdly, as fatigue is a subjective phenomenon, it is difficult to measure. There is a relatively poor relationship between objective tests of exercise limitation and the results of questionnaires designed to quantify life quality of which fatigue is a part in HF patients (Drexler and Coats, 1996).

Fatigue, lethargy and exercise intolerance in HF failure are mainly related to abnormalities in skeletal muscle structure and function caused by reduced cardiac output. A reduction in cerebral blood flow, when associated with abnormal sleep patterns can lead to somnolence and confusion in severe HF (Watson et al, 2000).

Ankle *oedema*, which tends to be worse in the evening, is another common and non-specific symptom of heart failure. Dyastolic HF may manifests as oedema, liver distension, abdominal swelling (ascites) which in turn may cause loss of appetite and rarely malabsorption (bowel oedema)

(Watson et al., 2000). Worsening oedema and short term weight gain may be associated with water retention, although cardiac cachexia and weight loss are important indicators of disease severity in some HF patients.

Sleep related breathing disorders (SRBDs), including obstructive sleep apnoea (OSA) and Cheyne-Stokes respiration (CSR) with central sleep apnoeas (CSA) are common in patients with HF[1]. The prevalence estimates of SRBDs in HF patients range between 40% and 60% (Yamashiro and Kryger, 1993; Javaheri et al., 1995; Javaheri, 1996). SRBDs and were found to represent a poor prognosis sign associated with worse health-related quality of life (Brostrom et al., 2001; Brostrom et al., 2003) and increased mortality (Javaheri et al., 1998; Lanfranchi et al., 1999). HF patients with SRBD often have a shorter total duration of sleep as well as a disturbed sleep structure with frequent awakenings and sleep stage changes (Yamashiro and Kryger, 1993; Staniforth et al., 1998). As a consequence, patients often compensate for the disturbed night sleep by sleeping in the daytime (daytime sleepiness), which was found to negatively affect all dimensions of quality of life (Hanly and Zuberi-Kohkhar, 1995; D'Ambrosio et al., 1999). For example, Brostrom et al., (2001) found that sleep disturbances in HF patients gave effects such as fatigue, listlessness, loss of concentration and loss of temper.

2.4.2 Measures of HF severity

As new pharmaceutical treatments and various medical device technologies are developed, indicators of disease severity have been used to stratify HF patients in order to match each HF patient to the appropriate therapy.

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[1] *Sleep apnoea syndrome* is defined as repetitive, prolonged cessations of airflow often associated with oxygen desaturation and arousals from sleep. Sleep apnoea can be obstructive (OSA), in which respiratory efforts persist despite occlusion of the oropharyngeal airway; central in which both respiratory effort and airflow cease (CSA) or a mixed central/obstructive pattern. The Cheyne-Stokes respiration (CSR) is characterised by periodic crescendo-decrescendo alterations in tidal volume separated by pauses that reflect cessation of respiratory effort (American Sleep Disorders Associations, 1997).

The most widely and internationally used classification of severity of HF is that proposed by the New York Heart Association (NYHA, 1994). Patients are grouped into four categories of increasing severity (class I to class IV) according to their level of impairment or degree of limitation experienced during everyday activities. (See table 2.4.2.1, below).

Table 2.4.2.1 NYHA classification of HF (adapted from Watson et al, 2000)

Class 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 investigations – for example, echocardiography
Class 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
Class III: moderate
More marked limitation of activity which interferes with work. Walking on the flat produces symptoms
Class IV: severe
Unable to carry out any physical activity without symptoms. Patients are breathless at rest and mostly housebound

NYHA has been found to be an effective measure in predicting outcome and responsive to effective therapy (Rogers et al., 1994). However, a note of caution should be said. Despite its ease of administration and widespread use, there are limited data on psychometrics proprieties of the NYHA classification criteria, such as inter-observer validity (Selzer and Cohn, 1972), sensitivity to change and criterion validity (Goldman et al., 1981). Therefore, the NYHA staging process represents the *clinician's subjective* interpretation of the patient's physical function. Nevertheless, in the current study, NYHA was conceptualised as an *objective* measure of HF severity because it was assessed by a cardiac consultant or a HF specialist nurse.

LVEF (Left Ventricular Ejection Fraction) is an ejection phase parameter representing the percent of the blood pumped out during each heartbeat and is used to assess the performance of the heart in normal and pathological state. LVEF can be measured using various tests, such as echocardiography, radionuclide ventriculography, angiocardiography and most recently magnetic resonance imaging or MRI (Lindenfeld, 2003). An EF fraction of 50% to 75% is normal. A cut-off point of 40% is generally used to separate systolic dysfunction (EF less or equal to 40%) from preserved systolic function (EF > 40%) (Tresch, 1995; Working Group Report. European Study Group on Diastolic HF, 1998).

LVEF has been used as entry criteria for many trials in HF, however the impact that an increased LVEF due to therapy has on morbidity and mortality is unclear (Fogel et al, 2002), no less because more elderly persons with HF have normal systolic function (Gottdiener et al, 2002). Moreover, although current guidelines for the management of HF in the US (Hunt et al, 2001; Heart Failure Society of Americana HFSA Practice Guidelines, 2000), Europe (Remme and Swedberg, 2002) and the UK (National Service Framework for CHD, chapter 6, 2000) recommend the measurement of EF as part of HF evaluation, the recommendations are not always followed. Recently, out of 2,239 Medicare patients discharged with a principal diagnosis of heart failure, only 59% had a measurement of EF; increasing age, but not gender was associated with a lower frequency of EF measurement (Lindenfeld, 2003). The Arrowe Park Audit revealed that 46% of patients admitted with HF had documented evidence of an echocardiogram, of which 52% had an EF of 40% or less (Ludgate, 2003). In the present study, both NYHA class and LVEF were conceptualised as objective measures of HF severity.

Useful objective indices to evaluate HF severity include precise parameters such as peak oxygen uptake (Vo_2) and minute ventilation-carbon dioxide output ($VE - Vc_2$), which are measured in cardiopulmonary exercise testing. However, the required technology is complex and not widely available (Sakurai et al, 2003). A less expensive and simpler way of measuring lung function is by using a spirometer, which allows objective measurements of the Forced Expired Volume in 1 second (FEV_1) and Forced Vital Capacity (FVC).

In recent years, a cardiac hormone secreted mainly by cardiac ventricles called B-type natriuretic peptide (BNP) was found to be increased in HF and to correlate with haemodynamic abnormalities such as left ventricular dysfunction (Yoshimura et al, 1991). BNP was proposed as a less expensive and useful indicator of cardiac dysfunction *that would require further investigation* (Nakamura and Hiramori, 2003). Furthermore, BNP was proposed as a potentially useful tool for predicting patient's chance of readmission within 30 days of discharge, thus helping to make discharge decisions and possibly reducing unplanned re-hospitalisations (Caldwell et al, 2003). At the time when this study was designed, this procedure was not available in APH. Recently (Wirral HF Group meeting, January 2004) plans to routinely introduce BNP readings were discussed. However, at the time when this study was designed, this procedure was not available in APH.

2.5 Summary

In this chapter the nature of heart failure in terms of its epidemiology, treatment, clinical presentation and clinical outcomes have been outlined. Evidence has been presented to show that heart failure affects both men and women, and it is found all over the world. Heart failure was labelled to be a "cardiogeriatric syndrome" (Rich, 2001) because its development is aided by significant alterations in the cardiovascular structure and function caused by the ageing process. Its incidence increases with age; its overall prevalence (unadjusted for age) ranges from 3 to 20 individuals per 1000, which increases to 30 to 130 individuals per 1000 for those age over 65 years. HF is as "malignant" as many common forms of cancer (Stewart et al., 2001), however unlike cancer with more predictable functional trajectories HF is marked by erratic patterns of functioning. Moreover, HF patients have a 50% risk of sudden death (Stevenson et al., 1993). As a result, patients and their physicians have little understanding of length of life and timing of future medical crises (Wiklund et al., 1987). One important aspect of the HF syndrome is the high number of unplanned hospital re-admissions, which present a substantial burden for the health system. Significantly, research has shown that up to 59% of readmissions may be preventable.

The detail given with respect to the presentation of disease should clearly indicate that the symptoms experienced by HF patients (breathlessness, oedema, sleep problems and extreme fatigue) have an impact on their quality of life and mood. Moreover, disability resulting from illness implies that patients have a need for assistance with activities of daily living. As suggested by Young's (1994) model of late life family illness (see page 3), patient health status is expected to influence both their own outcomes and their carer's outcomes. Therefore, in the present study we hypothesised that patient illness severity, as measured by *objective* and *subjective* measures of severity will be associated with increased patient and carer distress.

CHAPTER 3

PSYCHOLOGICAL FACTORS IN HEART FAILURE

3.0 Introduction

This chapter is organised into two parts. In the first part, the literature relating to factors that may influence the way in which patients react to illness is reviewed, namely cognitive status, illness knowledge, personality, coping strategies and social support. In the second part, patients' psychological outcomes are presented (anxiety, depression, quality of life and negative reactions to receiving care).

3.1 Patients characteristics

3.1.1 Cognitive aspects of heart failure

HF and cognitive impairment (CI) are both common problems in old age and often coexist (Krum and Gilbert, 2003). As presented above the prevalence of HF is estimated to be 10% in patients' age of 75 years rising to 15-20% over the age of 80 (Cowie et al., 1997), whereas the prevalence of dementia is estimated at 8% in the over 65s (Erkinjuntti et al., 1997). Moreover, a large number of patients with CI who do not fulfil the criteria for dementia are diagnosed with *cognitive impairment no dementia* (CIND) which is twice as common as dementia, occurring in up to 17% of the population age 65 and over (Graham et al., 1997).

While such common conditions such as HF and CI may occur by chance within the same individuals, there is some evidence to suggest that CHF is independently associated with CI. There are as yet no published longitudinal studies following the natural cognitive change in HF, although studies are ongoing (Taylor and Stott, 2002). A review of the association between HF and cognitive status carried out in 2001 highlighted the "enormous paucity" of comprehensive information in this field. Almeida and Flicker (2001) conducted a systematic review of Medline database for studies published between 1966 and 2000 using the following key words: "congestive heart failure", "cognition", "cognitive disorders", "short-term memory" and "attention". They identified 13 studies that reported cognitive impairment in HF patients, but only five studies met the inclusion criteria for systematic review.

In a case-control study, Acanfora et al., (1996) compared 183 HF patients with 684 patients suffering from other heart diseases. They found that HF patients scored on average one point lower on the MMSE by comparison to other heart patients but without HF. The authors reported a second study (HF Italian Study II) in which the cognition of 385 HF patients was assessed by means of MMSE and of several neuropsychological tests with the goal of identifying cognitive functions more specifically impaired in HF patients. HF patients reported subjective memory impairment and obtained significantly lower scores than patients without HF on all tasks with the exception of any verbal and visuospatial immediate memory, suggesting that HF may induce a generalized impairment in cognitive functions.

In a cross sectional community study of 1075 participants in southern Italy, Cacciatore et al., (1998) reported that in subjects aged 65 years or older the risk of CI was 1.96-fold greater (confidence interval 1.07-3.58) in subjects with HF than in those without HF. A score of lower than 24 was found in 56.8% of patients with CHF compared to 20% in those without HF.

Gorkin et al., (1993) showed that subjects with more severe forms of HF have greater difficulty that asymptomatic controls on digit span and trail making A. Zuccala et al., (1997) reported that CI conceptualised as MMSE scores lower than 24 were found in 53% of older patients with LVD (left ventricular dysfunction) and was independently associated with lower LVEF. Almeida and Tamai (2001) reported that 54% of CHF patients had MMSE scores lower than 24. Moreover, HF patients scored significantly lower scores on the CAMCOG (Cambridge Cognitive Examination of the elderly), digit span, digit symbol and letter cancellation scores and took longer to complete the Trail making A. It should be mentioned that the last two studies had low number of patients 57 and 50 respectively. However, recently Zuccala (2003) found that out of 1113 patients who were admitted with HF to hospitals throughout Italy 32% were cognitively impaired when CI was defined as a Hodkinson Abbreviated Mental test score lower than 7 from a maximum score of 10, a higher prevalence than expected for age norms.

However, not all studies found CI in HF patients. Grubb et al., (2000) compared 20 patients with previous MI, NYHA class III or IV and LVEF < 40% to a control group of 20 patients with previous MI, no HF symptoms and LVEF >50%. Memory function was assessed with Rivermead Behavioural Memory Test and digit span test. Results were controlled for affective state and estimated premorbid intellectual function with the National Adult Reading Test. The authors concluded that patients with prior MI and stable moderately severe HF *do not* have significant memory impairment. However, they found that estimated premorbid intellectual function appeared poorer in patients with cardiac failure (although the difference did not reach statistical significance) and affective symptoms were more prevalent among patients with HF.

To summarise, published studies have shown that HF is associated with a pattern of generalised cognitive impairment that includes memory and attention deficits. The association between CI and disability showed in Zuccala et al.'s study (2001) highlights that CI is problematic for both patient and caregiver. Moreover, cognitive impairment may be an important factor in *non-adherence* to medical treatments in HF, which was found to be an important predictor of re-hospitalisation and mortality (Vinson et al., 1990; Happ et al., 1997). Both HF and CI are associated with significant mortality (Smits et al., 1999; Bassuk et al., 2000; Stump et al., 2001;Portin et al., 2001; Neale et al., 2001), and recently CI was found to be an independent predictor of mortality in patients who are hospitalised with HF (Zuccala et al, 2003). Although a subject worth of future research, the present study is not looking at the prevalence or specific profile of cognitive impairment in older adults diagnosed with HF. Rather the aim is to investigate the effect that patient cognitive status has on patient's quality of life, mood and clinical outcomes at six months follow up and on carer level of distress. Moreover, it aims to examine whether a worsening of HF at six months follow up is associated with a reduction in cognitive status.

3.1.2 Illness knowledge: specific knowledge, self-care and uncertainty

3.1.2.1 Specific knowledge of HF

As presented in chapter 2 (section 2.2.3.2), a plethora of guidelines have been published that provide guidelines regarding the diagnosis and management of HF, including educational topics that should be delivered to the HF patient and family. However, the guidelines are based on what health care professionals believe patients should know rather than what the patients themselves want to know. It has been suggested that more effective and efficient educational interventions can be achieved by matching the program to patients learning needs (Chan et al, 2003), thus identifying *which* learning needs are important to the patient (Bubela et al., 1990) is essential.

Research has been carried out to highlight perceived learning needs among HF patients and to compare them with the perceived learning needs identified by nurses (Hagenhoff, 1994; Frattini, 1998; Wehby et al., 1999). They found that patients believe general information, risk factors, medication, signs and symptoms, prognosis, diet and activity are important to learn with knowledge of medications and signs and symptoms ranking high on the list of importance. Critically, nurses rated information items *lower* than patients did, suggesting that patients and their health providers may differ regarding their views on educational needs.

In a study of educational needs of patients with advanced HF (NYHA class III or IV), Walden et al., (2001) asked 82 outpatients and 74 of their caregivers to answer a 23-item questionnaire which used a 5-point Likert scale to assess their learning needs specific to HF. The majority of patients were male (71%), Caucasian (68%) with a mean age of 54 years, whereas the majority of caregivers were female (76%), Caucasian (80%) and had a mean age of 52 years. Interestingly, both patients and caregivers identified as most important the same three needs: hope for good quality of life, to receive honest explanations and to receive information about action steps to take in an emergency. Moreover, patients and caregivers singled out the same least important learning needs: appearance of the patient after transplant surgery, employment, and instructions about sexual activity and time alone for self.

Chan et al., (2003) asked thirty-four inpatients with HF from Toronto, Ontario to rank order the perceived importance of eight categories of HF knowledge. Patients also completed measures of emotional distress, fatigue, health beliefs locus of control and current HF knowledge. Patients rated information on medication, cardiovascular anatomy and physiology and treatment as the most important to learn. Those who were more fatigued wanted more information on those aspects of care that they managed on a day-to-day basis, such as diet, activity and psychological and risk factors.

It can be seen from the above review that in the few studies that considered patients' learning needs the focus was on what kind of information the HF patient and family want, in order to help nurses deliver that information. However no effort was made to understand how much illness information patients actually *have* about their illness (with the exception of Chan et al.'s study) and the factors that influence level of information. Moreover, no effort was made to investigate whether more information translated into better psychological status.

Others studies have concentrated on measuring what HF patients *actually know* about their condition. Table 3.1.2.1.1, below presents the studies that investigated HF patients' knowledge of their illness.

Table 3.1.2.1.1 Studies of illness knowledge in HF patients

Authors	**Country**	**No of informants**	**Mean age**	**Type of Study**	**Findings**
Bushnell et al., 1992	US	41	71	Descriptive	• almost all patients could not correctly define HF • more than half were unable to correctly identify their medications
Dunbar et al., 1998	US	67	54	Descriptive	• The majority reported limiting sodium and liquid intake • None weighed themselves daily • Most could not identify symptoms of worsening HF
Cline et al., 1999	Sweden	22	79	In –depth interviews	• 12 (55%) could correctly name the prescribed medication • 11 (50%) were unable to state the prescribed dose • 14 (64%) did not know what time of day and when in relation to meals the medication was to be taken. • Overall, 27% patients were found to be non-compliant with their prescribed medication.
Ni et al., 1999	US	113	-	Survey	• When asked how much they know about their HF 37% said little or nothing, 49% said some and only 14% said "a lot" • 40% did not recognise the importance of daily weighing • 80% knew they had to limit their salt uptake, but only one third always avoided salty foods • higher knowledge was associated with being married, prior hospitalisations and having received both advice and information about self-care • a poor adherence score was associated with being unmarried, lower perceived self-efficacy, a lack of knowledge about self-care and no prior re-hospitalisation
Rogers et al., 2002	UK	27	69	In-depth interviews	• patients had little understanding of the purpose off their medication • they were concerned about both the quantity and combination of drugs they were prescribed • had difficulties in differentiating between the side effects of drugs and symptoms of heart failure • had little knowledge to help them interpret and/or treat changing symptoms
Artinian et al., 2002	US	123	65	Descriptive	• Knowledge needed to produce HF self-care was deficient independently of gender and race • Knowledge of HF medications, weight monitoring and correct definition of HF were especially low

It can be seen from the above table that although patients perceive HF information to be important, they have low levels of *actual* knowledge about HF, especially medication information and information necessary to promote self-care and self-management. As a consequence, patient education and counselling have become pivotal to studies to improve outcomes in HF. There is an extensive literature to suggest that multidisciplinary interventions organised around patient education are beneficial to improving clinical outcomes in HF (Rich et al., 1995; Blue, 2001; Gattis et al. 1999, Holst et al 2001; Whellan et al. 2001; Ahmed, 2002; Doughty al., 2002; McDonald et al. 2001, 2002). However, it is unclear whether multi-disciplinary interventions actually increase knowledge, as studies typically report reduced hospitalisations as a result of an intervention that encompasses educating patients about their illness alongside medication monitoring and structured follow-up. The present study aims to assess whether higher level of *actual* knowledge about HF has a beneficial effect on patient psychological and clinical outcomes and on carer distress.

3.1.2.2 Heart Failure self-care behaviours

The concept of self-care is especially important in HF, because HF is a chronic condition that affects older adults mainly. Most older adults believe that chronic illness is an unavoidable part of the process of growing old, is determined largely by "chance" and outcomes cannot be influences by themselves, but rather by "fate" or are "in God's hands". Although there is some truth in these beliefs, it is also true that the goal of medical care is to improve the natural history of acute or chronic illnesses (Rich, 2002). A good example in which patients readily shift their "locus of control" from "fate" to their physicians is the treatment of an acute infection that is responsive to antibiotics. However, for patients suffering from chronic illnesses such as HF direct patient-physician contact is infrequent, a typical consultation with a GP or cardiologist occurring maybe once a month for 10-15 minutes (Wirral HF Group, 2002). Consequently, patients are "on their own" for 99.97% of the time and HCPs have little control over patients' behaviour during these periods (Rich, 2002).

Educating elderly patients about principles of self-care and self-management returns some of the responsibility for managing their illness back to the patient, empowering them to "take control" of their illness, leading to improved compliance and the adoption of healthier behaviours, which in turn lead to improved clinical outcomes (Lorig et al., 1999; Artinian et al., 2002).

Self-care has been defined as "an active cognitive process undertaken by a patient to maintain health or manage illness and disease" (Riegel et al., 2000, Calson et al., 2001) and is based on acquisition of appropriate knowledge. In HF, self-care consists of compliance with recommended healthy lifestyle practices such as proper diet, exercise and medication adherence and also the adoption of practices such as self-weighing and monitoring of symptoms and the interpretation of changes in weight and symptoms. Although research has shown that various educational based intervention are successful in improving self-care in HF patients (Jaarsma et al., 1999; Jaarsma et al., 2000a; Jaarsma et al., 2000b; Rydell et al., 2003; Sethares, 2003; Wright et al., 2003), levels of self-care, particularly symptom monitoring or management remains low (Ni et al., 1999; Carlson et al., 2001; Artinian et al., 2002). To our knowledge, no study has reported HF self-care behaviours in the UK and the influence that self-care has on patient psychological and clinical outcomes. The present study aims to answer these questions.

3.1.2.3 HF illness uncertainty

A host of evidence supports the assertion that uncertainty constitutes a powerful stressor, especially in the context of illness and hospitalisation (Greco and Roger, 2003). Research on uncertainty in illness was pioneered by Mishel (1981), who developed a questionnaire (the Mishel Uncertainty in Illness Scale, MUIS) that measures uncertainty in the lives of patients who face illness, treatment and hospitalisation. The theory of uncertainty in illness (Mishel, 1988; 1990) was developed from an extensive psychological and sociological literature on uncertainty, stress and responses to stress and views uncertainty as individuals' inability to make sense of illness events when these events are ambiguous, highly complex, lacking information, or when outcomes cannot be predicted (Mast, 1995). Researchers have reported a strong relationship between high uncertainty and emotional distress, mood disturbance and anxiety (Mishel, 1984; Richardson et al., 1987; Christman et al., 1988; Webster and Christman, 1988; Hawthorne and Hixon, 1994), poor quality of life (Braden, 1990a, 1990b; Padilla et al., 1992; Hawthorne and Hixon, 1994) and poor psychosocial adjustment to illness (Mishel and Braden, 1984; Mishel and Braden, 1987; Christman, 1990; Mishel and Sorenson, 1991). Social support has been shown to reduce uncertainty (White and Frasure-Smith, 1995).

Although uncertainty has been identified as a major source of stress for individuals with heart disease (Strauss et al., 1984), little is known about the uncertainty experienced by HF patients and the effect that uncertainty has on patient outcomes. In the last 15 years, two studies were published that measured illness uncertainty in HF. Hawthorne and Hixon (1994) in a descriptive study of patients diagnosed with chronic HF (n = 24) reported a positive association between high illness uncertainty and mood disruption and low quality of life. Winters (1999) used a qualitative approach to describe the uncertainty experienced by a convenience sample of 22 adults living in urban and rural areas of a western US state. Three major themes of uncertainty in HF patients were identified: uncertainty related to symptoms and treatment, attempts to stay well and quality of life and death. The author used MUIS to quantify uncertainty, and found the mean uncertainty score for the participants in the study to be consistent with the mean scores for persons with chronic illness reported by Mishel (Mishel, 1990).

Both studies had small samples. Moreover, this type of research was recently criticised as not considering the possible influence of personality on the perceived stressfulness of uncertainty (Greco and Roger, 2003). The present study attempts to report the extent of illness uncertainty in a relatively large sample of HF patients and to clarify the effect of illness uncertainty on both patient and caregiver outcomes when patient neuroticism is controlled.

3.1.3 Personality

The main objective of the medical care for HF patients is to relieve symptoms, prolong life and maintain quality of life. However, although advances in medical and pharmacological therapy has resulted in improved symptoms and prolongation of life (Garg et al., 1995, Lechat et al., 1998), HF is still believed to have a substantial negative effect on the patient's well being (Archana and Grey, 2002). However, psychological well being is also influenced by personality variables such as neuroticism (Costa and McCrae, 1980; Emmonds and Diener, 1985).

Although health is regarded as one of the most important components of quality of life (Argyle, 1987), the associations between *objective* health and psychological well-being has been found to be rather weak (Okun and George, 1984; Zautra and Hempel, 1984) and this was shown also in HF patients (Hugenholtz and Erdman, 1991; Dracup et al., 1992; Gorkin et al., 1993; Murberg et al., 1997; Juenger et al, 2002; Clark et al., 2003). A possible explanation for the weak correlation between objective health parameters and well-being is that people adapt to their medical conditions (Brickman et al., 1978; Worthman and Silver, 1987; Meyers and Diener, 1997). By contrast to these findings, a number of studies have shown that indicators of *subjective* health are highly correlated with psychological well-being (Campbell et al., 1976; Larson, 1978; Diener, 1984; Okun and George, 1984; Feist et al, 1995).

It has been proposed that most of the variance in psychological well-being can be explained by personality with neuroticism being the main contributor (Costa and McCrae, 1984; Emmons and Diener, 1985), however the mechanisms underlying these relations are still unclear (Pavot et al., 1990). Murberg et al. (1997) proposed three different mechanisms that could be involved in the effect of neuroticism as predictor of psychological well-being in HF patients.

Firstly, individuals high on neuroticism have a tendency to interpret all sorts of life events more negatively than others (Costa and McCrae, 1984; Watson and Clark, 1984), thus neuroticism may influence psychological well-being independently of the objective and subjective health status of the patient.

Secondly, the physical limitations and exercise intolerance experienced by HF patients may lead to feelings of helplessness regarding coping with everyday activities and a reduction in social activities. Neuroticism may affect patient's perception of hopelessness and ability to integrate socially, which can result in depression and poor quality of life.

Thirdly, neuroticism may serve as a "filter" that mediates the association between objective symptoms and physical limitations and psychological well-being (Eysenck, 1987). This hypothesis is supported by findings that individuals who are highly neurotic are found to be mores sensitive to aversive bodily symptoms than stable individuals (Costa and McCrae, 1980b), they tend to report more health complaints such as angina and chest pain than others (Costa et al., 1982; Costa and McCrae, 1987) and are more likely to misinterpret somatic symptoms as serious signs of body pathology (Costa and McCrae, 1985). According to this scenario, neuroticism and objective measures of severity in HF may interact in patients who score high on both measures to cause particularly low psychological well-being.

Recent research (Denolett et al., 2002; Denollet et al., 2003) found that type D personality, characterised by the tendency to experience negative emotions (negative affectivity) and the tendency to inhibit the expression of emotions in social interaction (social inhibition) is associated with higher levels of proinflammatory cytokine tumor necrosis factor alpha (TNF-alpha) which has consistently emerged as predictor of mortality in patients with HF (Rauchhaus et al., 2000; Deswal et al., 2001). The authors suggested that individual differences in personality contribute to the psychoneuroimmunological aspects of HF.

Given that personality affects an individual's characteristic pattern of behaviours across a large number of life domains it is surprising how little research has considered the direct or indirect effect that personality has on the psychological and clinical outcomes in HF patients. Below are presented the few studies that reported the effect of personality on psychological and clinical outcomes in HF. Denollet and Brutsaert (1998) carried out a longitudinal study of 87 patients (mean age 55 years) with MI and LVEF of 50% or lower. Psychological assessment at baseline included measures of anxiety, depression, anger and Type D personality (which was conceptualised as an interaction of negative affectivity and social inhibition). At follow up (6 to 10 years), 21 patients had experienced a cardiac event, defined as cardiac death or non fatal MI. Patients with a type D personality were more likely to experience an event over time compared with non-type D patients and type D personality was found to be an independent predictor of suffering a cardiac event (relative risk, 4.7; 95% confidence interval, 1.9 to 11.8, p = .001). Interestingly, although anxiety, anger and depression were also associated with an increased risk of experiencing a cardiac event, they did not add to the predictive power beyond that of type D. The authors concluded that anxiety, anger and depression, which were highly correlated reflected the personality domain of negative affectivity.

Murberg et al., (1997) recruited 119 clinically stable patients with CHF (mean age 65 years) to explore the role of objective health indicators and neuroticism in subjective health (physical limitations) and psychological well-being (general life satisfaction and depression). The authors reported that objective measures of illness severity were generally unrelated to psychological measures, whereas neuroticism was significantly correlated with both indicators of subjective health and psychological well-being. Moreover, there was a marginal significant interaction between NYHA class and neuroticism in relation to severity of depression, in that patients who had more severe disease *and* scored high on neuroticism were more depressed. In a later publication (Murberg et al., 2001), the authors used proportional hazard models to evaluate the effect of neuroticism on mortality at two years follow-up. Twenty deaths were registered in the follow up period, all from cardiac causes. Results indicated that neuroticism was an independent predictor of mortality with a hazard ratio of 1.14 (95% confidence interval, 1.02 to 1.26, p = .01)

Bradwin et al., (2000) also studied the utility of a personality measure (the Millon Behavioural Health Inventory, MBHI) as a predictor of pre- and post- transplant mortality in 103 HF transplant candidates (mean age 49 years). Cluster analysis of MBHI responses scores elicited two clusters characterised by high and low distress. Cluster membership predicted survival status at 1-year and 5-year follow - up, with high distress cluster patients having significantly higher mortality in both the total sample and a subgroup of patients who did receive a heart transplant.

Finally, Westlake et al., (2002) in a descriptive study purposing to explore correlates of health-related quality of life in 61 patients (mean age 56 years) with advanced HF found that neuroticism (as measured by the Eyesnck Personality Inventory) was related with the mental health component of quality of life measure, as did NYHA classifications and 6-minute walk distance.

Of critical importance to this research is the consideration of the direct and indirect role of patient personality in relation to both patient and caregiver outcomes.

3.1.4 Coping strategies

Coping represents the cognitive and behavioural efforts of individuals to manage stressful encounters (Lazarus and Folkman, 1984). These efforts translate in a variety of behaviours classified according to problem-focused and emotional-focused models, as differentiated by their function (Folkman and Lazarus, 1980; Lazarus and Folkman, 1984). Problem-focused coping includes various actions aimed at managing future danger or threat, whereas emotion-focused coping is aimed at reducing, preventing, or tolerating the emotional or bodily reactions that are perceived as stressful (Ben-Zur, 2002). Numerous studies have shown that situational coping strategies are associated with outcomes, insofar as problem-focused strategies show no significant correlations with state-anxiety (Zeidner and Ben-Zur, 1993), whereas emotion-focused coping has consistently been associated with psychological distress (Ben-Zur et al., 2001; Carver and Scheier, 1993; Zeidner, 1995). This was shown to be the case in survivors of MI: emotion-focused coping has been linked to delays in seeking medical assistance for cardiac symptoms (Nolan and Wielgosz, 1991), as well as poor psychosocial (Keckeisen and Nyamathi, 1990; Terry, 1992) and physiological recovery from MI (Fallen, 1990). However, almost no research has been carried out to investigate coping strategies used by HF patients to deal with their illness, and ways in which these strategies may affect patient clinical and psychological outcomes. The meagre research concerning coping and HF is presented below.

Murberg et al., (2001, 2002, 2004) were the first research group to publish on the subject. These papers described the results involving 119 clinically stable HF patients (85 men and 34 women, mean age 66 years) recruited from an outpatient HF clinic in Stavanger, Norway. The first study (Murberg and Bru, 2001) evaluated the effects of different coping styles on mortality risk among patients with symptomatic HF. They found that *behavioural disengagement* was a significant predictor of mortality at two year follow-up (hazard ratio 1.64, 95% confidence interval 1.0-2.82, $p <= .049$), whereas *acceptance* of HF showed a marginally significant association with mortality (hazard ratio .64, 95% confidence interval 0.38-1.07, $p = .09$). The authors suggested that patients who behaviourally disengage should be supported to develop active coping skills by in order to increase their longevity. Over a longer period (6-year) *behavioural disengagement* was still associated with increased risk of mortality in patients with symptomatic HF and the effect strength was similar (hazard ratio, 1.5, 95% confidence interval 1.06-2.24, p = .02; Murberg et al., 2004).

In 2002, Murberg et al., investigated whether coping styles are merely reflections of personality. They found that individuals' coping styles were only moderately associated with the personality traits of extraversion and neuroticism. Moreover, coping styles were considerable less stable than neuroticism over a two year period. They also accounted for a significant amount of unique variance (9.3%) in depression when personality traits were controlled in hierarchical regression analyses. It was concluded that, in contrast to previous research, the study findings suggest that coping styles are *not* merely reflections of personality. These findings might be explained by the fact that the study's participants were under relatively severe strain.

Buetow et al., (2001) described the results from a qualitative study involving 62 patients diagnosed with HF (mean age 71 years) who received GP care in 30 practices across central Auckland, New Zeeland. The aim of the study was to develop a framework for conceptualising how patients with HF cope mentally with their illness. The authors reported that overall, patients with HF used for different approaches of emotional-focused coping: *avoidance*, *disavowal*, *denial* and *acceptance*. These coping strategies were not mutually exclusive, although one usually was used predominantly. The study was reviewed in detail in chapter 1 (section 1.3).

To summarise, research investigating the way HF patients cope with their illness is almost non-existent. To date, only two studies, one qualitative and one quantitative (none of which were UK based) were published. The present study aims to investigate ways in which HF patients cope with their illness situation and also how patient coping strategies influence patient and caregiver outcomes.

3.1.5 Social support

Social support is difficult to define. However, Ducharme et al., (1994) in a review of major conceptualisations of social support noted that social support is multidimensional, encompassing many behaviours such as attachment, problem solving, information and material aid and reflecting interaction with others.

In the past two decades substantial evidence has accumulated demonstrating the independent association between inadequate social support and poor cardiovascular outcomes (House et al., 1988; Vogt et al., 1992; Bucher, 1994; Oxman et al., 1995; Reifman, 1995; Farmer et al., 1996; Uchino et al., 1996; Woloshin et al., 1997; Lomas, 1998; Hemingway and Marmot, 1999; Rozanski et al., 1999).

Several investigators have established that MI survivors who are socially isolated (Ruberman et al, 1984), living alone (Case et al, 1992), or who lack a source of emotional support (Berkman et al., 1992) are at substantially increased risk for recurrent infarction and death in the months and years following their initial event. However, it is unclear if these findings can be generalised to patients with HF.

Three studies have reported specifically on the relationship between social support and outcomes in patients with HF. These studies are presented below.

Krumholtz et al., (1998) studied 292 elderly patients hospitalised with HF who were originally part of the Established Population for the Epidemiologic Study of the Elderly. Social support was conceptualised as presence or absence of emotional support (being able to count on someone with whom to talk over problems) and as instrumental support (being able to count on someone for help with daily tasks if needed). After adjusting for demographic factors, patients' clinical severity, co-morbidity and functional status, the absence of emotional support, measured before admission was found to be a strong, independent predictor of the occurrence of fatal and nonfatal cardiovascular events in the year after admission. However, when the investigators examined the effect of patients' gender on this association they found that the relationship between lack of emotional support and greater incidence of events was strong for women but did not hold for men. This study is important in that it shows a direct association between absence of emotional support and worse clinical outcomes longitudinally. However, it would have benefited by using a validated questionnaire to use emotional support, rather than single item questions.

Chin and Goldman (1997) in a prospective study examined HF admissions to one urban teaching hospital in Massachusetts during a 2-year period to investigate predictors of early hospitalisation or death. A total of 257 patients (mean age 67 years, 51% female) were followed for 60 days. Within 60 days of initial admission 31% of patients had either died or were readmitted to hospital. Single marital status as an indicator of social support was a significant independent predictor of death or hospital readmission after controlling for other known traditional medical risk factors for these outcomes (hazard ratio 2.1, 95% confidence interval 1.3-3.3).

Murberg and Bru (2001b) also evaluated the possible effects of social relationships (perceived social support and perceived social isolation) upon mortality among 119 clinical stable HF patients (mean age 66 years, 71% male). Twenty deaths were registered during the 2-year follow up period. Results indicated that social isolation was an independent predictor of mortality (relative risk 1.50, 95% confidence interval 1.00 to 2.19, $p<.038$) controlling for depressive symptoms, HF severity, functional status and age. Moreover, perceived intimate network support was marginally significantly associated for increased risk of mortality in this population (relative risk, 0.60, 95% confidence interval 0.35-1.02, $p<.06$). However, the authors suggested that the results should be viewed with caution, as the sample was small and recognised that further research is required to either disconfirm or confirm these findings.

To summarise, although social support has been conceptualised differently among this group of investigators, the findings were consistent, suggesting that the adverse clinical outcomes in cardiac patients without HF may extend to those with HF (Moser and Worster, 2000). The fact that emotional support has been shown to be beneficial for women and not men is particularly relevant considering that HF is largely a condition of the elderly and elderly women more often are widowed and living alone than men.

The present study aims to answer two questions regarding social support in elderly patients with HF. Firstly, by using a multidimensional measure of social support aims to investigate which type of social support is most beneficial in terms of psychological and clinical outcomes in a HF population. Secondly, it aims to investigate whether patient perceived level of social support affects level of carer distress.

3.2 Patient psychological outcomes

3.2.1 Depression

A great deal of research has been carried out to investigate the association between HF and depression. Two research strategies have been typically used in the research: the first strategy involved collecting a sample of depressed and non-depressed patients *without* HF and following up to determine if depressed patients are at greater risk of developing HF. The second strategy involved collecting a sample of HF patients, determining the prevalence and /or severity of depression at baseline and following up to see if depressed HF patients had worse clinical outcomes than non-depressed HF patients.

The most comprehensive study using the first strategy is that of Williams et al., (2002). Starting with the assumption that depression has been linked with increased incidence of coronary heart disease (CHD) in many studies, the authors aimed to establish the impact of depression on the incidence of HF. The study was based on data from the Yale Health and Aging Project, a prospective cohort study of non- institutionalised individuals age 65 or older assembled in 1982. At baseline, 2501 individuals were free of HF and of these 188 (132 women and 56 men) scored as depressed (scores of 21+ on the Centre for Epidemiological Studies depression Scale, CES-D). During the 14-year follow-up period, 313 participants (146 men and 167 women) developed HF. After adjusting for baseline differences in demographic and comorbidity factors and functional status using Cox regression, the investigators found that depression is an independent risk factor for developing HF among elderly women (hazard ratio 1.96, 95% confidence interval 1.11-3.46, p=. 02), but not elderly men (hazard ratio 0.62, 95% confidence interval 0.23-1.71, p=. 05 for the interaction term between sex and depression). The authors suggested that presence of depressed mood should alert clinicians to a higher risk of not only ischaemic heart disease but also HF in their patients, as early diagnosis and treatment of depression may reduce both the burden of morbidity and mortality due to HF in the elderly and the public health costs associated with HF treatment.

The bulk of research regarding the association between HF and depression used the second research strategy, namely recruiting HF patients, establishing the prevalence of depression and following the patients to see if depression was associated with worse clinical outcomes. These studies are presented below.

MacMahon and Lip (2002) carried out a systematic review to assess the effects of depression in congestive HF. The review included all articles published between 1965 and 2000 which concerned adult patients diagnosed with HF with any aetiology and addressed issues of depression, anxiety and /or social support. Articles that insufficiently distinguished co-morbidity and/or involved patients which awaited surgery such as heart transplantation were not included in the review. The authors identified 23 studies, however only 12 met the inclusion criteria for the review. Eight studies specifically addressed the issue of depression in patients with HF. The results are presented in Table 3.2.1.1, below.

Table 3.2.1.1 Summaries of studies examining depression in patients with congestive HF (from MacMahon and Lip, 2002)

Study	Type of study	Study quality*	Patients no	NYHA class	Depression measure	Main results	Study limitations
Havraneck et al.,1999	Cross-sectional	IIb	45 (31men)	Not stated	CES-D	Higher level of depression in CHF group	Low numbers
Majani et al., 1999	Cross sectional, healthy control group	Ia	152 (all men)	<=III	CBA 2.0	Significant incidence of depression in CHF patients compared with controls	Control group healthy
Murberg et al., 1999	2-y longitudinal	Ia	119 (85 men)	2.4	Z-SRD	Depressed mood a significant predictor of mortality at 2-y follow-up	Outpatients only; self-selecting population
Koenig 1998	Cross-sectional	IIa	107 (51 men)	Not stated	CES-D	Major depression significantly higher in CHF patients	Covariance of medical illness results in reduction in correlation between CHF and depression
Krumholz et al., 1998	1-y longitudinal	Ia	292 (126 men)	Not stated	CES-D	No strong association between depression and cardiovascular events	
Zuccala et al., 1995	Cross-sectional	IIb	57 (31 men	Not stated	CES-D	85% prevalence of minor depression	Low numbers
Fraticelli et al., 1996	Cross-sectional	IIb	50 (25 men)	Not stated	GDS	Depression in 54.1%, severe depression in 16.7%	Low numbers, older age group
Freedland et al., 1991	Cross-sectional	IIb	60 (26 men)	2.6	Structured interview (modified DSM-III-R)	Significantly higher level of depression among white patients only. Trend toward higher mortality and more impatient days among depressed patients at 1 y	Low numbers

* Study quality scale: **Ia** prospective longitudinal study with sufficient patient number, well-matched groups and well validated measurement instruments; **IIa** cross sectional study with sufficient patient number, well matched groups and well validated measurement instruments; and **IIb** cross-sectional study with low patient number, but with well matched groups and well-validated measurement instruments.

As can be seen from Table 3.2.1.1 above, three cross-sectional studies (Zucccala et al., 1995, Majani et al., 1999 and Havraneck et al., 1999) have found that HF patients showed considerable greater levels of depression than their healthy counterparts. By contrast, Murberg et al., (1999) did not find that levels of depression in their sample of patients differed from normative data. However, the lack of depressive effect among Murberg et al.'s (1999) study might be a reflection of the recruitment method used. As patients were recruited from attendees at an outpatient clinic through invitation letters, it might be that self-selecting biases were involved, resulting in a healthier and younger study population. Moreover, MacMahon and Lip (2002) argued that patients who are depressed and anxious may not volunteer to a study dealing with anxiety and depression because of fear of exacerbating their own symptoms. Therefore, it could be that Murberg et al.'s (1999) study may *underestimate* the prevalence of depression an outpatients with HF.

The review did not find consistent trends of the effect of depression on patient clinical outcomes. Freeland et al., (1991) study reported a non-significant trend toward higher mortality rates in the depressed group than in the non-depressed group at one-year follow-up. However, the investigators did not control for illness severity. If disease severity was to be controlled, it is possible that the effect would disappear. Koenig et al., (1998) reported that depressed HF patients were more likely to be readmitted as inpatients in the 3 months following the baseline assessment. They also found a nonsignificant trend towards higher mortality rates during the following year, however, this relationship disappeared when illness severity was taken into account. Krumhotz et al., (1998) also found no association between initial level of depression and readmission or death in the following year. MacMahon and Lip have commented that Murberg et al.'s study (1999) was the most intriguing, because it showed that depressed mood was a significant independent predictor of mortality at 2-year follow-up, even when disease severity, sex and age were statistically controlled for. In summary, MacMahon and Lip suggested that overall, the link between depression and mortality in HF patients is unclear; although studies of *inpatients* demonstrate that the more severe the level of disease the greater the level of depression, depression does not emerge as an independent risk factor. However, Murberg et al.'s study (1999), which was based on less severe *outpatients* indicate that there may be some link between cardiac death and depression among HF patients and they suggest that the link merits further investigation.

Since MacMahon and Lip's (2002) review, eight more studies have been published. These studies are presented below.

Skotzko et al., (2000) examined the prevalence and relationship of depressive symptoms in HF to physical limitations. Their study sample consisted of 33 elderly ambulatory individuals with HF. They found that 42% of the patients scored in the depressed range (CES-D scores of 16 or greater). Contrary to MacMahon and Lip's (2002) review, Skotzko et al., (2000) found that depressive symptoms were unrelated to the severity of HF in this sample. Depressed patients tended to report worse physical functioning than non-depressed individuals despite the fact that objective assessment of energy expenditure was comparable. These findings prompted the authors to suggest that elderly patients with HF may *underestimate* their physical function and in turn, functional assessment based on patient reports may be inaccurate.

Friedman and Griffin (2001) conducted a study to determine the relative contribution of physical symptoms and physical functioning to depression in 170 adult patients (50 years old or older) with HF during hospitalisation and the early post-discharge period. The authors found that, although on the average subjects were not depressed, 30% of the sample had scores indicative of clinical depression on the CES-D short form. Moreover, patients with HF who had increased physical symptoms and poorer physical functioning were found to report increased symptoms of depression, with physical symptoms explaining a greater portion of variance in depression than did physical functioning.

Jiang et al., (2001) carried out a study to determine the prevalence and relationship of depression to outcomes in patients hospitalised with HF. Of 374 patients screened (mean age 64 years), 35.3% had mild depression (scores of 10 or higher on the Beck Depression Inventory BDI) and 13.9% were diagnosed with major depressive disorder (using a modified Diagnostic Interview Schedule). A diagnosis of major depression was found to be associated with increased risk of mortality at 3 months (odds ratio, 2.5 vs no depression, confidence interval 0.9-6.98, p=.08) and at 1 year (odds ratio, 2.23, confidence interval 1.04-4.77, p=.04) and hospital readmission at 3 months (odds ratio, 1.90, confidence interval 1.0-3.59, p=.04) and 1 year follow up (odds ratio, 3.07, confidence interval 1.41-6.66, p=.005), independently of patient's age, NYHA class, baseline ejection fraction and ishaemic aetiology of HF.

Vaccarino et al., (2001) also completed a study, which sought to examine whether depressive symptoms were associated with poorer prognosis in HF. The investigators followed 391 patients who were 50 years old or older and were admitted to hospital with decompensated HF prospectively. The outcomes of the study was death or decline in activities of daily living (ADLs) at six months relative to the baseline. Depressive symptoms at baseline were measured by the Geriatric Depression Scale (Short-Form). Scores of 6 to 7 symptoms, 8 to 10 symptoms and 11+ symptoms indicated mild, moderate and severe levels of depressive symptoms, respectively. The authors reported a strong and graded association between the severity of depressive symptoms at baseline and the rate of the combined end point of either functional decline or death at 6 months. It was concluded that an increasing number of depressive symptoms was a negative prognostic factor for patients with HF, just as it is for patients with CAD.

Faris et al., (2002) retrospectively examined a cohort of 396 consecutive adult patients with non-ischaemic HF due to dilated cardiomyopathy (mean age 53+/- 15 years) in a London hospital. They found that after 5 years, clinically depressed patients had significantly higher mortality (hazards ratio 3.0, 95% confidence interval 1.4-6.4, p=.004) and readmission rates (hazards ratio 0.25, 95% confidence interval 0.07-0.90, p=.03) than those non-depressed, independently of demographic factors, baseline functional status and clinical severity. This study is important because it used a clinical definition of depression rather than measuring depressive symptoms with questionnaires or familiar tests or instruments. In accordance with previous studies, the authors noted that interventions targeted at reducing depression in HF patients are warranted as a way of improving quality of life and outcomes in this population. It should be mentioned that Lip and Lane (2003) are presently undertaking a Cochrane review of psychological interventions for depression in HF, thus information will be available regarding the efficacy of various psychological interventions (for example Cognitive-Behavioural Therapy or CBT) in alleviating the negative effects of depression on mental and clinical outcomes in HF.

Turvey et al., (2002) carried out a cross-sectional study to examine the rates and correlates of depressive symptoms and syndromal depression in elderly people with self-reported HF living in community (n = 199) and compare them with those in people with other heart conditions (n = 1,856) and with those with no heart conditions (n = 4,070). The authors found that 11% of individuals with HF met criteria for syndromal depression, compared with 4.8% of people with other heart conditions and 3.2% of those with no heart conditions. The association between HF and depression was found to held even after controlling for disability, reported fatigue and breathlessness and number of comorbid chronic illnesses.

Freedland et al., (2003) reported the prevalence of depression in a large sample of hospitalised patients with chronic HF in Missouri, US. In the sample as a whole, the authors reported that 20% of the patients met the DSM-IV criteria for a current major depressive episode, 16% for a minor depressive episode and 51% scored above the cut off for depression on the BDI (scores 10+). However, the authors noted that the prevalence of major depression was influenced by many factors. Higher prevalence of major depression was seen in patients with a family history of major depressive disorder, those with past history of one or more major depressive episodes, female patients, those less than 60 years old, unable to work due to disability, unable to perform self-care or other ADLs without assistance, in a higher NYHA class or admitted with a history of congestive obstructive pulmonary disease (COPD) or sleep apnoea. In contrast, major depression was not affected by the presence of other medical comorbidities such as diabetes or renal disease, HF medications or LVEF.

Finally, Rumsfeld et al., (2003) conducted a multi-centre prospective cohort study (n= 460, mean age 60) to examine whether depressive symptoms are independently associated with HF-specific health status (symptoms, physical and social functioning and quality of life) in Denver, US. They found that approximately 30% of the patients had significant depressive symptoms at baseline, which were associated with worse HF-specific health status scores. At follow up (6+/- 2 weeks), depressive symptoms at baseline were the strongest predictor of short term worsening of HF symptoms, physical and social functioning and quality of life in multivariate models after adjustment for potential confounders.

3.2.1.1 Summary

Evidence shows that HF patients are a population with an elevated risk for depression. Prevalence rates have been found to range from 24 to 51% and varied greatly according to the populations studied, the method of diagnosis and the classification of depression. On average, studies of hospitalised patients (Freedland et al.,1991; Koening et al., 1998; Friedman and Griffin,2001; Jiang et al., 2001; Vaccarino et al., 2001) have reported higher levels of depression than studies of outpatients (Havraneck et al., 1998; Murberg et al., 1998 Skotzko et al., 2000). Depressed HF patients were found to have a reduced functional status, higher readmission rates and increased mortality by comparison to non-depressed HF patients, independently of known confounding factors, such as demographic factors, medical history, functional status at baseline and clinical severity. However, many studies did not control for the effect of patient personality on these relationships, despite evidence that self reports measures of anxiety, depression and anger correlate highly with each and reflect a negative affectivity factor of personality (Denollet and Brutsaert, 1998).

There is little agreement of the possible mechanisms through which depression affects outcomes in HF. Evidence shows that the pathways linking cardiovascular disease and mortality may be direct (i.e pathophysiological mechanisms) or indirect (i.e. mediated by lack of social support, non-compliance and poor self-care behaviours). For reference, see Strike and Steptoe's (2002) brief review of possible mechanisms through which depression may influence CAD, also Pasic et al.'s (2003) review of cytokines in depression and HF.

Notwithstanding the importance of the mechanisms through which depression influence clinical outcomes in HF patients, the present study is a psychological study not a psychobiological one. It aims to answer the following questions (i) which patient/illness factors *and* caregiver characteristics are best predictors of depression in HF patients *when patient emotionality is controlled and* (ii) what are the effects of patient depression on caregiver outcomes?

3.2.2 Anxiety

Few studies have examined anxiety in patients with HF. Majani et al., (1999) found that anxiety mean scores among inpatients with HF (n=114) were slightly but not significantly higher than those of healthy subjects (n = 895). The authors noted however that illness severity as measured by NYHA classification was associated with anxiety severity, in that patients in NYHA class III were significantly more anxious than patients in class I or II. This study was criticised because it did not report how many patients were actually aware of their diagnosis and prognosis (Macmahon and Lip, 2002). Evidence has shown that anxiety levels can vary during the course of illness, thus timing of assessment must be taken into consideration (Kvaal and Laake, 2003). Van Jaarsveld et al., (2001) in a prospective cohort study of 119 HF patients (mean age 74 years) found that 30% of participants reported heightened anxiety after diagnosis, and 35% showed a substantial increase in anxiety at 12 months follow up, by comparison with baseline levels. Another study (Levenson et al., 2000) investigated patients with HF during the last six months of life and revealed modest levels of anxiety and depression, though the levels increased in the last three days of life. In a secondary analysis of data taken from the Studies of Left Ventricular Dysfunction trials (Riedinger et al., 2002) women with HF (n = 691) were found to have significantly worse levels of anxiety than were healthy women, patients with hypertension, patients in two cancer cohorts and geriatric patients, *but better* than did patients with congestive obstructive pulmonary disease and those who had an acute MI one months before evaluation.

Haworth et al., (2003) in a cross-sectional study of 100 patients with HF (mean age 68 years) recruited from a specialist HF unit in the UK reported a prevalence rate of anxiety of 18.4% as measured by the anxiety subscale of the HADS (Hospital Anxiety and Depression Scale). Predictors of anxiety included previous reported history of mental health problems, diabetes and angina comorbidity and NYHA class. Other studies identified patient's level of breathlessness (Freedland et al., 2000) and physical impairment (Reschke et al., 1999) as major predictors of anxiety in HF patients. However, both studies noted that depression played an important role in determining patient anxiety level, in that anxious reactions to dyspnoea were more common in depressed patients and when anxiety and depression were analysed together, depression was found to be the stronger predictor of functional impairment.

3.2.2.1 Summary

Despite extensive evidence that anxiety is a frequent concomitant of depression (Vinson et al., 1990 Frasure-Smith et al., 1993; 1995; 1999; 2000) research investigating anxiety among individuals with HF is sparse. Anxiety has been earmarked as being of particular relevance to clinicians, as it can negatively affect the cardiac output in patients with HF (MacMahon and Lip, 2002). Moreover, studies which have investigated the relationship between HF and anxiety identified predictors of anxiety *without* taking into account patient's emotionality or neuroticism, despite evidence of their close relationship (Denollet and Brutsaert, 1998). The present study does not aim to describe the prevalence of anxiety in this patient population. However it aims to investigate a number of hypotheses: (i) which patient/illness factors *and* caregiver characteristics are best predictors of anxiety in HF patients *when patient neuroticism is controlled*; (ii) is patient level of anxiety at baseline predictive of patient psychological and clinical outcomes at phase 2 (iii) is there a positive association between LVEF and levels of anxiety; (iv) what are the effects of patient anxiety on caregiver outcomes.

3.2.3 Quality of life (QoL)

It is generally recognised that treatment of patients with HF has two main goals: to improve quality of life and to prolong life. It has been suggested that the term QoL should be more specifically used to mean "health-related QoL" (Testa and Simonson, 1996), because QoL is a multidimensional concept based on the patient's own perception of his or her health, which integrates not only the functional or physical dimensions of the disease, but also psychological and social dimensions (Guyatt et al., 1993).

Several tools, generic or disease- specific have been validated in HF patients and are used to evaluate changes in QoL linked to disease or to treatment (Berry and McMurray, 1999). However, condition-specific instruments such as The Minnesota Living with HF (MLWHF) questionnaire, Chronic HF Questionnaire (CHQ) and Quality of Life Questionnaire in Severe HF (QLQ-SHF) have been reported to be more sensitive to change than generic measures (Patrick and Deyo, 1989).

In the last decade, QoL measures have been increasingly incorporated in clinical intervention trials, ranging from trials assessing drugs (the SOLVD investigators, 1991), exercise (Mondoa, 2004), multidisciplinary interventions (Rich et al., 1995) and nursing support intervention (Blue et al., 2001) as a complementary endpoint to the traditional outcomes of mortality and morbidity. Moreover, QoL measurements have been increasingly regarded as potential measures *of change* than can be assessed more directly than traditional HF severity measures such as NYHA class, LVEF or even exercise tolerance (Lipicky and Packer, 1993).

Studies investigating the quality of life of HF patients have consistently found that quality of life is more severely impaired in HF than in both healthy individuals (Hobs et al., 2002; Juenger et al., 2002; Riedinger et al., 2002) and other disease groups (Stewart et al., 1989; Hobbs et al., 2002; Juenger et al., 2002). Although some studies have found that women HF patients reported worse QoL than male patients (Chin and Goldman, 1997; Riedinger et al., 2001; Hou et al., 2004), a large study involving 600 patients with HF found no gender differences in QoL (Riegel et al., 2003). There is a wealth of literature which emphases the deleterious effects of lower QoL on clinical outcomes such as mortality and hospitalisation (SOLVD investigators, Konstam et al., 1996; Bennett et al., 1997; Alla et al., 2001). Numerous factors have been reported to influence QoL in HF patients: NYHA class (Hobbs et al., 2002; Juenger et al., 2002; Westlake et al., 2002), age, gender, positive health beliefs, greater income and social support (Clark et al., 2003), changes in social support (Bennett et al., 2001), satisfaction with social activities and perceived stress (Janz et al., 2001), psychological adjustment to illness (Steptoe et al., 2000) neuroticism (Westlake et al., 2002) and hope and depression (Evangelista et al., 2003).

In the present study, the aim is to identify predictors of quality of life in elderly sample of HF patients. What the study adds to previous research is that (i) it considers the direct and indirect effect of patient personality on QoL and (ii) it considers the potential effects of *caregiver variables* on patient QoL.

3.2.4 Negative reactions to receiving care

Although there is a vast amount of literature documenting the important psychological effects that the burden of caregiving may have for the family members providing such care, research has consistently neglected the effects of caregiving *on the care-receiver*. Typically it is assumed that caregivers actions will automatically translate into beneficial effects to the care-receiver. However, studies has shown that this is not always the case.

In studies using general measures of reactions to help, care-recipients have reported unpleasant feelings in response to help provided with various daily activities (Newsom et al., 1998), negative perceptions of caregiving behaviours (Clark and Stephens, 1996) and dissatisfaction with help received (Thomas, 1993). Responses involving negative self-attributions such as feeling embarrassed, feeling weak and incapable and a loss of self-esteem have been reported to be the specific feelings most related to general ratings of unpleasantness in response to help (Newsom et al., 1998). Importantly, *helping distress* was found to predict depression as much as 1 year latter from baseline assessment, suggesting that there may be long term consequences of negative reactions to assistance.

In the present study, negative reactions to receiving care were included as a patient outcome. The aim is to identify primary predictors of help distress in a HF population. Moreover, in order to address

Newsom's (1999) suggestion that helping distress may be a function of biased perceptions of the care recipients, rather than a reflection of poor-quality of care, patient personality will be controlled in all significant associations between predictors and outcomes.

3.2.5 Summary

In this chapter, patients' characteristics that could influence the way in which HF is perceived and responded to has been reviewed. Moreover, psychological aspects of HF (depression, anxiety and quality of life) have been presented in depth. These reviews aimed to identify relevant variables to be included in the Young's (1994) model of late life family illness. A novel outcome (helping distress or negative reactions to care) was presented and judged important to be included in the present study because (i) literature regarding the negative effects of receiving care is scarce and (ii) no studies have reported the negative reactions to receiving care in a HF population.

CHAPTER 4

CAREGIVING IN HEART FAILURE

4.0 Introduction

In this chapter firstly an overview of the current caregiving literature is given. Secondly, methodological weaknesses of caregiving research are highlighted. Thirdly, the literature investigating caregiving for HF patients is critically reviewed. Fourthly, a model of late life family caregiving in HF is proposed as a guide for the present study.

4.1 Caregiving literature overview

In the past two decades more than 400 empirical studies on psychological effects on caregiving for older adults have been published (Pinquart and Sorensen, 2003a). Although the majority of studies have focused on the impact that caring for elderly mentally impaired patients (mainly Alzheimer's Disease patients) has on the family, research concerning family caregiving of older patients with cardiovascular problems has began to emerge since 1990s.

There is a broad consensus in the caregiving literature that providing care for disabled older adults is a stressful experience that places the caregiver at risk for compromised physical and mental health (see reviews by Gatz et al., 1990; Aneshensel et al., 1995; Whitlatch and Noelker, 1996) and indeed, in the case of spousal caregivers, at greater risk for mortality (Schultz and Beach, 1999). Broadly, the caregiving literature can be divided into two groups: studies that compare caregivers and non-caregivers' physical and mental health and studies that focus on predictors of caregiver "burden" in an illness situation.

In a meta-analysis of 84 studies on differences between caregivers and non-caregivers in psychological health and physical health, Pinquart and Sorensen (2003a) found that caregivers were more depressed, more stressed and had lower levels of subjective well-being, physical health and self-efficacy than non-caregivers. However, larger differences were found between dementia caregivers and non-caregivers than between heterogeneous samples of caregivers and non-caregivers. The meta-analysis is limited by the fact that most studies did not report potential predictors of caregiver outcomes, such as care-receivers' characteristics and the amount of care provision, thus these factors were not included in the analysis.

In the second group of studies, the term "caregiver burden" was used to express the overall impact of physical, psychological, social and financial demands of caregiving (George and Gwyther, 1986). The term was further dichotomised into *objective* burden (events and activities that are associated with negative caregiving experience) and *subjective* burden (emotional responses to caregiving, such as worry, anxiety, frustration and fatigue) (Montgomery et al., 1985). Although theoretically useful, empirically this dichotomisation is problematic since family members attach meanings to events, thus muddling the distinction between subjectivity and objectivity (Lidell, 2002). As a consequence, most researchers use a global burden measure that sums up indicators of objective and subjective burdens to a global burden score. The vast majority of past research focused on the negative consequences of caregiving (i.e burden), however, in recent times aspects of caregiving that are viewed as positive by the caregivers themselves have been included as useful caregiving outcomes. Examples of positive aspects of caregiving are feeling useful, appreciating closeness to the care-recipient and experiencing pride in one's own abilities to handle crises (Kramer, 1997).

Pinquart and Soresson (2003b) carried out a meta-analysis of 228 studies published between 1966 and 2002 on the association of six caregiving-related stressors (namely, care-receiver physical and cognitive impairments and behaviour problems, amount of care provided, duration of caregiving and positive aspects of caregiving or "uplifts") with burden and depressive mood. They found that care-recipients' behaviour problems showed stronger associations with caregiver outcomes than other stressors did, especially in studies of dementia caregivers. Amount of care provided and care-receivers' physical impairments were found to be less strongly related to burden and depression for dementia caregivers than for caregivers of nondemented older adults. Furthermore, physical impairments and care-recipients' behaviour problems were more burdensome for the spousal caregivers than for adult children caregivers. Finally, perceived uplifts of caregiving were associated with lower levels of caregiver burden and depression. Interestingly, the authors observed that perceived positive aspects of caregiving were largely independent of objective caregiving stressors, such as hours of care or number of caregiving tasks, suggesting that uplifts are entrenched in other aspects of the caregiver – care-receiver relationship, such as mutual closeness, caregiver's motivation or caregiver personality. It was suggested that longitudinal studies are necessary in order to relate changes of care-receiver impairments and caregiver involvement with changes in psychological outcomes.

4.1.1 Summary

A great deal of caregiving research has been conducted in the last decades. Although the vast majority of research concerned caregivers of dementing elderly, recently research on caregiving for older adults with cardiovascular problems has began to develop. Overall, meta-analyses have shown that caregiving for an elder family member has detrimental effects on the physical and mental health of caregivers by comparison to non-caregivers. Care-recipient impairments, caregiver involvement and perceived positive aspects of caregiving were found to be associated with caregiver burden and depression. Although caregiver research has seen a number of methodological improvements in the recent years (for example, measuring positive as well as negative aspects of caregiving), there are still a number of methodological issues that need to be addressed. These will be presented in the next section of this chapter.

4.2 Methodological problems in caregiving research

Recently, a number of methodological weaknesses in caregiving research have been recognised.

Firstly, caregiver burden is a multidimensional concept, yet the majority of caregiving studies had used a unidimensional global measure of distress. Cousins et al., (2002) argued that unidimensional global measures of caregiver burden are based on the presumption that it is the accumulation of stress, rather than a specific set of problems that leads to breakdown in informal caregiving. These measures (such as the commonly used Caregiver Burden Interview, Zarit et al., 1980) consist of items based on frequently mentioned problems from clinical interviews, such as impact of caregiving on dyadic relationship, social life, financial strain and emotional response. However, no effort is made to consider the contribution of the different types of item to the overall score. By contrast, Cousins et al., (2002) argued that a multidimensional measure of distress allows researchers to identify specific problematic areas that can be targeted by interventions tailored to the individual caregiver. She proposed a five dimensions scale of caregiver distress, measuring relationship distress, emotional burden, social impact, care-receiver demands and personal cost.

Secondly, caregiving is essentially an interpersonal process whose success depends on the interpersonal style and beliefs of *both* caregiver and recipient *and* is a dynamic process that may change over time (Hall, 1990). However, few studies have been designed in ways that allow the caring *process* to be examined. Traditionally in the literature, the care-recipient has been viewed as a potential stressor and the caregiver is seen in terms of his or her outcomes (e.g. depression, physical health), whereas the care-recipient and his or her perspective and outcomes are underemphasized and frequently completely ignored (Zarit, 1994; Pruchno et al., 1997). Moreover, even studies specifically addressed to caregiving focus on either the caregiver or the care-recipient, not both (Noelker, 1991). Additionally, the *patient's* psychological response to being helped has been almost completely neglected, yet negative reactions have been reported in up to 40% of physically disabled patients receiving family care. Such reactions predict patient depression up to a year later (Newsom and Schulz, 1998).

Thirdly, caregiving outcome studies have been too non-specific. Because they fail to take into account both the objective nature of the caregiving tasks and his or her personality, they assume that poor mental health found in the caregivers can be validly attributed to caring (Davies et al., 1998). This is not the case. Studies have shown that there are clear individual differences in outcomes in essentially similar caring situations (Hooker et al, 1998; Davies et al, 1998; Bookwala & Schulz, 1998). This may be due in part to differences in caregiver temperament, in part to differences in caregiver's experiences and expectations (Pot et al, 1998). These findings have practical implications for caregiver needs, since the same degree of 'respite' or aide will not suit all. Some caregivers will require more help in adjusting to caregiving than others and some may not be suited to caregiving at all.

Fourthly, although some progress has been made in measuring positive aspects of caregiving, this is by no means the norm. Yet we know that many dyads derive meaning and purpose from the caregiving relationship (Davies et al., 1998, 1999; Cohen et al., 2002). Assessing the positive aspects of caregiving are essential if we are to fully understand the caregiver experience and identify risk factors for negative caregiver outcomes.

4.2.1 Summary

A number of methodological problems have been identified in caregiving research. Most studies use unidimensional measures of caregiver distress and non-specific mental health measures without taking into consideration carer's personality. They fail to conceptualise caregiving as a caregiver/care-receiver interpersonal process, which changes over time, and often underemphasize or ignore the care-receiver perspective and outcomes. In the next section, research investigating caregiving in HF will be reviewed focusing on methodological strengths and weaknesses.

4.3 Caregiving for Heart Failure patients

4.3.1 Studies of HF caregiving

The literature examining the effects that providing care to patients diagnosed with HF is extremely sparse. In-depth searches of electronic databases, browsing through library shelves and looking up references found in other articles brought up only 14 publications investigating HF caregiving. Of these, four were abstracts only and two were qualitative studies. The majority of studies (11) were published in the last 3 years. A summary of the studies of HF caregiving is presented in Table 4.3.1.1, below.

