

**Psychological distress in non-cardiac chest pain patients: An
application of the common sense model of illness
representations**

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ABSTRACT

This thesis applied the Common Sense Model of Illness Representations to patients' experiences of acute non-cardiac chest pain (NCCP). A systematic review indicated high levels of distress and poor quality of life (QoL) in acute NCCP patients, although there were few studies on psychological outcomes in these patients, with very few considering the possible predictors of negative psychological outcomes. Study 1 was a longitudinal questionnaire-based study, assessing illness representations, psychological outcomes and continued chest pain in a sample of acute NCCP patients in an emergency department ($N=200$) and at one ($N=138$) and three month ($N=110$) follow-up. Levels of psychological distress were high, mental QoL was poor, and almost half the participants experienced continued chest pain. An increased belief in psychological causes, perception of a more chronic timeline and weaker perceptions of personal control were associated with poorer psychological outcomes. Continued chest pain was related to increased baseline psychological distress and cardiac worries, a stronger baseline perception of identity and a more chronic timeline, highlighting the role that anxiety and stress may play in causing and maintaining NCCP. The role of psychological factors and the lack of coherence (understanding) in NCCP, was demonstrated in Study 2, a qualitative study ($N=7$) of patients who experienced continued pain and distress at follow-up. Using the findings from Studies 1 and 2, and previous findings with NCCP patients, a self-help anxiety reduction intervention was developed. This was designed to improve patients' understanding of NCCP and to provide methods to reduce stress, anxiety and pain. During further qualitative work, the intervention was found to be acceptable, relevant and understandable to both NCCP patients ($N=11$) and the specialist nurses ($N=4$). Further research is needed to test the efficacy of the intervention in a randomised controlled trial.

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ABBREVIATIONS

ED	Emergency Department
NCCP	Non-Cardiac Chest Pain
CPOU	Chest Pain Observation Unit
RCT	Randomised Controlled Trial
MI	Myocardial Infarction
QoL	Quality of Life
CSM	Common Sense Model
IPQ	Illness Perceptions Questionnaire
IPQ-R	Revised Illness Perceptions Questionnaire
MUSs	Medically Unexplained Symptoms
CFS	Chronic Fatigue Syndrome
IBS	Irritable Bowel Syndrome
NES	Non-Epileptic Seizures
CCP	Cardiac Chest Pain
CHD	Coronary Heart Disease
CASP	Critical Appraisal Skills Programme
HADS	Hospital Anxiety and Depression Scale
CDU	Clinical Decisions Unit
ECG	Electrocardiogram
ETT	Exercise Tolerance Test
PCS	Physical Component Subscale (of SF-12)
MCS	Mental Component Subscale (of SF-12)
GP	General Practitioner
CBT	Cognitive Behavioural Therapy
BPD	Borderline Personality Disorder
MRC	Medical Research Council
GAD	Generalised Anxiety Disorder

PUBLICATIONS

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CHAPTER 1. INTRODUCTION

1.1 Introduction

Acute chest pain accounts for approximately 700,000 emergency department (ED) attendances each year in England and Wales and approximately a quarter of all medical admissions (Goodacre et al., 2005). Recent public information campaigns, such as the British Heart Foundation “Doubt Kills” campaign, have aimed to increase awareness of potential cardiac causes of chest pain and prompt use of emergency services. However, a potential consequence is increased anxiety-related chest pain and attendance at hospital with non-cardiac pain (Kainth et al., 2004). Between 30 and 60% of patients attending the ED do not receive a cardiac diagnosis for their pain (Eken et al., 2010; Mayou & Thompson, 2002). Current guidelines recommend that staff merely explain the non-cardiac nature of the pain to such patients (National Institute for Health and Clinical Excellence, 2010) based on the assumption that the rapid diagnosis of non-cardiac chest pain (NCCP) will alleviate any distress. However, cardiac testing itself may cause patients to believe they are suffering from a heart problem, and so the unclear diagnosis, along with a lack of follow-up, may cause psychological suffering (Nijher, Weinman, Bass, & Chambers, 2001). Furthermore, reassurance that test results are negative is often not sufficient to calm patients’ concerns (McDonald, Daly, Jelinek, Panetta, & Gutman, 1996). Despite having excellent long-term cardiac survival (Papanicolaou et al., 1986), patients with NCCP have been found to experience elevated levels of anxiety, reduced quality of life, further episodes of chest pain, and high use of health care services (e.g., Eslick & Talley, 2008; Goodacre, Mason, Arnold, & Angelini, 2001). This therefore highlights an important target for intervention. The work presented in this thesis will assess the levels of psychological distress, quality of life, service use and continued chest pain in a sample of acute NCCP patients. It will also seek to identify whether the dimensions of the Common Sense Model (CSM) of illness representations (Leventhal, Meyer, & Nerenz, 1980) are related to these outcomes, thus highlighting targets for intervention. The ultimate aim of this thesis is to develop a brief theory- and evidence-based intervention for NCCP patients.

1.1.1 A new age of acute chest pain care

Assessment and care of chest pain patients is changing in the UK. Where patients may have originally be admitted or referred to outpatient departments for testing, they can now be assessed and discharged directly from the ED. The development of more sensitive blood tests (e.g., the Troponin T assay) for assessing for cardiac damage (e.g., following a heart attack) have resulted in cardiac problems being ruled out quickly, within the ED, with patients being discharged as appropriate (e.g., Peacock et al., 2006). Some centres have developed dedicated Chest Pain Observation Units (CPOUs, Goodacre, Cross, Lewis, Nicholl, & Capewell, 2007) within EDs, where patients can be assessed for cardiac problems by specialist chest pain nurses within a few hours of being admitted to the ED. The setting in which the present study was conducted has a dedicated CPOU. The protocol for CPOU care (see Goodacre, Morris, Campbell, Arnold, & Angelini, 2002) involves a 2 to 6 hour observation period, during which patients undergo various tests designed to identify any cardiac pathology for their chest pain. These include serial Electrocardiogram (ECG), ST segment monitoring, cardiac enzyme measurement, and an exercise stress test. This is largely overseen by specialist chest pain nurses. If a serious or cardiac cause is identified (e.g., angina, Myocardial Infarction, MI), the patient is admitted or referred for further cardiological investigation. If no apparent serious cause is identified, the patient is discharged, with advice to seek care again if the pain returns and persists for more than 15 minutes. CPOU care has been shown to reduce hospital admissions and re-attendance at the ED, increase estimated Quality Adjusted Life Years, improve quality of life (QoL), and reduce depression and subsequent pain in comparison to routine care (Goodacre & Nicholl, 2004; Goodacre et al., 2004).

1.1.2 Non-Cardiac Chest Pain: Better off physically, worse off psychologically

Poor psychological outcomes in NCCP patients have been noted in many studies, including high levels of psychiatric disorders (e.g., Dammen, Arnesen, Ekeberg, & Friis, 2004; Kisely, 1998; White et al., 2008), particularly high levels of panic disorder (e.g., Beitman et al., 1989; Dammen, Arnesen, Ekeberg, Husebye, & Friis, 1999) and high levels of anxiety and depression symptoms in general (e.g., Cheng, Wong, Lai, Wong, Hu, Hui, et al., 2003; Demiryoguran et al., 2006; Eken et al., 2010; Fagring et al., 2008; Kuijpers et al., 2003). NCCP patients have also been found to experience further episodes of chest pain (Eslick & Talley, 2008; Potts & Bass, 1995), and high use of health care services (Eslick & Talley, 2004). Chest pain impacts strongly

on the lives of these patients, causing reduced ability to work (Potts & Bass, 1995), reduced physical activity (Jonsbu, Dammen, Morken, & Martinsen, 2010) and more sleep problems (Jerlock et al., 2008). NCCP intrudes into sufferers' lives, affecting work, social activities and relationships, and causing feelings of fear, anxiety, uncertainty and stress (Jerlock, Gaston-Johansson, & Danielson, 2005).

Jerlock et al. (2005) provide some insightful qualitative evidence into the daily experiences of NCCP patients. The participants spoke at length about how the pain affected their daily life. Many patients believed their pain would lead to MI, causing fears of serious illness and even death. Patients therefore clearly misunderstood the cause of their pain, despite it being diagnosed as non-cardiac. This is reflected in the amount of uncertainty many patients expressed about the actual cause of their chest pain. It is difficult to overcome this, as NCCP, by its nature, is often unexplained. The notion that NCCP patients maintain fears about cardiac causes for their pain is a common one, with many researchers documenting this fear (e.g., Carmin, Wiegartz, Hoff, & Kondos, 2003; Dumville, MacPherson, Griffith, Miles, & Lewin, 2007; Mayou, Bryant, Forfar, & Clark, 1994; Potts & Bass, 1993). Potts and Bass (1995) suggested that this may serve to maintain the distress associated with NCCP, as patients attribute anxiety related chest symptoms to a cardiac problem, which increases anxiety and functional incapacity (as patients fear possible MI and limit their activity to protect their heart), thus allowing their NCCP to affect their lives further. This therefore suggests a bi-directional relationship between the physical and psychological problems, whereby psychological problems, such as anxiety disorders, may play a causal role in the development of NCCP, and NCCP may also result in distress. Further to this, Jerlock et al. (2008) demonstrated that mental strain at work, more stress at home, and more negative life events were related to NCCP; however, the cross-sectional nature of the study precluded any conclusions regarding the direction of the relationship between these factors.

It is clear from the literature that the care of NCCP patients needs to take into account psychological needs. This, however, may be difficult given the more recent shift in care towards rapid rule-out and discharge within the ED. This focus on limited turn-around time and discharge upon negative test results is more on the diagnosis of cardiac problems than on psychosocial outcomes, which may exacerbate any psychological problems the patients may already be suffering. It has been noted by some that a more psychological, rather than

diagnostic, focus is needed in chest pain care. For example, Nijher et al. (2001) discussed how cardiac testing itself causes patients to believe they are definitely suffering from a heart problem; and when they are diagnosed with NCCP, the unclear diagnosis and lack of follow-up may cause suffering in these patients. They suggest that if NCCP patients are not dealt with appropriately, the advantages that may come from early diagnosis of cardiac problems may be offset by an increased burden of NCCP patients on the health care system. This idea is further supported by Bass and Mayou (2002), who recommend that NCCP patients (presenting in both primary and secondary care, including in the ED) require a stepped approach to treatment. They propose that while all NCCP patients may not need intensive psychological intervention, those presenting with any continuing symptoms at all should be encouraged to discuss their symptoms, and psychological support given. The intensity of the support and intervention should depend upon how persistent and disabling the pain is.

The negative effect of the diagnostic focus of chest pain care has been noted by nurses working in the ED. In a qualitative study of ED nurses, Hamer and McCallin (2006) noted that as their time was limited, the nurses were forced to prioritise how they spent their time, focussing almost exclusively on diagnosis and clinical aspects of care. This priority is exacerbated by the imminent need to rule out life-threatening conditions. While the nurses recognised the psychosocial needs of the patients, especially the uncertainty and anxiety exhibited in NCCP patients, they felt they were restricted by limits on time and the need to follow strict clinical protocol.

It is apparent that psychological needs in chest pain care are largely overlooked, whether it is due to a diagnostically focussed health care system, or limits on time in emergency care. Despite the wealth of previous literature regarding poor psychological outcomes in NCCP, there is currently no comprehensive, systematic review of this topic. A recent overview of the literature found that those with NCCP showed higher levels of psychological disorders (e.g. anxiety disorders), poor QoL and passive coping strategies (Eslick, 2008). However, this overview was extremely limited in the evidence it considered. Furthermore, much previous research has looked at patients who have been referred for coronary angiography (e.g., Beitman et al., 1991; Potts & Bass, 1995) or to cardiology outpatient departments (e.g., Cheng, Wong, Lai, Wong, Hu, & Hui, 2003; Dammen et al., 2004; Dammen, Ekeberg, Arnesen, & Friis, 1999; White, Craft, & Gervino, 2010; White et al., 2008). As discussed above, care for NCCP is

becoming increasingly focussed on rapid rule-out within CPOUs. The findings may be different in this setting, especially given that the evidence above suggests that rapid rule-out care may lead to detrimental psychological effects for patients (Hamer & McCallin, 2006; Nijher et al., 2001). Conversely, there is also evidence to suggest that CPOU care improves psychological outcomes (Goodacre & Nicholl, 2004). There is therefore a need to identify and collate the literature pertaining to psychological outcomes in acute patients specifically. A comprehensive review of the literature into psychological outcomes in acute NCCP patients is therefore presented in Chapter 2.

NCCP patients clearly suffer in terms of QoL, anxiety, depression, and also continue to experience further chest pain. However, there is a lack of longitudinal investigations of these patients looking into predictors of outcomes. On receiving a diagnosis of NCCP, it is understandable that patients may maintain a belief that their chest pain is the result of an underlying cardiac problem, experience poor psychological and functional outcomes, and continue to experience and seek help for their chest pain. Thus, patients' beliefs are likely to have an important impact on how they adjust to being diagnosed with NCCP and may actually serve to maintain the pain itself. Furthermore, identifying predictors of outcome in patients may highlight important targets for intervention. The Common Sense Model (CSM, Leventhal et al., 1980) of illness representations, which explains how patients response to chronic illness, provides a good theoretical framework in which to consider these issues. The evidence for this model, and its applicability to NCCP, will now be reviewed.

1.1.3 The Common Sense Model of illness representations

The Common Sense Model of illness representations (Leventhal et al., 1980) proposes that when faced with a health threat, individuals form illness representations based around a number of dimensions, which guide coping methods and subsequent outcomes (physical and psychological). These representations are thought to develop through the general lay information one holds, knowledge imparted from authoritative figures (e.g., parents, doctors), and one's direct experience of the illness (Leventhal et al., 1980). These sources of information are interpreted to form the illness representations. The original dimensions of illness representations proposed by Leventhal et al. (1980) were cause (i.e., what has caused the illness), consequences (i.e., the impact of the illness on one's life), identity (i.e., the label given to the illness and the symptoms associated with it), and timeline (i.e., the course and timescale

of the illness). Emotional representations of one's illness were also believed to work in parallel to these cognitive representations to influence coping and outcome (Leventhal et al., 1980). The nature of the illness representation dimensions are thought to influence the selection of coping strategies. Specifically, it is expected that more negative illness representations (e.g., a belief in serious consequences, a more chronic timeline and a stronger identity) will lead to emotion-focussed or avoidance coping (deemed to be less adaptive), while more positive illness representations (e.g., belief in less serious consequences, a weaker identity, and a less chronic timeline) will lead to more problem-focussed coping (deemed to be more adaptive). Leventhal et al. (1980) proposed that illness representations influence coping, and coping in turn influences outcomes, thus indicating a mediational model.

Since the original development of the model, more dimensions have been included and existing dimensions expanded. Lau and Hartman (1983) extended the model with a cure/controllability component, encompassing the belief in the efficacy of treatment and personal coping behaviours in controlling one's illness. The main assessment tool for illness representations was the Illness Perceptions Questionnaire (IPQ, Weinman, Petrie, MossMorris, & Horne, 1996), which consisted of 5 scales assessing identity, cause, timeline, consequences, and control/cure. Research showed the IPQ to lack internal reliability in the cure/control and timeline dimensions, and furthermore the measure lacked any assessment of emotional representations (Moss-Morris et al., 2002). The main extensions and modifications to the assessment of illness representations were made by Moss-Morris et al. (2002), who developed the Revised Illness Perceptions Questionnaire (IPQ-R), incorporating a measure of emotional representations, dividing the cure/control dimension into personal and treatment control, and dividing the timeline dimension into timeline acute/chronic (assessing the expected duration of the illness) and timeline cyclical (assessing the episodic nature and course of the illness). The IPQ-R also included a new dimension relating to illness coherence, designed to assess whether the patient felt they had a clear understanding of their illness.

The CSM has been successfully applied to the prediction of psychological adjustment to a range of illnesses, including Addison's disease (Heijmans, 1999), rheumatoid arthritis (Groarke, Curtis, Coughlan, & Gsel, 2005) and Huntington's disease (Kaptein et al., 2006). The CSM has been further supported by a meta-analytical review of studies (Hagger & Orbell, 2003), which showed that illness representations were predictive of various outcomes. In particular, the

consequences, identity, and timeline dimensions showed negative relationships with psychological well-being, role-functioning, social functioning and vitality, and positive relationships with psychological distress. Consequences and identity were also negatively related to physical functioning. Stronger belief in the cure/controllability of one's illness was related to better psychological well-being, social functioning and vitality, and negatively related to psychological distress. This meta-analysis showed that illness representations have a moderate to strong relationship to psychological and physical outcomes, with correlations ranging from .11 to .50. Therefore, a belief in more negative consequences, a longer timeline and a stronger identity of one's illness were found to be related to negative outcomes, and a positive belief in the curability or controllability of one's illness were found to be related to more positive outcomes. However, a variety of measures of both illness representations and outcome were included in this review, with some studies using the IPQ to assess illness representations, and some using the IPQ-R. The performance of new dimensions such as emotional representations and illness coherence (only included on the IPQ-R) were not included in this review. Furthermore, some studies used disease specific measures of illness representations, which may not be comparable to general measures. Moreover, while the illness representation dimensions were strongly supported in this review, the mediational role of coping, defined as an important part of the CSM by Leventhal et al. (1980), was not fully tested. While some relationships were found between the cure/control dimension and problem-focussed coping, and between the consequences, identity and timeline dimensions and emotional/avoidance coping, these relationships were only tested in half of the studies, preventing any strong conclusions about the mediational role of coping in the CSM.

Mixed findings for the mediational role of coping in the CSM have also been reported elsewhere in the literature. Carlisle, John, Fife-Schaw and Lloyd (2005) investigated the relationships between illness representations, coping, and outcomes in Rheumatoid Arthritis patients. While illness representations were shown to be related to physical and psychological outcomes, very little support was found for the role of coping. Avoidant and resigned coping partially mediated the relationship between identity and disability, and between identity and psychiatric morbidity, but no other mediational relationships were found. Rozema, Vollink and Lechner (2009) found that the relationship between illness representations and coping strategies in breast cancer patients was very weak, and only significant for a very small number of specific illness representations and coping strategies. In contrast, illness representations

were strongly related to psychological outcomes. Where the mediational role of coping has been supported, this is often only in cross-sectional analyses and not in longitudinal analyses (e.g., Evans & Norman, 2009), suggesting that this model does not work prospectively. In summary, while evidence for the mediational role of coping between illness representations and outcomes is mixed or weak, evidence for the relationship between illness representations and psychological outcomes is compelling.

1.1.4 Illness representations and Medically Unexplained Symptoms

There is a wealth of research into what are termed 'Medically Unexplained Symptoms' (MUSs). MUSs are physical symptoms that appear to have no underlying medical explanation. These include Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome (IBS), Fibromyalgia, and NCCP. MUSs may range from transient mild symptoms with little consequence, to extremely debilitating disorders (Brown, 2007). MUSs are diagnosed largely through the exclusion of any medical complaint, and account for 10-15% of primary care patients (Brown, 2007). Rief and Broadbent (2007) give a comprehensive review of the many explanations that have been proposed for MUSs, many of which incorporate psychological factors. For example, it may be the case that those with MUSs place more attentional focus on bodily sensations and cannot filter out those which are normal from those which are illness related. Memory and expectations of pain, increased illness worry and health anxiety, and lack of response to reassurance may also play a role. Rief and Broadbent (2007) also discuss the role of overestimating the consequences of illness in MUSs, thus suggesting that illness representations may be important in such conditions. Research has suggested that patients suffering from MUSs have unclear or incomplete illness representations (e.g., Sumathipala et al., 2008). It may be likely, given the strong relationships between illness representations and outcomes (e.g., Hagger and Orbell, 2003) that MUS patients may suffer as a result of their unclear illness representations. Frosthalm et al. (2007) performed a longitudinal investigation with a very large sample of both MUS and symptom free participants to assess the role of illness representations in MUSs. As with previous studies, illness representations were related to outcomes, namely self-reported physical and mental health. Patients with MUSs had more negative illness representations and reported especially low self-reported health in comparison to controls. However, when MUS patients were considered alone, illness representations were

less predictive of self-rated health outcomes, although this may be in part due to ‘floor effects’, given that self-rated health was low in this group.

Another type of MUS is Non-Epileptic Seizures (NES), whereby seizures occur with no underlying evidence of epilepsy. In a qualitative investigation of NES, Green, Payne and Barnitt (2004) found that the most prevailing theme was a lack of a label for the illness, and the difficulty this caused. Participants struggled to outline any identity to their illness, with some being unsure of whether they actually did have epilepsy, and many reporting uncertainty about what they were suffering from, even after discussing it with their doctor. Participants were also unsure of the cause of their illness, and had no ideas about the potential course or duration. They also reported a perceived lack of control over it. These participants evidently have unclear and/or negative illness representations, largely as a result of suffering from an unclear illness with an unclear label. Moreover, while direct conclusions about subsequent negative outcomes as a result of this cannot be drawn from such qualitative data, it does suggest that these patients suffer as a result of their NES, as many reported significant negative consequences on their lives, and no participants reported positive consequences of the illness. Such findings may also be transferable to NCCP patients.

1.1.5 Illness representations in cardiac patients

Before considering the evidence for illness representations in NCCP patients, it is important to consider whether illness representations play a role in patients with Cardiac Chest Pain (CCP). As NCCP patients may believe (before diagnosis, and even maybe after) that they are suffering from a cardiac problem, understanding the role of illness representations in cardiac patients, may help us to understand NCCP patients’ reactions.

In a large longitudinal study of Coronary Heart Disease (CHD) patients, Aalto et al. (2006) found that illness representations predicted global health status and QoL, both at baseline and one year later. Moreover, illness representations predicted outcomes over and above the effects of CHD severity, and even partially mediated the relationship between CHD severity and outcomes. Similarly, Alsen, Brink, Person, Brandstrom and Karlson (2010) found that negative illness representations predicted poorer QoL in post-MI patients, particularly perceptions of a more chronic timeline and lower perceptions of personal and treatment control.

An important unique aspect of the illness representations of NCCP patients is how their illness representations may be affected, even changed, as a result of testing and hospital procedures. They may access hospital care because they believe they are suffering from a cardiac problem and thus hold illness representations accordingly. However, they then receive a NCCP diagnosis, which may strongly influence how patients perceive their illness. To investigate this, Devcich, Ellis, Gamble and Petrie (2008) assessed patients before and after a diagnostic coronary angiogram, considering both those who received a positive and negative diagnosis of diseased arteries. In comparison to those diagnosed with diseased arteries, those diagnosed with normal arteries showed a reduction in the strength of identity of their illness, and a decrease in the number of negative consequences perceived to be associated with their condition. Emotional response was also reduced. The authors suggest that on receiving a negative diagnosis, patients reappraise their illness and subsequently change their illness representations, in a more positive, realistic direction. While this demonstrates that negative test results can cause a change in illness representations, this may not be directly comparable to those receiving a NCCP diagnosis in an emergency setting. The study focussed on those who had been referred to an outpatient clinic for routine coronary angiography, and so did not assess patients who had accessed hospital services in an emergency situation, who may not have time to form solid illness representations prior to testing. Moreover, no mention is made of why patients had been referred – it is not made clear whether they were experiencing any chest pain. It is therefore important to consider the illness representations of patient groups who may be more similar to ED NCCP patients.

1.1.6 Illness representations in NCCP

There is some existing previous research that has considered illness representations and outcomes in NCCP patients. Robertson, Javed, Samani and Khunti (2008) investigated illness representations and outcomes in patients attending a rapid access chest pain clinic – a diagnostic referral clinic for chest pain patients, where patients are usually seen and tested within 48 hours of referral. Patients (both those who received a cardiac and those who received a non-cardiac diagnosis) were assessed before clinic attendance, and 1 week and 2 months after, examining illness representations, depression and anxiety, and health anxiety. As previous research has shown (e.g., Demiryoguran et al., 2006; Eken et al., 2010), those diagnosed with NCCP showed raised levels of anxiety, which was still above community norm

levels at the 2 month follow-up, suggesting a negative psychological impact of NCCP. In contrast, depression was higher in the cardiac group at follow-up, which the authors suggest may be a result of living with a cardiac problem. Contrary to the results of Devcich et al. (2008), illness representations were shown to be more negative in those diagnosed with NCCP, with NCCP patients showing lower perceptions of control, less coherence (understanding) of their illness and a stronger emotional response in comparison to their cardiac counterparts. Those diagnosed with NCCP therefore suffered both heightened levels of anxiety and more negative illness representations, despite having received a negative cardiac diagnosis. Moreover, this was not a result of hypochondria, as while health anxiety was raised in the NCCP group, it still remained within normal parameters. However, illness representations were poorer in the NCCP group at the pre-clinic assessment, suggesting that they are not necessarily a result of a negative cardiac diagnosis. Moreover, while illness representations and psychological morbidity were assessed over time, the relationship between these variables was not assessed. The relationship between illness representations and psychological outcomes therefore cannot be determined.

Donkin et al. (2006) considered whether illness representations could predict reassurance in a group of patients who had been referred to a cardiology clinic for an exercise stress test – a test which forms part of the diagnostic procedure in the CPOU. Health anxiety, state anxiety, and illness representations were assessed before testing, and reassurance was assessed immediately after testing and one month later. Only participants who received a negative result were included, and all received routine reassurance that no cardiac pathology had been found. Reassurance had dropped at the one month follow-up, suggesting that any reassurance experienced by the negative test results was transient and soon diminished, supporting findings that negative diagnosis alone may not promote reassurance (e.g., McDonald et al., 1996). Perception of consequences, timeline, identity and emotional responses were related to reassurance following testing and one month later, and perceptions of control were related to reassurance at one month following testing. Perception of timeline and treatment control independently predicted reassurance, such that those who believed their illness would last longer and had a lack of belief in the efficacy of treatment to control one's illness were less likely to be reassured at follow-up. High levels of anxiety during the testing situation were also related to reassurance at one month. As the authors suggest, this may be because patients are too anxious to process any reassuring information whilst in the hospital situation.

1.1.7 Illness representations in practice

Research has shown that illness representations may be successfully utilised in practice in a number of ways. For instance, administering a communication skills intervention to GPs encompassing training in illness representations has been shown to improve patient satisfaction with GP consultation (Frostholm et al., 2005). The most effective way to incorporate illness representations into practice may be through patient interventions. Interventions aimed at improving illness representations have been effective at improving functional outcomes in patients who have had a MI (Petrie, Cameron, Ellis, Buick, & Weinman, 2002), and therefore might be appropriate for NCCP patients. Similar interventions have also been effective in other MUS patients. Hall-Patch et al. (2010) developed a 14-page information leaflet for patients with NES based on illness representations, using reviews of the literature, previous information sheets, and the authors' own clinical experience. The majority of patients assessed reported the leaflet as being easy to understand and liked it, and almost all felt that their questions had been answered by the leaflet. Seizure frequency improved in the majority of patients at follow-up. However, the study failed to include a control group, and so it cannot be concluded whether the intervention had any benefit over usual care. The authors perform little analysis of the IPQ-R scores, only assessing illness representations after receiving the intervention. An investigation of how these illness representations changed over time – or how they compared to a group who did not receive the intervention – would have been much more insightful. Despite these limitations, this study suggests the efficacy of illness representation based leaflet interventions to facilitate the diagnosis of MUS, and thus highlights how such a method may be very useful in NCCP patients. Assessing illness representations in NCCP, and how they relate to psychological and physical outcomes, may therefore provide an initial step for developing interventions for this group.

1.1.8 Conclusion

It is clear that those who are diagnosed with NCCP continue to have physical and psychological difficulties. Further research is needed into the psychological outcomes of ED NCCP patients, given the recent shift in care of NCCP patients towards ED rule-out and discharge. Furthermore, a consideration of the theoretical predictors of outcome may be important. The CSM has strong empirical support in relation to explaining outcomes in MUSs, cardiac illness, and NCCP. Evidence has also shown it to be useful as a basis for interventions. While some

previous research has considered links between NCCP and negative illness representations, and between negative illness representations and reassurance in NCCP patients, further research is needed to establish prospective relationships between illness representations and outcomes. Moreover, there is a need for research employing both quantitative and qualitative methods to provide a full, rich picture of the illness representations and experiences of NCCP patients.

CHAPTER 2. A review of the prevalence and correlates of psychological outcomes in Non-Cardiac Chest Pain (NCCP) patients accessing acute medical care

2.1 Abstract

Evidence has shown that around half of patients admitted to the ED with chest pain receive a non-cardiac diagnosis for their pain. These patients have a good prognosis in terms of cardiac problems and mortality; however, they tend to have poor outcomes in terms of psychological morbidity, QoL, further chest pain and re-attendance. Chest pain care is changing within the UK, with a shift to a more ED based, rapid cardiac rule out process. This review therefore sought to determine the psychological outcomes of NCCP patients who access this ED care, and to investigate what factors may predict poorer outcomes. The literature search identified 12 papers reporting 10 studies. The evidence was very heterogeneous, with a variety of outcome measures, study designs, and settings. Generally, NCCP patients had similar levels of anxiety, depression, and QoL to patients who received a cardiac diagnosis for their pain, and worse levels than healthy controls. The levels of anxiety were particularly high in NCCP patients. The evidence on depression was more mixed, and the research on QoL was lacking. A variety of factors were reported as predictors of poorer outcomes, including gender, age, previous psychiatric history and associated symptoms; however, there was little agreement between studies. More evidence is needed to look at poor outcomes in ED NCCP patients, especially looking at predictors of outcomes. It may be beneficial to consider theoretical predictors.

2.2 Introduction

As outlined in the Chapter 1, suffering with NCCP can heavily impact on one's life. Patients have been shown to experience high levels of anxiety and depression, poor QoL, more mental stress and strain, do less physical activity, and have more sleep problems than healthy controls (e.g., Eken et al., 2010; Eslick & Talley, 2008; Jerlock et al., 2008). Moreover, these patients are likely to experience further chest pain, and thus re-attend EDs; possibly due to the fact that many still feel that their chest pain may be caused by a cardiac problem, despite their negative diagnosis (Goodacre et al., 2001; Jerlock et al., 2008). This repeated accessing of health care, despite no apparent physical problem, is likely to have a strong impact on health care costs

overall, in addition to the personal and psychological impact of the chest pain on the suffering patient. It is therefore important to quantify the level of psychological distress in patients who experience acute chest pain, in order to identify the magnitude of the suffering to the patient and also to inform future interventions which may help alleviate the problem of NCCP and therefore reduce healthcare costs.

There is a wealth of research on psychological distress in NCCP patients. The majority of this focuses on patients who have been referred for coronary angiography (e.g., Beitman et al., 1991; Potts & Bass, 1995), or to cardiology outpatient departments (e.g., Cheng, Wong, Lai, Wong, Hu, & Hui, 2003; Dammen et al., 2004; Dammen, Ekeberg, et al., 1999; White et al., 2010; White et al., 2008). However, as discussed in Chapter 1, the nature of chest pain care has been changing. With the rise of more sensitive assessment of cardiac markers (e.g., Troponin-t), patients can undergo testing for cardiac causes of chest pain within the ED. After a period of 2-6 hours, patients can be either admitted (upon positive results), or discharged (upon negative results) (Goodacre & Nicholl, 2004). This therefore results in fewer unnecessary admissions to hospital, as patients can complete the testing procedure and receive a diagnosis within the ED (Goodacre et al., 2007). Chest pain patients (especially NCCP patients) are therefore now much more likely to be investigated and discharged within the ED, and thus may never access cardiology outpatient care or undergo coronary angiography. Patients who are referred for outpatient investigation may be a very different population to chest pain patients investigated in the ED, as they will most likely have already undergone repeated investigations, sometimes even receiving treatment for or a diagnosis of cardiac problems from their GP (Mayou et al., 1994). It is therefore important to consider the evidence regarding psychological outcomes in NCCP, given this recent change in service provision, and only take into account those patients that access this acute care. Moreover, it may be the case that such patients may now be especially susceptible to poor psychological outcomes, as they spend less time engaged in the health care system and feeling 'cared for'. Patients may feel that health professionals within the ED do not have time to consider their worries or queries. In addition to this, recent public information campaigns, such as the British Heart Foundation "Doubt Kills" campaign, have resulted in an increase in attendance at hospital with NCCP (Kainth et al., 2004), due to an emphasis on the importance of the prompt use of emergency services. Therefore, not only are NCCP patients now more likely to receive care solely within the ED, there may also be more

patients with chest pain accessing this acute care. It is therefore important to both quantify and qualify the outcomes of this population of patients.

Existing reviews of the evidence in this area have been brief and unsystematic. For example, Bass and Mayou (2002) provided an overview of chest pain, including NCCP, which was extremely brief, did not consider the methodological quality of the included studies, and included virtually no discussion of psychological outcomes in NCCP. Eslick (2008) produced a review of psychological factors, health care seeking and QoL in NCCP. While the review highlighted poor outcomes in NCCP patients (e.g., poor QoL, high levels of anxiety disorders), it was very brief and made no mention of the search terms used or the databases searched. Moreover, conclusions were drawn from limited evidence, with little investigation into the quality of the evidence. Little quantitative information was given, simply a narrative overview of the findings. The review also made no mention of the distinction between patients accessing outpatient care and those accessing emergency care, which could be important in light of the recent developments in health care.

The present review was conducted to determine the level of psychological distress and QoL in NCCP patients accessing acute care for their chest pain. This will be compared, where possible, to patients who receive a cardiac diagnosis for their chest pain, or healthy controls. Where this is not possible, levels of distress will be compared to standardised values (e.g., cut-off points within standardised questionnaires, published norms). Furthermore, the review investigates the possible risk factors for poor psychological outcomes. Therefore, the review questions are as follows: (i) What are the levels of anxiety, depression, and QoL in patients who attend acute care with chest pain but receive a non-cardiac diagnosis?; (ii) What are the risk factors for poor psychological outcomes following a diagnosis of NCCP?; and (iii) In those studies which use a cardiac or healthy comparison group, how do psychological outcomes following a diagnosis of NCCP compare to outcomes in cardiac patients and healthy controls?

The review will therefore assess whether patients diagnosed with NCCP will experience poor psychological outcomes (in terms of anxiety, depression, and quality of life) in comparison to population norms or healthy controls, and outcomes equal to, or worse than, patients who receive a cardiac diagnosis for their chest pain. Furthermore, the review will seek to identify the correlates of negative psychological outcomes.

2.3 Methods

2.3.1 Search strategy

For this review, a full protocol was developed by the author (RW), through discussion with her PhD supervisors. A copy of this can be found in Appendix 2.1. In order to obtain relevant articles, a literature search was performed during November 2010. Initially, an online database search was carried out, searching Psych Info (via Ovid, 1806 to November 2010), Medline (via Ovid, 1950 to November 2010), and CINAHL (via EBSCO, 1982 to November 2010), using the search terms *chest pain, anxiety, depression, quality of life*, mapped onto MeSH subject terms where possible and combined using Boolean operators. For full details of the search strategy, see Appendix 2.2. The conference proceedings citation index was also searched, via Web of Knowledge, using the free text terms *Non-cardiac chest pain, Non-specific chest pain, Benign chest pain, Chest pain of uncertain etiology, Quality of life, Psych*, Anx* and Depress**, combined using Boolean operators. All papers were assessed for inclusion by RW (using the criteria specified below), by reviewing the title and abstract, and then full text if appropriate. Reference lists of papers that were found to be suitable for inclusion at the full text stage were searched for any further relevant records. Citations of these suitable references were also searched using the Social Sciences Citation Index and the Science Citation Index (both via Web of Knowledge). Two well-published authors in the area of NCCP were contacted via email to ask of any further publications they were aware of. However, no further articles were identified for inclusion.

2.3.2 Study inclusion

Studies obtained through the above search strategies were subjected to a strict screening process using a number of set criteria. Study designs that were included were quantitative questionnaire based studies; including cohort studies, case-control studies, cross-sectional and longitudinal studies. Only studies written in English were included, due to time and resource constraints. However, only a small number were excluded on the basis of language. Regarding the patient populations, only patients who presented to acute care for their chest pain (i.e., EDs) were included. Only studies on patients over the age of 18 (i.e., adult patients) were included. All studies were included, even those which studied a narrow population (e.g., females only) so as to aid comparison between demographic groups where possible. The

patients studied must have received a diagnosis of non-cardiac or non-specific chest pain, or chest pain of uncertain aetiology, from a health professional. Studies incorporating a comparison group (e.g., patients who received a cardiac diagnosis for their chest pain, healthy controls) were included, but the review was not restricted to this type of study so as not to limit the breadth of studies included. The patient outcomes of interest were anxiety, depression, and QoL, as these are easily quantifiable by self-report measures (e.g., Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983, SF-12, (Ware, Kosinski, & Keller, 1996) and have shown to be impaired in NCCP patients in other research (e.g., Goodacre et al., 2001; Potts & Bass, 1995; White et al., 2008). Both cross-sectional and longitudinal assessments of these outcomes were included, so as not to exclude any important findings or limit the review.

2.3.3 Data extraction

The quality of each of the studies was assessed using the appropriate Critical Appraisal Skills Programme (CASP) checklist for the study design (Critical Appraisal Skills Programme, 2004; Public Health Resource Unit, 2006). Data was then extracted from each study by RW using a standardised extraction form, which can be found in Appendix 2.3. Data extracted included the population studied, any comparison groups, inclusion and exclusion criteria, recruitment procedures (and rates), baseline demographics, sample size, procedures used to diagnose/define NCCP, outcomes assessed, measurement tools used, what follow-up assessments were taken, statistical analysis techniques, details on attrition rates, the results for each outcome, and any correlates of poor outcomes. All studies were also reviewed independently by RW's first supervisor (PN) to ensure accuracy of extraction, and any disagreements were resolved through discussion.

2.3.4 Data synthesis

Due to the variation between the studies in study type (e.g., longitudinal vs. cross sectional), outcomes assessed and outcome measures, meta-analysis was considered inappropriate for this review. The results were therefore compared and synthesised narratively. Two studies (Fagring et al., 2008; Srinivasan & Joseph, 2004) reported data split by demographic or diagnostic group (e.g., by gender, or by diagnosis of panic disorder). Where this was the case, overall means were calculated, where possible, for NCCP and comparison group patients, in order to allow for comparison between studies.

2.4 Results

2.4.1 *Study selection*

The flow diagram in Figure 2.1 shows how studies were identified and selected/excluded. Overall, 772 records were identified through the searching of online databases, and a further 43 were located by searching the reference lists and citations of the articles identified through the database searching. After screening the records at title and abstract level, 87 papers remained. The primary reasons for exclusion at title and abstract screening stage were that papers were not directly related to the topic of psychological distress; for example, papers addressing physical aspects of NCCP such as physical outcomes and assessments to rule out

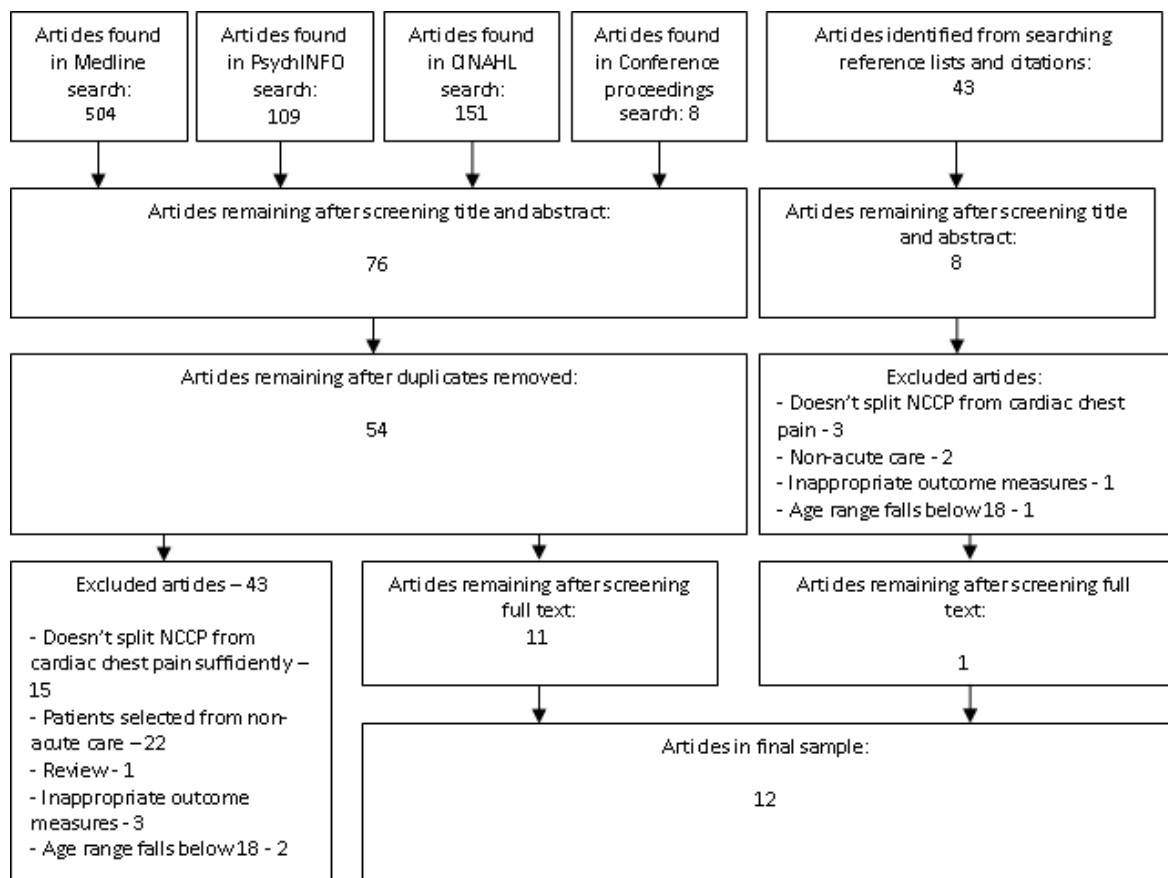


Figure 2.1 Flow diagram of study selection process

cardiac problems (e.g., alternative cardiac assays). After removing duplicates, 62 records remained. After screening the full text of the records, 12 papers reporting 10 studies remained. Jerlock et al. (2008) reported additional data on the same sample as that reported by Fagring

et al. (2008), and so the main data were drawn from Fagring et al. (2008), with significance values for the QoL findings drawn from Jerlock et al. (2008), as these were not reported in the former paper. Kuijpers, Denollet, Wellens, Crijns and Honig (2007) reported additional data on a sample which overlapped with the sample reported by Kuijpers et al. (2003), as they were recruited at a similar time but the recruitment period for Kuijpers et al. (2007) was slightly longer. The data from both papers therefore couldn't be included, as the samples were similar but not identical. The decision was made to include the data on the HADS scores from Kuijpers et al. (2003) as the sample size was larger. The main reasons for exclusion of articles were not splitting NCCP from cardiac causes of chest pain (e.g., considering all chest pain patients together, N=18), studies of patients from non-acute care (e.g., cardiology outpatient clinics, N=24), the age range of patients falling below 18 (N=3), and inappropriate outcomes measures (i.e., neither anxiety, depression, nor quality of life assessed, N=4). A summary of the included studies can be found in Table 2.1. A list of the studies excluded at the full text stage (with brief reasons) can be found in Appendix 2.4.

2.4.2 Quality of studies

All studies were assessed using the CASP checklist for either case-control studies (Public Health Resource Unit, 2006) or cohort studies (Critical Appraisal Skills Programme, 2004), as appropriate. The overall quality of studies was acceptable to high. The main issue with quality across the studies was due to a lack of reporting, particularly about the recruitment of participants. Only 4 studies (Demiryoguran et al., 2006; Kuijpers et al., 2003; Mayou & Thompson, 2002; Srinivasan & Joseph, 2004) reported sufficient information to make a judgement regarding the quality of recruitment, reporting the number of participants excluded and the reasons. Overall, the grounds for exclusion given were reasonable, suggesting that all suitable participants were included in these studies. One study (Fagring et al., 2008) provided sufficient information; however, they reported that participants were only recruited during weekday office hours, and a number of participants were not invited due to 'administrative' reasons. Therefore, all suitable participants may not have been included. However, this may only be the case in this study due to the transparency of the authors' reporting. Similar issues may have affected other studies, but they may not have been reported. Four studies (Aikens, Michael, Levin, Myers, et al., 1999; Eken et al., 2010; Eslick & Talley, 2008; Shahid, Rehmani, &

Khan, 2004; Soares-Filho et al., 2009) did not reported sufficient information for a judgement to be made on the quality of recruitment.

There was considerable variety in the methodology used across the papers. For example, only 2 studies (Eslick & Talley, 2008; Mayou & Thompson, 2002) employed longitudinal designs. Five studies reported data on both NCCP patients and a comparison group of CCP patients (Eslick & Talley, 2008; Mayou & Thompson, 2002; Srinivasan & Joseph, 2004) and one study reported on a population-based control sample as a comparison to NCCP (Fagring et al., 2008; Jerlock et al., 2008). One study (Soares-Filho et al., 2009) reported data on patients with chest pain of determined cause (including cardiac causes, but also causes such as pleuritic pain, pneumonia, tonsillitis and anxiety) in comparison to patients with chest pain of 'indetermined cause' (used here as the NCCP group). The remaining studies only reported data on NCCP patients, therefore restricting any meaningful comparisons and only indicating the levels of psychological outcomes in NCCP alone. The studies with the most high quality design were therefore Mayou and Thompson (2002) and Eslick and Talley (2008), reporting comparative outcomes in NCCP and CCP over time. Sample sizes across studies varied greatly, with the smallest being 50 (Shahid et al., 2004) and the largest being 1300 (Fagring et al., 2008).

Table 2.1 Summary of studies included in the review

Authors (date) and country	Samples	Baseline characteristics	NCCP diagnostic tests
Aikens et al. (1999) USA	NCCP = 80	46% male Mean age= 50.3 (SD=13.3)	12-23 hours of intensive observation and evaluation, including cardiac monitoring, enzyme analysis, toxicology screen, and stress echocardiography. 7% also underwent cardiac catheterisation.
Demiryoguran et al. (2006) Turkey	NCCP = 157	43.3% male Mean age=41.6 (SD=11.7, range 18-64)	ECGs, chest X-ray, followed up in ED for 6-8 hours. Doesn't explicitly state what tests done but does refer to cardiac markers. Further investigation done for other non-cardiac causes when necessary.
Eken et al. (2010) Turkey	NCCP = 194 CCP = 130	67% male Mean age=50.5 (SD=14 years)	Serial ECGs and cardiac enzymes for 6 hours after symptom onset.
Eslick & Talley (2008) Australia	NCCP = 126 CCP = 71	61.4% male Mean age=58 (SD=14) NCCP: 54.0% male CCP: 75.6% male	X-ray, troponin and CKMB, BP, temp, resting ECG and exercise stress test. Judgement made by physician.
Fagring et al. (2008), Jerlock et al. (2008) Sweden	NCCP = 231 Population-based controls = 1069	NCCP: 55% male, mean age=46.6(SD=11.5) Controls: 46% male, mean age=47.9(SD=12.3)	Patients were assessed and treated 'according to the routines of the ED'.
Kuijpers et al. (2003) The Netherlands	NCCP = 884	Data not available on full sample. Patients scoring above 8 on HADS for anxiety OR depression=53.8% male, mean age=55.8(SD=13.03)	Full history, physical exam, and ECG for all patients. Cardiac enzymes and troponin, exercise stress test, echocardiogram and X-ray as deemed appropriate according to standard practice.
Mayou & Thompson (2002) UK	NCCP = 107 CCP = 218	NCCP: 63% male, mean age=53.07(SD=12.2) CCP: 65% male, mean age=65.46(SD=9.3)	IHD excluded, according to guidelines. No information on this.
Shahid et al. (2004) Pakistan	NCCP = 50	64% male. No data on age.	Physical exam and ECG.
Soares-Filho et al. (2009) Brazil	Pain of indetermined cause (NCCP) = 71 Pain of determined cause = 59	58.5% male, mean age 61.2(SD=13.2, range 31-87) NCCP:53.5% male, mean age=61.9(SD=12.8) Determined cause: 64.4% male, mean age 60.4 (SD=13.6)	Upon admission and every 3 hours after CKMB and troponin-i were assessed, an 18 lead ECG on arrival and 12 lead ECG every 3 hours after, most patients underwent an echocardiogram. Where no MI or rest ischemia found, exercise stress test, or myocardial scintigraphy was performed.
Srinivasan & Joseph (2004) India	NCCP = 109 CCP = 206	NCCP: 55.0% male, mean age=39.68 CCP: 78.6% male, mean age 56.5	CAD diagnosed as either documented MI, coronary bypass surgery, angioplasty, coronary angiogram indicative of significant stenosis, abnormality on a treadmill test. NCCP is therefore absence of these.

The majority of studies used well-established and standardized measures for assessing outcomes, with Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) and the SF-36 (Ware et al., 1993) being the most widely used measures. One study used a less well established measure of anxiety and depression (Aga Kahn University Anxiety and Depression Scale, Shahid et al., 2004), and gave no evidence or references of previous use or validation of this measure. A brief search of the literature indicated that this measure has been used with similar populations to that in Shahid et al. (2004) - however, this was not reported in the original paper. Some studies controlled for confounding factors in their analysis (Eken et al., 2010; Eslick & Talley, 2008; Fagring et al., 2008; Mayou & Thompson, 2002; Srinivasan & Joseph, 2004), although some did not, mainly reporting only means and standard deviations or percentages in their results (Aikens, Michael, Levin, Myers, et al., 1999; Demiryoguran et al., 2006; Kuijpers et al., 2003; Shahid et al., 2004; Soares-Filho et al., 2009). There was also some variety in the procedures described for excluding cardiac causes of chest pain (see Table 2.1 for a full summary). Two studies (Fagring et al., 2008; Mayou & Thompson, 2002) did not provide sufficient information on the testing procedures, and one study (Shahid et al., 2004) only reported using physical examination and ECG to rule out cardiac causes. The remaining studies appeared to use sufficiently thorough techniques to rule out cardiac causes of chest pain.

2.4.3 Prevalence of psychological outcomes

2.4.3.1 Anxiety

The summaries of the results for each study can be found in Table 2.2.. Nine studies assessed anxiety (Demiryoguran et al., 2006; Eken et al., 2010; Eslick & Talley, 2008; Fagring et al., 2008; Kuijpers et al., 2003; Mayou & Thompson, 2002; Shahid et al., 2004; Soares-Filho et al., 2009; Srinivasan & Joseph, 2004), of which seven used the HADS (Zigmond & Snaith, 1983). NCCP patients were found to have similar anxiety scores to CCP patients (Eken et al., 2010; Eslick & Talley, 2008; Mayou & Thompson, 2002), but higher levels of anxiety than patients with a determined cause (be it cardiac or another complaint such as pneumonia) (Soares-Filho et al., 2009) and healthy controls (Fagring et al., 2008; Soares-Filho et al., 2009). Likewise, the percentage of respondents scoring above pre-defined cut-off scores for probable anxiety was similar for NCCP and CCP patients (Eken et al., 2010; Eslick & Talley, 2008), but higher among NCCP patients than those with a determined cause for their chest pain (Soares-Filho et al., 2009) and healthy controls (Fagring et al., 2008). The mean baseline anxiety scores for NCCP

patients tended to be just below the cut-off for mild anxiety; nonetheless, between 21.0% and 53.5% of NCCP patients were categorised as probably having anxiety, although it should be noted that different cut-off scores were used across studies. Two studies also reported that 58.0% and 53.9% of NCCP patients scored above threshold on the HADS for *either* anxiety or depression (Kuijpers et al., 2003; Shahid et al., 2004). The one study that charted changes in anxiety in NCCP patients over time reported that the percentage of those with probable anxiety decreased from 21.0% to 12.0% from baseline to two-year follow-up, but increased to 19.0% at four-year follow-up (Eslick & Talley, 2008).

Overall, the results indicate that NCCP patients experience high levels of anxiety, which were largely comparable to that in CCP patients, but higher than healthy controls. There also seems to be a difference between those who receive any diagnosis for their chest pain (be it cardiac or another complaint, such as pneumonia), compared to those who receive no diagnosis for their chest pain (pain of indetermined cause, or uncertain aetiology), with the latter being more likely to suffer from anxiety.

2.4.3.2 Depression

Nine studies assessed depression (Aikens, Michael, Levin, Myers, et al., 1999; Eken et al., 2010; Eslick & Talley, 2008; Fagring et al., 2008; Kuijpers et al., 2003; Mayou & Thompson, 2002; Shahid et al., 2004; Soares-Filho et al., 2009; Srinivasan & Joseph, 2004), six of which used the HADS. NCCP patients were found to have similar (Eken et al., 2010) or lower (Mayou & Thompson, 2002) depression scores than CCP patients, and similar depression scores to patients with a determined cause for their chest pain (Soares-Filho et al., 2009). Likewise, the percentage of NCCP patients scoring above pre-defined cut-off scores for probable depression was similar to CCP patients (Eken et al., 2010; Eslick & Talley, 2008) and those with a determined cause for their chest pain (Soares-Filho et al., 2009), although more NCCP patients were categorised as having probable depression than healthy controls (Fagring et al., 2008). The mean depression scores for NCCP patients were typically below the cut-off for mild depression; nonetheless, between 9.0% and 40.0% of NCCP patients were categorised as probably having depression, although it should be noted that different cut-off scores were used across studies. One study charted changes in depression in NCCP patients over time, reporting that the percentage of those with probable depression decreased from 9.0% to 7.0% to 2.0% from baseline to two- and four-year follow-up (Eslick & Talley, 2008).

The results for depression are more mixed than those for anxiety. The level of depression in NCCP is high in some studies; however, other studies do not report excess levels of depression. This may be due to the different scales used to assess depression, or the different cut-off points used within these scales. It seems that NCCP patients have at least similar levels of depression to CCP patients, and this may be worse than the levels of depression in the general population. The levels of depression in NCCP patients (and CCP) may diminish over time after diagnosis.

