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Degree of Doctor of Psychology (Health)

City University

**The Experiences of Partners of
Cardiac Patients: Sense of
Coherence and Cardiac Beliefs**

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Section A- Introduction

This doctoral research is made up of three sections: the main doctoral research, a literature review and a case study of professional practice.

Section B: Empirical research

The empirical research investigated the experiences of partners of cardiac patients. The aim of the study was to determine whether cardiac partners were distressed, and to determine the reasons for any distress. The study used the sense of coherence as a framework to understand why some partners coped better than others with the stress of the patient's illness. Theoretically, it explored the relationship between partners' sense of coherence, cardiac beliefs and levels of distress. The final part of the study examined partners' experience of health care services, their help seeking experiences, and their preferences for interventions that might alleviate their distress. The rationale for the research was that better understanding of how partners cope, would provide cardiac teams with the necessary evidence based research to provide suitable interventions for partners.

Section C: Literature review

The critical literature review investigated the empirical literature relating to posttraumatic stress following adult breast cancer. The core issues discussed included the diagnostic criteria for PTSD, the strategies used for diagnosing it, the prevalence and risk factors associated with PTSD, types of intervention, and an overview of the controversy surrounding the inclusion of cancer as a traumatic stressor. Finally the concept of Posttraumatic Growth was discussed in relation to breast cancer and post traumatic stress.

Section D: case study

The case study of professional practice reported the findings of a piece of consultancy work undertaken for the South East London cardiac Rehabilitation Strategy Group from April 2003-April 2005. The aim of the evaluation was to audit the six cardiac rehabilitation services within the sector (South East London), following investment in Cardiac Rehabilitation from CHD Choice monies, with the aim of improving patient experience and the equity of Cardiac Rehabilitation across the six PCTs. The case study includes a detailed summary of the two main reports relating to the two phases of the evaluation (Phase I and Phase II), together with an example of the individual supplementary reports that were prepared for each cardiac

rehabilitation service. It ended with a reflective analysis of the experience conducting this work.

These three pieces of work represent a significant part of the authors' personal and professional interest in the field of health psychology and counselling within health care settings. This included working with people affected by acute, chronic and terminal illness; promoting health and preventing illness through counselling, education and behaviour change; and promoting psychology within multi-disciplinary health settings. There is an underlying theme, amongst the three sections of adjusting to and coping with the stress and trauma associated with physical illness, either directly, as a patient following a cancer diagnosis (*section C*), or as partner of someone suffering from cardiac problems (*section B*). The case study described in *section D* explored both the patients' and partners experiences of cardiac rehabilitation services, as well as the numerous factors associated with improving the service provision across the sector.

Background behind the choice of topics

The evaluation of the cardiac rehabilitation services, described in *section D*, highlighted a gap in the service provision, in relation to the partners' experiences and needs. The interviews that took place, as part of the evaluation, provided a personal insight into how the patients' cardiac illness impacted on the lives of the partners, including their physical and psychological health, their social functioning and their relationship with the patient. Many of the partners interviewed, felt that they lacked the necessary information and support from the medical teams. This gap became the focus of the empirical research (*section B*), which began once the evaluation was complete. In addition to the interviews with the service users, numerous interviews were conducted with members of staff associated with the planning and delivering of cardiac rehabilitation services across the seven hospitals, and six PCTs. This resulted in detailed knowledge of the framework of cardiac rehabilitation services, the strengths and weaknesses of the system, and both admiration and sympathy for the care, attention and frustrations that went into providing cardiac rehabilitation services, often with severely restricted resources.

Working as a health psychologist and counsellor with clients who were either experiencing cancer first hand, or were family members of those affected, stimulated the interest in how both the patients and partners coped under traumatic situations associated with illness. Whilst some of the people diagnosed with cancer fell apart, or

became clinically depressed, others showed courage and bravery in fighting their illness, and adapting their behaviour to cope in the best way possible to ensure the optimum quality of life, throughout their treatments and recovery. This strength often extended throughout the end-stages of their lives. The partners faced different challenges to the patients. They had to deal with their own fears and concerns, whilst both providing support and comfort to the patient, and dealing with the practical demands of their lives, such as taking care of families and other responsibilities.

The review study of partners of cardiac patients, by Randal et al., (2009), described in *Section B*, stimulated the interest in post traumatic stress disorder (PTSD) in relation to illness. Investigating PTSD in relation to adult breast cancer became the focus of the critical literature review (*section C*).

There were many similarities between the prevalence, risk factors, symptomatology and treatment of PTSD following cancer and the psychological distress experienced by some of the cardiac partners. For example, the PTSD research has emphasised the tremendous variability in how women respond to breast cancer. For many, cancer may be experienced as a trauma and consequently lead to traumatic stress symptomatology. Likewise, a substantial minority of the cardiac partners in *section B* showed signs of both clinical and borderline distress. Further understanding is needed to distinguish between normal and clinical responses to such illness; for example, at what point does a period of adjustment following either a cancer diagnosis or a partners' illness constitute a pathological reaction.

For some, the trauma associated with cancer produced an opportunity for growth. Such growth may be also found in the cardiac partners. For example, many partners reported that their relationships had been strengthened as a result of the patient's illness.

This thesis has much to offer the field of psychology. The research offered a theoretical understanding of factors affecting partners' adjustment and coping behaviour. In addition, the research provided an insight into partners help seeking behaviour. This was used to suggest a stepped care model of partner interventions which could be applied to prevent, diagnose and treat trauma and distress.

The models used in the research were the sense of coherence (Antonovsky, 1979) and the cardiac beliefs (Furze et al., 2007). The sense of coherence (SOC), represented the ideal framework for the research. Antonovsky (1979) developed it as part of his

salutogenic model, to explain why some people, regardless of major stressful situations and severe hardships, stay healthy, while others do not; salutogenesis, literally means 'the origins of health.' Moreover, because SOC looks at the predictors of positive health outcomes in addition to looking at the causes of distress, the research becomes relevant to *all* partners (and patients), regardless of their physical and psychological health. The sense of coherence provides cardiac staff a framework to organise both the questions that they ask the partners and the information that they provide them.

It was an exciting opportunity to include the cardiac beliefs in the study, as it was still very much in its infancy at the start of the research. The cardiac beliefs questionnaire can be used not only as a research tool, but also as a clinical intervention that is simple to deliver and effective in its outcome. The cardiac beliefs, together with the SOC have a valuable role in cardiac partner interventions. In addition to providing support for partners in *distress*, both models could help staff promote the resources to ensure that the non-distressed partners (and patients) remain *healthy*. In this way early partner interventions could become both an integral and an intrinsic part of nursing care.

The partner is an essential source of support during the rehabilitation process, however the distress associated with caregiving burden can have detrimental effect on the recovery of cardiac patient. The research highlighted that those partners most in need, don't necessarily seek out the support that could assist them. The partner interventions may be a simple, yet effective opportunity for staff to form a relationship with the partners, to assess their needs and provide support and prevent those most in need from slipping through the net.

At a time when the NHS is stretched with severe budget cuts and organisational changes, there is a need to provide research that will stimulate the provision of valuable, cost-effective interventions to improve the patients' and family members' experiences. This will not only reduce the current health care cost, but serve as a proactive prevention of future psychological distress and illness.

Section B: Empirical Research

Abstract

The cardiac literature has shown that the stress of a patient's illness may increase the partner's vulnerability to develop psychological and physical illness. However, not all partners experience a crisis in response to the patients' illness.

The following study explored the experiences of being a partner of a person with cardiac problems. The aims of the study were a) to determine whether cardiac partners were distressed b) to investigate the reasons for the partners distress c) to explore the relationship between sense of coherence, cardiac beliefs and levels of partners distress d) to identify gaps in the care provided and opportunities for service development.

A cross-sectional questionnaire study, followed by smaller scale interviews of partners of patients eligible for cardiac rehabilitation was conducted.

89 partners completed a questionnaire which included data on a) The "Sense of Coherence Scale" (SOC); b) cardiac beliefs; c) HADS; d) general questions on demographics problems, needs and experiences. Following analyses of the questionnaire, it was decided that the interviews would focus on the group of partners with the lowest HADS scores, as they would benefit the most from additional support. 8 partners were interviewed.

In general, the sample of partners was in good health and coping well. The linear regression analysis showed that the partners' sense of coherence and cardiac beliefs accounted for 62.5% of the variance in the partners psychological distress. Out of the two variables, SOC was a better predictor of HADS. The main reasons for partners' dissatisfaction and distress included poor health, caregiver burden, conflict within the relationship, and inadequate support from health professionals.

A framework of partners interventions was discussed, so that partner interventions would become both an integral and an intrinsic part of nursing care.

The cardiac beliefs questionnaire has a valuable role in cardiac partner interventions, not only as a research tool, but also as a, cost effective, easy to deliver clinical intervention.

The SOC would provide cardiac staff a framework to organise both the questions that they ask the partners and the information that they provide them. In addition to providing support for partners in *distress*, a salutogenic framework could help staff promote the resources to ensure that the non-distressed partners (and patients) remain *healthy*.

Abbreviations or symbols

SOC Sense of coherence; HADS Hospital anxiety and depression scale

Chapter One: Introduction

1.0 Background

Coronary heart disease (CHD) is the single most common cause of death in the UK, causing over 90,000 deaths a year including one in five deaths in men and one in six deaths in women. British Heart Foundation statistics show that the cost of CHD to the UK economy is higher than any other single disease for which comparable analysis has been carried out (Peterson et al, 2004). However, the majority of the costs of CHD fall outside the healthcare system and are due to illness and death in those of working age and the economic effects of their families and friends who care for them (BHF, 2009).

A cardiac event, such as acute myocardial infarction (AMI) or cardiac surgery, is considered a life-threatening event and is a source of stress for patients and their families (Coyne & Smith, 1991; Skrotzki et.al., 2005; Skelton & Dominian, 1973; Wright & Leahey, 1984; Young & Kahana, 1987). The positive effects that a partner has upon the recovery, adjustment and rehabilitation of the individual who has suffered cardiac events has been recognised (Cobb, 1976; Dhooper, 1983; Kärner et. al., 2000; Lett et al, 2005; Randal et. al., 2009). The influence the family or carer have upon patient recovery after injury or illness has been acknowledged by nursing staff for some time and has been given increased attention by the recent and current government (DH, 1999; DH, 2008; DH 2010).

Caregiving has often been defined by the negative perspectives of caring including the physical, psychosocial and financial problems that can be experienced by the carer (Harkness & Tranmer, 2007). This has been described using terms such as caregiver burden, strain and stress and demands (Hunt 2003). Spouses of cardiac patients often live through an emotionally challenging time experiencing a range of fears and suffering from a variety of emotional stress symptoms. For a substantial minority of couples the consequences of caregiver burden are greater and more persistent than is physically justified by the severity of the patients' illness (Skelton & Dominian, 1973).

However research findings indicate that carers' needs are often not being met. For example, family members of cardiac patients receive little counselling or assistance in coping from health care professionals at the time of the patient's cardiac event or during recovery and convalescence. This may be an important unmet need (O'Farrell et al., 2000).

There has been a shift in the focus of research in the areas of stress, coping and illness. Early research in this area adopted a pathogenic orientation, focusing on the way in which stressful life events predispose an individual to a variety of negative health outcomes. In the last three decades a number of theorists and researchers including Antonovsky, (1970) Kobasa, (1979) and Wheeler, (1988) have adopted a salutogenic orientation, exploring the factors that assist an individual to maintain physical and psychological well-being in the face of stressors (Pallant & Leab, 2002). Antonovsky (1979), developed the salutogenic model to explain why some people, regardless of major stressful situations and severe hardships, stay healthy, while others do not.

Antonovsky, proposed the concept of sense of coherence (SOC), which he described as, 'a global orientation, a pervasive feeling of confidence that the life events one faces are comprehensible, that one has the resources to cope with the demands of these events, and that these demands are meaningful and worthy of engagement' (1987, p. 19). The sense of coherence has been successfully used amongst patients and partners as an explanation for successful adjustment following the stress of illness.

1.1 Outline of study

The following study explored the experiences of being a partner of a person with cardiac problems. It used the Hospital Anxiety and Depression Scores (HADS) to categorise distressed and non-distressed partners; and using questionnaire and interview data, it looked at the psychological wellbeing in partners and the particular reasons that they gave for their distress. Theoretically, it looked at the relationships between the partners' sense of coherence, their cardiac beliefs and distress levels, in order to understand why some partners cope better than others. The final part of the study examined partners' experience of health care services, their help seeking experiences and their preferences for interventions that might alleviate their distress. The rationale for the research was that better understanding of how partners cope, would provide cardiac teams with the necessary evidence based research to provide suitable interventions for partners.

The aims of the study were:

- a) to determine whether cardiac partners were distressed
- b) to investigate the reasons for the partners distress

- c) to explore the relationship between sense of coherence, cardiac beliefs and levels of partners distress
- d) to identify any gaps in the care provided and opportunities for service development

1.2 Outline of the following chapters

The remainder of Chapter 1 looks at the importance of studying the partners of cardiac patients. The following three chapters examine the literature. A review and critique of the current literature is given in Chapter 2. Chapter 3 explores the psychological consequences of caregiver burden in cardiac partners, i.e. what they are stressed about and how this is manifested. It also explores other issues such as the positive aspects of caring and gender differences. A theoretical and methodological critique of the literature is provided in Chapter 4, followed by an overview of the psychological models of adjustment in Chapter 5. The following two chapters look at the measures used that are central to our research question; Chapter 6 introduces the salutogenic model and the Sense of Coherence and Chapter 7 introduces the cardiac beliefs scale. Chapter 8 briefly looks at types of support interventions available for partners.

The rationale for the current study is given in Chapter 9, including the aims and outline of the study. Chapter 10 explores the design, measures and procedures used in the *questionnaire*. The results of the questionnaire are outlined in Chapter 11. The methodology used in the *interviews* is described in Chapter 12. This is followed by the analysis of the interviews in Chapter 13. The discussion and conclusions of the completed study is given in Chapter 14.

1.3 Definitions

In this research the term '**patient**' is used to describe the person with the cardiac problem. '**Partner**' is used to describe the spouse or long term partner of the patient with the heart condition. It is the **partner** who is the focus of this study. We preferred the term '*partner*' rather than '*spouse*' in order to include same sex relationships, non-married couples and other couples who were not necessarily co-habiting. Thus the term 'partner' will be used throughout, except when referring to previous research that specifically used participants wives or husbands.

The focus of this research is on the partners of patients with coronary artery disease. More specifically it focuses on partners of patients within the three main diagnostic groups that are invited to cardiac rehabilitation:

- those who had sustained a heart attack (MI)
- elective angioplasty (PCI)
- coronary artery bypass surgery (CABG)

According to The National Audit of Cardiac Rehabilitation (CR) Annual Statistical Report, (2009), referral to CR is almost entirely restricted to these three groups. Patients with other heart conditions such as heart failure, and those with implantable cardiac defibrillators (ICDs) have not been included in our research. These conditions differ in terms of severity of symptoms, prognosis, long term consequences of the disease and rehabilitation

1.4 Importance of studying partners

a) Partners can aid patient's recovery

The partner is generally the closest family member to the patient and is usually the central provider of support, particularly for middle aged and older age groups, when social networks beyond the family tend to naturally decline (Shaw et al, 2007). Many investigators and clinicians have suggested that successful recovery after a cardiac event and adaptation to living with a chronic condition may depend as much on positive support from a patient's partner as on patients' own coping resources (Moser & Dracup, 2004).

Although the majority of partners' studies have looked at the reaction of wives, both male and female partners have a crucial role in furthering the patient's emotional and cognitive adjustment (Ben-Sira & Eliezer, 1990), by giving care, support and assistance in developing and maintaining health-promoting behaviours (Marsden & Dracup, 1991; Theobald 1997).

Support from partners is associated with faster postoperative recovery, less psychological distress, fewer and less severe cardiac symptoms and decreased fear of recurrent cardiac problems and easier return to prior levels of social and recreational functioning, (Frasure-Smith, 1991; Helgeson, 1991; Chandra et al., 1983; Taylor, 1987; Coyne & Smith, 1991; Beach et al., 1992). It is also associated with adherence to risk-

reduction behaviours such as medication adherence (Doherty et. al., 1983; Rankin & Stallings, 2001), exercise (Daltroy, 1985) and dietary modifications (Bjovberg et. al. 1995). In a study of perceived self efficacy among men with CHD, men rated themselves as dependent on their wives' actions (Coyne & Smith, 1994). Likewise, practical spousal support is important for the recovering partner's self-esteem and mastery (Ben-Sira & Elizer, 1990).

Not all relationships are supportive, and research has shown that this can have a negative effect on the patients' recovery. For example, Walz et al (1988) reported a longitudinal study in which the marriages of MI patients with high levels of conflict were associated with negative health cognitions and high levels of patient anxiety. In contrast marriages with high levels of intimacy and low conflict were associated with lower depression scores.

Moser and Dracup (2004) compared the emotional responses and perception of control of MI and revascularisation patients and their partners. They found that firstly cardiac patients who perceived that they received inadequate emotional support experienced emotional distress and low self-esteem. Secondly pessimistic health perceptions and increased anxiety were common in patients who had negative relationships with their partners. Finally recovering cardiac patients who felt that their partner's support did not meet their needs were less likely to surrender the 'sick role' even when it was appropriate to do so.

b) Family members who provide care giving are at substantial risk for depression and declining health

Partners have the ability to influence recovery but may be less able to do so as a result of their own stress and coping demands associated with caregiver burden (Waltz, 1986; Coyne & Smith 1991; Beach et al., 1992; O'Farrell et al, 2000). Negative reactions reported by the partners of cardiac patients include high level anxiety and depression as well as other physical, emotional and psychosomatic symptoms (e.g. Skelton & Dominian, 1973; Thompson & Cordle, 1988; Shanfield, 1990; Hilbert, 1993).

Caregiving strain has been associated with higher cortisol levels. Although stress is not the only reason that cortisol is secreted into the bloodstream, it is secreted in higher levels during the body's 'fight or flight' response to stress, and is responsible for several stress-related changes in the body. Caregiving burden has been linked to lower immune functioning (Kiecolt-Glaser et al., 2002; Mills et al. 2004), infectious disease and even premature death (Schulz & Beach, 1999). Due to the higher incidence of

heart disease in mid to later life, caregivers are often elderly and /or suffer from existing chronic health problems of their own. Thus the stressors of caregiving could further damage their health.

c) The partner's stress and illness can hamper the recovery of cardiac patient

Overburdened partners who are psychologically distressed or physically ill may not have the emotional and physical resources to provide adequate care to the cardiac patient. This is likely to have an effect on the recovery and rehabilitation of the patient, as a patient's ability to adapt physically and emotionally to heart disease depends both directly and indirectly on the partner's ability to cope with situational stressors. For example, greater anxiety and depression in partners was associated with poorer psychosocial adjustment to illness in patients (Stewart, 2000). Likewise, partners' anxiety, depression and perceived control were correlated with patient psychosocial adjustment to illness even when patient anxiety and depression were kept constant. The patients' psychosocial adjustment to illness was worse when partners were more anxious or depressed than the patients (Moser and Dracup, 2004).

d) Shared risk factors

Family members often share cardiac risk factors due to lifestyle factors. For example it has been suggested that a shared unfavourable lifestyle, such as one that involves smoking, may result in a greater risk of disease, especially for women (Macken et al., 2000). Proactive interventions targeted at the partner could be a cost effective way of reducing the risk of partners themselves suffering from cardiac problems or other similar illness. It could also contribute to a co-operative attitude concerning changing risk behaviour in the patients (Kärner, et al., 2004). The interventions taught in cardiac rehabilitation such as a balanced diet, exercise, smoking cessation and stress management are the fundamental components of health promotion and linked both directly and indirectly to improved physical and mental health and wellbeing.

1.5 Summary

A cardiac event, such as acute myocardial infarction or cardiac surgery, is considered a life-threatening event and is a source of stress for patients and their partners. For a substantial minority of couples the consequences of caregiver burden are greater and more persistent than may be justified by the severity of the infarction.

It is important to study the partners because: a) the partner is generally the closest family member to the patient and has been seen as an essential source of support during the rehabilitation process b) family members who provide care giving are at substantial risk for psychological distress and declining health associated with caregiver burden c) the partner's distress can have detrimental effect on the recovery of cardiac patient d) family members often share cardiac risk factors due to lifestyle factors. Proactive interventions targeted at the partner could be a cost effective way of reducing the risk of partners themselves suffering from similar illness in the future and could contribute to a co-operative attitude concerning changing risk behaviour in the patients.

This study explored the experiences of being a partner of a person with cardiac problems. Using questionnaire and interview data, it looked at the psychological wellbeing in partners and the particular reasons that they gave for their distress. Theoretically, it looked at the relationships between the partners' sense of coherence, their cardiac beliefs and distress levels. The final part of the study examined partners' experience of health care services, and their preferences for interventions that might alleviate their distress.

The literature review, in the following chapters, outlines the wealth of studies on this topic, providing a context for the study as well as highlighting the flaws in methodology and gaps in the research.

Chapter 2: Literature review

In the early 1990s, Morse & Johnson (1991) argued that theories of illness should be developed from the perspective of the patient rather than from that of the health professional. Mayou & Bryant (1993) found that psychosocial factors had been largely ignored in cardiac disease research, despite the evidence suggesting that the psychological reactions of the patients were an important in determining their long-term quality of life. This was followed by a wealth of studies investigating the cardiac patients' experiences.

The examination of the early literature, found that these studies focused on the psychological and social consequences of the patients' cardiac event on the wives. For example Skelton & Dominian, (1973) described the feelings, reactions, and difficulties experienced by 65 wives from the time of the husband's admission to hospital to a year after the illness.

Other studies focussed on the influence of the partner on the patient's recovery (e.g. Hilbert, 1985), as well as on the partner's needs (e.g. Turton, 1998; Hentinen, 1983). Prior to his study in 1995, Thompson reported that no research had specifically examined the partner's experiences, even though the impact they had on the patient's recovery process was evident.

Thompson investigated the experiences of male patients and their partners one month after a first heart attack. A random sample of 20 married men and their partners were interviewed. An interpretive approach was used to analyse the data. His study highlighted that partners' emotional reactions may be significant and overlooked; a heart attack may affect a couple's relationship; and that both patients and partners require advice and information. This study provided very useful data and paved the way for further research and service development. However, limitations of this study, and of many subsequent ones, include the fact that the sample was restricted to patients who were male and married. Only including female partners meant that possibility of gender comparison was eliminated. This will be discussed in greater detail in Chapter 4. Thompson suggested that the fact that both patients and partners were interviewed together might have meant that they were reluctant to disclose their true beliefs and feelings in the presence of their spouses in such sensitive circumstances. Thompson acknowledged that limitations of time prevented follow-up visits and a

degree of theoretical sampling which would have allowed the study to achieve a greater degree of theoretical saturation of the concepts, and thereby add to the validity of the emerging themes. Many similar studies have indeed chronicled both the patients' and the partners' illness experience and the experiences, perceived needs and concerns of family members during the patient's illness.

In Finland, Kettunen et al., (1999) investigated the impact of patients' MI on the partners in terms of fears and symptoms during the patients' recovery period, and perceived sufficiency of support from health care professionals. 57 partners (10 male) completed a questionnaire 2 weeks and 4 months after the MI. All the partners reported a wide range of negative emotions including fears and stress symptoms within the first few weeks of diagnosis, during the 'appraisal phase' of the illness. Cullberg (1993) described such strong emotions experienced by the partners, as an 'emotional crisis.' Interestingly, they were not related to the severity of the infarction. Instead, the main factors influencing their fears and symptoms were the partners' own health concerns, negative life events experienced during the year and lack of support from health care professionals. The authors recommended that *all* partners needed attention from health care professionals, including those of patients suffering from milder infarctions. Although this study did include male partners, the weak gender distribution makes it hard to generalise the results. The study used a structured questionnaire which was developed by the authors. However, due to the nature of the closed-ended questions, there was a risk that participants' responses may have been restricted. The inclusion of some open ended questions and/ or interviews would have controlled for this.

In a larger study, O'Farrell et al., (2000), conducted a cross-sectional analysis of 213 female partners of patients undergoing cardiac rehabilitation (CR), in order to describe the needs of partners with respect to possible interventions. Partners completed 5 questionnaires aimed at assessing psychological distress, coping, marital intimacy, family functioning, and heart disease hassles. They were also interviewed over the telephone to ascertain demographic information. O'Farrell found that the majority (66%) of the partners were significantly distressed. He concluded that partners of patients undergoing cardiac rehabilitation should be screened for psychological distress and those in distress should be offered interventions such as stress-management techniques which encourage the use of engagement coping strategies. O'Farrell also suggested that marital and family concerns be directly addressed in support interventions. Once again, only female partners were included, thereby eliminating the possibility of gender comparison, and the study used close ended questionnaires,

which may have restricted the content of the responses. Another limitation would be that although a large sample was used, the population was not a random or necessarily representative sample, which restricts the generalisability of the findings. O'Farrell suggests that a self-selection bias may have affected the results because those people who were more overwhelmed by the cardiac event, and who predominantly used disengagement coping strategies, may have not agreed to participate. Hence the results may in fact underestimate the true level of partner distress, as those who were more distressed were more likely elected to seek more intensive treatment, and would have been specifically excluded from the sample.

Cardiac Surgery

There have been a growing number of studies specifically studying the partners of patients following cardiac surgery, which have shown consistent results with each other and also with that of partners of MI patients.

Gillis, (1984) interviewed 72 couples (including 61 male patients) following CABG and assessed their stress levels. Data were collected during the first post-operative week and six months later. Partners frequently described 'the early days' as the 'most demanding' and 'most frightening,' which is in line with Culberg's 'emotional crisis' mentioned above. Partners also expressed fears related to the responsibility of looking after somebody so soon after major surgery, even when the patient was happy to be discharged.

Artinian, (1991) found that the (female) partner's physical and psychological manifestations of stress significantly decreased six weeks after the patient's discharge. At this point the wives concerns mainly focussed on their uncertain future and their husband's physical and mental health, including concerns that things were not 'back to normal.' This was followed by a series of follow up studies (e.g. Artinian, 1992; Artinian, 1993), exploring partners' distress, quality of life, social support and marital relationships.

Moser et al. (1993) studied self-perceived needs of 49 couples five months after one them had been hospitalised for an acute cardiac event. They found that the partners needed to have some time to themselves, without having to be constantly alert to the needs of the patient. The problems of dealing with the patients' emotional reactions to their illness or surgery, while trying to maintain an environment conducive to recovery, left them feeling anxious, frustrated, angry and guilty.

Davies, (2000) conducted a descriptive survey of 59 carers of cardiac surgery patients in the UK. He reported that there was very little literature specifically focusing on the needs of relatives or carers of cardiac surgery (and coronary event) patients, outside North America. In his study, questionnaires were sent to carers one week after surgery and six weeks later. The questionnaire explored perceptions about timings of discharge, opinions of information provided by staff and The Hospital Anxiety and Depression Scale. The results of this study matched previous research showing that partners of surgical patients often lacked information from hospital staff and felt insecure when they assumed responsibility for looking after the patient at home. 49% of the partners felt that the patient had been discharged too early. Davies recommended that strategies aimed at the partner need to commence during the acute (early) stage of the patients' recovery and that cardiac rehabilitation needs to be aimed at partners as well as patients. Unfortunately the sample of partners used was 73% female. Davies acknowledged that a longitudinal design would have also provided more opportunity to compare the two groups and that it would have also been interesting to explore the experiences of partners at a later stage, to see how they developed.

Longitudinal research was carried out by Theobald et al., (2004), who used thematic analysis to study a range of issues (concerns and needs) in CABG patients and their partners 4–5 weeks after CABG and 1 year later. They found that the impact of surgery, especially when it was unexpected, proved to be enormous for both patient and partner. The partners experienced ongoing anxiety and stress due to factors such as relationship adjustments, adaptation to their new role, and financial problems. The effect on their family life was significant. The study concluded that partners' (and patients') needs for information and support were not being met. This included the need for guidance on their roles, strategies for monitoring patient progress without being overprotective, and some acknowledgement of the strains they may encounter in caring for others. They also needed specific, local information on the range of support services available in their community, as well as information on financial matters.

In summary, partners perceived cardiac surgery to constitute a major life-event for the patient and themselves. Whilst the patients were happy to go home following surgery, partners frequently expressed fears related to the responsibility of looking after somebody so soon after major surgery. They did not feel adequately prepared. The early days following discharge were consistently reported as the 'most demanding' and 'most frightening'.

Marital dyad

There has been a shift in recent research to explore the couple as a unit or marital dyad, rather than as 'patient' or 'partner'. Bennet & Connel, (1999) explain that in co-habiting couples, the response to cardiac problems is not simply that of two independent individuals: rather, it is a systemic transactional, response by *both* partners. They suggest that recovery should be conceptualised as a dyadic rather than individualised process, involving both patient and partner response. A dyadic response to the illness would include taking into account both the partner's and the patient's responses to the illness, their coping strategies, their beliefs and perceptions regarding the illness, relationship issues, and lifestyle factors, and how each of these factors would affect the other member of the partnership.

Bennet & Connel, (1999) examined the dyadic response in 43 cases where the male partner had experienced an MI. Each couple were interviewed briefly, to obtain family information and medical history, and then each partner completed a set of questionnaires. They found that partner's anxiety was correlated with patient's physical health limitations, quality of the patients' marriage and their social support (especially lack of a confidant). They also found that depression was primarily mediated through personal coping styles. Finally, when wives used mental disengagement as a strategy for dealing with the stress of the MI, patients reported higher anxiety levels than when they remained more engaged with the patient.

In a phonological study, Theobald, (2004) described the in-depth experiences of three partners of patients who suffered M I (two female and one male). Whilst the knowledge gained from such a study provides a framework with which practitioners and families can assist in the overall rehabilitation of clients, there is an issue about the ability to generalise the findings to the entire population, due to the small sample size.

Mahrer-Imhof et al., (2007) carried out a larger phenomenological study, describing the practices that twenty-four couples developed, and meanings they mutually assigned, after the onset of cardiac disease. Three in-depth interviews were obtained for each dyad: one couple interview and two individual interviews with each partner of the dyad. This study provided rich data on the experiences of the couple, their coping strategies and adjustment in order to understand the impact of the illness on the couple's relationships in everyday life. They found that couples often experience cardiac disease as a call to change, and attempt to deal with the illness experience jointly. Some assessed the illness as a positive, transformative experience in their lives, whilst others experienced the illness as a threat (to both partners). Couples who missed the

opportunity to change often become disenchanted about each other. The authors concluded that all couples have counselling needs that need to be individualised to their adjustment patterns but the most burdened couples have the greatest needs.

Partner and dyadic experience is widely documented in other research on other chronic and acute diseases, such as example cancer. However, the majority of cardiac research tends to use an individualistic focus (Randal et al., 2009). Randall et al., (2009), conducted a systematic review on the impact of an acute cardiac event on the partners of patients. 62 studies were identified and categorised. They concluded that partners were at significant risk of experiencing distress, anxiety and depression that may extend beyond the immediate recovery phase. Partners described a lack of social support and information. Their findings revealed that partner experience may play an important role in both partner and patient adjustment to an acute coronary event and that there is considerable scope for updating existing knowledge of partner experience.

Summary

Prior to Thompson's study in 1995, no research had specifically examined the partner's experiences, perceived needs and concerns during the patient's illness. This study provided paved the way for further research and service development.

Studies have found that partners have been significantly distressed yet this has been overlooked; cardiac problems may affect a couple's relationship; and that both patients and partners require advice and information.

Examples of recommendations from these studies include that a) *all* partners would benefit from attention from health care professionals; b) partners of patients undergoing cardiac rehabilitation should be screened for psychological distress and offered appropriate interventions; c) strategies aimed at the partner need to begin early and commence during the acute stage of the patients' recovery; d) cardiac rehabilitation needs to be aimed at partners as well as patients.

The following chapter explores the psychological consequences of caregiver burden in cardiac partners, i.e. what they are stressed about and how this is manifested. It also explores other issues such as the positive aspects of caring, age and gender differences.

Chapter 3: Psychological impact

Research has shown that partners of cardiac patients are at significant risk of experiencing distress, anxiety and depression. Other negative reactions reported by the partners include, fear, tension, listlessness, helplessness, fatigue, inability to concentrate, sleeping and appetite disturbances and loss of self esteem (Skelton and Dominian, 1973; Hentinen, 1983; Hilbert, 1985; Thompson & Cordle, 1988; Hilbert, 1993; Kettunen et al, 1999).

The period during hospitalisation, and immediately after, when the patient is discharged, is particularly stressful for the partners. The partners are often helpless witnesses to the clinical staff's efforts to treat the patient and can feel a total lack of control over the situation, leaving them feeling vulnerable, unsupported and over-protective towards the patient (e.g. Thompson & Cordle, 1988). They frequently experience high levels of anxiety and moderate levels of depression. The majority of longitudinal studies have found that distress may extend beyond the immediate recovery phase; symptoms have been found to persist in partners for up to a year (Artinian, 1993; Monahan et al., 1996; Mahler et al., 2002). Anxiety tends to gradually decrease over the first year, yet it still remains elevated compared to population norms (Randall et al., 2009). There are mixed reports about depression. Some studies report a reduction in depression by the one year follow up, although it may last for up to two years (e.g. Moore, 1994). Other studies have identified persistent low-moderate levels of depression up to 10 years post MI (e.g. Arefjord, et al., 1998; Skelton & Dominian 1973). Due to the variety of different measures that have been used in previous studies to measure partners' anxiety, stress and depression, a clear amalgamation into overall severity or prevalence of partners' distress is not possible (Randal et al., 2009).

On balance it appears that some partners seem to cope with the stress better than others, irrespective of the severity of the patient's condition.

Partner's concerns

Partners have complained about too much responsibility, assuming additional home tasks loss of time for themselves, change in roles, moodiness of the patient, sexual concerns, helplessness or apathy on the part of the patient, and increased partner responsibility (Bennet & Connel, 1999; O'Farrell et al., 2000). Behavioural

management and monitoring patient progress were reported as the greatest caregiver burdens and providing emotional support were the most difficult caregiving tasks (Halm et al, 2007; Stolarik et al., 2000).

The myriad of partners' worries and threats include:

- the fear of the patient having another MI and/or possible death
- worries about treatment, recovery and rehabilitation
- issues around the patients' reactions to their cardiac condition
- the patients' levels of residual disability and ability to resume previous social and work activities
- financial concerns
- sexual and marital concerns
- dealing with health professionals and the system,
- the financial stress associated with illness

(Skelton & Dominian, 1973; Svedlund et al., 1999a; Kettunen et al., 1999; O'Farrell et al., 2000).

Relationship issues

Relationship issues and conflicts between partners are common. Patients are not always appreciative of the help their partners' give and may resent the fact that they need care at all. Partners, in turn may resent the patient.

Rolland, (1994) looked at the impact that illness may have on a couple's relationship, drawing on the Family Systems – Illness Model, (Rolland, 1984, 1994) which is based on the concept of a systemic interaction between illness and a family that evolves over time. Rolland's paper addresses key issues regarding the couple's intimacy and communication throughout illness. For example, following a life threatening event such as an MI, which often comes as a traumatic shock, the couple come face to face with both their own, and their spouse' impending death, regardless of the prognosis. Existential anxiety surrounding death is both 'neurotic' and 'normal'. It is our cultural avoidance of death related issues that fosters patterns of intimacy based on denial of illness and loss, romantically relegating them to 'later life' and 'peaceful death' (Becker, 1973; Walsh & McGoldrick, 1991).

In the wake of a cardiac event, with the resulting role changes, demand for lifestyle change and affective demands, many couples (and families) have difficulty communicating clearly with each other, especially about their feelings, fears, needs,

and concerns. Many partners avoid disclosing their feelings for fear of distressing the patient. Poor marital communication and conflicted interactions between partners and patients such as avoidance, conflict or criticism, can not only offset supportive functions that are conducive to successful recovery and rehabilitation of the patient (Brenner et al. 1989), but also they can contribute to the depression and distress of caregivers (Newsom & Schulz, 1998). Cardiac events often have a negative impact on sexual functioning in the patient, which would also impact on the marital relationship. Psychological distress and relationship issues could further magnify any problems.

O'Farrell et al., (2000) found that distressed spouses reported both lower levels of marital intimacy and poorer family functioning. It is not clear whether these marital difficulties existed before the cardiac event, were exacerbated by it, or were event-related; nevertheless they concluded that marital and family concerns need to be addressed directly.

Often caregivers have a tendency to be over-protective through engaging in a type of surveillance behaviour, in which they closely monitored the activities of the patient, and become overwhelmingly concerned with the welfare of their partner (Mayou et al., 1978). This concern may counteract the desires of the patient to return to normal activity (Marsden & Dracup 1991; Joeke, Maes and Warrens, 2007) as well adding to the anxiety of the partner. Reasons for such surveillance may include lack of understanding about the patient's condition and his/her capabilities as well as the fear of losing the next of kin. Alternatively, partners may exert control to alleviate their sense of helplessness over the situation. (Svedlund & Axelsson, 2000; Svedlund & Danielson, 2004). According to Fiske et al., (1991), the traditional concept of overprotection may not be a unified construct. Partners (wives), in a healthy relationship, may cope by becoming overprotective, due to an overanxious desire to help when threatened with the loss of a close and affectionate relationship. It is only when the relationship is less close, and there is a lack of communication about how to deal with the difficulties, then it seems likely that the difficulties that the wives experience would be especially frustrating and lead to hostility.

The style of relationship-focused coping in which either partner hides his/her concerns from the other is called protective buffering and was described by Coyne and Smith, (1991). Although this coping style is adopted to protect the partner, concealing worries and suppressing arousing thoughts may exact costs for both parties (Suls et al., 1986; Pennebaker et al., 1987; Wegner, 1989; Gross and Levenson, 1993). Consequently, use of protective buffering may actually exacerbate distress. Sulz et al., (1997)

measured psychological distress and protective buffering in 43 couples (male patients) at 4 weeks and 6 months post-hospital discharge. They found that female partners, who concealed their worries from the patient, were more distressed, and that male MI patients who engaged in the same protective buffering also adjusted more poorly over time. Protective buffering was also associated with marital dissatisfaction. This suggests that couples that were doing well together felt less need to protect each other from their worries.

Coyne and Smith (1991) found an association between patient protective buffering and partner distress. However, Suls et al., (1997) did not find significant evidence of this.

Partners' stress greater than patients

There is growing evidence indicating that spouses of patients may have a higher level of distress, anxiety and depression associated with the cardiac event than patients do (Mayou et al., 1978a; Gillis, 1984; Marsden, & Dracup, 1991; Hilbert, 1996; Moser and Dracup, 1993; Bennet and Connel, 1998; Stewart et al., 2000). Suls et al., (1996) found that patients and partners reported similar levels of distress at four weeks but the partners' distress lasted longer than the patient's. Conway et al., (1994) found that partners had greater clinical anxiety than the patients throughout the year following CABG. However, there was no significant difference between partner and patient in the occurrence of depression.

Moser and Dracup, (2004) sent postal questionnaires to four hundred and seventeen patient-partner pairs. They found that 56% of partners experienced clinical anxiety and depression, (measured on the MAACL anxiety and depression scales), which was higher than the levels reported for the patients. Partner's anxiety and depression was associated with the patient psychosocial adjustment to the illness. It was also related, in part, to caregiving demands and a decreased sense of perceived control related to the patient's illness, since patients may experience greater perceived control than their partners. Moore (1994) attributed similar findings to the increased uncertainty partners experienced after their partners' cardiac surgery, the changing physical status of patients and the uncertainty of the recovery period. The majority of support from health care providers is directed toward the patient. This could mean that the patients benefit from being the focus of the health care system, whereas partners and other family members are isolated from the support of the healthcare team and consequently experience poorer emotional recovery than the patients (Dracup et al., 2004). The partner is subject to many caregiver demands and may have to also assume many of

the patient's roles for some time. As a consequence, he/she may develop and maintain higher levels of anxiety and depression and feel less control as the patient recovers from the cardiac event (Stewart, 2000).

Positive effects of caring

Harkness, & Tranmer, (2007) note that few studies within the broader caregiving literature adopt a positive conceptualisation of caregiving. 'Caregiving' has often become synonymous with 'caregiver burden,' and it is rarely defined in terms of potential 'gains' such as the sense of satisfaction that results from the process of providing care (Hunt, 2003; Scott, 2000) or the opportunity for growth within the couple's relationship (Rolland, 1994).

A recent study by Brown et al., (2009) suggests that caring for a partner could actually lengthen your life. The researchers suggested that past research has tended to conflate two issues: the act of care-giving itself, and the stress of worrying about an ailing loved one. Between 1993 and 2000, Brown's team followed 1688 married couples, all aged over 70, during which time 909 of the participants died. Crucially those participants who provided more than 14 hours per week care to their partner at baseline were at 36% reduced risk of dying over the course of the study compared with participants who provided no care, even when health and medical history were controlled for. The researchers suggest that this effect may be due to the hormone oxytocin, which is causally linked to helping behaviour. Oxytocin decreases activity of the hypothalamic-pituitary-adrenal (stress) axis, and contributes to cellular repair and storage of cell nutrients. It is worth noting that this study was based on patients who were healthy enough to still live at home and take part in a psychology survey. In contrast, general research investigating the costs of caregiving has tended to involve partners looking after patients who are more seriously ill.

It is possible that closer, more supportive relationship can develop between the couple post MI (Ford, 1989; Thompson et al., 1995; Thompson & Cordle, 1988). Some caregivers experience improved self worth and self esteem and feelings of pride in their ability to meet challenges. Others reported gaining a sense of meaning and pleasure in their relationship as a result of their caregiving responsibilities. High intimacy marriages have been shown to enhance the support perceived by MI patients, with the level of intimacy between partners being inversely related to depression (Waltz et al.,1988). This has implications for couples with marital difficulties (Shanfield, 1990). According to attachment theory, these couples might be securely attached to each other and

therefore believe that their partners will be effective in conquering the threat (Maunder & Hunter, 2001).

Over-protectiveness on the part of the partner has been linked with the couple becoming closer after a heart attack (Fiske et al., 1991). This may be related to the partner assuming a more dominant role in the relationship with the patient. Unfortunately, this has only been investigated in female partners, which makes the effect of gender hard to rule out. Mahre-Imhof, (2007) suggested that couples who are able to find benefits in their illness succeed in overcoming possible resentments within the relationship. In this paper, these couples appeared able to challenge rigid role enactments and come up with innovative and creative ways of dealing with the situation.

Finding benefits does assume a cognitive ability to reframe potential stressful experiences into positive, rewarding ones. This could include viewing the recommended lifestyle changes, such as reduced fat diet or smoking cessation, as new worthwhile possibilities, rather than as punishment.

Partners' age

There is some evidence in the cardiac literature that the partner's age is correlated with distress and that younger female partners experience more stress and more emotional and somatic symptoms, such as appetite disturbance, headaches than older ones (Michel, 1992). Younger women would have to cope with work demands as well as increased responsibility for child rearing and household concerns, in addition to the caregiving responsibilities. O' Farrell et al., (2000) found that partners who were younger, and who had children under the age of 16 years were more likely to be distressed. Stolarik et al., (2000) found that there was a curvilinear relationship between caregiver burden and caregiver age with younger and older caregivers of CABG patients experiencing the greatest burden

O' Farrell, (2000) suggested that younger women experience more distress because they generally encounter an abrupt shift from life with a healthy partner to dealing with severe illness, and they have less life experience to draw on as a resource for coping. Younger women may feel both resentful about constricted life cycle options and shame about such feelings. They may also have the added financial concerns due to their husband's long term compromised employability, whilst older couples are closer to retirement (Roland, 1994), and possibly more prepared. These findings show that

younger, and elderly women need to be targeted for intervention that addresses the life-stage specific concerns they face, (O' Farell, 2000).