Table 4.3.1.1 Summary of studies investigating caregiving in HF[1]

Study	Location	Participants	Type of study
Karmilovich, 1994	US	41 HF caregivers	Descriptive
Coyne et al., 1995 (abstract)	US	177 HF dyads 55 post MI dyads	Cross-sectional
Cranford et al., 1998 (abstract)	US	201 HF dyads	Cross-sectional
Bull et al., 2000a	US	130 HF dyads	Longitudinal (2 weeks, 2 months)
Bull et al., 2000b	US	158 HF dyads	Intervention study Longitudinal
Scott, 2000	US	20 end stage HF patients; 18 caregivers	Descriptive
Coyne et al., 2001	US	189 HF dyads	Longitudinal (4 year)
Martensson et al., 2001	Sweden	23 HF caregivers	Qualitative
Evangelista et al., 2002	US	103 HF dyads	Cross-sectional
Rohrbaugh et al., 2002	US	177 HF dyads	Cross-sectional
Brostrom et al., 2003	Sweden	25 HF caregivers	Qualitative
Howlett et al., 2003 (abstract)	Canada	50 HF dyads	Cross- sectional
Pihl et al., 2003 (abstract)	Sweden	47 HF dyads	Cross-sectional
Schwarz et al., 2003	US	75 HF caregivers	Cross-sectional

The first ever study to examine the burden and stress of spousal caregiving for HF patients done in 1994. Karmilovich (1994) used a descriptive design to investigate the caregiver burden in 11 male and 30 female spouses of HF patients. Caregiver age ranged from 51 to 60 years. Care-receivers had an EF of 35% or less and were classified as NYHA class III and IV (moderate and severe HF). Caregivers were mailed questionnaires that included three instruments: Caregiving Demands Scale (CDS, measuring physical care, role alteration and financial alteration), Derogatis Brief Symptom Inventory (BSI) and demographic information. The majority of caregivers were white females who worked full time. One-third of caregivers were diagnosed with cardiovascular disease themselves, and all caregivers received assistance from other family members, mainly their children. Women caregivers identified watching their spouses get sicker and feeling helpless in the situation as the most stressful items on the CDS. They also worried about the future and their ability to care for their spouses. For male caregivers having less intimate time with their spouses was reported as the most stressful. Women caregivers rated all categories of role alteration higher than the male caregivers.

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[1] One more qualitative study of patients and caregivers' perception of HF as a illness (Murray et al., 2002) was published from Glasgow. This study was reviewed in chapter 1.

For women, inability to participate in social activities and not feeling able to share concerns with their spouses were viewed as main issues. Overall, female caregivers reported performing more helping behaviours and more difficulty in performing them than the male caregivers. The author noted that replication of the study with a larger sample size was necessary. Moreover, she suggested that more qualitative analyses were needed, as the caregivers in her sample were eager to discuss more of their caregiving experience.

One of such study was carried out by Martensson et al., (2001). This qualitative study involved in-depth, semi-structured interviews with 23 spouses of severe HF patients (15 women, mean age 73 years and 8 men, mean age 75 years) and was designed to describe decisive situations that could potentially affect caregivers' ability to provide support to the patient. Two situations emerged from the study as predictors of spouses' ability to support the patient. The first of the two was the spouse feeling like an outsider. This included experiences of being ignored, uninformed and not acknowledged either by the patient or the health care professionals (HCPs). Spousal support was hindered when physicians or nurses gave the spouse little information about the patient's condition. Some HCPs made spouses feel as though they were in the way of patient care, whereas others seemed unwilling to discuss problems and fears. In some cases the patients themselves did not allow their spouses to go to follow-up appointments, contributing to the spouses' feelings of less involvement with the patient. Similar to Murray et al.'s (2002) study (chapter 1, section 1.3), when the patient's condition prevented spouses from living the house, spouses felt socially isolated.

The second situation that emerged in this study was spousal involvement with others. Involvement with others (children, friends, neighbours and nurses) was viewed positively by spouses. Children were identified as the most helpful in assisting with caregiving demands when necessary. This study underlies the beneficial effect of social support for caregivers of severe elderly HF patients.

Importantly, HCPs' behaviour towards caregivers was found to influence caregivers' capacity of taking care of their ill spouses.

These findings were also reported in further two studies, which examined outcomes in HF patients and their caregivers based upon caregiver involvement in discharge planning.

The first study of Bull et al., (2000a) investigated whether the level of family caregiver involvement in discharge planning for an elder hospitalised with HF made a difference in caregiver health, discharge planning satisfaction, perception of care continuity, preparedness to assist the elder and acceptance of the caregiving role at 2 weeks and 2 months post-discharge. Telephone interviews were conducted with caregivers of 130 HF patients (average age of patient was 72 years). 54% of caregivers were spouses and 40.4% were adult children. 26% of caregivers had no involvement in discharge planning whereas 32.3% were involved a lot. Family caregivers who reported more involvement in discharge planning had significantly higher scores on discharge satisfaction, feelings of preparedness, acceptance of the caregiver role and perception of care continuity two weeks following the elder's hospitalisation than those who reported little or no involvement in planning. At 2 months post-discharge, caregivers who reported more involvement in discharge planning reported better health and more acceptance of the caregiving role than those who had little or no involvement in planning.

The second study by Bull at al., (2000b) tested a discharge-planning model by comparing outcomes of patients and caregivers receiving the intervention with a control group who did not receive this care. Data was collected on 158 dyads prior to discharge and at two weeks post discharge. 140 dyads were followed up at 2 months. The average age of HF patients was 73.4 years. Most of the caregivers were white, female and half were spouses. The average age of caregivers was 58.5 years. The study found that caregivers in the intervention group reported higher scores on continuity of care, general health perception, better mental and physical health and less negative reactions to providing care than the control group. Interestingly, this is the first study to report caregiver difficulty in HF symptom management: 60% of the caregivers were found to have difficulty in recognising, treating and evaluating HF symptoms. Therefore, there is a need to educate both patient and caregiver.

The above studies reported the influence of caregiver involvement in patient care on caregiver outcomes and factors that can influence caregivers' ability to provide care. One study which investigated the effect of a frequent problem encountered by HF patients, namely *sleep problems* on caregiver well-being is that of Brostrom et al., (2003). The authors conducted a qualitative descriptive study with 25 spouses of HF patients. The informants were 10 men (age range 42 to 87 years) and 15 women (age range 35 to 79 years). The interview was guided by 8 questions regarding the effects that patients' sleep affected the caregiver, for example "Describe a situation in which you were affected by your spouse's sleep situation" (p 226). Two major themes emerged in the analysis: *support stimulating situations* and *support inhibiting situations.* Support stimulating situations portrayed how caregiver's support was positively affected by their own adaptation in psychosocial or practical situations and receiving help from others. Support inhibiting situations described how caregivers' ability to help patients was negatively affected by disturbances as a result of patient's symptoms, such as breathlessness, snoring, apnoeas, coughing and nocturia. They also reported waking up during the night because anxiety in relation to the disease: "I wake up four or five times a night and listen...to make sure that he is breathing. I never sleep through the night! I'm much more tired and anxious...and much more irritated now. It's hard to be supportive in situations like this" (p 228). Caregivers also reported that dissatisfaction with care related to the sleep situation and being left to cope alone with the problem further inhibited their capacity to support the patient. This study is important because it highlight the fact that caring for a HF patient is a 24-hour job rather than a "day job". Moreover, it shows that spouses state of hypervigilance and continuous anxiety ultimately affect their mental status and ability to provide care.

Schwarz and Dunphy (2003) investigated the moderating influence of social support on the negative effects of stress for family caregivers of elderly (65 years and over) HF patients. The caregiver sample consisted of 20 males and 55 females with an average age of 63+/- 15.3 years. 51% of caregivers were spouses. Perceived stress was measured subjectively with the Perceived Stress Scale (PSS) and objectively with salivary cortisol. Depressive symptoms were measured by the Center for Epidemiological Studies Depression Scale (CES-D) and anticipated social support was measured with the Modified Version of the Inventory of Socially Supportive Behaviours Scale. Caregiver data was collected in the hospital, prior to hospital discharge of the patient. Although it was anticipated that social support will moderate the effects of stress on depressive symptoms in HF caregivers, no support for this hypothesis was found. Moreover, the perceived stress scale scores were not associated with the salivary cortisol, suggesting that the scale cannot be used as a standard of stress measurement.

The six studies presented above addressed caregiving for HF patients from the caregiver perspective, without considering patient characteristics. Next, eight studies which collected data from both the caregiver and the patient are summarised.

Coyne et al., (1995)[1] compared the level of psychological distress in 170 HF dyads with 55 couples in which the patient suffered an uncomplicated MI. Both HF patients and their caregivers were significantly more distressed than the post-MI couples. Overall, 52.6% of patients and 50.8% of spouses met or exceeded the established clinical cut point on the Hopkins Symptom Checklist-25

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[1] Coyne et al., 1995 represent the Michigan research group that went on to publish three more studies on caregiving in HF, namely Cranford et al., 1998, Coyne et al., 2001 and Rohrbaugh et al., (2002).

(HSCL-25). Patient LVEF and pre-existing quality of the marriage was unrelated to patient and spousal distress, but patient NYHA classification and both positive and negative aspects of the couple's interactions around HF illness related issues were significant predictors.

This research group published another study (Cranford et al., 1998) exploring the associations between biomedical and functional indicators of health status and social support with distress among male (n = 149) and female (n = 52) HF patients and their spouses. They found a high level of distress among male and female patients with HF, however distress was heightened for wives, but not husbands of patients. Predictors of distress were found to vary by gender and patient status. For male patients, predictors of distress included higher NYHA class, high levels of spouse distress and low marital satisfaction. Among female patients only marital satisfaction predicted distress. Among caregivers, none of the biomedical or social psychological variables predicted distress among male spouses, but wives' distress was associated with the male patient's distress and their own marital satisfaction. This study is important in that it takes both patients and caregiver's perspectives into account when predicting patient and caregiver distress. Moreover, it emphasises the importance of marital satisfaction as a predictor of distress. However, neither patient nor caregiver emotionality was controlled.

Coyne et al., 2001, in a follow up of the Cranford et al., (1998) study has shown that a composite measure of marital quality at baseline predicted 4-year survival as well as the patient's concurrent NYHA class did. When HF severity was controlled, the prognostic significance of marital functioning was still statistically significant and appeared stronger for female than for male patients. The authors concluded that both illness severity and marital quality were significant independent predictors of HF patients' mortality at 4-year follow up.

In 2002 a further study was published by the Michigan research group. Rohrbaugh et al., (2002) assessed the marital quality and psychological distress in 177 (128 male and 49 female) patients with congestive HF and their spouses. The mean NYHA class for the sample was 2.3, indicating that the majority of patients were diagnosed with mild HF. The informants were recruited in HF clinics. The mean age of patients and spouses were 53.4 years (SD 10.1, range from 29 to 78 years) and 52 years (SD 10.8, range from 29 to 75 years) respectively. The authors reported that Hopkins Symptom Check List-25 scores were in the distressed range for 57% of patients and 40% of the spouses. This *role* (patient versus spouse) difference was found to be greater for men than for women, showing that male patients were more distressed than female patients. Furthermore, *gender* difference (more distress in women than men) was greater for spouses than for patients, therefore female caregivers were more distressed than male caregivers. The patient's distress (but not the spouse's) was associated with patient's severity of HF and distress for both partners was inversely associated with marital quality. However, female-patient couples described better relationship quality than male-patient couples and a mediation analysis indicated that the gender difference in spouse distress could be explained by marital quality. This study is the only one that measured participants' neuroticism. The authors reported that controlling for caregiver neuroticism did not affect the association between caregiver gender and distress, whereas controlling for marital quality deemed the relationship non-significant, suggesting that marital quality mediates the relationship between caregiver gender and distress. In accordance to Young's model, the study's results highlighted the contextual nature of HF distress. Moreover, they emphasized that role differences in distress (caregiver versus care-receiver) vary by gender.

It could be argued that Rohrbaugh's results could have been influenced by the fact that informants were relatively young (in their early fifties) and diagnosed with mild HF. By contrast Scott (2000) investigated the health-related quality of life (HRQOL) and caregiving/care-receiving among 20 end-stage HF patients receiving community-based inotropic infusions and their 18 family caregivers. Inotropic medications are potent pharmacologic agents that can be administrated as either an intermittent or continuous infusion for palliative measures or as a bridge to cardiac transplantation. The care-recipients were predominantly married and predominantly male between the ages of 47 and 82 years (mean age 69.3, SD 8.97). The caregivers were predominantly female and married with a mean age of 63 years (SD 12.25, range 40 to 80 years). Four major variables were studied: perceived caregiver preparation to provide care, recipient health, HRQOL (for both patient and caregiver) and biopsychosocial responses (measuring the effects of caregiving on carer's self-esteem, daily schedule, family support, health and finances). The analysis revealed that care-recipients perceived considerable physical impairment from their illness and poor HRQOL despite the used of inotropic infusions. Perceived powerlessness was identified as a predictor of the recipients' mental health status. Surprisingly, caregiver self-esteem was found to have a counterintuitive effect on care-recipients' HRQOL, in that as caregiver esteem increased, the care-recipients' HRQOL decreased. The authors suggest that this finding may reflect the escalation in feelings of hopelessness among care-recipients as their caregivers become more competent and secure in their role. Moreover, the caregivers' attempts to protect recipients from stress by concealing problems and issues may result in loss of intimacy with the caregiver, thus increasing the burden of the disease experienced by the patient, resulting in adverse effects of his or her HRQOL. Caregivers provided care for eight hours a day on average. They felt unprepared in handling the stress involved in this type of role and 45% reported feeling depressed. Eighty-nine percent of the caregivers had mental health scores less than the established age norm. As the caregivers become overwhelmed with caregiving responsibilities and experienced health problems, they perceived that there was insufficient family support for their caregiving role. All of the caregivers indicated the desire to provide care, but despite perceiving themselves to be in good to excellent health, constant fatigue was reported by 39% of the caregivers. Both patients and caregivers found satisfaction in spending time with their children and friends and religion. This study is valuable because it conceptualise caregiving as a process in which caregiver and care-receiver characteristics influence each other. However, the number of informants is small and their personality was not taken into account.

Similarly to Rohrbaugh's study, Evangelista et al., (2002) carried out a study to investigate the emotional well-being of HF patients and their caregivers and to identity factors associated with emotional well being of HF patients. The informers were 103 HF patients and caregivers dyads recruited from a single outpatients HF clinic. The patients in the sample were predominantly male (n = 69), white, married and retired (mean age 57.61, SD 12.05). The caregivers were primarily female (n = 73) and spouses (83%) with an average age of 59.47 years (SD 17.64). For both patients and caregivers emotional well-being was measured by the 12 item short form (SF-12) health survey, which is a general survey for monitoring outcomes with chronic conditions. The study found that patients had significantly poorer emotional well-being than caregivers. Both age and gender were found to be associated with patients' emotional well-being: male and younger participants had better scores than female and older patients. In a multivariate model, patient's age, gender and caregivers' emotional well-being accounted for 54% of the variance in the patients' emotional well-being. Moderately high levels of association were found between patients' and caregivers' emotional well-being. Caregiver gender was not associated with patients' emotional well-being scores. Evangelista's study found that, as proposed by Young's model caregivers' outcomes influence patients' outcomes. However, the study was based on a relatively young sample of HF patients and their caregivers and used a non-specific measure of psychological health. Moreover, it did not take into account patient and caregiver personality.

Recently, another two more studies were published which considered both patient and caregiver perspective when predicting patients and caregivers health outcomes.

Pihl et al., (2003) investigated whether older patients with HF and their spouses experience similar levels of HRQOL and depression. The study also aimed to identify those factors that contributed to HRQOL and depression in patient-spouse pairs. Data was collected from 47 dyads using the Short Form 36 (SF-36) and Zung Self-Rating Depression Scale (SDS). Patients suffering from HF and their spouses were found to significantly differ in their experience of the physical but not the mental dimension of QOL, with patients experiencing significantly worse physical functioning. The authors reported no significant differences in depressive symptoms as measured by SDS between patients and spouses. The patients' depressive symptoms were found to increase with having a higher NYHA class, more impaired mental and physical functioning and a spouse with more depressive symptoms. The spouses' depressive symptoms increased with higher age of the patients, more impaired mental health and depression in the patient and more impaired mental and physical health of the spouse. Again, this study showed that patient and caregiver outcomes affect each other, as proposed by Young (1994). However, this study used a general measure of mental health and did not control for patient and caregiver emotionality.

Howlett et al., (2003) also studied the relationship between patient and caregiver quality of life and depression in 50 HF outpatients and their primary caregiver. Patients' quality of life was measured by the Minnesota Living with HF questionnaire (LiFE) and caregivers were given the Zarit Caregiver Burden Interview (ZCB). Both patients and caregivers also completed the Beck Depression Inventory (BDI). Of 50 patients 72% were male with an average age of 72 and 80% of caregivers were female with an average age of 61. The study found that there was a significant correlation between patient QOL and patient depression, also between patient QOL and caregiver depression and burden. Moreover, caregiver burden was associated with both patient and caregiver depression. The authors conclude that HF patients and their caregivers experience poor quality of life and high levels of depression and high levels of caregiver burden. Consistent with Young's (1994) model of late life family illness, the authors stressed that these factors are *interrelated* and *progress* with HF syndrome. However, this study used a general, unidimensional measure of caregiver distress and did not control for patient or caregiver emotionality.

4.3.2 Summary

Although caregiving research has flourished in the last four decades, before 1994 studies investigating the effects that caring for HF patients has on the mental and physical health of the carer have been lacking. In the last nine years, 14 studies have been published. Out of 14 studies, 4 are abstracts and 2 are qualitative studies.

Overall, caring for HF patients have been found to be stressful (Karmilovich, 1994, Brostrom et al., 2003) and the level of distress was found to be more severe than in post MI patients and their caregivers (Coyne et al., 1995). Gender differences in caregiver distress have been reported, in that women caregivers were found to be significantly more distressed than male caregivers (Karmilovich, 1994; Cranford et al., 1998; Rohrbaugh et al., 2002). A number of factors have been reported to influence caregiver distress and caregiver's ability to provide care, namely health care providers' willingness to inform caregivers about HF and to include them in the treatment plan (Bull et al., 2000a, 2000b; Martensson et al., 2001; Brostrom et al., 2003), relationship quality (Coyne et al., 1995; Cranford et al., 1998; Martensson et al., 2001; Rohrbaugh et al., 2002), illness severity (Coyne et al., 1995) and social support, although the relationship between social support and caregiver distress is not clear. Some studies (mainly qualitative) have found that social support has a beneficial effect on caregiver distress (Scott, 2000; Martensson et al., 2001; Brostrom et al., 2003), however others found neither a direct positive effect of social support on caregiver distress (Cranford et al., 1998) nor a moderator effect between stress and depression (Schwarz et Dunphy, 2003).

Studies which considered both caregiver and care-receiver characteristics and outcomes also reported contradictory findings. While Evangelista et al., (2002) reported that patient and caregiver well-being were moderately associated, with patients reporting significantly poorer emotional well-being scores, Pihl et al., (2003) found that patients and caregivers significantly differ in their level of physical (patients scoring worse) but not emotional dimension of QOL. Howlett et al., (2003) also found associations between patients and caregiver outcomes, namely patient QOL was associated with caregiver depression and burden.

Although the reviewed studies greatly enriche the knowledge base about caregiving in HF, they suffer from a number of methodological weaknesses illustrated in section 4.3.

Firstly, all studies that measured caregiver burden (e.g. Caregiving Demands Scale, Karmilovich, 1994; Caregiver Burden Interview, Howlett et al., 2003) used global, unidimensional measures of distress, thus precluding the identification of problematic areas that could be targeted by interventions. The present study will used a multi-dimensional measure of distress in order to identify specific areas of intervention.

Secondly, out of 14 studies, only seven (Cranford et al., 1998; Scott, 2000; Evangelista et al., 2002; Rohrbaugh et al., 2002; Howlett et al., 2003 and Pihl et al., 2003) considered both (although limited) patient and caregiver characteristics when investigating patient and caregiver outcomes.

Thirdly, only four studies viewed caregiving for HF as a *process* in which caregiver and care-receiver characteristics and outcomes influence each other and the illness situation (Evangelista et al., 2002; Rohrbaugh et al., 2002; Howlett et al., 2003 and Pihl et al., 2003).

Fourthly, with the exception of Rohrbaugh's study, none of the other studies measured patient and caregiver neuroticism. Therefore, the findings reported are based on the assumption that poor mental health found in caregiving can be validly attributed to caring, despite the fact that research has shown that caregivers react differently to similar caring situations. In the present study study, differences in caregiver emotionality will be statistically controlled in all correlations between subjective measures of caregiver characteristics (for example self-esteem or mastery) and caregiver outcomes.

Finally, only three studies reported positive reactions to the role of caregiver, although one study conceptualised positive reactions to care as high levels of self-esteem (Scott, 2000) and two others reported acceptance of the caregiving role and less negative reactions to providing care (Bull et al., 2000a; Bull et al., 2000b). No studies attempted to measure negative reactions *to receiving* care. The present study will measure both positive reactions to providing care and negative reactions to receiving care using questionnaires *specific* to the caregiving / care-receiving situation.

4.4 Summary of hypotheses

In the course of reviewing qualitative studies of the experience of living with HF (chapter1), HF clinical presentation (chapter 2), psychological factors in HF (chapter 3) and caregiving in general and HF caregiving in particular (chapter 4), several hypotheses were raised that were to be investigated in the present research project. These are listed below.

1. *Heart failure severity* will be associated with worse patient psychological and clinical outcomes and higher levels of caregiver distress. Worsening clinical status between phases will be associated with increased patient and caregiver distress.

2. *Patient personality* will have a direct influence on patient and caregiver outcomes. Specifically, it was hypothesised that high patient neuroticism will be positively related to worse patient outcomes and greater caregiver distress. Where caregivers perceive a marked change in patient's core personality characteristics, caregiver distress will be greater. *Patient personality will moderate the relationship between illness variables and patient and caregiver outcomes.*

3. Impaired patient *cognitive status* will negatively affect patient psychological and clinical outcomes and caregiver distress.

4. *Patients' knowledge of HF*, their *coping style* and *social support* will influence patient and caregiver outcomes. Specifically, it was hypothesised that (i) greater patient knowledge of HF will be associated with better patient outcomes and lower caregiver distress; (ii) task oriented coping styles will be beneficial, whereas avoidance style coping will have deleterious effects of patient and caregiver outcomes; (iii) patients reporting high levels of social support (especially emotional support) will be less distressed than patients reporting low social support.

5. Worse patient *psychological status* at phase 1 will be associated with worse *clinical* outcomes at phase 2.

6. Caregiver characteristics (namely gender, job demand, length of role as caregiver and dyadic adjustment) will have a direct influence on both patient and caregiver outcomes. Specifically, it was hypothesised that (i) female caregivers will report higher levels of distress than male caregivers; (ii) high levels of job demand will be associated with worse caregiver outcomes; (iii) there will be a positive relationship between length of role as caregiver and caregiver distress and (iv) better quality of the dyadic relationship will be associated with better outcomes for both patients and caregivers.

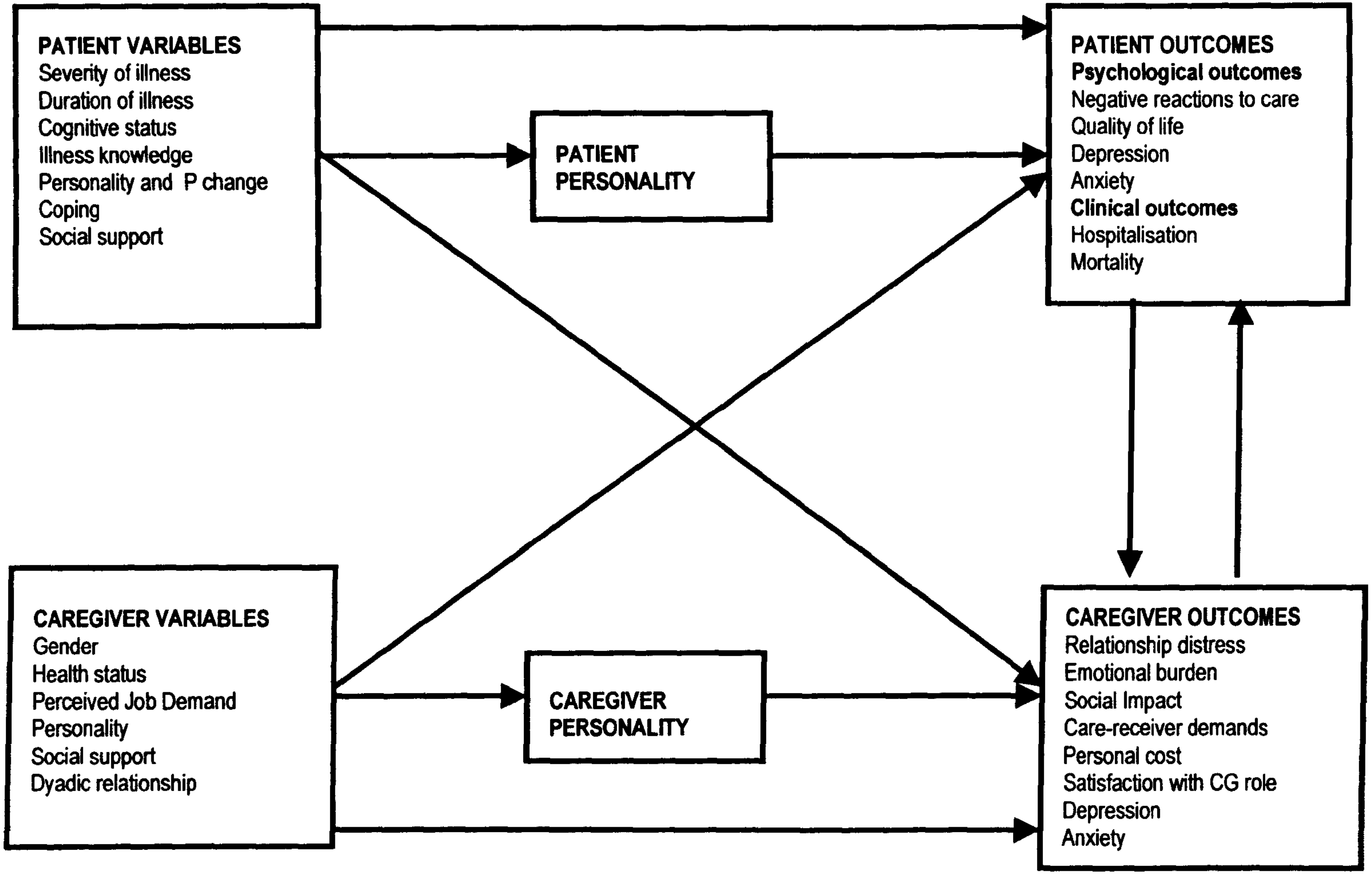
7. *Caregiver personality* will have a direct influence on caregiver outcomes. Specifically, it was hypothesised that caregiver neuroticism will be positively related to increased caregiver distress, whereas mastery and self-esteem will be negatively associated with caregiver distress.

8. Caregivers reporting high levels of *social support* will be less distressed than caregivers reporting low levels of social support.

9. Patient outcomes and caregiver outcomes will affect each other. These relationships will be mediated by patient and caregiver neuroticism.

Following from this, a simple model of the expected outcomes of giving and receiving care in a heart failure population is proposed (see Fig 4.4.1, below).

Figure 4.4.1 Hypothesised Model of Heart Failure Caregiving



CHAPTER 5

METHODS

5.0 Overview

This chapter has two purposes: firstly, to present a pilot study that was conducted prior to the main study and secondly, to describe the main study's methodology.

5.1 The pilot study

5.1.1 Outline

The implementation of an education class aimed at improving HF knowledge in patients hospitalised with HF in Arrowe Park Hospital provided the opportunity to carry out a pilot study prior to the study described in this thesis. The main goal of the pilot study was to investigate the proprieties of a 5-item HF knowledge questionnaire developed for the main study. Secondly, the semi-structured interview designed for the main study was tested to see how patients react to the wording and length of the interview and to examine if the interviews were to be conducted in the hospital or in the patients' home. Thirdly, the semi-structured interview data was used to investigate whether taking part in a 45-minutes, hospital based nurse delivered HF education class has a beneficial effect on patient clinical outcomes (re-hospitalisations, length of stay in hospital and mortality) at 6-months follow-up[1].

5.1.2 Pilot study methods

Eighty patients diagnosed with HF (40 in the intervention group and 40 controls) were interviewed by the current author using a 40 minutes semi-structured interview. The interviews was conducted blindly (without knowledge of whether the patient went to the class or not) and took place in the hospital in a private room if possible, on the ward if the patient was not mobile, or at

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[1] The results of the evaluation study are beyond the scope of the present study. For reference, an abstract presenting the evaluation study findings is included in Appendix 1

patient's home if the patient was discharged from hospital in the period between referral to the research worker and interview.

The semi-structured interview contained a variety of measures: demographic information (age, gender, years of education, smoking and drinking history), illness severity measures (NYHA class, Left Ventricular Ejection Fraction LVEF and co-morbidity index), subjective measures of health (participants were asked to rate their own health/ average health on a 5-point Likert scale, from very poor to very good), levels of anxiety and depression (HAD), emotional support (Krause and Markides, 1990) and satisfaction with hospital care (Cherkin, 1991).

A literature review of HF patients' knowledge of HF was not successful in producing a short questionnaire that could be used in the main study to assess patients' knowledge of *specific* information about HF. Therefore, a HF knowledge questionnaire (HFKQ) was developed for this study.

The questionnaire consisted of five statements (see Table 5.1.2.1) asking the patient to choose one of four possible answers: certainly true (4), probably true (3), probably false (2) and certainly false (1). The statements were designed to test very specific HF information. Questions 1,3 and 4 were developed to test patients' knowledge of the connection between heart failure, fluid retention, breathlessness and diuretics. HF is a chronic clinical syndrome in which the heart suffers a reduction in its ability to pump blood around the body. As a consequence, fluid builds up in different parts of the body and especially in the lungs resulting in patients becoming very breathless. Diuretics are then administered to help the body get rid of the excess fluid, thus "clearing the lungs", reducing breathlessness and easing the pressure on the heart. This knowledge is very important for both the patient and the health system, as patients' failure to recognise worsening HF and non-adherence to diuretics is often cited in the literature as predictors of unplanned hospital re-admissions (Vinson et al., 1990; Chin et al., 1997). Question two was designed to test patients' perception of their illness as an acute or chronic illness and question five was intended to test patients' knowledge of medication side - effects.

Table 5.1.2.1 Statements included in the HF knowledge questionnaire

1. Feeling out of breath is caused by water accumulating in the body.
2. Once on heart failure medication you are on it for life.
3. If you stop taking diuretics (water tablets), you will get breathless.
4. If you suffer from heart failure you shouldn't drink more than 3 and half pints of fluid a day, except in very hot weather.
5. Sometimes medicines you are prescribed cause unwanted symptoms, such as dizziness, coughing or sickness.

In order to help validate the HFKQ, five other measures of illness knowledge were used.

Level of self-care was measured using the Self-Care of Heart Failure Scale (SCHF) which was developed Riegel et al. (2000) to reflect HF patients' ability to maintain illness stability (self-care maintenance) and manage (self-care management) their symptoms when they occur. It consists of six subscales, of which three were used in this study: confidence in dealing with illness, self-care behaviours and importance of symptom recognition.

Medication knowledge was measured by asking the patients if they knew what medication are they on, what symptom the medication is for and dosage and schedule of taking their tablets. According to their answers, patients were divided into four groups: Group 1 - patients who had very little information or medication was administered by others; Group 2 - patients who had patchy information, but enough to take medication in correct amounts and Group 3 - excellent information.

Finally, general illness knowledge was measured using 12 items from the Mishel Uncertainty in Illness Scale (MUIS-C, Mishel, 1990). The MUIS–C is a 23 item, Likert format scale that was designed to measure perceived uncertainty in illness e.g. "I don't know what's wrong with me". There are five response options ranging from "strongly agree" to " strongly disagree".

5.1.3 Population characteristics

The sample consisted of 39 males and 41 female with a mean age of 75.08 years (SD ± 10.63), which is consistent to the mean age in population-based studies of HF. The average age of years of education was 10.13 years (SD ± 1.8). Patients had a mean of three co-morbid conditions. The majority of patients were diagnosed with mild (NYHA class II, 32.5%) or moderate (NYHA class III, 61.3%) heart failure and the mean LFEF was 38.67 (SD ±13.18).

5.1.4 Heart failure knowledge questionnaire (HFKQ)

5.1.4.1 HFKQ descriptives

Table 5.1.4.1.1 below, shows the means, SDs, frequencies and percentages of patients' answers on the HFKQ

Table 5.1.4.1.1 Patients' answers on the HFKQ

Means, ± SD Minimum 1, maximum 4*	Certainly true (4)	Probably true (3)	Probably false (2)	Certainly false (1)	%correct
HF1 (3.24, .83)	46 (46.3)	27(33.8%)	14 (17.5)	2 (2.5%)	80.1%
HF2 (3.43, .79)	47(58.8)	22(27.5%)	9(11.3%)	2(2.5%)	86.3%
HF3 (3.13, .80)	31(38.8%)	28(35%)	21(26.3%)	-	74.3%
HF4 (2.56, .91)	16(20)	20(25%)	37(46%)	7(8.8%)	45%
HF5 (3.10, .80)	29(36.3%)	31(38.8%)	19(23.8%)	1(1.3%)	75.1%

* Better knowledge is represented by higher scores

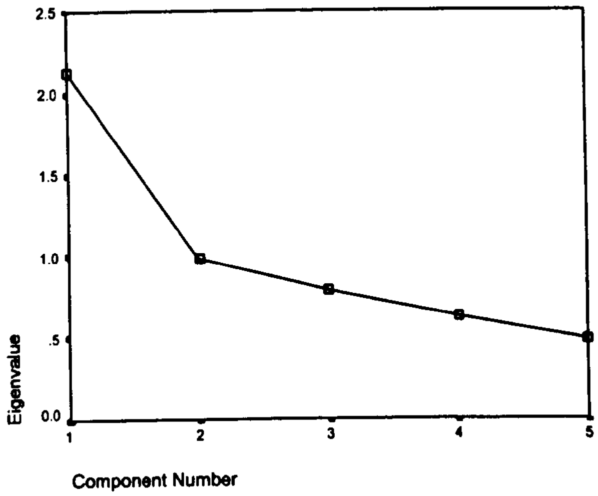
It can be seen from table 5.1.4.1.1, above, that knowledge of HF in this patient sample was good. All the scores were well above the chance levels of 25% and overall patients scored an average of nearly three quarters answers right (72.16%). However, there is no ceiling effect: 19.9% patients failed to make the connection between breathlessness and water retention, 14.7% wrongly viewed their illness as an acute illness, 25.7% misunderstood the association between breathlessness and diuretics, 55% were unaware of the necessity of limiting daily liquid consumption and 24.9% were not aware of possible medication side effects.

5.1.4.2 HFKQ psychometric evaluation

Psychometric evaluation of the HFKQ included reliability testing with item analysis and internal consistency reliability using Cronbach's alpha. Construct validity was examined by looking at the correlations between HFKQ and other measures of HF knowledge and investigating the questionnaire's sensitivity to detect increases in illness knowledge as a result of an intervention aimed at improving HF knowledge.

Item analysis proposes that items will produce higher reliability in a questionnaire if they discriminate well between individuals (Coolican, 1999). One way of checking the discriminatory power of items is to calculate the correlation between each person's score on the item and their score on the test as a whole. For our population, item-total correlations ranged from .51 to .68 and internal consistency reliability for the knowledge scale was relatively low (Cronbach's alpha = .65)[1]. However, a factor analysis of the five items showed that all items loaded on the same factor, explaining 42.63% of the variance (see figure 5.1.4.2.1, below) suggesting that the scale is unidimensional.

Figure 5.1.4.2.1 Factor scree plot for the factor analysis of the five-item HFKQ



Construct validity was tested by examining the correlation between the HFKQ and the other 5 measures of illness knowledge collected. Table 5.1.4.2.1 below, sets out the correlations between HFKQ and the other five measures of knowledge used.

Table 5.1.4.2.1 Correlations of HFKQ and other five measures of illness knowledge

	HFKQ
Self-care confidence	.53***
Self-care behaviours	.28**
Importance of recognising HF symptoms	.42***
Medication knowledge	.38***
Illness uncertainty	-.21*

*p<.05 **p<.01 ***p<.001 (one tailed)

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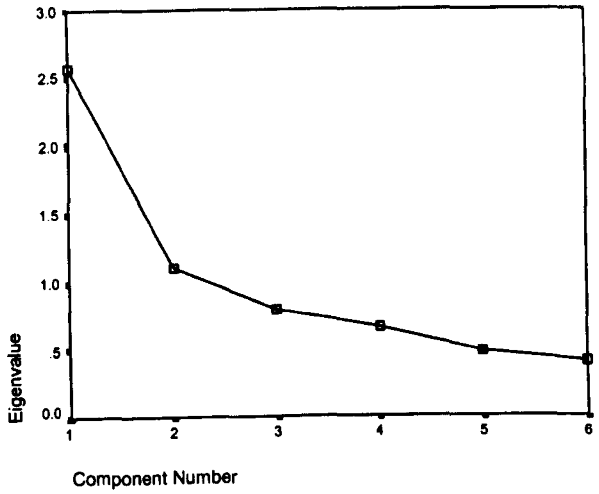
[1] In general, homogeneity is considered to be good if Cronbach's alpha > 0.70 (Streiner and Norm, 1995).

The HF knowledge questionnaire correlated with all other measures of illness knowledge, suggesting that the questionnaires share some variance but do not measure identical concepts. Furthermore, a principal components analysis was carried out followed by varimax rotation with Kaiser Normalization to see if the six measures of knowledge load one more than one factors. Two factors were extracted using the conventional criteria of eigenvalues greater than 1 and factors that explain more than five percent of the variance. The first factor had an eigenvalue of 2.56 and contributed 42.77 percent of the variance. The second factor had and eigenvalue of 1.10 and contributed to 18.42 percent of the variance, totalling 61.19 percent of the variance (see Figure 5.1.4.2.2).

Fig 5.1.4.2.2 Factor scree plot for the factor analysis of the six knowledge measures



An examination of the rotated component matrix of the six measures of knowledge (see Table 5.1.4. 2.2, below) showed that the self-care confidence scale and self care importance of recognising symptoms load roughly equal between the two factors.

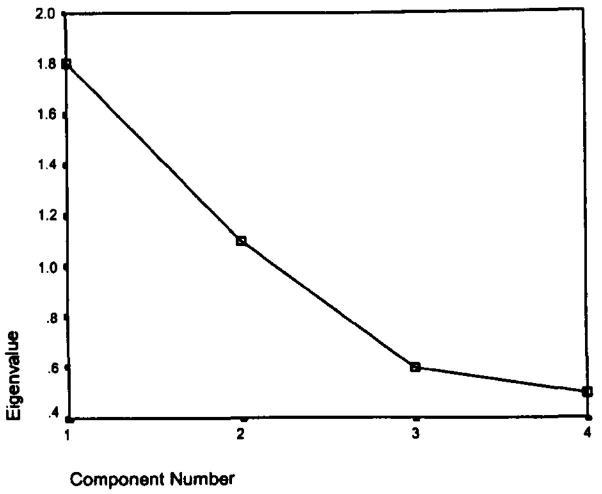
Table 5.1.4.2.2 Rotated Component Matrix of the six measures of knowledge

	Component	
	1	*2*
Self-care confidence scale	**.50**	**.54**
Self-care importance of recognising symptoms	**.53**	**.43**
Knowledge of self-care	**.77**	.12
Knowledge of HF (HFKQ)	.28	**.79**
Medication knowledge	-.11	**.76**
Uncertainty in illness scale[1]	**-.83**	2.260E-02

[1] – Higher scores represent higher uncertainty, thus *lower* general knowledge.

These two measures were eliminated, and a further factor analysis was carried out using four measures of knowledge: knowledge of self-care, HF knowledge, medication knowledge and illness uncertainty. Again, two factors (see Fig 5.1.4.2.3 below) had an eingenvalue of greater than 1. The first factor had an eigenvalue of 1.79 and contributed 44.98 percent of the variance, and the second factor had an eigenvalue of 1.10 and contributed to 27.52 percent of the variance. The two factors jointly contributed 72.50 of the variance.

Fig 5.1.4.2.3 Factor scree plot for the factor analysis of the four knowledge measures



An analysis of the rotated component matrix of the four measures of knowledge (see Table 5.1.4.2.3 below) shows clearly that the four measures of knowledge loaded on two different factors: knowledge of self-care (example of item: how often you exercise in a week) and illness uncertainty (example of item: I don't know what is wrong with me) are ***general*** measures of illness knowledge, *whereas* medication knowledge and HFKQ measure very ***specific*** knowledge of HF.

Table 5.1.4.2.3 Rotated Component Matrix of the four measures of knowledge

	Component	
	1	*2*
Knowledge of self-care	**.82**	.18
Knowledge of HF (HFKQ)	.27	**.76**
Medication knowledge	-.4.176E-02	**.86**
Uncertainty in illness scale	**-.87**	2.068E-02

Construct validity was further demonstrated by the finding that an intervention aimed at improving specific knowledge of HF[1] resulted in a significant improvement in the level of illness knowledge as measured by the 5-item HFKQ in the patients who took part in the class as compared with the control group ($t = 2.62$, $p < .01$).

5.1.4.3 Summary and implications for the measurement of HF knowledge in the main study

A *five-item HF knowledge questionnaire was developed to measure patients' knowledge of their* illness. The HFKQ correlated with other three measures of illness knowledge, suggesting good concurrent validity. Moreover, the HFKQ loaded on the same factor as medication knowledge, suggesting that HFKQ measures *specific* knowledge about HF, whereas knowledge of self-care behaviours and illness uncertainty measure *general* illness knowledge. The two factors accounted for 72.50 percent of the variance of an "overall" measure of knowledge, obtained by pooling the total scores of the four knowledge measures used. However, although all five items of the HFKQ loaded on the same factor, it explained only 42.63 percent of the variance in the HFKQ and the internal reliability for the scale was relatively low at .65. One way of improving the internal reliability of a questionnaire is to add relevant items to the original questionnaire. One important finding from the pilot study was that patients fail to recognise symptoms and signs that may signal worsening HF. Thus seven new statements were added to the HFKQ to test patients' recognition of breathlessness, fatigue, sudden weight gain, swelling of lower legs, dizziness or loss of balance, not being able to lie down because of feeling out of breath and not feeling well as potential signs of HF (see Table 5.1.4.3.1).

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[1] The class consisted of twenty-two informational slides presented by means of an overhead projector. Main themes were: Causes and symptoms of HF; Ways of helping yourself (Fluid restrictions, Smoking cessation, Alcohol reduction, Keeping active); Medicines for HF; Medication adherence and side-effects; Immunisations (Flu and pneumonia); Self-help (Monitoring weight, breathing and oedema). After the class, patients were provided with copies of the overheads for them to take home.

Table 5.1.4.3.1 HF knowledge questionnaire (HFKQ)

1. Trouble breathing is a symptom of HF
2. Feeling very tired or fatigued when you haven't done much is a sign of HF
3. Sudden weight gain is a sign of HF
4. Swelling of lower legs is a sign of HF
5. Dizziness, loss of balance or passing out is a sign of HF
6. Trouble sleeping because of trouble breathing is a sign of HF
7. Just not feeling well is a sign of HF
8. Feeling out of breath is caused by water accumulating in the body
9. Once on HF medication you are on it for life
10. If you stop taking diuretics (water tablets) you will get breathless
11. If you suffer from HF you should not drink more than 3 and a half pints of fluid a day, except in very hot weather
12. Sometimes medicines you are prescribed cause unwanted symptoms, such as dizziness coughing or sickness

It was decided that (i) the 12-item HFKQ will be used to measure patients' *specific* knowledge of HF alongside measurement of medication knowledge and ii) two measures of *general* HF knowledge namely, knowledge of self-care and illness uncertainty will be collected.

5.1.4.4 The semi-structured interview. Implications for the main study

Sixty-six percent of patients found the interview "quite helpful" and 27% found the interview "definitely helpful". Overall, patients understood the questions in the interview and found the length of the interview undemanding. Findings from the pilot study prompted a number of changes in the semi-structured interview.

Firstly, the pilot study showed that the place of the interview influences participants' responses: people interviewed in private (at home or in interview rooms in hospital) were significantly less satisfied with their stay in hospital than people interviewed on the ward, signifying that answers given on the ward may be biased. Consequently, it was decided that all the interviews for the main study will be carried out in the participant's own home, allowing them to speak in a familiar environment and at their own pace.

Secondly, it was found that a large proportion of HF patients (25 to 50%) failed to recognise symptoms of worsening HF, suggesting that they were unaware of symptoms of HF. It was decided that in the main study patients will be asked about each of the main three symptoms and signs of HF (breathlessness, fatigue and oedema) separately and in depth, in order to compute overall *subjective* scores of illness severity. Review of the relevant literature and discussions with the patients prompted the inclusion of two more measures of subjective illness severity in the semi-structured interview for the main study, namely difficulties in performing activities of daily living and a measure of daytime sleepiness. Patient subjective health was found to be associated with level of depression in the pilot study; thus the measure was used for the main study.

Thirdly, in this study *objective* measures of illness severity were not significant predictors of clinical outcomes at 6 months follow-up. However, patient reported level of emotional support accounted for 9% of the variance of re-hospitalisations number at six months follow-up. Therefore, the emotional support measure was included in main study, alongside with three other measures of social support (informational, tangible and integrational). It was concluded that both objective and subjective measurements of illness severity were to be collected in order to clarify whether subjective measures of illness severity are better predictors of outcomes than objective measures of severity.

During interviews for the pilot study it was observed that many patients were not aware of their diagnosis being "heart failure", although the nurses referring patients for the study made sure that patients do know their diagnosis. Thus in the main study patients a measure of "knowledge of diagnosis" was included.

5.2 Methods

5.2.1 Choice of measures[1]

In this investigation of the impact of illness factors and psychological variables on patient and caregiver outcomes in heart failure a considerable amount of information was collected from the patients and the caregiver.

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[1] A test manual containing the questionnaires used in the study and their internal consistency level (Cronbach's alpha) is included in Appendixes 2 and 3.

5.2.1.1 Patient variables

5.2.1.1.1 Illness severity: objective and subjective measures.

Four objective measures of illness severity were measured[2]: New York Heart Association class, Left ventricular ejection fraction (LVEF), number of co-morbid conditions and patient level of disability. Additionally, lung function was objectively measured with a spirometer, obtaining two scores: Forced Expired Volume in one second (FEV1) and Forced Vital Capacity (FVC).

Patients were assigned a NYHA class by a consultant cardiologist. Number of co-morbid conditions and LVEF data were collated from patients' medical notes. The Lawton Instrumental Activities of Daily Living scale (IADLs; Lawton and Brody, 1969) was used as a measure of patient functional independence in personal care and mobility.

Objective measures of illness severity have been shown to be associated with psychological and clinical outcomes in HF patients (Rogers et al., 1994; Gottdiener et al., 2002; Cioffi et al., 2003; Smith et al., 2003). However, recent research has suggested that objective measures of illness severity reflect a non-specific response to the physical impairments of a chronic illness " what can be predicted on the basis of cardiological diagnosis is only a generic pattern of psychological distress, which arise solely from the effect of being severely and chronically functionally impaired, no matter what the disease" (Majani et al., 1999, p 1584). The authors argue that *subjective* measures of illness severity are better suited to provide a picture of the impact that a specific illness (HF) has on patients' life. Consequently, in this study patients' subjective measures of overall health were assessed, as well as subjective measures of the most common symptoms of HF, namely breathlessness, fatigue, oedema, angina and daytime sleepiness.

One of the most frequently used measures of *self-reported health (SRH) status* is a single question asking patients to rate their overall health on a scale from very good to very poor. There

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[2] NYHA classification and LVEF have been discussed in detail in chapter 2 (section 2.4.2)

is widespread agreement that this simple global question provides a useful summary of how the patients perceive their overall health status, which was consistently found to be a powerful predictor of clinical outcomes and mortality in a wide range of disease areas (Fayers and Sprangers, 2002). In this study, patients were first asked, "Overall, how would you rate your health?" The patients choose their response from five alternatives: very good, good, fair, poor and very poor. Secondly, the pilot study has shown that a number of patients instinctively compare themselves with others of the same age. Therefore, a second question asked " In comparison with other men/women of your age living on the Wirral, would you say your health is: much above the average, above average, average, below average or much below average?" The scores on the two questions were added up to obtain an overall measure of subjective health.

Subjective breathlessness was measured by a *Visual Analogue Scale* (VAS-D) developed specifically to measure dyspnoea in congestive HF (Subratty et al., 1994). Patients were asked how breathlessness they become when performing ten increasingly difficult activities, from resting to walking for 12 minutes on a flat surface at patient's own pace. The numerical scale range from 1 to 10, each value relating to a verbal subjective description of the intensity of dyspnoea (1 meaning " not breathless eat all" and 10 meaning "effort impossible"). The scores on the overall scale ranged from 10 (no breathlessness at all) to 100 (extreme breathlessness).

Subjective fatigue was measured using the *Fatigue Impact Scale* (FIS; Fisk et al, 1994). The FIS consists of 40 items and measure patient perceptions of their functional limitations due to fatigue on cognitive (10 items), physical (10 items) and psychosocial (20 items) functioning during the past four weeks. Each item is scored from 0 (no problem) to 4 (extreme problem). The possible range of scores for the total FIS scale is between 0 and 160, 0-40 for the cognitive and physical dimensions and 0-80 for the psychosocial dimension. High scores reflect greater functional limitations. FIS has shown very high internal consistency, with Crombach's alpha for the total scale being .98 and .87 or greater for all subscales (Fisk et al., 1994).

Subjective oedema and *subjective angina* were measured using a composite measure developed for this study. For each symptom patients were asked about duration of symptom, feeling of being in control of the symptom, quality of the symptom (getting worse, staying the same or getting better), severity of symptom (on a scale from 1 to 10 where 1 means not at al severe and 10 means extremely severe) and level of distress experienced as a result of the symptom (again, on a scale from 1 to 10, where 1 means no distress and 10 means extreme distress). Factor analyses were carried out and factors analysis scores were used to characterise individuals for the purposes of analyses.

Subjective daytime sleepiness was measured using the *Epworth Sleepiness Scale* (ESS; Johns, 1991). The ESS is a self-administered questionnaire that measure sleep propensity on a 0 (would never dose off) to 3 (high chance of dosing) scale in eight standardised daily situations such as sitting and reading or being a passenger in a car. It has been well validated against objective EEG based measurements of daytime sleepiness (Johns, 1993) and has shown good reliability and internal consistency (Johns, 1992). ESS can range from 0 to 24, with higher scores signifying increased daytime sleepiness. A cut-off of 12 is typically used in assessment of narcolepsy; however older adults may demonstrate impairment through non-pathological scores.

5.2.1.1.2 Patient cognitive status

Patient cognitive status was considered an important variable that can affect both patient and caregiver outcomes. Research has shown that cognitively impaired patients are at risk for worse clinical outcomes (Smits et al., 1999) and are more burdensome to care for (Bedard et al., 2000).

The *Mini-Mental State examination* (MMSE; Folstein et al., 1975) was used as a measure of global cognitive function. The MMSE consists of brief subtests (personal orientation to place and time, recall ability, short term memory and arithmetic ability). The scale has proven to be sufficiently valid, reliable and reproducible (McKhann et al., 1992). Traditionally, a score of less than 24 (out of a maximum of 30) has been regarded as indicating cognitive impairment severe enough to be regarded as dementia. However, Hodges (1994) argued that although a score of less than 24 on the MMSE is a fairly good indicator of dementia, cognitively impaired people with a good background intellectual ability may attain a score above the cut off point of 24. Hodge's criteria was used to classify patients as intact (MMSE scores of 29 or 30), impaired (MMSE scores of 24 to 28) and demented (MMSE <24).

The *Rey Auditory Verbal Learning Test* (RAVLT; Rey, 1964) was used to measure verbal learning and memory. Patients are required to recall a list of fifteen nouns, which are presented to them at a rate of one word per second over a total of five learning trials (List A). Following the presentation of List A, a second list of fifteen nouns is read once (List B), and patients are asked to recall it. Directly afterwards, the patients are asked to recall as many words as possible from List A. After a delay of approximately thirty minutes, the patient is asked to recall List A, again without prompts. A score for each trial is calculated from the number of correct words from List A. The total RAVLT score is calculated from the sum of each trial score.

The *Reitan Trailmaking Test* (Reitan, 1958) was used to measure attention, visual scanning, speed of hand-eye co-ordination and information processing. Part B also assesses the ability to alternate between sets of stimuli, which is an executive function. The test consists of two parts A and B, which are preceded by a short practice. Part A requires the patient to connect 25 randomly placed circles in ascending numerical order. Part B requires the patients to connect 25 randomly placed numbers and letters alternating between ascending numerical and alphabetical order.

Patients are timed (seconds) for both parts of the test. For easier interpretation, the scores were standardised using the MOANS age corrected scaled score procedure (Ivnick et al., 1996). The age corrected scores were based of 359 cognitively normal, community- living, disability free volunteers age over 55.

Finally, the *Grooved Pegboard Test* (Matthews and Klove, 1964) was used to measure motor function. It consists of a metal board with a matrix of slotted holes angled in different directions. The task is to insert 25 metal pegs with ridges along the sides into each hole in sequence, first with their dominant hand, and then with their non-dominant hand. Scores represent time in seconds required to complete the matrix with each hand, with higher scores reflecting a lower level of performance.

The last four tests (RAVLT, trail A and B and the Pegboard test) were included in an attempt to measure longitudinal changes in cognitive status in HF patients. These tests were originally recommended as a "core battery" of neuropsychological tests that are particularly sensitive at measuring cognitive change following CABG surgery (Murkin et al., 1995; 1997). However, in the absence of a widely recognised battery of tests specific to HF, it was considered that they are general enough to detect changes in cognitive status in HF patients. The consensus within the research literature regarding the measurement criterion is that cognitive decline is defined as decline in test scores by at least 20% from baseline on at least 20% of the measures (individual tests) (Murkin et al., 1997).

5.2.1.1.3 Knowledge of HF

Following the findings of the pilot study, four measures of HF knowledge were assessed: two measures *specific* to the HF illness situation (HF Knowledge Questionnaire and medication knowledge) and two measures of *general* illness knowledge (the Self-Care Questionnaire and the

Illness Uncertainty Questionnaire). Patients were also asked if they know the medical term for their diagnosis.

5.2.1.1.3.1 HF knowledge Questionnaire

A 12-item knowledge questionnaire (HFKQ) was developed for this study. The questionnaire consists of statements aimed at measuring very specific knowledge of HF, for example patient's understanding of the relationship between fluid retention, breathlessness, diuretics and fluid intake. The participants were require to state whether in their opinion the statement was *certainty true* (scoring 4), *probably true* (scoring 3), *probably false* (scoring 2) or *certainty false* (scoring 1). A total score was obtained by summing the scores on each item, giving scores ranging from 12 to 48, higher scores representing higher specific illness knowledge.

5.2.1.1.3.2 Medication knowledge

Each patient was asked about the names, purpose and side effects of their medications. According to their answers, patients were grouped by the investigator into three categories (experimenter rated measure): *group 1* = poor medication knowledge (unable to offer any information about their medication; medication administered by others); *group 2= limited medication knowledge* (limited information, but sufficient to ensure that correct dose is taken at the right time or availability of blister pack) and group 3 = excellent medication knowledge (in depth knowledge of medication name, effects and side-effects).

5.2.1.1.3.3 Mishel Uncertainty in Illness Scale (MUIS-C; Mishel, 1990)

The MUIS-C is a 23-item questionnaire, which was designed to measure perceived uncertainty in illness. Example of statements are " I don't know what is wrong with me" and " I am unsure if my illness is getting better or worse". Patients are asked to choose from five possible answers: *strongly agree*, *agree*, *undecided*, *disagree* and *strongly disagree*. Possible uncertainty scores range from 23, indicating a low level of uncertainty to 115, reflecting a high degree of illness uncertainty. Coefficient alpha scores for the MUIS-C are reported in the moderate to high range (.75 to .90; Winters, 1999).

5.2.1.1.3.4 Self-Care in HF Questionnaire

Knowledge of self-care was measured by the self-care subscale of the Self-Management of HF instrument (Riegel et al., 2000). The scale consists of 7 items, asking the patients how often they undertake behaviours that help them monitor their illness, such as weighing themselves daily and contacting their health care provider when they need guidance. The patient can choose between four answers: *never or rarely* (scoring 1), *sometimes* (scoring 2), *frequently* (scoring 3) and *always* (scoring 4). The self-care scores can range from 7 to 28, higher scores representing better levels of self-care. Cronbach's alpha for this scale was reported to range from .62 to .68 (Jaarsma et al., 1999).

5.2.1.1.4 Patient personality

Two measures of personality were administred to the patients: the NEO-Personality Inventory-Revised (NEO-PI-R; Costa and McCrae, 1992) and the Inventory of Interpersonal problems (IIP-32; Horowitz et al., 2000).

5.2.1.1.4.1 The NEO-Personality Inventory-Revised (NEO-PI-R; Costa and McCrae, 1992)

Patients completed three subscales of the NEO-PI-R (Costa and McCrae, 1992), which is a well-established measure of personality that has been shown to predict health outcomes. Each of the three subscale (neuroticism, extraversion and conscientiousness) consisted of 12 items. The patients were asked to choose the response which best fits their opinion for all 36 items from five possible answers: *strongly agree*, *agree*, *neutral*, *disagree* and *strongly disagree*. This gave a score of 0-4 for each item, ranging from 0 to 48 for each subscale. Higher scores indicated higher neuroticism, extraversion and conscientiousness. This information was collected in order to investigate whether patient personality (i) affects his or hers psychological and clinical outcomes and (ii) it influences caregiver distress.

5.2.1.1.4.2 The Inventory of Interpersonal problems (IIP-32; Horowitz et al., 2000).

The Inventory of Interpersonal Problems (IIP) is a self-report instrument that identifies a person's most salient interpersonal difficulties. The theory behind the questionnaire is that social interaction plays a fundamental role in defining personality, because the interacting parties in an interpersonal situation always influence and are influenced by each other (Sullivan, 1953). This framework is very relevant to the present research, which is based on Young's (1994) model that patients and caregivers influence each other's outcomes in the late life illness situation.

The IIP-32 consists of 32 statements contributing to eight sub-scales (Domineering/Controlling; Vindictive/Self-Centred; Cold/Distant; Socially Inhibited; Non-assertive; Overly Accommodating; Self-Sacrificing and Intrusive/Needy). Each statement portrays a social situation that people may find difficult, for example " It's hard for me to say 'no' to other people". Respondents were asked to choose one of five possible answers: *not at all*, *a little bit*, *moderately*, *quite a bit* and *extremely*. The authors reported a Cronbach's alpha of .93 for the overall scale and alphas ranging from .68 (Intrusive/Needy) to .87 (Cold/Distant) for the eight subscales. The scores were standardised to increase the accuracy of interpretation.

5.2.1.1.5 Social relationships

Two measures of social relationships were collected: one measure assessed four types of social support, namely informational, tangible, emotional and integrational support (Krause and Markides, 1990) and a measure of social isolation (Murberg et al., 1998).

5.2.1.1.5.1 Social support

Patient level of social support was assessed using a 40-item scale developed specifically for measuring social support in older adults (Krause and Markides, 1990). Patients were asked how often in the last year they receive specific types of support and were invited to choose one of four possible answers: 1 = never, 2 = once in a while, 3 = fairly often and 4 = very often. The questionnaire measures four types of social support, namely informational support (7 items), tangible support (9 items), emotional support (11 items) and integrational support (helping others; 13 items). The Cronbach's alphas were reported as good (ranging from .81 to .82), with the exception of the tangible support subscale, which had a Cronbach's alpha of .66. Moreover, for each type of social support the patient is asked if they are happy or unhappy with the level of support received.

5.2.1.1.5.2 Social isolation

Social isolation was assessed using a 4-item scale developed by Murberg et al., (1998) to measure the extent to which HF patients judge their capacity to engage in social relationships to be compromised as a result of illness. The four items ask the patients if the disease made it difficult for them to (i) visit friends and family, (ii) receive visits from friends and family, (iii) participate in social events and (iv) go on holiday with family and friends. The social isolation items were scored according to a 6-step Likert scale ranging from "not at all" to "very much". The authors reported a Cronbach's alpha of .83 for the scale.

5.2.1.1.6 Coping

Patients' coping style was investigated using the COPE inventory (Carver et al., 1989). This is a 60-item inventory with 4 items for each of the 15 subscales. Each item presented a specific way in which people may behave in a stressful situation (for example "I discuss my feelings with someone") and patients were asked to choose one answer out of possible four: *1= I usually don't do this at all*; *2 = I usually do this a little bit*; *3 = I usually do this a medium amount* and *4 = I usually do this a lot*. For each subscale the range of possible values is 4 to 16, higher scores meaning that the patient uses that particular coping style frequently.

Out of the 15 subscales, five measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping and seeking of instrumental social support) and five scales measures aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial and turning to religion). The last five subscales measure the extent to which people used humour, focus on and venting of emotion, mental disengagement, behavioural disengagement and alcohol/drug use to cope with stressful situations. Carver et al., (1989) reported that the internal consistency of the COPE subscales was acceptable high (all had Cronbach's alphas over .60, with the exception of the mental disengagement subscale).

It should be noted that the questionnaire was administered by the researcher who prompted the patient to think about ways they were coping *with their HF* when answering the COPE items, rather than the extent to which they make used of each coping response when they experience stressful events. Thus the situational, rather than dispositional version of the cope was used.

5.2.1.2 Patient Outcomes

5.2.1.2.1 Negative reactions to care

Many studies are designed to determine whether family caregiving improves the psychological and clinical outcomes of the care recipient. Paradoxically, however, research neglects the possible negative effects that receiving care may have on the care-receiver (Gaugler et al., 2002). Many commentators have written about the demoralising effects of being dependent of others (Eustis and Fisher, 1991; Lustbader, 1991) and recent research has shown that negative perceptions of the received care was associated with reduced well-being in the care-recipient (Clark and Stephens, 1996; Newsom and Schulz, 1998; Martire et al., 2002; 2003). No research to date has investigated possible negative reactions to receiving care in HF patients.

In this study, negative reactions to receiving care in HF patients have been measured using a questionnaire proposed by Newsom et al., 1998. The questionnaire consists of 20-statements that present possible reactions to receiving care, for example "When a get help from my carer, I feel that I am a failure". Patients were asked to choose one answer from five possible choices: 5

= *strongly agree*, *4* = *agree*, *3* = *neither agree nor disagree*, *2* = *disagree* and *1* = *strongly disagree*. The 20 items contributed to 3 subscales: temporary loss of self-esteem (10 items), indebtedness (4 items) and negative perceptions of carer behaviour (6 items). The authors reported that the internal consistency of the indebtedness scale was quite low at .57, but the other two scales had Cronbach's alphas of .87 (negative perceptions of carer behaviour) and .81 (temporary loss of self-esteem) respectively. These three subscales were used in the present study to measure negative reactions to care in a HF population.

5.2.1.2.2 Quality of Life

Quality of life was investigated using a 21-item, disease specific measure of quality of life - the Minnesota Living with HF Questionnaire (MLHFQ; Rector et al., 1987). The inventory inquire about the effect that HF had on specific aspects of the HF patient's life in the last month, for example " Did your HF prevent you for living as you wanted during the last month by making your sleeping well at night difficult?" All items on this self-report instrument are measured on a 6-point response scale (0 to 5). The total summary score can range from 0 to 105, where a *lower* score reflects *better* quality of life. Two subscale scores reflect physical (8 items) and emotional (5 items) components of quality of life. The authors reported high internal consistency (Cronbach's alphas for the overall scale and physical and emotional dimensions were .94, .94 and .90, respectively). In the present study, the physical and emotional subscales were used to measure HF *specific* psychological outcomes.

5.2.1.2.3 Patient Depression

Patient depression was conceptualised as a general mental health outcome. In this study, patient depression was measured using the Geriatric Depression Scale (GDS; Brink et al., 1982; Yesavage et al., 1983). The questionnaire was specifically developed for screening elderly patients for depression (Yesavage et al., 1983) and was designed to concentrate on psychological aspects of depression, rather than somatic aspects of depression (such as appetite loss and sleep disturbance) that can be confounded by the normal effects of ageing. The original questionnaire consisted of 30 Yes/No items. However, Lyness et al., (1997) showed that a 15-item GDS had a sensitivity and specificity comparable to the GDS-30, thus in this study GDS-15 was used to measure patient level of depression.

5.2.1.2.4 Patient anxiety

Patient anxiety was assessed by the state part of the *Spielberger State-Trait Anxirty Inventory* (STAI; Spielberger et al. 1983). The STAI is a self-administered questionnaire consisting of ten items worded positively for the presence of anxiety (for example, " I feel nervous") and ten items worded negatively (for example, " I feel calm"). The latter were denoted as absence of anxiety by Spielberger et al., (1983). Each item has four possible answers *1* = *not at all*, *2* = *somewhat*, *3* = *moderately* so and *4* = *very much so*. The scores on the STAI range from 20 to 80, higher scores representing higher levels of anxiety.

5.2.1.2.5 Patient clinical variable

Patient mortality, cause of death, number of hospitalisations and length of stay in hospital in the follow up period were provided by the IT Department in APH.

5.2.1.3 Caregiver variables

5.2.1.3.1 Job demand: length of role as caregiver, hours of care per day, discretion and involvement in medication administering

Four measures of job demand were collected: length of role as caregiver, number of hours of care per day, discretion and caregiver involvement in administering patients' medication.

5.2.1.3.1.1 Length of role as caregiver

Caregivers were asked how long they have been providing care for their family member. According to their answers, they were assigned to one of seven categories: length of role *1* = *one month*, *2* = *6 months*, 3 = *1 year*, *4* = *2 years*, *5* = *2-5 years*, *6* = *5-10 years* and *7* = *more than 10 years*.

5.2.1.3.1.2 Hours of care

After an introductory discussion about the kind of things the caregiver does for their family member, they were asked, " In the average week, how many hours a day do you care for your relative?" The response was recoded in hours.

5.2.1.3.1.3 Discretion

Level of discretion was assessed by the following question: " What is the maximum time that you can leave your relative without worrying?" The response was recoded in hours.

5.2.1.3.1.4 Caregiver involvement in administering patients' medication

Caregivers were asked to what extent they were involved in giving or reminding the patient to take his/her medication. According to their answers, they were divided into three groups: Group 1 = *responsible for administering medication*; Group 2 = *reminding the patient to take his/her medication* and Group 3 = *not involved in patient's medication.*

5.2.1.3.2 Caregiver health

Caregivers were questioned with respect to their own health status during the interview. They were asked if they are diagnosed with any disabling chronic conditions, such as arthritis or cancer, and the number of conditions were coded as an indicator of objective health status. Additionally, their *self-reported health (SRH) status* was assess using the same two questions used to assess patients' health status and the scores on the two questions were added up to obtain an overall measure of subjective health.

5.2.1.3.3 Caregiver personality and caregiver perception of patient personality change

Carer personality has been shown to be an important predictor of caregiver outcomes (Hooker et al., 1998; Patrick and Hyden, 1999; Galant and Connell, 2003), however it is often overlooked in caregiving research. In this study, carer personality was measured in a variety of ways using the NEO-PI-R and measures of mastery, self-esteem and interpersonal problems. Moreover, *caregiver perception of patient personality change* was measured using two adaptations of the NEO-PI-R.

5.2.1.3.3.1 Caregiver neuroticism, extraversion and conscientiousness

Similarly to patient personality assessment, caregiver neuroticism, extraversion and conscientiousness were measured using the relevant subscales of the NEO-PI-R (Costa and McCrae, 1992).