Table 2.2 Prevalence of psychological outcomes

Authors (date) and country	Measures	Follow-up assessments	Anxiety results	Depression results	QoL results
Aikens et al. (1999) USA	BDI	None		NCCP mean on BDI=8.0 (SD=8.4) Cognitive-affective subscale=3.9 (SD=3.4) Somatic subscale=4.1 (SD=5.6)	
Demiryoguran et al. (2006) Turkey	HADS-A	None	NCCP mean=7.9 (SD=3.7) 31.2% scored ≥10		
Eken et al. (2010) Turkey	HADS	None	NCCP median=8, 38.1% scored ≥10 CCP median=8, 40% scored ≥10 (p=.737)	NCCP median=7, 52.1% scored ≥7 CCP median=7, 52.3% scored ≥7 (p=.965)	
Eslick & Talley (2008) Australia	HADS SF-36	2 years 4 years	Baseline: 21% in NCCP (95%CI:16-28%), 17% in CCP (95%CI:9-28%) 2 years: NCCP 12% (95%CI:6-21%) CCP 13% (95%CI:4-27%) 4 years: NCCP 19% (95%CI:10-30%) CCP 12% (95%CI:3-31%)	Baseline: 9% in NCCP (95%CI:5-13%) 7% in CCP (95%CI:2-16%) 2 years: NCCP 7% (95%CI:2-14%) CCP 5% (95%CI:1-17%) 4 years: NCCP 2% (95%CI:1-8%) CCP 4% (95%CI:1-20%)	NCCP patients: significant improvement in QoL between baseline and 2 years in role physical (Baseline mean =33.68, 2 year mean=52.47, p<.001), pain (Baseline mean=59.11, 2 year mean =69.25, p=.008), vitality (Baseline mean =45.37, 2 year mean =53.05, p=.02), social functioning (Baseline mean =61.24, 2 year mean =72.35, p=.001) and role emotional (Baseline mean =65.19, 2 year mean =77.38, p=.03). No significant differences between 2 and 4 years. CCP patients: significant improvement in QoL between baseline and 2 years in role physical (Baseline mean =25.67, 2 year mean =47.56, p=.002), pain index (Baseline mean =55.55, 2 year mean= 73.76, p=.003), social functioning (Baseline mean=56.53, 2 year mean=73.87, p=.002) and role emotional (Baseline mean=62.96, 2 year mean=81.37, p=.04). No significant differences between 2 and 4 years.

Fagring et al. (2008), Jerlock et al. (2008) Sweden	Zung depression scale Trait anxiety inventory SF-36	None	NCCP patients, 39.39% scored ≥ 43 Controls, 24.13% scored ≥ 43 Significantly more anxiety in male (Adjusted OR2.2, 95%CI:1.4-3.5) and female (Adjusted OR1.8, 95%CI1.1-2.8) NCCP patients.	NCCP patients, 40.26% scored ≥ 39 Controls, 23.01% scored ≥ 39 Significantly more depression in male (Adjusted OR2.3, 95%CI:1.4-3.6) and female (Adjusted OR2.5, 95%CI:1.6-3.9) NCCP patients.	NCCP patients significantly more likely to receive low scores on SF-36 than controls on all subscales - all $p < .0001$, except general health in all participants ($p < .01$), general health in men ($p = .006$), physical functioning in men ($p = .0001$), and role emotional in men ($p = .001$).
Kuijpers et al. (2003) The Netherlands	HADS	None	53.9% scored ≥ 8 for either anxiety or depression on HADS	53.9% scored ≥ 8 for either anxiety or depression on HADS	
Mayou & Thompson (2002) UK	HADS SF-36	3 months 1 year	NCCP mean=7.82 (SD=4.6) CCP mean=7.95 (SD=5.1) ($p = .857$) Figures not reported for follow-up assessments; however, 'no differences' were reported	NCCP mean=4.28 (SD=3.9) CCP mean=5.36 (SD=3.9) ($p = .045$) Figures not reported for follow-up assessments; however, 'no differences' were reported	On admission, NCCP patients had better QoL than CCP patients in physical function ($p < .001$), physical role limitation ($p = .002$), social functioning ($p = .021$), and pain ($p = .003$). CCP patients had worse QoL on specific questions on everyday activities at 3 and 12 months (no figures given).
Shahid et al. (2004) Pakistan	Aga Kahn University Anxiety and Depression Scale	None	58% scored above cut-off of 19	58% scored above the cut-off of 19	
Soares-Filho et al. (2009) Brazil	HADS	None	NCCP mean=8.20 (SD=4.5) PDC mean=6.29 (SD=3.96) ($p < .011$) NCCP 53.5% scored ≥ 8 PDC 33.9% scored ≥ 8 ($p = .025$)	NCCP mean=4.70 (SD=3.82) PDC mean=4.86 (SD=4.07) ($p = .819$) NCCP 25.4% scored ≥ 8 PDC 30.5% scored ≥ 8 ($p = .513$)	
Srinivasan & Joseph (2004) India	HADS	None	NCCP mean=6.13 CCP mean=4.16.	NCCP mean=4.10 CCP mean=2.93	

Table 2.3 Correlates of poor psychological outcomes

Authors (date) and country	Measures	Significant correlates of poor psychological outcomes
Aikens et al. (1999) USA	BDI	None reported.
Demiryoguran et al. (2006) Turkey	HADS-A	In NCCP patients: female gender ($p=.037$), associated symptoms ($p=.004$), previous referral with the same complaint ($p<.001$), family history of psychiatric illness ($p=.011$) were associated with an anxiety score of ≥ 10 .
Eken et al. (2010) Turkey	HADS	All CP patients: frequency of anxiety and depression higher in diabetic patients ($p=.027$). Women had a higher frequency of anxiety and depression ($p=.006$).
Eslick & Talley (2008) Australia	HADS SF-36	All CP patients: increased chest pain severity correlated with increased depression ($p=.03$) and with decreased mental health ($p<.001$) and vitality ($p<.001$) of QoL. Increased chest pain frequency correlated with decreased general health of QoL ($p<.001$). In the regression model, pain severity was associated with lower QoL mental health score ($p<.001$) and frequency with lower QoL general health scores ($p<.001$)
Fagring et al. (2008), Jerlock et al. (2008) Sweden	Zung depression scale Trait anxiety inventory SF-36	None reported.
Kuijpers et al. (2003) The Netherlands	HADS	In comparison to a subset of participants who did not score above the cut-off ($N=78$, not clear how these were identified), those who scored above the cut-off were significantly younger ($p=.001$), less likely to have received a diagnosis of atypical thoracic complaints and more likely to have received a hyperventilation diagnosis ($p=.03$), and more likely to have received a panic disorder diagnosis ($p=.04$).
Mayou & Thompson (2002) UK	HADS SF-36	None reported
Shahid et al. (2004) Pakistan	Aga Kahn University Anxiety and Depression Scale	None reported.
Soares-Filho et al. (2009) Brazil	HADS	None reported.
Srinivasan & Joseph (2004) India	HADS	Among those with a psychiatric disorder, NCCP patients had higher anxiety and depression scores than CCP patients ($p<.001$)

2.4.3.3 *Quality of Life*

Only three studies assessed QoL (Eslick & Talley, 2008; Fagring et al., 2008; Mayou & Thompson, 2002). NCCP patients were found to have better QoL than CCP patients in various domains (Mayou & Thompson, 2002) but worse QoL than healthy controls (Fagring et al., 2008). There was some evidence to suggest that QoL improves two years after diagnosis, but then remains stable over the longer-term (up to 4 years) (Eslick & Talley, 2008).

2.4.4 *Predictors of poor outcome in chest pain patients*

A summary of the predictors of outcome identified in each study can be found in Table 2.3. Only three studies reported variables which may be associated with poor psychological outcomes in NCCP patients alone (Demiryoguran et al., 2006; Kuijpers et al., 2003; Srinivasan & Joseph, 2004). Demiryoguran et al. (2006) reported that female gender, the presence of associated symptoms, previous referral with the same complaint, family history of psychiatric illness, and certain symptoms (such as fear of dying, light headedness, and chills or hot flushes) were associated with elevated levels of anxiety. Srinivasan and Joseph (2004) found that NCCP patients were more likely to experience anxiety and depression if they also had co-morbid panic disorder. Kuijpers et al. (2003) found that younger patients were more likely to score above the HADS cut-off for anxiety or depression. In addition, severe chest pain, diabetes and gender (female) have been found to be associated with poorer psychological outcomes in studies that have combined NCCP and CCP samples (Eken et al., 2010; Eslick & Talley, 2008).

2.5 Discussion

This review quantified the levels, and some correlates, of anxiety, depression, and QoL in ED NCCP patients. Generally, psychological outcomes in this patient group appeared to be worse than in healthy controls, and comparable to CCP patients. Correlates of poor outcomes were varied, but included younger age, previous psychiatric history, and female gender. It is clear that the literature on psychological outcomes in NCCP patients attending emergency care is somewhat lacking in comparison to the literature on psychological outcomes in NCCP patients from outpatient or non-acute care. This is probably due to the recent rise of rapid rule-out protocols in acute care (Taylor et al., 2002), meaning that chest pain patients are more likely to be investigated and discharged in acute care rather than accessing outpatient services. The nature of care, and thus the proportion of chest pain patients engaging in different stages of

the healthcare pathway, has therefore changed quite recently. However, there is still a reasonable evidence base, with 10 studies eligible for review. This evidence was, however, extremely heterogeneous, with a variety of study designs and outcomes assessed. The heterogeneity of the studies may be due to the broad inclusion criteria used for selection in these domains; however, it was decided to keep the criteria broad so as not to exclude important, insightful data, and to cover more than one important outcome. While it is important to consider the level of psychological problems in patients (i.e., levels of anxiety and depression), it is also important to ensure that they are not suffering in any domain of life as a result of their illness (i.e., by assessing QoL).

2.5.1 Levels of psychological outcomes

The data on QoL were especially limited, with only 3 studies reporting data on this outcome. Overall, QoL in NCCP patients appears to be similar to, or slightly better than, that of CCP patients, but worse than healthy controls. This is clearly therefore problematic – NCCP patients do not have any serious physical problem, so their QoL should be comparable to the general population. We may expect the QoL of CCP patients to be low, as they have been diagnosed with a cardiac problem, be it MI or angina; both of which have a significant impact on physical health and often warrant major lifestyle changes. Quality of life was shown to be worse in patients with more severe or more frequent pain, and improved over time. It may be the case that it is merely the pain itself that impacts on QoL, through disturbing general day to day activities. It may therefore be difficult to intervene to improve QoL while the patient is still experiencing pain. However, this data was drawn from self-report measures of pain frequency/severity. The way a patient views their pain could influence QoL. If NCCP patients can be encouraged to view their pain as less serious or limiting, QoL may be improved, consistent with the CSM of illness representations (Leventhal et al., 1980). QoL may also be low in this population due to the high level of psychological distress, evidenced within this review. Working to alleviate this distress may therefore subsequently have a positive impact on QoL.

The number of studies investigating anxiety in NCCP was much higher than those studying QoL. The evidence on anxiety is stronger, partly because of the increased number of studies and partly because the majority of the evidence suggest a similar pattern of results. As with QoL, evidence indicates that anxiety levels are high in NCCP patients, showing similar levels to CCP patients, and higher levels than healthy controls. This seems to improve over the 4 years

following diagnosis. This relationship raises the question of cause and effect, as it may be the case that the high levels of anxiety are actually causing the chest pain. A number of studies which have considered anxiety in chest pain patients have suggested that NCCP may be actually caused by anxiety (e.g., Ho, Kang, Yeo, & Ng, 1998; Jonsbu et al., 2009), or anxiety disorders such as panic disorder (e.g., Beitman et al., 1987). Furthermore, one study in this review showed that outcomes were worse in NCCP patients with panic disorder, suggesting that panic disorder may be a causal factor for NCCP (Srinivasan & Joseph, 2004). However, outcomes were also poor in NCCP patients without panic disorder, suggesting that NCCP cannot always be explained by such disorders, and poor outcomes can occur even in the absence of such disorders. Moreover, in the one study which compared patients with pain of indetermined cause to patients with pain of determined cause, the former group still displayed higher levels of anxiety, despite some patients in the latter group being diagnosed with anxiety related causes of their chest pain. Zachariae, Melchiorsen, Frobert, Bjerring and Bagger (2001) suggest that the high levels of psychological morbidity in *both* NCCP and CCP suggests that such outcomes are related to illness or chest pain in general, and are thus not the cause of NCCP. The evidence from this review suggests the same. Therefore NCCP patients may have high levels of anxiety as a result of their NCCP, rather than their NCCP being caused by anxiety. The anxiety, however, may serve to worsen the patients' chest pain, creating a 'vicious cycle', whereby neither the anxiety nor the pain is improved. It is therefore important to target anxiety with psychological intervention, to break this cycle and improve patient outcomes.

In the one study that compared anxiety in NCCP patients and healthy controls, anxiety levels were higher in NCCP patients than healthy controls; however, this relationship was no longer significant when anxiety was included in a model with various other demographic variables, suggesting that other factors may also be important in considering the differences between NCCP patients and healthy controls. This therefore highlights the importance of considering a range of predictors of psychological outcomes.

The evidence on depression is slightly more mixed, mainly due to the variation in measures used. Levels of depression in NCCP patients were similar to levels in CCP patients; one study reported higher levels of depression in CCP than NCCP. It is difficult to determine whether levels of depression in NCCP patients are excessively high. The data from the HADS indicates that the percentage of patients scoring above cut-off is very high (as high as 52.1%); however,

findings from other measures suggest that levels may be within normal range; Aikens et al. (1999) used the Beck Depression Inventory (Beck & Steer, 1987) to assess depression, and reported that the BDI scores were within the normal range. However, they did not report what this normal range is. A search of the literature indicated that the mean scores given for the subscales do fall within the normal range which demonstrates low risk for depression; however, the mean score (8) for the whole scale found by Aikens et al. falls within the 'medium' range (Beck, 1967).

While the one study comparing NCCP patients to healthy controls found a significant difference in depression levels, this was only significant in the multivariate model for females. It may once again be the case that only NCCP patients with certain risk factors may be more at risk of depression. Depression in general tends to be more prevalent in females than males (Scheibe, Preuschhof, Cristi, & Bagby, 2003), and this may therefore also be the case for NCCP. Females may therefore be a high risk group for poor psychological outcomes of NCCP.

One study which may be seen as contradictory to most of the evidence on anxiety and depression is that by Eslick and Talley (2008). The rates of anxiety and depression reported in this study are considerably lower than in the rest of the evidence in this review. This is most likely due to the cut-off point used to classify probable anxiety and depression. This varied between studies, usually with good justification for the cut-off used. As Eslick and Talley don't report or justify the cut-off used, it is difficult to know whether it is unusually high. Moreover, mean values are only reported for all participants (rather than NCCP and CCP separately), so it is difficult to gather information from this. However, the mean values given are comparable to those found in the other studies. This suggests that the low levels of anxiety and depression may be due to a high cut-off value. However, as there are no other studies in this review from within the same setting (i.e., the same country with the same healthcare system), it is difficult to confirm this.

2.5.2 Predictors of outcome

The evidence on risk factors for poorer outcomes in NCCP patients is unclear, as different studies reported a number of different factors which may be important. Gender seems to be the most prominent factor, with females being more likely to suffer (especially with depression); however, only two studies reported this. Only one study reported a significant

effect of age, showing that patients who scored above the HADS cut-off were more likely to be younger. This lack of agreement about important risk factors may simply be due to a lack of investigation or reporting of such factors. However, it may be the case that different factors need to be considered – theoretical or psychological factors, for example. One study, which could not be included in the review due to an overlap in sample with another study (Kuijpers et al., 2007), found that NCCP patients who scored above the HADS cut-off for either anxiety or depression were more likely to have a Type D personality, defined by Kuijpers et al. (2007) as ‘the tendency to experience negative emotions and the tendency to inhibit self-expression in social interactions’ (p.274). This suggests that psychological factors may have a strong influence on outcomes in NCCP patients. As outlined in Chapter 1, the CSM of illness representations (Leventhal et al., 1980) may play a key role in explaining and predicting outcomes in NCCP patients. Research has shown illness representations to be important in NCCP, with NCCP patients reporting worse illness representations than CCP patients (Robertson et al., 2008). However, further evidence is needed to consider how illness representations may impact on outcomes such as anxiety, depression and QoL over time in NCCP patients.

2.5.3 Further research

The evidence from this review supports that of previous research into NCCP patients, largely from outpatient care, which has demonstrated that NCCP patients largely show similar levels of psychiatric disorder to CCP patients (e.g., Dammen et al., 2004; Zachariae et al., 2001), with some studies having demonstrated that such patients are more likely to suffer from psychological problems than CCP patients (e.g., Karlson, Wiklund, Bengston, & Herlitz, 1994; Kisely, Creed, & Cotter, 1992). It may be the case that the increased engagement in the health care system of such patients (in comparison to patients who only access ED care and are discharged from there) serves to increase psychological morbidity. However, the current review still shows that ED NCCP patients have high levels of psychological morbidity, in addition to poor QoL, and therefore need to be investigated and considered for intervention. More evidence is needed, however, on ED NCCP patients who undergo a CPOU-like protocol. Goodacre and Nicholl (2004) demonstrated that CPOU care was associated with improved QoL and reduced symptoms of depression in comparison to patient who underwent routine care. Moreover, Nucifora et al. (2009) found that an accelerated diagnostic protocol (similar to CPOU

care) was associated with improved QoL in chest pain patients at low risk of cardiac problems. It is therefore important to consider patients who have undergone this sort of care independently of other acute chest pain patients. The settings within this review were too varied (and often lacking in detail) to draw any direct conclusions about the impact of such care pathways.

2.5.4 Limitations

Limitations regarding the individual studies are discussed within the quality assessment within the findings section. There are, however, also certain limitations within the review process which must be taken into account when considering its conclusions. Firstly, due to time and resources, only one reviewer performed the literature search and screened papers for inclusion. This increases the risk of bias within the review. However, strict criteria for screening and inclusion were adhered to in order to reduce this risk. Secondly, only papers written in English were included, thus potentially limiting the generalisability of the findings. However, there were only a very small number of papers in other languages found during the search process, and these were excluded at abstract level, so this is unlikely to bias the review. Lastly, there was a lack of grey or unpublished literature in the review, suggesting that the results may be subject to publication bias. However, an effort was made to include conference abstracts, and a number of dissertation abstracts were identified during the search process; however, none of these were suitable for inclusion. The diversity in settings across the studies (the 10 studies were conducted in 9 different countries) may indicate that the results are not comparable, as health care systems may vary greatly between countries. However, the fact that the results seem relatively consistent across studies indicates that the impact of NCCP on psychological outcomes may be extremely persistent, even across different settings and cultures.

2.5.5 Conclusions

This review shows that there is some existing literature on psychological outcomes in NCCP patients from emergency care; however, it is currently still limited in its lack of longitudinal designs and detailed investigation of correlates of outcomes. NCCP patients show similar outcomes to patients who receive a cardiac diagnosis for their chest pain, and worse outcomes than healthy patients who have not experienced chest pain. This group are therefore an

important target for intervention, as we would expect people with no extreme physical problem to experience reasonably good outcomes, and the increased suffering could lead to increased costs through repeat attendance at EDs. The poor outcomes in CCP patients are not of direct concern for intervention, as due to the nature of their physical problem they will most likely to remain under hospital care, and thus be monitored for any excessively poor outcomes. The current evidence base is lacking in a clear consideration of what factors may put NCCP patients at risk for poorer outcomes, and a move to a more theoretical basis for this may be appropriate. Moreover, patients who receive care and diagnosis in the ED should be studied, given the rise in this care for NCCP patients, and the general lack of evidence in this area in comparison to outpatient care.

CHAPTER 3. Study 1: The influence of illness representations on psychological outcomes, chest pain, and service use in Emergency Department Non-Cardiac Chest Pain patients

3.1 Abstract

The study reported in this chapter set out to quantify psychological outcomes in a sample of ED NCCP patients, and to assess whether the CSM of illness representations could explain psychological outcomes and continued chest pain in this group. A sample of ED NCCP patients were recruited from a CPOU, and completed measures of illness representations, anxiety, depression, QoL and cardiac worries at baseline ($N=200$), and one month ($N=138$) and three months ($N=110$) later. Levels of anxiety were found to be high, and mental QoL was impaired. Illness representations explained significant proportions of the variance in all of the outcomes variables at baseline and one month, and in anxiety, mental QoL and cardiac worries at three months. Illness representations largely did not explain variance in the outcome measures when controlling for baseline levels of distress. The most important dimensions for explaining poor psychological outcomes were a stronger belief in psychological causes of one's pain, a perception of a more chronic timeline, and less belief in personal control. Around 40% of participants experienced persistent chest pain. Increased baseline anxiety and depression, decreased baseline QoL, increased baseline cardiac worries, a stronger illness identity and the perception of a more chronic timeline were all associated with increased chest pain frequency at follow-up. Of the illness representation dimensions, perceived causes appear to be more important in NCCP patients than has been found in other patient groups. Potential interventions should primarily target psychological distress (particularly anxiety), and also the illness representation dimensions of timeline and personal control.

3.2 Introduction

Chapters 1 and 2 reviewed evidence suggesting that NCCP patients experience high levels of psychological distress, with persistent pain often interfering with their day to day lives. The majority of previous evidence (e.g., Beitman et al., 1991; Potts & Bass, 1995; White et al., 2008) has focussed largely on patients who attended coronary angiography or cardiology outpatient departments. Such patients are much more likely to be suffering with chronic, rather than

acute, chest pain as the pathway to reach this level of care can often be lengthy. In comparison, patients who access acute (emergency) care for their chest pain may now undergo testing and be discharged with a diagnosis much more quickly, due to the rise in more sensitive blood tests and the advent of dedicated ED CPOUs. It is therefore important to consider outcomes specifically in this acute emergency sample. The systematic review in Chapter 2 (see also Webster, Norman, Goodacre, & Thompson, 2012) demonstrated that there are a small number of existing studies assessing psychological outcomes in NCCP patients who accessed emergency care. These studies suggested that those with NCCP experience similar levels of anxiety, depression and QoL to patients with CCP, and worse outcomes than healthy controls. However, the evidence was extremely heterogeneous, and the review identified the need for more longitudinal studies using well-established measures of psychological distress and well-being; and also looking at theoretical predictors of outcomes.

If effective interventions are to be developed for this population, it is important to identify factors which predict (or may be risk factors for) poorer psychological outcomes. While some previous studies identified risk factors such as female gender (Demiryoguran et al., 2006; Eken et al., 2010), younger age (Kuijpers et al., 2003), and associated symptoms (Demiryoguran et al., 2006), none of the studies reviewed in Chapter 2 identified any theoretical predictors of poor psychological outcomes. As suggested in Chapters 1 and 2, the CSM of illness representations (Leventhal et al., 1980) may provide a suitable theoretical model for looking at predictors of outcome in this group. The model proposes that people form a representation of their illness, based around the dimensions of identity, cause, consequences, timeline (acute/chronic and cyclical), control (personal and treatment), coherence, and emotional representations. These representations have been found to explain both psychological and physical outcomes (e.g., Hagger & Orbell, 2003). Two studies have previously applied the CSM to NCCP patients. Donkin et al. (2006) found that illness representations, specifically timeline, treatment control and personal control, were predictive of reassurance one month following a negative exercise stress test. However, the study didn't investigate whether illness representations were related to psychological distress or further chest pain. Moreover, the study was conducted in a cardiology clinic, so the patients may differ from those accessing emergency care, as discussed above. Robertson et al. (2008) compared illness representations, anxiety, and depression in patients with cardiac and non-cardiac chest pain from a rapid access chest pain clinic, a service to which patients can be referred to rule out cardiac causes for chest

pain (as opposed to the CPOU, where patients are admitted directly from the ED). The participants were studied over a two month period, assessed before diagnosis, one week post-diagnosis, and two months later. It was found that levels of anxiety and depression were higher than community norms at baseline, and similar in both groups. Over time, levels of anxiety and depression remained raised in non-cardiac patients, and exceeded the levels in cardiac patients. Regarding illness representations, NCCP patients demonstrated lower perceptions of control and less coherence than cardiac patients at all time points, and greater emotional representations at baseline. Furthermore, while negative emotional representations significantly decreased over time in the cardiac group, this was not so for the NCCP patients. While this study considered longitudinal outcomes in these patients using well-established measures, the setting, while acute, was not an emergency setting. Furthermore, the relationship between illness representations and psychological distress was not considered; instead, the focus was on comparing the levels of these between cardiac and non-cardiac patients. There is therefore a need for research to focus on the relationship between illness representations at the point of diagnosis and psychological distress over time in a sample of acute NCCP patients recruited from an emergency setting.

The aim of the present study was therefore to assess illness representations, anxiety and depression, QoL, cardiac worries, service use and chest pain over time in a sample of ED NCCP patients, with a view to assessing whether illness representations at time of diagnosis were predictive of psychological distress, service use and chest pain at follow-up. Anxiety, depression and QoL were considered important outcomes to consider as they fully reflect both levels of psychological morbidity and mental and physical well-being in a number of domains, and furthermore have been showed to be raised/impaired in NCCP patients in a number of previous studies (e.g., Eslick & Talley, 2008; Fagring et al., 2008; Mayou & Thompson, 2002). Given that previous research has shown that patients often remain concerned that they might have a cardiac problem, despite receiving a negative diagnosis (e.g., Jerlock et al., 2005), cardiac worries were also assessed in order to determine whether this was the case in this acute sample of patients, and also whether illness representations were predictive of cardiac worries. Previous interventions with NCCP patients from EDs have shown positive effects on psychological outcomes, but not on 'hard' outcomes such as chest pain or service use (Arnold, Goodacre, Bath, & Price, 2009; Jones & Mountain, 2009), suggesting a need to target these

outcomes. This study therefore also assessed whether illness representations or psychological distress predicted continued chest pain and service use.

3.3 Method

3.3.1 Setting

Participants were recruited from an ED in a large teaching hospital in the city of Sheffield, UK. The department has an annual attendance of 90,000 patients per year (S. Goodacre, personal communication, 10th October, 2012). The CPOU is in the Clinical Decisions Unit (CDU) adjacent to the ED, which is managed by 2 to 3 specialist chest pain nurses between the hours of 9am and 7pm. All patients who attend the department with chest pain are reviewed by either a doctor or a specialist nurse, and a plan of care is decided upon. If the patient has an obvious, non-cardiac cause for their pain (e.g., musculoskeletal, chest infection) they are discharged as appropriate. If the patient's pain is suspected to be cardiac, they are admitted to the CPOU to undergo a chest pain rule-out process. Patients go through a period of 4-6 hours testing and observation. All patients undergo an Electrocardiogram (ECG) on admission and upon the report of any further pain. If their worst pain was experienced over 12 hours prior to attendance, patients receive a one-off Troponin blood test. If the worst pain was less than 12 hours prior to attendance, patients have a CK-MB blood test on admission, followed by another CK-MB and Troponin test at least 2 hours later, and at least 6 hours since their worst pain. These tests identify whether the patient has experienced a MI. If test results indicate a cardiac cause for the pain, the patient is admitted to a cardiac ward. If all tests are negative, the pain is still suspected to be possibly cardiac, and the patient is able, they will undergo an Exercise Tolerance Test (ETT) to rule out angina. If this test is negative, patients are discharged and a letter is written to their GP. If the test is positive, they are either admitted to a cardiac ward or referred to cardiology outpatients. On discharge, these patients are given an information sheet suitable for their diagnosis (devised by Arnold et al., 2009), outlining some other possible causes for the pain and some possible ways of coping with it in the future.

3.3.2 Inclusion criteria

The inclusion criteria for this study were based on a previous study in the same CPOU (Arnold et al., 2009). Patients were considered eligible for the study if they were admitted to the CPOU with acute chest pain of suspected cardiac origin. They were excluded from the study if they

received a cardiac diagnosis for their chest pain, had know CHD, were unable to comprehend written English or had other life threatening non-cardiac pathology. Participants aged under 25 were excluded from the study, as patients aged under 25 generally did not undergo cardiac rule-out due to their low risk for cardiac disease. These patients were often therefore never 'suspected cardiac' patients.

3.3.3 *Procedure*

The study received full ethical approval from NHS South Yorkshire Research Ethics Committee (see Appendix 3.1 for confirmation of ethical approval). Participants were recruited by either RW or the specialist chest pain nurses within the CPOU. The recruitment period ran from September 2010 to the end of July 2011. Once patients had been identified as suitable for participation in the study, they were given a standardised information sheet (see Appendix 3.2) outlining the aims of the study and what would be required of them. If they agreed to participate, they were asked to sign a consent form (see Appendix 3.3) and given the initial questionnaire (see Appendix 3.4). Participants were given the option of either remaining in the CPOU to complete this, or to take it away and return it in a business reply envelope. Participants were then sent follow-up questionnaires (see Appendices 3.5 and 3.6) by post one month and three months after their initial ED attendance, using the contact details obtained from the hospital computer records. Participants were assessed at one month in order to consider initial changes in outcomes following diagnosis, which may reflect a response to the diagnosis or the situation/setting (i.e., being within an acute healthcare setting). Participants were assessed at three months to address whether any initial changes outcomes persisted over the longer term. A longer follow-up period (e.g., 6 or 12 months) would have been preferable; however, this was precluded by the limited time-scale allowed for the project.

Initially, no attempt to follow-up non-respondents was made. However, because of a low response rate, ethical approval was sought to make reminder phone calls to participants. Phone calls were made to participants recruited from the 10th January 2011 onwards, approximately one week after they had been recruited, then again approximately one week after the time 2 and 3 questionnaires were posted. Thus, the first 161 participants recruited did not receive any reminder telephone calls.

3.3.4 Measures

Where appropriate, scale reliabilities for each measure are reported at each time point in Tables 3.2, 3.9 and 3.18. Copies of the questionnaires at all time points can be found in Appendices 3.4 to 3.6.

3.3.4.1 *Illness Representations*

Illness representations were assessed at all three time points using the Illness Perceptions Questionnaire-Revised (IPQ-R, Moss-Morris et al., 2002); a scale designed to assess all dimensions of illness perceptions, which has been previously used with non-cardiac chest pain patients (Robertson et al., 2008). This measure was selected as it provides an extensive examination of all dimensions of illness representations, including a detailed assessment of perceived causes which may be important for NCCP patients who often do not receive a diagnosis. While the brief IPQ (Broadbent, Petrie, Main, & Weinman, 2006) is considerably shorter, it provides a less detailed assessment of illness perceptions, and does not contain a standardised assessment of perceived causes. For the purposes of this study, the term 'my illness' this was substituted for the term 'my chest pain' in the questionnaire. The dimensions were assessed as follows:

Identity was assessed by asking patients to indicate whether they had experienced 14 symptoms since their initial episode of chest pain, and then asking them to indicate whether they believed the symptoms to be related to their chest pain. The sum of the 'yes' responses to the latter items were used to compute the identity scale scores.

The following seven dimensions were assessed using 5-point Likert scales ranging from 'strongly disagree' to 'strongly agree'.

Timeline acute/chronic was assessed using 6 items, e.g., 'My chest pain is likely to be permanent rather than temporary'.

Timeline cyclical was assessed by 4 items, e.g., 'I go through cycles in which my chest pain gets better and worse'.

Consequences were assessed by 6 items, e.g., 'My chest pain has major consequences on my life'.

Personal control was assessed by 6 items, e.g., ‘*What I do can determine whether my chest pain gets better or worse*’.

Treatment control was assessed by 5 items, e.g., ‘*The negative effects of my chest pain can be prevented (avoided) by my treatment*’.

Coherence was assessed by 5 items, e.g., ‘*I don’t understand my chest pain*’.

Emotional representations was assessed by 6 items, e.g., ‘*Having this chest pain makes me feel anxious*’.

Perceived causes were assessed by asking participants to review a list of 18 possible causes and rate whether they thought the causes were instrumental in causing their chest pain, using 5-point Likert scales ranging from ‘*strongly disagree*’ to ‘*strongly agree*’. These causes were classified into four groups, in line with Moss-Morris et al. (2002): *Risk factors* consisted of 6 items, e.g., ageing, heredity. *Psychological causes* consisted of 6 items, e.g., stress or worry, one’s mental attitude. *Immunity causes* consisted of 3 items, e.g., altered immunity, pollution. *Chance causes* consisted of 2 items, e.g., bad luck, accident. For the purposes of this study, two further possible causes of ‘a cardiac problem’ and ‘indigestion’ were also added, in line with Moss-Morris et al.’s (2002) suggestion that the scale can be adapted to specific study situations/illnesses.

With the exception of the identity dimension, mean scale scores were created. Where necessary, variables were recoded so that higher scores indicated beliefs in a stronger identity, a longer timeline, worse consequences, more control, more coherence, and more negative emotions. Higher scores on the cause items indicated a stronger belief that the particular cause led to the chest pain.

3.3.4.2 *Anxiety and depression*

Anxiety and depression were assessed at all three time points using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). This measure is used widely to assess anxiety and depression levels in patient populations. Previous research studies have used this scale with chest pain patients (e.g., Arnold et al., 2009; Goodacre & Nicholl, 2004), including specifically with non-cardiac patients (e.g., Eslick & Talley, 2008; Kuijpers et al., 2003; Robertson et al., 2008). While there have been recent criticisms of the HADS; for example, that it is a

better measure of general distress than two distinct sub-scales of anxiety and depression (Norton, Cosco, Doyle, Done, & Sacker, 2013); it was felt that the use of this measure would make the findings more comparable to previous research in NCCP, which has largely used the HADS (see Chapter 2, also Webster et al., 2012). The scale consists of 14 items; *Depression* is assessed using 7 items (e.g., ‘*I feel as if I am slowed down*’), as is *anxiety* (e.g., ‘*I get sudden feelings of panic*’). Each item has 4 response choices, scored 0-3. Items are recoded to ensure that higher scores indicate worsening anxiety/depression. The scores are then summed to create a scale score. Scores of 7 or less on each subscale indicate no anxiety or depression, scores of 8-10 indicate possible cases and scores of 11 or more indicate probable or definite anxiety or depression (Zigmond & Snaith, 1983).

3.3.4.3 *Quality of Life*

QoL was assessed at all three time points using the SF-12 (Ware et al., 1996), a shortened version of the SF-36 (Ware et al., 1993) which is a well-established measure of health status. The SF-12 contains two sub-scales, assessing mental and physical functioning. The SF-36 has been previously used in similar studies in this area (e.g., Arnold et al., 2009; Fagring et al., 2008; Goodacre & Nicholl, 2004; Mayou & Thompson, 2002). Results from the SF-12 have been shown to be highly comparable to those for the SF-36 (Ware et al., 1996). The measure consists of 2 subscales: Physical Component Summary (PCS) and the Mental Component Summary (MCS). Higher scores indicate better QoL. Although the suitability of the SF-12 (and SF-36) in measuring QoL has been questioned (Wilson, Parsons, & Tucker, 2000), as with the HADS, this measure was used to allow comparability to previous studies.

3.3.4.4 *Cardiac worries*

Cardiac worries were measured at all three time points using an adaptation of the 6-item Breast Cancer Worries scale (Lerman et al., 1991). This scale has previously been successfully adapted for assessing thrombosis worries, showing high internal reliability (Moore, Norman, Harris, & Makris, 2006). This 6-item scale assesses one’s concern for experiencing a cardiac problem in the future (e.g., ‘*How concerned are you about the possibility that you might have another cardiac problem (heart problem) some day?*’), on a 4-point Likert scale with the responses ‘*Not at all or rarely*’, ‘*Sometimes*’, ‘*Often*’, and ‘*All of the time*’. Higher scores, created by summing the 6-items, indicate greater worry.

3.3.4.5 *Demographics*

In addition to the measures outlined above, the initial baseline questionnaire also included items assessing age, gender, marital status, age leaving education, employment status, hours worked per week, and ethnicity. Information was also gathered from patients' hospital computer records, including contact details, and any re-attendance at the ED over the study period. The nurses recorded whether the patient had received an ETT.

3.3.5 *Participants*

During the study period, it was recorded that 4514 patients attended the ED with chest pain and were referred to the CPOU. Using the inclusion criteria, 3797 were excluded from the study and thus not invited; the reasons for which can be seen in Table 3.1. Of the 717 who were eligible, 228 patients were not invited. This is mainly due to the nature of the study setting; the ED is a very busy department, therefore recruitment was occasionally not possible due to time constraints, or because neither the main researcher nor the chest pain nurses involved in recruitment had a chance to contact the participant before they were discharged by a doctor. A large number of patients ($n=1,208$) were excluded from the study for 'other' reasons. These largely included patients who received their test results outside CPOU hours, those who were returning another day for an ETT, patients who were admitted for further investigation, patients whose chest pain was not suspected to be at all cardiac (and so did not undergo the rule-out process and were discharged immediately), patients who underwent a rule out for pulmonary embolism rather than cardiac problems, patients with cognitive impairment (e.g., dementia), or patients who were under the influence of alcohol or drugs. Information regarding exclusion was missing for 481 participants.

Overall, 489 patients were invited to participate in the study, 83 (17%) refused participation. Therefore, the final baseline sample consisted of 406 participants. Over the course of the study 8 participants contacted the researcher to express their wish to withdraw from the study, one participant died during the course of the study, and 7 participants could not be contacted at follow-up as they no longer lived at their contact address. Of the remaining 390 participants, 200 responded to the initial baseline questionnaire (51%). Of these 200, 138 subsequently then responded to the second questionnaire (69%), and 110 responded to all three questionnaires (55% of initial 200 baseline respondents). The demographic and clinical variables of this sample

of 110 were compared to the 296 non-responders in order to assess any significant differences between responders and non-responders. Responders were significant older than non-responders, $t(221)=4.20$, $p<.001$, and were more likely to be female, $\chi^2(1, n=201)=8.10$, $p=.004$. There were no significant differences between responders and non-responders in terms of who recruited the participant, $\chi^2(1, n=224)=0.10$, $p=.75$, whether the participant had an ETT, $\chi^2(1, n=219)=1.10$, $p=.30$, where they completed the baseline questionnaire, $\chi^2(1, n=224)=2.52$, $p=.11$, baseline marital status, $\chi^2(6, n=192)=7.19$, $p=.30$, ethnicity, $\chi^2(3, n=192)=3.38$, $p=.34$, age of finishing education $t(185)=0.70$, $p=.49$, or job hours worked, $t(120)=0.99$, $p=.32$. A chi-square test identified a significant difference between responders and non-responders in terms of employment, $\chi^2(4, n=192)=11.40$, $p=.02$; however, this was difficult to interpret due to small numbers within each group. The variable was therefore collapsed into three categories, employed, retired, and not in paid employment (which encompassed unemployed, student, and homemaker). This test was still significant, $\chi^2(2, n=192)=9.04$, $p=.01$, and indicated that responders were more likely to be retired, and non-responders were more likely to be employed.

Table 3.1 *Reasons for Exclusion*

Exclusion criteria	No. of participants excluded
Cardiac cause for chest pain	1068
Aged under 25	27
Other life-threatening non-cardiac pathology	135
Known CHD	827
Unable to speak/read English	51
Other	1208
Unknown	481
Total	3797

3.3.6 Statistical analysis

Data were entered by the first author, and accuracy of data entry was assessed using a selection of 10% of completed questionnaires. Differences between responders and non-responders at all three time points were assessed using *t* tests for continuous variables (i.e., age) and chi-square tests for categorical variables (e.g. gender, diagnosis). Scale reliabilities were assessed using Cronbach's Alpha, and are reported at each time point in Tables 3.2, 3.9 and 3.18. All scales showed reliabilities of $\alpha > .6$ at baseline, except the 'chance causes' scale, which had poor reliability ($\alpha = .24$). Given there were only 2 items in this scale, the second item was dropped and chance was assessed using a single item. This was maintained at all time points for consistency and comparability. Scale scores were created for each variable, accounting for less than 40% missing values by replacing with the mean for each participant. Bivariate relationships between independent variables, outcome variables and age were investigated using Pearson's *r* bivariate correlations. Results were considered significant if $p < .05$. Differences in gender and diagnostic group were assessed using *t* tests. Changes in outcome variables and illness representations over time were assessed using repeated measures ANOVAs.

Multivariate associations with the outcomes variables were assessed through a series of hierarchical regression analyses. Age was entered at the first step, followed by illness representations at step two. Only those illness representation dimensions which were significantly correlated with any of the outcome variables were entered in step 2. At follow-up, baseline levels of distress were controlled for in a final step of the model. For all regression models, multicollinearity among the independent variables was tested in two ways. Initially, correlations between the independent variables were examined. Following this, collinearity statistics (i.e., tolerance, variance inflation factors) and collinearity diagnostics (i.e., condition index, variance proportions) were computed for all analyses. The majority of these tests indicated that multicollinearity was no cause for concern; however, the condition indexes for the last 2 dimensions on each model were found to be >30 . To overcome this, all predictors in the models were mean centred, which rectified the problem and did not affect the outcomes of the models. Given this finding, the results for the non-centred variables are reported, for ease of interpretation.

To assess predictors of continued chest pain, one-way ANOVAs were performed for each of the psychological outcomes and for each of the illness representation dimensions. Variables which were found to be related to chest pain frequency were then entered into a Discriminant Function Analysis, to assess which variables could discriminate between chest pain frequency groups. Predictors of re-attendance at the ED were assessed using *t* tests.

3.4 Results

3.4.1 Baseline

3.4.1.1 Participants

Of the 406 participants recruited, 57.8% (n=235) were male, 42.1% (n=171) were female. The mean age was 51.39 (*SD*=11.73, range 27-84, missing data=3). The researcher recruited 42.6% (n=173) of the participants, while the other 57.4% (n=233) were recruited by the specialist chest pain nurses within the CPOU. Exercise tolerance testing was performed on 66.3% (n=269) of the sample. Only 3.4% (n=14) of the sample completed the baseline assessment within the CPOU, the remaining 96.6% (n=392) completed it away from the hospital, to be returned by business reply envelope.

Of the 406 participants recruited, 200 (49.26%) responded to the baseline questionnaire. Of this group, 50.9% (n=113) were male, 37.8% (n=84) were female (missing data=3). The mean age of respondents was 54.74 (*SD*=11.81, range 29-81, missing data=3). Data on marital status was provided by 192 participants, of whom 67.7% (n=130) were married, 14.1% (n=27) were single, 6.2% (n=12), 5.7% (n=11) were widowed, 3.1% (n=6) were cohabiting, 2.6% (n=5) were separated, and 0.5% (n=1) were engaged. Data on employment status was available for 192 participants, of whom 62% (n=119) were employed, 28.6% (n=55) were retired, 6.2% (n=12) were unemployed, 2.1% (n=4) classified themselves as a homemaker, and 0.9% (n=2) were students. The mean age at which the participants left education was 17.35 (*SD*=4.70, range 14-65), and the mean number of hours worked per week was 36.65 (*SD*=13.94, range 0-84).

3.4.1.2 Descriptive statistics

Table 3.2 shows the mean scores for each of the variables. The mean score for anxiety is somewhat higher than that for depression, suggesting that anxiety may be the more prevalent disorder in this sample. Nevertheless, both scores were higher than population norms (anxiety

$M=6.14$, $SD=3.76$, depression $M=3.68$, $SD=3.07$) (Crawford, Henry, Crombie, & Taylor, 2001). Closer examination of the data revealed that within the full sample 42.1% of participants scored above the cut-off of 8 for possible/moderate anxiety, 22.4% for depression, whereas 20.8% of participants scored above the cut-off of 11 for probable/severe anxiety, 8.7% for depression. These proportions are also higher than previously reported population norms (Crawford et al., 2001), which suggest that 12.6% and 3.6% scored above the cut-off for probable/severe anxiety and depression, respectively.

From examination of the QoL scores from the SF-12, the PCS is comparable to previous findings of patients with minor medical conditions ($M=47.42$) (Ware et al., 1996). The score for the MCS is lower ($M=53.82$) (Ware et al., 1996), suggesting that this group of patients may be suffering mentally, but not necessarily physically.

Table 3.2 *Means, standard deviations and alpha coefficients for independent and dependent variables at baseline*

Variable	Alpha coefficient	Mean	SD
Anxiety	.89	7.25	4.51
Depression	.86	4.52	3.95
Cardiac Worries	.90	4.14	3.52
QoL (mental)	N/A	41.17	11.76
QoL (physical)	N/A	47.40	9.52
Identity	N/A	1.62	2.14
Timeline – acute/chronic	.82	2.21	0.73
Timeline – cyclical	.78	3.08	0.84
Consequences	.84	2.27	0.83
Personal control	.84	3.31	0.83
Treatment control	.84	3.50	0.69
Coherence	.96	2.66	1.11
Emotional representations	.87	2.96	0.89
Risk causes	.74	2.53	0.69
Psychological causes	.86	2.70	0.89
Immunity causes	.62	2.28	0.78
Chance causes	.24	2.52	1.10
Cardiac causes	N/A	2.10	1.00
Gastrointestinal causes	N/A	2.81	1.23

Given that the maximum possible score for the identity subscale of the IPQ-R was 14, the mean score is somewhat low, suggesting that patients do not associate many symptoms with their NCCP. Pain was by far the most commonly endorsed symptom reported by participants, with

79 (39.5%) participants reporting this symptom in relation to their chest pain. Other commonly endorsed symptoms were breathlessness (n=39), fatigue (n=49), and sleep difficulties (n=30). In comparison to previous research on illness representations in non-cardiac patients (Robertson et al., 2008), scores for consequences (M=2.89), personal (M=3.07) and treatment (M=3.27) control and emotional representations (M=3.15) appear to be similar; however, timeline appears to be somewhat lower in this group (M=3.22), as does illness coherence (M=3.50).

Relationships between illness representations and the outcomes were initially assessed using bivariate correlations (see Table 3.3). The influence of age and gender was also assessed at this point. Increased age was significantly associated with lower levels of anxiety and depression, better mental functioning, and fewer cardiac worries. Age was therefore controlled for in all subsequent analyses. Gender was not significantly associated with any of the outcome measures, and so was not controlled for in subsequent analyses.

Anxiety was found to be significantly correlated with a stronger identity, longer timeline, more cyclical timeline, more serious perceived consequences, stronger emotional representations, and a stronger belief in risk, psychological, immunity and cardiac causes. Depression was significantly associated with a stronger identity, a longer timeline, more serious perceived consequences, decreased belief in the efficacy of treatment in controlling one's chest pain, decreased coherence (i.e., understanding of one's chest pain), stronger emotional representations, and a stronger belief in risk, psychological, immunity and cardiac causes of one's pain. Poorer physical QoL was associated with a stronger identity, longer timeline, more serious perceived consequences, and a stronger belief in immunity causes of one's chest pain. Poorer mental QoL was associated with a longer timeline, more serious perceived consequences, stronger emotional representations, and a stronger belief in risk, psychological, immunity and cardiac causes of one's pain. Increased cardiac worries were associated with a stronger identity, longer timeline, more cyclical timeline, more serious perceived consequences, decreased coherence, stronger emotional representations, and a stronger belief in risk, psychological and immunity causes of chest pain. Overall, chronic timeline, consequences, emotional representations, risk causes and psychological causes had the strongest and most consistent correlations with the outcome variables

Table 3.3 *Correlations between independent variables and outcome variables*

	Anxiety	Depression	SF-12-PCS	SF-12-MCS	Cardiac worries
Identity	.16*	.21**	-.24**	-.13	.16*
Timeline – acute/chronic	.37***	.33**	-.21**	-.31***	.32***
Timeline – cyclical	.21**	.14	-.14	-.11	.26***
Consequences	.37***	.35***	-.17*	-.37***	.41***
Personal control	-.09	-.13	.07	.09	-.08
Treatment control	-.13	-.16*	.01	.12	-.10
Coherence	-.12	-.16*	.08	.14	-.29***
Emotional representations	.49***	.39***	-.12	-.50***	.54***
Risk causes	.36***	.27***	-.06	-.31***	.47***
Psychological causes	.61***	.45***	.01	-.61***	.50***
Immunity causes	.16*	.15*	-.21**	-.19*	.20**
Chance causes	.05	.02	-.02	-.08	.06
Cardiac causes	.24**	.15*	-.05	-.17*	.52***
Gastrointestinal causes	-.03	.02	-.13	.09	.03
Age	-.29**	-.19**	-.12	.24**	-.24**
Gender	.07	-.04	-.07	-.07	.01

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.1.3 *Multivariate analyses*

Hierarchical regression models were run for each outcome measure, controlling for age at the first step, with the illness representation dimensions entered at the second step. Gastrointestinal causes and chance causes were not included in the models as they did not significantly correlate with any of the outcome measures. For the sake of brevity, only the results from the final steps of the regression analyses are reported. For each model, plots of the residuals were checked to assess for linearity, homoscedasticity and normality; none of the plots indicated that these assumptions had been violated.

3.4.1.3.1 Anxiety

The results of the multiple regression analysis in which anxiety was the dependent variable can be found in Table 3.4. The regression equation was highly significant and explained 39% of the variance in anxiety, Adj. $R^2=.39$, $F(13,147)=8.98$, $p<.001$. The significant independent predictors of anxiety were younger age and a stronger belief in psychological causes of one's chest pain.

Table 3.4 Summary of the regression analysis for variable predicting anxiety (N=161)

Variable	B	SE B	β
Age	-0.06	0.03	-.14*
Identity	0.09	0.14	.04
Timeline– acute/chronic	0.90	0.55	.14
Timeline – cyclical	0.00	0.38	.00
Consequences	0.05	0.47	.01
Personal control	-0.43	0.52	-.08
Treatment control	0.43	0.69	.07
Coherence	0.29	0.35	.07
Emotional representations	0.90	0.44	.17
Risk causes	-0.13	0.58	-.02
Psychological causes	2.47	0.43	.47***
Immunity causes	-0.15	0.43	-.03
Cardiac causes	0.05	0.36	.01

Note. Adjusted $R^2=.39^{**}$; * $p<.05$, ** $p<.01$, *** $p<.001$.

3.4.1.3.2 Depression

The results of the multiple regression analysis in which depression was the dependent variable can be found in Table 3.5. The regression equation was highly significant and explained 23% of the variance in depression, Adj. $R^2=.23$, $F(13,146)= 4.66$, $p<.001$. The only significant independent predictor of depression was a stronger belief in psychological causes of one's chest pain.

Table 3.5 Summary of the regression analysis for variable predicting depression (N=160)

Variable	B	SE B	β
Age	-0.02	0.03	-.04
Identity	0.23	0.14	.12
Timeline– acute/chronic	0.72	0.56	.13
Timeline – cyclical	-0.18	0.38	-.04
Consequences	0.34	0.48	.07
Personal control	-0.54	0.53	-.11
Treatment control	0.08	0.70	.01
Coherence	-0.04	0.36	-.01
Emotional representations	0.62	0.45	.13
Risk causes	-0.02	0.59	-.00
Psychological causes	1.62	0.43	.35***
Immunity causes	0.05	0.44	.01
Cardiac causes	-0.52	0.36	-.13

Note. Adjusted $R^2=.23^{**}$; * $p<.05$, ** $p<.01$, *** $p<.001$.

3.4.1.3.3 Physical QoL

The results of the multiple regression analysis in which physical QoL was the dependent variable can be found in Table 3.6. The regression equation was significant and explained 13% of the variance in physical QoL, Adj. $R^2=.13$, $F(13,147)=2.76$, $p=.002$. Stronger identity was a significant independent predictor of lower physical QoL. A stronger belief in cardiac causes of one's chest pain emerged as a significant predictor; however, this was in the opposite direction to the very small (non-significant) correlation between the variables (see Table 3.3). This findings is most likely an example of a suppressor effect, whereby the relationship between the predictor variables (or between other predictor variables and the outcome variable) can lead to variables emerging as significant predictors, when such relationships are, in fact, spurious (Conger, 1974).

3.4.1.3.4 Mental QoL

The results of the multiple regression analysis in which mental QoL was the dependent variable can be found in Table 3.7. The regression equation was highly significant and explained 39% of the variance in mental QoL, Adj. $R^2=.39$, $F(13,147)=8.70$, $p<.001$. The significant independent predictors of lower mental QoL were stronger emotional representations, and a stronger belief in psychological causes of one's chest pain.

Table 3.6 Summary of the regression analysis for variable predicting physical QoL (N=161)

Variable	B	SE B	β
Age	-0.17	0.07	-.19
Identity	-0.90	0.36	-.20*
Timeline– acute/chronic	-2.48	1.39	-.19
Timeline – cyclical	-1.32	0.95	-.11
Consequences	-0.45	1.20	-.04
Personal control	1.57	1.31	.14
Treatment control	-2.18	1.74	-.16
Coherence	-0.07	0.88	-.01
Emotional representations	-1.14	1.12	-.10
Risk causes	-0.24	1.48	-.02
Psychological causes	1.48	1.08	.13
Immunity causes	-2.03	1.09	-.16
Cardiac causes	1.94	0.90	.20*

Note. Adjusted $R^2=.13^{**}$; * $p<.05$, ** $p<.01$, *** $p<.001$.

Table 3.7 Summary of the regression analysis for variable predicting mental QoL (N=161)

Variable	B	SE B	β
Age	0.09	0.07	.08
Identity	-0.05	0.38	-.01
Timeline– acute/chronic	-1.08	1.47	-.07
Timeline – cyclical	1.30	1.00	.09
Consequences	-0.70	1.26	-.05
Personal control	1.14	1.38	.08
Treatment control	-0.82	1.83	-.05
Coherence	0.05	0.93	.01
Emotional representations	-3.49	1.18	-.25**
Risk causes	1.64	1.56	.09
Psychological causes	-6.94	1.14	-.50***
Immunity causes	-0.81	1.15	-.05
Cardiac causes	0.88	0.95	.07

Note. Adjusted $R^2=.39^{***}$; * $p<.05$, ** $p<.01$, *** $p<.001$.

3.4.1.3.5 Cardiac Worries

The results of the multiple regression analysis in which cardiac worries was the dependent variable can be found in Table 3.8. The regression equation was highly significant and explained 47% of the variance in cardiac worries, Adj. $R^2=.47$, $F(13,144)= 11.61$, $p<.001$. The significant independent predictors of cardiac worries were a less coherent understanding of one's chest pain, stronger emotional representations, and a stronger belief in psychological and cardiac causes of one's chest pain.

Table 3.8 Summary of the regression analysis for variable predicting cardiac worries (N=158)

Variable	B	SE B	β
Age	-0.03	0.02	-.09
Identity	-0.05	0.11	-.03
Timeline – acute/chronic	-0.13	0.41	-.02
Timeline – cyclical	0.24	0.29	.05
Consequences	0.46	0.35	.10
Personal control	0.07	0.39	.02
Treatment control	0.83	0.52	.15
Coherence	-0.56	0.26	-.17*
Emotional representations	1.01	0.33	.24**
Risk causes	0.84	0.44	.15
Psychological causes	0.70	0.32	.17*
Immunity causes	-0.49	0.32	-.10
Cardiac causes	1.17	0.27	.31***

Note. Adjusted $R^2=.47$ ***; * $p<.05$, ** $p<.01$, *** $p<.001$.

3.4.2 One month follow-up

3.4.2.1 Participants

Of the 200 participants who completed the baseline questionnaire, 138 responded to the one-month follow-up questionnaire. In this sample, 51.4% ($n=71$) were male, 48.6% ($n=67$) were female. The mean age was 56.58 ($SD=11.46$, range 28-82, missing data=1).

