Self-management of coronary heart disease in angina patients after elective percutaneous coronary intervention: A mixed methods study

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# Abstract

## Introduction and aim:

An estimated 100,000 people in the United Kingdom have percutaneous coronary intervention (PCI) each year to help alleviate angina symptoms. Thereafter, they are expected to modify their coronary heart disease (CHD) risk factors, adhere to medication and effectively manage any recurring angina symptoms. The rate of 'redo-revascularisation' in PCI patients seems disproportionately high (75%) when compared to patients who have their angina symptoms managed with coronary artery bypass surgery (<20%). PCI patients' self-management may be ineffective, however, existing research on this subject is limited by design (e.g. single methods of data collection), methodology (e.g. samples with patients of mixed diagnoses) and lack of theoretical underpinning.

Few theories had been used to help explain self-management in a PCI patient group. Researchers have used Leventhal's Self-Regulation Model to understand how people manage other chronic illnesses but not CHD after elective PCI. Bandura's Social Cognitive Theory was found to be the basis of self-management but had not been used to explain PCI patients' CHD selfmanagement. Consequently these two theories were tested to determine their ability to explain self-management in this PCI patient group.

The research questions used for this study were:

- How do patients self-manage their CHD after they have undergone elective PCI?
- What factors influence patients' self-management of CHD after elective PCI?
- To what extent do Bandura's Social Cognitive Theory and Leventhal's Self-Regulatory Model help explain self-management of CHD in patients after elective PCI?

# Design and method:

This mixed methods study used a sequential, explanatory design and recruited a convenience sample of patients (n=93) approximately three months after elective PCI. Quantitative data were collected in Phase 1 by means of a self-

administered survey and were subject to univariate and bivariate analysis. Path analysis was also used to identify factors that influenced CHD selfmanagement. Phase 1 findings informed the purposive sampling for Phase 2 where ten participants were selected from the original sample for an in-depth interview. Qualitative data were analysed using thematic analysis.

#### Findings:

After PCI, 74% of participants managed their angina symptoms inappropriately and one in five stated that they would consider using emergency care services for any recurrence of angina symptoms. Few patients adopted a healthier lifestyle after PCI: 75% were physically inactive, 65% were obese, and 27% made no lifestyle changes at all. Younger participants and those with threatening perceptions of their CHD were more likely to know how to effectively manage their angina symptoms. More educated, self-efficacious participants with fewer co-morbidities and less threatening perceptions of their illness had a greater likelihood of adopting healthier behaviours.

Qualitative analysis revealed that intentional non-adherence to some medicines, particularly statins, was found to be an issue. Some participants felt unsupported by healthcare providers and social networks in relation to their selfmanagement and seemed socially isolated. Others reported strong emotional responses to CHD such as fear, shock and disappointment. This had a detrimental effect on their self-management.

Neither the Self-Regulation Model nor the Social Cognitive Theory fully explained CHD self-management after PCI. The emotional perceptions participants had of their CHD influenced their cognition and that affected how they coped with their condition. That finding did not align with the Self-Regulation Model. Aspects of the Social Cognitive Theory helped to explain participants' likelihood of adopting more healthy behaviours but the other components of CHD self-management (manage angina symptoms and adhere to medication) were not explained using this theory.

### Conclusion:

This is the first study to report that patients experienced poor social and healthcare support after elective PCI. Patients had difficulty regulating strong emotions such as fear, shock and disappointment after PCI. This had a detrimental effect on their self-management and neither the Social Cognitive Theory nor the Self-Regulation Model could fully explain CHD self-management after elective PCI.

### Recommendations for practice / research:

Patients after PCI wanted (and should be given) more support to help them manage their CHD yet few accessed or were able to access the traditional means of support: cardiac rehabilitation. Emotional support should be included in such programmes. This is in addition to providing more traditional interventions that focus on: practical support to assist patients in adopting and maintaining healthier behaviours, guidance on angina symptom management and the need for adherence to medication after PCI.

Research could be conducted to investigate other means of supporting CHD patients after elective PCI. For example, the effectiveness of telehealth programmes in optimising CHD self-management. An intervention study could be conducted to determine which telehealth programmes are beneficial in optimising CHD self-management. A cohort study could also be considered to explore the effect telehealth has on PCI patients' revascularisation rates, morbidity and mortality.

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# Contents

Conte	ents		Page no.
Abstract			ii
Acknowledgements			V
List of contents			vi
List of tables			xi
List of figures			xii
References			267
Appe	ndices		317
Appe	ndix 1	Search strategy and key words	318
Appe	ndix 2	Ethics approval 1	321
Appe	ndix 3	Ethics approval 2	322
Appe	ndix 4	Ethics approval 3	324
Appe	ndix 5	Participant consent form	325
	ndix 6	Invitation to participate in study	326
	ndix 7	Participant information sheet	327
	ndix 8	Survey tool	329
	ndix 9	Permission to use Illness Perceptions	335
		Questionnaire	
Appe	ndix 10	Audit trail of participant recruitment	336
	ndix 11	Overview of Phase 2 participants	337
Appe	ndix 12	Interview schedule	338
	ndix 13	Annotated transcript	339
		troduction	
1.1		Introduction	1
1.2		Follow-up care in Scotland	1
1.3		Background to the clinical issue	3
	1.3.1	Incidence and prevalence of CHD	3
	1.3.2	Coronary heart disease	4
		Stable angina and its management	5
		<ul> <li>Other manifestations of CHD</li> </ul>	7
	1.3.3	Chronic disease management	9
1.4		Self-management	11
1.5		Theories linked to self-management	14
	1.5.1	Social Cognitive Theory	16
	1.5.2	Self-Regulation Model	18
1.6		Chapter summary	21
1.7		Organisation of thesis	22
	ter 2 – Li	terature review	
2.1			25
2.2			25
2.3		Searching the literature	26
	2.3.1	Aim of the literature review	27
	2.3.2	Databases and keywords used	28
	2.3.3	Inclusion and exclusion criteria	29
2.4		Approach to critical appraisal of the literature	30
	2.4.1	Organisation of the literature review	31

2.5		Review of the literature	32
-	2.5.1 Theme A: Patients' monitoring and management		32
		of angina symptoms	
	2.5.2	Theme B: Patients' adoption and maintenance of a	42
		healthy lifestyle	
	2.5.3	Theme C: Patients' adherence to a treatment	57
		regime	
	2.5.4	Theme D: Self-Regulation Model and CHD self-	64
		management	
	2.5.5	Theme E: Social Cognitive Theory and CHD self-	69
		management	
2.6		Conclusions from the literature review	74
	ter 3 – St	udy design and methodology	
3.1		Introduction	78
3.2		Research questions	78
3.3		Introduction to research methods	78
	3.3.1	Quantitative research	79
	3.3.2	Qualitative research	81
	3.3.3	Mixed methods research	83
3.4		Why a mixed methods design was chosen for the	85
		study	
	3.4.1	Purpose statement	85
	3.4.2	Rationale for the study	87
3.5		Study design	89
3.6		Approval to conduct the research	90
3.7		Research process Phase 1	91
	3.7.1	Sampling	91
		Location of study	91
		<ul> <li>Study participants</li> </ul>	92
		<ul> <li>Inclusion / exclusion criteria</li> </ul>	92
		Sample size	93
		<ul> <li>Sampling method</li> </ul>	94 05
		Recruitment of participants	95
	3.7.2	Data collection	97
		<ul> <li>Survey administration method</li> </ul>	97
		Questionnaire design	98
		<ul> <li>Study variables</li> </ul>	100
		<ul> <li>Validity of the survey tool</li> </ul>	108
		<ul> <li>Piloting the questionnaire</li> </ul>	110
		Data gathering	113
	3.7.3	Data management and analysis	114
		Descriptive statistics	115
		Bivariate statistics	115
		Multivariate statistics	117
3.8		Research process Phase 2	117
	3.8.1	Sampling	117
	3.8.2	Data collection	119
		How the Phase 1 findings informed Phase 2	119
		data collection	
		<ul> <li>Approach to interviews</li> </ul>	119

		Drevention for interviewing	120		
		Preparation for interviewing	120		
		Qualitative data gathering	121		
	3.8.3	Management of the data	122		
	3.8.4	Data analysis	123		
		Approach to data analysis	123		
		Method of data analysis	123		
0.0	3.8.5	Member validation	125		
3.9	1 an <b>A</b> 5	Chapter summary	126		
	oter 4 – FI	Indings from Phase 1	127		
4.1 4.2		Introduction	127		
		Overview of recruitment			
4.3	4.2.4	Description of the sample recruited	128		
	4.3.1	Sample demographics	128		
4.4	4.3.Z	Summary of sample characteristics	<u>129</u> 132		
4.4	1 1 1	Self-management components			
	4.4.1	Monitor and manage angina symptoms	<u>132</u> 134		
	4.4.2	Adopt and maintain a healthy lifestyle Adhere to a treatment regime	134		
4.5	4.4.3	Bivariate links with CHD self-management	136		
4.5	4.5.1	Bivariate links with participants' ability to adopt and	137		
	4.5.1	maintain a healthy lifestyle	137		
		<ul> <li>Age</li> </ul>	137		
		<ul> <li>Existence of co-morbidities</li> </ul>	138		
		<ul> <li>Existence of co-morbidities</li> <li>Sex</li> </ul>	141		
			141		
		Healthcare provider support	142		
		<ul><li>Illness perceptions</li><li>Level of education</li></ul>	142		
			142		
		Self-efficacy	144		
	450	Social support     Diversional links with participants' knowledge of how	144		
	4.5.2	Bivariate links with participants' knowledge of how to monitor and manage angina symptoms	144		
		• Age	144		
		Existence of co-morbidities	145		
		• Sex	145		
		Healthcare provider support	145		
		Illness perceptions	145		
		<ul> <li>Level of education</li> </ul>	146		
		Self-efficacy	146		
		Social support	146		
	4.5.3	Summary of correlations	146		
4.6		Path analysis	147		
	4.6.1	Adopt and maintain a healthy lifestyle path model	147		
	4.6.2	Knowledge of monitoring / management of angina	150		
17		symptoms path model	150		
4.7		Findings and theoretical frameworks	153		
4.8	404	Summary of findings	155		
	4.8.1	Adopt and maintain a healthy lifestyle	155		
	4.8.2	Monitor and manage angina symptoms	156		
	4.8.3	Adhere to a treatment regime	156		
	4.8.4	Bivariate and multivariate relationships with self-	156		

		management			
	4.8.5	Theoretical frameworks	157		
4.9	4.0.0	Findings for further exploration in Phase 2			
-	ter 5 – Fi	ndings from Phase 2	157		
5.1		Introduction	160		
5.2		Exploring the qualitative data	161		
5.3		Emergent themes	163		
5.4		Overarching Theme: Emotional response			
-	5.4.1	Fear	<u>    163    </u> 165		
		<ul> <li>Facing uncertainty</li> </ul>	165		
	5.4.2	Disappointment	169		
		I thought I would be better after the PCI	170		
		I can't do that now	171		
	5.4.3	Abandonment	174		
		<ul> <li>You are just left to get on with it</li> </ul>	174		
	5.4.4	Shock	176		
		<ul> <li>I've got a problem with my heart?</li> </ul>	176		
5.5		Overarching Theme: Perceptions of CHD self-	178		
		management			
	5.5.1	Perceptions of secondary prevention	179		
		What CHD means to me	179		
		<ul> <li>How I can prevent the CHD getting worse</li> </ul>	183		
	5.5.2	Perceptions of symptom monitoring / management	187		
		How I monitor and manage my angina	187		
		symptoms			
	5.5.3	Perceptions of pharmacological treatments	191		
		Why I take my medicines	191		
		How I take my medicines	193		
5.6		Overarching Theme: Support	196		
	5.6.1	Social support	196		
		Help from family	198		
		Help from friends	201		
	5.6.2	Healthcare support	203		
		Support from GP	203		
		<ul> <li>Support from hospital personnel</li> </ul>	205		
		<ul> <li>Support from cardiac rehabilitation</li> </ul>	207		
5.7		Chapter summary	209		
	ter 6 – In	tegration and interpretation of findings			
6.1		Introduction	210		
6.2		Integration and interpretation of the study findings	210		
6.3		Research question 1: How do patients self-manage their CHD after elective PCI?	210		
	6.3.1	Symptom monitoring and management	210		
	6.3.2	Adoption and maintenance of a healthy lifestyle	211		
	6.3.3	Adherence to a treatment regime	215		
6.4		Research question 2: What and how do factors	216		
		influence patients' self-management of CHD after elective PCI?			
	6.4.1	Influence of age	217		
	6.4.2	Influence of co-morbidities	219		

	6.4.3	Influence of educational attainment	220	
	6.4.4	Influence of illness perceptions	221	
	6.4.5	Influence of self-efficacy	224	
	6.4.6	Influence of support	226	
		<ul> <li>Influence of support from healthcare</li> </ul>	226	
		Influence of social support	228	
		<ul> <li>Influence of lack of support</li> </ul>	229	
	6.4.7	Influence of emotions	231	
		<ul> <li>Influence of being fearful</li> </ul>	231	
		<ul> <li>Influence of feeling disappointed</li> </ul>	233	
		Influence of shock	235	
		<ul> <li>Emotions and their regulation</li> </ul>	236	
6.5		Research question 3: To what extent do Bandura's	243	
		Social Cognitive Theory and Leventhal's Self-		
		Regulatory Model help explain self-management of		
		CHD in patients after PCI?		
	6.5.1	Social Cognitive Theory	243	
	6.5.2	Self-Regulation Model	246	
	6.5.3	Conclusions from the theories	249	
6.6		Chapter summary	249	
Chap	ter 7 – Co	onclusions and contribution to knowledge		
7.1		Introduction	250	
7.2		Conclusions from the research	250	
7.3		Limitations of the study	251	
7.4		Contribution to knowledge	254	
7.5		Implications of the research	256	
	7.5.1	Recommendations for practice	257	
	7.5.2	Recommendations for policy	260	
	7.5.3	Recommendations for research	262	
7.6		Reflexivity	264	

Tables		Page no.
Chapter 1		
Table 1.1	Overview of excluded theories	15
Chapter 2		
Table 2.1	Overview of literature included in integrative review	33
Table 2.2	Overview of theme A literature	36
Table 2.3	Overview of theme B literature	43
Table 2.4	Overview of theme C literature	60
Table 2.5	Overview of theme D literature	66
Table 2.6	Overview of theme E literature	70
Chapter 3		
Table 3.1	Mixed methods research designs	86
Table 3.2	Independent variables	102
Table 3.3	Pilot study procedure	111
Table 3.4	Demographics of pilot study participants	112
Table 3.5	Sampling framework	118
Table 3.6	Overview of thematic analysis process	124
Chapter 4	· · · ·	
Table 4.1	Overview of participant demographics	130
Table 4.2	Participants' management of prolonged angina episodes	133
Table 4.3	Frequency of lifestyle changes	134
Table 4.4	Pearson product moment correlations between influencing factors and self-management components	139
Table 4.5	Inter-variable correlation	140
Table 4.6	Coefficients of path model for 'Adopt and maintain a healthy lifestyle'	149
Table 4.7	Fit of path analysis for 'Adopt and maintain a healthy lifestyle'	149
Table 4.8	Coefficients of path model for 'Knows how to monitor and manage angina symptoms'	152
Table 4.9	Fit of path analysis for 'Knows how to monitor and manage angina symptoms'	152
Chapter 5		
Table 5.1	Initial Coding Framework	162
Table 5.2	Fear compared with participants' angina symptom management (from Phase 1)	168
Table 5.3	8 Comparison of causative factors, IPQ scores and 18 lifestyle change	
Table 5.4	Comparison of family support and lifestyle change	198
Chapter 6		
Table 6.1	Process model of emotional regulation	240

Figures		Page no.	
Chapter 1			
Figure 1.1	Stent insertion	6	
Figure 1.2	Social Cognitive Theory diagram		
Figure 1.3	Parallel process of self-regulation	20	
Chapter 3			
Figure 3.1	Explanatory sequential design	90	
Figure 3.2	Recruitment and participant contact	95	
Figure 3.3	Example of changes to survey	109	
Figure 3.4	Factors that potentially influence CHD self-	116	
Ū	management after PCI		
Chapter 4			
Figure 4.1	Recruitment to study	128	
Figure 4.2	Participants' age range compared with PCI patients at	129	
	the Centre		
Figure 4.3	Frequency of participants' angina symptoms	132	
Figure 4.4	Frequency of participants' limitations	133	
Figure 4.5	Amount of exercise most days	134	
Figure 4.6	Body mass index range	135	
Figure 4.7	Confidence compared with number of lifestyle changes	143	
_	made by participants		
Figure 4.8	Participant age compared with knowledge of angina	ngina 144	
	symptom management		
Figure 4.9	Path model 1 (adoption and maintenance of a healthy		
	lifestyle)		
Figure 4.10	Path model 2 (knowledge of monitoring and	151	
	management of angina symptoms)		
Figure 4.11	Adopt and maintain a healthy lifestyle force field	158	
	diagram		
Figure 4.12	Knowledge of symptom monitoring and management	158	
	force field diagram		
Chapter 5		101	
Figure 5.1	Overarching theme: 'Emotional response'	164	
Figure 5.2	Overarching theme: 'Perceptions of CHD self-	180	
	management'	4.0-7	
Figure 5.3	Overarching theme: 'Support'	197	
Chapter 6	Devices to be ordered as a fatter time of a state of the	047	
Figure 6.1	Barriers to knowledge of effective symptom monitoring	217	
	/ management	047	
Figure 6.2	Barriers to the adoption / maintenance of a healthy	217	
	lifestyle	0.40	
Figure 6.3	Bandura's Social Cognitive Theory	243	
Figure 6.4	Adapted Self-Regulation Model	248	

# Chapter 1 Introduction

# 1.1 Introduction

Every year there are almost 100,000 new cases of angina diagnosed in the United Kingdom (British Heart Foundation (BHF), 2008a). In an attempt to control angina symptoms, cardiac patients can undergo two main types of elective coronary revascularisation: percutaneous coronary intervention (PCI) and coronary artery bypass graft (CABG) surgery (Lilly, 2007). While these procedures should diminish patients' angina symptoms, they do not cure the underlying coronary heart disease (CHD) and patients are expected to manage their condition and prevent progression of the disease through adherence to a medication regime and by modifying risk factors known to contribute to CHD (Robinson and Maheshwari, 2005). They would also be expected to identify and deal with any recurring angina symptoms (Rolley et al., 2009). It is known, however, that three quarters of PCI patients will require further revascularisation within ten years for symptom management (BARI Investigators, 2007; Alderman et al., 2004). Of those who have the more traditional means of coronary revascularisation (CABG surgery), evidence from the United States of America indicates that less than 5% of patients need further intervention in the same timeframe (Barreiro and Bansal, 2006) and so the rate of redo-revascularisation in elective PCI patients seems disproportionately high.

# 1.2 Follow up care in Scotland

The reason for the difference in revascularisation rates is not apparent but what is known is that, once discharged from hospital in Scotland, the support and follow up of elective PCI patients is patchy when compared with CABG patients (Information Services Division Scotland, 2012). Patients who have CABG are followed up closely by the hospital where they received the surgery and their General Practitioner (GP) and are given rehabilitation. The same, however, cannot be said for patients who undergo elective PCI. For example, within Scotland, despite clinical guidelines advocating that all coronary revascularisation patients be offered cardiac rehabilitation (Scottish Intercollegiate Guidelines Network (SIGN), 2002), the reality is that less than a third of elective PCI patients actually are and this can be compared with more than 53% of CABG surgery patients (Information Services Division Scotland, 2012). It is also known that many PCI patients are often lost to follow up (Mainie *et al.*, 2005).

As a former Specialist Nurse in Cardiac Rehabilitation in Scotland, the researcher was aware of a disparity between CABG surgery patients and those who had elective PCI. Anecdotally, where the researcher worked, anxious patients were regularly readmitted to hospital soon after the PCI procedure with angina symptoms and they seemed not at all sure as to how they should deal with their condition. Some did not know why they were having angina symptoms again or how to deal with them and others thought that nothing more could be done and that their angina symptoms would get worse, regardless of what they did. The perceptions some patients' had of their CHD seemed to affect the way they dealt with their condition. Poor referral rates from the tertiary hospital where the PCIs were performed meant that patients were very often 'missed'. Alternatively, the CABG surgery patients were, without exception, all referred to the team for planned follow-up and cardiac rehabilitation. They were educated about their condition and how to prevent it progressing and seemed to know what was expected of them.

The researcher discussed the support needs and management of elective PCI patients with some consultant cardiologists. Their perception was that once the patients had the PCI they were "fine" and had no difficulty managing their CHD at home. The view of a cardiac rehabilitation consultant differed, however, as he thought PCI patients should be given comprehensive follow-up to ensure they were supported, similar to that offered to myocardial infarction (heart attack) and CABG surgery patients.

Reflecting on clinical experience and discussions with the consultants led the researcher to question how patients managed their CHD after PCI and why certain patients needed to be hospitalised soon after the procedure, while others seemed to 'manage' their condition at home. There was concern about whether the perceptions some patients had of their CHD affected how they

dealt with their condition. Perhaps the patients who had not been readmitted to hospital held similar beliefs about their condition and managed it in a different way but, as they were often missed in follow up, this was not known. Also, there was curiosity regarding the reason why PCI patients required further revascularisation sooner than their CABG counterparts. Essentially, the researcher was interested in exploring and trying to explain how patients managed their CHD after having elective PCI and whether any factors affected their efficacy in this which could account for the need for repeat revascularisation. Effective self-management of CHD after PCI is considered to be: adherence to a medication regime, modification of factors that contribute to CHD risk and to manage angina symptoms effectively according to the guidance given by healthcare professionals (adapted from the work of Holman and Lorig, 2004).

## 1.3 Background to the clinical issue

### 1.3.1 Incidence and prevalence of CHD

CHD is known to be the main cause of death in the Western world and is increasing in developing countries (Nichols *et al.*, 2013; World Health Organisation, 2013b). It is described as a true pandemic as it kills about 8 million people globally each year with around a quarter of those people in Europe (European Heart Network and European Society of Cardiology, 2012; World Health Organisation, 2004). The disease is known to be a major cause of premature death and disability in the United Kingdom (UK) (BHF, 2012; Department of Health (DoH), 2000) causing more than 80,000 deaths each year, which equates to one in five men and one in six women who die from this disease. Death rates are highest in Scotland and lowest in England (BHF, 2012) and although mortality rates are declining, the prevalence of the disease in the UK remains high. BHF statistics suggest that almost 3.5 million people in the UK have angina symptoms or have had a myocardial infarction, or both (BHF, 2010b).