Social support

The social environment of people is considered a salient factor not only in the precursor of disease (Goen, 1987) but also as a determinant of subsequent coping behaviour and adjustment to physical illness (Lazurus and Folkman, 1984; Waltz et al., 1988). Social support can have two faces, a health promoting one and a disease-enhancing one. This is particularly true of the marital environment and its impact during the life-span on subjective well-being (Waltz et al., 1988).

Social support has been conceptualised as having two core elements (Sarason et al., 1983); firstly, the perception that there are others to turn to in times of need, and secondly, a degree of satisfaction with the support available. Such support may be available within a marriage and also the wider social group, and there is consistent evidence of its health protective effects. Research suggest that social support during adverse life events reduces distress and promotes better partner adjustment, whereas partner's dissatisfaction with social support increases risk of maladjustment and depression (Hallaraker et al., 2001; Randall et al., 2009), and greater delayed anxiety (Arefjord et al., 1998). Hallaraker et al., (2001), found that adjustment was unrelated to the quantitative aspect of social support; it was the quality of it that was important.

In a healthy marriage, the partners' main form of social support would typically be from the spouse. However, when the spouse is ill, this support may be compromised and often reversed. Patients and partners regularly look to medical staff for support. However, partners (and patients) have reported a lack of social support from health care professionals (Kettenen et al., 1999; Moser et al., 1993; Thompson and Codle, 1988).

Patients who are unmarried, live alone, lack a source of emotional support or have less well-developed social networks, have a substantially higher risk of recurrent myocardial infarction, exhibit a greater risk of death, and a poorer psychosocial recovery compared with those who are married or have adequate sources of support (Mendes de Leon et al., 1992). Adult children are often the key carers for patients without partners. However there has been little research on the prevalence of psychological problems amongst patients without partners within the cardiac literature.

Gay and lesbian couples

Gay and lesbian couples facing chronic disorders might deal with issues related to social stigma in addition to all the same issues heterosexual couples face. A life-threatening illness often forces hidden or private relationships into public, possibly for the first time, at a moment of great vulnerability (Roland, 1994). There has been no research into homosexual partners in the cardiac literature.

Summary

A cardiac event is considered a life-threatening event and is a source of stress for patients and their partners. There is a large body of research examining the partners' experiences. There is significant evidence that partners are vulnerable to developing anxiety and depression that may persist beyond the patient's recovery (Randall et al. 2009).

Psychological distress may be related to caregiving demands and to a decreased sense of perceived control related to the spouses' cardiac illness.

Predictors of partners' emotional distress, dysfunction and vulnerability include:

- being younger and having children under the age of 16
- experiencing a negative life event in the last year (Kettunen et al, 1999)
- pre-existing psychological symptoms (Mayou et al, (1978)
- poor physical health
- lack of social support and confiding relationship
- less marital intimacy and poorer family functioning
- initial level of distress following patient's MI (Suls et al., 1997)

Research indicates that partners of patients may have a higher level of distress associated with the cardiac event than patients do. The partner is subject to many caregiver demands and may also have to assume many of the patient's roles for some time, whilst the majority of support from health care providers is directed toward the patient. However, caregiving can also be a positive experience, bringing couples together. On balance it appears that some partners seem to cope with the stress better than others, irrespective of the severity of their partner's condition.

The following chapter will explore the theoretical and methodological issues associated with the partners' literature.

Chapter 4: Theoretical & methodological issues

4.0 Methodological issues

According to The National Audit of Cardiac Rehabilitation (CR) Annual Statistical Report, 2009, the majority of people taking part in cardiac rehabilitation programmes are white British retired men in their mid to late '60s, who had recently experienced an MI or revascularisation (PCI or CABG). Very few people from the major ethnic groups or those recorded as permanently sick or disabled were referred or attended.

The National Audit also provided conclusive evidence that women are under-represented in cardiac rehabilitation both at referral and in the number actually taking part. For example, if men and women had entered rehabilitation in proportion to the case rates for MI they would expect there to be 63% men and 37% women in programmes. Instead, women made up 32% of referrals and only 28% of participants. However, it is mainly older women who are under-represented in cardiac rehabilitation; women after the age of 80 are less likely to take part than men of the same age. Randal et al, (2009) argues that many of the studies investigating partners (and patients) utilise samples recruited from cardiac rehabilitation sessions, which means that the samples may be intrinsically biased.

Such a selection bias is mirrored in the samples used in the majority of studies, even if they were recruited a wider sample group than cardiac rehabilitation sessions. The samples have a bias towards white female partners of male patients. There is a lack of exploration of cultural issues. Indeed, Randall et al, (2009), complains that only 25% of the studies included in the review provided basic detail about the ethnic constitution of the sample.

Another limitation of the studies to date is the cross-sectional design, as the direction of any association between outcome and moderator variables would be necessarily speculative (Bennet & Connel, 1999). For example, it would be hard to confirm whether partners' level of emotional distress predicts patients' psychosocial adjustment in the long-term; or that changes in the level of partners' emotional distress would predict changes in patients' psychosocial adjustment. Coyne & Smith, (1991) suggest that due to the reciprocal nature of dyadic behaviour, any suggested directionality of influence forms a 'provisional punctuation' of what are likely to be reciprocal and changing

relationships between affect, coping, marital and social support systems and health outcomes. Longitudinal studies would help to illuminate the nature of the relationship.

The bulk of the partners' studies described in the previous chapters have been found in the nursing literature; there is a need for more research which is developed from psychological theory.

Although descriptive studies are useful, the lack of outcome evaluations, small sample sizes and the use of untested measures limit the usefulness of the research. Randal et al., (2009) argued that many of the studies do not utilise standardised measures which limit generalisability and potential for replication. In addition the research is outdated with the majority of studies conducted prior to 2000, particularly with regard to the psychosocial and marital impact of acute coronary events on partners. They concluded their systematic review by saying that the research base was limited, methodological weak and outdated in relation to advances in cardiac care, and little attention had been paid to the experiences of non-Caucasian, same sex couples or male partners.

4.1 Gender issues

Although cardiac events are prevalent in both males and females, few studies have examined male partners and their perception of the cardiac event. Some of the later studies that were open to male partners, unfortunately only obtained small numbers of men. While this fact reflects gender differences in the epidemiology of myocardial infarction, investigations of adaptation by male spouses may reveal important aspects of care not usually considered by practitioners (National Heart Foundation,1995). In a series of studies, Svedlund,(1999a, 2000, 2004) explored the meanings of the experiences of being a (female) patient and a partner to an afflicted woman. However, the results were not discussed in terms of gender differences. Halm et al., (2007) found that caregiver burden was significantly higher in male vs. female partners and male partners found certain tasks such as medical or nursing treatments, personal care, mobility assistance, arranging care, and monitoring symptoms more difficult. However male partners reported significantly more positive outcomes of caring in various aspects of life than female partners. Although male caregivers in this study had more total burden, Halm cites other studies that showed that female caregivers experienced more total, objective, and subjective burden (e.g. Chou, 2000; Rankin, 1988).

Lemos et al., (2003), explored the sex differences in household responsibilities amongst cardiac patients (43 men) and their partners. They found that both patients

and partners maintained traditional sex type activities. For example female patient and female partners assumed greater responsibility for domestic tasks whereas male patients and partners tended to assume more responsibility for household repair and maintenance tasks. An explanation for this pattern is that the psychological costs of change are too prohibitive. Both female patients and their husbands may resist change to avoid feelings of resentment associated with inadequate reciprocity. Further, female patients report that the prospect of burdening other family members with domestic tasks produce guilt and distress.

Gender differences in caregiver burden appear to be quite consistent across health conditions. For example, the gender differences found among partners of patients with cancer were mainly consistent with the general literature on caregiver burden that focused on family members of patients with mental disorder. These differences are discussed below.

A review of 14 descriptive studies by Miller & Cafasso (1992) showed that male caregivers were less likely to carry out personal care and household tasks, and perceived a lower burden than female caregivers. In one of the few studies that included healthy control couples, Rose-Rego et al., (1998), demonstrated differences in psychological health between male and female partners of neuropsychologically ill and psychiatrically healthy spouses. More specifically, female partners especially, reported high levels of distress and low levels of life satisfaction. This finding is important, because it indicates that the gender differences in the psychological health of partners of patients were indeed a result of the illness experience. A review paper by Pitceathly & Maguire, (2003) outlines the psychological impact of cancer on patient's partners. Female partners and those with a history of psychiatric morbidity were more vulnerable, as are those who took a more negative view of the patient's illness and its impact on their lives. Partners were also more at risk when they lacked a support network of their own, and when there were relationship difficulties with the patient.

In considering social network size, Haan et al., (2001) found that gender and age were important variables. The marital relationship had a more positive effect on health for men, with women tending to obtain social support from a broader social network.

Hodges et al., (2004) conducted a meta-analysis with 21 independent samples of cancer patients and their partners, to quantify the relationship and difference between respective measures of psychological distress. These findings supported previous research that suggested that being female was associated with more psychological distress (Langer et al., 2003) and that the role within the couple mattered to a more

important degree for males—with male partners reporting less distress than male patients (Hagedoorn et al., 2000). The question remains as to what it is about being the partner that causes more psychological distress in women than men? Hagedoorn et al., (2000), suggested that it was impossible to conclude whether the differences in psychological distress and quality of life between cancer patients and partners were as a result of gender or role (i.e. patient vs. partner).

Higher levels of psychological distress in women carers could indicate a predisposition towards a focus on emotional relationships and or the influence of role expectations and obligations operating within that particular culture. Historically, values related to self respect and loyalty are closely tied for women to adequacy in nurturing and caregiving roles (McGoldrick, et al., 1989). In contrast, men, who are frequently inexperienced at caregiving, are often are very anxious or unskilled in caring emotionally for their partner and children. This may be accompanied by increased anger for being put in an unanticipated position and by guilt by the patient wife for becoming a burden.

According to Rolland, (1994), couples often have preconceived ideas about who will become ill first. Typically these ideas are gender related; women on average are both younger than their partner and have a greater life expectancy. From this vantage point, male carers commonly have problems adapting. Marsden and Dracup, (1991) suggested that couple's roles may become reversed. Men may feel unable to deal with the business of running a household, whereas women who have been in traditional roles may struggle with tasks that have always been performed by their husbands.

4.2 Summary

There has been a selection bias in the samples used in the majority of studies on cardiac patients and their partners, which has had a bias towards white female partners of male patients. A good grasp of English would also have been necessary to complete the lengthy questionnaires or interviews included in some studies.

Gender differences in partners of patients with cancer and mental disorder were described in order to provide a framework of understanding of the 'gender effect.'

Although descriptive studies are useful, the lack of outcome evaluations, small sample sizes and the use of untested measures limit the usefulness of the research.

The nature of cross-sectional designs mean that the direction of any association between outcome and moderator variables would be speculative. For example, it would be hard to confirm whether changes in the level of partners' emotional distress would predict changes in patients' psychosocial adjustment. Longitudinal studies would help to illuminate the nature of the relationship.

The bulk of the partners studies described above have been found in the nursing literature. There is a need for more research which is developed from psychological theory.

The following chapter will examine some psychological models of adjustment as tools for understanding the processes of coping with a partner's illness.

Chapter 5: Psychological Adjustment

Illness is an experience of loss and dysfunction and has more to do with perception, experience, and behaviour, than with physiological processes (Morse & Johnson, 1991).

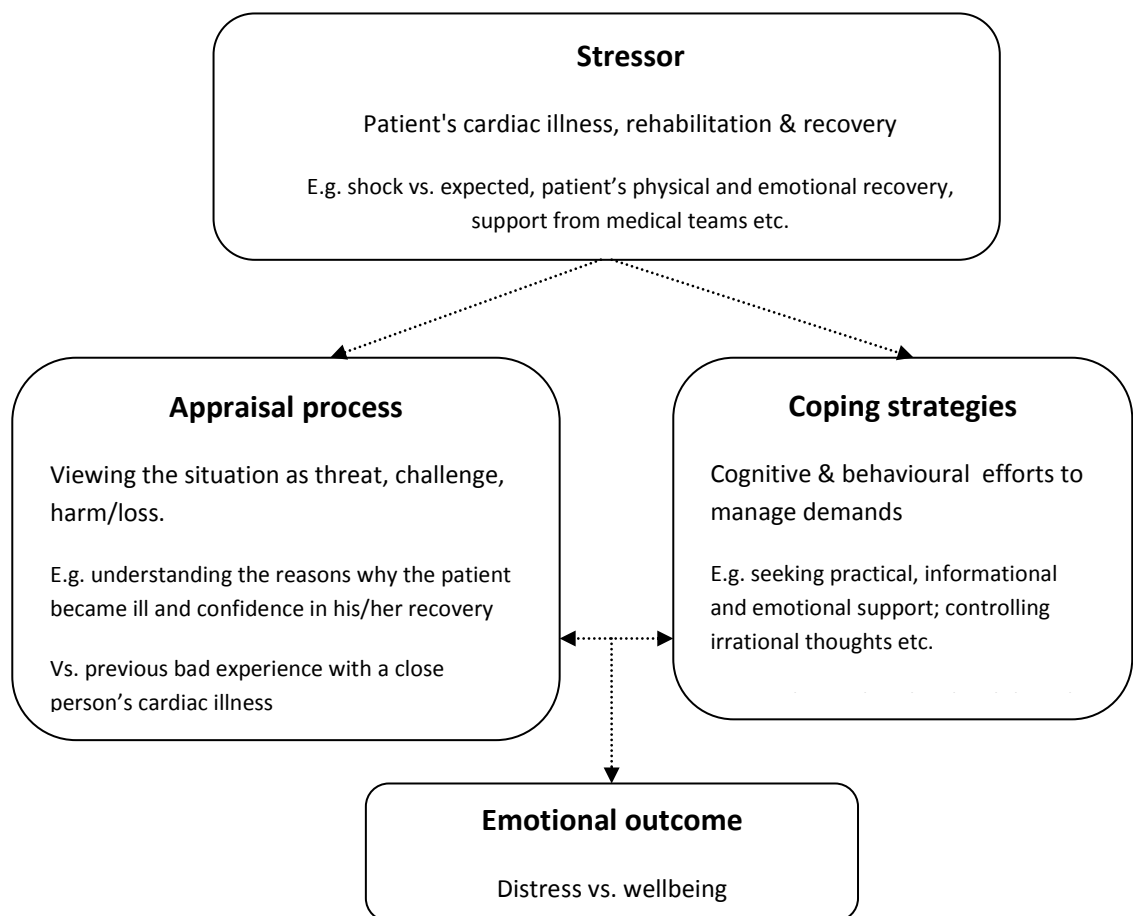
Psychological adjustment involves a dynamic interaction between the appraisal of the event and the appraisal of one's ability to cope. Psychological models of adjustment have traditionally been used to describe the ways that patients adapt to and learn to cope with chronic conditions over time. They provide a useful framework for describing the psychological needs reported by many people who experience mild to moderate difficulties, as well as those who have anxiety disorder or depression. This chapter will explore psychological models of adjustment as tools for understanding the processes of coping with a partner's illness, in order to understand why some partners adjust and cope very well, whilst others show symptoms of distress.

5.0 Transactional model of stress

The Lazarus and Folkman, (1984) transactional model of stress, offers a useful theoretical model by which the determinants of psychological adjustment to a patient's illness can be understood. They argue that stress is a process that involves the interaction of the individual with the environment. According to Lazarus and Folkman, the psychosocial impact of a stressor is influenced by both characteristics of the individual and characteristics of the stressor itself, see figure 5.1. A stressful situation would represent the **stressor stimulus**. This stimulus triggers an **appraisal process** and a **coping response**, which together determine the **emotional outcomes** of the experience. Adapting this model of stress to the experiences of the cardiac partners, as shown in figure 1 below, the situation experienced by partners of patient's following a cardiac event/ surgery and the subsequent recovery, would represent the stressor stimulus. The appraisal process would involve assessing the degree to which the stressful situation represents harm/loss, threat or challenge. It is not so much the event itself but the *interpretation* of the situation that is important i.e. what it means to the individual and this is influenced by situational and person characteristics. According to Lazarus et al., the way an individual appraises an event plays a fundamental role in determining, not only the magnitude of the stress response, but also the kind of coping strategies that the individual may employ in efforts to deal with the stress. The appraisal process, viewed in terms of illness perceptions, and coping strategies will be

explored in more detail in the section 5.1. The coping response is mediated via the individual's coping strategies. Coping strategies represent behavioural and cognitive efforts to manage stressful situations (Taylor, 2003). During stressful encounters, people draw on a variety of resources to aid them in the coping and adjustment process, including finances, social support, education, intelligence, and personality disposition (Lazarus & Folkman, 1984; Moos & Schaefer, 1993). These will be discussed in greater detail in section 5.2.

Figure 5.1: Transactional model of stress for partners of cardiac patients



5.1 The role of illness perceptions in appraisal

Leventhal et al., (1984) state that the experience of illness consists of two parallel processes. The first involves responding to cognitive representations of the illness threat and coping with the emotional reaction to the threat. The second involves coping with the implications of the illness itself. Leventhal et al., developed the Illness Perceptions Model, which proposed that people actively organise their beliefs about illness around five components that have been termed illness perceptions. These

components comprise beliefs about a) identity, i.e., the symptoms the patient associates with the illness; b) cause; c) consequences; d) time line, i.e., how long the patient believes the illness will last; e) cure/control. The Illness Perception Questionnaire (IPQ), (Weinmann et al, 1996) was developed to address these five components. These components provide a framework for patients and partners to make sense of the patient's symptoms, assess potential and current health risks, and direct their subsequent behaviour and coping response. This questionnaire has been revised and expanded and renamed the IPQ-R) (Moss-Morris et al., 2002).

Affleck et al., (1987) found the attributions of cardiac patients seven weeks following their MI were predictive of their health outcomes eight years later. Cardiac patients' illness perceptions have also been found to predict recovery factors such as attendance at cardiac rehabilitation and behavior change (Petrie et al, 1996).

Illness perceptions have also been found to play a prognostic role among partners. Randall et al., (2009), summarised the studies that explored cardiac partners' illness perceptions. Only two of them used the IPQ, the rest used non-standardised measures. The illness perceptions of the partner appeared to play an important role in determining the adjustment of both partner and patient. For example, Arefjord et al., (2002), found a significant correlation between partner's causal attribution regarding lack of exercise and the patient's increased exercise at six months. They also observed that attributing the causes to patient factors such as patient personality, stress and blaming the patient was associated with greater partner anxiety, depression and irritability at two-month follow up. This suggests that partner causal attribution may contribute to the experience of their psychological distress, (Randall, 2009).

Figueiras & Weinman, (2003), commented that research concerning the influence of beliefs of significant others such as the partner has been mainly restricted to the role of causal attributions and has generally neglected the possible role of the other components of the partners' illness perceptions in the recovery process. They said that although studies using the illness perception model have identified some ways in which the partner can influence the recovery of patients following MI, they have generally failed to assess the way individuals and their families make sense of, and cope with the illness.

In summary, the appraisal process involves the individual determining whether the event would be viewed as a threat or challenge. It is the individual's *interpretation* of the situation that is important and this is influenced by situational and person

characteristics. Illness perceptions are a useful way to frame this process and explore individual differences in coping and distress. Another way to look at the appraisal process would be to explore whether the number of misconceptions that the partner had about the patients' illness (which may relate to the perceived threat of the illness) would affect the partner's psychological distress. This will be discussed in greater detail in chapter 7.

5.2 Coping strategies

Lazarus and Folkman, (1984) classified coping strategies as either problem-focused or emotion-focused, delineating the function of coping as dealing with the problem or with its emotional and physiological outcomes, respectively.

Individual coping strategies and dispositional traits, such as optimism, mastery and hardiness, which might influence the availability or likelihood of coping strategies, can vary considerably amongst individuals. There is a small research literature exploring the types and efficacy of the coping strategies employed by partners to cope with the stressors associated with the patients' cardiac illness (Randall et al., 1998). In general, research suggests that partners fare better when they have a better sense of self efficacy (Coyne & Smith, 1994), non avoidance, mastery and active coping strategies (e.g. Christensen et al., 1998; Good et al 1998).

Active coping includes seeking social and informational support (Kettunen et al., 1999, O'Farrell et al., 2000), confrontative coping and problem solving (Santavirta et al., 2001). Coyne & Smith (1991) found that Partner's (wives) distress was decreased as a consequence of active involvement with their husband through discussion and constructive problem-solving. They found that wives' distress was increased by the patients' use of avoidant coping strategies such as hiding concerns and denying worries. Other research has found that distressed partners used disengagement coping strategies, such as withdrawal, avoidance and denial of the problem, significantly more than non distressed partners (O'Farrel, et al., 2000; Arefjord et al., 1998).

Perceived control is the self-generated belief that one has at one's disposal, a response that can influence the adversiveness of the event (Folkman, 1984). Researchers working among clinical populations have shown that feelings of control are associated with better psychosocial adjustment including less anxiety and

depression and improved self-esteem, in both partners and patients (Taylor et al., 1985; Mahler & Kulik, 1990).

Given et al., (1990) suggested that people who employ multiple strategies may cope better than do those that engage in one predominant coping style. Coping is dynamic and should be adapted to suit the needs of the situation and the stage of recovery. Coping strategies may be the most effective when they are matched to the particular problems for which they are most useful. If people have available to them multiple coping strategies they may be more able to engage in this matching process than those who have a predominant coping style. For example, confrontative coping might be better for coping with the aftermath of MI and problem solving would emerge as patients and partners attempt to modify their health habits and lifestyle, with the hope of reducing subsequent risk.

Recent coping research has taken a more interactive, dyadic approach, looking at the interaction of the coping strategies of both members of the marital dyad within the context within which these occur (Berg & Upchurch, 2007). However, none of the research looked specifically at dyadic coping following an acute cardiac event (Randall et al, 2008).

Ben-Zur, et al., (2001) point out that the cognitive paradigm views distress and emotion as outcomes of the coping process. Conceivably, however, the reverse process may occur: A high level of distress may lead to the use of emotion-focused coping and prevent efficient use of problem-focused coping by both patient and partner.

5.3 Sense of coherence & cardiac beliefs

Relatively few investigations have systematically looked at adjustment among the partners of chronically ill patient groups. The model that was chosen for this study was the sense of coherence (SOC), (Antonovsky, 1987). Antonovsky proposed the sense of coherence (SOC), which he described as a 'global orientation, a pervasive feeling of confidence that the life events one faces (such as coping with a patient's illness) are comprehensible, that one has the resources to cope with the demands of these events, and that these demands are meaningful and worthy of engagement' (1987, p. 19). A person with a strong SOC will have the capability to perceive that one could manage in a stressful situation.

Antonovsky explains that it is not the stressors themselves that lead to illness; stressors are everywhere and affect humans all the time. The concept of sense of coherence has been applied amongst patients and partners as an explanation for successful adjustment following the stress of illness. The studies using SOC have important implications for both research and practice. It was for this reason that the SOC was chosen for this present study.

In addition to sense of coherence, the current study looked at the partner's beliefs and misconceptions about the patient's illness, using the cardiac beliefs (Furze et al., 2007). It explored whether partners who overestimated the severity and consequences of the illness would be more likely to be anxious or depressed. The cardiac beliefs model was chosen in this study, firstly, because it was been recently developed by the reputable team in York, and this was an opportunity to put cutting edge research into practice. Secondly, it would be a very simple, and cost effective intervention to introduce, as the test itself could also become part of the intervention. Following the completion of the test, the partner (and patient) would also receive an answer / explanation sheet explaining why the beliefs were correct or incorrect. This could also be discussed with a member of the nursing team, or in a group intervention.

The sense of coherence and the cardiac beliefs scales will be examined in greater detail in the following two chapters. Both models complement each other in this study. Applying the models to Lazarus and Folkman's models of stress, the cardiac beliefs scale would examine factors relating to the **appraisal process** of the model. It would investigate whether the number of misconceptions that the partner had about the patients' illness (which would relate to the perceived threat of the illness) would affect the partner's psychological distress.

The concept of the sense of coherence (SOC) is a personality disposition hypothesized to affect the **appraisal** of stressors (Edman et al. 2001). Likewise, it would affect the factors mediating the partner's **coping response**, as it would look at the resources that the partner stress. Both of the models would be compared to external factors, such as disease related factors, relationship issues and health issues and partners social-demographics in explaining the partners' emotional wellbeing / psychological distress.

5.4 Summary

The way the partners appraise the patient's illness and how they cope with the demands placed on them are important mediators of their subsequent psychological adjustment. In order for an event to be appraised as a stressor, it must be personally relevant and there must be a perceived mismatch between a situation's demands and one's resources to cope with it. Positive adjustment when dealing with illness has been conceptualised in many ways. It is associated with the individual's (partner's) cognitions, including beliefs about the illness, coping strategies, behaviours and external factors including socio-demographics, health and relationship issues. Both the appraisal process and coping response are based mostly on an individual's own prior experiences and learning.

There are many factors that would determine partner adjustment. This section has explored the role of appraisal and coping processes in determining outcome, in the context of Lazarus and Folkman's (1984), transactional model of stress. Both the appraisal process and coping response are based mostly on an individual's own prior experiences, cognitions and learning. This may help to explain why partners' levels of distress is not necessarily related to the severity of the patients' condition.

Partner's adjustment would also be closely intertwined with other factors such as social and medical support, their help seeking behaviour, relationships, lifespan issues, socio demographics, physical and psychological health, lifestyle factors and the patient's recovery.

Relatively few investigations have systematically looked at adjustment among the partners cardiac patients. The two models that were chosen for this study were the sense of coherence (SOC) (Antonovsky, 1987), and the cardiac beliefs (Furze et al., 2007). The cardiac beliefs scale would examine factors relating to the **appraisal process**. It would investigate whether the number of misconceptions that the partners had about the patients' illness (the perceived *threat*) would affect their psychological distress. The sense of coherence would look at the factors mediating the partner's **coping response**, as it examines the resources that the partner has for responding to the stress. Both of these models will be explored in greater detail in the following two chapters.

Chapter 6: Sense of Coherence (SOC)

6.0 Background: salutogenic theory

Antonovsky, (1979) a medical sociologist, developed the salutogenic model to explain why some people, regardless of major stressful situations and severe hardships, stay healthy, while others do not. This theoretical model was designed to advance understanding of the relationships among stressors, coping and health. It later formed the foundation of the sense of coherence (SOC).

The salutogenic model contrasts to the traditional pathogenic (disease) model in several ways. Firstly, the pathogenic model assumes that people are either sick or they are healthy, whereas the salutogenic model proposes that human beings, at any point in time, are somewhere on a continuum between the two extreme poles of the 'health-ease' / 'dis-ease' continuum (Antonovsky, 1979). Secondly, the salutogenic model focuses on the predictors of positive health outcomes rather than to looking for the causes of disease (Antonovsky, 1979; Antonovsky, 1987).

Literally, salutogenesis means "the origins of health". The idea was developed after Antonovsky conducted an epidemiological study on problems in the menopause of women in Israel, using a target group of women who had survived the concentration camps of the Second World War. He was surprised to find that, among these women, there was a group that had the capability of maintaining good health and leading a good life in spite of all they had gone through. Antonovsky built upon a point initially identified by Selye (1974), that it is not what we face, but how we face it (1979). The two core factors in his salutogenic theory, are General Resistance Resources and the sense of coherence.

6.1 General Resistance Resources

The General Resistance Resources (GRR's) refer to any characteristic of the person, group or environment that can facilitate effective management of stress and tension (Antonovsky 1979). These include physical characteristics (diet, exercise), genetics, cognitive abilities (intelligence), material resources (especially money), emotional characteristics (self esteem and sense of identity), coping strategies (including attitude towards healthy living), interpersonal relationships (social support) and soci-cultural characteristics (culture, class and religion), childhood and life experience.

If stressors are viewed as increasing *disorder* in the system, GRRs tend to increase orderliness in the system (Sullivan, 1993). It is assumed that if a person has these kinds of resources at his/her disposal or in the immediate surroundings there is a better chance for him/her to deal with the challenges of life. The GRRs in the socio-cultural environment gives rise to life experiences that build up the individual's Sense of Coherence.

6.2 The “Sense of Coherence” (SOC)

The SOC is the core concept of salutogenic theory. It is assumed by Antonovsky to be involved in the mediation-process between stressful life events, well-being and health.

The SOC is a personal disposition, a global orientation to life. A person with a strong SOC will have the capability to perceive that one can manage in any situation independent of whatever is happening in life (Lindström & Eriksson, 2006). He/she will have the ability to successfully manage the infinite number of complex stressors encountered in the discourse of life and would respond with a sense that he/she can apply some structure to seemingly chaotic events. In contrast, the person with a low SOC tends to respond with a feeling of helplessness and burden (Antonovsky, 1987).

According to Antonovsky, (1979) the relationship between SOC and movement along the health continuum is indirect and is mediated by the role that SOC plays in the management of stress; Antonovsky predicts that a strong SOC will help to promote effective coping and resolve stress. Otherwise, it will lead to a decline toward health breakdown (Fok et al., 2005).

6.3 Components of SOC

The SOC concept is built up by three components:

- 1) *Comprehensibility* is the cognitive component; the extent of the belief that the problem is clear
- 2) *Manageability* is the extent of the belief that not only did one understand the problem, but one also had the resources to cope with the problem.
- 3) *Meaningfulness*, is the motivational component, the extent of the belief that coping 'makes sense' emotionally, and that one wishes to cope.

These three components constitute a person's coherent understanding of the world. Antonovsky states that the three SOC components should not be seen as independent dimensions but rather as interrelated 'accents' within the global concept of SOC. For example someone who lacks commitment to the activities of life (meaning) is not likely to be motivated to participate in shaping events, even if the situation is perceived as manageable (Sullivan, 1993). Although some researchers have given subscores for each of the three components, Antonovsky suggested that the very high intercorrelations would make this unwise.

6.4 SOC, coping and health

Sense of coherence is not a coping style and it does not refer to a specific type of coping strategy. It is the interaction of the resistance resources such as money, faith and coping strategies that work to enhance one's sense of comprehensibility, manageability and meaningfulness (SOC). In tension states, a strong SOC will help to mobilise GRR's, promote effective coping, resolve tension in a salutary manner, and reinforce the initial level of the SOC (Antonovsky, 1979).

While sense of coherence is not a coping strategy in itself, individuals with a high sense of coherence may be more likely to respond behaviourally with adaptive health behaviour (Antonovsky, 1987, p153). According to Antonovsky, we are confronted by stressors all the time and no specific coping style or resource is appropriate all the time. A person with a strong SOC would believe that he/she understands the problem, would see the problem as a challenge and would be more likely to flexibly adopt adaptive strategies, appropriate to the needs of the specific situation (Antonovsky, 1992). This has been confirmed by a number of studies which investigated the relationship between sense of coherence and the types of coping strategies adopted by participants when faced with a stressful situation (for example Margalit et al., 1992; McSherry & Holm, 1994). The results suggest that individuals with a greater sense of coherence are more likely to respond to a stressor with adaptive strategies, thus enhancing the likelihood of a positive outcome to the situation and reducing the chance of detrimental effects on health and well-being. Further research is needed in this area to determine the direction of causality (Pallant & Lea, 2002). Likewise research is needed to to examine SOC and coping behaviours in relation to health-related behaviours of interest to healthcare (Horsburgh, 2000).

The relationship between sense of coherence and ones movement along the health continuum is indirect and is mediated by the role that the SOC plays in the

management of tension. Antonovsky explains that it is not the stressors themselves that lead to distress, it is the individual *response* to stressors (tension management). If tension is managed appropriately, health (salutogenesis) can be enhanced, which could explain why some relationships grow even stronger following an illness. If the resulting tension is not managed, then stress (and distress) will result. Thus an individual's SOC may make the difference between appropriate tension management or pathogenic stress (Sullivan, 1993).

6.5 Comparisons between sense of coherence and other coping styles

The components of sense of coherence share similarities with many other coping styles, personal dispositional traits and cognitive models. For example, the *manageability* component is similar to Bandura's (1977) concept of self efficacy which stresses the instrumental aspect of coping – the belief that one can engage successfully in appropriate coping behaviour. However, whilst self efficacy is best used with reference to a specific situation or task, sense of coherence is seen as a global orientation.

Schüssler, (1992) looked at the coping styles of over 200 patients with chronic illness. He reported that those that saw illness as a challenge, and who had a sense of internal control, were connected with more favourable active coping factors. Likewise, those that saw illness as a weakness or punishment were associated with psychologically maladaptive defences. This ties in well with the Antonovsky's concept of *meaningfulness*. Empirical studies that discriminate among an increasing number of similar constructs, such as hardiness, locus of control, meaning in life and self-efficacy should receive high priority (Flannery & Flannery, 1990).

Sullivan, (1993) explored the concepts of locus of control, learned helplessness, and hardiness in relation to sense of coherence. According to Rotter, (1966) individuals who perceive that their situational outcomes are contingent upon their own actions are said to have an internal locus of control. Individuals who perceive situational outcomes as dependent upon chance, fate or the actions of others are said to have an external locus of control. The notion of perceived action and outcome has been expanded by Seligman (1975) in his theory of learned helplessness and model of depression, which was based on this theory of learned helplessness.

Sullivan, (1993) explains the sense of control as defined by Rotter (1966) and Seligman (1975) is often mistakenly equated with the manageability component of SOC and that there is a theoretical difference between the concepts of control. The individual who possess an internal locus of control, perceives a certain contingency between his actions and external events. This is distinct from Antonovsky's concept of manageability, in which the individual need *not* perceive events to be under his direct control, but only that they under some kind of control, though, perhaps not one's own, (although he has the conviction that he may participate in shaping the outcome). A strong sense of coherence might then be said to exist in an individual despite the absence of control.

Sullivan concludes that the body of work on control and helplessness, though similar in concept to coherence, is narrower in scope, has a pathogenic orientation, and may be culture-bound. The concept of hardiness (Kobasa, 1979) bears a much stronger resemblance to sense of coherence.

Antonovsky wrote that the hardiness construct 'perhaps has the greatest affinity with the sense of coherence.' (Antonovsky, 1993, p730), and the relationship between the two concepts have been studied by Tartasky, (1993), Sullivan (1993) and Williams, (1990), amongst others.

The three personality characteristics that hardiness comprises are commitment, control and challenge. Kobasa (1979) hypothesised that persons who believe that they can control events, who are deeply committed to the activities in which they are involved, and who accept change as challenge tend to remain healthier under stress.

A close analysis of the hardiness components (control, commitment and challenge) and the components of sense of coherence reveals subtle but important distinctions between the two. For example, Kobasa (1979) uses the term 'control' in a similar way to Rotter and Seligman, referring to a tendency to believe and act as though one can influence the course of one's life's events.

Challenge is based on the belief that the environment is ever changing and that the individual can perceive stress as opportunity for personal growth (Tartasky, 1993). Kobassa places challenge on a level with commitment, operating with its own health-promoting potential in the hardy personality typology. In comparison, the salutogenic model conceptualised challenge as a function of meaningfulness (a person who find some areas of life meaningful is likely to view the problems and demands as challenging rather than burdensome).

Antonovsky always maintained that the best way to analyse the relationship between sense of coherence and other constructs is empirically, not on theoretical grounds (Antonovsky, 1987; 1993). Empirical studies of sense of coherence demonstrated that sense of coherence was a stronger mediator of stress than hardiness (Williams, 1990). Newton, (1999) explored the relationship between hardiness and SOC to post-liver transplant return to work. Sense of coherence had a moderate and positive relationship with hardiness. However, sense of coherence had the stronger predictive capabilities for post liver-transplant return to work (the outcome most reflective of transplant of success) and accounted for most of the explained variance including any provided by hardiness.

Other stress-buffering variables have been studied including Mishel's (1988) concept of uncertainty and empathy (Onega, 1991). Onega concludes many of their components overlap with those of the sense of coherence. The components of sense of coherence may also overlap with some of the components of Illness Perceptions, including cure/control, consequences and identity, though this has not been investigated.

Eriksson, (2009) suggests how sense of coherence may fit in with other theories and concepts, contributing to an explanation of health and quality of life. The Salutogenic umbrella is shown in figure 6.1.

6.6 Development of sense of coherence

According to Antonovsky, (1984, 1987) the sense of coherence develops gradually through childhood and early adolescence and is determined by the GRRs. It is more or less stabilised by about 30 years of age when people of Western societies are assumed to have had sufficient experiences to have formed a view of life. When a person faces an unfamiliar stressor, the position on the sense of coherence continuum may decline. However, after a period of time, when the individual has mobilised his/her GGRs, the sense of coherence would return to its original position. Whilst Antonovsky (1984) viewed sense of coherence as largely established in adulthood, he argued that there is evidence that changes can occur if people can be enabled to alter their lives allowing a SOC-enhancing experience to occur.

Antonovsky claimed that sense of coherence was a universal mechanism that could be applicable to any culture. Empirical research has proved that this is the case (Bowman, 1996). Further it seems to be a property that develops over the lifespan, meaning it can be learned.

Has it happened that people whom you counted on disappointed you?

1 2 3 4 5 6 7

never happened
happened

always

SOC-29 includes 11 comprehensibility, 10 manageability, and 8 meaningfulness items. Thirteen of the items are formulated 'negatively' and have to be reversed in scoring, so that a high score always expresses a strong SOC. Previous studies have shown the SOC scale to possess validity and reliability (e.g. Antonovsky 1987; Langius & Björvell 1993). In over twenty studies, the instrument's Cronbach alpha of internal consistency has ranged from .82 to .95 (Antonovsky, 1993).

A shorter 13 item subset of the scale, known as the SOC-13, was proposed for use when time or space limitations prevented the use of the full scale. A review of studies using the condensed 13 item SOC suggests that, despite a reduction in the number of items, the SOC-13 also possesses adequate internal consistency with Cronbach alpha values ranging from 0.74 to 0.91 (Antonovsky, 1992). Other studies conducted using the 13 item SOC scale give support to the validity of the scale (e.g. Feldt et al., 2000; Ryland & Greenfeld, 1991; Pallant & Lea, 2002). This shortened scale was used in the current study.

SOC-29 or SOC-13 or both have been used by more than 113 research teams in 14 languages representing predominately Western, Judeo-Christian cultures . More than half of the respondents have been women and include adults of all ages, although a few studies examined adolescents and older children. Furthermore both measures have been examined with healthy, community-based and 'clinical' samples (Horsburgh, 2000). The SOC-29 has shown stronger empirical support for internal consistency than the SOC-13. This may be related to the sensitivity of Chronbach's alpha to the number of tool items – the SOC-29 has more than double the number of items (Horsburgh, 2000).

6.8 Sense of coherence and partners

Studies of sense of coherence have shown consistent results, indicating that Individuals with a high sense of coherence tend to cope more successfully with stressful life events including physical and psychological illness (Newton, 1999; Karlsson et al., 2000). Thus caregivers and partners with a strong sense of coherence are likely

to cope appropriately to their situation. The example below illustrates how a partner with a strong sense of coherence might cope.

‘Partner A,’ who has a strong sense of coherence, is confronted by the stressful experience of her husband’s cardiac event. It is assumed that she would be capable of:

- *Comprehensibility*: clarifying and structuring the nature of her husband’s cardiac condition; recognising the risk factors and the possible reasons that he became unwell, understanding the progress of the disease, his prognosis and the factors involved in his successful recovery and rehabilitation
- *Manageability* believing that she possesses the appropriate resources to cope and having the ability to mobilise her GGRs in order choose what seems to be the most appropriate strategy to cope. This could include as attending cardiac rehabilitation sessions, seeking smoking cessation support, speaking to her friends about her concerns or managing to maintain a positive attitude whilst coping with her husband’s mood swings and depression.
- *Meaningfulness* being motivated to deal with the stressor for example viewing smoking cessation, and coordination of medication as a challenge rather than a burden. She may decide to take the opportunity to lose weight together with her husband, so that they can motivate each other and share the experience.

There is a growing body of empirical work using sense of coherence to predict how families cope with patients’ illness and disability. Studies using sense of coherence have important implications for both research and practice, through the development of interventions that are designed to enhance SOC. The studies described below demonstrate this.

Svavarsdóttir and Rayens, (2003), used sense of coherence to identify factors that influence American and Icelandic parents’ health perceptions among families of children aged 6 or younger with asthma. Parents completed questionnaires regarding family demands, caregiving demands, family hardiness (FH), sense of coherence (SOC), and health perceptions. SOC and FH were both viewed as stress-resistance resources at the individual (SOC) and the family (FH) level. For both parents in the

study, their SOC mediated the effect of family demands on the outcome of parents' perceptions of their children's health. The interpretation of this finding is that the parent's inner feeling of confidence that the situation is manageable and meaningful, and that they felt comfortable in their role as a caregiver (i.e. their SOC), tempered their assessment of family demands and of perceptions of the health status of their young children. The researchers discuss the implications of their study for nursing practice. For example, interventions might be focused on discussing with parents their perceptions about their children's health, assessing parents' caregiving demands, and strengthening parents' ability to manage the chronic illness situation in the family. Such interventions might enable families to believe they are in better control over their family life, that they are able to manage having and caring for a child with asthma, and that they are more confident in using their resources to meet their demands.

In a study of 83 partners of individuals with first-ever stroke, Gunilla (2002) investigated the relationship between the partners' SOC, the severity of the disability of the stroke victim and the partners' subjective satisfaction with life before the stroke, view of the future and psychological wellbeing. Demographic data was collected, and the partners completed self-rating scales (The "Sense of Coherence Scale" , "Psychological General Well-Being (PGWB) Index" and "Life Satisfaction Checklist"). Finally a semi-structured interview included open questions on experience concerning life before the event, the ongoing life situation and belief in the future and on coping strategies and resources used.

The authors found that sense of coherence seems to be an important part of the spouses' capacity to cope after a critical life event such as stroke. They found that satisfaction with general life, close relationships and the socio-economic situation were significantly associated with the spouse's sense of coherence. Spouses with a low sense of coherence were more likely to have low psychological well-being and a more pessimistic view of their life in the future. Gunilla (2002) suggested that the results may have clinical relevance. To support spouses in their coping process, health care professionals should help them to increase their sense of meaningfulness, comprehensibility and manageability of the new life situation by giving them an understanding of what has happened and why and what the consequences may be, participating in shaping the outcome and of underload/overload balance in everyday life. Gunilla's study was very influential in shaping the design of our study with partners of cardiac patients, outlined later.

In a similar study Chumbler et al, (2004) found that life satisfaction, close relationships and the socio-economic situation were significantly associated with the partner's sense of coherence, one-month after the patient's stroke. Partners with a low sense of coherence were more likely to have low psychological well-being and a more pessimistic view of their life in the future. They concluded that determining factors that may lessen burden and depressive symptoms for caregivers of stroke survivors during the transition period after discharge to their residence are imperative for developing successful interventions.

Gallagher et al, (1994) examined the relationship between sense of coherence, the nature of patient pathology, situational coping responses, and role overload in partners of patients with dementia and compared this group to partners of chronically ill family members without dementia. A sample of 1261 Flemish-Belgian partners was used in this study. Sense of coherence appeared to influence the type of coping strategy adopted, with low levels of coherence associated with greater use of avoidant type coping. They found that sense of coherence was strongly associated with the adaptation of partners of patients with dementia. I.e. for problems related to emotional reactions, social isolation, sleep, and energy, sense of coherence has direct health promoting effects. They did not find a similarly strong association in partners of patients without dementia. They reported that the multidimensional impact of caring for a patient with dementia exerts a unique and particular strain that requires that caregivers redefine the meaning of their relationship with their dependent.

6.7 The current study

The cardiac literature has shown that the stress of a partner's illness may increase the partners' vulnerability to develop psychological and physical illness. However, not all partners experience a crisis in response to the patient's illness, and some demonstrate growth. Without identifying how the partners adjust to the stress of illness, it would be difficult to formulate appropriate responses to the partners health needs.

Based on the assumption that partners of cardiac patients have experienced a stressful life event, this study explored whether their level of sense of coherence was correlated with their psychological distress, and enabled them to cope more effectively. It would be useful to determine how health care providers can influence sense of coherence to enhance the partner's ability to be resilient in the face of their patient's illness.