Of this sample of 138, 41.3% ($n=57$) had been recruited by the main researcher and 58.7% ($n=81$) by the specialist chest pain nurses, 71% ($n=98$) had undergone ETT, and 95.7% ($n=132$) had completed their baseline questionnaire at home. At baseline, 65.2% ($n=90$) had reported themselves as being married, 12.3% ($n=17$) were single, 6.2% ($n=12$), 5.8% ($n=8$) were widowed, 3.6% ($n=5$) were cohabiting, 1.4% ($n=2$) were separated, and 0.7% ($n=1$) were engaged. Data on employment status at baseline was available for 133 of these participants, of whom 57.2% ($n=79$) were employed, 31.9% ($n=44$) were retired, 4.3% ($n=6$) were unemployed, 1.4% ($n=2$) classified themselves as a homemaker, and 1.4% ($n=2$) were students. The mean age at which the participants left education was 17.29 ($SD=3.46$, range 14-35), and the mean number of hours worked per week at baseline was 36.10 ($SD=11.30$, range 8-60).

Comparisons were made between participants who did or did not respond to the one-month follow-up questionnaire. There were no differences in terms of who recruited the participant, $\chi^2(1, n=200)=0.26$, $p=.61$, or whether the participant had an ETT, $\chi^2(1, n=196)=0.03$, $p=.86$.

Responders were significantly older than non-responders, $t(197)=-3.46$, $p=.001$, non-responders were significantly more likely to be male than female, $\chi^2(1, n=199)=7.42$, $p=.01$, and were more likely to have completed their initial questionnaire at home, $\chi^2(1, n=200)=4.81$, $p=.03$. Furthermore, analysis of the demographics assessed on the baseline questionnaire revealed that there were no significant differences between responders and non-responders at one month in terms of marital status, $\chi^2(6, n=192)=4.70$, $p=.58$, employment status, $\chi^2(4, n=192)=7.12$, $p=.13$, ethnicity, $\chi^2(3, n=192)=.86$, $p=.84$, age at which one finished education, $t(197)=-0.09$, $p=.93$ or job hours worked, $t(120)=0.59$, $p=.56$.

Regarding the baseline outcome variables, those who responded to the time 2 questionnaire were significantly less anxious ($t(195)=2.47$, $p=.014$), and had lower perceptions of risk ($t(182)=3.23$, $p=.001$) or psychological causes ($t(182)=2.36$, $p=.02$) than those who did not respond to the time 2 questionnaire. There were no differences between respondents and non-respondents in terms of depression ($t(194)=0.24$, $p=.81$), cardiac worries ($t(191)=1.66$, $p=.10$), mental QoL ($t(195)=1.37$, $p=.17$), physical QoL ($t(195)=0.56$, $p=.58$), identity ($t(193)=1.04$, $p=.30$), chronic timeline ($t(186)=0.10$, $p=.92$), cyclical timeline ($t(179)=1.33$, $p=.19$), consequences ($t(186)=0.98$, $p=.33$), personal control ($t(194)=0.92$, $p=.36$), treatment control ($t(171)=0.07$, $p=.94$), illness coherence ($t(179)=0.24$, $p=.81$), emotional representations ($t(182)=0.06$, $p=.95$), immunity causes ($t(180)=1.36$, $p=.18$), chance causes ($t(183)=1.00$, $p=.32$), cardiac causes ($t(180)=0.03$, $p=.98$), or gastrointestinal causes ($t(183)=1.36$, $p=.18$).

3.4.2.2 *Descriptive statistics*

Table 3.9 shows the mean scores for each of the variables. The mean score for anxiety was again higher than that for depression, suggesting that anxiety symptoms may be more prevalent in this group. The score for depression remained slightly higher than population norms; however, the score for anxiety was similar to population norms at one month (anxiety $M=6.14$, $SD=3.76$, depression $M=3.68$, $SD=3.07$) (Crawford et al., 2001). At one month, 35.6% of participants scored above the cut-off of 8 for possible/moderate anxiety, 17.0% for depression. In addition, 17.8% of participants scored above the cut-off of 11 for probable/severe anxiety, 7.4% for depression. These proportions were again higher than previously reported population norms (Crawford et al., 2001), which suggest that 12.6% and 3.6% scored above the cut-off for probable/severe anxiety and depression, respectively. Therefore, despite mean scores being more comparable to population scores at one month,

the proportion of NCCP patients suffering with probable anxiety and depression at one month was still raised above population norms. Considering QoL scores from the SF-12, the PCS scores are comparable to previous findings of patients with minor medical conditions (Mean=47.42) (Ware et al., 1996); the score for the MCS is lower than such findings (Mean=53.82) (Ware et al., 1996), suggesting that this group of patients may be suffering mentally, but not necessarily physically.

Again, the identity score was very low, suggesting that participants did not associate many symptoms with their chest pain. As at baseline, the most commonly advocated symptom was pain, with 42 (30.4%) participants associating this with their NCCP. Other commonly reported symptoms were breathlessness ($n=15$), fatigue ($n=13$), dizziness ($n=12$) and wheeziness ($n=10$).

3.4.2.3 Continued chest pain

At one month, 41.3% of patients ($n=57$) reported experiencing further chest pain. Of the sample, 10.1% ($n=14$) reported daily chest pain, 18.1% ($n=25$) reported weekly chest pain, 4.3% ($n=6$) reported monthly chest pain, and 8.7% ($n=12$) reported experiencing chest pain less than once a month.

3.4.2.4 Associations between baseline illness representations and one-month follow-up outcome variables

In order to assess whether illness representations at baseline were related to psychological distress at one month, initially, bivariate correlations between baseline independent variables and the outcome measures at one month were assessed (see Table 3.10). Increased anxiety at one month was significantly associated with a perception of a longer and more cyclical timeline, more serious consequences, less faith in personal or treatment control, stronger emotional representations, and stronger beliefs in risk, psychological, immunity and cardiac causes at baseline. Increased depression at one month was significantly associated with perception of a longer timeline, more serious consequences, less faith in personal and treatment control, stronger emotional representations, and an increased belief in risk and psychological causes at baseline. Poorer physical QoL at one month was not significantly associated with any of the illness representation dimensions at baseline. Poorer mental QoL at one month was significantly associated with younger age, perception of a longer timeline, more serious consequences, less faith in personal and treatment control, stronger emotional

representations, and increased beliefs in risk, psychological and immunity causes at baseline. Increased cardiac worries at one month were associated with perception of a longer and more cyclical timeline, more serious consequences, less faith in personal or treatment control, less coherence (or understanding) of one's illness, stronger emotional representations, and stronger beliefs in risk, psychological, immunity and cardiac causes at baseline.

Table 3.9 *Descriptive Statistics - One month follow-up*

Variable	Alpha coefficients	Mean	SD
Anxiety	.89	6.08	4.41
Depression	.83	4.15	3.68
Cardiac Worries	.89	2.39	2.70
QoL (mental)	N/A	46.82	10.57
QoL (physical)	N/A	48.33	10.15
Identity	N/A	0.99	1.60
Timeline	.81	2.28	0.83
Timeline – cyclical	.83	2.89	0.96
Consequences	.81	2.19	0.81
Personal control	.83	3.28	0.79
Treatment control	.87	3.48	0.77
Coherence	.94	2.77	1.08
Emotional representations	.88	2.62	0.90
Risk causes	.67	2.41	0.67
Psychological causes	.82	2.53	0.86
Immunity causes	.67	2.39	2.70
Chance causes	.29	2.28	1.11
Cardiac causes	N/A	2.16	1.05
Gastrointestinal causes	N/A	2.67	1.31

To assess any change over time in terms of both psychological distress and illness representations, paired samples *t* tests were performed. Findings showed that over the one month follow up period, anxiety, $t(133)=2.83$, $p=.01$, and cardiac worries, $t(126)=7.06$, $p<.001$, both significantly decreased, mental QoL significantly improved, $t(133)=-2.38$, $p=.02$, perceptions of identity, $t(129)=2.79$, $p=.01$, and cyclical timeline, $t(99)=2.14$, $p=.04$, and emotional representations reduced, $t(99)=3.81$, $p<.001$, and belief in chance causes of one's chest pain increased, $t(118)=2.01$, $p=.05$.

Table 3.10 *Correlations between baseline illness representations and Time 2 outcome measures*

	T2 Anxiety	T2 Depression	T2 SF-12-PCS	T2 SF-12-MCS	T2 Cardiac worries
Identity	.04	.10	-.14	-.06	.08
Timeline	.46***	.38***	-.16	-.32***	.39***
Timeline – cyclical	.25**	.17	-.07	-.14	.35***
Consequences	.36***	.33***	.03	-.29**	.36***
Personal control	-.18*	-.18*	.08	.19*	-.21*
Treatment control	-.21*	-.23*	-.04	.19*	-.21*
Coherence	-.12	-.13	.03	.07	-.22*
Emotional representations	.45***	.29**	.08	-.34***	.41***
Risk causes	.27**	.20**	-.08	-.18*	.38***
Psychological causes	.49***	.36***	.10	-.39***	.46***
Immunity causes	.22*	.11	-.13	-.21*	.19*
Chance causes	.06	.06	-.01	-.09	.00
Cardiac causes	.30**	.09	.04	-.14	.49***
Gastrointestinal causes	-.06	-.09	-.17	.14	.04

Note. T2= Time 2, * $p < .05$, ** $p < .01$, *** $p < .001$.

3.4.2.5 *Multivariate analysis*

In order to assess whether illness representations at baseline were predictive of psychological distress at one month, hierarchical regression models were run for each outcome measure, controlling for age at the first step, with the illness representation dimensions entered at the second step, and controlling for baseline psychological distress at the final step. Gastrointestinal causes and identity were excluded from the models as they did not significantly correlate with any of the outcome measures. Findings from these models can be found in Table 3.11 to 3.15. The beta values from steps 2 and 3 are reported for each model, as

these are considered to be of most importance. For each model, plots of the residuals were checked to assess for linearity, homoscedasticity and normality; most of plots did not violate these assumptions, with the exception of the plot for the model predicting cardiac worries, which indicated mild heteroscedasticity. To overcome this, independent variables which were significantly skewed were transformed, first using the square root method, then the logarithm method. However, while this significantly reduced the skewness of the variables, it made little difference to the residuals plot. Therefore, the conclusions drawn from this model should be accepted with caution.

3.4.2.5.1 Anxiety

The results of the multiple regression analysis in which anxiety was the dependent variable can be found in Table 3.11. In the second step of the model (assessing the contribution of baseline illness representations), the model was highly significant and explained 27% of the variance in anxiety at one month, $\text{Adj. } R^2=.27$, $F(13,96)=4.10$, $p<.001$. The significant independent predictors of anxiety at this step were the perception of a more chronic timeline and a stronger belief in psychological causes of one's pain. At the final step, controlling for baseline anxiety, the regression equation was again highly significant and explained 59% of the variance in anxiety, $\text{Adj. } R^2=.60$, $F(14,95)=12.51$, $p<.001$. In this step, timeline and psychological causes became non-significant; only baseline anxiety was a significant independent predictor of anxiety at one month. Increased coherence was marginally significant ($p=.055$); however, this was opposite in direction to the very small, non-significant, correlation between the variables (see Table 3.10), suggesting that this may be a suppressor effect.

3.4.2.5.2 Depression

The results of the multiple regression analysis in which depression was the dependent variable can be found in Table 3.12. In the second step of the model (assessing the contribution of baseline illness representations), the model was significant and explained 17% of the variance in depression at one month, $\text{Adj. } R^2=.17$, $F(13,96)=2.71$, $p=.003$. The significant independent predictors of depression at this step were a more chronic timeline, a stronger belief in psychological causes. At the final step, controlling for baseline depression, the regression equation was highly significant and explained 59% of the variance in depression, $\text{Adj. } R^2=.59$, $F(14,95)=12.02$, $p<.001$. In this step, timeline and psychological and cardiac causes became

non-significant; baseline depression was the only significant independent predictor of depression at one month. Less belief in cardiac causes of one's pain at step two and decreased coherence at step three were related to increased depression; however, the correlations between these two variables and depression were very small and non-significant (see Table 3.10), suggesting that they may be suppressor effects.

Table 3.11 *Summary of the regression analysis for variables predicting anxiety at one month (N=111)*

Variable	B	SE B	β
Step 2: Adj. R ² =.27***			
Age	-0.00	0.04	-.01
Timeline – acute/chronic	1.83	0.75	.31*
Timeline – cyclical	0.06	0.44	.01
Consequences	-0.24	0.64	-.05
Personal control	-0.52	0.63	-.11
Treatment control	0.06	0.84	.01
Coherence	0.65	0.46	.16
Emotional representations	0.78	0.55	.16
Risk causes	-1.02	0.77	-.15
Psychological causes	1.80	0.54	.37**
Immunity causes	0.59	0.57	.10
Chance causes	-0.36	0.36	-.09
Cardiac causes	0.24	0.48	.05
Step 3: Adj. R ² =.60***			
Age	0.01	0.03	.03
Timeline– acute/chronic	0.53	0.58	.09
Timeline – cyclical	0.07	0.33	.01
Consequences	-0.11	0.47	-.02
Personal control	-0.20	0.47	-.04
Treatment control	-0.62	0.63	-.11
Coherence	0.66	0.34	.17 [#]
Emotional representations	0.40	0.41	.08
Risk causes	-0.88	0.57	-.13
Psychological causes	-0.05	0.45	-.01
Immunity causes	0.36	0.42	.06
Chance causes	-0.24	0.27	-.06
Cardiac causes	0.42	0.36	.10
Baseline anxiety	0.79	0.09	.74***

Note. [#] $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3.12 Summary of the regression analysis for variables predicting depression at one month (N=111)

Variable	B	SE B	β
Step 2: Adj. R ² =.17**			
Age	0.01	0.03	.04
Timeline– acute/chronic	1.66	0.68	.33*
Timeline – cyclical	0.11	0.40	.03
Consequences	0.20	0.58	.04
Personal control	-0.44	0.57	-.11
Treatment control	-0.54	0.77	-.11
Coherence	0.21	0.42	.06
Emotional representations	-0.00	0.50	.00
Risk causes	-0.15	0.70	-.03
Psychological causes	1.37	0.49	.33**
Immunity causes	-0.14	0.52	-.03
Chance causes	-0.23	0.33	-.07
Cardiac causes	-1.00	0.44	-.27*
Step 3: Adj. R ² =.59***			
Age	0.01	0.02	.04
Timeline– acute/chronic	0.46	0.50	.09
Timeline – cyclical	0.07	0.28	.02
Consequences	-0.09	0.41	-.02
Personal control	-0.21	0.41	-.06
Treatment control	-0.76	0.54	-.15
Coherence	0.61	0.30	.18*
Emotional representations	0.03	0.35	.01
Risk causes	-0.35	0.49	-.06
Psychological causes	0.38	0.36	.09
Immunity causes	0.12	0.37	.00
Chance causes	-0.09	0.23	-.03
Cardiac causes	-0.15	0.32	-.04
Baseline Depression	0.66	0.07	.73***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.2.5.3 Physical QoL

The results of the multiple regression analysis in which physical QoL was the dependent variable can be found in Table 3.13. In the second step of the model (assessing the contribution of baseline illness representations), the model was significant and explained 11% of the variance in physical QoL at one month, Adj. R²=.11, $F(13,96)=1.99$, $p=.03$. At the final step, controlling for baseline physical QoL, the regression equation was highly significant and explained 62% of the variance in physical QoL, Adj. R²=.62, $F(14,95)=13.86$, $p < .001$. Baseline physical QoL was the only significant independent predictor of physical QoL at one month. At

step two, perception of a shorter timeline and less belief in cardiac causes of one's pain were related to worse QoL; at step three, shorter timeline, less serious consequences and stronger emotional representations emerged as significant independent predictors; however, the correlations between these variables and physical QoL were very small and non-significant, suggesting that these findings may be suppressor effects.

Table 3.13 *Summary of the regression analysis for variables predicting physical QoL at one month (N=111)*

Variable	B	SE B	β
Step 2: Adj. R²=.11*			
Age	-0.06	0.09	-.07
Timeline– acute/chronic	-7.09	1.87	-.54***
Timeline – cyclical	-0.53	1.09	-.05
Consequences	2.35	1.59	.20
Personal control	1.97	1.57	.18
Treatment control	-2.94	2.09	-.23
Coherence	-0.05	1.13	-.01
Emotional representations	1.28	1.37	.12
Risk causes	-2.00	1.90	-.13
Psychological causes	1.25	1.33	.11
Immunity causes	-1.98	1.41	-.15
Chance causes	0.86	0.90	.10
Cardiac causes	2.76	1.19	.28*
Step 3: Adj. R²=.62***			
Age	0.09	0.06	.10
Timeline– acute/chronic	-3.97	1.24	-.30**
Timeline – cyclical	0.12	0.71	.01
Consequences	2.81	1.03	.24**
Personal control	0.44	1.03	.04
Treatment control	-0.83	1.37	-.06
Coherence	0.28	0.74	.03
Emotional representations	2.02	0.89	.19*
Risk causes	-1.86	1.24	-.13
Psychological causes	0.26	0.87	.02
Immunity causes	-0.84	0.92	-.07
Chance causes	0.74	0.59	.08
Cardiac causes	0.78	0.79	.09
Baseline physical QoL	0.79	0.07	.75***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.2.5.4 *Mental QoL*

The results of the multiple regression analysis in which mental QoL was the dependent variable can be found in Table 3.14. At the second step, the regression equation was significant and explained 17% of the variance in mental QoL, $\text{Adj. } R^2=.17$, $F(13,96)= 2.65$, $p=.003$. The only significant independent predictor of mental QoL at this step was a stronger belief in psychological causes of one's pain. At the final step, controlling for baseline mental QoL, the regression equation was highly significant and explained 44% of the variance in mental QoL, $\text{Adj. } R^2=.44$, $F(14,95)=7.05$, $p<.001$. In this step, psychological causes was no longer significant, and the only independent predictor was baseline mental QoL. Coherence was also significant; however, the correlation between coherence and mental QoL was very small and non-significant, suggesting this may be a suppressor effect.

3.4.2.5.5 *Cardiac Worries*

The results of the multiple regression analysis in which cardiac worries was the dependent variable can be found in Table 3.15. At the second step, the regression equation was highly significant and explained 34% of the variance in cardiac worries, $\text{Adj. } R^2=.34$, $F(13,69)= 5.00$, $p<.001$. The significant independent predictors of cardiac worries at this step were a stronger belief in psychological and cardiac causes of one's pain. At the final step, controlling for baseline cardiac worries, the regression equation was highly significant and explained 57% of the variance in cardiac worries, $\text{Adj. } R^2=.57$, $F(14,88)=10.50$, $p<.001$. In this step, psychological and cardiac causes were no longer significant, and the only independent predictor was baseline cardiac worries.

Table 3.14 Summary of the regression analysis for variables predicting mental QoL at one month (N=111)

Variable	B	SE B	β
Step 2: Adj. R ² =.17**			
Age	0.11	0.09	.11
Timeline– acute/chronic	-1.45	1.98	-.10
Timeline – cyclical	0.25	1.16	.02
Consequences	0.05	1.68	.00
Personal control	1.78	1.66	.15
Treatment control	1.06	2.22	.07
Coherence	-2.04	1.20	-.21
Emotional representations	-1.79	1.45	-.15
Risk causes	2.69	2.02	.17
Psychological causes	-4.01	1.41	-.33**
Immunity causes	-2.68	1.49	-.19
Chance causes	0.14	0.96	.01
Cardiac causes	0.13	1.26	.01
Step 3: Adj. R ² =.44***			
Age	0.12	0.08	.12
Timeline– acute/chronic	-0.09	1.63	-.01
Timeline – cyclical	-0.03	0.95	-.00
Consequences	1.19	1.39	.09
Personal control	1.86	1.36	.16
Treatment control	1.02	1.82	.07
Coherence	-2.44	0.99	-.25*
Emotional representations	-1.19	1.19	-.10
Risk causes	1.81	1.66	.11
Psychological causes	0.41	1.32	.03
Immunity causes	-1.93	1.23	-.14
Chance causes	0.06	0.79	.01
Cardiac causes	-1.26	1.06	-.12
Baseline mental QoL	0.61	0.09	.66***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.2.1 Continued chest pain

Regarding continued chest pain at one month, the response options to the chest pain frequency question of ‘monthly’ and ‘less than once a month’ were collapsed into one ‘monthly’ category due to low frequencies in these groups and a lack of differences between the groups. In order to consider differences between those who were experiencing chest pain daily, weekly, monthly, or not at all at the one month follow-up, one-way ANOVAs and *t* tests

were performed for demographics, all the baseline outcome variables and also the baseline illness representations.

Table 3.15 Summary of the regression analysis for variables predicting cardiac worries at one month (N=104)

Variable	B	SE B	β
Step 2: Adj. R ² =.34***			
Age	0.00	0.02	.01
Timeline– acute/chronic	0.20	0.44	.05
Timeline – cyclical	0.50	0.26	.17
Consequences	0.01	0.38	.00
Personal control	-0.51	0.37	-.17
Treatment control	0.39	0.50	.11
Coherence	0.11	0.27	.05
Emotional representations	0.33	0.32	.11
Risk causes	0.08	0.47	.02
Psychological causes	0.91	0.33	.30**
Immunity causes	-0.08	0.33	-.02
Chance causes	-0.22	0.22	-.09
Cardiac causes	0.88	0.28	.32**
Step 3: Adj. R ² =.57***			
Age	0.01	0.02	.05
Timeline– acute/chronic	0.11	0.36	.03
Timeline – cyclical	0.33	0.22	.11
Consequences	-0.06	0.30	-.02
Personal control	-0.38	0.30	-.13
Treatment control	-0.16	0.41	-.04
Coherence	0.34	0.22	.14
Emotional representations	-0.06	0.26	-.01
Risk causes	-0.14	0.38	-.03
Psychological causes	0.38	0.27	.12
Immunity causes	-0.11	0.27	-.03
Chance causes	-0.11	0.18	-.04
Cardiac causes	0.30	0.24	.11
Baseline cardiac worries	0.48	0.07	.67***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 3.16 Means, SDs for variables by continued chest pain, with F values from ANOVAs – Time 2

Variable	Continued chest pain				F
	Daily n=14	Weekly n=25	Monthly n=18	No pain n=79	
Anxiety	7.50 (5.46)	8.72 (4.59) _a	6.33(3.07)	6.04 (3.87) _b	2.92*
Depression	4.69 (5.03)	6.81 (4.55) _a	3.78 (2.73)	3.86 (3.69) _b	3.85**
Physical QoL	40.78 (9.16) _a	45.33 (10.21)	47.00 (8.29)	49.76 (9.03) _b	4.57**
Mental QoL	40.59 (12.05)	40.49 (12.06)	49.37 (10.41)	46.12 (11.35)	3.12*
Cardiac Worries	3.17 (2.70)	5.36 (4.13)	3.07 (2.22)	3.57 (3.65)	2.00
Identity	3.14 (2.51) _a	0.92 (1.62) _b	1.94 (2.07)	1.31 (1.85) _b	4.76**
Timeline – acute/chronic	2.58 (0.98)	2.37 (0.68)	2.32 (0.71)	2.08 (0.75)	2.20
Timeline – cyclical	2.60 (1.15)	3.41 (0.74)	3.14 (0.87)	2.92 (0.95)	2.55
Consequences	2.45 (0.76)	2.47 (0.81)	2.14 (0.72)	2.26 (0.95)	0.63
Personal control	3.23 (0.92)	3.11 (0.88)	2.98 (0.75)	3.42 (0.95)	1.47
Treatment control	3.28 (0.92)	3.33 (0.63)	3.29 (0.56)	3.64 (0.82)	1.78
Coherence	2.56 (1.19)	2.47 (1.07)	2.55 (1.15)	2.81 (1.17)	0.65
Emotional representations	3.03 (0.81)	2.97 (0.98)	2.84 (0.93)	2.96 (0.96)	0.11
Risk causes	2.28 (0.70)	2.39 (0.61)	2.46 (0.58)	2.43 (0.75)	0.21
Psychological causes	2.17 (0.70)	2.88 (0.93)	2.38 (0.62)	2.65 (0.99)	2.09
Immunity causes	2.05 (0.71)	2.30 (0.80)	2.37 (0.70)	2.20 (0.84)	0.50
Chance causes	2.77 (1.42)	2.46 (1.06)	2.35 (1.00)	2.44 (1.18)	0.36
Cardiac causes	1.85 (0.69)	2.30 (1.02)	2.28 (1.02)	2.20 (1.08)	0.90
Gastrointestinal causes	2.54 (1.13)	2.78 (1.20)	2.81 (1.17)	2.76 (1.36)	0.13

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Means with different subscripts are significantly different from each other

3.4.2.1.1 *Demographics*

There was no significant age, $F(3,131)=0.04$, $p=.99$, or gender, $\chi^2(3, N=136)=0.04$, $p=.998$, difference between the chest pain frequency groups. These were therefore not controlled for in further analyses.

3.4.2.1.2 *Relationships between chest pain frequency at Time 2 and psychological distress and illness representations at Time 1*

To identify differences in baseline psychological distress and illness representations in each chest pain frequency group, ANOVAs were performed, with subsequent Tukey post-hoc analyses to look at between group differences (see Table 3.16). Those with weekly pain at one month reported higher levels of anxiety and depression at baseline than those with no pain. Those with daily pain at one month had worse physical QoL and a stronger illness identity at baseline than those with no pain. Those with daily pain also reported stronger illness identity at baseline than those with weekly pain at follow-up. There were no differences between chest pain frequency groups in cardiac worries, chronic timeline, cyclical timeline, consequences, personal control, treatment control, coherence, emotional representations, or risk, immunity, chance, cardiac or gastrointestinal causes.

For the anxiety analysis, Levene's test showed that homogeneity of variance was violated, $F(3,132)=3.07$, $p=.03$. In order to overcome this, the alternative Brown-Forsythe F statistic was calculated (which is robust to violations of homogeneity of variance); however, this was only borderline significant, $F(3,47.49)=2.52$, $p=.07$. The results of this test should therefore be interpreted with caution.

For depression, there was a borderline significant difference between those with weekly and monthly pain, with those with weekly pain reporting higher baseline depression than those with monthly pain, $p=.06$. For mental QoL, there was a borderline significant difference between those with monthly and weekly pain, with those reporting weekly pain at one month reported significantly lower levels of mental QoL at baseline than those with monthly pain at one month ($p=.06$).

While baseline perceptions of psychological causes did not differ significantly between chest pain frequency groups, Levene's test showed that homogeneity of variance was violated in this

test, $F(3,119)=3.07$, $p=.03$. In order to overcome this, the alternative Brown-Forsythe F statistic was calculated (which is robust to violations of homogeneity of variance), and this was just significant, $F(3,75.24)=2.76$, $p=.05$. Tukey post-hoc tests did not identify any specific between group differences.

3.4.2.1.3 Discriminant Function Analysis

To further investigate the relationship between baseline psychological status, illness representations and ongoing chest pain, a discriminant function analysis was performed. Baseline variables that were significantly related to chest pain frequency in the ANOVAs were included, which were identity, anxiety, depression, and physical and mental QoL.

In the analysis, 7 cases were excluded due to missing data. The analysis therefore consisted of 131 participants (no pain $n=74$, monthly pain $n=18$, weekly pain $n=25$, daily pain $n=14$). Three discriminant functions were calculated, which together significantly discriminated between the chest pain frequency groups, $\chi^2(15)=22.92$, $p<.001$. After the removal of the first function, there was still a significant association between the groups and predictors, $\chi^2(8)=18.75$, $p=.02$. The third function was not significant, $\chi^2(3)=6.41$, $p=.09$. The first function accounted for 19% of the total relationship between the predictors and group membership, Canonical $R^2=.19$, the second accounted for 9%, Canonical $R^2=.09$, and the third for 1%, Canonical $R^2=.01$. The three discriminant functions accounted for 59.8%, 26.7%, and 13.5% of the between group variability, respectively. Examination of the combined plot of discriminant functions (see Figure 3.1) and the functions at group centroids indicated that function one primarily discriminated between those with daily pain and all other chest pain frequency groups, and function two maximally discriminated between weekly pain and monthly/no pain, with daily pain falling between these groups. The structure loading matrix was examined (see Table 3.17), and loadings $>.30$ were interpreted as significant. This showed that the best predictor for distinguishing between daily pain and other pain frequency groups (function one) was identity, although physical QoL also loaded quite highly onto this dimension. Thus, those experiencing daily pain were more likely to report a higher illness identity and poorer physical QoL at baseline. The best predictors for distinguishing daily and weekly pain from monthly and no pain (function two) were anxiety, depression, and mental and physical QoL. Thus, those experiencing weekly pain reported worse anxiety, depression, and mental and physical QoL at

baseline than those reporting no or monthly pain, and the outcomes of those reporting daily pain fell between these groups.

Table 3.17 Summary of correlations of predictor variables with discriminant functions - Full sample analysis

Predictor variable	Correlation of predictor variables with discriminant functions		
	1	2	3
Identity	-.70	.05	.22
Anxiety	.00	-.78	.11
Depression	.14	-.86	.01
Physical QoL	.45	.68	-.25
Mental QoL	.09	.73	.48

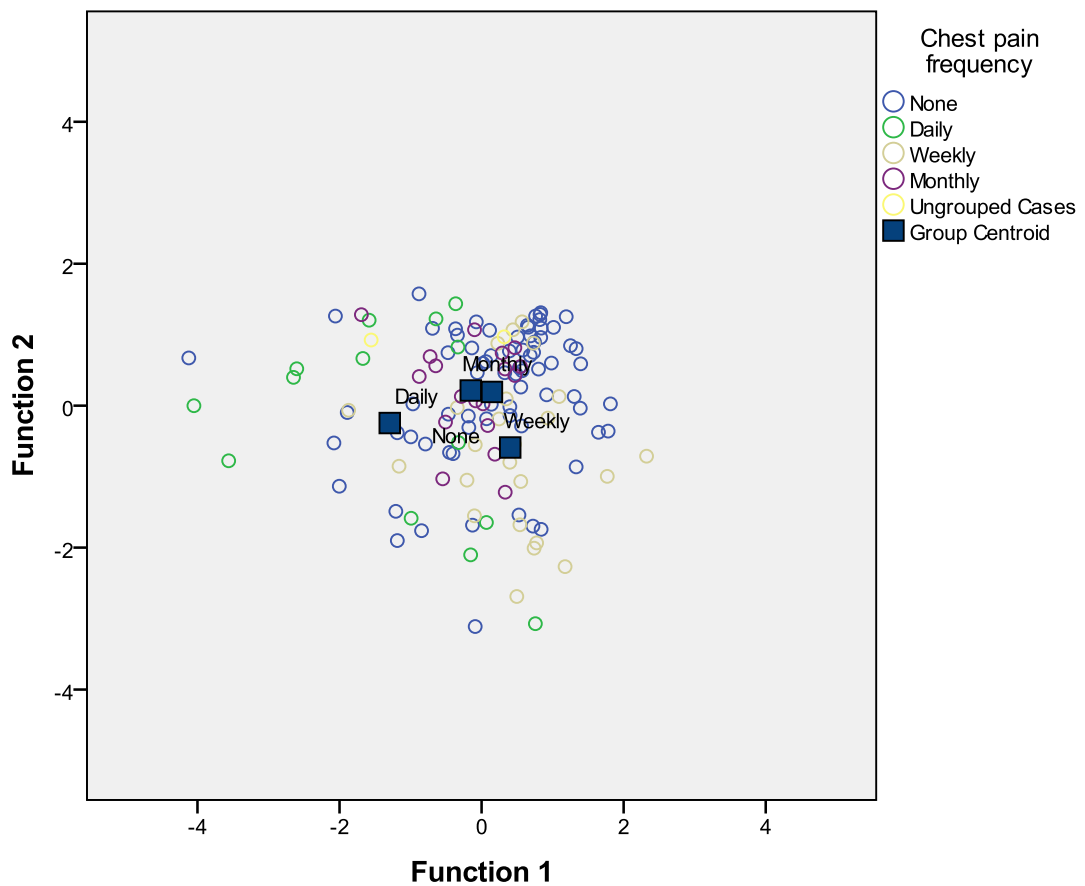


Figure 3.1 Combined plot of discriminant functions - Time 2 model including Identity, depression, anxiety, mental and physical QoL

3.4.3 Three month follow-up

3.4.3.1 *Participants*

Of the 200 baseline participants, 142 responded to the three-month follow-up questionnaire, 110 of which had also responded to the baseline and one-month follow-up questionnaires. Therefore at time 3, full data was available for 110 participants, and all time 3 analyses were performed on this sample.

In this sample, 48.2% ($n=53$) were male, 51.8% ($n=57$) were female. The mean age was 58.01 ($SD=10.94$, range 29-82, missing data=2). Of this sample of 110, 40% ($n=44$) had been recruited by the main researcher and 60% ($n=66$) by the specialist chest pain nurses, 70% ($n=7$) had undergone ETT, and 96.4% ($n=106$) had completed their baseline questionnaire away from the CPOU. At baseline, 65.5% ($n=72$) had reported themselves as being married, 12.7% ($n=14$) were single, 8.2% ($n=9$) were divorced, 7.3% ($n=8$) were widowed, 2.7% ($n=3$) were cohabiting, and 0.9% ($n=1$) were separated. Data on employment status at baseline was available for 107 of these participants, of whom 52.7% ($n=58$) were employed, 36.4% ($n=40$) were retired, 4.5% ($n=5$) were unemployed, 1.8% ($n=2$) classified themselves as a homemaker, and 1.8% ($n=2$) were students. The mean age at which the participants left education was 17.14 ($SD=3.11$, range 14-29), and the mean number of hours worked per week at baseline was 35.34 ($SD=11.42$, range 8-60).

Comparisons were made between participants who failed to respond to the three-month follow-up questionnaire, but had responded to the baseline and one-month questionnaires. There were no significant differences between responders and non-responders in terms of gender, $\chi^2(1, n=138)=2.32, p=.13$, who recruited the participant, $\chi^2(1, n=138)=0.38, p=.54$, whether the participant had an ETT, $\chi^2(1, n=135)=0.46, p=.50$, where they completed the baseline questionnaire, $\chi^2(1, n=138)=0.66, p=.42$, baseline marital status, $\chi^2(6, n=133)=9.20, p=.16$, baseline employment status, $\chi^2(4, n=133)=6.55, p=.16$, ethnicity, $\chi^2(3, n=132)=4.98, p=.17$, age at which one finished education, $t(128)=1.08, p=.28$, or job hours worked, $t(77)=1.00, p=.32$. Responders ($M=58.01, SD=10.94$) were significantly older than non-responders ($M=51.86, SD=11.95$), $t(135)=2.61, p=.01$.

Regarding the time one outcome variables, those who responded to the time 3 questionnaire had significantly stronger belief in treatment control, $t(112)=2.07, p=.04$, and a higher level of

coherence, $t(120)=2.06$, $p=.04$, than those who did not respond to the time 3 questionnaire. There were no differences between responders and non-responders in terms of anxiety, $t(134)=0.53$, $p=.60$, depression, $t(134)=0.28$, $p=.99$, cardiac worries, $t(130)=1.61$, $p=.11$, mental QoL, $t(134)=0.77$, $p=.44$, physical QoL, $t(134)=0.04$, $p=.97$, identity, $t(132)=0.01$, $p=.33$, chronic timeline, $t(127)=1.86$, $p=.07$, cyclical timeline, $t(121)=0.77$, $p=.98$, consequences, $t(127)=0.59$, $p=.16$, personal control, $t(126)=1.07$, $p=.29$, emotional representations, $t(123)=1.65$, $p=.10$, psychological causes, $t(123)=0.78$, $p=.44$, risk causes, $t(123)=0.99$, $p=.32$, immunity causes, $t(123)=0.86$, $p=.81$, chance causes, $t(123)=0.66$, $p=.51$, cardiac causes, $t(124)=1.90$, $p=.06$, or gastrointestinal causes, $t(126)=0.76$, $p=.45$.

3.4.3.2 Descriptive statistics

Table 3.18 shows the mean scores for each of the variables. The mean score for anxiety was again higher than that for depression, suggesting that anxiety symptoms may be more prevalent in this group. However, as at one month, the score for depression remained slightly higher than population norms; and the score for anxiety fell slightly below population norms at one month (anxiety $M=6.14$, $SD=3.76$, depression $M=3.68$, $SD=3.07$) (Crawford et al., 2001). At three months, 28.4% of participants scored above the cut-off of 8 for possible/moderate anxiety, 16.5% for depression, and 11% of participants scored above the cut-off of 11 for probable/severe anxiety, 6.4% for depression. These proportions were lower than previously reported population norms (Crawford et al., 2001), which suggest that 12.6% and 3.6% scored above the cut-off for probable/severe anxiety and depression, respectively. It therefore seems that the high proportions of anxiety and depression in NCCP patients are not persistent over time. As at one month, PCS scores were comparable to previous findings of patients with minor medical conditions ($M=47.42$) (Ware et al., 1996), the score for the MCS seems lower than such findings ($M=53.82$) (Ware et al., 1996), suggesting that this group of patients may be suffering mentally, but not necessarily physically.

Again, the identity score was very low, suggesting that participants did not associate many symptoms with their chest pain. As at baseline, the most commonly advocated symptom was pain, with 27 participants associating this with their NCCP. Other commonly reported symptoms were breathlessness ($n=13$), fatigue ($n=13$), dizziness ($n=11$), and sleep difficulties ($n=10$).

Table 3.18 *Descriptive Statistics - Three month follow-up*

Variable	Alpha coefficients	Mean	SD
Anxiety	.89	6.00	4.21
Depression	.87	4.10	3.98
Cardiac Worries	.91	2.16	2.87
QoL (mental)	N/A	48.22	10.32
QoL (physical)	N/A	48.57	10.19
Illness Representations	Identity	N/A	0.98
	Timeline	.77	2.27
	Timeline – cyclical	.87	2.83
	Consequences	.84	2.12
	Personal control	.77	3.40
	Treatment control	.86	3.57
	Coherence	.96	3.15
	Emotional representations	.93	2.57
	Risk causes	.68	2.49
	Psychological causes	.84	2.54
	Immunity causes	.64	2.27
	Chance causes	.55	2.29
	Cardiac causes	N/A	2.16
	Gastrointestinal causes	N/A	2.66

3.4.3.3 *Continued chest pain*

At three months, 38.2% of patients ($n=42$) reported experiencing further chest pain, including 6.4% ($n=7$) reporting daily chest pain, 10.0% ($n=11$) reporting weekly chest pain, 7.3% ($n=8$) reporting monthly chest pain, and 13.6% ($n=15$) reporting experiencing chest pain less than once a month.

3.4.3.4 *Changes in psychological distress over time*

In order to assess change over time in all of the outcome measures, repeated measures ANOVAs were performed, followed by t tests if significant changes were identified. Mean scores at all three time points, along with F values, can be found in Table 3.19.

Levels of depression, and physical QoL, did not significantly change over time. Levels of anxiety significant changed over time. Inspection of the means indicated that levels of reported anxiety decreased over time, and subsequent t tests indicated that anxiety significantly decreased between baseline and one month, $t(108)=2.15$, $p=.03$, and between baseline and three

months, $t(108)=2.46$, $p=.02$, but not between one month and three months, $t(107)=0.20$, $p=.84$. Levels of mental QoL also significantly changed over time. Inspection of the means indicated that it improved over time; subsequent t tests demonstrated that mental QoL increased between baseline and one month, $t(108)=2.00$, $p=.048$, and between baseline and three months, $t(108)=2.96$, $p=.004$, but not between one month and three months, $t(107)=1.56$, $p=.12$. There was also a significant change in levels of cardiac worries over time. Inspection of the means indicated that cardiac worries decreased over time, and subsequent t tests confirmed that cardiac worries significantly decreased between baseline and one month, $t(108)=6.17$, $p<.001$, and between baseline and three months, $t(108)=5.42$, $p<.001$, but not between one month and three months, $t(103)=0.13$, $p=.90$.

Table 3.19 Means, SDs and F values for outcome measures at all three time points - Final full sample (N=110)

Variable	Time 1	Time 2	Time 3	F
	M(SD)	M(SD)	M(SD)	
Anxiety	6.63 (3.90) _a	6.04 (4.34) _b	5.99 (4.21) _b	4.28*
Depression	4.47 (3.83)	4.15 (3.59)	4.10 (3.98)	1.47
Cardiac worries	3.62 (3.30) _a	2.26 (2.58) _b	2.16 (2.87) _b	25.06***
Mental QoL	45.32 (11.24) _a	47.22 (10.06) _b	48.22 (10.32) _b	5.64**
Physical QoL	47.67 (9.45)	48.55 (10.19)	48.57 (10.19)	1.41

Note. * $p<.05$, ** $p<.01$, *** $p<.001$

Means with different subscripts are significantly different from each other

3.4.3.5 Changes in Illness Representations over time

In order to assess change over time in the illness representation measures, repeated measures ANOVAs were performed, followed by t tests if significant changes were identified. Mean scores at all three time points for this sample can be found in Table 3.20.

There was no significant change over time in timeline, cyclical timeline, consequences, personal control, treatment control, belief in risk causes, belief in psychological causes, belief in immunity causes, belief in chance causes, belief in cardiac causes, or belief in gastrointestinal causes. Identity significantly changed over time, and inspection of the means indicated that strength of identity decreased over time; subsequent t tests demonstrated that identity significantly decreased between baseline and one month, $t(103)=2.64$, $p=.01$, and between baseline and three months, $t(9)=2.68$, $p=.01$, but not between one month and three

months, $t(98)=0.11$, $p=.91$. Coherence significantly changed over time, and inspection of the means indicated that coherence increased over time, and subsequent t tests demonstrated that coherence did not improve between baseline and one month, $t(79)=1.19$, $p=.24$, but significantly improved between baseline and three months, $t(83)=3.38$, $p=.001$, and between one month and three months, $t(72)=2.39$, $p=.02$. Emotional representations also significantly changed over time, and inspection of the means indicated that emotional representations decreased over time; and subsequent t tests demonstrated that emotion significantly decreased between baseline and one month, $t(81)=3.35$, $p=.001$, and between baseline and three months, $t(84)=3.84$, $p<.001$, but not between one month and three months, $t(74)=0.38$, $p=.70$.

Table 3.20 Mean, SDs and F values for Illness Representations at all three time points (N=110)

Variable	Time 1	Time 2	Time 3	F
	M(SD)	M(SD)	M(SD)	
Identity	1.62 (2.13) _a	1.05 (1.62) _b	0.98 (2.12) _b	5.04**
Timeline	2.16 (0.73)	2.23 (0.79)	2.27 (0.73)	0.53
Timeline cyclical	3.03 (0.93)	2.88 (0.98)	2.27 (0.73)	2.62
Consequences	2.26 (0.87)	2.13 (0.78)	2.12 (0.74)	0.70
Personal control	3.13 (0.94)	3.37 (0.80)	3.40 (0.81)	2.04
Treatment control	3.57 (0.77)	3.56 (0.70)	3.57 (0.74)	1.13
Coherence	2.77 (1.18) _a	2.86 (1.03) _a	3.15 (1.14) _b	6.10**
Emotional representations	2.90 (0.94) _a	2.59 (0.91) _b	2.57 (0.97) _b	7.01**
Risk causes	2.39 (0.68)	2.43 (0.66)	2.49 (0.64)	0.61
Psychological causes	2.57 (0.94)	2.54 (0.86)	2.54 (0.86)	0.45
Immunity causes	2.22 (0.79)	2.25 (0.85)	2.27 (0.79)	0.04
Chance causes	2.43 (1.10)	2.21 (1.03)	2.29 (1.02)	1.60
Cardiac causes	2.02 (1.04)	2.19 (1.06)	2.16 (1.04)	0.97
Gastrointestinal causes	2.78 (1.23)	2.73 (1.30)	2.66 (1.27)	1.01

Note. * $p<.05$, ** $p<.01$, *** $p<.001$

Means with different subscripts are significantly different from each other

3.4.3.6 Associations between baseline illness perceptions and three-month follow-up outcome variables

In order to assess whether illness representations at baseline were related to psychological distress at three months, initially, bivariate correlations between baseline independent variables and the outcome measures at three months were assessed, the results of which can be found in Table 3.21. Increased anxiety at three months was significantly correlated with a perception of a longer and more cyclical timeline, more serious perceived consequences, less

faith in personal control, stronger emotional representations, stronger belief in risk, psychological, immunity and cardiac causes at baseline. Increased depression at three months was significantly correlated with perception of a longer and more cyclical timeline, stronger emotional representations, increased belief in risk and psychological causes at baseline. Poorer physical QoL at three months was significantly correlated with a more cyclical timeline and less belief in gastrointestinal causes at baseline. Poorer mental QoL at one month was significantly correlated with perception of a longer timeline, more serious perceived consequences, less faith in personal control, stronger emotional representations, and an increased belief in risk and psychological causes at baseline. Increased cardiac worries at three months were correlated with perception of a longer and more cyclical timeline, perceived more serious consequences, less faith in personal or treatment control, less coherence (or understanding) of one's illness, stronger emotional representations, stronger belief in immunity and cardiac causes at baseline.

3.4.3.1 Multivariate analyses

In order to assess whether illness representations at baseline were predictive of psychological distress at three months, hierarchical regression models were run for each outcome measure, controlling for age and gender at the first step, with the illness representation dimensions entered at the second step, and controlling for baseline psychological distress at the final step. Chance causes and identity were excluded from the models as they did not significantly correlate with any of the outcome measures. Summary tables for each analysis are presented in Tables 3.22 to 3.26. Only the beta values from steps 2 and 3 are reported for each model, for the sake of brevity.

For each model, plots of the residuals were checked to assess for linearity, homoscedasticity and normality; most of plots did not obviously violate these assumptions, with the exception of the plot for the model predicting cardiac worries and the model predicting depression, which indicated mild heteroscedasticity. To overcome this, independent variables which were significantly skewed (the baseline psychological distress measures) were transformed, first using the square root method, then the logarithm method. However, while this significantly reduced the skewness of the variables, it made little difference to the residuals plots. Therefore, the conclusions drawn from these models should be accepted with caution. As before, the results of the non-transformed variables are reported, for ease of interpretation.

Table 3.21 Correlation between baseline illness representations and Time 3 outcome measures

	T3 Anxiety	T3 Depression	T3 SF-12-PCS	T3 SF-12-MCS	T3 Cardiac worries
Identity	-.01	.00	-.11	.00	.03
Timeline	.32**	.24*	-.14	-.31**	.32**
Timeline – cyclical	.28**	.21*	-.23*	-.16	.31**
Consequences	.28**	.17	-.01	-.26**	.24*
Personal control	-.20*	-.15	.10	.23*	-.21*
Treatment control	-.13	-.09	-.01	.17	-.23*
Coherence	-.13	-.01	-.04	.07	-.26*
Emotional representations	.40***	.29**	.01	-.39***	.34***
Risk causes	.30**	.25*	-.10	-.25*	.17
Psychological causes	.48***	.38***	-.03	-.41***	.19
Immunity causes	.22*	.16	-.14	-.17	.20*
Chance causes	.02	-.04	.01	.02	.10
Cardiac causes	.21*	.10	-.06	-.14	.47***
Gastrointestinal causes	.03	-.04	-.21*	.09	.06

Note. T2= Time 2, * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.3.1.1 Anxiety

The results of the multiple regression analysis in which anxiety was the dependent variable can be found in Table 3.22. In the second step of the model (assessing the contribution of baseline illness representations), the model was highly significant and explained 26% of the variance in anxiety at three months, $Adj. R^2 = .26$, $F(14,73) = 3.19$, $p = .001$. The significant independent predictors of anxiety at this step were greater belief in personal control and a stronger belief in psychological causes of one's pain. At the final step, controlling for baseline anxiety, the regression equation was again highly significant and explained 57% of the variance in anxiety,

Adj. $R^2=.57$, $F(15,72)=8.66$, $p<.001$. In this step, personal control and psychological causes became non-significant; only baseline anxiety was a significant independent predictor of anxiety at three months. Decreased coherence was borderline significant ($p=.06$); however, the correlation between coherence and anxiety was very small and non-significant (see Table 3.21), suggesting that this may be a suppressor effect.

Table 3.22 Summary of the regression analysis for variables predicting anxiety at three months (N=89)

Variable	B	SE B	β
Step 2: Adj. $R^2=.26^{**}$			
Age	-0.04	0.04	-.11
Gender	1.25	0.91	.14
Timeline	0.10	0.91	.02
Timeline – cyclical	0.28	0.54	.06
Consequences	-0.68	0.74	-.13
Personal control	-1.59	0.69	-.36*
Treatment control	0.62	0.97	.11
Coherence	0.86	0.49	.23
Emotional representations	0.78	0.60	.17
Risk causes	0.62	0.94	.10
Psychological causes	1.63	0.58	.35**
Immunity causes	0.61	0.65	.11
Gastrointestinal causes	-0.35	0.42	-.10
Cardiac causes	0.01	0.52	.00
Step 3: Adj. $R^2=.57^{***}$			
Age	-0.04	0.03	-.10
Gender	0.39	0.70	.05
Timeline	-0.10	0.70	-.02
Timeline – cyclical	0.18	0.41	.04
Consequences	-0.87	0.56	-.17
Personal control	-0.77	0.54	-.17
Treatment control	-0.21	0.75	-.04
Coherence	0.72	0.38	.19 [#]
Emotional representations	0.39	0.46	.08
Risk causes	0.35	0.72	.06
Psychological causes	-0.04	0.50	-.01
Immunity causes	0.58	0.49	.10
Gastrointestinal causes	-0.04	0.32	-.01
Cardiac causes	0.21	0.39	.05
Baseline anxiety	0.79	0.11	.71***

Note. [#] $p<.10$ * $p<.05$,** $p<.01$, *** $p<.001$.

3.4.3.1.2 Depression

The results of the multiple regression analysis in which depression was the dependent variable can be found in Table 3.23. In the second step of the model (assessing the contribution of baseline illness representations), the model was borderline significant and explained 12% of the variance in depression at three months, $\text{Adj. } R^2=.12$, $F(14,73)=1.82$, $p=.052$. A stronger belief in psychological causes of one's pain was a significant independent predictor of depression at this step. . At the final step, controlling for baseline depression, the regression equation was highly significant and explained 47% of the variance in depression, $\text{Adj. } R^2=.47$, $F(15,72)=6.04$, $p<.001$. In this step, psychological causes became non-significant; and baseline depression was the only significant independent predictor of depression at three months. Increased coherence also emerged as significant at both steps two and three, and a greater belief in personal control was borderline significant at step two ($p=.053$); however, the correlations between these variables and depression were very small and non-significant (see Table 3.21), suggesting that these are suppressor effects.

3.4.3.1.3 Physical QoL

The results of the multiple regression analysis in which physical QoL was the dependent variable can be found in Table 3.24. In the second step of the model (assessing the contribution of baseline illness representations), the model was non-significant, explaining only 2% of the variance in physical QoL at three months, $\text{Adj. } R^2=.02$, $F(14,73)=1.11$, $p=.36$. The only significant independent predictor of physical QoL at this step was greater belief in a cyclical timeline. At the final step, controlling for baseline physical QoL, the regression equation was highly significant and explained 49% of the variance in physical QoL, $\text{Adj. } R^2=.49$, $F(15,72)=4.63$, $p<.001$. In this step, greater belief in cyclical timeline, and baseline physical QoL were significant independent predictors of depression at three months. Stronger emotional representations did emerge as significant; however, however, the correlation between emotional representations and physical QoL was very small and non-significant (see Table 3.21), suggesting that this is a suppressor effect.

Table 3.23 Summary of the regression analysis for variables predicting depression at three months (N=89)

Variable	B	SE B	β
Step 2: Adj. R ² =.12			
Age	-0.03	0.04	-.07
Gender	-0.21	0.94	-.03
Timeline	0.55	0.95	.10
Timeline – cyclical	0.36	0.56	.08
Consequences	-0.78	0.77	-.16
Personal control	-1.41	0.72	-.33 [#]
Treatment control	0.36	1.01	.07
Coherence	1.05	0.51	.29*
Emotional representations	0.58	0.63	.13
Risk causes	0.85	0.97	.14
Psychological causes	1.22	0.60	.28*
Immunity causes	0.57	0.67	.11
Gastrointestinal causes	-0.57	0.44	-.17
Cardiac causes	-0.37	0.54	-.10
Step 3: Adj. R ² =.47***			
Age	-0.02	0.04	-.06
Gender	0.60	0.74	.07
Timeline	0.28	0.74	.05
Timeline – cyclical	0.12	0.44	.03
Consequences	-0.96	0.60	-.20
Personal control	-0.87	0.56	-.21
Treatment control	0.12	0.79	.02
Coherence	1.31	0.40	.37**
Emotional representations	0.50	0.49	.11
Risk causes	0.75	0.76	.12
Psychological causes	0.15	0.49	.03
Immunity causes	0.50	0.52	.09
Gastrointestinal causes	-0.51	0.34	-.15
Cardiac causes	0.38	0.43	.10
Baseline depression	0.66	0.09	.64***

Note. [#] $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3.24 Summary of the regression analysis for variables predicting physical QoL at three months (N=89)

Variable	B	SE B	β
Step 2: Adj. R ² =.02			
Age	-0.05	0.11	-.06
Gender	-1.02	2.32	-.05
Timeline	-3.13	2.33	-.24
Timeline – cyclical	-3.07	1.38	-.30*
Consequences	1.83	1.89	.16
Personal control	1.59	1.77	.16
Treatment control	-2.40	2.48	-.19
Coherence	-0.86	1.26	-.10
Emotional representations	1.62	1.54	.16
Risk causes	-0.90	2.39	-.06
Psychological causes	-0.87	1.49	-.09
Immunity causes	-1.01	1.65	-.08
Gastrointestinal causes	-0.06	1.07	-.01
Cardiac causes	0.85	1.31	.10
Step 3: Adj. R ² =.49***			
Age	0.10	0.09	.11
Gender	-1.99	1.84	-.10
Timeline	-1.51	1.86	-.12
Timeline – cyclical	-2.29	1.10	-.22*
Consequences	2.01	1.49	.18
Personal control	-0.29	1.43	-.03
Treatment control	0.34	2.01	.03
Coherence	-0.76	1.00	-.09
Emotional representations	3.07	1.24	.30*
Risk causes	-1.13	1.89	-.08
Psychological causes	-1.43	1.18	-.14
Immunity causes	0.23	1.32	.02
Gastrointestinal causes	0.09	0.85	.01
Cardiac causes	-0.84	1.07	-.09
Baseline physical QoL	0.67	0.10	.64***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.4.3.1.4 Mental QoL

The results of the multiple regression analysis in which mental QoL was the dependent variable can be found in Table 3.25. In the second step of the model (assessing the contribution of baseline illness representations), the model was significant and explained 17% of the variance in mental QoL at three months, Adj. $R^2 = .17$, $F(14,73) = 2.62$, $p = .013$. The significant independent predictors of mental QoL at this step were greater belief in personal control, and stronger

emotional representations. At the final step, controlling for baseline mental QoL, the regression equation was highly significant and explained 28% of the variance in mental QoL, Adj. $R^2=.28$, $F(15,72)=3.22$, $p<.001$. In this step, greater faith in personal control and baseline mental QoL were significant independent predictors of mental QoL at three months, and emotional representations ($p=.057$) and coherence ($p=.06$) were borderline significant

Table 3.25 Summary of the regression analysis for variables predicting mental QoL at three months (N=89)

Variable	B	SE B	β
Step 2: Adj. $R^2=.17^*$			
Age	0.06	0.11	.06
Gender	-0.96	2.38	-.05
Timeline	-0.83	2.38	-.06
Timeline – cyclical	0.66	1.41	.06
Consequences	1.64	1.93	.13
Personal control	4.59	1.81	.42*
Treatment control	-1.39	2.54	-.10
Coherence	-2.45	1.29	-.26
Emotional representations	-3.39	1.58	-.30*
Risk causes	-2.30	2.44	-.15
Psychological causes	-2.39	1.52	-.21
Immunity causes	-1.34	1.69	-.10
Gastrointestinal causes	1.56	1.10	.18
Cardiac causes	0.67	1.35	.07
Step 3: Adj. $R^2=.28^{***}$			
Age	0.11	0.11	.11
Gender	-0.76	2.22	-.04
Timeline	-1.59	2.23	-.11
Timeline – cyclical	0.72	1.32	.06
Consequences	2.63	1.82	.21
Personal control	3.95	1.70	.36*
Treatment control	-1.66	2.37	-.12
Coherence	-2.27	1.20	-.25
Emotional representations	-2.86	1.48	-.25
Risk causes	-2.33	2.28	-.15
Psychological causes	0.52	1.65	.05
Immunity causes	-0.96	1.58	-.07
Gastrointestinal causes	1.06	1.04	.12
Cardiac causes	-0.30	1.29	-.03
Baseline mental QoL	0.40	0.12	.43**

Note. * $p<.05$, ** $p<.01$, *** $p<.001$.