5.2.1.3.3.2 Caregiver mastery

Research has shown that a sense of mastery, or personal control is important to both physical and emotional health (Pearlin et al., 1981; Rodin, 1986; Krause, 1994) as well as to productivity in later life (Glass et al., 1995). In order to assess caregivers' level of personal control, they were asked to complete a 7-item scale developed by Pearlin and Schooler (1978). Participants were asked to respond to statements such as " I have little control over the things that happen to me" choosing one of five possible answers: *completely agree*, *mostly agree*, *neither agree nor disagree*, *mostly disagree* and *completely disagree*. The scores range from 7 to 35, higher scores indicating higher degrees of personal control. The authors reported a reliability coefficient of .75 for this test.

5.2.1.3.3.3 Caregiver self-esteem

In health psychology, self-esteem or self-worth has been typically viewed as a resource that can moderate the effects of a stressful event. In this study, caregivers' self-esteem was measures with the Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1989). The RSE scale consists of 10 items (e.g. "On the whole, I am satisfied with myself") to which the participant responds on a four-point scale of agreement: *strongly agree*, *agree*, *disagree*, and *strongly disagree*. The scores on the test can range from 10 to 40, higher scored indicating more negative self-esteem.

5.2.1.3.3.4 Caregiver interpersonal problems

Similarly to patients, caregivers' interpersonal problems were measured using the 32-item Inventory of Interpersonal problems (IIP-32; Horowitz et al., 2000).

5.2.1.3.3.5 Caregiver perception of patient personality and personality change

In order to investigate caregivers' perceptions of patient personality and personality change, they were given two adaptations of the neuroticism, extraversion and conscientiousness subscales of the NEO-PI-R (Costa and McCrae, 1992). The first was a simple conversion from the first person to the third person, for example "I am a worrier" was transformed into "He/She is a worrier", in order to assess caregiver perception of "present " care-receiver personality. The second adaptation was to assess carers' perception of their care-receivers' personality as it was when the care-receivers were in their thirties or "in their prime". Caregivers were invited to "think about the person you care for and how they used to be in their thirties or in their 'prime'" and then to select an answer for each of the 48 items of the NEO-PI-R. "Present" personality scores were then subtracted from "prime " personality scores in order to assess caregiver perception of care-receiver personality change.

5.2.1.3.5 Caregiver social relationships

Three measures of caregiver social relationships were measured: Social support, presence of confidant and the quality of the dyadic relationship.

5.2.1.3.5.1 Social support and satisfaction with social support

Caregiver level of social support and satisfaction with social support was assessed with the same 40-item questionnaire used to investigate patient social support (Krause and Markides, 1990).

5.2.1.3.5.2 Presence of confidant

Presence of confidant was assessed using three questions. Firstly, the caregivers were asked, " If you have a problem of some sort, who will be the first person with whom you would want to discuss it?" Secondly, they were asked, " Is this person someone you can talk to about your most private thoughts and feelings? Someone that you can really trust with a personal problem?" and finally, " Can you discuss any problem with X (your care-receiver), or are there certain topics which are impossible to discuss?" According to their answers, two measures were assessed (i) presence of confidant (1 = confidant present and 2 = confidant absent) and (ii) care-receiver as the caregiver's confidant (1 = the care-receiver was perceived as their confidant by the caregiver and 2 = care-receiver was *not* perceived as their confidant).

5.2.1.3.5.3 Quality of the dyadic relationship

The quality of the dyadic relationship was assessed using the 7-item short form of the Dyadic Adjustment Scale (DAS-7; Spanier, 1976; Hunsley et al., 1995). The scale yields one overall dyadic adjustment score, ranging from 0 to 36. Higher scores represent a higher quality of relationship. Hunsley et al., (1995, 2001) reported reliability coefficients of .82 and .91 for the overall scale.

5.2.1.4 Caregiver outcomes

5.2.1.4.1 Outcomes specific to the caregiving situation

5.2.1.4.1.1 The Caregiver Distress Scale (Cousins, Davies et al., 2002)[1]

Caregiver outcomes *specific* to the caregiving situation were assessed using the 17-item Caregiver Distress Scale (CDS; Cousins, Davies et al., 2002). The subjects are presented with statements portraying possible problems that may arise when providing care to a family relative, for example " I feel pressured between giving to (the care-receiver) and others in the family" and are asked to choose from five possible answers: *strongly disagree*, *disagree*, *neutral*, *agree* or *strongly agree*. The overall scale score can range from 17 to 85, higher scores indicating higher levels of distress.

The CDS comprises five distinct dimensions that have a potential negative impact on caregivers: *relationship distress*, *emotional burden*, *care-receiver demands*, *social impact* and *personal cost*.

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[1] The scale was obtained from the author in early 2000, before the publication of the article.

The authors report that all dimensions had high internal consistencies. In this study, the five dimensions of the CDS are used to measure specific negative outcomes resulting from giving care to a family relative suffering from HF.

5.2.1.4.1.2 Satisfaction with role of caregiver

Positive aspects of providing care were measured by the satisfaction with role as a caregiver subscale of the Sense of Competence Questionnaire (SCQ; Scholte et al., 1998). The subscale consists of 12 items measuring positive reactions to giving care, for example " I feel pleased with my interactions with my (care-receiver)". There are four choices of answer: *disagree very much, disagree, agree* and *agree very much*. The score on the subscale can range from 12 to 48, when higher scores represent *lower* levels of satisfaction with the role of caregiver. The authors reported a reliability coefficient of .75 for the subscale.

5.2.1.4.2 Outcomes non-specific to the caregiving situation

5.2.1.4.2. 1 Caregiver depression

Caregiver depression was measured using the Centre for Epidemiological Studies depression Scale (CES-D; Radloff, 1977). The original CES-D is a 20-item, single factor scale, which was designed to measure depressive symptoms in community populations and has been used successfully with caregivers (e.g. Hooker et al., 1992; O'Rourke and Tuokko, 2000). A shorter 10-item, yes/no format scale was proposed by Kohout et al., 1993 and recently reliability statistics confirmed that the proprieties of the 10-item CES-D are comparable to those reported for the original CES-D (Irwin et al., 1999). Consequently, the 10-item CES-D was used in this study to measure caregivers' level of depression.

5.2.1.4.2.2 Caregiver anxiety

Caregiver level of anxiety was measured with the same measured used to asses patients' anxiety, namely the state part of the Spielberger State-Trait Anxiety Inventory (STAI; Spielberger et al. 1983).

5.2.2 Design

The present study had a longitudinal design with two phases of testing, the second phase being approximately 6 months after the first phase. Each phase consisted of two visits to each dyad (or patient only if the patient did not have a caregiver). In the first of the two visits of each phase mainly patient data was collected. A pack of questionnaires (each) were left with the patient and the caregiver to complete during the week ahead. The second visits consisted in administering the neuropsychological tests to the patient, interviewing the caregiver and checking whether the questionnaires were completed fully.

5.2.3 Ethical Considerations

Participation in the study was voluntary and informants had the right to decide about participation or withdrawal from the study at any point in time. Each patient and caregiver was given or read an information sheet. They signed a consent form to acknowledge that they understood their voluntary status and that the data will be treated confidentially. Ethical approval for the research design was obtained from the Wirral Health Authority.

5.2.4 Subjects

The informants were 100 individuals diagnosed as suffering from heart failure and 53 caregivers. The patients were recruited from HF outpatient cardiac clinics at Arrowe Park Hospital (APH) by a cardiac consultant or a HF specialist nurse, according to the following inclusion and exclusion criteria:

Inclusion criteria

1. Patients should be identified as *stable* symptomatic HF patients at the beginning of the study (New York Heart Association class 2, 3 or 4).
2. Patients should be living at home and receiving family care. They should be age 65 or over[1].

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[1] Due to difficulties in recruiting patients to the study, this inclusion criteria was relaxed during the first phase to include some patients without caregivers and some younger patients.

3. Their MMSE score should be 17+ (to ensure they understand the questionnaires and interview).

Exclusion criteria

1. Patients who have a history of brain injury or neurological illness.
2. Patients diagnosed with major psychiatric symptoms in the previous five years.
3. Patients whose health status or their caregivers' health status was such that that they cannot reasonably be expected to survive to undertake a second interview at 6 and months after the first phase.

Consecutive patients who attended HF clinics at APH during the recruitment period were invited to take part in a research project entitled "Psychological aspects of Heart Failure". There was no payment for participation. Those who expressed interest in taking part in the project were given an information sheet containing brief details of the nature and design of the research to take away. The consultant (or HF specialist nurse) then forwarded the contact information to the researcher, who rang patients at home to make an appointment. Although no exact information regarding the percentage of patients who declined to take part in the project was collected, it was estimated that 20% of potential participants refused to take part at this stage.

5.2.4.1 Heart Failure patients

The sample of 100 patients consisted of 55 males and 45 females. At the first stage of testing the mean duration of illness was 4.27 years (SD ±1.81, range 1-7 years) and the mean age of patients was 76.31 (SD ± 7.48, range 56-91 years). Table 5.2.4.1.1 shows the clinical and socio-demographic data of patients with HF included in the present study.

Table 5.2.4.1.1 Clinical and socio-demographic data of HF patients

Gender (n)		Ejection Fraction	
Female	45	Mean (±SD)	36.5(±13.71)
Male	55	Range	15-86
Age (years)		MMSE score	
Mean (±SD)	76.31(±7.48)	Mean (±SD)	27.5(±2.31)
Range	56-91	Range	20-30
Illness duration (years)		Demented	7
Mean (±SD)	4.27(±1.81)	Non-demented	93
Range	1-7	Education (years)	
Severity of HF (NYHA class)		Mean(±SD)	10.05(±1.87)
Class II	37	Range	2-19
Class III	58	Living arrangements	
Class IV	5	Lives alone	40
Type of HF		Does not live alone	60
Left Ventricular Dysfunction	81		
Congestive Heart Failure	18		
Diastolic HF	1		

The majority of patients were classified as moderate HF (NYHA class III) and were diagnosed with Left Ventricular Dysfunction. The NYHA class allocation was assigned by either the cardiac consultant or HF nurse specialist. Seven patients were also demented (scored less than 24 on the MMSE).

5.2.4.2 Caregivers

Of the 53 caregivers, 41 were female and 12 were male. 42 were married to the patient, 10 were adult children and one was a sister of a male patient. With the exception of four of the daughters, one son and one sister, all the caregivers lived with the patient. Table 5.2.4.2.1 shows the socio-demographic and health status data of the caregivers.

Table 5.2.4.2.1 Socio-demographic and health status data of caregivers

Gender (n)		Health status	
Female	41	Very poor	1
Male	12	Poor	13
Age (years)		Fair	24
Mean (±SD)	66.701(±13.14)	Good	11
Range	34-86	Very good	4
Dyadic relationship		Number of co-morbidities	
Husband	10	Mean(±SD)	1.36(±1.03)
Wife	32	Range	0-4
Daughter	8	Education (years)	
Son	2	Mean(±SD)	10.7(±2.10)
Sister	1	Range	8-19
Residence (n)		Hours of care per day	
With patient	47	Mean(±SD)	6.66(±6.42)
Not with patient	6	Range	1-24

One average, caregivers reported helping the patients for 6.6 hours a day. The standard deviation is large by comparison to the mean, however. When the *mode* rather than the mean of hours of care was examined, the majority of carers reported two or three hours of delivering care per day.

5.2.5 Procedure

HF patients were approached by their cardiac consultant or the HF specialist nurse during routines visits to the HF clinics in APH and asked if they would like to take part in a research project. Those patients who were willing to participate were given a sheet with information about the study, and their address and phone number were forwarded to the researcher at the Liverpool University.

After receiving these details, the researcher contacted the potential participant by phone. They were reminded about the study, and asked if they are willing to take part. Seven patients declined participation, despite their original willingness to take part. For those patients who wanted to join the research project, an appointment was made to visit the dyad at home, usually for the next week. Unless not possible, the second appointment was arranged one week after the first appointment.

5.2.5.1 Phase 1

5.2.5.1.1 Visit 1

The first visit began with a short overview of the study. Efforts were made to explain that testing would be at patients' pace, that they could have a break at any time they wish and that the testing time would typically be around two hours. Quite frequently however, patients became very fatigue or breathless and the testing had to postponed or cut short.

The first visit began with the collection of socio-demographic information from the patient and the caregiver when present (see Fig. 5.2.5.1.1.1). Next, a brief history of how patient come to be diagnosed with HF was collected. Patient was also asked how many times s/he went to hospital on account of their heart overall and in the last 12 months. The caregiver (if present) was asked to stay during this time to supplement information provided by the patient. After this introductory part, it was explained to the caregiver that the rest of the interview will be conducted with the patient alone.

Fig. 5.2.5.1.1.1 Summary of the testing procedure for the first visit at phase 1

VISIT 1

Together
Introduction
Information Sheet
Consent Form
Demographic Information

Separate

PATIENT	**CAREGIVER**
Self-reported Health Co-morbidities Spirometer reading Subjective Breathlessness Subjective oedema Subjective Angina Medication and diagnosis knowledge HF Knowledge questionnaire Self-care Knowledge Lawton IADLs Social Isolation Questionnaire Negative reactions to care COPE	
Patient pack	**Caregiver pack**

Before leaving the patients' home, patients and caregivers were asked if they are willing to complete a set a questionnaires. Clear indications were given regarding the fact that they should complete the questionnaires *alone*. Moreover, it was stressed that any questions that prove too complicated or ambiguous should be left blank and that they will be discussed with the investigator at the following visit.

The *patient pack* consisted of nine self-administer questionnaires: ESS (Epworth Sleepiness Scale), FIS (Fatigue Impact Scale), GDS-15 (Geriatric Depression Scale), STAI (Anxiety Inventory), NEO-PR-I (personality), MLHFQ (Quality of life), IIP-32 (Interpersonal Difficulties), Social support questionnaire and MUIS (Illness Uncertainty).

The caregiver pack contained eleven self-administer questionnaires: mastery, self-esteem, IIP-32 (Interpersonal problems), NEO-PR-I (personality), CES-D-10 (depression), STAI (anxiety), social support, satisfaction with role of caregiver, CDS (Caregiver Distress Scale) and two NEO-PR-I questionnaires adapted to measure carer perception of patient personality at present and in the past.

5.2.5.1.2 Visit 2

The second visit consisted of assessing patients' cognitive status and interviewing the caregiver (see Fig. 5.2.5.1.2.1, below). The interview started by assessing the patient mental status. This was done separately from caregiver. When this was finished, patients were asked if they completed the questionnaire left in the previous week. Patient questionnaire pack was checked quickly to determine whether it had been done correctly, or if there are items missing. Patients were then helped to "fill out" items missing or unclear, however sometimes patients *choose* not to complete a specific item (or questionnaire) and it had to be accepted that they had a reason for not doing so.

Fig. 5.2.5.1.2.1 Summary of the testing procedure for the second visit at phase 1

VISIT 2

Together
Introduction

Separate

PATIENT

MMSE
RAVLT
Trail A
Trail B
Pegboard Test

CAREGIVER

Length of role as caregiver
Hours of care per day
Discretion
Self-reported health
Co-morbidities
Involvement in patient medication
Quality of the relationship (DAS)
Presence of confidant

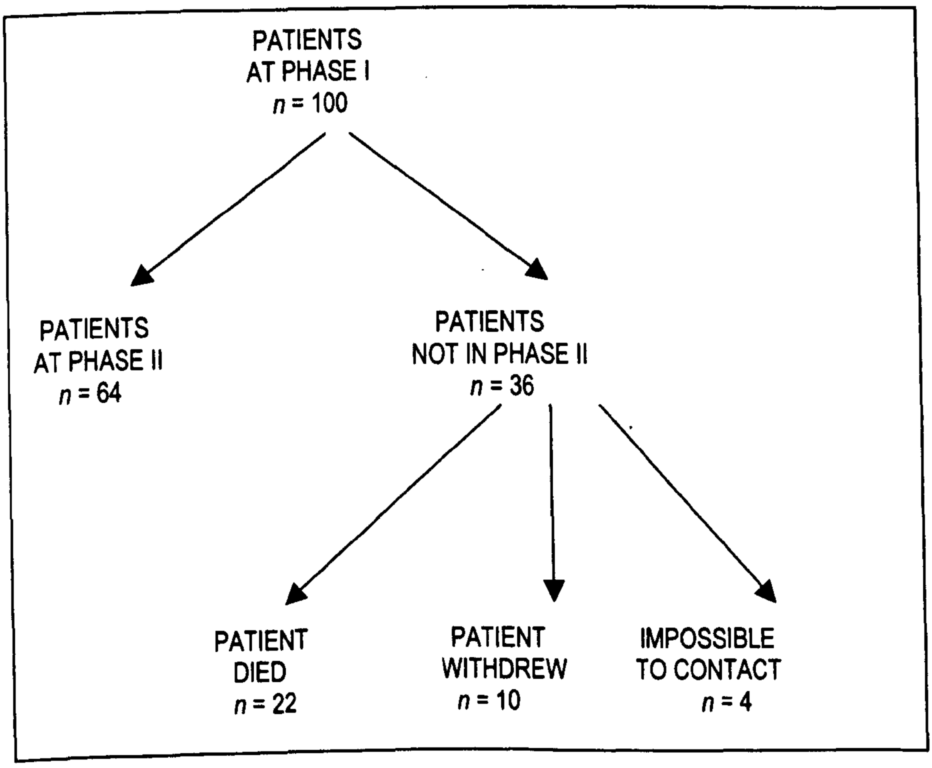
In the second part of visit 2, the caregiver (alone) was interviewed regarding their job demand (i.e. hours of care and discretion), length of role as caregiver, health status, involvement in administering patient medication and the quality of dyadic relationship. Similarly to the patient interview, at the end they were asked if they managed to complete the caregiver questionnaire pack. Again, the set of questionnaires were checked quickly, and attempts were made to complete all items/questionnaires not answered.

5.2.5.2 Testing interval

The period of testing for phase 1 was February 2001 to November 2002 and the period of testing for phase 2 was September 2001 to April 2003. The planned time for the follow-up study was 6 months after the first visits and for most patients this was the case. However, because of difficulties with recruitment at phase 1, there was a longer interval between the two phases for the earlier dyads. There was also a delay in follow up for some dyads because of patient being to ill or in hospital. The mean interval phase between phase 1 and phase 2 was 31 weeks (SD±6.2; range 28 to 95 weeks).

Sixty-four patients and 36 caregivers participated in phase 2 of the study. Figure 5.2.5.2.1 and 5.2.5.2.2, below illustrate rate and cause of attrition at phase 2.

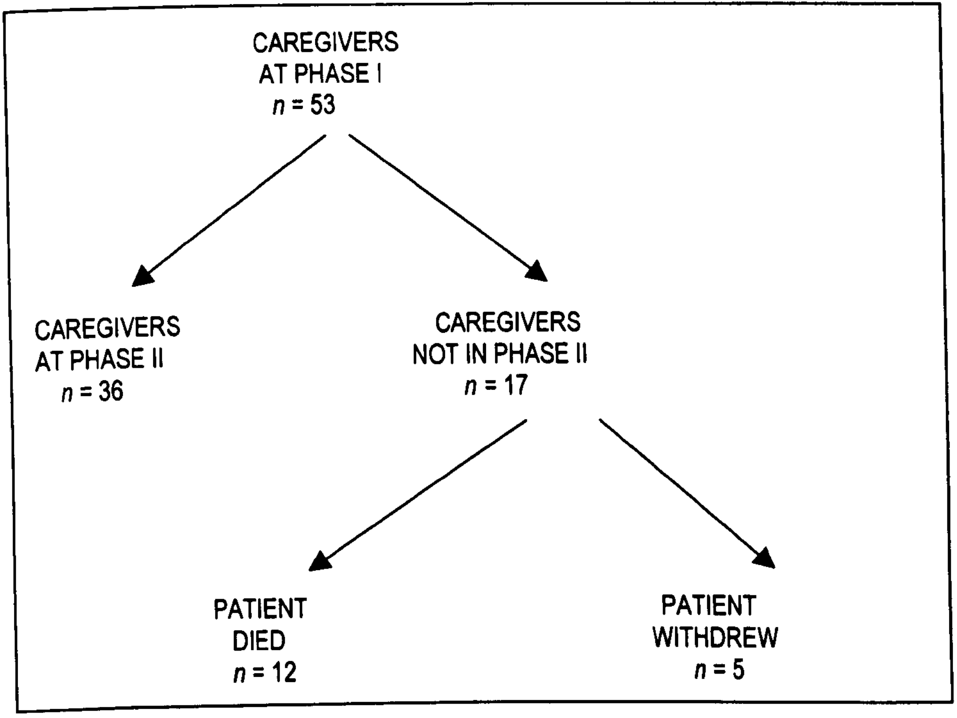
Figure 5.2.5.2.1 Patient participation and attrition at phase 2



It can be seen from Figure 5.2.5.2.1, above that the rate of patient attrition was 36%. Twenty-two patient died, 10 declined to take part in phase 2 and 4 were impossible to contact because they either moved house (3) or did not answer the phone (1).

Figure 5.2.5.2.2 illustrates caregiver attrition at phase 2.

Figure 5.2.5.2.2 Caregiver participation and attrition at phase 2



Thirty-six caregivers were interviewed in phase 2, giving a rate of attrition of 32%. The majority of caregivers did not participate at phase 2 because the care-recipient died in the follow-up period and five were caregivers of patients who opted not to participate in phase 2.

5.2.5.3 Phase 2

A number of measures were repeated at phase 2.

5.2.5.3.1 Visit 3

The emphasis was on how the patient has changed in the follow-up period. Measures of subjective health and subjective breathlessness, fatigue, oedema and self-care were repeated from phase 1. Patient level of disability was reassessed using the Lawton IADLs and spirometer readings were repeated. Measures of cognitive status (MMSE, RAVLT, Trail A and B and pegboard) were collected as in phase 1. Patients were also asked if they were hospitalised in the intervening period and if their answer was "yes" they were asked how many times and how long they were in hospital each. Visits to the GP (because of HF worsening) and cardiac clinic appointment were also noted. When the testing of the patient was completed patient and caregiver were given a questionnaire pack each to be completed in the following week.

Patient questionnaire pack consisted of three questionnaires repeated from phase 1, namely GDS-15 (depression), STAI (anxiety) and MLHFQ (quality of life). Caregiver questionnaire pack consisted of four questionnaires repeated from phase 1, namely CES-D (depression), STAI (anxiety), the CDS (caregiver distress scale) and a satisfaction with role of caregiver questionnaire.

5.2.5.3.2 Visit 4

At visit 4 mainly the caregiver was interviewed, repeating a number of measures given at phase 1 (caregiver health status, hours of care and discretion). The measure of dyadic adjustment was also collected. Caregiver and patient questionnaires were checked for items/ questionnaires missing and completed there and then if possible.

5.2.6 Data analysis

In the present study, a large amount of quantitative data was collected from both HF patients and their caregivers. The data were analysed using descriptive statistics, t-test, analyses of variance, correlation analyses, logistic and multiple regression using SPSS 11 for Windows. These results are presented in chapters six, seven and eight.

CHAPTER 6

RESULTS PHASE 1 - PATIENT PSYCHOLOGICAL OUTCOMES

6.0 Introduction and strategy of analyses

One major aim of this study was to identify variables of the HF illness situation that predict or influence patient distress and clinical outcomes. To do this, correlations of phase I patient distress measures and (i) patient variables and (ii) caregiver variables were examined. Important findings were further analysed using summary statistics, t-tests, correlations and partial correlations and ANCOVAs. Results of co-relational comparisons are presented at the conventional alpha significance level of 0.05. However, because of the large number of correlations conducted the probability of alpha error (rejecting a true null hypothesis) is high. To control for this, only results of bi-variate correlations significant at the more conservative level of 0.01 are interpreted. For all the other analyses the alpha significance level was set at 0.05. Many results are presented as tables for ease of reference. The effect of illness and patient variables on clinical outcomes at six months follow up will be presented in chapter eight. Mean scores, standard deviations and values of the Kolmogorov-Smirnov test of normality for each of the measures used are presented in Appendix 4 (patient) and 5 (caregiver).

One-hundred patients with heart failure and fifty three caregivers were interviewed. However, seven patients scored less than 24 on the MMSE, thus fulfilling the criteria for dementia. All *subjective* data from these patients was excluded from analyses, but the *objective* measures were included in relevant analyses. Negative reactions to care were collected from forty-eight patients who had a caregiver. Thus tables in this chapter contain the results of analyses of data obtained from 93 patients, with the exception of negative reactions to care questionnaire, which were collected from 48 patients. Seven different aspects of patient psychological distress were used as outcomes dependent variables. These were grouped into two categories: outcomes *specific* to the care-receiving situation and outcomes *non-specific* to the care-receiving situation (see Table 6.0.1).

Table 6.0.1 Summary of measures of patient psychological and clinical outcomes

Psychological outcomes (Phase I)		**Clinical outcomes (Phase II)**
Measures **specific** to the care-receiving situation	*Negative reactions (NR) to receiving care*: NR temporary loss of self-esteem = NRLSE NR indebtedness = NRI NR negative perceptions of carer behaviour = NRPCB	Mortality Re-hospitalisations Length of stay in hospital
Measures **non-specific** to the care-receiving situation	QoL Physical = QoLPHY QoL emotional = QoLEM Depression (GDS) Anxiety (STAI-P)	

Table 6.0.2, below sets out correlations between patient psychological distress measures.

Table 6.0. 2 Co-relation matrix of patient psychological outcomes (n = 48-93)

	NRLSE	NRI	NR PCB	QoL[1]-PHY	QoL[1]-EM	GDS	STAI-P
NRLSE	-	.38**	ns	ns	.36**	.38**	.41**
NRI			.34*	ns	ns	ns	.36**
NRPCB				ns	ns	ns	ns
QoL -PHY					.60***	.56***	.38***
QoL-EM						.77***	.70***
GDS							.71***
STAI-P							-

Pearson's correlations[1]; *p<.05 **p<.01 ***p<.001 (two-tailed)

[1] – Higher values represent *lower* quality of life

It can be seen from Table 6.0.2 above that the patient outcomes variables specific to the care-receiving situation (negative reactions to receiving care) are not correlated or weakly correlated to general measures of distress such as quality of life, anxiety and depression, suggesting that they measure different constructs.

The patient distress measures are known to be influenced by patient personality, especially by how emotional (neurotic) the patient is by temperament. The relation of these two sets of

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[1] Unless otherwise stated, all the correlations in this chapter are Pearson's correlations.

measures is fundamental to the way in which the analyses are conducted, since if there is a significant relationship between a personality factor and the distress measures this may confound correlations between various patient and caregiver factors and patient distress. If this is the case it is necessary to control for these differences in patient personality, in order to interpret the "true" relationship between various patient or caregiver variables and patient distress *independently* of patient personality. Table 6.0.3 below sets out the associations between patient psychological outcomes and patient neuroticism (PN).

Table 6.0.3 Correlations of patient personality measures and patient outcomes (N = 48-93)

	NR LSE	NRI	NR PCB	QoL-PHY	QoL-EM	GDS	STAIP
P neuroticism (PN)	.51***	ns	ns	.34***	.73***	.68***	.73***

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.0.3 above that PN is associated with five out of the seven measures of patient distress. To see the extent to which personality has to be partialled out, partial correlations were carried out between the patient outcomes controlling for P N (see Table 6.0.4).

Table 6.0.4 Partial correlation matrix of patient psychological outcomes (covarying PN) (N = 48-93).

	NR LSE	NRI	NR PCB	QoL-PHY	QoL-EM	GDS	STAIP
NRLSE	-	.31*	ns	ns	ns	ns	ns
NRI			.37*	ns	ns	ns	ns
NRPCB				ns	ns	ns	ns
QoL -PHY					.55***	.47***	ns
QoL-EM						.54***	.35***
GDS							.42***
STAIP							-

*p<.05 **p<.01 ***p<.001 (two-tailed)

Comparison of Table 6.0.2 and 6.0.4 shows that the net effect of controlling for caregiver emotionality is substantially to reduce the strength of all of the inter-correlations. For example the correlation between patient emotional quality of life and patient anxiety was reduced from the highly significant .70 to still significant but much reduced .35. In the unadjusted matrix (Table 6.0.2) the two variables can be considered to be measuring the same construct, but when the correction is made for the fact that patients in the sample differ in emotionality (Table 6.0.4) there is much less (12.25% as compared to 49%) of shared variance. Thus, although the constructs are related, the relationship is indirect, with PN taking the role of the "third variable". In other words, the unadjusted correlations in Table 6.0.2 are exaggerated by the differences in the sample in patient emotionality, which acts as a confounding variable. Cohen and Cohen (1983, cited in Cousins, 1997) propose that if a correlation coefficient between a predictor and a dependent variable was visible *reduced* when a potential moderator was controlled for, then that variable must have served as a **moderator** in the initial bivariate correlation analyses. If a correlation coefficient between a predictor and a dependent variable was notable *increased* when a potential moderator variable was controlled for in the equation, then that variable must have served as a **suppressor** in the initial bivariate correlation analyses. Therefore patient emotionality serves as a moderator of patient distress.

As a consequence, in this chapter patient neuroticism (PN) will be partialled out in all analyses involving patient *subjective* measures of illness, but will not be controlled in analyses of patient *objective* measures of illness and clinical outcomes.

6.1 Patient psychological outcomes

6.1.1 Patient variables and patient psychological outcomes

A large amount of information was collected from the patient. The associations between patient variables and patient psychological outcomes were organised into eight themes: *patient characteristics*, *objective illness severity* (objective measures of illness severity: age, illness duration, number of co-morbidities, LVEF, NYHA class, disability, FEV1 and FVC), *subjective illness severity* (subjective health, mental status, illness knowledge and self-care behaviours), *patient's personality*, *patient interpersonal functioning*, *patient coping style*, *patient social support and satisfaction with social support*. As stated in the introduction, because of the large number of variables in this investigation, an alpha level of 0.01 was used in all relational analyses.

(Correlations significant at an alpha level of 0.05 are presented with a star (*) for informational purposes, but are not interpreted).

6.1.1.1 Patient characteristics and patient psychological outcomes

Table 6.1.1.1.1 below sets out the inter-correlations between patient characteristics and psychological outcomes.

Table 6.1.1.1 Partial correlations of patient characteristics and patient psychological outcomes, covarying for PN (N = 48-93). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NR LSE	NRI	NR PCB	Qol PHY	QoL EM	GDS	STAI-P
Patient's age	ns (-.27*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Patient gender[1,2]	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Living alone[1]	ns (ns)	ns (ns)	.31* (.31*)	ns (ns)	ns (ns)	ns (ns)	.24* (ns)
Money trouble[1]	ns (ns)	ns (ns)	ns (-.27*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Education (years)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

ns = relationship is not statistically significant

*p<.05 **p<.01 ***p<.001 (two-tailed)

[1] – point bi-serial correlations

[2] – gender: 1 = male, 2 = female

The relationship between patient age and negative perceptions of carer behaviour was non-significant when the patient emotionality was accounted for. However, *younger* patients (under 65 years old, n = 6) reported more negative perceptions of caregiver behaviour than patient 65 years old or older (n = 46) independently of patient emotionality (ANCOVA, F = 4.14, p < .05).

Patients who had a caregiver but lived alone (n=8) reported *fewer* negative perceptions of carer behaviour that patients who lived in the same household as the carer (n = 40), independently of PN (ANCOVA, F = 7.04, p< .01).

In order to investigate the relationship between living arrangements and anxiety level, patients were divided into two groups: Group 1 consisted of people who scored below the average of 40.21(SD = 10.71) on STAI (n = 50) and Group 2 included patients who scored above the average (n = 43). Interestingly, significantly more patients *who did not live* by themselves scored above the mean on the STAI (chi-square = 5.55, p < .05), suggesting that living with someone else does not have a protective effect on anxiety levels in HF patients.

6.1.1.2 Objective measures of illness severity and patient distress

Table 6.1.1.2.1 below, sets out the correlations between the patient psychological outcomes and objective measures of HF severity when patient neuroticism is controlled.

Table 6.1.1.2.1 Partial correlations of objective measures of illness severity and patient outcomes, controlling for PN (N = 93). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NR LSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
Illness duration	ns (ns)	ns (ns)	ns (ns)	.24* (.26**)	ns (ns)	ns (ns)	ns (ns)
Co-morbidity index	ns (ns)	ns (ns)	ns (ns)	ns (.25*)	ns (.29**)	ns (.24*)	ns (.23*)
LFVF	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	-.23* (ns)	-.32** (ns)
NYHA class	ns (ns)	ns (ns)	ns (ns)	.57*** (.61***)	.35*** (.46***)	.38*** (.47***)	ns (.26**)
Disability (IADLs)	ns (ns)	ns (.26*)	ns (ns)	.55*** (.60***)	.34** (.47***)	.45*** (.55***)	ns (.32**)
FEV1	ns (ns)	ns (ns)	ns (ns)	ns (-.21*)	ns (ns)	ns (ns)	ns (ns)
FVC	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

Table 6.1.1.2.1 shows that there were strong positive correlations between two measures of objective illness severity (NYHA class and patient disability) and patient quality of life and depression *independently* of patient neuroticism. Interestingly, when PN *was* controlled, higher LVEF values were associated with lower levels of anxiety. This could be explained by the fact that increased anxiety has been reported to reduce cardiac output (McManon and Lip, 2000). Objective measurements of lung function were not associated with any of the outcomes measured. Further analyses were carried out to clarify the relationship between NYHA class and patient disability and patient quality of life and level of depression.

6.1.1.2.1 NYHA class and patient outcomes

There were only 4 patients classified as class IV (maximum) severity. For the purposes of analysis, those were added to class III patients and t-tests were performed on all measures of caregiver distress[1]. Table 6.1.2.1.1 presents the means, SDs and comparison t-values of patient distress according to NYHA class: group I consisted of class II patients (*n=36*) and group II consisted of class III and IV patients (*n=57*).

Table 6.1.1.2.1.1 T-test comparisons on all measures of patient distress according to NYHA class

	Group I: NYHA class II (means ±SD)	**Group II: NYHA class III and IV (means ±SD)**	**t**	**p**
Temporary loss of self-esteem	27.08(9.91)	27.39(4.93)	-.15	ns
Indebtedness	13.23(2.97)	13.05(2.79)	.20	ns
Negative perceptions of carer behaviour	14.62(3.73)	13.90(2.80)	.73	ns
Physical QoL	19.27(10.23)	31.45(5.58)	-6.61	p< .001
Emotional QoL	5.76(5.21)	12.50(6.89)	-5.35	p< .001
Patient depression	3.70(2.23)	7.13(3.59)	-5.66	p< .001
Patient anxiety	36.46(9.19)	42.70(11)	-2.95	p< .01

As can be seen from Table 6.1.2.1.1 above, patients in NYHA class III and IV reported significantly worse emotional and physical quality of life and more depression and anxiety than patients in NYHA class II.

ANCOVAs were performed to see if the association remained significant when patient neuroticism was covaried. When controlling for patient emotionality, the associations between severity of illness as measured by NYHA class and quality of life and patient depression remained highly significant (physical QoL: F = 34.85, p<.001; emotional QoL: F = 11.02, p<.001; depression: F = 10.59, p<.002). However, the relationship between NYHA class and patient anxiety was non-significant (anxiety: F = .15, p = .69), suggesting that that the relationship between NYHA class and anxiety is mediated by the patient neuroticism.

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[1] One inclusion criteria for this study was that patients should be *symptomatic*. Therefore no class I (asymptomatic) patients were recruited to the study.

6.1.1.2.2 Patient disability and patient distress

To further investigate the association of patient disability and distress, patients were divided into two groups: Group 1 consisted of patients who reported levels of disability below or equal to the population mean of 16.40, SD 5.22 (n =53) and Group 2 consisted of high disability patients (those who scored higher than the mean, n = 40). T-tests were then used to see if distress levels differ in the two groups (see Table 6.1.1.2.2.1, below)

Table 6.1.1.2.2.1 Means, SDs and t-test comparison of patient outcomes according to level of disability (Low versus high)

	Group I: low disability Means (±SD)	**Group II: high disability Means (±SD)**	**t**	**p**
Temporary loss of self-esteem	25.80(8.28)	27.87(4.74)	-1.13	ns
Indebtedness	12.25(2.91)	13.39(2.64)	-1.43	ns
Negative perceptions of carer behaviour	13.85(3.92)	14.16(2.46)	-.34	ns
Physical quality of life	23.02(10.67)	31.35(5.74)	-4.83	p< .001
Emotional quality of life	7.36(6.49)	13.08(6.54)	-4.18	p< .001
Patient depression	4.36(2.81)	7.63(3.56)	-4.93	p< .001
Patient anxiety	38.23(10.66)	42.85(10.33)	-2.09	p< .05

It that can be seen from table 6.1.1.2.2.1 above, that high disability patients reported significantly higher levels of depression and anxiety and lower quality of life than low disability patients. ANCOVAs were then carried out to test if these associations remained significant after controlling for patient emotionality. After covarying patient neuroticism, high levels of disability were still strongly correlated to higher levels of depression (F = 20.25, p<. 001) and lower physical (F = 12.71, p<. 001) and emotional (F = 13.57, p<. 001) quality of life. However, the associations between anxiety and level of disability became non-significant (F = .16, p=. 69), indicating that patient neuroticism acts as a mediator between patient anxiety and level of disability.

6.1.1.3 Subjective measures of illness severity and patient outcomes

Table 6.1.1.3.1 below sets out correlations between the dependent patient outcomes variables and potential patient subjective health predictor variables, controlling for patient emotionality.

Table 6.1.1.3.1 Partial correlations of patient outcome variables and subjective measures of illness severity covarying PN (N = 48-93). Values in brackets bivariate correlations (PN is NOT controlled)

		NR LSE	NRI	NR PCB	Qol PHY	QoL EM	GDS	STAIP
Subjective health		ns (-.31*)	ns (ns)	ns (ns)	-.48*** (.53***)	-.31** (-.43***)	-.45*** (-53***)	ns (-.26*)
Breathlessness		ns (ns)	ns (ns)	ns (ns)	.50*** (.54***)	.21* (.33***)	.33** (.41***)	ns (.23*)
Oedema		ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Fatigue	Cognitive	ns (.30*)	ns (ns)	ns (ns)	.35*** (.46***)	.40*** (.61***)	.26* (.52***)	ns (.46***)
	Physical	ns (ns)	ns (ns)	ns (ns)	.66*** (.71***)	.47*** (.61***)	.46*** (.62***)	ns (.37***)
	Social	ns (ns)	ns (ns)	ns (ns)	.41*** (.51***)	.29** (.54***)	.39*** (..60***)	ns (.49***)
Angina		ns (ns)	ns (ns)	ns (ns)	ns (.24*)	ns (.21*)	ns (ns)	ns (ns)
Sleep problems		ns (ns)	ns (ns)	ns (ns)	.34*** (.24*)	ns (.21*)	ns (.27*)	ns (.20*)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from table 6.1.1.3.1 above that better patient subjective health was associated with better quality of life and lower levels of depression independently of patient neuroticism. Patient reporting more subjective breathlessness had lower physical quality of life and more depression, suggesting that *subjective* reports of breathlessness are better predictors of patient quality of life than *objective measures* of breathlessness (FEV1 and FVC, see table 6.1.1.2.1). Patient reported levels of cognitive, physical and social fatigue were associated with lower quality of life and more depression even when patient neuroticism was controlled. Unsurprisingly, daytime sleepiness as measured by Epworth Sleepiness Questionnaire was associated with lower patient physical quality of life when patient neuroticism was partialled out. Interestingly, none of the subjective illness severity measures were predictive of patient anxiety after patient neuroticism was controlled, suggesting that patient neuroticism is a strong moderator of the correlations of patient anxiety and various predictor variables. For example, the strong correlation of r =. 46, p < .001 between patient anxiety and cognitive fatigue was reduced to a non-significant r = .15, p = .16 when patient emotionality was taken into account. Patient emotionality was found to be a *suppressor* of the association between daytime sleepiness and patient physical QoL, in that it strengthens the association from .24* to .34*** when controlled when PN is controlled. In other words, patient neuroticism masks the real association between high levels of daytime sleepiness and worse physical QoL.

6.1.1.4 Patient mental status and psychological outcomes

Table 6.1.1.4.1 sets out the correlations between measures of patient mental status and psychological outcomes at phase 1.

Table 6.1.1.4.1 Partial correlations of patient cognitive status and patient psychological outcomes when covarying for PN (N =48- 93). Values in brackets bivariate correlations (PN is NOT controlled)

	NR LSE	NRI	NR PCB	Qol PHY	QoL EM	GDS	STAIP
MMSE	ns (ns)	ns (ns)	ns (ns)	-.29** (-.33***)	ns (ns)	ns (-.24*)	ns (ns)
Trail A	ns (.36*)	ns (ns)	ns (ns)	ns (-.37**)	ns (-.32**)	ns (-.29*)	ns (ns)
Trail B	ns (-.35*)	ns (ns)	ns (ns)	ns (-.46***)	ns (-.27*)	ns -.29*)	ns (ns)
RAVLT	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Pegboard	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.1.1.4.1 above that when patient emotionality was controlled the only association significant at the stated .01 level was that between patient MMSE and physical quality of life: higher MMSE scores were associated with better physical quality of life. Interestingly, patient emotionality was a strong moderator between patient cognitive status and patient distress. For example, when patient neuroticism was controlled, the strong association between Trail B scores and physical QoL was deemed non-significant (-.46*** to -.23).

In order to further investigate the relationship between MMSE scores and patient distress, patients' scores on the MMSE were used to divide the sample into three groups: intact (29-30) *n=43*, impaired (24-28) *n=48* and demented (<24) *n*=7. This grouping is based on Hodges (1994) argument that although a score of less than 24 on the MMSE is a fairly good indicator of dementia, cognitively impaired people with a good background intellectual ability may attain a score above the cut-off point of 24. Therefore, three groups are needed. A one-way ANOVA using these three groups yielded the following results (see table 6.1.1.4.2)

Table 6.1.1.4.2 Means and SDs of patient quality of life and depression according to cognitive statusand group comparisons using ANOVAs.

	Group I: mentally intact (n = 43); means (±SD)	Group II: mentally impaired (n = 48) means (±SD)	Group III: dementing (n = 7) means (±SD)	F	p
Temporary loss of self-esteem	25.55(5.74)	28.03(6.66)	31.67(5.50)	1.70	ns
Indebtedness	13.10(3.25)	12.84(2.49)	15.67(2.08)	1.40	ns
Negative perceptions of carer behaviour	15.15(3.29)	13.32(2.76)	14.67(2.08)	2.39	ns
Physical quality of life	23.33(10.89)	29.63(57.54)	32.89(2.58)	7.26	p< .001
Emotional quality of life	8.44(6.64)	11.19(7.34)	14.89(6.15)	3.88	p< .05
Patient depression	4.81(3.20)	6.71(3.62)	9.11(3.70)	6.94	p< .01
Patient anxiety	38.40(11.16)	42.06(10.28)	46.44(14.84)	2.47	ns

It can be seen from Table 6.1.1.4.2 above that simple one- way ANOVAs indicated that there were significant differences in patient quality of life and level of depression according to their cognitive status. Further post-hoc analyses were conducted to investigate where the differences lay. Because the sample sizes were very different (only 7 cases in group III), Hochberg's GT2 post-hoc test (Field, 2002) was used to clarify between which groups the differences lay (see Table 6.1.1.4.3, below).

Table 6.1.1.4.3 Mean difference in patient quality of life and level of depression according to cognitive status

		Group I: mentally intact (n = 43)	**Group II: mentally impaired (n = 48)**	**Group III: dementing (n =7)**
		Mean difference		
Physical QoL	Group I	-	-6.30**	-9.56*
	Group II	6.30**	-	-3.26 *(ns)*
	Group III	9.56*	3.26 *(ns)*	-
Emotional QoL	Group I	-	-2.75 *(ns)*	-6.45*
	Group II	2.75*(ns)*	-	-3.70 *(ns)*
	Group III	6.75*	3.70 *(ns)*	-
Patient depression	Group I	-	-1.89*	-4.30**
	Group II	1.89*	-	-2.40 *(ns)*
	Group III	4.30*	2.40	-

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.1.1.4.3, above, that cognitively intact patient reported better physical quality of life and less depression that both the "impaired" and "dementing" patients. The emotional quality of life of cognitively intact patients was significantly better than of dementing patients, but not significantly better than that of impaired patients. There were no significant differences in patient quality of life and depression between impaired and dementing patients. ANCOVAs were used to test the above results when covarying patient neuroticism. When controlling for PN, the pattern of differences remained statistically significant. Therefore, level of cognitive impairment bears a direct relationship to psychological outcomes.

6.1.1.5 Patient knowledge of heart failure and psychological outcomes

Table 6.1.1.5.1 below sets out correlations between the dependent patient variables and patient specific and non-specific knowledge of HF when patient neuroticism is controlled.

Table 6.1.1.5.1Partial correlations of patient psychological outcomes and patient specific and non-specific measures of illness knowledge when PN is controlled (n = 48-93). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NR LSE	**NRI**	**NR PSB**	**Qol PHY**	**QoL EM**	**GDS**	**STAIP**
HF knowledge (HFKQ)	ns (-.29*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Medication knowledge	ns (-.28*)	ns (ns)	ns (ns)	ns (-.20*)	ns (ns)	ns (ns)	ns (ns)
Illness uncertainty	ns (ns)	ns (.36*)	ns (ns)	.24* (.36***)	ns (.41***)	ns (.35***)	ns (.32**)
Self-care behaviours	ns (ns)	ns (-.28*)	ns (ns)	-.32** (-.39***)	ns (-.34***)	-.23* (-.37***)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from Table 6.1.1.5.1 above, the relationship between patient uncertainty and self-care and non-specific measures of distress (quality of life, anxiety and depression) was mediated by patient neuroticism. When patient neuroticism was controlled, only one relationship remained significant at the agreed .01 level of significance: patients who reported higher levels of self-care perceived themselves as having better physical quality of life than patients who reported lower levels of self-care[1].

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[1] In the table the relationship is negative because of the way in which the variables were coded.

Further analyses were carried out to clarify the relationship between illness uncertainty and self-care behaviours and patient psychological status.

Patients were divided into two groups of illness uncertainty according to their scores by comparison to the population mean of 61.08, SD 14.95 (mean split). Group 1 consisted of patients who scored below or equal to the mean (n = 43) and Group 2 consisted of participants who scored above the mean on uncertainty questionnaire (n = 43). ANCOVAs were performed to investigate the relationship between level of uncertainty and patient outcomes when controlling for patient neuroticism. When patient uncertainty was grouped in low and high scores, patients who reported high levels of illness uncertainty perceived to have a poorer physical quality of life, independently of their neuroticism ($F = 5.53$, $p < .05$).

To confirm the findings from bivariate and partial correlations, patients were grouped according to their self-care knowledge scores into two groups (mean split): *low* self-care knowledge (scores below or equal to the mean of 17, SD 3.02, n = 43) and *high* self-care knowledge (n = 41). ANCOVAs (controlling for PN) were carried out to investigate the relationship between level of self-care and patient psychological outcomes. Patients who reported a higher than average knowledge of self-care behaviours also reported better physical quality of life ($F = 6.94$, $p < .01$), better emotional quality of life ($F = 4.83$. $p< .05$) and lower levels of depression ($F = 10.96$, $p< .001$) than patients who scored equally or below the mean on the self-care questionnaire, independently of their neuroticism.

6.1.1.6. Patient personality and patient psychological outcomes

As stated in the introduction, it was hypothesised that patient personality is a potential predictor of patient distress. In this research three subscales (neuroticism, extraversion and consciousness) of the NEO-PI-R (Costa & McCrae, 1992) were used as the assessment tool for both patient and carer personality because it has British validated norms (Egan et al, 2000). The alpha coefficients for this sample were good (see Table 6.1.1.6.1).

Table 6.1.1.6.1 Alpha coefficients of the NEO-PI-R according to patient sample

	Patients (n=86)
Neuroticism	.86
Extraversion	.76
Conscientiousness	.82

British norms were used to consider the personality distribution of HF patients (see table 6.1.1.6.2 below).

Table 6.1.1.6.2 Percentage of patient personality more than two standard deviations above or below the norm mean on NEO-PI-R personality scales.

	Patients (n = 86)	
	%Below normal range	%Above normal range
Neuroticism	1.1	1.1
Extraversion	12	2.2
Conscientiousness	1.1	4.3

It can be seen from Table 6.1.1.6.1, above, that in this sample, patients' levels of neuroticism and conscientiousness were comparable to those of the normative data (Eagan et al., 2000). However, 12% of the patients' responses on the extraversion scale were outside the normal range with respect to extraversion, suggesting that a random sample of HF patients have a certain "personality profile". T-tests were carried out to compare patient psychological status according to their reports of normal/abnormal extraversion (see table 6.1.1 6.3, below).

Table 6.1.1.6.3 Means, SDs and T-test comparisons of patient outcomes according to reported extraversion (N = 93)

	Group I: extraversion outside the normal range (n = 11) means (±SD)	Group II: extraversion within the normal range (n = 82) means (±SD)	t	p
NYHA class	3.00(.44)	2.62(.58)	2.55	P<.05
Temporary loss of self-esteem	28.40(6.46)	27.51(6.74)	.28	ns
Indebtedness	13.80(3.03)	13.19(2.67)	.68	ns
Negative perceptions of carer behaviour	15.60(3.64)	14.02(2.95)	1.10	ns
Physical quality of life	33.09(4.06)	26.22(10.19)	4.11	p< .001
Emotional quality of life	16.45(6.89)	9.60(6.95)	3.06	p< .01
Patient depression	9.73(3.17)	5.58(3.50)	3.65	p< .001
Patient anxiety	50.45(11.09)	39.80(10.99)	3.01	p< .01

It can be seen from Table 6.1.1.6.3, above that patients who perceived themselves as being outside the normal range with respect to extraversion were more ill, and reported lower physical and emotional QoL and worse levels of depression and anxiety than patients whose responses on the extraversion scale of the NEO-PI-R were within the normal range. However, when the patient neuroticism was controlled using ANCOVAs, all these relationships were deemed non-significant, suggesting that neuroticism moderates the association between low extraversion and worse patient psychological outcomes. These results are surprising, because personality factors are reported to be independent (Costa and McCrae, 1992). However, recent research carried in the UK has suggested that the neuroticism, agreeableness and conscientiousness factors of the NEO are more stable than the openness and extraversion factors (Egan et al., 2000).

Further correlations were carried out to investigate the relationships between patient personality (neuroticism, extraversion and conscientiousness) as reported by patient (P) and patient outcomes (see Table 6.1.1.6.4, below).

Table 6.1.1.6.4 Partial correlations between patient personality variables and patient psychological status when PN is controlled (n= 48-93). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL - PHY	QoL-EM	GDS	STAIP
P neuroticism	(.51***)	(ns)	(ns)	(.34***)	(.73***)	(.68***)	(.73***)
P extraversion	ns (ns)	ns (ns)	ns (ns)	-.27* (-.34**)	-.26* (-.39***)	-.40*** (-.48***)	ns (-.34***)
P conscientiousness	ns (-.30*)	ns (ns)	ns (ns)	ns (ns)	ns (-.36***)	ns (-.40***)	ns (-.38***)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.1.1.6.3 above that patient neuroticism is strongly correlated with five out of the seven patient outcome measures. Patient extraversion was found to be associated with patient level of depression independently of patient emotionality, in that more extraverted patients were significantly less depressed than less extraverted participants.

6.1.1.7 Patient variables and patient interpersonal problems

The Inventory of Interpersonal Problems IIP-32 (Horowitz et al. 2000) was completed by the patients in order to identify patient level of difficulty in eight domains of interpersonal functioning: Domineering/Controlling, Vindictive/Self-Centred, Cold/Distant, Socially Inhibited, Non- Assertive, Overly Accommodating, Self-sacrificing and Intrusive/ Needy. Table 6.1.1.7.1 sets out the correlations between patient domains of interpersonal functioning and patient psychological outcomes, controlling for patient emotionality.

Table 6.1.1.7.1 Partial correlations of patient interpersonal functioning and patient psychological outcomes when controlling for patient neuroticism (n = 48-73). Values in brackets represent bivariate correlation (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL - PHY	QoL- EM	GDS	STAIP
Domineering/ Controlling	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Vindictive / Self-centred	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Cold/Distant	ns (ns)	ns (-.33*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Socially inhibited	ns (.35*)	ns (ns)	ns (ns)	ns (.26*)	ns (.40***)	ns (.41***)	ns (.36**)
Non-assertive	ns (.40**)	ns (ns)	ns (ns)	ns (.24*)	ns (.47***)	ns (.47***)	ns (.53***)
Overly accommodating	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.41***)	ns (.29*)	ns (.41***)
Self-sacrificing	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.23*)	ns (ns)	ns (.31**)
Intrusive/needy	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.28*)	ns (ns)	ns (.30**)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from Table 6.1.1.7.1 above, none of the patient domains of interpersonal functioning was associated with patient outcomes when patient emotionality was partialled out. Patient emotionality was a strong *moderator* of the associations between thee domains of interpersonal functioning and various aspects of patient psychological status. Firstly, patient personality moderated the relationship between higher scores on the "socially inhibited" domain and lower emotional QoL (.40***→ .16), higher depression (.41***→ .19) and higher anxiety (.36**→. 08). Secondly, it moderated the relationship between higher scores on the "non-assertive" domain and lower emotional QoL (.47***→.11), higher depression (.47***→.15) and higher anxiety (.53***→.21). Thirdly, it moderated the relationship between higher scores on the "overly accommodating" domain and lower emotional QoL (.41***→ .11) and higher anxiety (.41***→. 11).

In order to further analyse these relationships, for each interpersonal domain patients were grouped according to their score in relation to the population mean (mean split). ANCOVAs (controlling for patient emotionality) were then carried out to explore the relationships between interpersonal domains and patient outcomes. Patients who had a caregiver and scored above the mean on two domains on interpersonal functioning (Cold-Distant and Vindictive-Self-centered) reported higher *levels of indebtedness* to the carer than patients who scored below the mean on theses domains (see Table 6.1.1.7.2), even when patient neuroticism was taken into account.

Table 6.1.1.7.2 Means, SDs and F-value of patient reports of indebtedness according to high and low levels on "vindictive/self-centred" and "cold/distant" domains of interpersonal functioning (controlling for patient emotionality)

Interpersonal domain		Indebtedness Mean (SD)	F	p
Vindictive/ Self-centred	High level (n=29)	14.57(2.02)	4.81	p <. 05
	Low level (n = 14)	12.69(2.81)		
Cold/ Distant	High level (n=25)	14.78(2.31)	11.04	p <. 01
	Low level (n = 18)	12.24(2.50)		

Interestingly, on one hand, when a direct effect between difficulties in interpersonal functioning and patient psychological outcomes was sought, associations were identified between interpersonal difficulties and patient outcomes *non-specific* to the care-receiving situation. However, all these relationships were found to be non-significant when patient neuroticism was controlled, suggesting that interpersonal difficulties did not explained unique variance in the outcome over and above neuroticism. On the other hand, a number of associations between patient interpersonal difficulties and outcomes *specific* to the caregiving situation remained significant when patient emotionality was controlled. It could be argued that the interpersonal domains measured by the IIP-32 (Horovitz et al., 2000) reflect the social facet of personality and represent *more* than patient neuroticism. Moreover, they are meaningful only when viewed in an interpersonal process framework, such as caregiving – care-receiving.

6.1.1.8 Patient coping style and patient psychological outcomes

COPE (Carver et al., 1989) was administrated to patients in order to ascertain ways in which they deal with their illness. COPE consists of fifteen different ways of coping: active coping, planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, turning to religion, positive reinterpretation and growth, restraint coping, acceptance, focus on and venting of emotion, denial, mental disengagement, behavioural disengagement, alcohol/drug use and humour. Table 6.1.1.8.1 below sets out correlations between patient coping style and patient outcomes variables controlling for patient emotionality.

Table 6.1.1.8.1 Partial correlations of patient coping styles and patient outcomes when patient emotionality is controlled (n = 48-73). Values in brackets represent results bivariate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
Active coping	ns (-.29*)	ns (ns)	ns (ns)	ns (-.33**)	ns (-.40***)	ns (-.40***)	ns (-.33**)
Planning	ns (-.30*)	ns (-.30*)	ns	ns (-.32**)	ns (-.34**)	ns (-.37***)	ns (-.28*)
Seeking instrumental social support	ns (ns)	-.32* (-.36**)	ns (ns)	ns (ns)	ns (-.25*)	ns (-.33**)	ns (ns)
Seeking emotional social support	ns (ns)	ns (ns)	-.36* (-.36*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Suppression of competing activities	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.27* (-.28*)	ns (ns)	ns (ns)
Turning to religion	ns (ns)	-.34* (-. 31*)	-.41** (-.42**)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Positive re- interpretation and growth	ns (-.34*)	ns (-.29*)	-.48*** (-.41**)	ns (ns)	ns (-.35**)	ns (-.34**)	ns (-.35***)
Restraint coping	ns (-.36*)	-.30* (-.34*)	ns (ns)	ns (ns)	ns (ns)	ns (-.32**)	ns (-.29**)
Acceptance	ns (ns)	ns (ns)	-.32* (ns)	ns (ns)	ns (ns)	ns (ns)	.24* (ns)
Focus on and venting of emotions	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.27*)	-.27* (ns)	ns (.40***)
Denial	ns (ns)	ns (ns)	.30*	ns (ns)	ns (.30**)	ns (.29**)	ns (.22*)
Mental disengagement	ns (ns)	ns (ns)	ns (ns)	-.23* (-.24*)	ns (ns)	ns (ns)	ns (ns)
Behavioural disengagement	ns (.31*)	ns (ns)	ns (ns)	ns (.27*)	ns (.46***)	.24* (.51***)	ns (.46***)
Alcohol/drug use	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Humour	-.38** (-.32*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.1.1.8.1 above that patient emotionality acted as a powerful moderator between various ways of coping with the illness situation and patient outcomes. For example, controlling for patient neuroticism notably reduced the highly significant bi-variate correlations between coping through behavioural disengagement and emotional QoL (.46***→ .16), depression (.51***→.24*) and anxiety .46***→.12).

Patients who used religion and positive re-interpretation and growth as coping mechanisms reported significantly less negative perceptions of carer behaviour, independently of patient neuroticism. Patients who used humour as a way of coping with illness reported significantly less temporary loss on self-esteem than those who used humour less (controlling for PN).

To further investigate the relationships between coping ways and patient outcomes, for each way of coping patients were divided into two groups according to their score in relation to the population mean (mean split). ANCOVAs were performed (controlling for patient emotionality) to test if scoring below or above the mean on various ways of coping influenced patient outcomes.

Seeking instrumental social support as a way of coping with illness was associated with fewer negative perceptions of carer behaviour when patient personality was taken into account ($F = 5.64$, $p < .05$).

Patients who sought emotional social support as a way of coping with illness reported significantly less levels of depression than patients who scored below the mean, independently of PN ($F = 5.55$, $p < .05$). Using religion and positive re-interpretations of events were associated with significantly fewer negative perceptions of carer behaviour when patient neuroticism was partialled out (religion: $F = 9.38$, $p < .01$; positive re-interpretation and growth: $F = 6.44$, $p < .05$).

Using behavioural disengagement to cope with illness was associated with worse patient outcomes on five out of seven outcome measures used when patient emotionality was accounted for. Scoring above the mean for behavioural disengagement was associated with worse physical quality of life (F = 9.27, p < .01), worse emotional quality of life (F = 47.60, p < .001), more temporary loss of self-esteem (F = 6.34, p < .01), more depression (F = 44.08, p < .001) and more anxiety (F = 69.62, p < .001). Therefore, behavioural disengagement which is similar to the concept of *denial of illness* (Sarafino et al., 1998) is associated with poor psychological outcomes, both specific and non-specific to the care-receiving situation.

6.1.1.9.1 Patient social support and patient outcomes

Table 6.1.1.9.1 below sets out the correlations between measures of patient social support and patient outcome variables.

Table 6.1.1.9 1 Partial correlations of patient social support and patient outcomes when patient N is controlled (n = 48-92). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
Social isolation	ns (ns)	ns (ns)	ns (ns)	ns (.23*)	ns (ns)	ns (ns)	ns (ns)
Social support T	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.32**)	ns (ns)	ns (ns)
Informational SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.24* (.32**)	ns (ns)	ns (ns)
Tangible SS	ns (ns)	ns (ns)	-.30* (-.30*)	ns (.21*)	ns (.24*)	ns (ns)	ns (ns)
Emotional SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.29* (ns)	ns (ns)	ns (ns)
Integrational SS	ns (ns)	ns (ns)	ns (ns)	-.22* (-.20*)	ns (ns)	-.25* (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from Table 6.1.1.9.1 above, none of the bivariate correlations of patient social support measures and patient outcomes reached the agreed level of significance of .01 when patient neuroticism was controlled. However, in order to further investigate these associations patient were divided into two groups on each measure according to their scores in report to the population mean on that score (mean split). ANCOVAs were then performed (co-varying patient emotionality) to analyse the relationship of low and high social support and patient outcome variables.

Interestingly, patients who scored lower than the mean on the informational support scale reported *better* emotional quality of life than patients who scored above the mean on this measure (F = 8.76, p < .01) when patient neuroticism is taken into account. It could be that patients who scored above the mean on the informational support subscale know that heart failure prognosis is poor, thus increasing their emotional distress.

Patients who scored above the mean on the tangible support and emotional support subscales reported less negative perceptions of carer behaviour (tangible support: F = 5.05, p < .05; emotional support: F = 6.02, p < .05) when patient emotionality was kept constant. There was a non-significant trend for patients who scored above the mean on the integration scale (helping others) to report less depression (F = 3.91, p = .051).

6.1.1.9.2. Patient distress and patient satisfaction with emotional support

Patients were also asked if they were satisfied with various forms of social support. Table 6.1.1.9.2.1 below sets out the frequencies of patients who were satisfied or not satisfied with their level of social support.

Table 6.1.1.9.2.1 Frequencies and percentages of patients' satisfaction with social support

Type of social support (SS)	Satisfied	Not satisfied
Informational SS	90 (96.8%)	2 (2.2%)
Tangible SS	87(93.5%)	5(6.5)
Emotional SS	85(91.4)	7(8.6%)
Integrational SS	76(81.7%)	16(17.4)

It can be seen from Table 6.1.1.9.2.1 above that the majority of patients were satisfied with their levels of informational support. Further ANCOVAs were carried out to investigate the relationship between satisfaction with tangible, emotional and integrational social support and patient outcome variables when patient emotionality was controlled.

Patients who were satisfied with their level of integrational support (helping others) reported less anxiety (ANCOVA, $F = 5.97$, $p < .05$) than patients who were not satisfied with integration, when patient neuroticism was controlled.

6.2 Patient distress and caregiver variables

According to Young's model (1994), it was expected that caregiver characteristics would influence patient outcomes. In this section, caregiver characteristics will be systematically correlated to patient outcomes measures to identify which caregiver characteristics are the best predictors of patient outcomes.

6.2.1 Caregiver characteristics and patient outcomes

Table 6.2.1.1.below sets out the correlations of caregiver characteristics and patient outcomes when patient emotionality was controlled.

Table 6.2.1.1 Partial correlations of patient outcomes and CG characteristics (PN controlled) (n = 53). Values in brackets represent bivariate correlations (PN is NOT controlled

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
CG age	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.28*)	ns (ns)	ns (ns)
CG gender[1]	-.40** (-.32*)	ns (ns)	ns (ns)	.32* (.32*)	ns (ns)	ns (ns)	ns (ns)
CG hours of care	ns (ns)	ns (ns)	ns (ns)	.35* (.40**)	ns (.33*)	ns (ns)	ns (ns)
CG discretion	ns (ns)	ns (ns)	ns (ns)	-.30* (ns)	ns (ns)	ns (ns)	ns (ns)
CG subjective H	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG co-morbidities	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

[1] – Point bi-serial correlation; 1 = male; 2 = female

It can be seen from Table 6.2.1 1 above, that caregiver gender was predictive of the level of negative reaction to care behaviour and patient physical quality of life. Further ANCOVAs (controlling for patient neuroticism) confirmed that patients whose *caregivers were male* reported significantly more temporary loss of self-esteem that patients whose caregivers were female ($F = 8.42$, $p < .01$). Moreover, patients whose caregivers were male reported significantly lower physical quality of life that patients whose caregiver was female. As all care-recipients of male caregivers were female, these findings suggest that a loss of the traditionally role of "nurturer" and provider of care is perceived as distressing by female patients. Caregiver hours of care and discretion were associated with patient physical quality of life: patients of caregivers who delivered care for a greater number of hours per day and had less discretion perceived themselves to have a *poorer* physical quality of life. However, the correlation could signify the association between job demand and discretion and patient physical disability. Accordingly, controlling for both patient emotionality *and* level of disability (IADLs), the relationship between patient physical quality of life and carer hours of care and discretion became non-significant (hours of care: r = 13, p = 37, discretion = -.10, p = .51), suggesting that patients who were more disabled require more care.

6.2.2.Patient outcomes and caregiver personality measures

Table 6.2.2.1 below sets out the correlations between caregiver personality measures and interpersonal functioning and patient outcomes.

Table 6.2.2.1 Partial correlations of caregiver personality, mastery, self-esteem and interpersonal functioning measures and patient outcomes when patient emotionality is controlled (N = 40 – 49). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
CG Neuroticism	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG Extraversion	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG Conscientiousness	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.31*)	ns (-.33*)
CG Mastery	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.41**)	ns (-.33*)	ns (-.40**)
CG self-esteem	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.32*)	ns (ns)	ns (.33*)
CG domineering	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG vindictive/self-centred	ns (ns)	ns (ns)	.38* (.39*)	ns (ns)	.37* (ns)	ns (ns)	ns (ns)
CG cold/distant	ns (ns)	ns (ns)	.42* (.42*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG socially inhibited	ns (ns)	-.44* (-.47**)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG non-assertive	ns (ns)	-.51** (-.54**)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

CG overly accommodating	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG self-sacrificing	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG Intrusive/need	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.2.2.1, that none of the caregiver personality measures correlated with patient outcomes at the agreed level of .01 significance when patient neuroticism was controlled, with one exception. Patients whose caregivers reported high scores on the "non-assertive" (or non-demanding) domain of interpersonal functioning reported *less indebtedness* to their caregivers than patients whose caregivers scored lower on this domain. Patient emotionality acted as a moderator between caregiver mastery and patient emotional QoL (-41**→-.20) and caregiver mastery and patient level of anxiety (-.40**→-.19).

To further investigate the relationships between caregiver personality and patient outcomes, for each personality measure caregivers were grouped into two groups, according to their score in relation to the population mean (mean split). Group 1 included caregivers who scored below the mean on a specific measure and group 2 contained caregivers who scored above the mean on that measure. ANCOVAs (controlling for patient neuroticism) were then performed to investigate the relationship between carer personality measures and patient outcomes. Patients whose caregivers scored above the mean on the vindictive/self-centred and self-sacrificing IIP domains reported significantly more *negative perceptions of carer behaviour* (Vindictive/self-centred subscale: F = 10.61, p < .01; Self-sacrificing subscale; F = 4.80, p< .05) than patients whose caregivers scored below the mean on these two subscales.