Chapter 7: Cardiac beliefs

It has been argued that beliefs about illness/disease contribute to the experience of the disease and thus form the individual's feelings about the condition to a greater extent than the condition itself (Wright et al., 2002). Cardiac misconceptions about the impact of the disease on one's health and recovery can result in behaviours that adversely affect overall and cardiac health, and long-term outcome (Furze, 2007), thus leading to distress and impaired quality of life for both patients and their families (Newens, 1996). For example, people with more misconceptions about their heart disease have poorer physical and psychological health and more admissions to hospital with false alarms of chest pain, than those with fewer misconceptions. Reversing misconceptions is a better predictor of improvements in physical functioning than any change in severity of symptoms (Furze et al., 2007).

7.0 Cardiac misconceptions

The cardiac misconception scale (CMS) was developed by Maeland and Havik (1987). It consists of 12 true/false statements on prognosis and recovery from MI. The scale were developed with input from expert panels of cardiologists, cardiac nurses, and physical therapists. 383 post-MI patients were followed up for five years to determine the medical, social and psychological consequences of MI. Examples of the misconceptions include:

'After a typical heart attack, the patient must always avoid physical exertion' (False)

'Almost everyone can resume their sexual activities after a typical heart attack' (True)

It was found that the patients with more misconceptions about MI in this study were associated with poorer outcomes and increased costs from unnecessary hospital admissions following their initial discharge. They felt less in control of their lives, had less confidence in their overall health and were less likely to return to work than patients with fewer such misconceptions. .

Furze et al., (2003) outlined some flaws in the Cardiac Misconceptions Scale. For example the wording of one of the questions is inaccurate, leading to that item being erroneously scored as a misconception. Another question is now incorrect owing to

changes in post-MI management that have occurred over the past decade. In addition, she explains that the authors do not explain how they arrived at their list of common misconceptions, and that later work in this area has indicated that there are other, more common, misconceptions that patients hold about the causes of MI and the best way of coping afterwards, which were not included.

7.1 The Cardiac Beliefs Questionnaire

The Cardiac Beliefs Questionnaire was developed by Furze et al, (2007) from the British Heart Foundation Care and Education Research Group, based in York. This was the same team that designed 'The York Angina Beliefs Questionnaire (Furze et al, 2003). The York Angina Beliefs Questionnaire was successful in identifying commonly held misconceptions or potentially maladaptive beliefs about Angina. In a study of 133 people drawn from general practice and diagnosed with angina, the questionnaire was found to be valid and reliable. People with more misconceptions about their angina were more likely to be anxious, depressed and/or physically limited. The questionnaire is included in the Angina Plan, as it is very quick to complete and easy for health care professionals to elicit and dispel misconceptions.

The Cardiac Beliefs Questionnaire was derived from interviews with people with various forms of CHD who were awaiting coronary artery bypass, and also included the most predictive items from earlier questionnaires of angina beliefs and cardiac misconceptions.

The first form of this questionnaire has been found to be valid and reliable; the alpha scores and test-retest were both above 0.8. The Cardiac Beliefs Questionnaire is due to be published at the end of the year.

The questionnaire consists of 20 true/false statements that are designed specifically to uncover cardiac misconceptions. The answer sheet comes with an explanation about each misconception. Examples of the questions include:

'Once you have had one heart attack you are bound to have another one'. Agree / disagree.

(Answer: No, most people who have had one heart attack never have another)

'It's OK to disagree with people with heart problems'. Agree / disagree

(Answer: Yes, disagreements are part of everyday life. Bottling things up can make them worse)

The Cardiac Beliefs Questionnaire would be a useful clinical intervention for cardiac staff to employ. The simple questionnaires, which take minutes to complete, can be used to find out whether patients hold erroneous beliefs about cardiac functioning and education to reverse misconceptions can then be targeted at the specific beliefs. Moreover, the questionnaire eliminates those patients who already have all of the right ideas, and so is a more efficient use of healthcare professionals' time. The questionnaire could be used with patients with both angina and post MI and also their partners Furze et al, (2007). For this reason it has been included in this study.

7.2 The current study

The current study explored the relationships between the partners' sense of coherence, their cardiac beliefs and distress levels, in order to understand why some partners cope better than others. Specifically, it looked at whether the partners with more misconceptions about the patient's heart disease experienced more distress

Chapter 8: Support interventions for partners

Partners' needs & support

Several studies found that spouses were not very satisfied with the informational and emotional support from health professionals (e.g. Thompson et al., 1995; Davies, 2000; Steward et al., 2000; Tarrka, et al., 2003; O'Farrell et al., 2000; Thompson & Codle, 1988) and that partners felt neglected by health care professionals (Kettunen et al., 1999). Dissatisfaction with information has been associated with anxiety and depression amongst both partners and patients (Davies, 2000).

Moser et al (1993) found that *informational* needs were the most highly ranked by both patient and partner. This included receiving specific facts about the patient's condition, prognosis, progress and lifestyle changes. They found that most of the partner's (and patient's) needs were unmet. Partners also reported a high incidence of unmet social and *emotional support* needs and they received little counselling or assistance in coping.

Sources of help and information available to partners include face to face support from the medical staff, written material such as the BHF booklets, online information and group support.

Cardiac rehabilitation

Cardiac rehabilitation is a multidisciplinary activity that aims to facilitate physical, psychological and emotional recovery and to enable patients to achieve and maintain better health (NHS Centre for Reviews and Dissemination, 1998). Many programmes now invite partners to attend cardiac rehabilitation programmes. Studies have shown that couples participating in cardiac rehabilitation programmes perceived that these had positive effects on their coping, and also on the quality of their marital relationship (Stewart et al., 2001). In addition, partners who share the cardiac risk lifestyles with the patient would also benefit directly from the interventions such as smoking advice, stress management and healthy eating (Macken et al., 2000).

Although the efficacy of cardiac rehabilitation programmes is well established, low participation is a significant problem (Dusseldorp et al., 1999). O Farrel et al., (2000) suggested that the support a patient receives from a cardiac rehabilitation program and the opportunity for partners to participate in the rehabilitation program education sessions are not enough to prevent or diminish clinical distress in partners. He

recommended that partners of patients (undergoing cardiac rehabilitation) should be screened for psychological distress, and those in distress should be offered interventions focused on assisting them to deal with specific stressors related to their experience.

Group support

It has been suggested that distressed partners need to be encouraged to have contact with others in the same situation, and that a cardiac rehabilitation **support group** for partners could address this. (Coyne & Smith, 1991; O'Farrel et al., 2000). Partners would benefit from having contact with others in the same situation. It would help to identify with and support others who share similar experiences (Borkman, 1990). This could validate and normalise their experiences and adjustment.

In a group support, O'Farrel et al., (2000) explained that partners would have the opportunity to express their emotions; increase their use of engagement coping strategies, such as problem solving and cognitive restructuring; and learn to respond more adaptively to the stressors that are within and beyond their control. This could help to relieve the demands, pressure and sense of vulnerability and distress they experience.

A support intervention for partners would be a cost-effective medium to provide the necessary support to partners. It is for this reason that this current study wanted to explore partners' interest in attending a group and gain a better understanding of the best way to implement it.

Stewart et al., (2001) designed, implemented and evaluated a support group intervention, involving peer and professional supporters, for persons with first-time MI and their partners. Five different support groups took place, each 1 hour weekly for 12 weeks. All participants were satisfied with the support intervention. They perceived that these groups had a positive effect on their coping, confidence and perceived control, and on the quality of their spousal relationship. The authors concluded that the group interventions provided emotional and informational support, and that social learning and social comparison were prevalent processes.

There are many different formats that support groups could take. For example groups could take place with or without the patient being present. Likewise, they could have a fixed number of sessions, occur just once or be a rolling, drop in programme.

The current study

One of the aims of this current study was to investigate the type of assistance that partners received from health professionals, their help seeking experiences, preferences for support interventions and barriers to participation. This information was used to design a framework for partner intervention.

Summary

Studies have shown that, in general, partners are not satisfied with the informational and emotional support from health professionals, and that they often felt neglected by health care professionals. Dissatisfaction with information has been associated with anxiety and depression amongst partners (and patients).

Many Phase III cardiac rehabilitation programmes now invite partners to attend. Studies have shown that couples participating in these programmes perceived that these had positive effects on their coping. O'Farrell et al., (2000) suggested that this would not be enough to prevent or diminish clinical distress in partners. He recommended that partners should be screened for psychological distress, and offered relevant interventions.

In a support group, partners would benefit from having contact with others in a similar situation. There are many different formats that support groups could take.

Support interventions that include cognitive behavioural therapy would be useful in challenging assumptions and beliefs about the patient's illness as well as examining behaviour, and teaching methods to strengthen internal resources such as stress management and relaxation.

The current study investigated the type of assistance that partners received, their help seeking experiences, preferences for support interventions and barriers to participation. The information was used to design a framework for partner intervention.

Chapter 9 Rationale for the current study

9.0 The current study

A great deal is already known about the experiences of being a partner of a person with cardiac problems. However, there are also gaps in knowledge, especially in understanding why some partners cope better than others.

The current study aimed to explore the experiences of being a partner of a person with cardiac problems. Specifically, it investigated whether partners were distressed, and if so, the particular reasons they gave for this. Theoretically, it looked at the relationships between the partners' sense of coherence, their cardiac beliefs and distress levels, in order to understand why some partners cope better than others. Finally, the study examined partners' experience of health care services, and their preferences for interventions that might alleviate their distress. The rationale for the research was that better understanding of how partners cope would provide cardiac teams with the necessary evidence based research to provide suitable interventions for partners. The bulk of the partners' studies have been found in the nursing literature, and there is a gap in the research developed from psychological theory.

The focus of the current research was supported by Randall et al (2009), who concluded their systematic review by arguing that due to the important role of partner support in recovery following an acute cardiac event, and the influence of partner adjustment on his or her ability to provide support, the experiences of partners merited detailed investigation. They also maintained that not only was there a need for more research, but the research needed to be translated into practice through the implementation of partner interventions.

It was hoped that the study would include a representative sample, as limitations of previous studies included the fact that many samples were restricted to white, female partners.

9.1 Aims of the study

The aims of the study were:

- a) to determine whether cardiac partners are distressed;
- b) to explore the relationship between sense of coherence (independent variable), cardiac beliefs (independent variable), and levels of distress (dependent variable).
- c) to investigate the reasons for the partners distress;
- d) to identify any gaps in the care provided and opportunities for service development.

9.2 Outline of the study

A cross-sectional questionnaire study, followed by a smaller scale interview of partners of patients undergoing cardiac rehabilitation was conducted.

The research design was influenced by the many successful studies outlined in the literature review, including Bennet & Connel, (1999), O'Farrell et al., (2000), Kettunen et al., (1999) and Thompson (1995). The research used a mixed methodology approach (Tashakkori, & Teddlie, 1998), combining standardised scales, closed and open-ended questions with semi-structured interview data. This was felt to be the most appropriate approach to answer our research question.

a) Part 1: questionnaire

The first phase of data collection used a self-report, non-invasive questionnaire. The questionnaire was chosen as it is an effective medium to test the psychological theory and highlight general themes from a large sample of participants.

Questionnaire variables and their measurement

The Hospital Anxiety and Depression Scores (HADS) was used to categorise distressed and non-distressed partners. The HADS was selected as a quick and easily self-completed scale which has been fully validated (Moorey et al. 1991) and used extensively with hospital populations, including cardiac patients (Thompson, 1990; Underwood et al., 1993).

The cardiac literature has shown that the stress of a partner's illness may increase the partners' vulnerability to develop psychological and physical illness. However, not all

partners experience a crisis in response to the patient's illness, and some demonstrate growth. Without identifying how the partners adjust to the stress of illness, it would be difficult to formulate appropriate responses to the partners health needs. There is a growing body of empirical work using sense of coherence to predict how families cope with patients' illness, and SOC has been found to play an important part of the partners capacity to cope. Moreover, previous studies have shown the SOC scale to possess validity and reliability. Although there is a growing body of empirical work using SOC to predict how families cope with patients' illness and disability, SOC has never been used with partners of cardiac patients.

Studies using sense of coherence have important implications for both research and practice, through the development of interventions that are designed to enhance SOC. It would be useful to determine how health care providers can influence sense of coherence to enhance the partner's ability to be resilient in the face of their patient's illness. For this reason, it was included in this study. The partners' Sense of Coherence was tested to see if it was associated with their psychological distress, thus enabling partners with stronger SOC's to cope more effectively.

The partners' beliefs and misconceptions about the patients' illness were explored, using the cardiac beliefs scale (Furze, 2007), in order to determine whether partners with more negative misconceptions about the patients cardiac illness fared worse in terms of psychological wellbeing. The Cardiac Beliefs Questionnaire would be a useful clinical intervention for cardiac staff to employ. The simple questionnaires, which take minutes to complete, could be used to find out whether patients hold erroneous beliefs about cardiac functioning and education to reverse misconceptions can then be targeted at the specific beliefs. Moreover, the questionnaire eliminates those patients who already have all of the right ideas, and so is a more efficient use of healthcare professionals' time. The questionnaire could be used with patients with both angina and post MI and also their partners Furze et al, (2007). For this reason it was included in this study.

The partners demographics, severity of the partner's illness and relationship factors were also investigated. Finally, the study examined partners' experience of health care services, and their preferences for interventions that might alleviate their distress.

b) Part 2: interview

In the second phase of the study, a small sample of participants who had completed a questionnaire, and given their consent, were interviewed. The interviews were an opportunity to follow up and expand on specific issues and themes that had emerged from the analysis of the questionnaire, as well as to capture some personal experiences.

Whilst completing the questionnaire, partners indicated if they would be willing to be interviewed over the telephone at a later stage. The willing participants included relevant contact information.

A sample of partners, who had given consent, were chosen for a telephone interview. This was to follow up on themes that had emerged during the analyses.

Data were collected by one interviewer by means of semi-structured informal-style interviews over the telephone. It was decided that due to the informal nature of the material, telephone interviews would be the most efficient way of interviewing as they would be informal, private, less intrusive and quicker to set up and deliver than a home visit.

Each interview averaged 20 minutes in duration. Notes were made throughout. During the process of gaining consent, the couples were informed that the purpose of the research interview was to explore their experiences in order to assist the development of possible interventions for partners in the future.

It was decided that the interviews would follow up on themes that had emerged during the analyses. This meant that the actual content of the interviews was not established until the analysis of the questionnaires had been completed, although it was known that some of this would focus on the development of possible interventions. It was hypothesised that possible themes that might have been explored could include age and gender issues as well as specific areas of concern that might have been relevant to the partner's coping. For this reason, the themes explored in the interview and the procedure for choosing the partners to be interviewed is discussed in Chapter 12, following the analysis of the questionnaire.

9.3 Outline of the remainder of the thesis

Chapter 10 explores the design, measures, procedures and analyses used in the questionnaire. The results of the questionnaire are outlined in Chapter 11. The interview methodology is described in Chapter 12. This includes a detailed summary of the interview design and the procedure, the methods used to choose the sample of partners, as well as the profiles of the partners interviewed. This is followed by the analysis of the interviews in Chapter 13. The discussion and conclusions of the complete study are given in Chapter 14.

Chapter 10: Questionnaire design & methodology

10.0 The questionnaire pack

The questionnaire pack was contained within a sealed A4 envelope. On the front of each envelope was a label saying: 'Carer's Questionnaire. Please give this to you Husband / Wife or Partner.' On the back of the envelope was another label saying:

'We are interested in your experiences of being a partner of someone with heart problems. We will use your responses to improve our service. Please fill in the enclosed questionnaire and return it in the stamped address envelope provided to Katy Filer, who is conducting this research. Your responses will be totally confidential and will not be read by the nursing team and won't affect your partner's care. Further information can be found inside, or you can call Katy on 07957 219755. Thank you for your time, it is really helpful.'

Each envelope contained: an information sheet (Appendix N), two consent forms (Appendix N), the main questionnaire (Appendix O) and a stamped addressed envelope (SAE).

10.1 Participants

The questionnaires were given to the partners of patients who fulfilled the hospitals' criteria to be *invited* to attend phase III cardiac rehabilitation (CR). Neither the patient nor the partner needed to have actually attended CR. Both male and female partners were included.

The inclusion criteria were the following: (a) the spouse understood written and spoken English; (b) the patient was invited to cardiac rehabilitation; and (c) informed consent was obtained from the partner. Exclusion criteria included partners of patients with other heart conditions such as heart failure and those with implantable cardiac defibrillators (ICDs) and any other carer who was not a long term partner, such as son, daughter or nurse.

10.2 Distribution of the questionnaire

414 questionnaires were given out over a three and a half year period at two large NHS trusts.

The questionnaire packs were handed out:

- 1) At the cardiac assessment clinic prior to phase III cardiac rehabilitation, by a clinical psychologist. The questionnaire packs were offered to those patients with partners, to take home to give to the partner. If the partner attended the sessions, the partner received the questionnaire directly.
- 2) The questionnaire packs were also offered at cardiac rehabilitation classes, either by the cardiac nurses or by the researcher.
- 3) The questionnaire packs were handed directly to the partners at the Phase II home visits, by members of the cardiac team. This meant that the packs also reached the partners of people who chose not to attend cardiac rehabilitation, which widened the representativeness of the sample.

10.3 Completing the questionnaire

The participant (the **partner** of the person with cardiac problems) read the information sheet provided in the pack. On deciding to take part, they signed the two consent forms keeping the information sheet and one consent form for their records. The partner then completed the questionnaire and sent it back to the main researcher in the SAE along with the consent form.

10.4 Content of the questionnaire

The questionnaire consisted of four sections; general questions and three scales.

- Section 1: The “Sense of Coherence Scale” (SOC)
- Section 2: Cardiac beliefs
- Section 3: The Hospital Anxiety and Depression Scale HADs (Zigmond, & Snaith, 1983).
- Section 4: General questions

a) **The “Sense of Coherence Scale” (SOC)**

Sense of coherence was measured using the 13 item short form of the Orientation to Life Scale (Antonovsky, 1987), abbreviated to SOC-13.

After reversal of five items, the total score was summed, which could range from 13 (low sense of coherence) to 91 (high sense of coherence).

In this sample, the alpha reliability was 0.889

b) **Cardiac beliefs**

The cardiac belief scale was used to look at partners’ misconceptions of facts surrounding heart disease and whether this was related to their distress. The questionnaire consists of 20 true/false statements that were designed specifically to uncover cardiac misconceptions. The scores could range from 0 (no incorrect beliefs) to 20 (all beliefs inaccurate). The scale came with answers and explanations that were sent to the participants on request.

c) **The Hospital Anxiety and Depression Scale**

Distress (Anxiety and depression) were measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond, & Snaith, 1983). It consists of 7 items for anxiety and 7 for depression, each scored from 0–3. Each sub-scale is therefore scored out of 21. A score of 11 or more is considered to constitute a ‘definite case’, scores of 8–10 are ‘borderline’ and scores of 7 or less do not constitute ‘caseness (Snaith, 1993).

In this study the Cronbach’s Alpha reliability was .906

d) **General questions**

This section of the questionnaire was developed by the authors with the aim of eliciting partners’ problems, needs and experiences via self-rating scales, whilst also allowing the respondents to elaborate on their answers when relevant, so that they would not be restricted by the scales. Whenever a list of items was provided, such as ‘list of concerns’ and ‘further sources of help’, participants were also able to include additional items reflecting their own experiences. The questions were constructed based on a careful literature review of previous research, discussions with cardiac rehabilitation

teams including cardiac nurses, physiotherapists, occupational therapists and psychologists and the authors' previous experience.

General questions included:

- i. Socio-demographic data to ensure comparability between the participants included age, sex, ethnicity and employment.
- ii. Information concerning the medical condition of the patient and length of stay in hospital.

Although referral to CR is almost entirely restricted to those who had sustained a heart attack (MI), elective angioplasty (PCI) and coronary artery bypass surgery (CABG), no assumptions were made about the patients' condition. Therefore the partners were asked to state which event(s) the patient had experienced from a list that included cardiac surgery, angina, heart attack, angioplasty / STENT, 'not sure' and 'others (please state)'.

- iii. Two self-rated questions on the general health of the partner and current health issues.

These questions were included to investigate whether the additive stress of the patients' illness may lead to the development of health problems in the partners as suggested by Rolland, (1990) and Boss et al., (1990).

- iv. Partners self assessment on how they were feeling about their life in general, using a 7-point scale with the statements; 'delighted / pleased / mostly satisfied / mixed / mostly dissatisfied / unhappy / terrible'.

Respondents were asked to state the main reason for their satisfaction and/or dissatisfaction in an open question.

- v. Questions concerning the duration and quality of their relationship and the degree their partners illness had affected it.
- vi. Assessments of how well they thought the patient was coping and how well they thought they were coping.
- vii. Assessment of the degree to which they found a range of concerns problematic or not.

The partners' range of concerns were made up of ten concerns, which included 'too many responsibilities, not enough time for myself, patients' ability to do less things, financial worries, the patients' moods and emotional concerns, patients' attitude towards his/her recovery, helping the patient to carry out lifestyle changes such as stop smoking, patients' future work prospects, social activities, worries about patients' future health.' The 5-point response scale for each statement was anchored with 'no problem at all' (1) and 'yes, very much a concern' (5).

The partners were asked whether they felt that they could talk to their partner about their concerns.

- viii. Assessment of the quality of information and advice received from medical staff about both their partners' physical and emotional condition.
- ix. Indication of the sources of help and information which they used throughout the patient's illness.

The sources of help and information included 'discussion with the nursing team, British heart Foundation (BHF) material, advice line, Internet, attending cardiac rehabilitation, local library and information booklets.'

- x. Indication of the sources of help and information help which they might have been interested in receiving, if they were available. These included: i) more written information and advice about caring for someone with heart problems, ii) a group session with other partners to discuss issues such as lifestyle changes and help with the emotional problems that may result when caring for someone with heart problems, iii) more one-to-one discussion with nursing staff, iv) education in basic life support skills (resuscitation).

The 3-point response scale for each item was interested / not sure / not interested. A further question invited respondents to add anything else that would have been, or still would be, helpful for them.

- xi. Partners were asked whether they a) would be willing to be interviewed over the telephone to discuss matters in greater detail; b) wanted to receive the answers

to the cardiac beliefs questions; c) wanted to receive a copy of the completed study. For the above, they were required to include their name, address and/or telephone number.

10.5 Ethical considerations

A favourable ethical opinion for the research was granted by Lewisham Local Research Ethics Committee, 10/05/05. R&D approval was granted by each NHS care organisation, see Appendix 3. The research also met the BPS standards of ethics.

Participants were: a) informed that all information that they provided would be treated as strictly confidential and used only for the purpose of the study; b) informed that they had the right to withdraw from the study at any time; c) provided with written information regarding the study; d) signed a consent form.

10.6 Response

112 questionnaires were returned and 89 partners fulfilled the criteria for inclusion in the study. There were 13 participants who did not meet the criteria for the study; some of the forms were filled in by the patients' children and other carers, another was completed by the patient, six were rejected because there was inadequate information, another person returned the wrong form.

10.7 Outcome measures & statistical analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS).

By convention a *P* value of 0.05 was accepted as the level of significance (Bowling 1997).

Multiple linear regression analysis, using the enter method, was used to investigate predictors of psychological distress (HADS). The dependent variable was the partners' HADS, which was used as a general measure of their distress. The independent variables were the cardiac beliefs and the sense of coherence.

Pearson correlations were used to quantify the relationship between continuous variables.

One way ANOVA, between subjects, was used to see if there was a difference between HADS of three groups of partners (those '*interested*', '*not interested*' and '*not sure*') in relation to receiving specific interventions.

Qualitative analysis was used on the analysis of the open-ended questions in the questionnaire as well as the interview data. It was analysed by the main researcher, a psychologist, who was neither associated with the patients' care, nor was employed by either of the NHS Trusts.

The content of this data was broken down on an excel spreadsheet into categories, in order to identify common themes and emerging patterns. Each category was then explored in order to gain further insight into both general patterns and individual behaviour.

For example partners experiences whilst the patient was *in the hospital* were broken down into:

- General experiences
- Patients' illness (e.g. shock, vs. being expected / prepared; first time cardiac event vs. ongoing history; type of event)
- Quality and quantity of information provided (was it enough / inadequate; initial information)
- Who provided the information (cardiologist, nurse, GP)
- Discharge information
- Medication information & concerns
- What they found hard
- What they found helpful
- What help & support they would have liked to have received
- Suggestions
- Psychological support

Triangulation is a method of cross-checking data from multiple sources, including questionnaire and interview data, to search for regularities in the research data, in order to give a more detailed and balanced picture of the situation (O'Donoghue & Punch, 2003; Altrichter et al., 2008). Having access to quantitative data from the same participant and being able to refer to it in interviews would help to increase the validity of results in line with the principles of methodological triangulation described by Denzin, (2006).

10.8 Missing data

The two missing SOC scores were replaced by the mean (66.86). This raised the mean to 66.865 (SD 15.21). The median value, 67, remained the same.

The three missing cardiac beliefs scores were replaced by the mean (7.43). This lowered the mean was 7.42 (SD 3.907) and the median remained the same.

The mean scores were *not* used to fill in the missing data for the five partners who did not adequately complete the HADS, as the HADS was the dependent variable in the regression analysis.

10.9 Checking the data

The distribution of each of the measures (SOC, Cardiac beliefs and HADS) were checked via the frequencies and descriptive statistics and there were no errors. The CBQ and HADS were slightly positively skewed. The SOC scores were slightly negatively skewed and clustered a little, with a uniform distribution.

Scatterplots of each independent variable were explored against the dependent variable to check for linearity and outliers. There were no outliers of more than 2 standard deviations from the mean.

The variance of the measures was what would be expected. The reliability of each scale was estimated by Cronbach's coefficient α .

The data was tested for heteroscedasticity. There was homoscedasticity of variance.

The following graphs are displayed in Appendix 2

- Histogram to test the regression standardized residual (Figure 2.1).
- Scatterplot to show the regression standardized residual against the regression Standardized predicted value, to examine outliers, linearity of the fit etc. (Figure 2.2)
- Partial regression plots (HADS / SOC) (Figure 2.3)
- Partial regression plots (HADS/ cardiac beliefs) (Figure (2.4)
- A normal P-P plot to test the normality of the distribution of residuals (error) (Figure 2.5)

Chapter 11: Results of the questionnaire

Contents: chapter 11

- Section 1: Sample Characteristics
- Section 2: Exploring the variables: Distress, SOC and cardiac beliefs
- Section 3: Impact of the patient's illness
- Section 4: Support & Interventions

Section 1: Sample Characteristics

11.0 Partners' demographics

a) Age

The mean age for the partners was 57.29 years, (S.D.= 12.86), the median and mode were both 59 years and the age range was 24–89 years. The range of ages is displayed in figure 11.1.

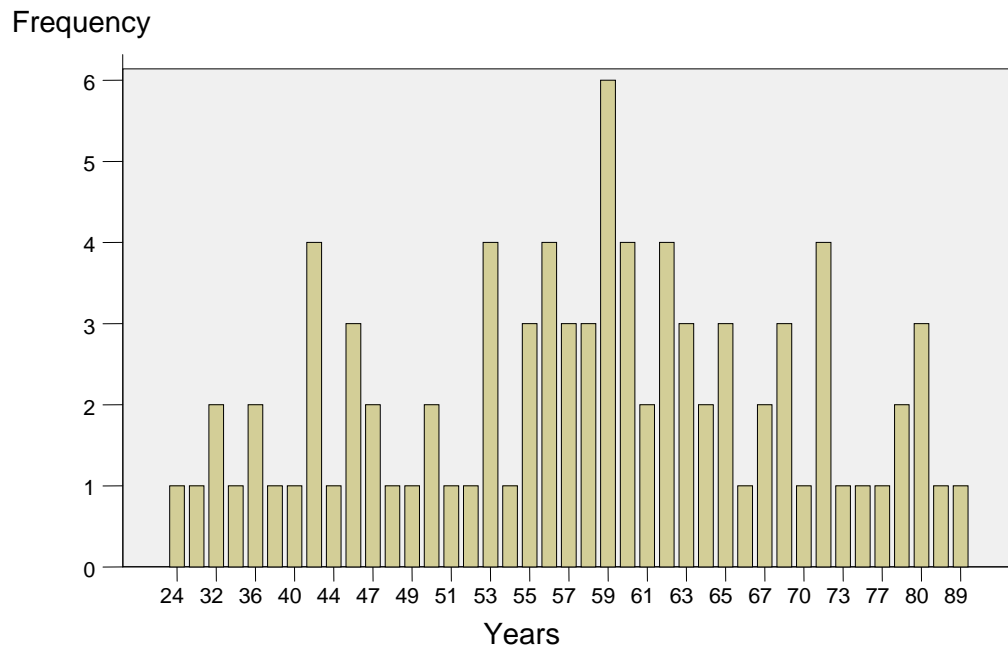
b) Gender

The majority were of the sample was female ($n = 59$, 66.3%) with 29 men (32.6%)

c) Ethnicity

The ethnic breakdown showed that 72 partners were white (80.9%), with a small spread of Black-Caribbean ($n = 3$), Indian Pakistani ($n = 3$), Chinese ($n = 1$) Other Asian ($n = 3$) and 'Other' ($n = 5$) which included Kurdish, Turkish, Goan/Portugese and Latino). Due to the high proportion of white partners, the categories were combined for analysis so that there were just two categories: 'white' and 'non-white'.

Figure 11.1 Partners' age



d) Employment

The categories were combined into 'employed' (full or part time), and 'not working,' (unemployed, retired or homemakers). The majority of the group were not working ($n = 53, 59.6\%$), the rest were employed ($n = 36, 40.4\%$).

e) Relationship

87.5% of the couples were cohabiting ($n = 77$).

The number of years that the couples had been together ranged from under one year ($n=4, 4.5\%$) to 60 years ($n=3, 3.4\%$). Table 11.1 shows the length of the partners' relationships.

Table 11.1 Length of partners' relationships

Years together	0-10	11-20	21-30	31-40	41-50	51-60
Frequency	18	14	16	24	4	13

85% ($n = 74$) of the partners rated their relationship as 'good' or 'excellent'. The remainder ($n=13, 14.9\%$) rated their relationships as neutral. None of the partners rated their relationship negatively.

11.1 Information about the patient

a) Length of time that the patient was in hospital

The number of days that the patient was in hospital ranged from 0 days (outpatient) to one year, as shown in table d. 87.1% ($n = 74$) were in hospital for 14 days or less, see table 11.2.

Table 11.2 Length of time in hospital

Time in hospital	Frequency	Valid Percent
0-1 day	9	10.6
2-7 days	48	56.5
8-14 days	17	20.0
Over 2 weeks	11	12.9
Total	85	100.0

b) Patient's illness

39.8% ($n=35$) of the patients had cardiac surgery and/ or 39.8% ($n=35$) had a MI; and 40.9% ($n=36$) had a STENT.

15.9% ($n=14$) had angina and 6.8% ($n=6$) indicated 'others,' these included atrial fibrillation, ablation and pace electrode.

11.2 Partners' health & wellbeing

77.3% ($n=68$) of the partners reported that they were in good / very good general health; 22.7% ($n=20$) of them were in fair / poor general health.

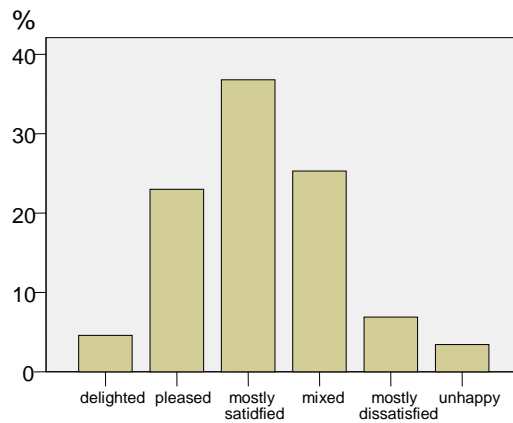
35.6% ($n= 31$) partners reported that they had current health concerns; 64.4% ($n=56$) had no concerns.

Satisfaction with their lives

The frequency of partners' life satisfaction ratings are displayed in figure 11.2. 27.6% ($n=24$) partners rated their feelings about their 'life in general' as pleased (23%; $n=20$), or delighted (4.6%; $n=4$).The majority of the partners were mostly satisfied (36.8%;

$n=32$) and 25.3% ($n= 22$) of partners had mixed feelings. 10.3% ($n=9$) of the partners were either mostly dissatisfied (6.9%; $n=6$), or unhappy (3.4%; $n=3$).

Figure 11.2 Partners' life satisfaction



There were no significant gender differences in mean life satisfaction, with women scoring 3.07 (SD .958) and men 3.24 (SD 1.179).

Age was significantly correlated with life satisfaction ($r=.282$; $p> 0.09$). The older partners were less happy.

The main reasons, elicited by an open question, given for life satisfaction were to do with having a happy marriage, being pleased that the patient was alive and making a good recovery, and having good social support.

Examples of comments made by partners who were mainly satisfied include:

'I am very happy with the outcome of my partner's surgery but I feel utterly exhausted by the experience'

'I am pleased that my partner has come through bypass surgery well. I was not prepared for the amount of disruption to our lives that it would cause'

The main reasons for dissatisfaction followed a similar theme to those given for satisfaction. These included poor physical and mental health, the stress and disruption due to the patients' illness (feeling trapped, the patients' poor recovery, balancing work and caring responsibilities with other family commitments and fears for the future) and

general life stress. Pregnancy was given as a source of joy and also concern (makes partner tired in addition to all the other stress; inability to conceive).

'I work too hard and this has adversely affected my health. I need to work on my weight and fitness problems. My son's 10 years of horrendous health problems have taken their toll and my husband's heart attack is yet another cause of stress' (rated 4 = mixed feelings)

'I enjoy our life together as much as ever, but I am worn out' (rated 4)

The partners who were the most negative, complained about their ill health (including ongoing depression), having too many problems at once, having more than one sick person to care for; work stress and financial worries, lack of motivation, having no leisure time and no sex life.

Summary I

89 partners fulfilled the criteria for inclusion in the study. The mean age for the partners was 57.29 years. 66.3% of the sample was female. 80.9% of the partners were white. 59.6% of the group were unemployed, retired or homemakers, the rest were employed. The majority of the couples were cohabiting (87.5%). The number of years that the couples had been together ranged from under one year to 60 years.

In general, the sample of partners was both in good health and coping well. The majority of partners rated their relationship with the patient positively. The remainder rated their relationships as neutral, and none of them rated it negatively.

The majority of the partners reported that they were in good/very good health. Just over a quarter of partners rated their 'life satisfaction' as pleased or delighted. The majority of them were mostly satisfied, and 10.3% were either mostly dissatisfied or unhappy. The older people were significantly less satisfied. There were no significant gender differences.

The main reasons given for life satisfaction were having a happy marriage, being pleased with the patients' recovery, and having good social support. The reasons for dissatisfaction included poor physical and mental health, caregiving stress and general life stress, additional caregiving responsibilities, work stress and financial worries.

Section 2: Exploring the variables: Distress, SOC and cardiac beliefs

11.3 Psychological distress (HADS)

84 partners completed HADs. The mean scores were *not* used to fill in the missing data for the 5 partners who did not complete the HADS. This was because the HADS was the dependent variable in the regression analysis. Scores from the HADS were used to classify partners as either definitely anxious/depressed, borderline or not so, as recommended by Snaith (1993). The HADS scores are displayed in table 11.3 below.

a) HADS: Anxiety scores

21.6% ($n=18$) of the partners had a 'definite case' of clinical anxiety and 26.2% ($n=22$) were considered to be sub-clinical or borderline. There was no clinical evidence of anxiety in 52.4% ($n=44$) of the partners.

b) HADS: Depression scores

8.4% ($n=7$) people had a 'definite case' of clinical depression and 7.2% ($n=6$) were considered to be sub-clinical or borderline. There was no clinical evidence of depression in 84.5% ($n=71$) of the partners.

There was a higher proportion of cases of anxiety than depression. On average the partners scores fell within the non-clinical groups for both anxiety and depression, (scores of 7 or less), as outlined in table c. However mean anxiety scores (7.69) were close to the borderline cut off score (8.0 or more).

Table 11.3 Partners' HADS Statistics

	Anxiety scores	Depression scores	Total HADs
N	84	84	84
Mean	7.6905	4.5238	12.2143
Median	7	4	11
Std. Deviation	4.32693	4.20119	7.73830

c) Comparison of partners and UK cardiac patients

According to The National Audit of Cardiac Rehabilitation: Annual Statistical Report (2009), 17% of patients were borderline or clinically depressed and 28% of patients had similar incidence of anxiety. There was only a small improvement in these figures three months after starting rehabilitation and no sign of any further improvement at 12 months. Compared to the statistics for the UK cardiac patients, our sample of partners were slightly less depressed and much more anxious (see table 11.4).

Table 11.4 Comparison of partners and patient population: borderline or clinically distressed

	% partners with clinical or sub-clinical depression	% partners with clinical or sub-clinical anxiety
Patients*	17%	28%
Partners	15.6%	47.8%

* Source: The National Audit of Cardiac Rehabilitation - Annual Statistical Report 2009

d) Comparison of partners and normal UK population

Crawford et al., (2001) provided normative data for the HADS by administering it to a non-clinical sample, broadly representative of the general adult UK population (N = 1792), in terms of the distributions of age, gender and occupational status. For the Anxiety scale, the mean score was 6.14 (SD = 3.76, median = 6); for Depression, the mean score was 3.68 (SD = 3.07, median = 3); and for the Total scale, mean =9.82 (SD = 5.98, median = 9). Table 11.5 shows that the partners in our study were both more anxious and depressed than the general UK population.

Table 11.5 Comparison of partners and general population: mean HADS scores

	HADS Depression	HADS Anxiety	Total HADS
Partners	4.5238	7.69	12.21
General pop. *	3.68	6.14	9.82

* Source: Crawford et al, (2001)

11.4 SOC

The mean of the SOC score was 66.86 (SD 15.38) and the median 67. The total range of SOC scores was 18-91 (possible range 13-91). The two missing SOC scores were replaced by the mean. This raised the mean to 66.865 (SD 15.21). The median value, 67, remained the same.

SOC was not related to the partners' gender or employment status. However, SOC was significantly related to the age of the partner. The older the partner, the higher the SOC ($r=.343$, $p<0.001$, $n=88$).

a) Comparisons of mean SOC scores with other studies

Comparisons of the mean SOC score with other normative data from nursing research using the SOC showed that the population of partners had similar, yet slightly higher mean sense of coherences than a population of Swedish healthy women and female American nurses, see table 11.6 below.

Table 11.6 Comparison of partners and general population: mean SOC scores*

Population	N	Mean (29 item)	Equivalent mean (13 item)	Reference
Swedish healthy women	30	147.5	66.12	Langius, Bjorvell and Antonovsky, (1992)
Female American nephrology nurses	49	148.7	66.56	Lewis, Bonner, Cambell, Cooper and Willard (1994)
Partners	89		66.86	

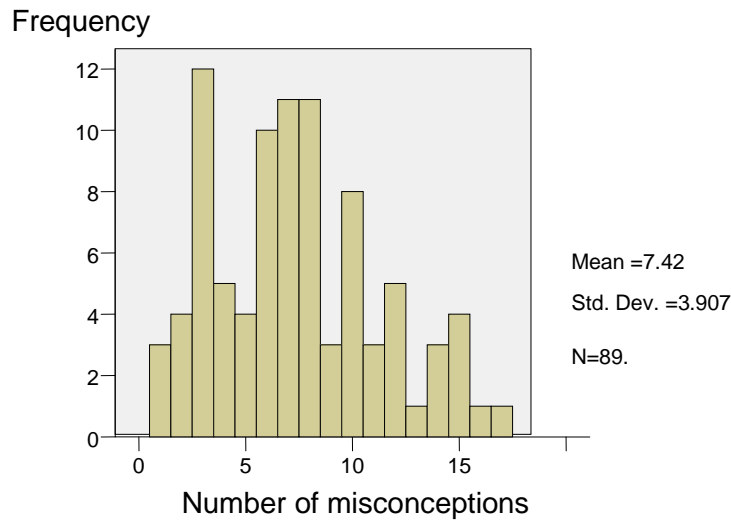
* Source: Horsburgh, (2000).

11.5 Cardiac beliefs score

The cardiac beliefs scores ranged from 1 misconception / mistake to 17, out of a possible total of 24. The mean score was 7.43, (SD 3.975) and median 7, see figure 11.3. When the missing data for three partners was filled in, the new mean was 7.42 (SD 3.907) and the median remained the same.

There was no relationship between the number of misconceptions made and either the age or gender of the partners. However, the number of misconceptions made was significantly correlated with the partners' employment status. The unemployed (unemployed, homemaker, retired) people made significantly more mistakes than the employed (full and part time) $r = .342, p = 0.001$.

Figure 11.3 Cardiac beliefs



11.6 Regression analysis

A regression analysis was performed to test the effect of the partners' cardiac beliefs and sense of coherence (SOC) and on their psychological distress.

The dependent variable was the partners' HADS, which was used as a general measure of their distress.

The independent variables were the cardiac beliefs and the sense of coherence. The cardiac beliefs scale investigated whether the number of misconceptions that the partner had about the patients' illness (relating to the perceived threat of the illness) would affect the partner's psychological distress. The sense of coherence looked at the resources that the partner has for responding to the stress, (i.e. the factors mediating the partner's *coping* response).

The forced entry (ENTER) method of regression analysis was chosen

The regression was initially run on 4 variables: partners' age, gender, cardiac beliefs and sense of coherence.

Although they were both significantly correlated with HADS, the t tests for this analysis showed that neither variables 'age' nor 'gender' on their own were significantly strong enough to predict HADS.

The regression was then repeated using only the significant independent variables, **SOC** and **CBQ**. This procedure is described below. The procedure used to check the data is described in section 10.7.

a) Describing the data

The mean and standard deviation of the three variables are displayed in table 11.7.

Table 11.7: Descriptive Statistics

	Mean	Std. Deviation	N
HADS (dependent variable)	12.2143	7.73830	84
Cardiac beliefs (independent variable)	7.46	3.992	84
SOC (independent variable)	66.4167	15.29092	84

b) Correlations of the variables

There were significant correlations between all three of the variables, see Table 7. The strongest correlation was between the SOC and HADS ($r = -.770$; $p < .000$); showing that the partners' with the lowest sense of coherence had the higher distress.

There was a positive correlation between levels of distress and number of misconceptions made in the cardiac beliefs questionnaire ($r = .421$; $p < .000$); the partners who were most distressed made the most mistakes.

There was a significant correlation among the two independent variables. The partners with the lowest sense of coherence, made the higher the number of mistakes ($r = -.297$; $p < .003$). However, there was not collinearity among the independent variables, as they did not correlate at the .7 level or above.

The summary matrix, displayed in Table 11.8, shows that the SOC Beta value was -.708 indicating that SOC was the best predictor of HADS. The Beta value for cardiac beliefs was .211. 62.5% of the variance was accounted for by the two variables, SOC and cardiac beliefs.

Table 11.8 Summary matrix for variables

Variables	Correlations				Regression		
	HADS		SOC	Cardiac beliefs	B	BETA	SIG
SOC	-.770				-.358	-.708	.000
Cardiac beliefs	.421		-.297		.408	.211	.004
MEAN	12.2143		66.4167	7.46	R Square = .634		
STDEV	7.73830		15.29092	3.992	Adjusted R Square = .625 St. Error = 4.74069		

The B values showed that: a) partners distress (HADS) went down by .358 for each additional point that their SOC scores went up; b) partners' HADs score rose .408 every time a question was answered incorrectly in the cardiac beliefs.

c) Multicollinearity test of SOC and HADS

HADS and SOC were tested for multicollinearity. Multicollinearity is a situation in which two or more variables are very closely linearly related; i.e. when there is a very strong correlation between two or more predictors in a regression model.

The data showed that there was no multicollinearity between the predictors (Tolerance values were all above 0.2). According to Mernard (1995), only values below 0.2 are worthy of concern.