The prevalence of patients with angina is higher than those who have had a myocardial infarction with approximately 5% of men (1.2 million men) and 4% of women (900,000 women) affected by angina in the UK (BHF, 2010a). The

prevalence of the disease increases with age and males are more susceptible than females (BHF, 2010a). Treating this chronic disease is estimated to cost the UK economy over £3 billion per year (BHF, 2009a).

Treatments for patients with CHD in the UK have improved and increased in number over the last few years, aided by the advancement of medicine and the publication of clinical guidelines (Scottish Intercollegiate Guidelines Network (SIGN), 2007; Department of Health, 2000). For UK patients with angina, the number of operations to alleviate their symptoms by opening up or 'revascularising' the coronary arteries has increased. In the last decade in the UK there has been a gradual decline in the number of CABG operations and, now, just under 18,000 are performed per year, but the number of PCI procedures has grown substantially from around 10,000 in 1990 to almost 90,000 in 2010 (BHF, 2012).

### 1.3.2 Coronary heart disease

The heart receives its own blood supply from a system of blood vessels known as the coronary arteries. Over time, and in combination with risk factors, these arteries become narrowed when deposits of a fatty substance are laid down in their lining. The fatty deposits or 'atheromatous plaque' cause a restriction in the blood supply to the heart and can lead to the person experiencing angina symptoms or having a myocardial infarction (Chest, Heart and Stroke Scotland, 2014).

Risk factors for CHD can be either modifiable (e.g. high intake of saturated fat, high cholesterol, smoking, lack of exercise, hypertension, type II diabetes and obesity) or non-modifiable (e.g. increasing age, and male sex) (World Heart Federation, 2014; Capewell *et al.*, 2008). Although familial hypercholesterolaemia is a condition caused by a genetic disorder (i.e. the condition is not preventable), it can be controlled through diet and medication and so this is also a modifiable CHD risk factor (FH Foundation, 2015). It is known that 80% of CHD is preventable (Capewell, 2009) but, commonly, patients lack awareness and understanding of its cause (Momtahan *et al.*, 2004; Potvin, Richard and Edwards, 2000; Zerwic, King and Wlasowicz, 1997).

CHD can manifest in different ways, the main ones being angina (either stable or unstable) and myocardial infarction. For the purposes of this thesis, the focus will be on patients with stable angina who undergo an elective PCI to alleviate angina symptoms. The rationale for excluding patients with other manifestations of CHD is that their heart pathophysiology may differ, and their care management and recovery time may also be different from those who have elective PCI for angina management. This is explained further in the subsequent sections of the chapter.

#### Stable angina and its management

Angina is classed as a symptom and not a disease (the underlying disease is CHD). It typically can be defined as a pain or discomfort located in the chest that is caused by myocardial hypoxia, secondary to a restricted coronary blood flow caused by atheromatous plaque in the coronary arteries (National Institute for Health and Care Excellence (NICE), 2011). The patient often experiences symptoms, including chest pain, that can radiate to the surrounding area and these symptoms are known as angina pectoris (this will now be referred to as 'angina symptoms'). Stable angina symptoms predictably occur when the demands of the heart are high (e.g. during exercise and strong emotions) and the supply of blood and oxygen to the heart is unable to meet the demand due to CHD. When patients experience angina symptoms, often the lumen of their coronary arteries can be stenosed by more than 70% and, while a sufficient amount of blood can be supplied to the myocardium when the patient is at rest, it is unable to compensate when there is an increased demand (Lilly, 2007). It is not associated with myocardial necrosis and so stable angina causes no damage to patients' hearts (Grubb and Newby, 2006).

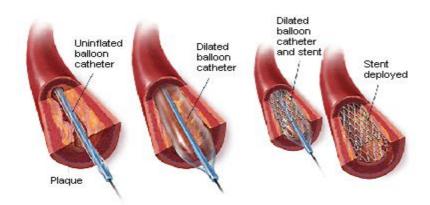
According to NICE (2011) the goal of managing stable angina centres around alleviating patients' angina symptoms, improving their quality of life and reducing morbidity and mortality. It is recommended that patients with stable angina are prescribed, amongst other things, anti-anginal medicines (SIGN, 2007) but when these are ineffective, consideration is given to elective coronary revascularisation, either CABG surgery or PCI (NICE, 2011), to help relieve angina symptoms by restoring an adequate blood supply to the heart.

PCI (also known as coronary angioplasty and percutaneous transluminal coronary angioplasty) (Perkins and Jenkins, 1998; Jensen *et al.*, 1993; Gaw, 1992) is a procedure that is used to re-open patients' narrowed coronary arteries. It is considered a safe, viable and less invasive alternative to 'open heart' CABG surgery as it is performed under local anaesthetic (Lauck, Johnson and Ratner, 2009).

In contemporary healthcare, patients who have elective PCI are most often in hospital for less than 24 hours and advances in post-procedure care can mean that some may be in hospital for just a few hours as a 'day-case' patient (BHF, 2014; Brayton *et al.*, 2013). During the PCI, patients are taken to a cardiac catheterisation laboratory in the hospital and while lying on a trolley / bed, the cardiologist makes a small incision and introduces a balloon catheter into the patient's artery (e.g. radial, brachial or femoral) and advances this to the site of coronary artery narrowing (Reynolds, Waterhouse and Miller, 2001). The balloon is then inflated several times which pushes the plaque into the inner wall of the artery, opening the blood vessel (Brar and Stone, 2009). A stent device (a small tube of stainless steel mesh) is inserted to hold the artery open and improve the blood flow. See Figure 1.1 for an illustration of this. Once the procedure is complete the balloon catheter is removed, the artery is 'sealed' and the patient would be transferred to a ward area or day case unit and remain in bed for a few hours prior to discharge (BHF, 2014).

#### Figure 1.1

**Stent insertion** (Boston Scientific, 2008) (Image provided courtesy of Boston Scientific. © 2014 Boston Scientific Corporation or its affiliates. All rights reserved.)



The PCI should lessen or fully relieve the patients' angina symptoms rapidly. Patients who have elective PCI for stable CHD are generally in hospital for less than 24 hours and are expected to return to normal activities and work, if appropriate, within two weeks (BHF, 2009b; BHF, 2009c; Shaw *et al.*, 1986). Although the procedure relieves the angina symptoms, the underlying CHD remains. As mentioned briefly before, findings from a large longitudinal study showed that more than three quarters (n = 915) of PCI patients require further revascularisation for symptom relief within ten years (BARI Investigators, 2007; Alderman *et al.*, 2004). The results demonstrate that the underlying CHD continues to progress after PCI and it is essential, therefore, that this is managed as a chronic condition with long-term pharmacological treatment and risk factor modification to slow the progression of the disease (SIGN, 2002).

Managing stable angina with CABG surgery is vastly different for patients. CABG surgery is a major procedure that is performed under general anaesthesia and involves the chest cavity being opened. While the heart is stopped and a 'heart-lung' machine does the work of both the heart and lungs, healthy blood vessels are taken from the leg, arm or chest and stitched in place on the heart to bypass the narrowed section(s) of the coronary arteries (Mullany, 2003). The surgery takes a few hours and the patients would remain in hospital for 5 - 7 days (Michaels and Chatterjee, 2002). In comparison with patients after PCI, recovery from CABG surgery can take up to three months (Vaccarino *et al*, 2003). The rationale for excluding CABG surgery patients from the patient group of interest was due to the differences in the revascularisation procedure, hospitalisation period and subsequent recovery.

#### Other manifestations of CHD

As indicated previously, manifestations of CHD include myocardial infarction and unstable angina and these differ in pathophysiology from stable angina.

A myocardial infarction occurs when some unstable atheromatous plaque fissures causing platelet aggregation and clot formation in a coronary artery (Lilly, 2007). The clot causes complete coronary artery occlusion and quickly results in an area of myocardium becoming ischaemic and cells becoming necrotic. If the infarct affects a significant portion of the myocardium, the patient may experience symptoms of heart failure (Lilly, 2007). In order to salvage jeopardized myocardial cells and limit the damage, reperfusion therapy using, ideally, emergency / primary PCI is given within the first two hours of the patient presenting but despite this, patients are generally left with some damage to their heart (SIGN, 2013; Grubb and Newby, 2006). Although it has been deemed safe to discharge patients from hospital after only two days (Jones *et al.*, 2012), myocardial infarctions induce a process known as 'cardiac remodeling' where the necrotic cells are ultimately replaced with fibrous, scar tissue and this takes around six weeks (Ertl and Frantz, 2005). During the period the heart is 'healing', patients are advised to pace up their activity gradually and this results in a recovery time of around 4 - 6 weeks before they can begin cardiac rehabilitation (Chest, Heart and Stroke Scotland, 2013).

Consequently, the recovery time differs between those who have had a myocardial infarction and stable angina patients who undergo PCI. Although myocardial infarction patients are also treated with PCI, this is done with a primary aim of re-establishing the blood flow down the occluded coronary artery and salvaging myocardial tissue and this clearly differs from the purpose of using PCI in stable angina patients.

Unstable angina has similar pathophysiology to myocardial infarction but the clot formation in the coronary artery does not result in complete occlusion. It can cause the patient to have more frequent, prolonged episodes of angina symptoms that occur with lesser degrees of exertion (Lilly, 2007). Unstable angina is classed as an 'acute coronary syndrome' and may progress to cause myocardial necrosis if not identified and treated promptly and the consequences of that would be similar that myocardial infarction.

PCI can, therefore, be performed as an emergency when patients have unstable angina or myocardial infarction but the purpose of the procedure, length of hospitalisation and subsequent recovery period differs for those patients when compared with patients who have PCI for relief of angina. Patients where PCI is performed as an elective procedure to alleviate symptoms will be considered as a discrete group and the focus of this thesis.

#### 1.3.3 Chronic disease management

Chronic conditions affect a significant proportion of society and, although they are commonly associated with older people, the prevalence of them is increasing in all age groups (Conn, 2011; Jerant, Friederichs-Fitzwater and Moore, 2005; Dongbo *et al.*, 2003; Lorig *et al.*, 2001). A recent cross-sectional study found that over 42% of Scots had one or more co-morbidity with almost a quarter of those studied being classed as 'multi-morbid' (>2 co-morbidities) (Barnett *et al.*, 2012). Around 70% of healthcare expenditure in the UK and Australia is spent on providing care for people with chronic conditions (College of Medicine, 2013; Gallagher *et al.*, 2008b). In Scotland £160 million is spent on prescriptions dispensed for CHD alone (Information Services Division Scotland, 2012). As the population ages, the prevalence of people with chronic conditions is set to increase but Barnett *et al.*'s (2012) epidemiological survey found that half the people with multi-morbidity were less than 65 years old.

Care of patients with acute diseases was the focus of the majority of healthcare providers in the world but a shift around the 1950s was necessary to concentrate more on the management of the increasing prevalence of chronic conditions (Holman and Lorig, 2004).

Modern healthcare aims to involve patients more in their care to reduce the incidence of complications linked to chronic disease and the number of readmissions to hospital, while also attempting to improve patients' quality of life and well-being (Mead *et al.*, 2010; Munir *et al.*, 2009). It was necessary, therefore, for healthcare to move away from the paternalistic style of patient care, where patients were relatively passive recipients of care provided by healthcare experts, to a more shared responsibility model, wherein patients are central to the approach but are supported by healthcare practitioners to together, strive for the best possible outcomes (Self Management UK, 2013; Du and Yuan, 2010; Long Term Conditions Alliance Scotland (LTCAS) and Scottish Government, 2008; Townsend, Wyke and Hunt, 2006). So called self-management.

Support for patients' self-management is multifaceted but PCI patients require support from healthcare professionals to manage their CHD. Several years

ago, research including that from Clare (2002), Campbell *et al.* (1998) and Van der Weijden and Grol (1998) reported findings that indicated that support for CHD patients was deficient. Since then, clinical guidelines have been published that recommend patients are supported by healthcare professionals and given information about topics including CHD, how to manage angina symptoms, behaviour modification to reduce CHD risk, as well as the benefits and purpose of any pharmacological treatment they receive (NICE, 2011: SIGN, 2007). The guidelines were informed by findings from randomised controlled trials that provided strong evidence that supporting and giving information and health promotion advice to those with CHD results in reduction in their CHD risk factors and improves their quality of life but the support needs to be structured and ongoing (Murchie *et al.*, 2003; Cupples and McKnight, 1999).

In light of the evidence, NHS Boards in Scotland established Cardiac Services Managed Clinical Networks in an attempt to integrate services more to improve the care and support for all patients with CHD (Hamilton *et al.*, 2005; Scottish Executive, 2004). Also GPs were incentivised in the UK to identify patients who had CHD and support them more in their self-management (Vidal-Alaball, 2011). Despite these initiatives, however, it was found that support from healthcare professionals was still lacking (Buckley, Byrne and Smith, 2010) and this was not unique to the UK (Batic-Mujanovic, Zildzic and Beganlic, 2006).

Support may also be provided through comprehensive cardiac rehabilitation where patients receive help with lifestyle modification, secondary prevention of CHD and psychosocial health (NICE, 2013; British Association for Cardiovascular Prevention and Rehabilitation, 2012; World Health Organisation, 1993). Despite a UK target of 85% participation in cardiac rehabilitation after revascularisation, as few as 6 – 10% of PCI patients are enrolled (BHF, 2008b; Bethell *et al.*, 2006; Bethell *et al.*, 2001). Other cognitive-behavioural rehabilitation programmes have been developed such as the 'Angioplasty Plan', which is based on the 'Angina Plan' (Lewin *et al.*, 2011), the uptake is limited.

Whilst these rehabilitation programmes are considered to be lifesaving and inexpensive (Scottish Government, 2009a), it is reported that they are under

resourced in the UK and, consequently, struggle to meet the needs of the cardiac patients (BHF, 2008b). The lack of resourcing, combined with the number of CHD patients who should be given cardiac rehabilitation, leads to significant waiting times (BHF, 2013) and so many patients often miss out on the support from a cardiac rehabilitation team when they most need it and are subsequently left to manage their condition alone.

# 1.4 Self-management

Self-management (or self-care as it is often termed) is what individuals do for themselves to maintain their health and wellbeing, to preserve their physical function and to prevent further illness (Conn, 2011; Department of Health, 2005). Dickson, Tkacs and Riegel (2007; page 424) define it as:

"an active process intended to maintain health through treatment adherence, symptom monitoring, recognition and treatment and an evaluative process whereby learning occurs in response to prior self-care [self-management]".

Its aim is for the person to be able to live independently with a good quality of life (Holman and Lorig, 2000) but it is not a substitute for providing healthcare services (Scottish Government, 2009b). Healthcare providers should support and educate patients to enable them to solve any problems they have, make decisions regarding their disease management and take appropriate action if required (Self-Management UK, 2013; Clark *et al.*, 2010; Gibson *et al.*, 2009; LTCAS and Scottish Government, 2008; Coulter, Parsons and Askham, 2008).

Self-management is considered a key component of how patients with CHD deal with their chronic condition on a daily basis (Scottish Government, 2009b). Adapted from the work of Holman and Lorig (2004), the following components make up self-management of CHD following elective PCI:

- Effective monitoring and management of angina symptoms
- Adoption and maintenance of a healthy lifestyle
- Adherence to a pharmacological treatment regime

According to Gately, Rogers and Sanders (2007), the ability of the person to engage in self-management improves their chronic disease management. While some research has found self-management to be effective (Ricci-Cabello *et al.*, 2014; Deakin *et al.*, 2009; Gibson *et al.*, 2009; Lau-Walker and Thompson, 2009), other studies have had more ambiguous findings (Jonsdottir, 2013; Khunti *et al.*, 2012; Oliveira *et al.*, 2012; Deaton *et al.*, 2006; Warsi *et al.*, 2004) but the reasons for that are not known.

Ultimately, the responsibility for management of CHD lies with the patients and this is termed 'self-management'. It is known though that about 90% of the time, patients manage their chronic conditions alone with little in the way of support and education from healthcare providers (The Heath Foundation, 2011; Lorig and Holman, 2003).

It has been documented that when patients are not supported in their CHD selfmanagement, they have difficulty modifying CHD risk factors. The study from Chow *et al.* (2010) illustrates this as they found that where support and advice was given initially after an acute coronary syndrome, any behaviour change made by patients in the first four weeks was not sustained beyond six months.

Even where some support is given, issues arise in relation to the provision of ongoing assistance to patients for behaviour change. Cole *et al.* (2013) found that general practitioners stopped giving patients support when their health promotion advice had not been acted on. Newer technologies, such as telehealth, may be beneficial in that they can be accessible to patients who would not normally join cardiac rehabilitation programmes or seek support from primary care healthcare providers but evidence suggests that this type of support may not be valued or used effectively by patients and resultantly, behaviour change and CHD risk factor reduction is often not attempted or not maintained beyond just a few weeks (Dalleck, Schmidt and Lueker, 2011; Kerr *et al.*, 2010). This is unfortunate given that lifestyle factors can be extremely challenging to modify.

Behaviours often originate in childhood or adolescence and the long-standing nature of them, coupled with potential pressure from the patients' social

environment, hinder their modification (Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice, 2012). It seems that despite clinical guidelines advocating that CHD patients are supported in their CHD self-management, ongoing assistance from healthcare professionals is not given, newer methods of providing support are not valued by patients and the result is that any initial gains in risk factor modification are not sustained. Patients consequently, are left to self-manage CHD alone and evidence shows that this may not be effective (Department of Health, Social Services and Public Safety, 2011; Kotseva *et al.*, 2009).

Lack of support from healthcare professionals also seems to have an impact on the efficacy of angina symptom management. The study from Tod *et al.* (2001) found that patients with angina would often deny they were having symptoms and delay reporting them to healthcare professionals, in some cases, for years. The functional ability and quality of life of participants in Tod *et al.*'s study deteriorated as they managed their symptoms by reducing or avoiding activity and so it seems clear that they were unable to effectively manage their angina symptoms without help. Richards, Reid and Watt (2002) also found that people in a low socioeconomic class would not seek help for angina management as they perceived that they would be chastised by healthcare professionals for not engaging in behaviour that would lessen the risk of CHD. Consequently, it appears that even though support is available to patients, it may not be accessed.

The notion of a shared responsibility model where patients are supported by healthcare professionals to, together, effectively self-manage CHD is not apparent. Resultantly, poor self-management of CHD is common (Conn, 2011) and this can be evidenced through greater use of unscheduled care services and failure to meet outcomes associated with health (The Kings Fund, 2010; Ryan, 2009). Indeed, it is claimed that those with angina symptoms are one of the most unsupported groups of patients with cardiovascular disease (Buckley and Murphy, 2009). Also, research has shown that CHD patients perceive the psychological support provided by healthcare professionals to be lacking

(Asadi-Lari, Packham and Gray, 2003) and this may also have a negative effect on successful self-management.

Other factors may also contribute to ineffective CHD self-management. For example, having misconceptions about a chronic illness has been found to affect people's ability to effectively manage conditions such as diabetes, osteoarthritis, chronic obstructive pulmonary disease, asthma, and heart failure (Mead *et al.*, 2010; Bayliss, Ellis and Steiner, 2007; Jerant, Friederichs-Fitzwater and Moore, 2005; Riegel and Carlson, 2002; Carlson, Riegel and Moser, 2001). From the literature, it seems that factors including co-morbidities, gender, age, lack of social support, and low self-efficacy may influence patients' ability to cope with CHD (Mead *et al.*, 2010; Bayliss, Ellis and Steiner, 2005; Chriss *et al.*, 2004; Riegel and Carlson, 2002; Carlson, Riegel and Carlson, 2002; Carlson, Riegel and Carlson, 2002; Carlson, Riegel and PCI patients.

There are several factors that seem to contribute to ineffective CHD selfmanagement and what is known already about this in relation to patients who have undergone elective PCI will be discussed in the subsequent literature review chapter.

### 1.5

# Theories linked to self-management

Several theories were explored to determine which could perhaps be used to help explain self-management of a chronic disease such as CHD. Discussion was had between the researcher and the supervision team overseeing the work and decisions were made regarding which theories / models would be used to explore CHD self-management after patients have undergone elective PCI. Table 1.1 outlines the theories that were considered but excluded from use. The following sections of the chapter introduce the two theories that were used to try to understand CHD self-management in patients who have elective PCI.

Theory and theorists	Focus of theory	Underpinning assumptions	Previous use	Comments
Health Belief Model (Rosenstock, 1966 as cited in Green, 2010; Becker, 1974)	Preventative health behaviours – Model attempts to explain and predict health behaviors by focusing on the attitudes and beliefs of individuals	People are scared of disease. The actions they take are linked to the extent of their concern. Premise: the greater the perceived risk, the more chance the person will change behaviour to reduce risk (Becker, 1974).	To explain and try to predict why people do not engage in health screening or act on advice to improve their health (Glanz, Rimer and Viswanath, 2008; King, 1982)	The model focuses on explaining single phenomena such as why people stop smoking. It fails to consider the influence emotions have on behaviour (Glanz, Rimer and Viswanath, 2008). The perceived severity of an illness was found to be a weak predictor of people adopting preventative health behaviours (Janz and Becker, 1984). Self-efficacy is a key factor within the model but this has been criticised for being a separate entity and should be considered as such (Rosenstock, Strecher and Becker, 1988).
Theory of Reasoned Action / Theory of Planned Behaviour (Armitage and Connor, 2001; Ajzen, 1985 as cited in Kuhl and Beckmann, 1985)	Theory attempts to determine people's intention to engage in certain behaviours. Encompasses attitudes towards the behaviour and social pressures to behave in a particular way (Ajzen and Fishbein, 1980).	The immediate precursor of any behaviour is a person's intention to perform the behaviour (Ajzen and Madden, 1986). Premise: behaviour is under a person's control (Ajzen and Fishbein, 1980).	To predict deliberate behaviours such as smoking and drinking alcohol (Ajzen and Madden, 1986).	Does not incorporate the influence of peer, social or environmental influences that may affect a person's ability / desire to change behaviour.
Transtheoretical / Stages of Changes Model (Prochaska and DiClemente, 1983)	Behaviour change – Model attempts to explain the different stages involved in altering behaviour.	Premise: behaviour change involves multiples stages and these stages are progressed through at an individual's own pace (Kern, 2008).	Used initially to explain how people were able to stop smoking.	Does not incorporate the influence of peer, social or environmental influences that may affect a person's ability / desire to change behaviour.