Patients of caregivers who scored above the mean on the cold-distant IIP subscale reported significantly lower emotional quality of life than those of caregivers who scored below the mean on this measure (F = 4.86, p <. 05), independently of patient neuroticism. Similarly to the results in Table 6.2.2.1, patients whose caregivers scored above the mean of the Non-assertive IIP subscale reported fewer feelings of indebtedness than patients whose carers scored below the mean on this measure (F = 4.61, p <. 05).

Surprisingly, neither bivariate correlations nor ANCOVAs revealed significant associations between caregiver neuroticism, extraversion and conscientiousness and patient outcomes, with one exception: patients whose caregivers scored above the mean on the conscientiousness subscale of the NEO-PI-PR reported significantly better physical quality of life than patients of caregivers who scored below the mean on this measure (F = 4.75, p <. 05).

6.2.3. Patient outcomes and caregiver social support

Table 6.2.3.1 below sets out the correlations of caregiver social support and patient outcomes, controlling for patient neuroticism.

Table 6.2.3.1 Partial correlations between patient outcomes and CG social support when patient N is controlled (n= 45). Values in brackets represent bivariate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
CG informational SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG tangible SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG emotional SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG integrational SS	ns (ns)	ns (ns)	-.37* (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.2.3.1 above that none of the measures of *caregiver* social support were associated with patient outcomes at the agreed level of .01 when patient emotionality was partialled out. Further analyses were carried out to investigate the relationship between caregiver satisfaction with social support and patient outcomes. Table 6.2.3.1 below sets out the frequencies and percentages of caregiver satisfaction with social support.

Table 6.2.3.1 Frequencies and percentages of caregiver satisfaction with social support

Type of social support (SS)	Satisfied	Not satisfied
Informational SS	42 (93.3%)	3 (6.7%)
Tangible SS	43(95.6%)	2(4.4)
Emotional SS	38(84.4%)	7(15.6%)
Integrational SS	38(84.4%)	7(15.6%)

It can be seen from table 6.2.3.1 above that the majority of caregivers were satisfied with their level of informational and tangible social support. Further analyses were carried out to investigate the relationship between caregiver satisfaction with emotional and integrational support and patient outcomes. Patients of caregivers who were satisfied with their level of emotional support reported significantly fewer negative reactions to carer behaviour than patients of caregivers who were unhappy with their level of emotional support (ANCOVA, F = 5.14, p< .05) when patient neuroticism was accounted for. Caregiver satisfaction with level of integrational support (helping others) did *not* affect any of patient outcome measures after patient neuroticism was controlled.

6.2.4 Dyadic relationship and patient outcomes

Table 6.2.4.1 below sets out the correlations between caregiver reported relationship quality as measured by DAS-7 and patient outcomes. Therefore, this is another way (besides the interpersonal difficulties measure) of conceiving the *reciprocal nature of caregiving* from the caregiver point of view.

6.2.4.1 Partial correlations between patient outcomes and caregiver reported relationship quality when patient emotionality was controlled (n = 49) Values in brackets represent bivariate correlations (PN is NOT controlled)

	NRLSE	**NRI**	**NR PCB**	**QoL PHY**	**QoL EM**	**GDS**	**STAIP**
CG DAS	ns (ns)	-.35* (-.41**)	-.40** (-.35*)	ns (ns)	ns (-.32*)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.2.4.1, above that overall, relationship quality as reported by the caregiver was associated with less indebtedness and fewer negative perceptions of carer behaviour when patient emotionality was controlled. Caregivers were also asked if the patient was their confidant. Patients of caregivers who viewed the patient as their confidant reported significantly *less* indebtedness than patients who were not perceived as the caregiver's confidant after controlling for patient emotionality (ANCOVA, F = 4.18, p < .05).

In the associations between relationship quality as reported by the caregiver and patient outcomes, patient emotionality acted both as a moderator and as a suppressor. It weakened the associations between quality of relationship and patient indebtedness (-.41**→-.35*) and patient emotional QoL (-.32*→-.05), thus acting as a moderator. However, it also strengthened the association between good relationship quality and fewer negative perceptions of carer behaviour (-.30*→-.40**), thus acting as a suppressor.

Therefore, an overall measure of relationship quality - as reported by the carer – was found to affect patient outcomes, thus reinforcing Young's (1994) argument that caregiver variables influence care-receiver outcomes. A limitation of the present study is that relationship quality as *perceived by the care-receiver* was not measured. However, it would be interesting to show that relationship quality (as reported by the patient) affects his/her psychological status.

6.2.5 Patient outcomes and caregiver outcomes

Table 6.2.5.1 below sets out the correlations between caregiver outcomes and patient outcomes when patient emotionality was controlled.

Table 6.2.5.1 Partial correlations of patient outcomes and caregiver outcomes controlling for patient emotionality (n=53). Values in brackets biavriate correlations (PN is NOT controlled)

	NRLSE	NRI	NR PCB	QoL PHY	QoL EM	GDS	STAIP
CG relationship distress	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG emotional burden	ns (ns)	ns (ns)	ns (ns)	ns (.37**)	.35* (.53***)	ns (.37**)	ns (.37**)
CG social impact	ns (ns)	ns (ns)	ns (ns)	.32* (.38**)	ns (.34*)	ns (.30*)	ns (ns)
CG care-receiver demands	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG personal costs	ns (ns)	ns (ns)	ns (ns)	ns (.30*)	.43** (.58***)	.33* (.51***)	ns (.42**)
CG satisfaction with role	ns (ns)	ns (ns)	.34* (.33*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
CG depression	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.39**)	ns (ns)	ns (.32*)
CG anxiety	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.45***)	ns (.42**)	.31* (.49***)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 6.2.5.1, above that one association between patient and caregiver outcomes reached the agreed significance of.01 when patient neuroticism was kept constant:

patients of caregivers who reported high "personal cost" due to providing care perceived their emotional QoL to be lower than that of patients whose caregivers reported less "personal cost" due to caregiving. Patients whose caregivers were *dissatisfied* with their role as carers reported significantly more negative perceptions of carer behaviour, however the relationship was significant only at .05 level. Interestingly, there was a positive relationship between patient and caregiver anxiety, but not between patient and caregiver depression.

The relationship could be relevant to the high number of re-hospitalisations in HF patients: patient anxiety could potentially increase caregiver level of anxiety, who may decide the patient should go to hospital "just to be on the safe side".

Again, patient neuroticism was found to be a powerful moderator of many associations between patient and caregiver outcomes. For example, the strong inverse relationship between caregiver emotional burden and patient emotional QoL was substantially reduced from .53*** to .35* when patient emotionality was kept constant. It also weakened the associations between caregiver "personal cost" due to caregiving and patient emotional QoL (.58***→.43**), patient depression (.51***→.33*) and patient anxiety (.42**→.16) and between caregiver anxiety and patient emotional QoL (.45***→.25), patient depression (.42**→.22) and patient anxiety (.49***→.31*). Therefore, patient and caregiver psychological outcomes are associated, albeit in a complex way, with patient neuroticism accounting for some, though not all of the shared variance.

6.3 Summary

As this chapter focuses on predictors of *patient* psychological well-being, it was found that illness severity, cognitive status, coping style, social support and especially neuroticism are important correlates. However, a number of *caregiver factors* also influenced patient well-being, namely carer level of distress, interpersonal problems, aspects of the care task and carer reported relationship quality, even when patient neuroticism was accounted for. However, Young's (1994) model stresses the reciprocal nature of the patient - carer relationship, therefore, causation cannot be attributed to caregivers' behaviours themselves. Nevertheless, these findings provide a starting point from which to address how changing caregiver behaviours via appropriate interventions such as Cognitive Behavioural Therapy (CBT) may influence not only their own well-being, but also that of their care-recipient.

CHAPTER 7

CAREGIVER DISTRESS OUTCOMES

7.0 Introduction and strategy of presentation of results

In the chapter six, variables of the illness situation that predict or influence *patient* psychological outcomes have been identified. In this chapter, the aim is to isolate variables of the HF illness situation that predict or influence *caregiver* distress. To do this, first phase 1 correlations of caregiver distress and (i) patient variables, (ii) caregiver variables were examined. Important findings were further analysed using summary statistics, t-tests, correlations, partial correlations, ANOVAs and ANCOVAs.

Results of relational comparisons are presented at the conventional alpha significance level of 0.05. However, as argued in chapter 6, because of the large number of correlations conducted the probability of alpha error (rejecting a true null hypothesis) is high. As a consequence, only results of bivariate correlations significant at the more conservative level of 0.01 are interpreted. For all the other analyses the alpha significance level was at 0.05.

When possible, results are presented in tables for ease of reference. Mean scores, standard deviations and values of the Kolmogorov-Smirnov test of normality for each of the measures used are presented in Appendix 4 (patient) and 5 (caregiver).

Eight different aspects of caregiver distress were used as outcomes dependent variables. Six outcomes are specific to the caregiving situation and two are general measures of psychological distress (see Table 7.0.1, below).

Table 7.0.1 Caregiver outcomes measures

Specific measures of caregiving distress	***Non-specific measures of caregiving distress***
Relationship Distress (RD)[1] Emotional Burden (EB)[2] Social Impact (SI)[3] Care-Receiver Demands[4] (CRD) Personal cost[5] (PC) Satisfaction with role of caregiver (SAT)	Depression (CESD) Anxiety (STAICG)

Correlations between caregiver (CG) outcome measures are presented in table 7.0.2.

Table 7.0.2 Correlation matrix of the eight caregiver distress outcome measures (N = 47-53).

	EB	SI	CRD	PC	SAT	CESD	STAICG
RD	.60***	.38**	.49***	.47***	.39**	.51***	.35**
EB		.42**	.43***	.64***	.51***	.61***	.67***
SI			.46***	.54***	ns	.31*	.27*
CRD				.37**	ns	ns	ns
PC					.31*	.42***	.51***
SAT						.42**	.38**
CESD							.60***

*p<.05 **p<.01 ***p<.001 (two-tailed)

Although on *theoretical* grounds the caregiver outcomes variables specific to the caregiving situation are separate from the general measures of distress such as anxiety and depression, *empirically* there are high to medium correlations between three measures of caregiver distress (relationship distress, emotional burden and personal cost) and caregiver depression and anxiety. Moreover, satisfaction with the role of caregiver (a positive outcome measure) is associated with both non-specific caregiving outcomes. The exception is the social impact subscale and the care-receiving demands subscale, which relate weakly (i.e. social impact) or not at all (i.e. care-receiver demands) with caregiver depression and anxiety. Therefore, although the outcome measures are related, it is clear however that they do not measure identical constructs.

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[1] **Relationship Distress**: This scale measures the effect that caring for a relative with HF has on their relationship. Example of item: " My relationship with (the care-receiver) no longer gives me pleasure".

[2] **Emotional Burden**: This scale measure the effect that providing care for a relative with HF has on the psychological status of the carer. Example of item "I feel overwhelmed" (by the caregiving).

[3] **Social Impact**: This scale measures the effects that providing care for a relative with HF has on the social life of the carer. Example of item: "(Because of caregiving) I take part in organised activities less".

[4] **Care-Receiver Demands**: This scale measure carer perception of patient demands on the carer due to their HF. Example of item: "(the care-recipient) makes more requests than necessary".

[5] **Personal Cost**: This scale the effects that providing care to a relative with HF has on the personal life of the carer. Example of item: "I feel that my personal life has suffered because of (taking care of the care-recipient)".

7.0.1 The case for controlling for caregiver personality

The caregiver distress measures are known to be negatively affected by carer personality, especially by how emotional (neurotic) the caregiver is by temperament. Similarly to the method with which analyses were carried out with patient outcomes in chapter 6, the relation between carer neuroticism and carer distress was considered to be fundamental to the way in which the analyses are conducted. Therefore, if there is a significant relationship between a personality factor and the distress measures this may confound correlations between various patient and caregiver factors and caregiver distress. *If this is the case,* it is necessary to control for these differences in caregiver personality, in order to interpret the "true" relationship between various patient or caregiver variables and caregiver distress *independently* of caregiver personality. Table 7.0.1.1 shows the correlations between caregiver neuroticism and caregiving outcomes.

Table 7.0.1.1 Correlations of caregiver personality factors with caregiver distress measures (N = 47)

	RD	EB	SI	CRD	PC	SAT	CES	STAICG
CG neuroticism	.43**	.57***	ns	.33*	.37**	.41**	.67***	.59***

*p<.05 **p<.01 ***p<.001 (two-tailed)

Table 7.0.1.1 shows clearly that caregiver neuroticism has strong links to caregiver outcomes, implying that it should be statistically controlled when relating other predictor variables to caregiver distress. To gauge the extent to which personality should to be partialled out, correlations were conducted between the different caregiver distress measures, controlling for caregiver neuroticism (CGN, see Table 7.0.1.2, below).

Table 7.0.1.2 Partial correlations of caregiver personality factors with caregiver distress measures controlling for CG N (N=47).

	EB	SI	CRD	PC	SAT	CESD	STAICG
RD	.47***	.31*	.41**	.37**	ns	.34*	ns
EB		.36*	.31*	.56***	.36*	37*	.50***
SI			.42**	.50***	ns	ns	ns
CRD				ns	ns	ns	ns
PC					ns	ns	.39**
SAT						ns	ns
CESD							.33*

Pearson's correlations[1] *p<.05 **p<.01 ***p<.001 (two-tailed)

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[1] Unless otherwise stated, all the bivariate correlations in this chapter are Pearson's correlations.

Comparison of Table 7.0.2 and Table 7.0.1.2 shows that controlling for CG neuroticism substantially weakened all of the inter-correlations. For example the correlation between emotional burden and depression is reduced from the highly significant .61 to just .37. In the unadjusted matrix (Table 7.0.2) the two variables can be considered to be measuring the same construct, but when the correction is made for the fact that caregivers in the sample differ in emotionality (Table 7.0.1.2) there is much less (13.6% as compared to 37.2% of the shared variance). Thus, although the constructs are related, the relationship is ***moderated*** by the caregiver emotionality. In other words, the unadjusted correlations in Table 7.0.2 are exaggerated by the differences in the sample in caregiver emotionality, which acts as a confounding variable.

Caregiver emotionality (CGN) acts as a confounder in interactions between various potential predictors of caregiver distress and caregiver distress measures, thus in order to examine the relationship of caregiver distress to other patient and caregiver variables it is paramount to control for the effects of N. Throughout this chapter caregiver N will be partialled out in all analyses involving caregiver outcomes.

7.1 Patient variables and caregiver distress

A large amount of information was collected from the patient. The associations between caregiver distress measures and patient variables are grouped into eight themes: *illness severity* (objective measures of illness severity: age, illness duration, number of co-morbidities, LVEF, NYHA class, disability, FEV1 and FVC), *patient subjective variables* (subjective health, cognitive status, illness knowledge and self-care behaviours), *patient's personality and caregiver perception of patient's personality change*, *patient interpersonal functioning*, *patient coping style*, *patient social support and satisfaction with social support* and *patient psychological status* (anxiety, depression, quality of life, negative mood and negative reactions to care).

Because of the large number of variables in this investigation, an alpha level of .01 was used in all relational analyses. Correlations significant at an alpha level of 0.05 are presented with (*) for informational purposes, but are not interpreted. Caregiver neuroticism (CGN) is controlled in all correlations involving caregiver outcomes.

7.1.1 Objective illness severity and caregiver distress

Table 7.1.1.1, below, sets out correlations between the dependent caregiver outcomes variables and potential patient predictor variables.

Table 7.1.1.1 Partial correlations of caregiver outcomes and objective measures of illness severity when controlling for CGN (n=53). Values in brackets represent bivariate correlations (CGN is NOT controlled)

		RD	**EB**	**SI**	**CRD**	**PC**	**SAT**	**CESD**	**STAI CG**
	Patient's age	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.32*)	ns (-.30*)	ns (-.29*)
Illness severity	Illness duration	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
	Co-morbidity index	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
	LFVF	ns (ns)	ns (-.26*)	ns (ns)	ns (ns)	ns (-.27*)	ns (-.28*)	ns (-.24*)	ns (ns)
	NYHA class[1]	ns (ns)	ns (ns)	.33* (.33**)	ns (ns)	.27* (.28*)	ns (ns)	ns (ns)	ns (ns)
	Disability (IADLs)	ns (.31*)	ns (ns)	.36** (.37**)	ns (ns)	.51*** (.51***)	ns (ns)	ns (ns)	ns (ns)
	FEV1	ns (ns)	ns (ns)	-.31* (-.34*)	ns (ns)	ns (-.28*)	ns (ns)	ns (ns)	ns (ns)
	FVC	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from table 7.1.1.1 above that caregivers who provided care for older HF patients reported fewer non-specific symptoms of distress (less anxiety and less depression), and were more satisfied with their role as caregivers[2]. However, all these relationships were mediated by caregiver neuroticism and were deemed non-significant when CG N was partialled out. However, the positive and strong relationships between patient level of disability and caregiver social impact and personal cost were unaffected by CGN, suggesting that patient disability affects caregiver distress independently of CG N. Interestingly, an objective measure of patient

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[1] The correlation is presented for reference only. Statistically, bi-variate correlations cannot be applied to NYHA class, which is a categorical variable with unequal variances. Further analyses are presented in section 7.1.1.1

[2] The relationship is negative because coding: high scores on the satisfaction scale represent *less* satisfaction with role of caregiver.

breathlessness (Forced Expiratory Volume in one second, FEV1) was positively but weakly correlated with caregiver social impact. Many patients reported that, because of their breathlessness they avoid going to places where there may be cigarette smoke. Thus this may impact on the carers' social life.

To summarise, seven objective measures of illness severity were considered to be potential predictors of caregiver distress, but only NYHA class and patient level of disability were associated with measures of caregiver distress *independently* of CGN. Further analyses will therefore concentrate on these two measures of heart failure severity.

7.1.1.1 NYHA class and caregiver distress

There were only 4 patients classified as class IV (maximum) severity. For the purposes of analysis, those were added to class III and t-tests were performed on all measures of caregiver distress. Table 7.1.1.1.1 sets out the means, SDs and comparison t-values of caregiving distress according to NYHA class: group I consisted of class II patients (*n=13*) and group II consisted of class III and IV patients (*n=40*)

Table 7.1.1.1.1 T-test comparisons on all measures of caregiver distress according to NYHA class

	Group I: NYHA class II (n=13) means (±SD)	Group II: NYHA class III and IV (n=40) means (±SD)	t	p
Relationship distress (RD)	6.77(3.14)	7.10 (2.76)	-.36	ns
Emotional Burden (EB)	9.15(4.29)	10.25(3.83)	-.87	ns
Social impact (SI)	6.15(2.73)	8.80(3.21)	-2.66	p<.01
Care-receiver demands (CRD)	5.31(2.05)	6.33(2.67)	-1.25	ns
Personal cost (PC)	6.77(3.49)	8.78(3.00)	-2.01	p<.05
Satisfaction with CG role SAT	23.58 (4.31)	23.21(4.00)	.27	ns
Caregiver depression (CESD)	3.23(2.61)	3.50 (2.42)	-.34	ns
Caregiver anxiety (STAI)	42.38(12.98)	43.05(13.17)	-.15	ns

As can be seen in table 7.1.1.1.1 above, caregivers who care for patients in class III or IV reported significantly more social impact and personal cost that those who care for class II severity. ANCOVAs co-varying CGN showed that theses associations remain significant after controlling for caregiver emotionality: social impact (F = 6.60, p<. 05) and personal cost (F = 4.16, p< .05). Therefore, illness severity clear impact on two facets of CG life, though other domains are less affected.

7.1.1.2 Patient disability and caregiver distress.

As reported above (Table 7.1.1.1) increased patient disability is associated with higher caregiver social impact and personal cost independent of CGN. However caregiver *non-specific* distress measures were not affected. To further investigate these relationships, patients were divided into two groups (mean split): low disability (scores lower or equal to the mean sample of 17, *n* =22) and high disability (scores higher than the mean, *n* = *31*). T-tests were then used to see if distress levels differ in the two groups (see Table 7.1.1.2.1 below)

Table 7.1.1.2.1 Means, SDs and t-test group comparison for caregiving outcomes according to patient level of disability (Low versus high).

	Group I: low disability means (±SD)	Group II: high disability means (±SD)	t-value	p
Relationship distress (RD)	6.27(2.45)	7.55(2.99)	-1.64	ns
Emotional Burden (EB)	8.86(3.63)	10.90(3.94)	-2.08	p<.05
Social impact (SI)	7.09(3.05)	8.90(3.28)	-2.03	p<.05
Care-receiver demands (CRD)	5.68(2.07)	6.35(2.84)	-.94	ns
Personal cost (PC)	6.68(2.35)	9.42(3.28)	-3.34	p<.01
Satisfaction with CG role SAT	23.05(4.44)	23.47(3.82)	-.35	ns
Caregiver depression (CESD)	2.50(2.48)	4.10(2.24)	-2.44	p<.05
Caregiver anxiety (STAI)	40.32(13.33)	44.71(12.66)	-1.21	ns

Caregivers of high disability patients reported more emotional burden, social impact, personal cost and higher levels of depression than caregivers of low disability patients. However, when CGN was controlled using ANCOVAs, only one relationship remained significant: caregivers of high disability patients reported significantly more personal cost than caregivers of low disability patients, independently of CGN (F = 6.96, p<.05). Therefore, severity of illness had a similar impact on carer distress, independently of the way it was measure: NYHA class was assessed by a cardiac consultant or HF specialist nurse (thus a clinical judgement) whereas disability was experimenter rated.

7.1.2 Caregiver variables and patient subjective health, mental status, illness knowledge and self-care behaviours

It was hypothesised that more severe scores on all the above patient severity variables will be associated with higher levels of caregiver distress. As stated in the introduction, because of the large numbers of variables in this investigation, a one-tailed alpha level of .01 was used in all relational analyses.

7.1.2.1 Caregiver variables and patient subjective health

Table 7.1.2.1.1 below sets out correlations between the dependent caregiver outcomes variables and potential patient subjective health predictor variables.

Table 7.1.2.1.1 Partial correlations between caregiver variables and patient subjective health measures when controlling for CGN (n=37-53). Values in brackets represent bivariate correlations (not controlling for CGN)

		RD	EB	SI	CRD	PC	SAT	CED	STAI CG
P subjective health		ns (ns)	-.29* (-.32**)	-.30* (-.33**)	ns (ns)	-.25* (-.25*)	ns (ns)	ns (ns)	-.25* (-.25*)
Breathlessness		ns (ns)	.28*	.33* (.36**)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Oedema		ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Fatigue	C^1	ns (.25*)	.37** (.37**)	.39** (.41***)	ns .24*	.33* .35**	ns (ns)	.35** (.34**)	ns (ns)
	P^2	ns (ns)	.34* (.43***)	.48*** (.51***)	.27* (.34**)	.30* (.38**)	ns (ns)	ns (.35**)	ns (.28*)
	S^3	ns (.27*)	ns (.33**)	.39** (.43***)	ns (ns)	.38** (.44***)	ns (ns)	ns (.30*)	ns (.32*)
Angina		ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Sleep problems		ns	.45*** (.24*)	.42** (.35**)	.39** (.29*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (Two-tailed)
C^1 – Fatigue cognitive sub-scale
P^2 – Fatigue physical sub-scale
S^3 – Fatigue social subscale

The relationship between patient subjective health measures and caregiver distress is complex. Caregivers of patients who perceived their health to be good reported less emotional burden and less social impact than caregivers of patients who perceive their health to be poor. However, these relationships were weakened (from .01 to .05 significance) when *CGN was controlled.* Similarly to the objective measure of breathlessness (FEV1), *increased subjective patient breathlessness* was associated with higher caregiver social impact and again, the relationship was mediated by CGN. Subjective measures of patient cognitive, physical and social fatigue were associated with specific (emotional burden, social impact and personal cost) and non-specific (depression) measures of carer distress, although CGN moderated all these relationships. Interestingly, CGN was found to be a strong *suppressor* of the relationships between patient sleep problems and emotional burden (.24*→. 45***), social impact (.35**→. 42**) and care-receiver demands (.29*→. 39**). In other words, caregiver neuroticism masks the "real" associations between patient daytime sleepiness and carer distress. Carers of patients who reported high levels of daytime sleepiness were more burdened emotionally, reported higher level of social impact and increased care-receiver demands that carers of patients who reported low levels of daytime sleepiness, independently of CGN. Therefore, specific aspects of patient subjective health, in particular fatigue and daytime sleepiness had a clear impact on caregiver well-being.

7.1.2.2 Caregiver variables and patient mental status

It was hypothesised that greater caregiver distress would be experienced by HF caregivers whose care-recipient scored lower on measures of cognitive status. Table 7.1.2.2.1 presents the correlations between measures of caregiver distress and the patient cognitive measures collected.

Table 7.1.2.2.1 Partial correlations between caregiver distress and patient cognitive status when controlling for CGN (n=46-52). Values in brackets represent bivariate results (not controlling for CGN)

	RD	EB	SI	CRD	PC	SAT	CED	STAI CG
MMSE	ns	ns (ns)	-.32* (-.33**)	ns (ns)	-.44*** (-.45***)	ns (ns)	ns (ns)	ns (ns)
Trail A	ns (ns)	ns (ns)	ns (ns)	ns (ns)	-.37* (ns)	ns (ns)	ns (ns)	ns (ns)
Trail B	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
RAVLT	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Pegboard	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.40* (.35*)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

Patient mental status as measured by the MMSE (Folstein et al, 1975) was associated with two *specific measures* of caregiver distress, namely social impact and personal cost. When caregiver personality was taken into account, the relationship between MMSE scores and social isolation weakened (-.33** →-.32*), however the association between patient MMSE scores and caregiver personal cost remained significant at .001 level. None of the associations between other measures of patient cognitive status and caregiver distress achieved significance at the agreed .01 level.

In order to further investigate the relationship between MMSE scores and caregiver distress care-recipients' scores on MMSE were used to divide the sample into three groups: intact (29-30), n=22, impaired (24-28), n=26 and demented (<24), n=5. This classification is based on the argument that although a score of less than 24 on the MMSE is a fairly good indicator of dementia, cognitively impaired people with a good background intellectual ability may attain a score above the cut-off point of 24 (Hodges, 1994). Therefore three groups may provide more information than two. A one-way ANOVA using these three groups detected significant differences in the social impact subscale of the caregiver distress scale (F=3.66, p <. 05). Further Tukey HSD tests illustrated that caregivers of cognitively "intact" patients reported significantly *less* social impact that caregivers of dementing patients. There was no difference in any other measures of caregiver distress. T-tests of caregiver distress measures when the care-recipients were grouped in "dementing" (n=5) and "non-dementing" (n=48) confirmed the above findings, namely caregivers of dementing patients reported higher levels of social impact as a result of providing care than caregivers of non-dementing HF patients (t = 2.60, p<.05). *Therefore, in the present study patient cognitive status mainly impacted on carer perceived social impact due to caregiving.*

7.1.2.3 Caregiver outcomes and patient knowledge of heart failure

Table 7.1.2.3.1 below, sets out correlations between the dependent caregiver variables and patient knowledge of HF.

Table 7.1.2.3.1 Partial correlations of patient knowledge of HF and self-care behaviours and caregiver distress measures when CGN is controlled. (n = 44-51). Values in brackets represent bivariate correlations (not controlling for CGN)

	RD	EB	SI	CRD	PC	SAT	CED	STAI CG
Medication Knowledge	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.30*)	ns (ns)	ns (ns)	ns (ns)
HF Knowledge (HFKQ)	ns (ns)	ns (-.27*)	ns (ns)	ns (-.24*)	ns (ns)	ns (ns)	ns (-.28*)	ns (ns)
Illness uncertainty	.32** (.41***)	ns (.28*)	.37** (.41***)	ns (ns)	.35** (.41***)	ns (ns)	.29* (.38**)	.25* (.35*)
Self-care behaviours	-.33* (-.44***)	-.33* (-.47***)	-.30* (-.36**)	ns (ns)	-.44*** (-.52***)	-.28* (-.39**)	-.38** (-.51***)	ns (-.28*)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from Table 7.1.2.3.1, above, patient specific knowledge of heart failure (such as understanding the connection between diuretics and breathlessness) was connected with *neither* specific or non-specific measures of caregiver distress. However, higher patient illness *uncertainty* (for example, not being sure that current medication is helping or not) was associated with both specific (greater relationship distress, social impact and personal cost) and non-specific (greater depression and anxiety) measures of caregiver distress. These relationships were mediated by caregiver neuroticism, in that when caregiver neuroticism was partialled out, all relationships became weaker, but were still statistically significant. Higher levels of patient self-care behaviours (such as exercising and diet) were correlated with *lower* levels of distress on all the outcomes specific to the caring situation (with the exception of care-receiver demands) and with lower carer depression. Thus, patient's level of specific knowledge of HF did not seem to affect CG outcomes, but the presence of uncertainty (which was found to be related to patient neuroticism) predicted greater CG distress. Moreover, greater patient knowledge of self-care behaviours predicted lower carer distress. It well may be that when patients use self-care, the carer perceives that patients are "in control" of their own situation and thus burden is reduced, whereas when patients display uncertainty they increase carer burden with responsibility for reassurance and possibly greater levels of care.

7.1.2.4 Caregiver variables and patient's personality and caregiver perception of personality change.

It was hypothesised that patient personality is a potential predictor of caregiver distress. In this research three subscales (neuroticism, extraversion and consciousness) of the NEO-PI-R (Costa & McCrae, 1992) was used as the assessment tool for both patient and carer personality because it has British validated norms (Egan et al, 2000). These norms were used to consider the personality distribution of HF patients and caregiver perception of patient personality (see table 7.1.2.4.1 below).

Table 7.1.2.4.1 Distribution of patients' and caregivers' perceptions of patient personality in relation to the population mean (±2 SD normal range)

	Patients (n=86)		Carer's perception of patients (n=43)	
	%Below normal range	%Above normal range	%Below normal range	%Above normal range
Neuroticism	1.1	1.1	2.3	4.7
Extraversion	12	2.2	14	-
Conscientiousness	1.1	4.3	2.3	4.7

It can be seen from the table above that caregiver's perception of their care recipient was quite similar to that of the patient. All personality subscales as reported by patient correlated to carer' s perception of patient personality as follows: neuroticism .67***, extraversion .49*** and consciousness .41**. Thus patient and caregiver perception of patient personality show good agreement overall. Reliability coefficients for the NEO-PI-R were acceptable, with the exception of carer's perception of patient conscientiousness, which was low (see Table 7.1.2.4.2, below).

Table 7.1.2.4.2 Alpha coefficients of the NEO-PI-R according to sample

	Patients (n=86)	Carer's perception of patients (n=43)
Neuroticism	.86	.89
Extraversion	.76	.81
Conscientiousness	.82	.61

Table 7.1.2.4.3, below, sets out correlations between patient personality as reported by patient (P), carer's perception of patient personality (CG) and carer's perception of patient personality change[1] when caregiver N is controlled.

Table 7.1.2.4.3 Partial correlations between patient personality as reported by patient, patient personality as reported by CG and CG perception of personality change and CG distress measures when CGN is controlled (n=38-45). Values in brackets bivariate correlations (CGN is NOT controlled)

	RD	**EB**	**SI**	**CRD**	**PC**	**SAT**	**CED**	**STAI CG**
P Neuroticism (P)	ns (ns)	.42** (.43**)	ns (.26*)	ns (ns)	.41** (.43***)	ns (ns)	.26* (.29*)	.39** (.40**)
P Extraversion (P)	-.34* (-.41**)	-.25* (-.36**)	ns (ns)	ns (ns)	-.48*** (-.53***)	ns (-.26)	ns (ns)	ns (ns)
P Consciousness (P)	-.30* (ns)	-.40** (-.28*)	-.31* (-.29*)	ns (ns)	-.38** (-.33*)	ns (ns)	-.30* (ns)	ns (ns)
P Neuroticism (CG)	ns (.29*)	.46*** (.60***)	.40** (.44**)	ns (.31*)	.59*** (.65***)	.34* (.48***)	ns (.48***)	.45** (.59***)
P Extraversion (CG)	ns (ns)	ns (ns)	-.35* (-.35*)	ns (ns)	-.32* (-.31*)	ns (ns)	-.28* (ns)	ns (ns)
P Consciousness (CG)	-.34* (-.39**)	ns (-.33)	ns (ns)	ns (ns)	-.43** (-.47***)	-.37** (-.42**)	-.29* (-.36**)	ns (-.26*)
P Neuroticism change (CG)	ns (ns)	.31* (.31*)	.45** (.46**)	ns (ns)	.57*** (.57***)	ns (ns)	ns (ns)	.33* (.33*)
P Extraversion change (CG)	ns (ns)	ns (ns)	.58*** (.50***)	.39* (ns)	.48** (.34*)	ns (ns)	ns (ns)	.45** (ns)
P Conscientiousness change (CG)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.42** (.44**)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As patients' accounts of their neuroticism, extraversion and conscientiousness were highly associated with carers' reports of patient personality, it was expected that similar associations will be found when correlating patient personality measures and carer distress. This was indeed the case. However, the strength of the associations were stronger when *carers*' perception of patient personality were used, as opposed to patients' perceptions of their *own* personality. For example, the strength of relationship between patient neuroticism and carer personal cost due to caregiving was .41** when using patient reports, but this increased to .59*** when using caregivers' reports of patient neuroticism. Caregivers of highly neurotic patients reported high levels of emotional burden due to providing care and high levels of anxiety, independently of CGN.

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[1] Carer's perception of personality change was investigated using an adaptation of the NEO-PI-R

Patient personality was consistently associated with carer personal cost as a result of caregiving. High patient neuroticism had a deleterious effect on this measure of carer distress, whereas high patient extraversion and conscientiousness had *beneficial* effects. Changes in patient personality over time (an increase in patient emotionality and a decrease in extraversion and conscientiousness) related to increased personal costs to the carer, independently of carer N. Moreover, a decrease in patient extraversion was strongly associated (r = .51***) with caregiver social impact due to caregiving. *Therefore, changes in patient personality (which may relate to loss of "role" as a spouse) has a negative impact on carer outcomes.*

Carer emotionality had both a moderator and a suppressor effect on the interactions between patient personality and personality change and caregiver distress. For example, controlling for CGN weakened the relationship between patient neuroticism as perceived by the caregiver and caregiver anxiety (.59***→.45**), thus acting as a moderator, but it strengthened the relationship between patient change in extraversion and carer social impact (.41**→.56***), thus acting as a suppressor. This complexity again reinforces the reciprocal nature of the dyadic relationship, presenting challenges to current methods and analysis.

7.1.2.5. Caregiver variables and patient interpersonal problems.

The Inventory of Interpersonal Problems IIP-32 (Horowitz et al. 2000) was completed by the patients in order to identify patient level of difficulty in eight domains of interpersonal functioning: Domineering/Controlling, Vindictive/Self-centred, Cold/ Distant, Socially Inhibited, Non – Assertive, Overly Accommodating, Self-sacrificing and Intrusive/ Needy. Bivariate correlations between these measures and caregiver distress outcomes (*n=42*) indicated that patient high scores on Cold/Distant domain was associated with higher caregiver relationship distress (r = .36**) and patient high scores on Self-Sacrificing domain were related with higher caregiver anxiety (r = .35**). When caregiver emotionality was controlled, all these relationships were found to be non-significant, suggesting that caregiver N mediates the relationship between patient interpersonal functioning and caregiver distress.

In order to further analyse these relationships, patients were divided into two groups for each interpersonal domain, using the mean scores in this population as the cut-off point: e.g. low on cold/distant (raw score lower or equal to the mean) and high on cold/distant domain (raw score higher than the mean).

Caregivers of patients who scored above the mean on the Domineering/Controlling domain reported more social impact (t = -.2.54, p< .05) and more care-receiver demands (t = -.30, p<. 01). ANCOVAs (controlling for CGN) confirmed these relationships: social impact (F= 4.82, p<. 05) and care-receiver demands (F = 6.81, p<. 05.)

Caregivers of patients who scored above the mean on Cold/Distant domain reported more relationship distress (t = -3.70, p<. 001) and more depression (t = -2.28, p<. 05) than caregivers of patients who scored less than the mean on this domain. When CGN was controlled, only the association between high patient scores on the cold/distant domain and increased carer relationship distress remained significant (F = 7.90, p< .01). *Therefore, specific patient personality types are associated with poorer psychological outcomes for the CG beyond the effect of patient neuroticism.*

7.1.2.6 Caregiver variables and patient coping style

COPE (Carver et al., 1989) was administrated to the patient in order to ascertain ways in which they deal with their illness. It was hypothesised that patient task orientated coping styles will positively affect caregiver outcomes, whereas avoidance style coping will have a deleterious effect on caregiver outcomes. COPE consists of fifteen different ways of coping: active coping, planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, turning to religion, positive reinterpretation and growth, restraint coping, acceptance, focus on and venting of emotion, denial, mental disengagement, behavioural disengagement, alcohol/drug use and humour. Table 7.1.2.6.1, below sets out correlations between patient coping styles and caregiver outcomes variables when caregiver emotionality is controlled[1].

Table 7.1.2.6.1 Partial correlations of CG distress variables and patient coping styles when CGN is controlled (n=41). Values in brackets represent bivariate correlations (CGN is NOT controlled)

	RD	**EB**	**SI**	**CRD**	**PC**	**SAT**	**CED**	**STAI CG**
Seeking Instrumental SS[1]	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.38*)	ns (ns)	-.44** (-.50***)	ns (ns)
Seeking emotional SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (-.41**)	ns (-.40**)	ns (ns)
Turning to religion	ns (-.38*)	ns (-.34*)	ns (ns)	ns (ns)	ns (ns)	ns (-.42**)	ns (-.48***)	ns (-.33*)
Restraint coping	ns (ns)	ns (ns)	ns (-.31*)	ns (ns)	-.51*** (-.49***)	ns (ns)	-.38* (ns)	ns (ns)
Behavioural disengagement	ns (ns)	ns (ns)	ns (ns)	ns (ns)	.54*** (.51***)	ns (ns)	ns (ns)	.40** (.33*)

*p<.05 **p<.01 ***p<.001 (two-tailed)

1 – SS = social support

It can be seen from Table 7.1.2.6.1, above that caregivers of patients who actively looked for instrumental social support (such as seeking advice, assistance or information) to help them cope with their heart failure reported lower levels of depression, independently of carer neuroticism. Seeking emotional social support and turning to religion to cope with HF were also associated with reduced carer depression and increased satisfaction with role as caregiver, however these relationships were mediated by carer's neuroticism. Restraint coping was conceptualised as an active coping strategy in the sense that the person's behaviour is focussed on dealing effectively with the stressor by waiting until an appropriates opportunity to act presents itself, holding oneself back and not acting prematurely (Carver et al., 1989). In this population, caregivers of patients who reported higher use of this coping strategy reported reduced personal cost as a result of providing care, independently of carer's neuroticism. Use of behavioural disengagement as a way of coping in HF patients was associated with increased carer personal cost and increased carer anxiety, independently of carer emotionality.

In this way, CG outcomes in response to patient coping style are similar to patient outcomes to the same styles. Active coping strategies are beneficial to both patient and caregiver, whereas

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[1] Only significant relationships are shown.

behavioural disengagement is deleterious to both. This may be due to increased patient well-being which in turn affects the CG beneficially.

7.1.2.7 Caregiver outcomes and patient social support.

Table 7.1.2.7.1, below sets out the association between caregiver distress measures and patient level of informational, tangible, emotional and integrational social support.

Table 7.1.2.7.1 Partial correlations of caregiver distress measures and patient social support (n = 44 –49). Values in brackets represent bivariate correlations (CGN is NOT controlled

	RD	EB	SI	CRD	PC	SAT	CED	STAI CG
P informational support	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.28*)	ns (ns)	ns (ns)	ns (ns)
P tangible support	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
P emotional support	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
P integrational support	ns (-.37**)	ns (ns)	ns (ns)	ns (ns)	ns (-.30*)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 7.1.2.7.1, above that the only significant relationship at the set level of .01 significance was between higher patient integrational support (helping others) and reduced carer relationship distress. However, the relationship was mediated by the carer personality, in that it disappeared when CGN was controlled.

Patients were also asked if they were satisfied with level of social support received. The majority of patients reported to be happy with their level of social support. Only one patient was unhappy with level of informational and tangible support received, four patients were unhappy with level of emotional support received and eleven patients were unhappy with integrational social support. Further t-tests were carried out to investigate the associations between patient satisfaction with level emotional and integrational support and carer distress.

7.1.2.7.1 Caregiver distress and patient satisfaction with emotional support

Independent t-tests were used to see if patient satisfaction with emotional support influenced the level of caregiver distress (see table 7.1.2.7.1.1 below).

Table 7.1.2.7.1.1 Means, SDs and T-test comparison between caregiver outcomes according to patient satisfaction with emotional support (ES).

	Group I: not satisfied with ES (n=4)[1]	Group II: satisfied with ES (n=48)	t-value	p
Relationship distress	10.25(3.59)	6.77(2.66)	2.45	p<.05
Emotional Burden	14(4.08)	9.54(3.74)	2.27	p<.05
Social impact	9.50(2.51)	8.02(3.36)	.85	ns
Care-receiver demands	8.75(3.77)	5.85(2.37)	2.39	p<.05
Personal cost	11.75(2.21)	7.94(3.13)	2.37	p<.05
Satisfaction with CG role	24.74(5.90)	23.07(3.88)	.79	ns
Caregiver depression	5.00(1.41)	3.35(2.48)	1.29	ns
Caregiver anxiety	52.00(13.36)	42.31(12.90)	1.43	ns

As can be seen from the above table, there was an overall tendency for caregivers to report more distress when patient is unhappy with level of emotional support. All specific measures of caregiver distress (with the exception of social impact) were associated with patient satisfaction with emotional support. All of these relationships remained significant at .05 level after CGN was controlled using ANCOVAs (relationship distress: F=5.29, p<.05; emotional burden: F= 6.18, p<.05; care-receiver demands: F = 4.86, p<.05; personal cost: F = 5.06, p<.05). Therefore, CG psychological outcomes seem to be affected by patient *satisfaction* with emotional support, rather than level of emotional support *per se.*

7.1.2.7.2 Caregiver distress and patient satisfaction with integrational support

Independent t-tests were used to ascertain whether patient satisfaction with integrational support (helping others) influenced the level of caregiver distress. Caregivers of patients who were unhappy with their level of integratonal support (mean 4.55, SD 1.44, n=11) reported significantly *less* care-receiver demands (t=- 2.26, p<. 05) than caregivers of patients satisfied with their level of integrational support (mean 6.48, SD 2.70, n = 40). At first this finding seems counterintuitive given that patients who were satisfied with their level of integrational support reported less anxiety (see section 6.1.1.9.2). However, as heart failure patients are very ill their desire to help others may translate into extra requests to their caregivers. This relationship was mediated by carer

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[1] Although the two samples vary greatly in sample size, the Levene's test for equality of variances was not significant, suggesting that the variances of the two sample was similar.

neuroticism, in that it disappeared when the caregiver emotionality was taken into account (F = 1.46, p=. 24).

7.1.2.8 Caregiver distress and patient psychological outcomes

Table7.1.2.8.1 Partial correlations of caregiver variables and patient's anxiety, depression, QoL and negative reactions to care. (n = 44 – 53). Values in brackets represent bivariate correlations (CGN is NOT controlled)

	RD	EB	SI	CRD	PC	SAT	CED	STAI CG
P temporary loss of self-esteem	ns (ns)	ns (.31*)	ns (ns)	ns (ns)	ns (.32*)	ns (ns)	ns (ns)	ns (ns)
P indebtedness	ns (ns)	ns (ns)	ns (.33*)	ns (ns)	ns (ns)	ns (ns)	ns (.29*)	ns (ns)
P negative perceptions of carer behaviour	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (.32*)	ns (ns)	ns (ns)
Quality of life (physical)	ns (.27*)	.32* (.38**)	.39** (.42***)	ns (ns)	.29* (.34**)	ns (ns)	ns (ns)	ns (ns)
Quality of life (emotional)	ns (.31*)	.50*** (.55***)	.34* (.38**)	ns (ns)	.57*** (.61***)	ns (ns)	.31* (.39**)	.39** (.46***)
Patient depression	ns (ns)	.46*** (.42**)	.37** (.37**)	ns (ns)	.58*** (.56***)	ns (ns)	.29* (.26*)	.47*** (.42**)
Patient anxiety	ns (ns)	.36* (.41**)	ns (.29*)	ns (ns)	.42** (.46***)	ns (.27*)	ns (.33*)	.47*** (.50***)

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 7.1.2.8.1, above that the associations between caregiver distress measures and patient outcomes measures are complex.

Caregivers of patients who perceived their physical QoL to be good reported less social impact due to caregiving independently of their emotionality, suggesting that there was a "real" association between patient physical status and impact on carer social life. Better patient emotional QoL was associated with less specific and non-specific caregiver distress when carer emotionality was kept constant. Worse patient anxiety and depression correlated weakly to carer depression, however they were strongly associated with worse carer anxiety, independently of carer emotionality.

Caregiver emotionality acted as both moderator and suppressor on various interactions. For example on one hand, controlling for carer emotionality weakened (moderated) the associations between patient physical QoL and carer emotional burden (.38**→.32*); patient physical QoL and carer personal cost due to caregiving (.34**→ .29*) and between patient emotional QoL and carer depression (.39**→.31*). On the other hand, controlling for caregiver N strengthened the associations between patient level of depression and caregiver emotional burden (.42**→.46***) and between patient depression and carer anxiety (.42**→.47***), thus caregiver N acted as a suppressor of these relationships.

7.2 Caregiver variables and caregiver distress

A great deal of information was collected from the caregiver. This section of results was grouped in four sub-sections, caregiver distress and (1) carer characteristics and job demand, (2) caregiver personality and interpersonal problems profile and (3) caregiver social support support.

7.2.1 Caregiver outcomes and carer's characteristics and job demand

Table 7.2.1.1, below sets out the correlations coefficients of the caregiver distress measures and caregiver characteristics and job demand.

Table 7.2.1.1 Partial correlations of caregiver variables and carer's characteristics and job demand. (n=53). Values in brackets represent the biavariate correlations (CGN is NOT controlled)

	RD	**EB**	**SI**	**CRD**	**PC**	**SAT**	**CED**	**STAI CG**
CG age	ns (ns)	ns (-.39**)	ns (ns)	ns (-.27*)	ns (ns)	ns (ns)	ns (ns)	ns (-.32*)
CG gender¹	ns (ns)	ns (ns)	ns (ns)	ns (.29*)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Subjective health	-.30* (-.38**)	-.36* (-.45***)	ns (ns)	ns (-.27*)	ns (-.27*)	-.34* (-.41**)	ns (-.33**)	ns (-.27*)
CG number of medical conditions	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Length of care-giving role	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Hours of care per day	.37* (.44***)	.29* (.39**)	.36* (.40**)	ns (ns)	.38** (.45***)	ns (ns)	ns (.36**)	ns (ns)
Discretion (hours)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

1- Gender: male = 1; female =2; r = point bi-serial correlation

It can be seen from Table 7.2.1.1, above, that controlling for carer emotionality substantially reduced the magnitude of the associations between carer subjective health and hours of care and carer distress, thus CGN acted as a strong moderator of these associations. One association remained significant at the p< .01 level of significance after controlling for carer neuroticism: caregivers who provided longer hours of care reported more personal cost due to caregiving. Further analyses were carried out to out to examine these relationships in depth.

7.2.1.1 Caregiver distress and caregiver age

In order to further analyse the relationship between caregiver age and caregiver distress, caregivers were divided into two groups, using the mean age of the sample (mean age = 66 years, SD 13.19) as the cut-off point. T-tests were then used to test whether caregiver age influences caregiver distress. Young caregivers (n=21) reported significantly more emotional burden (t = 2.41, p<. 05) than old caregivers (n= 32). However, young caregivers also reported higher levels of neuroticism than older caregivers (t= 2.87, p<. 01). When an ANCOVA (co-varying caregiver N) was carried out, the association between caregiver age and emotional burden disappeared (F=1.18, p=. 28). Therefore, the increased emotional burden as a result of caring for a HF relative reported by younger caregivers was due to caregiver emotionality.

7.2.1.2 Caregiver gender and caregiver distress

It has often been reported that caregiver *gender* is a significant predictor of caregiver distress with the outcomes for female carers being worse than the outcomes for male carers (Karmilovich, 1994 reported worse outcomes for male caregivers in a HF population). T-tests were used to examine the difference in all the caregiving outcome measures according to gender (see Table 7.2.1.2.1 below).

Table 7.2.1.2.1 Means, SDs and T-test comparisons of caregiver outcomes according to caregiver gender

	Group I Male =11 Means (±SD)	Group II. Female = 42 Means (±SD)	t-value	p
Relationship distress	5.64 (1.69)	7.38 (2.97)	-1.86	ns
Emotional Burden	9.82 (3.92)	10.02 (3.99)	-.15	ns
Social impact	7.73 (2.93)	8.26 (3.39)	-.47	ns
Care-receiver demands	4.64 (1.62)	6.45 (2.63)	-2.17	p<.05
Personal cost	8.27 (2.90)	8.29 (3.32)	-.01	ns
Satisfaction with CG role	22.82 (4.46)	23.44 (3.96)	-.44	ns
Caregiver depression	2.45 (1.96)	3.69 (2.52)	-1.50	ns
Caregiver anxiety	39.73 (10.35)	43.71 (13.59)	-.90	ns

Group I = Male (n=11) Group 2 = Female (n= 42)

Table 7.2.1.2.1 above, clearly supports the trend towards higher levels of distress in female carers, however in this population these differences were significant for only one specific measure of caregiver distress: women caregivers reported more care-receiver demands than men caregivers. There also was a significant difference between levels of neuroticism, women carers scoring significantly higher than men carers (t = -2.21, p<. 05). When caregiver emotionality was controlled by using ANCOVA, the relationship between gender and care-receiver demands disappeared (F = 3.30, p<. 07). Therefore, previous findings of worse outcomes for female caregivers may have been affected by failure to control for CGN.

7.2.1.3 Caregiver distress and caregiver subjective health

Caregivers were divided into two groups using the mean subjective health score (mean 6.25, SD 1.67) as the cut-off point. Group 1 consisted of caregivers with low subjective health (scores below mean, n=33) and group 2 consisted of caregivers with high subjective health (score above the mean, n=18). T-tests were then used to test if caregiver subjective health affects caregiver outcome measures. There was an overall tendency for caregivers who reported high subjective health to score better on all measures of caregiver distress. Four relationships were significant: better caregiver subjective health was associated with less relationship distress (t=2.74, p<. 01), less emotional burden (t=3.79, p<.001), more satisfaction with role as caregiver (t=2.94, p<. 01) and less depression (t=2.53, p<. 05). However, when caregiver N was controlled using ANCOVAs, only two out of these five associations remained significant: higher caregiver subjective health was related to less emotional burden (F=8.96, p<. 01) and higher satisfaction with role as caregiver (F=7.56, p<. 01). This is interesting, as we might expected that lower subjective health will be associated with increased personal cost.

7.2.1.4 Caregiver distress and length of caregiving role

Caregivers were divided into two groups according to the time they spent caring for their relative. Group 1 consisted of caregivers who were in the role of caregivers for one year or less (*n*=23), and Group 2 consisted of caregivers who were in this for more than a year (*n*= 29). T-tests were used to test if the length of role as caregiver affects caregiver distress. Caregivers who were in the caregiver role for more than a year reported more social impact (t=-2.19, p<. 05) than caregivers who took care of the care-recipient for less than a year, and the relationship held even after caregiver N was controlled using ANCOVA (F=5.29, p<. 05). Therefore CG perceived social impact may increase in parallel to disease severity.

7.2.1.5 Job demand (hours of care per day) and discretion and caregiver distress.

Caregivers were divided into two groups according to the number of hours they spent caring for their relative per day. The mean number of hours spent caring a day (mean 6.6 hours, SD 6.4) was used as the cut-off point. Group 1 reported *low job demand* (they spent less hours caring than the average for the sample, *n*=35) and Group 2 consisted of caregivers who reported *high job demand* (more than the average for the sample, *n*=17). T-tests were then performed to test if level of job demand influences caregiver distress. The high-level job demand caregivers reported more relationship distress (t=-2.62, p<. 05), emotional burden (t=-3.17, p< .01) and personal cost (t=-3.32, p<. 01) than caregivers in the low job demand group. When caregiver N was controlled using ANCOVAs, a high level of job demand was associated with more emotional burden (F=5.41, p<. 05) and more personal cost (F=7.22, p<. 01) than a low level of job demand.

A similar strategy was used to classify discretion (number of hours that the care-recipient can "be left" without the carer), however no association was found between low or high discretion and caregiver distress variables.

7.2.1.6 Caregiver involvement in patient medication monitoring and caregiver distress

Caregivers were asked to what extent they were involved in giving or reminding the patient to take his/hers medication. Using this criteria, they were divided into three group: group 1 - *responsible* for giving medication (n=19, 36.5%), Group 2 - *reminding* the patient to take the medication (n=24, 46.2%) or and Group 3 - not involved (n=9, 17.3%). One-way ANOVAs were used to examine the difference in the caregiver outcome measures according to the caregiver's involvement in patient medication (see table 7.2.1.6.1 below).

Table 7.2.1.6.1 Means, SDs, and comparison F-values of caregiver outcomes according to their involvement in patient medication monitoring[1]

	Group I n= 19 mean (±SD)	Group II n = 24 mean (±SD)	Group III n= 9 mean (±SD)	F-value	p
Relationship distress (RD)	6.47(2.38)	7.17 (3.11)	7.50 (3.33)	.46	ns
Emotional Burden (EB)	10.89 (3.41)	9.00 (4.18)	10.38 (3.06)	1.41	ns
Social impact (SI)	8.84(3.32)	7.04 (2.85)	8.88 (3.83)	2.04	ns
Care-receiver demands (CRD)	6.67 (2.31)	5.92 (2.94)	5.75 (2.31)	.31	ns
Personal cost (PC)	10.00 (2.78)	6.71 (2.74)	9.13 (3.31)	7.45	p<.01
Satisfaction with CG role SAT	22.53 (2.52)	23.09 (4.77)	26.13 (2.94)	2.52	ns
Caregiver depression (CESD)	3.42 (2.14)	2.50 (2.35)	6.00 (1.41)	7.85	p<.001
Caregiver anxiety (STAI)	44.89 (8.97)	37.21 (13.9)	51.38 (6.04)	5.46	p<.01

1 - Group 1= the carer is responsible for administering medication; Group 2 = the carer only reminds the patient to take his/her medication and group 3 = the carer is not involved in administering patient medication.

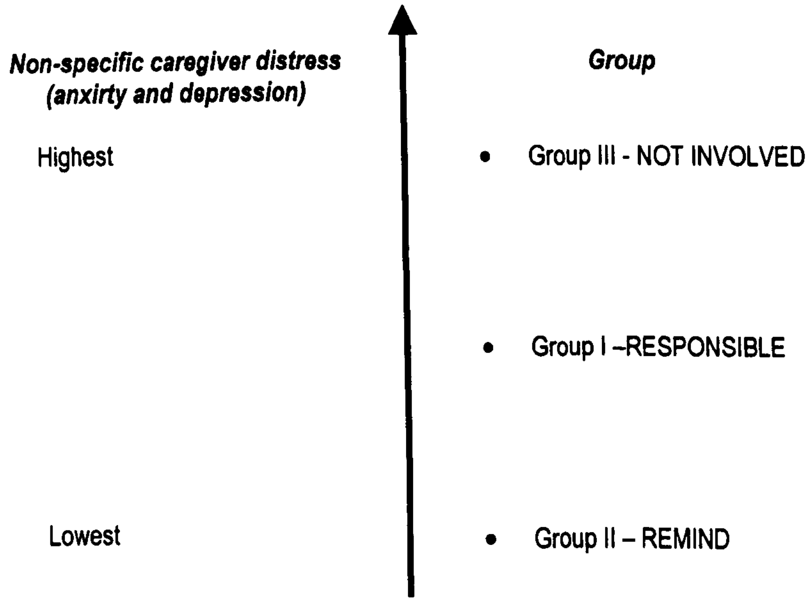
As can be seen from table 7.2.1.6.1, above, there were significant differences in caregiver distress measures according to carer involvement in administering medication to the patient. Tukey HSD post-hoc tests were carried out to identify where about these significant differences lay. The results are presented in Table 7.2.1.6.2, below.

Table 7.2.1.6.2 Mean differences, SDs and significance of Tukey HSD post hoc tests to identify where significant differences in caregiver distress lie according to their involvement in patient medication.

CG outcome variables	Group	Mean difference	SD	p
Personal cost	I + II	3.29	.87	p<.001
	I + III	.88	1.2	ns
	II + III	-.42	1.16	ns
CG depression	I + II	.92	.66	ns
	I + III	-2.58	.91	p<.01
	II + III	-3.50	.88	p<.001
CG anxiety	I + II	7.69	3.48	ns
	I + III	-6.48	4.78	ns
	II + III	-14.17	4.63	p<.01

As can be seen from the table, the RESPONSIBLE group (Group 1) scored significantly higher on the personal cost subscale of the caregiver distress scale than the REMIND group suggesting that being responsible for giving the patient his/her medication in correct dosage at the correct time is stressful for the caregiver. The REMIND group was the most advantaged on the non-specific measures of caregiver distress: they reported less depression and less anxiety that both other two groups (Fig. 7.2.1.6.1)

*Fig. 7.2.1.6.1 Graphical representation of levels of **non-specific** caregiver distress according to their involvement in patient medication monitoring.*



7.3 Caregiver personality and interpersonal problems and caregiver distress outcomes.

7.3.1 Caregiver personality and caregiver distress

Table 7.3.1.1 shows the correlations between patient neuroticism, extraversion and conscientiousness and caregiver distress measures.

Table 7.3.1.1 Correlations of caregiver personality and caregiver distress (*n*=47).

	RD	EB	SI	CRD	PC	SAT	CES	STAI CG
Neuroticism	.43**	.57***	ns	.33*	.37**	.41**	.67***	.59***
Extraversion	ns	ns	ns	ns	ns	-.31*	ns	ns
Conscientiousness	ns	ns	ns	ns	ns	-.44**	ns	-.42**

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 7.3.1.1 above that carer neuroticism was associated with both caregiving specific and non-specific measures of caregiving distress. Interestingly, there was no association between any of personality facets measured and caregiver social impact. These findings are similar to those of Davies et al (1998), who found no significant associations between the neuroticism of caregivers of Parkinson Disease (PD) patients and impact on their social life.

No association between caregiver extraversion and measures of caregiver distress reached the agreed significance level of .01. Higher caregiver consciousness was associated with higher satisfaction with role of caregiver, and less caregiver anxiety (all relationships were significant at .01 level). These findings suggest that conscientious caregivers resolve anxieties by "getting the job done".

7.3.2 Caregiver interpersonal problems and caregiver distres.

Similarly to the patients, caregivers were asked to complete the Inventory of Interpersonal Problems IIP-32 (Horowitz et al. 2000) in order to identify possible interpersonal difficulties. Table 7.3.2.1, below shows the correlations of caregiver domains of interpersonal functioning and caregiver distress[1].

Table 7.3.2.1 Partial correlations of caregiver variables and caregiver interpersonal functioning (n=38). Values in brackets represent bivariate correlations (CGN is NOT controlled).

	RD	**EB**	**SI**	**CRD**	**PC**	**SAT**	**CES**	**STAI CG**
CG Cold/Distant	ns (ns)	ns (.34*)	ns (ns)	ns (ns)	ns (ns)	.41* (.50***)	ns (ns)	ns (ns)
CG Self-Sacrificing	ns (ns)	ns (.32*)	ns (ns)	ns (.36*)	ns (ns)	ns (ns)	ns (ns)	.30* (.43**)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen in Table 7.3.2.1, above, caregiver emotionality was a strong moderator of the relationship between scores on the "Cold/Distant" domain and carer satisfaction with role as a carer: when CGN was controlled the strength of the relationship between these two measures was greatly reduced (.50***→.41*). Similarly, carer neuroticism acted as a moderator of the association between high scores on the "Self-Sacrificing" domain and higher carer anxiety

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[1] Only statistically significant correlations are presented.

(.43**→.30*). Therefore, CGN "swamps" the effect that interpersonal problems may have on carer distress.

7.3.3 Caregiver mastery and self-esteem and caregiver distress

Table 7.3.3.1, below shows the associations between caregiver mastery and self-esteem and carer distress.

Table 7.3.3.1 Partial correlations of caregiver outcomes and caregiver mastery, self-esteem and optimism when CGN was controlled (n=42). Values in brackets represent bivariate correlations (CGN is NOT controlled)

	RD	EB	SI	CRD	PC	SAT	CES	STAI CG
Mastery	ns (-.35*)	-.44** (-.58***)	-.50*** (-.54***)	ns (ns)	-.49*** (-.57***)	ns (ns)	-.57*** (-.67***)	-.42*** (-.56***)
Self-esteem	ns (.40**)	.44** (.66***)	.34* (.40**)	ns (ns)	.31* (.47**)	.51*** (.62***)	ns (.62***)	ns (.47**)

*p<.05 **p<.01 ***p<.001 (two-tailed)

High level of carer mastery (or personal control) was associated with beneficial effects on three specific measures of distress (reduced emotional burden, social impact and personal cost) and both non-specific measures of caregiver distress (reduced depression and anxiety) even when CGN was controlled. Higher self-esteem correlated with lower emotional burden and higher satisfaction with role of caregiver, independently of carer N.

Patient emotionality was a strong moderator of the associations between carer mastery and self-esteem measures of carer distress. For example, controlling for CGN significantly weakened the relationship between carer mastery and emotional burden (-.58***→-.44**) and relationship distress (.40**→.19) and between self-esteem and emotional burden (.66***→.44**), anxiety (.62***→.16) and depression (.47**→.15).

7.3.4 Correlations of caregiver outcomes and carer social support

Table 7.3.4.1 sets out the correlation coefficients of the independent caregiver variables and caregiver social support.

Table 7.3.4.1 Partial correlation coefficients of caregiver outcomes and caregiver social support (n=48). Values in brackets represent bivariate (CGN is NOT controlled)

	RD	EB	SI	CRD	PC	SAT	CED	STAI
Social support (total)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Informationsal SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Tangible SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	-.34** (-.39**)	ns (ns)	ns (ns)	ns (ns)
Emotional support	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Integration SS	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)	ns (ns)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from the Table 7.3.4.1 above, the only type of social support which was associated with carer distress was level of tangible support: high levels of tangible support are associated with less personal cost, independently of carer emotionality.

Caregivers were also asked how satisfied were they with different types of social support. The majority of caregivers were satisfied with levels of support received (see Table 7.3.4.2).

Table 7.3.4.2 Frequencies and percentage of caregivers satisfied and not satisfied with levels of social support received.

Caregiver satisfaction with social support	Number of CGs satisfied (percent)	Number of CGs *not* satisfied (percent)
Informational support	45 (93.8%)	3 (6.3%)
Tangible support	45 (93.8%)	3 (6.3%)
Emotional support	40 (83.3%)	8 (16.7%)
Integrational support	40 (77.1%)	8 (16.7%)

The small numbers of caregivers not satisfied with their informational and tangible support prohibited further analyses involving these two measures. Additional analyses were carried out for emotional and integrational support.

7.3.4.1 Carer satisfaction with level of emotional support received

T-tests were used to examine the difference in all the caregiver outcomes measures according to caregiver satisfaction with levels of emotional support received.

Table 7.3.4.1.1 Means, SDs and comparison t-values of caregiver outcomes according to caregiver satisfaction with emotional support.

	Group I (n=8)	Group II (n=40)	t-value	p
Relationship distress	10.63(3.33)	6.33 (2.28)	4.49	p<.001
Emotional Burden	12 (4.14)	9.45 (3.96)	1.65	ns
Social impact	9.63 (3.96)	7.80 (3.12)	1.41	ns
Care-receiver demands	7.63 (3.42)	5.73 (2.41)	1.89	ns
Personal cost	10.63(3.96)	7.75 (3.03)	2.32	p<.05
Satisfaction with CG role	25.75(2.86)	22.97(4.17)	1.79	ns
Caregiver depression	6.63(1.06)	2.83(2.18)	4.78	p<.001
Caregiver anxiety	48.25(21.27)	42(11.47)	1.2	ns

Group 1: unhappy with level of emotional support (n=8)
Group 2: happy with level of emotional support (n=40)

As can be seen from table 7.3.4.1.1 there was a trend for caregivers who were happy with their level of emotional support received to score lower on all the measures of distress, significantly so on relationship distress, personal cost and depression. However, there was also a significant difference between levels of neuroticism of caregivers happy and unhappy with their emotional support in that caregivers unhappy with level of emotional support were significantly more neurotic than caregivers happy with their ES. Further ANCOVAs were carried out to see if the relationships were still significant when CG N was taken into account. When caregiver neuroticism was controlled, carers who were satisfied with their level of emotional support reported less relationship distress (F=15.10, p<. 001) and less depression (F = 17.57, p<. 001) than caregivers who were unhappy with their level of emotional support, independently of their emotionality. It may be that satisfaction with emotional support actually measures dyadic relationship quality.

7.3.4.2 Satisfaction with the level of integrational support

Caregiver level of satisfaction with integrational support (helping others) was not associated with any of the measures of caregiving distress.

7.3.5 Quality of the dyadic relationship and caregiver distress

Correlations between caregiver reported present quality of the dyadic relationship and current happiness and caregiver distress measures are presented in Table 7.3.5.1, below.

Table 7.3.5.1 Partial correlations of quality of relationship as reported by caregiver and caregiver distress when CGN is controlled n=(52). Values in brackets represent bi-variate correlations (CGN is NOT controlled)

	RD	EB	SI	CRD	PC	SAT	CED	STAI CG
DAS -7	-.37** (-.50***)	ns (-.44***)	-.35** (-.41***)	-.33* (-.43***)	-.30* (-.42***)	ns (ns)	ns (-.42***)	ns (ns)
Happiness	-.26* (-.42***)	ns (-.36**)	-.39** (-.44***)	-.34* (-.44***)	ns (-.37**)	ns (-.23*)	ns (-.40**)	ns (-.27*)

*p<.05 **p<.01 ***p<.001 (two-tailed)

As can be seen from table 7.3.5.1, quality of present relationship as measured by DAS-7 (Hunsley et al, 2001) and relationship happiness were significantly related to all specific measures of caregiver distress (with the exception of satisfaction with role as caregiver) and carer depression. Although all these relationships were moderated by CGN, the relationship quality also had direct effects on level of carer distress. Namely, better relationship quality was associated with *less relationship distress* and *less social impact* independently of CGN, and higher relationship happiness was associated with less social impact.

7.3.5.6 Presence of a confidant

Caregivers were asked if they had somebody to confide in; if they answered "yes" they were also asked if the patient was their confidant.

Fifty-two out of fifty-three caregivers reported a confidant present. However, only 21 caregivers (39.6%) said that the patient was their confidant. Significantly more women reported that their confidant is **not** the patient than men did (chi square = 12.389, p<. 001). T-tests were then used to test if having the patient as your confidant makes a difference to the level of caregiver distress experienced.

Caregivers who reported that the patient was their confidant experienced less relationship distress (t=-2.40, p<. 01) and were less depressed (t=-.2.86, p<. 01). However, when caregiver emotionality was controlled using an ANCOVA, all these relationships became non-significant.

When only women caregivers were considered (n=38), women whose care-recipient was their confidant reported significantly less depression than women whose confidant was not the patient, independently of caregiver emotionality (ANCOVA, F=4.96, p<. 05).