Summary II

Anxiety amongst the sample of partners was more marked than depression. The partners in our study were more anxious and depressed than the general UK population. Compared to the statistics for the UK cardiac patients, they were slightly less depressed and much more anxious.

The linear regression analysis showed that the partners' sense of coherence and cardiac beliefs are important, and they accounted for 62.5% of the variance in the partners' psychological distress. Out of the two variables, SOC was the best predictor of HADS. The causality of these results will be explored in the discussion, together with the implications of these findings on the design of clinical interventions.

Section 3: Impact of the patient's illness

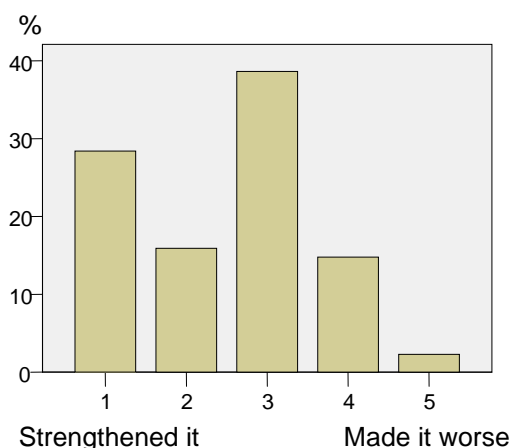
11.7 Relationship, coping & concerns

a) Relationship

38.6% of the partners felt that their relationship hadn't been affected by the patient's illness ($n=34$). 44.3% ($n=39$) felt that it had been strengthened and 17.1% ($n=15$) felt that it had been weakened as a consequence of the illness, see figure 11.4.

The number of years that the couple had been together had no effect on the partners' distress. However the quality of their relationship was significantly correlated to the partners' distress levels ($r=-.474$, $p<0.01$). The distressed partners were significantly more likely to rate their relationship negatively. They were also significantly more likely to rate the affect of the patients illness on their relationship negatively ($r=.323$, $p<0.01$).

Figure 11.4 Affect of the illness on the relationship



b) Coping

11.3% of the partners ($n=10$) felt that they were not coping well. 10.2% ($n = 9$) felt that they were coping neither well nor badly), see figure 11.5a. This meant that the majority of partners in our sample felt that they were coping well, 78.4% ($n= 69$).

The majority of partners, 69.3% ($n=61$), felt that the patients were coping well, as shown in figure 11.5b. Only 12.5% ($n=11$) of partners thought the patients weren't coping well. 18.2% ($n= 16$) were neutral.

In general, the partners assessment of how well the patients were coping was higher than that of themselves (mean patients' coping = 3.1, S.D. = 1.977; mean partners' coping = 2.1, S.D. = 1.04).

Figure 11.5a Partners' self-assessment of how well they are coping

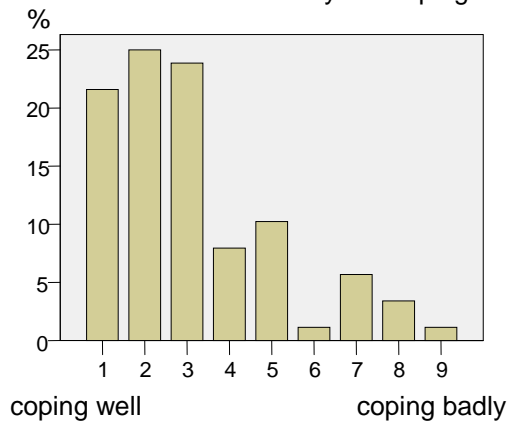
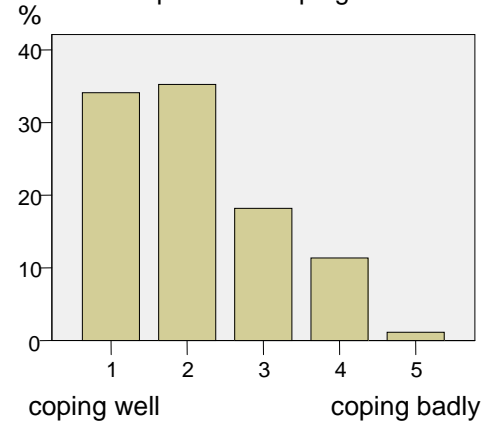


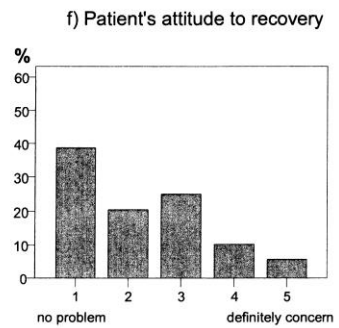
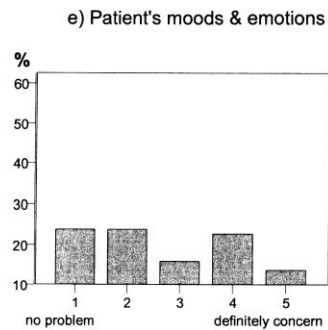
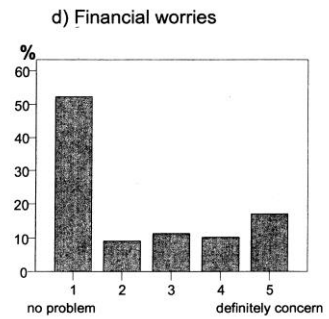
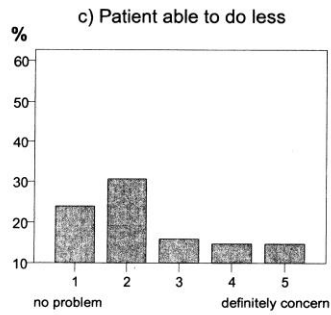
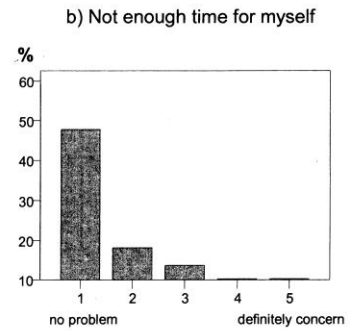
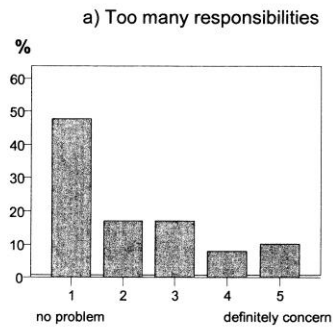
Figure 11.5b Partners' assessment of how well the patient is coping



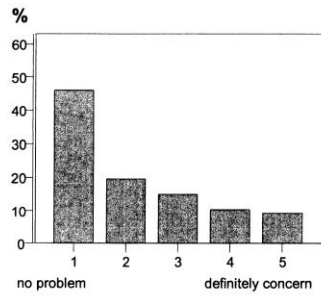
c) Partners' concerns

The bar charts displayed in figure 11.6 show the partners' assessments of the degree to which they found specific concerns problematic or not. The graphs show the percentages of responses for the five categories of the response scale, which had the anchors of 1, indicating 'no problem at all' and 5, 'definitely a concern'. Most of the charts in figure 11.6 have a negative skew, except for chart j, '*worries about patient's future health*' which is positively skewed towards being a definite concern. Graph e, '*patient's moods and emotional concerns*' and c, '*patient is able to do less*' are more uniformly distributed than the others.

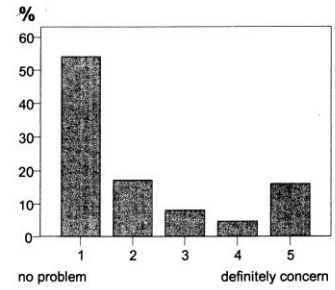
Figure 11.6 Partners' concerns



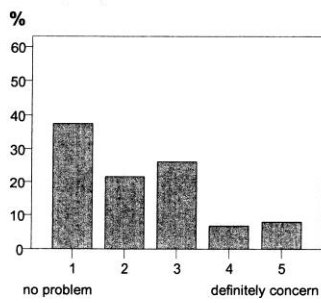
g) Help patient with lifestyle changes



h) Patient's future work



i) Impact on social activities



j) Worries about patient's future health

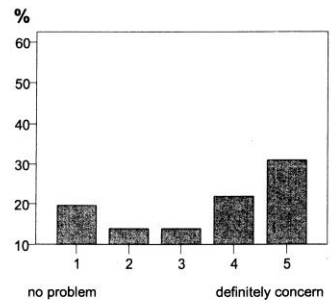


Table 11.9 Mean scores for concerns

Concern	mean	SD
Too many responsibilities	2.16	1.372
Not enough time for myself	2.17	1.391
Patient able to do less things	2.66	1.380
Financial worries	2.31	1.586
Patient's moods & emotional concerns	2.78	1.393
Patient's attitude to recovery	2.24	1.232
Helping the patient carry out lifestyle changes	2.17	1.357
Patient's future work	2.11	1.505
Social activities	2.66	1.255
Worries about patient's future health	3.31	1.520

The mean scores for the concerns, displayed in table 11.9, suggest that '*worries about patient's future health*' was the most concerning (mean 3.31, SD 1.520) with 52.8% of partners rating it as a definite concern, followed by '*patient's moods & emotional concerns*' (mean 2.78; SD 1.393) with 36.3% of partners rating this as a definite concern, and then '*patient able to do less things*' (mean 2.66, SD 1.38) with 29.6% of partners rating it as a definite concern.

'*social activities*' had a high mean score of 2.66 (SD 1.255). However due to the uniformity of the distribution, a lower percentage of partners rated it as a definite concern (14.8%).

The less problematic concerns were '*patient's future work*' (mean 2.11, SD 1.505), '*too many responsibilities*' (mean 2.16, SD 1.372), '*not time for myself*' (mean 2.17, SD 1.391) and '*helping the patient carry out lifestyle changes*' (mean 2.17, SD 1.357).

'*Patient's future work*' obtained the lowest mean score, suggesting that it was less concerning to the partners. Yet it was also the concern that had the second highest percentage of partners giving it the highest concern rating (16.1% of partners rated '*worries about patient's future health*' as a problem. Two partners commented that future work prospects were not a concern as the couple were already retired. The partners' age was correlated with this concern (see below). However there was no correlation between the partner's employment and future work. Unfortunately, there was no data on the patient's employment status and/or age to analyse this further.

The partner's age was negatively correlated with their assessment of the following six concerns: '*financial worries*' (-.403 $p < 0.00$), '*patient's attitude to recovery*' (-.378 $p < 0.00$), '*worries about patient's future health*' (-.368 $p < 0.00$), '*patient's moods & emotional concerns*' (-.331 $p < 0.02$), '*patient's future work*' (-.287 $p < .007$), '*social activities*' -.267 $p < 0.01$) and '*partner able to do less things*' (-.249, $p < .02$).

None of the concerns were significantly correlated with gender. All the concerns were significantly correlated, at the 0.01 level, to the partners' total HADS, as well as to both the individual anxiety and depression subscores.

It is worth noting that SOC was significantly correlated with all the concerns at the 0.01 level, except for '*future health*' which was significant at the 0.05 level.

The concern "worries about patient's future health" was not related to the number of days that the patient spent in hospital, (which was a possible indication of the severity of the illness), but it was significantly correlated to the partners' assessment of how well the patients were coping (.294 $p < 0.006$).

d) Additional comment about concerns

17.98% of partners ($n=16$) included additional comments when asked if there had any concerns that hadn't been listed in the questionnaire.

The remarks were grouped around the following themes:

- Health: worries about partner's health in general, worries about (his) future sex life and struggling to come to terms with the illness, having trouble with the medication
- Patient's mood and short temper
- Caregiver issues: explaining to children what had happened, sense of domestic inadequacy (male partner), getting over the shock of the illness and concerns that it may happen again, taking on additional work responsibilities whilst the patient is unable to work.

'I worry about his well-being when he is away from home for more than the stated time e.g. one and a half hours out, when he said he would be only be an hour'

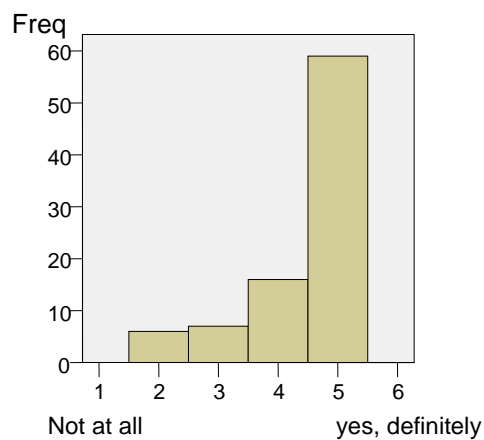
- Work issues: A few people had work related concerns for example convincing an employer to accept that the patient would be well enough to return to work.

Other comments included difficulties in planning ahead and being a parent's carer at the same time.

e) Talking to the patient about their concerns

The majority of partners felt that they could talk to the patient about their concerns, with 67% of them ($n=59$) giving the highest rating of 5, and 18.2% ($n=16$) rating of 4. The frequencies of responses are shown in figure 11.7.

Figure 11.7 Partners' ability to talk to the patient about their concerns



11.8 Further analysis: correlations

a) Coping

How well the partners rated themselves coping was significantly correlated to their HADs ($r=.619$ $p=0.000$). This would be expected

How well they thought the patient was coping was also significantly related to their own HADs ($r=.351$ $p=0.001$)

How well the partners rated themselves coping was significantly correlated to how well they thought the patient was coping ($.291$, $p=0.006$).

b) Health & wellbeing

Table 11.10 shows that the partners' general health and their current health concerns were significantly related to their distress at the 0.01 level. Partner's who rated their

general health as poor, were significantly more distressed ($r = -.344$), than are those with *current* health concerns ($r = -.350$). The partner's SOC was also significantly related to their health.

Life satisfaction was significantly correlated with the partners' SOC ($-.596$, $p < 0.00$), those with higher SOC also had greater life satisfaction.

Table 11.10 Correlations with health

	General health	Current health concerns
HADS	-.344, $p < 0.001$	-.359, $p < 0.001$
SOC	.224, $p < 0.036$.278, $p < 0.009$

c) Relationship

The number of years that the couple had been together had no effect on the partners' distress. However the *quality of their relationship* was significantly correlated to the partners' distress levels ($r = -.474$, $p < 0.01$). The partners who were more negative about their relationship were more distressed. Likewise, the distressed partners were significantly more likely to rate the effect of the patients illness on their relationship negatively ($r = .323$, $p < 0.01$).

d) Partners' ability to talk to patients about their concerns

Being able to talk to the patient about their concerns was negatively correlated with the partners' HADS ($-.430$, $p < 0.000$), showing that partners who couldn't talk to the patient about their concerns were more distressed. Not being able to talk to the patient was also significantly related to the partner's SOC ($.425$, $p < 0.000$); those who could talk about their concerns had a higher SOC.

Being able to talk the patient about their concerns was significantly related to the age of the partner ($.231$; $p < 0.05$); the older they were, the more able to talk about them. Being able to talk the patient about their concerns was not correlated with the number of years the couple had been together. However, it was related to the strength of the couple's relationship ($.261$; $p < 0.05$).

The quality of their relationship was significantly correlated to the partners' distress levels. Likewise, the distressed partners were significantly more likely to rate the effect of the patients illness on their relationship negatively.

Summary III

The majority of partners in our sample felt that both the patients and themselves were coping well. In general the partners' felt that the patients were coping better than themselves.

How well the partners rated themselves coping was significantly correlated to their assessment about the patient and also to their HADS.

Partner's with health concerns were significantly more distressed and had a lower SOC.

Distressed partners were more likely to rate their relationship negatively. Distressed partners were also significantly more likely to rate the effect of the patients illness on their relationship negatively.

'Worries about patient's future health,' 'patient's moods & emotional concerns,' and *'patient able to do less things'* were the biggest concerns.

'Patient's future work' obtained the lowest mean score. However, it was also the concern that had the second highest percentage of partners giving it the highest concern rating. There was no correlation between the partner's employment and this concern, and there was no data on the patient's employment status and/or age to investigate this further.

The partner's age was negatively correlated with their assessment of the following six concerns. None of the concerns were significantly correlated with gender. All the concerns were significantly correlated, at the 0.01 level, to the partners' HADS.

'Worries about patient's future health' was significantly correlated to the partners' assessment of how well the patients were coping.

Other concerns were grouped around the following themes: health, patient's mood, caregiver issues, work issues, difficulties in planning ahead and having additional caregiving responsibilities.

The majority of the partners felt that they could talk to the patients about their concerns. Partners who couldn't talk to the patient about their concerns were significantly more distressed and had a lower SOC.

Older partners were significantly more able to talk the patient about their concerns. This was significantly related to the strength of the couple's relationship.

Section 4: Support & Interventions

11.9 Information & advice from cardiac teams

In general, the partners rated the information and advice given to them by cardiac teams, about the patients' *physical condition*, higher than that of the patients' *emotional concerns*.

The mean score for the information on the physical condition was 4.09 (SD 1.210) and the median was 5 (very helpful). Figure 11.8a shows the percentages of scores. 73.9% of partners rated the information as helpful /very helpful. 11.4% found the information unhelpful ($n=88$). Three people reported that they hadn't received any advice or information on the patient's condition. One partner said that although she personally hadn't received any information, her husband had, and they had discussed it together.

The mean score for the information on emotional concerns was 3.33 (SD 1.468) and the median was 3 (mixed), see figure 11.8b. 49.5% of the partners found this information and advice helpful (31.3% very helpful and 18.% helpful). 32.6% found it unhelpful. Six partners reported that they hadn't received any advice or information

Figure 11.8a Advice on physical condition

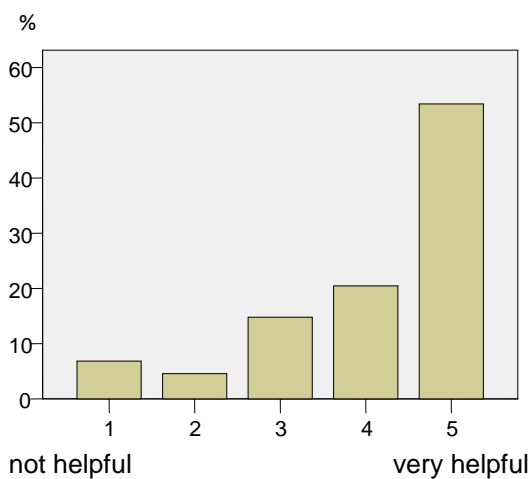
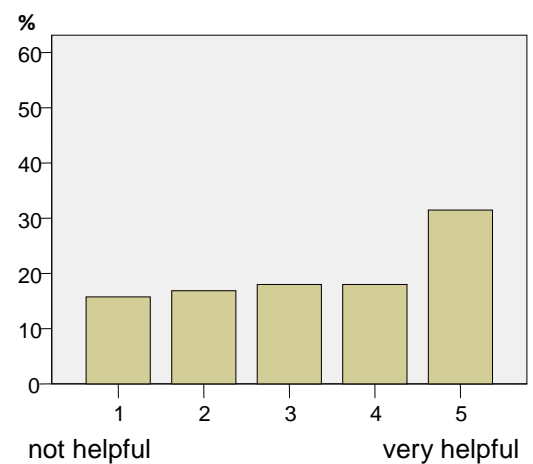


Figure 11.8b Advice on emotional concerns



There was a significant correlation between those who found the advice on the *physical* condition of the patient unhelpful and those that found the advice on *emotional concerns* unhelpful ($r=.744$, $p<0.000$).

Further investigations into the differences between the partners who assessed the information and advice as unhelpful showed that the partners that rated themselves as *not coping* with the patient's condition were significantly more likely to assess the information and advice given to them as *unhelpful*, see table 11.11. There was a stronger correlation between how well they were coping and the assessment of the advice and information on the patients' *physical condition* than that of their *emotional concerns*. However both correlations were significant.

There was **no** correlations between the assessment of the information and advice and their ratings of how well the *patient* was coping, their HADS, their gender or their ethnicity.

Table 11.11 Correlations between rating the advice and information and how well partners felt they were coping

	Coping with patients' condition
Advice on physical condition	$r=-.309$, $p<0.003$
Advice on emotional concerns	$r=-.233$, $p<0.029$

Finally, the partners' age was related to how they assessed the information and advice on *emotional concerns* ($r=.255$, $p<0.16$), suggesting that younger partners were more likely to assess the information negatively. Age was not related to the assessment of the information and advice on the patients' *physical condition*.

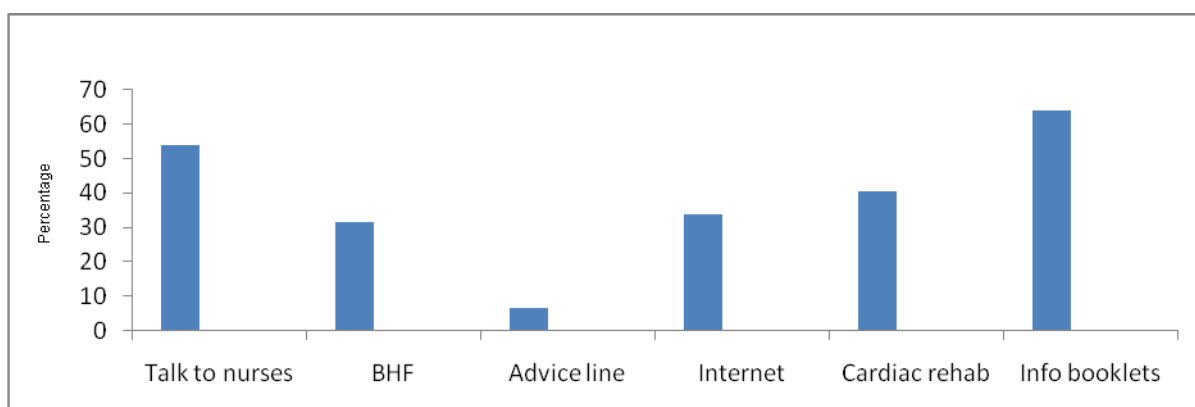
11.10 Sources of help & information

Figure 11.9 shows the sources of help and information that the partners had used. 64% had used the information booklets given out at the hospital and 31.5% had used the BHF material. It is important to note that the information booklets may have been BHF material. This was not made clear by the wording of the question.

53.9% of partners indicated that they had talked with the nursing staff and 40.4% counted cardiac rehabilitation classes as a source of information. 6.7% had contacted the cardiac rehabilitation advice line.

33.7% used the internet to find out information, and only 1.1% of the partners had used the local library. One partner commented that he had relied on his wife (the patient) for his information. Another remarked that the hospital staff had not addressed her at all about her husband's condition or needs, even during the daily visits.

Figure 11.9 Sources of help & information that partner's had used

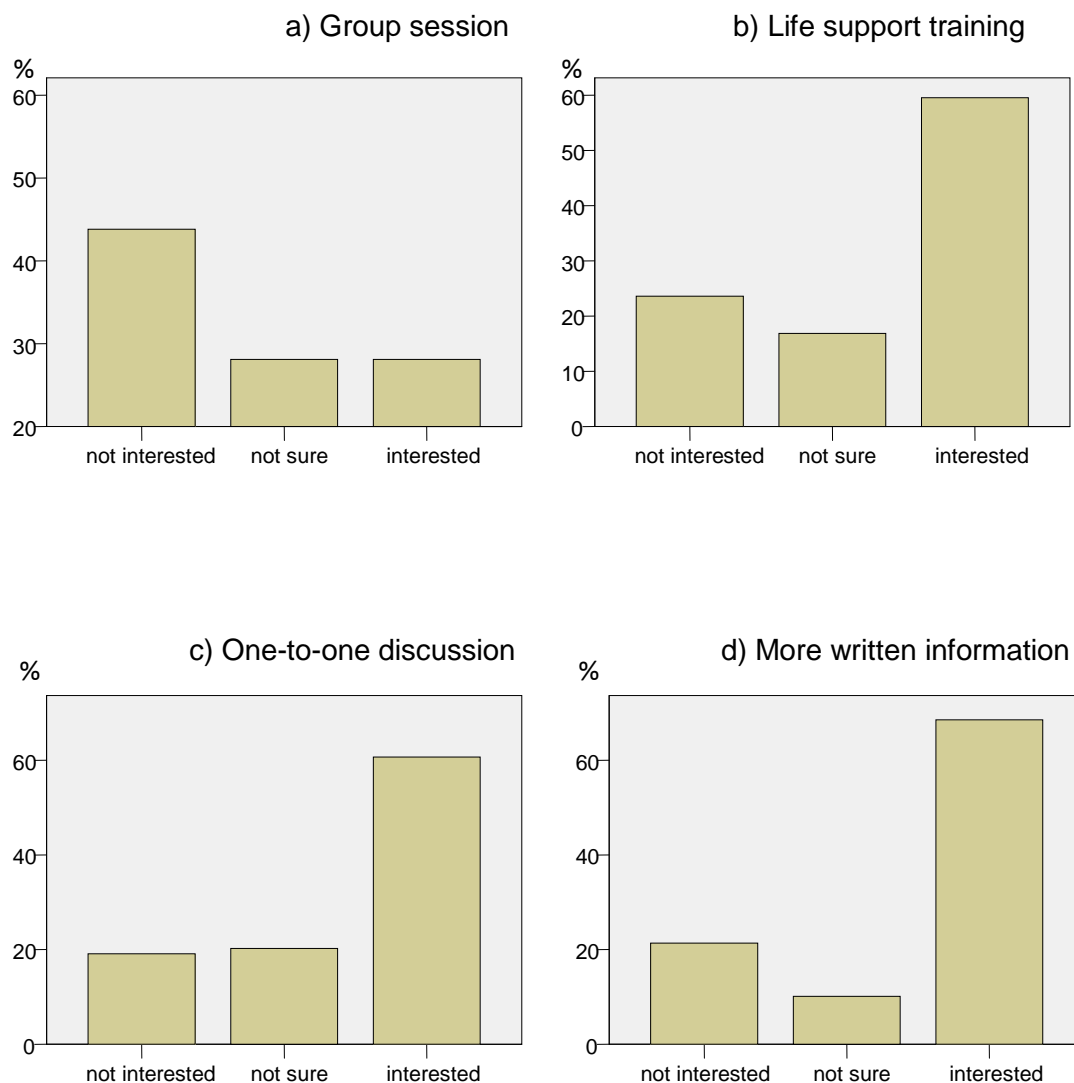


11.11 Additional sources of help

Partners were asked to indicate if they might have been interested in four other sources of help and information had they been made available. Figure 11.10 shows that 68.5% of partners would have been interested in receiving further written information and advice about caring for someone with heart problems. 60.7% would have wanted more one to one discussion with nursing staff, 59.6% would have liked to have been taught basic life support and 28.1% would have been interested in attending a group session. The interest in life support training may actually be higher, as some partners who ticked '*not interested*' indicated that they already had attended a training course in the past.

One partner said that information in Turkish would have been helpful, as she couldn't read English. Another partner said she would have been interested in more information had her husband's condition been more serious. A couple of partners said that the problem with attending a group was that there would be difficulty getting time off work during the day.

Figure 11.10 Partners' interest in further sources of support & information



A one way ANOVA between subjects was conducted to see if there was a difference between the HADS of the three groups of partners (*interested*, *not interested* and *not sure*). This was done in order to gain a better understanding about partners who turn down offers of support interventions.

There was no significant difference between the partners' HADS for the categories d) (receiving further written information and advice about caring for someone with heart problems) and c) (more one to one discussion with nursing staff). These two categories were the ones that had received the most interest.

There was a significant difference between the partners' HADS for the other two questions, a) a group session with other partners to discuss issues such as lifestyle changes and help with emotional problems that may result when caring for someone with heart problems and d) basic life support training.

For the question about group support, there was a significant difference between the HADS of the '*not interested*' partners and the '*not sure*.' $F= 3.319$ (df 2, $p < 0.05$). The means of the '*not sure*' HADS were significantly higher than the '*not interested*' group. Likewise the HADS for the partners who were '*not sure*' about receiving life support training were significantly higher than those of the '*not interested*' group $F=3.175$, (df. 2, $p<0.05$). This raises an interesting question as to whether it is a general trait of people who are distressed, to be ambivalent about seeking help.

b) Partners' additional comments & suggestions

The majority of the additional comments revolved around communication with the medical team. These included wanting more information on the patients' specific condition, over and above general information, including a detailed review on the patient's medication; better communication during the cardiac episode and at discharge; information specifically designed for heart patients partners; discussion of coping strategies and action plans; up to date telephone numbers for the ward; and what to look out for in the future to prevent a recurrence of the patient's condition.

'I would have appreciated a designated person who could tell me what was going on when my partner was in hospital - it was difficult to find out things and difficult to get his needs met for non-clinical things'

'..more direct information from nurses/doctors, or even a questions/answers group session,'

'a copy of the angiogram report should be given to the patient'

Several partners wanted more contact with the cardiologist prior to surgery and also to discuss test results. A couple of partners requested learning relaxation techniques and seeing a dietician. This would have been discussed in Phase III cardiac rehabilitation. One partners would have liked home assistance for the patient while he/she worked full time.

Summary IV

The partners rated the information and advice given to them by cardiac teams, about the patients' *physical condition*, higher than that about the patients' *emotional concerns*.

There was a significant correlation between those who found the advice on the *physical* and *emotional* condition of the patient unhelpful. This was *not* related to their distress (HADS).

The partners that rated themselves as *not coping* with the patient's condition were significantly more likely to assess the information and advice given to them as unhelpful.

There was no correlation between the assessment of the information and advice and their ratings of how well the *patient* was coping.

Younger partners were significantly more likely to assess the information on *emotional concerns* negatively.

The majority of partners had used the information booklets given out at the hospital and had also held discussions with the nursing staff. Cardiac rehabilitation classes were useful sources of information for those that attended, as well as the internet.

68.5% of partners would have been interested in receiving further written information and advice about caring for someone with heart problems and 60.7 % would have wanted more one to one discussion with nursing staff. 59.6% would have liked to have been taught basic life support and 28.1% would have been interested in attending a group session.

There was a significant difference between the partners' HADS for the questions about attending a group session and receiving basic life support training. In both cases the means HADS of the '*not sure*' were significantly higher than the '*not interested*' group. This raises an interesting question as to whether it is a general trait of people who are distressed, to be ambivalent about seeking help. They are also the most difficult group to support, as they don't know what they want.

The majority of the additional comments revolved around wanting to receive better communication with the medical team.

Chapter 12: Interview design & methodology

12.0 Summary: Interview design & methodology

- A cross-sectional analysis of partners of patients undergoing cardiac rehabilitation was conducted.
- Whilst completing the questionnaire, partners indicated if they would be willing to be interviewed over the telephone at a later stage. The willing participants included relevant contact information.
- In the second phase of the study, a small sample of participants who had completed a questionnaire, and given their consent, were then interviewed.
- Data were collected by one interviewer by means of semi-structured informal-style interviews over the telephone. It was decided that due to the informal nature of the material, telephone interviews would be the most efficient way of interviewing as they would be informal, private, less intrusive and easier to set up and deliver than a home visit.
- Each interview averaged 20-40 minutes in duration. Notes were made throughout. During the process of gaining consent, the couples were informed that the purpose of the research interview was to explore their experiences in order to assist the development of possible interventions for partners in the future.
- The interviews followed up on themes that had emerged during the analyses of the questionnaire. This meant that the actual content of the interviews was not established until the analysis of the questionnaires had been completed.

Following analyses of the questionnaire, it was decided that the interviews would focus on the group of partners with the lowest HADS scores, as they would benefit the most from additional support and should be given highest priority. The interviews explored the experiences of these partners throughout the patients' recovery and rehabilitation, as well as discussing their perceptions of healthcare.

12.1 Choosing the sample of partners

The sample of partners selected to be interviewed included a range of ages as well as a spread of SOC scores. Gender and age were not to be explored specifically, as although they were both significantly correlated with HADS, neither variables 'age' nor 'gender' on their own were significantly strong enough to predict HADS.

46 partners (51.7%) indicated that they would be willing to be interviewed. These partners were ranked according to their anxiety and depression HADS subscores. Partners with at least one definite case (either anxiety or depression) were given the highest ranking. Partners were only included if they had at least one subscore of 'borderline' or more. 33 partners fulfilled this criteria.

Due to the high proportion of women volunteering to be interviewed (n=38 women) compared to the men (n=6 men), both of the men who fulfilled the above criteria were included.

The remaining 31 partners were categorised both by age and also according to the length of the delay between filling out the questionnaire and the interview, in order to get a wide spread of experiences.

From this selection, a sample of 12 partners was chosen to be interviewed. However, two of them were no longer at the telephone number provided, one was unobtainable and one partner no longer wanted to be interviewed.

The partners were contacted by telephone to schedule an interview appointment, at a time convenient to the participants. The main researcher, working alone, scheduled all eight interviews over a 2-week period.

12.2 Profiles of the partners interviewed

The profiles of the 8 partners who were interviewed are shown in table 12.1.

Age & sex

6 of the partners interviewed were women and 2 were men.

3 of them were in their forties, 1 was in her fifties, 3 in their sixties and 1 was over seventy.

Questionnaire HADS

At the time of completing the questionnaire, 4 partners had been identified as having a definite case of clinical anxiety (scored over 11), and 4 were borderline (scoring 8-10). 2 of the partners who had had a clinical case of anxiety had also been clinically depressed. The remainder of the partners interviewed had been neither clinically or borderline depressed. However, it is worth noting that 2 of them had obtained a score of 7, which was only one point less than borderline.

Time gap between questionnaire and interview

The delay between completing the questionnaire and being interviewed ranged from 4 months to just under 4 years. 3 people were interviewed within 6 months of completing the questionnaire, 2 people after 13 months, 2 people after 25-26 months and 1 person was interviewed 46 months later.

Table 12.1 Profiles of the partners interviewed

Partner	sex	Age at interview	HADS Depression (Q)	HADS Anxiety (Q)	Delay (months) (Q-I)
Partner 1	f	58	7	15 ***	6
Partner 2	f	64	4	9 **	25
Partner 3	f	66	6	14 ***	26
Partner 4	m	42	7	8 **	13
Partner 5	f	45	18 ***	16 ***	13
Partner 6	f	66	5	9 **	46
Partner 7	m	47	4	9 **	4
Partner 8	f	73	15 ***	13 ***	4

*** clinical HADS >11

** borderline HADS 8-10

Q questionnaire

I interview

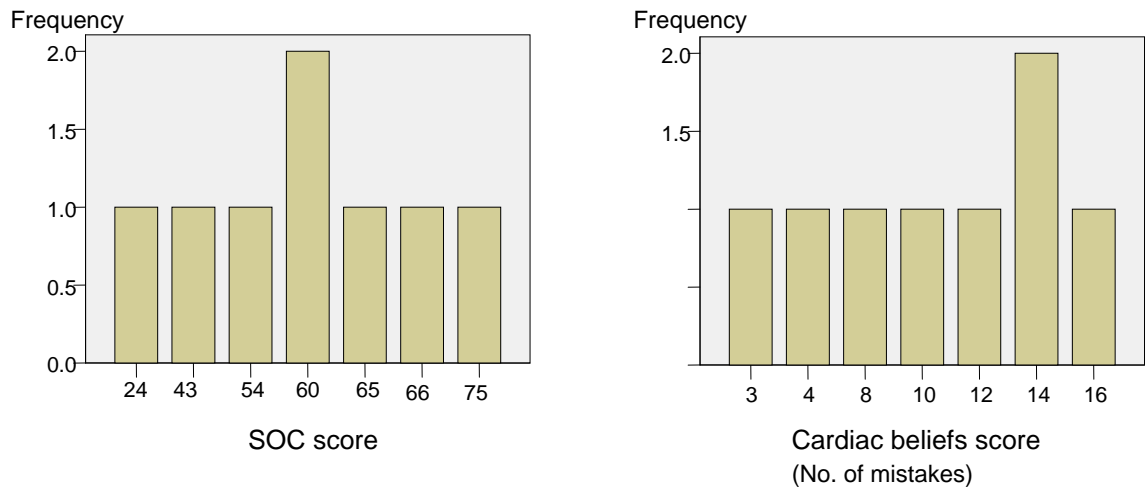
Questionnaire SOC and cardiac beliefs scores

The scores are displayed in figure 12.1 The mean SOC score, measured in the questionnaire, for the interviewed partners was 55.875 (SD 15.91) and the median was

60. These scores were lower than the averages for the total sample of partners who completed the questionnaire (mean: 66.865, SD 15.21; median 67).

The mean cardiac beliefs score (number of mistakes) for the interviewed sample was 10.13 (SD 4.794) and the median was 11. The number of mistakes made by this sample was higher than that of the total sample of partners (mean 7.42, SD 3.907 and median 7).

Figure 12.1 SOC and cardiac beliefs scores for interviewed partners



HADS at time of interview

The partners repeated the HADS at the interview, see table 12.2. Only one partner (partner 6) scored a higher anxiety score in the interview; the rest of them experienced a drop in anxiety.

There were two partners (partner 5 and partner 6) who were both clinically anxious and depressed at the time of the interview.

- Partner 5 had also been clinically anxious and depressed when completing the questionnaire, (the HADS were slightly lower at interview, although still clinical).
- Partner 6 had experienced a rise in both anxiety and depression, from borderline at the time of the questionnaire to clinical at interview.

There were four partners whose interview HADS were no longer clinical or borderline.

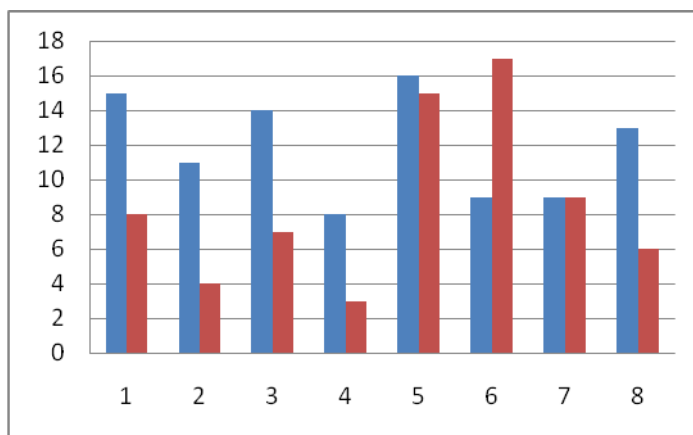
- Partners 2, 3 and 8 had experienced clinical anxiety at the time of the questionnaire, and partner 4, had been was borderline at the time of the questionnaire,

Two partners had borderline interview HADS

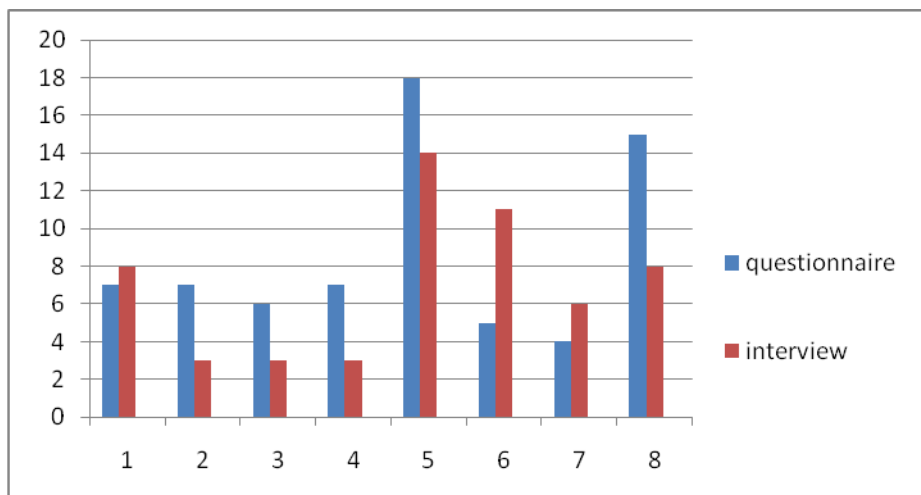
- Partner 1 had previously been clinically anxious and Partner 7 had been borderline

Table 12.2 Interviewed partners' HADS: comparisons of scores over time

a) Anxiety



b) Depression



The partners' depression shows a different pattern to that of anxiety. Although the partners scored lower depression than anxiety at both time periods, half of the

interviewed partners experienced a **rise** in depression levels over time, compared to a fall in anxiety.

- Partners 2, 3 4 were neither anxious nor depressed.
- Partner 1's anxiety had fallen and depression has risen slightly and was now borderline for both anxiety and depression.
- Partner 7 remained borderline anxious. Depression remained as not clinical/borderline, although the HADS had risen slightly.
- Partner 8, was no longer clinically anxious, but was still borderline depressed.

12.3 Content & structure of interviews

Structure of interviews

The interviews were based on an interview guide designed by the researcher to explore the relevant topics. This guide was used in a flexible way. The intention was to construct open questions that would invite the partners to talk, allowing the interviewer the opportunity to follow upon themes identified by previous partners, as well as adapting the questions to each partner's situation, if relevant.

The interviewer was sensitive to the fact that the majority of the partners interviewed had been either clinically or borderline distressed at the time of completing the questionnaire and tried to establish early on, whether their psychological health had improved over time. No assumptions were made about their experiences. Upmost care was taken to avoid causing distress. All partners were reminded that they were not obliged to take part in the interview and that they could stop the interview at any point, should they wish. All participants were given the contact details of the interviewer, should they wish to make contact after the interview, and where relevant, the partner was directed to sources of further support.

Content

Each interview began in the same way, with the researcher encouraging the participant to speak freely about his or her experiences regarding the patient's recovery and rehabilitation. This was followed by a general discussion on how the partner had coped throughout this period. Partners were asked about their concerns related to the

patient's illness, how the patient's illness had affected them both physically and emotionally, and whether anything had changed in the time period between them completing the questionnaire and the interview.

The partners were told specifically that the information gained from the interviews would be used to identify the barriers to partner participation, to identify any gaps in the care provided and develop partner interventions

They were asked about the types of support that they had received and any ideas that they had for partner interventions. More specifically:

- whether they sought additional help, how they accessed this, and what they found most useful
- additional sources of help that they hadn't been offered, but may have found useful
- support that they had refused and the reasons for this and whether, on reflection, they would have benefitted from it
- ideas for the planning, content and logistics of partner interventions

Particular attention was paid to the reasons for the overall lack of interest in the group support, as group intervention has been recommended by researchers (e.g. Stewart, 2001), as an optimal medium to provide to partners.

When relevant, the interviewer reminded the partner about the responses that he/she had made when completing the questionnaire and these were discussed.

The partners' HADS were repeated, with the questions being read out over the telephone. In most cases this generated further discussion about their emotional wellbeing and experiences.

12.4 Analysis of the interviews

The interviews were analysed by the main researcher, a psychologist, who was not associated with the patients' care.

The content of each interview was broken down on an excel spreadsheet into categories, in order to identify common themes and emerging patterns.

As is common in qualitative research, not all respondents spoke of the same issues. Each category was then explored in order to gain further insight into both general

patterns and individual behaviour. The major themes of their experiences are described in chapter 13

12.5 Summary

Following analyses of the questionnaire, it was decided that the interviews would focus on the group of partners with the highest HADS scores, as they would benefit the most from additional support and should be given highest priority.

The sample of partners selected to be interviewed included a range of ages as well as a spread of SOC scores.

The intention of the interviews was to construct open questions that would invite the partners to talk, allowing the interviewer the opportunity to follow up on themes identified by other interviewed partners as well as adapt the questions to each partner if relevant.

The interviewer was sensitive to the fact that the majority of the partners interviewed had been either clinically or borderline distressed at the time of completing the questionnaire and tried to establish early on, whether their psychological health had improved over time.

The interviews explored the experiences of these partners throughout the patients' recovery and rehabilitation, as well as discussing their perceptions of healthcare.

Chapter 13: Analysis of interviews

The interviewed partners' repeated HADS were calculated. Scores from the HADS were used to classify partners as either definitely anxious/depressed, borderline or not so, as recommended by Snaith (1993). For ease of analysis, the partners were divided into two groups; 'no distress' and 'borderline & clinical HADS.'