3.4.3.1.5 *Cardiac worries*

The results of the multiple regression analysis in which cardiac worries was the dependent variable can be found in Table 3.26. In the second step of the model (assessing the contribution of baseline illness representations), the model was significant and explained 21% of the variance in cardiac worries at three months, Adj. $R^2=.21$, $F(14,70)=2.61$, $p=.004$. The only significant independent predictor of cardiac worries at this step was a stronger belief in cardiac causes of one's pain. At the final step, controlling for baseline cardiac worries, the regression equation was highly significant and explained 39% of the variance in cardiac worries, Adj. $R^2=.39$, $F(15,69)=4.56$, $p<.001$. In this step, stronger belief in cardiac causes and baseline cardiac worries were significant independent predictors of cardiac worries at three months.

3.4.3.1 *Continued chest pain*

Regarding continued chest pain at three months, the response options were collapsed in the same way as at time 2, to allow for comparison. Again, in order to consider differences between those who were experiencing chest pain daily, weekly, monthly, or not at all at the three month follow-up, one-way ANOVAs and t tests were performed for demographics and diagnostic group, all the baseline outcome variables and also the baseline illness representations.

There was no significant age, $F(3,105)=0.54$, $p=.65$, or gender, $\chi^2(3, N=110)=2.27$, $p=.52$, difference between the chest pain frequency groups. There were also no significant differences in the other demographic or clinical variables. These were therefore not controlled for in further analyses.

To identify differences in baseline psychological distress and illness representations in each group, ANOVAs were performed; with subsequent Tukey post-hoc analyses to look at between group differences (see Table 3.27).

Those with weekly pain at time 3 had higher baseline levels of anxiety than those with no pain or monthly pain, and more baseline cardiac worries and a more chronic timeline than those with no pain. Baseline identity was higher in those with daily pain than any of the other pain frequency groups; those with monthly pain also had significantly stronger baseline identity than those with no pain.

Table 3.26 Summary of the regression analysis for variables predicting cardiac worries at three months (N=86)

Variable	B	SE B	β
Step 2: Adj. R ² =.21**			
Age	-0.02	0.03	-.07
Gender	-0.41	0.66	-.07
Timeline	0.39	0.66	.09
Timeline – cyclical	0.35	0.39	.11
Consequences	-0.41	0.53	-.11
Personal control	-0.13	0.50	-.04
Treatment control	0.34	0.72	.08
Coherence	-0.08	0.36	-.03
Emotional representations	0.66	0.43	.20
Risk causes	-0.72	0.69	-.15
Psychological causes	0.28	0.43	.08
Immunity causes	0.25	0.47	.07
Gastrointestinal causes	0.08	0.30	.03
Cardiac causes	1.32	0.37	.46**
Step 3: Adj. R ² =.39***			
Age	-0.00	0.03	-.01
Gender	-0.89	0.59	-.15
Timeline	0.59	0.59	.13
Timeline – cyclical	0.31	0.34	.09
Consequences	0.62	0.47	-.17
Personal control	-0.09	0.44	-.03
Treatment control	-0.04	0.64	-.01
Coherence	0.15	0.32	.06
Emotional representations	0.33	0.39	.10
Risk causes	-0.94	0.61	-.20
Psychological causes	-0.05	0.38	-.01
Immunity causes	0.29	0.41	.08
Gastrointestinal causes	-0.02	0.27	-.01
Cardiac causes	0.80	0.34	.28*
Baseline depression	0.47	0.10	.54***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3.27 Means, SDs for variables by continued chest pain, with F statistics from ANOVAs – Time 3

Variable	Continued chest pain				F
	Daily n=7	Weekly n=11	Monthly n=23	No pain n=69	
Anxiety	6.71 (3.69)	10.00 (4.77) _a	6.35 (3.76) _b	6.18 (3.69) _b	3.27*
Depression	4.23 (2.75)	6.64 (4.13)	4.59 (3.52)	4.11 (3.93)	1.40
Physical QoL	45.38 (6.64)	41.75 (11.57)	46.90 (6.91)	49.09 (9.77)	2.22
Mental QoL	43.89 (9.15)	40.73 (12.00)	46.08 (11.56)	45.95 (11.24)	0.75
Cardiac Worries	2.86 (1.95)	6.29 (2.38) _a	3.70 (2.95)	3.23 (3.49) _b	3.00*
Identity	4.57 (2.51) _a	1.55 (2.34) _{b,c}	2.39 (2.35) _b	1.06 (1.62) _c	8.56***
Timeline – acute/chronic	2.40 (0.52)	2.70 (0.68) _a	2.18 (0.62)	2.03 (0.76) _b	3.12*
Timeline – cyclical	3.33 (0.41)	3.50 (0.63)	3.12 (1.01)	2.87 (0.96)	1.83
Consequences	2.48 (0.81)	2.29 (0.79)	2.02 (0.79)	2.25 (0.94)	0.18
Personal control	3.12 (0.83)	3.15 (0.75)	3.13 (0.70)	4.43 (1.05)	0.82
Treatment control	3.20 (0.52)	3.25 (0.21)	3.57 (0.68)	3.65 (0.85)	1.16
Coherence	2.40 (1.25)	2.64 (1.06)	2.59 (1.02)	2.90 (1.24)	0.65
Emotional representations	3.39 (0.54)	3.42 (0.43)	2.85 (0.92)	2.77 (1.00)	2.16
Risk causes	2.11 (0.39)	2.52 (0.68)	2.30 (0.62)	2.42 (0.72)	0.62
Psychological causes	2.42 (0.91)	2.80 (0.72)	2.41 (1.00)	2.60 (0.96)	0.52
Immunity causes	2.11 (0.46)	2.27 (0.68)	2.35 (0.82)	2.17 (0.83)	0.33
Chance causes	2.17 (1.17)	2.45 (0.52)	2.30 (1.11)	2.50 (1.18)	0.29
Cardiac causes	1.33 (0.52)	2.64 (0.67)	2.09 (1.16)	1.95 (1.05)	2.35
Gastrointestinal causes	2.17 (0.98)	3.09 (1.30)	2.78 (1.31)	2.78 (1.29)	0.67

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Means with different subscripts are significantly different from each other

There were some issues with homogeneity in these tests. The Levene's statistic was significant in the analyses for physical QoL ($p=.047$), emotional representations ($p=.01$), chance causes ($p=.03$). In order to overcome this, the alternative Brown-Forsythe F statistic was calculated for each of these tests (which is robust to violations of homogeneity of variance). For physical QoL, $F(3,30.42)=2.45$, $p=.08$, and chance causes, $F(3,23.93)=0.36$, $p=.78$, this result was non-significant. For emotional representations, however, this finding was significant, $F(3,55.19)=3.67$, $p=.02$, suggesting a possible difference in emotional representations between the chest pain frequency groups. However, post-hoc analyses revealed no individual differences between the groups.

3.4.3.1.1 *Discriminant Function Analysis*

To further investigate the relationship between baseline psychological status, illness representations and ongoing chest pain, a discriminant function analysis was performed. All baseline psychological outcomes and illness representations that were significantly related to chest pain frequency in the ANOVAs were included. This therefore included identity, timeline, anxiety, and cardiac worries.

In the analysis, 7 cases were excluded due to missing data. The analysis therefore consisted of 103 participants (no pain $n=62$, monthly pain $n=23$, weekly pain $n=11$, daily pain $n=7$). Three discriminant functions were calculated, which together significantly discriminated between the chest pain frequency groups, $\chi^2(12)=37.82$, $p<.001$. After the removal of the first function, the association between the groups and predictors remained significant, $\chi^2(6)=15.24$, $p=.02$. The third function was not significant, $\chi^2(2)=0.41$, $p=.82$. The first function accounted for 21% of the total relationship between the predictors and group membership, Canonical $R^2=.21$, the second accounted for 14%, Canonical $R^2=.14$, and the third for 0%, Canonical $R^2=.00$. The three discriminant functions account for 60.7%, 38.3%, and 1.0% of the between group variability, respectively. Examination of the combined plot of discriminant functions (see Figure 3.2) and the functions at group centroids indicated that function one primarily discriminated between those with daily pain and all other chest pain frequency groups, and function two primarily discriminated between weekly pain and all other chest pain frequency groups. The structure loading matrix was examined (see Table 3.28), and loadings $>.30$ were interpreted as significant. This showed that the best predictor for distinguishing between daily pain and other pain frequency groups (function one) was identity, although timeline also loaded highly onto

this function (although it loaded highest onto the second function). Thus, those experiencing daily pain were more likely to report a higher illness identity and perceived a more chronic timeline at baseline. The best predictors for distinguishing weekly pain from the other chest pain frequency groups (function two) were anxiety, timeline, and cardiac worries. Thus, those experiencing weekly pain reported worse anxiety, a more chronic timeline, and more cardiac worries at baseline than those reporting no pain, monthly pain, or daily pain.

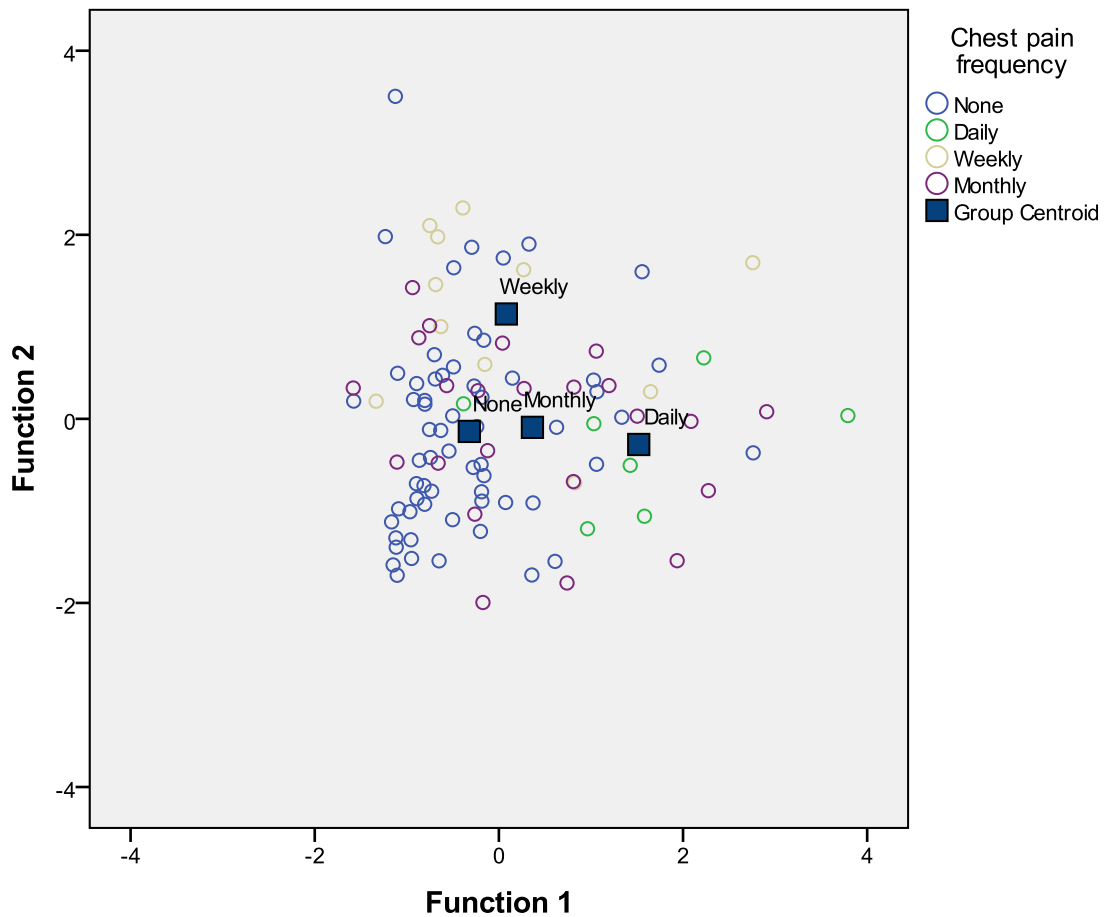


Figure 3.2 Combined plot of discriminant functions - Full sample, Time 3, second model including Identity, timeline, anxiety and cardiac worries

Table 3.28 Summary of correlations of predictor variables with discriminant functions at Time 3- Full sample analysis

Predictor variable	Correlation of predictor variables with discriminant functions		
	1	2	3 (ns)
Identity	.96	-.12	.07
Timeline	.43	.75	.02
Anxiety	.11	.75	-.47
Cardiac worries	-.00	.71	.54

3.4.4 Service use

Following the end of the study period, hospital computer records were reviewed to assess whether any of the patients in the study had re-attended the emergency department for chest pain. Over this period, of the 406 patients in the full initial baseline sample, 13 had returned to the emergency department at least once with a presenting complaint of chest pain. Of these patients, 9 received a diagnosis of NCCP on at least one of occasions; 6 had received a cardiac diagnosis, of whom 3 also had received a non-cardiac diagnosis. One participant had received a cardiac diagnosis on a visit prior to receiving a further non-cardiac diagnosis at a later visit; two received a cardiac diagnosis after receiving a second non-cardiac diagnosis. Of the 110 patients in the final sample, 5 had returned to the emergency department at least once with a presenting complaint of chest pain. All 5 of these received a diagnosis of NCCP on at least one of these returning visits (2 received a cardiac diagnosis prior to receiving a further non-cardiac diagnosis). To investigate differences between those who re-attended with chest pain and those who did not (in the final sample of 110), *t* tests were performed. The only significant difference was in physical QoL, whereby those who re-attended the ED with chest pain (Mean=38.00, *SD*=8.23) reported lower QoL at baseline than those who did not re-attend (Mean=48.13, *SD*=9.28), $t(108)=2.40, p=.018$. However, given the very small number of patients who re-attended, this difference should be accepted with caution.

3.5 Discussion

This longitudinal, questionnaire based study sought to examine whether patients with NCCP who presented to an ED were suffering psychologically; to identify whether such suffering could be predicted using the Common Sense Model of illness representations (CSM; Leventhal

et al., 1980); and to assess whether persistent chest pain and service use were related to either illness representations or levels of psychological distress. The results supported previous findings suggesting high levels of psychological distress and poor psychological well-being in NCCP patients (see Chapter 2, also Webster et al., 2012), and furthermore demonstrated that the CSM has some utility in explaining levels of psychological distress, with the a belief in psychological causes emerging as the strongest predictor. Furthermore, chest pain frequency at follow-up was related to both the illness representation dimensions of identity and chronic timeline and levels of psychological distress at baseline.

3.5.1 Levels of psychological distress and well-being

The mean level of baseline anxiety in the sample was slightly below the cut-off for moderate anxiety of 8, which is also slightly lower than previous findings from a rapid access chest pain clinic, where mean scores were found to exceed 9 on the HADS (Robertson et al., 2008). These findings are comparable to a number of other studies of acute care patients, which also identified mean scores below this cut-off (e.g., Demiryoguran et al., 2006; Mayou & Thompson, 2002). Nonetheless, the percentage of participants scoring above the cut-off points for moderate anxiety in our sample was high at baseline, with 42.1% of patients suffering with moderate anxiety falling towards the high end of previous estimates of between 21.0% and 53.5% in other acute NCCP samples (See Chapter 2, also Webster et al., 2012). Furthermore, 20.8% of these patients scored over the cut-off for severe anxiety. After initial attendance at the ED, mean levels of anxiety dropped significantly and remained at this lower level over the 3 month follow-up period, suggesting that this anxiety may not be a persistent issue. However, there was still a relatively high proportion of patients scoring above the cut-off values for the HADS, even at 3 months, suggesting that there still may be a reasonable proportion of patients within this sample that continue to suffer from high levels of anxiety, despite reassurance about their chest pain.

In comparison to the scores for anxiety in this sample, the scores for depression were somewhat lower. This appears to be a common theme among NCCP patients in general, as the mean score was very similar to a number of other studies in the area (Mayou & Thompson, 2002; Robertson et al., 2008; Soares-Filho et al., 2009; Srinivasan & Joseph, 2004). Baseline estimates for the percentage of patients scoring above the cut-off for moderate depression in this study were towards the lower end of the range of previous estimates in similar samples

(9%-40%, see Chapter 2, also Webster et al., 2012). This low level of depression in the sample also remained stable over time. It may therefore be concluded that depression may be less of an issue for this group of patients, with the main source of psychological distress being anxiety.

Regarding QoL, baseline scores for the Physical Component Subscale were found to be comparable to data from a large scale study for patients with minor medical complaints, but the scores for the Mental Component Subscale were considerably below this, and more similar to scores for those with serious mental and physical complaints (Ware et al., 1996). It is difficult to compare the QoL scores in this study to those in other studies of acute NCCP patients, given that many previous studies have used the SF-36 rather than the SF-12, and often have not reported the subscale summary scores (e.g., Eslick & Talley, 2008; Fagring et al., 2008; Mayou & Thompson, 2002). Nevertheless, the findings here suggest that physical QoL is not impaired in patients with NCCP and, moreover, this level of QoL was maintained at this level over the 3 month follow-up period. Levels of mental QoL did improve in the one month following initial ED attendance; however, the level still remained below those reported by Ware et al. (1996), thus suggesting that this sample of NCCP patients experienced a persistent impairment in mental QoL.

As mentioned in the introduction, much of the existing research into psychological outcomes in NCCP patients has been conducted in non-acute settings. It is difficult to compare our results to such findings as many such studies used psychiatric interview to assess the levels of anxiety and depression. However, a small number of studies have used the same measures as used in the current study (e.g., Channer, James, Papouchado, & Rees, 1987; Channer, Papouchado, James, & Rees, 1985; Cheung et al., 2009). These studies reported mean levels of anxiety similar to (Channer et al., 1987) or lower than (Cheung et al., 2009) the levels found in the present study; however, the mean levels of depression were generally higher in other studies (Channer et al., 1987; Cheung et al., 2009). Channer et al. (1985) reported a larger proportion of NCCP patients scoring above the cut-off for the HADS; however, they used a cut-off of ≥ 8 , whereas a cut-off of > 8 was used in the present study. Levels of QoL were found to be very similar (Cheung et al., 2009). Minor differences between these findings and those in the present study may be due to the difference in setting; however, further existing research also reports depression to be more of a problem in NCCP patients than was found in the present sample (Naidoo & Patel, 1993; Safdar, Foody, & D'Onofrio, 2010). However, one of these

studies had a very limited sample of South African men of Indian origin (Naidoo & Patel, 1993), and the other had a solely female sample and the measure of depression used was less well established and validated than the HADS (Safdar et al., 2010). It therefore seems reasonable to conclude that the findings from the current study are a relatively fair representation of acute NCCP patients.

At all time points, the mean score for cardiac worries was well below the maximum score of 18 on the scale and also decreased over time, indicating that overall, this sample were not overly concerned that they still may experience a cardiac problem. As this measure was adapted for this specific study, it is difficult to compare it to other research; however a previous adaptation of the scale, used to assess thrombosis worries, reported mean scores of around 11, much higher than the mean found in this study of around 3. This lack of concern about cardiac worries is unexpected, given that previous research has suggested that patients remain concerned about cardiac problems despite receiving a negative cardiac diagnosis (e.g., Carmin et al., 2003; Dumville et al., 2007; Mayou et al., 1994; Potts & Bass, 1993) and show hyper vigilance to possible cardiac sensations which may serve to worsen such fears (White et al., 2010). However, this previous research has involved patients from outpatient care, and may therefore be qualitatively different to the present, acute care, sample. Nevertheless, qualitative evidence from patients within an emergency department setting have also shown that patients do still fear that their pain may be caused by a cardiac problem (Jerlock et al., 2005); however, the qualitative nature and small sample of this study precludes generalisation. It therefore seems appropriate to conclude that patients who access emergency care for their chest pain, and thus are less likely to spend a long period of time suffering with chest pain prior to diagnosis, are less likely to maintain concerns about a cardiac cause for their pain following a negative diagnosis. This may be because patients who are referred by their GP for outpatient clinics and/or coronary angiogram may have their concerns about a cardiac cause reinforced by the long period of extensive cardiac testing. Moreover, some patients are even given a preliminary diagnosis of a cardiac problem by the GP, and prescribed medication for such a problem (Mayou, Bass, & Bryant, 1999). It may therefore be more difficult to rectify these beliefs by negative diagnosis alone. This therefore supports the notion that rapid rule-out in a CPOU setting may be beneficial for NCCP patients in giving them reassurance that their chest pain is not cardiac in nature.

3.5.2 The nature of illness representations

Mean scores for consequences, personal control, treatment control, and emotional representations were comparable to a similar study using the same measure of illness representations in NCCP patients (Robertson et al., 2008). This remained consistent through follow-up, with the exception of emotional representations, which significantly reduced over time in the present sample, but did not in the Robertson et al. (2008) study. With regard to coherence and timeline, these dimensions differed from the levels found by Robertson et al., whereby the present sample showed less coherence and perceived a less chronic timeline. Coherence improved over time in this sample, reaching levels more similar to those found by Robertson et al. Perceptions of timeline were less chronic than in the Robertson et al. sample at all time points. These discrepancies may be due to the different nature of the samples. While Robertson et al. do not specifically define the diagnostic processes used in the Rapid Access Chest Pain Clinic from which they recruited patients, as an outpatient service it is unlikely to be a similar environment to the ED setting of the CPOU. In the CPOU, while the dedicated chest pain nurses are well equipped and experienced in delivering non-cardiac diagnoses, the nature of the emergency environment often means that less time is allowed per patient than may be in a less acute environment (i.e., outpatient departments). Therefore, if patients have a lack of understanding of their diagnosis, they may be reluctant to ask the chest pain nurses for clarification if they perceive them to be busy. The rapid rule-out process may also allow patients less time to process their diagnosis. This may lead to a lower level of coherence in acute care NCCP patients than those who receive their diagnosis in non-acute settings. Regarding timeline, the acute nature of the present sample may mean that they perceive their pain to be acute rather than chronic. It is, however, difficult to draw comparisons with the Robertson et al. (2008) study, given that while it was outpatient care, it was 'rapid access' outpatient care, whereby patients are seen between 48 hours and 2 weeks following referral. Comparisons to more long term outpatient care are precluded by the lack of studies in this area, specifically using the same measure of illness representations.

In comparison to previous reports in both chronic and acute pain patients (Moss-Morris et al., 2002), the mean level of identity was especially low in this sample. Moreover, this level decreased over time. This may be due to the fact that the patients were experiencing an

episode of pain (possibly a one-off), rather than an illness, per se. Moss-Morris et al. (2002) did note that those with acute pain (as in our sample) reported significantly lower identity than chronic pain patients. However, as the level of identity in this sample was even lower than those experiencing acute pain, it seems that there may be another explanation. As these patients may have received no clear diagnosis for their pain, they may not have a clear idea of what they are suffering from. Because of this, they may not relate other symptoms to their pain, as they see 'chest pain' itself as a symptom rather than an illness, as such. The concept of identity may therefore not be so clear cut for this sample, and may need to be assessed in a different way.

3.5.3 The relationship between illness representations and psychological outcomes

Illness representations explained significant amounts of variance in all psychological outcome variables at baseline and one month, and in anxiety, mental QoL and cardiac worries at three months.

Stronger perceptions of psychological causes emerged as an important predictor, particularly of anxiety, depression, mental QoL and cardiac worries. Other important predictors of these outcomes were emotional representations (for mental QoL and cardiac worries), timeline (for anxiety and depression), and perceptions of personal control (for anxiety and mental QoL). As is to be expected, belief in cardiac causes was consistently predictive of cardiac worries. The pattern of these predictors changed over time, with the relationship between psychological causes and outcome strongest at baseline, diminishing over time, but still remaining significant at three months for anxiety and depression. Timeline was not an independent predictor at baseline, but emerged at follow-up as important, and perceptions of personal control were most related to outcomes at the three month follow-up. The illness representation dimensions related to physical QoL appeared to have much less overlap than with the other outcomes. While timeline emerged as important predictors of this outcome (particularly at follow-up), the other main predictors were identity, belief in cardiac causes, and perception of consequences. Possible reasons for these differences will be discussed later.

While this evidence supports, to some extent, previous findings that illness representations are predictive of psychological outcomes (e.g., Hagger & Orbell, 2003), previous research has shown more support for dimensions of the model other than cause. For example, in their large-

scale meta-analysis, Hagger and Orbell (2003) found strong support for the connection between identity, consequences, and timeline and psychological distress and well-being. However, despite the large number of studies in this analysis, the variation in the categories of causes reported in the individual studies was too great to allow any comparisons. The review therefore did not assess the relationship between the cause dimension and psychological outcomes, only assessing the contribution of consequences, timeline, control (personal and treatment), and identity. Conclusions about cause therefore cannot be deduced from this review. Furthermore, in previous assessments of illness representations in NCCP patients, the cause dimension has either not been assessed (Donkin et al., 2006), or no findings have been reported for this dimension (Robertson et al., 2008).

Another related area in which the role of illness representations has been assessed is MUSs. Illness representations have been shown to not only to be negative in this group (Frostholm et al., 2007; Moss-Morris, 2005; Sumathipala et al., 2008), but are also related to psychological well-being (Frostholm et al., 2007; Moss-Morris, 2005). Moreover, illness representations in response to a minor physical ailment such as gastroenteritis have been shown to predict the actual development of the MUS of Irritable Bowel Syndrome (IBS, Spence & Moss-Morris, 2007). Moss-Morris (2005) reported that identity, consequences and timeline were the main predictive dimensions in Chronic Fatigue Syndrome (CFS). Frostholm et al. (2007) collapsed illness representations together, so it is difficult to determine the contribution of each of the dimensions. With regard to perceptions of causes in MUS, Moss-Morris (2005) noted that in CFS, attributions to psychological causes were negatively related to psychological well-being. In addition, Green et al. (2004) found attributions to psychological causes common in non-epileptic seizures. Nevertheless, it seems apparent that the role of psychological causes is far more prominent in the present sample than has been found in previous research of illness representations in general.

There is an insightful strand of research into the role of causal attributions in MUSs, albeit not directly testing the CSM of illness representations. Robbins and Kirmayer (1991) suggested that causal attributions for unlabelled somatic symptoms may be more powerful in explaining outcome than attributions for labelled illnesses, as the latter are already associated with preconceived ideas about cause. They developed a tool for assessing causal attributions for somatic symptoms, and found that generally, such attributions remained consistent over time,

suggesting that patients have a type of attributional style. Moreover, psychological attributions were related to the number of chronic psychiatric problems. Subsequent studies using the same (or a modified version of the) scale have shown psychological causal attributions to be related to somatic symptoms and negative affect (Lundh & Wangby, 2002), depression and anxiety disorders (Rief, Nanke, Emmerich, Bender, & Zech, 2004), and general anxiety, even independently from hypochondriasis (MacLeod, Haynes, & Sensky, 1998). However, the relationship between belief in psychological causes and psychological outcomes may be due to a bias in reporting. Moss-Morris (2005) notes that this relationship in CFS patients may be due to an increased tendency to report psychological causes as one is already experiencing poor psychological well-being. Moreover, Robbins and Kirmayer (1991) also suggest that patients who are more likely to endorse psychological explanations may be more likely to report past psychological problems. Furthermore, while perception of psychological causes suggests that patients are aware that their chest pain may be anxiety related, not all chest pain might be anxiety related. Around half the patients in the present study had been diagnosed with an alternative cause for their chest pain (e.g., musculoskeletal, gastrointestinal, chest infection). While some of these causes may themselves be caused by stress (e.g., through muscle tension), many of the NCCP patients in this study may have had chest pain that wasn't caused by anxiety. In support of this, Henningsen, Zimmerman and Sattel (2003) reviewed the role of anxiety and depression in MUSs, and concluded that there is a relationship, but MUSs are not entirely dependent on anxiety and depression. However, Spence and Moss-Morris (2007) did identify that anxiety and stress were stronger predictors of the development of IBS. It may be the case that anxiety plays a causal role in NCCP, and also anxiety may result from NCCP.

The direction of relationships between NCCP and anxiety and stress is a matter of interest. There is a wealth of early research into NCCP which suggests that anxiety disorders, such as panic disorder, can be a cause of NCCP (Beitman et al., 1987; Beitman et al., 1989; Fleet et al., 1996; Fleet et al., 2003), and comorbid panic disorder in chest pain patients is related to poor outcomes, both in terms of continued chest pain and psychological distress (Beitman et al., 1991; Fleet et al., 2003; Wulsin, Arnold, & Hillard, 1991). This evidence supports the suggestion that patients should be screened for psychological problems when they present with NCCP, and that such psychological problems should be addressed (Beitman et al., 1991; Fleet et al., 1996; Fleet et al., 2003). However, more recently, researchers have suggested that psychological distress and poor well-being may result from experiencing continued, chronic

chest pain (Eslick & Talley, 2008). Furthermore, it has been found that levels of anxiety and depression are similar in cardiac and non-cardiac patients, and that levels of psychological distress alone cannot differentiate between cardiac and non-cardiac patients (Eken et al., 2010), thus suggesting that not all NCCP may be the direct result of a psychiatric disorder. Moreover, in the present study, while the proportion of those scoring above the cut-off for probable anxiety was high, not all patients were experiencing anxiety related chest pain. Nevertheless, even in patients where anxiety was not the cause of their pain, they may experience anxiety as a result of their pain, as such symptoms are generally associated with serious cardiac problems, and even if this association isn't made, the pain itself may be quite severe and thus distressing. This anxiety may serve to worsen the pain, creating a vicious cycle whereby neither the pain nor the anxiety is alleviated. Despite the differing nature of some of this evidence, anxiety is likely to play a role in NCCP. Some have suggested that this role is through anxiety sensitivity increasing hypervigilance to pain sensations (Keogh, Hamid, Hamid, & Ellery, 2004; White et al., 2010). The findings from the present study indicate that patients who are suffering psychologically are more likely to attribute their pain to psychological causes, indicating that anxiety is causing their pain, and they are aware of this. This is contrary to previous findings in MUSs, which suggest that patients with unexplained symptoms are more likely to adopt physical, organic explanations (Rief et al., 2004). Psychological explanations of chest pain may be more readily accepted due to the well known connections between stress and cardiac problems (e.g., Stansfeld & Marmot, 2002). Whatever the nature of the relationship, it is imperative that anxiety is assessed and treated in NCCP patients, in order to help patients cope with, or remove the cause of, their chest pain.

While perception of psychological causes was the main predictor of outcome in this sample, it is important to discuss the contribution of the other illness representation dimensions.

Perception of a more chronic timeline was associated with anxiety and depression at the one month follow-up, and physical QoL at both the one and three month follow-ups. The lack of predictive value at baseline could have been due to the acute nature of the sample, whereby patients were all somewhat distressed at the point of accessing emergency care, and so any concern about a more chronic timeline had less impact on their levels of distress and QoL than other, more immediate concerns. However, at follow-up, those who had perceived their pain to be more chronic at baseline were suffering more distress and poorer QoL. It may therefore

be the case that in patients who held a very pessimistic view about the chronicity of their pain, this led to them experiencing persistently poor psychological outcomes, as opposed to an immediate emotional response. This chronic view of their pain may have also impacted on physical QoL, as these patients may have felt they needed to limit their activity in order to relieve their long term pain. Alternatively, the poorer psychological outcomes in those with a more chronic baseline perception of timeline may be due to the fact patients with this perception actually experienced more frequent pain at follow-up. The pain itself may therefore have been impacting on outcome. Those who experience chronic (as opposed to acute) pain have been shown to report a more chronic timeline (Moss-Morris et al., 2002); moreover, timeline has previously been shown to be a very strong predictor of psychological outcomes (Hagger & Orbell, 2003), including in MUSs (Frostholm et al., 2007; Moss-Morris, 2005), and NCCP patients (Donkin et al., 2006). Timeline may therefore be a target for intervention. However, if patients are given a way to cope with, or reduce, their pain, this may indirectly reduce perceptions of timeline.

Personal control emerged as a strong predictor of mental QoL at the final follow-up, and was also a predictor of anxiety at this point. This relationship, however, only emerged at 3 months, suggesting that as with timeline, perceptions of personal control only predicted long term outcomes. It may be the case that those who felt they had little way to manage their pain at baseline deteriorated in terms of anxiety and QoL. Not having a way to manage their pain could have caused them to feel helpless when their pain did not ease over time. It may therefore be beneficial to equip patients with ways in which to manage their pain at the point of diagnosis. Previous research has found that personal control was predictive of reassurance in NCCP patients (Donkin et al., 2006), suggesting that this is an important dimension for this group. This may be due to the lack of treatment offered to NCCP patients. Treatment control had no influence on outcomes at any time point. This may be because patients were unlikely to receive medical intervention for their pain, given that the cause is often unknown. This is reflected in the fact that very few patients re-attended the ED to access further care.

Emotional representations emerged mainly as a predictor of QoL. It may seem surprising that this dimension was related to QoL but not to anxiety or depression, given that the items assess one's emotional responses to chest pain. However, this may imply something about the direction of causation; it may be the case that anxiety and depression cause the chest pain, but

the emotional response that results from the chest pain impacts on QoL. QoL has been previously shown to be reduced as a result of NCCP (Eslick & Talley, 2008; Jerlock et al., 2008), and this finding suggests that a negative emotional response to one's chest pain may influence this. As with coherence, emotional representations were not considered in the meta-analysis by Hagger and Orbell (2003) as this dimension was a later inclusion in the IPQ-R (Moss-Morris et al., 2002). Donkin et al. (2006) found that emotional representations were associated with reassurance in NCCP patients, but they were not independently predictive of it. Emotional representations have, however, been related to outcomes in chronic pain patients (Hobro, Weinman, & Hankins, 2004), and the present study suggests that this dimension can impact on QoL. Investigating and dealing with patients' emotional reactions to their non-cardiac diagnosis may therefore be beneficial.

Coherence had very small correlations with all outcome variables, and only emerged as significant in the regression models as a suppressor effect. This lack of relationship between coherence and the outcome variables is somewhat surprising given the unexplained nature of NCCP which would suggest that uncertainty could be a key factor in people's responses to NCCP. Moreover, previous studies have found uncertainty to be a common theme among people with MUSs (Green et al., 2004). The potential role of coherence/uncertainty will be explored further in the qualitative study.

At all time points, the pattern of predictors of physical QoL was different to that for other outcomes. This may be because this outcome is different in nature – all the other measures relate to psychological adjustment, whereas this outcome relates to physical impairment. It is therefore unsurprising that the pattern of predictors is somewhat different. Furthermore, the variance explained in physical QoL was consistently lower than that for other outcomes. This mirrors previous findings that, in MUSs, illness representations predict psychological outcomes more strongly than physical outcomes (Frostholm et al., 2007). At baseline, identity was a strong predictor of physical QoL, which is unsurprising, given the number of experienced symptoms is likely to actually limit physical activity. Interestingly, cardiac causes emerged as a strong predictor of physical QoL. This may suggest that patients who believed that their pain was caused by cardiac problems may limit their activity, in order to protect their heart. Previous evidence has shown that avoidance of certain behaviours is common in NCCP (Jonsbu

et al., 2010; Ockene, Shay, Alpert, Weiner, & Dalen, 1980) and this can be related to distress and health care utilization (Aikens, Michael, Levin, & Lowry, 1999).

Baseline illness representations were found to predict psychological distress over time. However, most of the effects became non-significant when controlling for baseline levels of distress. This may be understandable, given that while levels of distress did reduce over time, they still remained relatively high – thus showing that distress was, to some extent, persistent. However, it may be the case that level of psychological distress at baseline is a stronger predictor of outcome at follow-up than illness representations. Therefore, patients who are distressed at point of diagnosis are more likely to experience distress at follow-up, irrespective of the nature of their illness representations. In previous research, anxiety has been shown to be more important than illness representations in the development of another MUS, IBS (Spence & Moss-Morris, 2007). The effect of perceived psychological causes consistently became non-significant when baseline distress was controlled for. This may be because psychological causes and baseline distress were strongly related – those who attribute their pain to psychological causes are likely to be also experiencing some form of psychological distress, which they feel has resulted in chest pain. Whichever explanation holds true, it clearly remains important to deal with psychological distress at baseline, in order to improve outcomes over time.

3.5.4 Service use

The level of repeated service use was low in this sample. This differs from previous studies which have found much higher rates of healthcare utilisation in NCCP patients (Aikens, Michael, Levin, & Lowry, 1999; Aikens, Michael, Levin, Myers, et al., 1999; Potts & Bass, 1993; Wong et al., 2004). The patients in this sample may have been less likely to access healthcare due to their beliefs about psychological causes of chest pain. Attribution of physical symptoms to psychological causes has been found to be negatively related to health behaviours such as accessing healthcare (Bishop, 1987; Rief et al., 2004). Conversely, it may be the case that the nature of the CPOU care caused this lack of re-attendance. In comparison to routine care, CPOU care has been shown to reduce anxiety, depression and subsequent pain (Goodacre & Nicholl, 2004), as well as re-attendance at the ED (Goodacre et al., 2004). It may therefore be the case that with this provision of chest pain care, re-attendance of chest pain patients may not be a major issue. Nevertheless, patients may still continue to suffer, despite not returning

to the ED. Moreover, we did not assess whether patients accessed further care from their GP, which may have been common given that this is what patients are advised on discharge.

3.5.5 *Chest pain*

Almost half of the patients were still experiencing chest pain at one month, over half of whom were experiencing pain weekly or daily. These proportions are high, and although the number of people still experiencing chest pain decreased over time, it still remained high at the three month follow-up. A significant proportion of these chest pain patients therefore continued to experience pain, despite receiving a non-cardiac diagnosis. This supports the wealth of previous evidence suggesting that patients with NCCP experience persistent and continued pain following diagnosis (e.g., Eslick & Talley, 2008; Jonsbu et al., 2010; Kisely, 1998; Kisely et al., 1992; Ockene et al., 1980; Potts & Bass, 1993; Roll, Kollind, & Theorell, 1992; Tew et al., 1995).

With regard to predictors of continued chest pain, identity and timeline were the only illness representation dimensions which were predictive of chest pain frequency at follow-up. In their large meta-analysis of illness representations, Hagger and Orbell (2003) found both identity and consequences to be important predictors of physical outcome. Identity was particularly important for discriminating patients with daily pain from patients in other chest pain frequency groups, such that those with daily pain associated more physical symptoms with their chest pain than those with weekly, monthly or no pain. Those experiencing daily pain may be experiencing a higher number of symptoms generally, and be subsequently associating these with their chest pain. This group of patients may therefore be experiencing a lot of physical suffering, which is why identity, rather than psychological distress, was the main discriminating variable for this group.

Timeline was only related to chest pain frequency at the three month follow-up. This dimension has not been previously connected to physical outcomes (Hagger & Orbell, 2003). This relationship may be due to expectancy. Participants who reported a more chronic timeline at baseline were evidently expecting their pain to last a long time. This expectancy may make them more aware of their pain, or cause them to feel more helpless in overcoming it. Negative expectancies (Boersma & Linton, 2006) and helplessness (Samwel, Evers, Crul, & Kraaimaat, 2006) have been shown to predict pain outcomes in chronic pain patients. Giving patients a

tool to show them that their pain doesn't necessarily have to be chronic could improve expectancies and subsequently help them to be more effective in reducing their pain.

Anxiety, depression, and physical and mental QoL were found to be associated with chest pain frequency at the one month follow-up. At the three month follow-up, anxiety and cardiac worries were predictive of chest pain frequency. This supports previous findings that psychological distress is associated with continued chest pain (Kisely, Guthrie, Creed, & Tew, 1997; White et al., 2008). The fact that cardiac worries emerged as predictive of chest pain frequency supports previous findings that NCCP patients who are anxious about their heart are more likely to report more physical symptoms (Eifert, Hodson, Tracey, Seville, & Gunawardane, 1996).

It is unclear why the baseline psychological variables did not discriminate daily pain from other pain groups. Generally, the daily pain group fell between the weekly and the monthly and no pain groups, suggesting that they were more distressed than those with monthly or no pain, but not significantly so, and not as distressed as those with weekly pain. As suggested above, it may be the case that physical, symptomatic concerns are primary in the daily pain group. This is supported by the fact that physical QoL loaded highly on the function which discriminated daily pain from other groups at one month, suggesting that physical problems were a primary concern for this chest pain frequency group. This also reflects the findings regarding the predictors of psychological outcomes, whereby physical QoL had a consistently different pattern of predictors to the other outcome variables. There may therefore be two separate groups of patients with differing outcomes – those who experience high levels of distress and weekly pain, and those who experience less psychological distress, but worse physical QoL and more physical symptoms, who experience continued daily pain. It appears that this latter group experience much less psychological suffering in general, and have a very much physical focus to their problem. They may therefore be more suitable for treatment by medical health professionals, rather than psychological intervention.

3.5.6 Strengths and Limitations

This study extended previous research by assessing purely ED referred NCCP patients over a period of time, assessing predictors of outcomes. It extends current knowledge by giving insight into theoretical predictors of outcomes, a consideration which has been lacking in

previous research (see Chapter 2, also Webster, Norman, Goodacre, & Thompson, 2011). Nevertheless, the research has a number of limitations that need to be kept in mind when interpreting the conclusions drawn here. While the initial number of participants recruited was quite high, over time this diminished due to attrition. This response rate was lower than that seen in previous studies in the same setting (e.g., Arnold et al., 2009). This may be due to the postal nature of the follow-up; with the rise in email and text communication in recent years, participants may now be more reluctant to respond to mailed questionnaires. The remaining number of participants did, however, exceed 100, and given the postal nature of the follow-ups some attrition was to be expected. The final sample size exceeded that found at follow-up in a similar study by Eslick and Talley (2008), and was only slightly less than that found at final follow-up in a similar study by Mayou and Thompson (2002). Respondents were consistently older than those who failed to respond; however, age was controlled for within analyses.

There may be concerns about the generalisability of the sample, given that it was only drawn from one ED within the UK. However, the proportions of male and female participants, and the mean age of the participants, reflected rates found in previous studies of acute care NCCP patients, and the results were also comparable to such studies (see Chapter 2, also Webster et al., 2012), suggesting that while the findings may not be comparable to all other care settings, they may generalise to other emergency care settings.

Concerns about generalisability may also rise from the process of recruitment. While there was relatively good recording of the reasons for exclusion, some were not recorded. Furthermore, some patients were not invited, despite being eligible. However, these problems were a product of the challenge of conducting research within an emergency care setting, where staff are extremely busy, and turnover of patients is high.

Another caveat that should be considered is the potential heterogeneity of the sample. While all participants were 'non-cardiac chest pain patients', recruited from within an emergency department, there may be some variability within this group. For example, the length of time patients had been suffering with chest pain, and whether they had sought care previously, was not assessed. Some patients may have been presenting with their first episode of chest pain, while others may have been experiencing chest pain for a long time, and sought care previously. However, patients who were known to be 'frequent attenders' at the ED were generally not included in the study. Furthermore, the assessment of chest pain at follow-up

may have reflected whether the pain was chronic or acute. Nevertheless, some assessment of these factors may have been beneficial. Participants may also have been heterogeneous with regard to their diagnosis. While all patients had had cardiac causes for their chest pain ruled out, some received preliminary diagnoses whilst in the ED (e.g., gastrointestinal or musculoskeletal pain). In fact, a distinction is sometimes applied in the ED between those with benign non-cardiac chest pain (for which an alternative cause is identified) and chest pain of uncertain aetiology (Arnold et al., 2009). This was assessed during the course of this study; however, analyses showed that there were no differences between these two diagnostic groups (analyses not reported for the sake of brevity). This may be due to the fact that while alternative diagnoses may be suspected in the ED, it is rare that tests will be done to confirm them, due to the focus on ruling out urgent or life-threatening causes. As a result, this distinction is often arbitrary and based on judgement, rather than diagnostic tests.

The validity of the findings may also be questioned due to the large number of hypotheses that were tested, thus increasing the likelihood of spurious positive findings. Given the wealth of positive findings, however, along with the strength of some associations, this may not be an issue. Nevertheless, some caution should be maintained when accepting the findings.

3.5.7 Future directions

With regard to the concept of NCCP, this study showed limited support for previous findings that those with NCCP experience a high level of heart focussed anxiety, which increased vigilance to and perception of chest pain, thus exacerbating pain and causing it to reoccur and continue (Eifert, Zvolensky, & Lejuez, 2000). While cardiac worries were low in the present sample, they were predictive of continued chest pain at the follow-up. This suggests they may be a small subset of participants who maintained concerns about cardiac causes, and thus experienced chest pain up to three months post diagnosis. Nevertheless, this finding was not as prominent as in previous literature. This may be due to the difference in assessment; the studies reviewed by Eifert et al. (2000) largely relied on the Cardiac Anxiety Questionnaire (Eifert, Thompson, et al., 2000) or other measures of cardiac distress symptoms (e.g., Aikens, Michael, Levin, & Lowry, 1999; Aikens, Zvolensky, & Eifert, 2001), which mainly focussed on distress in response to symptoms. Our measure of cardiac worries assessed concerns about experiencing cardiac problems more generally. Conversely, differences may be due not to the measures used but to the different nature of care in the present sample. The previous research

was conducted around the late 1990s and early 2000s, when chest pain care may not have been so focussed within the ED. In sum, while Eifert et al. (2000) suggest that 'heart focussed anxiety' may be an alternative label to 'non-cardiac chest pain', the present findings suggest that the current generation of NCCP patients may not fall easily into such a category. It may be better to revert to the original idea, that NCCP is a manifestation of anxiety symptoms (Beitman et al., 1987; Beitman et al., 1989; Fleet et al., 1996; Fleet et al., 2003), and that distress related to this pain can subsequently, itself, result in poorer outcomes, in terms of both psychological distress and pain (Beitman et al., 1991; Fleet et al., 2003; Kisely et al., 1997; White et al., 2008; Wulsin et al., 1991). Nevertheless, cardiac concerns at diagnosis clearly do have some impact on continued chest pain, suggesting that clarifying the non-cardiac nature of patients' diagnoses may still be important.

Given the relationship between psychological distress and continued pain, and the finding that those who perceive themselves to be suffering from pain of psychological origins experience more distress, it is likely that intervening to address such psychological distress may serve to alleviate pain and improve psychological outcomes. Previous studies have shown Cognitive Behavioural Therapy (CBT) to be effective for NCCP patients (see Kisely, Campbell, Yelland, & Paydar, 2012), suggesting that treatment with a psychological focus may be appropriate for this group. Esler and Bock (2004) suggested that such a model may not be appropriate, as patients must first accept that their pain is psychological in origin. They suggest that this may be unacceptable to patients who view their pain as a medical illness, and a more biopsychosocial approach should be adopted. Given the strong role of perception of psychological causes in this sample, this may not be the case, especially for patients who are suffering high levels of anxiety (i.e., those who were shown to be more likely to attribute their pain to psychological causes). Esler and Bock (2004) did, however, suggest that a brief intervention delivered in the ED may be the most feasible and thus appropriate option for these patients. Information leaflets delivered in the ED have shown some efficacy (Arnold et al., 2009), but did not impact upon certain outcomes such as pain or planned actions in response to future pain. Developing an intervention in line with the findings from this study may help to improve efficacy. Delivering a brief, but immediate intervention at point of diagnosis, may serve to improve outcomes in the long term. It has been recommended that such an intervention could be incorporated into a stepped care model, whereby patients may all be delivered a low-cost intervention, then only those who do not respond to this need to be

referred for further, more intensive, intervention (Esler & Bock, 2004; Mayou et al., 1999; Mayou et al., 1997).

Timeline, perception of psychological causes, and personal control all emerged as important predictors of outcomes at time 3. In developing an intervention for NCCP patients, one should therefore aim to improve patients' understanding of their symptoms, reduce psychological distress which may be leading to the pain, and enhance a sense of personal control and reduced timeline by giving patients direct ways to effectively manage their pain.

3.5.8 Conclusion

This study set out to examine whether the CSM of illness representations (Leventhal et al., 1980) could explain the variance in psychological and physical outcomes in NCCP patients, and to consider what factors (illness representations and psychological distress) were related to continued chest pain. With regard to illness representations, perception of psychological causes, a more chronic perception of timeline, and less belief in personal control were all related to psychological outcomes. This contradicts previous evidence that consequences, identity, and timeline are the dimensions most related to outcomes (Hagger & Orbell, 2003), which may be due to the medically unexplained nature of NCCP. At follow-up, illness representations generally could not explain psychological outcomes independently of baseline psychological distress. This may be because distress was so persistent in this sample, or that baseline distress predicts continued distress, regardless of the nature of illness representations. With regard to chest pain, those with daily pain at follow-up were more likely to report a stronger identity at baseline, suggesting that physical symptoms were prominent in this group. Those with weekly pain, however, reported more psychological distress, worse QoL and increased cardiac worries at baseline. This relationship of psychological well-being to continued chest pain, along with the strong relationship between perceived psychological causes and outcomes, suggests that it should be a priority to target psychological distress (in particular anxiety) in NCCP patients when developing interventions.

CHAPTER 4. Study 2: A qualitative investigation of the experience of persistent non-cardiac chest pain: An in-depth exploration of illness representations

4.1 Abstract

The study presented in this chapter sought to investigate the experience of living with NCCP from the patients' perspective, using qualitative methods, to give a more detailed picture of the illness representations of patients with NCCP, and to see whether their accounts were similar to the findings in Study 1. Participants ($N=7$) were selected from the sample in Study 1, on the basis that they were experiencing continued pain and distress at the final follow-up. Participants were interviewed using a semi-structured interview schedule, informed by the CSM. Generally, participants' experiences mapped onto the model of illness representations, and findings mirrored those from Study 1. In addition to the themes relating to the illness representation dimensions, two further themes were identified: healthcare seeking and support. There was a high degree of uncertainty in participants' illness representations, particularly regarding cause. Most participants advocated psychological factors as playing a causal role in their chest pain, although many struggled to understand the nature of this connection. Concerns about cardiac causes subsided quickly for most participants. Participants had some ways of managing their pain, and these often revolved around psychological methods to reduce pain or improve mood. In the main, participants had not been offered any treatment besides physical remedies such as pain relief, which many were dissatisfied with. Chest pain impacted on a number of domains of participants' lives, although physical limitations were not widespread. The findings support the need for an intervention to explain the NCCP diagnosis to patients in order to explain the role of psychological factors, improve illness understanding, and provide patients with established methods of reducing their pain.

4.2 Introduction

Study 1 identified excess anxiety and depression and impaired mental QoL in patients with acute NCCP. The CSM of illness representations (Leventhal et al., 1980) explained significant amounts of the variance in such outcomes. The main finding indicated that a tendency to advocate psychological causes to chest pain, such as stress and anxiety, was related to poorer

psychological outcomes. It may be the case that the psychological distress is actually causing the chest pain in some cases, and, furthermore, patients are aware of this, but do not have the tools to manage it. A perception that the pain will be more chronic, and weaker belief in one's ability to personally control the pain were also related to more negative psychological outcomes. Baseline psychological distress, QoL, cardiac worries, symptoms associated with pain and a perception of a more chronic timeline were all associated with increased chest pain frequency at follow-up. To further elucidate the nature of illness representations and psychological distress in NCCP patients a qualitative interview study was conducted. For this, participants were identified on the basis of their responses to the final follow-up in study one. This was done to identify patients who were experiencing continued chest pain and psychological distress, in order to investigate the experience of those who continue to suffer beyond diagnosis, and subsequently may be in danger of re-accessing healthcare, and thus be an important target for intervention.

Qualitative data can be of great value when considering patient experience and provides the opportunity to identify novel constructs that may be of theoretical importance. Yardley (2000) suggested that qualitative methodologies 'offer a complementary set of investigative approaches which can bring fresh insights into health and illness' (p.216), thus providing a much more detailed exploration of experience rather than restricting responses to pre-specified variables. Combining quantitative and qualitative methodology has long been advocated as an effective way of strengthening research findings (Creswell & Plano Clark, 2011; Jick, 1979). Over 30 years ago, Jick (1979) outlined how combining quantitative and qualitative methods can help to account for respective weaknesses in each approach, with triangulation between the methods allowing researchers to see how findings may converge or diverge, thus either giving strength to findings, or prompting an investigation of whether and how findings may be the product of a particular research method.

Only a few studies have qualitatively examined the experience of NCCP patients (e.g., Jerlock et al., 2005; Johnson, Goodacre, Tod, & Read, 2009), although other studies have considered the experiences of patients with MUSs. For example, in an examination of illness representations in those with MUSs in primary care (within which 27 out of the 68 participants were experiencing chest pain), Sumathipala et al. (2008) discovered that while patients had a clear idea of the consequences and emotional impact of their symptoms, few could offer a clear explanation of

cause or identity (label) for their symptoms. Of those who did give a label for their symptoms, the majority gave a physical suggestion, with only one offering a psychological interpretation. Causal explanations varied widely, including physical, environmental, and even supernatural explanations, with only a small proportion offering psychological explanations for their symptoms. The perceived consequences and the emotions related to one's symptoms generally revolved around fear of physical consequences, such as serious physical illness or death. Despite reporting a general lack of knowledge about the causes of, or labels for, their symptoms, most patients reported that they sought care mainly for relief of symptoms, rather than diagnosis or further investigation. These findings indicate that while these patients may not have reported clear or coherent illness representations, many of their cognitions were focussed around physical aspects of their symptoms. Other qualitative studies have considered individual MUSs. For instance, Green et al. (2004) used qualitative methods to investigate the illness representations of patients with non-epileptic seizures (NES). Patients were found to have an unclear representation of their symptoms. In particular the identity of, or label given to, the condition was poorly defined. The authors suggest that this is what subsequently led to a lack of coherence in other aspects of their representations, implying that a clear identity is necessary in order to develop clear ideas about the other aspects of one's illness. Patients expressed some ideas about cause, which mainly revolved around psychological causes such as stress. Physical causes were also mentioned, often alongside psychological causes, producing some contradiction; however, no links between these two types of cause were made (e.g., psychological stress leading to physical damage). Participants had very little idea about how to cure or control their condition, saw the consequences as generally negative and restrictive, and had an unclear view of the timeline or course of their symptoms. These findings indicate that the illness representations of patients with NES are generally unclear, although psychological causes of their symptoms are advocated by most participants.