7.4 Summary

The relationship between potential predictors of caregiver distress and caregiver distress outcomes is extremely complex. Caregiver emotionality acted mainly as a moderator of various correlation between patient, caregiver and relationship variables and caregiver distress, but in some relationships acted as a suppressor or had no effect. Emotional burden is associated with caregiver neuroticism (r = .57***), thus caregiver N was partialled out in all correlations between potential predictor variables and caregiver emotional burden. Caregiver N acted as a **moderator** (inflating the strength of correlations) in ten correlations between caregiver burden and patient physical fatigue, patient emotionality, caregiver perception of patient emotionality, patient overall quality of life, patient quality of emotional life, caregiver subjective health, caregiver job demand, caregiver mastery and self-esteem. It acted as a **suppressor** (thus masking the real strength of the associations) in four correlations between caregiver emotional burden and patient daytime sleepiness, patient conscientiousness, patient depression and patient anxiety. And finally, had **no effect** on the relationship between emotional burden and patient cognitive fatigue and patient satisfaction with emotional support.

In chapter eight, multiple regression analyses will be used to determine those variables which significantly added to the variance of each of the eight specific and non-specific caregiver distress outcomes measured.

CHAPTER 8

RESULTS PHASE 2

8.0 Introduction

In this chapter, data from phase 2 is presented. Firstly, predictors of *clinical* outcomes for patient are identified. Secondly, longitudinal comparisons of both patient and caregiver outcomes are made from phase 1 to phase 2. Specifically, it was hypothesised that there will be an increase in patient and caregiver distress in relations to the progression of the HF disease and that worse patient psychological status at phase I will be associated with worse clinical outcomes at phase 2. Finally, all of the key predictor variables for each of the patient and caregiver outcomes measures were analysed using multiple regression techniques in order to identify those variables that significantly accounted for unique variance in outcomes.

Demographic data for the reduced phase 2 sample at 6-month follow up is presented in Tables 8.0.1 and 8.0.2, below.

Table 8.0.1. Demographic data for HF patients at phase 2 (n = 64)

Gender		MMSE score	
Female	29	Mean	27.38 (1.79)
Male	35	Range	24-30
Age (years)		Demented	0 (<24)
Mean (±SD)	75.55 (8.06)	Without dementia	64 (>23)
Range	56-91	Education (years)	
Severity of illness (NYHA class)		Mean (±SD)	9.95 (1.79)
Mild (II)	28	Range	2 – 15
Moderate (III)	30	Living arrangements	
Severe (IV)	8	Lives alone	25
Mean (±SD)	2.72 (±.67)	Does not live alone	39

A comparison between Table 8.0.1 above and Table 5.2.4.1.1 (in the methods chapter) shows that the rate of attrition of participating patients from phase 1 to phase 2 was 36%. Twenty-two patients died, 10 declined to take part in the second phase and 4 were impossible to contact, despite repeated efforts to contact them. The male/female ratio in the sample was identical from phase 1 to phase 2 (male/female ratio = 1.2), and the mean age was similar (76.3 years at phase 1 and 75.5 years at phase 2) and consistent with the average age of presenting with clinical HF in population-based studies (Cowie et al., 2000). There was a slight *increase* in illness severity as measured by NYHA class (mean class was 2.68 at phase 1 and 2.72 at phase 2) and a slight *decrease* in patient cognitive status as measured by the MMSE (mean MMSE at phase 2 was 27.38 as opposed to 27.5 at phase 1). There were no demented (MMSE <24) patients at phase 2, however seven patients were classified as demented at phase 1. Of the seven demented patients, 5 died in the follow-up period and 2 improved (scored at least 24 on the MMSE at phase 2).

Table 8.0.2 Demographic data for HF caregivers at phase 2 (n = 36)

Gender		Residence	
Female	28	With patient	32
Male	8	Not with patient	4
Age (years)		Education (years)	
Mean (±SD)	66.67 (14.01)	Mean (±SD)	10.69 (1.90)
Range	34-86	Range	8 – 16
Dyadic relationship		Hours of care per day	
Husband	8	Mean (±SD)	5.62 (±5.22)
Wife	22	Range	1-24
Daughter	5	Mode	4
Sister	1		

The ratio between female/male caregivers was similar at phase 1 and 2 (female/male ratio at phase 2 was 3.5 and 3.41 at phase 1). The mean age of caregivers was 66.7 years at phase 1 and 66.67 years at phase 2. The mean age of "hours of care" decreased from 6.66 hours (at phase 1) to 5.62 hours at phase 2. However, the majority of carers reported providing care for 4 hours per day at phase 2, as opposed to 2 or 3 hours at phase 1.

8.1 Patient clinical outcomes at six - month follow up

The following clinical data was collected: total number of heart-related hospitalisations over the lifetime of the patient (retrospective data), total number of heart related re-hospitalisations and days in hospital in the 12 months period before the interview (retrospective data), total number of re-hospitalisations and days in hospital in the 6 months after the interview and total number of re-hospitalisations and days in hospital *due to HF* in the six -months follow-up. Table 8.1.1, below presents the correlations between the data collected. Both the latter variables were obtained from hospital records.

Table 8.1.1 Pearson's[1] correlations of re-hospitalisations data collected (n=64-100)

		2	3	4	5	6	7
1.	**Life -long number of heart related hospitalisations**	.69***	.34***	.23*	.11	.32***	.18
2	**Heart related re-hospitalisations in the twelve - months before the interview**		.62***	.32***	.14	.45***	.29**
3	**Heart related days in hospital in the twelve- months before the interview**			.19	.09	.17	.15
4	**Total number of re-hospitalisations in the six -months follow - up period**				.66***	.72***	.49***
5	**Total number of days in hospital in the six-months follow - up period**					.48***	.67***
6	**Total number of HF re-hospitalisations in the six-months follow-up period**						.68***
7	**Total number of HF-related days in hospital in the six-months follow-up period**						-

*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 8.1.1, above that there was a positive correlation between total number of hospitalisation from heart trouble over the patient's lifetime and re-hospitalisations in the 12 months before the interview *and* 6- month follow up period suggesting that going to hospital at two time points *prior to the interview* was associated with going to hospital during the follow-up period.

An attempt was made to classify re-hospitalisations in the six-month follow-up period as HF-related and overall number of re-hospitalisations. However, there was a high association (Pearson's $r = .72$, $p < .001$) between the two measures, also between total days in hospital and HF related days in hospital in the six months follow up (Pearson's $r = .67$, $p < .001$). Therefore, for the purpose of this

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[1] All bivariate correlations in this chapter are Pearson's correlations, unless otherwise stated.

study "re-hospitalisations" and "length of stay in hospital" will refer to the *overall* number of re-hospitalisations and days spent in hospital in the six-month follow-up period.

In the six-month follow-up period 22 (22%) patients died (14 men and 8 women). Although women who died were older than the men who died, the difference did not reach statistical significance (women mean age 79.13, SD ± 7.79; men mean age 76.74, SD ±4.48; t = -.92, p = .36). These findings are in agreement other studies reporting gender differences in HF mortality (e.g. Muntwyler et al., 2002).

Fifty-one patients (51%) were re-hospitalised at least once in the follow-up period. The mean number of re-hospitalisations was 1.57, (SD ±.70), range one to three re-hospitalisations. The mean length of stay in hospital was 14.82 days, (SD±17.60), range 1-61 days in hospital. Correlations were carried out to identify possible predictors of re-hospitalisations, length of stay in hospital and mortality.

8.1.1 Patient characteristics and clinical outcomes at six - month follow-up

There were no significant associations between patient age, gender, education and living arrangements (living alone) and clinical outcomes. However, patients who answered "Yes" to the question " Do you have money troubles?" were more likely to be hospitalised in the follow-up period that patients who did not have money troubles (t = 2.52, p< .05). Further analyses showed that this association was significant *only for women* (t = 2.22, p< .05). An ANCOVA (dependent variable = number of re-hospitalisations, fixed factor = money trouble and covariate = patient neuroticism) was carried out to test if patient neuroticism was a mediator of this relationship. Indeed, when patient neuroticism was controlled, the relationship between money trouble and number of re-hospitalisations disappeared (F =2.60, p = .11). Therefore, patient neuroticism is a stronger predictor of re-hospitalisations than 'life events' or objective concerns.

8.1.2 Illness severity and patient clinical outcomes

Seven objective measures of illness were collected: illness duration, co-morbidity index, LVEF, NYHA class, patient disability (IADLs), FEV1 and FVC. Initial bivariate and point-serial correlations have indicated that the NYHA class is the only predictor of clinical outcomes at six-month follow up.

One-way ANOVAs were used firstly to investigate whether higher severity class HF patients were more likely to be re-hospitalised in the follow-up period, secondly whether if hospitalised they spent more days in hospital and, thirdly whether they were more likely to die in the follow up period than patients in lower severity NYHA class. There were 37 patients classified as NYHA class II and 58 classified as NYHA class III. However, there were only 5 patients classified as class IV. One-way ANOVAs confirmed that more severe patients (NYHA class III and IV) were more likely to be hospitalised ($F = 8.19$, $p < .001$) and spend more days in hospital than less severe (NYHA class II) patients ($F = 3.52$, $p < .05$). However, the Levene test of homogeneity of variances was significant in both cases suggesting that the group sizes were unequal and that avoiding type I error was not guaranteed. Therefore, further t-tests were carried out to compare only NYHA II and III patients.

T-tests confirmed that NYHA class III patients were more likely to be re-hospitalised ($t = -.42$, $p < .001$) and spend more time in hospital when hospitalised ($t = -2.95$, $p < .01$) than class II patients. The same relationship was not showed with NYHA class IV patients due to small number of patients in class IV. However, four out of five patients classified as NYHA IV died in the follow up period. Therefore, attrition was higher for the more severe patients.

The same difficulties were encountered when investigating the association between HF severity as measured by NYHA class and six-month mortality. A chi-square test between NYHA class and mortality was significant (chi-square = 11.36, p<. 01). However, although a chi-square test detects whether there is a significant association between two categorical variables, it does not say anything about how strong that association might be. Furthermore, 2 cells (33.3%) had expected counts of less than 5. A chi-square test between patients in class II or III only and six-months mortality failed to detect an association. In summary, NYHA class severity was not found to be a mortality predictor in this sample; the reason may be the small number of patients classified as NYHA class IV.

8.1.3 Patient subjective health measures and clinical outcomes

As explained in the introduction of chapter 6, only subjective measures collected from patients who scored 24 or more on the MMSE scale were analysed. Three measures of subjective health were associated with number of re-hospitalisations at six-month follow up, independently of patient neuroticism; overall subjective health (r = -. 37, p <. 001), subjective physical fatigue (r = .28, p < .01) and subjective angina (r = .33, p < .01). Better scores on the subjective health questionnaire were associated with shorter stays in hospital (r = -. 23, p< .05). However, none of the subjective health measures used were associated with mortality at six-months follow-up.

8.1.4 Patient mental status and clinical outcomes

No significant associations were found between patient measures of mental status (MMSE, Trail A and B, RAVLT and pegboard) and number of re-hospitalisations and length of stay in hospital. However, people who *died* in the six-month follow-up period scored significantly lower on the MMSE (t = 2.12, p <. 05) and were slower on the Trail A (t = - 3.03, p <. 01) than people who were alive at phase 2, when interviewed at baseline. Dementing patients at phase 1 (n = 7) were more likely to die in the six- month follow up period than non-dementing patients (n = 91) (chi-square 6.49, p <. 05). Therefore, only certain cognitive tests may be of use in predicting patient clinical outcomes over six months.

8.1.5 Patient knowledge of HF at phase 1 and clinical outcomes at phase 2

Better knowledge of self-care behaviours at phase 1 was associated with fewer re-hospitalisations at phase 2 (r = -.28, p <. 01). No other significant associations were found between patient measures of HF knowledge at phase 1 and six-month clinical outcomes. To further investigate the relationships between knowledge and outcomes, patients were divided into two groups: Group I consisted of patients who were *not* re-hospitalised in the follow up period (n = 47) and Group II was made of patients who went to hospital at least once in the follow-up period (n= 46). Independent t-tests between the two groups showed that patients who went to hospital at least once in the follow up period were more uncertain about their illness (t = -2.65, p <. 01) and knew less about self-care behaviours (t = 2.68, p <. 01) at phase 1. However, when controlling for patient neuroticism, only the relationship between level of self-care at phase 1 and re-hospitalisations at phase 2 held (F = 5.13, p< .05), suggesting a direct relationship between level of self-care and re-hospitalisations, but an indirect relationship (mediated by patient neuroticism) between illness uncertainty and re-hospitalisations. Therefore, more objective measures of knowledge and behaviour such as self-care had a stronger relationship to re-hospitalisations than does more subjective concerns such as illness uncertainty, which are more strongly related to neuroticism.

8.1.6 Patient personality and clinical outcomes

There was a positive correlation between patient neuroticism and length of stay in hospital (r = .22, p< .05); more neurotic patients spent more days in hospital than less neurotic patients. No other significant correlations were found between patient neuroticism, extraversion, conscientiousness and inter-personal functioning and clinical outcomes at six - month follow up. This suggests that 'neurotic ' patients may be more- or *over* attentive to bodily symptoms, thus reporting worse health status and possibly influencing the health care professionals decisions about hospital discharge. Alternatively, neuroticism itself may be related to poorer outcomes. To assess which hypothesis is correct, a longer follow up period, reassessing change in NYHA class would be necessary.

8.1.7 Patient coping style and clinical outcomes at follow up

No specific styles of coping were significantly beneficial in reducing number of re-hospitalisations and length of stay in hospital in the follow-up period. Surprisingly, *mental disengagement* had a protective effect in this population: patients who scored higher on this measure were more likely to be alive at six-months follow up (Mann-Whitney U = 321.5, $p < .05$). Whether this coping style is beneficial in the long-term cannot be determined by the current study. However, the literature suggests that avoidance coping styles ultimately have a deleterious effect on clinical outcomes in HF patients (Murberg and Bru, 2001; Murberg et al., 2004).

8.1.8 Patient distress at phase 1 and clinical outcomes at phase 2

It was hypothesised that poorer psychological outcomes at phase 1 will be associated with worse clinical outcome sat phase 2. Table 8.1.8.1, below sets out the correlations between patient outcome measures at phase I and patient clinical outcomes at 6-month follow-up.

Table 8.1.8.1 Correlations of patient psychological variables at phase I and clinical outcomes at 6 months follow up

	Number of re-hospitalisations	Length of stay in hospital	Mortality+
Temporary loss of self-esteem	ns	ns	ns
Indebtedness	ns	ns	ns
Negative perception of carer behaviour	ns	ns	ns
QoL physical	.34***	.26*	ns
QoL emotional	.37***	.30**	ns
Patient depression	.34***	.27**	ns
Patient anxiety	.27**	.26**	ns

*p<.05 **p<.01 ***p<.001 (two-tailed)
+ Point bi-serial correlations 1 = alive at six months 2 = deceased at six months

It can be seen from Table 8.1.8.1, above that measures of patient distress *specific* to the caregiving situation were *not* predictive of patient clinical outcomes at six-month follow up. However, increased *non-specific* measures of patient distress (quality of life, anxiety and depression) *were* associated with increased number of re-hospitalisations and longer stays in hospital, *but not with mortality*.

8.1.9 Caregiver variables at phase 1 and patient clinical outcomes at phase 2

Patients of caregivers who reported a better quality of dyadic relationship were more likely to be alive at six months follow up (chi-square = 4.26, p <. 05).

Caregiver happiness with relationship at phase 1 was associated with shorter stay in hospital in the follow up period (r = -.27, p < 05), whereas caregiver level of anxiety at phase 1 was associated with longer patient stays in hospital (r = .28, p < .05). Surprisingly, there was a direct relationship between caregiver interpersonal problems and re-hospitalisations, in that caregivers of patients who went to hospital at least once in the follow up period scored *higher* on the overall inventory of interpersonal problems (t = 2.99, p< .01). Further t-tests showed that being overly accommodating (t = 3.03, p < .01) and intrusive and needy (t = 2.15, p <. 05) as a caregiver was associated with the care-receiver *not* going to hospital in the follow-up period. This suggests that caregivers with a specific profile (those who "find meaning" through providing care) can influence patient risk of hospitalisation in a relatively short period of time. It could be that caregivers who are "overly accommodating" and "needy" would prefer patients to be at home, where they "can keep an eye" on them for 24 hours a day. They may also be more likely to call the GP to come and see the patient at home when the patient's condition worsen, therefore *preventing* a visit to hospital.

8.1.10 Patient visits to the GP, participation in HF clinics and clinical outcomes

At phase 2 patients were asked how many times they went to see their GP *because* of their HF and whether they went to HF clinics (and how many times) in the follow up period. GP visits and cardiac clinics visits were added up to obtain a composite measure of the consistency of professional HF follow up. Patients reporting higher numbers of follow-up visits were more likely to have fewer hospitalisations (Pearson's r = -.39, p<.001) and to stay fewer days in hospital when hospitalised

(Pearson's r = -.35, p<.01) than patients who reported less systematic follow up. These findings are consistent to reports that the poor follow-up visits are a risk factor for futures re-hospitalisations in HF patients (Tsuchihashi et al, 2001).

8.1.11 Summary

Patient risk of re-hospitalisation in the six-month follow-up period was influences by *illness and patient characteristics* (NYHA class, subjective severity of illness, MMSE, level of self-care, neuroticism, quality of life at baseline, level of anxiety and depression), *caregiver characteristics* (quality of dyadic relationship, carer anxiety and interpersonal problems) and *quality of professional follow-up*. Two measures influenced the risk of dying in the follow-up period, namely patient cognitive status (MMSE and Trail-A scores) and patient coping styles (mental disengagement).

8.2 Longitudinal changes in patient measures and outcomes

8.2.1 Replication of the associations between illness severity measures and patient psychological outcomes at phase 2

Heart failure is a progressive illness. Consequently, an exact replication of results from phase 1 at six-month follow up is unlikely. However, it was expected that if illness severity measures are strong predictors of both patient and carer distress, then associations between measures of HF severity and patient and carer outcomes should be strong at both phase 1 and phase 2. Table 8.2.1.1 below, sets out the correlations between measures of illness severity and patient cognitive status and patient outcomes at phase 2.

Table 8.2.1.1 Partial correlations of illness severity measures and patient psychological outcomes at phase 2 (controlling for PN, n = 55-60). Values in brackets represent bivariate correlation (PN is NOT controlled)

		Qol PHY	**QoL EM**	**GDS**	**STAI-P**
Objective illness severity	Phase 2 NYHA class	.60*** (.65***)	.49*** (.55***)	.52*** .58***)	.ns (.40***)
	Phase 2 FEV1	-.29* (-.42***)	-.26* (-.44***)	ns (ns)	ns (ns)
	Phase 2 FVC	ns (-.38**)	ns (-.32*)	ns (ns)	.24* (ns)
	Phase 2 Disability (IADLs)	.23* (.56***)	.32** (.59***)	.27* (.51***)	ns (.44***)
Subjective illness severity	Phase 2 subjective health	-.58*** (-.65***)	.43*** (-.54***)	-.45*** (-.55***)	ns (-.48***)
	Phase 2 Fatigue	.80*** (.84***)	.50*** (.62***)	.42*** (.55***)	ns (.49***)
	Phase 2 Breathlessness	.71*** (.74***)	.45*** (.52***)	.43*** (.51***)	.ns (.46***)
Patient cognitive status	Phase 2 MMSE	ns (ns)	ns (ns)	ns (ns)	ns (ns)
	Phase 2 Trail A	ns (-.31*)	-.33* (-.40**)	ns (-.30*)	ns (ns)
	Phase 2 Trail B	ns (-.35*)	-.36* (-.43**)	ns (-.36*)	ns (-.31*)
	Phase 2 RAVLT	ns (ns)	-.31* (ns)	ns (ns)	ns (ns)
	Phase 2 Pegboard	ns (ns)	ns (ns)	ns (ns)	ns (ns)
Self-care behaviours	Phase 2 Self-care	-.48*** (-.50***)	-.37** (-.38**)	.30* (-.33**)	ns (-.33**)

ns = relationship is not statistically significant
*p<.05 **p<.01 ***p<.001 (two-tailed)

It can be seen from Table 8.2.1.1 above, that the pattern of correlations between illness severity measures at phase 2 and psychological outcomes at phase 2 is similar to the phase 1 findings. Increased NYHA class and more patient disability were associated with lower patient perceptions of physical and emotional quality of life and increased depression, independently of patient neuroticism. Objective measures of lung function were *not* related with any of the outcomes at the agreed set level of p<.01 significance. Similarly to phase 1, subjective measures of illness severity (subjective health, fatigue and breathlessness) were strongly associated with patient perceived quality of life and level of depression, independently of patient neuroticism. Moreover, as in phase 1, patient neuroticism was a strong moderator between objective and subjective measures of HF severity and patient anxiety.

Differently to phase 1, however, in phase 2 no significant associations were found between patient cognitive status as measured by the MMSE and patient physical quality of life. This may be explained by the fact that patients who died in the follow up period had significantly lower scores on the MMSE at phase I (mean 26.29, SD±3.18) as opposed to patients who were alive at 6-month follow up (mean 27.83, SD±1.91; t = 2.12, p<.05).

To summarise, the associations between illness severity variables and patient psychological outcomes at phase 1 were replicated at phase 2, suggesting that they are relatively stable over time. Of course, a longer follow-up period would be essential in confirming the stability of these associations.

8.2.1.1 The effect of NYHA class on patient outcomes at phase 2

There were only four patients with class IV severity in phase 1, thus more complex analyses were not possible to see if class patient outcomes varied according to NYHA class. In phase 2, eight patients were classified as NYHA class IV severity, allowing for a three level factor comparison of patient outcomes. Table 8.2.1.1.1 below, presents the means, SD and F-values of one- way ANOVAs according to NYHA class.

Table 8.2.1.1.1 Means, SDs and ANOVA comparisons of patient outcomes according to HF severity at phase 2.

	NYHA class				
	Class II (n=26) means (±SD)	Class III (n = 30) means (±SD)	Class IV (n = 8) means (±SD)	F-value	p
Patient depression	3.77(2.14)	6.60(2.99)	9.38(2.92)	16.08	p< .001
Patient anxiety	35.08(8.54)	41.77(9.98)	46.63(10.05)	5.99	p< .01
Patient physical QoL	20.77(7.51)	31.23(5.79)	35.25(3.77)	25.48	p< .001
Patient Emotional QoL	6.62(3.74)	13.30(4.18)	13.13(4.64)	20.62	p< .001

These results indicate that as the severity of HF increases, patients report worse outcomes on all outcome measures used. Post-hoc Tukey HSD comparisons demonstrated that the difference between NYHA class II and III, II and IV and III and IV were significant for depression: as patient became more severe the level of depression increased. There was a significant difference in levels of anxiety, physical and emotional QoL between severity class II and III and II and IV, but not between III and IV. This suggests that level of depression increases gradually from mild, to moderate, to severe HF, whereas patients diagnosed with mild HF perceived their quality of life to be significantly better and reported less anxiety than both moderate and severe HF patients. Of course, subtler differences between classes III and IV may have emerged had the class IV group been larger. Therefore the present study found that although level of depression increases as illness severity increases, there seems to be a qualitative "drop" between class II (mild HF) and class II and IV (moderate and severe HF) in terms of quality of life and level of anxiety.

8.2.2 Longitudinal changes in illness severity measures and patient outcomes at phase 2

It was hypothesised that an increased HF severity from phase 1 to phase 2 would be associated with worse patient psychological outcomes at phase 2. Table 8.2.2.1 below, sets out the means, SDs, t-values and significance level of paired t-tests between patient variables, cognitive status and patient outcomes at phase 1 and phase 2. In other words, within-subjects comparisons were used to detect change in psychological status between the two phases.

Table 8.2.2.1 Means, SDs and paired (longitudinal) t-tests comparisons of illness measures, severity and cognitive status between phases (n = 64)

		Phase 1 means (±SD)	Phase 2 means (±SD)	t-value	p
Objective illness severity	NYHA class	2.58(.52)	2.72 (.67)	-2.60	p< .05
	Patient disability	16.27(4.90)	16.45(5.03)	-.54	ns
	FVE1	1.58(1.31)	1.48(.73)	.76	ns
	FVC	1.92(.80)	1.87(.83)	.87	ns
Subjective illness severity	Patient subjective health	5.24(1.64)	5.65(1.73)	-2.72	p< .01
	Patient breathlessness	45.03(19.71)	48.30(20.99)	-2.10	p< .05
	Patient fatigue	22.29(10.01)	23.63(10.02)	-2.23	p< .05
Patient cognitive status	MMSE	27.86(1.87)	27.38(1.79)	2.41	p< .05
	Trail A	8.64(2.61)	7.89(2.58)	2.60	p< .05
	Trail B	8.56(3.02)	8.46(3.08)	.28	ns
	RAVLT	60.56(18.07)	62.71(16.74)	-1.50	ns
	Pegboard	122.15(59.24)	124.30(57.47)	-.46	ns
Patient outcomes	Patient physical QoL	27.14(9.27)	27.48(8.51)	-.37	ns
	Patient emotional QoL	10.27(6.86)	10.56(5.18)	-.44	ns
	Patient depression	6.20(3.55)	5.80(3.24)	1.20	ns
	Patient anxiety	41.31(10.66)	39.66(10.15)	1.24	ns

It can be seen from table 8.2.2.1 above, that although patients reported significantly worse breathlessness and fatigue at phase 2, overall they perceived their subjective health to be better. There were no significant differences between *objective* measures of breathlessness (FVE1 and FVC) between the two phases. Overall, mean NYHA class increased. Overall, the mean MMSE significantly decreased over the follow-up period, however patients were faster on the Trail A test. This could be because patients had some degree of practice of the test by phase 2. Moreover, there were no significant longitudinal changes in patient psychological status between phase 1 and phase 2. Further analyses were carried out to investigate whether there were significant differences in phase 2 outcomes between patients *who become more ill* between phase 1and 2.

8.2.2.1 Changes in NYHA class from phase 1 to phase 2 and patient psychological status at phase 2

Four patients who were NYHA class II at phase I were class III at phase 2 and seven patients who were class III at phase 1 were class IV at phase 2, totalling a number of eleven patients whose HF severity (as measured by the NYHA class) increased over the six-month follow up period (see Table 8.2.2.1.1, below).

Table 8.2.2.1.1.1 NYHA class at phase 1 and phase 2 cross tabulation count

		NYHA class (phase II)			**Total**
		II	III	IV	
NYHA class (phase I)	II	24	4		**28**
	III	2	26	7	**35**
	IV			1	**1**
Total		**26**	**30**	**8**	**64**

To test if a change in HF severity was associated with worse patient outcomes, independent t-tests were carried out comparing patients who became more severe and those who remained constant or improved (see table 8.2.2.1.1.2 below).

Table 8.2.2.1.1.2. ANCOVA comparisons of illness severity measures, cognitive status and psychological outcomes between patients who maintained their NYHA class at phase 2 (n=53) and those who became worse (n=11), covarying PN

	Group I: same NYHA class or better (n = 53) means (±SD)	Group II: worse NYHA class (n = 11) means (±SD)	F-value	p
Subjective health	6.02(1.61)	4.27(1.84)	10.74	p<.01
Subjective breathlessness	42.38(19.47)	57.55(16.29)	14.89	p<.001
Subjective fatigue	22.00(9.89)	31.73(5.33)	11.21	p<.001
Patient disability	15.79(5.08)	19.64(3.50)	6.63	p<.05
FEV1	1.52(.71)	1.33(.76)	.74	ns
FVC	1.91(.81)	1.63(.80)	.99	ns
MMSE	27.73(1.99)	28.45(1.03)	-1.16	ns
Trail A	7.95(2.44)	7.78(3.15)	.17	ns
Trail B	8.45(3.04)	8.67(3.27)	-.19	ns
RAVLT B	62.57(16.49)	61.67(18.82)	.14	ns
Pegboard	123.50(60.66)	118.75(30.60)	.15	ns
Self-care	22.28(3.35)	18.91(2.73)	10.39	p<.01
Patient depression	5.40(3.09)	7.73(3.40)	6.33	p<.05
Patient anxiety	41.11(10.77)	42.27(10.58)	-.32	ns
Patient QoL physical	26.30(8.68)	33.18(4.60)	7.15	p<.01
Patient QoL emotional	10.26(5.34)	12.00(4.24)	1.12	ns
Number of re-hospitalisations	.58(.81)	1.36(1.12)	-2.35	p<.05
Days in hospital	4.21(11.57)	18.00(21.26)	-2.04	p<.05

It can be seen from Table 8.2.2.1.1.2, above, that a change in heart failure severity as measured by higher NYHA class was reflected also in worse measures of patient subjective health, subjective breathlessness and subjective fatigue and increased disability. Increased illness severity was not reflected in objective measures of lung function (FEV1 and FVC) or changes in patient cognitive status, however. As NYHA classification is a clinical assessment, it measures only patient symptoms and not objective function. However, LVEFs (left ventricular objective fraction) were not available at phase 2 and so it cannot be determined whether lack of change in objective lung function was reflected by lack of change in EF, as the 'gold-standard' assessment of HF severity.

Patients who maintained their health status were more likely to report higher levels of self-care behaviours than patients who became more ill. Patients who became more severe in the follow up period reported significantly higher levels of depression and worse physical QoL than people who maintained their illness severity, independently of their neuroticism. They also were more likely to be re-hospitalised and to stay longer in hospital when admitted than patients those who maintained or improved their HF severity.

8.2.2.2 Changes in patient level of disability from phase 1 to phase 2 and patient outcomes at phase 2

A new variable "increased disability" was computed by comparing scores on IADLs questionnaire from phase 1 to phase 2. Twenty-eight patients were coded as *increased disability* and 35 were coded as *maintained* level of disability. An ANCOVA (controlling for patient neuroticism) showed that patients who were more disabled at phase 2 by comparison to their level of disability at phase 1 reported significantly higher levels of anxiety at phase 2 (F = 12.19, p<.001) than patients who maintained their level of disability between phase 1 and 2.

8.2.2.3 Changes in patient subjective breathlessness from phase 1 to phase 2 and patient outcomes at phase 2

A new patient variable, "increased breathlessness" was computed by comparing scores on visual analogue score of breathlessness from phase 1 to phase 2. Forty-five patients reported that their breathlessness became worse in the six months follow up, and 18 reported that their level of breathlessness remained constant or improved. ANCOVAs (controlling for patient neuroticism) showed that patients who perceived their breathlessness to be worse at phase 2 also reported worse physical QoL (F = 6.82, p<. 05) and higher levels of depression (F = 4.39, p<. 05) than patients who perceived their dyspnoea to improve or to remain constant, *independently of patient neuroticism*. Therefore, the relationship between increased subjective breathlessness and worse psychological outcomes at phase 2 was *not* a reflection of increased patient neuroticism.

8.2.2.4 Correlations of patient outcomes between phase 1 and phase 2

Table 8.2.2.4.1 below, sets out the correlations of patient outcomes between phase 1 and six-months follow up.

Table 8.2.2.4.1 Pearson's correlations between patient psychological outcomes at phase 1 and 2 (n=64)

	r	p
Patient depression	.68	$p < .001$
Patient anxiety	.42	$p < .001$
Patient physical QoL	.67	$p < .001$
Patient emotional QoL	.63	$p < .001$

It can be seen from table 8.2.2.4.1 above, that all patient outcomes measured at phase 1 were strongly associated with the same outcome variables at phase 2. Therefore, it can be concluded that despite a slight but significant increase in illness severity as measured by NYHA class, patient outcome variables were not significantly different in phase 1 and phase 2. In view of the fact that some of the important predictor variables of patient distress were only collected at phase 1, it was decided that phase 1 data will be used to identify those variables that significantly added to the variance in multiple regression analyses using *phase 2 outcomes*. One exception are the *negative reactions to care outcomes*, which were collected only at phase 1. Therefore, negative reactions to care outcome *at phase 1* will be predicted from phase 1 data.

8.3 Phase 2 caregiver outcomes

8.3.1 Longitudinal changes in caregiver outcome

Within subjects comparisons (paired t-tests) were used to detect longitudinal changes in carer distress between the two phases.

Table 8.3.1.1 Means, SDs and paired (longitudinal) t-tests comparisons of caregiver outcomes between phases (n=36)

	Phase 1 means (±SD)	Phase 2 means (±SD)	t	p
Relationship distress	7.03(2.68)	8.00(3.28)	-1.41	ns
Emotional burden	9.94(3.68)	10.60(3.95)	-1.43	ns
Social impact	8.06(3.05)	8.60(3.41)	-2.15	ns
Care-receiver demands	5.86(2.26)	6.37(2.25)	-1.41	ns
Personal Cost	8.54(3.17)	8.20(3.00)	-2.07	ns
Satisfaction with role as CG[1]	24.12(3.67)	25.88(4.97)	-.28	p<.01
Depression	3.17(2.33)	3.49(2.28)	-2.73	ns
Anxiety	43.20(14.29)	44.11(12.46)	-1.63	ns

It can be seen from table 8.3.1.1 above that, although *overall* there was a trend for all measures of carer distress to increase between phase 1 and phase 2, only one association was significant. Namely, at phase 2, caregivers were significantly *less satisfied* with their role as caregiver than they were at baseline (higher scores signify *less* satisfaction). It could be that as they become "established" in their role as caregivers, the implications of what the role of caregiver entails (for example, limiting social interaction see section 7.2.1.4) becomes more apparent, thus affecting caregiver satisfaction with role as caregiver.

Therefore, with the exception of satisfaction with role as caregiver, levels of distress at phase 1 and phase 2 were similar. This could be a reflection of the fact that measures of distress of carers whose relative died in the follow-up period were not collected.

8.3.2 Changes in NYHA class and caregiver outcomes at phase 2

It was hypothesised that a worsening of patient clinical status between phases will be associated with worse carer outcomes at phase 2. To test the hypothesis, t-test comparisons were performed comparing the carer outcomes at phase 2 according to patient "maintained" or "worse" illness severity. Table 8.3.2.1 below sets out the means, SDs, t-values and significance level of comparisons.

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[1] CG = Caregiver

Table 8.3.2.1 Means, SDs and t-test comparisons of caregiver outcomes at phase 2 according to change in patient illness severity (n=36)

	Group I: same NYHA class or better (n = 31) means (±SD)	Group II: worse NYHA class (n = 5) means (±SD)	t	p
Relationship distress	7.58(3.38)	9.80(2.04)	-1.41	ns
Emotional burden	10.03(3.66)	12.80(5.89)	-1.43	ns
Social impact	7.94(3.25)	11.60(3.67)	-2.15	ns
Care-receiver demands	6.06(2.36)	7.60(1.14)	-1.41	ns
Personal Cost	7.65(3.01)	10.60(2.40)	-2.07	p<.05
Satisfaction with role as CG	25.48(5.29)	26.20(4.71)	-.28	ns
Depression	3.03(2.07)	5.80(2.28)	-2.73	p<.01
Anxiety	42.23(11.02)	52.00(19.88)	-1.63	ns

It can be seen from Table 8.3.2.1 above that caregivers of patients who became more ill in the follow-up period were more depressed and reported more personal cost due to caregiving than caregivers of patients who maintained their HF severity. These relationships remained significant when caregiver neuroticism was controlled (personal cost, ANCOVA, F=3.94, p<. 05; depression, ANCOVA, F=7.15, p< .05). Therefore, an increase in patient HF severity between phases was associated with worse caregiver outcomes, independently of carer neuroticism.

8.3.3 Correlations between caregiver outcomes between phase 1 and phase 2

Table 8.3.3.1 below sets out the correlations of caregiver outcomes between phase 1 and phase 2.

Table 8.3.3.1 Pearson's correlations between caregiver psychological outcomes at phase 1 and 2 (n=36)

	r	p
CG relationship distress	.36	p < .05
CG emotional burden	.62	p < .001
CG social impact	.58	p < .001
CG care-receiver demands	.30	p < .05
CG personal cost	.55	p < .001
CG satisfaction with role as caregiver	.66	p < .001
CG depression	.63	p < .001
CG anxiety	.75	p < .001

It can be seen from table 8.3.3.1 above, that all caregiver outcomes measured at phase 1 were medium to strongly associated with the same outcome variables at phase 2. Therefore, it can be concluded that despite a slight but significant increase in illness severity as measured by NYHA class, caregiver level of distress *was not* significantly different in phase 1 and phase 2. In view of the fact that (i) some of the important predictor variables of caregiver distress were only collected at phase 1 and (ii) the number of caregivers interviewed at phase 2 was relatively small, it was decided that phase 1 data will be used to identify those variables that significantly added to the variance in phase 1 carer distress measures in multiple regression analyses.

8.4 Predictors of patient and caregiver outcomes

8.4.1 Predictors of patient outcomes

This section presents predictors of each of the eleven psychological and clinical patient outcomes. As data on *negative reactions to care* was collected only at phase 1, they will be predicted using only phase 1 data. Phase 2 outcomes will be used to identify predictors of patient psychological and clinical from phase 1 variables.

In the previous chapters, analyses conducted demonstrate that both patient variables *and* caregiver variables influenced HF patient outcomes. In this section multiple regression analyses were used to determine those variables which significantly added to the variance for each of the patient outcome measures.

Field (2002) argued that a multiple regression should use potential predictors that do not share a lot of variance, in other words potential predictors should add some "unique variance " to the equation. To prevent entering variables that share a lot of variance into the regression equation, preliminary stepwise regression analyses were undertaken to eliminate those variables that had no "unique" variance to add. The process was repeated for each patient outcome measure.

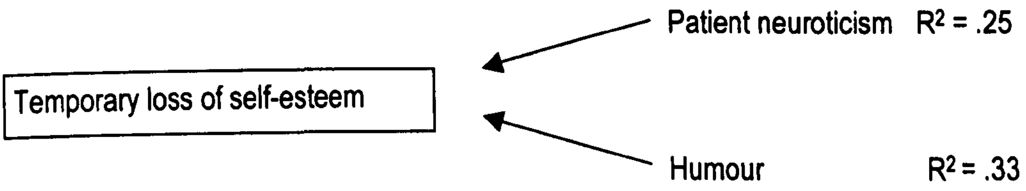
8.4.1.1 Predictors of temporary loss of self-esteem

Table 8.4.1.1.1 Regression model for ***temporary loss of self-esteem*** *(n=53)*

	B	SE	ß	Adjusted R²	Accumulative R²
First step					
Patient Neuroticism	.37	.08	.50***	.25	.25
Second step					
Coping style (humour)	-.62	.24	-.31*	.08	.33

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.1.1 Predictors of patient temporary loss of self –esteem



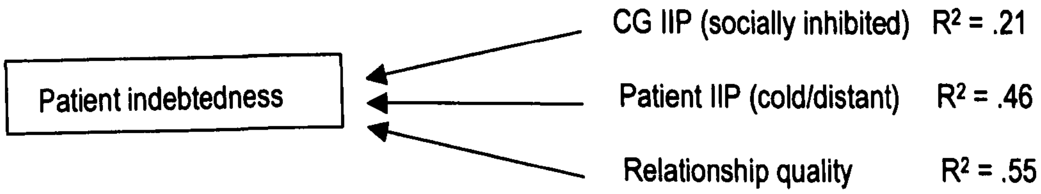
8.4.1.2 Predictors of patient indebtedness towards the carer

Table 8.4.1.2.1 Regression model for ***patient indebtedness*** *(n=53)*

	B	SE	ß	Adjusted R²	Accumulative R²
First step					
Caregiver IIP (socially inhibited)	-.12	.02	-.54***	.21	.21
Second step					
Patient IIP (cold and distant)	2.06	.75	.36**	.25	.46
Third step					
Relationship quality	-.15	.05	-.34*	.09	.55

*p<.05 **p<.01 ***p<.001
IIP- Interpersonal problems

Figure 8.4.1.2.1 Predictors of patient feelings of indebtedness towards the carer



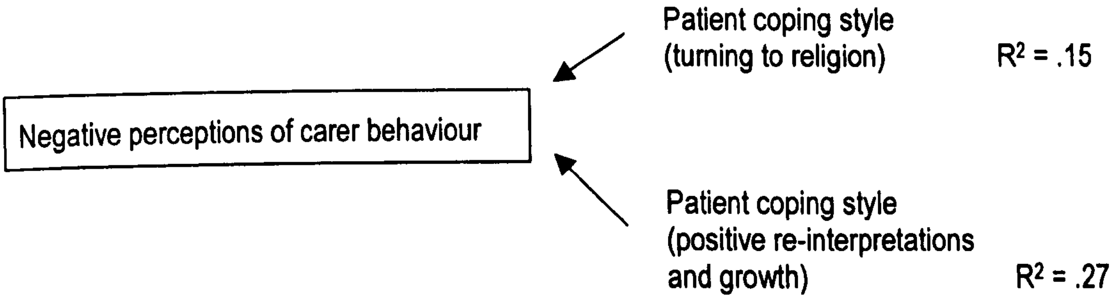
8.4.1.3 Predictors of negative perceptions of carer behaviour

Table 8.4.1.3.1 Regression model for ***patient negative perceptions of carer behaviours*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Patient coping style (religion)	-.26	.08	-.37**	.15	.15
Second step					
Coping style (positive reinterpretation and growth)	-.44	.15	-.36**	.12	.27

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.3.1 Predictors of patient negative perceptions of carer behaviours



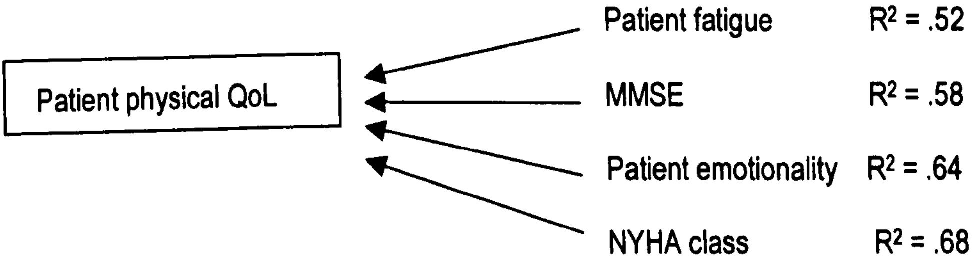
8.4.1.4 Predictors of patient physical quality of life

Table 8.4.1.4.1 Regression model for ***patient physical quality of life*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Patient Fatigue	.47	.08	.47***	.52	.52
Second step					
MMSE	1.6	.32	.43***	.06	.58
Third step					
Patient neuroticism	.23	.07	.24**	.06	.64
Fourth step					
NYHA class	4.9	1.7	.33**	.04	.68

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.4.1 Predictors of patient physical quality of life



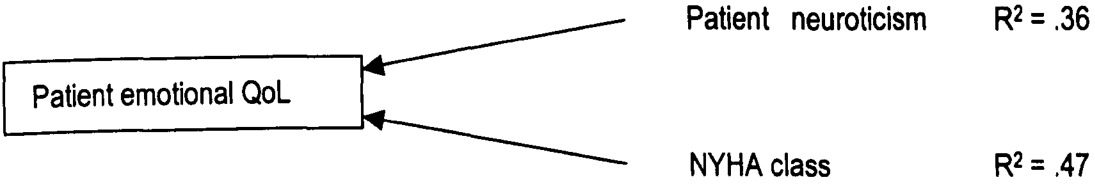
8.4.1.5 Predictors of patient emotional quality of life

Table 8.4.1.5.1 Regression model for patient ***emotional quality of life*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Patient neuroticism	.28	.06	.47***	.36	.36
Second step					
NYHA class	3.38	.91	.37***	.11	.47

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.5.1 Predictors of patient emotional quality of life



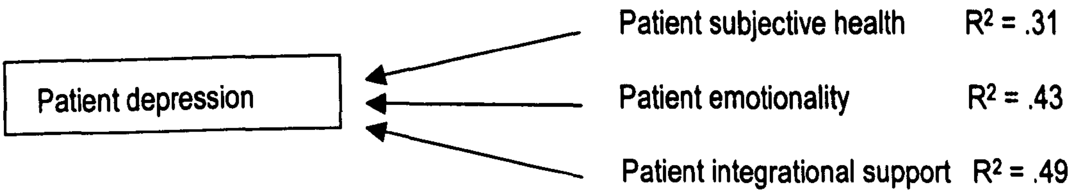
8.4.1.6 Predictors of patient depression

Table 8.4.1.6.1 Regression model for ***patient indebtedness*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Subjective overall health	-.76	.19	-.38***	.31	.31
Second step					
Patient neuroticism	.15	.03	.39***	.12	.43
Third step					
Integrational support	-.13	.04	-.26**	.06	.49

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.6.1 Predictors of patient depression



8.4.1.7 Predictors of patient anxiety

Table 8.4.1.7.1 Regression model for ***patient anxiety*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Patient neuroticism	.79	.15	.67***	.43	.43

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.7.1 Predictors of patient anxiety

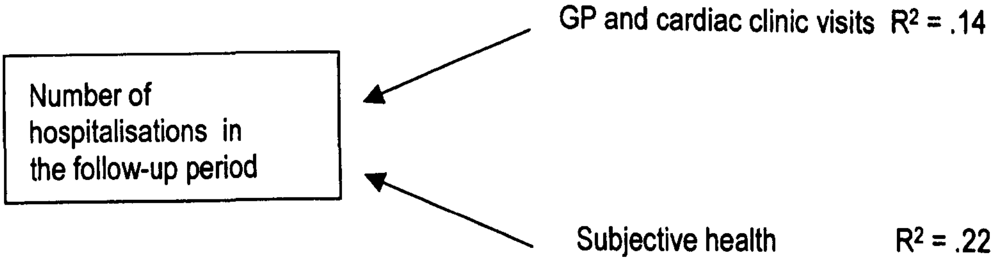
8.4.1.8 Predictors of number of re-hospitalisations in the follow-up period

Table 8.4.1.8.1 Regression model for patient ***number of re-hospitalisations*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
GP and cardiac clinic visits	-.14	.04	-.34**	.14	.14
Second step					
Subjective health	-.18	.06	-.31**	.08	.22

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.8.1 Predictors of number of re-hospitalisations in the follow-up period



8.4.1.9 Predictors of length of stay in hospital

Table 8.4.1.9.1 Regression model for ***length of stay in hospital*** *(n=64)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
GP and cardiac clinic visits	-1.44	.51	-.33**	.10	.10

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.9.1 Predictors of length of stay in hospital in the follow-up period

8.4.1.10 Predictors of going to hospital at least once in the follow up period

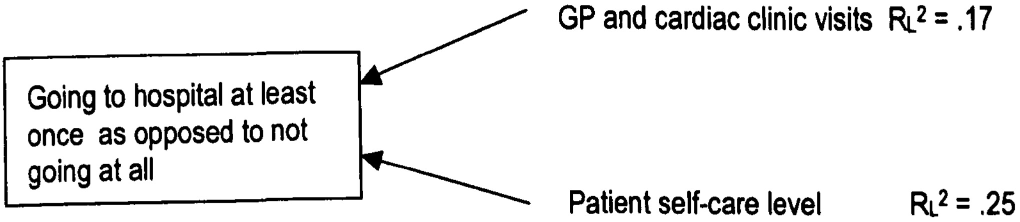
Logistic regression was used to identify predictors of being re-hospitalised at least once, as opposed to not going to hospital at all. Two predictors were found to add unique variance to the outcome: number of HF- related visits to the GP and cardiac clinic and level of self-care at phase 1. These two variables were entered stepwise in the logistic regression model. There is some controversy in logistic regression theory regarding what would make a good analogue to the R^2 value in linear regression and Hosmer and Lemeshow's measure (R_L^2) was proposed as an easy to calculate analogue (Field, 2002).

Table 8.4.1.10.1 Regression model for patient ***going to hospital at least once in the follow-up period*** *(n=64)*

	B	SE	Wald	Exp(B)	95%C.I for EXP(B)	
					Lower	Upper
First step						
GP and cardiac clinic visits	-.61	.19	10.32***	.54	.37	.78
Second step						
Self-care level	-.25	.10	6.25*	.77	.63	.94

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.10.1 Predictors of going to hospital at least once in the follow up period (accumulative $R_L^2 = .25$)



8.4.1.11 Predictors of mortality

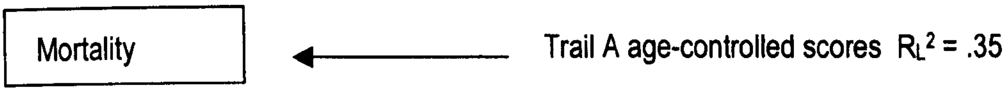
Logistic regression was used to identify predictors of mortality at six months follow up. Trail A scores were found to add unique variance to the outcome and were entered into the logistic regression model. Hosmer and Lemeshow's measure (R_L^2) was used to interpret the significance of the model.

Table 8.4.1.11.1 Regression model for patient mortality (n=100)

	B	SE	Wald	Exp(B)	95%C.I for EXP(B)	
					Lower	Upper
First step						
Trail A score (age controlled)	-.73	.22	10.32***	.47	.30	.75

*p<.05 **p<.01 ***p<.001

Figure 8.4.1.11.1 Predictors of patient mortality



8.4.2 Predictors of carer distress

This section presents predictors of each of the eight psychological measures of carer distress. Because some of the important predictors of carer distress were collected at phase 1 only *and* the number of carers interviewed at phase 2 was relatively small, in this section multiple regression analyses were used to determine those variables from *phase 1* which added unique variance to each of the distress measures at *phase 1*. Similarly to analyses used to predict patient outcomes, for each carer distress measure preliminary stepwise regression analyses were undertaken to eliminate those variables that had no "unique" variance to add to the distress measure predicted.

8.4.2.1 Predictors of relationship distress

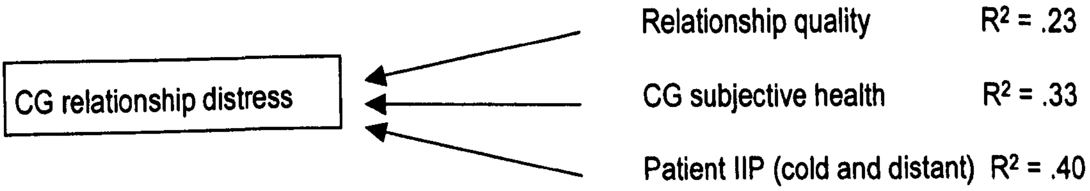
*Table 8.4.2.1.1 Regression model for carer **relationship distress** (n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
Relationship quality	-.17	.06	-.35**	.23	.23
Second step					
CG subjective health	-.52	.21	-.30*	.10	.33
Third step					
P IIP[1] (Cold and distant)	1.87	.81	.31*	.07	.40

*p<.05 **p<.01 ***p<.001

[1] – Patient interpersonal difficulties (cold and distant)

Figure 8.4.2.1.1 Predictors of CG relationship distress



8.4.2.2 Predictors of caregiver emotional burden

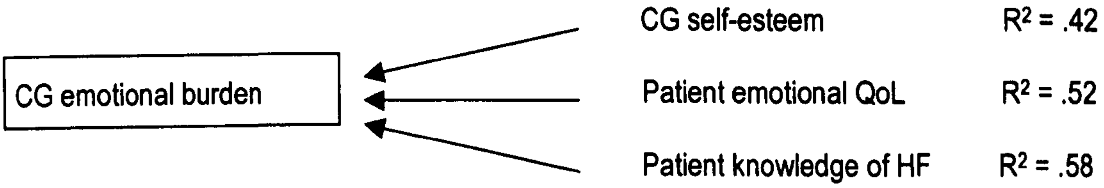
Table 8.4.2.2.1 Regression model for carer ***emotional burden*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG self-esteem	.47	.09	.54***	.42	.42
Second step					
P emotional QoL	.18	.06	.33**	.10	.52
Third step					
P knowledge of HF [1]	-.16	.06	-.24*	.06	.58

*p<.05 **p<.01 ***p<.001

[1] - Patient specific knowledge of HF, as measured by the HFKQ

Figure 8.4.2.2.1 Predictors of CG emotional burden



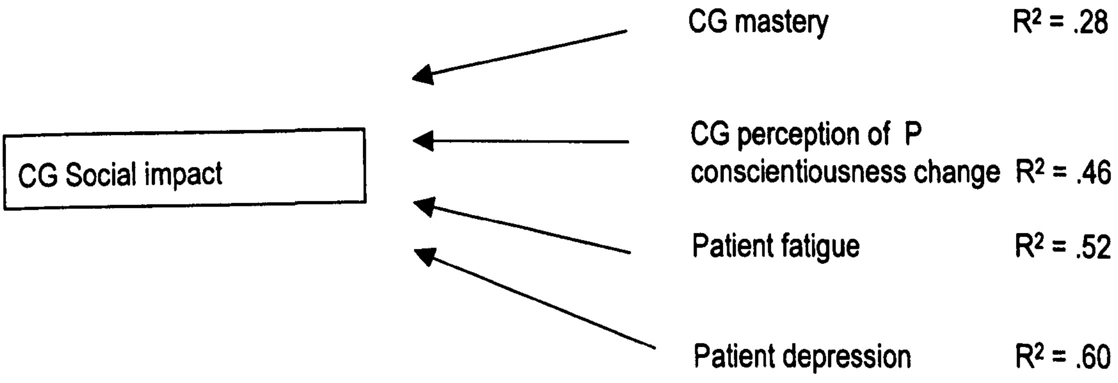
8.4.2.3 Predictors of caregiver social impact

Table 8.4.2.3.1 Regression model for carer ***social impact*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG mastery	-.29	.06	-.51***	.28	.28
Second step					
CG perception of Conscientiousness change	1.605E-02	.004	.52***	.18	.46
Third step					
Patient fatigue	.17	.04	.50***	.06	.52
Fourth step					
Patient depression	-.39	.14	-.44**	.08	.60

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.3.1 Predictors of CG social impact



8.4.2.4 Predictors of care-receiver demands

Table 8.4.2.4.1 Regression model for ***care-receiver demands*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG neuroticism	.14	.04	.50**	.22	.22

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.4.1 Predictors of care-receiver demands

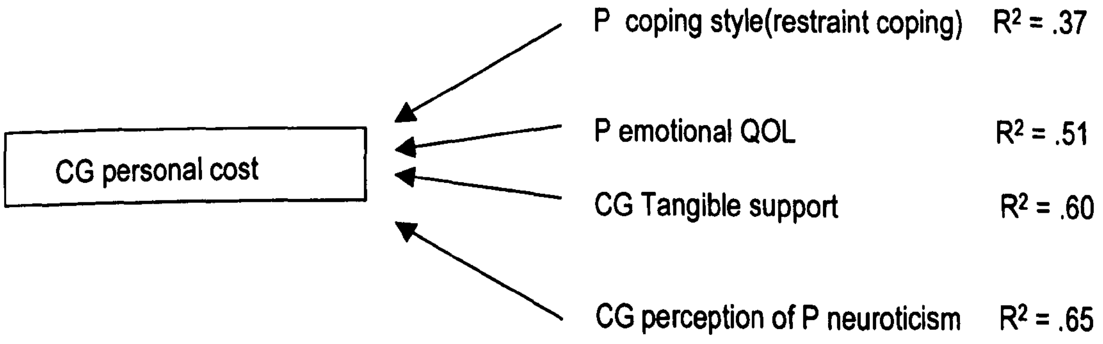
8.4.2.5 Predictors of caregiver personal cost

Table 8.4.2.5.1 Regression model for carer ***personal cost*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
P coping style (restraint coping)	-.48	.17	-.34**	.37	.37
Second step					
P emotional QoL	.12	.05	.27*	.14	.51
Third step					
CG Tangible support	-.25	.08	-.33**	.09	.60
Fourth step					
CG perception of P neuroticism	.12	.06	.29*	.05	.65

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.5.1 Predictors of CG personal cost



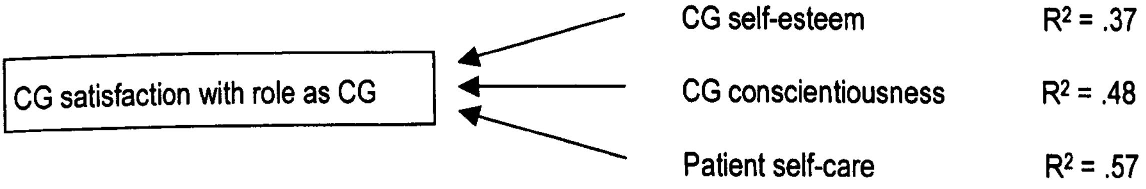
8.4.2.6 Predictors of caregiver satisfaction with role as caregiver

Table 8.4.2.6.1 Regression model for carer **satisfaction with role as caregiver** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG self-esteem	.51	.12	.50***	.37	.37
Second step					
CG conscientiousness	-.26	.09	.34**	.11	.48
Third step					
P self-care	-.47	.18	-.31*	.09	.57

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.6.1 Predictors of CG satisfaction with role as caregiver



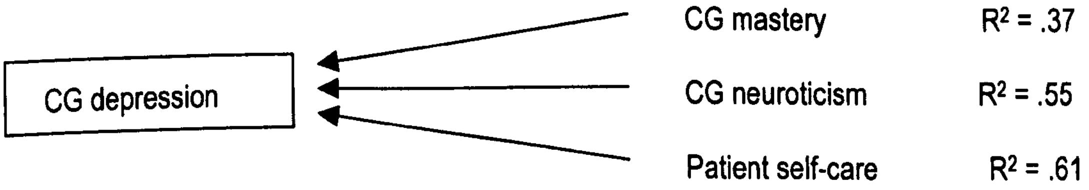
8.4.2.7 Predictors of caregiver depression

Table 8.4.2.7.1 Regression model for carer **depression** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG mastery	-.16	.05	-.39**	.37	.37
Second step					
CG neuroticism	.12	.03	.41**	.18	.55
Third step					
P self-care	-.24	.10	-.28*	.06	.61

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.7.1 Predictors of CG depression



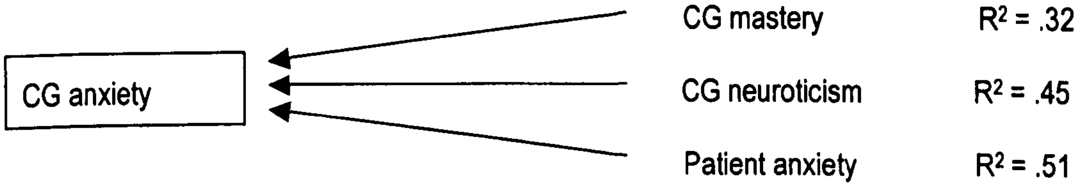
8.4.2.8 Predictors of caregiver anxiety

Table 8.4.2.8.1 Regression model for carer ***anxiety*** *(n=53)*

	B	SE	ß	Adjusted R^2	Accumulative R^2
First step					
CG mastery	-.66	.28	-.33*	.32	.32
Second step					
CG neuroticism	.55	.17	.41**	.13	.45
Third step					
P anxiety	.28	.12	.29*	.06	.51

*p<.05 **p<.01 ***p<.001

Figure 8.4.2.8.1 Predictors of CG anxiety



8.5 Summary

The phase 2 analyses found that, as in the proposed model, there were illness variable, patient variables and caregiver variables that directly predicted patient psychological and clinical outcomes and caregiver distress. The majority of the significant and non-significant associations of potential predictors and distress measures at phase 1 were replicated at phase 2. Patient and caregiver neuroticism were found to be strong moderators of the association between various predictors and patient and caregiver outcomes, therefore changes were required to the hypothesised model.

An investigation of the changes in the illness situation in the 6 months interval between phase 1 and phase 2 revealed that overall the HF severity increased and patient cognitive functioning (as measured by the MMSE) slightly decreased. However, there was no change in patient and carer distress level, suggesting that a six-month follow up period is maybe too short a follow up period to detect significant changes in patient psychological status and carer distress. When comparisons were made between patients who became more ill and those who maintained their health status in the follow up period, it was found that patient and caregiver distress increased with an increase in illness severity.

An investigation of the best predictors of HF patient psychological status and clinical outcomes and HF caregiver distress found that there was no one overwhelming contributor to patient or caregiver outcomes. However, patient neuroticism explained various amount of unique variance in five of the eleven patient outcomes measured (temporary loss of self-esteem, physical and emotional quality of life, depression and anxiety). The quality of professional follow up (HF related GP visits and visits to the cardiac clinics) was a strong predictor of morbidity in the follow up period (i.e. hospitalisations and length of stay in hospital). The only significant predictor of patient mortality in the follow-up period were the Trail A scores at baseline, suggesting that a simple measure of attention, visual scanning, speed of hand-eye co-ordination and information processing is powerful enough to predict mortality in a relatively short follow up period in HF patients.

Caregiver neuroticism was a strong predictor of carer mental health (anxiety and depression). Interestingly, all specific and non-specific (to caregiving) measures of *carer distress* (with the exception of care-receiver demands) were consistently predicted by *both* caregiver *and* patient characteristics, whereas *patient* psychological status was mainly predicted by illness and patient characteristics. One important example is the contribution of *patient anxiety* to explaining 6% of the unique variance in *caregiver anxiety*. As carer anxiety was found to be associated with increase number of hospitalisations and longer stays in hospital, interventions targeted at reducing caregiver anxiety (such as CBT) may ultimately reflect in reduced hospitalisations for HF patients.

In the present study, the conceptualisation of patient and carer distress as consisting of different components (both specific to the caregiving situation and non-specific, mental status measures) was justified, in that the predictor variables accounting for the maximum variance were different for each aspect of patient and carer distress.

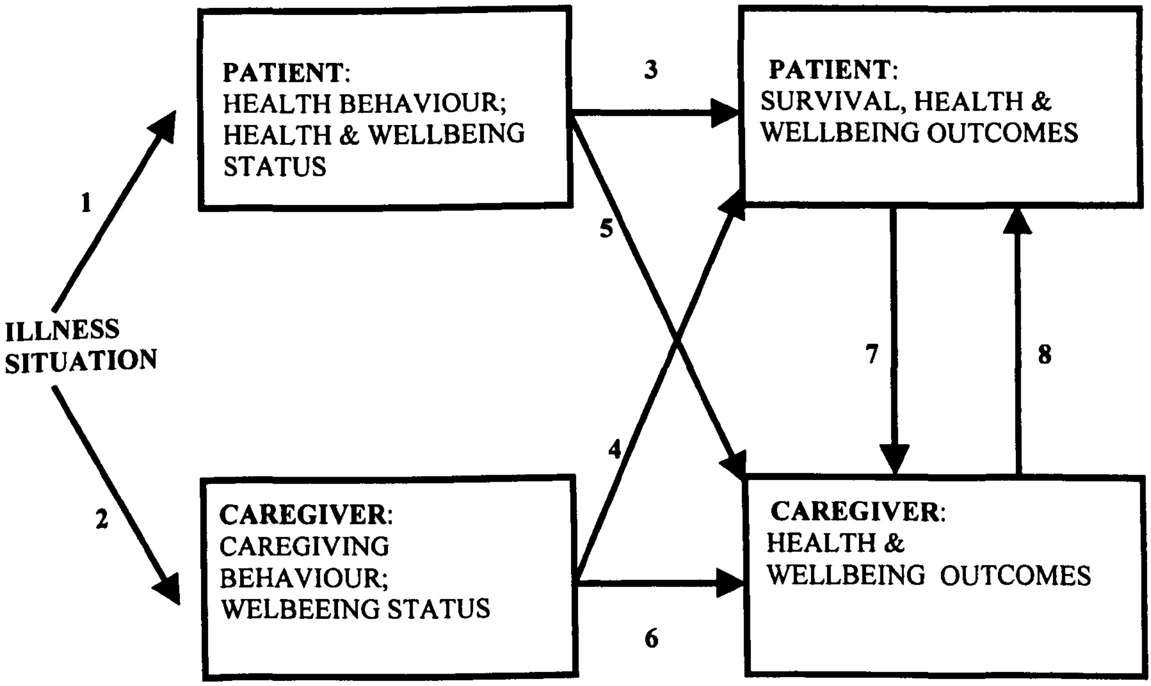
CHAPTER 9

DISCUSSION

9.1 Introduction

In this chapter, the results of the investigation of the effect of illness factors on patient and caregiver outcomes in heart failure are discussed. The chapter is divided into three sections, mirroring the links in Young's (1994) model of late life family illness (see Fig. 9.1.1, below). The first section represents links 3 and 5 of the model and illustrates the effects that *illness* and *patient* characteristics have on patient and caregiver outcomes. The second section follows links 4 and 6 and shows the effects that *caregiver* characteristics have on caregiver and patient outcomes. Finally, the third section illustrates links 7 and 8 and shows how patient and carer outcomes affect each other. The hypotheses of the study are reiterated and presented systematically and other important findings to come out of the research are pointed out. A revised model of HF caregiving based on the findings of the study is presented.

Fig 9.1.1 Late life family illness: Patient-caregiver Interaction model (from Young, 1994)



9.2 The influence of illness and patient characteristics on patient and caregiver outcomes

9.2.1 The influence of HF severity on patient and caregiver outcomes

It was hypothesised that increased heart failure severity will be associated with worse patient psychological outcomes and higher levels of caregiver distress at both phases of the study and worse patient clinical outcomes at phase 2.

9.2.1.1 Severity of illness and patient outcomes

9.2.1.1.1 Objective measures of illness severity and patient outcomes

The hypothesis was supported in that the most common measure of illness severity, the New York Heart Association classification, was significantly related to all measures of psychological distress non-specific to the caregiving situation. Increased NYHA class was associated with worse physical and emotional QoL and worse depression and anxiety at both phases of the study, independently of patient neuroticism. The relationship between illness severity and patient anxiety was mediated by patient neuroticism at both phases. This is not surprising, as patient neuroticism was found to be the strongest predictor of anxiety, explaining 43% of the unique variance in anxiety. The finding that the NYHA class is predictive of patient quality of life supports the work of Juenger et al., (2002) and Westlake et al., (2002). Both studies reported that an increase in NYHA class was associated with decreased quality of life as measured by the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36; Ware et al., 1993). The present study strengthens these findings by using a questionnaire that was designed specifically for HF patients (The Minnesota Living with Heart Failure Questionnaire, LHFQ; Rector et al., 1987). The finding that patient level of depression increased as NYHA class increased replicated those of Elatre et al., (2003) who reported that chi-square analyses indicated a significant relationship between the severity of depression as measured by HAD and NYHA class in 120 patients with HF. However, this study's findings are in contrast to those of Murberg et al., (1998) who reported that path analyses showed non-significant direct associations between NYHA class and patient depression (as measured by the Zung Self-rating Depression Scale, SDS, Zung, 1965) in 119 clinically stable heart failure patients.

The present study found that although the level of depression increases gradually in patients with mild to moderate to severe HF, patients classified as mild (NYHA class II) HF reported significantly less anxiety than *both* moderate and severe HF patients replicating the findings reported by Majani et al., (1999). Patients who become more severe at phase 2 (increasing their NYHA class) were more likely to be more often hospitalised in the follow-up period and to stay longer in hospital when admitted than patients who maintained their NYHA class. However, in contrast to the Muntwyler et al., (2002) study, NYHA class was not predictive of mortality in this study. This may be due to the low number of NYHA class IV patients in phase 1.