13.0 No distress

Three of the partners' HADS had improved to levels of 'no distress.' In the interview they all acknowledged that they felt much better.

This group had all completed the questionnaire 1-2 years previously (25 months, 26 months, and 13 months). They all reported that their husbands (the patients) had experienced a good recovery and were feeling much better. The partners were finding things much easier now that everything had settled down. They acknowledged that they had found it very difficult at the beginning, and the reasons for their earlier distress, and later improvement, were discussed.

a) Shock

Two of them reported that their husbands' cardiac event had been a big shock and very distressing. One of them had witnessed her husband's heart attack, and found it traumatic. The other said that the experience of her husband's three operations had been very stressful for her.

There is growing research into the area of patients experiencing post traumatic stress disorder (PTSD) following a MI (Wiedemar et al., 2008). Randall suggested that partners who shared this experience may also be vulnerable to the development of PTSD themselves. There is currently no research exploring PTSD in partners of cardiac patients. This would indeed be an interesting area for future research. Cardiac staff should be sensitive to the after effects of this kind of shock, and provide the necessary support to the partner. Both of the partners said that the shock had died down over time.

b) Patient's behaviour

One partner said that her husband's mood swings had been terrible, and she found them very hard to deal with. Another said that trying to get her husband to make behavioural changes such as stop smoking had been very hard. This had caused her a

great deal of anxiety and had put pressure on their relationship. When asked what had changed now, both these partners now felt much more in control over their situations. For example, one of the husbands still smokes, but it no longer stresses his partner. She explained that they had discussed it, and her husband had rationalised his need to smoke as a form of stress management, and she feels comfortable with that. Likewise, the other partner said that she no longer gets upset by the patient's mood swings; due to a combination of the mood swings being less intense, her getting used to them and learning how to manage them.

In both these examples the negative health behaviour (patient's smoking and mood swings), that used to stress the partners, still occurs. However, the partners have adapted to it, in a way that the behaviour no longer upsets them. In doing so, they have developed the cognitive resources that would give them a sense of control over the situation. These examples also suggest a working collaboration between the couple in restoring the cohesive balance to their relationship. This is backed by the general research that suggests that partners' depression is associated with lack of dyadic cohesion (Bennet & Connell, 1999).

In both these examples, the patients' physical health improved over time, (as would be expected), and the partners mental health suffered in the early stages of recovery and improved over time. It is beyond the scope of this paper to draw conclusions about the reasons and direction of this recovery, for example the improvement in the patient's mood swings, could be both the cause and result of the partner's improved wellbeing.

c) Patient's recovery: need for support

In general, the partners said that they had received good support from cardiac teams and from family and friends, although they would have liked more contact with the cardiologist. They would have liked more support once they had come home, and this was a contributing factor to their distress. For example, one partner had received good support from the cardiac team, but found it very difficult when her husband's GP surgery was not interested in his recovery. She said that no-one had checked his blood pressure once he left the hospital, so she had no indicator about whether he was recovering 'normally'.

One of the partners said that she had been very worried that her husband was recovering too slowly. She had been told that it would take 3 months to recover. She said that it was only after other patients told her that it could up to one year, (in fact their partners said it would be more like two years) that her fears subsided. She said that she wouldn't have worried had she known that earlier. This has important

relevance with regards to the information given to partners (and patients) about realistic recovery expectations. It also shows the benefit of peer support interventions.

13.1 Borderline & clinical HADS

Three partners were still experiencing sub-clinical or borderline anxiety when interviewed, and two of them were experiencing clinical levels of anxiety and depression. All three of the *sub-clinical (borderline)* partners were interviewed under 6 months after completing the questionnaire. One of the *clinical* partners was interviewed 13 months after the questionnaire, the other at 46 months.

The reasons for their distress at the time of the questionnaire were similar to those experienced by the 'improved partners.' This included concerns about the patient's health and lack of support by the cardiac teams. The clinical and borderline groups differed from the 'no score' group in the language that they used to describe their negative experiences; their experiences sounded more intense and more upsetting. No conclusions can be drawn from this. This is due to factors such as the different lengths of times between the questionnaire and being interviewed, the influence of subjective recollection and distortion amongst people whose distress had improved compared to those who distress had remained or worsened and also due to the negative affect of the borderline & clinical group. However, an idea for future research would be a longitudinal study that would investigate the relationship between the intensity of partners early negative experiences and the time line and intensity of their distress throughout the patient's recovery.

Sub-clinical /borderline partners

These partners had been extremely worried about their husbands throughout their hospital stay. One of the partners said that she hadn't received enough information from the cardiac teams, *'it was a touch and go situation, at the beginning and we did not receive adequate information . No-one spoke to either of us.'*

This partner had also felt let down by the team at discharge, when she felt let down and disheartened. She had no-one to talk to and ask questions and she felt that the leaflets were just about lifestyle changes; whereas she had wanted to know who to speak to in the event of a problem or emergency. She was particularly upset about having to hunt for a wheelchair to take her husband downstairs. It had made her feel more vulnerable in an already sensitive situation.

The other two partners said that although they had received information and support, the benefit of it was 'diluted' by their distress. For example, one said that although the cardiac team explained everything to her very well, she was only able to calm down once the medical teams were happy with the patient's progress. Another one said that distress took over everything, and she couldn't hear what (the nursing teams) were saying to reassure her. This has important implications for the timings and delivery of support to partners. The support teams must be aware that distressed partners may not be able to benefit from informational and emotional support, due to their own distress. Partners may need to be monitored for stress and given some stress reduction before they are given the information regarding the patient. This also has important implications for interpretation of research that asks partners to recall the support they had received. Partners who reported that they did not receive support, may have actually received it, but they were not able to remember this (and benefit from it) due to the high levels of their underlying distress. This would be an area for further research.

Reason for current elevated HADS

a) Patient's health & recovery

The partners all had fears about the patients' health and long term recovery. One of the patients had to return to hospital twice due to a bad fall and a chest infection in which he had experienced pains in his chest. She is constantly worried that it will happen again. Another was worried by the 'slow' recovery of her husband, for example although he was attending the gym, he still can't work. Until he is 'back to normal' she will be worried. One of the partners was upset because she still didn't know why her husband suffered his (two) MIs in the first place. These partners would have benefitted from a group intervention in order to share their experiences with other partners. For example the partner worried about her husband's slow recovery may have been reassured by other partners that it is unrealistic to expect a full recovery in under six months.

Patients' incomppliance with their recovery was another source of stress and concern. For example one patient had originally lost weight, but had now put it all on again. Another patient '*sits in front of TV all day from 8.00 am, doing nothing.*' The patients' illness/risk behaviour was a constant threat for the partners as it reminded them that the patients were compromising their health, tapping into their existential anxieties over the patient's health. In contrast to the partners whose HADS had normalised, there was no sign of any dyadic cohesion between patient and partners. The patient's

behaviour remained a source of stress and worry for the partner, and they hadn't found any cognitive or behavioural responses that would reduce this.

One partner felt that she was more stressed because she couldn't make any long term plans. She had adapted to this by taking each day as it comes, and allowing her husband to take over the planning.

b) Long term mental health issues

One of the partners has suffered from occasional bouts of depression, for many years. She had also suffered from panic attacks in the past. Her depression was exacerbated by her husband's illness, but was not always related to her husband.

She acknowledged that she was currently feeling more relaxed. However, because she has recently changed GP, no one was currently supervising her depression. She hadn't told the cardiac team about her depression. She said that this was because nobody had asked her. However, she is not sure if would have done if asked.

c) compounding stresses

One partner was forced to move to a much smaller house (due to regeneration) while her husband was in hospital. She feels that the enormous stress associated with this move on top of her husband's illness was 'coming out' now that her husband getting better. She feels very stressed and has high blood pressure.

Another partner had only been together with her husband for 4 years, and her previous partner had died from heart problems. Her current husband became ill within 6 months of them being together. His illness had brought back bad memories and negative associations, which had affected her appraisal of his situation throughout his recovery.

Clinical partners

There were several similarities between the two partners who were still experiencing clinical levels of distress.

Both of the patients had made a good physical recovery, but were suffering psychologically; one from severe mood swings, and the other, from depression. Both partners were experiencing difficulties with the patients as a result of this; they felt that their own mental health had suffered and their relationship had deteriorated. They both felt helpless and unable to cope.

One partner felt that everything with her husband was a constant battle. They had fallen into a pattern of her nagging him, and him refusing to comply. Although he had managed to give up smoking, he had refused to change his diet, and has returned to original drinking levels (after cutting down). The other partner was consumed with irrational fears about her husband's illness. She acknowledged that he was being closely monitored and had been compliant in every stage of his recovery, and moreover, she had been told that he was recovering well. However, she was convinced that he was getting worse. Her fears over her husband had been reinforced several months previously, when he collapsed at a wedding and she didn't know what to do. She has since attended resuscitation classes at the hospital, but she can't remember the details, which adds to her anxiety (she would have liked a video to remember it). She was aware that she was very anxious, worried a great deal (about the future, feeling that she couldn't cope if her husband dies), and couldn't relax, but she couldn't help it.

Both of these partners closely monitored the activities of the patient, and become overwhelmingly concerned with their welfare. In addition to the stress caused by their husbands' illness, both partners attributed their high distress to own ongoing physical health issues, which had began prior to their husbands illness. Neither of them had thought about the between their elevated distress and their physical health.

13.2 Psychological support (all interviewed partners)

Out of the three borderline partners, only one was receiving psychological support. This was only because she had broken down in a cardiac rehabilitation session. She hadn't considered asking for support prior to this, although her children had tried to intervene. The cardiac nurse had been extremely helpful. They had discussed how she was feeling and the nurse had directed her to further sources of help. She now attends relaxation classes at the hospital and has seen her GP. Although she can't take medication due to suffering from epilepsy, she has been referred for counselling next month.

The other two borderline partners hadn't asked for support. The partners were aware of their distress and how it fluctuated. For example one partner said that her situation was improving, as now she can talk to people about her worries and concerns, before she could only cry. The other said that the stress is off and on, sometimes it is OK and other times it is worse. One of the partners had suffered from long term depression, yet hadn't discussed this with the cardiac team or her current GP. Likewise the other one

hadn't thought about it discussing it. Their lack of desire to seek support could be both a symptom and cause of their elevated HADS. The one partner who had let her distress be known, albeit unintentionally, received immediate support and was directed to further sources of help.

In contrast to the borderline group, both of the clinical partners had sought psychological support. One had received her assessment session with the counsellor and was waiting for her first appointment. She had already found it useful to voice the things that she couldn't say to her husband. The other currently attends a psychological group, through her GP. However, she felt that it wasn't helping her, as she feels the other people 'brought her down.' We discussed the possibility of her talking about this with her GP.

Once again, neither of them had mentioned their psychological concerns to the cardiac nurses, although they would have been willing to. They were not sure why that hadn't. One admitted that she would have appreciated some advice from the cardiac teams on how to deal with her husband's mood swings, and calm him down, yet she hadn't discussed it with them. Both of them had received good support from the health professionals. One of them had gone to cardiac rehabilitation and had actively sought out as much information as she could, such as sending off for more BHF literature, when her husband hadn't been interested.

13.3 Interest in a group intervention

All of the partners had been distressed at the time of completing the questionnaire and they had shown very little interest in a support group. In comparison, they had shown a collectively large interest in receiving more written advice, more one-to-one contact and first aid. **All** of the partners, with no relation to their current mental health, were much more positive toward the group. Only one said that she still wouldn't have wanted to attend the group, this was because she felt that her situation would be so different from the others. Another said that the group would definitely be useful, but would ultimately be of limited use if the patient's behaviour does not change. This would be an interesting topic for discussion in a future group.

They all agreed that in hindsight, participation in a group intervention would have been helpful. They felt that they would have liked the peer support and meeting other people in a similar situation.

'It's is a learning curve. Although everyone is different, I would have liked advice on how to handle it'

Some of them were unclear about their reasons for not being interested in it earlier. They hadn't understood how they might have benefitted from group support. Others were put off by the logistics of attending a group, whilst working, as she had already taken so much time off to attend hospital appointments with her husband. One partner said that she had been so focussed on the immediate situation and caring for the patient, feeling slightly overwhelmed by everything, that a group just seemed like added burden, another thing to 'fit in'. They hadn't understood how they might have benefitted from group support. Another felt so focussed on caring for the patient and looking after his medical concerns, that she did not have the time to think about her needs.

The suggestions and preferences for the group included holding it during evenings and/or afternoons (otherwise it is hard for those who are working). A one-off group support was suggested, to coincide with cardiac rehabilitation classes. Even partners who are working could manage it just once, then partners could be referred on to further one- on-one sessions if appropriate. One partner specifically did not want the patients to attend the group.

A question and answer (Q &A) session, *'either together with the patients but definitely with other partners.'*

Suggestions included holding the group after the first month of coming home, and holding it a couple of months after discharge, once things had settled down.

Further one-on-one support was also suggested.

13.4 Summary

In general, partners who were interviewed one year following the questionnaire were less anxious and depressed than those interviewed at up to six months, which is consistent with the cardiac literature. The severe distress of the two partners with clinical anxiety and depression, who were interviewed forty six months and thirteen months after completing the questionnaire, suggests causes that are over and above the patient's cardiac event.

All of the partners reported that their husbands (the patients) had experienced a good physical recovery.

The reasons for the partners' distress included:

- The shock of the cardiac event. (This was discussed in terms of PTSD).
- Concerns about the patient's health, and long term recovery.
- Fear that the patient was recovering too slowly
- Not understanding why the patient became ill
- Psychological issues with the patient (mood swings & depression)
- Patients in compliance to lifestyle changes (this caused a great deal of anxiety and put pressure on their relationships)
- Concerns over long term plans
- Other major stresses such as moving home
- Long term mental health issues (Partner)
- Partner's physical health issues.
- Relationship issues (overprotection, lack of cohesion)

Factors that helped recovery included good relationships between the GP & hospital, and good patient recovery as well as having a good support network and a cohesive relationship. The non scores had adapted to their partner's needs and felt much more in **control** over their situations.

In general, the partners were satisfied with the support that they had received from the cardiac teams, although they would have liked more support once they had come home. Partners were highly sensitive to bad experiences. Partners need to be monitored for stress and given some stress reduction before they are given the information regarding

the patient.

The clinical partners were the only ones that had actively sought psychological support. They all had been reluctant to discuss their concerns with the cardiac teams. Cardiac teams must be aware of potential mental health problems as this can prevent partners actively seeking support.

The majority of partners expressed a positive attitude towards developing a group intervention for partners, despite earlier ambiguity about it in the questionnaire. They agreed that participation in a group intervention would have been useful for peer support.

Chapter 14 Discussion

14.0 Summary of the study

The current study aimed to explore the experiences of being a partner of a person with cardiac problems. Specifically, it investigated whether partners were distressed, and if so, the particular reasons they gave for this. Theoretically, it looked at the relationships between the partners' sense of coherence, their cardiac beliefs and distress levels, in order to understand why some partners cope better than others. Finally, the study examined partners' experience of health care services, and their preferences for interventions that might alleviate their distress.

The aims of the study were:

- a) to determine whether cardiac partners were distressed
- b) to investigate the reasons for the partners distress
- c) to explore the relationship between sense of coherence, cardiac beliefs and levels of partners distress
- d) to identify any gaps in the care provided and opportunities for service development

14.1 Content of the discussion

- 14.2 Partners distress: were the partners distressed?
- 14.3 Reasons for partners' wellbeing and distress
- 14.4 Application of SOC to categorise and explain partners' distress
- 14.5 Cardiac beliefs
- 14.6 Use of SOC and cardiac beliefs
- 14.6 Information & support
- 14.7 Partner interventions
- 14.8 Limitations of the study
- 14.9 Future research
- 14.10 Conclusions

14.2 Partners' distress: were the partners distressed?

Psychological distress

Fewer than half the sample of partners who completed the questionnaire had clinical or borderline anxiety, compared to just over a quarter of partners who had clinical or borderline depression. The partners in our study were more anxious and depressed than the general UK population. Compared to the statistics for the UK cardiac patients, they were slightly less depressed but much more anxious.

Although these figures are in line with previous research which found that partners (and patients) experienced considerable emotional distress, with partners faring worse than the patients, (e.g. Gillis, 1984; Moser and Dracup, 2004; Hilbert, 1996; Stewart et al, 2000), these figures are lower than those found in others studies. For example O'Farrell et al., (2000) found that 66% of the 213 partners were significantly distressed, even though there were many similarities between the two samples. In fact O'Farrell

suggested that his results may in fact underestimate the true level of partner distress, as those who were more distressed may have not agreed to participate. Such a self-selection bias may well have occurred in our sample, and will be discussed later.

Interviewed partners distress

Eight partners who had experienced elevated HADS at the time of completing the questionnaire were then interviewed at a later date. The HADS of three of these interviewed partners had improved to levels of 'no distress.' This group had all completed the questionnaire 1-2 years previously (25 months, 26 months, and 13 months).

Three of the interviewed partners were still experiencing *borderline* HADS. They all had been interviewed within 6 months after completing the questionnaire. The remaining two interviewed partners both experienced clinical HADS. One of them had been interviewed 13 months after completing the questionnaire, the other after 46 months. These findings are in line with general research that found that partners may experience high distress in the early stages of the patients' recovery, and that the distress gradually declines over the first year, (Mahler et al., 2002; O'Farrell et al., 2000), although anxiety levels may still remain elevated compared to population norms (e.g. Arefjord et al., 1998; Skelton & Dominion, 1973). The severe distress experienced by one partner 46 months later suggests causes that are over and above the patient's cardiac event, and this was confirmed by her long term mental health problems.

In general, the wellbeing of the sample of partners who completed the questionnaire was high. The majority of partners reported that they were in good/very good general health and that they had no current health concerns. Likewise the majority of the partners were positive about their life. As expected, their life satisfaction was significantly correlated with their HADS. The majority of partners in our sample felt that both the patients and they, themselves, were coping well. In general the partners' assessment of how well the patients were coping was higher than that of themselves. How well the partners rated themselves coping was significantly correlated to how well they thought the patient was coping and also to their own psychological distress.

The sample was also positive about their relationships. The majority of the sample rated their relationship as 'good' or 'excellent,' and none of the partners rated their relationship negatively. The majority of this sample felt that their relationship had either been strengthened by the patient's illness or hadn't been affected. Whilst these figures

confirm the suggestions of both Ford (1989) and Thompson et al., (1995), that a patient's illness could result in a closer, more supportive relationship to develop between the couple, once again they may point to an underlying bias in the disposition of partner willing to complete the questionnaire.

These results have implications on how carers, in general, are viewed. Most of them were coping well, which confirms Randal et al.'s (2009) conclusions that carers, as a group, shouldn't be pathologised, without individual investigation. Carers with health concerns, other caring responsibilities and mental health issues should be targeted for support.

14.3 Reasons for partners' wellbeing and distress

The reasons for the interviewed partners' improved psychological health and life satisfaction included the patient making a successful recovery as well as having a cohesive relationship, happy marriage, good relationships between the GP & hospital, and adequate social support. It appeared that those who were no longer distressed had adapted to their partner's needs and felt much more in control over their situations.

The main reasons for partners' dissatisfaction and distress included both the patients' and partner's ill health, caregiver burden, lack of leisure time, conflict within the relationship, lack of sex life, inadequate support from health professionals and experiencing multiple stresses. These reasons are in line with the general cardiac literature (e.g. Svedlund et al., 1999a; Kettunen et al., 1999, Bennet & Connel, 1999; O'Farrell et al., 2000; Halm et al, 2007; Stlarik et al., 2000).).

Concerns about the patient's health, and long term recovery

In the questionnaire, over half the sample of partners rated '*worries about patient's future health*' as a definite concern. Those who rated patient's health as a concern were significantly more likely to rate the patient as *not* coping with the illness.

In the interviews, the distressed partners all reported having fears about the patients' health and long term recovery. Some of these fears had been reinforced by medical emergencies including the patient being re-admitted to hospital with chest pains (due to a chest infection) and the patient suddenly collapsing. However, other times these fears were irrational and contrary to the assurances given by the medical teams. Some of the partners didn't understand why the patients and become ill in the first place, and others were concerned because they thought the patient was recovering too slowly.

Some of these partners may have benefitted from a group intervention in order to share their experiences with other partners. One of the partners who had been worried about her husband's slow recovery was reassured by other partners that it was unrealistic to expect a full recovery in under six months.

Partners were also concerned about the patient not being able to do as much as he/she once could and the impact of the illness on making long term plans. Concerns about the patient's future work obtained the lowest mean score in the questionnaire, suggesting that it was less concerning to the partners. However, it was also the concern that had the second highest percentage of partners giving it the highest concern rating. This is most likely to be explained by the work status of the patient prior to the cardiac event. There was no correlation between the partner's employment and this concern, but unfortunately there was no data on the patient's employment status and/or age to check this further. Partners' work stress and financial worries were cited as reasons for concern, as well as having to take a lot of time off work to attend hospital appointments.

Shock

Experiencing a serious illness is a threat to people's existence. The partners and patients must learn to live with the daily reminder that not only did it happen, but also with the threat that it could happen again. Several partners reported that the patient's cardiac event and the subsequent treatment had been a big shock and very distressing. The wide range of negative emotions including fears and stress symptoms commonly reported within the first few weeks of diagnosis, were described by Cullberg (1993) as an 'emotional crisis.' There is growing research into the area of patients experiencing post traumatic stress disorder (PTSD) following a MI (Wiedemar et al., 2008). Randall suggested that partners who shared this experience may also be vulnerable to the development of PTSD themselves. There is currently no research exploring PTSD in partners of cardiac patients. This would indeed be an interesting area for future research.' Cardiac staff should be sensitive to the after effects of this kind of shock, and provide the necessary support to the partner.

Patients' attitude, mood and response

In both the questionnaire and the interview, concerns over the *patient's moods & emotional concerns* were rated highly. Likewise the patient's attitude to recovery and lifestyle changes also caused a great deal of anxiety and put pressure on their relationships.

The patients' illness/risk behaviour was a constant source of concern for the partners. This may have been as it reminded them that the patients were compromising their health, tapping into their existential anxieties over the patient's health.

The cardiac research that suggests that partners' distress is often associated with lack of dyadic cohesion (Bennet & Connell, 1998) and that distant marital relationships are associated with a continuous high level of partner distress (Arejford et al, 1998). This was apparent in the interviews. The interviewed partners, whose distress had improved, gave clear evidence of dyadic cohesion, when describing their relationship and how they had dealt with sources of anxiety, in particular, when it had been the patient's behaviour that had previously been a source of concern. Over time, the couple had communicated with each other about their feelings surrounding the behaviour and had adapted together to restore the cohesion in their relationship. In one case, the patient was able to rationalise his reasons for continuing smoking, in a way that satisfied the partner. In another example, the patient had moderated his behaviour (mood swings), and the partner, her response. It must be noted that in this example, the patient's mood swings may have decreased in intensity due to the natural healing process, and not due to any behavioural efforts on behalf of the patient.

Perceived control

In both the above examples the source of the stress (patient's smoking and mood swings) continued to occur. However, over time, the partners developed the cognitive resources to reframe the problematic behaviour, so that it was no longer upsetting, thus increasing both their sense of control and wellbeing. The interrelationship between control and wellbeing was a recurring theme in the interviews; the perceived control that the partners experienced in relation to the patient's health and behaviour seemed to be important in determining the level of their own emotional well-being. This is line with previous research conducted amongst patients and partners following a cardiac event (Dracup et al., 2004, Moser & Dracup, 1995). This has important implications for health care providers on helping partners' regaining that control; strategies that enhance the feelings of perceived control may be key to maximising the emotional well-being (Manne & Glassman, 2000; Dracup et al., 2004).

Anxiety is often viewed as a generalised or chronic state of fear. Both fear and anxiety have been conceptualised as a response to threat (Walker, 2001), (such as that presented by patient's illness), and may persist unless the threatening situation has resolved or a suitable coping response is found to deal with it. Walker explains that whilst fear reflects a potential loss of control due to a tangible threat, anxiety often

reflects unpredictability and loss of control, and it may persist in absence of knowing the precise nature of the threat, or how to deal with it.

Partners' age

The partners ages ranged from 24–89 years. Age was significantly correlated with their ratings of life satisfaction and their distress. The data supports the findings by Michel, (1992) and O'Farrell et al., (2000), amongst others, that younger (female) partners experience more stress and more emotional and somatic symptoms than older ones. Although age related issues were not a specific focus of this research, the findings concur with O'Farrell's recommendation that younger women should be directed to interventions that address the specific life-span related concerns that they may face.

Partner's health

Partners' pre-existing psychological symptoms and physical health issues impacted greatly on their wellbeing; partners with health concerns were significantly more distressed. These findings correspond to those of Kettunen et al., (1999), who suggested that the partners' own health concerns were a main factor influencing their distress following a patient's cardiac condition. It would be helpful if partners were asked about their physical and psychological health, and directed to the relevant channels of support, where necessary.

Relationship issues

The partners who were more distressed were significantly more negative about their relationship and the effect of the patients illness had had on their relationship.

These results correspond to those of O'Farrell et al., (2000) who found that distressed spouses reported both lower levels of marital intimacy and poorer family functioning. They also mirror Waltz et al., (1988) findings that the level of intimacy between partners was inversely related to patients' depression following a MI.

Whilst, it is possible that the partners' negative affect may have clouded their judgement when rating the quality of their relationship, these finding are backed up by the previous studies. For example, Randall et al., (1998) suggests that the quality of the marriage may be important to the psychosocial adjustment of both patient and partner. Dhooper, (1990) reports that while most families move from a crisis through a transition to recovery, some end up in a chronic state of inadequacy when affected by AMI.

The majority of the partners felt that they could talk to the patients about their concerns, and in both the questionnaire and interviews, the partners who felt that they couldn't talk to the patient about their concerns were significantly more distressed.

In the interviews, the majority of the distressed partners reported that they did not share their experiences and concerns with the patient and that they withheld their feelings. There was also evidence, in our interviews, of overprotection amongst the distressed partners. They closely monitored the activities of the patient, and had become overwhelmingly concerned with their welfare.

Cardiac literature has shown that overprotection interferes with the recovery of the patient, (Marsden & Dracup 1991; Joeke, Maes and Warrens, 2007) as well adding to the anxiety of the partner. Likewise, the use of protective buffering has been found to exacerbate distress in both partners and patients. It is associated with marital dissatisfaction (Suls et al., 1997). This was reflected by the partners' elevated HADS.

In this study, older partners were significantly more able to voice their concerns. This was *not* related to the number of years the couple had been together. However it was significantly related to the strength of the couple's relationship.

In the interviews, the distressed partners often described the roles of 'caregiver' and 'patient' and in a similar fashion to that of 'nagging parent' and 'naughty child,' especially in the context of changing behaviour and overprotection. For example, one partner felt that everything with her husband was a constant battle, and that they had fallen into a pattern of her nagging, and him refusing to comply. Conflicted interactions between partners and patients such as avoidance, conflict or criticism, can offset supportive functions that are conducive to successful recovery and rehabilitation of the patient (Brenner et al. 1989), and contribute to the depression and distress of partners (Newsom & Schulz, 1998).

According to Roland's family systems of illness (1994), we cannot understand illness or reactions to illness in isolation from other the context of one's life and relationships. The onset of illness often changes many of the traditional familial roles, albeit temporarily. The patient during the early stages of hospitalisation and recovery is removed from daily responsibility and both patient and partner become very focussed on the patient, in a similar manner that a parent will focus on a young child. It would be counter-productive to the health of both partner and patient, as well as to their relationship, if these roles persist throughout the latter stages of recovery. Such couples would benefit from assistance in restoring the balance to their relationship, so

that they both could talk to each other 'adult' to 'adult.' It is when the relationship is less close, and there is a lack of communication about how to deal with the difficulties, then it seems likely that the difficulties that the partners experience would be especially frustrating and lead to both hostility and distress.

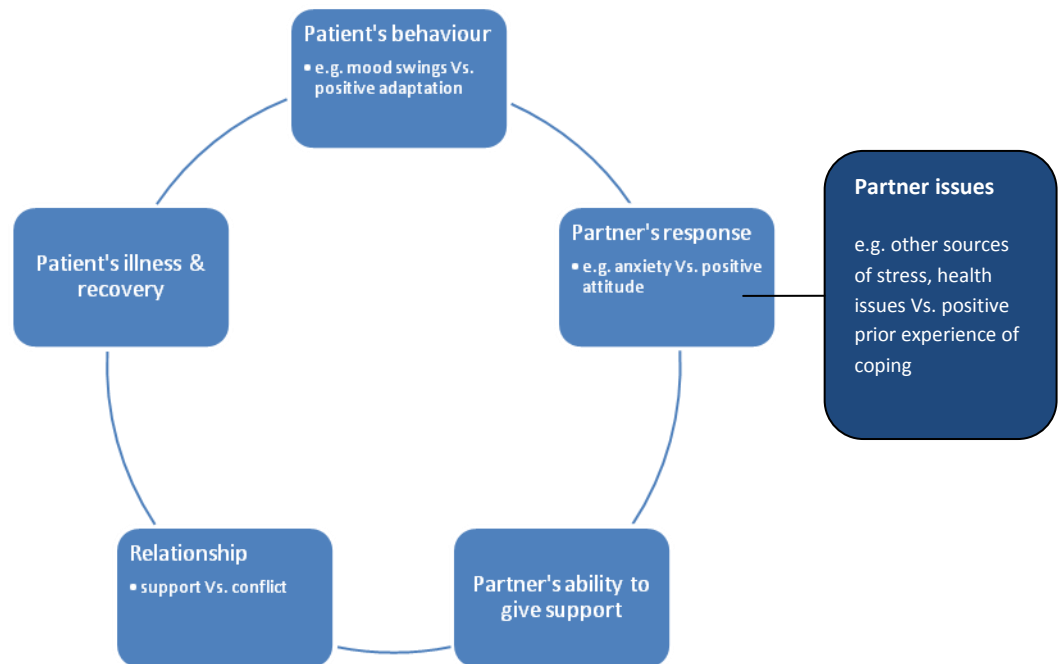
Summary: cycle of distress & wellbeing

In this study, the interviewed partners who were no longer distressed, had been able to restore their sense of control over the situation, and there was a sense of dyadic cohesion to their relationship. This is likely to have had positive effects on the couple's relationship, the patient's recovery and the further wellbeing of the partner. The patients' physical health improved over time, (as would be expected), and the partners mental health, which had suffered in the early stages of recovery, had improved over time. It is beyond the scope of this paper to draw conclusions about the reasons and direction of such a recovery, for example the improvement in the patient's mood swings, could have been both the cause and result of the partner's improved wellbeing. In comparison, the clinical and borderline partners hadn't found any cognitive or behavioural adaptations that suited them in managing their distress. The patient's behaviour continued to be a source of stress and worry for the partner and this had a negative impact on the couple's relationship, and on both their physical and emotional health.

The model of recovery, shown in figure 14.1, describes the interaction between factors such as the patient's illness and attitude towards recovery, the partner's own distress and wellbeing, the quality of the couple's relationship, and the partner's ability to give support on both the recovery of the ill patient and the health of the distressed partner. For example, an acute cardiac event may exacerbate existing marital and psychological problems, increasing the stress experienced, in an already stressful situation, and thus affect the partner's ability to give support (Randall et al., 1998). In such a prevailing situation, where both members of the couple has emotional needs, it is likely that neither of them could provide adequate emotional support for the other. Instead, it is likely that they each added to the anxiety of each other. Individuals with longstanding marital role strains may feel themselves threatened both by the stress of the illness and the stress originating in their relationship. The double burden may lead to the development of overly negative appraisal of threat, harm and loss Walz et al., (1988).

Research has also shown that less distressed partners would be then capable of giving better support to the patients, thus further aiding their recovery, strengthening their relationships (Helgeson, 1991) and the further wellbeing of the partners (and patients).

Figure 14.1 Model of recovery



14.4 Sense of coherence and partners

Background

The cardiac literature has shown that the stress of a partner's illness may increase the partners' vulnerability to develop psychological and physical illness. However, not all partners experience a crisis in response to the patient's illness, and some demonstrate growth. Without identifying how the partners adjust to the stress of illness, it would be difficult to formulate appropriate responses to the partners health needs.

The model that was chosen to look at psychological adjustment among the cardiac partners was the sense of coherence (SOC), (Antonovsky, 1987). Antonovsky (1979), developed this salutogenic model to explain why some people, regardless of major stressful situations and severe hardships, stay healthy, while others do not. The concept of sense of coherence has been applied amongst patients and partners as an explanation for successful adjustment following the stress of illness. Based on the assumption that partners of cardiac patients have experienced a stressful life event, this study explored whether their level of SOC was correlated with their psychological distress.

In the current study, the partners' SOC was significantly correlated with their distress. Furthermore, the linear regression analysis showed that the partners' sense of coherence and cardiac beliefs accounted for close to two thirds of the variance in the partners' psychological distress. Out of the two variables, SOC was the best predictor of HADS. In addition, SOC had a strong correlation to perceived health, mental well-being and life satisfaction, which is consistent with other studies (e.g. Eriksson and Lindström, 2005). Partners with health concerns had a significantly lower SOC. This is consistent with the SOC literature (e.g. Gallagher et al, 1994), as health is one of the determining factors of an individual's SOC.

a) SOC to explain partners' distress

The sample's mean sense of coherence was 66.86. From published SOC studies (Horsburgh, 2000), this samples' mean coherence score would rank highly. Sense of

coherence strengths of this size would mean that, in general, the partners perceived their lives to be coherent and that they were successful in managing the tension in their lives. Comparisons of the mean SOC score with other normative data from nursing research using the SOC showed that the population of partners had similar, yet slightly higher mean sense of coherences than a population of Swedish healthy women and female American nurses. Antonovsky defined coherence as ‘the enduring dynamic feeling of confidence that one’s internal and external environment are predictable and that there is a high probability that things will work out as well as can be reasonably expected (1985, p123). A person with a strong SOC would have the capability to perceive that one could manage when faced with a stressful situation. According to Sullivan, (1989) high sense of coherence may actually enhance one’s ability to deal with subsequent stressors.

The sample also included SOC score as low as 18 which would indicate that at least some of the partners viewed their life quite differently. Scores on the low end of the range are indicative of a weak SOC. Recipients with a weak SOC would be less able to deal effectively with the stressors of life and less likely to find purpose in their lives, according to Antonovsky, (1987).

I. General Resistance Resources (GRR’s)

The General Resistance Resources (GRR’s) refer to any characteristic of the person, group or environment that can facilitate effective management of stress and tension (Antonovsky 1979, p99). In the current study there was evidence that partners who had adequate GRR’s, including a happy marriage, social support and good assistance by the medical teams, experienced less distress. It is assumed that if a person has these kinds of resources at his/her disposal or in the immediate surroundings there is a better chance for him/her to deal with challenges such as a patient’s cardiac event. Likewise those partners who felt that they hadn’t received adequate support or who had experienced recent negative life events, such as a previous husband dying of cardiac problems, suffered.

II. Components of sense of coherence

It is possible to view the reasons for partners’ distress and wellbeing, discussed in the section above, within the three components of sense of coherence; manageability, meaningfulness and comprehension.

Comprehensibility involves understanding factors such as the course of the disease, its treatment and its side effects. Examples of comprehensibility issues in our study included partners not understanding why the patients suffered the cardiac event in the first place, unrealistic recovery expectations and cardiac misconceptions.

Manageability is the extent of the belief that one had the resources to cope with a problem. Examples in this study of manageability issues, that affected the partners' ability to cope, included experiencing multiple stressors, relationship difficulties, ongoing physical or mental health issues and feeling shocked and overwhelmed.

Meaningfulness, is the extent that the one has the motivation to cope with the stressor, for example by viewing the experience as a challenge rather than a burden. In this study the partners with strong SOC were pleased that the patient was alive, and some felt that they had got a 'second chance'. In comparison the partners with low SOC dwelt on the fact that the patient had suffered in the first place. Others' sense of meaningfulness might have been threatened by the dominant fear that the patient may have a relapse.

b) Clinical implications

Salutogenesis is the study of why and how people stay well and the salutogenic model provides a helpful way for health care professionals to organise their thinking processes and ultimately improve health care services they offer to the patients (Fox, 1986). The usefulness of the salutogenic model for healthcare and nursing has been discussed by Sullivan, (1989), Onega (1991), Horsburgh, (2000) and Bahrs (2003).

Antonovsky, (1985) suggests that the medical team as a potential resistant resource (GRR), has the possibility of structuring life experiences for people that would reinforce their SOC. A positive experience, with information and support may open the possibility for the contribution of the medical team in reestablishing the SOC.

Nurses in clinical practice can use the knowledge gained from study of the SOC and its potential stress-buffering effect in every step of nursing process. Assessment of the strengths and weaknesses of the client, including not only illness-susceptibility factors (sources of stress) but resistance factors such as the sense of coherence, would enable nurses to plan nursing actions directed at the strengthening of these factors.

Whilst SOC does not dictate practice the cardiac nurse can use the components of SOC to guide partner assessment, setting goals and focussing the interventions on what is meaningful to the partner (Gunilla et al., 2002).

Comprehensibility

Does the patient's cardiac event make sense? Do the partners understand the reasons for it happening in the first place, and what the consequences may be? Are they realistic about the patient's prognosis, the progress of the disease and long term recovery? Do they understand the course of the disease, its treatment and its side effects (e.g. mood swings)? Do they understand the risk factors? The cardiac beliefs questionnaire would be a useful tool to explore misconceptions about the condition.

Manageability

Does the partner have the adequate resources to help the patient and manage their own worries and concerns? Does the partner have the ability to mobilise her GGRs in order to choose the most appropriate strategy to cope? Does the partner have health concerns? What could be done to help them seek solutions to their problems?

Meaningfulness.

Does the partner feel comfortable in his/her role as a caregiver? Does the partner view the patient's recovery as a challenge rather than a burden?

The cardiac nurse may see a family unit very briefly in new and stressful circumstances and it may be hard to expect them to form intimate knowledge of the social and biographical background about the partner. However, the nurse has the potential to act as a gatekeeper for problems. Bahs et al., (2003) encouraged the cardiac nurses to develop active listening to give (the partners) the feeling that the staff were dealing with their concerns and that the concerns were justified and acknowledged (and thus meaningful). Zdread, (1969) discussed how successful empathy used by nurses, would assist the patient in finding meaning in his/her situation.

Individuals lacking in any of the above issues (indicative of a weak sense of coherence), could be directed to direct to the relevant channels of support. (e.g. counselling, behaviour management, and emotional support.

Onega, (1991) suggests assessing each category of GRRs, in order to intervene when appropriate. For example:

- Physical –e.g. assessing health issues, nutrition, sleep

- Valuative – inclusion of the (partner) in the provision of feedback
- Interpersonal – inclusion of family in care
- Macrosociocultural – patients perceptions of beliefs (cardiac beliefs)

Proactive preparation for the partner would be useful, such as preparing them, in advance, for the issues that many partners face. For example, it would be useful if they could warn friends and family about the patient's impending operation, so that they can mobilise their support in advance.

The majority of the partners in the current study were in good physical and emotional health. Thus, in addition to providing support for partners in *distress*, a salutogenic framework could help staff promote the resources to ensure that the non-distressed partners (and patients) remain *healthy*.

c) Salutogenesis, SOC & health promotion

Onega, (1991) discussed how the salutogenic model could provide a helpful way for (psychiatric) nurses to organise their nursing processes and ultimately improve the health care service. Nursing has been influenced by the disease-orientated (pathogenic) models. Despite nursing's ideological commitment to 'health' rather than 'sickness', nursing research has persistently focussed on illness as the dependent variable, (Ellis, 1982; Sullivan, 1993). The development of a health-oriented theoretical model in nursing may be actualised through salutogenic theory. And research which explores the relationship between stress, resistance and health in various populations (Sullivan, 1993).

The salutogenic model looks at the complex conditions that foster a person's wellbeing. Bahrs et al., (2003). Lindström, (1994) argued that the salutogenetic framework could be considered as a theoretical framework for health promotion. Eriksson & Lindström (2007) conducted a systematic review on the salutogenic concept, sense of coherence (SOC), and its correlation with quality of life (QoL). It explored 458 research publications published in 1992–2003. They concluded that the SOC seems to be a resource that enhances the QoL directly, or mediated by a good perceived health. The stronger the SOC, the better the perceived health and the quality of life. They argued that such findings correspond to the core principles of health promotion, as presented in the Ottawa Charter (WHO, 1986) —that is, the process of enabling people to live a good life (Eriksson & Lindström, 2007). Furthermore, Eriksson (2007), proposes that

salutogenic theory to be a valuable approach to public health and health promotion research and practice.

d) Summary: SOC

SOC was found to be a useful research tool to predict distress amongst partners and to explain why some partners cope better than others with the stressors of a patients' illness. A person with a strong SOC would have the capability to respond to a stressful situation with strength and understanding, and would view life as comprehensible, meaningful and manageable; whilst the person with a low SOC would be more likely to become overburdened and distressed.

The reasons for partners' distress, which were obtained from both the questionnaires and interviews data, were explained via the framework of the three components of sense of coherence; manageability, meaningfulness and comprehension.

The SOC questionnaire could be used in cardiac research to explore how partners and patients adapt to both the illness and the resulting challenges, both individually and as a marital dyad. For example, how would the interaction of the patients' and the partners' SOC correlate with their distress or wellbeing? In addition to being a theoretical framework and a useful research tool to predict distress, the SOC has much to offer clinically. It was discussed how the components of SOC could be used to frame the types of questions that cardiac staff could ask the partners. This has important implications for the development and implementation of psychosocial interventions for partners. The SOC would provide cardiac staff a framework to organise both the questions that they ask the partners and the information that they provide them. In this way early partner interventions would become both an integral and an intrinsic part of nursing care.

Salutogenesis is the study of why and how people stay well, and the salutogenic model provides a helpful way for health care professionals to organise their thinking processes and ultimately improve health care services they offer to the patients (Fox, 1988). The salutogenic theory is a valuable approach for health psychology and health promotion research and practice.

14.5 Cardiac beliefs

The cardiac beliefs were significant in predicting partners distress. There was no relationship between the number of mistakes/misconceptions made and the age or gender of the partners. However, the number of mistakes was significantly correlated with the partners' employment status; those not working (either because they were unemployed, homemakers, or retired) made significantly more mistakes than the employed (full and part time). This may be explained by factors such as the partners' level of education and social class, although this data had not been collected.

The study has shown that the cardiac beliefs questionnaire would be a useful clinical tool for cardiac staff to employ with partners. It could be used solely as an assessment tool, although the benefits of this would be probably be limited to research purposes. The real strength of the questionnaire would be the fact that it is an educational device, which means it can be used directly as an intervention. Partners could be given the questionnaire to complete, and then either the answers and explanation sheets to read alone, or, ideally, to be used as a means for nursing staff to discuss their concerns and misconceptions. The explanation sheet could be given out as part of the patient's after care, so that it can be referred to at any stage of the patient's recovery.

Summary

The cardiac beliefs, together with the SOC have a valuable role in cardiac partner interventions, both as a research tool, but also, as clinical interventions.

14.6 Partners' view of the information & support

The majority of partners in the questionnaire indicated that they were pleased with the information given to them about the patient's physical condition. However, they were less satisfied with the information given to them regarding the patient's emotional concerns. This finding is more positive than that of previous studies, which have highlighted the inadequate informational support from health professionals (e.g. Thompson et al., 1995; Kettunen et al., 1999; Steward et al., 2000). In these studies, partners ranked practical information, such as what to do in an emergency, care

following discharge and lifestyle advice, more highly than emotional information (Moser et al., 1993; Turton, 1998).

Many of the partners would have liked better communication with the medical team about the patients' condition, especially during the cardiac episode and at discharge. They also wanted more contact with the cardiologist prior to surgery and to discuss test results. They requested more information specifically designed for cardiac partners, including instructions on how to cope and care for the patient during the couple of weeks following the operation and/or discharge.