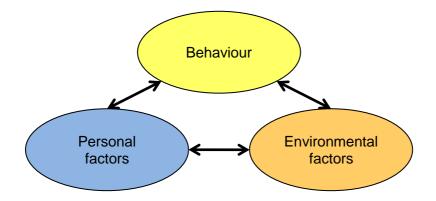
# Table 1.1 Overview of excluded theories

## 1.5.1 Social Cognitive Theory

It is suggested that self-management is based on Bandura's Social Cognitive Theory, which asserts that environmental and personal factors influence people's behaviour (Bandura, 2001; Clark *et al.*, 1991) and so this theory was critiqued to determine its suitability to inform / help explain the current research.

The Social Cognitive Theory asserts that direct reinforcement does not account for all types of learning and that there are environmental and personal factors, which can also influence behaviour (Boston University School of Public Health, 2013a; Bandura, 2001). See Figure 1.2 for a diagram of the theory.

### Figure 1.2 Social Cognitive Theory diagram



The Social Cognitive Theory suggests that:

- People learn by observing others (known as vicarious learning).
- People do not always apply what they have learned (this is based on perceptions and known consequences of behaviour).
- People regulate their behaviour.
- Self-regulation encompasses self-efficacy.

Self-efficacy refers to the beliefs or confidence that people have in their ability to perform specific behaviours necessary to achieve a desired goal (O'Sullivan and Strauser, 2009; Dongbo *et al.*, 2003; Clark and Dodge, 1999). People's beliefs about how efficacious they will be are influenced by four main things:

- Performance mastery Personal accomplishment provides the most influential source of self-efficacy. Problems arise when people come to expect quick or easy success, as they are likely to become discouraged by failure when this is not the case (Bandura and Adams, 1977).
- 2. Vicarious experience Vicarious experience relies on inferences people draw from social comparison where they compare themselves with others to gauge what they can and cannot do (Chadee, 2011). If people witness others, particularly when they are perceived to be similar achieving successful outcomes, they too will believe they are able to achieve their goals. The greater the perceived similarity, the more influence it has on the person's efficacy beliefs (Bandura, 1994). This vicarious experience or modelling can, however, also have negative effects on the person's self-efficacy. If individuals observe failure, they will come to expect failure also.
- 3. Social or verbal persuasion This is widely used to convince people that they can be successful in achieving their goals. This persuasion may not, however, have a lasting effect and can be influenced by who is trying to persuade the person and what they know about the goals and methods of attaining them (Bandura, 1994).
- Physiological states If people experience stress or have a low or despondent mood they may feel vulnerable and have a low degree of self-efficacy (Bandura, 1995).

Self-efficacy influences how people feel, think and act as well as how much effort they will expend and how long they will try or persist to meet their goals (Bandura, 1991; Bandura and Adams, 1977). It also depends on how difficult the task or change in behaviour is perceived to be (Burket *et al.*, 2012).

Self-efficacy is considered an important factor that can influence effective selfmanagement (Gallagher *et al.*, 2008b; Carlson, Riegel and Moser, 2001). Indeed, research has found that it has a direct influence on CHD patients' adoption of healthier behaviours (Sol *et al.*, 2011). As this theory reportedly forms the basis of self-management and self-efficacy appears to be an important factor, it seemed appropriate to consider its use in helping to explain CHD self-management. In chapter 2 the literature related to this theory and elective PCI patients' CHD self-management will be explored to determine what is known.

#### 1.5.2 Self-Regulation Model

The Self-Regulation Model is one theory that has been used by researchers to understand how people self-manage chronic illnesses (Fischer *et al.*, 2010; Deary, 2008; McAndrew *et al.*, 2008; Green, Payne and Barnitt, 2004; Jayne and Rankin, 2001; Watkins *et al.*, 2000) and so this model was considered to determine its suitability to underpin the current research.

Developed at the start of the 1970s by Leventhal and colleagues (Leventhal, Meyer and Nerenz, 1980, as cited in Petrie *et al.*, 1996), the model (also known as the Illness Perceptions / Illness Representations / Parallel Process / Common-Sense Model) is based on a theory that hypothesises that people generate perceptions of their illness based on cognitive and emotional information available to them and that information determines how they appraise and cope with their illness (Hale, Treharne and Kitas, 2007; Hagger and Orbell, 2003). From this, Nerenz and Leventhal (1983) subsequently created a model of an adaptive system that was organised in a hierarchical manner with three main components:

- Illness representation how the illness is interpreted by the individual (e.g. symptoms, social messages, cues and possible consequences).
- Coping strategies the coping actions the individual takes or plans to take (e.g. seeking medical attention, self-prescribing, discussing with others, avoidance).
- 3. Appraisal assessment of whether the coping strategies have been successful or not and a reflection on the need for modifications.

According to this Model, when an individual experiences symptoms of an illness (the threat), two sets of representations are generated: the cognitive representation where the individual objectively considers the nature of the threat and the emotional representation, which is the individual's subjective reaction to the threat (e.g. fear, sadness) (Scollan-Koliopoulos, Walker and Rapp, 2011; Wearden and Peters, 2008; Petrie *et al.*, 2002; Leventhal, Meyer and Nerenz, 1980, as cited in Petrie *et al.*, 1996). The cognitive and emotional representations are parallel processes that interact with each other (see Figure 1.3) (Bishop, Yardly and Lewith, 2008).

The premise is that people are problem solvers (Green, Payne and Barnitt, 2004). The self-regulation comes from individuals' attempts to maintain the status quo and return to their 'normal' state of health by being active participants in their care, making decisions, problem solving and coping with their condition on a daily basis (Johnson *et al.*, 1997); all aspects that underpin the self-management of any chronic disease. The self-regulation is influenced by how people feel about their illness, its symptoms and, their coping strategy (O'Connor, Jardine and Millar, 2008). The beliefs or perceptions people have about their illness is a key feature of the model and the following five themes comprehensively capture the basis of those illness perceptions (Phillips, Leventhal and Leventhal, 2012; Petrie and Weinman, 2006; Petrie *et al.*, 1996):

- 1. <u>Identity</u>: the label / name given to the condition or what the condition is and the accompanying symptoms.
- <u>Cause</u>: the perceived cause of the condition (this may not be medically correct). This is based on individuals' experience, the beliefs of their spouses / significant others, lifestyle, environment, information from healthcare professionals and media.
- <u>Time-line</u>: people's perception of how long the illness may last e.g. whether it is acute or chronic
- 4. <u>Consequences</u>: the beliefs about the consequences of the condition and how this will impact on people physically, socially and financially.

5. <u>Curability / controllability</u>: individuals' perceptions of whether the condition can be controlled or cured either by them or by doctors.

#### **Figure 1.3 Parallel process of self-regulation** (Adapted from Jayne and Rankin, 2001; page 54)

Emotion Cognition Representation Representation Emotional perceptions of illness Cognitive perceptions of illness formed by thinking about: formed by thinking about: Causes of the illness Causes of the illness How the person labels • Dual influence How the person labels the symptoms the symptoms How the person How the person perceives the perceives the consequences of consequences of threat or illness threat or illness Perception of illness as Perception of illness as a short or long-term a short or long-term problem problem Influence Influence Dual influence Coping with objective Coping with emotion-related features of the illness features of the illness Influence Influence Dual influence Appraisal of effects of coping Appraisal of changes in strategies emotional responses

Illness perceptions evolve over time and are based on individuals' knowledge and past experiences of illness (also vicarious experiences), the advice of family and friends who have similar symptoms or conditions, the comparisons the individuals make with society, their culture and the media (Shiloh, 2006; Benyamini, Gozlan and Kokia, 2004; Furze *et al.*, 2002). As a result, illness representations are unique to each individual and are dynamic (Phillips, Leventhal and Leventhal, 2012; Johnson, 1999).

The coping strategies individuals develop will differ according to how the illness threat is interpreted (McAndrew *et al.*, 2008) and will be considered the most appropriate for the situation (Benyamini, Gozlan and Kokia, 2004). Misconceptions about an illness may, however, lead to maladaptive coping strategies being adopted by individuals and this can affect their emotional response (e.g. fear) and eventually cause them to incorrectly appraise the illness, which further feeds-back to compound future representations of the illness (Furze *et al.*, 2002).

The appraisal stage in the model is where individuals reflect on whether their coping strategies have been successful or not. If people believe they are able to control their illness, they are more likely to think their coping methods have been successful (Watkins *et al.*, 2000).

This model seems to provide a framework that would allow comprehension of how people self-regulate or self-manage their chronic condition and the related literature on the topic will be critiqued in chapter 2

# 1.6 Chapter summary

The chapter began with an account of how the researcher came to have an interest in the phenomenon of how patients who have angina symptoms manage their condition after elective PCI. Comparisons were made with the clinical outcomes of PCI patients compared with CABG patients who undergo a more invasive method of coronary revascularisation. It was found that the rate of redo-revascularisation was disproportionately high in PCI patients when compared with their CABG counterparts. How PCI patients are currently

managed and followed-up in Scotland was discussed. To contextualise the number of people affected by CHD, the prevalence / incidence of the disease was mentioned. An overview of the pathophysiology of CHD was given, and how stable angina differs from other manifestations of CHD was outlined. What is involved in the PCI procedure was mentioned and the difference between elective PCI and that performed in an emergency for other manifestations of CHD was clarified. In order to deal with CHD after PCI, patients are expected to engage in self-management and so this was defined and an outline of the expectations of patients given. Some factors that have been found to influence patients' self-management of chronic diseases were mentioned and these will be discussed in more detail in the review of the literature. The theories explored that were considered to underpin the research are summarised. The two theories that were chosen to help explain the phenomenon are introduced towards the end of the chapter.

# 1.7 Organisation of thesis

The following section of the chapter will provide an overview of how the thesis is organised.

### Chapter 2: Literature review

This chapter will provide details of how the literature concerning patients' selfmanagement of CHD after elective PCI was systematically sourced and reviewed. Details of the search method will be given and the approach to reviewing the literature discussed. The literature review is organised into themes in which included studies are critiqued, findings interpreted and synthesised and conclusions drawn. This will enable a detailed discussion to be given of what is known about the subject, including theory that is commonly used and the gaps in the current evidence-base. From there, a reasoned argument of the need for the study will be provided and the chapter will conclude with the aim of the study and the research questions.

### Chapter 3: Research methods

Details will be given of the study design and method adopted to explain CHD self-management in patients after PCI. Justification will be given for using a

sequential, mixed methods study to explore and explain. An outline of the process followed to obtain ethical approval to undertake the research will be provided. The two phases of the study will be described separately so that the methodology adopted in each is clear. Specific information will be given regarding what each phase sought to explore and how the second qualitative phase was used to explain the findings of the initial quantitative phase. The tools used for data collection and the intended methods of data analysis will be discussed.

#### Chapter 4: Findings from Phase 1 (Quantitative)

This chapter begins with details of the study sample. Thereafter, it is divided into three main sections according to the method used to analyse the quantitative data. Discussion of the findings from descriptive statistical analysis will encompass details of how the participants monitored and managed their CHD, their adoption of more healthy lifestyles and adherence to a pharmacological treatment regime. Factors that were found to have a relationship with the individual components of CHD self-management will be outlined in the part of the chapter related to bivariate analysis. Discussion of the quantitative findings will conclude with specific information regarding the multivariate, path analysis that was conducted. How each set of findings relate to the research questions will be made obvious. An overview will be provided of the quantitative findings that were further explored in Phase 2.

#### Chapter 5: Findings from Phase 2 (Qualitative)

In this chapter the qualitative findings are presented. It will begin with information regarding the approach taken to qualitative data analysis. As thematic analysis was used with the qualitative data, details will be given of how the themes emerged and, thereafter, the findings from each theme will be discussed. Excerpts from patients' interview transcripts will be used to support and inform discussion of the findings.

#### Chapter 6: Integration and interpretation of findings

The two sets of findings will be integrated to demonstrate how the qualitative data helped to explain the quantitative findings. The integrated findings will be

analysed and synthesised and discussed in the context of contemporary literature.

### Chapter 7: Conclusions and contribution to knowledge

The final chapter of the thesis will outline the conclusions that could be drawn from the research, including the contribution to knowledge. Limitations of the study and its design will be acknowledged. The implications the research has for clinical practice, healthcare policy and further research will be discussed. The thesis will conclude with a reflexive account from the researcher regarding the experience of planning, conducting and writing up the research study to provide some insight into the 'journey' that has taken place.

# Chapter 2 Literature review

## 2.1 Introduction

This Chapter will begin with a brief overview of the importance and purpose of a literature review and then the approach used to search the literature will be outlined. The objectives for this literature review will be set out and the key words and databases used will follow. Inclusion and exclusion criteria will be detailed and justification given for the criteria set. Information will be given regarding the approach and framework used to critically appraise the research evidence found in the search. How the literature review will be organised will be mentioned and thereafter the critique of the literature will be provided. The chapter will end with conclusions from the literature review, identification of gaps in the existing evidence and the research questions used for the study.

## 2.2

## The purpose of the literature review

The purpose of this literature review was to identify what was known about CHD self-management following elective PCI and highlight any gaps in the literature. A thorough search, conducted in a systematic manner, and review of the literature was necessary to establish what was known about the topic and to identify gaps in that body of literature (Randolph, 2009). This included any theories that had been used previously in the subject area.

Clare and Hamilton (2003) state that the literature review is key to ensuring the researcher is knowledgeable about the subject area and is able to identify the research 'problem' so that an argument of the significance of the research can be formed (Grix, 2004). Once identified, the literature was interpreted and synthesised in an unbiased manner to enable a summary of the evidence to be provided in this chapter (Hemingway and Brereton, 2009). This aided the development of research questions and helped to provide a rationale for conducting the research and the feasibility of performing the study.

# 2.3 Searching the literature

Typically, literature reviews are used to provide a theoretical basis for research by reporting information from published literature on a particular topic area. There are several different types of review including traditional, integrative, and systematic reviews (University of British Columbia, 2014).

Traditional literature reviews are generally used to set out background information on the topic rather than address pre-determined objectives (Crawford and Johnson, 2011). While the rigour can be enhanced by using a systematic approach to literature searching, this type of review has limitations in that the reproducibility may be difficult, it can be incomplete and subject to bias, both in the selection of literature to be reviewed and the conclusions / recommendations that are drawn from it (University of British Columbia, 2014; Cronin, Ryan and Coughlan, 2008). Due to the inadequacies of this type of review, it was discounted from use.

Although systematic reviews are considered to be one of the most comprehensive approaches to identifying and reviewing literature, they can be restrictive about the type of research as often only empirical evidence is included (National Health and Medical Research Council, 1999). Systematic reviews have a narrow focus and resultantly, can be inadequate in addressing broad topic areas (Norman and Griffiths, 2014; Pluye, 2013) such as selfmanagement of coronary heart disease in a PCI patient group. As the topic was quite complex it was possible that it had been investigated through both qualitative and quantitative approaches, and so it was decided that a systematic review may not be appropriate.

Mallett *et al.* (2012) suggest that rather than being confined to the rigid constraints of a systematic review of the literature, researchers may improve the breadth of literature found if a more flexible approach is used. It was decided that an integrative literature review would be used as this allows studies that used diverse methodologies to be considered together (Wittemore and Knafl, 2005). The aim of an integrative review is to enable a balanced evaluation of what is known about a particular subject area to be achieved using the

principles of systematic review methods to search and appraise the literature. According to Russell (2005) it should follow a process that is as intensive and rigorous as primary research. Integrative reviews are robust in their ability to provide a comprehensive appraisal of the literature as they have focused search aims, the quality of the research is appraised and the evidence synthesised (Wittemore and Knafl, 2005; Torraco, 2005).

The integrative literature review conducted used the following principles:

- Clearly stated objectives
- Predefined inclusion and exclusion criteria
- Reproducible methodology
- Systematic exhaustive searches
- Assessment of the validity of each study that was included

Cognisance needed to be paid to the possibility that the integrative review would not capture all of the research relevant to elective PCI patients' selfmanagement of CHD. Evidence shows that studies with more 'positive' results (i.e. ones that show a particular treatment has a beneficial effect or certain factors have an influencing effect) are three times more likely to be published in peer reviewed journals than research that found little or no effect (King's College London, 2014). One method of discovering the unpublished research is by searching grey literature (Social Care Institute for Excellence, 2010).

Grey literature is considered to be literature that is difficult to locate through conventional sources and databases and so to reduce any publication bias, alternative sources were used such as government and charitable organisation websites (Huffine, 2010).

## 2.3.1 Aim of the literature review

In order to focus the search for relevant literature, a strategy for conducting the literature review was required with clearly stated objectives. The objectives for this literature review relate to what was discussed in Chapter 1 regarding the self-management of CHD after PCI. As mentioned previously, CHD self-management is multi-faceted and it was essential that the search for literature was comprehensive enough to include all aspects of this (monitoring /

management of angina symptoms, adoption of a healthy lifestyle and adherence to a medication regime). As indicated in the preceding chapter, patients who have stable angina and are revascularised using elective PCI have a different manifestation of CHD from some other cardiac patients, for example, myocardial infarction patients. Also the procedure involved in PCI is much less invasive than CABG surgery and so the literature that was searched was that pertinent to patients who had undergone elective PCI to alleviate stable angina symptoms. Previous studies have found that patients' knowledge of CHD can influence their self-management (McKinley *et al.*, 2009; Alm-Roijer *et al.*, 2004) but that was not the focus of this research or literature review as that topic area is broad. Essentially, the researcher was interested in exploring how patients managed their CHD after having elective PCI and so the aim of the literature review was to determine what was known about patients' CHD self-management after elective PCI.

## 2.3.2 Databases and keywords used

The following electronic databases were used for the literature search:

- British Nursing Index
- CINAHL (Cumulative Index of Nursing and Allied Health Literature)
- Cochrane Library
- MEDLINE
- PsycInfo

The research database Ebscohost was used to access each of these databases individually to ensure the correct Medical Subject Headings (MeSH) were used, as each differed slightly in terminology. Appendix 1 provides a comprehensive list of the keywords and search terms used in this literature review. To ensure a comprehensive list of keywords was used, synonyms for each term were considered. Also, during the search, truncation was used at the end of a word to make sure all variations were covered (Smith and Shurtz, 2012). For example 'self-manage\*' included self-manage, self-management, self-manages, and self-managed.

Search terms included Medical Subject Headings (MeSH) around:

• PCI, coronary revascularisation

- Coronary heart disease
- Self-management / self-care
- Secondary prevention
- Medication adherence
- Angina symptom management

The grey literature sourced included that from: National Institute for Health and Care Excellence, Scottish Intercollegiate Guidelines Network, BHF, Chest, Heart and Stroke Scotland, and Self-Management UK. This, therefore, helped to ensure a comprehensive approach to research evidence identification.

### 2.3.3 Inclusion and exclusion criteria

The studies included should be determined by the literature review aim but it is appropriate to set criteria regarding which should be incorporated. The rationale for any inclusions and exclusions should be made explicit to ensure that the decisions are based on sound judgement, rather than merely to reduce the pool of articles to be reviewed (Carnwell and Daly, 2001). It was essential to exercise caution when setting the criteria for reviewing the literature. Setting criteria that are too narrowly defined could result in potentially missing relevant research evidence, whereas broad criteria can result in evidence that is difficult to compare and synthesise (Centre for Reviews and Dissemination, 2008).

For this literature review a number of criteria were set. Firstly, the patients of interest were those who had had coronary revascularisation with PCI and so CABG surgery patients were excluded. Also, research with samples of patients who solely had other manifestations of CHD, such as myocardial infarction and heart failure, were excluded from the literature search. The population studied was restricted to adult patients only as it is known that the pathology of CHD is unlikely to affect any child or adolescent. In order to ensure only primary research studies were included, any papers that did not report empirical research, were excluded. To ensure the quality of the research was acceptable, only papers that had been published in peer-reviewed journals were searched for. As the literature review was being conducted as part of a time-constrained research degree, it was decided to include only studies that had been published in English as translation would have been time consuming

and costly. The search was confined to research that had been published between 2000, when PCI became a routine procedure used for coronary revascularisation (Ludman, 2007) and 2010, when the literature review was conducted. If the evidence reviewed cited other studies that were considered seminal, these were also sourced and reviewed.

# 2.4 Approach to critical appraisal of the literature

It is essential when reviewing literature that the relevance and trustworthiness of the publication are considered. In order to have a consistent approach to the critique of the literature, the CASP (Critical Appraisal Skills Programme) (CASP UK, 2013) tools were used. CASP provide critical appraisal checklists for the majority of research methodologies, including randomised controlled trials, cohort studies and qualitative research. These checklists have been designed to appraise three main areas in research studies:

- 1. Is the study valid?
- 2. What are the results?
- 3. Are the results useful?

The CASP framework is considered as an appropriate tool to allow the systematic assessment of research evidence (Masood *et al.*, 2011; Spittlehouse, Acton and Enock, 2000). These tools were, however, found to be less sensitive in appraising some aspects of the validity of qualitative research (Hannes, Lockwood and Pearson, 2010). Only one qualitative study was found in the literature review and to ensure the appropriate data were extracted from the publication, it seemed necessary to ensure additional information regarding appraisal of the research validity was captured. As the study used a grounded theory approach, it was deemed appropriate to add in information regarding the methodological stages of the research, particularly in relation to the notion that the research should be conducted with as few predetermined ideas as possible and that the review of the literature should come after the data have been collected and open coding used to analyse it (Charmaz, 1990). The only amendment to the CASP tool for qualitative studies therefore, was that additional information regarding validity was added to it. The impact of adding

such information posed no risk to the framework of the tool but provided more detail to allow the researcher to appraise the research more comprehensively.

In addition to the criteria set out by CASP, it was deemed necessary to explore each publication more thoroughly and make value judgements about the authenticity of the source as suggested by Gray (2009). This involved giving consideration to four things: the authors, accuracy, bias and objectivity and, finally, the publication's intended audience.

Thought was given to the people who had written the publication (e.g. are they individuals who are known to have published in this field?). Literature from those who were relatively unknown in the subject area was not automatically discounted but where the reliability was questionable (e.g. no evidence of peer review), they were not included. Generally, if the literature had been published in peer-reviewed journals, the accuracy was good. Evaluation of bias and objectivity was evaluated through critique of the language used, whether the discussion seemed balanced, the references cited and whether ethical principles had been applied or not. All of the research evidence sourced had been published in peer-reviewed health or social care journals and so the intended audiences were acceptable.

## 2.4.1 Organisation of the literature review

There are various ways of arranging and discussing the literature reviewed (e.g. chronologically, methodologically) (Saint Mary's University, 2013), but the approach taken was to organise it thematically. It is essential that the evidence found is arranged into a conceptually organised synthesis of the results (Scutt, 2008). Phillips and Pugh (2005; Page 57) suggest that "*reasoned organisation and evaluation*" of literature is needed and the way to facilitate that is through the use of themes to discuss the review findings.