A second measure of objective illness severity measured in this study was patient disability (IADLs; Lawson et al., 1975). Increased patient disability was associated with worse physical and emotional quality of life and higher depression at both phases 1 and 2 of the study, independently of patient neuroticism. As with NYHA class, the relationship between patient disability and patient anxiety was mediated by patient neuroticism. However, patients who become more disabled at phase 2 reported significantly higher levels of anxiety than patients who maintained their level of disability, independently of patient neuroticism.

As in other studies (Taffet et al., 1992; Gottdiener et al., 2002; Fogel et al.,2002), *objective* measures of left ventricle function (left ventricular ejection fraction; LVEF) and lung function (FEV1 and FVC) were not associated with patient outcomes in this study, with one exception. Interestingly, a low LVEF was found to be significantly related to increased patient anxiety, independently of patient neuroticism. This result indicates that MacMahon and Lip (2002) were correct in advising that anxiety should be of relevance to clinicians because it can negatively affect the cardiac output of patients with HF. Although *correlation does not mean causation* (e.g

Coolican, 1995), it is well known that stress increases heart rate, resulting in reduced coronary artery perfusion (and thus reduced oxygen *supply*) through shorter diastole, while increasing myocardial *demand*. A "spiralling process" results, in which patients' increased anxiety regarding their physical state translates into even poorer cardiac output. At present, this study is the first to show an association between LVEF and anxiety level in HF patients under stringent methodological conditions: firstly, the significance level was set at $p< .01$ instead of the conventional $p< .05$ level, and secondly, patient neuroticism was partialled out.

To summarise, in this study NYHA class and patient level of disability were directly associated with their quality of life and depression level, whereas the association with patient anxiety was mediated by patient neuroticism. No associations were found between objective measures of left ventricular and lung function and patient outcomes with one important exception: patients with low LVEFs were significantly more anxious than patients with high LVEFs, independently of patient neuroticism.

9.2.1.1.2 Subjective measures of illness severity and patient outcomes

According to Majani et al., (1999) what can be predicted on the basis of cardiological diagnosis is only a generic pattern of psychological distress, which is the result of the effect of being severely and chronically functionally impaired, no matter what the disease. In order to investigate the effect that HF severity has on the patient outcomes, in this study *subjective* measures of HF illness severity were collected in addition to the *objective* measures. A review of qualitative studies of living with HF identified three symptoms that were viewed as problematic by both HF patients and their carers: breathlessness or dyspnoea, fatigue and sleep problems. Self-report questionnaires were administered to patients in order to quantify how problematic they perceived these symptoms to be to their everyday life. In addition, a measure of *subjective general health*, which was consistently found to be a powerful predictor of clinical outcomes and mortality in a wide range of disease areas (Fayers and Sprangers, 2002), was used to determine patients' perceptions of their overall health status. Increased levels of patient perceived breathlessness and fatigue and worse overall health were strongly associated with decreased physical and emotional quality of life and worse depression at both phases 1 and 2, independently of patient neuroticism. The associations between breathlessness, fatigue and overall health and anxiety were strongly moderated by patient's neuroticism.

It can only be assumed that patients who report high levels of breathlessness and fatigue will also perceive their overall health to be poor. Indeed, this was the case in that subjective overall health was strongly correlated with both fatigue and breathlessness at both phase 1 and phase 2 of the study, independently of patient emotionality. Fatigue was found to be strongest predictor of patient physical quality of life: in phase 1 it accounted for 52% of the variance in physical quality of life, which rose to 70% in phase 2. This finding confirms previous reports that fatigue is often rated by patients with chronic diseases as one of the key factors leading to a decrease in their quality of life (Swain, 2000). However, because of the subjective nature of fatigue and the lack of specific therapies available to treat fatigue, it is a symptom that is often overlooked or ignored by physicians.

Nevertheless, recent research has shown that low impact exercise, such as home walking and muscle strength training has beneficial effects on patients' ratings of fatigue and breathlessness in HF patients (Radzewitz et al., 2002; Corvera-Tidel et al., 2004). Therefore, GPs and cardiac specialists are in a position to recommend low impact exercise to HF patients, in order to reduce the impact of symptoms on their quality of life.

The present study found that daytime sleepiness was associated with reduced physical quality of life in HF patients. This finding replicates results of studies of both HF patients (Brostrom et al., 2003) and older non-depressed, non-demented adults (Gooneratne et al., 2003). Interestingly, in the present study patient neuroticism served as a *suppressor* of the relationship between the two variables. In other words, patient neuroticism served to mask or suppress the real relationship between daytime sleepiness and physical quality of life. This could be because highly neurotic patients may justify daytime sleepiness in a way that is not connected with their illness, for example boredom. Moreover, there was a near significant association (chi-square = 3.26, p <. 07) between excessive daytime sleepiness at phase 1 (scores >10 on the Epworth Sleepiness Scale) and mortality at six-month follow up. These findings are similar to those reported by the Cardiovascular Health Study Research Group (Newman et al., 2000), which found that daytime sleepiness was the only sleep symptom significantly associated with mortality in both men and women in a longitudinal study (the follow up period was on average 4.85 years) of 5888 older adults living in community.

To summarise, subjective measures of illness severity were found to be important predictors of quality of life and mood in HF patients. Particularly, patient fatigue was a strong predictor of physical quality of life, suggesting that interventions targeted to alleviate fatigue may be a way of reducing this symptom, thus increasing patients' perceptions of their quality of life.

9.2.1.2 Severity of illness and carer distress

9.2.1.2.1 Objective measures of illness severity and caregiver outcomes

When we turn to the relationship between illness characteristics and carer distress, illness severity was also hypothesised to be a significant factor. This hypothesis was supported, in that objective heart failure severity (as measured by NYHA class and patient disability) was associated with worse carer distress at both phases. Specifically, caregivers of patients who were more severely ill reported significantly more social impact and personal cost of caregiving than caregivers of less ill HF patients (independently of carer neuroticism). Moreover, at phase 2 caregivers of patients whose HF severity increased between the two phases were significantly more depressed than caregivers of patients who maintained their HF severity. These results are in agreement with Pinquart and Sorensen (2003a) findings. In a meta-analysis of 228 studies of the associations of six caregiving-related stressors and caregiving burden and depressed mood, they reported that care-receivers' physical impairments were associated with carer burden and depression. Moreover, if we assume that an increase in illness severity is translated into increased caregiver demands, our study replicated Nieboer et al., (1998) and Beach et al., (2000) findings that increased patient impairment results in increased depressive symptomatology in caregivers.

9.2.1.2.2 Subjective measures of illness severity and caregiver outcomes

Worse subjective measures of patient health status (overall subjective health, breathlessness and fatigue) were associated with increased carer distress at both phases. Specifically, carers of patients who perceived their health to be poor reported more emotional burden, social impact and personal cost than carers of patients who perceived their health to be good (independently of carer neuroticism). Interestingly, subjective measures of illness severity were associated with carer *emotional burden*, whereas *objective* measures did not. Similar to objective measures of illness, however, subjective measures were associated with worse carer non-specific (to caregiving) measures of mental health (i.e. anxiety and depression) at phase 2. Therefore, a worsening of patient HF as measured by both objective and subjective illness measures is associated with greater carer anxiety and depression.

Of particular importance is the association between patient daytime sleepiness and carer distress. This study found that worse patient daytime sleepiness was associated with three measures of carer distress *specific* to the caregiving situation: namely, worse patient reported daytime sleepiness was related with greater carer emotional burden, increased social impact and more care-receiver demands (independently of carer neuroticism). To date, this study is the first to quantitatively report associations between HF patient sleep problems and carer specific distress. Moreover, the findings can be interpreted as "true" because the statistical analyses involved were stringent. Firstly, only associations significant at the more conservative p< .01 level of significance were interpreted, and secondly, the effect of carer neuroticism was partialled out. These results reinforce in a quantitative manner Brostrom et al.'s (2003) findings that the HF patient sleep problems affect carers' ability to provide help by negatively influencing their psychological status. Future research is warranted to assess the effect that HF sleep problems have on their carer's sleep quality, and to investigate possible interventions directed at improving the dyadic sleep situation.

9.2.2 Worsening clinical status between phases and patient and caregiver distress

It was hypothesised that an increase in HF severity, as shown by NYHA class would be associated with an increase in patient and carer distress. The hypothesis was supported. Eleven patients changed their NYHA class (to worse) between study phases. Patients whose HF worsened reported a decrease in their physical quality of life and more depression than patients who maintained their HF severity. Correspondingly, *caregivers* of patients who worsened between phases reported an increase in social impact and personal cost due to caregiving and higher levels of depression than caregivers of patients who maintained their level of health. This results support the "wear-and-tear" hypothesis of the association between the duration of performing the caregiver role and psychological effects of caregiving (Pinquart and Sorensen, 2003a), which predicts that the longer caregiving is sustained, the greater the decline in caregiver subjective well being.

9.2.3 The effect of patient personality on patient and carer outcome

It was hypothesised that patient personality would directly affect patient and caregiver outcomes. This hypothesis was strongly supported. The results are systematically discussed in this section.

9.2.3.1 The effect of patient personality on patient outcomes

9.2.3.1.1 The effect of patient personality on patient psychological outcomes

It was hypothesised that patient personality, particularly patient neuroticism would affect patient psychological status. This hypothesis was strongly supported in that higher patient neuroticism was directly associated with lower patient quality of life and worse levels of anxiety and depression at both phase 1 and phase 2, suggesting that the associations are stable in time. These findings are in agreement with Costa and McCrae's (1984) proposition that the variance in psychological well being can be explained by personality, with neuroticism being the main contributor. Various mechanisms have been proposed to explain the effect of neuroticism as predictor of psychological well being in HF patients (see section 2.5.3 in chapter 2). This study provides support for the proposition that neuroticism may serve as a "filter" that mediates the associations between objective symptoms and physical limitations and psychological well-being in HF (Murberg et al., 1997). For example, the relationship between patient NYHA class and overall quality of life and depression was significantly reduced when patient neuroticism was accounted for. Moreover, stepwise regression analyses showed that NYHA class and patient neuroticism explained 52% of the variance in overall patient quality of life and 57% of the variance in patient depression at phase 1.

Beside patient neuroticism, two other of the "Big Five" personality traits were measured (extraversion and conscientiousness). In the present study, higher patient extraversion and conscientiousness were associated with better quality of life and lower levels of depression and anxiety. However, all the associations were strongly mediated by patient neuroticism with one exception, namely higher patient extraversion was related to reduced levels of patient depression, independently of patient neuroticism.

A comparison of the study sample to normative British data (Eagan et al., 2000) showed that this HF population has a "personality profile" characterised by normal neuroticism and conscientiousness, but "abnormally" low extraversion, in that 12% of the patients' responses on the extraversion scale were two standard deviations below the normal range. Patients whose levels of extraversion were "abnormally" low reported lower quality of life and higher levels of anxiety and depression than patients who scored within normal limits on the extraversion scale.

However, these relationships disappeared when patient neuroticism was accounted for. Therefore, in agreement to our hypotheses, patient neuroticism is both a strong *direct* predictor of patient psychological outcomes and a *moderator* of the relationships between patient extraversions and conscientiousness and patient distress. It also implies that neuroticism is a critical variable when investigating predictors of well being in patients with chronic conditions that should be always measured.

9.2.3.1.2 The effect of patient difficulties with interpersonal functioning on patient psychological outcomes

In the present study, patients and carers completed the inventory of interpersonal problems (Horowitz et al., 2000), which identifies levels of difficulty in eight domains of interpersonal functioning. To date, no other studies have reported the effect that interpersonal difficulties may have on the outcomes in a care-giving - care-receiving situation, therefore analyses were exploratory and no specific hypotheses were formulated. This study found that patients who scored high on three domains of interpersonal functioning (namely, being socially inhibited, non-assertive and overly accommodating) reported increased temporary loss of self-esteem due to care-receiving, had a lower quality of life and higher levels of depression and anxiety than patients who scored low in these domains. However, all these associations disappeared when patient neuroticism was statistically controlled. Therefore, difficulties in interpersonal functioning do not affect HF *patient* psychological outcomes beyond the effect of their own neuroticism. However, they do affect *caregiver* outcomes, as discussed in section 9.2.3.2, below.

9.2.3.1.3 The effect of patient personality on patient clinical outcomes

It was hypothesised that patient neuroticism would affect patient clinical outcomes at six months follow up. This hypothesis was based on reports that patients who are highly neurotic are more sensitive to aversive bodily symptoms, tend to report more health complains and are more likely to misinterpret somatic symptoms as signs of body pathology than stable individuals (Costa and McCrae, 1980b, 1985, 1987; Costa et al., 1982). In this study, highly neurotic patients were more likely to be hospitalised in the follow up period, and to spend longer periods in hospital when admitted than less neurotic patients. Moreover, when a composite measure of "adverse effects in the follow up period" was used (death or hospitalisation or both), it was found that highly neurotic HF patients were more likely to suffer adverse effects than low neurotic patients. However, no relationship between patient neuroticism and mortality was found. Therefore, our hypothesis that highly neurotic patients will be "disadvantaged" from a clinical point of view at six-month follow up was only partially supported. The finding that patient neuroticism is *not* associated with mortality in HF patients is in disagreement to Murberg et al.'s (2001) study, which found that high neuroticism was an independent predictor of mortality in HF patients. However, it could be that a six-month follow up is too a short follow up period to detect a significant association between neuroticism and mortality. Murberg's study had a longer follow up period than our study (2 years), as had other studies that found that personality is predictive of morbidity and mortality in CHD patients (Denollet et al., 1996; Denolett and Brutsaert, 1998). Therefore, a longer follow up period of the present study is warranted in order to determine whether patient neuroticism is predictive of mortality in this HF population.

To summarise, patients with HF who are highly neurotic are more likely to be hospitalised and to spend a longer time in hospital when admitted. In the view of the significant economic burden that HF hospital admissions exert on the health system (Stewart et al., 2002), there is a pressing need to identify patients who are predisposed to express high levels of neuroticism in order to develop interventions tailored to the individual patient which may help may reduce HF morbidity and mortality.

9.2.3.2 The effect of patient personality on carer distress

9.2.3.2.1 The direct effect of patient personality on carer distress

It was hypothesised that patient personality, particularly patient neuroticism would affect carer distress. This hypothesis was strongly supported.

In this study, *current* patient neuroticism, extraversion and conscientiousness were measured twice. Firstly, the patient was asked to complete the NEO-PI-R and secondly, the caregiver completed an adapted form of the NEO-PI-R to investigate *carer perception* of patient personality. There was a good level of agreement between patient and carer perception of patient personality. In particular, carer perception of patient neuroticism was strongly associated to patients' self-reports of neuroticism, suggesting that carers can accurately report patient neuroticism. Carers of patients who were highly neurotic reported higher levels of specific and non-specific distress and lower levels of satisfaction with the role of caregiver than caregivers of low emotionality patients. Interestingly, the relationship between patient neuroticism and carer depression was moderated by carer neuroticism, however the positive association between high patient neuroticism and high carer anxiety remained strong even when carer neuroticism was accounted for.

Carers of highly conscientious patients reported less personal cost due to caregiving and more satisfaction with role of caregiver than caregivers of less conscientious patients, independently of carer neuroticism. Patient extraversion was not associated with any of the caregiver distress measures used.

Therefore, in our study patient neuroticism had a detrimental effect on carer distress, whereas patient conscientiousness had a protective effect.

9.2.3.2.2 The direct effect of patient interpersonal difficulties on carer distress

In the present study, caregivers of patients who scored high on the Cold-Distant subscale of the Inventory for Interpersonal Problems (Horowitz et al., 2000) reported significantly more relationship distress than caregivers of patients who score low on this interpersonal domain, independently of carer neuroticism. Patient being "cold" and "distant" explained 7% of the variance in carer relationship distress, which rose to 40% when relationship quality and carer subjective health were added in the multiple regression equation. Therefore, patient interpersonal difficulties add unique variance to carer reported relationship distress due to caregiving.

9.2.3.2.3 The effects of patient personality change on carer distress

It was hypothesised that caregivers who perceived a marked change in patient's core personality characteristics would be more distressed than caregivers of patients whose personality did not change. This hypothesis was strongly supported. An increase in patient neuroticism and a decrease in patient extraversion and conscientiousness were associated with increased caregiver distress. Although research with Parkinson Disease patients and their caregivers has found associations between changes in patient personality and caregiver distress (Davies, Cousins et al., 1998), the present study is the first to show that a perceived change in personality in *heart failure* patients is associated with increased caregiver distress, independently of carer neuroticism.

Additionally, the finding that caregivers perceived patients' personality *to change in time* is of particular interest. Overall, caregivers reported that by comparison to how they were "in their prime" patients became *significantly* more neurotic, less extraverted and less conscientious. This is interesting from the view of current personality research. Firstly, the results are in stark contrast to the traditional view that after age 18, neuroticism declines and conscientiousness increases (Costa and McCrae, 1994). Secondly, research has shown that people who have experienced major changes in physical health (such as heart disease) are just as stable in their personality traits as those who have not (Costa et al., 1994). Thirdly, the most striking and best - documented changes in personality are those associated with changes in the brain attributable to dementia or to traumatic brain injury (Costa and McCrae, 2000) and HF was shown to be associated with cognitive impairment (see section 3.1.1 for a review). Therefore, it could be argued that changes in the personality of HF patients may be due to cognitive changes caused by their illness. However, the present study cannot answer these question because (i) changes in patient personality are reported by the carer *not* the patient and (ii) patient adult personality was measured retrospectively, thus its reliability is questionable. Future longitudinal studies of HF patients are warranted to confirm that (i) there is a measurable change in patient personality *as reported by the patient* and (ii) patient personality change is associated with cognitive status change due to heart failure.

9.2.4 The moderating effect of patient neuroticism on relationships between illness variables and patient and carer outcomes

It was hypothesised that patient neuroticism will be a strong moderator of the relationship between illness variables and patient and caregiver outcomes. Consequently, throughout this thesis patient neuroticism was statistically controlled in associations between variables of interest in order to discover the "real" relationships between various predictors and outcomes. The hypothesis was strongly supported, in that with little exception, controlling for patient neuroticism systematically reduced the strength of the associations between illness variables and patient and carer outcomes. Some relationships became non-significant when patient neuroticism was controlled (for example, the associations between patient fatigue and level of anxiety and Trail A and B and quality of life) and others were significantly reduced (for example, the associations between behavioural disengagement coping and patient depression or carer hours of care and patient physical quality of life). One exception was the association between patient daytime sleepiness and patient physical quality of life. Controlling for patient neuroticism *strengthened* the relationship, suggesting that patent neuroticism acts as a "suppressor", thus masking the "true" relationship between increased daytime sleepiness and lower physical quality of life.

These findings stress the importance of controlling for patient neuroticism when relating various predictors to outcomes. It should be mentioned that some authors view controlling for personality as disadvantageous, in that personality may in fact be "the distant and causal factor" that underlies the predictor of interest (Wrosch and Scheier, 2003). However, as recommended by these authors, our study included personality in the theoretical model, thus making possible the distinction between background variables – such as personality and other mediating processes, such as coping.

9.2.5 The influence of patient cognitive status on patient outcomes and carer distress

9.2.5.1 The influence of patient cognitive status on patient and carer distress

It was hypothesised that worse patient mental status will be associated with worse psychological outcomes. The hypothesis was partially supported, in that patients who scored lower on the MMSE also reported worse *physical* quality of life, when patient emotionality was controlled. No other associations were found between scores on the neuropsychological battery used (Trail A and B, Rey Auditory Verbal Learning Test and the Grooved Pegboard Test) and patient psychological outcomes. Surprisingly, patient neuroticism strongly mediated the relationship between scores on Trail A and B and patient physical and emotional quality of life, in that controlling for patient neuroticism reduced medium strong associations (for example, the association between Trail B and physical quality of life was $r = -.46$, $p < .001$) to non-significant. It could be that highly neurotic individuals "cognitively appraise" tests such as Trail A or B as "threatening", thus performing poorly. Research has shown that the way in which an individual appraises a situation mediates the relationship between event and outcome, and negative affectivity affects the process of cognitive appraisal (Oliver and Brough, 2002). This seems to be the case here, as in phase 2 patients performed *better* on both Trail A and B, significantly so on Trail A. However, priming and knowing the investigator may also have played a role. More importantly, patients who scored less than 24 on the MMSE and thus may be viewed as "dementing" (Hodges, 1994) reported significantly lower quality of life (physical and emotional) and more depression than cognitively "intact" patients.

Caregivers of patients who scored low on the MMSE reported more social impact and personal cost due to caregiving. However, no association was found between patient cognitive impairment and caregiver depression. The results of the present study reflect the state of the current caregiving research. Bedard et al., (2000) in a review of mixed (dementia and non-dementia) caregiving studies found that only 12% of the studies reported associations between cognitive status of the care-receiver and caregiver burden, whereas in another 20% the association were unclear. As may be the case in this study, Pinquart and Sorensen (2003b) suggest that the association between patient cognitive impairment and caregiver depression is small, thus hard to detect in small studies.

9.2.5.2 The influence of patient cognitive status on patient clinical outcomes

It was hypothesised that cognitively impaired patients will have worse clinical outcomes at six months follow-up. The hypothesis was partially confirmed, in that although patients' mental status did not influence the number of re-hospitalisations or length of stay in hospital in the follow-up period, it did affect mortality. Patients who died in the six months between the phases scored significantly lower on the MMSE and were slower on the Trail A test at baseline than patients who survived. Moreover, "dementing" patients were more likely to die in the follow-up period than non-dementing patients. These results are in agreement to studies reporting the association between cognitive impairment and mortality in both HF patients (Gussekloo et al., 1997; Rozzini et al., 1998, 2004; Zuccala et al., 2003) and general population (Neale et al., 2001).

9.2.6 The influence of patient HF knowledge, coping style and social support on patient and caregiver outcomes

9.2.6.1 The influence of patient knowledge of HF on patient and caregiver outcomes

9.2.6.1.1 The influence of patient knowledge of HF on patient psychological status and clinical outcomes

It was hypothesised that patients who knew more about their illness would be less distressed and have better clinical outcomes at six months follow up. The hypothesis was partially supported.

Four measures of HF knowledge were used: two measures *specific* to the illness situation (knowledge of medication and a questionnaire developed specifically for this study) and two *non-specific* measures (illness uncertainty and self-care knowledge). Surprisingly, *specific* knowledge of HF was *not* related to either patient psychological status or clinical outcomes at follow up. However, a look at the scores of the HF Knowledge Questionnaire shows that specific knowledge of HF in our sample is low (mean 36.5, mode 30, range 24 - 48). These findings are in agreement to studies exploring illness knowledge in HF patients (e.g. Dunbar et al., 1998; Rogers et al., 2002; Artinian et al., 2002). Therefore, in could be argued that low HF knowledge *per se* does not necessary have a negative effect on patient distress and clinical outcomes. Significantly improving HF knowledge through multidisciplinary interventions, however has been shown to have a *beneficial* effect in reducing unplanned re-hospitalisations and HF mortality (e.g. Rich et al., 1995; Blue, 2003).

In contrast, *non-specific* measures of HF knowledge *were* associated with patient psychological status and clinical outcomes. Specifically, patients who reported high levels of illness uncertainty also reported poorer quality of life, more depression and more anxiety than patients who were less uncertain about their illness. These findings are in agreement to those reported by Hawthorne and Hixon[1], (1994) and others. However, these studies were criticised for not disregarding the potential effect of patient's personality on the relationship between illness uncertainty and mood and quality of life (Greco and Roger, 2003). Indeed, in the present study, when patient neuroticism was controlled, all these relationships became non-significant, suggesting that patient neuroticism is a *powerful moderator* of the association between illness uncertainty and mood and quality of life.

Similarly, the association between patient knowledge of *self-care* and patient quality of life and depression was moderated by patient neuroticism, suggesting an indirect association. However, the relationship between patient knowledge of self-care and *physical* quality of life was also direct: patients who reported a high knowledge of self-care also perceived themselves to have a better physical quality of life. Moreover, patient's level of knowledge of self-care was an

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[1] Hawthorne and Hixon's (1994) study was based on HF patients.

independent predictor of patients going to hospital at least once in the follow-up period (it explained 8% of unique variance in multiple regression analyses). Therefore educating HF patients to self-care may be a more direct approach at improving quality of life and reducing unplanned re-hospitalisation than giving patients specific information about HF. Indeed, recent research has shown that interventions aimed at improving HF patient's level of self-care (especially immediately after hospital discharge) has beneficial effects on reducing death and readmission (Stewart et al., 1998, 1999, 2002; Wright et al., 2003) and improving quality of life (Ryder et al., 2003; Vavouranakis et al., 2003).

9.2.6.1.3 The influence of patient knowledge of HF on caregiver distress

Qualitative studies of the effects that HF has on the patient and their families have shown repeatedly that lack of information about the condition resulted in increased distress not only in the patient, but also in the caregiver (Stull et al., 1999; Mahoney, 2001; Murray et al., 2002). The present study aimed to show in a *quantitative* way the effects that patient lack of illness knowledge has on carer distress. Therefore, it was hypothesised that *greater* patient knowledge of HF will be associated will *less* carer distress. The hypothesis was partially supported. Similarly to findings regarding the associations between patient *specific* knowledge of HF and patient mood, there was no significant association between patient specific knowledge of HF and carer distress at the more stringent p< .01 level of association, when carer neuroticism was controlled. However, the relationships between patient illness uncertainty and self-care knowledge and carer distress presented an interesting pattern.

High levels of patient illness uncertainty reflected in high levels of carer distress *specific to the caregiving situation*, independently of carer neuroticism. Namely, carers of patients who were highly uncertain about their condition reported more relationship distress, more social impact and personal cost due to caregiving than carers of less uncertain patient, independently of carer neuroticism. However, the association between patient illness uncertainty and carer depression and anxiety level, although significant at the conventional level of $p< .05$, was mediated by carer neuroticism.

The association between patient self-care knowledge and carer distress presented a slightly different profile. Caregivers of patients who reported high levels of self-care knowledge were less distressed overall than carers of patients who had low levels of self-care knowledge. However, the associations were mediated by carer neuroticism, with two exceptions: carers of patients who knew more about self-care reported significantly less personal cost of caring and less depression than carers of patients who knew less about self-care *independently* of carer neuroticism. The personal cost scale measures the effect that caring for a relative with HF has on the personal life of the carer. For example, one item of the scale is: *" I feel my personal life has suffered because of taking care of the [care-recipient]".* It could be that patients who know more about self-care may feel to be more in control of their illness, thus reducing the carer's load of responsibility. Dracup et al., (2003) found that HF patients who had high-perceived control of their illness could walk longer distances and experienced less emotional distress than patients with low perceived control.

The present study shows that patients knowledge of self-care not only influence *their* well being, but also that of *their caregivers*. This finding is important in the light of current research that shows that educating patients about self-care has beneficial results on their clinical status and quality of life. In this study, only the patients were asked about their knowledge of HF. Of interest would be to ask caregivers what *they* know about their relative's illness in order to identify the mechanism by which patient self-care knowledge influences carer distress and mood.

9.2.6.2 The influence of patient coping style on patient and caregiver outcomes

Previous research has shown that avoidance coping styles have a detrimental effect on the mood and mortality of patients with HF (Murberg and Bru, 2001; Murberg et al., 2002; Murberg et al., 2004). In the present study we hypothesised that task-oriented coping styles will be beneficial, whereas avoidance coping styles will have deleterious effects on patient and caregiver outcomes. The hypothesis is exploratory because, although there is a consensus in the literature that avoidant strategies may be less adaptive in the long run than task-oriented strategies, it is also argued that the impact of these coping strategies are highly depended on the characteristics of the stressful situation (Lazarus and Folkman, 1984, Manuel et al., 1987).

9.2.6.2.1 The influence of patient coping style on patient psychological and clinical outcomes

In the present study, patient neuroticism was a powerful moderator of the associations between patient coping styles and patient outcomes. However, in accord to Murberg et al.'s (2002) findings, although coping and neuroticism shared significant amounts of variance, there was still unshared variance suggesting that an individual's coping styles may illustrate *more* than stable personality traits.

The hypothesis that avoidant coping style has a deleterious effect on patient mood was supported in that, similarly to Murberg et al.'s (2002) study, patients who use behavioural disengagement to cope with their illness reported higher levels of depression, independently of patient neuroticism. However, no association was found between behavioural disengagement and mortality. It could be that a six months follow-up period is just too short a period to detect a significant association, considering that Murberg et al.,'s (2001, 2004) findings are based on a two- and six year follow-up period, respectively. Surprisingly, the present study found that *mental disengagement* had a *protective* effect, in that HF patients who scored high on this scale were more likely to be alive at six months than those who scored low on the scale. This finding supports the view that disengaging from a goal may sometimes be a highly adaptive response (Klinger, 1975 cited in Carver et al., 1989), although it was shown in long term to prevent adaptive coping (Aldwin and Revenson, 1987 cited in Carver et al., 1989).

The hypothesis that task-oriented coping will be associated with better patient psychological outcomes was supported, however the association was indirect (was moderated by patient neuroticism). Namely, patients who used *positive re-interpretation and growth* and *turning to religion* to deal with their illness reported significantly fewer *negative reactions to carer behaviour* than patients who scored low on these measures, independently of patient neuroticism. Moreover, these two measures accounted for 27% of the variance in *negative reactions to carer behaviour*. At present, this study is the first to show the care-recipient's negative reactions to receiving care are associated to their coping style. A larger sample, longitudinal study is necessary to confirm these intriguing findings.

9.2.6.2.2 The influence of patient coping style on carer distress

It was hypothesised that patient task oriented coping styles will positively affect carer distress, whereas avoidance coping styles will be associated with an increase in carer distress. The hypothesis was supported. On one hand, carers of patients who scored high on the *seeking instrumental social support* subscale of the COPE (a task-oriented coping style) reported lower levels of depression than carers of patients who scored low on this subscale, independently of carer neuroticism. Moreover, there was a strong association between higher patient use of *restraint coping* (waiting until an appropriate opportunity to act presents itself, again a task oriented coping style) and *lower* carer personal cost due to caregiving, independently of carer neuroticism. Restraint coping explained 37% of variance in caregiver personal cost to caregiving measure. On the other hand, patients' use of *behavioural disengagement* (avoidant coping style) was associated with more personal cost due to caregiving and higher levels of anxiety in carers, independently of carer neuroticism. The association between patient behavioural disengagement and carer distress is not surprising, considering that behavioural disengagement was suggested to reflect *helplessness* (Carver et al., 1989). Moreover, studies have shown that observing a spouse that is in pain or distress is emotionally difficult for caregivers (Finlayson and McEwen, 1977; Karmilovich, 1994).

9.2.6.3 The influence of patient social support on patient and caregiver outcomes

Studies had consistently shown that inadequate social support is associated with poor cardiovascular outcomes in cardiac patients *without* HF, and suggestions have been made that these findings may be extended to patients *with* HF (Moser and Worster, 2000). In the present study, it was hypothesised that higher level of social support will be associated with better patient psychological status and better clinical outcomes at six months follow up and less carer distress.

9.2.6.3.1 The influence of patient social support on patient mood and quality of life and clinical outcomes

Surprisingly, the hypothesis that higher levels of social support will have a beneficial effect on patient mood and quality of life was not supported, neither cross-sectionally (phase 1), nor longitudinally (at phase 2). Moreover, there was a significant association (moderated by patient neuroticism) between higher social support and *lower* emotional quality of life. An analysis of the types of social support which contributed towards the "total" social support scale showed that lower emotional quality of life was related to higher levels of informational support, independently of patient neuroticism. In other words, patients who reported higher levels of informational support also perceived their emotional quality of life to be reduced. There are two possible explanations for this unexpected finding. Firstly, as illustrated in qualitative studies of the experience of living with HF (Buetow et al., 2001b) many HF patients may deliberately avoid information regarding their illness, especially if it may be unfavourable. Thus, receiving information about the severity of their HF from health care professionals may *reduce* patients' emotional quality of life if the information is not wanted. Secondly, the questions regarding the amount of informational support received in the questionnaire used in this study (Krause and Markides, 1990) were ambiguous from the point of view of *the source* of informational support. For example, the question "*In the last year, how often someone gave you information that made a difficult situation clearer and* *easier to understand*" could be answered with respect to health care professionals *or* family and friends, and research has shown that people are not always fond of informational support provided by family and friends (Helgeson, 2003).

Another unexpected finding was that *high* levels of emotional support were associated with *lower* emotional quality of life at the conventional level of significance of $p< .05$, independently of patient neuroticism. Further analyses showed that the relationship is significant only for male patients and the association remained significant even when patient neuroticism and quality of the dyadic relationship were statistically controlled. Considering the average age of the men in this sample (mean age 74.85, SD ±6.98), it could be that this cohort view themselves as the "providers" in the family, and their HF affects the way they can fulfil this role. This assumption is supported by data from the interviews. One patient said " *I am not good company to my wife anymore. I sleep all day, even in the chair*" (patient 15). Another confessed his distress at his physical weakness " *If a burglar comes through the window, I will not be able to do anything. I will have to stay in the chair and let him take what he wants*" (patient 81).

In the present study satisfaction with social support was also measured. It was found that high levels of satisfaction with integrational support (helping others) was associated with reduced levels of anxiety in HF patients, independently of patient neuroticism. This may reflect patients *positive* reactions towards the care-giver. One study (Cox and Dooley, 1996) has shown that care-receivers can provide support to caregivers through emotional support, humour and direct assistance. Importantly, patients who were *not* satisfied with their level of emotional support at baseline were more likely to be hospitalised at least once in the follow up period. This finding is in concordance to Krumholtz et al.'s (1998) study, who found that the absence of emotional support measured before hospital admission was a strong and independent predictor of the occurrence of fatal and nonfatal cardiovascular events in the year after admission.

9.2.6.3.2 The influence of patient social support on carer distress

No *a priori* hypotheses were formulated regarding the effects that *patient* social support may have on carer distress. Nevertheless, in the light of the scarcity of research in the area of HF caregiving it was considered appropriate to discuss a number of findings. In the semi-structured interview, caregivers were asked if they considered themselves to be the caregiver of the patient. If they answer "yes", they were further asked if they were the "main caregiver". Without exception, all the caregivers responded "yes" to both questions. Therefore, it is within reason to assume that the caregiver is the main provider of social support to the care-recipient. Analyses were performed in chapter 7 to investigate whether patient satisfaction with social support influences level of carer distress. Firstly, the present study found that carers of patients who were unhappy with their level of *emotional support* reported increased distress on four of the five subscales of the Caregiver Distress Scale (Cousins et al., 2002). Namely, carers of patients who were unhappy with their emotional support reported significantly more relationship distress, emotional burden, care-receiver demands and personal cost due to caregiving than carers of patients who were happy with their level of emotional support, *independently* of carer neuroticism. Secondly, carers of patients who were unhappy with their level of integrational support (helping others) reported *less* care-receiver demands than carers of patients who were happy with their level of integrational support. It could be that, because of their HF, patients are unable to provide help to others directly, therefore "requesting" the help to be delivered by the carer, thus resulting in an increase in care-receiver demands. However, this relationship was moderated by carer neuroticism.

9.2.6.4 The influence of patient mood and quality of life at baseline and clinical outcomes at phase 2

In one of the largest studies of quality of life in HF patients (The Studies of Left Ventricular Dysfunction, SOLVD), Konstam et al, (1996) found that quality of life at baseline independently predicted mortality and HF-related hospitalisations at 36.5 months follow-up. In the present study, lower quality of life (as a whole) at baseline was associated with increased number of re-hospitalisations at phase 2 and longer stays in hospital, independently of patient neuroticism. However no association was found between quality of life and mortality at phase 2. It could be that six months is too short a follow-up period to detect a significant association between these measures. Similar findings were reported by Bennett et al., (1997), who found that baseline quality of life as measured with the same instrument used in this study (Minnesota Living with HF Questionnaire, Rector et al., 1987) was associated with going to hospital at least once for problems related to HF in a six- month follow up period.

In the present study, patient level of anxiety and depression were also associated with the number of re-hospitalisations in the follow up period, however, the associations were mediated by patient neuroticism. It is important to point out that although quality of life at baseline was associated with increased the number of re-hospitalisations at phase 2, it was not found to be a primary predictor of number of re-hospitalisations at phase 2. Two primary predictors of "number of re-hospitalisations" explained 22% of unique variance in stepwise multiple regression, namely the number of visits to GP and/or cardiac clinic (14% of variance) and patient subjective health status (8% of variance).

9.3 The influence of caregiver characteristics and carer personality on patient and caregiver outcomes

In the section 9.2, above, results concerning the effects that illness and patient characteristics have on patient and caregiver outcomes were discussed. In this section, the influence of *caregiver variables* on patient and carer outcomes are examined.

9.3.1 The impact of caregiver characteristics on carer and patient outcomes

9.3.1.1 The effects of caregiver gender on caregiver distress and patient psychological outcomes

It is a well-known fact in the care giving literature that the majority of informal carers are women (Navaie-Waliser et al., 2002). In 1999 the Department of Health published "Caring for Carers", a national strategy for carers which identified that in Britain there are 5.7 million carers of which 58% are women. In the present study 78% of caregivers were female, and only 22% were male. Gender differences in caregiving have been the subject of much study in the literature. A meta-analysis of 14 published studies that had investigated gender differences in caregiving for elderly individuals (Miller and Caffaso, 1992) found that women caregivers tended to be more distressed and to provide more "hands-on" care than male caregivers. However, they found no gender differences in their degree of caregiving involvement (number of hours of care) or in care-receiver level of functional impairment. In the present study, similar results were found. There were no gender differences in the amount of care provided (hours of care) or in the degree of impairment (mental or physical) of the care-receiver. Moreover, there was an overall tendency for women caregivers to report higher levels of distress on all *specific* and *non-specific to caregiving* measures of distress, however only one association was statistically significant. Namely, women caregivers reported more care-receiver demands than men caregivers. This finding is in agreement to Karmilovich's (1994) study, which reported that female caregivers of HF patients reported performing more helping behaviours and more difficulty in performing them than male caregivers. What the present study adds to the Karmilovich's findings is that *when carer neuroticism is taken into account, the relationship between care-receiver demands and gender becomes non-significant.* This is a clear example of the usefulness of controlling for carer neuroticism when relating possible predictors to carer distress. Moreover, the use of a *multi-dimensional* scale of carer distress, as opposed to a *global measure* of distress allowed the uncovering of a very specific facet of the caregiving process.

One interesting finding in this study is that the care-receiver's negative reactions to care were influenced by the gender of the caregiver. Specifically, patients whose carers were male reported significantly more *temporary loss of self-esteem* than patients whose caregivers were female, independently of patient neuroticism. As all male caregivers provided care for female patients, this finding could indicate that a loss of the traditionally female role as the provider of care and nurture has negative implications for the self-esteem of the patient.

To conclude, in the present study no direct associations were found between carer gender and carer distress, however carer neuroticism moderated the association between carer gender and distress caused by care-receiver demands that were perceived to be excessive. Moreover, female patients who were cared for by male carers reported a significant loss of self-esteem.

9.3.1.2 The associations between carer job demand and length of caregiving role and caregiver distress and patient psychological outcomes

Traditionally, the amount of care provided has been assessed by the number of caregiving hours and the number of caregiving tasks (Pinquart and Sorensen, 2003a). Although theoretical models of caregiving outcomes have suggested that more care is related to more caregiver distress and depression, studies have shown contradictory results. In the present study, caregivers who reported a higher number of hours of care per day also reported significantly more distress on five of the six measures of distress collected. However, all these associations were strongly moderated by carer neuroticism, with two exceptions: carers who provided more hours of care than the mean hours of care for this population sample (6.6 hours, SD ±6.4) reported significantly more emotional burden and personal cost due to caregiving than carers who provided care for less than 6.6 hours a day, independently of carer neuroticism. Unsurprisingly, patients whose caregivers reported longer hours of care perceived their quality of life to be lower than patients whose caregivers provided care for fewer hours per day. Partial correlations showed that the association was moderated by patient level of disability.

One interesting finding in the present study is the profile of caregiver distress according to their involvement in administering patient's medication. Due to the empirical nature of the question asked, no *a priori* hypothesis was proposed. Caregivers were asked if they were involved in giving or reminding the patient to take his or her medication and according to their answers they were divided into three groups. The first group was *responsible* for giving the medication to the patient in the right dose at the right time; the second group just *reminded* the patient to take his or her medication and the third group consisted of caregivers who were *not involved* in the patient's medication regimen. Caregivers who were responsible for giving the medication to the patients reported significantly more personal cost due to caregiving that those who just reminded the patients to take their medication, but did not differ significantly on this measure to caregivers who were not involved. Thus, when considering measures of distress *specific* to the caregiving situation, the most advantaged group was the *remind group*, followed by the *not involved group*, followed by the *responsible* group. By contrast, when *non-specific* distress measures were considered (anxiety and depression), the pattern of distress was different. The less distressed group was *the remind* group, followed by the *responsible group*, followed by the *not involved* group. Therefore caregivers who were not involved in patient's medical regimen were the most anxious and depressed, whereas being responsible for giving the patient his or her medication was associated with high personal cost.

In the caregiving literature, there are three contradictory hypotheses regarding the association between duration of caregiving and carer distress (Pinquart and Sorensen, 2003b). The *wear-and-tear hypothesis* predicts a positive association between length of caregiving and carer distress. The *adaptation hypothesis* suggests that, after an initial increase in distress after taking over the carer role, the carer will adapt to the stressful situation and thus negative affect will decrease in time. The third hypothesis is the *trait hypothesis*, which suggests that caregiver pre-existing resources (for example coping skills) will help the carer maintain a constant level of adaptation even if the carer-receiver condition worsens. Considering that HF is a chronic condition, which is punctuated by phases of acute decompensation, the wear-and-tear hypothesis may be the most feasible. Therefore, it was hypothesised that the longer the role of caregiver, the higher the distress. The hypothesis was not supported: no association was found between length of role as caregiver and any of the specific and non-specific measures of caregiver distress collected. However, caregivers who provided care for a relative suffering from HF for *more than a year* reported significantly more social impact due to caregiving role than carers who provided care for *less than a year*, independently of carer neuroticism. This finding is interesting, in the light of the difficulties of defining the onset of family caregiving (Gaugler et al., 2002). The present study shows that a simple categorical measure of the length of caregiving role was sufficient to detect the association between caregiver role and social impact found in other studies (Seltzer and Li, 2000).

9.3.1.3 The influence of relationship quality caregiver and patient outcomes

Consistent with the growing acknowledgement of positive aspects of caregiving (Lawton et al., 1991), some researchers have noted that often caregivers want to and continue their helping role despite adversities (such as care recipient problem behaviours or problems associated with toileting, Gubrium and Lynott, 1987). One factor that has been proposed to be important in the motivation to continue providing care despite the costs is the quality of the dyadic relationship (Pearlin et al., 1990; Lawrence et al., 1998). Specifically for HF patient-spouse dyads, research has found that a composite measure of marital quality at baseline was an independent predictor of patient survival at four-year follow-up (Coyne et al., 2001). Therefore, in the present study it was hypothesised that better quality of the dyadic relationship will be associated with better carer and patient psychological status at phase 1 and better patient clinical outcomes at phase 2.

The hypothesis that better relationship quality will be associated with lower carer distress was supported, in that relationship quality was inversely related to both *specific* to caregiving and *non-specific* to caregiving measures of distress. However, the associations were strongly moderated by carer neuroticism, with one exception: better relationship quality was associated with significantly lower relationship distress, independently of carer neuroticism. Indeed, relationship quality explained 23% of the variance in the relationship distress measure at phase 1 and 21% at phase 2. Moreover, caregivers who considered the patient to be their *confidant* reported less relationship distress and less depression than caregivers whose patient was not their confidant, but these relationships were moderated by carer neuroticism. However, women caregivers whose patient was their confidant reported significantly less depression than women caregivers who did not identify the patient as their confidant, independently of carer neuroticism. This findings replicate in a quantitative form Karmilovich's (1994) reports that for women who are carers of HF patients, not being able to share concerns with their spouses was a major cause of distress.

When we turn to the effects that relationship quality has on *patient* outcomes, one note of caution needs to be said. Namely, in the present study the measure of relationship quality (Short Dyadic Adjustment Scale, Hunsley et al., 1995) was collected *only* from the caregiver at both phases. However, research has shown that couples are usually matched in their perception of their relationship (Langer et al., 2003). Therefore in this section we assume that the care-receiver has a similar perception of relationship quality to the caregiver. Interestingly, relationship quality influenced the patient negative perceptions to receiving care, but had no effect on their perceived quality of life or mood. Namely, patients whose caregivers perceived their quality of relationship to be good reported significantly less levels of *indebtedness* to the caregiver and fewer *negative perceptions of carer behaviour*, independently of patient neuroticism. Moreover, patients whose caregivers identified them as their confidant reported less *indebtedness* than patients who were not perceived as the caregiver's confidant (independent of patient neuroticism). This finding is interesting because it reflects the concept of reciprocity of support in caregiving relationships (Finch 1989, 1995).

Similarly to results published by Coyne et al., (2001), the present study found that patients of caregivers who reported better quality of the dyadic relationship at baseline *were more likely to be alive at six months follow-up*. Moreover, when only "*relationship happiness*" was considered, patients of caregivers who were happier with their relationship at baseline were more likely to have shorter stays in hospital in the follow-up period.

9.3.2 The direct and indirect influence of carer personality on carer distress and patient outcomes

Starting in early 90s, caregiving research has begun to acknowledge the importance of including personality of the caregiver in theoretical and empirical models of the caregiving process (Hooker et al., 1992). Although the majority of studies concerned caregivers of dementia patients (Hooker et al., 1992; Reis et al., 1994; Hooker et al., 1998; Gallant and Connell, 2003), research has since shown that neuroticism exerts direct and indirect effects on negative well-being in other caregiving groups (e.g. carers of Parkinson Disease patients, Hooker at al., 1998; Davies, Cousins et al., 1998; caregivers of adult children with a chronic disability, Patrick and Hayden, 1999). The sparse literature on caregiving heart failure, however, consistently failed to consider the effects that carer neuroticism may have on the carer well being. Therefore in the present study it was hypothesised that carer neuroticism will have strong direct and indirect effects on carer distress. The hypotheses were strongly supported.

Firstly, carer neuroticism was strongly connected to both the *non-specific mental health measures* (depression and anxiety) and to the measures of distress *specific* to the caregiving situation (relationship distress, emotional burden, care-receiver demands and personal cost). One exception was the effect of neuroticism on social impact due to caregiving. Similarly to Davies, Cousins et al.'s (1998) findings in their work with Parkinson Disease patients, carer neuroticism was *not* associated with impact on social life due to caregiving. Moreover, the present study found that *high* carer neuroticism was related to *lower* satisfaction with role of caregiver, suggesting that carer neuroticism influences not only carer distress, but also positive aspects of caregiving.

Secondly, measures of carer mastery and self-esteem were also collected. In the caregiving literature, two definitions of mastery were proposed. The first definition describes mastery as a positive view of one's ability and ongoing behaviour during the caregiving process (Lawton et al., 1989). Secondly, mastery was defined as a relatively stable view of the self that encompasses the belief that one is capable of dealing with, or *has control* over issues in their lives as they come up (Pearlin et al., 1990). Both definitions imply that mastery is negatively related to distress, specifically distress due to providing care (Miller et al., 1995). Self-esteem (or perceived self-worth) is typically seen in health psychology as a personal resource, which may moderate the effects of threatening events (Johnston et al., 1995).

In this study it was hypothesised that high levels of carer mastery and self-esteem will be associated with lower levels of carer distress. The hypothesis was partially supported, in that carer mastery and self-esteem were associated with all measures of carer distress with the exception of care-receiver demands. Although the associations *were* moderated by carer neuroticism, some relationships were also direct. On one hand, caregiver mastery was an important independent predictor not only of carer distress measures *specific* to the caregiving situation (namely, emotional burden and personal cost due to caregiving), but also of *non-specific mental health measures.* At phase 1, caregiver neuroticism and mastery explained 45% on the variance in carer anxiety and 55% of the variance in carer depression. These findings replicate closely those reported by Bookwala and Schulz (1998). They carried out a large study (more than 300 spousal caregivers) looking at the effects of caregivers' personality attributes (neuroticism and mastery) on carer distress in a population of older carers for CHD and stroke patients. Similarly to the findings of the present study, Bookwala and Schulz (1998) reported that carers high in neuroticism and /or low in mastery experienced more strain and depressive symptoms associated with caregiving relative to caregivers with lower neuroticism or higher mastery scores. An inverse association between carer mastery and carer depression was also found by Yates et al., (1999), in a study of the relationships between caregiving stressors and caregiver well-being in a representative community sample of disabled elders and their informal caregivers.

At present, this study is the first to report an association between higher levels of *carer self-esteem* and higher satisfaction with the role as carer. In phase 1, carer level of self-esteem explained 42% of the variance in the satisfaction with role as carer. Moreover, carer self-esteem explained 42% of the variance in carer *emotional burden* caused by providing care to a relative with HF.

Thirdly, one of the strongest finding in this study is the moderator effect that carer neuroticism has on the associations between illness characteristics, patient characteristics, carer characteristics *and* carer distress. Virtually all the significant associations between possible predictors of carer distress and measures of distress were moderated by carer neuroticism. Therefore, Hooker et al., (1998) was right to enunciate that "*It appears that how one handles the stresses of living with a spouse with chronic illness does indeed depend, to some extent, on one's personality*" (Hooker et al., 1998, p 82).

Fourthly, although no *a priori* hypothesis was proposed, the present study found that patients of caregivers who reported higher levels of interpersonal problems were more likely *not to go* to hospital in the follow up period. Further tests (controlling for carer neuroticism) showed that patients whose caregivers scored high on the "*overly accommodating*" subscale of the Inventory for Interpersonal Problems (Horowitz et al., 2000) were *less likely* to go to hospital at least once in follow-up period.

9.3.3 The influence of carer social support on carer distress

Caregivers stand at the intersection of two distinct lines of social support: they are both *donors* of support in the caregiving relationship itself and *receivers* of support from individuals in the surrounding networks (Pearlin et al., 1996). Social interaction and support variables have been shown to be important determinants of the outcomes of stressful situations, including caregiving (Gold et al., 1995). However, *satisfaction with social support*, rather than social support *per se* was found to mediate the negative effects of caregiving and to make caregiving more satisfactory (Gesten and Jason, 1987; Pearlin et al., 1990).

In the present study, a general measure of carer level of social support was *not* associated with any of the distress measures used. However, carers who reported high levels of *tangible support* also reported *less personal cost* due to caregiving (independently of carer neuroticism) and tangible support explained 9% of the variance in personal cost measure. Similarly to Yates and al.'s (1999) study, carers who pronounced themselves satisfied with the level of *emotional support* received reported less relationship distress due to caregiving and were *less depressed* than carers who were unhappy with their level of emotional support, independently of their neuroticism. Again, these findings may represent the reciprocity in giving/receiving support in the framework of late life family illness (Lewinter, 2003). Furthermore, women carers who considered their ill relative to be their confidant also reported significantly less levels of depression than women carers whose confidant was not the patient.

Therefore, in the present study an overall measure of carer social support was not associated with carer distress or mood. However, carers who received high levels of tangible support reported low levels of personal cost due to caregiving and those who were satisfied with the level of emotional support received were at lower risk of depression.

9.4 The reciprocal influence of patient and caregiver outcomes

According to Young's (1994) model of late life family illness, patient recovery (or non-recovery) directly affects caregiver outcomes, whereas caregiver distress directly influences the care-recipient's outcomes (links 7 and 8 in Fig. 9.1.1).

9.4.1 The influence of patient negative reactions to care, quality of life and mood on caregiver outcomes (link 7 in Young's 1994 model)

In order to investigate the effects that patient outcomes have on carer distress, partial correlations (***controlling for caregiver neuroticism***) between patient and carer outcomes were performed.

Lower patient *physical* quality of life was significantly associated to increased carer social impact due to caregiving. This finding shows in a quantitative manner Murray et al., (2002) qualitative reports that severely ill HF patients have a low quality of life of which one contributing factor is social isolation. Lower patient *emotional* quality of life was associated with higher carer emotional burden, higher personal cost due to caregiving and increased carer anxiety, independently of carer neuroticism. The relationship between patient depression and carer distress had a similar pattern of association with carer distress as emotional quality of life did, however, by contrast to patient emotional quality of life, patient level of depression was also associated with carer *social impact* due to caregiving, independently of carer neuroticism. Thus carers of patients who report higher levels of depression perceived themselves to suffer more social impact due to caregiving. Moreover, carers of highly anxious patients reported more personal cost due to caregiving and *were highly anxious themselves.*

Therefore, in the present study patient level of depression was weakly correlated with carer level of depression, however *patient level of anxiety* was strongly associated with *carer level of anxiety* (Pearson's r = .47, p< .001), when carer neuroticism was kept constant.

9.4.2 The influence of caregiver distress and mental status on patient outcomes (link 8 in Young's 1994 model)

In order to investigate the effect that patient distress and mental status has on patient outcomes partial correlations were performed between the measures, ***controlling for patient neuroticism***. Results have shown that the influence that carer distress has on patient psychological status is overall much smaller than the influence that patient psychological status has on the caregiver distress when relevant levels of neuroticism are kept constant. The only significant association at the agreed level of p< .01 significance is the relationship between high *carer personal cost* due to caregiving and lower patient *emotional quality of life*. Patient level of depression was not associated with carer level of depression when controlling for carergiver neuroticism and the association between patient and carer anxiety was weak (Pearson's r = .31, p< .05). If we make the comparison between the contribution of patient and caregiver anxiety to each other's level of anxiety, stepwise multiple regressions show that whereas patient anxiety is only explained by patient neuroticism (43%), carer anxiety is explained by carer mastery (32%) carer neuroticism (13%) and patient anxiety (6%). Therefore, it could be that highly anxious patients increase the anxiety in caregivers and this may result in the caregiver calling and ambulance or taking the patient to hospital when a GP visit may be more appropriate. This finding suggests that there is a degree of similarity in patient and caregiver well being. According to Bookwala and Schultz (1996) a variety of mechanisms (such as contagion, mate selection and common environmental influences) may explain spousal similarity in subjective well being in older adults.

9.5 Summary

This investigation of the influence of illness and psychological factors on patient and caregiver outcomes in heart failure began with the presentation of a simple model of late life illness, proposed by Young (1994). Given the scarcity of research into psychological aspects of living with HF, a review of qualitative studies of the experience of living with heart failure pinpointed illness "themes" which were relevant to both patients and their caregivers. These themes were mapped on to broad psychological concepts, such as role loss, affective responses, coping and compensation and social support. The hypotheses presented at the end of chapter 4 took account of previous findings of outcomes of living with a chronic progressive illness and caring for a person with a chronic illness.

In line to other work it was found that the severity of heart failure and level of patient disability was predictive of patient psychological and clinical status and caregiver distress. Although NYHA class predicted patient outcomes as expected, further analyses indicated that a subjective measure of illness severity, namely *fatigue*, was a better predictor of patient physical quality of life than NYHA class was. An increase in HF severity from phase 1 to phase 2 was associated with increased patient and caregiver distress, as proposed.

In contrast to previous research with HF patients, it was hypothesised that patient personality, specifically neuroticism, will have a direct and indirect on patient and caregiver outcomes. The hypothesis was supported. Importantly, patient neuroticism not only directly affected the psychological status of patient and caregiver, but also affected morbidity (number of re-hospitalisations, length of stay in hospital and adverse events) over a six-month follow up period. Patient neuroticism was a strong moderator of the associations between illness variables and patient characteristics and patient and carer outcomes, as hypothesised. Moreover, it was hypothesised that caregivers who perceive a marked change in patient's core personality characteristics would be more distressed than caregivers of patients whose personality did not change. This hypothesis was supported. Therefore, the present study adds to the body of knowledge of caregiving studies in general and caregiving in HF in special by conceptualising patient neuroticism as a *key variable* which affects both patient and caregiver outcomes and the way in which they interact.

Corresponding with other work it was found, as hypothesised, that patient impaired cognitive status negatively affected patient psychological and clinical outcomes *and* carer distress. Specifically, patients who scored higher on the MMSE also reported better quality of life, but "demented" patients (MMSE scores< 24) were more likely to die in the follow up period than "non-dementing" patients. Caregivers of patients who scored low on the MMSE reported increased level of distress, however in contrast to other caregiving studies, no association was found between patient level of cognitive impairment and carer depression. This may be a result of the relatively small sample of caregivers (Pinquart and Sorensen, 2003b).

In agreement to other work with HF patients, it was hypothesised that higher levels of patient illness knowledge will be reflected in better patient outcomes and lower carer distress. Because of the way illness knowledge was measured, it can only be said that the hypothesis was partially supported. Firstly, *specific* knowledge of HF was not related to either patient psychological status, nor clinical outcomes at follow up, suggesting that low illness knowledge *per se* does not necessary have a negative effect on patient outcomes. However, illness uncertainty and knowledge of self-care *were* associated with patient outcomes, although in a different way than specific knowledge. Namely, high illness uncertainty and level of self-care had an *indirect* (moderated by patient neuroticism) effect on patient mood and quality of life, whereas self-care also *directly* affected patient physical quality of life. Level of patient self-care at phase 1 was predictive of patient being admitted to hospital at least once in the follow up period. Patient level of self-care also had a direct and indirect (moderated by carer neuroticism) beneficial effect on carer distress.

In line with other studies with patients with chronic illnesses, it was found that avoidant coping styles were associated with deleterious effects on patient mood whereas task-oriented coping reflected in fewer negative reactions to carer behaviour. What the present study added to the body of literature is that patient coping style also affected *carer distress*. Carers of patients who used avoidant coping styles reported increased distress, whereas carers of patients who used task-oriented coping styles reported less distress, *independently of carer neuroticism*.

Following previous studies, it was hypothesised that higher levels of social support will be associated with better patient outcomes. However, the hypothesis was not supported. Moreover, *increased* patient informational support was associated with *lower* emotional quality of life. This may reflect in an empirical way findings from qualitative studies (Buetow et al., 2001) that suggest that many HF patients deliberately avoid information regarding their illness, especially if it may be unfavourable. Therefore, if patients are given information that they do not want, this may reflect in reduced emotional quality of life. In the present study, *satisfaction with social support* emerged as a more important measure of social support than an overall measure of social support. Namely, caregivers of patients who were unhappy with their level of emotional support reported higher levels of distress than caregivers of patients who were satisfied with their emotional support, independently of carer neuroticism.

As hypothesised, and in accordance with other studies with HF patients (Konstam et al., 1996; Bennett et al., 1997) it was found that poorer patient psychological status at phase 1 was associated with greater morbidity (number of hospitalisations and length of stay in hospital) in the follow up period. However, no associations were found between psychological status at phase 1 and mortality at phase 2, possibly because six-month follow up period is too short a follow-up period to detect a significant association between these measures.

It was hypothesised that caregiver psychological characteristics and characteristics of the caregiving task would have a direct influence on carer outcomes. As in other caregiving situations, this hypothesis was supported. Hours of care, involvement in patient medication, duration of caregiving and dyadic relationship quality were all associated directly or indirectly (through carer neuroticism) with carer distress. Importantly, highly neurotic carers reported increased distress on all measures (both specific to the caregiving situation and general mental well being), with one exception. As reported in caregiving of Parkinson Disease patients (Davies et al., 1998), carer neuroticism was *not* associated with social impact of caregiving. Consistent with other work, caregiver increased mastery and self-esteem had a beneficial effect on carer level of distress.

The hypothesis that carers reporting high level of social support would be less distressed was partially supported. Whilst a *general* measure of social support *was not* associated with carer distress, increased levels of tangible support (direct, practical help, Krause and Markides, 1990) translated into reduced levels of caregiving personal cost. Moreover, carers who were happy with their level of emotional support reported lower levels of relationship distress and depression than carers who were not satisfied with their emotional support. Therefore, caregivers were at a higher risk of distress if (i) their care-recipients were not satisfied with emotional support available and (ii) they themselves were not satisfied with level of emotional support available to them. These findings may represent the reciprocity in giving and receiving support in the framework of late life family illness (Lewinter, 2003).

As proposed in Young's (1994) model, it was hypothesised that patient and caregiver outcomes affect each other. The hypothesis was supported. On one hand, caregivers of patients who perceived their quality of life to be low reported high levels of anxiety and were more emotionally burdened as a result of providing care (independently of carer neuroticism). Patient depression and low quality of life impacted on carers' social life, also independently of carer neuroticism. On the other hand, the impact that carer distress had on patient outcomes was less evident. Patients whose caregivers perceived a high personal cost of caregiving reported lower quality of life, independently of patient neuroticism.

The associations between patient and carer anxiety and depression presented an interesting pattern. Patient level of depression and carer level of depression were weakly associated when controlling for carer neuroticism, but were not associated when controlling for patient neuroticism. Therefore, patient mental well being is *not* affected by carer depression, whereas carer mental status *is* affected by patient depression.

Patient level of anxiety and carer level of anxiety were associated when each of the relevant neuroticism was controlled. However, as with depression, the effect that patient anxiety had on carer anxiety was significantly more marked than the effect of carer anxiety on patient anxiety. Moreover, patient anxiety explained 6% of the variance in carer anxiety in multiple regression analysis, suggesting that patient anxiety is an important predictor of carer anxiety. This is important for patient management, in the light of the findings that patients of highly anxious carers stayed longer in hospital when admitted to hospital. Moreover, there also was a trend for patients of highly anxious carers to be admitted to hospital more often over the follow up period than patients of less neurotic carers.

9.6 Conclusions

9.6.1 Theoretical advancements

The present study proposes a model of caregiving and care-receiving in a relatively unstudied population, heart failure patients (see Fig. 9.6.1.1 on page 285). Most family caregiving research has relied on the perspective of the caregiver but has not systematically examined the views and characteristics of the elder who is receiving care. By contrast, the present study conceptualises caregiving as an interpersonal dynamic process, whose success depends on the interpersonal style and beliefs of both caregiver and recipient. Moreover, an attempt has been made to apply the interpersonal circumplex theory (Horowitz et al., 1997), which provides a framework for examining how dyads complement each other's styles or act in opposition, to the caregiving - care-receiving situation. Furthermore, patient and caregiver neuroticism were conceptualised as *key variables* that directly and indirectly affected patient and caregiver outcomes.

Traditionally in the literature the care-recipient has been viewed as a potential stressor and the caregiver is seen in terms of his or her *negative* outcomes, such as depression or affected health. The care-recipient has been seen as always as *benefiting* from caregiver's actions. The present study extends the knowledge base by also measuring the care-recipient's *negative reactions to receiving care* and the caregiver's positive reactions to giving care, *satisfaction with role as caregiver.* Moreover, patient and caregiver outcomes were measured using both measures *specific* to the caregiving – care-receiving situation and general, *non-specific* measures of mental state, such as anxiety and depression.

The most widespread used measure of severity of HF is NYHA criteria (NYHA class) which is a single item four-category classification system of physical function. Essentially, the NYHA staging process represents the clinician's subjective interpretation of the patient's physical function rather than the patient's perspective (Smith et al., 1993). In the present study, patients were also asked *directly* about the severity of their symptoms, therefore collecting *subjective* measures of illness severity.

9.6.2 Methodological advancements

Recent research has indicated that neuroticism was an independent predictor of distress both in heart patients (e.g. Pedersen et al., 2002) and in caregivers of dementing and non-dementing patients (Davies et al., 1998; Gallant and Connell, 2003). Therefore, in the present study it was hypothesised that patient and carer neuroticism will directly and indirectly affect patient and carer outcomes. The hypothesis was strongly supported. Importantly, patient and carer neuroticism were found to be strong *moderators* of the associations between illness variables and psychological factors and patient and caregiver outcomes. Therefore, the findings justified the need for controlling for patient neuroticism and carer neuroticism in relevant associations between possible predictors of distress and outcomes. Moreover, these findings cast a shadow of doubt over published findings which do not take patient and caregiver neuroticism into account when predicting outcomes. For example, Hawthorne and Hixon (1994) in a study of HF patients reported an association between high illness uncertainty and low quality of life. The present study replicated this finding, however, when patient neuroticism was statistically controlled, the association became non-significant, suggesting that patient neuroticism was a powerful moderator of the relationship between illness uncertainty and quality of life.

Furthermore, by contrast to other studies, the present study used a powerful tool (multiple regression analyses) to predict patient and carer outcomes. Multiple regression analyses are particularly useful when trying to predict an outcome from a number of possible predictors because it compares the strength of each predictor at the same time (Field, 2002).

In contrast to other work, the present study aimed to predict patient and carer outcomes from both carer *and* patient variables. Although carer variables had a limited impact on patient outcomes, the effect of patient variables *on carer distress* was strong. With the exception of the care-receiving demands measure, all seven measures of carer distress were predicted by a mixture of carer and patient variables in multiple regression analyses. For example, in multiple regression analyses 60% of the carer's social impact of caregiving variance was explained by caregiver mastery (28%), caregiver perception of change in patient conscientiousness (18%), patient reported fatigue (6%) and patient depression (8%). These findings acknowledge the importance of considering both patient and carer variables when identifying predictors of carer distress *and* the importance of using a multidimensional scale to measure distress. As suggested in literature (Cousins et al., 2002) multidimensional scales of carer distress, through identifying distressing caregiving situations, provide a focus for needed interventions.

9.6.3 Study limitations

One major draw back of the current study is that the complexity of data and the relatively small number of caregivers prohibits its encasement into a model more complex (such as path-analyses or mediational models) than the simple correlational model provided in Figure 9.6.1.1 (p 285).

It is always difficult to estimate power in an area where not much previous work has been done and the size of effect to-be-found is not known. Moreover when a range of independent and dependent variables is to be utilised, calculations are by their nature uncertain. Cohen (1988) defines three magnitudes of effect size 0.2 (small), 0.5 (medium) and 0.8 (large). The present study aimed to detect medium to large effect sizes when using an alpha level of 0.05. Using Cohen's (1992) tables for a repeated measures analysis and taking t test for related means (as a sample of the statistics to be carried out) it was estimated that a group of 80 patients and caregiver dyads were necessary to detect a medium effect. However, difficulties in recruiting caregivers at phase 1 and the high rate of attrition at phase 2 resulted in a sample of 56 patient caregiver dyads at phase 1 and 36 dyads at phase 2. The reduced sample size is likely to *lower* the statistical power of the present study, by reducing the likelihood of various analyses to detect a significant difference when the null hypothesis is false. Therefore, caution needs to be employed when discussing negative findings in the present study, i.e. possible significant associations were not detected due to small sample size, especially for the caregiver sample. Moreover, the use of non-validated measures (such as the Negative Reactions to Care Scale and the HF Knowledge Questionnaire) may be responsible for the absence of predicted associations between various predictors and outcomes. The HF Knowledge Questionnaire, in particular suffers from the shortcoming of not containing "dummy" items, thus response bias were possible (i.e. patients could have been tempted to answer positively to all the items), although the reliability of the questionnaire was acceptable at $\alpha = .86$. Furthermore, the use of multiple comparisons to predict outcomes may be problematic when the sample size is relatively small. Field (2000) recommends that in multiple regression analyses only predictors with good theoretical grounding should be included and the sample size should allow a minimum of 15 subjects per predictor. However, in the present study the scarcity of research concerning psychological factors in HF patients and their caregivers and small sample size permits the use of multiple regression analyses only for exploratory model building.

Nevertheless, the results of this investigation suggest that the dynamic and unpredictable nature of HF will prohibit an "all-inclusive" model that can be used to describe the full course of HF caregiving and care-receiving. Therefore, simple models like that illustrated in Figure 9.6.1.1 (p 285), may provide a starting point for the initial planning of interventions in a population that is vastly understudied.