In the interviews, the majority of the partners said that overall, they had received good support from cardiac teams and from family and friends. These partners were extremely sensitive to the quality of support given to them. They were particularly vulnerable during the early stages at hospital and early discharge, when some had felt isolated and neglected. They had needed a lot of support regarding the patient's condition and progress and found it difficult when they weren't given enough information about this, or if they felt that his progress wasn't being monitored adequately. A bad experience would counteract the benefits of previous good support.

In the questionnaire, the partners that rated themselves as *not coping* with the patient's condition were significantly more likely to view the information and advice given to them as unhelpful. It would be helpful if the support teams were aware that distressed partners may not be able to benefit fully from informational and emotional support, due to their initial shock. This may have implications for the timings and delivery of support to partners.

This also has implications for the interpretation of research that asked partners to subjectively recall the support they had received. The general cardiac research suggests that many patients and partners have been dissatisfied with the quality and quantity of information given to them by cardiac teams. It should be considered that their recollections of the support may have been distorted by any intense shock or distress they may have experienced as well as by their affect at the time of recollection. This could be an area for further research.

14.7 Partner interventions

A systematic literature review that looked at targeted interventions for partners of cancer patients recommended that carer interventions should aim to be i) grounded in the theory and evidence; ii) in a format seen as useful and appropriate by partners and accessible, so that all partners are able to access services should they wish to do so; iii) and effective i.e. shown to improve intended outcomes for partners using rigorous evaluation methods) (Ussher et al., 2009).

This section explores ideas for partner interventions. These suggestions are based on the findings of this study, on previous research as well as consultation with health care providers. The effectiveness of these interventions could be validated by future research.

Ideally, support for partners would be made available through a combination of media and at various stages throughout the patient's (and partner's) illness experience. Strategies aimed at the partner need to begin early and commence during the acute stage of the patients' recovery (Davies, 2000; Svedlund 2000).

It may be beneficial if protocols of partner support could be developed by cardiac teams. This could include the types of routine support that cardiac nurses could provide, and the pathways of stepped care for appropriate follow up support. An example of such a framework of support is given in table 14.1. Such a model could be consistent with care pathways for depression and long term conditions. A range of health care professionals in both primary and secondary care should be aware of partners' issues and be able to direct partners to the necessary support. Patients requiring further psychological treatment should be identified and referred to appropriate support. Stepped care models have already been developed for cardiac patients and have resulted in a significant reduction in depression (BDI) amongst patients treated by a psychologist. Strategy teams could look into extending this model to partners.

The following section will explore the sources of support in greater detail.

Table 14.1 Framework of support

Medium	Provider
<p>Literature & one-to-one information</p> <p>Discussing general partner issues Specific patient/partner concerns Cardiac beliefs Referral to life support training & group support</p>	<p>Cardiac nurse</p> <p>(repeated at follow up visits, GP, cardiac rehabilitation)</p>
<p>Support group</p> <p>(one-off or longer programme)</p>	<p>Cardiac nurse & psychologist</p>
<p>Psychological therapy</p> <p>(group or individual) Referred via GP, or cardiac teams Including referral to outside agencies e.g. marriage support, psychiatry</p>	<p>Psychologist</p>

a) Literature designed for partners

In both the questionnaire and interviews the majority of partners were keen for there to be specific literature developed for partners of the patients. This could be a relatively easy intervention to implement and evaluate. It could take the form of a leaflet that is handed out and displayed in waiting rooms. The information could also be repeated on a website.

Ideas of content could include:

- General partner information including what to expect following discharge, (Nb. this could be given out with the patient information, to avoid replication of specific facts).
- The reasons why partners are important in the recovery of the patient and how important it is to look after the health and needs of the partners, as an unhealthy partner will not provide the necessary help to the patient. It could also state that some partners may be at risk for anxiety and depression if their needs are not met.

- Common concerns that partners report including the shock of the illness, concerns over recovery, patient mood swings & depression and resistance to making lifestyle changes.
- Encouraging the partners to discuss issues & concerns (such as partner health issues, multiple caring responsibilities and patient issues) with cardiac teams or their GP, and not to hide them.
- Sources of support for partners including the GP, cardiac nurses and support groups, referral to life support training and the reasons these might be beneficial.
- Cardiac rehabilitation contact numbers and 'what to do in an emergency'.
- The cardiac beliefs questionnaire and explanations could either be included in the leaflet, or given out separately

The partners could refer to the literature whenever they need to. Having it in writing, would hopefully counteract any effect of their initial shock filtering out the information given to them by staff.

Having specific literature for partners could help partners feel supported and remind them that their needs are valued. It would also make them aware of common concerns and the importance of addressing them, for the sake of both the patient and their own health, rather than soldier on regardless.

b) One to one discussion

Almost all of the partners in the study would have been interested wanting more one to one discussion with the nursing staff. With increasing pressures in the NHS leading to early hospital discharge the one-to-one nurse–patient relationship occurring during the acute stage of recovery may be the time when nurses have the greatest contact with partners (Davies, 2000). This is also a time that partners are especially vulnerable to experiencing shock, anxiety and depression. Explanations and emotional support given to carers at this time may influence the patients' longer-term recovery and the partners' physical and psychological health. The cardiac nurse could go through the literature with the partner whilst inviting dialogue to address specific concerns. This way, partners may feel more able to open up about their own concerns, rather than feeling that their needs are secondary to those of the patients. Svedlund, (2000) recommended using checklists containing the necessary information for both the patient and partner. Ideas for discussion are discussed below.

Partners need to be prepared about what can happen and what it will feel like after an AMI or surgery. Partners should be given specific facts about the patient and the prognosis and progress and receiving honest information in understandable terms (Moser et al., 1993), especially during hospitalisation (Theobald, 1997). Likewise, the couple should be given a realistic picture of the patients' possible physical and psychosocial reactions to prevent undue anxiety. Partners may need to be monitored for stress and given some stress reduction before they are given the information regarding the patient.

They could discuss particular information relevant to specific partners such as the particular life-stage issues relevant for younger (or older) partners (O'Farrell et al., 2000), the particular needs of partners with chronic physical and mental health concerns and the overlapping roles that partners often have including work responsibilities and family support. When necessary, the partners could be assessed using the Hospital Anxiety and Depression Scale (HADS). Those with particular concerns could be targeted for further support.

They could discuss questions raised by the cardiac beliefs questionnaire. Cardiac staff could then discuss further sources of assistance including the support groups available, and why the partner might benefit from them. Partners could have a chance to voice their concerns over the barriers to participation in the group, and this could be discussed.

Partners should be encouraged to attend cardiac rehabilitation with the patients. Couples participating in cardiac rehabilitation programmes perceived that these had positive effects on their coping, and also on the quality of their spousal relationship (Stewart et al., 2001). Cardiac rehabilitation would be an ideal opportunity to promote specific support interventions for partners. However, due to the high number of non-attendees, it should not be the only source of promotion for these interventions. The literature and conversations should be repeated at phase II, home visits, at cardiac rehabilitation and at further follow up appointments.

c) Group support

There was a low level of interest in the group support among the partners who completed the questionnaire. This was concerning, as the group support has been recommended by Stewart et al., 2001; O'Farrell et al., 2000). The relatively healthy

sample of partners who volunteered for the study could be a reason for this lack of interest, as someone who is coping well, may not feel the need to take part in an additional intervention. However, in the interviews, **all** of the interviewed partners, regardless of whether their mental health had improved, were much more positive about the group. They all agreed that in hindsight, participation in a group intervention would have been helpful. They felt that they would have liked the peer support and meeting other people in a similar situation.

Some of them were unclear about their reasons for being uninterested in the group in the questionnaire. Some hadn't understood how they might have benefitted from group support. Others had been put off by the logistics of attending a group, whilst working, as they had already taken so much time off to attend hospital appointments. Some of the partners had been so focussed on the patient's needs, whilst also feeling overwhelmed by the situation, that a group just seemed like a burden, another thing to 'fit in'. These partners hadn't thought about how they might have benefitted from group support and they felt that they didn't have the time to prioritise their own needs. Only one partner said that she wouldn't have wanted to attend the group, because she felt that her situation would be so different from the others.

The means HADS of the partners who were '*not sure*' about the group were significantly higher than those of the partners who said that they were '*not interested*' in the group. This raises an interesting question as to whether it is a general trait of people who are distressed, to be ambivalent about seeking help. They are also the most difficult group to support, as they don't know what they want. Findings of a survey by the Healthcare Commission, (2005) showed that the main reason patients gave for not attending cardiac rehabilitation was that CR was not offered to them. The second most common reason was 'patient not interested'. Previous research has shown that if patients are encouraged to attend by their doctor, uptake is greatly increased. This suggests that cardiac partners could be encouraged by both cardiac staff and GP's to attend the support groups and this should be repeated at every opportunity. If the partner remained convinced that they wouldn't want to attend the group, then alternative solutions should be found.

Cardiac staff might consider asking past cardiac partners if they would be willing to become 'buddies' to current partners. This could involve a telephone conversation where they discuss experiences. This peer support could be an opportunity to promote the group, or it could be used as intervention for those not interested in the group.

Structure, content and delivery of a group

Stewart et al, (2000) recommended that careful consideration should be given to issues of similarity of peers, leadership, and optimum timing and duration of a support group. The suggestions and preferences that the partners in this study gave for the group included holding it during evenings and/or afternoons to encourage participation by working partners. Some partners suggested that holding the group after the first month prior to discharge, others suggested holding it a couple of months later, once things had settled down.

A one-off group would enable a large section of the partners to have access to important information, without committing themselves to weekly sessions. However, a longer programme could encourage greater group dynamics and peer support. There are many different formats that a group programme could take. For example, it could be a closed group with a definite start and finish date or a more flexible rolling programme.

This group session(s) could either be open just for partners, or it could be for both patients and partners together. There could be a time when the mixed group splits into patient / partner groups to give some partners the opportunity to voice their concerns without the patient being there. If this session were to be held at a similar time to cardiac rehabilitation, it would be easy to accommodate both these groups.

Monahan et al., (1996) suggests a stress-management group format, to give the partners the tools to tackle their issues.

Content

The support group could be jointly led by a cardiac nurse and psychologist. Although the specific content would be determined by the timings and length of the programme, some examples may include:

- The impact of the patient's illness including shock, recovery and rehabilitation issues
- Appraisal of the illness, cardiac beliefs and misconceptions
- Caring for the emotional and physical needs of the patient without hindering one's own health and wellbeing

- Supporting (and participating in) behavioural interventions such as smoking cessation, problem drinking and weight management. Managing non-compliance
- Marital and relationship concerns. The partner should be encouraged to give support without being overprotective and to communicate to avoid buffering and smothering. Although the provision of marital and family counselling may be beyond the capability and mandate of most support programmes, it would be beneficial to patients and partners if such needs were identified and referral to community-based counselling services was offered (O'Farrell et al., 2000)
- Restoration of life-work balance
- A question and answer (Q & A) session, with the partners being able to address their specific concerns as well as share support and experiences with the other participants
- Special focus should be placed on any interventions that may enhance partner perception of control (Dracup et al., 2004; Manne & Glassman, 2000). This may help to relieve the sense of vulnerability and demand that partners often experience
- Cognitive behavioural therapy would be useful in issues such as exploring and/or challenging assumptions and beliefs about the patient's illness and their response to it; examining behaviour such as vigilance, buffering and over control; problem solving and cognitive restructuring; teaching methods to strengthen internal resources such as stress management and relaxation. This may help partners to respond more adaptively to the stressors and improve their sense of perceived control
- Strategies should be aimed at improving the partners' emotional, cognitive, and motivational processing and their behavioural competencies. Promoting concepts such as mastery, locus of control and self-efficacy as well as strengthening sense of coherence, as discussed in section 14.4
- Stress management could include relaxation techniques such as breathing exercises and visualisation, as well as Mindfulness techniques such as meditation and body awareness. Partners could be encouraged to create 'my time,' where they take time off from their intense experience of being constantly

vigilant and 'on-call'. This could include ideas such as going for a walk, enjoying a bath with candles, keeping a diary or listening to music. Such activities do not have to be time consuming, expensive or dependant on another person helping out

d) Psychological therapy

The concept of counselling in health care settings has been discussed in great detail in Bor et al., (1998). Psychological therapy may be provided by a psychologist or counsellor. Counselling can help the partners adjust to and cope with the demands associated with the patients' illness. There are many forms that the counselling can take, including cognitive-behavioural, psychodynamic and systemic. It is common for counsellors to adopt an integrative approach would combine these approaches. The length of counselling may vary according to the setting in which it takes place, and the level of distress experienced by the client (partner). For example, most health care settings provide short-term, time limited counselling. It may be enough for partners to receive a one-off session with a psychologist, to help organise their thoughts and reactions. Partners may be referred to other agencies such as marital therapy or psychiatry.

14.8 Limitations of the study

a) Response rate & selectivity bias

The response rate for the study was 27.05%. This was very low. The study was also limited by the fact that the sample population was neither random nor necessarily representative, which restricts the generalisability of the findings.

It is likely that there was a selectivity bias in those partners that volunteered to participate in the questionnaire. This might have consequences on the internal validity of the research findings. However, it wouldn't necessarily have an effect on the types of interventions suggested. The sample population was in very good health and wellbeing, suggesting that the sample may have been biased toward partners who experienced better recovery and support and who were in a higher socioeconomic situation. This would mean that the results may have underestimated the true levels of distress amongst partners. Partners experiencing high levels of distress may have felt reluctant, or too burdened, to fill out the questionnaire, alternatively, they have been unwilling to disclose the truth, and thus 'improved' their situation.

The low response rate may be explained by the fact that the main researcher was not working in either of the hospitals and had to rely on busy cardiac nurse and therapists to give out the questionnaires. Alternatively, partners may have been put off by the lengthy and wordy questionnaire, which required a good grasp of English. The low response rate may also show that many partners weren't interested in improving partner support.

Many questionnaires were given out to patients to give to their partners, which meant that some may have got lost in the process. Likewise, some important information such as the relevance of participating in the study and assurances of participant confidentiality may not have been passed on. Partners may have been worried that any negative comments may influence the patient's subsequent care. Although these points were addressed in the patient information sheet contained inside the envelope, this might not have been read. In addition, the modifications required by ethics committee to the patient information sheet, also made it a lengthy and wordy sheet to read. Potential participants may have been put off before they even began.

Future studies may address the question of whether the response rate and the prevalence rate of anxiety and depression would be different from that observed in our study if alternative recruitment strategies. Partners could be targeted via different strategies such as the hospital making joint follow-up appointments for patients and partners i.e. making it normal for partners to be involved (and also easier to hand out the questionnaire directly to the partner). Researchers could also look into incentives such as payment or participants being entered into a prize draw.

Nearly two thirds of the sample was female. Although this is an improvement from previous studies that had an even greater gender bias, there is still a gender imbalance, and as a result, accurate gender comparisons are harder to perform. Likewise, a high majority of the partners were white. Despite planning to address all aspects of ethnic diversity in the study, the execution of this was restricted by language, as non-English speakers would have been excluded from the study.

b) Limitations of the questions

To a degree, the questionnaire categorised partner's responses according to predetermined categories. It could be argued that using these approaches to research limits the potential response of participants. Hopefully use of additional comments and the subsequent interviews counteracted this.

The immediate experience of an acute cardiac event varies substantially between patients. There may be a difference between MI and revascularisation experience for patients and partners, as well as difference between acute and chronic conditions, those experiencing it for the first time compared to those who have suffered over many years and sudden events and procedures compared to expected ones. Due to the multiple conditions that were listed, it was hard to draw any conclusions about the type of patient event. Future studies could explore these differences in greater detail, and they may need to be taken into account in the design of the interventions.

This study had wanted to investigate the partners of *all* patients who were eligible to be invited to cardiac rehabilitation. It did not want to restrict its findings to one condition, such as MI or CABG. This was because in reality patients suffer from a variety of conditions, as shown by our results, and cardiac rehabilitation does not differentiate between these conditions. It was hoped that the range of patient conditions would provide a rich data of partners' experiences. However, as a result, it meant that some analysis was difficult. For example, it was hard to obtain conclusive data to determine the *severity* of the patient's condition. Previous research has suggested that for a substantial minority of couples the consequences of caregiver burden are greater and more persistent than is physically justified by the severity of the patients' MI (Skelton & Dominian, 1973; Kettunen et al, 1999). It may have been interesting to have examined this further. Although the questionnaire asked about the number of days that the patient had been in hospital, and the information about the patients' illness, including dates, most of the partners did not fill in the dates of the condition, and this made it impossible to build a proper picture of the patients' condition. Future studies would need to ask specific questions about the length of *each* hospital visit, the time period over which the patients had been suffering from the various heart problems (in some cases it was over decades) or previous attendance (or non-attendance) at cardiac rehabilitation. However, the lack of data on severity of the patient's condition may not be too important, as Kettunen et al., (1999) among others, recommended that *all* partners needed attention from health care professionals, including those of patients suffering from milder conditions.

It was requested that the questionnaires be completed within a three month period, in order to obtain a wide partner experience. Unfortunately, due to the multiple conditions that patients had suffered from over varying time periods, it was hard to make any direct comparisons using 'time since event' as a variable. The study did not want to be restricted to partners of 'first time' cardiac patients.

In the questionnaire, partners were not specifically asked about the advice or information given to them by their GP or a counsellor. Although this was discussed in the interviews, this information would have added to the richness of the data provided by the questionnaire, and should be included in future studies.

c) Methodological limitations

The telephone interviews were not recorded and transcribed. This meant that the content of them could not be checked and verified by other researchers. On reflection, this would have the potential to affect the reliability of the content.

Due to the length of time of the study, there was a considerable variation in the time period between partners completing the questionnaire and participating in the interviews (four months – four years). From the partners who were eligible to be interviewed, some were specifically chosen because of the variation in this time gap, as it had been hoped that this wide spread of experience would add to the richness of the data. However, this spread of experiences could also be a limitation of the study.

14.9 Future research

Future research is needed to evaluate partner interventions to investigate the effectiveness of the support as well as the timings and delivery of it. Research should look at the most effective way to include *all* partners regardless of their gender, class or ethnicity. Likewise, it should look at the best way to include specific information and support for younger partners and those with added carer responsibilities and long term mental health concerns.

Future studies could also explore how the ideas generated by the current research on partner interventions could be adapted to *patients*. Many of the ideas suggested could be discussed with the couple, thus improving the outcomes for both partner and patient. In order to demonstrate whether there is a causal relationship between partners' emotional distress and patients' psychosocial recovery, it would be also be useful if research tested the impact of partner interventions on the patients. A longitudinal, dyadic study investigating the impact of the patients' illness and the outcomes of interventions on both partner and patient would be both relevant and important.

The SOC questionnaire could be continued to be used in cardiac research to explore how partners and patients adapt to both the illness and the resulting challenges, both individually and as a marital dyad. For example, how would the interaction of the patients' and the partners' SOC correlate with their distress or wellbeing? It may be possible to also use the Family SOC (Antonovsky & Sourani, 1988) to investigate family support and coping..

Further collaborative work between acute Trusts, Mental Health Trusts and PCTs needs to be undertaken to examine the longer-term service delivery and outcomes. For example, whether the support groups, could be offered within acute trust settings or within the community.

14.10 Conclusions

The majority of the partners in our study were in good physical and emotional health, although the true levels of distress may have been underestimated .

The extent to which spouses experience adjustment problems limits the amount of support that they are able to seek for themselves such as attending group support and asking for help. Targeting family members of chronically ill individuals through psychosocial or behavioural strategies may have the potential to improve outcomes for the partner, the patient and reduce health costs.

The cardiac beliefs, together with the SOC have a valuable role in cardiac partner interventions, both as a research tool, but also, as clinical interventions.

The salutogenic theory is a valuable approach for health psychology and health promotion research and practice.

The sense of coherence provides cardiac staff a framework to organise both the questions that they ask the partners and the information that they provide them. In this way early partner interventions would become both an integral and an intrinsic part of nursing care.

In addition to providing support for partners in *distress*, a salutogenic framework could help staff promote the resources to ensure that the non-distressed partners (and patients) remain *healthy*.

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Appendix 1 Questionnaire

We are interested in how people in general cope with their partners' illness and what we could do to help this. Please complete the following questionnaire. It is important that you do this on your own.

YOUR EXPERIENCES

Please complete these questions by circling the best option or writing your answers in the spaces provided.

Today's date:..... **Date of birth:**..... **Sex:** M___ F___

Are you: employed full time / employed part time / unemployed / homemaker / retired

Ethnicity (please tick) White... Black-Caribbean... Black-African... Black-Other...
 Indian ... Pakistani Bangladeshi... Chinese....
 Other Asian Other).....
 (please state) (please state)

1 **What kind of event did your partner have:** (Please tick and put month and year)
 Cardiac surgery Angina Heart attack
 Angioplasty / STENT Not sure Others (please state)

2 **Approximate number of days did your partner stay in hospital:**
Approximate date that your partner was discharged from hospital:

3 Currently **your** general health is: poor / fair / good / very good
 Do you have any concerns about your health at the moment? Yes / No

4 Please rate how you are feeling about your life in general by circling one of the following:
 Delighted / pleased / mostly satisfied / mixed / mostly dissatisfied / unhappy / terrible

Please state the main reason for satisfaction or dissatisfaction:

5 How long have you and your partner been together?.....
 (If relevant) Are you cohabiting? Yes / No

In general how do you rate you and your partner's relationship?

1 2 3 4 5
 poor excellent

6 To what degree has your partner's illness affected the quality of your relationship?

1 2 3 4 5
 Made it stronger no change made it worse

7 As a partner of someone with a heart problem how well do you think **you** are coping?

1 2 3 4 5 6 7 8 9 10
 Coping extremely well not coping at all

8 How well do you think **your partner** is coping?

1 2 3 4 5
 coping very well not coping at all well

9 From the range of concerns below, which, if any, have bothered you since your partner's heart problem?

	No problem at all				Yes, definitely a concern
	1	2	3	4	5
Too many responsibilities	1	2	3	4	5
Not enough time for myself	1	2	3	4	5
My partner is able to do less things	1	2	3	4	5
Financial worries	1	2	3	4	5
Your partners moods and emotional concerns	1	2	3	4	5
Partner's attitude towards his/her recovery	1	2	3	4	5
Helping my partner to carry out lifestyle changes e.g. stop smoking	1	2	3	4	5
Partners future work prospects	1	2	3	4	5
Social activities	1	2	3	4	5
Worries about his/her future health	1	2	3	4	5

10 Any other effects not mentioned above? _____

11 Do you feel able to talk to your partner about any concerns about their heart problem?

1 2 3 4 5
 not at all yes definitely

12 How would you rate the information and advice you received from the hospital about your partner's physical condition

1 2 3 4 5
 not helpful at all very helpful

13 How would you rate the information and advice you received from the hospital about your partner's emotional concerns?
 1 2 3 4 5
 not helpful at all very helpful

14 Which of the following have you used for help and information: (Please tick)
 Discussion with nursing team ___ BHF material ___ Advice line ___ Internet ___
 Attending cardiac rehabilitation ___ Local library ___ Information booklets ___

15 If the following were available which might you be interested in using: (please circle)

More written information and advice about caring for someone with heart problems	interested / not sure / not interested
A group session with other partners to discuss issues such as lifestyle changes and help with emotional problems that may result when caring for someone with heart problems	interested / not sure / not interested
More one-to-one discussion with nursing staff	interested / not sure / not interested
Would you like to be taught basic life support (resuscitation)	interested / not sure / not interested

16 Is there anything that we could offer you that you think would have been, or would be, helpful for you?

.....

<p>Telephone Interview # Would you be willing to be interviewed over the telephone to discuss these matters in greater detail? Yes / No</p> <p>If you agree to this, please write down your first name and telephone number. Katy Filer will call you at a time convenient to you. The conversation will last approximately fifteen minutes. You may change your mind at any point. Please write your first name and telephone number below.</p> <ul style="list-style-type: none"> • First name: • Telephone number: Best day / times to call:.....

The next 4 pages contain three different questionnaires relating to different aspects of your life.

PART ONE ORIENTATION TO LIFE QUESTIONNAIRE

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1; if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. **Do you have the feeling that you don't really care about what goes on around you?**
1 2 3 4 5 6 7
very seldom or never very often
2. **Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?**
1 2 3 4 5 6 7
never happened always happened
3. **Has it happened that people whom you counted on disappointed you?**
1 2 3 4 5 6 7
never happened always happened
4. **Until now your life has had:**
1 2 3 4 5 6 7
no clear goals or purpose at all very clear goals and purpose
5. **Do you have the feeling that you're being treated unfairly?**
1 2 3 4 5 6 7
very often very seldom or never
6. **Do you have the feeling that you are in an unfamiliar situation and don't know what to do?**
1 2 3 4 5 6 7
very often very seldom or never
7. **Doing the things you do every day is:**
1 2 3 4 5 6 7
a source of deep pleasure and satisfaction a source of pain and boredom
8. **Do you have very mixed-up feelings and ideas?**
1 2 3 4 5 6 7
very often very seldom or never
9. **Does it happen that you have feelings inside you would rather not feel?**
1 2 3 4 5 6 7
very often very seldom or never

10. Many people - even those with a strong character - sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

1 2 3 4 5 6 7
never very often

11. When something happened, have you generally found that:

1 2 3 4 5 6 7
you overestimated or underestimated its importance you saw things in the right proportion

12. How often do you have the feeling that there's little meaning in the things you do in daily life?

1 2 3 4 5 6 7
very often very seldom or never

13. How often do you have feelings that you're not sure you can keep under control?

1 2 3 4 5 6 7
very often very seldom or never

PART TWO THE CARDIAC BELIEFS QUESTIONNAIRE

We'd like you to fill in these questions. They are about **your opinions and what you do about your partner's heart problems**. Tick whether you agree or disagree with the statement.

It is important that you answer **EVERY** question. If you are not sure which answer to choose we want you to **guess**. Don't think too long about your answers, the first thought that comes into your head is probably the best one.

	Tick if you AGREE	Tick if you DISAGREE
1 A heart attack makes a weak area in the heart wall that can easily rupture		
2 People who have heart problems should never get excited or upset		
3 Once you have had one heart attack you are bound to have another one		
4 It's OK to disagree with people with heart problems		
5 People develop heart disease because of worry in their life		
6 Angina is a kind of small heart attack		
7 People with heart problems should live life to the full		
8 There's not much you can do about heart problems		
9 Any sort of excitement could be bad if you have heart problems		
10 It's a good idea to check to see how you feel before doing something		
11 Doing exercise can strengthen the heart muscle		
12 Heart problems are a sign that you have a worn out heart		
13 You can reduce your risk of more heart problems		
14 Heart problems will definitely shorten your life whatever age you are		
15 One of the main causes of heart disease is stress		
16 It is dangerous for people who have heart problems to argue		
17 People with heart disease should take life easy		
18 It is important to avoid anything that might bring on angina or chest pain		
19 Heart problems are often caused by people's lifestyle		
20 People who have a heart problem should always avoid stress		
21 Rest is the best medicine for heart problems		
22 It is important for people with heart problems to carry on doing enjoyable things		
23 Your heart is like a battery, the more you do, the faster it runs down		
24 Changing your lifestyle can reduce your risk of more heart problems		

Would you like us to send you the answers to the cardiac beliefs questions? Yes / NO
If 'Yes' Please write your name and address in the space below.

PART THREE

Please read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	I feel as if I am slowed down:	
Most of the time	Nearly all of the time	
A lot of the time	Very often	
Time to time, occasionally	Sometimes	
Not at all	Not at all	
I still enjoy the things I used to enjoy:	I get a sort of frightened feeling like 'butterflies in the stomach':	
Definitely as much	Not at all	
Not quite so much	Occasionally	
Only a little	Quite often	
Not at all	Very often	
I get a sort of frightened feeling like something awful is about to happen:	I have lost interest in my appearance:	
Very definitely and quite badly	Definitely	
Yes, but not too badly	I don't take as much care as I should	
A little, but it doesn't worry me	I may not take quite as much care	
Not at all	I take just as much care as ever	
I can laugh and see the funny side of things:	I feel restless as if I have to be on the move:	
As much as I always could	Very much indeed	
Not quite so much now	Quite a lot	
Definitely not so much now	Not very much	
Not at all	Not at all	
Worrying thoughts go through my mind:	I look forward with enjoyment to things:	
A great deal of the time	As much as I ever did	
A lot of the time	Rather less than I used to	
From time to time but not too often	Definitely less than I used to	
Only occasionally	Hardly at all	
I feel cheerful:	I get sudden feelings of panic:	
Not at all	Very often indeed	
Not often	Quite often	
Sometimes	Not very often	
Most of the time	Not at all	
I can sit at ease and feel relaxed:	I can enjoy a good book or radio or TV programme:	
Definitely	Often	
Usually	Sometimes	
Not often	Not often	
Not at all	Very seldom	

Thank you once again!

Would you like us to send you a copy of the completed study? Yes / No

If 'Yes,' Please write your name and address below (if you haven't already written it on p6)

Appendix 2 Checking the data

The distribution of each of the measures (SOC, Cardiac beliefs and HADS) were checked via the frequencies and descriptive statistics and there were no errors. The cardiac beliefs and HADS were slightly positively skewed. The SOC scores were slightly negatively skewed and clustered a little, with a uniform distribution.

Scatterplots of each independent variable were explored against the dependent variable to check for linearity and outliers. There were no outliers of more than 2 standard deviations from the mean.

The variance of the measures was what would be expected. The reliability of each scale was estimated by Cronbach's coefficient α .

The data was tested for heteroscedasticity. There was homoscedasticity of variance.

Table A2 Descriptive Statistics

	Mean	Std. Deviation	N
HADS	12.2143	7.73830	84
Cardiac beliefs	7.46	3.992	84
SOC	66.4167	15.29092	84

Figure A2.1 Histogram to test the regression standardized residual

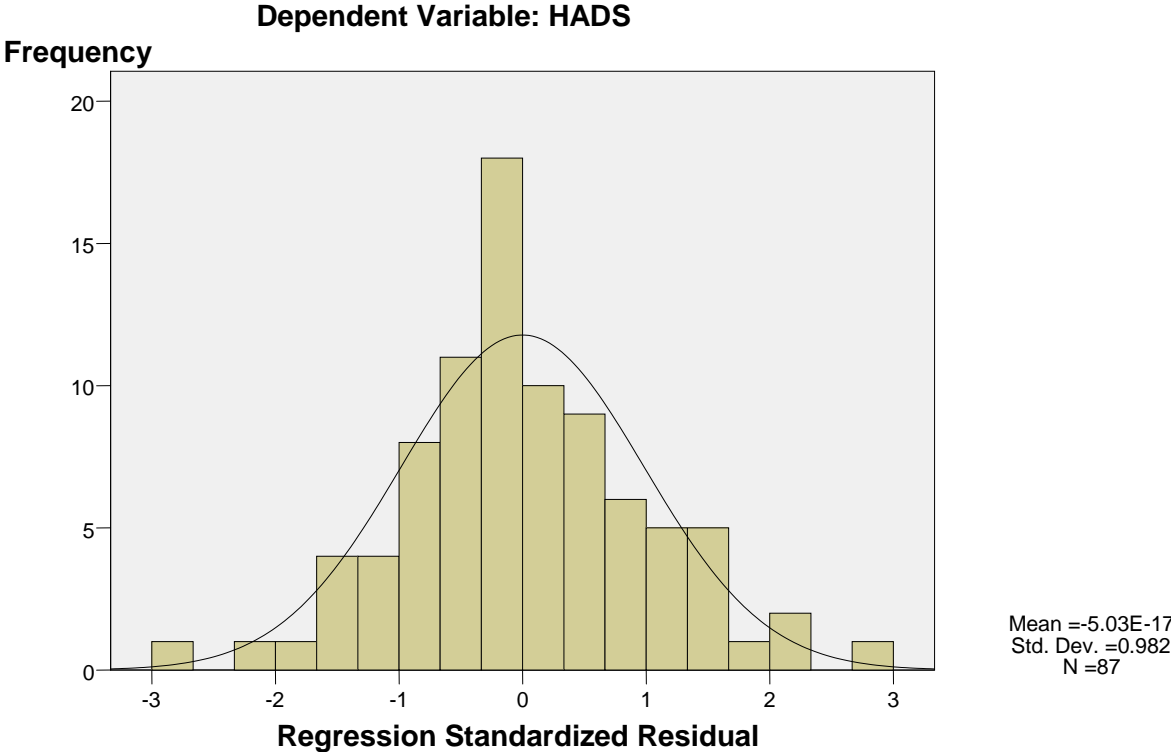


Figure A2.2 Scatterplot; regression standardized residual against the regression standardized predicted value

Dependent Variable: HADS

Regression Standardized Residual

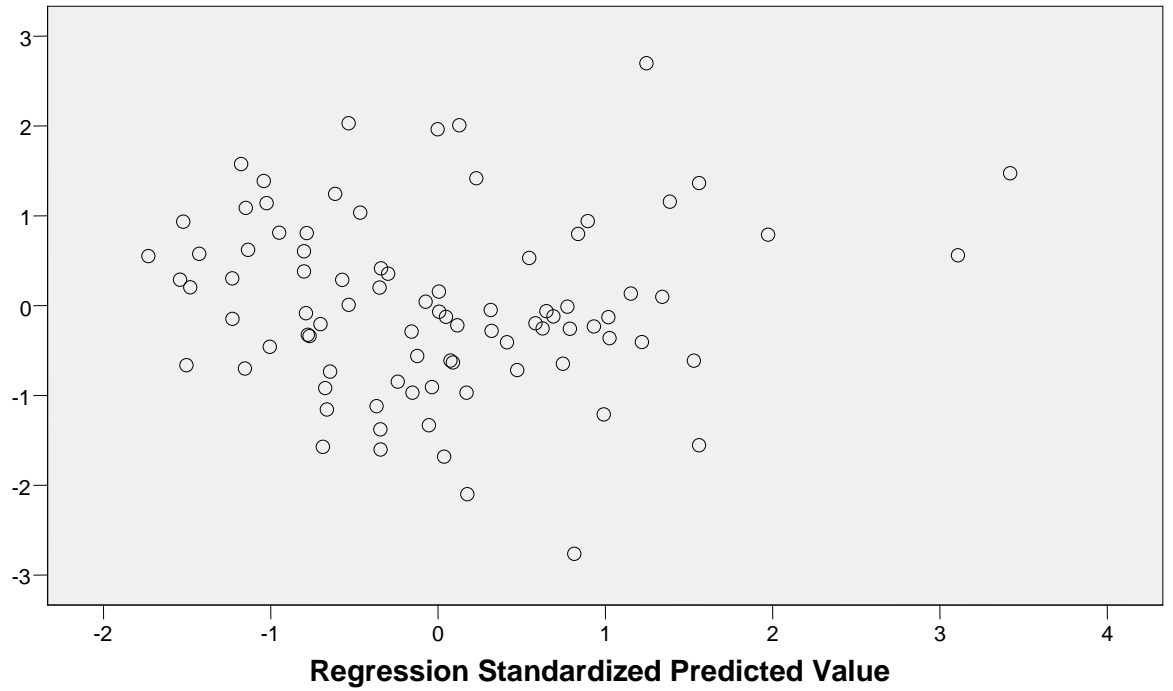


Figure A2.3 Partial Regression Plot (HADS / SOC)

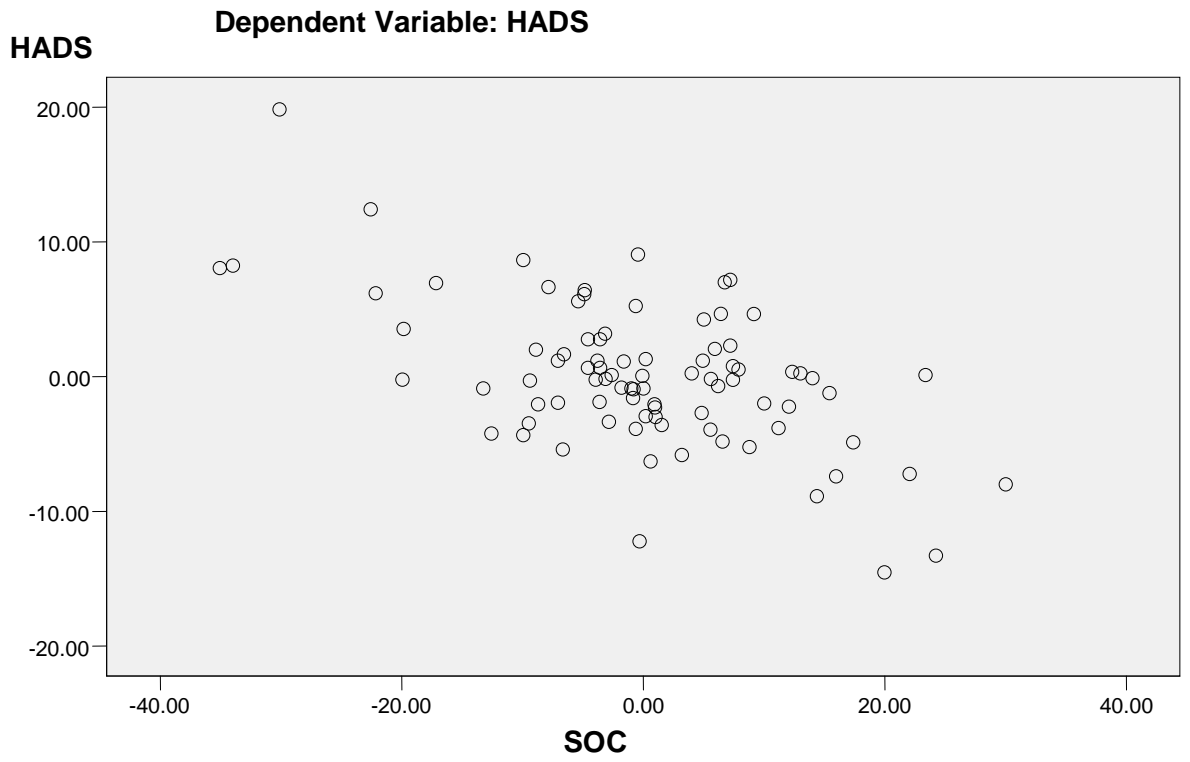


Figure A2.4 Partial Regression Plot (HADS / Cardiac Beliefs)

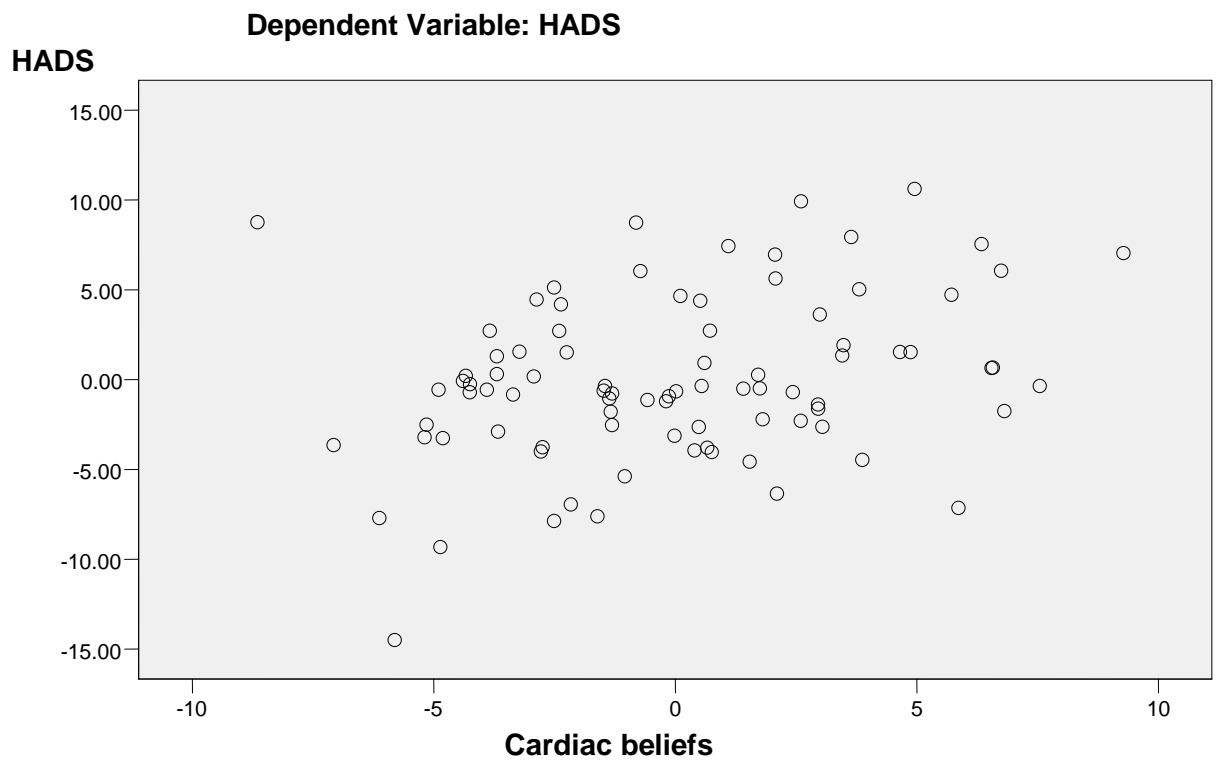
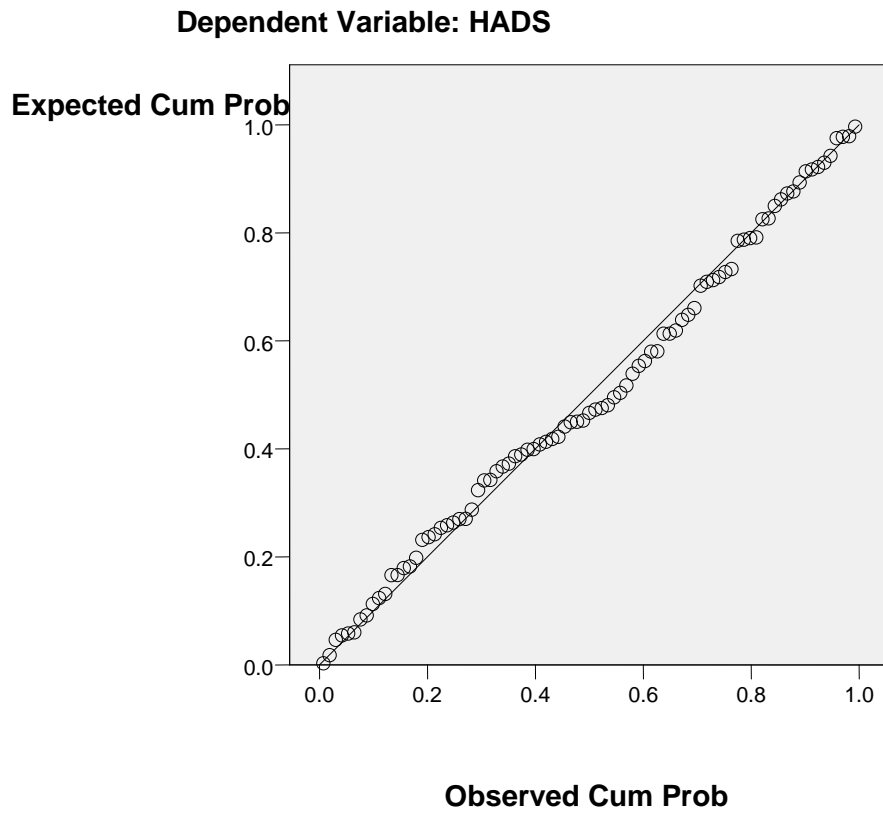


Figure A2.5 Normal P-P Plot of Regression Standardized Residual



Appendix 3

Ethical approval



Lewisham Local Research Ethics Committee

University Hospital Lewisham
1st Floor Research Centre
Lewisham High Street
London
SE13 6LH

10 May 2005

Ms Katy S. Filer
City University
Flat 3
25 Exeter Rd
London
NW2 4SJ

Dear Ms Filer

Full title of study: *The experiences of partners of cardiac patients: the relationship between of sense of coherence and cardiac beliefs in modifying stress*

REC reference number: 05/Q0701/31

Protocol number:

Thank you for your letter of 28 April 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The Committee has designated this study as having "no local investigators". There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application		04/03/2005	07/03/2005

An advisory committee to South East London Strategic Health Authority

Investigator CV		04/03/2005	07/03/2005
Protocol		04/03/2005	07/03/2005
Covering Letter		04/03/2005	07/03/2005
Summary/Synopsis		04/03/2005	07/03/2005
Letter from Sponsor		04/03/2005	07/03/2005
Compensation Arrangements		04/03/2005	07/03/2005
Copy of Questionnaire		04/03/2005	07/03/2005
Letters of Invitation to Participants		04/03/2005	07/03/2005
Participant Information Sheet		04/03/2005	07/03/2005
Participant Consent Form		04/03/2005	07/03/2005
Response to Request for Further Information	Revised study (version 2), Revised questionnaire (version 2), Revised Patient Information Sheet (version 2) & summary of all changes made	28/04/2005	09/05/2005

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation(s)] that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0701/31	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely,


P. Martin
Mr Chris Cairns
Chair

E-mail: pat.martin@uhl.nhs.uk

Enclosures *List of names and professions of members who were present at the meeting and those who submitted written comments*

Standard approval conditions

Section C: Literature Review

Posttraumatic Stress Disorder in Breast Cancer: A Critical Literature Review

This paper will review the empirical literature relating to posttraumatic stress following adult, breast cancer, and it will outline the core issues.