Qualitative methods have been previously used with patients with NCCP, albeit not within the framework of the CSM. To supplement a larger trial of emergency care for chest pain, Johnson et al. (2009) performed a qualitative examination of chest pain patients' opinions of acute care. It was found that patients who received a non-cardiac diagnosis experienced high levels of uncertainty, and subsequent frustration due to this. NCCP patients also wanted more information at point of diagnosis. However, the main purpose of this study was to compliment a concurrent quantitative trial of chest pain care. As such, the focus of the interviews and the

analysis was on aspects of care, rather than patient experience. As a result, it may be inappropriate to draw deductions regarding the experience of NCCP, as the findings were produced within the framework of assessing the model of care. Furthermore, this study was not focussed on NCCP patients specifically, and it was also unclear how long the participants had been experiencing chest pain. This study is therefore not overly insightful with regard to the experience of NCCP patients who are suffering with persistent pain.

Jerlock et al. (2005) used qualitative interviews to learn more about the daily life experience of patients with NCCP recruited from an ED. These were patients who had been experiencing chronic NCCP, some for a number of years. The main theme identified was the intrusive nature of NCCP, and how it dominated all areas of patients' lives. Within this, there were various themes related to fear and anxiety (mainly of MI) and the unpredictable and uncertain nature of NCCP. Furthermore, patients felt the need to abstain from physical activity due to fear of the pain. Stress was advocated as a cause by some patients, as well as a consequence of the pain. Participants also talked about a loss of physical and mental strength due to chest pain, which had consequences for various areas of life, such as preventing them from partaking in everyday activities, or causing irritability which caused problems with their relationships. This study highlights strongly the impact of chronic NCCP, both emotionally and functionally. Interestingly, while the study had no theoretical framework, the findings fit well into the dimensions of the CSM. Participants talked about the nature and severity of pain, which would fit into the identity dimension, and the discussion of the impact of pain on life maps directly onto the consequences dimension. Participants also highlighted various causes. Patients with NCCP do therefore seem to spontaneously discuss their NCCP in a manner that can be understood using the CSM. A detailed qualitative investigation of this may provide further information regarding the nature of patients' illness representations and enable exploration as to how well the model fits with naturalistic discussion of the experience of living with NCCP. Despite insightful findings, particularly regarding the CSM and the experience of persistent NCCP, this study only reports using content analysis, and may therefore be lacking in an interpretive aspect. As a result, important information regarding chest pain experience may be missed. Nevertheless, the authors do report latent content regarding experience of chest pain, which required interpretation. This suggests that the analysis was in fact deeper than simple content analysis, and thus the nature of the analysis may therefore be unclear and poorly

defined. This further supports the need for additional qualitative investigation of NCCP, with well defined analysis and a clear rationale.

Consequently, this study aimed to build on the findings of Study 1, by providing a more in depth analysis of the experience of NCCP patients, and to gain specific information regarding patients' illness representations. Interviews were analysed using thematic analysis in order to identify the factors that were implicated in patients' ongoing concerns and how they may be explained using the model of illness representations. This method was deemed appropriate in this instance, given the study was conducted using the framework of the CSM. While other, more inductive, methods of analysis (e.g., Interpretive Phenomenological Analysis) may have given insight into personal experience, it would have been inappropriate to use them given the over-arching theoretical framework. Thematic analysis allows for both inductive and deductive themes to be identified/emerge, which therefore allows for both identification of the CSM dimensions, as well as a more personal insight into the experience of NCCP (Braun & Clarke, 2006).

4.3 Method

Participants were recruited from patients who attended an ED in Sheffield, UK (for full details, see Chapter 3). Following the longitudinal questionnaire study, participants were selected for interview based on their report of pain and psychological outcomes on the final follow-up questionnaire in order to identify participants who were suffering persistently following diagnosis (both psychologically and regarding continued pain).

4.3.1 Inclusion criteria

In order to be considered for inclusion, participants must have responded to the time 3 questionnaire in Study 1, and have selected the box on the time 3 questionnaire which indicated they would be happy to be contacted about further research. On their time 3 questionnaire they must have reported experiencing chest pain at least monthly, and have scored either ≥ 8 on either the anxiety or depression subscale of the HADS or >1 Standard Deviation below the mean on either the physical or mental QoL subscale

4.3.2 Procedure

Participants who met the above criteria were posted an information sheet regarding the study (see Appendix 4.1), using the contact address obtained for Study 1. If a contact telephone number had been obtained for the participant, they were telephoned to tell them to expect to receive this information sheet, and then phoned again after one week. Three attempts were made by the researcher to contact the participant by phone, and answer phone messages left where possible. Those for whom we did not have a contact telephone number were sent a letter accompanying the information sheet, asking them to contact the researcher. Of those who agreed to participate, the interview was arranged at a date and time to suit the participant, and they were given the option whether the interviews would be conducted in either the participants' home or in the Department of Psychology at the University of Sheffield. Five opted to have the interview at the University, and two at home.

Before the interview was conducted, participants were asked whether they had any questions regarding the study, and whether they wished to view the information sheet again. They were then asked to sign a consent form (see Appendix 4.2). Interviews were recorded using a digital recorder, except one initial interview (participant 12) which was recorded on a tape recorder as the digital recorder was not available.

All interviews used the same semi-structured interview schedule (see below), and were conducted by the same researcher (RW). Participants were encouraged to talk freely about their experience of NCCP. Interviews lasted between 20 minutes and 1¼ hours.

4.3.3 Participants

Participants were selected for inclusion using their Time 3 questionnaire responses. All participants who returned their Time 3 questionnaire were eligible ($N=142$). Of these participants, 60 agreed to be contacted regarding further research, 26 of whom also experienced continued chest pain. A further 8 participants were excluded due not meeting any of the criteria for levels of anxiety, depression or QoL. Eighteen participants were therefore contacted regarding involvement in the present study. Of these, 8 could not be contacted, either due to lack of a contact telephone number, or no response from the contact number. Three declined participation. The final sample size for this study was therefore 7.

Of the 7 participants, 5 were female and 2 were male, and they were aged between 40 and 76 years (Mean=53.33, *SD*=13.16). Details of the participants can be found in Table 4.1. During the interviews, the majority of participants disclosed that they experienced some comorbidity, such as IBS or other muscular problems. P1 disclosed that she had recently received a diagnosis of Borderline Personality Disorder.

Table 4.1 Participant details

Participant ID	Age (at time of interview)	Gender	Interview location
P1	47	Female	Participant's home
P2	61	Male	University
P3	51	Female	University
P4	76	Female	Participant's home
P5	40	Male	University
P6	45	Female	University
P7	(Unknown)	Female	University

4.3.4 Interview schedule

The semi-structured interview schedule used contained a number of open-ended questions and probes to elicit an accurate representation of the participants' experiences. In order to develop these questions, a variety of studies that have used qualitative methods to investigate illness representations or NCCP were gathered (Goodman, Morrissey, Graham, & Bossingham, 2005; Green et al., 2004; Jerlock et al., 2005; O'Neill, 2002; Sumathipala et al., 2008). The questions used in these interview schedules were collated, and appropriate questions were selected and adapted to develop a schedule designed to elicit a biographical account of living with NCCP, loosely based upon the dimensions of illness representations. Care was taken to keep questions deliberately open in order to allow novel constructs (outside of the CSM) to emerge. A copy of this schedule can be found in Appendix 4.3. The main interview topics and questions can be found in Table 4.2.

Table 4.2 Study 2 interview schedule topics and questions

Topic	Questions
Probing for an account of individual's experience of NCCP	Try and think back to when you first experienced your chest pain. When, where and what did you first notice (probe for specific examples of early occurrences of the experience)?
	What happened when you went to see the doctors (probe for account of seeking help)?
	What has happened since then?
	Tell me about your last experience of chest pain.
Participants' current view or understanding of their chest pain (illness representations)	Do you feel you have a clear idea of what you are suffering from?
	What sort of symptoms do you suffer from related to your chest pain?
	What do you think may have caused it?
	How do you feel about it?
	What do you think will happen with your chest pain in the future?
	What do you do when you experience your chest pain?

4.3.5 *Analysis*

All interviews were transcribed by the researcher, verbatim, using a specifically developed transcription protocol (see Appendix 4.4), devised using the guidance of McLellan, MacQueen and Neidig (2003). All transcripts were double-checked against the recordings.

The interviews were analysed using thematic analysis. The transcripts were repeatedly read, and initially free coding was performed, whereby the interviews were individually coded, using illness representations as a template but also coding for individual nuances and important concepts in addition to this. This stage produced a large number of codes, and so these were reviewed to identify how they could be integrated into the illness representation dimensions (occasionally recording individual sub-categories within each dimension), or whether they were a stand-alone theme, independent of the model of illness representations. Once this process had been performed at an individual level, transcripts (and their related codes) were compared to integrate the themes into a master coding frame. This was then checked in relation to the original interview transcripts in order to confirm that all examples were consistent with the codes.

4.3.6 *Quality control*

In order to avoid researcher bias, transparency was maintained throughout the process, with a record being kept of all stages of data collation and analysis. In order to facilitate transparency each stage of the analysis was discussed and reviewed in PhD supervisory meetings (with AT). Transparency of process is a widely recommended way of ensuring quality in qualitative research (Mays & Pope, 2000; Yardley, 2000). Moreover, to further eliminate bias, an audit of transcripts and analyses were performed by one of the researcher's PhD supervisors (AT); 2 transcripts were reviewed to assess comparability to the codes and themes derived from them. This method has been suggested in the literature as a way of ensuring quality (Mays & Pope, 2000).

4.4 Findings

The participants' responses could largely be understood within the dimensions for the CSM, thus supporting the relevance of illness representations in NCCP. In addition to the eight main themes of each of the illness representation dimensions, two additional themes were identified; 'healthcare seeking' and 'support'. Most of the themes had sub categories. All themes and subthemes can be found in Table 4.3. Emotional representations seemed to overlap with the discussion of the consequences of the pain, and so are integrated with this dimension in the reporting of the findings. Lack of coherence was evident throughout the participants' interviews, and so is discussed in the context of the other dimensions where appropriate. The findings give a detailed account of illness representations in NCCP patients, mainly highlighting both the uncertainty related to the condition and the representations of it, and the focus on psychological factors. Participants often struggled to understand their condition, and often had unclear illness representations as a result. Potential causes were discussed in detail, suggesting that the lack of a clear cause is an important issue for these patients. The majority of participants advocated psychological causes, although some had a higher level of understanding of this than others.

Table 4.3 Themes and subthemes from Study 2 interviews

Theme	Subtheme
Identity	Label/name for condition
	Symptoms associated with condition
	Nature of pain
Timeline	Duration of pain (from onset)
	Expected duration of pain
Consequences	
Cause	Ideas about cause
	Psychological causes
	Physical causes
	Cardiac causes
Personal control	
Treatment control	
Healthcare seeking	Patterns of healthcare seeking
	Motivations to seek healthcare
	Low perceived seriousness
Support	

Each of the themes will now be outlined in detail to describe the nature of illness representations and the additional themes. Quotes from the interviews will be used to support these descriptions, demonstrating examples of aspects of the themes from individual participant experience.

4.4.1 *Identity*

4.4.1.1 *Label/name for condition*

Participants generally did not have a name for their condition, or struggled to come up with one. As a result, they seemed to have an unclear idea of what they were suffering from. One participant reported suffering with two types of pain, one which she clearly labelled as panic attacks, and one that she did not have a clear label for. Where participants did have a label for their condition, this was either muscular or stress-related pain. Some participants had been given a label/diagnosis by healthcare professionals, but could not remember the name of it.

Interviewer: *'Do you have a sort of clear idea of what you're suffering from, do you have a name for it or anything like that?'*

P4: *'No. Not that no my other complaints yes but not that no I 'aven't a clue what it is'*

P1: *'I get err [what] I call tightness of chest, panic attacks but it's not pain, and I understand that erm I know what that is erm so...gym chest pain is a different thing really err so I dunno what that is'*

4.4.1.2 Symptoms associated with the condition

Participants reported a general lack of other symptoms besides pain. The fact that pain is the primary symptom in this group may be due to the fact that the condition is essentially symptom based, as opposed to an illness which may have a number of complex symptoms. Where participants did report symptoms, these included anxiety and panic-related symptoms, reflecting a psychological aspect to the pain. Other symptoms included loss of sleep, sweating and tingling of the face, and difficulty breathing.

Interviewer: *'Do you get any other physical symptoms beside the pain and tightness?'*

P1: *'No not at all'*

P7: *'On one or two occasions when I was quite worried ya know I got a dry mouth like ya do when ya really anxious like when ya really nervous'*

P4: *'I started avin' this heaviness in me chest, an little tingling all over me face, an' as if there were little things crawling all over me face an' then after that I'd get this sweat an' it was just running down me face and my neck'*

4.4.1.3 Nature of pain

Participants were asked during the interview to rate their pain on a scale of one to ten. Ratings of pain severity varied both between participants (from 2 to 9) and within participants (e.g., from 3-9). This suggests that the experience of pain may be quite variable, and thus unpredictable. Severity had generally reduced, with the episode where participants had visited ED being the worst, suggesting that pain severity had improved over time.

P6: *'It started off less and got worse...Erm so initially it were probably ya know two or three, I could cope with it...An' then towards the end of the second week ya know it were- it was increasing'*

Most participants described the pain as a novel sensation. The main type of pain reported was a tightness or heaviness, but participants also reported stabbing or sharp pain. Some reported pain spreading to other areas of the body, and onset varied from quick to gradual. Pain experience may therefore vary greatly between individuals. This may be due to the

heterogeneous aetiology in this group, whereby different causes of the pain (e.g., anxiety, gastrointestinal, muscular) may manifest in different types of pain.

P4: *'I've never 'ad anything like that before this, but it wasn't a pain it was an' 'eaviness'*

P7: *'...tight right across here, but sometimes I have had as well little stabbing pains so they'll be stabbing round here and round here'*

P5: *'Because it isn't just localised in me chest it- it's through me shoulders me arms me back'*

P1: *'It comes on er gradually an' it just gets worse'*

4.4.2 Timeline

4.4.2.1 *Duration of pain*

There was some variation in the amount of time participants had been experiencing pain, with duration ranging from one month to a number of years. Chest pain was therefore very much a chronic problem for some, and a more recent problem for others.

P7: *'just periodically really [...] I couldn't tell you how often or when, but down the years really on an' off'*

All participants described their pain as episodic in nature, and thus the duration and frequency of these episodes was often discussed. As with pain severity, the duration of these episodes varied greatly between and within participants. The frequency of episodes also varied between and within participants, with frequency often being worst at the point of healthcare seeking. This implies that pain frequency may direct healthcare seeking, or that pain has improved since (potentially as a result of) attending the ED. Frequency was either daily or a few days a week for most participants, at least at some point.

P4: *'I could praps go for a few weeks an' not 'ave one an' then I 'ave a quite a few of them an' ya know an' then it'll stop an' might just get an odd one an' then few weeks later 'ave quite a lot'*

P5: *'Could be a couple o' minutes, could be a few hours, could be all day'*

4.4.2.2 *Expected duration of pain*

Most participants had general uncertainty about how long their pain might last, or hadn't considered it. This shows a potential lack of consideration or understanding of the course of the pain and how it might be controlled (either due to ignorance or avoidance), which may impact on pain coping and management. Most talked about a hope for being pain free, but had

few ideas about how this might happen. Some acknowledged this may be a slow process. One participant had been told by health professionals that his condition would be life-long.

Interviewer: *'What do you think might happen to your chest pain in the future, can you ever see you being without it?'*

P6: *'I would hope so...I don't know'*

Interviewer: *'Right...No visions of it being cured or anything like that?'*

P6: *'...I don't know maybe it'll just go away as quick as it came (laughs)'*

P5: *'They told me also yeah ya gonna be on painkillers for the rest of ya life if ya want to be pain free'*

4.4.3 Consequences

Chest pain appeared to have at least some impact on all participants, with a strong impact on some. Some reported a physical impact of the pain, whereby it could either prevent or restrict physical activity, or even simple daily activities such as eating or household chores. Participants were sometimes fearful of the potential serious consequences of their pain (e.g., disability, death, nervous breakdown). The pain had a psychological impact on most of the participants, reflecting the emotional representations dimension of the CSM. For some, this was in the form of general negative emotion, with the pain making them 'feel down'. This reflects previous findings regarding high levels of depression in NCCP. The main emotional impact of the pain was worry and concern; all participants were immediately concerned about their pain, and for most this worry persisted. Even in those participants who were reassured by their non-cardiac diagnosis, concerns were still maintained, mainly relating to potential causes and a lack of understanding about causal mechanisms. Some ruminated about their pain and anticipated the onset of pain episodes. Some participants may therefore be have been worsening or maintaining their chest pain through persistent worry and rumination.

P5: *'Am I gonna be a cripple by time I'm sixty?...Ya know that's the thing that I'm lookin' forward, well to not lookin' forward to (laughs) lookin' towards is the possibility of maybe in ten years or twenty years am I gonna be a cripple?'*

P3: *'I've kept thinkin' well I'll not eat that in case I get that pain again'*

P6: *'It still can be quite worryin''*

Interviewer: *'What kind of things do you worry about when it comes on?'*

P6: *'So ya know whether...It does come on when I'm stressed but why- why would- the reasons as to why you would get a pain in your chest just because you're stressed'*

P1: *"Cos even if you got a panic attack it's just like fearful of where- ya know how far it's gonna go because I know I've had that extreme one now with the chest pain (laughing) Like 'is that gonna come now?"*

P7: *You can't help but think about it'*

P2: *'Ya get fed up of it don't ya, pain'*

Some found that the pain impacted on the way they related to others by making them snappy, irritable, angry and short tempered. This impacted on both relationships working life as it impacted negatively on the way they interacted with family, partners, colleagues and managers. The pain also impacted on working life in other ways, such as feeling overwhelmed by workloads or struggling physically to work. This clearly shows a wider impact of the pain beyond individual suffering. It was sometimes difficult to tease apart whether these issues were caused by the pain itself, or by the stress that was either related to or causing the pain. This may be because stress and pain are strongly interlinked, influencing each other bidirectionally.

'I can get a bit snappy...with people...Noticeably at [work], sometimes with me girlfriend' (P5)

Interviewer: *'Do you ever find that erm the pain that you get or the stress that you have erm has a negative impact on any of your relationships in your family or at work or anything?'*

P6: *'Oh yeah I think it does any- I think it would on anybody'*

Interviewer: *'Right, in what way?'*

P6: *'Because if I get stressed then I sorta get snappy'...An' I'll snap at people and...probably say things that I should- I shouldn't say (laughs)'*

Interviewer: *'So you find yourself quite irritable?'*

P6: *'Irritable yeah'*

Some participants showed a level of resilience to their pain, refusing to allow to pain to impact on their psychological well-being, daily activity, or relationships.

'Just carry on don't ya, ya just 'ave to...carry on (laughs) I don't sit there and wait for it to 'appen (laughs)' (P6)

4.4.4 Cause

4.4.4.1 *Ideas about cause*

Participants discussed a variety of causes for their pain. Often participants had considered more than one cause, some still maintained a belief that there were multiple causes for their pain. This reflects the level of uncertainty that may arise from lacking a clear diagnosis. Some participants, however, had received a diagnosis. Despite this, they often still expressed some

uncertainty, largely related to the actual physical mechanisms of cause. Uncertainty about cause was also a common factor for other participants. Ideas about cause often changed over time, with many participants initially considering cardiac causes, often then deciding either psychological or other physical causes were more likely. This uncertainty regarding cause reflects a strong lack of coherence regarding NCCP, showing that the nature of the dimension of coherence may be particularly negative. This lack of understanding was mainly focussed on what caused the pain, potential mechanisms of cause, failure to identify triggers to pain, and the unpredictable nature of the pain.

P6: 'I don't really understand why [stress] causes chest pains but (laughs) I suppose that's another thing'

P4: 'No I don't know why I've got it nobody knows why I've got it (laughing) so that's it'

P3: "cos like ya think oh well it's not 'eart everythin's fine so what is- why does it- why does it 'appen?'

P5: 'It is aggravated as I say by bein' in situations or...through work...or if I'm sat funny or...But sometimes it'll just say 'hello, remember me?' bum int' chest, oh thank you'

Participants mainly developed ideas about cause through either diagnosis by a health professional or making connections between events/feelings and the pain for themselves. Both physical and psychological diagnoses had been received. Even where participants had received a diagnosis, they often also made connections for themselves. This often confirmed the diagnosis; however, sometimes participants made connections regarding alternative causes (e.g., making connections about psychological causes after receiving a physical diagnosis). Connections participants made were often between events, feelings, and pain, or from other illnesses that they had experienced. Some participants did, however, struggle to make connections between specific events/times and their pain, suggesting that this is not always an easy task. Assisting patients in making these connections may therefore be beneficial. Ideas about cardiac causes were sometimes due to suggestions or concerns from other people; however, some also made this connection due to family history of heart problems, or the high severity of the pain.

P3: 'I were tryna think when it first 'appened what I'd 'ad to eat'

P2: 'But then it travels up to me neck especially on [...] about half past five, five thirty an' there seems always seems to be around then gets worse...Whether it's throughout the day I've been using it too much'

P1: *'Now because I've just recently been diagnosed with all these bloody ulcers and bowels not working and I wonder if it's something to do with that'*

P4: *'Ya don't know whether it's the medication I mean I was on Benzofluoride for years, an' then I started with trouble with me foot'*

P2: *'I don't know. I don't know what brings it on. It 'urts now so nothing wha' I know of I do brings it on'*

4.4.4.2 Psychological causes

The majority of participants mentioned psychological factors as a potential cause of their chest pain. Some had made explicit connections implicating stress/anxiety as a cause prior to the interview. This was largely a result making connections between stressful events/feelings and the pain; however, a small number had received a diagnosis which was psychological in nature. Some participants were initially reluctant to discuss psychological factors but as the interview developed and rapport became established the majority did disclose (often spontaneously) beliefs about psychological causes. This initial reluctance might reflect stigmatisation associated with psychological issues. Some struggled to understand the nature of the connection between stress and chest pain, finding it difficult to connect psychological and physical feelings. There was some disagreement between participants regarding the direction of the relationship between stress and pain, with some seeing stress as solely causal, and others viewing it as a bidirectional relationship. Some saw the pain as a warning indicator of stress and anxiety, thus demonstrating their view that the pain is a result of psychological factors. This shows a differing level of understanding amongst participants, and reinforces the need for an explanation of this relationship.

P6: *'Now I can relate it to the stress levels whereas before I thought about it but I didn't really relate it [...] but now I can definitely [...] I 'ad chest pain the other evening, not yesterday day before, erm but I 'ad 'ad quite a stressful day at work, an' then in the evenin' I thought oof feel quite... So now I can definitely relate it to it'*

P1: *'Just from talking to you just now cos I've been thinking haha wonder if it's psychological (laughs) [...] cos I've had it once and now I get it every time...But I don't know...whether it is, cos I don't get it when I'm rowing and I don't get it on the cross trainer'*

P7: *'I worry about the pain so because I get all stressed, I think this is what's happening, the pain gets worse and then I worry more'*

P6: *'It's more of a warnin' indicator ya know that it's sorta that sorta feelin' ooh gosh I need to calm down a bit now'*

P5: *'Then I get wound up about somethin' an' then that starts to 'urt again, I don't know if it's that's causin' it or what but I know it- like I said earlier it's- it's...I know it's a physical thing'*

Participants identified a number of sources of stress in their lives, which they often felt played a causal role in their pain. These included bereavement, occupational stress, busy family life, psychiatric diagnosis (one participant had been diagnosed with Borderline Personality Disorder), and financial worries. Participants who did not draw a direct causal link between stress and pain still reported a number of sources of stress in their lives, suggesting that stress may play a causal or maintaining role in their pain without their awareness.

P7: *'I decided to take early retirement because things'd got so stressful at work, so I left work in the summer an' then I thought...I thought everything would be ok I thought oh I'll be fine now cos I'll just be able to relax but then I wasn't but [...] I think there was so many things'd been building up, cos my husband died two years ago, I'd gone back to work quite soon after that cos I didn't really know what else to do, so I've 'ad all this stress, and erm...I think there was this huge relief at having finished work, And but then boom it was sort of like I came down with a bang and...whereas I thought everything would be alright it wasn't because I suddenly was faced with well what am I gonna do now? And I had sort of vaguely thought about that but I did really think that once I'd got the stress of work out of the way I'd be fine, an' I wasn't an' then I started getting' all this chest pain again'*

P6: *'It's definitely a build up, so you- I mean everybody gets stressed ya know when you've an 'ectic life if you want to put it ya know work life, 'ome life ya know I think everybody gets stressed but I think with me it's more of erm a build up of it an ongoing thing it's not just oh yeah you've 'ad a bit of stress today it's just [...] a build up'*

P4 and P2 made no allusion to any form of psychological causes for their pain. Neither talked about any psychological factors in detail (generally or as a result of the pain), suggesting potentially this could be due to a failure to develop a rapport with the interviewer. This could certainly be the case for P2, as the interview was very short and the participant disclosed very few personal details. Alternatively, given that neither participant made any mention of psychological causes (even to deny them), it could be the case that they had no awareness that such causes could be possible. As noted above, sources of stress were still often present even when participants had not connected them to their pain. This is reflected in the lack of understanding of psychological causes in the other participants, suggesting a lack of knowledge in general regarding this. Raising awareness of psychological causes may therefore be beneficial.

4.4.4.3 Physical causes

The majority of participants discussed physical causes for their pain, most of which had also discussed psychological causes. Some participants had received a diagnosis of muscular causes; however, most were still uncertain about the mechanisms of this, despite their diagnosis. Participants themselves had considered physical factors such as muscular and gastrointestinal causes to be potentially involved, however these were often as a possibility amongst other causes, seemingly due to uncertainty about the cause in general. Some participants felt that muscular causes of pain could have been caused by past physical exertion. One participant strongly felt that side effects of the medication she was taking for her blood pressure were causing her chest pain episodes.

P6: 'I also went to see me GP erm...afterwards erm an' he diagnosed erm tets- Tietze- Tietze's [...] apparently it's inflammation of ya joints in ya er ya chest [...] my GP said to me go home and Google it (laughs) so I did...Erm because if ya press- when it came on if ya press just there, it were quite tender'

P5: 'It was a two part name an' that's all I can remember...Something cretosis that's all I can remember that's about it I can never remember what the' called it'

P2: 'Before I used to do all this runnin' 60 70 mile a week an' playin' squash...It's no good fo' ya'

P4: 'One tablet can cure one thing an' cause something else...An' that's what I wonder with what the medication that I'm on'

Where physical causes were discussed, participants had a rather unclear understanding of the processes involved in cause and maintenance, as with psychological causes. Generally, such causes were considered as possibilities among other causes – ideas that the participants had come up with in the absence of a firm diagnosis. Even when participants had a physical diagnosis, they sometimes considered other causes. There was a general lack of understanding about the underlying cause of physical causes of pain. This all may be a product of the fact that most of these participants did not have a firm diagnosis that fully explained their symptoms.

4.4.4.4 Cardiac causes

All participants initially considered a cardiac cause for their pain. These concerns quickly subsided for most participants; however, some still maintained a belief that their pain could be cardiac, either due to health anxiety or a mistrust of diagnostic tests. These participants still maintained some uncertainty about cardiac causes, often holding alternative explanations at

the same time. Some saw exertion with a lack of pain or cardiac event, a lack of a cardiac event in general, or the efficacy of indigestion remedies as evidence of no cardiac cause.

P5: *'When the pain eased off, I weren't so worried. I thought well...it dunt feel like me heart'*

P7: *'And the' said everything was fine, I've been able to keep tellin' meself it's not my heart, it's ok but then I've 'ad this irrational fear'*

Interviewer: *'Do you have any idea about one specific cause that you think might be more likely than the others?'*

P1: *'Er yeah to be honest I think there's summat wrong with my heart (laughs)'*

Interviewer: *'Really?'*

P1: *'Yeah'*

Interviewer: *'Yeah and why do you think that?'*

P1: *'Cos of past history in my family I s'pose. 'Cos it's very tight stitch like pain but I don't know what that means'*

P4: *'I mean it's always at the back of ya mind well they made a mistake with 'im it could 'appen with me but if I'm going to go I want to go with a heart attack I'm not- I don't want a stroke (laughs) I've told 'em at doctors I do not want a stroke'*

P7: *'I'm fine don't have any pain when I'm exercising, which is another reason I know there's nothing wrong with my heart'*

P3: *'I did 'ave some milk an' it it did go off...So I thought it can't be me 'eart'*

4.4.5 Personal control

Participants used a variety of methods to control or cope with their pain. Individual methods included using a fan to cool down, physically manipulating one's body, exercise, using alcohol to improve mood, and even sex; most of which were effective.

P2: *'That's why I drink Guinness, cheers me up'*

P5: *'Usually when I've had sex it's gone (laughs) it's a great cure all (laughs)'*

One method which many participants discussed was the use of was pain relief (i.e., painkillers such as paracetamol, or prescribed painkillers). Some participants had used pain relief in an attempt to control their pain; however, this was either ineffective, or participants did not like it. This was either due to a reluctance to take too many tablets (due to taking medication for other conditions) or a dislike of the effects strong pain relief had on mood. One participant noted how she had not considered taking pain relief for her chest pain, despite using them for other pains. This may suggest that she viewed her pain as different in nature to other pains,

such as headache (potentially more psychological in origin). Some participants had used other physical treatments besides pain relief, such as gastrointestinal remedies.

P6: 'An' nothin' really took it away either, ya know so Ibuprofen, paracetamol'

P5: 'I don't like takin' painkillers, especially strong one's because the' just zombify you an' I just sit there, an' ya in a bit of a daze, an' I don't like bein' like that'

P3: 'I can like just a glass of aired water some I know [...] me mum used always to 'ave aired water when she got indigestion'

Besides using physical remedies, participants also had other physical methods of relieving or avoiding pain, which were mainly focussed on avoiding certain activities, or resting the body. This mainly involved restricting activity (e.g., running, walking, household chores), often in response to pain. One participant even considered this despite advice from a health professional to the contrary. Participants generally thought that if they continued activity, they may make the pain worse, or it could lead to an adverse event (e.g., MI, death). While this was effective for some in the short term, it may be seen as unhelpful. Pain behaviours such as avoidance of activity can serve to maintain pain and disability (e.g., Vlaeyen & Crombez, 1999). As such, these participants may be increasing their disability by restricting their activity, and these methods of controlling the pain may therefore be unhelpful. Reintroducing activity in a graded, paced manner may thus be beneficial.

P4: 'While I've got this 'eaviness 'ere ya don't want to move ya- about too much [...] ya think if it's muscular ya makin' it worse aren't ya if ya do'

P1: 'I have to stop running well I stop and go into walking and then it goes away'

P1: 'It just gets worse an then I 'ave to stop running...Cos I think 'if I carry on what's gonna happen?' (laughs) ya don't know'

Interviewer: 'Yeah, what do you think might happen?'

P12: 'If I might fall down dead (laughs)'

Many participants had more helpful ways of controlling their pain, which mainly focussed on relaxation and improving mood. Some participants reported using relaxation to cope with their chest pain, although one participant had no established way of doing this, and little awareness of available methods. Some, however, had a strong awareness of established relaxation techniques. Where relaxation was used, it was effective. It is possible that improving wider awareness of these techniques may therefore be beneficial. Participants also had other ways of defocusing on their pain (besides relaxation), including using 'self-talk' (to counteract unhelpful

thoughts) and distraction, which was found to be effective. For one participant, it made him feel better psychologically rather than physically; however, this was seen as preferable.

P6: *'I just sit down and try an' just yeah an' relax an' think-'*

Interviewer: *'Is there anything specific that you do to relax?'*

P6: *'Erm no probably just watch TV or ya know take meself off, by meself'*

P1: *'[The] gym I go to, Friday morning he practices [...] mindfulness or it's meditation and yoga so ya do [...] 45 minutes of yoga 45 minutes of er bein' mindful if you like meditating...So a lot of people are doing it more because it's erm just helps with stress'*

P7: *'[I] try and talk to myself ya know talk to myself say 'come on just stop this, this is irrational''*

P5: *'But I do go out to like try an' get me 'ead around things to distract me from it I do just go out walkin' an' stuff like that I mean I do suffer with other joint pains in various other parts of me body like but it does help me distract from the fact that sometimes [...] I can forget about me troubles just go out an' walk meself to bits for a bit so (laughs)'*

P5: *'Even though I might be physically quite tired...Ya know an' things are 'urtin but I'm in a better mental space then I'll ever be if I've taken a tablet'*

Some saw managing the causes of pain as key to getting rid of their pain. This was mainly focussed on stress, with participants seeing a reduction in stress as key to reducing pain. This reflects the strong focus on psychological causes (see above *Causes* section).

P6: *'Routine helps, ya know we have quite a strict routine at home, who does what ya know er sorta ya know little one 'e goes to karate on this day [my daughter] dances on this day an' who's doin' what so...so erm...We've just 'ad the holidays ant we an' so that's been a bit 'iggledy piggledy but now we're all back into into yeah that I think that 'elps'*

More generally, there was very little discussion about how much faith participants had in their own abilities to control their pain. Some participants did state that they felt very much in control of their pain. For one participant, this was a result of the psychological treatment she had received. One participant felt that she had no control over her episodes; however, she viewed her pain very much as a physical problem, and consequently outside of her control.

P7: *'I've come to realise that I've got- that perhaps it's in my power to do something about it either because of me telling myself that or somebody else telling me, so yes it has changed in that [...]I feel that I can be more in control of what's happening. I don't know whether I am yet but I do feel that I'm starting on that path as it were'*

P4: *'I thought oh 'ere comes another one [...] an' that's it can't do anything about it nothing stops it'*

4.4.6 Treatment control

Few participants had received curative treatment for their chest pain. This is probably due to the fact that most NCCP patients receive no diagnosis for their pain, and so health professionals often do not have a method of treatment to give. Some had, however, received advice on how to manage or relieve their pain in the short term. This was mainly pain relief prescribed by GPs; however, one participant had received physiotherapy (self-referred), and some had received psychological therapy or counselling. Pain relief was largely ineffective, and participants were generally reluctant to use it. Physiotherapy was also ineffective, and the participant who received it had consequently considered going against the advice he had received. There was a general lack of faith in treatment methods in reducing pain, most likely due to the inefficacy of previous treatments, or general lack of treatment received. One participant even felt a lack of faith in the diagnostic tests used to assess her pain. There was one exception, whereby one participant had faith that the support of her counsellor would aid her in coping with her pain. This may be because she had received psychological treatment (rather than physical), as these methods were particularly effective, especially for this participant.

P5: 'They [the specialist] told me also yeah ya gonna be on painkillers for the rest of ya life if ya want to be pain free, ya gonna be livin' on like ibuprofen an' codeine or paracetamol or whatever ya can take like to get rid of it'

P2: 'So anyway they [the physiotherapist] gave me some exercises...But it still comes on so whatever they've gave me it dunt made a difference'

P5: 'I think there's little the' can do about it an' it does get to me, ya know, it does'

P1: 'I s'pose what I 'aven't got with the chest pain one is I 'aven't got confidence in the doctors [...] because they were gonna do an ECG but it's like I'm telling them it's happenin' when I'm in the gym when I'm running fast and nobody's monitored me running fast an' if they did that, that would be good, my mind would be put at rest...If they could actually whilst I was doin' it an' I got the chest pain an' they monitored it then that would put my mind at rest but it's not gonna happen' doin' these ECG lyin' down in the doctors'

P7: 'The erm counsellor gave me this...erm CD with relaxation techniques on...So that helps...That does help so if I do that it does ease or if breathing ya know steady breathing and so on does help it as well, so if I can do that it will last for less ya know a shorter period of time'

For some participants, their interaction with healthcare had improved their coherence, either through diagnosis or explanation. For one participant, interaction with a counsellor had greatly improved the coherence of her NCCP, and she found this very beneficial.

'Those facts probably, because of the sort of person I am, those facts have helped me to rationalise what's going on an' [...] it does feel like I've had a weight lifted off me really, even though there's still some of this tension there, it literally does feel like a weight's been lifted off 'cos I'm beginning to understand what's happening' (P7)

4.4.7 Healthcare seeking

4.4.7.1 *Patterns of healthcare seeking*

The majority of participants had initially sought care from their GP, either by telephoning or in an appointment, which suggests that patients potentially see this is their first point of call regarding chest pain. Participants' GPs then advised them to attend the ED, which is consistent with current protocol. Most participants delayed seeking healthcare, often by a few days or weeks, suggesting an initial lack of immediate concern.

'Well I'd left it a couple o' days...An' er I thought sod it I'll just take meself to [...] walk in centre...So I went in there put me on a few ECGs [...] I says I well yeah I got tinglin' down me arm through it an' stuff like this 'e went ah right whip ya up t' [the ED]' (P5)

'I rang my doctor in the evening and then they just sent an ambulance out' (P1)

Some participants had sought further care since their visit to the ED, mainly from their GP, although one participant self-referred to a physiotherapist. Of those who returned to their GP, one had been referred for counselling, one was undergoing further cardiac investigations, and one had repeatedly been referred on to the ED. Some participants were reluctant to seek care again, partly because they felt that little could be done to help them.

'My doctor [...] she was really good she was very supportive an' I was quite upset when I went to see her, felt better when I'd seen her an' she then has referred me to the practice counsellor' (P7)

'Three times now I've been to the doctors an' each time they've shipped me off to the hospital...So ya scared stiff to go anymore (laughs)' (P4)

Most participants found their experience of the ED very positive, often reporting that they were pleased not to have been made to feel as though they were wasting health professionals' time. These concerns may reflect a feeling among participants that their chest pain wasn't a real medical problem. However, the reactions of the health professionals in the ED clearly dispelled this fear.

'It was very thorough I was very impressed and at no time did I feel that I was wasting their time which is what I was worried about, I've always been worried about that but ya know at no point did they make me feel that I'd been silly to go' (P7)

4.4.7.2 Motivations to seek healthcare

Participants sought care for a number of reasons. The main factor was pressure or concern from other people. Another prominent reason for seeking care was due to concern about the pain and its cause. This is unsurprising, given that chest pain can be a symptom of serious underlying problems. Some participants accessed care in response to an increased frequency of pain episodes. Only one participant reported that she sought care in search of a cure. One participant returned to her GP due to emotional distress.

'I went to hospital mainly through pressure from family an' friends, an' just because they said 'oh you really need to get that checked'' (P6)

'I was a bit worried about it I thought it might be something else...Erm...So that was what prompted me eventually [to go to the GP]' (P7)

'I got it quite a bit a fortnight ago an' I thought Oh I'll go t' doctors again see if the' can give me a tablet ya know before I go away' (P4)

'An' I was worried an' panicky and then I started thinking that there was something the matter with me, wondering whether to go back to the doctor anyway eventually...sometime in September...when I was sort of in a bit of a state, an' I hadn't really told anybody...Erm I decided I thought go to the doctor, this is ridiculous go to the doctor and do something about it' (P7)

4.4.7.3 Low perceived seriousness

One theme that emerged in the discussion of healthcare seeking was a sense that participants had not viewed their pain as potentially very serious. Participants' reactions to situations and experience in health care demonstrated a feeling that chest pain was not always seen as a serious medical problem. This generally manifested itself in a reluctance to follow healthcare professionals' advice, such as an unwillingness to attend the ED. It seemed that health professionals viewed the participants' chest pain as a potentially serious problem, in need of immediate treatment; however, the participants themselves, despite reporting concern, did not seem to have the same sense of urgency and potential seriousness. When in the ED, there was also a general feeling among the participants that their problem was not as serious as other patients, that they didn't need to be there, or they were wasting health professionals' time.

'I went with my son, he went cos the doctor'd said somebody else should drive, well I drove because I felt alright by then' (P7)

'The' put me onto a bed, trolley, an I thought 'I can't lay on that' so just stood at side of it I thought 'can't lay on bed' (laughs)' (P2)

'I looked at some of the people the' were poorly [...] collapsed, so I thought 'wheer ya worse than me'' (P2)

'When they were asking me have you got any pain now I was thinkin' 'no I haven't, no I haven't', an' I thought, and I did feel, there was that element of me thinking I shouldn't 'ave bothered with this and I would've been alright' (P7)

This may be partly due to the episodic nature of NCCP. While experiencing pain, people may feel very fearful, concerned, and unwell. Once that episode passes (e.g., once they have got to the ED), they may view the pain in a more rational manner, and no longer see it as serious. When no longer in pain, the participants didn't seem to feel their health or safety was at risk.

4.4.8 Support

Participants often told someone at the initial onset of their pain. Often this was simply those who happened to be around them, such as work colleagues or a significant other. Sometimes these people offered advice on how to relieve the pain or that they should seek help.

P3: 'As I woke up me 'usband woke up an 'e says 'what's the matter?' an' I went 'I got a pain in me chest' 'e says 'which side' an' I went...'that side'...An 'e went "ow bad is it?" I says 'oh it'll go off'... An' [...] 'e says 'are ya sure it'll go off?' I say 'oh yeah it'll be fine' an' I did go back to sleep'

Some participants reported sharing with significant others about their pain. Often these people provided them with support, reassurance, or assistance. Some, however, spoke about how they didn't share with those close to them (either talking or in terms of assistance with daily activities), due to not wanting to burden others. In those who chose not to talk to significant others about their pain, they often found it helpful to talk to someone more distant, such as a colleague or their counsellor. One participant felt that she would have shared with her recently deceased husband, and not having this support had a negative impact, causing her to feel very alone. It may therefore be the case that some kind of support (whether from family, friends, or someone impartial) is important for patients with NCCP.

*P6: '[My husband] knows yeah I 'ave I've said...'I'm getting stressed now and I've got pain in my chest' (laughs) an' 'e'll say 'Well go and sit down then an' stop getting stressed' (laughs)'
Interviewer: 'Do you find that he's quite supportive then, when it comes on?'*

P6: *'Erm yeah lightly supportive ya know 'e's not sort of 'oh never mind come and sit down ya know I'll make you a cup' it's not like that but that's not our relationship ya know 'e'll just sorta say 'well ya know ya need to calm yaself down go on then' ya know, that sorta (laughs)*

P5: *'I just feel like... I don't wanna like burden somebody else with it...An' why should I burden somebody else with it...Ya know...me work colleague 'e's got similar- 'e's got problems of 'is own 'e 'as a lot of joint pains 'imself like, so I feel like I've got somebody to talk to about it wi' at work'*

P7: *'[My deceased husband's] the one I would've talked to ya see about it...And that's why, why I don't talk to other people because he would've been the one that I would've talked to... an' I would've been alright then cos I'd've offloaded it ya see at the beginning before it got out of control, erm and he'd've just said 'I'm sure you're alright ya know' an' he'd've said 'I'm sure everything's ok' and ya know it just I'd just've had that comfort'*

4.5 Discussion

This study set out to provide a detailed examination of the illness representations of NCCP patients, thus complimenting the findings in Study 1. In general, while this study provides a detailed description of illness representations within this group, it reflects a strong lack of coherence, across all dimensions. Illness representations were therefore often not well-established or defined, as may be found with more established illnesses. This may well be due to the unexplained nature of the diagnosis, and has been evident in other studies of NCCP and MUSs (Green et al., 2004; Jerlock et al., 2005; Johnson et al., 2009; Sumathipala et al., 2008). This is in contrast to the finding in Study 1 that coherence was not related to outcomes, which may be due to issues with measurement of illness representations in NCCP. This issue will be discussed later. In contrast, the findings here compliment the findings from Study 1 and provide further information on the role of psychological factors in NCCP. The acceptance of psychological causes in this sample contrasts to previous findings in MUSs (e.g., Sumathipala et al., 2008), and this important finding will be discussed later.

Regarding identity, the majority of participants focussed solely on chest pain, with few other physical symptoms being discussed, thus reflecting the low scores for identity found in Study 1. Participants generally did not have a label for their condition (with the exception of those who had received a diagnosis) which is common in patients with MUSs (e.g., Sumathipala et al., 2008). The nature of the pain was novel for participants, and varied in severity and nature between participants. Severity also varied greatly within participants. Most participants didn't seem to have a clear idea about the expected timeline of their pain, although most were very

clear about how the pain was episodic in nature. Again, these episodes were highly variable, both between and within participants. This variable, episodic nature has been found in other qualitative studies of NCCP (Jerlock et al., 2005), and the episodic nature of NCCP has been previously reported in the quantitative literature (e.g., Eslick & Talley, 2008; Potts & Bass, 1993; van Peski-Oosterbaan et al., 1999).

The consequences of the participants' pain varied from physical impacts, such as having to limit or change activities, to psychological impacts, such as feeling down or irritable, and impacts upon relationships. This is consistent with previous findings that NCCP impacts heavily on everyday life and activities (e.g., Mayou et al., 1994). Furthermore, Jerlock et al.'s (2005) qualitative examination of NCCP mirrors the present study in terms of the impacts of NCCP, such as limiting daily physical activities (due to fear or lack of strength), interrupting concentration, or causing irritability which impacted upon relationships. Participants in the present study also spoke about how their NCCP had impacted on work, either through physically limiting them or affecting the way they interacted with colleagues. Previous research has found NCCP to have similar impact upon working and social life as cardiac problems (Cheung et al., 2009). This highlights the importance of dealing with NCCP and its psychological consequences, as any impact on working life may have subsequent impacts on the wider economy.

The impact on daily life demonstrated here may reflect previous findings, from both Study 1 and previous quantitative studies (Cheung et al., 2009; Fagring, Gaston-Johansson, Kjellgren, & Welin, 2007), that NCCP patients suffer reduced QoL. Participants in the present sample only reported limited physical impacts of NCCP (e.g., changing swimming technique or eating habits, limiting some daily activities). This reflects the results in Study 1 which showed that physical QoL was not as reduced as mental QoL, and suggests that patients with NCCP may not be physically impaired. Moreover, some participants refused to let the pain impact upon their lives and relationships, demonstrating a form of stoical coping, previously referred to as Stoic-Fortitude, described as a propensity to demonstrate courage or fortitude in regard to one's pain (Yong, Bell, Workman, & Gibson, 2003). It may also reflect a high level of resilience in this sample. Resilience may be defined as positive adaptation in the face of adversity (Luthar, Cicchetti, & Becker, 2000). The present sample had clearly faced adversity (i.e., ongoing chest pain), but the majority appeared to have adapted well, having identified some coping

mechanisms and developed some insight into causal explanations (albeit lacking in clarity). Furthermore, in Study 1, levels of anxiety and depression returned to normal levels in the final follow-up, suggesting that psychological distress may not be as persistent as previously thought. This may suggest that while intervention may be beneficial for this group, lower level interventions (such as self-help) may suffice. The topic of interventions for NCCP will be discussed in detail in Chapter 5.

Potential causes for chest pain were discussed extensively throughout the interviews. This is most likely because of the unexplained nature of NCCP, whereby most participants had not been given a clear explanation of cause. Similarly, Study 1 found cause to be a much more prominent dimension than had been found in other studies of the CSM, and it is suggested that this is because symptoms like NCCP do not have predefined explanations, as diagnosed illnesses often do (e.g., Robbins & Kirmayer, 1991). Participants had many ideas about cause, and some still maintained multiple causal explanations. Maintaining multiple causal attributions has been previously found in patients with MUSs (Rief et al., 2004), and uncertainty about cause has been demonstrated in NCCP patients (Jerlock et al., 2005). Most participants had considered some form of psychological cause (e.g., stress, tension, panic), often alongside physical explanations; however, no connections were drawn between these two types of explanation. Green et al. (2004) found a similar pattern of causal explanation in patients with NES, whereby most participants offered psychological explanations, often alongside seemingly contradictory physical explanations, but they drew no connections between the two. This incoherent pattern of causal beliefs may be due to a lack of understanding of the causal pathways between stress and physical illness. Only two participants in the present study had a clear idea about these pathways, and these were people with diagnosed psychological causes. Others could not easily define the connection, and one even explicitly expressed her confusion about this. One participant, who had received a physical diagnosis, had considered psychological causes but found great difficulty in reconciling this with the physical nature of the pain. Offering patients with a clear explanation of how stress might cause pain may therefore be helpful. For some, this explanation may not be sufficient, as patients with NCCP may struggle to accept a psychological explanation for their physical symptoms (Esler & Bock, 2004). For these patients, more intensive intervention, assessing causal beliefs and their strength, may be necessary.

As in the Green et al. (2004) study, a small number of participants thought their pain to be purely physical, not considering any psychological influence. This may be due to the purely physical nature of the pain, whereby sufferers do not make the connection between psychological factors and physical symptoms. Previous findings have suggested that patients with unexplained symptoms are more likely to adopt physical, organic explanations (Rief et al., 2004). However, given that this is not widespread in the present sample (or in Study 1), this seems not to be the case for NCCP. Psychological explanations of chest pain may be more readily accepted due to the well known connections between stress and cardiac problems (e.g., Stansfeld & Marmot, 2002). Nevertheless, some of these patients clearly do see their pain as purely physical. This may simply be due to the fact that sometimes the pain *is* solely physical. There are a number of physical causes that may result in repeated non-cardiac pain, such as musculoskeletal and oesophageal disorders (Bass & Mayou, 2002). Conversely, as suggested in the above *Findings* section, this lack of discussion of psychological factors in these patients may be due to a failure to develop rapport, or a lack of awareness of potential psychological causes. Raising awareness of the role of psychological factors in chest pain may therefore be important.

All participants had initially considered a cardiac cause for their pain, but for most these concerns subsided quickly. This is contrary to previous findings that NCCP patients generally continue to maintain fears about cardiac problems (Carmin et al., 2003; Dumville et al., 2007; Jerlock et al., 2005; Mayou et al., 1994; e.g., Potts & Bass, 1993), but supports the Study 1 findings that cardiac concerns were not prominent in this sample. As discussed in Chapter 3, this lack of continued concern about cardiac problems may be due to the acute, rapid-rule out nature of ED care. However, two participants in the present study still maintained the idea of a possible cardiac cause. One viewed this as irrational, and saw it as a product of health anxiety (which had been diagnosed by her counsellor). The other, despite considering a number of physical and psychological explanations, still viewed cardiac problems as the most likely cause of her pain. This was largely because she was mistrusting of the diagnostic tests she had received (and was due to receive). This lack of reassurance following negative diagnosis is consistent with health anxiety (Salkovskis, Rimes, Warwick, & Clark, 2002). It may be the case that this participant would benefit from further investigation of this potential health anxiety. Nevertheless, it remains imperative that patients' cardiac concerns are dealt with and reassurance is provided at the point of diagnosis.

Ideas about cause did sometimes come from others (e.g., health professionals, friends and family), but they were mainly drawn from the connections participants had made between their pain, experiences, and feelings. This included making connections between times of stress and the onset of pain, suggesting that encouraging patients to do this may be beneficial in helping them to understand the role that stress may play in causing their pain. Some participants also viewed the lack of pain or cardiac event during exertion as evidence of no cardiac cause. This suggests that encouraging NCCP patients to exercise more could be helpful in reducing any fears about cardiac problems. Given that people with NCCP tend to avoid physical or work related activity for fear that it may cause pain or damage their heart (Jerlock et al., 2005; Jonsbu et al., 2010) and this avoidance of activity is related to both cardiac distress and ED attendance (Aikens, Michael, Levin, & Lowry, 1999), increasing exercise in NCCP patients may reduce immediate pain and stress. Furthermore, aerobic exercise can reduce both the physiological and psychological impact of stress, particularly on the cardio vascular system (Blumenthal et al., 1990) and so may also reduce long-term cardiac risk.

With regard to controlling their pain, few participants had well-defined methods of pain management. Personal control methods were varied and included pain relief, resting in response to pain, and psychological management (e.g., relaxation, distraction). These showed some efficacy, but no participant had identified a way to control their pain over the long-term. Jerlock et al. (2005) and Sumathipala et al. (2008) did not consider methods of personal control in detail, but both discussed how patients felt they should rest in response to or prevent NCCP and MUSs (respectively). This notion of needing to rest was also common in the present study. As discussed above, NCCP patients often limit their physical activity, when actually this can reduce stress and anxiety. This therefore highlights the importance of emphasising the need to keep active when delivering a NCCP diagnosis.

Treatment control methods focussed mainly around physical management such as pain relief or physiotherapy. This was mostly in participants who had received a physical diagnosis, and, as such, was most likely appropriate care. Nevertheless, participants often spoke about how this was partially or completely ineffective. Furthermore, within both personal and treatment control, there was a general reluctance to take medication, either because it was ineffective, had effects on mood, or because of general negative feeling towards it. A more holistic approach to care might therefore be more appropriate, introducing other methods of coping

with pain in the event that pain relief is ineffective or undesirable. Recommendations for MUSs include introducing the role of psychological factors early on in the investigation process (Mayou, 1991), and current chest pain guidelines do recommend discussing anxiety where the cause of chest pain is unknown (National Institute for Health and Clinical Excellence, 2010). However, participants had generally been prescribed pain relief by their GP, who have been known to focus solely on the physical aspects when patients present with somatic symptoms associated with psychological problems (e.g., Weich, Lewis, Donmall, & Mann, 1995). GPs may be reluctant to approach psychological factors if they do not feel they have the skills (Williams et al., 1999), training (Richards, Ryan, McCabe, Groom, & Hickie, 2004) or resources (Wilson & Read, 2001) to deal with them. GPs should therefore be aware of resources to which patients can be referred for advice or assistance with psychological factors such as stress, such as self-help resources. Brief interventions have shown some efficacy in assisting patients in dealing with NCCP (Arnold et al., 2009; Esler et al., 2003). Some patients may need more intensive care; CBT is supported for use in MUSs (Mayou, 1991) and in NCCP (Kisely et al., 2012), and GPs should recognise where patients might need referring on for further assistance.

Few participants had faith in treatment controlling or curing their pain, but most were hopeful for a cure or to be pain free. This lack of faith may stem from the ineffectiveness of previous treatments, causing a lack of faith in any future treatment. Given that treatment expectancies are strongly related to treatment outcomes (e.g., Goossens, Vlaeyen, Hidding, Kole-Snijders, & Evers, 2005) it might be important to improve expectancies of participants by offering them alternative treatment, different in nature from previous treatments. It may be the case that the lack of diagnosis in NCCP leads to a lack of belief in a cure, as has been found previously (Jerlock et al., 2005). Explaining alternative reasons for NCCP more clearly (e.g., stress, gastrointestinal) may provide patients with more hope of finding a way to manage their pain.