To guide the search strategy and the discussion of the literature found in this integrative review, the components of CHD self-management and the theories used to help explain CHD self-management outlined in chapter 1 were used. It was apparent that few studies explored all aspects of CHD self-management. What literature was found could be divided into three main topic areas and

these topics aligned with what patients would be expected to do after elective PCI to manage their condition. The first three themes, therefore, focussed on patients' monitoring and management of angina symptoms, the lifestyle factors and what influenced patients' adoption of behaviours that lessened their risk of CHD progression and finally, their adherence to a pharmacological treatment regime. Literature relevant to the Self-Regulation Model and CHD self-management will be covered within the fourth theme and finally, the integrative review of literature for the Social Cognitive Theory and CHD self-management will be discussed.

The themes covered within this literature review have been titled themes A to E:

- Theme A: Patients' monitoring and management of angina symptoms
- Theme B: Patients' adoption and maintenance of a healthy lifestyle
- Theme C: Patients' adherence to a treatment regime
- Theme D: Self-Regulation Model and CHD self-management
- Theme E: Social Cognitive Theory and CHD self-management

# 2.5

## **Review of the literature**

In the remainder of the chapter themes A to E will be addressed in turn. The studies included in each theme will be described and then an integrative critique will be given in relation to the methodological and theoretical quality of the studies. The findings will be outlined and each theme will finish with the conclusions that can be drawn from the published literature and that will identify gaps in current knowledge. An overview of the literature sourced for each theme can be found in Table 2.1.

# 2.5.1 Theme A: Patients' monitoring and management of angina symptoms

Using the keywords outlined in Appendix 1 for theme A, 1049 citations were found, of which 1036 were excluded. Many publications were excluded as they reported research of topics not relevant to the study. For example, intervention studies considering topics such as the efficacy of different types of stent and the effect of different treatments on patients' coronary pathology. Of the 13 citations found that met the inclusion / exclusion criteria, eight were duplicates

(due to multiple database searching) and one paper was of an abstract only, which was subsequently reported later in another research article. Four papers were therefore included within the integrative review for theme A – patients' monitoring and management of angina symptoms.

Theme	Number of	Methodologies	Location of study
	citations	used	
	included		
Theme A: Patients'	4	Qualitative: 0	North America: 2
monitoring and		Quantitative: 4	Australia: 2
management of angina		Mixed method: 0	
symptoms			
Theme B: Patients'	11	Qualitative: 1	North America: 4
adoption and		Quantitative: 10	Australia: 3
maintenance of a			
		Mixed method: 0	United Kingdom: 1
healthy lifestyle			Iceland: 1
			Netherlands: 1
			Bosnia and Herzegovina: 1
Theme C: Patients'	2	Qualitative: 0	North America: 1
adherence to a		Quantitative: 2	Australia: 1
treatment regime		Mixed method: 0	
Theme D: Self-	2	Qualitative: 0	Ireland: 1
Regulation Model and		Quantitative: 2	Australia: 1
CHD self-management		Mixed method: 0	
Theme E: Social	2	Qualitative: 0	North America: 2
Cognitive Theory and	-	Quantitative: 2	
CHD self-management		Mixed method: 0	
one sen-management		wined method. U	

# Table 2.1Overview of literature included in integrative review

## Description of the studies

All four studies within theme A (see Table 2.2 for an overview of these) explored the incidence of angina symptoms after PCI and how the patients subsequently managed these symptoms. Gallagher *et al.* (2008a) and Langley (2003) also examined the characteristics of the patients' symptoms and Nones Cronin *et al.* (2000) went on to investigate the information needs of the patients. None of these studies distinguished between symptoms of short duration and those that lasted for a longer time.

Lauck, Johnson and Ratner (2009) (abstract from Lauck and Johnson, 2007) conducted a descriptive, correlational study to examine self-management behaviour in patients soon after PCI, including the incidence of angina symptoms and how these were managed. They also sought to determine if any

factors were associated with cardiac self-efficacy and self-care agency. (Selfcare agency is defined by Gonzalo (2011) as a person's capacity to care for him / herself). A convenience sample of patients (n=98) who had undergone elective PCI at a large teaching hospital in Canada participated in the study and data were collected by means of a telephone survey administered between 2 and 5 days after PCI. The survey tool consisted of some items that had been tested for reliability and validity (CAD-specific Co-morbidity Index, STOP-Distress psychological screening tool). Additionally, the patients' self-efficacy related to their CHD was explored using questions modelled on the Cardiac Self-Efficacy Questionnaire, the Jenkin's Self-Efficacy Expectation Scale and other published work on self-efficacy but this did not appear to be tested for reliability or validity prior to use. Self-care agency was investigated using a learning needs inventory for PCI patients that was used nationally in Canada. No information was given as to whether the items related to that had been tested for validity / reliability. Data were examined using descriptive, bivariate and multivariate statistical tests.

Gallagher *et al.* (2008a) report that their study used a prospective, descriptive design to gather data from a convenience sample of 129 PCI patients. All of the participants had undergone PCI in the previous month and data were collected, using a survey, at two time points: 4 and 10 weeks post-PCI. The survey was administered either by telephone or face-to-face when the patients attended cardiac rehabilitation. The survey consisted of the McGill Pain Questionnaire and a "post-stent chest symptom questionnaire" (Gallagher *et al.*, 2008a; page 74) that had been specifically developed for the study. The survey tool used to investigate chest symptoms was tested for face validity by an expert panel of CHD specialists. Following pilot testing, modifications were made to the tool prior to use in the main study. Study data were analysed using univariate statistical tests as well as chi-square and t-tests.

The third study to be included was that from Langley (2003). This pilot study used a cross sectional design and over a seven month period, 19 participants were recruited. In the convenience sample, 17 patients had suffered a myocardial infarction and had primary PCI to lessen the damage to the heart. The other two patients had elective PCI to control their angina symptoms. Data

were again collected using a survey, this time self-administered. Data were collected when the participants attended a cardiac rehabilitation class. Langley gives the list of questions used in the survey but does not provide any information regarding what informed the questions and if they had been taken / informed by other survey tools. It appeared that the survey tool had not been tested for reliability / validity. Descriptive statistics were used for data analysis.

Nones Cronin *et al.* (2000) conducted a cross-sectional study to ascertain the incidence of chest pain and patients' management of it following PCI. Only patients who had undergone PCI for the first time were included. A stratified random approach to sampling was used to select 35 participants from a group of 105 patients and subsequently divide the sample into three groups of equal size where each had a different time lapse from PCI: one (n=11), three (n=17) and six months (n=16) following the procedure. Contact was made by telephone to recruit patients to the study and face-to-face structured interviews were used to collect data. Questions taken from national databases in the United State of America were used to gather data on the incidence of angina symptoms. There was scant information given regarding the survey tool, including if it had been tested for reliability and validity. Descriptive statistics and Chi-square tests were used to analyse the data.

### Methodological quality of the studies

All four studies included within theme A were non-experimental, cross-sectional studies and one (Langley, 2003) was conducted as a pilot study. Resultantly, the methodological quality of these studies was low if compared with the hierarchy of clinical evidence and study design (McKeon, Medina and Hertel, 2006) albeit, the methodologies used appeared to match each study's aims.

There seemed to be a risk of procedural bias in Langley's study as no indication was given that ethical approval had been obtained to conduct the study and that patients were recruited without coercion (National Patient Safety Agency, 2013; Pannucci and Wilkins, 2010; Dickert, 2006).

# Table 2.2Overview of theme A literature

Citation included	Methodology / study design	Location of study	Study aim(s)	Sample	Method of data collection
Gallagher <i>et al</i> . (2008a)	Quantitative / prospective descriptive design	Australia	To describe the pattern and characteristics of "chest symptoms" in patients attending cardiac rehabilitation. (Gallagher <i>et al.</i> , 2008a; page 73)	Convenience sample (n=129) of PCI patients	Self-administered survey collected data at two time points: 4 and 10 weeks post-PCI.
Langley (2003)	Quantitative / pilot study	Australia	To explore the incidence, characteristics and psychological effects of recurring pain after PCI.	Convenience sample of n=19. 2 of the 19 had undergone elective PCI	Self-administered survey
Lauck, Johnson and Ratner (2009)	Quantitative / Cross- sectional correlational study	North America	To describe patients' self- management behaviour 2 - 5 days after PCI and factors associated with cardiac self-efficacy and self- care agency.	Convenience sample (n=98) of PCI patients	Telephone survey
Nones Cronin <i>et al.</i> (2000)	Quantitative / cross-sectional study	North America	To ascertain the incidence of chest pain and patients' management of it after PCI. To ascertain the information needs of patients and the modifications they may make to their lifestyle after PCI.	n-105 PCI patients. Stratified random sampling approach used to divide group into 3 sub-groups where each had a different lapse time from PCI: 1 month (n=11) 3 months (n=17) 6 months (n=16)	Telephone survey

Langley's sample comprised very few patients who had undergone PCI for angina management (2 of the 19). The other patients had PCI, but to treat acute myocardial infarction and so as indicated earlier in Chapter 1, the purpose of the PCI differed from that used to treat stable angina symptoms. Consequently, it is difficult to generalise the findings to a wider PCI patient population, as the strength of the evidence for elective PCI patients was poor.

Only Nones Cronin *et al.* reduced the risk of sampling error by using stratified random sampling to allow comparisons to be made within patient groups (Shuttleworth, 2009). The strata, however, had relatively small numbers of participants that limited the ability to detect associations between the groups (Fox, Hunn and Mathers, 2009). The other studies used convenience samples and that non-probability approach to sampling limits the generalisability of the results (Price, 2013; Bryman, 2004). How the sample size for each study was determined was not apparent and so it was difficult to know if the studies had adequate power to detect any statistical significance and relationships between the variables (Suresh and Chandrashekara, 2012). Not using a power calculation to determine sample size limits the ability to draw inferences about the patient population (Kadam and Bhalerao, 2010).

All of the studies identified in this theme (Lauck, Johnson and Ratner, 2009; Gallagher *et al.*, 2008a; Langley, 2003; Nones Cronin *et al.*, 2000) used a survey to collect data and that poses a risk of response bias / social desirability bias (Peer and Gamliel, 2011; Bowling, 2005). Langley (2003) and Nones Cronin *et al.* (2000) gave no information regarding the reliability and validity of the survey tools in their studies. Alternatively, Gallagher *et al.* (2008a) used a pre-validated tool in their survey and new questions that they had developed were tested for face validity by an expert panel. Lauck, Johnson and Ratner (2009) used some pre-validated questionnaires and cited as a limitation, that non-validated items were also included in their survey.

Conducting a pilot study to test survey tools is known to enhance reliability and validity (Radhakrishna, 2007; Teijlingen and Hundley, 2001) and yet only Gallagher *et al.* (2008a) did this (Langley's study was a pilot study but there is no evidence that this led to a larger study).

During the telephone surveys in the study by Nones Cronin *et al.* (2000) researchers had to judge if participants' pain was cardiac in nature but the conclusions drawn were subjective and so posed a risk of inconsistency (Randall and Fernandes, 1991). Gallagher *et al.*'s (2008a) method of administering the survey was inconsistent and that may have caused procedural bias (Shuttleworth, 2009).

The tests used for data analysis in all of the studies in this theme seemed appropriate (Hole, 2009; Diener-West, 2008). The way some findings were presented by Langley was misleading with some reporting bias (McGauran *et al.*, 2010). For example, Langley concludes that chest pain was alarming for patients' relatives and healthcare professionals yet did not collect any data from these people. Also, she reports that participants' chest pain had resolved prior to their first consultation with a cardiologist after the PCI but some people reported experiencing symptoms when the data was collected and so it does not appear that the study data could be used to confirm that notion.

Lauck, Johnson and Ratner (2009) used multiple regression analysis to explore how certain variables related to the participants' self-management and the regression model seemed to be a 'good fit' (Foster, Barkus and Yavorsky, 2006). Multiple regression analysis would not, however, determine if there were any relationships between independent variables. The extent of the findings from that study may consequently be limited by the multivariate statistical test used (Foster, Barkus and Yavorsky, 2006).

### Theoretical underpinning of the studies

Mention is made in the study from Lauck, Johnson and Ratner (2009) that Bandura's self-efficacy theory would help to explain participants' ability and confidence to self-care. The details of why this theory was chosen are scant however. After the researchers set out their intention to use this theory, no mention was made of how it helped to explain participants' behaviour in relation to angina symptom monitoring / management.

It was not obvious in any of the other studies that theory was used to underpin the research or that it was used to help explain findings. Gilbert (2008) states that theories are essential in 'shaping' the way research is conducted and yet, none of these studies used a theoretical framework. This could have compromised what was investigated and the method used.

#### What is known from the findings

The publication from Lauck, Johnson and Ratner (2009) was the only one to comment on patients' monitoring of angina symptoms. In their sample, 31% (n=129) said that they were unsure of what symptoms to expect.

All four studies found that patients regularly experience angina symptoms after PCI. The incidence of recurring angina symptoms in two studies (Gallagher *et al.*, 2008a and Langley, 2003) was found to be 68% and 75% respectively. Nones Cronin *et al.* (2000) had a much smaller incidence (42%), with the largest proportion of patients experiencing pain in the 3 months post-PCI group. Despite Lauck, Johnson and Ratner (2009) collecting data within five days of PCI, around a third of the sample had experienced angina symptoms.

Gallagher *et al.* (2008a) found that age was an influencing factor as younger participants were more likely to experience pain compared to the older people in the sample. In Langley's study, the characteristics of the pain described by participants was disparate and so it was difficult to see how the researchers could make generalisations about the angina symptoms from such a small sample (Jensen, 2011). Participants in Gallagher *et al.*'s study attributed recurring pain to the PCI procedure itself but what aspect of that was not explained, perhaps due to the single method of data collection.

Participants in each study seemed unsure of how to manage their angina symptoms and methods of dealing with them were diverse. A proportion of patients would seek help from healthcare professionals (>50% in Langley's study, >30% in Nones Cronin *et al.*'s study and 4% in Gallagher *et al.*'s study). Nones Cronin *et al.* found that a third of patients took no action at all for recurring angina symptoms but in Lauck, Johnson and Ratner's study, most (80%) did nothing to manage them and the reason for that was unclear. Half the sample in Langley's study indicated that they limited their activity and that was attributed that to fear, negative thoughts and lethargy but that was not

substantiated with evidence so suggests some reporting bias (The Cochrane Collaboration, 2013).

None of the studies included in theme A distinguish between patients' management of angina symptoms of short duration and those that last longer. It is known from clinical guidelines that patients should initially rest and use their nitrate spray and then if the symptoms continue for 10 - 15 minutes, an emergency ambulance should be called (NICE, 2011). This therefore, seems to indicate a gap in the current literature.

### Conclusions from theme A

Four studies were included in theme A and, despite a variation in quality, all seemed to explore the incidence of angina symptoms and how these would be managed by PCI patients.

None of the studies indicated how many participants should be recruited to the samples and so it was difficult to determine if they had adequate power to detect any statistical significance and relationships between the variables (Suresh and Chandrashekara, 2012). This particularly affected the studies from Gallagher *et al.* (2008a), Lauck, Johnson and Ratner (2009), and Nones Cronin *et al.* (2000), where data were subject to bivariate statistical analysis. Consequently, the ability to interpret the findings with confidence is compromised as they may give an over or under estimation of the incidence of angina symptoms in patients after PCI and provide unrealistic assumptions about how these patients manage their angina symptoms or the factors than can affect that management (Suresh and Chandrashekara, 2012).

There was a heavy dependence on the use of surveys to collect data from participants. The single approach to data collection limited the depth of understanding of the findings. The reason that patients chose to manage their angina symptoms the way they did is, therefore, not known due to limitations of the study designs and method of data collection. Multiple data sources would have strengthened the understanding of how and why patients managed their angina symptoms the way they did (Curry, Nembhard and Bradley, 2009) and each study would have benefited from more exploration through a qualitative

element to the study (Plano Clark and Creswell, 2008). Studies that have one method of data collection, particularly when behaviour is self-reported are at risk of response bias, are less objective and provide sub-optimal explanations of findings than studies that have used multiple sources of data collection (Inter-University Consortium for Political and Social Research, 2013; Van de Mortel, 2008; Adams *et al.*, 2005).

The studies found that patients commonly experience chest pain or angina symptoms after PCI and the management of these is suboptimal. PCI patients would often seek help from healthcare professionals to help them deal with their pain and that did not always seem to be the most appropriate management. While all studies considered patients' experience of pain and its management post PCI, there did not seem to be any differentiation of pain that was short-lived and that which lasted for a longer period of time. Patients are normally educated that pain should be appraised and certain initial action should be taken (i.e. rest and take GTN spray) but the management of any pain lasting for a longer period of time (>15 minutes) should be escalated to emergency healthcare professionals to deal with due to the potential for serious cardiac complications (SIGN, 2007). None of these studies appeared to consider that which created an impression that the management of angina symptoms was not explored comprehensively.

Previous research by Nease *et al.* (1995) found from their sample (n=220) that patients with stable angina had a variation in their response to angina symptoms of different severity and this is echoed in a cross-sectional study by Ronnevig *et al.* (2003) (n=192) that explored the incidence of angina symptoms in patients immediately after PCI (i.e. in the few hours after PCI while the patients were in hospital). Both studies found that patients responded differently when they perceived symptoms to be less intense. None of the studies reviewed in theme A seemed to consider this and that seems to be a gap in the literature that requires investigation in a PCI patient population that self-manages angina symptoms.

Reports from the study by Steingart *et al.* (1991) (n=2231) indicated that female patients were less likely to use nitrate medicines to relieve angina symptoms

but they considered their symptoms to have a greater effect on their functional ability than males. While the sample in this study was patients after myocardial infarction, it gives an impression that the sex of the patient can influence how they manage angina symptoms. This was not explored in any of the studies included in theme A. They may be other demographic factors that can affect the efficacy of angina management and these should be explored to provide a comprehensive picture of this subject area.

None of the studies used a theoretical framework to underpin the research so it is not possible to determine if a certain theory can help to explain the findings. Lauck, Johnson and Ratner (2009) suggested that Bandura's self-efficacy theory would help to explain their participants' ability and confidence to selfcare. The details of why this theory was used however, are scant. Consequently, it is not known which theory would be most appropriate to help explain patients' self-management of angina symptoms after PCI and so this is worthy of exploration to better understand the phenomenon.

### 2.5.2 Theme B: Patients' adoption and maintenance of a healthy lifestyle

Using the keywords outlined in Appendix 1 for theme B, 320 citations were found. Of those, 37 publications met the inclusion / exclusion criteria but, 25 were found to be duplicates due to multiple database searching and two were not available so ten papers were included. Additionally, from the literature review, other researchers often cited a particular study (Gaw-Ens and Laing, 1994), and so, despite it being out-with the date limitations of the integrative review, it was included. This gave a total of 11 research publications that were reviewed within theme B - Patients' adoption and maintenance of a healthy lifestyle. An overview of the theme B studies can be found in Table 2.3.

### Description of the studies

The studies included in theme B can be divided into two main categories:

Studies that explored changes patients made to their lifestyle after PCI (Astin and Jones, 2006b; Campbell and Torrance, 2005; Fernandez *et al.*, 2006; Gaw-Ens and Laing, 1994; Lauck, Johnson and Ratner, 2009; Peterson *et al.*, 2010; Vulic *et al.*, 2010).

Table 2.3
<b>Overview of theme B literature</b>

Citation included	Methodology / study design	Location of study	Study aim(s)	Sample	Method of data collection
Aldana e <i>t al.</i> (2003)	Quantitative / case control study	North America	To compare changes in CHD risk factors over a six-month period (2 x intervention groups and control group).	Convenience sample (n=141) of myocardial infarction, CABG surgery and PCI patients	? Face-to-face interviews.
Astin and Jones (2006b)	Quantitative / cohort study	Australia	To evaluate changes in patients' lifestyle factors after PCI.	Convenience sample (n=140) of PCI patients	Self- administered survey
Campbell and Torrance (2005)	Quantitative / cross sectional study	Australia	To explore patients' understanding of CHD and their modification of risk factors.	Convenience sample (n=560) of PCI patients	Postal survey
Fernandez <i>et</i> <i>al.</i> (2006)	Quantitative / cross sectional study	Australia	To examine the management of CHD risk factors.	Convenience sample (n=270) of myocardial infarction patients who had primary PCI and elective PCI patients	Self- administered survey
Gaw-Ens and Laing (1994)	Quantitative / cross sectional study	North America	To explore patients' knowledge of CHD risk factors and their motivation to modify behaviour.	Convenience sample (n=301) of PCI patients	Postal survey
Lauck, Johnson and Ratner (2009)	Quantitative / Cross-sectional study	North America	To describe patients' self-management behaviour 2 - 5 days after PCI and factors associated with cardiac self- efficacy and self-care agency.	Convenience sample (n=98) of PCI patients	Telephone survey

Citation included	Methodology / study design	Location of study	Study aim(s)	Sample	Method of data collection
Mainie <i>et al.</i> (2005)	Quantitative / cohort study	United Kingdom	To examine patients' CHD risk factors and investigate the effectiveness of a nurse-led secondary prevention of CHD programme.	Convenience sample (n=563) of myocardial infarction, CABG surgery and PCI patients	Face-to-face interviews
Peterson <i>et al.</i> (2010)	Qualitative / grounded theory	North America	To explore the attitudes, values and beliefs of patients who had been successful or not successful at lifestyle change 3 years after PCI.	Purposive sample (n=61) of PCI patients	Semi-structured interviews
Scholte op Reimer <i>et al.</i> (2002)	Quantitative / cross sectional study	Netherlands	To investigate if clinical guidelines on CHD risk factor management are adhered to and to explore the contribution of nurses to patients' CHD risk factor management.	Convenience sample (n=357) of myocardial infarction, CABG surgery and PCI patients	Structured interview
Sigurdsson, Jonsson and Thorgeirsson (2002)	Quantitative / cross sectional study	Iceland	To evaluate the implementation of secondary prevention and treatment of CHD in general practice.	Convenience sample (n=402) of myocardial infarction, CABG surgery and PCI patients	Survey ? method of administration
Vulic <i>et al.</i> (2010)	Quantitative / cross sectional study	Bosnia and Herzegovina	To explore the risk factor control / goal attainments in CHD patients. To explore adherence to secondary prevention treatments.	Convenience sample (n=601) of myocardial infarction, CABG surgery and PCI patients	Face-to-face interviews

 Studies that investigated the influence healthcare support had on patients' CHD risk factors (Aldana *et al.*, 2003; Mainie *et al.*, 2005; Scholte op Reimer *et al.*, 2002; Sigurdsson, Jonsson and Thorgeirsson, 2002).