Although the present study has confirmed that neuroticism was an independent predictor of distress in both HF patients and their caregivers, it fails to identify the *mechanism* involved in the effect of neuroticism as predictor of the individual's psychological well being. It could be that neuroticism influences psychological well-being independently of the objective and subjective health status of the individuals, by predisposing individuals high in neuroticism to interpret life events more negatively than others. Therefore, it could act as a nuisance confounding variable which needs to be controlled. However, it could also act as a substantive determinant of outcome. Recent research (Zobel et al., 2004) has found that the endocrinological basis for both high neuroticism and depressive temperament lays in the dysfunctional regulation of the hypothalamic –pituitary-adrenocortical system in healthy volunteers. Finally, neuroticism could act as a moderator of the impact of stressful exposures, intensifying feelings of helplessness due to illness and reduced ability to participate in social activities, which in turn may lead to depression and reduced quality of life (Murberg et al., 1997).

During interviews with patients and carers, a number of problems were encountered. Firstly, as a HF is a highly debilitating illness, patients were not always in a position to be interviewed extensively. Therefore, not all the questionnaires were administered to all patients, depending on the particular case. Secondly, the quality of dyadic relationship questionnaire was administered only to caregivers. If this data were to be collected from patients as well as caregivers, it would have been possible to investigate how dyadic *discrepancy* regarding relationship quality reflect on both patient and carer outcomes. Thirdly, *patient negative reactions to care* were measured using a non-validated questionnaire. Although in multiple regressions 27-55% of variance in the subscales was predicted by patient and caregiver characteristics, use of a validated questionnaire (such as the recently published 10-item "Feelings of Being a Burden to Caregivers" questionnaire, Cousineau et al., 2003) may be a better measure of negative reactions to care. Fourthly, consistently with other work (Houde, 2002) the caregivers mainly consisted of females, thus limiting the generalisation of the study to male caregivers.

Regarding hospital readmissions and mortality, this study is limited in that the key physiological determinants of HF severity were not available. Recent research has shown that a cardiac hormone (B-type natriuretic peptide, BNP) was a useful indicator of cardiac dysfunction and was proposed as a potentially useful tool for predicting HF patients' change of readmission within 30 days of discharge (Nakamura and Hiramori, 2003; Caldwell et al., 2003). Therefore, data on physiological determinants of HF severity, such as the BNP may provide a more objective measure of HF severity than NYHA class, thus permitting for a more accurate prediction of hospitalisation and mortality. Moreover, in a parallel manner, assessing caregiver distress may be carried out in a more objective fashion using physiological indices of stress such as cortisone profiles over the day and waking cortisone response (Vitaliano et al., 2003).

9.6.4 Future work

The present study identified a number of hypotheses to be tested in future work.

Firstly, caregivers who perceived a marked change in patient personality were significantly more distressed than carers of patients whose personality did not change. However, the carer, *not the patient*, reported the change in personality. Moreover, the best-documented changes in personality are those associated with change in the brain attributable to dementia or traumatic brain injury, and HF was shown to be associated with cognitive impairment (Almeida and Tamai, 2001). Therefore, longitudinal studies are warranted to confirm that (i) there is a measurable change in personality caused by HF as reported by patient and (ii) patient personality change is associated with cognitive status change due to HF.

Secondly, even though in the present study HF knowledge data was collected from patients only, specific knowledge of HF (as reported by the patient) explained 6% of the variance in carer emotional burden of caregiving, and patient knowledge of self-care explained 6% of the variance in carer satisfaction with role as caregiver and 6% of variance in carer depression. Therefore, it would be of interest to investigate whether *carers*' knowledge of HF also affects their level of distress and patient outcomes.

Thirdly, patients coping style not only affected their own outcomes, but also those of their caregivers. A longer follow up study will allow to confirm or refute Mulberg et al.'s (2001, 2004) findings that higher use of behavioural disengagement at baseline is predictive of HF mortality at 2 and 6 years follow-up respectively.

Fourthly, an unexpected finding in this study was that male patients reporting higher levels of emotional support were more distressed than male patients reporting low levels of emotional support, independently of patient neuroticism. This finding is in stark contrast to Krumholz et al's (1998) reports that absence of emotional support measured before hospital admission was found to be a strong independent predictor of the occurrence of fatal and nonfatal cardiovascular events in the years after admission. Therefore, there is scope in investigating gender differences in the effect of emotional support on psychological and clinical outcomes in HF patients.

Fifthly, at present, this study is the first to show that patients' sleep problems are associated with carer distress *specific* to caregiving in a HF population. It would be of interest to assess the effect that HF sleep problems have on their carer's sleep quality, and to investigate possible interventions directed at improving the dyadic sleep situation.

9.6.5 The practical application of the research

This study has emphasised the importance of viewing the HF patient as part of a dyad. Results have shown that patient and caregivers influence each other's outcomes. Therefore, this stresses the need for family therapy approach (when available), rather than focusing on the patient as the target for interventions.

Literature on the influence of knowledge of HF illness on patients' outcomes have shown that multidisciplinary interventions revolving around education of patient have beneficial effects on clinical outcomes, especially unplanned re-hospitalisations. However, the present study has shown that low HF knowledge *per se* does not necessary have a negative effect on patient distress and clinical outcomes. Moreover, *unwanted* information has deleterious effects on patient emotional quality of life. However, high knowledge of *self-care* does have beneficial effects on both patient and carer distress. Therefore, it is suggested that educating patients *and* their caregivers about self-care may be a more direct approach to improving quality of life and reduce re-hospitalisations than giving patients *specific* information about HF.

The level of caregiver involvement in administering medication to the patients was found to be a source of distress for the caregivers. Both being *responsible* for giving medication and *not being involved* in giving medication were perceived to be stressful by the carer, whereas *reminding* the patient to take his/her medication was less stressful. Therefore, where appropriate, medication prepared in blister packs[1] may be one way to involve the carer in patient medication, without being responsible for it.

One important finding in this study was that patients who are highly anxious make their caregivers anxious, and that patients of highly anxious caregivers are more likely to be admitted to hospital and to stay in hospital longer that patients of less anxious caregivers. Therefore, educating the carer about ways in which he or she may deal with crisis situations (by calling the GP for a house visit or contacting the HF specialist nurse) may be an effective way of reducing unplanned HF re-hospitalisations.

This study has consistently shown that high levels of patient neuroticism were associated with worse psychological and clinical outcomes and worse carer distress. Therefore, in clinical practice screening for particular personality traits in patients, especially neuroticism could identify patients at risk of distress *and* recurrent cardiac events.

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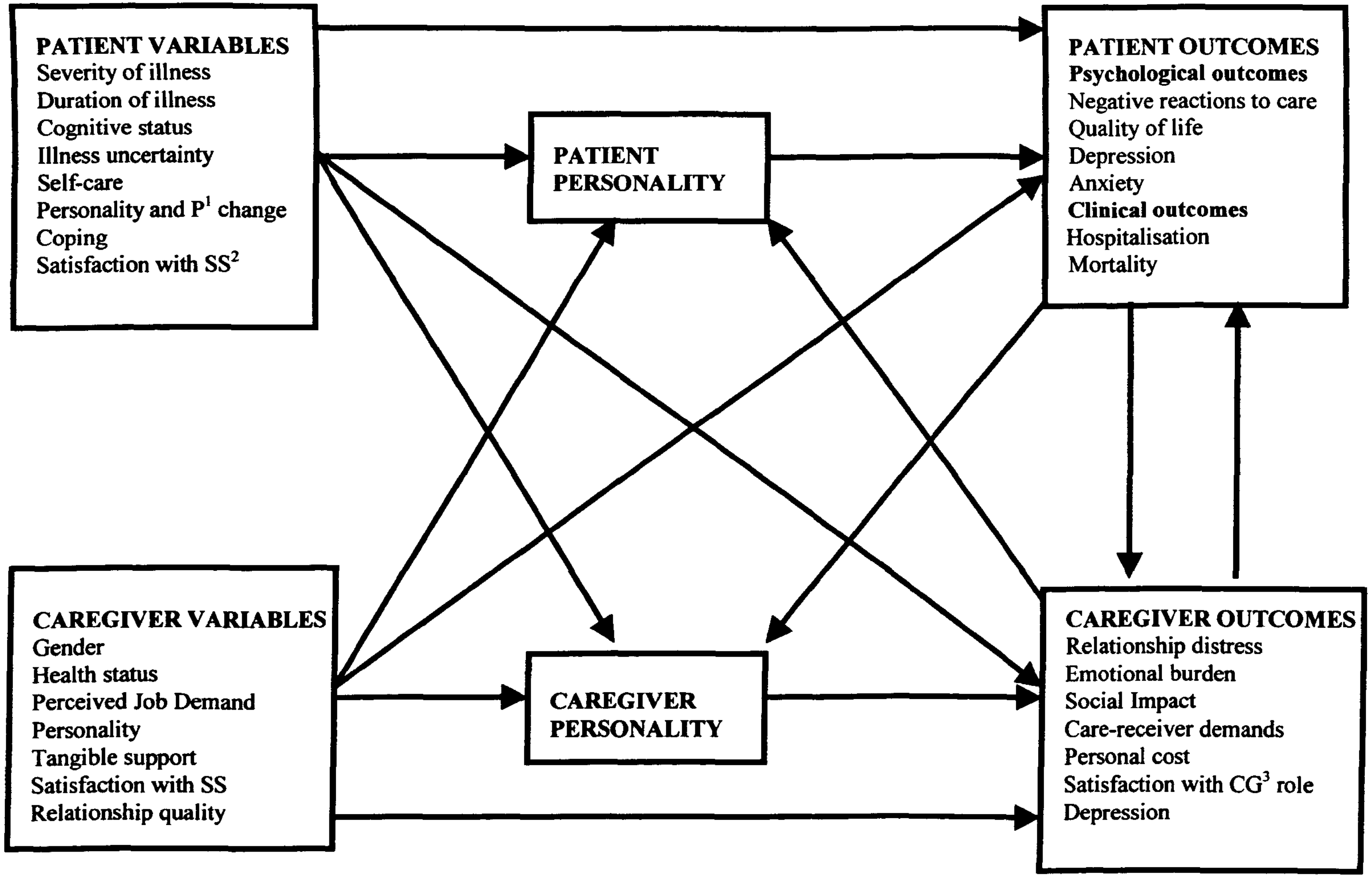
[1] Blister packs are provided by pharmacists at the recommendation of the patient's GP. Some pharmacies also provide a home delivery service. In a blister pack tables are arranged in days and for each day tablets to be taken together are organised in morning, afternoon and evening. This prevents patients forgetting to take their medication, or forgetting that *they have already taken* their medication.

Figure 9.6.1.1 A Model of Heart Failure Caregiving – Care-receiving



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[1] P - Personality,

[2] SS- Social Support

[3] CG - Caregiver

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APPENDIXES

Appendix 1

An evaluation of a hospital based heart failure education class

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Management of heart failure after an acute hospitalisation is typically organised by cardiologists supported by specialist heart failure nurses. The specialist nurse is seen as having an important role in increasing patients' knowledge of heart failure, their self-care skills and their, satisfaction with the hospital stay. It is frequently also assumed that if patients have adequate knowledge of their condition they will be less likely to seek re-hospitalisation.

This study aimed to assess the effectiveness of a 45-minute education intervention delivered in hospital by a specialist nurse or pharmacist, to medically stabilised heart failure patients prior to discharge. A longitudinal two phase design was used, Phase I being completed shortly after the hospitalisation and Phase II, 6 months later.

Two samples of 40 patients matched for age, HF severity and social support were identified through the hospital computer system. The group attending the class (mean age, 74.9,sd 11.5; 18M/22F) were recruited on the hospital wards on which the class was running as part of their clinical care. The comparison group (mean age 75.22,sd 9.9; 21 M, 19F) were in general on other hospital wards or on the DME wards when the class was not running.

The class was delivered in a illustrated 'talk with questions' format and covered 'causes and symptoms of HF', 'ways the patient could help him or herself' and an overview of heart failure medication.

A research psychologist carried out a 45 minute semi-structured interview to assess what participants knew about heart failure and self care and how uncertain they were about their illness. Mood measures and satisfaction with the hospital were also assessed. Hospital records were later scanned to ascertain the number and duration of re- hospitalisations in the six months since discharge and mortality data were compiled..

Patients attending the class had significantly more factual knowledge about their heart failure and self care and felt more confident about their self care. They had less illness uncertainty and were more satisfied with their hospital stay ($p<.01$ for all comparisons). However those attending the class did not know more about their medication. Over the six months after discharge there were no differences in death or re-hospitalisation rates.

It was concluded that the heart failure education class had a significant and beneficial role in increasing patients' knowledge and satisfaction. However no long-term benefit in terms of decreased mortality or reduction in re-hospitalisation was found.

Appendix 2. Patient Test and Measures Manual[1]

Test and variables	Scoring direction	Min. Score	Max. Score	Assessment method
COPE Carver et al., 1989	For each subscale, higher scores represent frequent use of the particular coping style	4	16	Patients' coping style was investigated using the COPE inventory (Carver et al., 1989). This is a 60-item inventory with 4 items for each of the 15 subscales. Each item presented a specific way in which people may behave in a stressful situation (for example "I discuss my feelings with someone") and patients were asked to choose one answer out of possible four: *1= I usually don't do this at all*; *2 = I usually do this a little bit*; *3 = I usually do this a medium amount* and *4 = I usually do this a lot*. For each subscale the range of possible values is 4 to 16, higher scores meaning that the patient uses that particular coping style frequently. Out of the 15 subscales, five measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping and seeking of instrumental social support) and five scales measures aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial and turning to religion). The last five subscales measure the extent to which people used humour, focus on and venting of emotion, mental disengagement, behavioural disengagement and alcohol/drug use to cope with stressful situations. Carver et al., (1989) reported that the internal consistency of the COPE subscales was acceptable high (all had Cronbach's alphas over .60, with the exception of the mental disengagement subscale). In the present study internal reliability for the 15 subscales ranged from α = .62 (suppression of competing activities) to α = .96 (turning to religion).
Clinical outcomes		-	-	Patient mortality, cause of death, number of hospitalisations and length of stay in hospital in the follow up period were provided by the IT Department in APH.
ESS Epworth Sleepiness Scale Johns, 1991	Higher scores represent worse daytime sleepiness	0	24	The ESS is a self-administered questionnaire that measure sleep propensity on a 0 (would never dose off) to 3 (high chance of dosing) scale in eight standardised daily situations such as sitting and reading or being a passenger in a car. It has been well validated against objective EEG based measurements of daytime sleepiness (Johns, 1993) and has shown good reliability and internal consistency (Johns, 1992). A cut-off of 12 is typically used in assessment of narcolepsy; however older adults may demonstrate impairment through non-pathological scores. In this study the reliability was acceptable: α = .80
FEV1 (Forced Expired Volume in one second) **FVC** (Forced Vital Capacity)	Higher values represent better objective lung function	-	-	These measures were collected by the investigator with a spirometer at both phases.

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[1] The references for the Appendices are included in the main reference section

Test and variables	***Scoring direction***	***Min. Score***	***Max. Score***	**Assessment method**
FIS Fatigue Impact Scale, Fisk et al, 1994	Higher scores represent increased fatigue	0	160	Subjective fatigue was measured using the Fatigue Impact Scale. The FIS consists of 40 items and measure patient perceptions of their functional limitations due to fatigue on cognitive (10 items), physical (10 items) and psychosocial (20 items) functioning during the past four weeks. Each item is scored from 0 (no problem) to 4 (extreme problem). The possible range of scores for the total FIS scale is between 0 and 160, 0-40 for the cognitive and physical dimensions and 0-80 for the psychosocial dimension. At phase 1 the reliability for the overall scale was $\alpha = .91$, and the reliabilities foe subscales ranged between $\alpha = .88 - .95$. At phase 2 reliabilities were similarly high.
GDS-15 Geriatric Depression Scale, Lyness et al., 1997	Higher scores indicate higher levels of depression	0	15	Patient depression was conceptualised as a general mental health outcome. In this study, patient depression was measured using the Geriatric Depression Scale (GDS; Brink et al., 1982; Yesavage et al., 1983). The questionnaire was specifically developed for screening elderly patients for depression (Yesavage et al., 1983) and was designed to concentrate on psychological aspects of depression, rather than somatic aspects of depression (such as appetite loss and sleep disturbance) that can be confounded by the normal effects of ageing. The original questionnaire consisted of 30 Yes/No items. However, Lyness et al., (1997) showed that a 15-item GDS had a sensitivity and specificity comparable to the GDS-30, thus in this study GDS-15 was used to measure patient level of depression. In the present study the scale reliability was $\alpha = .81$ at phase 1 and $\alpha = .80$ at phase 2.
Grooved Pegboard Test Matthews and Klove, 1964	Higher scores represent better motor function	-	-	The Grooved Pegboard Test was used to measure motor function. It consists of a metal board with a matrix of slotted holes angled in different directions. The task is to insert 25 metal pegs with ridges along the sides into each hole in sequence, first with their dominant hand, and then with their non-dominant hand. Scores represent time in seconds required to complete the matrix with each hand, with higher scores reflecting a lower level of performance.
HFKQ Heart Failure Knowledge Questionnaire	Higher scores represent better specific knowledge of heart failure	12	48	A 12-item knowledge questionnaire (HFKQ) was developed for this study. The questionnaire consists of statements aimed at measuring very specific knowledge of HF, for example patient's understanding of the relationship between fluid retention, breathlessness, diuretics and fluid intake. The participants were require to state whether in their opinion the statement was *certainty true* (scoring 4), *probably true* (scoring 3), *probably false* (scoring 2) or *certainty false* (scoring 1). A total score was obtained by summing the scores on each item, giving scores ranging from 12 to 48, higher scores representing higher specific illness knowledge. In this study, the reliability of HFKQ was high: $\alpha = .86$
IADLs The Lawton Instrumental Activities of Daily Living scale, Lawton and Brody, 1969	Higher scores indicate *higher* levels of disability	8	31	The IADL scale provides separately defined 5-point scales for observer ratings of bathing, dressing, toileting, eating ambulation and grooming. For example, the "shopping" item permits choosing five choices from "takes care of all the shopping needs independently" to "completely unable to shop".

Test and variables	***Scoring direction***	**Min. Score**	**Max. Score**	**Assessment method**
IIP-32 The Inventory of Interpersonal problems, Horowitz et al., 2000	Higher scores represent more interpersonal difficulties.	0	16	The IIP-32 is a self-report instrument that identifies a person's most salient interpersonal difficulties. The IIP-32 consists of 32 statements contributing to eight sub-scales (Domineering-/Controlling; Vindictive/Self-Centred; Cold/Distant; Socially Inhibited; Non-assertive; Overly Accommodating; Self-Sacrificing and Intrusive/Needy). Each statement portrays a social situation that people may find difficult, for example " It's hard for me to say 'no' to other people". Respondents were asked to choose one of five possible answers: *not at all*, *a little bit*, *moderately*, *quite a bit* and *extremely*. The possible range of scores for each subscale is 0 to 16. The authors reported a Cronbach's alpha of .93 for the overall scale and alphas ranging from .68 (Intrusive/Needy) to .87 (Cold/Distant) for the eight subscales. In this study, the scores were standardised to increase the accuracy of interpretation. The overall scale reliability was α = .88, and reliabilities for subscales ranged from α = .69 (intrusive/needy) to α = .89 (cold and distant).
LVEF Left ventricular ejection fraction	Higher scores indicate higher cardiac output	-	-	LVEF is an ejection phase parameter representing the percent of the blood pumped out during each heartbeat and is used to assess the performance of the heart in normal and pathological state. An EF fraction of 50% to 75% is normal. A cut-off point of 40% is generally used to separate systolic dysfunction (EF less or equal to 40%) from preserved systolic function (EF > 40%). LVEF was collected from patient files.
Medication Knowledge	Higher scores indicate better medication knowledge	1	3	Each patient was asked about the names, purpose and side effects of their medications. According to their answers, patients were grouped by the investigator into three categories (experimenter rated measure): *group 1* = poor medication knowledge (unable to offer any information about their medication; medication administered by others); *group 2= limited medication knowledge* (limited information, but sufficient to ensure that correct dose is taken at the right time or availability of blister pack) and group 3 = excellent medication knowledge (in depth knowledge of medication name, effects and side-effects).

Test and variables	***Scoring direction***	**Min. Score**	**Max. Score**	***Assessment method***
MLHFQ Minnesota Living with HF Questionnaire, Rector et al., 1987	Higher scores represent *lower* quality of life	Overall scale 0 Emotional QoL 0 Physical QoL 0	 105 25 40	Quality of life was investigated using a 21-item, disease specific measure of quality of life - the Minnesota Living with HF Questionnaire (MLHFQ; Rector et al., 1987). The inventory inquire about the effect that HF had on specific aspects of the HF patient's life in the last month, for example " Did your HF prevent you for living as you wanted during the last month by making your sleeping well at night difficult?" All items on this self-report instrument are measured on a 6-point response scale (0 to 5). The total summary score can range from 0 to 105, where a *lower* score reflects *better* quality of life. Two subscale scores reflect physical (8 items) and emotional (5 items) components of quality of life. The authors reported high internal consistency (Cronbach's alphas for the overall scale and physical and emotional dimensions were .94, .94 and .90, respectively). In the present study, reliabilities were α = .89 (overall scale), α = .85 (emotional QoL) and α = .92 (physical QoL). At phase 2 reliabilities were similarly high.
MMSE Mini-Mental State Examination Folstein et al., 1975	High = good mental status	0	30	The *Mini-Mental State examination* was used as a measure of global cognitive function. The MMSE consists of brief subtests (personal orientation to place and time, recall ability, short term memory and arithmetic ability). The scale has proven to be sufficiently valid, reliable and reproducible (McKhann et al., 1992). Traditionally, a score of less than 24 (out of a maximum of 30) has been regarded as indicating cognitive impairment severe enough to be regarded as dementia. However, Hodges (1994) argued that although a score of less than 24 on the MMSE is a fairly good indicator of dementia, cognitively impaired people with a good background intellectual ability may attain a score above the cut off point of 24. Hodge's criteria were used to classify patients as intact (MMSE scores of 29 or 30), impaired (MMSE scores of 24 to 28) and demented (MMSE <24).
MUIS-C Mishel Uncertainty in Illness Scale Mishel, 1990	Higher scores represent increased levels of illness uncertainty	23	115	The MUIS-C is a 23-item questionnaire, which was designed to measure perceived uncertainty in illness. Example of statements are " I don't know what is wrong with me" and " I am unsure if my illness is getting better or worse". Patients are asked to choose from five possible answers: *strongly agree*, *agree*, *undecided*, *disagree* and *strongly disagree*. Coefficient alpha scores for the MUIS-C are reported in the moderate to high range (.75 to .90; Winters, 1999). In this study the reliability was high at α = .89.
Negative reactions to care Newsom et al., 1998	Higher scores represent more negative reactions to care	10 4 6	50 20 24	In this study, negative reactions to receiving care in HF patients have been measured using a questionnaire proposed by Newsom et al., 1998. The questionnaire consists of 20-statements that present possible reactions to receiving care, for example "When a get help from my carer, I feel that I am a failure". Patients were asked to choose one answer from five possible choices: *5 = strongly agree*, *4 = agree*, *3 = neither agree nor disagree*, *2 = disagree* and *1 =*

				strongly disagree. The 20 items contributed to 3 subscales: temporary loss of self-esteem (10 items), indebtedness (4 items) and negative perceptions of carer behaviour (6 items). The authors reported that the internal consistency of the indebtedness scale was quite low at .57, but the other two scales had Cronbach's alphas of .87 (negative perceptions of carer behaviour) and .81 (temporary loss of self-esteem) respectively. The reliabilities for the 3 subscale used in this study were α = .71 (temporary loss of self-esteem), α = .76 (indebtedness), α = .80 (negative perceptions of carer behaviour).

Test and variables	**Scoring direction**	**Min. Score**	**Max. Score**	**Assessment method**
NEO-PI-R The NEO Personality Inventory Revised ,Costa and McCrae, 1992	Higher scores represent higher neuroticism, extraversion and conscientiousness.	0	48	Patients completed three subscales of the NEO-PI-R,which is a well-established measure of personality that has been shown to predict health outcomes. Each of the three subscale (neuroticism, extraversion and conscientiousness) consisted of 12 items. The patients were asked to choose the response which best fits their opinion for all 36 items from five possible answers: *strongly agree*, *agree*, *neutral*, *disagree* and *strongly disagree*. This gave a score of 0-4 for each item, ranging from 0 to 48 for each subscale. Higher scores indicated higher neuroticism, extraversion and conscientiousness. In the present study reliabilities for the subscales were: α = .86 (neuroticism), α= .76 (extraversion) and α = .82 (conscientiousness).
Number of co-morbidities	Higher number represents more co-morbid conditions	-	-	The number of co-morbid conditions was coded from patient file.
NYHA class	Higher scores indicate greater HF severity	2	4	The New York Heart Association (NYHA, 1994) HF class is the most widely and internationally used classification of severity of HF. Patients are grouped into four categories of increasing severity (class I to class IV) according to their level of impairment or degree of limitation experienced during everyday activities. **Class 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 that is confirmed by investigations – for example, echocardiography. **Class 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. **Class III: moderate** More marked limitation of activity which interferes with work. Walking on the flat produces symptoms. **Class IV: severe** Unable to carry out any physical activity without symptoms. Patients are breathless at rest and mostly housebound. In the present study, the NYHA class was estimated by a consultant cardiologist or a HF specialist nurse.
RAVLT The Rey Auditory Verbal Learning Test Rey, 1964	Higher scores represent higher verbal learning and better memory	0	105	The Rey Auditory Verbal Learning Test was used to measure verbal learning and memory. Patients are required to recall a list of fifteen nouns, which are presented to them at a rate of one word per second over a total of five learning trials (List A). Following the presentation of List A, a second list of fifteen nouns is read once (List B), and patients are asked to recall it. Directly afterwards, the patients are asked to recall as many words as possible from List A. After a delay of approximately thirty minutes, the patient is asked to recall List A, again without prompts. A score for each trial is calculated from the number of correct words from

				List A. The total RAVLT score is calculated from the sum of each trial score.

Test and variables	Scoring direction	Min. Score	Max. Score	Assessment method
Reitan Trail-making Test Reitan, 1958	Higher scores represent better attention, visual scanning, speed of hand-eye coordination and information processing	-	-	The Reitan Trail-making Test was used to measure attention, visual scanning, speed of hand-eye co-ordination and information processing. Part B also assesses the ability to alternate between sets of stimuli, which is an executive function. The test consists of two parts A and B, which are preceded by a short practice. Part A requires the patient to connect 25 randomly placed circles in ascending numerical order. Part B requires the patients to connect 25 randomly placed numbers and letters alternating between ascending numerical and alphabetical order. Patients are timed (seconds) for both parts of the test. For easier interpretation, the scores were standardised using the MOANS age corrected scaled score procedure (Ivnick et al., 1996).
Self-care questionnaire Riegel et al., 2000	High scores represent higher knowledge of self-care	7	28	Knowledge of self-care was measured by the self-care subscale of the Self-Management of HF instrument (Riegel et al., 2000). The scale consists of 7 items, asking the patients how often they undertake behaviours that help them monitor their illness, such as weighing themselves daily and contacting their health care provider when they need guidance. The patient can choose between four answers: *never or rarely* (scoring 1), *sometimes* (scoring 2), *frequently* (scoring 3) and *always* (scoring 4). Cronbach's alpha for this scale was reported to range between .62 to .68 (Jaarsma et al., 1999). In the present study scale reliability was relatively low at $\alpha = .60$ at both phases
Social support Krause and Markides, 1990	Higher scores represent higher levels of social support	40	160	Patient level of social support was assessed using a 40-item scale developed specifically for measuring social support in older adults (Krause and Markides, 1990). Patients were asked how often in the last year they receive specific types of support and were invited to choose one of four possible answers: 1 = never, 2 = once in a while, 3 = fairly often and 4 = very often. The questionnaire measures four types of social support, namely informational support (7 items), tangible support (9 items), emotional support (11 items) and integrational support (helping others; 13 items). The Cronbach's alphas were reported as good (ranging from .81 to .82), with the exception of the tangible support subscale, which had a Cronbach's alpha of .66. Moreover, for each type of social support the patient is asked if they are happy or unhappy with the level of support received. In the present study, the reliability for the social support scale was $\alpha = .91$, and for subscales were $\alpha = .92$ (informational support), $\alpha = .80$ (tangible support), $\alpha = .91$ (emotional support) and $\alpha = .80$ (integrational support).

Test and variables	Scoring direction	Min. Score	Max. Score	Assessment method
Social isolation Murberg et al., 1998	Higher scores represent increased social isolation due to illness	4	24	Social isolation was assessed using a 4-item scale developed by Murberg et al., (1998) to measure the extent to which HF patients judge their capacity to engage in social relationships to be compromised as a result of illness. The four items ask the patients if the disease made it difficult for them to (i) visit friends and family, (ii) receive visits from friends and family, (iii) participate in social events and (iv) go on holiday with family and friends. The social isolation items were scored according to a 6-step Likert scale ranging from "not at all" to "very much". The authors reported a Cronbach's alpha of .83 for the scale. In this study reliability of scale was α = .81.
SRH Self-reported health	Higher scores represent better subjective health	2	10	The self-reported health (SRH) status is a single question asking patients to rate their overall health on a scale from very good to very poor. There is widespread agreement that this simple global question provides a useful summary of how the patients perceive their overall health status, which was consistently found to be a powerful predictor of clinical outcomes and mortality in a wide range of disease areas (Fayers and Sprangers, 2002). In this study, patients were first asked, "Overall, how would you rate your health?" The patients choose their response from five alternatives: very good, good, fair, poor and very poor. Secondly, the pilot study has shown that a number of patients instinctively compare themselves with others of the same age. Therefore, a second question asked " In comparison with other men/women of your age living on the Wirral, would you say your health is: much above the average, above average, average, below average or much below average?" The scores on the two questions were added up to obtain an overall measure of subjective health.
Subjective angina	Higher scores represent worse angina	-	-	Subjective angina was measured using a composite measure developed for this study. Patients were asked about duration of angina, , feeling of being in control of angina, quality of the angina (getting worse, staying the same or getting better), severity of angina (on a scale from 1 to 10 where 1 means not at al severe and 10 means extremely severe) and level of distress experienced as a result of the experiencing angina (again, on a scale from 1 to 10, where 1 means no distress and 10 means extreme distress). Factor analyses were carried out and factors analysis scores were used to characterise individuals for the purposes of analyses.
Subjective oedema	Higher scores represent worse oedema	-	-	*Subjective oedema* was measured using a composite measure developed for this study. Patients were asked about duration of oedema, feeling of being in control of oedema, quality of the oedema (getting worse, staying the same or getting better), severity of oedema (on a scale from 1 to 10 where 1 means not at al severe and 10 means extremely severe) and level of distress experienced as a result experiencing oedema (again, on a scale from 1 to 10, where 1 means no distress and 10 means extreme distress). Factor analyses were carried out and factors analysis scores were used to characterise individuals for the purposes of analyses.

Test and variables	*Scoring direction*	**Min. Score**	**Max. Score**	**Assessment method**
STAI Spielberger State-Trait Anxiety Inventory, Spielberger et al. 1983	Higher scores represent higher levels of anxiety	20	80	Patient anxiety was assessed by the state part of the Spielberger State-Trait Anxirty Inventory . The STAI is a self-administered questionnaire consisting of ten items worded positively for the presence of anxiety (for example, " I feel nervous") and ten items worded negatively (for example, " I feel calm"). The latter were denoted as absence of anxiety by Spielberger et al., (1983). Each item has four possible answers 1 = *not at all*, 2 = *somewhat*, 3 = *moderately* so and 4 = *very much so*. The scores on the STAI range from 20 to 80, higher scores representing higher levels of anxiety. The reliability of STAI in the present study was high at α = .92 (phase 1) and α = .90 at phase 2.
VAS-D Visual Analogue Scale for Dyspnoea (Subjective breathlessness) Subratty et al., 1994	Higher scores represent worse breathlessness	10	100	VAS-D was developed specifically to measure dyspnoea in HF. Patients were asked how breathlessness they become when performing ten increasingly difficult activities, from resting to walking for 12 minutes on a flat surface at patient's own pace. The numerical scale range from 1 to 10, each value relating to a verbal subjective description of the intensity of dyspnoea (1 meaning " not breathless eat all" and 10 meaning "effort impossible"). In this study reliability was high: α = .93 at phase 1 and α = .90 at phase 2.

Appendix 3. Caregiver Test and Measures Manual[1]

Test and variables	Scoring direction	Min. Score	Max. Score	Assessment method
CES-D-10 Centre for Epidemiological Studies Depression Scale, Radloff, 1977	Higher scores represent higher levels of depression	0	10	Caregiver depression was measured using the Centre for Epidemiological Studies depression Scale (CES-D; Radloff, 1977). The original CES-D is a 20-item, single factor scale, which was designed to measure depressive symptoms in community populations and has been used successfully with caregivers (e.g. Hooker et al., 1992; O'Rourke and Tuokko, 2000). A shorter 10-item, ye/no format scale was proposed by Kohout et al., 1993 and recently reliability statistics confirmed that the proprieties of the 10-item CES-D are comparable to those reported for the original CES-D (Irwin et al., 1999). Consequently, the 10-item CES-D was used in this study to measure caregivers' level of depression. The reliability of the CES-D-10 was α =.76 at phase 1 and α =.71 at phase 2.
CDS The Caregiver Distress Scale, Cousins et al., 2002	Higher scores indicate higher levels of carer distress	17	85	Caregiver outcomes *specific* to the caregiving situation were assessed using the 17-item Caregiver Distress Scale (CDS; Cousins et al., 2002). The subjects are presented with statements portraying possible problems that may arise when providing care to a family relative, for example " I feel pressured between giving to (the care-receiver) and others in the family" and are asked to choose from five possible answers: *strongly disagree, disagree, neutral, agree* or *strongly agree*. The overall scale score can range from 17 to 85, higher scores indicating higher levels of distress. The CDS comprises five distinct dimensions that have a potential negative impact on caregivers: *relationship distress, emotional burden, care-receiver demands, social impact* and *personal cost*. The authors report that all dimensions had high internal consistencies. In this study, the five dimensions of the CDS are used to measure specific negative outcomes resulting from giving care to a family relative suffering from HF. In the present study, internal reliability for the overall scale and subscales were high at both phases (all α > .80).
DAS -7 Dyadic adjustment scale, Hunsley et al., 1995	Higher scores represent better dyadic relationship quality	0	36	The quality of the dyadic relationship was assessed using the 7-item short form of the Dyadic Adjustment Scale (DAS-7; Spanier, 1976; Hunsley et al., 1995). The scale yields one overall dyadic adjustment score, ranging from 0 to 36. Higher scores represent a higher quality of relationship. Hunsley et al., (1995, 2001) reported reliability coefficients of .82 and .91 for the overall scale. In the present study internal reliability for the scale was α = .87 at phase 1 and α = .82 at phase 2.
Discretion	Higher scores indicate more discretion	-	-	At both phases, level of discretion was assessed by the following question: " What is the maximum time that you can leave your relative without worrying?" The response was recorded in hours.

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[1] The references for the Appendices are included in the main reference section

Test and variables	*Scoring direction*	*Min.* Score	*Max.* Score	*Assessment method*
Carer perception of patient personality and personality change	Higher scores represent higher patient neuroticism, extraversion and conscientiousness and higher level of change in patients neuroticism, extraversion and conscientiousness	0	48	In order to investigate caregivers' perceptions of patient personality and personality change, they were given two adaptations of the neuroticism extraversion and conscientiousness subscales of the NEO-PI-R (Costa and McCrae, 1992). The first was a simple conversion from the first person to the third person, for example "I am a worrier" was transformed into "He/She is a worrier", in order to assess caregiver perception of "present " care-receiver personality. The second adaptation was to assess carers' perception of their care-receivers' personality as it was when the care-receivers were in their thirties or "in their prime". Caregivers were invited to "think about the person you care for and how they used to be in their thirties or in their 'prime'" and then to select an answer for each of the 48 items of the NEO-PI-R. "Present" personality scores were then subtracted from "prime " personality scores, and then they were squared (to eliminate negative scores) in order to assess caregiver perception of care-receiver personality change.
Hours of care	Higher scores indicate more hours of care	-	-	At both phases, after an introductory discussion about the kind of things the caregiver does for their family member, they were asked, " In the average week, how many hours a day do you care for your relative?" The response was recorded in hours.
IIP-32 The Inventory of Interpersonal problems, Horowitz et al., 2000	Higher scores represent more interpersonal difficulties.	0	16	Similarly to patients, caregiver interpersonal problems were measured with the IIP-32, which is a self-report instrument that identifies a person's most salient interpersonal difficulties. The IIP-32 consists of 32 statements contributing to eight sub-scales (Domineering-/Controlling; Vindictive/Self-Centred; Cold/Distant; Socially Inhibited; Non-assertive; Overly Accommodating; Self-Sacrificing and Intrusive/Needy). Each statement portrays a social situation that people may find difficult, for example " It's hard for me to say 'no' to other people". Respondents were asked to choose one of five possible answers: *not at all*, *a little bit*, *moderately*, *quite a bit* and *extremely*. The possible range of scores for each subscale is 0 to 16. The authors reported a Cronbach's alpha of .93 for the overall scale and alphas ranging from .68 (Intrusive/Needy) to .87 (Cold/Distant) for the eight subscales. In this study, the scores were standardised to increase the accuracy of interpretation. The overall scale reliability for caregivers was $\alpha = .89$, and reliabilities for subscales ranged from $\alpha = .60$ (overly accommodating) to $\alpha = .95$ (vindictive and self centred).
Caregiver involvement in administering patients' medication				Caregivers were asked to what extent they were involved in giving or reminding the patient to take his/her medication. According to their answers, they were divided into three groups: Group 1 = *responsible for administering medication*; Group 2 = *reminding the patient to take his/her medication* and Group 3 = *not involved in patient's medication*.

Test and variables	**Scoring direction**	**Min. Score**	**Max. Score**	**Assessment method**
Length of role as caregiver	Higher values represent longer length of role as caregiver			Caregivers were asked how long they have been providing care for their family member. According to their answers, they were assigned to one of seven categories: length of role *1 = one month*, 2 = *6 months*, 3 = *1 year*, *4 = 2 years*, *5 = 2-5 years*, *6 = 5-10 years* and *7 = more than 10 years*.
Mastery, Pearlin and Schooler, 1978	Higher scores indicate higher degrees of personal control	7	35	Research has shown that a sense of mastery, or personal control is important to both physical and emotional health (Pearlin et al., 1981; Rodin, 1986; Krause, 1994) as well as to productivity in later life (Glass et al., 1995). In order to assess caregivers' level of personal control, they were asked to complete a 7-item scale developed by Pearlin and Schooler (1978). Participants were asked to respond to statements such as " I have little control over the things that happen to me" choosing one of five possible answers: *completely agree*, *mostly agree*, *neither agree nor disagree*, *mostly disagree* and *completely disagree*. The scores range from 7 to 35. The authors reported a reliability coefficient of .75 for this test. In the present study internal reliability of the scale was α = .81.
NEO-PI-R The NEO Personality Inventory Revised ,Costa and McCrae, 1992	Higher scores represent higher neuroticism, extraversion and conscientiousness.	0	48	Similarly to patients, caregivers completed three subscales of the NEO-PI-R. Each of the three subscale (neuroticism, extraversion and conscientiousness) consisted of 12 items. The caregivers were asked to choose the response which best fits their opinion for all 36 items from five possible answers: *strongly agree*, *agree*, *neutral*, *disagree* and *strongly disagree*. This gave a score of 0-4 for each item, ranging from 0 to 48 for each subscale. Higher scores indicated higher neuroticism, extraversion and conscientiousness. In the present study reliabilities for the subscales were: α = .89 (neuroticism), α= .62 (extraversion) and α = .77 (conscientiousness).
Number of co-morbidities	Higher number represents more co-morbid conditions	-	-	Caregivers were asked if they are diagnosed with any disabling chronic conditions, such as arthritis or cancer, and the number of conditions were coded as an indicator of objective health status.
Presence of confidant		-	-	Presence of confidant was assessed using three questions. Firstly, the caregivers were asked, " If you have a problem of some sort, who will be the first person with whom you would want to discuss it?" Secondly, they were asked, " Is this person someone you can talk to about your most private thoughts and feelings? Someone that you can really trust with a personal problem?" and finally, " Can you discuss any problem with X (your care-receiver), or are there certain topics which are impossible to discuss?" According to their answers, two measures were assessed (i) presence of confidant (1 = confidant present and 2 = confidant absent) and (ii) care-receiver as the caregiver's confidant (1 = the care-receiver was perceived as their confidant by the caregiver and 2 = care-receiver was *not* perceived as their confidant.

Test and variables	*Scoring direction*	*Min. Score*	*Max. Score*	*Assessment method*
SCQ Sense of Competence Questionnaire, Scholte et al., 1998	Higher scores represent *lower* levels of satisfaction with the role of caregiver	12	48	Positive aspects of providing care were measured by the satisfaction with role as a caregiver subscale of the Sense of Competence Questionnaire (SCQ; Scholte et al., 1998). The subscale consists of 12 items measuring positive reactions to giving care, for example " I feel pleased with my interactions with my (care-receiver)". There are four choices of answer: *disagree very much*, *disagree*, *agree* and *agree very much*. The score on the subscale can range from 12 to 48, when higher scores represent *lower* levels of satisfaction with the role of caregiver. The authors reported a reliability coefficient of .75 for the subscale. In the present study the internal reliability of SCQ was α = .80 at phase 1 and α = .81 at phase 2.
Self-esteem Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1989)	Higher scores represent more *negative* self-esteem	10	40	In health psychology, self-esteem or self-worth has been typically viewed as a resource that can moderate the effects of a stressful event. In this study, caregivers' self-esteem was measures with the Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1989). The RSE scale consists of 10 items (e.g. "On the whole, I am satisfied with myself") to which the participant responds on a four-point scale of agreement: *strongly agree*, *agree*, *disagree*, and *strongly disagree*. The scores on the test can range from 10 to 40, higher scored indicating more negative self-esteem.
Social support Krause and Markides, 1990	Higher scores represent higher levels of social support	40	160	Caregiver level of social support and satisfaction with social support was assessed with the same 40-item questionnaire used to investigate patient social support. Caregivers were asked how often in the last year they receive specific types of support and were invited to choose one of four possible answers: 1 = never, 2 = once in a while, 3 = fairly often and 4 = very often. The questionnaire measures four types of social support, namely informational support (7 items), tangible support (9 items), emotional support (11 items) and integrational support (helping others; 13 items). The Cronbach's alphas were reported as good (ranging from .81 to .82), with the exception of the tangible support subscale, which had a Cronbach's alpha of .66. Moreover, for each type of social support the caregiver was asked if they were happy or unhappy with the level of support received. In the present study, the reliabilities caregivers were α = .92 (overall scale), α = .82 (informational support), α = .72 (tangible support), α = .91 (emotional support) and α = .89 (integrational support).
SRH Self-reported health	Higher scores represent better subjective health	2	10	Caregivers were asked the same two questions about their general state of health as the patients. Firstly, they were asked, "Overall, how would you rate your health?" The caregivers choose their response from five alternatives: very good, good, fair, poor and very poor. Secondly, they were asked " In comparison with other men/women of your age living on the Wirral, would you say your health is: much above the average, above average, average, below average or much below average?" The scores on the two questions were added up to obtain an overall measure of subjective health.

Test and variables	Scoring direction	Min. Score	Max. Score	Assessment method
STAI Spielberger State-Trait Anxiety Inventory Spielberger et al. 1983	Higher scores represent higher levels of anxiety	20	80	As with the patient, caregiver anxiety was assessed by the state part of the Spielberger State-Trait Anxirty Inventory . The STAI is a self-administered questionnaire consisting of ten items worded positively for the presence of anxiety (for example, " I feel nervous") and ten items worded negatively (for example, " I feel calm"). Each item has four possible answers *1 = not at all*, *2 = somewhat*, *3 = moderately* so and *4 = very much so*. The scores on the STAI range from 20 to 80, higher scores representing higher levels of anxiety. Reliabilities values were for caregivers were high at α = .91 (phase 1) and a α = .93 at phase 2.

Appendix 4

Mean scores, SDs and distributions of the Patient measures used

Measure	Mean score	SD	Distribution (K-S* [1]test)
Patient Self-reported Health phase 1	5.18	.16	.06
Patient Self-reported health Phase 2	5.72	.22	.06
Subjective Breathlessness (VAS) phase 1	47.15	2.02	.20
Subjective Breathlessness (VAS) phase 2	48.31	2.6	.20
Subjective Angina	1.62	2.6	.20
Subjective Oedema	.69	.08	.20
HF Knowledge Questionnaire	36.5	.59	.06
Self-care knowledge Phase 1	17.19	.59	.06
Self-care knowledge Phase 2	21.70	.43	.06
Lawton IADLs Phase 1	16.91	.55	.06
Lawton IADLs Phase 2	16.45	.63	.20
Social Isolation Questionnaire	12.88	.56	.76
Negative reactions to care Questionnaire	66.24	1.40	.20
COPE	113.58	1.84	.20
Epworth Sleepiness Scale	8.75	.53	.06
Fatigue Impact Scale	97.63	3.2	.20
Geriatric Depression Scale Phase 1	6.11	.37	.06
Geriatric Depression Scale Phase 2	5.80	.40	.06
State Trait Anxiety Inventory Phase 1	40.8	1.12	.06
State Trait Anxiety Inventory Phase 2	39.66	1.26	.06
Minnesota Living with HF Questionnaire Phase 1	50.22	1.97	.20
Minnesota Living with HF Questionnaire Phase 2	48.64	2.10	.20
Inventory of Interpersonal Difficulties	52.54	.99	.20
Social Support Questionnaire	79.45	1.74	.20
Mishel Uncertainty in Illness Questionnaire	62.26	1.14	.06
Patient Neuroticism	18.93	.89	.06
Patient Extraversion	21.96	.66	.20
Patient Conscientiousness	32.60	.60	.06

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[1] **Kolmogorov-Smirnov** test of normality – a significant value (sig.<.05) indicates a deviation from normality

Appendix 5

Mean scores, SDs and distributions of the Caregiver measures used

Measure	Mean score	SD	Distribution (K-S* [1]test)
Caregiver Self-reported Health phase 1	6.25	.23	.06
Caregiver Self-reported health Phase 2	6.17	.22	.06
Caregiver Neuroticism	22.89	1.36	.20
Caregiver Extraversion	25.64	.70	.20
Caregiver Conscientiousness	33.09	.78	.20
Caregiver Mastery	23.66	.87	.20
Caregiver Self-esteem	19.83	.70	.20
Caregiver Interpersonal Problems Inventory	54.55	1.58	.11
Caregiver Perception of Patient Neuroticism (present)	23.00	1.37	.20
Caregiver Perception of Patient Extraversion (present)	21.47	1.06	.20
Caregiver Perception of Patient Conscientiousness (present)	31.09	1.30	.12
Caregiver Perception of Patient Neuroticism (past)	16.61	.95	.20
Caregiver Perception of Patient Extraversion (past)	28.59	1.03	.20
Caregiver Perception of Patient Conscientiousness (past)	35.61	.93	.06
Caregiver Social Support Questionnaire	81.77	2.54	.20
Caregiver Quality of Dyadic Relationship Phase 1	21.47	.85	.20
Caregiver Quality of Dyadic Relationship Phase 1	21.58	1.09	.20
The Caregiver Distress Scale Phase 1	39.47	2.55	.20
The Caregiver Distress Scale Phase 2	39.56	2.55	.20
Caregiver Satisfaction with Role as Carer Phase 1	23.30	.57	.06
Caregiver Satisfaction with Role as Carer Phase 2	25.58	.86	.20
Caregiver Depression Phase 1	3.43	.33	.06
Caregiver Depression Phase 2	3.42	.38	.06
State Trait Anxiety Inventory Phase 1	42.89	1.78	.20
State Trait Anxiety Inventory Phase 2	43.58	2.11	.20

---

[1] **Kolmogorov-Smirnov** test of normality – a significant value (sig.<.05) indicates a deviation from normality

PATIENT SEMI-STRUCTURED INTERVIEW – PHASE 1

DATE:	**Code No:**		
NAME:	**DOB:**	**AGE:**	**M** **F**
ADDRESS:		**PHONE:**	

EDUCATION:

Which of these **qualifications** do you have?

- θ **1 or more O levels / CSE / GCSEs (any grade)** (a)
- θ **1 or more A levels or AS levels** (b)
- θ **Degree** (c)
- θ **NVQ** (d)
- θ **Other qualification (e.g. City and Guilds, RSA)** (e)
- θ **No qualifications**

HEALTH:

I. Overall, how would you rate your health?

Very good	Good	Fair	Poor	Very poor
5	4	3	2	1

II. Do you suffer of any of the following illnesses? (12 months prior the interview)

Asthma or chronic bronchitis		Diabetes mellitus	
Pulmonary emphysema		Thyroid gland disorder	
Heart condition		Back problems for at least three months or slipped disk	
Hypertension		Joint conditions or arthritis	
(consequences of) stroke		Migraine or chronic headache	
Leg ulcer		Serious dermatological disorders like psoriasis and eczema	
Stomach ulcer		Cancer	
Liver disorder or gallstones		Multiple sclerosis	
Kidney disease		Parkinson Disease or epilepsy	
Prostate disease			

III. In comparison with other men/women of your age living on the Wirral would you say your health is:

Much above average	Above average	Average	Below average	Much below average
5	4	3	2	1

DIAGNOSIS:

HF:

LVEF:

NYHA Class:

DURATION OF ILLNESS

0-1 mth 1-6 mths 6-12 mths 1-2 yrs 3-5 yrs 5-10 yrs over 10 yrs

Spirometer reading :
Now I would like to see what you are like at breathing out. I will ask you to breathe into this little cardboard tube. We will take the best of three goes, so do not worry if the first one is not as good as you think you can manage.

	FEV1	FVC
Try 1		
Try2		
Try3		

VISUAL ANALOGUE SCALE FOR ASSESSMENT OF DYSPNOEA IN HF (SUBRATTY ET AL., 1994)

---

10. effort impossible
9. very very uncomfortable
8. very uncomfortable
7. uncomfortable
6. slightly uncomfortable
5. breathless
4. slightly breathless
3. very slightly breathless
2. very very slightly breathless
1. not breathless at al

List of activities as performed by the HF patients

	Rest
	Coming out of bed
	Buttoning one's shirt
	Climbing in bed
	Walking 10 steps at patient's own pace
	Putting on shoes in a sitting position
	Walking 20 steps at patient's own pace
	Walking for 2 minutes on a flat surface at patient's own pace
	Walking for 6 minutes on a flat surface at patient's own pace
	Walking for 12 minutes on a flat surface at patient's own pace

OEDEMA

Some people with your condition (but not necessarily all), get swelling in some part of their body. Has this happen to you?

- **Duration**: How long have you been suffering swelling?

0-1 mth 1-6 mths 6-12 mths 1-2 yrs 3-5 yrs 5-10 yrs over 10 yrs

- **Control**: Do you feel that you are in control of your swelling:

Code: in control 1 partial control 2 nothing that patient can do 3

- **Course**: Has the swelling been getting worse or better?

Code: worse 3 no change 2 better 1

- **Subjective severity scale:** if you had a scale where 1 was no swelling at all and 10 was the worse swelling you can have, where would you place the swelling you have been experiencing in the **last four weeks**?

Not at all swollen	→								The worse swelling you could experience
1	2	3	4	5	6	7	8	9	10

- **Subjective distress scale**: How distressed have you been by your breathlessness?

Not at all distressed	→								As distressed as I have ever be
1	2	3	4	5	6	7	8	9	10

Objective measure of oedema severity:

Swelling	at ankle level	
	at knee level	
	sacral oedema	
	abdominal oedema	

The Dutch Exertion Fatigue Scale (Tiesinga et al, 1998, 9 items, score range 0-36)

Not fatiguing 0	A little fatiguing 1	Fatiguing 2	Severely fatiguing 3	Too fatiguing 4

	Is it fatiguing for you to walk for 30 minutes?
	Is it fatiguing for you to upstairs and downstairs?
	Is it fatiguing for you to walk for 10 minutes?
	Is it fatiguing for you to take a shower standing?
	Is it fatiguing for you to shop?
	Is it fatiguing for you to clean up your household waste?
	Is it fatiguing for you to hover?
	Is it, broadly speaking, fatiguing for you to pay a visit to someone?
	Is it fatiguing for you to go to a birthday party?

________ **TOTAL**

PAIN (ANGINA)

Some people with your condition (but not necessarily all) experience pain. Has this happen to you because of your heart problems?

- **Duration**: How long have you been experiencing pain?

0-1 mth 1-6 mths 6-12 mths 1-2 yrs 3-5 yrs 5-10 yrs over 10 yrs

- **Control**: Do you feel that you are in control of your pain:

Code:	in control	partial control	nothing that patient can do
	1	2	3

- **Course**: Has the pain been getting worse or better?

Code:	worse	no change	better
	3	2	1

- **Subjective severity scale:** if you had a scale where 1 was no pain at all and 10 was the worse pain you can have, where would you place the pain you have been experiencing in the **last four weeks**?

Not at all pain	$\longrightarrow$								The worse pain you could experience
1	2	3	4	5	6	7	8	9	10

- **Subjective distress scale**: How distressed have you been by your pain?

Not at all distressed	$\longrightarrow$								As distressed as I have ever be
1	2	3	4	5	6	7	8	9	10

REHOSPITALIZATIONS

- **How many times have you been in hospital on account of your heart problems since you were diagnosed?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Have you been in the hospital in the past year (12months)? How many times? For how many days each time?

	Year	Month	For ------days.	**Why** you had to go back to hospital ?
1.				
2.				
3.				
4.				

MEDICATION

Medication general

- What medicines are you on?

Medicine (name 1 point)	**Knows what symptom is for (1point)**	**Knows effect (1point)**	**Knows benefits (1 point)**	**Total**
1.				
2.				

3.				
4.				
5.				
Mean______				

Heart Failure Knowledge Questionnaire

1. Trouble breathing is a symptom of heart failure.

Certainly true	Probably true	Probably false	Certainly false

2. Feeling very tired or fatigued when you haven't done much is a sign of heart failure.

Certainly true	Probably true	Probably false	Certainly false

3. Sudden weight gain is a sign of heart failure.

Certainly true	Probably true	Probably false	Certainly false

4. Swelling of lower legs is a sign of heart failure.

Certainly true	Probably true	Probably false	Certainly false

5. Dizziness, loss of balance or passing out is a sign of HF.

Certainly true	Probably true	Probably false	Certainly false

6. Trouble sleeping because of trouble breathing a sign of heart failure.

Certainly true	Probably true	Probably false	Certainly false

7. Just not feeling well is a sign of heart failure.

Certainly true	Probably true	Probably false	Certainly false

8. Feeling out of breath is caused by water accumulating in the body.

Certainly true	Probably true	Probably false	Certainly false

9. Once on heart failure medication you are on it for life.

Certainly true	Probably true	Probably false	Certainly false

10. If you stop taking diuretics (water tablets), you will get breathless.

Certainly true	Probably true	Probably false	Certainly false

11. If you suffer from heart failure you shouldn't drink more than 3 and a half pints of fluid a day, except in very hot weather.

Certainly true	Probably true	Probably false	Certainly false

12. Sometimes medicines you are prescribed cause unwanted symptoms, such as dizziness, coughing or sickness.

Certainly true	Probably true	Probably false	Certainly false

Self-care/ monitoring.

In the last four weeks, how often did you carry out the following? Please tick the appropriate box to show your response.

		Never or rarely 1	Some Times 2	Frequently 3	Always 4
1	Weigh yourself daily?				
2	Keep the salt in your diet to lower than 2000-3000 mg (2-3Gm) each day? (approximately ½ a teaspoon)				
3	Exercise at least three times each week?				
4	Take medications as prescribed?				
5	Keep your weight within 10% of your ideal weight?				
6	Talk to your doctor whenever you needed guidance?				
7	Over the last 4 years, how often have you had a flu jab each year?				

Lawton IADL scale

A. Ability to use telephone
1. Operates telephone on own initiative –looks up and dials numbers etc
2. Dials a few well-known numbers.
3. Answer telephone but does not dial
4. Does not use telephone at all

B. Shopping
1. Takes care of all shopping needs independently.
2. Shops independently for small purchases.
3. Needs to be accompanied on any shopping trip
4. Completely unable to shop.

C. Food preparation.
1. Plans, prepares, and serves adequate meals independently.
2. Prepares adequate meals if supplied with ingredients.
3. Heats and serves prepared meals, or prepares meals but does not maintain adequate diet.
4. Needs to have meals prepared and served.

D. Housekeeping.
1. Maintains house alone or with occasional assistance (e.g. "heavy work – domestic help").
2. Performs light daily tasks such as dishwashing, bedmaking.
3. Performs light daily tasks but cannot maintain accepted level of cleanliness.
4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping tasks.

E. Laundry
1. Does personal laundry completely.
2. Launders small items – rinses socks, stockings etc.
3. All laundry must be done by others.

F. Mode of transportation
1. Travels independently on public transport or drives own car.
2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when assisted or accompanied by another.
4. Travel limited to taxi or automobile with assistance of another.
5. Does not travel at all.

G. Responsibility for own medications
1. Is responsible for taking medication in correct dosage at correct times.
2. Takes responsibility if medication is prepared in advance in separate dosages.
3. Is not capable of dispensing own medication.

H. Ability to handle finances.
1. Manages financial matters independently (budgets, write checks, pays rent, bills, goes to bank) collects and keeps track of income.
2. Manages day to day purchases, but needs help with banking, major purchases, etc.
3. Incapable of handling money.

TOTAL SCORE ________________

Social isolation (Mulberg, 2001)

		NOT AT ALL					**VERY MUCH**
1.	Do you feel that the disease makes it difficult to visit family and friends?	**1**	**2**	**3**	**4**	**5**	**6**
2.	Do you feel that the disease make it difficult to receive visits from family and friends?	**1**	**2**	**3**	**4**	**5**	**6**
3.	Do you feel that the disease make it difficult to participate in social events?	**1**	**2**	**3**	**4**	**5**	**6**
4.	Do you feel that the disease make it difficult to go on holiday with family and friends?	**1**	**2**	**3**	**4**	**5**	**6**

PATIENT SEMI-STRUCTURED INTERVIEW – PHASE 2

DATE:	**Code No:**		
NAME:	**DOB:**	**AGE:**	**M** **F**
ADDRESS:		**PHONE:**	

NYHA Class now: II III IV

Change of class YES NO

IF YES Better Worse No change

HEALTH & HEALTH EVENTS DURING THE LAST 6 MONTHS

Overall, how would you rate your health at the moment?

Very good	Good	Fair	Poor	Very poor
5	4	3	2	1

Since I last saw you (approximately 6 months ago) have you been diagnosed with any new condition?

Asthma or chronic bronchitis		Diabetes mellitus	
Pulmonary emphysema		Thyroid gland disorder	
Heart condition		Back problems for at least three months or slipped disk	
Hypertension		Joint conditions or arthritis	
(consequences of) stroke		Migraine or chronic headache	
Leg ulcer		Serious dermatological disorders like psoriasis and eczema	
Stomach ulcer		Cancer	
Liver disorder or gallstones		Multiple sclerosis	
Kidney disease		Parkinson Disease or epilepsy	
Prostate disease			

In comparison with other men/women of your age living on the Wirral would you say your health is:

Much above average	Above average	Average	Below average	Much below average
5	4	3	2	1

Spirometer reading : Now I would like to see what you are like at breathing out. I will ask you to breathe into this little cardboard tube. We will take the best of three goes, so do not worry if the first one is not as good as you think you can manage.

	FEV1	FVC
Try 1		
Try2		
Try3		

OEDEMA YES NO

Ankle level	Knee level	Sacral	Abdominal

Oedema: **Worse** **The same** **Better**

VISUAL ANALOGUE SCALE FOR ASSESSMENT OF DYSPNOEA IN HF (SUBRATTY ET AL. 1994)

10. effort impossible
9. very very uncomfortable
8. very uncomfortable
7. uncomfortable
6. slightly uncomfortable
5. breathless
4. slightly breathless
3. very slightly breathless
2. very very slightly breathless
1. not breathless at al

List of activities as performed by the HF patients

	Rest
	Coming out of bed
	Buttoning one's shirt
	Climbing in bed
	Walking 10 steps at patient's own pace
	Putting on shoes in a sitting position
	Walking 20 steps at patient's own pace
	Walking for 2 minutes on a flat surface at patient's own pace
	Walking for 6 minutes on a flat surface at patient's own pace
	Walking for 12 minutes on a flat surface at patient's own pace

The Dutch Exertion Fatigue Scale

Not fatiguing 0	A little fatiguing 1	Fatiguing 2	Severely fatiguing 3	Too fatiguing 4

	Is it fatiguing for you to walk for 30 minutes?
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	Is it fatiguing for you to take a shower standing?
	Is it fatiguing for you to shop?
	Is it fatiguing for you to clean up your household waste?
	Is it fatiguing for you to hover?
	Is it, broadly speaking, fatiguing for you to pay a visit to someone?
	Is it fatiguing for you to go to a birthday party?

_________ TOTAL

REHOSPITALISATIONS

Have you been in the hospital in the 6 months? How many times? For how many days each time?

	Year	Month	For -----days.	**Why you had to go back to hospital ?**
1.				
2.				
3.				
4.				

Since I saw you last time, have you been attending the cardiac clinic at APH?

NO YES How many times? 1 2 3 4 5 6

Have you seen your GP on account of your HF?

NO YES How many times? 1 2 3 4 5 6

MEDICATION Now I would like to ask you about the medicines you take.

- What medicines are you on?

Medicine (name 1 point)	**Knows what symptom is for (1point)**	**Knows effect (1point)**	**Knows benefits (1 point)**	**Total**
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
		Mean______		

2 = excellent, convincing information about medication and compliance. Patient responsible for his/her medication.

1 = patchy information, someone else responsible for administering medication.

0 = very patchy information, not convincing about adequate compliance.

Self-care/ monitoring.

In the last four weeks, how often did you carry out the following? Please tick the appropriate box to show your response.

		Never or rarely 1	Some Times 2	Frequently 3	Always 4
1	Weigh yourself daily?				
2	Keep the salt in your diet to lower than 2000-3000 mg (2-3Gm) each day? (approximately ½ a teaspoon)				
3	Exercise at least three times each week?				
4	Take medications as prescribed?				
5	Keep your weight within 10% of your ideal weight?				
6	Talk to your doctor whenever you needed guidance?				
7	Over the last 4 years, how often have you had a flu jab each year?				

Lawton IADL scale

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4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping tasks.

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2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when assisted or accompanied by another.
4. Travel limited to taxi or automobile with assistance of another.
5. Does not travel at all.

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosage at correct times.
2. Takes responsibility if medication is prepared in advance in separate dosages.
3. Is not capable of dispensing own medication.

H. Ability to handle finances.

1. Manages financial matters independently (budgets, write checks, pays rent, bills, goes to bank) collects and keeps track of income.
2. Manages day to day purchases, but needs help with banking, major purchases, etc.
3. Incapable of handling money.

TOTAL SCORE ________________

REACTIONS TO BEING CARED-FOR QUESTIONNAIRE

SA (5) Strongly agree	A(4) Agree	N(3) Neither agree nor disagree	D(2) Disagree	SD(1) Strongly disagree

When my spouse (caregiver) helps me with something………

1. I feel embarrassed	SA	A	N	D	SD
2. I become angry with him/her.	SA	A	N	D	SD
3. I feel like a weak or incapable person	SA	A	N	D	SD
4. I worry about my spouse hurting himself/ herself	SA	A	N	D	SD

When I get help from my spouse (caregiver) ………

5. I feel that I am a person of worth, at least as much as others. **(INV)**	SA	A	N	D	SD
6. I still feel I have a number of good qualities. **(INV)**	SA	A	N	D	SD
7. I feel that I am a failure	SA	A	N	D	SD
8. I feel that I am able to do things as well as most other people of my age. **(INV)**	SA	A	N	D	SD
9. I feel that I do not have much to be proud of.	SA	A	N	D	SD
10. I feel positively toward myself. **(INV)**	SA	A	N	D	SD
11. I feel satisfied with myself. **(INV)**	SA	A	N	D	SD
12. I wish I could have more respect for myself.	SA	A	N	D	SD
13. I feel useless.	SA	A	N	D	SD
14. I think I am no good at all.	SA	A	N	D	SD

When I get help from my spouse (caregiver)……..

15. It makes me feel dependent on him/her .	SA	A	N	D	SD
16. I feel that I am indebted to him/her.	SA	A	N	D	SD
17. I wish I could give more to my spouse in return for helping me.	SA	A	N	D	SD
18. I feel I am never able to return the favour.	SA	A	N	D	SD

When I get help with something.......					
19. He/she is always courteous. **(INV)**	SA	A	N	**D**	**SD**
20. It is done in a caring way. **(INV)**	SA	A	N	**D**	**SD**
21. My spouse is reluctant to help out.	SA	A	N	**D**	**SD**
22. My spouse seems to resent helping me.	SA	A	N	**D**	**SD**
23. He/she becomes angry.	SA	A	N	**D**	**SD**
24. My spouse is critical of me.	SA	A	N	**D**	**SD**

IIP-32 Question/ Scoring Sheet

Name: ____________________________________

Date: ______ / ______ / ______
Month Day Year

Sex: Male ☐ Female ☐

People have reported having the following problems in relating to other people. Please read the list below, and for each item, consider whether it has been a problem for you with respect to **any** significant person in your life. Then fill in the numbered circle that describes how distressing that problem has been.

The following are things you find hard to do with other people.

It is hard for me to:

	Not at all	A little bit	Moderately	Quite a bit	Extremely	
1. Say "no" to other people	⓪	①	②	③	④	1.
2. Join in on groups	⓪	①	②	③	④	2.
3. Keep things private from other people	⓪	①	②	③	④	3.
4. Tell a person to stop bothering me	⓪	①	②	③	④	4.
5. Introduce myself to new people	⓪	①	②	③	④	5.
6. Confront people with problems that come up	⓪	①	②	③	④	6.
7. Be assertive with another person	⓪	①	②	③	④	7.
8. Let other people know when I am angry	⓪	①	②	③	④	8.
9. Socialize with other people	⓪	①	②	③	④	9.
10. Show affection to people	⓪	①	②	③	④	10.
11. Get along with people	⓪	①	②	③	④	11.
12. Be firm when I need to be	⓪	①	②	③	④	12.
13. Experience a feeling of love for another person	⓪	①	②	③	④	13.
14. Be supportive of another person's goals in life	⓪	①	②	③	④	14.
15. Feel close to other people	⓪	①	②	③	④	15.
16. Really care about other people's problems	⓪	①	②	③	④	16.
17. Put somebody else's needs before my own	⓪	①	②	③	④	17.
18. Feel good about another person's happiness	⓪	①	②	③	④	18.
19. Ask other people to get together socially with me	⓪	①	②	③	④	19.
20. Be assertive without worrying about hurting the other person's feelings	⓪	①	②	③	④	20.

The following are things that you do too much.