The emotional impact of pain was largely related to concern, anxiety or worry about the pain itself. This was mainly related to the cause of the pain, either because of a lack of a clear causal explanation, or concern about a serious or cardiac cause. This concern subsided for most, but did maintain for some, sometimes exacerbating pain in a 'vicious cycle'. Chest pain also led to some participants feeling down or upset, which was sometimes related to uncertainty about the pain. Feelings of irritability, short-temperedness, and embarrassment were also reported. Emotional distress related to NCCP is widely known, with levels of anxiety and depression

being high in this population, along with reduced mental QoL (Webster et al., 2012, see also Chapters 2 and 3). Jerlock et al. (2005) found a similar pattern of concern regarding pain or the cause of pain, stress, and worry in NCCP; however, fear of MI was much stronger in their study. Similarly, Sumathipala et al. (2008) found a high level of fear within MUS patients, particularly related to death or serious illness. The lack of serious fear or concern in the present study reflects the lack of persistent concern about cardiac causes.

There was a general lack of coherence or understanding of NCCP, which was mainly with regard to the cause of the pain, the unpredictable pattern of the pain, or triggers for the pain. Participants struggled to identify one particular cause, to identify connections and triggers and to understand mechanisms, even among those who had received a diagnosis. Coherence was also demonstrated in the other dimensions; for instance, the lack of a clear label, ideas about duration, or established methods of management. This finding is in contrast to that in Study 1, where coherence was not related to the outcome variables. The findings in the present study may explain this lack of a relationship – while issues of uncertainty and coherence were very prominent, they emerged in relation to the other themes, rather than as a standalone theme in their own right. It appears that people with NCCP may have a lack of coherence in relation to other dimensions of their illness representations (e.g., an unclear idea about cause or duration), rather than a generalised lack of coherence about their illness. This reflects findings in previous studies of NCCP, where illness representations were not well formed, showing uncertainty across dimensions (e.g., Sumathipala et al., 2008). Therefore, the measurement of coherence as a unique dimension may be inappropriate in NCCP patients (and potentially in wider MUSs in general) – it may be more appropriate to assess the coherence in relation to the individual dimensions. Uncertainty is common in the previous literature on NCCP (e.g., Jerlock et al., 2005), MUSs (e.g., Sumathipala et al., 2008), and in NES (e.g., Green et al., 2004). This uncertainty is not surprising given the unexplained nature of NCCP – most of the participants had not received a diagnosis for their pain, and so had come up with ideas themselves which subsequently had not generally been diagnostically confirmed. Even among the participants who had received a diagnosis, most could not understand what had brought that cause about, or the underlying mechanisms of it. Providing some explanation about these mechanisms may help to reduce any uncertainty. Furthermore, assisting patients in drawing connections between triggers and pain may be useful in helping them to understand their pain, what triggers it, and what pattern it may follow.

In addition to the illness representation dimensions, two additional themes were identified. These were healthcare seeking and support.

In the discussion of healthcare seeking, a general lack of perceived seriousness about pain emerged. This manifested in not only participants accessing lower levels of care initially (e.g., GP, walk-in centre) and the need for others to motivate care seeking, but also in a reluctance to follow health professionals' advice, feeling like their pain was not serious enough to warrant emergency care, and a concern for wasting health professionals' time. This is consistent with the construct of perceived seriousness which is included in the Health Belief Model (HBM, Rosenstock, 1966), which proposes that the perceived seriousness of a condition is important for seeking care and following health advice (Janz & Becker, 1984). If participants didn't view their symptoms as having serious consequences, this may explain why they were reluctant to follow advice/seek care. Alternatively, the lack of perceived seriousness may reflect the episodic nature of chest pain. Despite initially having serious pain, all participants reported that the pain had subsided by the time they were in the ED. This lack of pain may have taken away the lack of perceived immediate threat, and so reduced the perceived seriousness. Retrospective reports of pain have been shown to be related to current pain status (Brauer, Thomsen, Loft, & Mikkelsen, 2003); therefore, if participants were experiencing no, or very little, pain at the time of seeking healthcare, they may perceive that the pain was less serious than initially thought, and thus fears related to the pain (e.g., of a cardiac event) may be less prominent.

With regard to support, most participants initially spoke to others about their pain, and some continued to do this, particularly with significant others. Three participants, however, spoke of how they were reluctant to share with others (either with regard to talking or practical burden) for fear of burdening them. Some spoke of how the feeling of burdening others would actually make them feel worse with regard to their pain. This suggests a degree of selflessness, whereby these participants placed the well-being of others above their own. Most participants felt that they had support from those around them, either in day to day life or in dealing with their pain. There has been little previous discussion into the role of significant others in NCCP, besides the finding that pain can limit social activities (e.g., Cheung et al., 2009; Jerlock et al., 2005). In the wider pain literature, social support has been shown to improve pain coping, and subsequently improve pain (Holtzman, Newth, & DeLongis, 2004); however, it may also have a

negative impact by reinforcing pain behaviours (Gil, Keefe, Crisson, & Van Dalftsen, 1987). Social support can be beneficial for improving physical activity (Ståhl et al., 2001) and also adherence to prescribed treatments (DiMatteo, 2004). Involving significant others in care and encouraging them to play an active role in improving or coping with pain may therefore be beneficial.

4.5.1 *Strengths and Limitations*

This study compliments the findings in Study 1. The combination of the two different methods (i.e., quantitative and qualitative) allows for triangulation which provides some support for the findings in Study 1 and provides an in depth account of the experience of living with NCCP. Triangulation using different methods can help to ensure that findings are not simply a product of the methodology used (Jick, 1979). However, despite this, the studies were grounded in one predominant theoretical viewpoint, which may have influenced the findings so as to cause them to not be a true reflection of participant experience. In short, there is a danger that the dimensions of illness representations were only identified because they were being sought. As such, the findings from both studies may be biased as a result of studying participants using a theoretical framework. However, the CSM is a model that has been consistently applied across a range of conditions (e.g., Hagger & Orbell, 2003), including MUSs (e.g., Green et al., 2004; Moss-Morris, 2005) and NCCP (e.g., Robertson et al., 2008, Donkin et al., 2006) and the study reported here took steps to allow novel material to emerge and to ensure that the methods used were rigorous. The interview schedule was developed in order to initiate a discussion of chest pain experience before commencing questioning regarding illness representations. This was done to provide the opportunity for some inductive examination of experience, so as to extend the findings slightly beyond an investigation of a theoretical framework. To reflect this, analysis was completed to identify emergent themes, rather than simply performing a content analysis based on the CSM. Further, the aim of the present study was to provide a detailed examination of the illness representations of NCCP patients, and as such, it is appropriate to ground the work within that theoretical framework, rather than using a purely inductive approach. The findings should not be seen as a reflection of NCCP patients in general, but as a detailed description of the nature of illness representations within this sample of NCCP patients living with persistent pain.

As the same researcher who had conducted the initial questionnaire study also conducted the interviews, there is potential for bias. The researcher had a strong awareness of the theoretical

model on which the study was based, and was aware of preliminary findings from Study 1. There is therefore a possibility that they may have inadvertently biased the findings to correlate with the initial study. This bias would have been minimised, however, by the fact that a pre-devised interview schedule was adhered to throughout the interviews. This influence of prior knowledge and opinions could have also affected the analysis, as the researcher who completed the interviews also completed the analysis. However, quality control procedures were incorporated to account for this; a high level of transparency was maintained throughout the process, and an audit of the analysis was performed, alongside close supervision by the researcher's supervisor.

There may be a question regarding the sample, specifically concerning the transferability of the findings. The number of available participants was limited, due to the inclusion criterion that stated participants had to agree to be contacted regarding the research study on their final questionnaire in Study 1. Some attempt was made to purposively sample, through selecting participants who were experiencing continued pain and suffering; however, this was difficult due to the limited number of participants agreeing to be contacted regarding further research. As such, not as many interviews were conducted as initially planned. It may be the case that if more interviews were conducted, new themes may have emerged. Because of this, the findings may not be transferable to other groups of NCCP patients, as there may be other themes that are prominent which weren't identified in the present study. The context of the research should be taken into account when considered how the findings might be transferred, i.e., in the present study, the sample was drawn from a group of ED patients who responded to questionnaires regarding their chest pain. As such, chest pain may be a more prominent or important issue to them than in other groups of NCCP patients.

It was noted in Chapter 3 that the sample of participants may be heterogeneous with regard to duration of chest pain and diagnosis. The findings of the present study support this concern, demonstrating that even within this small sample, there was great variation with regard to duration of pain, whether a diagnosis had been received, and the nature of any diagnosis. While this may be considered a limitation, this might be unavoidable when researching NCCP patients. NCCP is, by nature, a heterogeneous condition, with a variety of potential causes, including gastrointestinal, musculoskeletal, and psychological. Furthermore, these causes may also often overlap (for example, psychological causes such as stress may exacerbate

gastrointestinal or musculoskeletal symptoms). This, along with the fact that patients often are not tested in the ED to confirm other causes, would make it very difficult to select a distinct, homogenous group of NCCP patients. As such, it is therefore appropriate to group these patients by the general symptom of 'non-cardiac chest pain', despite the potential heterogeneity.

Limitations also arise from the use of a single interview methodology. For example, during transcribing, some of the intonations involved in non-verbal communication may be lost (Potter & Hepburn, 2005). However, in an attempt to avoid this, the researcher who conducted the interviews also transcribed the recordings. A detailed transcription protocol was developed, indicating how non verbal sounds and pauses should be recorded, and the interviews were transcribed verbatim. Furthermore, as the interviewer also conducted the analysis, they had an awareness of how the interview had been conducted and any non-verbal communication which was portrayed by the participants. This was supported by notes that the interviewer made during the interviews. It may be the case that one interview was insufficient to gain comprehensive data from the participants. Some of the interviews were short, and some participants didn't engage in any discussion of personal issues. This may be due to a lack of rapport being developed with the interviewer, which could have developed over time given repeated interviewing (Murray et al., 2009). Finally, the timing of the interview may have been not optimal. Participants were recruited for this study after the final (3 month) follow-up questionnaire in Study 1. As such, there was some distance between the initial ED visit and the interviews. However, this was done to provide a reflection of the experience of chronic NCCP. To demonstrate this, all participants were selected on the basis that they were still experiencing chest pain at 3 months. Furthermore, many participants had experienced chest pain for a number of years. Nevertheless, memory bias may have influence responses due to the timing of the interviews.

4.5.2 Conclusions and future directions

The experiences of NCCP in this study were consistent with the model of illness representations, and compliment many of the findings from Study 1. Overall, the findings of Studies 1 and 2 together indicate that cause is a very prominent dimension among patients with NCCP, with a particular focus on psychological causes. This study also showed that coherence is very prominent across the illness representation dimensions, with participants

often demonstrating poor understanding or confusion regarding their chest pain and its cause. There seems to be a strong emphasis on personal control, rather than treatment control, most likely due to the lack of treatment options. Generally, this group of NCCP patients seem to be suffering psychological morbidity, which may be a cause or a result of their chest pain. The direction of the relationship, however, is unclear. Conversely, physical impairment due to chest pain was limited. Contrary to prior research, concerns about cardiac causes were low in this group, and any initial concerns subsided quickly for most.

The main factor that seemed to emerge across the themes in this study was uncertainty. This manifested mainly as confusion about potential causes and causal mechanisms, but it was also evident among other themes. For instance, few participants had a well defined label for their condition, and symptoms were often varied and unpredictable, suggesting a lack of clear identity. No participants had a clear idea about the potential timeline or duration of their illness, and the episodic nature of the pain was, again, unpredictable and variable. While participants had some ideas about how to control their pain, these were often not well defined and techniques were not well-established for most. This high level of uncertainty and lack of understanding could be seen as demonstrative of the nature of illness representations in general in this group. As suggested by Green et al. (2004), it may be the case that a lack of a clear identity (i.e., label) for an illness/symptoms may cause difficulties in developing clear ideas regarding the other dimensions of illness representations. This lack of coherence may therefore be difficult to overcome due to the lack of clear diagnosis and treatment often associated with NCCP, but efforts should be made where possible to clarify the diagnosis of NCCP and offer recommendations for management, and uncertainty should be a target for intervention. Furthermore, further investigation regarding the incoherence of illness representations in MUSs may also be beneficial.

Another factor which predominated throughout this study was participants' awareness of the potential role of psychological factors. Almost all participants talked about sources of stress that they had in their lives, and most made connections between this stress and their pain. Many, however, needed some clarification regarding these connections, as they did not have a clear understanding of the mechanisms by which stress might cause pain. Furthermore, there was a preference for psychological methods of management (e.g., relaxation, improving

mood), with a desire for less focus on less pharmacological treatments. Many participants did not like using pain medication, and often found it ineffective.

Overall, interventions should aim to target uncertainty in NCCP, to highlight and explain the role of psychological factors in causing chest pain, to help patients to draw connections between events, feelings, and pain, and also give participants the tools to deal with pain and associated stress. Increasing physical activity and CBT techniques are potential options for intervention. CBT techniques may help to change beliefs about the cause and potential consequences of pain, and could also incorporate established relaxation techniques to relieve stress and anxiety. Graded exposure to activity may challenge beliefs that exercise will worsen pain or lead to a cardiac event by reducing fear of bodily sensations (Jonsbu, Dammen, Morken, Moum, & Martinsen, 2011), and graded exercise interventions have been shown to improve functioning (Staal et al., 2004). Further discussion of interventions for NCCP will follow in Chapter 5.

CHAPTER 5. Study 3: The acceptability and feasibility of an anxiety reduction intervention for people with non-cardiac chest pain

5.1 Abstract

This chapter reports of the development of a self-help intervention for NCCP patients, and the initial acceptability of the intervention. A leaflet based intervention was developed using the findings presented in Chapters 2, 3 and 4, and previous successful interventions for NCCP. Mixed qualitative methods were used to examine patient and professional views on acceptability and feasibility. A sample of 11 NCCP patients with high levels of anxiety was recruited, and interviews assessing acceptability and understanding of the intervention were conducted, using a 'think aloud' method. A focus group was also conducted with the specialist chest pain nurses who care for patients with NCCP ($N=4$). Findings indicated that both patients and nurses felt very positively about the intervention, and identified a great need for it. Some minor changes and additions were suggested, which will be incorporated into future revisions. The intervention was seen as understandable by all patients, despite the wide educational range. In general, the intervention was very relevant and acceptable to all patients, with many reporting problems with stress and difficulty relaxing. The intervention seemed to serve more than one need: for some, the relaxation techniques and were very relevant; whereas for others the section encouraging an increase in physical activity was seen to be useful. This study represents the first step towards developing a new intervention. Further research should seek to determine the efficacy of the intervention in a pilot trial.

5.2 Introduction

In Studies 1 and 2 it was demonstrated that anxiety, illness representations, and psychological distress play an important role in causing and maintaining chest pain and influencing psychological outcomes in NCCP. The findings of these two studies therefore highlighted important targets for intervention. This third study aimed to develop an intervention based upon these findings and assess initial acceptability of it.

The need for intervention in NCCP patients is clear from the preceding chapters. In addition to the evidence reviewed in Chapters 1 and 2, Study 1 empirically demonstrated high levels of psychological suffering in NCCP patients (particularly anxiety), and a high proportion of patients experiencing continued chest pain. Although psychological distress returned to normal levels at the three month follow-up, there was still a proportion experiencing anxiety and depression. Furthermore, the proportion of participants that experienced continued chest pain was high; given the findings, it may be concluded that this continued distress was causing or maintaining their pain. Study 2 confirmed and extended these findings, demonstrating the intrusive nature of NCCP, the strong focus on psychological causes of pain, and the lack of understanding (i.e., poor coherence) expressed by the participants. Current guidelines for the treatment of NCCP patients recommend that staff provide reassurance that the pain is non-cardiac, only referring for further investigation when deemed necessary (National Institute for Health and Clinical Excellence, 2010). Reassurance that a test result is negative may not be enough to calm patients' concerns (McDonald et al., 1996), and reassurance may be prevented by high levels of anxiety or negative illness representations in NCCP patients (Donkin et al., 2006). As a result, it may be necessary to supplement this reassurance and advice with some further intervention.

5.2.1 Existing interventions for NCCP

Given evidence that NCCP patients suffer continued pain and psychological distress, many interventions have been developed to improve outcomes in this patient group. Some previous interventions have been pharmacological, based around the idea that NCCP has an underlying gastrointestinal cause (Achem, 2008). However, given the psychological distress associated with the disorder, it has been suggested that a more heterogeneous approach is needed (Achem, 2008), with the main focus now being on psychological treatments (Kisely et al., 2012; White, 2010). This corresponds with the findings of Studies 1 and 2, which suggested that psychological distress, such as stress and anxiety, are important targets for intervention.

Kisely et al. (2012) conducted a Cochrane review of psychological treatments for NCCP, and found them to be efficacious in reducing pain (e.g., Asbury, Kanji, Ernst, Barbir, & Collins, 2009; DeGuire, Gevirtz, Hawkinson, & Dixon, 1996; Esler et al., 2003; Jones, Cooper, Miller, Brooks, & Whorwell, 2006; Kisely, Campbell, & Skerritt, 2005; Mayou et al., 1997; Potts, Lewin, Fox, & Johnstone, 1999; Spinhoven, Van der Does, Van Dijk, & Van Rood, 2010; Tyni-Lenne, Stryjan,

Eriksson, Berglund, & Sylven, 2002; van Peski-Oosterbaan et al., 1999) and also psychological distress (e.g., Asbury et al., 2009; Asbury et al., 2008; Esler et al., 2003; Jones et al., 2006; Jonsbu et al., 2011; Mayou et al., 1997; Spinhoven et al., 2010; Tyni-Lenne et al., 2002; van Peski-Oosterbaan et al., 1999). The review sought to compare a variety of psychological interventions, including CBT, relaxation therapy, hyperventilation control and talking therapies; however, the lack of rigorous trials of interventions within the literature precluded this. In total, 8 of the 15 included studies had assessed CBT. The remaining studies assessed interventions such as breathing retraining, hypnosis and relaxation. While the review found moderate support for psychological interventions for NCCP (particularly CBT), conclusions were limited by the small number of studies and methodological issues, such as small sample size, lack of blinding, and inadequate outcome measurement. Furthermore, while CBT was shown to be effective, it can be difficult to implement due to limited time and resources (Esler & Bock, 2004; Kisely et al., 2012), particularly in an acute setting like the ED. This may explain why current guidelines (National Institute for Health and Clinical Excellence, 2010) do not recommend any immediate psychological treatment for NCCP. As a result, a stepped approach to treatment of NCCP has been proposed, whereby all patients are initially offered a low-level, low cost treatment, and are then 'stepped-up' to more intensive treatments if deemed necessary or if less intensive treatments have been ineffective (Kisely et al., 2012; Mayou et al., 1999). While this approach may seem cost effective, previous research has shown brief interventions for NCCP to be ineffective or of limited efficacy (Arnold et al., 2009; Sanders et al., 1997; Van Etten et al., 2005). For example, Sanders et al. (1997) developed a one hour intervention to be delivered by a nurse following negative angiography. Despite using similar techniques to previous successful CBT-based interventions (e.g., Klimes, Mayou, Pearce, Coles, & Fagg, 1990; Mayou et al., 1997), the treatment did not improve outcomes, and was generally unacceptable, particularly to those patients who maintained concerns about cardiac problems. This is of great concern, given that this particular group may be more in need of intervention: anxiety about cardiac problems has been related to increased anxiety sensitivity, more negative illness attitudes (including increased healthcare seeking), and limited daily activities (Eifert, Thompson, et al., 2000). Sanders et al. conclude that the lack of efficacy may be due to methodological issues (e.g., lack of power, nature of follow-up assessment); however, they did also consider the possibility that the nature of the intervention and its delivery were an issue. The intervention was delivered by nurses, who may not have had sufficient training to deal

with psychological issues, and did not have had adequate support or involvement from more senior members of staff (e.g., cardiologists). Moreover, Sanders et al. suggest that the intervention may have been delivered too quickly following diagnosis, making it difficult for participants to process the sudden change in potential diagnosis from physical to psychological. This suggests that an intervention delivered with the support of all staff, either some time after diagnosis or to be taken away, may be more effective.

The issue of a psychological diagnosis being difficult to accept by NCCP patients has been previously identified as a potential problem when treating NCCP. Esler and Bock (2004) suggested that CBT treatments for chest pain may have too much of a psychological focus, which may be unacceptable to patients who believe their pain to be physical in origin, causing treatment uptake rates to be low. This may be exacerbated when the treatment is brief, as there is insufficient time to change the patient's causal attributions. They suggested that treatments need to be focussed more on a biopsychosocial model of treatment, which does not require patients to attribute their chest pain solely to psychological causes (as with traditional CBT), but instead gives them ways to manage their symptoms regardless of causal attribution. They suggest that:

'A new approach to the treatment of NCCP patients is greatly needed. Interventions which educate patients about the causes and nature of chest pain, the appropriate use of medical services, and methods of coping with and reducing the incidence of chest pain symptoms such as stress management training are needed' (Esler & Bock, 2004, p. 266)

Although Sanders et al. (1997) found their brief intervention to be ineffective, and Esler and Bock (2004) propose an argument to support reasons for this, Esler et al. (2003) found an ED based brief intervention (60 minutes) to be effective at reducing pain, anxiety, and cardiac symptoms. This intervention was based on CBT principles, and included information regarding the connection between stress and pain, breathing techniques, and cognitive restructuring about the perceived cause of pain. Participants were also given written information to take away, and the authors suggest that self-help materials alone may be effective, and also convenient in a busy 24-hour ED. Guided self-help has been shown to be effective in treating patients with functional neurological symptoms (i.e., neurological symptoms with no apparent underlying physical cause, such as NES) (Sharpe et al., 2011), and so may also be effective for

NCCP. Numerous systematic reviews and meta-analyses of self-help for anxiety disorders have been produced, suggesting that the method is significantly more effective than control treatments (Bower, Richards, & Lovell, 2001; Coull & Morris, 2011; Cuijpers, Donker, van Straten, & Andersson, 2010; Den Boer, Wiersma, & Van den Bosch, 2004; Hirai & Clum, 2006; Lewis, Pearce, & Bisson, 2012; Menchola, Arkowitz, & Burke, 2007; van Boeijen et al., 2005), and largely equal to face to face treatments (Cuijpers et al., 2010; Den Boer et al., 2004; Menchola et al., 2007). Moreover, recommendations have been made for its inclusion in a stepped care model (Bower & Gilbody, 2005; Hirai & Clum, 2006), which is the model of care suggested to be appropriate for NCCP patients (Kisely et al., 2012; Mayou et al., 1999), as discussed above. In addition, there is a well-established connection between NCCP and high levels of anxiety (Webster et al., 2012) and even diagnosed anxiety disorders (e.g., Dammen, Bringager, Arnesen, Ekeberg, & Friis, 2006; Fleet et al., 1996). This therefore suggests that self-help may be an effective early step in the care of NCCP patients.

Other bibliographic interventions have previously been used with chest pain patients within the setting of an ED (Petrie et al., 2007). A leaflet based intervention for chest pain patients currently exists in the CPOU in which the present research has been undertaken. Arnold et al. (2009) developed these information sheets for chest pain patients through pilot interviews with patients. Four sheets were developed for different diagnostic outcomes – definite angina, definite benign non-cardiac chest pain, uncertain cause requiring further cardiology investigation, and uncertain aetiology suitable for expectant (“wait and see”) management – thus tailoring reassurance information for specific patients’ needs. Patients were randomly assigned to receive an appropriate leaflet, or routine care. The majority of patients (88%) received a diagnosis of either definite benign NCCP or chest pain of uncertain aetiology suitable for expectant management; the majority of the sample thus had NCCP. In comparison to controls, those in the intervention group (including both cardiac and non-cardiac patients) demonstrated reduced anxiety and depression and better mental health and general health perception; thus showing significant positive effects of the information leaflets. However, the effect of the intervention on NCCP patients alone was not assessed, and so the efficacy within this group cannot be determined from the findings. Furthermore, no effect was found on patient satisfaction, frequency or severity of further chest pain, planned actions in response to further chest pain, or planned changes in lifestyle. Therefore, while the leaflet may have had positive psychological effects, the effects on satisfaction, pain, and behaviour were limited.

Jones and Mountain (2009) suggest that it is important to determine the effect information leaflets may have on these 'hard' outcomes, before concluding them to be effective. The next step, therefore, is to work on improving this type of information leaflet in an attempt to influence such hard outcomes. While Arnold et al. (2009) used a thorough strategy in the development of their leaflets (e.g., pilot interviews with patients), no direct empirical work on patient outcomes formed the basis of the leaflets and, furthermore, no theoretical model was used to underpin the leaflets. There is therefore a clear need for an empirical and theoretical grounding for such an intervention.

The present study will serve to extend and improve upon the existing intervention developed by Arnold et al. (2009), by using the findings from Studies 1 and 2, and the CSM, to develop an intervention for use in the ED with NCCP patients. Given the previous evidence regarding the efficacy of self-help in anxiety disorders (e.g., Lewis et al., 2012), the high levels of anxiety in NCCP (e.g., Webster et al., 2012, Studies 1 and 2), and the efficacy of CBT for NCCP (Kisely et al., 2012), a brief, self-help anxiety reduction intervention was developed for NCCP patients.

5.2.2 *The intervention*

The intervention content was developed using the findings in Studies 1 and 2, and also the content of previous successful CBT interventions for NCCP (Esler et al., 2003; Jonsbu et al., 2011; Klimes et al., 1990; Mayou et al., 1997; Potts et al., 1999; van Peski-Oosterbaan et al., 1999). In Study 1 it was found that NCCP patients who had a stronger belief in psychological causes, the perception of a more chronic timeline, and a weaker belief in personal control experienced increased psychological distress at follow-up. Furthermore, increased baseline anxiety, depression, and cardiac worries, decreased baseline QoL, a stronger illness identity (i.e., more symptoms associated with chest pain) and the perception of a more chronic timeline were all associated with increased chest pain frequency at follow-up. Study 2 also demonstrated the importance of perceptions of cause in these patients, with the strong focus on psychological causes of chest pain. Furthermore, this qualitative study revealed high levels of uncertainty within these patients, with a strong lack of understanding and poorly established illness representations. An intervention was therefore developed to target perception of personal control, perceived timeline, illness coherence, psychological causes of chest pain and psychological distress, and remaining concerns about cardiac causes.

5.2.3 *The importance of acceptability*

The problems faced by Sanders et al. (1997), and the issues raised by Esler and Bock (2004), highlight the need for the testing of the acceptability of an intervention. A good way to assess acceptability and patient views is by using qualitative methodology. Qualitative methods have been strongly recommended for use in the development of healthcare interventions; the Medical Research Council (MRC) incorporate such methods into a framework for the design and evaluation of interventions to improve health, recommending that qualitative research can help identify relevant components of interventions while also identifying any potential barriers to use (Campbell et al., 2000). The aim of this study was, therefore, to use qualitative methods to assess the acceptability and usability of the self-help intervention for NCCP patients. The views of both NCCP patients and the nurses who care for them were considered. A similar technique has previously been effectively applied to the development of an intervention to promote patient participation and self-management in long-term conditions (Protheroe, Blakeman, Bower, Chew-Graham, & Kennedy, 2010). As discussed above, patient views of acceptability may be crucial to the success of an intervention (Sanders et al., 1997). In practice, the specialist chest pain nurses would have most contact with the patients who are the target of the intervention, and thus deliver the intervention materials in most cases. We therefore felt it important to gain their opinions on whether they feel the intervention is suitable and feasible for delivery in an emergency care setting. The aims of the study were therefore to assess whether the intervention material was viewed as acceptable, feasible, and useful to the specialist chest pain nurses, and whether it was viewed as understandable, useful and acceptable to NCCP patients who were suffering with anxiety.

5.3 Method

The study consisted of two stages using different qualitative methods of data collection from different sources. In the first stage, a focus group was conducted with the specialist chest pain nurses who would deliver the proposed intervention to assess their views on the content and delivery of the draft intervention. In the second stage, a small number of patients who would be eligible to receive the intervention in practice were recruited from within the CPOU from which the participants in Studies 1 and 2 were recruited. These patients were given the intervention and then interviewed about their views as to its usefulness and content, using a 'think aloud' method (see 'procedures' section). The study received ethical approval from NHS

North West - Lancaster Research Ethics Committee (see Appendix 5.1 for confirmation of ethical approval).

5.3.1 *Participants*

For the first part of the study, all specialist chest pain nurses who worked within the collaborating CPOU were eligible for participation. All specialist chest pain nurses (of which there were 7) were invited to participate. Given the busy nature of the department, and the fact that the focus group had to be conducted during working hours, the number of nurses who could participate was limited. However, while it has been suggested that the most effective focus groups contain between 6 and 8 participants, this should be reduced where the participants have specific expertise in an area (Krueger, 1995). The sample size ($N=4$) therefore seems appropriate.

For the second part of the study, 14 people who had received a diagnosis of NCCP were recruited. Previous studies have shown this number of participants to be sufficient for gathering information regarding intervention/material development using think aloud methodology (Hagen et al., 2008; Protheroe et al., 2010; Yardley, Miller, Teasdale, Little, & Primit, 2011). Participants were recruited using the following criteria. In order to be eligible, patients must: (i) have attended the ED with NCCP as a primary complaint, (ii) not receive a cardiac diagnosis for their pain, (iii) not have self-disclosed or be known to have any other significant health complaint (including mental health condition), (iv) be aged over 18, (v) not have known CHD, (vi) be able to comprehend English, (vii) score above a threshold on a brief measure of anxiety (see 'Materials' section).

Participants were recruited to the study over a 10 week period between February and April 2012, between the hours of 09.30 and 17.30, Monday to Friday. During this period, 40 patients were identified as suitable by the specialist chest pain nurses and subsequently approached regarding participation. Of these patients, 9 declined participation (reasons unknown), 4 took an information sheet expressing that they wished to have more time to consider their participation (none of these contacted the researcher), 4 were found to have a cardiac cause for their pain, and 9 did not score highly enough on the GAD-7 to be eligible for inclusion. As a result, 14 patients were recruited to the study. Following recruitment, but prior to interview, 3 participants contacted the researcher expressing their wish to be withdrawn from the study

(reasons unknown). The final sample was therefore 11 participants. The characteristics of these can be found in Table 5.1.

Table 5.1 Participant characteristics

Identification number	Age	Gender	Highest qualification achieved	Age at which they left education	GAD-7 score	Interview location
P01	59	Female	O levels	15	14	Participant's home
P02	42	Male	Bachelors degree	40	6	Participant's home
P03	46	Male	Bachelors degree	21	7	Participant's home
P05 ¹	55	Female	Postgraduate degree	18	10	Participant's home
P06	30	Female	GNVQ	17	5	Participant's home
P07	40	Female	College	16	9	ED
P08	49	Male	College	17	9	ED
P09	44	Male	None	15	17	Participant's home
P10	70	Female	School	15	7	Participant's home
P11	54	Female	Bachelors degree	15	8	Participant's home
P13	45	Male	ONC	16	7	University

¹ Participant registered blind. Large print format of the intervention booklet used.

Information about gender, age, highest qualification held and age that one left education was recorded to assess the representativeness of the sample (see Table 5.1). There was a good gender balance in the sample, with a wide age range (30-70), and the mean age falling slightly lower than in the studies in Studies 1 and 2 (Mean=48). There was a good range of educational levels within the sample, with some having received University education, and some declaring only school level qualifications or none at all. With regard to the levels of anxiety, these varied widely, from 5 (borderline mild anxiety) to 17 (well over the cut-off for moderate anxiety).

5.3.2 *Procedure*

For the first part of the study, all specialist chest pain nurses were given an information sheet (see Appendix 5.2) a week before the date of the pre-arranged focus group, outlining the purposes and aims of the study, to allow them to make a decision regarding participation. The facilitator obtained consent at the beginning of the focus group using a standardised consent form (see Appendix 5.3).

Focus group methodology was deemed to be an appropriate method as the specialist nurses involved work closely together as a team, and focus groups are known to elicit rich data as a result of the interactions within the group (Asbury, 1995). It has also been suggested that using focus group methodology helps to concentrate on the more pertinent topics, helps gain an idea of the extent to which the views are shared, and encourages people to contribute where they might not in an individual interview situation (Robinson, 1999).

At the start of the focus group, the nurses were given the intervention materials (see Appendix 5.10) and reminded that they were designed for NCCP patients showing signs of anxiety. Audio recording was started as soon as the session began (i.e., before the nurses receive the materials), in order to record any spontaneous comments while the nurses viewed the material. A semi-structured interview schedule was used to guide the nurses towards certain issues of interest (see Appendix 5.4 for full schedule, or

Table 5.2 for an overview of the main topics), and they were encouraged to talk to each other about the materials. The facilitator prompted the participants for further information where necessary. The focus group was audio recorded and transcribed.

For the second part of the study, potential participants were identified by the chest pain nurses in the CPOU. Suitable participants were then approached and provided with an information sheet about the study (see Appendix 5.5). Once the attending nurse/doctor had confirmed that no cardiac cause for the pain could be identified and no further investigations were needed, interested participants were asked to complete the GAD-7 (see Appendix 5.6). Those who scored ≥ 5 were eligible for participation and asked to sign a consent form (see Appendix 5.7). Interviews were then either conducted immediately, within a private room within the ED, or arranged for a later date either at the participant's home, or at the University of Sheffield.

Table 5.2 Interview schedule topics - nurse focus group

Research aim	Questions
General opinion	What is your general opinion of the leaflet?
Understanding	Is the leaflet understandable to you?
	What do you think about the length of the material?
	Do you think there is anything missing from the material?
	Is there anything within the leaflet that you didn't like (if so will be followed up by why)?
Acceptability	How suitable do you think the intervention would be for chest pain patients?
	How appropriate is it in targeting the important issues for this patient group?
	How would you feel about delivering the intervention leaflet yourselves?
Promise	How effective do you think it would be in treating patients with anxiety-related chest pain?
Feasibility	What are the costs of delivering an intervention like this?
	How are the information leaflets for patients currently in place used?
	At the moment it is all in paper format. What do you think about this?
	Might it be delivered in other ways?

During the interview, participants were given the intervention materials and asked to comment on them as they viewed them, using a 'think aloud' method. This technique focuses on asking participants to verbalise their thought processes during a task, in order to gain insight into their decision making processes and opinions (Boren & Ramey, 2000; Ericsson & Simon, 1984). It was hoped that this would give an insight into the patients' opinions of the materials, whether they found them acceptable, and also help identify any barriers to the use of them. This methodology has been successfully used in the area of intervention development in healthcare in a number of studies (e.g., Protheroe et al., 2010; Sadasivam et al., 2011; Yardley et al., 2011; Yardley, Morrison, Andreou, Joseph, & Little, 2010).

At the beginning of each interview, the participants were informed of what was required of them for the think-aloud method using a standardised script (see Appendix 5.8), followed by a chance to ask any questions. They were then be given the opportunity to practice the method, using a piece of health information material unrelated to NCCP. In accordance with guidance from Boren and Ramey (2000), the focus was on the participant as the expert, and the intervention materials as the subject which is being tested. Once the participant felt competent with the method and happy to go on with the main experiment, the audio recording was

started and the participant was given the intervention materials. Continuous prompts (e.g., ‘mmm hmm’, ‘yes’, ‘OK’) were used to give the impression of the researcher as an engaged listener and to promote more speaking in the participant (Boren & Ramey, 2000). If the participant was silent for 15 seconds (Ericsson & Simon, 1984), prompts were used to remind the participant to continue thinking aloud, such as ‘Please remember to think aloud?’, or ‘And now?’ (Boren & Ramey, 2000). Following this, participants were asked various questions about the acceptability and usability of the materials using a semi-structured interview schedule (see Appendix 5.9 for full schedule, or Table 5.3 for a summary of the main questions).

Table 5.3 Interview topics - individual participant interviews

Research aim	Questions
General opinion	What is your general opinion of the leaflet?
Understanding	Is the material written in a way that’s clear and understandable?
	Do you think the length of the material is OK?
	Do you think there is anything missing from the information and suggested techniques?
	Is there anything within the leaflet that you didn’t like?
Acceptability	Do you think the leaflet is relevant to you, as a non-cardiac chest pain patient?
	Do you think it could meet your needs?
	Do you think it could help you to reduce or cope with your chest pain?
Promise	Would it be something you’d like to try?
	Would you consider using these techniques on a regular basis, in order to help cope with your chest pain?
	After reading the material, do you feel capable of using/doing the techniques described in it?
	Would you show it to anybody else (in your family)?
	Do you think the format of it – a leaflet – is useful?

5.3.3 Materials

GAD-7: In the patient sample, all participants were screened for inclusion using the brief measure for assessing Generalised Anxiety Disorder, the GAD-7 (Spitzer, Kroenke, Williams, & Lowe, 2006). This short 7-item measure has been shown to have high internal consistency, good test-retest reliability, and good procedural validity (Spitzer et al., 2006). Furthermore, the measure has been shown to be very effective in identifying various anxiety disorders (Kroenke, Spitzer, Williams, & Lowe, 2010), and has been previously used with patients with persistent pain (Poleshuck et al., 2009), and specifically in ED settings (Shah et al., 2011). The authors

recommend a cut-off score of ≥ 5 for mild anxiety, or ≥ 10 for moderate anxiety. In order to target as many patients suffering with anxiety as possible, the cut off for 'mild' anxiety was used (i.e., a score of 5).

The Intervention: The aim of the study was to assess the acceptability, feasibility and usefulness of a self-help intervention for people with NCCP and associated anxiety. The development and content of the intervention is described below, and a copy of the intervention is included in Appendix 5.10. The material was developed by the main researcher (RW) in collaboration with one supervisor (AT). An early version of the intervention materials were viewed and commented on by the Sheffield Emergency Care Forum for Patient and Public Involvement in Clinical Research, which is a group representing patients, service users, carers and the general public that promote their involvement in the development of research. This was done in order to ensure the materials were understandable, accessible and had good face validity before assessing them further. Comments were generally very positive, and only minor changes were recommended. These changes were incorporated into the intervention. The Flesch reading ease score for the intervention booklet is 75.3, which is classed as 'fairly easy' (Flesch, 1948).

The intervention was based on the content of previous successful CBT interventions for NCCP patients (Esler et al., 2003; Jonsbu et al., 2011; Klimes et al., 1990; Mayou et al., 1997; Potts et al., 1999; van Peski-Oosterbaan et al., 1999), and on the findings of Studies 1 and 2 that perception of personal control and perceived timeline, psychological causes of chest pain and psychological distress, and cardiac concerns are all important targets for intervention. The intervention already developed by Arnold et al. (2009) was also integrated into the present intervention content. Specifically, the initial section of the intervention regarding explaining the diagnosis, and offering potential causes, was adapted from the leaflets in the Arnold et al. (2009) study. This was thought to be appropriate, as the materials in the Arnold et al. study were developed by specialist chest pain nurses and ED consultants, who have great expertise in the area of assessing and diagnosing NCCP. The present intervention extends this material by explaining the diagnosis and possible causes in more detail and by offering concrete instructions for techniques to reduce anxiety and chest pain.

Providing patients with a self-help intervention should hopefully improve perceptions of personal control and timeline. Within anxiety disorders, patients have reported that self-help materials improved their perceptions of self-efficacy, and made them feel as though they were personally taking control of the situation (Rogers, Oliver, Bower, Lovell, & Richards, 2004). Regarding timeline, as discussed in Chapter 3, the relationship between timeline and continued pain may be due to negative expectancies, which can be related to pain outcomes (Boersma & Linton, 2006). These negative expectancies are most likely a result of the fact that many NCCP patients do not receive a clear diagnosis, and they will most likely also receive no treatment. This lack of treatment combined with continued pain may lead the patient to believe that there will be no end to the pain, thus causing psychological distress. Therefore, giving patients a tool to cope with (and hopefully reduce) their pain may also improve timeline perceptions, and/or the impact that timeline perceptions may have on psychological distress.

The aim of the intervention content is therefore to reduce anxiety and pain, and also to improve coherence and reduce any remaining cardiac concerns. This is done by demonstrating to patients how stress may play a role in their chest pain, and giving them techniques to cope with their chest pain and reduce their stress and anxiety generally.

The intervention booklet (found in Appendix 5.10) consists of three sections. It opens with a brief introduction as to why they have been given the intervention, and an outline of the three sections.

Section 1: To begin with, patients are introduced to the notion of NCCP. Their diagnosis is explained, and they are given a list of various other possible causes. The list of causes given was adapted from the intervention developed by Arnold et al. (2009). The lack of coherence demonstrated by NCCP patients may be due to the acute nature of their care, whereby health professionals have less time to deliver their diagnosis, and patients have less time to process the information and ask questions. Therefore, providing patients with information that they can take home and process in their own time may be beneficial.

At this point, the role of stress is introduced as both a causal and maintaining factor in NCCP. It is hoped that this will reduce cardiac worries and improve coherence. Continued cardiac worries were related to persistent pain both in Study 1 and also in previous research (e.g., Eifert et al., 1996). During the interviews in Study 2, one factor which emerged was the

difficulty that participants had in drawing connections between situations, feelings, and their pain, and they often struggled to understand why stress may cause pain. Furthermore, those who had made connections between feelings/situations and pain found this very beneficial in helping them cope with their pain. Previous successful interventions for NCCP have focussed on encouraging patients to shift their causal view of their pain from cardiac to psychological (e.g., Esler et al., 2003; Mayou et al., 1997; van Peski-Oosterbaan et al., 1999) and understand the relationships between stress, tension and pain (e.g., Esler et al., 2003). It was therefore thought that in addition to providing information about the non-cardiac diagnosis, specific information about the stress/pain relationship should be provided, and patients should be encouraged to make connections themselves. Various anonymous quotes are presented, drawn from Study 2, demonstrating the connections patients have made between stress and their pain. The relationship between feelings, thoughts, behaviours and physical sensations is demonstrated using the 'hot cross bun' diagram, commonly used in CBT, adapted from Padesky and Mooney (1990). Examples are given within this diagram, but also blank spaces are left and patients are encouraged to fill in their own examples, thus formulating their own experience into this model. Patients are also recommended to complete a diary of their pain, and their associated thoughts and feelings, in an attempt to help them make these connections for themselves. Inclusion of a pain diary has been shown to be effective in improving outcomes in chronic cancer pain patients (Allard, Maunsell, Labbe, & Dorval, 2001), and similar diaries have been included in previous effective interventions for NCCP (e.g., Potts et al., 1999; van Peski-Oosterbaan et al., 1999).

Section 2: This section includes techniques designed to help patients cope with pain, promote relaxation and reduce stress.

First, participants are advised that exercise is a good way to reduce stress, and so are encouraged to make an exercise diary. We felt it important to include this element, given that people with NCCP tend to avoid physical or work related activity for fear that it may cause pain or damage their heart (Jerlock et al., 2005; Jonsbu et al., 2010), and this avoidance of activity is related to both cardiac distress and ED attendance (Aikens, Michael, Levin, & Lowry, 1999). Lack of physical activity has long been known to lead to cardiac problems such as heart disease (Powell, Thompson, Caspersen, & Kendrick, 1987), therefore putting these patients at risk of cardiac events in the future. Furthermore, aerobic exercise can reduce both the physiological

and psychological impact of stress, particularly on the cardio vascular system (Blumenthal et al., 1990), while also improving psychological outcomes such as depression and anxiety (DiLorenzo et al., 1999). Increasing exercise in NCCP patients may therefore reduce their immediate pain and stress, as well as their long-term cardiac risk. Encouragement to increase physical activity was incorporated into the intervention by asking patients to make a list of activities they felt they could achieve, and then fitting these into a diary. Planning is a helpful way to both initiate and maintain physical activity (Ziegelmann, Lippke, & Schwarzer, 2006). Furthermore, previous successful interventions for NCCP have included some exercise element (e.g., Asbury et al., 2008; Jonsbu et al., 2011; Potts et al., 1999; Tyni-Lenne et al., 2002). Such methods reduced fear of bodily sensations (Jonsbu et al., 2011), suggesting that exposure to exercise may quash any existing cardiac concerns patients may have. This is also supported by the finding in Study 2 that participants viewed exercise with the lack of a subsequent adverse event as evidence of no cardiac problem.

Next, three relaxation techniques are introduced. As anxiety is the main target of the intervention, it was thought that the most effective way to target this would be by using established anxiety reduction methods, such as relaxation techniques focused on muscle relaxation or breathing. Relaxation techniques are a common component in self-help materials for anxiety disorders (Cuijpers & Schuurmans, 2007). The majority of previous CBT interventions for NCCP have included some element of relaxation or breathing retraining (Esler et al., 2003; Klimes et al., 1990; Mayou et al., 1997; Potts et al., 1999; Spinhoven et al., 2010; van Peski-Oosterbaan et al., 1999), and some successful interventions for NCCP have focussed solely on relaxation (Asbury et al., 2009) or breathing retraining (DeGuire et al., 1996; Lahmann, Loew, Tritt, & Nickel, 2008). Scripts were developed by a one of the researcher's PhD supervisors (AT), who has extensive experience in delivering such techniques:

Mindful breathing: Mindfulness is a type of meditation which focuses on paying attention in a specific way – on purpose, in the present, and non-judgementally (Kabat-Zinn, 1994). In mindful breathing, this attention is focussed on breathing. Mindfulness has been shown to be effective in improving psychological functioning and well-being (Baer, 2003; Keng, Smoski, & Robins, 2011), and mindfulness-based stress reduction techniques have been successfully used with chronic pain patients (e.g., Kabat-zinn, Lipworth, & Burney, 1985; Morone, Greco, & Weiner, 2008; Wong et al., 2011), patients with MUSs including IBS (Gaylord et al., 2011) and

CFS (Surawy, Roberts, & Silver, 2005) and in patients with anxiety disorders (Evans et al., 2008; Kabatzinn et al., 1992). The intervention leaflet gives the patient instructions for doing mindful breathing, and recommends that they do it in response to pain, or on a regular basis to help reduce stress and anxiety.

Guided imagery: This technique, originally defined by Leuner (1969), involves encouraging the subject to visualise a pleasant scene and focusing on it. This technique has been shown to be effective in managing physical and psychological symptoms, including stress, anxiety, and pain (Eller, 1999), tension headaches (Mannix, Chandurkar, Rybicki, Tusek, & Solomon, 1999) and musculoskeletal pain (Posadzki & Ernst, 2011). The script used in this study asks the patient to imagine being in a calm or safe place, and encourages them to notice sensations in that place. Again, instructions are given to use this when they experience pain, or on a regular basis to help reduce stress.

Progressive muscle relaxation: This technique, originally described by Jacobson (1938), Bernstein and Borkovec (1973), and Ost (1987), involves directing the subject to focus in turn on different areas of the body, either tensing the muscles in that area for 5-7 seconds then relaxing the muscles, or simply relaxing the muscles, and focussing on the release of tension. The technique has been shown to be widely effective for anxiety disorders (Conrad & Roth, 2007; Jorm et al., 2004; Pluess, Conrad, & Wilhelm, 2009), although the evidence for reducing chronic pain has been mixed (Carroll & Seers, 1998; Kwekkeboom & Gretarsdottir, 2006). Given that NCCP patients have been found to have high levels of anxiety (Webster et al., 2012) which may cause or exacerbate the pain, dealing directly with this anxiety may be beneficial. The script included in the intervention leaflet outlines a progressive muscle relaxation activity, which patients are advised to do either daily or 2 to 3 times a week, in order to help reduce their stress and anxiety levels.

Section 3: In section three, patients are invited to make a specific plan about when to use the new techniques that they have learned. One issue with self-help materials can be the extent to which patients use the materials and the techniques included in them. The rate at which patients adhere to interventions (i.e., use the materials and complete the prescribed course) can be as low as 50% (Glasgow & Rosen, 1978). One potential way of improving adherence levels is by including an implementation intention (Gollwitzer, 1999; Gollwitzer & Sheeran, 2006), whereby participants are asked to make a specific 'if-then' plan, specifying a specific

situation or trigger (e.g., getting into bed in an evening) and the behaviour they plan to do in response to it (e.g., doing a specific relaxation exercise). The inclusion of such a plan within self-help materials can improve the beneficial effect of the intervention on anxiety reduction (Varley, Webb, & Sheeran, 2011). Furthermore, given that the method is very simple, it is a straightforward, low-cost way of potentially improving the effects of an intervention. Participants are therefore asked, at the end of the intervention, to first make a plan about what to do when they experience pain, and then to remind them to practice the relaxation techniques. Boxes are provided to write these plans down, and participants are then recommended to repeat these plans aloud in order to help commit them to memory.

Interview schedules:

For the focus group with the nurses, questions were devised around the concepts in the research question concerning acceptability, feasibility, and usefulness. The open-ended questions were designed to encourage the nurses to discuss between themselves issues concerning the content of the intervention itself, its suitability for use with NCCP patients, and the feasibility of delivering it in practice. A copy of this schedule can be found in Appendix 5.4.

For the interviews with the patients, a script outlining the instructions for the think aloud part of the interview was developed using previous research studies using the technique (Protheroe et al., 2010; Yardley et al., 2010) and an extensive overview of using the method for usability testing (Boren & Ramey, 2000). For the part of the interview following this questions were developed, again with respect to the research questions, concerning whether the intervention is seen as understandable, acceptable, and useful to patients. The questions considered the content of the leaflet, dealing with each section separately. Questions also assessed the relevance and suitability of the intervention, as well as the participants' willingness to use the techniques given on a regular basis. Participants were also asked whether they would find it useful to receive the relaxation techniques in another format (e.g., audio). A copy of this schedule can be found in Appendix 5.9.

5.3.4 Analysis

All interviews were transcribed by an independent party and subsequently checked for accuracy by the researcher. This use of an independent transcriber had been approved by the Research Ethics Committee, and the transcriber signed a confidentiality agreement prior to

undertaken transcription. Data were then analysed using thematic analysis (Braun & Clarke, 2006), whereby commonly occurring concepts, opinions, and comments were organised into categories to identify common themes regarding the opinions of and reactions to the intervention material. Thematic analysis has previously been used to analyse data from both focus groups (Robinson, 1999) and think-aloud studies (MacNeela et al., 2010; Yardley et al., 2011; Yardley et al., 2010).

The data from the nurses and the patients were initially analysed separately but alongside each other in order to identify similarities/differences and any overarching themes. All transcripts were repeatedly read, and then initial free coding was performed. These codes were then reviewed and collapsed into a smaller number of more broad codes, and put into a coding frame. Once each interview had been coded into a frame, the codes were collapsed further to provide a more coherent understanding of the data (e.g., some codes were put into sub-categories under larger, overarching codes). At this stage, the coding frames from all patient interviews were compared and integrated. Where appropriate, new major themes and sub-themes were created in order to incorporate all the data. The final master coding frame for the patient data was then compared to the coding frame for the focus group.

In order to avoid researcher bias, transparency was maintained throughout the process, with a record being kept of all stages of data collation and analysis. Furthermore, analysis was discussed in detail during supervisory meetings (with AT). Transparency of process is a widely recommended way of ensuring quality in qualitative research (Mays & Pope, 2000; Yardley, 2000).

5.4 Findings

5.4.1 Nurse focus group

5.4.1.1 Positive aspects of the intervention

5.4.1.1.1 General

The nurses were all very positive about the intervention. They felt it was useful, helpful, beneficial, simple to use, and of minimal cost. They particularly liked how it did not use technical medical language, which might concern patients. They also felt it was a positive tool as it was quite detailed, so patients wouldn't feel they had been 'fobbed off'.

N03: *'I think the process, the idea of all of this is brilliant'*

N01: *'I think that, because like if they've got a big leaflet given to them they feel like someone's taking time to explain it to them properly like you say instead of fobbing them off with just an A4 side of paper'*

5.4.1.1.2 Need

There was a general sense of a need for an intervention of this nature. The nurses felt that they currently had little to offer patients with anxiety (either knowledge or resources), and anxiety was often a cause for frequent attendance at the ED. They often referred these patients back to their GP, who referred them back to the ED, creating a vicious cycle whereby the patient doesn't get treated for either their anxiety or their chest pain. It was felt that the intervention provided an extra tool to offer these patients. They talked about how NCCP patients were often sent home with nothing but a negative cardiac diagnosis, and this tool would be beneficial as it was at least giving them something, and showing them that NCCP is a common problem and that it is taken seriously. They also felt that it would be helpful for clarifying causes, particularly muscular tension, as patients often misunderstood this diagnosis, presuming that muscular pain must be caused by a strain.

N01: *'So it's really good for us that we can kind of, because I've had people which have asked me about, you know, where they can get help in the past, and I've not really known to be honest because it's not my area'*

N04: *'Yeah because people like they go to their GP, their GP sends them here, we say you've not got this wrong with you, and send them back to their GP and people feel like they're stuck in a bit of a vicious circle'*

N02: *'Because I know quite a few patients that you treadmill and they bang on like 'oh I've just wasted your time, just been stressed', but if you give them that then they realise that it does exist, chest pain caused by stress, and it is something that's noticed and it's not something that's just brushed under the carpet by health professionals, that it does exist and there's stuff there that they can do, so they might feel that they're not going crazy'*

5.4.1.1.3 Wider scope of intervention

Two aspects of the wider scope of the intervention were discussed. Firstly, it was pointed out that the content of the intervention would be useful for anyone, including those who are found to have cardiac related pain.

N03: *'Ultimately, these strategies are useful to anybody aren't they really, because even if they have known, if we find out that it is heart related, there isn't anything in here that is a bad thing'*

Secondly, it was felt that the intervention would be useful when delivering diagnoses to non-English speaking patients, if it were translated to different languages, as it would help them to understand their diagnosis better.

N01: 'Are you looking at producing ones in different languages? Because obviously we have quite a lot of Asian people don't we, which English, they don't speak much of it, so it'd be useful if we could get some made up wouldn't it? [...] Because they kind of miss out don't they, really [...] they're often the ones which come back, and you think sometimes it's probably because they've not understood what we're telling them'

5.4.1.2 Content of the intervention

5.4.1.2.1 Sections

Section one – With regard to the individual sections of the intervention, the nurses felt that the information included in section one about causes was sufficient, and used good simple language so as not to panic patients. They also like the speech bubbles as it broke up the text.

N01: 'That like yeah, that's fine that you've got there, you don't need any [more]. Because if you start putting other causes which are actually stuff that need treating they're going to get confused as to when to come [to the ED] and when not'

The nurses felt the pain diary was a positive aspect, encouraging patients to recognise what triggers their pain and to be more aware of psychological causes.