Aldana *et al.* (2003) used a case control study to compare changes in CHD risk over a six-month period in those participating in one of three groups. The groups were: the Ornish heart disease reversing programme, traditional cardiac rehabilitation and a control group. A convenience sample (n=141) of patients who had undergone either PCI or CABG surgery after myocardial infarction was recruited and each person self-selected the group they wanted to join. The groups were not comparable however, as the patients' medical insurance would cover the cost of cardiac rehabilitation but the cost of participating in the Ornish programme would not be. Also, the control group consisted of those who did not want to participate in either of the other two groups and so this reduced the reliability of the 'no intervention' control group.

The Ornish group had the fewest participants (n=28) while the cardiac rehabilitation and control group had 58 and 55 participants respectively. Data were collected at three time points: baseline, 3 and 6 months and participants were incentivized to participate through the use of monetary gifts when data were collected. The method of data collection was not apparent from the publication but it appeared to be face-to-face interviews and from patient diaries. Data were gathered in relation to the participants' CHD risk factors. For example patients' cholesterol, body mass index and blood pressure were measured and recorded. Using a survey tool that had been tested for reliability and validity, information was gathered about the physical activity participants engaged in during the week prior to data collection. The data were analysed using linear growth curves.

The second study included in theme B was that from Astin and Jones (2006b). Using a cohort study design, they evaluated changes in elective PCI patients' lifestyle factors. Participants in the convenience sample (n=140) completed a self-administered survey at two timepoints: before the PCI and between 6 and 8 months post-procedure. A response rate of 84% was realised. The survey tool contained items from the National Heart Foundation of Australia but little detail is given about these, including whether it had been tested for reliability / validity or not. Paired t-tests were used to analyse the data. Scale and ordinal data were analysed using the non-parametric equivalent Wilcoxon Signs Ranks test.

Campbell and Torrance (2005) explored patients' modification of CHD risk factors after elective PCI. They used a cross-sectional, non-experimental study design to investigate the understanding patients had of their CHD. A postal survey was administered to the convenience sample (n=560) between 3 and 9 months after the PCI procedure and this achieved a response rate of 41.7%. An indication was given that the content of the survey tool was based on the Health Belief Model and contained questions related to patients' demographics as well as their nutrition, exercise, stress, health promoting behaviours and relationships in what was termed the 'Health Promoting Lifestyle Profile II'. It was indicated that the survey tool had undergone testing for reliability / validity. Data were entered into SPSS and descriptive statistical analysis was used for the demographic data. The Health Promoting Lifestyle Profile allowed a score for the participants' overall health-promoting lifestyle to be calculated using the means of the sub-scale scores.

In 2006 Fernandez *et al.* published the findings from their study that examined the risk factors patients had after PCI. The convenience sample consisted of 270 patients who had a PCI either as an emergency to treat a myocardial infarction or as an elective procedure to alleviate angina symptoms. Fernandez *et al.* used a cross-sectional study design and collected data a year after the participants had undergone PCI by means of a self-administered questionnaire. The survey contained non-validated items related to the participants' demographic details, past medical history and CHD risk factors (smoking status, physical exercise frequency, body mass index, cholesterol and blood pressure). The survey also included the previously validated Depression, Anxiety and Stress Scale. The survey tool was piloted before use. Data was subject to univariate and bivarite tests (t-tests and chi-square).

When reviewing the literature for theme B it became apparent that many of the studies cited the research of Gaw-Ens and Laing (1994) and so this publication

was also included in the review of literature concerning patients' adoption and maintenance of a healthy lifestyle. The study by Gaw-Ens and Laing set out to address two main aims: to explore patients' knowledge of risk factors that contribute to CHD and to identify patients' motivation to alter their lifestyle. Using a cross-sectional, non-experimental study design, a convenience sample of 301 patients who had undergone elective PCI was recruited to the study. A survey was mailed to participants between 4 and 12 months after their PCI with a response rate of 70%. While Gaw-Ens and Laing mention in the publication the potential influence of motivation and self-efficacy on patients' likelihood of behaviour change, no theories related to these factors were used to underpin the research. The survey tool was a modified version of the Prediction of Habits or Lifestyle Modification Questionnaire. It is not clear from the publication whether the original tool had been tested for reliability and validity and no mention was made that it had been tested for use with PCI patients after its adaptation. The researchers gave no indication of how the data were analysed but they subsequently compared their findings with those from an earlier study that had used a patient group with a different manifestation of CHD (myocardial infarction). The study used for comparison differed considerably in methodology, method of collecting data and sample demographics.

The study described in theme A from Lauck, Johnson and Ratner was also included in theme B. Seemingly divergent from the study aim, an impression was created that the survey focused more on gathering information about the participants' knowledge of self-management rather than their actual behaviour. The examination of patients' CHD self-management 2 to 5 days after PCI included an investigation of participants' lifestyle factors. The study appeared to focus on participants' physical activity and little mention was made of other CHD risk factors. The study did, however, explore the participants' knowledge of which risk factors contributed to CHD and what alterations to lifestyle could be made to reduce the risk. Data analysis involved univariate, bivariate and multi-variate statistical tests.

Mainie *et al.* (2005) set out to explore patients' CHD risk factors status approximately six months after a 'cardiac event'. They also investigated how effective a nurse-led secondary prevention clinic was in encouraging patients to adopt healthier lifestyles. This cohort study (n=563) included patients who had suffered a myocardial infarction, had undergone CABG surgery or PCI. The number of PCI patients within the sample is not evident. Data were gathered from participants when they attended a secondary prevention clinic. Some patients attended the clinic only once whereas others had multiple visits. An assessment was made of participants' CHD risk factors either using objective measures or patient self-reports. No information was given regarding the tools used for data collection but data were analysed using descriptive statistics only.

The study from Peterson *et al.* (2010) was the only study to use a qualitative methodology (n=61). The aim of their grounded theory study was to explore the attitudes, values and beliefs of patients who had been successful or not successful at lifestyle change around 3 years after PCI. The study was a substudy of a randomised controlled trial (RCT), the Healthy Behaviour Trial. Patients who had PCI performed either as an emergency or elective procedure were included in the study. Purposive sampling was used to select equal numbers of participants from the original RCT sample who had been successful and not successful in adoption of healthier behaviours. The data used to inform the sampling could have been collected more than a year before they were used and so the accuracy of behaviour change may have been questionable. The Transtheoretical Model was used to inform the sampling process in that participants were considered to be successful in behaviour change if they were in either the action or maintenance phases of the model. Semi-structured interviews around three years after the patients' PCI were used to collect data. Using grounded theory methods, an iterative approach was used to refine the interview questions. Audio-recorded interviews were transcribed and analysed using the software package, Ethnograph. The process of data analysis and theory development continued until data saturation had been achieved.

Scholte op Reimer *et al.* (2002) also conducted research as a sub-study of a larger study, the EUROASPIRE II survey. Using a cross-sectional, non-experimental study design, they aimed to ascertain if European clinical guidelines related to reducing CHD risk in patients through lifestyle change had been adhered to. The study also sought to explore the contribution of nurses to patients' CHD risk factors management. Myocardial infarction, CABG surgery

and patients after elective or emergency PCI were recruited to the convenience sample (n=357). A survey containing seemingly non-validated items related to the provision of health promotion advice from healthcare professionals was administered to participants during face-to-face interviews approximately six months after the 'cardiac event'. The majority of the lifestyle factors were self-reported by the participants and this data was supplemented with a few objective measures (for example carbon monoxide testing for smoking status assessment). Descriptive statistics were used to analyse the data.

In 2002 Sigurdsson, Jonsson and Thorgeirsson published findings from their cross-sectional study that evaluated the implementation of secondary prevention and treatment of CHD in general practice in Iceland. Of the 553 patients with CHD who were eligible to participate in the study, 402 (75%) gave consent to take part. PCI patients accounted for 14% of the convenience sample that also included patients after myocardial infarction, CABG surgery and those with angina symptoms who had not undergone revascularisation. Data was collected from patients' medical notes and they were also invited to complete a questionnaire. Information regarding the content of the survey, how it was administered and whether it was tested for reliability / validity was scant in the publication. The main outcome measures for the research were patients' blood pressure, body mass index, smoking status and serum cholesterol level. Chi-square and analysis of variance statistical tests were used to analyse the data.

The final study included in theme B was that of Vulic *et al.* (2010). The aims of their study were to explore the risk factor control / goal attainments in patients with CHD and to explore the patients' adherence to secondary prevention treatments. Again, using a cross-sectional study design, a convenience sample of 601 patients after myocardial infarction, CABG surgery and PCI was recruited. In this study the PCI patients were proportionately 8% of the total sample size. General practitioners interviewed and examined participants between 6 and 12 months after their 'cardiac event'. Vulic et al. stated that not every participant had undergone risk factors measurement but it was unclear how many people this affected and whether this could have skewed the results or not. Only one behavioural risk factor (smoking) was mentioned in the

publication. The statistical test chosen to analyse data for this study was the chi-square test.

### Methodological quality of the studies

The majority of studies in this theme were non-experimental, cross-sectional studies (Vulic *et al.*, 2010; Lauck, Johnson and Ratner, 2009; Fernandez *et al.*, 2006; Campbell and Torrance, 2005; Scholte op Reimer *et al.*, 2002; Sigurdsson, Jonsson and Thorgeirsson, 2002; Gaw-Ens and Laing, 1994). The others were: a grounded theory study (Peterson *et al.*, 2010), a case control study (Aldana *et al.*, 2003), and two cohort studies (Astin and Jones, 2006b; Mainie *et al.*, 2005). Again, making reference to the hierarchy of study types, the methodological quality of most of this research is low with the exception of the case control and cohort studies (SIGN, 2011).

Ethical approval for research is essential to safeguard patients (National Patient Safety Agency, 2013) but Vulic *et al.* (2010), and Mainie *et al.* (2005) omitted to mention that they had obtained that in their publications. Gaw-Ens and Laing (1994) seemed to have permission to collect some but not all data. This suggests a risk of procedural bias (Pannucci and Wilkins, 2010), which may have compromised the research.

The majority of the studies used samples of patients of mixed CHD manifestations. Only Peterson *et al.* (2010), Astin and Jones (2006b), Campbell and Torrance (2005) recruited solely PCI patients who had the procedure for angina symptom management. The proportion of PCI patients in some studies was relatively small (8 – 27%) or not evident which limits the ability to generalise the results to the wider PCI patient population. All but one study (Peterson *et al.*, 2010) used a convenience sample and this non-probability approach to sampling also limits the generalisability of the results (Price, 2013).

None of the studies using quantitative methodology gave an indication of how large a sample size they aimed for, even the case control study from Aldana *et al.* (2003), and instead often selected their sample using date constraints (i.e. recruit patients over a year). Calculating the sample size required to detect statistical significance in studies is deemed crucial at the point the research is

being designed as too small a sample could produce results that are statistically inconclusive (Suresh and Chandrashekara, 2012).

There appeared to be some design and sampling bias in Aldana *et al.*'s study (Shuttleworth, 2009), as one intervention would incur additional expense for participants. This clearly had a discriminatory effect. The reliability of the 'no intervention' control group was also questionable. Control groups should contain participants who resemble those in the intervention groups (Cherry, 2014b), not unwilling participants as this could skew the results.

Aldana *et al.* (2003) were the only researchers to incentivise participants to take part in their study. While Grant and Sugarman (2004; Page 717) think that the use of incentives is *'innocuous'* and can improve participation rates (Shaw *et al.*, 2001), Singer (no date) indicates that they can change the composition of a sample, which could lead to bias.

The method of data collection that predominated in all studies included in Theme B was a survey, mostly self-administered (Astin and Jones, 2006b; Fernandez *et al., 2006*; Campbell and Torrance, 2005; Sigurdsson, Jonsson and Thorgeirsson, 2002; Gaw-Ens and Laing, 1994). Of these researchers however, only Fernandez *et al.* and Campbell and Torrance ensured their survey tools were tested for reliability and validity. Testing the reliability and validity of a survey tool helps to ensure the tool accurately measures what was intended in a consistent way (Mora, 2011).

Scholte op Reimer *et al.* (2002) administered their survey at face-to-face patient interviews and this allowed them the opportunity to validate participants' self-reported responses by conducting some additional objective tests, for example carbon monoxide monitoring to detect recent smoking (Bedfont Scientific, 2010), which minimised the effects of response bias. Vulic *et al.* (2010) also undertook patient interviews to survey their participants but the consistency with which the data were collected seemed problematic. Information regarding how Aldana *et al.* (2003) collected their data was unclear. In most of the studies there was a risk of social desirability bias in the patients' responses (Peer and Gamliel, 2011) and that was exacerbated through a single approach to data collection.

Most data was gathered within the first year after patients had undergone PCI. The time lapse in the study by Campbell and Torrance (2005) was less obvious though. Peterson *et al.* (2010) collected data three years after the participants' PCI and as a result, the opinion participants had of their condition may have been affected by the passage of time (Bijsterbosch *et al.*, 2009; Astin and Jones, 2006a) and that could have skewed the findings. In the study from Lauck, Johnson and Ratner (2009) the time span between PCI and data collection (2 - 5 days) seemed too short to gauge the efficacy of patients' CHD self-management, particularly the adoption of more healthy behaviours.

In Mainie *et al.*'s (2005) cohort study there seemed to be some variability in the intervention given to participants, which suggests some design / procedural bias (Pannucci and Wilkins, 2010).

In relation to data analysis, Campbell and Torrance (2005) used descriptive statistics and while that seemed reasonable, it provided no more than a simplistic description of the data (Trochim, 2006). Other studies that used descriptive statistics to analyse data would have benefitted from the use of more advanced types of statistical testing to detect comparison between data sets (Mainie *et al.*, 2005) and the influence of independent variables (Scholte op Reimer *et al.*, 2002) (Hole, 2009; Bewick, Cheek and Ball, 2003). Non-parametric tests seemed to be used appropriately when the sample was not evenly distributed in Astin and Jones' study (Boston University School of Public Health, 2013b). Aldana *et al.* (2003) analysed data with linear growth curves and that seemed reasonable considering how these have been used in other studies (Hassen *et al.*, 2004). Unfortunately, Gaw-Ens and Laing (1994) failed to provide any information regarding how their data were analysed and so it is impossible to critique the methods used. It also limits the reproducibility of their studies (Bryman 2004).

### Theoretical underpinning of the studies

The majority of the studies included in the review for Theme C made no mention of any theory that was used to underpin the research or help to explain the findings. Three studies (Peterson *et al.,* 2010, Lauck, Johnson and Ratner,

2009 and Campbell and Torrance, 2005) made reference to theories that influenced aspects of their research.

In the study from Peterson *et al.* (2010), the Transtheoretical Model was used to inform the sampling process but the model was not used thereafter. The model (also known as the Stages of Change Model) infers that people go through a number of stages before they adopt more healthy behaviours (Prochaska and DiClemente, 1983). The purpose for which Peterson *et al.* (2010) used it was appropriate.

As indicated in Theme A Lauck, Johnson and Ratner (2009) stated that Bandura's self-efficacy theory would be used to help to explain participants' ability and confidence to self-care but no mention was made of how it helped to explain participants' adoption of healthier lifestyles. In Gaw-Ens and Laing's study (1994) there was an inference that the Self-Efficacy Theory was considered when the influence of motivation and self-efficacy on behaviour change was discussed but the researchers failed to mention any theories related to these factors.

Campbell and Torrance (2005) based their survey on the Health Promotion Model. This model, developed in the 1980s, was designed to help nurses understand what influenced health behaviours so that they could encourage patients to adopt healthier lifestyles (Pender, no date). Campbell and Torrance provide much discussion related to the survey tool but no further mention was made of the model in the findings or discussion sections of their publication.

Both the Health Promotion Model and the Transtheoretical Model are specific to the adoption of more healthy behaviours and would only help to inform one component of CHD management (i.e. adoption of healthy behaviours after PCI). Self-efficacy could potentially be applied to all components of CHD selfmanagement but the studies reviewed in Theme B provide no evidence that these theories have been used to underpin research concerning elective PCI patients' adoption of healthier behaviours.

### What is known from the findings

Overall, the adoption rates of a healthy lifestyle after PCI seemed poor. Several studies reported that many participants' risk of CHD progression remained high as a result of inactivity and obesity (Lauck, Johnson and Ratner, 2009; Fernandez et al., 2006; Astin and Jones, 2006b; Sigurdsson et al., 2002; Scholte op Reimer et al., 2002). Astin and Jones (2006b) discovered that patients made no changes to smoking or body mass index (BMI) after PCI. Fernandez et al. (2006) reported a relatively low smoking rate (11%) whereas almost a third of Scholte op Reimer et al.'s sample continued to smoke (Scholte op Reimer et al., 2002). Gaw-Ens and Laing (1994) found that two-thirds of participants made changes to their diet and they surmised that participants found it easier to make dietary alterations than change other modifiable risk factors but there was no evidence to substantiate that. Participants in Campbell and Torrance's study (2005) thought that social support was important for lifestyle change but no statistical tests were performed that would detect correlations between the variables and so there was some reporting bias (The Cochrane Collaboration, 2013; McGauran et al., 2010).

Mainie *et al.* (2005) reported that their nurse-led secondary prevention intervention improved participants' exercise frequency, BMI and smoking rates whereas nurses were found to give the least amount of advice support in Scholte op Reimer *et al.'s* study (2002).

Aldana *et al.* (2003) concluded that the participants in the Ornish programme 'arm' of their study had improvements in their coronary risk factors (though not statistically significant) when compared with those in the other two study arms. It was noted however, that those in the Ornish group had lower mean risk factor scores at baseline, which could have skewed the results. The number of participants in that arm of the study was relatively small and so it is difficult to generalise the results to the wider PCI patient population.

It was suggested by Gaw-Ens and Laing (1994) that participants were fearful of recurring angina symptoms and, consequently, restricted their activity. This assertion seemed to be opinion rather than evidence-based which suggests some degree of reporting bias. These researchers also seemed to have serious

flaws in the reporting of their findings since they compared their data with that of another study conducted years before but it was difficult to see how comparisons could be drawn.

Having used grounded theory methods to analyse data, Peterson *et al.* (2010) reported four themes emerging from their study. Participants who had been successful in behaviour change saw the PCI as a life-threatening event and were fearful of dying. Other 'successful' participants saw the PCI as an opportunity to make changes to their lifestyle and thought that social support was important. Unsuccessful participants were physically disabled and either had a perception that there was nothing they could do to improve their health or thought they were cured. Four other studies (Lauck, Johnson and Ratner, 2009; Fernandez *et al.*, 2006; Campbell and Torrance, 2005; Gaw-Ens and Laing, 1994) also found that some patients thought their disease had been cured after PCI.

Despite evidence that certain factors, including co-morbidities (Willett *et al.,* 2006), depression (Ziegelstein *et al.,* 2000), and social deprivation (Lawlor *et al.,* 2003) reduce patients' likelihood of changing behaviours, these factors do not seem to have been investigated in the studies reviewed in Theme B. This seems to be a gap in the literature that warrants further investigation.

### Conclusions from theme B

Considering the methodology of these studies, almost all were quantitative studies with some compromised by poor study design that did not address study aims. This has clear implications for the conclusions that can be drawn from these studies (Altman, 1994). Findings from quantitative data were often unexplained due to the limitations of using a single method.

Four of the studies did not mention that they had obtained ethical approval to conduct the research. This has implications for procedural bias and affects the ability to interpret the findings with the confidence that appropriate ethical principles were adhered to (BMJ Group, 2014).

Also, the majority of studies recruited patients with mixed manifestations of CHD. Where elective PCI patients were included, they were in the minority and so, again, it is difficult to accept the findings as a true representation of a PCI patient group. Also, findings from elective PCI participants in studies using samples of patients with mixed manifestations of CHD were not separated and so it was difficult to determine if the different patient groups differed in their adoption of more healthy behaviours.

Most of the studies used self-administered surveys as a single method of data collection and that raised concerns regarding the possibility of response bias / social desirability bias (Dillman, 1978). Few researchers tested the survey tools for reliability and validity or conducted a pilot study to ensure they appropriately and consistently measured what was intended (Fink and Kosecoff, 2006). The response rates of the survey were reasonable except in the study from Campbell and Torrance (Mangione, 1995).

It seemed that rates of adoption / maintenance of a healthy lifestyle after PCI were poor so the risk of CHD progression remained in many patients. Many studies found that participants had made lifestyle changes, mainly to diet, but what actually had been altered was not obvious in many cases. High BMI scores indicated that obesity seemed common but little detail was given of how these scores were generated (e.g. from self-reported height and weight values or objective measures).

The single method of data collection adopted in most of these studies limited the understanding of why patients did or did not adopt more healthy lifestyles. The qualitative study from Peterson *et al.* gave more detailed information regarding what helped and hindered patients' adoption of a healthier lifestyle but the sample size was too small to allow generalisability and the validity of the study was questionable as the purposive sampling was based on data from a RCT that was more than a year old.

Despite Astin and Jones in 2006 calling for further research to determine what factors influence lifestyle change in this patient population, little evidence exists. It was suggested that social support may be helpful but the evidence to

substantiate that was minimal. Fernandez *et al.* gathered data related to the incidence of anxiety and depression in PCI patients but no mention was made of whether these factors influenced participants' likelihood of adopting healthier behaviours or not. Several studies collected demographic data and yet, little seems to be known about the influence of factors such as age, sex, existence of co-morbidities and ethnicity on CHD self-management. Consequently, there is a paucity of research that has explored whether certain factors affect elective PCI patients' adoption and maintenance of a healthier lifestyle and this requires investigation.

### 2.5.3 Theme C: Patients' adherence to a treatment regime

For the purpose of this thesis, the adherence to a treatment regime component of CHD self-management will refer to patients' adherence to pharmacological treatment (i.e. medication). Searching the literature for publications that reported research findings relevant to this topic found most concerned with the rates of prescribing medications for secondary prevention of CHD after PCI and if the prescribing practices aligned with clinical guidelines.