Introduction

Receiving a diagnosis of a life-threatening illness, such as cancer can be traumatic. Life after cancer is often associated with chronic adjustment problems, including anxiety and depression (Redd et al., 2001). Cancer is the general term used to refer to a malignant tumour. Cancers are classified according to the type of cell from which they are derived as well as the organ of origin (*Black's Medical dictionary, 1992*). There are endless physical, psychological, social and occupational problems associated with cancer and its treatment¹. Those with a cancer diagnosis often find themselves overwhelmed by fears of death, disfigurement, life changes or pain, (Levine, et al., 2005) as well as the confrontation with uncertainty, a broad range of cancer- and treatment-burdens, the search for causes of the disease and meaning (Mehnert & Koch, 2007).

Although breast cancer has been recognised as a potential life threat, only recently have researchers began to investigate the traumatogenic nature of the disease (Levine, et al., 2005). Results of these studies show that people diagnosed with and treated for cancer suffer a considerable degree of psychological distress and/or impairment of function (Andrykowski et al, 2002; Luecken & Compass, 2002), and symptoms of distress may persist for as long as 10-20 years after treatment (Kornlith et al., 2003). Psychological distress often manifests in the form of post-traumatic stress disorder.

¹ Treatments include chemotherapy, radiotherapy, surgery and hormone treatment. Each form of treatment has negative side effects, including nausea, disfigurement, vomiting, hair loss, irritability and pain.

Posttraumatic stress disorder (PTSD) is an anxiety disorder occurring after exposure to severe trauma. In 1994, the DSM-IV committee (*Diagnostic and Statistical Manual of Mental Disorders: DSM-IV*) (American Psychiatric Association, 1994) broadened the definition of traumatic stressor to include life threatening illness. This has led to an increase of research on PTSD associated with burn accidents, cardiac procedures and cancer (Smith et al., 1999). As a result, the literature concerning PTSD and cancer has steadily expanded (Palmer et al., 2004). Studies on prevalence of PTSD in adult cancer patients have predominantly focussed on breast cancer patients. PTSD has been increasingly diagnosed among cancer patients. However, there have been questions raised over the extent to which the PTSD diagnosis is applicable to cancer (e.g. Mehnert & Koch, 2007).

This paper will explore the main issues relating to post traumatic stress disorder following adult breast cancer. It will begin with a brief overview of the development of the research. This will be followed by an outline of the diagnostic criteria for PTSD, the strategies used for diagnosing it and a discussion about the controversy surrounding the inclusion of cancer as a traumatic stressor. The remainder of the paper will critically review the empirical literature concerning the prevalence of PTSD, the risk factors associated with developing it, and the type of treatment interventions available. Finally the concept of Posttraumatic Growth will be discussed in relation to breast cancer and post traumatic stress.

Overview of the development of research

In 1999, Smith et al. published a thorough review of the literature on PTSD in cancer. The focus of this review was to explore the evidence for including PTSD as a traumatic stressor. The review only included 4 studies of adult (breast) cancer. These studies were based on the prevalence and identification of PTSD and PTSD-like symptoms in breast cancer survivors (Alter et al., 1996; Green et al., 1998; Cordova et al., 1995; Tjemsland et al., 1998).

Research continued over the following years, and some of the initial studies were followed up a few years later (e.g. Andrykowski et al., 2002). Two further reviews of the expanding literature were published (Kangas et al., 2002 and Gurevich et al., 2002). These reviews included a more detailed examination of the core conceptual and assessment issues pertaining to cancer-related PTSD, including diagnostic issues, mechanisms and course of PTSD following diagnosis, risk factors, treatment implications and theoretical issues.

As well as exploring PTSD in other types of cancer and at various stages (e.g. Hegel et al., 2006; Mehnert, & Koch, 2007) the research also explored in greater detail the risk factors and coping mechanisms involved in posttraumatic stress (e.g. Sears, Stanton, & Danoff-Burg, 2003; Black & White, 2005; Okamura et al., 2005; Kangas et al., 2005b; Shelby et al., 2008), the treatment options (Levine, et al., 2005), the validity of some of the assessment instruments in other languages (e.g. Spanish; Costa-Requena, & Gil, 2010), the physiological consequences of emotional distress (Luecken et al., 2004), and the differentiation between PTSD and other stress disorders (Palmer et al, 2004, Kangas et al., 2005; Shelby et al., 2005). Finally, in the last decade, research has explored the concept of posttraumatic growth in breast cancer survivors. This has included investigations into the factors predicting posttraumatic growth and the relationship between posttraumatic stress and growth (Bellizzi, & Blank, 2006; Cordova et al., 2007; Morrill et al., 2008; Sumalla et al, 2009).

Diagnostic criteria for PTSD

The diagnostic criteria for PTSD, according to the fourth edition of the DSM-IV, require the combination of exposure to an event involving 'actual or threatened death or serious injury, or a threat to the physical integrity of self or others' (criterion A1) and that 'the person's response involved intense fear, helplessness or horror' (criterion A2) (American Psychiatric Association, 1994). The criteria include 17 symptoms that fall into three symptoms clusters: i) reexperiencing symptoms (criterion B), such as intrusive thoughts and flashbacks; ii) avoidance or numbing (criterion C), and iii) hyperarousal (criterion D). The individual must display a minimum of one-re-experiencing symptom, three avoidance symptoms, and two symptoms of hyperarousal. These symptom clusters must have persisted for at least one month (criterion E) and have caused clinically significant distress or impairment in daily functioning (criterion F). Criterion F is important because it addresses the clinical severity of the disorder, separating PTSD from sub-clinical expressions of anxiety. Individuals meeting these criteria are also at heightened risk for certain co-morbid mental disorders, including other anxiety disorders (American Psychiatric Association, 1994).

The PTSD can be *delayed*, (symptom onset occurs 6 or more months following trauma exposure), *acute* (duration of symptoms is less than 3 months); and *chronic* (Duration of symptoms is more than 3 months (Smith et al., 1999).

Symptoms that persist for between 2 days to one month after a traumatic event and that causes significant distress may meet the DSM-IV criteria for acute stress disorder (ADS). ASD has similar criteria to PTSD, with the exception that it focuses heavily on dissociative symptoms² (Kangas & Brynat, 2002). ASD often occurs as a prodrome of PTSD, (Koopman et al., 1995) which can then be diagnosed when these symptoms persist for at least one month. However, empirical research has suggested that an ASD diagnosis had only modest predictive power for identifying recently diagnosed cancer patients who will develop PTSD (Kangas et al., 2005; Marshall & Schell, 2002).

Strategies for diagnosing PTSD

The optimal strategy for diagnosing PTSD is a multimodal approach, involving different types of data being collected from various sources using various methods (Smith et al., 1999). PTSD interview and self report measures have been developed to correspond to the DSM-IV symptoms and symptom clusters. There is no PTSD symptom report designed specifically to assess trauma associated with severe illness.

Structured clinical interviews represent the 'gold standard' for assessing PTSD (Smith et al., 1999). Examples of these include Clinician-Administered PTSD Scale (Blake et al., 1990) and the structured clinical Interview for DSM-IV (SCID), (First et al., 1996). Unfortunately these measures are time consuming and require trained interviewers, thus limiting their use in research. In over 40 cancer-related PTSD studies reviewed by Gurevich et al., (2002) and Kangas et al., (2002) only 8 studies used diagnostic interviews (Shelby et al., 2008).

Most studies have relied exclusively on self report (Gurevich, et al., 2002). Self report measures offer an alternative that is time efficient and lower in cost (Shelby et al., 2005). The most frequently used measure has been the Impact of Events Scale (IES) (Horowitz, et al., 1979). Another commonly used measure is the PTSD Checklist-Civilian Version (PCL-C) (Weathers et al., 1991). The PCL-C has been updated for patients with breast cancer and includes an open-ended component that inquires about the nature of the symptoms. Other self report measures include PTSD Symptom Scale (Foa et al., 1993) and Primary Care PTSD Screen (PC-PTSD) (Prins et al., 2004).

Discrepancies in estimates of PTSD prevalence between self report questionnaire and clinical-administered have been reported (Mehnert & Koch, 2007; Kangas et al., 2002;

² which may include emotional numbing, reduced awareness of one's surroundings, derealisation, depersonalization, and dissociative amnesia (Criteria B)

Sellick & Crooks, 1999). The questionnaires have been criticised for not providing enough detail. In addition, some of the tests (such as the IES-R and the PCL-C) may overestimate the prevalence rates (Mehnert & Koch, 2007). For example, Palmer et al., (2004) suggest that IES measures emotional distress and adjustment problems rather than PTSD symptoms. However, Andrykowski et al., (2000) compared the diagnostic value of the self report PCL-C with the clinical interview, SCID, using 82 posttreatment patients with breast cancer, and concluded that PCL-C is a cost effective screening tool for PTSD, with diagnoses subsequently confirmed by structured diagnostic interview.

According to *DSM-IV*, diagnosis of PTSD requires individuals to meet a number of symptoms from each of the three symptom clusters (reexperiencing, avoidance & numbing and hyperarousal factors). Shelby et al., (2005), conducted exploratory factor analysis (EFA) on the PCL-C for cancer survivors and suggested that a *four* symptom clusters would be more appropriate for cancer patients and survivors, and they separated 'avoidance and numbing' into two categories. This finding is consistent with prior research that also suggested that these symptoms represent separate mechanisms (McFarlane, 1988; Foa et al., 1992).

Questioning cancer as a traumatic stressor

The applicability of a PTSD diagnosis secondary to cancer is potentially problematic because of ambiguity surrounding the stressor itself, the nature of the psychiatric symptoms experienced, and the role of an ongoing, and sometimes deteriorating, medical condition. (Kangas & Bryant, 2002). Three reviews on cancer and PTSD examined the evidence for including cancer as a traumatic stressor, (Smith et al., 1999; Gurevitch et al., 2002; Kangas & Bryant, 2002) and the key findings will be briefly discussed below.

Cancer differs in many ways from more typical traumatic stressors such as rape, combat exposure, violence, childhood sexual abuse and natural disasters. Specific features of the cancer experience challenge what characterises a qualifying PTSD trauma. Green et al., (1998) asserted that cancer is an *internal* experience with threats coming from within, in contrast to an external environmental threat, seen in most 'classic' traumas. This feature means that one cannot physically avoid the "stressor" following its onset because of its internal status.

The immediacy and degree of life threat experienced by cancer patients would vary, depending on tumour type and treatment options (Smith et al., 1999). Unlike discrete

trauma events, (e.g. rape, and motor vehicle accidents) the precipitating stressor may vary from individual to individual and may consist of a single or combination of cancer related traumatic events including diagnosis, surgery, adjuvant therapy and for some women, recurrence (Shelby et al., 2005; Mehnert & Koch, 2007). The threat to one's physical integrity is not necessarily immediate (Kangas & Bryant, 2002). The responses to multiple, prolonged, or intermittent traumatic exposures may differ qualitatively and quantitatively from stress responses following a discrete traumatic event (Gurevich et al., 2002). It can also be difficult to identify the point at which cancer survivors becomes truly posttraumatic (Smith et al., 1999). However, Mehnert & Koch, (2007) argue that the course of trauma exposure, in cancer, is potentially similar in time course to other chronic traumatic stressors such as war, domestic violence or incest.

Unlike other traumas, individuals can exert control over some aspects of the trauma (Smith et al., 1999; Kangas et al., 2002). For example, the anticipation of impending stressful events, such as surgery may give opportunity to prepare and seek support and thus reduce the impact of the trauma (Mehnert & Koch, 2007).

With cancer, the outcome of the stressor is often future orientated. The traumatic stressor might not be memory of the diagnosis, or the treatments, but the preoccupation with possible recurrence or death. For example, waiting for the results of the diagnosis tests, which is an anticipatory threat, has also been cited as one of the most stressful aspects of cancer experience (Green et al., 1998). Dunkel-Schetter et al., (1992) found that fear and uncertainty about the future were the most commonly identified cancer-related problem in cancer survivors.

Some PTSD symptoms items may not reflect PTSD in cancer patients. For example, many traditional PTSD symptoms such as 'having difficulty concentrating' and 'feeling your future may be cut short', may be confounded with factors associated with the illness and its treatment (such as sedative medication) rather than PTSD. This is especially relevant as these symptoms are the most frequently reported PTSD symptoms in cancer patients (Cordova et al., 2007; Green et al., 1998; Jacobson et al., 1998, Smith et al, 1999). For this reason, Smith et al., (1999) argued that studies should exclude individuals who are not disease free. For example, Tjemsland et al., (1998) reported that intrusion and avoidance symptoms were reduced at six weeks post-surgery and one year later. The stressors in this case may have been the surgery itself, the effects of which can decrease over time. Using these symptoms items in cancer samples may lead to overdiagnosis or misdiagnosis of PTSD and inflated rates

of PTSD symptoms (Gurevich et al, 2002). However clinical assessment together with a structured interview could allow for this.

Clinicians need to keep in mind that there is considerable overlap between common grief reactions associated with a cancer diagnosis, and symptoms of posttraumatic stress, including avoidance, arousal, and intrusive thoughts (Horowitz et al., 1997; Stroebe et al., 2000). Kangas et al., (2002) discussed the need for an adjustment period to process the information and come to terms with significant changes the cancer experience may impose on one's physical, social, occupational and personal functioning. Palmer et al, (2004) examined PTSD among a waiting room sample of 115 women with breast cancer. Although an intense negative emotional reaction to breast cancer was common, the distress only amounted to PTSD in a few cases. The authors suggested that using a trauma framework to understand the experience of most patients with cancer may be inaccurate, and it may be reasonable for health care providers to *expect* these reactions and be prepared to normalise their experience via supportive, nonpsychiatric intervention (Palmer et al, 2004).

Mehnert & Koch, (2007) aimed to identify the prevalence of acute and post-traumatic stress responses in breast cancer patients during primary cancer care. The authors suggested that a number of patients develop cancer- (or treatment) related PTSD. However for the majority of patients, the anxiety disorder (AD) diagnosis seemed more appropriate, since this diagnosis refers to reactions to an identifiable psychological stressor less specific than a trauma.

Prevalence of cancer-related PTSD

Studies on prevalence of PTSD in adult cancer patients predominantly focussed on breast cancer patients with early or mixed tumors stages, and with a wide time range between initial cancer diagnosis and cancer treatment, spanning from a few days to over 11 years. The majority of the data was collected in samples of women at post-surgical stages of treatment. Sample sizes varied between 29 to 209 patients, and the majority of studies were cross sectional (Mehnert & Koch, 2007). The prevalence of PTSD ranges from 3-4% in patients recently diagnosed with early stage cancer, and 0 to 35% in patients after treatment (Smith et al., 1999; Mundy et al., 2000; Kangas et al., 2002; Palmer et al., 2004; Akechi et al., 2004; Hegel et al., 2006).

There were few longitudinal studies on long term prevalence of PTSD symptoms (Kangas et al., 2002; Smith et al., 1999). However, further longitudinal studies have

been carried out in the last decade, which have been useful to distinguish between normal and pathological response to cancer diagnosis and treatment. Comparisons of the research that has been done, it is not clear what the extent of the natural course of PTSD is in women with breast cancer (Levine et al., 2005). Some research proposed that the prevalence of PTSD symptoms declined considerably for the majority of individuals within 3 months post-diagnosis or following treatment completion (Mundy et al., 2000; Tjemslund et al., 1996a,1996b). However, other research suggests that PTSD symptoms do not necessarily decline at the end of treatment for breast cancer, and can in fact *increase*, if left untreated (Gurevich et al., 2002; Bleiker et al., 2000). Following a longitudinal study, Andrykowski et al., (2000) suggested that PTSD symptoms fluctuated over the course of an individual's experience. Palmer et al, (2004) found no effect for time since diagnosis. Koopman et al., (2002) examined symptoms in 117 who were women having treatment. When they were examined six months later, there was a significant decrease in trauma symptoms. However, at six months there was also an increase in the number of women who would qualify for a diagnosis of PTSD.

Diagnosis may be complicated when PTSD is only one component of a patient's psychopathology. Comorbidity is high for those with (general) PTSD and subsyndromal PTSD. Kangas et al., (2002) reported on two studies that evaluated the incidence of comorbidity of psychological disturbances with cancer-related PTSD onset and found a relatively high prevalence of major depression in these patients (Mundy et al., 2000; Green et al., 1998). Considering that psychological comorbidity can further compromise the individual's physical and emotional well-being, it is important to comprehensively assess for the range of possible disorders that may coexist with PTSD (Shelby et al., 2008).

Subthreshold PTSD: PTSD Symptoms

Research has indicated that a high number of patients, are likely to encounter PTSD symptoms following cancer (Kangas et al., 2002; Akechi et al., 2004; Cella et al., 1990). Prevalence and intensity of symptoms can vary depending on the measures used (Kangas et al, 2002). Posttraumatic symptoms can range from 20% in patients with early stage cancer (Andrykowski et al, 1998) to 80% in those with a recent recurrence of cancer (Rhode et al., 1997).

Subthreshold, or partial PTSD is associated with significant social, interpersonal and physical impairments and psychiatric co-morbidity (Tjemslund et al., 1996). It is likely to

be more common than full syndrome in non psychiatric populations. Interest in subsyndromal PTSD is relatively recent, and as yet there are no specified diagnostic criteria (Shelby et al., 2008). For example Stein et al., (1997) defined subsyndromal PTSD as having at least one symptom in each of the three *DSM-IV* PTSD symptom clusters; others require cases to meet criteria for two of the three clusters (Shelby et al., 2008).

Risk factors: PTSD and subsyndromal PTSD

Both PTSD and subsyndromal PTSD may be disabling for individuals, and can be associated with emotional distress and depression and disrupted quality of life, employment absenteeism and the seeking of mental health services (Shelby et al., 2008; Golden-Kreutz & Anderson, 2004). In addition, the level of emotional distress of breast cancer patients has been shown to have physiological consequences. Luecken et al., (2004) found that women with PTSD (current or past) showed significantly lower morning cortisol levels. Variations in cortisol levels can directly impact neoplastic growth and immune parameters (e.g., T-cell proliferation) relevant to the progression of breast cancer, suggesting that psychological factors that influence immune function may also influence cancer outcomes.

Across studies, higher ratings of PTSD were associated with greater pre-cancer trauma history (Cordova & Andrykowski, 2003). Shelby, et al., (2008) found that PTSD cases were distinguished by having experienced both violent traumas and anxiety disorders predating cancer, whereas subsyndromal cases were not. Other risk factors include prior negative life stressors (Andrykowski & Cordova, 1998; Andrykowski et al., 2000; Butler et al., 1999; Green et al., 2000; Mundy et al., 2000; Tjemmland et al., 1996b, 1998), a history of psychological disturbance (Shelby, et al., 2008; Green et al., 2000; Mundy et al., 2000), and elevated psychological distress subsequent to the diagnosis (Baider & De-Nour, 1997; Jacobsen et al., 1998; Lepore & Helgeson, 1998; Smith et al., 1999; Tjemmland et al., 1996a, 1996b). Okamura et al., (2005) evaluated the prevalence of PTSD, among patients with a first recurrence of breast cancer. Those who had a major depressive episode after the first onset of breast cancer were at higher risk of repeated psychiatric disorders at recurrence.

Higher ratings of PTSD and PTSD symptoms were associated with lower social support, (Cordova & Andrykowski, 2003; Green et al., 2000) poor social functioning (Smith et al., 1999), fewer financial resources and lower education (Cordova et al., 1995; Jacobsen et al., 1998).

Andrykowski et al., (2000) followed up Cordova et al.'s (1995) study. The only demographic that significantly predicted change in PTSD was age, with older women reporting a greater decrease in symptoms than younger women. Both Green et al., (1999) and Palmer et al., (2004) also found more PTSD symptoms among younger patients. This could reflect a lack of preparedness amongst the younger women for the possibility of imminent death, as well as the more aggressive treatment regimen prescribed to younger adults (Smith et al., 1999). Koopman et al., (2002), did not find that trauma symptoms at baseline were related to age, (or income, or time since diagnosis), but at six months they were related to age. Cordova et al., (2007) did not find any relation between age, education and PTSD symptoms.

The data on cancer stage are mixed and insufficient (Gurevich et al., 2002). Some studies have found no association between type, severity, stage, and prognosis of cancer and subsequent PTSD (Alter et al., 1996; Cordova et al., 1995; Green et al., 1998). Other studies have noted that, more advanced stages (Cordova & Andrykowski, 2003; Andrykowski & Cordova, 1998; Jacobsen et al., 1998) and experiencing at least one cancer-recurrence (Butler et al., 1999; Cella et al., 1990) were associated with more severe PTSD symptoms.

Stress responses in cancer have been associated with diagnostic knowledge, treatment intensity and recency of treatment at assessment (Gurevich et al., 2002; Cordova & Andrykowski, 2003; Andrykowski & Cordova, 1998). Cella and Tross (1986) found that a shorter time since diagnosis was associated with greater degree of intrusive anxiety, higher levels of global psychopathology, reduced work adjustment and higher death anxiety. However, Palmer et al., (2004) found no effect for time since diagnosis.

Emotionally reactive, anxious, depressed personality styles (Tjemsland et al., 1998), avoidant coping style (Manuel et al., 1987; Nordin & Glimelius, 1998), and helplessness/hopelessness (Okamura et al., 2005) were all significantly associated with a diagnosis of major depressive disorder, adjustment disorders or PTSD. Cordova and Andrykowski (2003) suggest that greater social constraints on expression of cancer-related concerns resulted in poorer cognitive processing of the cancer experience, which was related to depression and more serious distress. Cordova et al., 2007 used the social-cognitive processing (SCP) model (Lepore, 2001) to explain why women, who perceived their friends and family as less receptive to discussing the breast cancer experience, were more distressed. The SCP model posits that negative social responses to attempts to discuss the cancer experience, whether overt (e.g.,

directives to stop worrying/thinking about it) or covert (e.g., looking uncomfortable, concealing own feelings), may lead to avoidance of thinking or talking about the illness, which in turn may inhibit cognitive processing and exacerbate emotional distress.

There is a need to identify the extent to which factors that increase the likelihood of cancer, also contribute to PTSD development. Kangas et al., (2002) suggested that the vulnerability factors for developing PTSD may overlap with vulnerability for developing cancer. For example, lower socioeconomic status, poorer utilisation of health services, excessive smoking, or alcohol use may predispose people to engage in behaviours that increase the likelihood of developing cancer, or not receiving appropriate treatment; these same factors may also predispose people to develop PTSD. This potential interaction may exacerbate the vulnerability for PTSD in cancer populations.

Methodological concerns

The marked variability in findings concerning cancer-related PTSD may be attributed, in part, to a number of core methodological issues (Kangas et al., 2002). For example, Palmer et al., (2004) argued that some of the sample sizes were too small (for example N=37, Mundy et al., 2000; N=31, Naidich & Motta, 2000). Entry criterion for the studies have sometimes been so stringent as to restrict generalisability, (e.g. no surgery, chemotherapy, or radiotherapy for 6 to 72 months, and remission of cancer) (Andrykowski et al, 1998). There have been few longitudinal studies on long term prevalence of PTSD symptoms (Kangas et al., 2002; Smith et al., 1999). Cross-sectional, retrospective design precludes the ability to draw conclusions regarding causal and temporal relationships, and some of the longitudinal studies relied on the same or overlapping samples in ways that make summaries and comparisons difficult (Palmer, et al., 2004). The majority of studies have focused on adult women with early to middle-stage breast cancer from a primarily Caucasian background. This raises the question whether the findings would generalise to other groups such as more advanced stages of cancer, cancer types that involve predominantly male patients (e.g., prostate and bowel), and those cancers that involve more physically intrusive and disfiguring treatments (e.g., head and neck carcinomas) (Kangas & Bryant, 2002). Finally, there has been a reliance on self-report measures to assess the incidence of PTSD responses, which have a tendency to increase the rate of false-positive identifications and fail to establish whether an individual satisfies the stressor criterion for PTSD (Andrykowski et al., 2000; Palmer et al, 2004).

Posttraumatic Growth

Many individuals experiencing cancer, or other stressful experiences, view the struggle with the event as a catalyst for personal growth and transformation. Researchers have used various terms for perceived positive outcomes including benefit finding, positive reappraisal coping, existential growth, and posttraumatic growth. Tedeschi and Calhoun, (1996) used the term 'posttraumatic growth' to describe a positive change in one's previous level of functioning following a traumatic event. They developed the Posttraumatic Growth Inventory (PTGI), a 21-item scale that measures positive outcomes reported by people who have experienced a negative event. The PTGI provides scores on five domains of life (relationship with others, new possibilities-purpose, appreciation of life, spiritual change, and personal strength).

There has been a growing body of research on posttraumatic growth following cancer, (Bellizzi & Blank, 2006). The evidence suggests that many breast cancer survivors, like many survivors of other cancers and life threatening diseases, report positive life changes following their diagnosis (e.g. Sears, Stanton & Danoff-Burg, 2003, Bower et al., 2005). Such positive changes include their relationships with others, self-confidence, positive changes in spirituality as well as an appreciation for life priorities and purpose.

Attempts to identify correlates and predictors of posttraumatic growth in cancer have yielded inconsistent results (Cordova et al., 2007). Reports of cancer-related posttraumatic growth have been associated with marital status, employment, social support, socio-economics and education (Bellizzi & Blank, 2006; Sears, Stanton & Danoff-Burg 2003; Schulz & Mohamed, 2004). However, Cordova et al., (2007) found no relationship between social constraint, education, and growth.

Several studies have reported that younger women reported the highest levels of posttraumatic growth (Bellizzi & Blank, 2006; Bower et al., 2001; Cordova et al., 2007). This may be because older women are dealing with more comorbidities or other significant life events than their younger counterparts. Younger women are both more likely to suffer from posttraumatic stress disorder and also develop posttraumatic growth. This falls in line with the theory that the perception of cancer as a traumatic stressor is associated with greater posttraumatic growth, (Cordova et al., 2007) which will be discussed in greater detail in the following section.

Active coping has been consistently related to psychological growth (Bellizzi and Blank 2006; Stanton et al., 2006; Bower et al., 2001). However, positive outlooks such as

optimism and hope were not significantly related to reports of posttraumatic growth (Bower et al., 2001; Sears, Stanton & Danoff-Burg, 2003; Belizzi & Blank, 2006).

Cordova et al., (2001) found an increased prevalence of posttraumatic growth in cancer patients with longer time since the initial trauma, and suggested that the greater time period allowed for more affective cognitive processing to take effect. However, other researchers (e.g. Bower et al., 2001) did not find any relationship between time since trauma. Sears, Stanton & Danoff-Burg, (2003) explored and compared the outcomes of benefit finding (identification of benefits, number of benefits) and positive reappraisal coping in predicting posttraumatic growth. They found that positive reappraisal predicted posttraumatic growth 12 months later. However, benefit finding did not predict any outcome. They concluded that 'Positive reappraisal coping may be an important path along the yellow brick road to the Emerald City of posttraumatic growth, the pursuit of which may have positive psychological and physical health effects' (Sears, Stanton & Danoff-Burg, 2003).

The relationship between posttraumatic growth and distress

Cordova et al., (2007) assessed both PTSD and posttraumatic growth in a sample of women with primary breast cancer to evaluate the interrelationships between the symptoms. They found that both PTSD symptoms and posttraumatic growth were common, but posttraumatic growth was unrelated to PTSD symptoms. This finding is consistent with other studies (e.g. Widows et al., 2005; Sears, Stanton & Danoff-Burg, 2003), that also found perception of positive change following cancer to be unrelated to indices of distress.

The perception of cancer as a traumatic stressor was associated with both greater posttraumatic growth and PTSD. This is consistent with stress and coping frameworks, such as that proposed by Lazarus & Folkman, (1984), that emphasise the role of subjective appraisal. Black & White, (2005), for example, applied Ehlers and Clark's (2000) cognitive model of persistent PTSD, in explaining fear of recurrence in cancer patients. The model proposes that PTSD only occurs if the individual processes the trauma in a way that leads to a *sense of serious current threat*. Fear of recurrence could be described as a sense of serious current threat (Black & White, 2005). In order for psychological growth to occur, one must be exposed to an extremely undesirable and intense event that causes a breakdown in past and future assumptions about one's life. It is through the process of building that some people reconstruct a revised life structure that is perceived to be of a higher quality than their old one. From this perspective, it would be predicted that greater perceived degree of threat posed by

cancer would be associated with a greater likelihood of both PTSD symptoms and posttraumatic growth (Cordova et al., 2007).

Limitations of Cordova et al.'s (2007) study, in common with those of the PTSD in general include the cross-sectional, retrospective design and the fact that data were collected via self-report measures that, although well-validated, are potentially susceptible to reporting biases. Future research is needed in order to generalise the findings to the larger population of women with breast cancer, as participants were predominantly Caucasian, well-educated with middle to upper income who volunteered to participate in the study.

Interventions & treatment

There has been little research on interventions for women with breast cancer and PTSD (Palmer et al, 2004; Levine et al., 2005). The types of treatments that have been used to treat PTSD include cognitive behavioural therapies (CBT) (including anxiety management, cognitive therapy, and exposure) (Beatty & Koczwara, 2010; Bryant, 1999; Foa, 2000), pharmacotherapy (Marmur et al., 2001), and EMDR eye movement desensitization and reprocessing (Gurevich et al., 2002).

The success of the interventions have been mixed. Classen et al., (2001) found that supportive expressive therapy intervention reduced symptoms of traumatic stress for women with metastatic breast cancer, but the intervention did not seem to reduce psychological distress. Winzelberg et al., (2003), used an internet support group for women with breast cancer and found no significant decrease in PTSD symptoms at the end of the 12 week intervention. Levine et al., (2005) compared a standard support group with a complementary/alternative (CAM) orientated intervention, which included Yoga, meditation, imagery and expressive arts. Although both interventions were useful in reducing distress and PTSD symptoms, the two interventions may have focussed on different aspects of living with cancer. They concluded that the standard group may be more cost effective and produce similar results to the CAM group.

A multi-dimensional approach is recommended to treating PTSD and subsyndromal PTSD. Teaching adaptive coping strategies (Belizzi & Blank, 2006) and psycho-educational interventions (Okamura et al., 2005) have been recommended. Palmer et al, (2004) suggested that supportive, nonpsychiatric interventions that strengthen personal and social resources may be the more appropriate strategy to adopt. Likewise, allowing the individual to express cancer-related concerns in a non-

threatening surrounding would promote post-traumatic growth, and would help reduce distress (Levine et al., 2005). Cognitive restructuring would typically need to address issues that are explicitly relevant for cancer patients, which may include reevaluating life goals, assessing the likelihood of recurrence, and managing the knowledge of poor prognosis (Kangas et al., 2002). Kangas et al., (2002) suggested that clinicians should initially provide anxiety management strategies that include relaxation training, controlled breathing, guided imagery, and distraction techniques during the acute phase of the intensive medical treatment. More active treatments, such as exposure, should only be introduced when the most demanding aspects of medical treatments are completed.

Cordova et al., (2007) suggest that given that posttraumatic growth and PTSD symptoms are both relatively common and unrelated to one another, psychosocial assessment should include evaluation of both emotional distress and perception of growth. Interventions that provide education, anxiety management skills, and direct engagement with and cognitive-emotional processing of the stressful aspects of the cancer experience may be particularly useful in both reducing distress and enabling patients to re-order their life goals and priorities.

Tedeschi & Calhoun, (2000) warn that imposing an expectation of growth could be potentially harmful to patients. They suggest that clinicians could listen to and attend to articulations of growth during counselling sessions, and if signs of growth are identified, then clinicians can validate their experiences.

Future research could evaluate the effectiveness of the specific components of cancer intervention, including the timing and delivery of them. Research could consider whether such interventions should be offered to all patients showing signs of distress, as a matter of course, or restricted to those with specific trauma symptoms including PTSD.

Conclusion

Research has emphasised the tremendous variability in how women respond to cancer (Belizzi & Blank, 2006). Subjective appraisal had a central role in adjustment. For many, cancer may be experienced as a trauma and consequently lead to traumatic stress symptomatology. For some, the trauma may also produce an opportunity for growth. Factors affecting both positive and negative adjustment include the type and stage of cancer, treatment severity, prior trauma, current and past social support, personality and coping styles.

There have also been problems with diagnosing PTSD in cancer patients and some of the diagnostic tools may over-estimate PTSD prevalence rates. Likewise the appropriateness of PTSD diagnosis must be considered with regard to cancer patients. Further understanding is needed to differentiate between distinguish between normal and pathological responses to cancer diagnosis and treatment.

There are many unanswered questions relevant to cancer-related PTSD; there is a need for further validation of existing PTSD tools and investigations into the optimal timings and content of interventions to guide clinical management of PTSD in cancer patients. Psychosocial interventions for cancer and PTSD should be sensitive to the potential for posttraumatic growth, both in treatment design and in assessment of outcomes. Interventions should enhance communication and promote cognitive processing in order to reduce the likelihood of psychological trauma and distress in cancer survivors than those used to promote posttraumatic growth.

The research into PTSD and cancer has increased knowledge and understanding of the significant psychological distress experienced by the patients that occurs in addition to the physical effects of the illness and treatment. Despite the theoretical controversies, the empirical research has expanded the scope of understanding, for example, by raising awareness that women may experience trauma many months after treatment has finished; and as a result, has provided the opportunity for treatment interventions to be developed, which will ultimately improve the outcomes for these women.

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Section D: A Case Study of Professional Practice

**Case study for the Degree of Doctor of
Psychology (Health)**

CHD Choice

**South East London Cardiac
Rehabilitation Strategy Group**

Evaluation Report

Summary

This case study reports the findings of a piece of consultancy undertaken for the South East London Cardiac Rehabilitation Strategy Group from April 2003-April 2005. It describes an evaluation to complement the investment in Cardiac Rehabilitation from CHD Choice monies in the six cardiac rehabilitation services within the sector (South East London): to audit the services in light of Cardiac Rehabilitation patient experience with the aim of improving the equity of CR across the six PCTs. This was the first piece of consultancy work that I did as a Health Psychologist. I was employed through City University.

This report is a detailed summary of the two main reports (Phase I and Phase II), together with the supplementary reports. It ends with a reflective analysis of my experience conducting this work.



CHD Choice:

**South East London Cardiac Rehabilitation Strategy
Group**

Evaluation Report

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Many people have been involved in both phases of the South East Sector Cardiac Rehabilitation Evaluation. The hard work and dedication of those involved in cardiac rehabilitation in all six PCTs has been impressive. Thanks to the members of the South East Sector Cardiac Rehabilitation Strategy Group who spent time in the meetings and interviews providing information and helping to plan this evaluation. The help of all of the following people is gratefully acknowledged:

Due to ethical issues of confidentiality the names of all people have been removed.

EXECUTIVE SUMMARY

Part of the NHS Modernisation Agency, the Coronary Heart Disease (CHD) Collaborative, is a NHS-funded programme designed to make improvements in the way CHD services are delivered to patients. The CHD Collaborative is a key element in the delivery of standards laid out in the National Service Framework (NSF) for CHD. The goal is to improve the experience and outcomes for patients with suspected or diagnosed CHD by optimising care delivery systems across the whole integrated pathway of cardiac care. The South East London CHD Choice Committee allocated recurrent funding (£630,000) from CHD Choice slippage money to the CHD Collaborative to be spent on developing Cardiac Rehabilitation (CR) Services across the SE London Sector. Service developments across the sector were achieved as a result of this investment. This evaluation was commissioned to audit the services in light of Cardiac Rehabilitation patient experience with the aim of improving the equity of Cardiac Rehabilitation across the six PCTs within the Sector (Bexley, Bromley, Greenwich, Lambeth, Lewisham & Southwark).

This evaluation came within the oversight of the South East London Cardiac Rehabilitation Strategy Group and was conducted in two phases over a two-year period (April 2003 – March 2005). It was decided that a patient-focussed, action research approach was the optimum way to explore the issues. Phase 1 evaluated the service as it was in 2003, identified gaps and made recommendations for improvements. 72 patients were interviewed about their experiences in the hospital, at home and through the four phases of Cardiac Rehabilitation³. The Interim Report for Phase 1 was presented to the Commissioners in October 2003.

Phase 2 was more extensive, investigating the extent to which CHD Choice funding had led to improvements in services, identifying the remaining gaps and recommending

³ Phases of Cardiac Rehabilitation

Cardiac Rehabilitation has been described as having four phases, Phase I is prior to discharge. Phase II is the period when the patient is at home and waiting to start the 6-12 week Phase III programme (involving exercise and a taught component) and Phase IV is long term maintenance of health behaviour change, usually in the UK through special facilities provided at leisure centers or gyms in the private sector.

further improvements in their light. 178 participants were interviewed. As in Phase 1, they included patients who were taking part in (or had completed) phase III Cardiac Rehabilitation, those that declined rehab, those that dropped out, and partners. In addition, over fifty interviews were carried out with NHS staff within the Sector's Cardiac Rehabilitation services.

Analysis of the interview data from both phases has generated 23 recommendations for the improvement of Cardiac Rehabilitation services in the South East Sector. Recommendations fall into seven categories: (A) Funding; (B) Quality and Consistency of Services; (C) Psychological Support; (D) Education and Support; (E) Communication; (F) Cardiology; (G) Audit and evaluation.

The quality of the present service is as good as it is because of the additional resources from the Choice monies and due to the sterling efforts of individual staff members to make it so. What is lacking in regard to the issues revealed in this report are the resources to make the improvements which the patients and the staff are all aware are necessary as shown by the shortfall in services indicated in interviews with patients. Currently no cover is available for staff when they go on leave and this creates pressure points and breaks in continuity. The seamless ideal as the ultimate goal of an effective service is yet to be achieved.

There is concern across the Sector about the provision of services for patients in Phase IV. No other equivalent resource exists within the PCTs to cover this work. Exit strategies for Phase IV are being developed in some hospitals and these should be developed across the entire Sector.

The evaluation team attended meetings of the South East Sector Cardiac Rehabilitation Strategy Group over a period of two years. The South East Sector Cardiac Rehab Strategy Group meetings are a useful forum for the sharing good practice and discussion of issues affecting Cardiac Rehabilitation services over the sector.

With the formation of the new CHD Network it is important that Cardiac Rehabilitation services maintain such a forum and that they have direct communication links with the Network Board.

The Sector should continue to work towards a standardised service with joint planning across the sector, linking the four phases in a seamless fashion so that all patients, including those living on the borders, can attend consistently high quality services and not miss out.

Whether Cardiac Rehabilitation is to remain a basic service or change gear and provide the high levels of performance envisioned in the NSF will depend upon the availability of significant amounts of new resources and how Cardiac Rehabilitation services across the Sector are organised. Ways and means for creating a greater degree of collaboration across the Sector are worth serious consideration. It is recognised that further development of CHD rehab services has to be considered alongside other priorities and that the level of resources required will differ by Borough to reflect differing levels of current service provision. The Choice monies were helpful, and the Commissioners will want to consider the likely impact of Cardiac Rehabilitation on patient bed days, reduced re-admissions and GP visits, lower complaint levels and reduced litigation, which the current evaluation was unable to include. However, in light of the 250 patient interviews, significant gaps remain, as reflected in the Recommendations that follow.

RECOMMENDATIONS

Recommendations fall into seven overlapping categories: (A) Funding; (B) Quality and Consistency of Services; (C) Psychological Support; (D) Patient Preparation; (E) Communication; (F) Cardiology; (G) Audit. Recommendations that appear most urgent are printed in **bold**.

A Funding of Cardiac Rehabilitation services

1. A key issue has been the allocation of funding to each service. Many of the hospitals have not been able to fully utilise the funds allocated for Cardiac Rehabilitation owing to wider cost pressures within PCTs. In some cases the monies allocated for Cardiac Rehabilitation have been impossible to identify. For example, two services 'lost' £16K allocated for equipment and they haven't been able to track this. One service received only £95K initially and recurrent allocations reflect this difference. It is recommended that the allocation of funds for Cardiac Rehabilitation services be made equitable, identifiable and Cardiac Rehabilitation-specific.

B Quality and Consistency of Services

2. Within the limits of the available resources, the quality of care being provided was excellent for all rehab teams. Patients felt that staff are approachable, caring, and professional. However, in spite of some leveling as a result of the CHD Choice slippage monies, such as new posts, the vast differences between hospitals in terms of services, staff and facilities referred to in the Phase 1 report remain evident in the patient reports. Three hospitals in particular will require a major effort to bring their standards up to the level achieved by the majority of others. In the opinion of the evaluators vigorous efforts are necessary to achieve equity across the Sector.

3. Community services should be expanded and improved to enable more people to be seen, reduce the stress on hospital resources, and aim to provide a more individualised and integrated service. All cardiology patients, regardless of their diagnosis, age, ethnicity, or locality should be included in rehab. Currently this is not the case.

4. **A uniformly effective and equitable service of physiotherapy, psychology, dietetics and occupational therapy is required across the Sector. Psychology and dietetics within Cardiac Rehabilitation remain weak or non-existent in several hospitals. All six services require a minimum of 0.5 WTE health/clinical psychologist and a 0.5 WTE dietician to fill the gaps identified by this report and to bring services into alignment with the NSF.**

5. Waiting times need to be reduced and information and support given to patients while they are waiting. The interviews showed that people who did not receive rehab and long waiters were emotionally and physically vulnerable following discharge. When waiting is unavoidable, detailed information about recovery and rehab should be provided to every waiting patient and enough contact maintained to enable patients to feel supported and informed while they are waiting (see sections B and C below).

6. The reasons for not attending rehab or dropping out are diverse. Many patients would have liked to have attended but could not do so for reasons outlined in the report. Rehab teams should ensure that decliners are well informed about rehab and have adequate information about their recovery and have the opportunity to join later if they wish. **One-off sessions (e.g. a mini Lifestyle day) to cover the main rehab issues, enabling a large section of the non-attenders and their partners to have access to important information, without committing themselves to weekly sessions, should be available across the entire Sector. A menu of optional services for tailoring to patient needs should be developed Sector-wide, as recommended by the NSF and British Association for Cardiac Rehabilitation (BACR).** 'Hospital Y' Cardiac Rehabilitation services have developed a Home Exercise programme for the unwell or those incapable of attending rehab. This is a good example of a service that could be made Sector-wide.