N02: 'They don't always think, they just think 'oh I've got chest pain', makes them feel worse, and they might not realise it's related, [they] might not realise you can get pain with stress, and they think, some people think if you've got pain, there's got to be a physiological cause for having it'

Most of the nurses expressed negative comments on the 'hot-cross bun' diagram designed to encourage patients to draw connections between pain, feelings, behaviours and thoughts. This included both a lack of understanding and general dislike. It was felt that the important points in the diagram had been covered by the text on the previous page, and so it was unnecessary. One of the nurses pointed out, however, that the diagram may be preferable to some patients, especially those who may have trouble understanding the text explanation.

N01: 'I don't like the little diagram [...] but I don't like those diagrams [...] You know the, yeah, because I just think it's confusing, sorry'

N02: 'Yeah I don't get that yeah'

N01: *'I just never get them. We have them in nursing all the time and I hate them. That's just my personal op- and I just, ahh, I don't feel that that really adds anything to it'*

N02: *'But somebody probably have difficulty probably wouldn't understanding reading all that text, might get it to grips with [the diagram]'*

Section two – All of the nurses were very positive about the relaxation techniques and the instructions. They thought it was especially good that more than one technique was offered, allowing patients to make a choice.

N04: *'See I think they're, I think they work really well'*

N02: *'I really like them'*

N04: *'Yeah I do'*

N01: *'It's good, like, you do give different options, because some people won't be able to do some but will be able to try the others'*

N02: *'It's nice that they don't, not made to feel like they've got to do all three, they can pick and choose'*

The nurses were very positive about the part of the intervention which encourages patients to engage in exercise, saying how patients often asked whether it was safe for them to exercise. They felt the exercise diary would be beneficial. They also liked that the suggested activities were very manageable, and felt that this would be a good way to encourage people to do not exercise to be more active.

N01: *'So and that's the main question when people come in with pain, when you tell them it's non-cardiac, they do always ask 'am I ok to do like exercise?''*

N03: *'Yes...And in your physical activity, sort of, saying, it's in there to suggest that you don't actually have to go out to do this, you can find activities at home that would do it, like you've put sort of household chores, everyday activities and what have you... Is good'*

N04: *'Yeah because think increase your exercise, people may think you have to go and start running on a treadmill, which you don't do you, if you do very little, just increasing it a bit is going to make a difference'*

Section three – The plan (implementation intention) in section three was felt to be useful, although it was not discussed in detail. The nurses were positive about the further support section, and didn't feel any contacts were missing from the list.

N01: *'And I like the back, you've got the further support bit in the back, so if like it's not helping there's other places they can turn to'*

5.4.1.2.2 Length

There was a general feeling that the intervention may be too long, but equally nothing could be taken out to shorten the booklet. The nurses also felt that the length of the booklet might

actually be a benefit, providing patients with some explanation that they can take home and process, rather than being 'fobbed off' with a brief leaflet.

N02: *'It's a bit lengthy as well to read'*

N04: *'See I don't think there is, to explain it properly, I don't think there really is things that you could probably take out of it'*

N04: *'And in that way actually people sometimes prefer something a bit more that they can actually, a bit more in depth don't they?'*

N03: *'Yeah'*

N04: *'Rather than a really quick guide, yeah, sometimes that is better'*

N02: *'Sometimes they feel like they're fobbed off don't they'*

5.4.1.2.3 *Understanding*

The nurses themselves had no trouble understanding the intervention; however, some did express concern that some patients may struggle to understand it. It may therefore be necessary to simplify the booklet, although the understanding of the patients would need to be taken into consideration. It was suggested that some minimal guidance may be beneficial for understanding, an idea which is discussed in more section in the below section '*Delivery*'.

N04: *'And it's simple as, because you've done it through step by step of how to- you've not just sort of put a heading, know what I mean, you've explained very well how to do it all'*

N02: *'But even the ones that probably won't understand some of it if we sit down and speak to them first and they understand the basics, they'll get some of the basics, be able to do it, because it's not all too technical is it, so they can read the basics and get it because some of the- that bit where it tells you what to do is quite straightforward so, they get it'*

5.4.1.3 *Negative aspects of the intervention*

5.4.1.3.1 *Changes*

A number of possible changes were suggested. These included putting in more pictures and less writing, as the nurses generally found the pages which were broken up by pictures more preferable. A number of typographical errors were identified, which can easily be rectified. There was a discussion regarding the wording of section three, whereby some of the nurses felt that this section was patronising, instructing patients that they must write a plan, rather than giving them the option. They suggested that the plan should be introduced as a possibility that patients may find helpful. It was also thought that in order to avoid any problems with misuse (i.e., the intervention being delivered to the wrong patients), the title should be

changed to 'Coping with *non-cardiac* chest pain'. These changes are all minor may be easily incorporated into the intervention.

N03: *'The section three bit 'make a plan to use your coping methods', sort of like...maybe, some people might find this kind of thing helpful, as opposed to saying, 'after you've tried these relaxation techniques, select one or two and make a plan in the boxes below', I don't know I just feel like it, just is a bit, a little bit patronising, maybe .For some people I think that would be a useful thing, [...] but more in the context of 'some people find it useful to write down a plan''*

N02: *'Might it be on there if you don't want to give it that, 'coping with non-cardiac chest pain' on the front, because otherwise someone might say 'oh you've come in with chest pain' and give it to somebody that's coming in that's having a STEMI [heart attack], thinking it's quite nice, saying have a read of that'*

5.4.1.3.2 Additions

No suggestions for additions were made. One of the nurses initially suggested adding an additional cause to section one of Costochondritis; however, she then decided that it would come under the bracket of 'tension and strain'. Also, inclusion of such a cause would contradict the earlier discussion about the positives of using non-medical language.

N02: *'You've got one bit have you where it's got what can cause chest pain, sometimes, but it's mainly women it's like, erm you've got muscles, I suppose you've got muscles there, that'd come under costochondritis we get quite a few that come-'*

N03: *'Yeah tension and strain in the chest '*

N02: *'But it'd probably come under that'*

5.4.1.3.3 Barriers

The nurses identified a number of barriers, both with use and delivery. They felt that some people, particularly males, may be reluctant to use it due to stubbornness. This shows the importance of trying to engage all patients.

N02: *'I think it'd be helpful for the stresses that they have, I think the only thing you might have problems with is the typical stubborn Yorkshire bloke'*

The main barrier to delivery was that doctors may not give them out, and thus they would need to be educated and have the booklets close to hand. These factors can be taken into account when putting the intervention into place.

N04: *'If these are to hand, like in lots of places, the doctor's very likely to pick it up and give it to a patient, if they have to go and look for it, they will not give it out'*

The nurses did, however, discuss how there were a lack of barriers to actually using the intervention, as participants weren't required to go anywhere and the techniques were very simple to use.

N01: 'Yeah because often like CBT stuff's quite like, because I've done some stuff, it's like really complex and like you're asking them to do quite a lot where all these they are all like relaxation things are quite simple aren't they'

5.4.1.3.4 Not accessible/acceptable to all

The nurses expressed concern that the intervention might not be accessible to all patients, as some may have difficulty understanding the wording and terminology, and those with a lower reading age may be overwhelmed by it. The content of the intervention may therefore need to be simplified.

N03: 'I think it sort of seems, reading it you're aiming at a specific group of patients really, a certain population, because you need to be articulate you need to actually be able to understand the terminology, just as in the words really'

It was also suggested that there may be a group of patients who would find it unacceptable, and thus it may only be useful for a particular group of people (mainly female).

N04: 'Erm yeah it is really good, I do agree that probably women are probably more likely to sit and read it than sort of ya know with pain and things like that, especially if it is sort of more muscular, I think the chances for a man to sit down and start doing those sorts of things are very slim really aren't they (laughs)'

5.4.1.3.5 Adverse consequences

Regarding potential adverse consequences, there was initial concern that these may occur if other staff in the department inadvertently gave the intervention to someone with cardiac problems; however, it was felt that with education this would be avoided. It was thought that the discharge advice given about further pain, along with the advice regarding seeking care at the end of the leaflet, would be sufficient to stop any preventing of patients returning to the ED if necessary.

Facilitator: 'Right, so you don't think there'd be a problem with missed diagnoses or anything?'

N04: 'No, because even if we educate the nurses to give these, the doctors still have to- should give, whether do or not is a different thing, but they still should still give the standard advice, as this isn't from your heart, but you know what I mean'

5.4.1.4 Relevance

There was some discussion about who the intervention would be relevant for, with a concern that women might be more likely to take the intervention on than men. However, most agreed that they had recently seen a number of men who were having problems with stress-related chest pain, suggesting that it may be more widely relevant. There was also a suggestion that individual people will find different sections relevant for themselves personally, the intervention thereby serving different needs for different people.

N01: *'I think lately, like loads I've looked after lately which are like men in the stages of losing their job'*

N03: *'Yeah, yeah'*

N01: *'And when you chat to them it is all like anxiety and you find out they've been really stressed'*

N04: *'And men don't sort of talk and release anxiety and stress to people they kind of hold it on board a lot more don't they'*

N03: *'Yeah, yeah. It's like some people may well not want to use, actually interact with it and write in it and whatever, but will find the [...] techniques themselves really useful'*

N04: *'Whereas other people might be the complete opposite way round and disregard the exercise but think yeah that's really good idea, logging'*

N03: *'Yeah'*

N01: *'Just if they can identify what's triggering, they can recognise a pattern they'll be happy that they can, you know, that's why, and they won't bother with the techniques'*

5.4.1.5 Practice aspects

5.4.1.5.1 Delivery

There was some disagreement about the delivery of the intervention. One of the nurses felt that some patients (particularly those with lower understanding) may need extra guidance when delivering the intervention, describing 'the basics'. The other nurses disagreed with this, suggesting that the advice that they currently give is 'the basics', and the intervention should be supplementary to this, and very much 'self-help'. Most were concerned about the lack of available time to give patients any guidance, and the associated increase in workload, and it was suggested that a short script or monologue describing the intervention may be beneficial. They did feel, however, that simply delivering the leaflet would be very feasible in practice.

Facilitator: *'Do you think that that might be something that you'd find yourselves capable of doing, or?'*

N01: *'I think capable, it's just going to be having the time to do it'*

N02: *'But you can choose your patients carefully because you know which one's are going to need a bit of help, most patients we get will understand it, and you'll know the ones we get through who won't and you can just take 5 minutes out and just... briefly'*

N03: *'I think we need a succinct little monologue, just something that you'*

N04: *'Yeah, yeah, brief description'*

N03: *'Just a statement'*

There was some discussion about whether guidance would be beneficial or make patients less likely to read through the booklet themselves.

N04: *'I think it could work- because if you spend time going through it, they may just toss it to the side and not bother'*

It therefore seems that the nurses feel they would lack the time to deliver any associated guidance alongside the intervention. It may be appropriate to follow the suggestion of a short script, to be delivered alongside the intervention leaflet. The feasibility of this would have to be investigated in further research.

Regarding other staff in the department delivering the intervention, there was some concern that this might not be done, or it might be done incorrectly (e.g., giving the intervention to cardiac patients). It was felt that the staff in the department would need to be educated about the intervention – that it needs to be delivered, and who it is to be delivered to. It was suggested that the weekly departmental teaching sessions would provide a good opportunity to do this. This is something that would need to be taken into account when implementing the intervention in practice.

N04: *'And we would be better, it would mean educating the other nurses in the department, the same as if somebody's come in with a head injury, we send them home with a head injury advice, for it to be a standard thing [...] if we're not here, someone gets discharged with chest pain that's not cardiac, they need one of those'*

N01: *'Yeah because the other nurses would be quite good at it, whereas some of the doctors might be quite bad at it'*

N02: *'But a problem you might get though, there might be a patient that might be misguided by somebody, and it might actually be cardiac and might be giving who might have cardiac chest pain'*

5.4.1.5.2 *Current leaflets*

There was a general negative opinion about the existing leaflets for NCCP patients, whereby some of the nurses simply didn't like them, and some felt that had too little information in. They were also generally only given to patients who had received a treadmill test, as this test is mentioned on the leaflet. It was noted that if they had something more sufficient, they would be more likely to deliver it to a wider group of patients.

N01: *'Oh I hate the non-specific one'*

N03: *'I don't think that's got a lot in it'*

N01: *'Yeah so at the minute we're only giving to a select number of people, people that treadmill, whereas if we had this we could kind of give it to them all couldn't we, on discharge, we could make sure' (General agreement)*

5.4.1.6 Extending the intervention

5.4.1.6.1 Audio

The nurses were initially negative about the prospect of an audio CD. They spoke about a DVD which they deliver to patients with deep vein thrombosis, which they did not feel that patients utilised. However, once it was made clear that the CD would be supplementary and contain the relaxation techniques, they were much more positive, suggesting that it could be useful to increase accessibility to those with lower levels of understanding, and useful when doing the relaxation techniques. There was some concern, however, about who would be responsible for the cost of this resource.

N04: *'And, and when you're trying to do it and do the relaxation things but you're trying to read it through at the same time, when you're trying to close your eyes and do things, it'd be nice if somebody came 'now do this, now do that' without you having to read it, wouldn't it'*

N03: *'And you've got a cost with CDs'*

N04: *'And it's who would set it all up and who would do it all and who would be sort of'*

N03: *'Yeah, responsible'*

5.4.1.6.2 Online

Regarding the inclusion of an online component, there was some concern that this could exclude a large number of patients. However, it was suggested that some may find it useful (particularly office workers). There was also great concern about the cost of the set-up and maintenance of any online component. The nurses concluded that given the age group of their patients, any online component would not be worth the cost. Before drawing any conclusion about the utility of an online component, it will be useful to assess the views of the patients themselves.

N02: *'Not everybody has a computer at home, so you'd probably be excluding quite a lot of patients, and it's probably the ones who are socially deprived who'd probably get a lot of benefit from it'*

N01: *'It tends to be the younger ones which want to look everything up online, and the biggest majority of our patients will be people which will be happy with it in the paper format, you know, for what it costs'*

5.4.2 Patient interviews

5.4.2.1 *Positive aspects of the intervention*

5.4.2.1.1 *General*

Like the nurses, the patient participants generally had a very positive opinion of the intervention. They didn't find it patronising or worrying, and many reported that they found it reassuring. Most felt that it was comprehensive and contained nothing superfluous. Participants felt it was helpful, useful, and informative. Many were pleased with the layout and how easy it was to read.

P09: *'I think it is a good idea, I do, honest, I think it's brilliant'*

P10: *'Yes its very, very helpful and very good and I, I would be very pleased to have something like that and I think it would help'*

5.4.2.1.2 *Need*

Generally, across all participants, there was a sense of need for the intervention. Unlike the nurses who talked about a general need where care provision is lacking, the patients talked about personal need for the intervention. This was largely due to widespread problems with stress and trouble relaxing, but also to clarify problems, give more information, prompt to increase exercise, and to calm cardiac concerns. P08 also talked about a wider societal problem with stress and lack of exercise, and thus a wider need for the intervention.

P05: *'You start then worrying on having an heart attack [...] and its like you say you do need to have the breathing and relaxation techniques to cut that out so that you haven't got the vicious circle'*

P08: *'you are absolutely right but people don't do enough activities without question'*

P09: *'I suffer a lot with stress. I can't relax. I get a lot of anxiety stress related things'*

P10: *'yeah I think we need information on this amount of stress and anxiety and pain, it's good to have more information on that because you don't realise that it causes all that tension and strain'*

5.4.2.1.3 *Not feeling alone*

One positive aspect of the intervention which was discussed was the benefit participants felt by not feeling alone in their suffering. Some participants spoke about how they felt reassured by the fact that the problem was common and that they were supported. P01 even suggested enhancing this feeling by including case studies in the intervention. This reflects what the nurses said about the intervention being a positive tool in that it may make patients feel as though the problem is taken seriously, and that NCCP is a common problem.

P03: 'the whole document here, it has inferred that people do suffer from chest pains and it's not necessarily cardiac related, it's stress, I think it probably, probably would be sort of helpful to let people know in some way, either, it's not an uncommon issue erm it's probably surprisingly uncommon'

P13: 'it does make you aware that a lot of, perhaps a lot of people have the same sort of diagnosis, and you're not, you're not alone, a lot of people perhaps go into A & E and the doctors with chest pains and you know it's quite common not to be serious'

5.4.2.1.4 Previous care

Among the participants, there was a general dissatisfaction with the previous care that they had received. Some felt there was too much focus on medication and pain relief, which participants were often reluctant to take, either due to side effects or a general dislike. There was a general feeling that GPs should be focussing more on stress-related problems at an earlier stage. Two participants had received some care for stress (P03, P09), but were still experiencing problems in this area. The intervention was seen as something additional that isn't generally offered by GPs, and thus very positive.

P03: 'I don't think the doctors have ever pushed this even though my blood pressure and stress are sort of related and I think it would be useful to have something like this that even in the earlier stages of somebody being err diagnosed with blood pressure, which is likely to be stress related, which was fairly obvious in my case'

P09: 'Cos it tells you things in here that your Doctor wunt event tell you...And do you know how to... do you know how it says relax yourself and find a quiet place and things like that you don't get that from your Doctor (LAUGH) you just get tablets'

5.4.2.2 Content of the intervention

5.4.2.2.1 Sections

Section One – P07 and P13 expressed specifically that they liked the start of section 1, explaining their diagnosis.

P13: *'I mean the first sections quite helpful in't it you know, telling you about non cardiac chest pain, it's quite, it's quite helpful really'*

Participants generally didn't like the diagram, struggled to understand it, or found it irrelevant. Only one participant (P05) spoke positively about the diagram, and she only mentioned it briefly.

P06: *'The only one thing that I keep going back to is err, is that page with the arrows, I don't know why, I don't if it's cos I didn't understand all, it just... it just isn't very clear what, what spaces are for and I don't know I just tend to veer away from it so whether that's not needed I don't know but it does go with this vicious, yeah vicious cycle of pain. I don't know what I'd say about it, I just find that completely unclear, whether or not it needs to be in I don't know, but yeah'*

Most participants felt positively about the pain diary which was provided to record the onset of pain and associated situations and feelings. Despite P03 saying he probably wouldn't use it, he did say he could see the benefit of it.

P06: *'Yeah that's a good idea, keeping a diary. That's something you say you'll do if somebody suggested it but you wunt necessarily but actually for somewhere to write it down makes sense'*

Some didn't like the pain diary, mainly because they didn't like the idea of writing things down or diary keeping (P02, P03, P07). Some felt they would have difficulty using it due to not being in a working environment, and so would struggle to draw connections to specific times and situations. P13 said he would find it difficult to complete as his pain onset was gradual. Some felt that despite it not being to their personal taste, it would still be useful for others (P01, P02).

P03: *'I've never been that sort of person to sort of note down sort of, I suppose in a way I sort of am [...] I suppose it's a case of being formal enough to change my character to write things down as they are actually happening'*

P01: *'I suppose it would for people that would work, you know, that say they were at a computer or dashing about but erm not really for me because like I said mine is when I rest mainly'*

Section two – Regarding the section encouraging participants to increase physical activity, participants generally felt positively, finding it relevant and important, with some finding the exercise diary very useful.

P06: *'Yeah, yeah cos often you don't think about it but walking the dog, things like that are all exercise but yeah you need a diary to, cos if you do do something you know not majorly, like*

walking the dog, just walking down to shop you don't think of it as exercise but then you can log it all on there and remember what you've done'

However, P02 felt it could be insulting, and both P02 and P10 had a problem with the example of dog walking, which could be irrelevant for some. The examples given may therefore need to be reconsidered.

P02: 'some people haven't got dogs, if you've got a dog you've got an excuse to walk but don't tell everyone to go out and get dogs'

Most participants felt positively about the relaxation techniques and felt capable of doing them.

P06: 'I was just, you do, you do it as you're reading sit comfortably with your eyes closed, start to breath and I was doing it then, thoughts feelings and external noises oh my (LAUGH) I suddenly heard that dog bark, I'd not noticed it before and then I, yeah it is quite relaxing to just take, take everything in. Mmm interesting not something I've thought about, it is quite relaxing'

P07 and P02, however, both expressed dislike of the relaxation techniques. P02 felt it was quite 'middle-class' and 'hippy'.

P02: 'Mindful breathing umm (SIGH) mindful breathing, it's very middle class that, mindful breathing [...] it's some hippy wrote this, this is a hippy, a hippy wrote this'

Section Three – Most participants spoke positively about the use of the implementation intention plans, with some being especially positive about using them.

P11: 'I will do this now because its brought it back to me now really but that's what's missing, I haven't, the plan wasn't there err and like I say my life style isn't regular, I do need a plan, I do need to make more of a routine for the areas I can and this needs to be in a routine'

Some didn't like the plans in section three, or were reluctant to use them (P01, P02, P07). P13 liked the idea of planning but didn't feel he would need to write it down. P07 also felt that she wasn't the type of person to write things down.

P02: 'Yeah the plan it switches me off totally, I don't think most people are going to take that in, I know my partner she went to a counsellor and stuff and she had to have all these... urgh no, it's not for me that type of thing, I don't think that'll help, not going to work'

Some participants noted that they particularly liked the Further Support section, as it made them aware of further resources.

P06: 'The further support's really useful, I dint know, I don't know that Self-Help, Anxiety UK, I didn't know any of these, that's useful'

Images – Some participants didn't like some of the images used. P02 especially didn't like some of the clip art images or the speech bubbles. P05 didn't like one of the clip art images. P03 found the layout of the speech bubbles confusing.

P05: *'I'm confused (LAUGH) well you've got eg walking the dog eg using the stairs then we've got a little picture of somebody running (LAUGH) that looks like on a treadmill (LAUGH)'*

Some, however, made specific comments about certain pictures that they liked (P03, P05).

P05: *'I like the big question mark'*

5.4.2.2.2 *Understanding*

There was generally a very high level of understanding of the intervention, with only some minor sections and parts being described as unclear. Some found the instructions for the techniques a little difficult to understand in places, but only one described them as containing jargon. Two participants had some difficulty initially understanding the plans in section three (P03, P09), suggesting a change in wording may be necessary here; especially given that the nurses felt that the wording of this section was not good. P08 seemed to misunderstand the purpose of the exercise diary, presuming it should be completed retrospectively to highlight awareness of previous exercise and lifestyle, rather than used to plan ahead. However this participant did not read all the intervention material in detail, and so this may be due to a lack of attention paid to the instructions. Nevertheless, it will be assessed whether these instructions may be made any clearer. P09 did not understand one of the words used in the booklet ('chores'), and so this may be removed. No sections or parts were consistently unclear across participants, suggesting that there are no parts that are especially difficult to understand. This finding is very positive given the wide educational range within the sample, and also addresses the concerns of the nurses that the intervention may be difficult to understand by some. This would need to be confirmed, however, in a larger sample.

P09: *'I mean I never went to school but I understood everything that was to be understood, do you know what I mean, so'*

P10: *'it's plain speaking this, it's easy enough follow, there's no, I don't think anybody would find a part in this which they wunt understand and they couldn't follow it cos it's easy enough to*

follow, yes it's good. I think even kids could do this, my grandkids would be able to do that (LAUGH)

P03: 'Yeah this section three, making plans, I just had to go back and re-read it I don't know why I just sort of lost track, just working my way down the page there. I think that needs to be a little bit more sort of bold in the way that's sort of presented, I don't know, I can't explain why I just think it needs to be make a plan, if stressed or take time out if you're feeling stressed this is what you do instead of the little boxes that you've got there'

5.4.2.2.3 Length

Some participants were concerned that the booklet was too long and needed to be cut down (P02, P05). It was felt by some that stress/pain would be a barrier to reading it due to it being so long (P03, P06). Like the nurses, some participants thought that although it may be a little too long, there was nothing that could really be cut out to make it any shorter (P08, P11, P13), but half the participants were happy with the length of it (P01, P03, P07, P09, P10), particularly because it was broken into short sections and therefore easy to read (P09, P10).

P02: 'Yes yes it were too long, yes too, long very too long yes'

P10: 'Its good, it's not boring or it's not weighed down with a lot of jargon and it's straight forward and you would be able to get through this and keep turning to this and going back on it quite easy. Its length is alright and everything in it's alright yeah. It's not too long, it's not hard, it's easy to understand and I think it will be very helpful'

5.4.2.3 Negative aspects of the intervention

5.4.2.3.1 Changes

Participants identified a number of changes that they felt could be made. These were mainly minor changes, regarding things such as typographical errors, layout, phrasing and punctuation use, which can be easily incorporated.

One aspect that a number of participants felt should be changed was the length of the booklet. P02 felt that it should be cut down considerably, keeping only crucial parts explaining the diagnosis. Others felt that it could be cut down by combining or cutting out some of the sections (e.g., P05, P13); for example, P13 felt that the relaxation techniques were repetitive, and it wasn't necessary to include all three. This contradicts what the nurses said about the fact that there were a choice of techniques was a positive element. P05 made the recommendation that the intervention could be split into separate booklets. However, this

would contradict the idea of a single, comprehensive self-help tool, and may lead to patients not reading all the sections.

P02: 'You can go through it with a red pen and you can probably get rid of most of it because it's all verbal, verbal diarrhoea that's what I call it, verbal diarrhoea, I'm good at it, talking shite, but that bit, that's the bit that is really, really useful'

P05: 'I think maybe splitting it so that you've got the explanation of the fact that it's not a heart attack basically, although it might be if it goes on and on and on erm and then having the erm relaxation and the diary maybe together because then you've got the relaxation techniques that they can look at and think yeah I can make a plan with that, yeah that would be best the relaxation techniques and the diary together'

Some participants suggested changes to the diagram which was provided. P05 thought a different image could be used in the centre. P06 felt that the text explanation of the diagram should be incorporated on the same page as the figure, in order to make this section clearer. P13 also found the diagram unclear, and said he would have preferred it to match the small picture which was on the previous page alongside the text explanation. Given the above discussion about the negative feeling toward the diagram, and the fact that the nurses did not like it either, the format or even the inclusion of this page will need to be strongly considered.

P06: 'I don't quite understand what you've got to... have I not read something right, what you've got to do with these, err figure one on the following page, right yeah shows how thoughts, behaviours... I think maybe that part where it says figure one on the following page should be writ on the following page (LAUGH) so you remember what its there because then there's a whole paragraph about that, I think that part needs to be on top of that on next page'

Some changes were suggested by individual participants, which may largely be due to personal preference. For instance, P02 expressed a desire for important or interesting parts of the intervention to be highlighted by a small picture or symbol. This would be difficult to include, given that different sections of the intervention may be relevant for different people. P09 felt that there should be less emphasis on concerns about cardiac problems, as this may actually increase worry. However, no participants stated that they found the intervention worrying, and when relating the intervention to personal experience, many found they could relate to the concerns about cardiac problems which is mentioned in section one. It therefore seems suitable to not make this change. P06 felt that she wouldn't like to be alone to do the relaxation techniques (as she didn't like to be alone when in pain), and that the option to do them with others around her should be included in the instructions. It may be possible to make the instructions more general, instructing people to sit quietly and comfortably somewhere,

rather than alone. P03 felt that the pain diary could be changed to recommend people to write down their general state of mind, rather than specific thoughts. This could make it easier for patients to complete the diary and could also be incorporated quite easily. P03 also felt the wording of the plan section could be changed, to invite people to make a plan that fits easily into their life. As the nurses also highlighted issues with the wording of section three, this will be reviewed and revised in accordance with these comments.

P03: 'I think you could probably phrase that slightly differently erm in the fact that we mentioned already that sort of practice makes perfect okay. It's probably wise to go back and say, along the lines of the fact that erm, it's a case of developing your own personal culture to cope with stress and utilise the techniques within your sort of living environment and to develop a plan that best fits in to use techniques to frequently practice the techniques and over a period of time you will hopefully see the benefits'

Both P06 and P13 felt that the booklet would be better if it were a smaller format, such as A5. This will be considered as A5 would be a 'handier' size; however, there may be problems with the sections that patients are asked to complete. Also regarding the appearance of the intervention, P03 suggested that the title page could be changed to be more visually appealing.

P06: 'A5, but obviously I'm not saying make it thicker or anything, get the same amount of text on each page but err smaller font and a smaller size pages, I don't, I don't know it just seems a bit big (LAUGH) yeah, yeah literally. Not too much information on the pages just big sized paper that's all, yes'

5.4.2.3.2 Additions

Participants suggested a number of potential additions to the intervention. Many of these were minor, and many were only suggested by one participant, for example:

P01: 'Erm it would be nice if there was some information and scenarios from other people, you know little paragraphs of other people experiencing the same so that you don't feel alone?'

P05: 'Sensory impairments you could perhaps use the err senses that you would normally use in daily life because obviously if your blind you don't know colours (LAUGH). Well some blind people don't know colours they just are light and dark, I'd correct that whereas touch and hearing is more important to them rather'

These additions were often related to the participants' personal experience of stress and pain. For example, some wished for information about specific causes to be included which they had felt had played a role in causing their own chest pain. Others wished for more information relevant to their own personal experience, such as their own lifestyle, impairments, and use of pain relief. Other suggestions may be more relevant to all patients, as they were more generic

in nature. For instance, P01 suggested that case studies of others' personal experience be included. Other participants also discussed the positive aspect of not feeling alone, and, furthermore, P03 also suggested that emphasising that NCCP is a common problem could be a good addition. An inclusion such as this could enhance this aspect of the intervention. P03's suggestion of encouraging participants to find ways of fitting the intervention into their personal everyday life could be a good way to make the intervention more inclusive for a wider variety of participants. Some of these changes may therefore be incorporated into future revisions of the intervention.

P03: 'Yeah, yes it's a self-help thing and also the..., I think also a sort of case of using that erm ... the issue of the fact that stress is not uncommon erm you are not some freak cos you suffer from pressure or stress or anything like that it's a case of, its, it's part of the modern environment, the modern way we live'

There were some additions which were suggested by more than one participant, and may therefore be more appropriate for inclusion into the intervention (given they may not be simply due to individual personal preference). For example, two participants (P01, P03) talked about how they would find it helpful if some information about the physiological mechanisms of how stress can actually lead to pain was included. This reflects the confusion shown in Study 2 where some participants struggled to understand this connection.

P03: 'you don't really say why people have chest pains because of stress now I'm assuming it's sort of muscle spasms or tense muscles, they're keeping things tight and I'm not sure whether things rub together or whatever else that causes the pain (LAUGH) but erm if you could, if you could sort of put that in a light hearted way, I mean not get all sort of, not get long words of Latin normally but err just sort of explain the fact that, I mean it could be another cartoon, I mean a guy there with a huge rubber band round his sort of chest or something like that, this is what the tensions doing to you, it's sort of, sort of filtering everything up to here and that's what, that what's creating the pain.'

Two participants (P02, P03) suggested different images should be included in the intervention. This will be considered, but given the personal nature of the recommendations (for example, P02 felt that an image from one of his favourite films should be included), it will need to be assessed whether these suggestions would be appropriate.

P02: 'It's just me, I've just got a vision of fight club when he sees this little penguin, slide. Penguin, get a penguin on that, that would be quite humorous that, especially for people that are a bit rougher, have slide'

Two participants (P02, P05) had concerns that there should be stronger, more prominent, advice about seeking care in the event of further problems (which could potentially be cardiac). As the discussion of adverse consequences arose in both the nurse focus group and in the patient interviews, this aspect could be beneficial in calming these concerns.

P02: 'Either the back page or preferably right at the front at the top, coping with stress pain, this will stop your stress levels hopefully but if you get, in really big letters, if it doesn't work and you have more pain later on please phone up (LAUGH), get yourself rushed in, front page (LAUGH)'

Three participants (P08, P11, P05) felt that the intervention should include more information about improving lifestyle, such as diet.

P08: 'I think there's, like I explained to you I think you've probably missed a bit out in that respect and I bet, I would imagine when you get people in here, part of it would be., if they are my age it will be down to drink and food with that question, lack of exercise with that question on that'

5.4.2.3.3 Barriers

Participants identified a number of barriers to using the intervention, in themselves and others. Some felt that the pain itself, or stress levels, may prevent people from engaging with and using the intervention. Many participants talked about practical barriers which may get in the way of using the intervention, such as a hectic lifestyle, work, or a lack of available local activities. There was also some general concern that people simply wouldn't read or engage with the intervention. Some participants identified physical barriers to doing the techniques or increasing activity, such as disability (P05) or other health problems (P09). P03 felt that some patients may have difficulty accepting stress as a cause due to embarrassment or the 'British stiff upper lip'. He also felt that some may prefer relief from medication rather than making the effort to help themselves. Given that the acceptability in this study seems to be rather high, we would hope that this may not be a problem. In addition, the findings of Studies 1 and 2 seem to indicate that people are happy to accept a psychological explanation for their pain. P06 and P10 had concerns about being alone – P06 felt that she wouldn't like to be alone when practising the relaxation techniques, and P10 felt that she may struggle to motivate herself to use the techniques, due to being alone. It may be therefore beneficial to emphasise the role of involving significant others in supporting patients in using the intervention.

P11: *'I will definitely consider using them and I will try and do them, whether or not I can fulfil it all at the moment and if I'm not doing something I say I will do that adds to my stress so I'm not going to make unreasonable commitments on myself'*

P06: *'Like I say the only thing and that's a personal thing for me with the guided imagery I don't particularly like to go on my own, you know some where on my own, (SIGH) you know I like to keep [my husband] around me or [my daughter] or I just like to have somebody with me when I go like that because I don't, I really don't know its just a personal choice, I don't like to be, be on my own when I've got these chest pains, I'm a bit panicky and like I want somebody around me so whether or not when I'm actually in that situation that's something I'd try I don't know '*

5.4.2.3.4 *Not accessible/acceptable to all*

Despite the participants finding the intervention generally understandable themselves, there was some concern about the intervention not being accessible to all, either due to understanding or acceptability. This was a concern that was also expressed by the nurses, and so may need to be considered closely and monitored in any further research. P02, P03, and P05 all expressed that they had a relatively high level of understanding/education, but that others may not have sufficient understanding to find the booklet accessible. P02 was particularly concerned about this, and spoke of how the intervention was too complicated to be understood by all, and it needed simplifying. He also thought that some would find the intervention not acceptable, and not engage with the material due to it being too 'middle-class' and 'hippy'. He felt that the intervention may only be useful for those who had prior inclination towards the content of it. The findings of the present study seem to suggest that there are few problems with understanding and accessibility; however, this would need to be investigated further in a larger scale study.

P02: *'the type of people that this is aimed at, the ones that are stressing, the ones that will understand this, I, I've got a funny feeling those who will understand it are the ones that will utilise it or they, they, they've been taught it while they are growing up and they understand it, something like hobby people and stuff, they will read, they will read things and they will be stressed but when they read this, they will go 'oooh' and it will, you, you, you are touching on parts between people's lives and how they've been brought up and I think they just can't look at it and go 'ooooh' and it will make them make that connection and then they'll start employing what they used to do, what they've read here as well, into it and sort themselves out if it is a stress problem and it will be good for them but there is more types of people who don't, there's a lot nice people, there's people that will look at that and they'll just see some hippy, they'll look at it and think 'some hippies just told me, I might as well just smoke a spliff [...]'it is good, it is good but I think it wont get across to everybody, it will only get across to the ones that are already is it inclined, the ones that are already like in a way, they've got it already'*

5.4.2.3.5 *Adverse consequences*

Three participants discussed potential adverse consequences of using the intervention. P02 and P09 had concerns that if they were assured that their pain was stress related, they may later delay care if they experienced pain which could be cardiac, and therefore they might be in danger of dying. P11 suggested briefly that the intervention may cause people to focus on their pain when they shouldn't be dwelling on it. The nurses also discussed the possibility of adverse consequences, but they did feel that it was unlikely if the correct advice was given to patients. The likelihood of adverse consequences would need to be assessed in a full trial.

P09: 'But when you get chest pain do you think is it caused by stress or is it a chest pain, do you know what I mean, that's why you have to do something about it because if you just sit here and think 'oh I've got a reyt chest pain, its only stress what's causing it' and its summat else, then you either get through day and get it sorted or you just, I don't know, keel over and that's it, you're dead aren't you when it's a chest pain'

P11: 'The only thing I think about this is, you know about, erm, and I think this is right, I'm sure this is right but you know how often they say [...] don't dwell on things'

5.4.2.4 Relevance

5.4.2.4.1 Recognising the role of stress

Participants generally had all recognised that stress played a role in causing and/or maintaining their pain, thus suggesting that an intervention aimed at stress is relevant to this group of patients. This supports the findings of Study 1 that NCCP patients with higher levels of distress were more likely to advocate psychological causes for their pain. Some were not completely sure of this relationship, for instance P03 felt that he was stressed and this could play a role in causing his pain, but he did not want to confirm that his pain was definitely caused by stress. Nevertheless, he thought that the intervention was relevant to his high stress levels. Some had drawn the conclusion about the stress-pain relationship prior to interview (e.g., P01, P02) others made it as a result of seeing the intervention (e.g., P08).

P03: 'I'm not even sure whether its anything to do with the stress cos its only very recently I've experienced the chest pain and it, strangely enough I've had this chest infection and which, although I've been taking more, I had taken antibiotics for a week for it, I'm fairly certain in my own mind that it was probably part of the cause in the previous three weeks to this. [...] Some it might be stress related I don't know or the two might sort of coincide and it might of just made me more aware of it so personally I can probably think that the way I deal with stress at the moment, it could partly be stress related yes so, cos it has been an extremely stressful two months I've just run through unnecessarily, so, yeah'

P08: 'Yeah definitely with me err with me its stress I would think without a question and not just erm not home related but I would say more work related definitely is the case with me cos its err

yeah people with tension, I agree with that definitely, I would, I find myself sometimes getting really angry sometimes'

5.4.2.4.2 *General relevance*

All but two participants found the intervention to be very relevant to them, largely due to high levels of stress and difficulty relaxing. Even participants who didn't feel their pain was completely caused by stress still felt the intervention was relevant to their high stress levels (e.g., P03). P02 had concerns about possible irrelevance to some people as their pain may be caused by other factors (e.g., muscular), and described a mixed picture of relevance, talking initially about how he felt his pain was stress related, but later revealing that he didn't see himself as stressed. P07 didn't see herself as stressed and wasn't concerned about experiencing continued pain, and therefore found the intervention generally irrelevant, although she did take some messages from it. P13 seemed to have an unclear view of his pain and how stress was involved, and whether he was experiencing stress, and seemed to be overly focussed on the fact that he hadn't received any diagnosis for his pain. Use of the intervention may therefore help clarify this for him. All participants related at least some part of the intervention to their personal experience of chest pain, even those who did not feel the intervention was relevant in general. This suggests that the intervention captures the range of experiences of living with NCCP.

P02: 'your are going for the stress thing aren't you trying to say what makes you anxious but its not always that what's causing the pain sometimes it is just a torn muscle or something in your chest'

P06: 'there were a lot of things relevant, a vicious cycle of pain I think might be relevant, I found that interesting to read [...] I think it's all quite relevant'

P07: 'Is like when they say here 'are people still worrying about it', I'm actually one of them that if I'm told I'm alright then I'll go home and that's it so that's fine'

5.4.2.4.3 *Sections*

Generally, where participants didn't find one or more sections relevant, they found other sections relevant. The intervention appeared to provide different things for different people, but was beneficial for most in at least one area. Primarily, participants focussed on either exercise or relaxation. This supports the view of the nurses that the intervention services more than one need, and may meet different needs for different people. For instance, some participants who saw the relaxation techniques irrelevant found the section on increasing

exercise as very relevant. Some participants, however, saw the exercise section as irrelevant. P03 felt the diary was irrelevant to him; however, he did have trouble connecting pain and stress, suggesting that he may benefit from using the diary.

P05: *'To me because I, I do erm, I don't plan, If I do things happen so that doesn't work (LAUGH) erm in daily life things have a habit of doing that to me, I plan things and then something will crop up but erm no, I think its, it's the relaxation bit I need to do'*

P08: *'its right what you say about the cycle of stress and, and they say relaxing but I find it sometimes difficult to relax like your relaxation techniques, I understand what you're saying but I don't think it would be relevant to me, I think to me just to be able to freeze off a bit, you know like to just read'*

P03: *'Interesting yeah. I haven't intentionally avoided exercise and this is one of the things I was concerned about when I was travelling away cos err the last visit to the doctor he actually handed be the leaflet about stress counselling and err I was a bit busy but I must have read it in a traffic jam and sort of the first section I read was about erm the fact that you don't, when your stressed and your under tension you don't to participate in the things that you used to enjoy doing and some people might think a hobby isn't particularly stress, err sort of exercise but it is and to have, I have avoided doing that'*

5.4.2.4.4 *Helpful for others*

Where some participants didn't feel the intervention was relevant for them, they did feel it could be helpful for others, such as those with less knowledge, higher stress/anxiety levels, or continued pain (P01, P07, P13).

P07: *'I'm not diary writer but you know I think that could work for somebody who are like proper anxious, yes definitely. Erm yeah it's not for me though but I do think it would work'*

P01: *'Its helpful for anybody that doesn't know any of that'*

5.4.2.5 *Using the intervention*

5.4.2.5.1 *Prior knowledge/use*

Most participants had some prior knowledge or experience of the intervention materials, largely the relaxation techniques. Most had previously used similar techniques or knew others who had, or used techniques they devised themselves that mirrored those in the intervention. Some had previously used relaxation tapes or CDs. Some found the information in the intervention novel. The fact that the intervention materials were familiar to most participants may have increased the acceptability. Most who had prior awareness said that the intervention had reminded them of techniques that they should be practicing. Furthermore, for those

whom the intervention was novel, it was found to be very positive and informative. This suggests that the intervention could be useful to both patients with prior experience of the mechanisms of stress and relaxation techniques, but also those with less knowledge and experience.

P03: 'I must admit when I was younger, very much younger, I was very much into sort of other cultures and sort of err, using sort of Buddhist and the Chinese approach to medicine and err sort of concentration and meditation and things like that, I was quite focussed on and it's something that err (LAUGH) I wish I could, once you maintained that more than anything else but it's easy to get out of sort of alternative approaches to problems. I mean particularly when you are stressed and you are suffering other things, hectic lifestyles of today, you forget sort of the simple things that you used to do as well'

P09: 'it's not every day that you can read summat that's telling you about chest pains and stress'

P10: 'Yep I'm agreeing with all this, this sounds very good, I wouldn't have thought about a lot of this and I wouldn't have thought a lot of this would help but I can see where it's coming from this'

5.4.2.5.2 Willingness to use

Participants were generally positive about using at least some part of the intervention (e.g., techniques, exercise, or diary). Where participants felt slightly negatively about using the relaxation techniques, for example, they were very positive about increasing their exercise (e.g., P07, P08). Others were very positive about using the relaxation techniques regularly (e.g., P03, P06, P10, P11), and some were keen to use the pain diary (e.g., P02) or the plan in section three (e.g., P06, P11). Others suggested that they would 'try anything' to try and reduce their stress and chest pain (e.g., P01, P05). Some expressed that they would like to keep a copy (e.g., P03, P11), and some said that they wished they had received it sooner, such as when they first got their diagnosis, or when they'd had previous problems (e.g., P03, P10). Some participants talked about how they would only use the intervention regularly if they found it to be effective at reducing pain.

P05: 'Oh I will try it, I will try anything like I say (LAUGH) I've got that many stresses in my life but yes I, I will try it'

P06: 'The mindful breathing and things I will try and hopefully, fingers crossed it might work yeah. Yeah, obviously I wont know that until I try it but hopefully (LAUGH)'

P07: 'I will start exercising more though. Exercising diary's a good idea. I might take that one on board'

It therefore seems positive that, if the intervention was implemented in practice, patients would be willing to use at least some section of it, and some patients may find a lot of it very useful. This would need to be confirmed in further research on a larger scale, in which adherence would need to be assessed.

5.4.2.5.3 Beliefs about efficacy

Participants were generally positive and hopeful about the intervention being effective at reducing pain and stress. P08 wasn't sure whether the relaxation techniques would work for him, but did say he thought the intervention would be effective at reducing chest pain in general. P06 and P11 felt that they didn't want to confirm conclusions about the efficacy of the intervention in reducing chest pain until they had used it and found it to be effective at reducing pain. This shows the importance of the intervention actually being effective in reducing pain, and therefore this would need to be confirmed in further research.

P05: 'I think it could reduce the causes of chest... some of the causes of chest pain yes erm some of reasons of that could reduce the stress which aggravates the pain'

5.4.2.5.4 Other methods of coping and relaxation

Participants mentioned other methods that they used to relax or cope with their chest pain, such as doing hobbies, walking, listening to music, reading, taking painkillers, or sleeping. Some of these they had previously used, some they currently used, and some were suggested as potential methods. Participants also had their own ways of fitting exercise into their lives (e.g., incorporating with children, using weights). Sometimes participants expressed that they didn't need the intervention so much as they had these methods. Encouraging patients to increase the frequency that they use their own methods of relaxation in order to reduce their stress and pain (rather than trying to get them to use new methods) may therefore increase the scope of the intervention.

P01: 'I suppose listening to a nice classical CD would help as well'

P02: 'Get yourself a nice hobby painting, like I do'

P07: 'when I'm stressed you know like tension headache and I'm just like you know take paracetamol or whatever and go and have a lie down, have a sleep, just chill out you know, going to, go into my own little corner and have an hour so'

5.4.2.6 Practice aspects

5.4.2.6.1 Delivery

Three participants made comments about the delivery of the materials. P02 felt that some guidance was necessary for patients. He also felt that group relaxation would be beneficial. P05 felt that the ED staff would need to be mindful about who they gave the intervention to. She also felt that returning to hospital/GP with the intervention after receiving it would motivate people to use it/fill it in. P09 felt the leaflet could be delivered while waiting to be seen in the ED, which may be difficult due to the need for a non-cardiac diagnosis to have been received before delivery. Given the discussion among the nurses regarding concerns about increasing their workload, it seems unlikely that any detailed guidance could be provided. However, it may be possible, as the nurses suggested, to deliver a short instructional script alongside the intervention. Advising patients to engage in group relaxation would be possible, and may overcome problems with feeling alone. Returning to a health professional with the intervention would be difficult, as the intervention is designed to be a stand-alone self-help intervention. Any problems with adherence because of this would need to be investigated in further pilot work.

P02: 'I don't think you can learn that from a piece of paper you need, not a counsellor you need somebody who's just going to do that with them'

I: 'Some guidance?'

P02: 'Guidance, half an hour if that, it will only take half an hour just to sit down with somebody and after you've had a cuppa just sit down and say 'what do you feel' and then just go through all this'

P05: 'I think that, that erm people unless they keep a diary, a personal diary anyway aren't in the habit of doing so and its good practice to do so to then monitor their own health erm and to do that they will need the encouragement of going back, the feedback of more helpful suggestions or whatever from whether it's a nurse at the doctor's or whoever erm cos a lot will start to... 'I don't see the point in that, I'm not going back there, they won't know if I've done it''

5.4.2.7 Extending the intervention

5.4.2.7.1 Audio

Participants were questioned on their opinions of having some elements of the intervention (e.g., relaxation techniques) on audio. Some expressed interest in this prior to being questioned (e.g., P11, P05), often due to prior experience of using audio relaxation. Some (e.g., P02, P05, P07, P10) thought that audio could increase accessibility to those who can't read or have disability, an idea that was also highlighted by the nurses. Most felt positively about

audio, either for themselves (P01, P08, P09, P10, P11, P13), or others (P03, P06, P07). P02, however, wasn't particularly positive about an audio element, and felt that group relaxation would be more beneficial. Most said that they would prefer to have the audio on CD, although P13 said that he would be happy to access it online.

P06: *'Possibly yes, yes why not erm, personally for my self I don't use audio cos I'm not sure you take it in as, as much as you do reading the words and..., but some people might benefit from it being audio. I don't think I would personally but it's not fair to say other people wouldn't (LAUGH)'*

P10: *'It would help people perhaps who have got difficulty to reading or perhaps don't read very well and things like that, it would, it would because personally years, and years and years ago I had a relaxation, it was a cassette, a small one and it was a erm a man reading it with the most relaxing voice I have ever heard and it did, it made you relax just listening to him talking, and he was putting you through things like this and unfortunately I lent it to somebody and never got it back and I can't remember who had it so that's years ago but yes I think it would help as well, yes'*

5.4.2.7.2 Online

Some participants felt they wouldn't use any online element (P01, P05, P09, P10), but P05 did feel it would be useful for other (younger) people. Some felt positive about online access (P13, P06, P03, P07, P08). Like the nurses, some were concerned that having an online element may be inaccessible for some people (P02, P13).

P06: *'Yeah definitely I mean I pointed out when I read that last page that I tend to go on't internet and you know, and have a look, muse through so probably would. Anxiety UK for instance, I didn't know that existed, possibly something I'd go and have a look at now so yeah, any sort of on-line, yeah why not (LAUGH)'*

P02: *'I don't like saying on-line because there's a lot of people that are internet poor so no, I don't agree with that, I'm a socialist at heart, we are all going to get it or nobody's going to get it'*

5.4.2.7.3 Wider scope of the intervention

Just as the nurses had discussed the intervention serving a wider purpose, some participants (P03, P07, P08, P11) talked about the intervention having a wider scope than simply dealing with NCCP. Some felt that it could be applied to stress in general, rather than just pain (P03, P08, P11). P07 felt that it could be applied to other pains such as headache. P08 felt the intervention could be delivered more widely, such as by GPs and in workplaces. This shows how the participants generally felt very positively about the intervention material, as they felt

it could potentially serve a wider need. Any extension of the intervention (e.g., delivery by GPs) would depend upon an assessment of the efficacy of the material.

P08: 'It needs to be something like that, like the thing with that err 'change for life' they've actually sent it to houses, they've made it available like that, something like this should be done like that, or people should be made aware of it, you know I think so, if you are going to have it in GP's so Doctors can give it to people that come to them'

P11: 'Yeah I mean this is great for anybody isn't it with stress, anybody with or without chest pains, I think it would be great to give it to... in every department because its very clearly done, its easy to work through, and its all in one booklet so I, so I would, I've got lots of little booklets of the different types of things but I like the way you've got it all together and I think with or without chest pain, so far this is great'

5.4.2.8 *Sharing the intervention*

5.4.2.8.1 *To help others*

When questioned about sharing the intervention, most participants presumed that this was to assist them in dealing with their stress. This is mainly because people generally had a lot of people around them (family, colleagues) who suffered high levels of stress, and they felt the intervention would be helpful to them. This, again, demonstrates the positive feeling toward the intervention, as the participants felt that it would also be helpful to others, not just themselves. However, it may also lead to inappropriate use of the intervention (e.g., with those who have cardiac pain). Patients receiving the intervention should therefore be advised that it is only to be used in those who have received a negative cardiac diagnosis.

P02: 'I think perhaps we'd discuss it all way through but yeah I think there is a bit, I think there is a bit in there that yeah I would, the stress bit cos [my partner's] a proper stress head, she's far worse than me and sometimes her stress acts on me and that's worst bit'

P08: 'And in my work environment I would definitely take that to work. They might sneer at it whatever but we all have the same kind of problems'

5.4.2.8.2 *For support*

When questioned about sharing the intervention with others, most immediately presumed that this would be as a way to help them (see above). However when prompted, and some without prompting, most participants talked about involving others in supporting them in using the intervention. Most felt that they would be supported (P01, P05, P06, P10, P11, P13),

however some felt that their family wouldn't support them in using the intervention, mainly because they didn't want them to (P07, P09).

P10: 'I would discuss it with my family and say this is what they've given me, erm and they would read it, I know that they would read it and most likely say 'well they're right and do', and my family would say 'and don't forget to do it and start doing it' (LAUGH). They would egg me on and say 'this is what you need to do'. Yes and they would, they would be interested in reading it because they are very good with anything like this'

P09: 'I would rather try dealing with it myself than me mum saying 'do this, do that' you see if I show me mam this she says 'well I don't you... you wanna do, relax more, leave dog, leave dog on back' and this, that and other then I would start getting stressed about it and I'd take it out on me mum'

5.5 Discussion

The aim of this study was to assess the acceptability and relevance of a self-help intervention for patients with NCCP. To assess this, a focus group was initially conducted with a group of specialist chest pain nurses who care for patients with NCCP. Following this, interviews were conducted with a group of NCCP patients, using think aloud methodology. The findings from both the focus group and the interviews revealed very positive opinions of the intervention. Overall, the intervention was seen as very good, and fulfilling a need where treatment options are lacking or not optimum for patients with high levels of stress and difficulty relaxing. Both groups talked about how the intervention could be used more widely, thus demonstrating their positive feeling towards it. A few minor changes and additions were suggested, some of which will be considered for inclusion. Overall, the intervention appears to be acceptable, relevant, and feasible.

5.5.1 Intervention content

Regarding the individual sections of the intervention, the patients felt positively about at least some part of the intervention, if not all. There were a significant number, however, who felt quite negatively about the 'hot cross bun' diagram that described the relationship between thoughts, emotions, behaviours and physical sensations. Similarly, the nurses were positive about all sections except this diagram. This was mainly due to a lack of understanding, which may result from a lack of accompanying guidance; the diagram from which it was adapted is designed to be delivered during a therapy session, with a therapist or counsellor guiding the

patient through the diagram step by step (Padesky & Mooney, 1990). Using a diagram like this to structure a personalised 'case formulation' within CBT is strongly advised and supported, helping the therapist to model the individual's experience to a model of their disorder, allowing level of need to be determined, and the intervention to be individualised (Persons & Tompkins, 2007). However, given the self-help nature of our intervention, it may be difficult to personalise the material in this manner in response to such a formulation, rendering the diagram potentially redundant and/or confusing. Moreover, the evidence for the efficacy of this method in improving outcomes is weak (Bieling & Kuyken, 2003), and it can be restrictive or emotionally upsetting (Johnstone, 2006). This diagram may therefore not be suitable for inclusion, especially given the lack of understanding and general dislike found in the present study.

The general feeling amongst both the nurses and the patients was that the intervention booklet may be too long, but there was little that could be removed or cut down in order to make it shorter. Some of the patients felt that it needed to be cut-down; however, the nurses felt that the length may be an advantage, as the patients may feel that they were being provided with a substantial treatment, rather than being 'fobbed off' with a negative diagnosis and some brief information. While previous research suggests that the longer the course of self-help treatment, the smaller the effect of that treatment (Gould & Clum, 1993), there appears to be little evidence regarding the length of self-help manuals or materials, most likely because intervention manuals are often not made readily available (Michie & Abraham, 2008). Given the mixed responses about cutting the intervention down, and the general positive feeling about the intervention content, it is not felt that the length needs to be altered at this stage. However, given there are a number of different sections in the intervention, and not all participants found all of these relevant, patients could be informed that they do not need to engage with all parts of the intervention, only those that they feel are relevant to them.