As indicated in Appendix 1, a thorough search was conducted. Initial searching yielded no papers and so the search was repeated using 'coronary heart disease' instead of 'percutaneous coronary intervention' (and other variations of this) to ensure any studies that did have PCI patients in the sample were found. Four papers were found that explored medication adherence in patients with CHD (Ma et al., 2010; Cheng et al., 2004; Kopjar et al., 2003; Tolmie et al., 2003) but none specifically mentioned that patients in the sample had undergone PCI and so these were not included in the review. Also to make sure no papers would be missed that explored adherence to certain medications, a search was performed using the names of the common medicines given after PCI as keywords. Clinical guidelines indicate that patients after PCI should have secondary prevention treatments to lessen the risk of CHD progression (SIGN, 2007). Patients are, therefore, frequently prescribed anti-platelet medicines such as Aspirin and also Statin therapy to reduce cholesterol levels. Aspirin and Statin were consequently used as key words in the search.

Of the 231 citations found, two publications met the inclusion / exclusion criteria and specifically explored patients' adherence to a medication regime after PCI. An overview of the two studies included in theme C can be found in table 2.4.

### Description of the studies

Fernandez *et al.* (2007) conducted a cross-sectional study that evaluated patients' adherence to medicines one to two years after PCI. This study explored the type of medication patients took, how they stored their medicines and their adherence. The researchers recruited a convenience sample of patients who had undergone PCI either for alleviation of angina symptoms or for the primary management of acute myocardial infarction. It was not evident from the publication how many patients had had PCI for angina management. Participants were recruited over the period of 12 months and from the 541 who underwent PCI, a sample of 270 was recruited. Data were collected using a postal survey and the response rate was 75%.

The survey response rate was enhanced by the use of telephone reminders for participants. A 20-item survey tool was used, containing questions on participants' demongraphics, the medications they took and their adherence to medicines. This included the pre-validated Morisky Medication Adherence Scale. T-tests were used to analyse the continuous variables and chi-square for the categorical variable data.

The second study included in theme C was that of Lauck, Johnson and Ratner (2009). This study has been described before in themes A and B and so this section will not duplicate what has been described already but will outline the relevant information about how the study collected data related to patients' adherence to medications. The discharge recommendations given to the PCI patients were used as a framework to explore their adherence to them. The publication states that 'participants were questioned about their adherence to the instructions' (Lauck, Johnson and Ratner, 2009; page 192) but the specific questions asked of them in relation to medication adherence are not apparent. The researchers provide details of the univariate, bivariate and multivariate statistical tests that were performed but there is no specificity regarding which was used to analyse the data related to medication adherence.

### Methodological quality of the studies

As before, both studies used a non-experimental, cross-sectional study design and that is considered of low methodological quality based on the criteria from the hierarchy of study types (SIGN, 2011). Albeit, the designs chosen for each study aligned with the their aims.

The sample in Fernandez *et al.*'s (2007) study contained patients who had suffered a myocardial infarction and required a PCI as an emergency as well as those who had undergone the procedure to help relieve angina symptoms. Patients who have damage to their heart as a result of a myocardial infarction may have different perceptions of why they need medicines compared with patients who have PCI as an elective procedure for angina management and that could affect their adherence. For example, Choudhry *et al.* (2008) found in their study of more than 30,000 patients that those who had had a myocardial infarction were more likely to adhere to certain medicines than patients who had CABG surgery. It is possible, therefore, that patients with different diagnoses or who have different cardiac interventions may differ in their adherence rates. Consequently, medication adherence may be divergent in patients who undergo PCI for angina management compared to other CHD patients. Fernandez *et al.* did not however, distinguish between the two different groups of patients in their sample.

It seems that 518 patients were eligible to participate in Fernandez *et al.'s* study but only 52% were recruited. There was no reason given for the poor recruitment rate. Indeed, cross-sectional studies tend to have less difficulty recruiting participants since data are collected at just one time point with no commitment to follow-up necessary (Patel, Doku and Tennakoon, 2003).

The survey items used in Fernandez *et al.'s* study appeared to focus on medicines taken for other conditions and this may have affected the reliability and validity of the participants' responses. For example, participants were

# Table 2.4Overview of theme C literature

Citation included	Methodology / study design	Location of study	Study aim(s)	Sample	Method of data collection
Fernandez <i>et al.</i> (2007)	Quantitative / Cross- sectional study	Australia	To evaluate patients' adherence to medicines and their medicines management.	Convenience sample (n=270) of myocardial infarction and PCI patients	Postal survey
Lauck, Johnson and Ratner (2009)	Quantitative / Cross- sectional study	North America	To describe patients' self- management behaviour 2 - 5 days after PCI and factors associated with cardiac self-efficacy and self- care agency.	Convenience sample (n=98) of PCI patients	Telephone survey

asked if they took medicines for certain conditions (including diabetes, hypertension and depression) but there seemed to be no questioning related to medicines taken specifically for the heart condition and that was considered unusual given that the study explored medicine adherence after PCI. Also, there seemed to be some evidence of design bias in that a few questionnaires that had been previously tested for reliability and validity were included in the survey but some of these had been modified without further testing. Unfortunately, Lauck, Johnson and Ratner gave no detail of the questions they used to collect their data medication adherence and so it is not possible to ascertain the reliability and validity of the tools used.

Fernandez *et al.* (2007) stated that they encouraged patients who did not speak English to complete their survey with translation assistance. Inevitably, translating survey questions from one language to another requires interpretation and that may alter the meaning of some questions or question responses (Nes *et al.*, 2010). This would have affected the reliability and validity of the research through methods bias.

#### Theoretical underpinning of the studies

As indicated previously, Lauck, Johnson and Ratner (2009) mentioned that Bandura's self-efficacy theory would be used to help to explain participants' ability and confidence to self-care but how this theory was used to better understand participants' adherence to medication was not explained.

It was not obvious that Fernandez *et al.* (2007) used any theory to underpin their research that helps to explain the findings. As before, this could have compromised what was investigated and the method used.

## What is known from the findings

Overall, the findings from both studies indicated that almost all participants adhered to their medication regime: 97% in the study by Lauck, Johnson and Ratner (2009) and 95% in Fernandez *et al.'s* (2007) study.

The largest proportion of participants in Fernandez *et al.'s* (2007) study took medicines to control blood pressure and cholesterol (97%) and to prevent blood

clots and half the sample was taking polypharmacy (Duerden, Avery and Payne, 2013).

Lauck, Johnson and Ratner (2009) did not seem to explore reasons for nonadherence but they did report that around 77% of participants understood the reason for taking the medicines, particularly anti-platelet therapy.

In Fernandez *et al.'s* (2007) study, almost 95% self-reported that they adhered to their medication regime and only a small number said that they had intentionally been non-compliant if they perceived their health to get better or worse.

#### Conclusions from theme C

To summarise, the two studies included in the review for theme C both explored patients' adherence to medication, albeit the extent to which this was investigated in Lauck, Johnson and Ratner's (2009) study was limited.

Once again, it was noted that neither of the studies indicated how many participants should be recruited and so it was difficult to determine if the studies had adequate power to detect any statistical significance and relationships between the variables (Suresh and Chandrashekara, 2012). Certainly, Fernandez *et al.* (2007) conducted bivariate analysis of the data and without knowing if the sample was adequately powered to ascertain statistical significance, the findings should be viewed with caution. Which statistical tests Lauck, Johnson and Ratner (2009) used was not clear and so it is difficult to drawn conclusions from them with confidence that they accurately reflect the patient population. It is necessary, therefore, that a study which can demonstrate that it is adequately powered to allow a robust exploration of elective PCI patients' medication adherence be conducted.

Although Fernandez *et al.* (2007) stated that patients were recruited after they had undergone PCI for angina symptom management, the discussion focused on adherence to medication after myocardial infarction. It is not obvious whether this is reporting bias or if the proportion of PCI patients was deemed too small to warrant discussion (Cochrane Bias Methods Group, 2013).

Consistent with much of the research already reviewed, there was a reliance on the use of surveys to collect data from participants. As indicated previously, it is known that using a single method of data collection can produce findings that are less objective where self-reporting is used and subsequently, there is a risk of bias (Gilbert, 2008; Van de Mortel, 2008). The findings of these studies would have been strengthened if multiple methods of data collection had been used, particularly the inclusion of a qualitative aspect to the studies. The depth of understanding that is possible from a qualitative study can be demonstrated using the research from Tolmie *et al.* (2003) and West, Lefler and Franks (2010) where qualitative studies were used to explore CHD patients' adherence to medications. Although both studies used a single method of data collection (interviews), the ability to have an in-depth discussion with patients about their medication adherence seemed to allow a greater understanding of the causal factors known to have a relationship with medication non-adherence. It would be beneficial, therefore, when exploring medication adherence in elective PCI patients that multiple methods of data collection are used and that a qualitative component is included where narrative can help to explain the study findings.

The reporting of which survey items Lauck, Johnson and Ratner (2009) used to gather data on medication adherence from their subjects was inadequate and that compromises the reproducibility of that aspect of their study. Some survey questions used by Fernandez *et al.* (2007) asked participants to identify the conditions that they took medicines for. This, however, requires an understanding of the purpose of the medicines and it seems from other studies that patients often do not know what medicines they take or their action (Pallarito, 2009). This could have led to response or social desirability bias.

As mentioned in the introduction to Theme C, most of the literature related to medication adherence concerns prescribing rates after PCI. While it is important to ensure patients are properly prescribed medicines that are known to reduce the risk of CHD progression, these studies did not explore whether patients actually took their medicines as intended. Other studies have found certain factors, including patients' beliefs about their illness, younger age, gender, ethnicity, social circumstances, prescription charges and educational attainment (Munger, Van Tassell and LaFleur, 2007; Gibson *et al.*, 2006;

Kripalani *et al.*, 2006; Kopjar *et al.*, 2003; Tolmie *et al.*, 2003), inhibit adherence to certain medicines, but these factors do not seem to have been explored in a PCI patient group. This is one area of elective PCI patients' CHD self-management that seems to warrant exploration.

#### 2.5.4 Theme D: Self-Regulation Model and CHD self-management

Theme D concerned the literature where the Self-Regulation Model or aspects of this model were explored in relation to CHD self-management in a sample that included elective PCI patients.

The details of the search can be found in Appendix 1 but essentially, using all variations for PCI, combined with self-regulation or illness perceptions (a component of it), a search of the literature was completed. Only one paper linked both these things and so that paper was included. To ensure no relevant literature was missed, the search criteria was widened to CHD patients and of that literature, any research that had included patients after elective PCI was also included in the review for theme D.

Of the citations found, two publications met the inclusion / exclusion criteria and specifically explored the Self-Regulation Model or aspects of it in relation to CHD self-management. An overview of the two studies included in theme D can be found in table 2.5.

#### Description of the studies

The publication from Astin and Jones (2006a) provided a detailed account of their cohort study that examined how illness perceptions in patients altered from before to after PCI. A convenience sample of 140 consecutive patients scheduled to have elective PCI were recruited over a two-year period. Data were collected at two timepoints (pre-PCI and 6 – 8 months post-PCI) using a modified version of the Illness Perceptions Questionnaire (IPQ) (Weinman *et al.,* 1996). One section of the original version of the validated IPQ was deemed not relevant to patients with stable angina having PCI. The disease identity section was changed from participants selecting symptoms from a predetermined list of generic symptoms to an open-ended question that asked what symptoms the participants had experienced. The modified version of the

IPQ was tested for reliability using Cronbach's alpha reliability coefficients test. Face-to-face interviews were used to collect the data and of the sample recruited, complete data sets were collected from 117 participants and that gives a response rate of 84%. Data were subject to descriptive statistical analysis and non-parametric tests were also used as the sample was of abnormal distribution.

Byrne, Walsh and Murphy (2005) conducted a cross-sectional study that sought to investigate how illness perceptions and perceptions of treatment (medication) could be used to explain non-adherence to secondary prevention behaviour. A stratified random sampling approach was used to select 58 general practices in Ireland. 35 practices agreed to take part in the study (response rate 60%). Stratification was done according to whether the practices were in an urban or rural locality and whether they had one general practitioner or more. In the 35 practices, 1611 patients were identified as eligible to participate in the study. Participants had mixed manifestations of CHD: myocardial infarction and stable angina with or without coronary revascularisation (CABG surgery or elective PCI). Data were gathered from patients' medical records and a postal questionnaire was used to collect data on participants' lifestyles including factors such as smoking, exercise, diet and adherence to medicines. The survey appeared to consist of a number of tools, some of which had been previously tested for reliability and validity. It was not evident if the entire survey tool had undergone further testing for reliability or validity. The survey included the Beliefs about Medication Questionnaire, the Revised Illness Perceptions Questionnaire, the Godin Leisure Time Exercise Questionnaire and the Dietary Instrument for Nutrition Education and a response rate of 69% was achieved. Chi-square and independent samples t-tests were used to analyse the data. Regression analysis was also used to examine the link between participants' illness perceptions and their secondary prevention of CHD.

# Table 2.5Overview of theme D literature

Citation included	Methodology /	Location	Study aim(s)	Sample	Method of data
	study design	of study			collection
Astin and Jones	Cohort study	Australia	To examine how illness	Convenience sample of 140	Face-to-face
(2006a)	-		perceptions alter before and after	patients who had	structured interviews
			elective PCI.	undergone PCI	
Bryne, Walsh	Cross-	Ireland	To investigate the utility of illness	CHD patients with multiple	Postal questionnaire
and Murphy	sectional study		perceptions and medication beliefs	manifestations of CHD were	/ review of medical
(2005)			in predicting secondary prevention	recruited from 35 randomly	notes
			behaviour in patients with CHD.	selected general practices.	

#### Methodological quality of the studies

The methodological quality of these studies was low if comparisons are made with the hierarchy of clinical evidence and study design (McKeon, Medina and Hertel, 2006). The study design in each case seemed appropriate for the study aims. As indicated previously, Byrne, Walsh and Murphy (2005) adopted a stratified random sampling approach to identify general practices that were subsequently invited to participate in the research. The randomisation of the practices was performed initially and thereafter, each practice was systematically invited to participate. When a practice declined the offer, the next one on the list was asked to participate. Given that 40% of the practices chose not to take part, the true random nature of the sample may be compromised. Although the strata were clearly defined, it is not evident if there was representation from an appropriate proportion of rural / urban and single GP / GP partnership practices (Black, 1999).

#### What is known from the findings

Astin and Jones (2006a) discovered that after the PCI, participants were more likely to believe their condition would last longer than the perceptions of an acute illness of short duration found in the data collected before PCI. The researchers surmise that this is a result of the sudden resolution of angina symptoms after PCI causing patients to believe the illness is acute rather than chronic but this seems contradictory and hints at some reporting bias. Perhaps linked to that finding, it appeared that participants perceived that they had more control of their illness before the PCI. Despite participants believing that their CHD was chronic in nature and less controllable after PCI, they thought it had less serious consequences.

A link between inaccurate illness perceptions and poor self-management was made in the discussion section of Astin and Jones' publication but this did not seem to be based on evidence. What is not known from the findings of Astin and Jones' study is what effect these perceptions had on PCI patients' CHD self-management.

Byrne, Walsh and Murphy (2005) found that participants' perceptions of their illness had a weak relationship with behaviours they adopted for secondary

prevention of CHD. Few facets of illness perceptions were found to predict health-related behaviours. A strong perception of how a person behaves can lead to illness linked to a higher intake of alcohol in the participants. It was also discovered that lower levels of emotional perceptions of CHD linked to participants exercising more but this also increased their likelihood of consuming more alcohol.

It seems that little research has been conducted on the impact of illness perceptions, particularly the emotional representations of CHD and the adoption of health-related behaviours. From what is known, it appears that the findings from Byrne, Walsh and Murphy's (2005) study contrast research done with other patient groups, as osteoarthritis patients who have negative perceptions of their disease adhere to lifestyle modification advice (Hampson, Glasgow and Zeiss, 1994). Consequently, the disparity between the research findings suggests that further exploration is needed to confirm or refute the conclusions from Byrne, Walsh and Murphy's (2005) study and indeed whether illness perceptions influence CHD self-management or not.

A link was found in Byrne, Walsh and Murphy's (2005) study that beliefs participants had of their medication affected their adherence to it. Where participants perceived that the medication was necessary and they had fewer concerns about taking it, the rates of adherence were very good.

#### Conclusions from theme D

The study from Astin and Jones provides some insight into the illness perceptions patients have before and after PCI but, unfortunately, what effect these perceptions had on patients' CHD self-management was not explored. Byrne, Walsh and Murphy (2005) examined the relationship between illness perceptions and the adoption of healthy behaviours and adherence to medication to lessen the risk of CHD progression. The link between illness perceptions and adoption of a healthier lifestyle was not strong and that differed from previous research with other patient groups. The relationship between these factors though does not seem to have been studied much and the contrasting findings suggest that further exploration is needed to establish how illness perceptions affect CHD self-management in patients after elective PCI. The single method of data collection in both studies limits the understanding of the topic and so it would be recommended that any research on this subject be designed to not only examine the influence of illness perceptions on selfmanagement but also to allow exploration and understanding of any relationships found between these variables.

Although the study from Byrne, Walsh and Murphy (2005) used the Self-Regulation Model to underpin their research, only the emotional and cognitive representations were explored. No indication was made that the other sequential steps in the model, coping strategies and appraisal of effects of coping strategies, were explored. It seems therefore, that the Self-regulation model has not been explored in its entirety to determine whether it can help to explain CHD self-management in an elective PCI patient population and so a gap seems to exist in the literature.

## 2.5.5 Theme E: Social Cognitive Theory and CHD self-management

The literature related to the Social Cognitive Theory or aspects of it were explored in relation to PCI patients' CHD self-management.

The details of the search can be found in Appendix 1 but using all variations for PCI, combined with social cognitive theory or self-efficacy (a component of it), a search of the literature was completed. Only one paper linked both these things and so that paper was included. To ensure no relevant literature was missed, the search criteria was widened to CHD patients and of that literature, any research that had included patients after elective PCI was also included in the review for theme E.

Of the initial search 15 citations were found (see Appendix 1 for details of the key words used), and only one was relevant to this theme and it was that of Lauck, Johnson and Ratner (2009). After widening the search criteria one further publication was found to potentially include PCI patients in the sample and so both studies were included in the review for theme E (see Table 2.6).

# Table 2.6Overview of theme E literature

Citation included	Methodology / study design	Location of study	Study aim(s)	Sample	Method of data collection
Lauck, Johnson and Ratner (2009)	Quantitative / Cross- sectional study	North America	To describe patients' self- management behaviour 2 - 5 days after PCI and factors associated with cardiac self-efficacy and self- care agency.	Convenience sample (n=98) of PCI patients	Telephone survey
Sarkar, Ali and Whooley (2007)	Quantitative / Cross- sectional study	North America	To examine the link between cardiac self-efficacy and health status in patients with CHD.	Sampling method not apparent but 1024 participants recruited.	Face-to-face interview, questionnaire completion, physical examination, treadmill test, echocardiogram

#### Description of the studies

As the study from Lauck, Johnson and Ratner was critiqued earlier in the chapter in themes A, B, and C, the discussion that will follow will be specific to how they set out to identify factors that related to PCI patients' cardiac self-efficacy. The publication states that researchers found no validated survey tool that would appropriately explore how prepared patients were for discharge following PCI and so a new survey was created for administration to participants 2 - 5 days after PCI. This tool was informed by a number of other questionnaires and studies including the Cardiac Self-Efficacy Scale (Sullivan *et al.*, 1998), the Jenkins Self-Efficacy Expectation Scale (Jenkins, 1989 as cited in Perkins and Jenkins, 1998) and a study of self-efficacy from other researchers. Analysis of the link between patient demographics and the self-efficacy variables was performed using a variety of statistical tests including correlation for continuous variables, t-tests for dichotomous variables and analysis of variance for variables where there were more than three responses.

Examination of the link between cardiac self-efficacy and CHD patients' symptoms, physical limitations, quality of life and general health was the aim of the cross-sectional study by Sarkar, Ali and Whooley (2007). This research, conducted as part of the 'Heart and Soul' study recruited over a two-year period a heterogenic sample of 1024 patients who had a history of myocardial infarction, hypertension, and coronary revascularisation. Patients who had had coronary revascularisation accounted for 59% of the sample and although it was assumed that this would include patients who had undergone PCI revascularisation, this was not explicit in the publication. Data were collected in a number of ways: face-to-face participant interview, survey, physical examination, echocardiogram and exercise treadmill test. No information was given about the time lapse from the cardiac event or revascularisation procedure to the gathering of data. Demographic data were collected by means of a survey that seemed to be self-administered. It is not clear from the publication if that survey tool was tested for reliability / validity. The Seattle Angina Questionnaire was used to explore participants' symptom burden and added to this was an extra item that asked participants to compare themselves with others in relation to their general health. It was not clear if the extra question was a validated item. Cardiac self-efficacy was measured using the

validated Sullivan's 'maintain function' scale and depressive symptoms explored using the Patient Health Questionnaire. Physiological tests were also used to measure the participants' heart function. As the aim of the study was to examine the links between cardiac self-efficacy and health status, bivariate statistical tests were used to analyse the data. Further data analysis was performed using multivariate ordinal logistic regression.

#### Methodological quality of the studies

No validated survey tool was considered appropriate to explore patients' selfefficacy and so Lauck, Johnson and Ratner used the Cardiac Self-efficacy Questionnaire, the Jenkins Self-efficacy Expectation Scale and other literature to inform their seven-item survey. The survey explored patients' confidence in: taking medicines, exercising, returning home, coping alone, caring for themselves and following instructions. Sarkar, Ali and Whooley (2007) alternatively used a number of pre-validated survey tools as well as ones that appeared not to have been tested to gather demographic patient data.

As indicated in the description of the study from Sarkar, Ali and Whooley, patients were recruited after coronary revascularisation but details of whether that was CABG surgery, PCI or both is not evident and that limits the reproducibility of the study.

#### What is known from the findings

The findings of Lauck, Johnson and Ratner's study were mostly given in tabular form with limited explanation. It was found that self-efficacy was lower in participants who lacked social support, were unmarried and felt anxious. The relationships self-efficacy had with other study variables were not fully explained and that may be a consequence of the single method of data collection. The researchers concluded that the self-management of the sample was suboptimal but the single method of data collection restricted the depth of understanding of that.

A clear link was found in Sarkar, Ali and Whooley's research between selfefficacy and health status. Participants who had low self-efficacy were more likely to have symptoms that were more burdensome and they perceived themselves to have more physical limitations and a poorer quality of life. It was also found that participants with low self-efficacy had more chance of being older, female, less educated and suffering from a number of co-morbidities.

#### Conclusions from theme E

Both studies reviewed in theme E explored only one aspect of the Social Cognitive theory, self-efficacy, but made no mention of the Social Cognitive Theory. It can be assumed therefore that having found no literature that explores the use of the theory in explaining CHD self-management in an elective PCI patient population, the theory has not been explored with this phenomenon. A gap in the literature therefore, seems to exist.