7. **In the opinion of the evaluators Cardiac Rehabilitation services would be more manageable, consistent and sustainable if they were given their own cost codes and annual budgets. 'Hospital X' already has this facility; it is much easier for the Cardiac Rehabilitation team at 'Hospital X' to manage their service in comparison to the other Cardiac Rehabilitation services in the Sector.**

8. Home visits are a key component of Cardiac Rehabilitation services that is highly appreciated by patients across the Sector. Unfortunately the skeleton staff levels within each hospital are insufficient to provide Home Visits when staff are on leave. Thus some patients do not receive a Home Visit when a visit would be highly beneficial. This is unacceptable and in need of urgent action. With the establishment of a CHD Network from 1 April 2005 comes the possibility of greater Sector-wide collaboration between PCTs. The development of a Sector-wide Home Visit Service would ensure that all patients receive this service at the most crucial time of their recovery.

C Psychological Support

9. There has not been a uniform improvement in this area since Phase 1. 'Hospital X' has employed a full time clinical psychologist and 'Hospital Z' has employed a 0.5WTE psychologist. 'Hospital Y' has access to 0.1 WTE. Recommendation 3 above specifies how the necessary improvements in psychological support could best be achieved. Patients' needs for psychological support during the first days and weeks following MI, surgery and discharge should be given a higher priority in the service. Many studies suggest that emotional distress and negative emotions are useful predictors of negative outcomes for cardiac patients and that assessment and therapy of these emotions should be standard procedures in any Cardiac Rehabilitation approach. The degree of anxiety and depression of all patients should be assessed using the Hospital Anxiety and Depression Scale (HADS) and patients' misconceptions about their illness should be corrected. Cardiac Rehabilitation should include follow-up assessments of patients to determine if the rehab has been effective both physically and psychologically. Outcomes should be assessed using a standard dataset (see Recommendation 22) for details).

10. Specific issues that should be more effectively dealt with at a psychological level are:

- (A) Emotional support of patients, partners and families
- (B) Smoking cessation interventions for all smoking patients

(C) Reliable detection of alcoholism and problem drinking and effective interventions or problem drinkers/alcoholics including therapy, counselling or advice on moderate/social drinking

(D) Provision of social goals and restoration of life-work balance

(E) Other high-risk behaviours should be assessed including non-concordance (non-adherence) to therapy regimes.

D Patient Preparation

11. Additional cost-effective methods of education and support should be provided. Examples are as follows:

- **an advice line service for all cardiac patients such as the one at 'Hospital X'**
- **a cardiac support group such as the one at 'Hospital W' which gives support once a month for any cardiac patient including those not on rehab**
- **a rehab video for patients to view, buy or rent**
- **Multi-ed education DVD material or similar to provide information and promote rehab.**

12. Preparation of patients is not being delivered uniformly across the sector. All patients waiting for cardiology diagnoses, procedures or surgery should be fully informed and prepared for these procedures and told what activities they could be involved in while they are waiting (prehab).

13. Partners of patients should be more actively involved in rehab by being given more information about how to help to care for their partner's physical and emotional needs.

14. First aid information including resuscitation should be provided to patients and their families.

15. Surgical patients should be fully informed by cardiologists or nurses during assessment/prehab about the scar and how it should heal as this can have a strong emotional effect on patients.

E Communication

16. Across both phases of the evaluation it was the case that clear and reliable communication about the nature of Cardiac Rehabilitation services was insufficiently available among hospital personnel. Misconceptions and uncertainty were still evident in the patient data.

17. Contacts and home visits with patients across the sector should be improved to the level specified in the NSF. Those living alone or in inadequate conditions (including stairs) should be offered the necessary support in all cases, including patients without telephones.

18. Patients in Phase 2 should be given a starting date for Phase 3 and be informed of any changes to this.

19. Patients who miss appointments should be followed up consistently to a fixed set of criteria, which should be followed in all cases.

20. In general, services for ethnic minority patients, and in particular those who are non-English speaking, are relatively inaccessible. Greater efforts to include patients from minority groups are necessary, e.g. by providing multi-language information, translators, and special trans-cultural open days.

21. The administration procedures that follow patients from tertiary centres should be streamlined and made more reliable.

F Cardiology

22. Patients' interactions with their cardiologists are a salient part of their hospital experience. They remember their experiences with the cardiologist and relate these experiences to their fellow patients, family and friends. While there are many positive reports, there are also reports that leave much room for improvement. Cardiologists should receive further training in psychosocial skills concerning listening and empathy when talking to patients, answering their questions and tracking their emotional state. Such skills are equally

important to technical knowledge about the cardiovascular system and its pathology. Continuous professional development for cardiologists on psychosocial aspects of care would be a good investment within the Sector.

G Audit and evaluation

23. The South East Sector's Cardiac Rehabilitation services in future will need to be audited using the indicators of the (British Association of Cardiac Rehabilitation / British heart Foundation (BACR/BHF) database, namely the Hospital Anxiety and Depression Scale (HADS), Dartmouth COOP charts and the Short Measure of Physical Activity, together with other data contained within the BHF BACR Data Set for Cardiac Rehabilitation: Record Form. The consistent and systematic use of the BACR/BHF database would enable efficient and rational planning of services which could be regularly audited and evaluated over the longer term. Other key evaluation tools worthy of consideration are the Cardiac Misconceptions Scale and Cardiac Beliefs Scale. The measurement of Sector-wide patient outcomes using the BACR/BHF database (currently being piloted at 'Hospital V') and NSF performance measures would ideally be included in future audit and evaluation of Cardiac Rehabilitation services in the South East Sector.

INTRODUCTION

BACKGROUND & AIMS OF THE EVALUATION

The evaluation was set up as part of the South East London Cardiac Rehabilitation Strategy Group. This group had been convened in response to South East London Sector Chief Executives' desire to create a co-ordinated approach to Cardiac Rehabilitation (CR) within the sector to complement the investment in Cardiac Rehabilitation from Coronary Heart Disease (CHD) Choice monies and to operate within the CHD clinical network as this develops.

CHD Collaborative

Part of the NHS Modernisation Agency, the Coronary Heart Disease (CHD) Collaborative, is a NHS-funded programme designed to make improvements in the way CHD services are delivered to patients. The CHD Collaborative is a key element in the delivery of standards laid out in the National Service Framework (NSF) for CHD. The goal is to improve the experience and outcomes for patients with suspected or diagnosed CHD by optimising care delivery systems across the whole integrated pathway of cardiac care. The South East London CHD Choice Committee allocated recurrent funding (£630,000) from CHD Choice slippage money to be spent on developing Cardiac Rehabilitation (CR) Services across the South East London Sector. Service developments across the sector were achieved as a result of this investment.

This evaluation was commissioned to audit the services in light of Cardiac Rehabilitation patient experience with the aim of improving the equity of Rehabilitation across the six PCTs within the Sector (Bexley, Bromley, Greenwich, Lambeth, Lewisham & Southwark).

CHD Choice Monies⁴

The bids were an attempt to establish a minimum level of service across the six boroughs. Recurrent allocations of CHD Choice funding for rehab and other schemes were agreed as follows on 18 February, 2003:

'Hospital Z'	£100K
'Hospital Y'	£100K
'Hospital X'	£100K
'Hospital W'	£95K
'Hospital V'	£131K
'Hospital U'	£104K
Total	£630,000

* *Due to ethical issues of confidentiality the name of the hospitals and any identifiable factors has been changed.

In addition to the above, non-recurrent monies were agreed to fund a number of initiatives such as reducing waiting lists, piloting treat and transfer and this evaluation of Cardiac Rehabilitation services across the Sector.⁵ However, it should be noted that: (i) the distribution varied across services and (ii) it was not ring-fenced and some Cardiac Rehabilitation services did not receive or are not receiving the full amounts allocated.

The aim of the evaluation was to evaluate the provision and impact of Cardiac Rehabilitation across the sector and to agree a core framework of service provision that could improve equity of the services while being tailored to local needs.

National context and definition of cardiac rehabilitation

Cardiac Rehabilitation has been identified as an area for development in the Coronary Heart Disease National Service Framework (CHD NSF) [1]. The SE Sector

⁴ Choice bids for rehabilitation services development was based on a 'Gap Analysis' previously carried out by a member of the CHD Collaborative. These gaps were identified in relation to a previously agreed set of core elements for cardiac rehabilitation services.

⁵ Funding for the evaluation was held by Chair of the CHD Choice Executive. However, when Patient Choice ended, the remaining money was transferred to the SEL CHD Collaborative

Cardiac Rehabilitation Strategy Group defined Cardiac Rehabilitation as a programme of secondary, primary and community care as described in the CHD NSF. Cardiac Rehabilitation is seen as an integral component both of the acute stages of care and of secondary prevention, and it encompasses the provision of skilled help, support and supervision tailored to individual patients to:

- help them understand their illness
- provide psychological and emotional support
- improve their success in making beneficial lifestyle changes
- help them make the transition back to as full and normal a life as possible

Stokes [2] has commented that Cardiac Rehabilitation has been slowly and unevenly developed over the UK. For example, in the 1990s about a half of the health districts in the UK were not providing Cardiac Rehabilitation services and where services did exist, they were diverse and inequitable. The formation of the British Association for Cardiac Rehabilitation⁶ (BACR) in 1992 was instrumental in facilitating Cardiac Rehabilitation service development.

The BACR/BHF (British Heart Foundation) database [3] indicates that there are approximately 300 Cardiac Rehabilitation centres in the UK of which 68% are hospital-based, 9% are community-based, and 19% encompass both settings.

Standard Twelve of the NSF/CHD (Cardiac Rehabilitation) states that:

“NHS Trusts should put in place agreed protocols/systems of care so that, prior to leaving hospital, people admitted to hospital suffering from coronary heart disease have been invited to participate in a multidisciplinary programme of secondary prevention and Cardiac Rehabilitation. The aim of the programme will be to reduce their risk of subsequent cardiac problems and to promote their return to a full and normal life.” [1: Chap 7, p4].

The specific NSF/CHD goals are that every hospital should ensure:

- a) that more than 85% of people discharged from hospital with a primary

diagnosis of AMI or after coronary revascularisation are offered Cardiac Rehabilitation;

⁶ British Association for Cardiac Rehabilitation (BACR) is the national organisation for all professionals involved in the field of cardiac rehabilitation and is an affiliated group of the British Cardiovascular Society.

b) that one year after discharge at least 50% of people are non-smokers, exercise regularly and have a BMI <30 kg/m²; these should be demonstrated by clinical audit data no more than 12 months old.

The National Service Framework for Coronary Heart Disease and national clinical guidelines for Cardiac Rehabilitation state that Cardiac Rehabilitation should be based on a patient's individual needs and be 'menu driven'. Cardiac Rehabilitation programmes need to audit their outcomes using a set of valid and reliable measures. The BACR/BHF database currently consists of the Hospital Anxiety and Depression Scale (HADS), the Dartmouth COOP charts and the Short Measure of Physical Activity [3].

Overview of the evaluation

Dates and duration of the evaluation

Phase 1	April 2003 until September 2003 (6 months)
Phase 2	April 2004 until March 2005 (12 months)

Investigators (Evaluation Team)

Principal:	David F Marks, Professor of Psychology, City University
Audit Consultant:	Katy Filer, Health Psychologist, City University
Interviewers (Phase 2):	Two Health Psychology Trainees, City University

Other Staff Involved in Study

Cardiac Rehabilitation staff and members of South East London Cardiac Rehab Strategy Group provided all of the necessary patient information and local facilities necessary to evaluate the services.

Methodology

The methodology was designed following discussions within the South East Sector Rehabilitation Strategy Group. It was decided that a patient-focused, action research approach was the optimum way to explore the issues.

The aim was to explore both processes and outcomes of the Cardiac Rehabilitation services in the six hospitals and PCTs that carry out cardiac treatment and rehabilitation of patients from the six boroughs in the sector.

The audit would complement the data that was already being collected at hospitals in order to establish a standard data set on all patients across the sector. However the evaluation would be over and above any evaluation already being done in order to establish the difference made to the service by CHD Choice monies, and to take an overview of all six PCTs.

The evaluation team attended the Strategy group meetings over a period of two years. The findings of each phase were fed back to the strategy group for consultation. The strategy group gave comments and suggestions at all stages and fed back into the evaluators' procedures and reports.

Phase One & Phase Two

Phase 1 evaluated the service as it was in 2003, identified gaps and made recommendations for improvements. It acted as a baseline, exploring the situation immediately after the funding was received. 72 patients were interviewed about their experiences in the hospital, at home and through the four phases of Cardiac Rehabilitation.

The results of phase one were presented to the CHD Collaborative meeting in December '03 and to the South East Sector Strategy Group in January '04. Twenty recommendations concerning potential improvements divided into four overlapping categories: (A) Quality and Consistency of Services; (B) Psychological Support; (C) Education and Support; (D) Communication were identified.

Phase 2 was a more extensive follow-up, investigating the extent to which CHD Choice funding has led to improvements in the service and to identify any remaining gaps and the necessary improvements in their light. As in Phase 1, they included patients who were taking part in (or had completed) phase III Cardiac Rehabilitation, those that declined rehab, those that dropped out, and partners. In addition, over fifty interviews were carried out with NHS staff within the Sector's Cardiac Rehabilitation services.

Both reports evaluated each service on its merits, and did not attempt to make any comparison across hospitals a focal point of the evaluation. Both times that the reports were presented, a request was received to make specific, confidential recommendations for each hospital.

The intertwined effects of the Evaluation of South East Sector Cardiac Rehabilitation Strategy Group policy

The feeding back of results throughout the study, by its very nature influenced the work in progress. This meant that although the design was in two parts, the affects of the feedback and of the gradual spending of the monies throughout the two years meant that the services were continuously changing.

The results of Phase 1 directly influenced the rehab priorities outlined by the strategy group for 2004/2005⁷. However the Strategy Group agreed that many of the issues raised in Phase One had been or were being addressed and therefore there were no longer so many gaps in service. It was therefore not appropriate to base the 2004/05 work plan on all these issues. Hence, an interim report of the service improvements provided through the CHD Choice funding was prepared by the SE London Sector Cardiac Rehabilitation Strategy Group. This report was useful for the evaluation team in designing Phase 2 of the evaluation.

Ethical Issues

Ethical approval was obtained at the beginning of Phase One by representatives of the ethical committees for each of the six PCTs. It was stressed that this study was strictly evaluation, that no research was going to be conducted and that there were no aspects of the procedures that were not part of routine clinical care. The patients

⁷ **Cardiac Rehabilitation priorities were:**

- Equity across the Sector
- To identify the “pots” of money to access
- Uniform delivery of information for patients
- Raising the profile of CR – through the Sector Commissioning Network and the Cardiac Network
- Input from Psychology services
- Increase Phase III in the community

who were invited to the interviews were told explicitly the reason for the interview and that they would also be allowed to decline.

Prior to commencing Phase Two, the members of the Strategy group were concerned that there was an issue around Data Protection and Caldicott principals. Therefore all the relevant local research ethics committees (LRECs) were contacted again to ensure there was agreement for patient information to be passed on. All six LRECs agreed that the evaluation did not require formal ethical approval, as it was not research. However, members of the Sector group raised concerns over releasing the patient details without the patients previously being informed before hand in the light of data protection legislation. For this reason 'Hospital W' submitted the report to their Clinical Practice Committee. 'Hospital W's' Clinical Practice Committee meeting raised concerns with the following:

- Absence of evidence of patients written consent
- Confidentiality, both with the data generated and patient and trust anonymity
- The relationship and agreed process between the researchers and the strategy group of generated data and distribution of results
- Absence of honorary contracts for the researchers to undertake patient interviews on trust property
- The process of identifying sample and contacting patients

The committee needed to be fully satisfied that their concerns have been adequately addressed, because of vicarious liability, before they agree to Phase Two of the evaluation being carried out.

In response to these concerns a 'Sector Pack' was prepared for each member detailing the measures taken to ensure patient confidentiality. These are summarised below. Evaluation Team members signed a confidentiality agreement and copies were sent to all six units.

Audit Interviews were conducted inside the unit or over the telephone. All data was coded anonymously by allocating code numbers. Code numbers not names were used in all data recordings and analyses. All data was recorded in an anonymous format and will be destroyed after two years.

DESIGN

It was decided that, as the PCTs varied in terms of services, needs, and population, an action research model of evaluation was the optimum way to explore the issues. The evaluation was a flexible process and much of the information was analysed as it was collected. The CHD group was informed regularly of its progress and feedback was given.

Participants

The evaluation included interviews with:

- Phase III patients who were taking part in, or who had completed, a Cardiac Rehabilitation programme at each hospital. It was decided to interview patients near to the end of phase III to ensure the minimum impact on the patients of the programme, for example by raising issues that might cloud the treatment.
- Phase IV patients who were currently taking part in a community scheme.
- Patients that were invited to a Cardiac Rehabilitation programme, but had declined to accept it.
- Patients that had accepted the invitation to a Cardiac Rehabilitation programme, but who had not attended it (DNA).
- Patients who began attending a Cardiac Rehabilitation programme, but dropped out.
- Carers and family members of the above.

The evaluators aimed to reach a broad spectrum of patients in order to gain an accurate picture of the situation. It was originally hoped that patients would be matched in numbers of non-attendees and attendees (providing that the non-attendees would agree to participate). However, owing to changes in procedures to maximise confidentiality, the numbers of non-attenders who consented to take part was reduced dramatically.

METHOD

Recruitment

Attendees

Evaluation Team member invited patients in a routine phase III Cardiac Rehabilitation clinic to volunteer to participate in the study. Patient explanation sheets and consent forms (two copies) were given to the patients. A copy was kept by the evaluation team. The second copy was given to rehab team to keep in patient files.

Carers

Patients were given an invitation letter, explanation sheet and consent form for their partners/spouses/carers asking for volunteers. The signed forms were then returned to the evaluation team.

Non-attendees

The Strategy group members were consulted over the best way to obtain 'non-attender' data. Group members agreed, once ethical issues had been cleared, that patient lists would be provided. However this was not done by all hospitals either because members had not attended the Strategy Group meeting when the concerns were discussed or because individual hospitals differed in their policies of providing data.

Method One: obtaining non-attender data

The hospitals provided a list of patients who had declined rehab. They were asked to fill in the following details:

- Patient name
- Sex
- Date of birth
- Ethnic origin
- Date admitted or discharged
- Condition
- Contact details

The sector staff were consulted over the best way to transfer patient data. Some hospitals sent the data by mail and others by email. Bromley required one of the team to collect it by hand from the Hospital. The Evaluation Team member kept the patient details locked in a filing cabinet, and deleted emails. The Evaluation Team wrote to all the patients on the list including an invitation, explanation and consent form with a stamped addressed envelope (SAE) for return. Positive Responders were telephoned and interviewed afterwards.

Method Two: obtaining non-attender data

Hospital staff gave out invitation letters, explanation sheets and consent forms in person to any patient who declined rehab. These signed forms were either sent to the evaluation team in the same way as discussed above. Positive Responders were telephoned and interviewed afterwards.

Interviews

A patient-focused approach was employed to tap into the patients' experiences of the service with the aim of improving services. Patient focused approaches to care are becoming a mandatory requirement in clinical governance reviews conducted by the Commission for Health Improvement. The evaluators decided to explore patients' experiences through a series of interviews. It was felt that individual interviews would be less superficial than questionnaires, as they allow the patient to have more say, and express their concerns and experiences freely without being restricted.

Originally it had been hoped to invite all the participants to a face-to-face interview on-site at the hospitals' Cardiac Rehabilitation units. Phase One showed that many patients were unwilling to come into the hospital, especially those who had been unwilling to attend rehab classes in the first place. Therefore the interviews were a mixture of face-to-face interviews and telephone interviews. Fifteen of the interviews were carried out face-to-face; the remainder were telephone interviews.

The interviews were carried out during the period May-October 2004.

Interview Questions

The interviews followed a fixed structure so that the same topics were covered by each patient. However the interviews were also flexible in terms of using open

questions to allow the patients to explain in their own words their individual experiences. Although the results were confined to Cardiac Rehabilitation only, the patients' context was important for background information.

The interview questions can be found in Appendix 1. The questions covered the patient demographics, experience of the patient, phase III rehab, lifestyle factors, psychological wellbeing, cultural issues and recommendations for the hospital teams. Some additional questions were added as a result of requests from the Cardiac Rehabilitation teams. These questions were adapted for carers of the patients.

Interviews with SE sector members and nursing teams

Thirty interviews were arranged with members of the SE London Cardiac Rehabilitation Strategy Group as well as with members of the Cardiac Rehabilitation teams, PCT members, phase IV co-ordinators and psychological teams to discuss local service provisions, gaps, needs and aspirations. Second and third interviews were then arranged with Cardiac Rehabilitation teams to account for the changes throughout the course of the study.

Cardiac teams were asked to provide data on:

- Annual attendance / non-attendance to rehab
- HADS scores
- Home visits
- Reduction in waiting times
- Population data
- Information on local evaluations that had been carried out

FINDINGS

The analysis employed a mixture of quantitative and qualitative measures. Qualitative evaluations were based on the interviews designed to evaluate patient experience of the service. The evaluators explored the material in order to look for themes and categories that emerged in reference to gaps in services and ideas for improvement. Quantitative analysis were also used whenever possible.

Quantitative data

Demographical data

The sample consisted of 124 males and 52 females. Their average age was 57.46 with a standard deviation of 21.6. In terms of ethnic group, the sample was categorised as follows: 154 were white, 6 were black, 4 were Asian, 4 were Indian, 1 was Pakastani, and 7 were of unknown ethnic group.

The rehab status of the sample was as follows:

138 attenders 17 decliners 4 drop-outs 17 carers

Stage of rehab when interviews took place

The stage of rehab when the interview took place is given in Table 1.

Table 1: Number of sessions attended when interviewed

Sessions	Hospital W	Hospital Y	Hospital X	Hospital U	Hospital V	Hospital Z
6+	55%	14%	60%	17%	36%	38%
5-6	25%	43%	15%	50%	32%	42%
3-4	20%	37%	15%	25%	27%	8%
1-2	0%	6%	10%	8%	5%	12%

Home visits and phone calls

The numbers of participants at each hospital who received home visits and phone calls are recorded in Table 2.

Table 2: Number of home visits or phone calls prior to interview

	Hospital W	Hospital Y	Hospital X	Hospital U	Hospital V	Hospital Z
Home Visit*	1 home visit 1 district nurse visit 1 GP nurse visit	14	14	9	9	25
Phone call	4	4	3	1	1	0
Nothing	11	7	3	24	13	2

*NB some people had more than one visit or phone call, which is not reflected in the table

Qualitative data

The results of the interviews was organised into the following areas:

1 Phase I: Care & Information given by medical teams

- Care received in the cardiac ward
- Information given by medical teams about the patients' condition and treatment
- Information given on leaving hospital / Individual sessions prior to discharge
- Medication

:

2 Phase I & II cardiac rehabilitation: Information following discharge

- Information about Cardiac Rehabilitation sessions and waiting times
- Scar
- Home visits / calls
- Cardiologist

3 *Phase III cardiac rehabilitation*

- Rehab teams
- Reasons for not attending rehab / dropping out
- Barriers to rehab by the attenders
- Cultural issues
- Misconceptions of patients
- Social support of classes

4 *Lifestyle day ('Hospital Z & X')*

5 *Lifestyle factors*

- Exercise
- Diet
- Smoking
- Alcohol
- Family / social support
- Implications of their illness on their families
- The patient as a carer

6 *Psychological health*

- Sexual activity
- Counselling
- Stress
- Returning to work
- Attitude and recovery
- Complementary health and spiritual support
- Recommendations for changes
- Advice for partners on caring

7 *Phase IV Cardiac Rehabilitation*

Sample restrictions

The study included people from a range of ethnic backgrounds including African-Caribbean, Indian, Pakistani and Bangladeshi. Despite planning to address all aspects of ethnic diversity in the evaluation, our ability to do so was restricted by several factors:

The South east London CHD Collaborative started to increase the number of discovery interviews⁸ in the sector. There is also a separate project going on to do discovery interviews with ethnic minorities. Thus care had to be taken to ensure that patients weren't overwhelmed with invitations to be interviewed.

Some patients were interviewed before completing the entire rehab programme and thus were asked about things that they hadn't yet covered. Care needed to be taken in analysis to take this into account.

There was difficulty in recruiting non-attenders.

There was a problem with attendance and lack of continuity of membership in strategy group meetings by members, which led to problems in communication regarding the evaluation.

Language was a barrier. Without the use of an interpreter, non-English speakers were nearly all excluded from the study. We tried to talk to the people through relatives, but without reading the letter of introduction, relatives couldn't always understand who we were. The same barrier existed for the services themselves.

⁸ The TMDiscovery Interview aims to explore and learn from, the impact of illness on people's everyday lives. Discovery Interviews provide opportunities for patients and their carers to directly tell the story of their illness or condition using a framework — referred to as a 'spine' — that guides them through the key stages of their experience.

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APPENDIX ONE

Interview questions

1 Demographics

Age admitted	Rehab (hospital)	Sex	Family status	Date
Language	Rehab status	Ethnicity	Type of interview (phone / face to face)	

2 Experience of the patient

- Condition/s /Brief explanation of experience
- Care & Information given by medical teams (Phase 1). Which hospital
- Information given on leaving hospital / Individual sessions prior to discharge / Contact details
- Experience at home (Home visit / calls)
- Emotional / confidence at home
- Information about their condition / treatment
- Information given prior to operation / Stent
- Medication instructions
- Scar
- Who told you about rehab classes
- Cardiologist - When seen? / How were you contacted / Attitude of cardiologist
- GPs -
- Missed appointments (cardiologist / rehab) - Follow up call / Did you get in touch

3 Rehab (Phase III)

Wait for rehab

- Advice / info while waiting (exercise, social support etc)
- How were you informed when rehab began / Follow-up service / reminders
- QE – wait between lifestyle day / exercise

Classes

- Reasons for not attending rehab / dropping out
- Number of sessions of rehabilitation attended? reasons for absenteeism
- Concerns / problems about attending rehabilitation
- Rehab team
- Suitability / usefulness / enjoyment of the programme
- Misconceptions of patients vs what they have learnt
- Social support of classes

4 Lifestyle factors

- Changes made as a result of rehab (Short term / Long term changes to health?)
- Goals, methods of maintaining / improving these changes
- How much control they feel they have over long term recovery?

4.1 Diet / Dietary adjustments

How did you receive the information

Do you feel you need further help with diet / weight? / Referral to see a dietician

Support of family members in making a dietary changes

Maintaining change / Barriers to changing eating habits

4.2 Smoking

How many? / How many years?

Did you ever smoke? / When did you give up? / How did you give up?

Advice / support / aids. Would you want it?

4.4 Alcohol

How much / when / where vs how much before?

Advice by rehab?

4.5 Exercise

Rehab - useful?

Exercise before rehab / What exercise do you do now / will you keep it up long term?

Barriers to exercise?

Phase IV - Invited / attended / How did they hear about it / Reason for not attending?

5 Psychological wellbeing

5.1 Family/social support

Partners attending classes

Advice for partners on caring

5.2 Shock of illness?

implications of their illness on their own lives and on their families'

Confidence immediately following operation / in hospital / first days at home

Depression / Anxiety / Changes in mood

How have your partners coped

Concerns about resuming previous social / leisure activities

5.3 Sex

Advice about resuming sexual activity (emotional fears and worries),

5.4 Counselling

Offered counselling? (by whom)

Do you need further help to cope with your emotional problems?

5.5 Stress

Stress talk in rehab / relaxation exercises.

Ongoing domestic problems

Visits to hospital stressful

5.6 Work and / or travelling to work

Extended sick leave / returning to work / retirement

Do you want advice about what you are entitled to demand from work following sick leave.

5.7 Attitude and recovery

Have they taken the advice given to them

6 Cultural issues

- Barriers to rehab Stigma, language, minority member, gender, age
- Language Mother tongue, Fluency in English, Translator? Info received
- Migrants - 1st / 2nd / 3rd generation
- Faith / religion Religious / community support, Influence on coping with illness, Prayer

7 Alternative / complementary health

Herbal medicine, homeopathy, witchcraft, faith healing, Chinese medicine (acupuncture, Shiatsu & herbs), meditation, massage, yoga, Tai Chi etc. Alternative vs. complementary methods

8 Recommendations for changes

9 On a scale of 1-10 (10 = best), how do you rate the hospital/ Cardiac Rehabilitation?

APPENDIX TWO

Example of an Individual Hospital Report Requested by the South East Sector Strategy Group

Hospital X*

*Due to ethical issues of confidentiality the name of the hospital has been changed to 'Hospital X' and any identifiable factors changed.

The focus of the final evaluation report is cardiac rehab services in the South East Sector considered in their totality. This supplementary report responds to a request from the South East Sector Cardiac Rehabilitation Strategy Group for a specific report for each hospital service. While every effort has been made to provide this more specific feedback, each hospital service is invited to reflect on its position vis a vis the recommendations within the main body of this report considered as a whole.

'Hospital X' is a large tertiary centre offering a high quality service to patients both locally and regionally. The dedicated Continuing Cardiac Care Team has implemented many changes to the service as a result of the CHD Choice money, thus improving an already high standard of service. Changes have also been made possible from funding sources other than Choice money. 'Hospital X' and 'Hospital Z' work very closely together, although it is sometimes hard to share facilities as the different boroughs offer different services.

'Hospital X' is the only Cardiac Rehabilitation service in the sector to be given their own cost codes and annual budgets, making it easier for them to manage their service efficiently, locate funding sources and prevent some of the financial insecurity experienced by the other services.

Choice funding has enabled the recruitment of a 1WTE hospital cardiac rehabilitation nurse, a physiotherapist, an exercise trainer and administration support. Additional funding has provided two hospital cardiac rehab nurses, a community cardiac liaison nurse and psychologist.

Administration

Choice funding has enabled 'Hospital X' to recruit a full-time administrator. This has removed admin pressure from the nurses and has improved the speed and quality of discharge referrals.

Physiotherapist

'Hospital X', like the other services in the sector, were unable to recruit a fulltime physiotherapist. Instead, they employed a junior physiotherapist working in cardiac rehab for six months at a time as part of the rotation. The physiotherapist has replaced the nurses in leading the sessions and has developed protocols of the exercise session.

Psychologist

'Hospital X' is currently the only hospital in the sector to employ a full time psychologist, ensuring that the psychological needs of cardiac patients can be appropriately addressed. This position was made possible by charitable trust funding for three years. The psychologist offers supervision, consultancy, psychological interventions and has direct contact with cardiac rehab patients during phase III cardiac rehabilitation.

Phase 1

Patient Choice funding helped the staff to identify and subsequently see more patients within the hospital. They also contact the local services of routine angioplasty patients.

Phase II

Owing to the additional cardiac liaison nurse, the number of patients seen has doubled compared to the situation before the Choice funding. Before the funding the cardiac liaison nurse saw only post-surgery, MI and very few angioplasty patients. Now all post-MI, surgery, angioplasty and pre-cardiac surgery patients are seen.

Multi-ed has been piloted at Hospital Three by the cardiac liaison nurse on home visits. The feedback to date hasn't been positive. The nurses feel that it is more beneficial to utilise the time talking to patients and that multi-ed would be more useful in phases I or III.

Phase III

Hospital based rehab has been extended to patients with stable angina, post PCI⁹ and Acute Coronary Syndrome. House-bound patients who cannot attend phase III Cardiac Rehabilitation are visited by the physiotherapist in order to develop a home exercise programme.

Heart health morning

The new heart health morning is based on the lifestyle days offered in other boroughs. The aim is to target patients who declined phase III Cardiac Rehabilitation. It will give them the chance to meet the team and receive rehab advice. It may motivate people to reconsider attending the exercise classes.

Phase III in the community

There is currently no phase III in the community, which is a gap in the service.

Heart Failure pilot

Heart failure patients will be starting hospital-based Phase III Cardiac Rehabilitation. They will also be assessed individually to see if they are able to access phase IV.

A community BACR instructor attends the hospital-based phase III Cardiac Rehabilitation programme on a weekly basis. This has helped increase the uptake of phase IV.

Community Phase IV

There is a joint service across the boroughs as they share patients.

A full-time co-ordinator and two cardiac instructors (three part-time) have begun work in two local boroughs in a cross-borough phase IV. This has been funded with 'Hospital V' charitable foundation and choice money.

The new heart club coordinator will be setting up new classes and locating venues, identifying volunteers to work with the instructors (if they work long enough, they have the BACR instructor award) and developing audit and exit routes. There is a need to

⁹ Percutaneous coronary intervention (PCI), a set of procedures used to treat coronary heart disease

develop exit route for phase IV across the borough. The joint project will increase the capacity of phase IV and allow more people to access phase III.

There is a small pilot, taking CHD patients directly into phase IV. This is taking place in one leisure centre and involves a small number of GP referrals. Although there are capacity and funding problems, but staff are interested in extending the scheme across the borough.

Health Lifestyles Manager

The new Health Lifestyles Manager is in post. This role is to manage physical activity and health initiatives in the local borough including GP exercise referral schemes, walking projects and the heart club. The healthy walks initiative programme could become an exit strategy from Phase IV.

Smoking Cessation

There is a smoking cessation service at 'Hospital X' for inpatients. Smoking cessation advice is offered on an individual basis.

Alcohol

The Cardiac Rehabilitation team has the option of giving patients details of a national alcohol helpline or referring them to the psychologist.

Diet

Patients can be referred to the dietician. This service is offered at cardiac rehab and also at the six month/ annual follow up clinic.

Occupational Therapist (OT)

The patients see the OT at phase III Cardiac Rehabilitation. Currently, there is no provision for the OT to go to patient homes.

Advice line

All cardiac patients can contact the advice line service.

Other services include:

- A nurse-led post MI service, developed to take pressure off outpatients.
- Developing a Cardiac Liaison Service pre and post surgery funded by Hospital Three charitable foundation.
- A nurse-led assessment clinic for the exercise-referral scheme in the Healthy Living Centre, Location S.

Tertiary service

'Hospital X' is a large tertiary centre for cardiac patients across Kent. CHD choice money has helped to achieve a quality referral system for non-local patients.

Comment by patients

The majority of patients interviewed were extremely happy with the service and staff. They felt well informed about their condition and the available services and follow up appointments. One patient complained that the hygiene at the hospital could have been better.

All patients attending Cardiac Rehabilitation found it useful and enjoyable. They found the staff supportive, professional and caring. Two ethnic minority patients had been worried about attending the classes before they started, but had enjoyed it. Many people had seen the dietician. Although they were well informed about diet, they would welcome more ideas about eating healthily on a budget

Patients at 'Hospital X' reported receiving very useful advice about resuming sexual activity and related concerns.

Patients also appreciated the presentation preparing them for operations.

One patient suggested more home help for the elderly.

Reflective Analysis

Initial Involvement in the Evaluation / Preparation for the job

I first became aware of this opportunity whilst I was a class tutor for the Health Promotion Module of the MSc. Health Psychology at City University, supervised by Prof. David Marks. Prof. Marks had just won the tender for the evaluation and was looking for an audit officer. I was extremely interested in this work. I was currently working towards my Chartership in Health Psychology, working part time in a cancer charity, and also as a class tutor/ guest lecturer at City University. I was also in the process of finishing a Diploma in Psychodynamic Counselling. This meant that I had flexible working hours, which would both accommodate and welcome extra work.

I felt that this job would be an excellent opportunity to gain direct and practical experience in the field of Health Psychology:

- working on a medium to large scale evaluation, being involved from the very early stages of design and implementation
- working as part of a team from a Large University with professional supervision from the Head of Psychology
- working within the context of the NHS

Although I had no experience in Cardiac Rehabilitation, I had several years experience working with people with chronic illnesses and felt that I had transferable skills. However, it was necessary for me to do background preparation for the project including: a) understanding of the internal setup of the NHS. For example how the South East Sector Cardiac Rehabilitation Strategy Group fitted in to the CHD Collaborative, and the individual roles of all its members b) familiarising myself with the seven hospitals in South East Sector c) a thorough understanding of heart disease and the four phases of cardiac rehab d) literature searches on evaluations and research in Cardiac Rehabilitation (and other related areas).

I remember feeling daunted by the project and was keen to make a good impression. I felt more in control once we had established the structure of the study and discussed the methodological details; when I understand what would be expected of me.

Originally my role was to be an audit officer, carrying out the interviews. As the evaluation progressed I took over the day to day running of the project whilst my

supervisor took more of a consultant role. I welcomed the challenge of being allowed to 'get on with things,' within a supervised context, being both independent and contained. In hindsight I appreciate that this is the way that I perform the best.

Phase One

In the first stages of the evaluation I arranged individual meetings with the members of the strategy group and other relevant people in the sector, in order to establish a relationship with them and find out about their service. As a result of these initial meetings, I no longer felt like an outsider in the Strategy Groups meetings. I felt that I became an accepted part of the group. Throughout my two years working on the project, I was aware that many people 'came and went' in the Sector. The staff were used to meeting someone once and then rarely seeing them again.

I became aware of the huge disparity among the sector services in terms of funding, resources and staffing. I was not sure how the Choice Money could ever address this. For example, one cardiac rehabilitation service was run solely by a physiotherapist (who was about to go on maternity leave) whilst other services were staffed by teams of five or six times the size, and still struggling for resources.

I was quite shocked by the lack of resources that the majority of the staff had to deal with. I was touched by their dedication and commitment to their work and appreciated their heavy work loads. As a result, I realised how important it was for the design of the evaluation to be flexible in order to accommodate each individual service without putting excessive demands on their resources, or making demands that they simply could not meet. For example, it had originally been hoped that participants would be matched in terms of their stage of rehabilitation (phase III) by choosing patients who had had their cardiac event within the same time window (from Jan 1st, 2003). However, due to factors such as the large variances in waiting times between some of the hospitals such uniformity was not be possible.

Following discussion among the SE sector group, it was decided that the aim of the evaluation was not to make direct comparisons between the hospitals, as baseline differences between the services occurred. Moreover, it would enhance the study by having patients who experienced a wide range of waiting times and stages of rehabilitation.

I was aware that some of the cardiac nurses may have been wary of my role as an 'evaluator.' I was keen to reassure the team members that I was not there to judge or criticise, but to be a useful resource for them – to find out as much as I could about their departments so that they could feedback the results to their financial managers in order to gain more resources. The majority of the staff appreciated the evaluation as something that they had requested. They were very accommodating. I also invited the cardiac teams to suggest specific questions related to their individual service for me to include in the interviews, which would help them with their work. In the majority of cases the interview process was very smooth.

Originally, we had planned to invite all the participants to a face-to-face interview on-site at the hospital's cardiac rehabilitation unit at a set time and date, coinciding with the current rehab classes so that those attending rehab wouldn't have to come in twice. Even though they were offered a refund for the travel expenses, the pilot study showed that many patients were unwilling to come into the hospital, especially if had been unwilling to attend rehab classes in the first place (often on the grounds of ill health or return to work). Therefore the interviews were a mixture of face-to-face interviews (with either one or two participants) before or after the Phase III sessions and telephone interviews.

The telephone interviews required the cardiac teams to provide me with a list of non attenders including their telephone numbers. From this a sample of people were contacted. The research team was keen to get a mix of age, sex and ethnicity.

Whilst most sector members were extremely helpful in providing the basic information for the evaluation, one district was unable to provide the data until the final month of the evaluation, which hindered the analysis of data and completion of the project. To this day I have not fully understood the reasons for this as this particular cardiac nurse was extremely helpful at Sector meetings and would always promise to provide the data, but in practice would always fail to deliver. I believe that were internal politics and hidden agendas that the evaluation team had no control over. I also felt that there was a certain culture within the NHS that was acceptable to filter out unnecessary demands in order to survive in such a pressurised, environment. This was an interesting learning experience for me as I adapted to the system and found ways to become more demanding in order to get the information I required, without causing offence. This is an extremely useful skill in all aspects of my professional life.

The early stages of the evaluation were clouded by the climate of confusion and financial uncertainty that surrounded the allocation of the funds to each PCT. It was several months into the evaluation before the committee members were confident of the location of the funding at the PCT's, despite numerous attempts to clarify this. Sector members were frustrated, as some had begun to spend the funds whilst others had been waiting. The matter was cleared up several months later and arrangements were made to prevent the confusion happening in the future. It is highly likely that this delay affected the evaluation.

Phase Two

There was a gap of three or four months before phase two of the project. During this time two stage two trainees were recruited to do the patient interviews. My role involved project managing the evaluation, interviewing the cardiac rehab teams and also the carers (partners) of the patients.

Prior to commencing Phase Two, the members of the Strategy group were concerned that there was an issue around Data Protection and Caldicott. Therefore all the relevant LRECs were contacted again to confirm that the evaluation did not require formal ethical approval, as it was not research. However, members of the Sector group raised concerns over releasing the patient details without the patients previously being informed before hand in the light of data protection legislation. One hospital submitted the report to their Clinical Practice Committee, who raised a list of concerns which we met by designing a sector pack outlining and addressing every possible detail and potential problem. I learnt from this to be thorough and exact when addressing such concerns in order to gain the professional confidence of my colleagues. The SE Strategy members were satisfied with the information provided and the modifications, and were happy to begin Phase Two. Unfortunately not all members of the group had attended this meeting. This was extremely frustrating for us, as it felt that we had made every effort to accommodate their demands, and we still could not begin our work. There was further confusion by one hospital over applications for honorary contracts which had got lost in human resources twice. This meant that the collection of data began several months later in this hospital.

Unfortunately, there were problems with the interviewers, who were inexperienced and immature in their attitude to their work. They were both health psychologists undertaking the Stage 2 training towards their doctorate. This involved taught modules

at City University and completing a paid work placement. Both students were undertaking this work as their placement and they were also hoping to use the research towards their own research. The interviewees were both young, with very little work experience. They found it difficult to work independently and needed to be monitored closely. For example they had to be constantly reminded to do designated tasks, and they lacked initiative in making small decisions. This only became apparent as the work progressed, and tasks that had been delegated, such as sending correspondence, or keeping record of their interviews were not done. I found it extremely frustrating, as the nature of my role meant that although I supervised their work, I was not their boss and had no authority over them in order to discipline them. As a result, I developed strategies to motivate and encourage them, although sometimes I felt that such high levels of encouragement should not be necessary in paid employment. I felt compromised professionally, as their inadequacies were affecting my workload. I was worried that it would not only affect my reputation, but also that of City University, as the interviewees were in constant contact with hospital teams and were often relied upon for communication. I voiced my concerns to Prof. Marks, who understood. We agreed that we were not in a position to sack them. However he began imposed strict work boundaries for them, giving them deadlines to achieve each month, before payment. In addition, there was also the risk that they wouldn't pass their work placement module if they didn't complete the project effectively.

There were many times that I felt that it would have been easier to have done the whole job on my own, rather than delegate to people who did not seem motivated or trusted to do it, as it led to more work for me in the long term. In hindsight, I would have established firmer professional boundaries from the beginning and would have been clearer about the specific roles, expectations and deadlines from every member of the evaluation team. It may have then been easier to identify and address motivation problems at later stages. On a positive note, I have learnt from this experience, and in my subsequent career, have been able to manage trainees and colleagues without any difficulties.

The evaluation was a positive challenge. Over the two years I increased in confidence and experience until I felt very competent. I became aware of how I needed to manage my workload in order to remain in control of a large schedule. Phase One of the study was completed smoothly and relatively effortlessly. I felt that I had had completed a huge learning curve - from being involved in designing the study, working with the

cardiac teams, facilitating the interviews, analysing the data and writing the draft report, which my supervisor then completed. In hindsight Phase One was quite extraordinary, as it really was a dream job. It was stimulating, exciting, rewarding and fun, with no sources of concern. The only stress was self-imposed, I was very eager to perform well had very high expectations for myself. I was often worried that I wouldn't be good enough. In comparison, Phase Two was more of a challenge due to the challenges of working with the interviewers and also due to the communication issues with some of the hospital teams. However, I learnt a great deal from them and the experience set me up for later work in the NHS, where communication blocks, busy workloads and internal politics are common.

I am very grateful for the experience that the work gave me. It felt an achievement to have been involved in such a study from beginning to end. After following the South East London cardiac Rehabilitation Strategy Group for two years, I became attached to them and felt very sad (and relieved) to finish. I felt that the submitted report was both accurate and important and I hope it has stimulated further improvements to the services.