Understanding of the intervention content was very high across both the nurses and the patients, suggesting that the intervention is generally easy to understand, especially given the wide educational range in the patient sample. There were some sections which some of the patients found unclear, and so the wording will be reconsidered in these; however, no sections showed a consistent lack of understanding. Despite this, both the nurses and the patients had concerns about the wider understanding of the intervention, suggesting that those of a lower

reading age, for example, would struggle to understand much of the content. This may be unlikely, as all participants in the present study understood the intervention, and some had a low educational level. However, the sample in the present study is too small to draw any conclusion about widespread understanding. The Flesch reading ease score for the intervention booklet is 75.3, which is classed as 'fairly easy' (Flesch, 1948). A score of 60-70 is considered acceptable (the higher the score indicates greater ease of reading), and our current intervention actually scores higher than a number of previous self-help materials (Martinez, Whitfield, Dafters, & Williams, 2008). The readability of the intervention may therefore not be of concern. However, as mentioned above, some re-wording the instructions in some sections in order to make the intervention easier to use will be considered.

5.5.2 Acceptability and Relevance

In addition to the concerns regarding the intervention not being understandable to all people, there were also some concerns (among both the nurses and the patients) that the nature of the intervention may not be acceptable to all patients. This was mainly concerning those who might be resistant to psychological methods such as relaxation. Given the high level of acceptability in the present study, and the findings in Studies 1 and 2 that psychological causes were important, it seems that this may not be a problem in the present target sample. This high level of relevance and acceptability provides support for the underlying theory (i.e., the CSM) which guided the intervention development. Nevertheless, there may be some patients who do not engage with the psychological nature of the intervention, and in the present study there were a small number of patients who were reluctant to use parts of the intervention such as the relaxation techniques. This supports the previous ideas of Esler and Bock (2004) that a psychological intervention may be unacceptable to patients presenting with a physical problem. However, in the present study, where participants found the psychological techniques not of use to them they did engage with the part of the intervention emphasising an increase in physical activity. A previous CBT intervention for NCCP containing a strong physical activity element was found to be very effective at increasing physical activity, reducing fear of bodily sensations, and improving Quality of Life (Jonsbu et al., 2011). This suggests that the physical activity element of the present intervention is an important one – not only will it help to calm any existing cardiac concerns and improve general health and well-being, it may

also make the intervention more accessible and relevant to all patients. The booklet therefore seems to serve more than one need, and may serve different needs for different people, as the nurses discussed within the focus group. This reflects the findings regarding relevance for the patients: while most felt the intervention was generally relevant, often recognising the role stress played in their pain, some did not find certain sections relevant, but all found at least one section relevant. This is not a new phenomenon: Potts et al. (1999) also suggested that different elements of their varied intervention would be useful for different subgroups of patients.

5.5.3 Changes to the intervention

Few major changes were suggested by either the nurses. The patients suggested a number of potential changes (often minor); however, these were diverse and often contradictory and related to personal preference and experience. In order to make the intervention generic enough for all patients, it would not be possible to include such alterations. The wealth of suggestions made, however, could reflect the fact that the participants were engaged with the intervention and felt enthusiastic about it.

The nurses suggested that they would prefer the booklet to have more pictures and less text; however, this was not suggested by any of the patients, who often talked about how much they liked the existing layout. This will therefore not be incorporated. The main changes that the patients discussed were decreasing the length and removing the diagram (both discussed above), and the actual physical size. The physical size could not easily be reduced as there would be little space for patients to complete the sections such as the diaries. There were also certain additions suggested by the patients that could not be incorporated. For instance, some felt that there needed to be a stronger emphasis on re-accessing care in the event of further problems. However, one aim of the intervention is to reduce re-attendance in a group who are known to have high levels of healthcare utilisation (Eslick & Talley, 2004). The importance of this was emphasised by the nurses, and so any change such as this would need to be carefully considered, most likely with input from the nurses. Many patients thought that there could be more information in the booklet about lifestyle changes, such as changes in diet. The main focus of the present intervention is to reduce stress and chest pain, and therefore additions such as this may not be relevant to the goal of the intervention. Furthermore, evidence suggests that people should not be advised to engage in multiple health improvement

behaviours at the same time, as their self-regulation mechanisms will be depleted, and they may therefore be more likely to fail in their attempts (Hagger, Wood, Stiff, & Chatzisarantis, 2009).

Suggested additions that may be included are individual case studies and information about physiological mechanisms. The incorporation of individual case studies from patients who have experienced NCCP would emphasise how patients are not alone in their suffering, which was highlighted as important by both patients and nurses in the present study. These examples could be drawn from the interview work in Study 2. This inclusion may also help to increase the empathic tone of the intervention, demonstrating understanding of the patients' suffering. Increasing empathy in self-help has been identified as a good way to foster the feeling of a therapeutic relationship where no guidance is available (Richardson & Richards, 2006). Using case studies of the intervention being effective may also increase faith in the intervention and thus improve adherence (Richardson & Richards, 2006). Regarding the inclusion of physiological explanations, there is evidence to suggest that in order to effectively reassure patients with MUSs, it is helpful to provide concrete mechanisms to explain symptoms, often connecting physical and psychological processes (Dowrick, Ring, Humphris, & Salmon, 2004). While the intervention currently explains some of the connections between pain and stress, it may be beneficial to make these more concrete by including some explanation of physiological mechanisms. This will have to be explained using very simple language, so as not to decrease the readability level, and could incorporate diagrams. Providing concrete information with specific examples, combined with some visual information, has been suggested as an effective way to communicate health information to patients (Weinman, 1990).

One addition to the intervention, which all participants were specifically questioned about, was the inclusion of an audio element, namely the instructions for the relaxation techniques. Both nurses and patients were very positive about the inclusion of this, particularly if it was provided on an audio CD (as opposed to online). Combining media in self-help (e.g., both written and audio) has been shown to significantly improve the efficacy of self-help for anxiety (Gould & Clum, 1993; Lewis et al., 2012). The inclusion of an online element was seen as positive; however, there were some concerns about reduced accessibility and increased costs. Web- and computer-based self-help interventions for anxiety have shown strong efficacy (Andrews, Cuijpers, Craske, McEvoy, & Titov, 2010; Lewis et al., 2012); however, at this stage it may be

important to keep costs to a minimum, and thus keep the intervention restricted to written and audio format. If further research shows that this is insufficient, a web- or computer-based alternative or addition may be developed.

5.5.4 *Using the Intervention*

Regarding use of the intervention, all patients reported that they would be willing to use at least part of it, with some very keen to use the majority of it. However, given that intentions do not always translate into behaviour (Sheeran, 2005), there is a concern that this reported willingness to use the intervention may not be translated into action. However, implementation intentions are an effective way of bridging this intention-behaviour gap (Sheeran & Orbell, 1999; van Hooft, Born, Taris, van der Flier, & Blonk, 2005), and so it is hoped that the inclusion of this element will overcome any potential issues here. There may be a concern that patients may not choose to make an implementation intention, as the response to this section was somewhat mixed. However, it was highlighted by both the nurses and one of the patients that the wording of this section was poor, and so re-wording of this section may make people more likely to engage with this. The section could be re-worded to make it more persuasive, demonstrating the utility of implementation intentions. It could also be more readily demonstrated how patients can adapt these plans to their own personal experience (e.g., by including more examples).

For some, planned regular use of the intervention was based on the expectation that the intervention would be effective at reducing pain and stress. Beliefs about efficacy were generally positive but sometimes unclear, and some participants didn't want to draw any conclusions regarding efficacy without experiencing evidence of it. As beliefs about credibility and expectancy of outcome can be related to adherence to self-help (Nordgreen et al., 2012), it is important to promote positive beliefs about efficacy. If the intervention were to be delivered by the specialist chest pain nurses as part of the patients' medical care, they may view it as a more credible treatment. Furthermore, as suggested above, inclusion of case studies of the intervention's efficacy could improve perceptions of credibility and expectations of effectiveness (Richardson & Richards, 2006).

There may be a question of whether some prior knowledge or usage of the concepts that were in the intervention would be necessary for patients to engage in usage. This was pointed out by

one of the patients explicitly, and reflects the concerns by the patients and the nurses that the intervention might not be acceptable to all. Most of the participants had some prior awareness or knowledge of concepts such as relaxation, or even CBT more specifically. This prior awareness may explain the high level of acceptability within the present sample. Nevertheless, some participants spoke of how the techniques within the intervention were novel to them, and something that they had not thought of doing. These participants were amongst those who viewed the intervention most positively, and showed strong willingness to use it, suggesting that it may not be necessary to have any prior awareness. Asking patients to come up with their own activities which they find relaxing, and encouraging them to engage in these more often, could be a potential addition to the booklet. This may make the intervention accessible to a wider range of participants, including those without prior awareness or inclination towards methods such as mindful breathing. Personalising self-help materials has been recommend (Richardson & Richards, 2006), and it may make participants more likely to engage with the materials, as it would reduce the barriers of having to commit to and learn a novel method of relaxation.

A small number of barriers to use of the intervention were identified by both the nurses and the patients. Both groups were concerned that some patients wouldn't engage with the material; however, the acceptability and positive responses in the present sample suggests that this may not be a large concern. Nevertheless, further research would be needed with a larger sample to assess uptake of, and adherence to, the intervention. Some of the patients were concerned that pain and high levels of stress could prevent people from reading or engaging with the intervention, reflecting previous findings that pain and psychological comorbidities can be barriers to self-management (Jerant, Friederichs-Fitzwater, & Moore, 2005). It may therefore need to be emphasised on delivery of the intervention that it should be read when the patient is not in pain or under extreme stress, but outside these times, in order to prepare them to cope with times of extreme stress or during episodes of pain. Barriers such as stress and pain, and also lifestyle and practical barriers which were identified by patients, would hopefully be overcome by the completion of the implementation intention, as these plans are effective in helping people overcome barriers and obstacles when pursuing a goal (Gollwitzer & Brandstatter, 1997). On a positive note, the nurses felt that there were few barriers to using the intervention, as it could be used by patients in their own homes at their convenience, and didn't require them to go anywhere.

Regarding the delivery of the intervention, some of the patients had expressed that some guidance would be preferred, and one of the nurses also suggested that some patients might benefit from this. The rest of the nurses felt that they would not have the time to guide patients through the intervention, and were concerned about an increased workload. It will therefore most likely not be possible to fulfil the patients' preference of some accompanying guidance. The nurses did suggest, however, that a short script could be developed, designed to be read to the participant on intervention delivery, describing the general aims and how it should be used. This could easily be developed, and also be included in the staff education which the nurses felt would be important. This staff education would ensure the intervention is delivered appropriately by all staff members, and help to avoid any adverse consequences, which was a concern of both nurses and patients.

5.5.5 Strengths and limitations

The present intervention extends previous interventions for NCCP by providing a self-help format of CBT style techniques that can be easily delivered within an acute environment by medical staff. It also expands on previous work by using a strong theoretical and empirical basis, and incorporating a high level of sandpit development, whereby the public and service users have been involved in the development process. Despite previous concerns about the acceptability of a brief psychological intervention to NCCP patients (Esler & Bock, 2004; Sanders et al., 1997), the acceptability testing in the present study suggests that this will not be a problem for the present target sample. An intervention such as this could easily be incorporated into a stepped care model, a model of care which has been suggested as being appropriate for NCCP patients (Kisely et al., 2012; Mayou et al., 1999).

Although this study provides a strong starting point in the development and assessment of a self-help intervention for NCCP patients, there are some limitations which should be considered. For example, while the sample size was most likely sufficient to achieve saturation regarding the main issues, it may not have represented the diverse nature of ED NCCP patients. For example, there may be a particular group who could have major problems with the intervention, who were not represented in the sample. Furthermore, as the intervention is currently only available in English, the applicability non-English speaking groups cannot be confirmed.

Another limitation is that the researcher who had led the development of the intervention conducted the interviews. The participants were aware of this, as the interviewer's name was listed on the front of the intervention booklet in the list of authors. The interviewer may therefore have biased the interviews to a more positive angle, or participants may have felt pressure to respond positively. However, a standardised script was used to introduce the think aloud technique, and the interview was guided by a semi-structured schedule. Furthermore, all participants were repeatedly asked to give their open and honest opinion of the intervention, and encouraged to be critical where possible.

Some of the patients had great difficulty with the think aloud methodology, most likely because it is a very novel and unusual scenario for most people. While detailed guidance was adhered to, including the opportunity to practice (Boren & Ramey, 2000), some participants still struggled, and not all participants took the opportunity to practice the method. As a result, there was some variation between the interviews, with some having a very large think aloud component (and thus fewer direct questions) and some with a very small think aloud component (warranting more direct questions). The interview transcripts may therefore not be comparable. Nevertheless, a wealth of data was still gathered, with consistent themes across participants. Furthermore, as the interview questions were very detailed in places, the think aloud part of the procedure could be seen as an additional component supplementary to this, highlighting areas of interest that could be probed in the later interview section. Despite this, it may be the case that think aloud methodology is more suited to interactive interventions (e.g., computer based), rather than those which predominantly require the participant to read. Nevertheless, the technique could be developed or adapted to improve its use in this context. For instance, participants could be instructed to verbalise at the end of every paragraph.

The finding that participants often found different sections of the intervention relevant reflects the concerns in Chapters 3 and 4 that NCCP patients are a highly heterogeneous group. The different needs of the participants, potentially caused by the differing cause and nature of their chest pain, were served by different sections of the interventions. As discussed in Chapter 4, the heterogeneity of NCCP patients may well be unavoidable, as this is the nature of the condition. This may therefore highlight a strength of the intervention, demonstrating that it can serve the needs of such a heterogeneous group. This therefore supports the need for a multi-faceted intervention for NCCP patients.

5.5.6 Future directions

The next step would be to test whether this intervention is effective at improving both psychological and physical outcomes, thus extending previous attempts to develop brief ED based interventions for NCCP (Arnold et al., 2009; Van Etten et al., 2005). Following on from the present study, changes will be made to adapt the intervention to make it more acceptable, understandable and usable to both staff and patients. Practical aspects such as the nature of the delivery of the intervention and staff education will be organised. Once these changes have been made, the intervention can be assessed for its efficacy, by initially conducting a pilot trial and then conducting a full scale randomised control trial (RCT). If the intervention is found to be effective, it should be strongly considered for inclusion in the care plan for NCCP patients.

5.5.7 Conclusions

This study set out to assess the acceptability, feasibility, and level of understanding of a self-help anxiety reduction intervention for patients with NCCP and high levels of anxiety. Despite previous research suggesting that a brief psychological intervention would not be acceptable to NCCP patients (Esler & Bock, 2004), the present intervention was viewed as highly positive and acceptable to both NCCP patients and the specialist nurses who care for them. There was a strong sense of need for the intervention, both from patients and nurses, with the material providing an additional tool where care provision is currently lacking, and showing strong relevance to a group of patients suffering with high levels of stress and difficulty relaxing. A number of changes or additions were suggested, some of which will be incorporated into the intervention. Some, however, would be unfeasible to include, or were based on personal preferences and so may not be seen as relevant to all users of the intervention. The intervention seemed to serve more than one need due to the multiple components (e.g., pain diary, encouragement to increase physical activity, relaxation techniques), and would hopefully therefore be appropriate for a wide range of patients. A number of potential barriers to use were highlighted, which will need to be considered further in a larger scale study. The next step for this research will be to adapt the intervention, and its planned delivery, in accordance with the present findings, and then assess the efficacy of the intervention on a larger scale. If the intervention is shown to be effective, there will hopefully be scope for its implementation in practice as an initial step in a stepped care model for NCCP patients.

CHAPTER 6. General Discussion

This thesis set out to examine the experiences of people with NCCP; to assess levels of psychological distress, continued pain, and service use; to consider the theoretical predictors of outcome; to examine patients' personal experiences; and to develop an intervention for use in acute care. On the basis of the findings presented in this thesis a self-help intervention was developed, which was found to be acceptable and relevant to NCCP patients. Future work is needed to test the efficacy of the intervention in a trial.

Chapter 1 introduced the problem of NCCP, highlighting the poor psychological outcomes and impact on everyday life, and explaining the current model of care (ED-based). The need for a systematic review of outcomes of acute NCCP patients was identified, as well as an investigation of patients in an acute setting, both longitudinally and qualitatively. The CSM of Illness Representations (Leventhal et al., 1980) was presented as an appropriate model for assessing and improving outcomes in NCCP patients.

Chapter 2 sought to systematically review the literature on psychological outcomes in NCCP patients in acute care. No existing review of this was available, and the majority of previous research had focussed on patients with chronic NCCP in outpatient care. It was found that levels of anxiety, depression, and QoL in acute NCCP patients were comparable to those with cardiac pain, and worse than healthy controls. Levels of anxiety were especially high. There was a general paucity of literature looking specifically at patients from acute care, and also considering predictors of psychological outcome. This review also demonstrated the absence of research using theoretical frameworks when considering the predictors of psychological outcomes in ED NCCP patients. This therefore identified a need for further work looking at psychological outcomes in acute patients using a theoretical model, such as the CSM, to assess predictors of outcome, in order to identify targets for intervention.

Chapter 3 reported a longitudinal questionnaire study (Study 1), assessing whether illness representations could predict psychological and physical outcomes in a sample of acute NCCP patients recruited from an ED. It was found that levels of anxiety and depression were high and mental QoL was particularly impaired. It was found that a stronger belief in psychological causes of one's pain, the perception of a more chronic timeline, and a weaker belief in personal control were related to psychological distress at follow-up. Increased baseline anxiety,

depression and cardiac worries, decreased baseline QoL, a stronger illness identity (i.e., more symptoms associated with chest pain) and the perception of a more chronic timeline were all associated with increased chest pain frequency at follow-up. An intervention targeting these predictors was therefore thought to be appropriate, particularly focussing on reducing anxiety levels.

Chapter 4 involved interviews with participants (Study 2) who had particularly poor physical and psychological outcomes. This chapter complimented the findings of Study 1, and suggested that the experience of NCCP patients fits into the model of illness representations, although there was some diversity of experience reported between participants, possibly explained by differences in comorbidity. However, overall a strong emphasis on cause, psychological factors, and uncertainty was found.

In Chapter 5, a self-help intervention was developed based on the findings of Studies 1 and 2, as well as the background literature. Qualitative work was conducted (Study 3) with both NCCP patients with high levels of anxiety and the nurses who care for them. The feedback regarding the intervention was very positive; it was found to be acceptable, relevant, understandable, and usable. Areas requiring changes and modifications were identified which can easily be incorporated into a modified version of the intervention booklet. This serves as a starting point for future work, which could assess the efficacy of the intervention in reducing pain and anxiety in patients in EDs.

Conclusions from each of the studies, along with comparisons to the wider literature, strengths and limitations, and recommendations for further research are included in the discussion section of each chapter. In this more general discussion, the overarching themes of the thesis will be discussed, with a comparison to the wider literature. Three main themes of interest can be drawn from the current research: (i) the relationship between chest pain and anxiety, (ii) the uncertainty of a NCCP diagnosis, and (iii) the care of NCCP patients.

6.1 The relationship between chest pain and anxiety

The initial aim of this thesis was to consider theoretical predictors of physical and psychological outcome in NCCP patients with a particular focus on dimensions of illness representations. However, while some illness representation dimensions showed importance, one important

theme which has emerged and remained consistent through the studies was the role of anxiety and stress in causing and maintaining chest pain.

In Chapter 1, the concept of a bi-directional relationship between chest pain and anxiety and stress was introduced, in the context of a study by Potts and Bass (1995), who proposed that chest pain can be caused by anxiety disorders, but the pain itself, and the distress and worry associated with it, can serve to reduce psychological well-being even further. In the discussion of the systematic review in Chapter 2, the direction of the relationship between chest pain and anxiety was considered, again comparing previous evidence that chest pain is caused by anxiety or anxiety disorders (e.g., Beitman et al., 1987; Ho et al., 1998; Jonsbu et al., 2009), or that psychological morbidity is a result of the chest pain itself (e.g., Zachariae et al., 2001). This relationship was considered empirically in Chapter 3, where it was found that a stronger perception of psychological causes was related to worse psychological outcome, suggesting that NCCP patients themselves may have felt that their pain was caused by factors such as anxiety and stress. Furthermore, continued chest pain was consistently related to levels of anxiety at baseline. These findings suggest that anxiety is most likely both a causal and maintaining factor in NCCP. This was supported in Chapter 4, where during interview many participants spoke of how stress and anxiety caused, triggered, or exacerbated their pain. Based on these findings, the intervention that was developed in Chapter 5 was largely targeted at explaining the connections between anxiety/stress and pain, and at reducing anxiety/stress. The idea that stress may cause and maintain chest pain was well accepted in Chapter 5, with all participants finding the intervention positive and relevant. This intervention will be useful regardless of whether anxiety is a cause or a result of chest pain: if it is a causal factor, it should hopefully reduce chest pain, whereas if it is a result of chest pain, it should reduce general psychological suffering and improve well being. Nevertheless, it is important to consider the relationship between anxiety and chest pain in the context of previous literature.

Previous research in the area of NCCP has identified high levels of panic disorder, both in outpatient settings (e.g., Beitman et al., 1987; Beitman et al., 1991; Beitman et al., 1989; Dammen et al., 2004; Dammen, Arnesen, et al., 1999; White et al., 2008), and in EDs (e.g., Fleet et al., 1996; Worthington, Pollack, Otto, Gould, & et al., 1997; Yingling, Wulsin, Arnold, & Rouan, 1993), suggesting this as a potential diagnosis for patients with NCCP (Beitman et al., 1989; Fleet et al., 1996). Given that symptoms of NCCP episodes do overlap with panic attacks

(e.g., chest pain, shortness of breath, Fleet et al., 2003), and panic disorder is associated with poorer outcomes in NCCP patients, both psychologically and in terms of chest pain (Beitman et al., 1991; Dammen et al., 2006; Fleet et al., 2003; Srinivasan & Joseph, 2004), the suggestion that NCCP patients should be assessed for psychological problems as a potential cause (Dammen, Arnesen, et al., 1999; Fleet et al., 1996; Fleet et al., 2003) should be considered. Despite a large proportion of NCCP patients qualifying for a diagnosis of panic disorder, some authors have admitted that it is difficult to conclude a direct causal relationship (Beitman et al., 1987), and that panic disorder most likely explains around 25% of cases of NCCP (Beitman et al., 1989), leaving the remaining 75% related to other causes. Furthermore, patients do show persistent, continued pain and psychological distress even in the absence of panic disorder (Fleet et al., 2003). Other psychiatric disorders besides panic disorder may also play a role in NCCP. For example, somatoform disorders are also present in a minority of NCCP patients (Jonsbu et al., 2009), suggesting that for some, chest pain may be a physical manifestation of psychological distress. Anxiety disorders and mood disorders in general are prevalent in NCCP (Demiryoguran et al., 2006; Kisely, 1998; White et al., 2008; Wulsin et al., 1991), including Generalised Anxiety Disorder (GAD, e.g., Kisely et al., 1992; Logue et al., 1993; White et al., 2010), agoraphobia (e.g., Kisely et al., 1992), dysthymia (e.g., Kisely et al., 1992), depression (e.g., White et al., 2008; Wulsin et al., 1991) specific and social phobias (e.g., White et al., 2010; White et al., 2008), alexithymia (White, McDonnell, & Gervino, 2011) and also subclinical psychiatric disorders, particularly anxiety (White et al., 2008). White et al. (2008) proposed that as other psychological problems are also prominent in this group, NCCP is not solely a manifestation of panic disorder. Some have suggested that these disorders co-exist with NCCP, with other potential physical causes being possible (Kisely et al., 1992), and few authors draw direct causal links between psychiatric disorders and chest pain, largely because of purely correlational relationships (e.g., Katon et al., 1988).

One way in which anxiety may be related to chest pain is through the mechanisms of anxiety sensitivity and hypervigilance to bodily sensations (Eifert et al., 1996; Eifert, Zvolensky, et al., 2000; e.g., White et al., 2010). Eifert et al. (1996) introduced the idea of healthy patients with heart-focussed anxiety, and suggested that this could be an alternative causal explanation to panic disorder for NCCP. Heart-focussed anxiety typically manifests as a fearful response to chest symptoms (which may be initially caused by muscle tension or hyperventilation) and a misinterpretation of the symptoms as a sign of serious cardiac problems, leading to anxiety,

increased perceived pain, disability, fear, increased healthcare utilisation, avoidance of activity and the development of subtle 'pain/safety behaviours' (Eifert et al., 1996; Eifert, Zvolensky, et al., 2000). This is a similar mechanism to panic disorder, but specific to cardiac related symptoms (Eifert, Zvolensky, et al., 2000). It is suggested that this is a cardiac specific type of anxiety sensitivity, which can be defined as a fear of anxiety related symptoms due to beliefs about the negative consequences of those symptoms (Reiss, Peterson, Gursky, & McNally, 1986). This work has been supported by more recent findings which have demonstrated that NCCP patients, particularly those with anxiety disorders, are in fact hypervigilant to bodily sensations which may be perceived as cardiac (e.g., chest pain, palpitations), and this hypervigilance was related to increased chest pain and impairment (Aikens et al., 2001; White et al., 2010). Moreover, this relationship is mediated by interoceptive fear, which is a fear of the internal bodily sensations associated with anxiety (White et al., 2010), thus supporting the model suggested by Eifert et al. (1996; 2000). This therefore presents an aetiological model of chest pain whereby patients are hypervigilant to anxiety related chest symptoms, which are then interpreted fearfully (i.e., that they are indicative of a serious cardiac problem), leading to further pain, disability, distress, and healthcare utilisation.

Two prominent researchers in the field, Bass and Mayou, attempted to bring together these causal explanations of NCCP in an aetiological model, encompassing biological, psychological, and social factors (Bass & Mayou, 2002). They suggest that an interactive, multicausal approach should be adopted, recognising that psychological factors influence bodily perceptions, and also impact on outcomes such as QoL and healthcare utilisation. A causal model is proposed (See Figure 6.1), which is applicable to all MUSs. They suggest that minor physical symptoms are misinterpreted, often as a result of psychosocial factors and illness experience. Panic disorder is therefore considered to be either a primary cause (as a cause of the initial symptoms) or a maintaining factor (causing the fearful misinterpretation of the symptoms). Iatrogenic factors (e.g., a provisional diagnosis of or treatment for cardiac problems) and the concern of others may reinforce concerns and worry about serious causes of symptoms. Persistent symptoms then result, which lead to disability, both physical and psychological. This supports a bi-directional relationship between chest pain and anxiety, with anxiety playing a role in causing and maintaining the pain, but also with distress resulting from continued pain. However, there is still very much a strong emphasis on fear of cardiac problems as a causal and maintaining factor in NCCP, as with the models proposed by White et

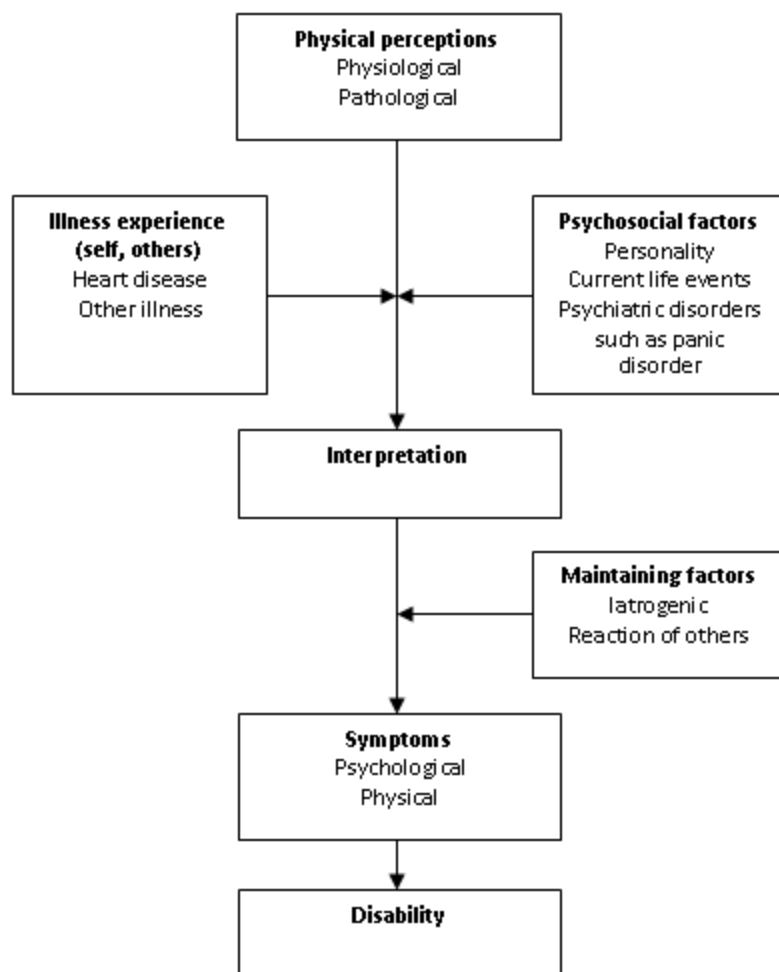


Figure 6.1 Aetiological model of NCCP. Adapted from Mayou, (1998) and Bass and Mayou (2002)

al. (2010) and Eifert et al. (1996; 2000). This emphasis on fear and negative interpretation of bodily sensations doesn't seem to fit with the results in this thesis. As outlined in the discussion of Chapter 3, level of concern about cardiac causes was very low in the present sample. Furthermore, in Chapter 4, while all participants had initial cardiac concerns, these quickly subsided for most. However, some did maintain such concerns, and in Chapter 3 cardiac worries were predictive of chest pain at the final follow-up assessment. This suggests that such a model may be applicable to some NCCP patients, but not all. A 'one size fits all' explanation of the aetiology of NCCP may therefore not be appropriate. Nevertheless, White et al. (2011) found that anxiety sensitivity in general (not just heart-focused anxiety) was related to pain and healthcare utilisation, suggesting that anxiety may generally play a wider role, rather than cardiac specific anxiety.

There is also an argument that distress may purely be a result of pain, rather than a causal or maintaining factor. Zachariae et al. (2001), for example, found levels of psychiatric morbidity to be similar in those with NCCP and those with cardiac problems, as has been found previously (e.g., Chapter 2, Webster et al., 2012), and suggest that these psychological problems therefore are a result of pain or illness in general, rather than the cause of pain. The authors concluded that stress was not a causal factor for NCCP, and other causes such as undetected cardiac problems and depression should be investigated more readily. While this proposes an interesting alternative view to those above, it is difficult to accept that distress must be a result of NCCP simply because levels or morbidity are comparable between NCCP patients and those with cardiac pain. Zachariae et al. (2001) seem to presume this on the basis that both groups of patients are experiencing similar symptoms (i.e., chest pain), and thus the psychological distress must be a result of these symptoms. However, those with cardiac pain have received a serious medical diagnosis, which is likely to require numerous lifestyle changes. It is reasonable to expect that this alone would have a strong psychological impact. NCCP patients have not received such a diagnosis, suggesting that the cause for their distress must be different. Moreover, those who experience more depression and anxiety are more prone to cardiac problems (Booth-Kewley & Friedman, 1987), thus suggesting that poor psychological outcomes may not simply be a result of pain and illness in cardiac patients either. It therefore seems unlikely that the relationship between NCCP and psychological distress is as simple as the psychological impact of physical symptoms. It is more likely that the relationship is much more complex.

Given the aetiological mechanisms outlined above proposed by Bass and Mayou (2002) and Eifert (1996; 2000) may be inappropriate for all patients given their focus on fear of cardiac events, alternative mechanisms for the relationship between psychological distress and NCCP should be considered. A potential mechanism is the direct physiological effects of stress. For example, Roll and Theorell (1987) found that those with NCCP experienced a high number of negative life events in the preceding year, and suggested that this stress may manifest as chest pain due to chronic muscular tension. Stress has been related to increased muscular tension and subsequent musculoskeletal pain (Lundberg et al., 1999; Lundberg et al., 1994). In NCCP patients, stress can also increase oesophageal contractions, which can be a cause of chest pain (Anderson, Dalton, Bradley, & Richter, 1989). The relationship may also be understood in terms of the effects of stress on the neural and endocrinal pain systems. Chronic stress can lead to

changes in the endocrine stress system (namely a change in cortisol production by the hypothalamic–pituitary–adrenal axis), which can lead to pain, fatigue and increased stress sensitivity (Fries, Hesse, Hellhammer, & Hellhammer, 2005). This pain may become continued and chronic, as activation of neural pain pathways may lead to lower thresholds for repeated activation of those pain pathways (and thus lower thresholds for experiencing continued pain) through the mechanism of long term potentiation (Rygh et al., 2005). Stress may therefore cause or exacerbate actual physical causes for chest pain, suggesting that the relationship between anxiety and NCCP may be direct, rather than mediated by concerns about cardiac problems.

Given this complex pattern of potential causal mechanisms for NCCP, it may be beneficial to integrate these into an aetiological model. The model above by Bass and Mayou (2002) is insufficient due to its focus on the fearful interpretation of cardiac symptoms, thus making it not necessarily appropriate for all patients. A more encompassing, broader model is therefore needed. It may be appropriate to consider MUSs more widely, given extensive research has considered the aetiology of these. It has been suggested that for MUSs, a cognitive-behavioural, multifactorial, self-perpetuating model of the aetiology and maintenance of conditions may be appropriate (Deary, Chalder, & Sharpe, 2007). This model (see Figure 6.2) contains a number of components that predispose, precipitate, and perpetuate MUSs such as NCCP, and therefore each patient's individual experience may fit into this model in their own unique manner. This would help to account for the apparent heterogeneity in the aetiology of NCCP. The general propositions of the model are that innate predisposition to high levels of neuroticism, psychological comorbidity and sensitivity to distress may combine with childhood adversity to increase the amount of physical symptoms experienced, and also reduce the threshold for detection of symptoms. Increased negative life events and stressors may lead to physiological changes (e.g., neurological/endocrinal stress response) which increase symptoms, and also promote sensitisation (due to persistent activation of stress responses) and attention to symptoms (due to repeated symptoms).

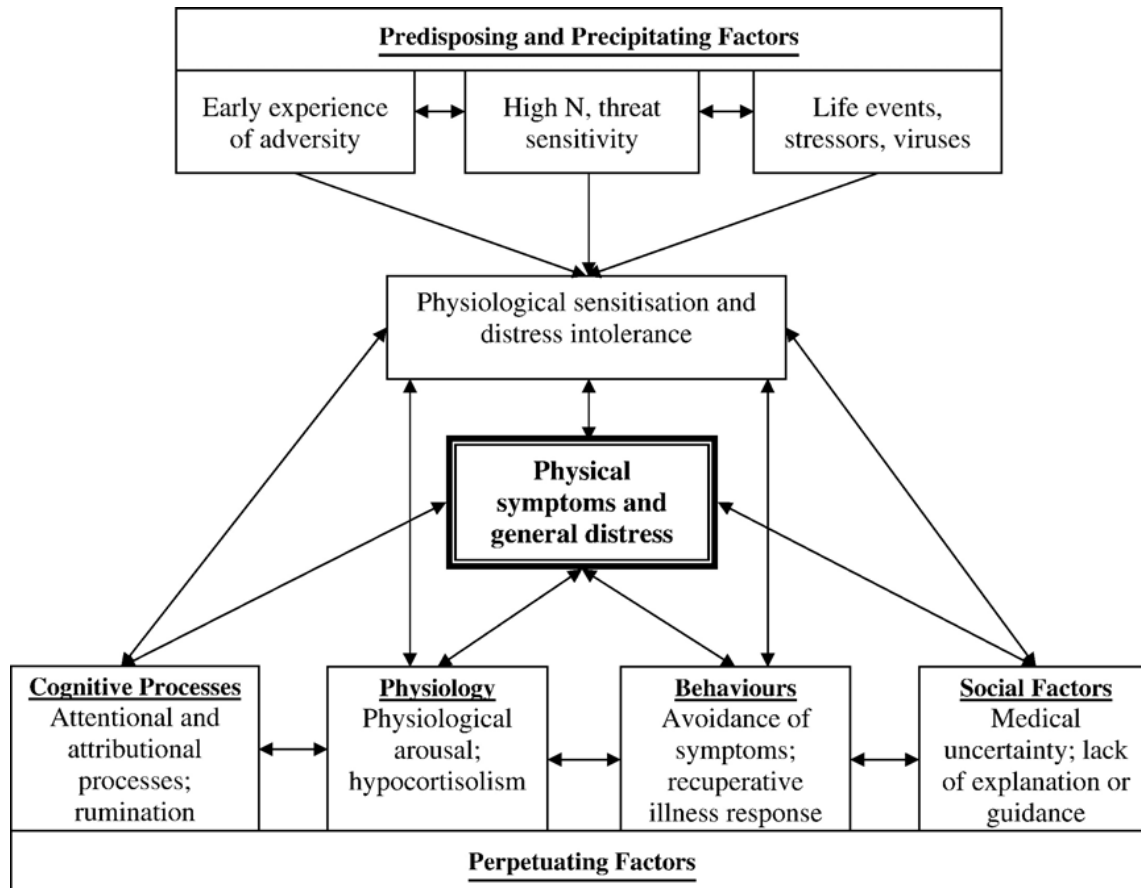


Figure 6.2 Cognitive behavioural model of MUSs, from Deary et al. (2007), Copyright Elsevier (2007)

Lack of explanation and uncertainty, avoidance of activity, persistent physiological arousal, and attention to, and rumination about, symptoms then serve to maintain symptoms and distress. This model could potentially be applicable to NCCP patients, given that these patients have been shown to demonstrate high levels of psychological distress (e.g., Webster et al., 2012), a high number of negative life events and general daily stress (Jerlock, Gaston-Johansson, Kjellgren, & Welin, 2006; Roll & Theorell, 1987), childhood adversity (Biggs, Aziz, Tomenson, & Creed, 2004), sensitisation to symptoms (White et al., 2010), high levels of uncertainty and poor understanding (see Studies 1 and 2), and avoidance of activity (Jerlock et al., 2005; Jonsbu et al., 2010). Mechanisms of physiological arousal and attentional processes need further investigation; however, findings suggest that NCCP does intrude onto everyday life (Jerlock et al., 2005), suggesting it imposes on thoughts, a concept talked about by some of the participants in Study 2. Furthermore, continued stress and pain is likely to evoke a continued physiological response. This model may therefore show some utility in explaining the aetiology and maintenance of NCCP, and provides tangible physiological mechanisms by which

psychological morbidity and life stressors may lead to chest pain. It could also encompass the model proposed by Bass and Mayou (2002), as it incorporates mechanisms such as sensitivity and overt attention to symptoms.

There seems to be a complex pattern of the aetiological role of anxiety in NCCP. The evidence outlined above suggests that anxiety, and anxiety disorders, can play some form of a role in causing and maintaining chest pain, as well as resulting in poorer psychological status, QoL, and increased pain. This reflects the findings in the present thesis, although no aetiological processes can be confirmed by the present findings. In Studies 1 and 2, it was demonstrated that patients themselves recognised stress and anxiety as a cause of their chest pain, and Study 3 showed that a stress reduction intervention was acceptable and relevant. For the present sample, this causal relationship doesn't always seem to involve the previously suggested mechanisms of hypervigilance to bodily sensations, panic attacks, and fearful interpretation of symptoms (Eifert et al., 1996; Eifert, Zvolensky, et al., 2000; White et al., 2010), but may be a combination of external stressors and physiological responses. Participants also saw stress as a trigger to the onset of their pain episodes, and experienced life consequences and reduced QoL as a result of their pain. The pattern of the causal relationship between anxiety and pain may differ between patients. For instance, cardiac worries were predictive of continued chest pain in Study 1, and some participants in Study 2 maintained cardiac concerns. This suggests that the mechanisms of cause and maintenance of chest pain may vary between patients, and for some, fearful interpretation of symptoms and worry may be a maintaining factor. Regardless of the direction of the relationship between anxiety and chest pain, evidence demonstrates that co-morbid anxiety disorders in NCCP have been previously related to continued pain and increased healthcare utilisation (e.g., White et al., 2008), and in the present research, baseline anxiety was related to continued pain and distress. It therefore seems imperative that anxiety is dealt with at an early stage to reduce both pain and suffering.

6.2 The uncertainty of a NCCP diagnosis

One major theme which emerged throughout the present research was that of uncertainty and a lack of understanding among patients. In Study 2, patients discussed at length how they didn't understand their pain, largely with regard to what had caused it, or what triggered it. Furthermore, for those who had had their understanding improved, this was very beneficial. Lack of coherence was demonstrated across all dimensions, suggesting that the reason that

this dimension did not emerge as important in Study 1 was that uncertainty relates to all dimensions of illness representations in NCCP, rather than existing as a standalone dimension. In Study 3, participants found the part of the intervention clarifying the diagnosis very helpful. This supports previous findings in NCCP and other MUSs that a lack of understanding is very prominent in patients' experience (Green et al., 2004; Jerlock et al., 2005; Sumathipala et al., 2008), and suggests that improving coherence by explaining the diagnosis and helping patients to establish connections between pain and triggers may be very beneficial.

This lack of coherence is most likely a result of a lack of diagnosis, compounded by the acute nature of care precluding extensive explanations and the opportunity for patients to ask questions.

NCCP is a diagnosis of exclusion, whereby this diagnosis is given when other potential causes for chest pain (e.g., cardiac) have been ruled out (Cremonini, Wise, Moayyedi, & Talley, 2005; Kachintorn, 2005). As a result, the diagnosis isn't actually a diagnosis at all, merely a recognition that the pain is not caused by any other identifiable cause. While some have suggested that addressing patients' fears is more important than giving a diagnosis (Nijher et al., 2001), responses to this (Eslick, Coulshed, & Talley, 2002), and the findings from this thesis, suggest that patients do in fact need a label for their condition to help them understand and clarify the problem. Johnson et al. (2009) demonstrated the need for diagnostic reassurance in CPOU patients, and that the NCCP diagnosis was frustrating due to the uncertain nature of it. NCCP has been given numerous different labels over the years, including 'chest pain of undetermined origin', 'unexplained chest pain', 'functional chest pain', 'soldier's heart', 'irritable heart', 'sensitive heart', 'neurocirculatory asthenia', 'Gorlin-Likoff syndrome', 'DaCosta's syndrome', 'cardiac syndrome X' (microvascular angina), and 'chest pain with normal coronary angiograms' (Kachintorn, 2005); however, the most commonly used label now appears to be 'non-cardiac chest pain' or 'unexplained chest pain', largely reflecting the initial (often only) focus on ruling out immediate serious causes. There has been some discussion over what label is appropriate for NCCP. Eslick et al. (2002) suggested that 'chest pain of unexplained origin' is most appropriate. However, Ramanan (2002) responded suggesting that this still allows for the possibility of a cardiac cause. Ramanan (2002) also suggested that 'non-cardiac chest pain' is insufficient, as it often cannot be completely confirmed to be definitely non-cardiac. He thus suggests 'non-anginal pain with normal electrocardiogram' to be a

potential alternative, although also admitting that an alternative diagnostic label needs to be sought. Given the heterogeneity of potential causes in NCCP patients (e.g., muscular, gastrointestinal, stress, or a combination) it may be difficult to come up with a diagnostic label which encompasses all cases. Nevertheless, a clearer diagnosis could help improve patients' understanding and coherence, which could subsequently improve psychological outcomes. Given the prominent role of anxiety in the present study, it may be the case that 'stress-related chest pain' could be a potentially useful diagnosis, at least for some patients. One way to identify these patients may be to use a brief screening measure for anxiety when assessing NCCP patients. It has previously been suggested that NCCP patients should be assessed for psychological problems (Dammen, Arnesen, et al., 1999; Fleet et al., 1996; Fleet et al., 2003), and the use of a brief screening measure could be a suitable way to incorporate this into acute care. Self-reported screening measures have been suggested as a potential tool for assessing ED NCCP patients (Wulsin, Hillard, Geier, Hissa, & Rouan, 1988). Patients scoring highly for anxiety could then be provided with a means for reducing that anxiety, such as the intervention developed in Study 3. However, the cardiac rule-out tests used in the ED are not always 100% effective in identifying cardiac causes for pain, and cannot determine longer term outcomes (Goodacre et al., 2002). Some health professionals therefore may be reluctant to provide an alternative diagnosis such as stress; as if incorrect it may lead to litigation. Evidence has shown that when investigating potential cardiac problems, ED doctors' increased fear of litigation is related to ordering more tests and often unnecessary admissions in low risk cases (Katz et al., 2005). Nevertheless, if it is made clear to patients that they are to re-access care if they experience continued chest pain in the future, this should help to avoid any adverse consequences of diagnosing stress-related chest pain. Furthermore, in Study 3, providing patients with a stress-related explanation of chest pain was highly acceptable to the specialist chest pain nurses, suggesting that this may be an acceptable diagnosis. They also felt that if staff were educated to provide patients with appropriate discharge advice, adverse consequences of using an anxiety reduction intervention would most likely be avoided.

Regardless of the diagnostic label given to patients, it is likely that the amount of explanation patients receive about their diagnosis is important to ensuring understanding. Research has shown that in ED encounters between doctors and patients, the focus is normally on gathering information from the patient, rather than giving information to the patient, with discharge advice often lacking in content, follow-up instructions, and the opportunity for the patient to

ask questions (Rhodes et al., 2004). In the aetiological model shown in Figure 6.2 (Deary et al., 2007), medical uncertainty combined with a lack of adequate explanation of symptoms is suggested as a maintaining factor for NCCP. In their qualitative examination of a number of CPOUs, Johnson et al. (2009) found that patients received different levels of information from each site. Explaining diagnoses clearly, integrating psychological and physical factors (e.g., muscle tension and chest pain), and avoiding telling patients that there is 'nothing wrong' can be very important when assessing and treating MUS patients (Hatcher & Arroll, 2008). Salmon, Peters and Stanley (1999) found that medical encounters which MUS patients found empowering were those that provided tangible explanations of causal mechanisms (e.g., connecting psychological and physical factors), exculpated patients from blame for their symptoms, and provided practical ways in which they could manage or reduce their symptoms. Such an explanation for NCCP might therefore be beneficial to patients; however, in the ED this may not always be possible, due to staff being busy and overstretched, and sometimes uneducated about psychological mechanisms. Providing standardised information that the patient can take away (like the intervention developed in Chapter 5) may therefore be an effective way to explain diagnoses. The use of information sheets in emergency care have been shown to improve knowledge and satisfaction in parents of child patients (Johnson & Sandford, 2005), and have been recommended for chest pain patients discharged from the ED (Jones & Mountain, 2009), showing some efficacy in this group (Arnold et al., 2009). The intervention developed in Study 3 may therefore help improve understanding, reduce uncertainty, and thus psychological outcomes.

6.3 The care of NCCP patients

The high levels of uncertainty in NCCP patients, along with the strong involvement of anxiety in NCCP, supports the notion discussed in Chapter 1 that chest pain care needs a shift in focus from a more physical, rapid diagnostic approach, to incorporating a more psychological emphasis, addressing patients' fears and taking time to discuss psychosocial issues with patients (Hamer & McCallin, 2006; Nijher et al., 2001). The findings in the present research clearly support this conclusion, demonstrating evident psychological needs within NCCP patients, and a general dissatisfaction with current, medically oriented, care. In Study 2, many participants spoke about how they were reluctant to take medication which had been prescribed for them, and in Study 3 some participants talked about how they had only been

offered pain relief, and felt that GPs tended to avoid psychological issues like stress, when they should in fact be targeting them. This clearly shows utility of an intervention such as the one developed in Study 3, providing health professionals with a tool to offer patients to deal with stress and anxiety, an alternative remedy to stress. A stepped care approach managing psychological problems in NCCP, starting with a low-cost intervention such as that developed in Study 3, has been recommended for many years (Mayou, 1998). It is therefore very surprising that no brief psychological intervention is currently in place. There is a clear need to incorporate a more psychological focus into the care of NCCP patients. As discussed in the above section on the uncertainty of NCCP, this could be done in the ED through brief psychological screening (and subsequent delivery of a brief intervention); however, it could also be introduced at GP level. It has been suggested that GPs should have more confidence in diagnosing chest pain as non-cardiac at an earlier stage, a process which is generally avoided due to the ease of access to rapid rule-out protocols in EDs (Mackenzie, 2001). Participants in Study 3 talked about how they wished they could have received the intervention sooner, even before they had accessed the ED. If GPs could introduce the role of stress in causing problems like chest pain at an early stage, this could prevent over-accessing of ED care. This is supported by the fact that almost all the participants in Study 2 presented initially to their GP, expecting them to be able to provide care for them. GPs are therefore clearly at the frontline of care for chest pain patients. There may be a concern, however, that cardiac cases of chest pain may therefore be missed. As such, GPs may be better suited to providing care for those who experience repeated chest pain after their initial ED rule-out, rather than referring them repeatedly to the ED. Awareness of the role of stress in chest pain needs to be raised in primary care, the ED, and with patients.

Despite the dissatisfaction with previous care in general found in Study 2, participants were all very positive about the care that they had received in the ED. This is consistent with previous findings that CPOU care can improve psychological outcomes (Goodacre & Nicholl, 2004) and promote reassurance (Goodacre et al., 2001). Furthermore, some outcomes in Study 1 were preferable in comparison to previous research (e.g., re-attendance, levels of depression), which may be a result of the nature of care.

6.4 Strengths and limitations

The main difficulty faced during this research was the challenge posed by conducting research in an acute care environment. The ED, by nature, is a very busy department, and the staff are often over stretched by their clinical duties alone. The addition of research duties only serves to increase this workload. As such, data regarding recruitment is not always recorded, and potential participants are sometimes not invited to participate. This was reflected in the recruitment data in Study 1, in which 32% of eligible participants were not invited to participate, and 13% of patients were excluded for unknown reasons. This was often unavoidable as, although the main researcher spent as much time in the department as possible (3 days per week), the specialist chest pain nurses were relied upon for recruitment the remainder of the time. While they were extremely helpful in assisting with recruitment, if they were busy or understaffed it was difficult to maintain recruitment. Furthermore, not all patients with chest pain who were referred for chest pain rule-out were actually seen by the specialist chest pain nurses – some remained under the care of the doctors and were discharged before being seen by the nurses. As such, it was difficult to identify and contact these patients to recruit them before they were discharged. These recruitment problems were exacerbated by the fact that participants could only be recruited once they had received a non-cardiac diagnosis. As such, patients were often in the department for a long time awaiting results, and then asked to participate once they had received their results and were keen to be discharged. It was originally hoped that participants would complete the questionnaires in the study in Study 1 and the interviews in Study 3 within the ED; however, due to the timing of recruitment and consent (due to ethical constraints), many participants wished to take the questionnaire away with them or arrange the interview for a later date. This is likely to have reduced the response rate in Study 1, and the number of potential participants in Study 3. Future research should therefore consider involving all staff in the ED with the research, rather than just the specialist chest pain nurses. Furthermore, a system could be incorporated, whereby suitable patients are ‘flagged up’ on their ED notes, in the form of a slip or ticket, notifying that they need to be approached regarding participation before discharge. This would help to avoid any suitable patients being discharged before being invited to participate. It may be difficult to overcome issues with the timing of recruitment of NCCP patients, as ethical constraints would prevent earlier recruitment. The main way to encourage participants to complete measures while still in the ED may be to make them as brief as possible (without

compromising the data collected). Despite the difficulties in working in an acute healthcare environment, it was still possible to recruit sufficient numbers of participants into each of the three studies.

The main strength of the programme of research within this thesis is the use a range of different methodologies. As discussed in Chapter 4, triangulation of quantitative and qualitative findings helps to account for weaknesses within each individual approach, allows for comparison of findings to see how they converge or diverge, and highlights when findings may be a product of the research method used (Jick, 1979). The findings of Studies 1 and 2 are therefore strengthened by the fact that they corroborate each other. The use of qualitative methods in the development of the intervention in Study 3 is also important, to identify relevant components and potential barriers (e.g., Campbell et al., 2000). It also served to confirm the acceptability of the intervention, something that has previously been a concern regarding psychological interventions for NCCP patients (Esler & Bock, 2004; Sanders et al., 1997). Using qualitative methods in intervention development helps to overcome potential problems with acceptability, and the validity of intervention research that does *not* incorporate qualitative methods should be questioned (Nastasi & Schensul, 2005). A phased approach to intervention development, strongly grounded in pilot work and mixed methodology, is strongly recommended in MRC guidance on intervention development (Campbell et al., 2000). Study 3 therefore provides an important initial stage for the development of this intervention. Involvement of patients and the public in health research is strongly recommended and now well established, showing to contribute to improvements in the quality and delivery of research (Stewart, Wilson, Selby, & Darbyshire, 2011). The acceptability work in Study 3 may be classified as patient involvement in intervention development, and there was also public involvement during the early development of the intervention. This helped to ensure the intervention would be understandable to patients.

6.5 Future directions

The next step for this research would be to test whether the intervention developed in Study 3 is effective at improving both psychological and physical outcomes, thus extending previous attempts to develop brief ED based interventions for NCCP (Arnold et al., 2009; Van Etten et al., 2005). Using the findings in Study 3 changes will be made to adapt the intervention to make it more acceptable, understandable and usable to both staff and patients. Practice aspects such

as the nature of the delivery of the intervention and staff education will be organised. Once these changes have been made, the intervention can be assessed for its efficacy, by initially conducting a pilot trial and then conducting a full scale randomised control trial (RCT). The purpose of a pilot trial would be to assess the feasibility of a full trial, and also to assess the acceptability of the intervention in a larger, more varied sample than in the present study. It would also provide information regarding potential adherence and necessary sample size for a full trial. A full RCT could then confirm the efficacy of the intervention. If the intervention is seen to be effective, it should be strongly considered for inclusion in the care plan for NCCP patients.

With regard to further research on a wider scale, attempts could be made to clarify the aetiological mechanisms of NCCP. This may be difficult, given the apparent heterogeneity of the condition, whereby different patients may suffer different causes. However, if direct causal links between anxiety, chest pain, and problems like muscle tension, gastrointestinal upset, and panic could be confirmed, this could help more patients to receive clear diagnoses, or at least a more detailed explanation of their pain. This could be done by testing the mechanisms proposed in the model in Figure 6.2. There should also be attempts made to raise awareness of NCCP among GPs, introducing the role of stress and anxiety in the cause and maintenance of pain. There may be scope for the development of an intervention for use by GPs, or an extension of the intervention developed in Study 3 to a GP setting. Overall, NCCP, and wider stress and anxiety in general, needs to be recognised sooner, and resources made more readily available for patients.

6.6 Conclusion

This thesis sought to quantify the levels of psychological distress, QoL, and continued chest pain in acute NCCP patients; to assess whether the CSM of illness representations was predictive of outcomes in this group; and to develop an intervention for NCCP patients. While illness representations showed some efficacy in explaining outcomes, psychological distress and anxiety were prominent factors throughout the research. This therefore raises questions regarding the direction of the relationship between anxiety and chest pain. There is also a high level of uncertainty and a lack of understanding among NCCP patients, suggesting that patients need more explanation regarding their diagnosis. In order to target these factors, a self-help anxiety reduction intervention was developed for use with acute NCCP patients. This was

found to be understandable, acceptable, and feasible, and could improve the care of NCCP patients by providing a more psychological focus. Future research should assess the efficacy of this intervention in reducing pain and anxiety.

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