Lauck, Johnson and Ratner sought to explore factors that linked to cardiac selfefficacy in patients 2 – 5 days after PCI. The data of patients' self-efficacy captured so soon after PCI may not be a true reflection of their ongoing confidence as they would not have been fully recovered from the PCI procedure by that time (BHF, 2009b; BHF, 2009c; Shaw *et al.*, 1986). The study did not, however, determine how self-efficacy related specifically to patients' CHD selfmanagement.

Sarkar, Ali and Whooley found that CHD patients with low self-efficacy perceived their symptoms to be more troublesome but the study did not set out to investigate if self-efficacy affected patients' management of symptoms and so that remains unexplained. Greater perceived physical limitations were also found to be associated with low self-efficacy but these factors also linked to reduced exercise capacity, which may be a consequence of the CHD. The statistical tests used in this study did not, however, allow the causal directions of the relationships between variables to be established. Whether this study had elective PCI patients in the sample was not evident and so the findings must be viewed with caution, as they may not be relevant to that patient population without clarity of which coronary revascularisation patients were included. The adoption of healthier behaviours after PCI was not explored in the study from Sarkar, Ali and Whooley and so this suggests that there is a gap in the literature in relation to elective PCI patients.

The methodology used in both studies was quantitative and while relationships between variables could be detected, the single method of data collection appeared to limit the depth of explanation that could be gained from the data.

Other studies of CHD patients have established a link between self-efficacy and the adoption and maintenance of a healthy diet and exercise regime (Clark and Dodge, 1999) but it is not known if this is true for elective PCI patients. Clark and Dodge (1999) found no link between self-efficacy and CHD patients' adherence to a medication regime. Further exploration of this with a PCI patient sample is needed to determine whether the Social Cognitive Theory can be used to help explain patients' CHD self-management after PCI.

# 2.6 Conclusions from the literature review

Although CHD is a common condition in the UK, this literature review provides some indication that studies related to how patients manage their CHD after having elective PCI are relatively few in number.

None of the studies reviewed appeared to comprehensively explore the three components of CHD self-management in a patient population who had undergone elective PCI. For example, no study that explored patients' symptom management (Lauck, Johnson and Ratner, 2009; Gallagher *et al.*, 2008a; Langley, 2003; Nones Cronin *et al.*, 2000) distinguished between angina symptoms that were short-lived and those that lasted longer. The clinical guidelines for symptom management have clear recommendations that angina symptoms of short duration are managed in a specific manner, whereas patients whose angina symptoms persist should call for emergency healthcare assistance to minimise their risk of mortality and morbidity (SIGN, 2007). Also, most of the literature related to medication adherence concerned prescribing rates after PCI. While it is important to ensure patients are properly prescribed medicines that are known to reduce the risk of CHD progression, the studies reviewed (Lauck, Johnson and Ratner, 2009; Fernandez *et al.*, 2007) did not explore whether patients actually took their medicines as intended.

In general, the studies reviewed seemed to have an over reliance on quantitative methodology to explore the phenomenon. Multiple data sources would have strengthened the understanding of how and why PCI patients self-managed their CHD the way they did (Curry, Nembhard and Bradley, 2009). It was found that rates of adoption / maintenance of a healthy lifestyle after elective PCI were poor so the risk of CHD progression remained in many patients but the rationale for patients not making any lifestyle changes was not obvious in many of the studies and that can be attributed to the predominance of quantitative approaches to data collection.

Few studies (Peterson *et al.*, 2010; Lauck, Johnson and Ratner, 2009; Astin and Jones, 2006b; Campbell and Torrance, 2005; Gaw-Ens and Laing, 1994) included in the literature review used a homogeneous sample where findings could be related to elective PCI patients. Consequently, it was often difficult to generalise the findings to an elective PCI patient population (Bryman, 2004).

Some of the studies appeared to be methodologically flawed with poor study designs (Vulic *et al.*, 2010; Aldana *et al.*, 2003; Sigurdsson, Jonsson and Thorgeirsson, 2002), dubious ethical principles (Mainie *et al.*, 2005; Langley, 2003; Gaw-Ens and Laing, 1994), samples that lacked power to allow statistical significance to be established (Lauck, Johnson and Ratner, 2009; Gallagher *et al.*, 2008a; Astin and Jones, 2006b; Aldana *et al.*, 2003; Nones-Cronin *et al.*, 2000) and reporting bias (Fernandez *et al.*, 2006; Sigurdsson, Jonsson and Thorgeirsson, 2002).

Given that many previous studies are limited through their methodological approach, their lack of separation of elective PCI patients when reporting findings and their lack of comprehensive exploration and explanation of how elective PCI patients self-manage CHD the first research question to be investigated is:

 How do patients self-manage their CHD after they have undergone elective PCI? Some studies investigated the relationship between components of CHD selfmanagement and other independent variables (Sarkar, Ali and Whooley, 2009; Gallagher *et al.*, 2008a; Sigurdsson, Jonsson and Thorgeirsson, 2002) but this did not cover the potential influence of patients' demographics or their support network on CHD self-management. As factors, including age (Gallagher *et al.*, 2008b), sex (Chriss *et al.*, 2004), healthcare support (Deakin *et al.*, 2009; Lau-Walker and Thompson, 2009) and social support (Gallant, 2003), are known to affect self-management efficacy in patients with other manifestations of CHD, the need for more research with patients after elective PCI to understand the relationships of these variables with self-management is necessary. A second research question for this study is, therefore:

 What factors influence patients' self-management of CHD after elective PCI?

The use of theories to underpin research was almost non-existent in the studies reviewed and this omission may have had implications for the way studies were designed, the research questions used and how data were analysed and interpreted (Kelly, 2009). Consequently, it is recommended that appropriate theory is used to underpin a study that seeks to allow better understanding of how elective PCI patients self-manage their CHD. Neither the Social Cognitive Theory nor the Self-Regulation Model were used in their entirety to explore CHD self-management in PCI patients: only the emotional and cognitive representations of the Self-Regulation Model (Byrne, Walsh and Murphy, 2005) and self-efficacy from the Social Cognitive Theory (Sarkar, Ali and Whooley, 2007) were investigated. Other research from Clark and Dodge (1999) using a CHD patient sample suggests that self-efficacy may affect self-management of the condition but this does not seem to have been explored in PCI patients and consequently, there is a need to better understand that phenomenon. As outlined in chapter 1, both these theories seem to align closely with selfmanagement of a long-term condition such as CHD but further research is needed to explore their usefulness in explaining CHD self-management in patients after elective PCI. With this in mind, a third research question is:

• To what extent do Bandura's Social Cognitive Theory and Leventhal's Self-Regulatory Model help explain self-management of CHD in patients after elective PCI?

The study aimed to explore and explain elective PCI patients' CHD selfmanagement. And the research questions arose from the gaps in the current literature. The following chapter will explain the methodology used to explore this topic.

# Chapter 3 Study design and methodology

# 3.1 Introduction

This chapter will highlight the research questions that emerged from the literature. The research method considered most suitable for the research questions will be discussed and justification will be given for this. The study design will be stated and the study population described. An overview of ethical considerations regarding this study will be given. The research process will then be described, including the sampling strategies, data collection tools used and how the data were analysed.

# 3.2 Research questions

The research questions that emerged from gaps in the literature are:

- How do patients self-manage their CHD after they have undergone elective PCI?
- What factors influence patients' self-management of CHD after elective PCI?
- To what extent do Bandura's Social Cognitive Theory and Leventhal's Self-Regulatory Model help explain self-management of CHD in patients after elective PCI?

# 3.3 Introduction to research methods

The origins of social and healthcare research come from a scientific research base where human phenomena were subject to measurement and objective study (Moule and Goodman, 2009). This scientific paradigm, with roots in positivism, was concerned with experimental and correlational studies that tested theory using quantitative data (Gelo, Braakmann and Benetka, 2008). Since the first part of the twentieth century there was also a tradition of using methods of description concurrently with the experimental methods (Flick, 2009). That type of research, which had an epistemological position described as interpretivism (Bryman, 2004), aimed to provide a detailed understanding of a phenomenon (Liamputtong and Ezzy, 2005). Regardless of the epistemological orientation, healthcare research has been described as:

"...the systematic and rigorous process of enquiry which aims to describe phenomena and to develop explanatory concepts and theories. Ultimately, it aims to contribute to a scientific body of knowledge".

(Bowling, 2002; page 1)

Researchers should consider which design and method of data collection are most appropriate for their research questions and be able to justify why these were chosen (Griffiths, 2009). The main research approaches can be divided into two paradigms: quantitative and qualitative. These can also be used together in a mixed methods study.

## 3.3.1 Quantitative research

In healthcare research, quantitative methods use a deductive approach in understanding a phenomenon by breaking it down into component parts, thus enabling it to be studied from an objective and neutral standpoint (Campbell and Roden, 2010). The main types of quantitative research studies are experimental and observational studies.

The main features of these and limitations are briefly outlined below:

- Experimental studies these are used to assess the effect / efficacy of a particular treatment or intervention (Peat *et al.*, 2002). Randomised control trials, one type of experimental study, are considered in healthcare to be the 'gold standard' of research methods and are frequently cited as the best evidence in clinical guidelines where the quality of the research is graded using a hierarchical approach (SIGN, 2011; NICE, 2012). Limitations to this method include inconsistent results, insufficient power calculation to detect a statistical effect, a risk of bias and ethical limitations where one group of participants may be perceived as disadvantaged (Oxman, 2009).
- Observational studies There are three main types of study in this category:

- Longitudinal this type of research is used to measure the effect of changes over a period of time and require data to be collected at a series of time points during the study. The main purpose is to determine any causal effect that may be influenced over time. Limitations are mainly due to the time-span with participants lost to follow up and increased time and cost to conduct this research (Bryman, 2004).
- Cross-sectional surveys these are often referred to as survey design. Data are collected from a number of people to establish whether there is any variation between them. It is relatively easy to conduct this type of research however, the main disadvantage is that it cannot be excluded that the relationship between variables is purely a causal relationship. Also, as the data are usually collected at one point in time, the data and findings are likely to be time limited (Moule and Goodman, 2009).
- Case-control studies these help to establish causal relationships between phenomena and require multiple sources of data to be gathered (Gray, 2009). Researchers need to consider the underpinning theory to guide what data is collected to avoid becoming overwhelmed with it. The generalisability however, from specific cases is not really possible (Yin, 2003).

Quantitative research has been criticised in the past as having limitations and for reducing human phenomena to mere mathematical formulae (Speziale and Carpenter, 2007). According to Flick (2009) and Griffiths (2009), most phenomena in social research are complex in nature and difficult to explain in isolation and so are not always amenable to empirical methodologies. Using solely quantitative research methods makes it difficult to gain any understanding of people's values, cultures and relationships where human subjectivity and interpretation are involved and so qualitative methods were developed to address this.

#### 3.3.2 Qualitative research

Qualitative research aims to explore and provide an in-depth understanding of the nature of experience or action in the real world context (Liamputtong and Ezzy, 2005). This type of research tends to focus on words rather than numbers (Cobb and Hagemaster, 1987) and has an ontological position described as constructionist (Bryman, 2004; Guba and Lincoln, 1982 as cited in Moule and Goodman, 2009). Depending on the method of data collection and the viewpoint of the researcher, Gilbert (2008) suggests that qualitative data can be either constructivist or realist.

Qualitative researchers use an inductive approach to generate theory out of research. Strauss and Corbin (1990) suggest that qualitative methodologies can be used where little is known about a phenomenon or to gain new perspective on what is known already. For example, Moule and Goodman (2009) suggest that qualitative research can be used to explore people's experience, perceptions, beliefs, motivations and actions. Many different qualitative approaches have now been developed, including ethnography, phenomenology, and grounded theory.

It is suggested that the diverse way of reporting qualitative research however, makes it challenging to ascertain the validity of a study of this kind and so this methodology has often been critically viewed in healthcare research (Knafl and Howard, 1984). Despite this, many different qualitative approaches have now been developed, the main three being ethnography, phenomenology, and grounded theory. The key features and limitations of these three qualitative approaches will be briefly outlined below:

Ethnography – this involves the use of observational types of data collection to explore people and their cultures (Bryman, 2004). To enable the researcher to learn and observe that lived experience or culture he/she becomes involved in the research participants' daily lives, usually for a prolonged period of time. There may be difficulties however gaining access to the participants. Decisions need to be made as to whether the researcher assumes a covert or overt role in the community.

Either way, there is a risk that the role could be perceived as a threat (Liamputtong and Ezzy, 2005).

- Phenomenology involves the rigorous, systematic exploration of the every-day lived experience of people and allows theories to be generated from facts obtained within the natural setting of the phenomenon. There are different phenomenological approaches (including hermeneutic, reductive and interpretive (Speziale and Carpenter, 2007) and these need to be considered and decided upon to determine which fits best with the research aims. This research approach cannot explore causal relationships between phenomena. To alleviate any influence or interference researchers may have on the study phenomena, they need to consider their pre-conceived ideas, beliefs and prejudices about the study phenomena (Liamputtong and Ezzy 2005).
- Grounded theory this starts with a general area of concern and seeks to develop theories from observations of the social world rather than just describe social phenomenon (Speziale and Carpenter, 2007; Liamputtong and Ezzy, 2005; Christensen, 1993). Grounded theory uses an iterative approach to generate theories or hypotheses out of the data collected, however, this can sometimes be a lengthy procedure. The inconsistent use of terminology and terminology more akin to quantitative methods can make this method confusing for some researchers though (Charmaz, 2000 as cited in Denzin and Lincoln, 2000; Strauss and Corbin, 1998; Coyne, 1997).

Qualitative research according to Buckman and Rieman (1987; page 74) is needed to

"explore those human phenomena which cannot be broken down into smaller pieces without losing sight of the whole".

That said, due to the rather complex nature of the phenomena identified in healthcare, not all research questions will be addressed using solely a qualitative approach, or indeed a quantitative method. Some studies require both numerical and narrative data to be collected to answer the research questions (Doyle, Brady and Byrne, 2009; Plano Clark and Creswell, 2008).

#### 3.3.3 Mixed methods research

For many decades, quantitative and qualitative researchers have disputed each other's research paradigms and the purists believe that these are separate entities that cannot be mixed. In recent years it has become more accepted that neither quantitative or qualitative approaches are superior and that research practice generally lies at some point on a continuum between the two opposing paradigms (Creswell, 2003). Mixed methods research emerged as the third research paradigm and the aim of that was not to replace either of the other approaches but to capture the strengths and minimise the weaknesses methods in a single research study (Johnson and Onwuegbuzie, 2004).

Mixed methods researchers often use pragmatism a worldview that offers an alternative to those of positivism / postpositivism and constructivism where the main focus is to use all approaches to find a solution to a problem (Feilzer, 2010). Creswell and Plano Clark (2011) suggest that pragmatism allows the researcher to be liberated and not constrained by the necessity to choose between positivism and constructivism. Pragmatists tend to focus, not on the method being important, but on understanding the problem and consequently, rejecting dualism of epistemological standpoints to offer the best opportunity to answer the research questions (Johnson and Onwuegbuzie, 2004). As Doyle, Brady and Byrne (2009; Page 178) describe it, *'the end justifies the means'*.

Pragmatic researchers, according to Onwuegbuzie and Leech (2005), are more likely to consider research holistically and use qualitative data to explain quantitative findings or vice versa. For example, including a quantitative phase to a research study may alleviate the issue that qualitative findings typically cannot be generalised to a particular patient population. Alternatively, qualitative data may allow a more comprehensive understanding of correlations found through quantitative research. Creswell (2003) suggests that pragmatic, mixed methods researchers tend to consider the 'what' and 'how' of research, based on its intended consequences. As indicated in Chapter 1, the proposed research study emerged from anecdotal evidence in the researcher's clinical practice where patients who had elective PCI would be readmitted to hospital, seemingly unsure as to how they were to manage their condition. Reflection on that practice suggested to the researcher that the method was not the focus but instead, exploring and understanding how patients managed their CHD after elective PCI. In essence, the issues of truth, reality and philosophy that lend themselves to empirical enquiry were not the focal point of the research but more the experiential world of CHD patients after PCI with a view to better understanding how efficacious their CHD self-management is (Feilzer, 2010; Creswell, 2003).

As the name implies, mixed methods research combines both qualitative and quantitative approaches and involves the mixing of numerical and narrative data (Aaron, 2011). Mixed methods research allows the opportunity for researchers to use qualitative data to explore individuals' experiences in depth, while the quantitative data can allow conclusions to be drawn that are generalisable to the study population (Andrew and Halcomb, 2006). There have been many purposes identified for conducting a mixed methods study, including triangulation, completeness, explanation and illustration (Bryman, 2004).

Mixed methods research has, however, been criticised for trying to combine qualitative and quantitative methods in a single study when each has a different ontological and epistemological standpoint (Gonzalez Castro *et al.*, 2010; Doyle, Brady and Byrne, 2009; Carr, 1994; Corner, 1991; Duffy, 1985; Bryman, 1984). Tashakkori and Teddlie (2003), however, suggest that it is justifiable to do this if it is more appropriate for the research questions.

It appears, however, that the philosophical underpinning of mixed methods research is not clear. Some researchers emphasise the research methods (Creswell and Plano Clark, 2011) while others introduce the methodology more broadly (Tashakkori and Teddlie, 2003). Subscribing to the principles of Creswell and Plano Clark (2011), there are three main features to their worldview. Firstly, that when researchers use multiple paradigms, they are explicit in their use. Secondly, that multiple worldviews can be used within a mixed methods study but it is important that the worldviews relate to the mixed methods study design and not to the researchers notion of how to understand the study phenomenon. When multiple worldviews are combined in a single study, researchers must respect them as separate and consequently, write about them as such. The notion that mixed methods research is promoted as a method in its own right where the scholarly community share a consensus of the study designs and procedures that are considered most appropriate to address research questions.

It is important in any research study that the study design matches the research questions. Where mixed methods are being used to address the study questions, Creswell and Plano Clark (2011) suggest that researchers should consider the timing of the quantitative and qualitative 'strands', and how they will be mixed when designing their research. Many designs exist where qualitative and quantitative research is combined at different stages of a mixed methods study e.g. research question formulation, sampling, data collection and data analysis (Bryman, 2006). The weighting or emphasis of the strands should also be explicit. An overview of the more common mixed methods research approaches can be seen in Table 3.1.

# 3.4

# Why a mixed methods design was chosen for the study

The gap that was identified in the literature at the end of the Chapter 2 was considered and the research questions were formed from that information. It was decided that mixed methodology would be the most suitable approach. There were several reasons for selecting that particular method.

## 3.4.1 Purpose statement

As indicated in the literature review, all studies provided a relatively superficial understanding of how PCI patients managed their CHD. There was evidence that PCI patients' symptom management and lifestyle modification were suboptimal but the literature gave no explanation of why that was the case. The reason for the unexplained findings was consequently attributed to the single method of data collection used in each study.

Subscribing to the principles of mixed methods research from Creswell and Plano Clark (2011), it is essential that a 'purpose statement' be used to convey the aims and purpose of the mixed methods study. The following purpose statement will seek to clarify the intent of the study, the mixed methods study design and the rationale for collecting both qualitative and quantitative data.

# Table 3.1 Mixed methods research designs

(Adapted from Creswell and Plano Clark, 2011; pages 73 - 76)

Design	Definition	Purpose of design	Mixing strategies
Convergent design	Concurrent quantitative + qualitative data collection, separate data analysis then merging of data sets with equal emphasis on both data sets.	To achieve a more complete understanding of a topic	Merging of two strands after separate data analysis
Explanatory design	Sequential design starting with quantitative first (phase 1 data collection and analysis) then qualitative (phase 2 data collection and analysis). Phase 2 builds on phase 1. Emphasis on quantitative data.	To provide greater explanation for quantitative results	Connecting the two strands. Use quantitative results to make decisions regarding qualitative questions, sampling and data collection (phase 2)
Exploratory design	Sequential design starting with qualitative first (phase 1 data collection and analysis) then quantitative (phase 2 data collection and analysis). Phase 2 builds on phase 1. Emphasis on qualitative data.	To test or measure qualitative exploratory findings	Connecting the two strands. Use qualitative results to make decisions about quantitative questions, sampling and data collection
Embedded design	Either concurrent or sequential data collection. Either qualitative or quantitative data will take a subordinate role.	To conduct preliminary exploration before an experimental trial or to obtain a more complete understanding of an experimental trial	Embedding one strand within the other.

Purpose statement:

This study will seek to investigate and explain the CHD self-management of patients who have undergone elective PCI to alleviate stable angina symptoms. An explanatory, sequential, mixed methods design (Creswell and Plano Clark, 2011), has been chosen where quantitative data will be collected first, followed by qualitative data. The qualitative data will be used to provide an in-depth explanation for the quantitative data. In the initial quantitative phase of the study a survey will be administered to patients who have undergone an elective PCI procedure at a regional cardiology centre and will seek to gain information on how patients generally self-manage their condition as well as to explore the factors that may influence CHD self-management after PCI revascularisation. The first phase will also set out to assess the extent to which portions of the Self-Regulation Model (illness perceptions) and Social Cognitive Theory (selfefficacy) can help to explain self-management in this patient population. The second phase will see purposive sampling of participants who were involved in phase 1 of the study used to gather more detailed information to help explain the quantitative findings. The rationale for collecting both quantitative and qualitative data is using the strengths of both approaches to provide a more comprehensive understanding of CHD self-management in elective PCI patients (Andrew and Halcomb, 2006).

## 3.4.2 Rationale for the study

There was a risk that using solely a quantitative framework to study CHD selfmanagement would, like the majority of the studies critiqued in chapter 2, fail to explain why it differed across a sample. It was possible that in collecting quantitative data alone, the current study may produce findings that contradict previous studies, without understanding why the differences occurred.

Most studies reviewed in Chapter 2 used heterogeneous samples of patients with differing manifestations of CHD, where PCI patients were in the minority. Resultantly, that made it difficult to draw conclusions about a PCI population. There seemed to be a need to collect data specifically from an elective PCI patient sample so that findings could be generalised to the wider PCI population and so gathering quantitative data was necessary to achieve that. As highlighted previously, however, doing that was unlikely to suffice in providing a

comprehensive evidence-base of PCI patients' CHD self-management and so collection of qualitative data was also necessary.