21. I open up to people too much.	⓪	①	②	③	④	21.
22. I am too aggressive toward other people.	⓪	①	②	③	④	22.
23. I try to please other people too much.	⓪	①	②	③	④	23.
24. I want to be noticed too much.	⓪	①	②	③	④	24.
25. I try to control other people too much.	⓪	①	②	③	④	25.
26. I put other people's needs before my own too much.	⓪	①	②	③	④	26.
27. I am overly generous to other people.	⓪	①	②	③	④	27.
28. I manipulate other people too much to get what I want.	⓪	①	②	③	④	28.
29. I tell personal things to other people too much.	⓪	①	②	③	④	29.
30. I argue with other people too much.	⓪	①	②	③	④	30.
31. I let other people take advantage of me too much.	⓪	①	②	③	④	31.
32. I am affected by another person's misery too much.	⓪	①	②	③	④	32.

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1 2 3 4 5 6 7 8 9 10 11 12 A B C D E

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EPWORTH SLEEPINESS SCALE

How likely are you to **doze off** or **fall asleep** in the following situations. in contrast to just **feeling tired?** This refers to your usual way of life in recent times. Even if you have not done some of **these things** recently, try to work out how they would have affected you

Please circle **the most appropriate number** for each situation

SITUATION	CHANCE OF DOZING
Sitting and reading	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
Watching TV	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
Sitting, inactive, in a public place (e.g. a theatre or a meeting)	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
As a passenger in a car for 1 hour without a break	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
Lying down to rest in the afternoon when circumstances permit	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
Sitting and talking to someone	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
Sitting quietly after lunch without alcohol	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing
In a car, while stopped for a few minutes in the traffic	0 = Would **never** dose off 1 = **Slight** chance of dozing 2 = **Moderate** chance of dozing 3 = **High** chance of dozing

TIREDNESS QUESTIONNAIRE (FIS)

Some people in your condition (but not necessarily all) get quite tired or fatigued. How much of a problem fatigue/tiredness has caused you during the past month, including today, in reference to the statements listed below?
PLEASE CIRCLE THE APPROPRIATE RESPONSE FOR EACH STATEMENT:

No problem 1	**Small problem** 2	**Moderate problem** 3	**Big problem** 4	**Extreme problem** 5

During the past month, including today, because of my fatigue / tiredness:

I felt less alert.	1	2	3	4	5
I have difficulty paying attention for a long period	1	2	3	4	5
I feel that I cannot think clearly.	1	2	3	4	5
I find that I am more forgetful.	1	2	3	4	5
I find it difficult to make decisions.	1	2	3	4	5
I am less motivated to do anything that requires thinking.	1	2	3	4	5
I am less able to finish tasks that require thinking.	1	2	3	4	5
I find it difficult to organise my thoughts when I am doing things at home or at work.	1	2	3	4	5
I feel slowed down in my thinking.	1	2	3	4	5
I find it hard to concentrate.	1	2	3	4	5

During the past month, including today, because of my fatigue / tiredness:

I am more clumsy and uncoordinated.	1	2	3	4	5
I have to be careful about pacing my physical activities.	1	2	3	4	5
I am less motivated to do anything that requires physical effort.	1	2	3	4	5
I have trouble maintaining physical effort for long periods.	1	2	3	4	5
My muscles feel much weaker than they should.	1	2	3	4	5
My physical discomfort is increased.	1	2	3	4	5
I am less able to complete tasks that require physical effort.	1	2	3	4	5
I worry about how I look to other people.	1	2	3	4	5
I have to limit my physical activities.	1	2	3	4	5
I require more frequent or longer periods of Rest.	1	2	3	4	5

During the past month, including today, because of my fatigue / tiredness :

I feel that I am more isolated from social contact.	1	2	3	4	5
I have to reduce my workload or responsibilities.	1	2	3	4	5
I am more moody.	1	2	3	4	5
I work less effectively (this applies to work inside or outside the home)	1	2	3	4	5
I have to rely more on others to help me or do things for me.	1	2	3	4	5
I am more irritable and more easily angered.	1	2	3	4	5
I am less motivated to engage in social activities.	1	2	3	4	5
I have few social contacts outside of my own home.	1	2	3	4	5
Normal day-to day events are stressful for me.	1	2	3	4	5
I avoid situations that are stressful for me.	1	2	3	4	5
I have difficulty in dealing with anything new.	1	2	3	4	5
I feel unable to meet the demands that people place on me.	1	2	3	4	5
I am less able to provide financial support for myself and my family.	1	2	3	4	5
I engage in less sexual activity.	1	2	3	4	5
I am less able to deal with emotional issues.	1	2	3	4	5
I have difficulty participating fully in family activities.	1	2	3	4	5
I am not able to provide as much emotional support to my family as I should.	1	2	3	4	5
I have difficulty planning activities ahead of time.	1	2	3	4	5
My ability to travel outside my home is limited.	1	2	3	4	5

Mood scale

Circle the best answer for how *you have felt over the last week.*

1. Are you basically satisfied with your life? YES NO
2. Have you dropped many of your activities and interests? YES NO
3. Do you feel that your life is empty? YES NO
4. Do you often get bored? YES NO
5. Are you in good spirits most of the time? YES NO
6. Are you afraid that something bad is going to happen to you? YES NO
7. Do you feel happy most of the time? YES NO
8. Do you often feel helpless? YES NO
9. Do you prefer to stay at home, rather than going out and doing new things? YES NO
10. Do you feel that you have more problems with memory than most? YES NO
11. Do you think it is wonderful to be alive? YES NO
12. Do you feel pretty worthless the way you are now? YES NO
13. Do you feel full of energy? YES NO
14. Do you feel that your situation is hopeless? YES NO
15. Do you think that most people are better off than you are? YES NO

Self-evaluation questionnaire (STAI)

A number of statements which people use to describe themselves are given below. Read each statement carefully, and then circle the appropriate number, to indicate how you have been feeling recently. There are no right or wrong answers.

	Not at all	Some what	Moderately so	Very much so
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I am regretful	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel rested	1	2	3	4
9. I feel anxious	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self-confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I am jittery	1	2	3	4
14. I feel "high strung"	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel over-excited and "rattled"	1	2	3	4
19. I feel joyful	1	2	3	4
20. I feel pleasant	1	2	3	4

Personality questionnaire

This questionnaire contains 36 statements. Read each statement carefully.
For each statement circle the response that best represents your opinion, according to whether you strongly agree (SA), agree (A, neither agree nor disagree (N), disagree (D) or strongly disagree (SD).

SA	**A**	**N**	**D**	**SD**
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

---

1. I am not a worrier. SA A N D SD
2. I like to have a lot of people around me. SA A N D SD
3. I keep my belongings clean and neat. SA A N D SD
4. I often feel inferior to others. SA A N D SD

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5. I laugh easily. SA A N D SD
6. I'm pretty good about pacing myself so as to get things done on time. SA A N D SD
7. When I'm under a great deal of stress, sometimes I feel I'm going to pieces. SA A N D SD
8. I don't consider myself especially "light-hearted". SA A N D SD

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9. I am not a very methodical person. SA A N D SD
10. I rarely feel lonely or blue. SA A N D SD
11. I really enjoy talking to people. SA A N D SD
12. I try to perform all the tasks assigned to me conscientiously. SA A N D SD

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13. I often feel tense and jittery. SA A N D SD
14. I like to be where the action is. SA A N D SD
15. I have a clear set of goals and work towards them in an orderly fashion. SA A N D SD
16. Sometimes I feel completely worthless. SA A N D SD

SA	**A**	**N**	**D**	**SD**
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

17. I usually prefer to do things alone.	SA	A	N	D	SD
18. I waste a lot of time settling down to work.	SA	A	N	D	SD
19. I rarely feel fearful or anxious.	SA	A	N	D	SD
20. I often feel as I'm bursting with energy.	SA	A	N	D	SD
21. I work hard to accomplish my goals.	SA	A	N	D	SD
22. I often feel angry at the way people treat me.	SA	A	N	D	SD
23. I am a cheerful, high-spirited person.	SA	A	N	D	SD
24. When I make a commitment. I can always be counted on to follow through.	SA	A	N	D	SD
25. Too often, when things go wrong, I get discouraged and feel like giving up.	SA	A	N	D	SD
26. I am not a cheerful optimist.	SA	A	N	D	SD
27. Sometimes I'm not as dependable or reliable as I should be.	SA	A	N	D	SD
28. I am seldom sad or depressed.	SA	A	N	D	SD
29. My life is fast-paced.	SA	A	N	D	SD
30. I am a productive person who always gets the job done.	SA	A	N	D	SD
31. I often feel helpless and want someone else to solve my problems.	SA	A	N	D	SD
32. I am a very active person.	SA	A	N	D	SD
33. I never seem to be able to get organised.	SA	A	N	D	SD
34. At times I have been so ashamed I just wanted to hide.	SA	A	N	D	SD
35. I would rather go my own way than be a leader of others.	SA	A	N	D	SD
36. I strive for excellence in everything I do.	SA	A	N	D	SD

QUALITY OF LIFE QUESTIONNAIRE (MLHFQ)

DIRECTIONS: These questions concern how your heart condition has prevented you from living as you wanted DURING THE LAST MONTH. The items listed below describe different ways some people are affected. If you are sure an item does not apply to you or is not related to your heart condition then circle 0 (No) and go on to the next item. If an item does apply to you, then circle the number rating how much it prevented you from living as you wanted. Remember to think about ONLY THE LAST MONTH.

To what extent has your heart condition prevented you from living the way you wanted during the last month :	No	Very Little				Very Much
1. Causing swelling in your ankles, legs, etc.?	0	1	2	3	4	5
2. Making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. Making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. Making your working around the house or garden difficult?	0	1	2	3	4	5
5. Making your going places away from home difficult?	0	1	2	3	4	5
6. Making your sleeping well at night difficult?	0	1	2	3	4	5
7. Making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. Making you working to earn a living difficult?	0	1	2	3	4	5
9. Making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. Making your sexual activities difficult?	0	1	2	3	4	5
11. Making you eat less of the foods you like?	0	1	2	3	4	5
12. Making you short of breath?	0	1	2	3	4	5
13. Making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. Making you stay in a hospital?	0	1	2	3	4	5
15. Costing you money for medical care?	0	1	2	3	4	5
16. Giving you side effects from medications?	0	1	2	3	4	5
17. Making you feel you are a burden for your family and friends?	0	1	2	3	4	5
18. Making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. Making you worry?	0	1	2	3	4	5
20. Making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. Making you feel depressed?	0	1	2	3	4	5

Social Support Scale

Here is a list of some things that other people do for us or give us that may be helpful or supportive. In the last year, how often were the following kinds of support available to you when you need it?
Please circle the appropriate response. Use the following 1 - 4 scale:

1 = Never **2 = Once in a while** **3 = Fairly often** **4 = Very often**

In the last year, how often someone...				
1. Told you what they did in a stressful situation that was similar to the one you were experiencing	1	2	3	4
2. Suggested some action that you should take in dealing with a problem you were having	1	2	3	4
3. Gave you information that made a difficult situation clearer and easier to understand	1	2	3	4
4. Helped you understand why you didn't do something well	1	2	3	4
5. Told you who you should see for assistance with a problem that you were having	1	2	3	4
6. Commented on how you were dealing with a problem without saying it was good or bad	1	2	3	4
7. Checked back with you to see if you followed advice you were given on how to deal with a problem	1	2	3	4

The seven questions you answered until now concerned the amount of information that people might have given you to help you deal with problems you might have had. During the last year, do you feel that this type of help was provided often enough, or do you wish it was given to you more often or less often? Please circle the most relevant answer.

More often **Satisfied** **Less often**

In the last year, how often someone...				
8. Provide you with a place where you could get away for a while	1	2	3	4
9. Watched after your possessions while you were away	1	2	3	4
10. Gave or loaned you a small amount of money	1	2	3	4
11. Provided you with some transportation	1	2	3	4
12. Loaned or gave you something that you needed	1	2	3	4
13. Provided you with a place to stay overnight	1	2	3	4
14. Helped you do something that needed to get done, like housework chores or garden work	1	2	3	4
15. Looked after a family or household member while you were away	1	2	3	4
16. Helped you with shopping	1	2	3	4

The last nine questions you answered concerned things that people might have done for you or things they might have given you. Thinking back over the past year, would you say you feel satisfied with this type of help or do you wish it was provided more often or less often?

More often **Satisfied** **Less often**

In the last year, how often someone...				
17. Was there with you (physically) in a stressful situation	1	2	3	4
18. Told you you were OK just the way you are	1	2	3	4
19.Comforted you by showing you physical affection	1	2	3	4
20. Listen to you talk about your private feelings	1	2	3	4
21.Told you they felt very close to you	1	2	3	4
22. Joked to try to cheer you up	1	2	3	4
23. Expressed interest and concerned in your well-being	1	2	3	4
24. Went with you to see someone who helped you with a problem that you were having	1	2	3	4
25. Told you that they will keep the things you talked about privately just between the two of you	1	2	3	4
26. Did some activity together with you to help you get your mind off things	1	2	3	4
27. Told you how they felt in a situation that was similar to yours	1	2	3	4

The last eleven questions you answered concerned the amount of emotional support that you might have received from others in the past year. Are you satisfied with the amount of emotional support that you have received from others, or do you wish that others gave you this type of help more often or less often?

More often **Satisfied** **Less often**

In the last year, how often someone...				
28. Depended on you for your guidance and advice	1	2	3	4
29. Depended on you for financial help	1	2	3	4
30. Talked over their problems and private feelings with you	1	2	3	4
31. Depended on you for transportation	1	2	3	4
32. Depended on you for something they needed (a physical object other than money)	1	2	3	4
Helped someone with their household chores				
34. Helped someone with their shopping?	1	2	3	4
35. Been right there with someone (physically) when they were experiencing a stressful situation ?	1	2	3	4
36.Comforted someone by showing them physical affection	1	2	3	4
37. Expressed interest and concern in someone's well- being	1	2	3	4
38. Told someone what you did in a stressful situation that was similar to one they were going through	1	2	3	4
39 - Suggested some action someone should take to deal with a problem they were having	1	2	3	4
40 - Told someone where they could go for assistance with a problem they were having	1	2	3	4

The last thirteen questions you answered concerned things that you may or may not have done for others. Thinking back over the pat year, are you satisfied with the amount of help that you have been able to give to others or do you wish that you had helped others more often or less often? Please circle an answer.

More often **Satisfied** **Less often**

Uncertainty in Illness Scale (MUIS)

This questionnaire contains 23 statements. Please read each statement. Take your time and think about what each statement says. Then circle the answer that most closely measures how you are feeling TODAY. Please respond to each statement, using the following answers:

Strongly agree (SA)	**Agree (A)**	**Neutral (N)**	**Disagree (D)**	**Strongly Disagree (SD)**
5	4	3	2	1

1. I don't know what is wrong with me.	SA	A	N	D	SD
2. I Have a lot of questions without answers.	SA	A	N	D	SD
3. I am unsure if my illness is getting better or worse.	SA	A	N	D	SD
4. It is unclear how bad my pain will be.	SA	A	N	D	SD
5. The explanations they give seem hazy to me.	SA	A	N	D	SD
6. The purpose of each treatment is clear to me.	SA	A	N	D	SD
7. My symptoms continue to change unpredictably.	SA	A	N	D	SD
8. I understood everything explained to me.	SA	A	N	D	SD
9. The doctors say things to me that could have many meetings.	SA	A	N	D	SD
10. My treatment is too complex to figure out.	SA	A	N	D	SD
11.It is difficult to know if the treatments or medications I am getting are helping me.	SA	A	N	D	SD
12.Because of the unpredictability of my illness, I cannot plan for the future.	SA	A	N	D	SD
13.The course of my illness keeps changing; I have my good and bad days.	SA	A	N	D	SD
14. I have given many different opinions about what is wrong with me.	SA	A	N	D	SD
15. It is not clear what is going to happen to me.	SA	A	N	D	SD
16. The results of my tests are inconsistent.	SA	A	N	D	SD
17. The effectiveness of the treatment is undetermined.	SA	A	N	D	SD
18. Because of the treatment, what I can do and cannot do keeps changing.	SA	A	N	D	SD
19. I'm certain they will not find anything else wrong with me.	SA	A	N	D	SD
20. The treatment I am receiving has a known probability of success.	SA	A	N	D	SD
21. They have not given me a specific diagnosis.	SA	A	N	D	SD
22. The seriousness of my illness has been determined.	SA	A	N	D	SD
23. The doctors and the nurses use everyday language so I can understand what they are saying.	SA	A	N	D	SD

COPE

NFER-NELSON
Health & Social Care

Name: ……………………………………………………………………………………

Date: ……………………………………… Record Number: ……………………………………

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU – not what you think 'most people' would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1. I try to grow as a person as a result of the experience. ☐
2. I turn to work or other substitute activities to take my mind off things. ☐
3. I get upset and let my emotions out. ☐
4. I try to get advice from someone about what to do. ☐
5. I concentrate my efforts on doing something about it. ☐
6. I say to myself "this isn't real". ☐
7. I put my trust in God. ☐
8. I laugh about the situation. ☐
9. I admit to myself that I can't deal with it, and give up trying. ☐
10. I restrain myself from doing anything too quickly. ☐

11. I discuss my feelings with someone. ☐
12. I use alcohol or drugs to make myself feel better. ☐
13. I get used to the idea that it happened. ☐
14. I talk to someone to find out more about the situation. ☐
15. I keep myself from getting distracted by other thoughts or activities. ☐
16. I daydream about things other than this. ☐
17. I get upset, and am really aware of it. ☐
18. I seek God's help. ☐
19. I make a plan of action. ☐
20. I make jokes about it. ☐

21. I accept that this has happened and that it can't be changed. ☐
22. I hold off doing anything about it until the situation permits. ☐
23. I try to get emotional support from friends and relatives. ☐
24. I just give up trying to reach my goal. ☐
25. I take additional action to try to get rid of the problem. ☐
26. I try to lose myself for a while by drinking alcohol or taking drugs. ☐
27. I refuse to believe that it has happened. ☐
28. I let my feelings out. ☐
29. I try to see it in a different light, to make it seem more positive. ☐
30. I talk to someone who could do something concrete about the problem. ☐

31. I sleep more than usual. ☐
32. I try to come up with a strategy about what to do. ☐
33. I focus on dealing with this problem and, if necessary, let other things slide a little. ☐
34. I get sympathy and understanding from someone. ☐
35. I drink alcohol or take drugs, in order to think about it less. ☐
36. I kid around about it. ☐
37. I give up the attempt to get what I want. ☐
38. I look for something good in what is happening. ☐
39. I think about how I might best handle the problem. ☐
40. I pretend that it hasn't really happened. ☐

41. I make sure not to make matters worse by acting too soon. ☐
42. I try hard to prevent other things from interfering with my efforts at dealing with this. ☐
43. I go to the cinema or watch television, to think about it less. ☐
44. I accept the reality of the fact that it happened. ☐
45. I ask people who have had similar experiences what they did. ☐
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot. ☐
47. I take direct action to get around the problem. ☐
48. I try to find comfort in my religion. ☐
49. I force myself to wait for the right time to do something. ☐
50. I make fun of the situation. ☐

51. I reduce the amount of effort I'm putting into solving the problem. ☐
52. I talk to someone about how I feel. ☐
53. I use alcohol or drugs to help me get through it. ☐
54. I learn to live with it. ☐
55. I put aside other activities in order to concentrate on this. ☐
56. I think hard about what steps to take. ☐
57. I act as though it hasn't even happened. ☐
58. I do what has to be done, one step at a time. ☐
59. I learn something from the experience. ☐
60. I pray more than usual. ☐

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MMSE

TOTAL SCORE:

____/30

DATE: ___/___/___/

Participant Number: ________________

- Please could you me tell what ……. it is ?

Year ____________

Month ____________

Day of the week ____________

Date ____________

Time ____________0-5

- Please could you tell me ……. ?

Country ____________

County/City ____________

Town /District ____________

Road/Hospital ____________

House number /Ward ____________0-5

- I am going to name three objects ***apple, table*** and ***penny***
  Please can you repeat them for me now

____

____

____________0-3

Now try to learn these names, and I will ask you again what they were later.

- Can you spell 'train' backwards for me ? N I A R T

__ __ __ __ __0-5

- Can you tell me the names of the three objects you learned earlier?

____

____

____________0-3

MMSE

- Can you name these two objects for me? (**Pen, Watch**)

____

______________0-2

- Can you repeat this phrase for me: **'No ifs, ands, or buts'**?

______________0 -1

- Next can you place your index finger of your right hand on your nose,
  and then on your left ear.

______________0-3

- Please could you follow the instructions I have written on this piece of paper
  (*'Close your eyes'*)

______________0-1

(*Enquire how writing is, if poor get them to dictate*)?

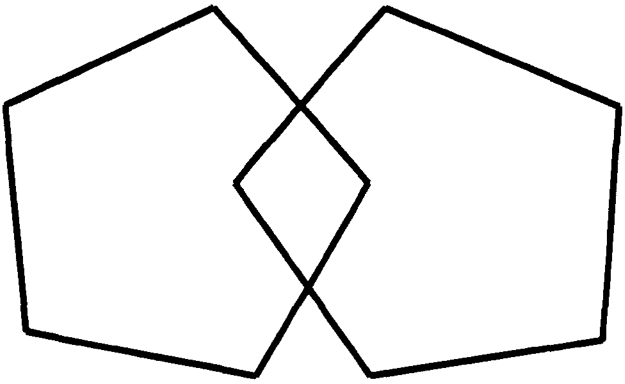
- Please can you write a sentence for me on this piece of paper ?

____

0-1

- Can you copy this picture for me? 0 –1 ☐
  (*Pentagons*)

On This page: __________**/12**



RAVLT Instructions

Trial I

I am going to read a list of words. Listen carefully, for when I stop you are to say back as many words as you can remember. It doesn't matter in what order you repeat them. Just try to remember as many as you can.

Trial II –V

Now I'm going to read the same list again, and once again when I stop I want you to tell me as many words as you can remember, including words you said the first time. It doesn't matter in what order you say them. Just say as many words as you can remember, whether or not you said them before.

Trial B

Now I'm going to read a second list of words. This time, again, you are to say back as many words of this second list as you can remember. Again, the order in which you say the words does not matter. Just try to remember as many as you can

Trial VI and VII – Recall

Now try to remember as many words as you can from the first list I read to you. Again, it does not matter what order you say them in.

RAVLT

A

NAME ____________________ DATE _________

I	II	III	IV	V	A	VI
DRUM	DRUM	DRUM	DRUM	DRUM	DESK	DRUM
CURTAIN	CURTAIN	CURTAIN	CURTAIN	CURTAIN	RANGER	CURTAIN
BELL	BELL	BELL	BELL	BELL	BIRD	BELL
COFFEE	COFFEE	COFFEE	COFFEE	COFFEE	SHOVEL	COFFEE
SCHOOL	SCHOOL	SCHOOL	SCHOOL	SCHOOL	STOVE	SCHOOL
PARENT	PARENT	PARENT	PARENT	PARENT	MOUNTAIN	PARENT
MOON	MOON	MOON	MOON	MOON	GLASSES	MOON
GARDEN	GARDEN	GARDEN	GARDEN	GARDEN	TOVEL	GARDEN
HAT	HAT	HAT	HAT	HAT	CLOUD	HAT
FARMER	FARMER	FARMER	FARMER	FARMER	BOAT	FARMER
NOSE	NOSE	NOSE	NOSE	NOSE	LAMB	NOSE
TURKEY	TURKEY	TURKEY	TURKEY	TURKEY	GUN	TURKEY
COLOUR	COLOUR	COLOUR	COLOUR	COLOUR	PENCIL	COLOUR
HOUSE	HOUSE	HOUSE	HOUSE	HOUSE	CHURCH	HOUSE
RIVER	RIVER	RIVER	RIVER	RIVER	FISH	RIVER

TOTAL ☐

RAVLT A

DELAYED RECALL

DRUM
CURTAIN
BELL
COFFEE
SCHOOL
PARENT
MOON
GARDEN
HAT
FARMER
NOSE
TURKEY
COLOUR
HOUSE
RIVER

RAVLT

B

NAME ____________________ DATE __________

I	II	III	IV	V	A	VI
BOOK	BOOK	BOOK	BOOK	BOOK	DRUM	BOOK
FLOWER	FLOWER	FLOWER	FLOWER	FLOWER	CURTAIN	FLOWER
TRAIN	TRAIN	TRAIN	TRAIN	TRAIN	BELL	TRAIN
RUG	RUG	RUG	RUG	RUG	COFFEE	RUG
MEADOW	MEADOW	MEADOW	MEADOW	MEADOW	SCHOOL	MEADOW
HARP	HARP	HARP	HARP	HARP	PARENT	HARP
SALT	SALT	SALT	SALT	SALT	MOON	SALT
FINGER	FINGER	FINGER	FINGER	FINGER	GARDEN	FINGER
APPLE	APPLE	APPLE	APPLE	APPLE	HAT	APPLE
CHIMNEY	CHIMNEY	CHIMNEY	CHIMNEY	CHIMNEY	FARMER	CHIMNEY
BUTTON	BUTTON	BUTTON	BUTTON	BUTTON	NOSE	BUTTON
LOG	LOG	LOG	LOG	LOG	TURKEY	LOG
KEY	KEY	KEY	KEY	KEY	COLOUR	KEY
RATTLE	RATTLE	RATTLE	RATTLE	RATTLE	HOUSE	RATTLE
GOLD	GOLD	GOLD	GOLD	GOLD	RIVER	GOLD

TOTAL ☐

RAVLT

B

DELAYED RECALL

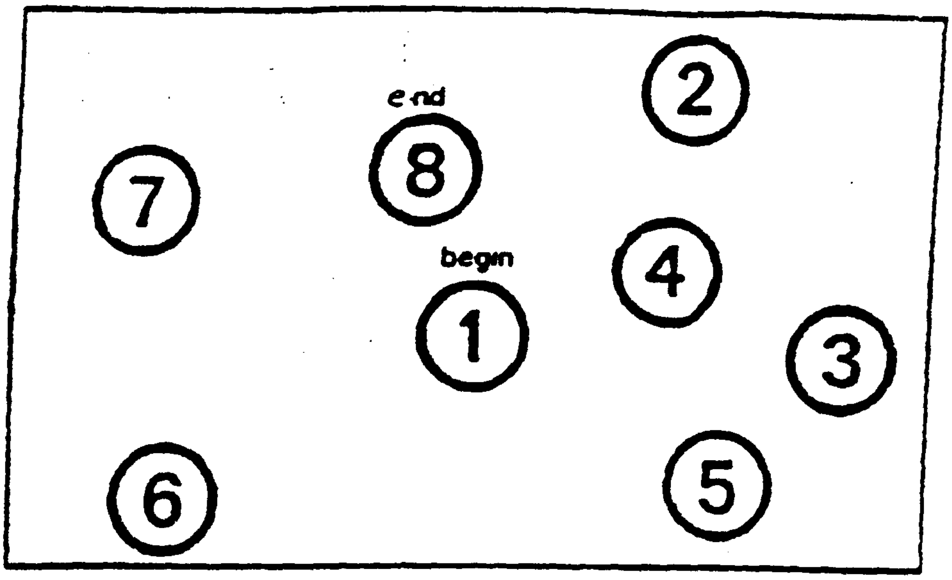
BOOK
FLOWER
TRAIN
RUG
MEADOW
HARP
SALT
FINGER
APPLE
CHIMNEY
BUTTON
LOG
KEY
RATTLE
GOLD

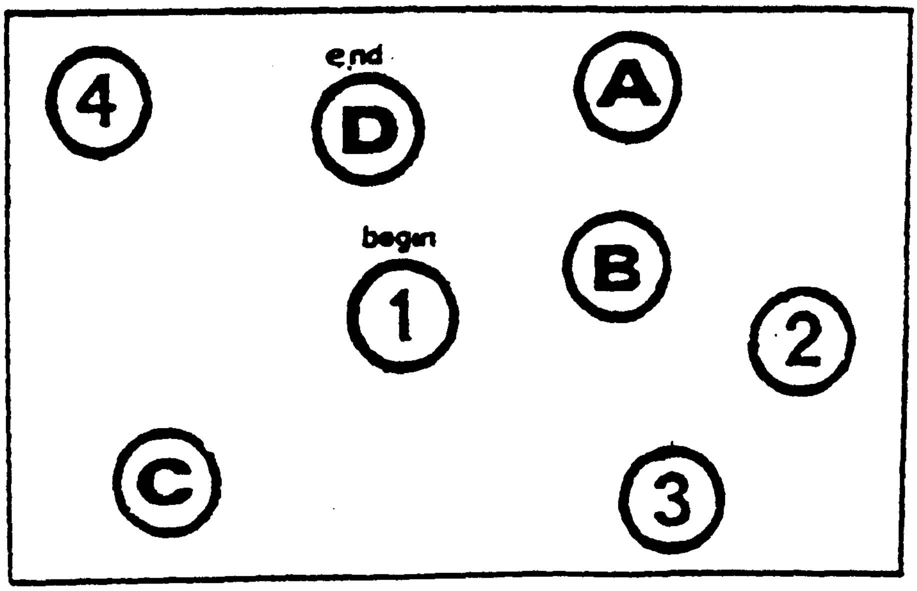
TRAIL MAKING TEST – INSTRUCTIONS

***Trail A** – this sheet of paper contains 25 numbers from 1 to 25. Could you please draw a line to connect the circles as fast as you can without lifting the pencil from the paper? You can practice on this paper.*

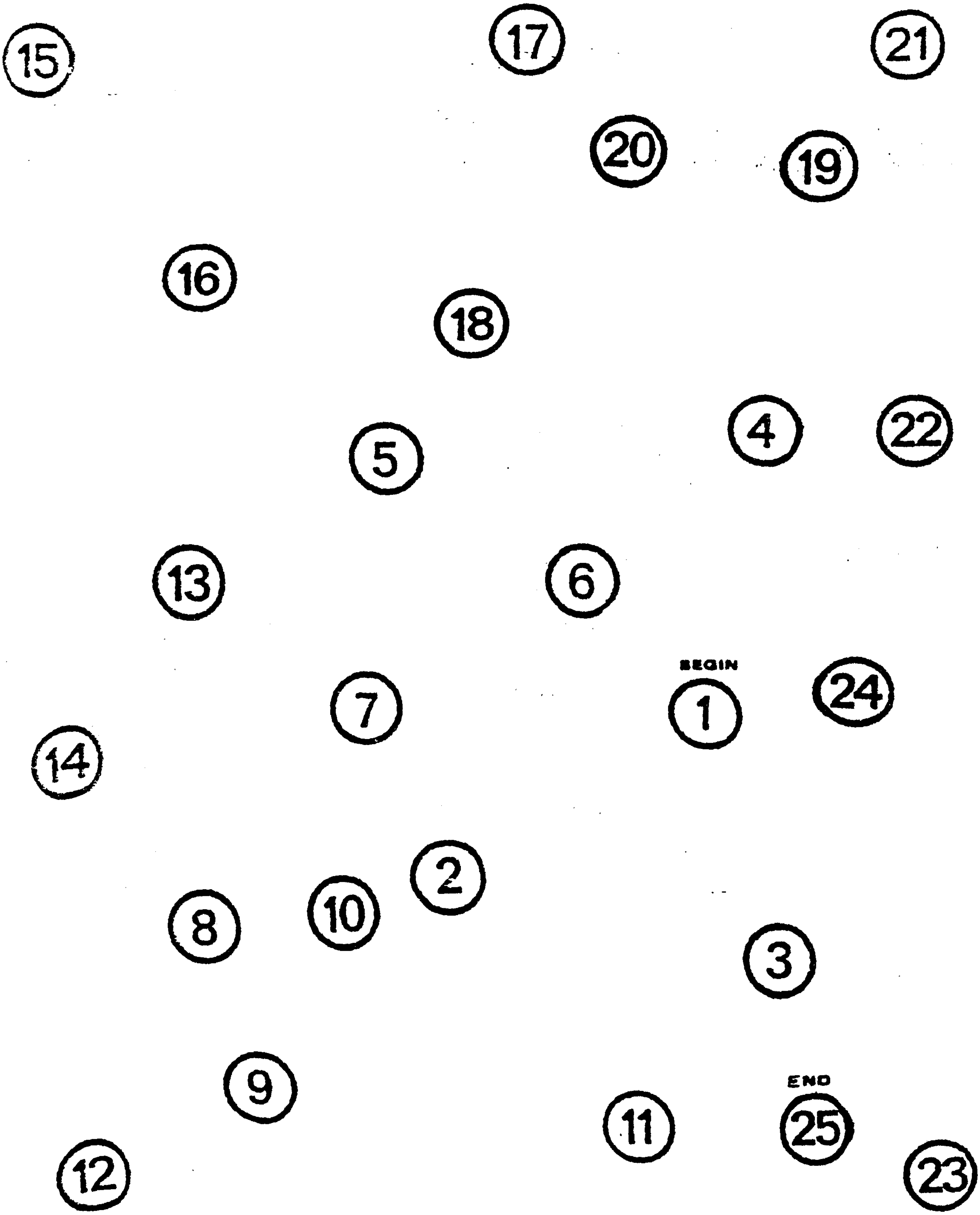
***Trail B** - this exercise is very similar to the one you just done, with the difference that we now have numbers and letters. Could you please connect numbers and letters by drawing a line as fast as you can, without lifting the pencil from the paper? You can practice on this paper.*

TRAILMAKING
PRACTICE

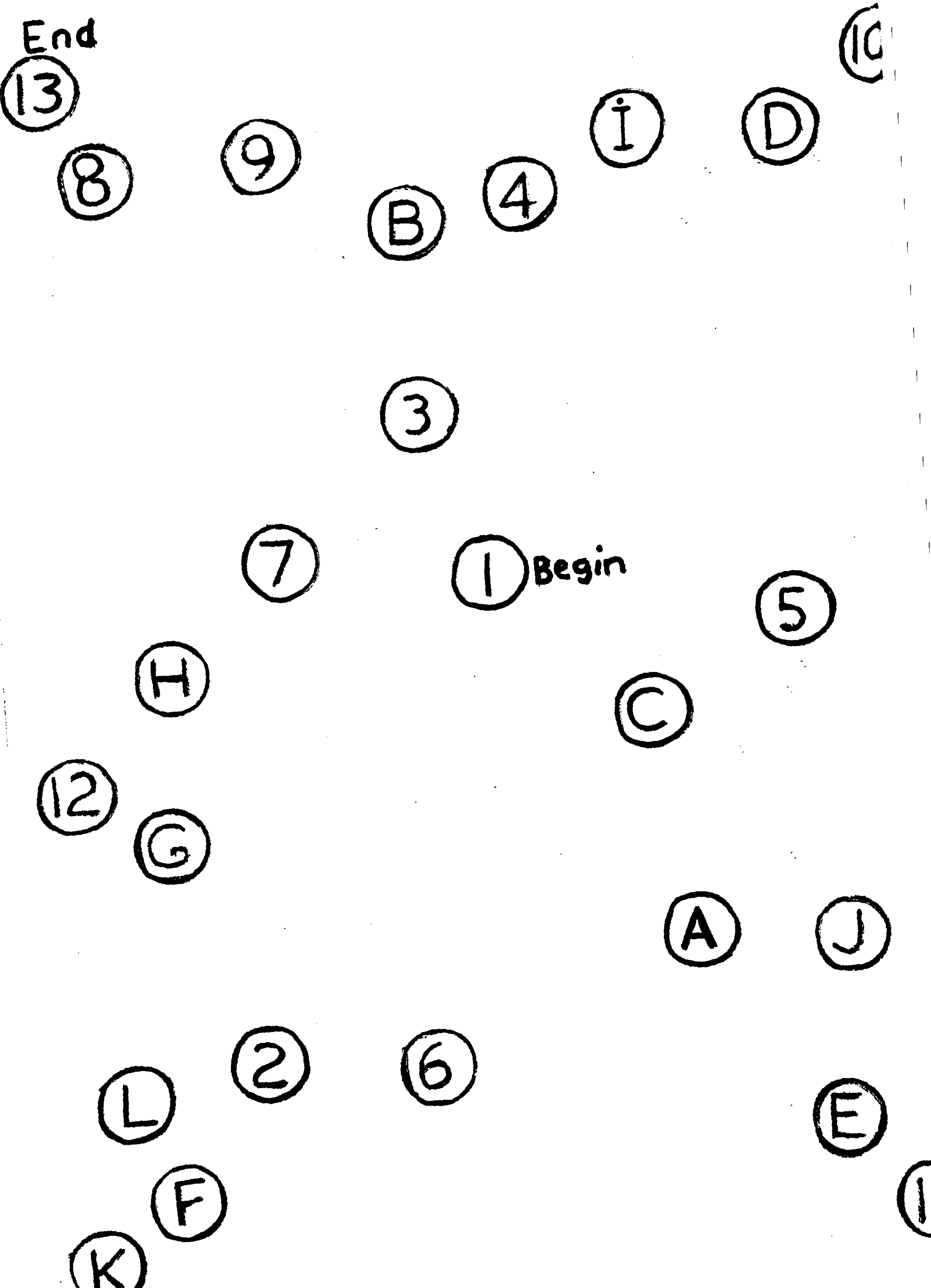




TRAILMAKING A



TRAILMAKING B



CAREGIVER SEMI-STRUCTURED INTERVIEW - PHASE 1

DATE:	**Code No:**		
NAME:	**DOB:**	**AGE:**	**M** **F**
ADDRESS:		**PHONE:**	

Relation to the patient	husband	wife	daughter	son	other
Living with patient:	YES				
	No – but under 1 hour away				
	No, more than I hour away				

EDUCATION

θ **1 or more O levels / CSE / GCSEs (any grade)** (a)

θ **1 or more A levels or AS levels** (b)

θ **Degree** (c)

θ **NVQ** (d)

θ **Other qualification (e.g. City and Guilds, RSA)** (e)

θ **No qualifications** (f)

Work History							
How long have you been caring for your relative?	1 mth	6 mths	1yr	2 yrs	2-5 years	5-10 years	More than 10 years

Do you consider yourself the caregiver of your relative? **YES** **NO**
Are you the main person to do things for your relative, or is there somebody else? (e.g. children)
In the average week, how many hours a day do you care for your relative?

HEALTH

Overall, how would you rate your health?

Very good	Good	Fair	Poor	Very poor
5	**4**	**3**	**2**	**1**

Do you suffer of any of the following illnesses? (12 months prior the interview)

Asthma or chronic bronchitis		Diabetes mellitus	
Pulmonary emphysema		Thyroid gland disorder	
Heart condition		Back problems for at least three months or slipped disk	
Hypertension		Joint conditions or arthritis	
(consequences of) stroke		Migraine or chronic headache	

Leg ulcer		Serious dermatological disorders like psoriasis and eczema	
Stomach ulcer		Cancer	
Liver disorder or gallstones		Multiple sclerosis	
Kidney disease		Parkinson Disease or epilepsy	
Prostate disease			

In comparison with other men/women of your age living on the Wirral would you say your health is:

Much above average	**Above average**	**Average**	**Below average**	**Much below average**
5	**4**	**3**	**2**	**1**

In the last year, how many times have you visited your GP?

1 2 3 4 5 more than 5

In the last year, how many days you had to stay in bed because you did not feel very well?

None one day two days three days one week two weeks more than 2w

Have you been hospitalised during the last 12 months? YES NO

If yes, how many times ______________ For how long ______________

Do you know the diagnosis/medical term for your relative's illness?

Heart failure Weak heart Something with the heart Don't know Other

Do you help your relative with taking her medication? In what way (Remind, actively involved..)

Do you think your relative complies with his/her medication? (Takes the medication as recommended by doctors/pharmacists or are there times when he/she does not comply?)

Do you think there are times when your relative does not take her medication as prescribed? If yes, why?

Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate below the approximate extend of agreement or disagreement between you and your partner for each item on the following list.

Always agree	Almost always agree	Occasionally agree	Frequently Disagree	Almost always disagree	Always disagree
5	4	3	2	1	0

________ 1.Philosophy of life____

________ 2.Aims, goals and things believed important.

_________ 3. Amount of time spent together.

Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
0	1	2	3	4	5

________ 4. Have a stimulating exchange of ideas.

________ 5. Calmly discuss something together.

________ 6. Work together on a project.

7. The dots on the following line represent different degrees of happiness I your relationship. The middle point, "happy" represents the degree og happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
●	●	●	●	●	●	●
Extremely unhappy	Fairly unhappy	A little unhappy	Happy	Very happy	Extremely happy	Perfect

Caregiving demand and discretion

What do you regularly do for your relative?

In the average week, how many hours a day do you care for your relative?

Discretion

What is the maximum time you can leave your relative without worrying?

Life -events and difficulties

If you have a problem of some sort who would be the first person with whom you would want to discuss it? (CONFIDANT)

Confidant Present Absent No need

Is the patient the confidant? YES NO NA

CAREGIVER SEMI-STRUCTURED INTERVIEW – PHASE 2

DATE:	**Code No:**		
NAME:	**DOB:**	**AGE:**	**M** **F**
ADDRESS:		**PHONE:**	

HEALTH:

Overall, how would you rate your health at the moment?

Very good	**good**	**fair**	**poor**	**very poor**
5	**4**	**3**	**2**	**1**

Since I last saw you (approximately 6 months ago) have you been diagnosed with any new condition?

YES **NO**

If yes:

In comparison with other men/women of your age living on the Wirral would you say your health is:

Much above average	**Above average**	**Average**	**Below average**	**Much below average**
5	**4**	**3**	**2**	**1**

Since I last saw you, how many times have you visited your GP?

1 2 3 4 5 more than 5

Since I last saw you, how many days you had to stay in bed because you did not feel very well?

None one day two days three days one week two weeks more than 2w

Have you been hospitalised since I last saw you? YES NO

If yes, how many times ____________ For how long ____________

Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate below the approximate extend of agreement or disagreement between you and your partner for each item on the following list

Always agree	Almost always agree	Occasionally agree	Frequently Disagree	Almost always disagree	Always disagree
5	4	3	2	1	0

1.Philosophy of life.	
2.Aims, goals and things believed important.	
3. Amount of time spent together.	

Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
0	1	2	3	4	5

	NOW
4. Have a stimulating exchange of ideas.	
5. Calmly discuss something together.	
6. Work together on a project.	

7. The dots on the following line represent different degrees of happiness I your relationship. The middle point, "happy" represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
●	●	●	●	●	●	●
Extremely unhappy	Fairly unhappy	A little unhappy	Happy	Very happy	Extremely happy	Perfect

Total ______________

CAREGIVING DEMAND

In the average week, how many hours a day do you care for your relative? ________________ **(hours)**

Comments:

What do you regularly do for your relative?

Comments:

Do you think you do more/ spend more time caring for your relative since I last saw you? Why?

LESS TIME **THE SAME** **MORE**

DISCRETION

What is the maximum time you can leave your relative without worrying? ______________ **(hours)**

By comparison to when I spoke to you lat time, do you think you have .... discretion?

LESS TIME **THE SAME** **MORE**

MASTERY QUESTIONNAIRE

Below are statements about life that people often feel differently about. Place circle a number from 1 to 5 to indicate how much you agree/ disagree to each statement.

	COMPLETELY AGREE 1	MOSTLY AGREE 2	NEITHER AGREE NOR DISAGREE 3	MOSTLY DISAGREE 4	COMPLETELY DISAGREE 5
1. I have little control over the things that happen to me.	1	2	3	4	5
2. There is really no way I can solve some of the problems I have	1	2	3	4	5
3. There is little I can do to change many of the important things in my life.	1	2	3	4	5
4. I often feel helpless in dealing with the problems of life.	1	2	3	4	5
5. Sometimes I feel that I'm being pushed around in life.	1	2	3	4	5
6. What happens to me in the future mostly depends on me.	1	2	3	4	5
7. I can do just about anything I really set my mind to.	1	2	3	4	5

ROSENBERG SE SCALE

Here is a list of statements dealing with your general feelings about yourself. If you **agree** with the statement, circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D and if you **strongly disagree**, circle SD. Thank you.

	STRONGLY AGREE SA	AGREE A	DISAGREE D	STRONGLY DISAGREE SD
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. AT times I think I am not good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel I am a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

IP-32 Question/ Scoring Sheet

Date: ______ / ______ / ______
Month Day Year

Sex: Male ☐ Female ☐

ople have reported having the following **problems** in relating to other people. Please read the list below, and for each m, consider whether it has been a **problem for you** with respect to **any** significant person in your life. Then fill in the mbered circle that describes how **distressing that problem** has been.

Following are things you find hard to do with other people.

hard for me to:

	Not at all	A little bit	Moderately	Quite a bit	Extremely	
Say "no" to other people	⓪	①	②	③	④	1.
Join in on groups	⓪	①	②	③	④	2.
Keep things private from other people	⓪	①	②	③	④	3.
Tell a person to stop bothering me	⓪	①	②	③	④	4.
Introduce myself to new people	⓪	①	②	③	④	5.
Confront people with problems that come up	⓪	①	②	③	④	6.
Be assertive with another person	⓪	①	②	③	④	7.
Let other people know when I am angry	⓪	①	②	③	④	8.
Socialize with other people	⓪	①	②	③	④	9.
Show affection to people	⓪	①	②	③	④	10.
Get along with people	⓪	①	②	③	④	11.
Be firm when I need to be	⓪	①	②	③	④	12.
Experience a feeling of love for another person	⓪	①	②	③	④	13.
Be supportive of another person's goals in life	⓪	①	②	③	④	14.
Feel close to other people	⓪	①	②	③	④	15.
Really care about other people's problems	⓪	①	②	③	④	16.
Put somebody else's needs before my own	⓪	①	②	③	④	17.
Feel good about another person's happiness	⓪	①	②	③	④	18.
Ask other people to get together socially with me	⓪	①	②	③	④	19.
Be assertive without worrying about hurting the other person's feelings	⓪	①	②	③	④	20.

Following are things that you do too much.

open up to people too much.	⓪	①	②	③	④	21.
am too aggressive toward other people.	⓪	①	②	③	④	22.
try to please other people too much.	⓪	①	②	③	④	23.
want to be noticed too much.	⓪	①	②	③	④	24.
try to control other people too much.	⓪	①	②	③	④	25.
put other people's needs before my own too much.	⓪	①	②	③	④	26.
am overly generous to other people.	⓪	①	②	③	④	27.
manipulate other people too much to get what I want.	⓪	①	②	③	④	28.
tell personal things to other people too much.	⓪	①	②	③	④	29.
argue with other people too much.	⓪	①	②	③	④	30.
let other people take advantage of me too much.	⓪	①	②	③	④	31.
am affected by another person's misery too much.	⓪	①	②	③	④	32.

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rt Assessment Company

1 2 3 4 5 6 7 8 9 10 11 12 A B C D E

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Personality questionnaire

This questionnaire contains 36 statements. Read each statement carefully.
For each statement circle the response that best represents your opinion, according to whether you strongly agree (SA), agree (A), neither agree nor disagree (N), disagree (D) or strongly disagree (SD).

SA	A	N	D	SD
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

1.	I am not a worrier.	SA	A	N	D	SD
2.	I like to have a lot of people around me.	SA	A	N	D	SD
3.	I keep my belongings clean and neat.	SA	A	N	D	SD
4.	I often feel inferior to others.	SA	A	N	D	SD

5.	I laugh easily.	SA	A	N	D	SD
6.	I'm pretty good about pacing myself so as to get things done on time.	SA	A	N	D	SD
7	When I'm under a great deal of stress, sometimes I feel I'm going to pieces.	SA	A	N	D	SD
8.	I don't consider myself especially "light-hearted".	SA	A	N	D	SD

9.	I am not a very methodical person.	SA	A	N	D	SD
10.	I rarely feel lonely or blue.	SA	A	N	D	SD
11.	I really enjoy talking to people.	SA	A	N	D	SD
12.	I try to perform all the tasks assigned to me conscientiously.	SA	A	N	D	SD

13.	I often feel tense and jittery.	SA	A	N	D	SD
14.	I like to be where the action is.	SA	A	N	D	SD
15.	I have a clear set of goals and work towards them in an orderly fashion.	SA	A	N	D	SD
16.	Sometimes I feel completely worthless.	SA	A	N	D	SD

SA	**A**	**N**	**D**	**SD**
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

17. I usually prefer to do things alone. SA A N D SD
18. I waste a lot of time settling down to work. SA A N D SD
19. I rarely feel fearful or anxious. SA A N D SD
20. I often feel as I'm bursting with energy. SA A N D SD

21. I work hard to accomplish my goals. SA A N D SD
22. I often feel angry at the way people treat me. SA A N D SD
23. I am a cheerful, high-spirited person. SA A N D SD
24. When I make a commitment, I can always be counted on to follow through. SA A N D SD

25. Too often, when things go wrong, I get discouraged and feel like giving up. SA A N D SD
26. I am not a cheerful optimist. SA A N D SD
27. Sometimes I'm not as dependable or reliable as I should be. SA A N D SD
28. I am seldom sad or depressed. SA A N D SD

29. My life is fast-paced. SA A N D SD
30. I am a productive person who always gets the job done. SA A N D SD
31. I often feel helpless and want someone else to solve my problems. SA A N D SD
32. I am a very active person. SA A N D SD

33. I never seem to be able to get organised. SA A N D SD
34. At times I have been so ashamed I just wanted to hide. SA A N D SD
35. I would rather go my own way than be a leader of others. SA A N D SD
36. I strive for excellence in everything I do. SA A N D SD

CES-D Scale

Below is a list of the ways you might have felt or behaved. Please choose the best answer for how you felt over ***the past week***.

During the past week:	Response	
1. I felt depressed	YES	NO
2. I felt that everything a did was an effort	YES	NO
3. My sleep was restless	YES	NO
4. I was happy	YES	NO
5. I felt lonely	YES	NO
6. People were unfriendly	YES	NO
7. I enjoyed life	YES	NO
8. I felt sad	YES	NO
9. I felt that people disliked me	YES	NO
10. I could not get going	YES	NO

Self-evaluation questionnaire (STAI)

A number of statements which people use to describe themselves are given below. Read each statement carefully, and then circle the appropriate number, to indicate how you have been feeling recently. There are no right or wrong answers.

		Not at all	**Some what**	**Moderately so**	**Very much so**
1.	I feel calm	1	2	3	4
2.	I feel secure	1	2	3	4
3.	I am tense	1	2	3	4
4.	I am regretful	1	2	3	4
5.	I feel at ease	1	2	3	4
6.	I feel upset	1	2	3	4
7.	I am presently worrying over possible misfortunes	1	2	3	4
8.	I feel rested	1	2	3	4
9.	I feel anxious	1	2	3	4
10.	I feel comfortable	1	2	3	4
11.	I feel self-confident	1	2	3	4
12.	I feel nervous	1	2	3	4
13.	I am jittery	1	2	3	4
14.	I feel "high strung"	1	2	3	4
15.	I am relaxed	1	2	3	4
16.	I feel content	1	2	3	4
17.	I am worried	1	2	3	4
18.	I feel over-excited and "rattled"	1	2	3	4
19.	I feel joyful	1	2	3	4
20.	I feel pleasant	1	2	3	4

Social Support Scale

Here is a list of some things that other people do for us or give us that may be helpful or supportive. In the last year, how often were the following kinds of support available to you when you need it?
Please circle the appropriate response. Use the following 1 - 4 scale:

1 = Never	2 = Once in a while	3 = Fairly often	4 = Very often

In the last year, how often someone...				
1. Told you what they did in a stressful situation that was similar to the one you were experiencing	1	2	3	4
2. Suggested some action that you should take in dealing with a problem you were having	1	2	3	4
3. Gave you information that made a difficult situation clearer and easier to understand	1	2	3	4
4. Helped you understand why you didn't do something well	1	2	3	4
5. Told you who you should see for assistance with a problem that you were having	1	2	3	4
6. Commented on how you were dealing with a problem without saying it was good or bad	1	2	3	4
7. Checked back with you to see if you followed advice you were given on how to deal with a problem	1	2	3	4

The seven questions you answered until now concerned the amount of information that people might have given you to help you deal with problems you might have had. During the last year, do you feel that this type of help was provided often enough, or do you wish it was given to you more often or less often? Please circle the most relevant answer.

More often **Satisfied** **Less often**

In the last year, how often someone...				
8. Provide you with a place where you could get away for a while	1	2	3	4
9. Watched after your possessions while you were away	1	2	3	4
10. Gave or loaned you a small amount of money	1	2	3	4
11. Provided you with some transportation	1	2	3	4
12. Loaned or gave you something that you needed	1	2	3	4
13. Provided you with a place to stay overnight	1	2	3	4
14. Helped you do something that needed to get done, like housework chores or garden work	1	2	3	4
15. Looked after a family or household member while you were away	1	2	3	4
16. Helped you with shopping	1	2	3	4

The last nine questions you answered concerned things that people might have done for you or things they might have given you. Thinking back over the past year, would you say you feel satisfied with this type of help or do you wish it was provided more often or less often?

More often **Satisfied** **Less often**

In the last year, how often someone...				
17. Was there with you (physically) in a stressful situation	1	2	3	4
18. Told you you were OK just the way you are	1	2	3	4
19.Comforted you by showing you physical affection	1	2	3	4
20. Listen to you talk about your private feelings	1	2	3	4
21.Told you they felt very close to you	1	2	3	4
22. Joked to try to cheer you up	1	2	3	4
23. Expressed interest and concerned in your well-being	1	2	3	4
24. Went with you to see someone who helped you with a problem that you were having	1	2	3	4
25. Told you that they will keep the things you talked about privately just between the two of you	1	2	3	4
26. Did some activity together with you to help you get your mind off things	1	2	3	4
27. Told you how they felt in a situation that was similar to yours	1	2	3	4

The last eleven questions you answered concerned the amount of emotional support that you might have received from others in the past year. Are you satisfied with the amount of emotional support that you have received from others, or do you wish that others gave you this type of help more often or less often?

More often **Satisfied** **Less often**

In the last year, how often someone...				
28. Depended on you for your guidance and advice	1	2	3	4
29. Depended on you for financial help	1	2	3	4
30. Talked over their problems and private feelings with you	1	2	3	4
31. Depended on you for transportation	1	2	3	4
32. Depended on you for something they needed (a physical object other than money)	1	2	3	4
Helped someone with their household chores				
34. Helped someone with their shopping?	1	2	3	4
35. Been right there with someone (physically) when they were experiencing a stressful situation ?	1	2	3	4
36.Comforted someone by showing them physical affection	1	2	3	4
37. Expressed interest and concern in someone's well- being	1	2	3	4
38. Told someone what you did in a stressful situation that was similar to one they were going through	1	2	3	4
39 - Suggested some action someone should take to deal with a problem they were having	1	2	3	4
40 - Told someone where they could go for assistance with a problem they were having	1	2	3	4

The last thirteen questions you answered concerned things that you may or may not have done for others. Thinking back over the pat year, are you satisfied with the amount of help that you have been able to give to others or do you wish that you had helped others more often or less often? Please circle an answer.

More often **Satisfied** **Less often**

THE SENSE OF COMPETENCE QUESTIONNAIRE

Please read the following statements and consider how accurate they are with respect to the person you give care to. Make your response by circling one of the provided answers.

Agree very much 1	Agree 2	Disagree 3	Disagree very much 4

1. It is clear to me how much care my ______ needs.	1	2	3	4
2. I am capable to care for my______.	1	2	3	4
3. I feel that I don't do as much for my ______ as I could or should.	1	2	3	4
4. I feel angry about my interactions with my ______ .	1	2	3	4
5. I feel that in the past I haven't done as much for my ______ as I could have or should have.	1	2	3	4
6. I feel guilty about my interactions with my _______ .	1	2	3	4
7. I feel nervous or depressed about my interactions with my _______.	1	2	3	4
8. My _______ benefits from everything I do for him/her.	1	2	3	4
9. I feel pleased about my interactions with _______ .	1	2	3	4
10. I feel useful in my interactions with my _______ .	1	2	3	4
11. I feel strained in my interactions with my _______ .	1	2	3	4
12. I wish that my _______ and I had a better relationship.	1	2	3	4

CAREGIVER DISTRESS SCALE

Instructions: Specific aspects of family life are affected by the demands of caregiving. With respect to your current situation as caregiver for _____ , please indicate whether **YOU personally** disagree or agree with the following statements using the five point scale below.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

______ 1. My relationship with ______ depresses me.

______ 2. My relationship with ______ is strained.

______ 3. I feel resentful towards ______ .

______ 4. My relationship with ______ no longer gives me pleasure.

______ 5. I feel frustrated.

______ 6. ______ tries to manipulate me.

______ 7. ______ makes more requests than necessary.

______ 8. ______ I feel pressured between giving to _____ and others in the family.

______ 9. I am nervous.

______ 10. I feel helpless.

______ 11. I feel overwhelmed.

______ 12. I feel that my personal life has suffered because of _____ .

______ 13. I feel _____ can only depend on me.

______ 14. I feel that my own health has suffered because of _____ .

______ 15. I take part in organised activities less.

______ 16. I visit my family/friends less.

______ 17. I take part in other social activities less.

Personality questionnaire (Your family member NOW)

Think about **the person you care for** and how they are **now**, and in recent times. For each statement circle the response that best represents your opinion, according to whether you strongly agree (SA), agree (A), neither agree nor disagree (N), disagree (D) or strongly disagree (SD).

SA	**A**	**N**	**D**	**SD**
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

1. He/she is not a worrier. SA A N D SD
2. He/she likes to have a lot of people around . SA A N D SD
3. He/she keeps his/her belongings clean and neat. SA A N D SD
4. He/she often feels inferior to others. SA A N D SD

5. He/she laughs easily. SA A N D SD
6. He/she is pretty good about pacing himself/herself so as to get things done on time. SA A N D SD
7. When he/she is under a great deal of stress, sometimes he/she feels he/she is going to pieces. SA A N D SD
8. He/she did not considers himself/herself especially "light-hearted". SA A N D SD

9. He/she is not a very methodical person. SA A N D SD
10. He/she rarely feels lonely or blue. SA A N D SD
11. He/she really enjoys talking to people. SA A N D SD
12. He/she tries to perform all the tasks assigned to him/her conscientiously. SA A N D SD

13. He/she often feels tense and jittery. SA A N D SD
14. He/she likes to be where the action is. SA A N D SD
15. He/she has a clear set of goals and works towards them in an orderly fashion. SA A N D SD
16. Sometimes he/she feels completely worthless. SA A N D SD

SA	A	N	D	SD
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

17. He/she usually prefers to do things alone. SA A N D SD
18. He/she wastes a lot of time settling down to work. SA A N D SD
19. He/she rarely feels fearful or anxious. SA A N D SD
20. He/she often feels as if he/she is bursting with energy. SA A N D SD

21. He/she works hard to accomplish his/her goals. SA A N D SD
22. He/she often feels angry at the way people treat him/her. SA A N D SD
23. He/she is a cheerful, high-spirited person. SA A N D SD
24. When he/she makes a commitment, he/she can always be counted on to follow through. SA A N D SD

25. Too often, when things went wrong, he/she gets discouraged and feels like giving up SA A N D SD
26. He/she is not a cheerful optimist. SA A N D SD
27. Sometimes he/she is not as dependable or reliable as he/she should be. SA A N D SD
28. He/she is seldom sad or depressed. SA A N D SD

29. His/her life is fast-paced. SA A N D SD
30. He/she is a productive person who always gets the job done. SA A N D SD
31. He/she often feels helpless and wants someone else to solve his/her problems. SA A N D SD
32. He/she is a very active person. SA A N D SD

33. He/she never seems to be able to get organised. SA A N D SD
34. At times he/she has been so ashamed he/she just wanted to hide. SA A N D SD
35. He/she would rather go his/her own way than be a leader of others. SA A N D SD
36. He/she strives for excellence in everything he/she does. SA A N D SD

Personality questionnaire (Your family member in "his/her prime")

Think about the person you care for and how they used to be in their thirties or in their 'prime'. For each statement circle the response that best represents your opinion, according to whether you strongly agree (SA), agree (A), neither agree nor disagree (N), disagree (D) or strongly disagree (SD).

SA	**A**	**N**	**D**	**SD**
Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**

1.	He/she was not a worrier.	SA	A	N	D	SD
2.	He/she liked to have a lot of people around.	SA	A	N	D	SD
3.	He/she kept his/her belongings clean and neat.	SA	A	N	D	SD
4.	He/she often felt inferior to others.	SA	A	N	D	SD

5.	He/she laughed easily.	SA	A	N	D	SD
6.	He/she was pretty good about pacing himself/herself so as to get things done on time.	SA	A	N	D	SD
7.	When he/she was under a great deal of stress, sometimes he/she felt he/she was going to pieces.	SA	A	N	D	SD
8.	He/she did not consider himself/herself especially "light-hearted".	SA	A	N	D	SD

9.	He/she was not a very methodical person.	SA	A	N	D	SD
10.	He/she rarely felt lonely or blue.	SA	A	N	D	SD
11.	He/she really enjoyed talking to people.	SA	A	N	D	SD
12.	He/she tried to perform all the tasks assigned to him/her conscientiously.	SA	A	N	D	SD

13.	He/she often felt tense and jittery.	SA	A	N	D	SD
14.	He/she liked to be where the action was.	SA	A	N	D	SD
15.	He/she had a clear set of goals and worked towards them in an orderly fashion.	SA	A	N	D	SD
16.	Sometimes he/she felt completely worthless.	SA	A	N	D	SD

SA	A	N	D	SD
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

17. He/she usually preferred to do things alone.	SA	A	N	D	SD
18. He/she wasted a lot of time settling down to work.	SA	A	N	D	SD
19. He/she rarely felt fearful or anxious.	SA	A	N	D	SD
20. He/she often felt as if he/she was bursting with energy.	SA	A	N	D	SD

21. He/she worked hard to accomplish his/her goals.	SA	A	N	D	SD
22. He/she often felt angry at how people treated him/her.	SA	A	N	D	SD
23. He/she was a cheerful, high-spirited person.	SA	A	N	D	SD
24. When he/she made a commitment, he/she could always be counted on to follow through.	SA	A	N	D	SD

25. Too often, when things went wrong, he/she got discouraged and felt like giving up.	SA	A	N	D	SD
26. He/she was not a cheerful optimist.	SA	A	N	D	SD
27. Sometimes he/she was not as dependable or reliable as he/she should have been.	SA	A	N	D	SD
28. He/she was seldom sad or depressed.	SA	A	N	D	SD

29. His/her life was fast-paced.	SA	A	N	D	SD
30. He/she was a productive person who always got the job done.	SA	A	N	D	SD
31. He/she often felt helpless and wanted someone else to solve his/her problems.	SA	A	N	D	SD
32. He/she was a very active person.	SA	A	N	D	SD

33. He/she never seemed to be able to get organised.	SA	A	N	D	SD
34. At times he/she was so ashamed he/she just wanted to hide.	SA	A	N	D	SD
35. He/she would rather have gone his/her own way than be a leader of others.	SA	A	N	D	SD
36. He/she strived for excellence in everything he/she did.	SA	A	N	D	SD

Appendix 8

Patient and Caregiver Code, gender, age, relationship and presence at phase 2

P code	P gender	P age	CG code	CG gender	CG age	Relationship	Interviewed at phase 2
P1	F	85					YES
P2	F	90					YES
P3	F	83					YES
P4	F	80					YES
P5	F	83					YES
P6	F	74					YES
P7	M	83					YES
P8	M	83					NO
P9	M	71					YES
P10	M	79					YES
P11	F	80					YES
P12	M	77					YES
P13	M	75	CG13	F	73	WIFE	NO
P14	M	80	CG14	F	78	WIFE	YES
P15	M	82	CG15	F	82	WIFE	YES
P16	M	67	CG16	F	55	WIFE	NO
P17	F	78	CG17	M	83	HUSBAND	YES
P18	M	78	CG18	F	73	WIFE	NO
P19	M	83	CG19	F	82	WIFE	YES
P20	F	78	CG20	M	80	HUSBAND	NO
P21	M	73	CG21	F	70	WIFE	NO
P22	F	57	CG22	M	57	HUSBAND	YES
P23	M	74	CG23	F	74	WIFE	NO
P24	F	72	CG	F	34	OTHER	YES
P25	F	77	CG	F	54	DAUGHTER	NO
P26	F	76	CG	M	74	HUSBAND	YES
P27	F	80	CG	M	82	HUSBAND	YES
P28	F	71					YES
P29	F	80					YES
P30	F	85					NO
P31	F	79					NO
P32	F	56					YES
P33	F	74					YES
P34	M	71	CG34	F	71	WIFE	YES
P35	M	84					YES
P36	F	61	CG36	M	66	HUSBAND	YES
P37	M	75					NO
P38	M	72	CG38	F	64	WIFE	YES
P39	M	79	CG39	F	74	WIFE	YES
P40	M	73					YES
P41	M	60	F	CG41	42	WIFE	YES
P42	M	75					YES
P43	F	86	CG43	F	45	DAUGHTER	NO
P44	M	75	CG44	F	61	WIFE	YES
P45	M	74	CG45	F	72	WIFE	YES
P46	M	74					YES
P47	F	69					NO

P48	F	59	CG48	M	65	HUSBAND	YES
P49	M	60	CG49	F	58	WIFE	YES
P50	F	83					NO
P51	M	73					NO
P52	F	85					YES
P53	F	81					YES
P54	M	67	CG54	F	60	WIFE	NO
P55	M	88					YES
P56	F	76	CG56	M	81	HUSBAND	YES
P57	M	91	CG57	F	86	WIFE	YES
P58	F	84	CG58	F	61	DAUGHTER	YES
P59	F	91					NO
P60	M	71	CG60	F	68	WIFE	YES
P61	F	75	CG61	F	37	DAUGHTER	YES
P62	F	68					NO
P63	F	72	CG63	F	47	DAUGHTER	YES
P64	M	69	CG64	F	69	WIFE	YES
P65	M	86	CG65	F	82	WIFE	NO
P66	M	77	CG66	F	58	WIFE	YES
P67	F	73					NO
P68	F	86					YES
P69	M	73	CG69	F	44	DAUGHTER	YES
P70	F	79	CG70	M	86	HUSBAND	YES
P71	M	70	CG71	F	68	WIFE	YES
P72	M	81					NO
P73	M	75					NO
P74	F	72					NO
P75	F	78					YES
P76	F	84	CG76	F	53	DAUGHTER	NO
P77	M	69	CG77	F	71	WIFE	YES
P78	M	76	CG78	F	74	WIFE	YES
P79	M	78					NO
P80	F	88	CG80	M	58	SON	NO
P81	M	90	CG81	F	80	WIFE	YES
P82	F	82					NO
P83	M	80	CG83	F	71	WIFE	YES
P84	F	80					YES
P85	F	86	CG85	M	56	SON	YES
P86	M	72					YES
P87	F	67					YES
P88	M	63					YES
P89	M	64	CG89	F	59	WIFE	YES
P90	M	76	CG90	F	75	WIFE	NO
P91	M	69					NO
P92	M	75	CG92	F	72	WIFE	NO
P93	F	81	CG93	F	46	DAUGHTER	YES
P94	M	76					NO
P95	M	75					NO
P96	F	81	CG96	M	79	HUSBAND	YES
P97	M	73	CG97	F	80	WIFE	YES
P98	M	74	CG98	F	72	WIFE	YES
P99	M	76	CG99	F	73	WIFE	NO
P100	M	83					NO