Little was known about how certain factors, including age, sex, social support, and co-morbidities related to PCI patients' CHD self-management and so it seemed reasonable to collect data that were representative of this patient group. To establish any relationships between variables, it was necessary to collect data from a large enough sample that was determined by a power calculation, to allow statistical significance to be detected. It would also be difficult though to gain understanding of why factors influenced CHD selfmanagement using a single, quantitative method and so a qualitative aspect to the study was necessary.

The studies critiqued in Chapter 2 were limited in that they failed to provide a depth of evidence regarding CHD self-management. A more open, qualitative approach could be used to provide a deeper understanding of how PCI patients self-managed their condition and the factors that influenced this. Sample sizes of qualitative research studies are however, relatively small and the findings of such a study could not be considered representative of the PCI population. Using solely a qualitative approach would have precluded the generalisability of the study findings to the wider patient population.

The theories (Social Cognitive Theory and Self-Regulation Model) that were identified to underpin the research are complex in nature and it would have been difficult to capture how these theories explained the phenomenon using only a quantitative method. As indicated in Chapter 1, the Self-Regulation Model is an adaptive system that is organised in a hierarchical manner. While the illness representations / perceptions could be captured reliably using a survey (this will be discussed later in the chapter), the patients' coping strategies and methods of appraising situations are far more complex and would have been extremely difficult to explore and understand using only quantitative methodology. The Social Cognitive Theory is also complex in that it exerts that direct reinforcement does not account for all types of learning and that there are environmental and personal factors that influence behaviour and knowledge acquisition. These factors are too intertwined and complicated to

explore using only quantitative data. The exploration of both theories was considered more suited to a mixed methods approach.

Having considered both quantitative and qualitative methods for this study, it was clear that no one method could be used to comprehensively answer all of the research questions. Similar to other healthcare research, the phenomena considered in this study were complex and difficult to research using one approach and so a mixed methods study design was chosen.

# 3.5 Study design

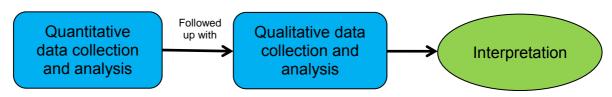
This mixed methods study used an explanatory, sequential design (Creswell and Plano Clark, 2011) as illustrated in the schematic diagram in Figure 3.1 to investigate and explain elective PCI patients' CHD self-management. Using this type of design, one set of data was collected at a time: quantitative first then qualitative. Explanatory design also lent itself to emergent approaches where the qualitative phase was informed by the initial quantitative one. The mixing between methods occurred in a number of ways:

- Themes from the quantitative data were identified and qualitative data in Phase 2 used to clarify these and elaborate on them, thus providing a more complete understanding of the subject area (Doyle, Brady and Byrne, 2009; Ivankova, Creswell and Stick, 2006; Greene, Caracelli and Graham, 1989).
- Quantitative data were used to inform the sampling for the follow up qualitative phase of the study.
- Quantitative findings were used to inform the themes for the interview schedule used in Phase 2.
- A priori codes were developed from the quantitative findings to help direct the qualitative data analysis.

The main challenge of using this study design was the time implication of implementing two phases of data collection (Moule and Goodman, 2009). The sample for inclusion in phase two of the study was only determined after the

quantitative data had been analysed so could not be planned in advance and that contributed to the length of the study.

# Figure 3.1 Explanatory sequential design



# 3.6 Approval to conduct the research

In order to conduct the study, the researcher was required to obtain permission and approval from three different organisations. The following section outlines the approval process.

• University Research Ethics Committee:

The researcher was undertaking the study in part fulfillment of a research degree and so it was necessary to obtain permission from the university where the researcher was based. After a request for clarification of the methods of data analysis to be used was met, this committee provided approval (see Appendix 3).

• Regional Research Ethics Committee:

As the study concerned patients in NHS settings, the researcher was required to submit an application to the appropriate Regional Research Ethics Committee to gain approval to conduct the research. An application was submitted and approval from the Committee was granted (see Appendix 4), albeit this was dependent on obtaining permission from the Regional Centre's Research and Development Department (where the patients underwent PCI).

• Research and Development at the Regional Centre:

A proposal for this research study was submitted to the regional Centre and site-specific approval to conduct the research was granted (see Appendix 5).

# 3.7 Research process Phase 1

In phase 1 of the study, a survey (self-administered questionnaire) was used to collect quantitative data to determine how PCI patients self-managed their CHD and whether any factors influenced that. The survey was also used to explore the illness perceptions aspect of Leventhal's Model and self-efficacy from Bandura's Theory in relation to CHD self-management.

# 3.7.1 Sampling (identification of participants and recruitment)

## Location of study

Consideration was given to where the study would be conducted. Of primary concern was access to and availability of potential participants who had undergone elective PCI to alleviate stable angina symptoms.

In 2011 there were more elective PCI procedures performed proportionate to the population in Scotland than in Wales or England (National Institute for Cardiovascular Outcomes Research, 2011). It seemed important to be aware of the number of patients undergoing PCI procedures at each hospital site to ensure availability of potential participants. Scotland has five hospital sites where the procedure is performed, with two hospitals performing the bulk of these (Pell and Slack, 2010). Procedures rates at these two hospitals are among the highest in the UK (National Institute for Cardiovascular Outcomes Research, 2011; Pell and Slack, 2010). Participants for the study were therefore, sought from the hospital that performed the most PCI procedures per year. This hospital will now be referred to as the 'Centre' and it carries out in excess of 700 PCI procedures every year (Pell and Slack, 2010).

The researcher had worked at the Centre previously and had good working relationships with the multidisciplinary team in the cardiology department. The cardiologists and senior managers at this Centre were happy to provide their support and this made it possible to gain access to the potential patient population that was to be studied.

## Study participants

Patients with stable angina symptoms only were sampled. As indicated in chapter 1, patients who have PCI performed as an emergency (usually myocardial infarction patients) have a different manifestation of CHD pathophysiology. Also, the unstable angina patients were excluded as they are usually admitted to hospital as an emergency and often have accompanying complications. The sample therefore, consisted of a group of patients who had recent (within the previous 3 months) elective PCI for management of stable angina symptoms.

# Inclusion / exclusion criteria

The criteria for inclusion / exclusion of participants are summarised below:

Inclusion criteria:

- Patients with angina symptoms who had elective coronary revascularisation with PCI.
- Patients under the care of consultant cardiologists in one regional centre in Scotland.
- Patients who lived within the geographical area of the regional Centre.
- Patients who spoke / read English.

Exclusion criteria:

- Patients with angina symptoms who had suffered a serious complication during revascularisation with PCI (e.g. stroke, coronary artery dissection).
- Patients who were unable to speak / read English.
- Patients who were unable to provide consent to participate in the study.
- Patients who had impaired cognition.

Some elective patients who have PCI can experience complications during or after the procedure which results in further / ongoing treatment and so they were excluded from the study.

Patients were required to provide their written consent to participate (see consent to participate form – Appendix 6) and so they were required to have

intact cognition. Any patients with impaired cognition were not invited to participate. Registered nurses and cardiologists within the outpatient department assessed the patients and used their clinical judgment to ascertain whether the patients had intact cognition and would meet the criteria for the study or not.

The Centre chosen for this research was a tertiary centre for PCI provision and accepted patients from other regions of Scotland and occasionally England. The geographical spread of these patients was enormous and from a practical perspective it would have been difficult and costly to access all of them for the second phase of the study. Consequently, only patients who lived in the geographical region were included (approximately 400 per year).

The survey tool used in Phase 1 of the study was developed and available in English only (further information about this will be given later in the Chapter). As any translation of the questionnaire could have altered the context of the wording, it was decided that the study should only be open to participants who were able to speak and read / write English.

#### Sample size

In order to ascertain whether the factors identified in the literature had any influence on participants' CHD self-management after elective PCI or not, a representative patient sample was required. To achieve this, it was necessary to recruit enough participants to allow sufficient precision to detect a statistical difference between those who were deemed to have effective CHD self-management and those who had less effective self-management. The determination of *apriori* sample size was informed by the Hospital Anxiety and Depression Scale (HADS), the brief Illness Perceptions Questionnaire (IPQ) (both contained within the survey tool for this study) and studies that had used these tools for data collection previously. The likely variance to be encountered was taken from the study by Broadbent *et al.* (2006) who found that the standard deviation of responses to different brief IPQ questions and different categories of illness ranged between 1.2 and 3.4 with a mean of 2.6. To err on the side of safety the estimate of the standard deviation was taken as 3.0 and the degree of precision that required to be detected was one unit on the brief

IPQ scale. Using these parameters and a power of 85% a sample size calculation was performed in MINITAB v15. This gave a minimal sample size of 81.

#### Sampling method

Many medical research studies recruiting cardiac patients have limitations due to their sampling technique, where they tended to recruit primarily young males (Gurwitz and Goldberg, 2011; Bugerja, Kumar and Banerjee, 1997). The hope was to use quota sampling in the initial quantitative phase of the study with the aim of selecting participants to reduce the chances of over or under-representation of one particular sex or age group of patient as some literature indicated that these factors could influence patients' CHD self-management (Wright and London, 2009).

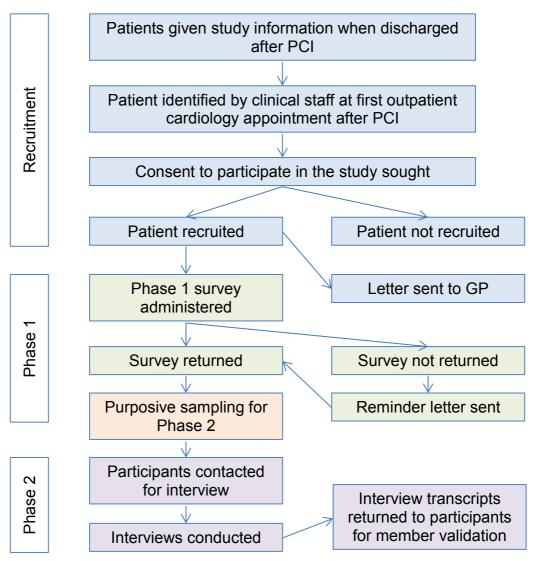
The purpose of quota sampling is to produce a sample that is representative of a particular population in terms of the relative proportions of people in individual categories such as age and sex (Bryman, 2004). The categories and the number of people to be recruited in each category are determined before recruitment begins. People who fit the categories are then selected for the study. Quota sampling is a type of non-probability sampling that relies on researchers having knowledge of the characteristics of the population being studied (Crossman, 2014).

Quota sampling was, however, difficult to achieve. While the demographic data of patients who underwent elective PCI at the Centre from the previous year was available for comparison, the researcher had no information as to which elective PCI patients were scheduled to attend the outpatient clinics and so an infinite number of clinics could have been attended to recruit participants in this way. This was not feasible given that the research was conducted for a time-constrained research degree. Pragmatically then, the researcher decided to use a convenience sample of 80 - 100 participants.

## Recruitment of participants

The majority of patients were admitted to a day case unit at the Centre before their elective PCI. Figure 3.2 provides a brief summary of the contact with participants during the study.





Prior to discharge from the unit, patients were given a pack of information to take home containing information about the study. This pack contained a letter of invitation to participate (Appendix 7) and a participant information sheet (Appendix 8). The aim of this was to allow patients time to read about the study and make an informed choice about their participation (National Patient Safety Agency, 2013). Additionally, according to Burns *et al.* (2008), cover letters and participant information sheets create the first impression and if these are clear

and the study aims are understood, participants are more likely to complete the questionnaire.

Approximately three months after the PCI procedure, patients attended an outpatient clinic where they were seen by their cardiologist for follow-up. According to the literature, PCI patients should be able to return to normal activities and work (if appropriate) within two weeks (BHF, 2009b; Shaw *et al.*, 1986) and so the time span between PCI procedure and clinic attendance should have been sufficient for recovery. Although CHD self-management is not a specific requirement after elective PCI, it should be ongoing to manage any angina symptoms and to lessen the risk of CHD progression. Consequently, the time lapse between procedure and data collection should have afforded participants the time to return to their normal self-management activity. The PCI procedure itself may have been an impetus for participants to alter their CHD self-management strategies. A decision was therefore made to recruit participants at this time and collect Phase 1 data.

At the outpatient clinics, clinical staff identified potential participants and their suitability for inclusion was considered in relation to the pre-determined inclusion / exclusion criteria. The clinical staff were knowledgeable about the study and were happy to answer any questions the patients had about it. Thereafter, the researcher approached patients and, those willing to participate, provided their written consent (Appendix 6). At that time the patients were again offered the opportunity to read the participant information sheet to inform their decision. The researcher ensured that the patients willing to participate in the study did so voluntarily and in no way felt coerced (Moule and Goodman, 2009). Another opportunity was given to the patients to ask the researcher any questions they had about the study before they consented to take part. Patients gave their consent to participate for either phase 1 of the study where, in addition to the questionnaire, consent was given for interviews.

Nine months after starting recruitment, the sample size was achieved for Phase 1 (n=93) and recruitment to the study was closed. In total 63 (67%) elective PCI patients consented to both phases of the study (completion of the

questionnaire and interview) and 30 (32.3%) consented to complete the questionnaire only.

#### 3.7.2 Data collection

#### Survey administration method

Surveys can be administered in a variety of ways: face-to-face, online, postal questionnaires and by telephone with completion of the questionnaire done either by the researcher or participant (self-completion or self-administered). The various methods of administering the survey have definite benefits and drawbacks. Surveys can be a relatively inexpensive method of gathering data from a large sample although poor participation and response rates are problematic. Online and postal surveys are particularly limited by very poor response rates, which can be as low as 20% in some cases according to Gilbert (2008). Adequacy of the response rate to surveys is dependent on what the data are being used for (Nulty, 2008). For example, in the current study, if the number of questionnaires returned did not meet the power calculation figure, the ability to detect statistical significance during data analysis would have been compromised.

There are ways, however, to improve the number of participants returning their questionnaires. Making sure the questions in the survey are suitably worded to make them easily understood will help, but the length of the questionnaire is a significant factor, as the longer the questionnaire, the less likely it will be completed (Jepson *et al.*, 2005). Regardless of the length or wording, participation is greater where the subject matter of the questionnaire is of importance to the participants or they see value in completing it (Gilbert, 2008; Krosnick, 1999).

As the general patient population undergoing PCI tends to be older, it was felt that conducting an online survey would not be appropriate, as not all patients would necessarily have had access to the internet, or indeed have the skills to participate in this way and so this approach was discounted. Using the telephone to gather survey data was considered, but, again, an elderly population may have encountered difficulties with this (i.e. hearing difficulties). Moule and Goodman (2008) also suggest that participants from ethnic groups may find this method more challenging due to different dialects, so this too was not thought to be the most suitable method.

Face-to-face administration of this survey subsequently seemed the best approach and certainly the one reportedly with the best response rate. However, the researcher was conscious of the influence she may have had on that phase of data collection. Cognisance needed to be given to the so-called 'Hawthorne effect' when the presence of the researcher impacts on the behaviour and responses of the study participants (Moule and Goodman, 2009). Gray (2009) indicates that face-to-face administration of the survey may lead participants to give answers that they consider to be more acceptable to the researcher and not necessarily the true response. The researcher consequently chose to administer the survey face-to-face but using a selfcompleted (self-administered) questionnaire to alleviate response bias and the Hawthorne effect. With this method there is a necessity that survey questions are clear, unambiguous and self-explanatory to ensure participants understand what is asked in a particular question.

#### Questionnaire design

For this particular study, there seemed to be no valid or reliable questionnaire that was able to address all aspects of the research questions and so, a new one was designed with much consideration given to content and format. According to Ballinger and Davey (1998), designing a questionnaire that is reliable and valid can take considerable time and so, where possible, pre-tested questions were incorporated.

Previous studies suggest that the appearance of the questionnaire could affect participants' decisions to complete it and so text clarity, use of colour, and general visual appeal were considered when drafting this document (Burns *et al.*, 2008; Edwards *et al.*, 2003; McColl *et al.*, 2001). The questionnaire was also printed on university headed paper to give it a more professional appearance and enhance the credibility of the research. The questionnaire can be found in Appendix 9.

While the participant information sheet provided general information about the study, detailed instructions written in plain English on how to complete the questionnaire were printed on it to guide participants. In order to help participants navigate their way through the survey, each question was numbered, section and sub-section titles were used and each question was contained on one page of the document. It was important that the topics covered within the questionnaire were grouped together to help guide the respondents' thought process (Burns *et al.*, 2008). The survey tool was therefore divided into four sections:

- <u>Section A</u>: 'About you'. This section focused on patient demographics.
- <u>Section B</u>: 'Before and after the coronary angioplasty procedure' (PCI). The monitoring and management of angina symptoms was included in this section as well as questions on self-efficacy, contact with healthcare professionals and information needs of the participants. Questions on medication adherence, lifestyle factors and lifestyle modifications were included.
- <u>Section C</u>: 'About how you feel at present'. This section contained the Hospital Anxiety and Depression Scale (HADS).
- <u>Section D</u>: 'What you think of your condition now'. The brief Illness Perception Questionnaire was in this section.

The language used was also a primary concern for the researcher. Since the questionnaire was administered using a self-completion approach, the questions needed to be clear and easily understood by all participants and so medical terminology was kept to an absolute minimum and, where it was used, it was referred to in lay person terms / plain English for clarity (Gilbert, 2008). The PCI procedure was referred to as 'coronary angioplasty' as this is the term medical staff use to inform patients of the procedure and much of the patient information literature uses this term too. The language used was checked with lay people and patients prior to the study commencing. Cognisance was also paid to creating questions that were unambiguous, not biased and capable of coping with every possible response (Ballinger and Davey, 1998; Stone, 1993). Keeping the questionnaire as brief as possible could improve completion rates but the researcher was cognisant that, to do this, some detail may need to have

been sacrificed (Ballinger and Davey, 1998). Jepson *et al.* (2005) found a 'threshold' effect when it came to questionnaire completion. They found it statistically significant that completion rates were poorer for questionnaires exceeding 1000 words and so the wordage for the survey was kept to a minimum. The type of questions chosen would influence the completion time and so, where possible, closed questions were used, where a selection of responses were given that participants could choose from. The responses were also pre-coded which made the input of data into the statistical package SPSS easier and faster (Field, 2009). A few open questions were used which provided richer, more in-depth data but these took longer for respondents to complete and resulted in a more prolonged time for analysis.

A funnel design to the questionnaire advocated by several authors (Ballinger and Davey, 1998; Stone, 1993; Oppenheim, 1992) was used where general questions were asked at the beginning of the questionnaire and more specific or sensitive ones were positioned towards the end. Stone (1993) suggests placing questions about the patient's demographic at the end of the questionnaire as he suggests that these can be considered to be 'boring questions'. General questions about the participant can be answered easily and are not considered threatening, so it seemed appropriate to place them at the start of the questionnaire (Gilbert, 2008). Also and more importantly, patient demographics were factors that could influence patients' CHD self-management and, as these data were essential to collect, they were positioned in the first section of the questionnaire.

#### Study variables

The three components of CHD self-management, angina symptom monitoring and management, adherence to a medication regime and the adoption and maintenance of a healthy lifestyle, were considered as dependent variables. Literature was searched to explore factors that had been found to have relationships with the dependent variables in other CHD patient populations and Table 3.2 provides an overview of these findings and the independent variables identified. The Household Questionnaire used in Scotland's Census 2011 (Scottish Government, 2011a) helped inform the first section of the survey related to patient demographics. It was important to ensure the questions in that part of the survey were relevant to the population studied. For instance, the ethnic mix within Scotland is not as diverse as other areas of the UK and so the most common ethnic groups according to the Census were listed as nominal variable responses with an additional free text option for participants to select if they did not consider themselves to be in one of the ethnic groups listed.

The questions in the next section of the questionnaire (section B) related to the participants' day-to-day CHD self-management and included questions related to the three components of self-management: monitor and manage angina symptoms, adopt and maintain a healthy lifestyle, and adhere to a medication regime. As no survey tool existed for measuring self-management in patients with CHD, the questions in this section were adapted from other questionnaires on self-management (Jaarsma *et al.*, 2003: Toobert, Hampson and Glasgow, 2000) and angina symptom management (Garratt, Hutchinson and Russell, 2001).

The Self-Care Behaviour scale developed by Jaarsma *et al.* (2003) was validated for use specifically with heart failure patients. Many of the questions in this tool concerned specific aspects of heart failure management (including questions related to symptom monitoring, prevention of complications, and contact with healthcare professionals). While only some of the questions were relevant to a PCI population, the topic areas explored had similarities to the components of CHD self-management after PCI (e.g. symptom management and behaviour change for secondary prevention of coronary heart disease). As the internal consistency of the tool had been questioned previously (Shuldham *et al.*, 2007), caution was exercised when considering the relevant questions and, consequently, the categories used in the heart failure scale were only used to inform the new survey tool.

#### Table 3.2 Independent variables

Independent variables	Evidence for inclusion				
Age	No evidence of relationship with self-management of CHD in PCI patients. Contrasting findings from studies considering self-management of other chronic conditions (Munir <i>et al.</i> , 2009; Gallagher <i>et al.</i> , 2008b; Chriss <i>et al.</i> , 2004; Spitzer, Bar-Tal and Ziv, 1996).				
Sex	Could have a relationship with CHD self-management but contradictory findings from previous studies (Gallagher <i>et al.</i> , 2008b; Chriss <i>et al.</i> , 2004; Riegel and Gocka, 1995).				
Ethnicity	Certain ethics groups have a higher incidence of CHD compared to white Scots (Bhopal <i>et al.</i> , 2011). No evidence that this could be an influencing factor to CHD self-management.				
Educational attainment	Higher educational attainment correlates to a lower risk of developing CHD (Liu <i>et al.</i> , 2013; Goldman and Smith, 2011; Marins <i>et al.</i> , 2007; Pitsavos <i>et al.</i> , 2002). No evidence found of link to self-management of CHD in PCI patients.				
Level of deprivation	Deprivation known to increase CHD incidence (World Health Organisation, 2013a) but no link found to self-managemen				
Social support	<ul> <li>Has been considered as a dependent variable in its own right (Rosland <i>et al.</i>, 2010; Jerant <i>et al.</i>, 2005; Riegel and Go 1995) but also evidence of indirect effect on self-management through self-efficacy (Gallant, 2003).</li> </ul>				
Co-morbidities (including anxiety and depression)	managed in patients with depression and they have a lower functional status (Mayou <i>et al.</i> , 2000). Anxiety increase				
Healthcare support	The forming of a patient / healthcare practitioner partnership is, by some, considered a component of self-management chronic illness (Gately, Rogers and Sanders, 2007). Lack of partnership was found to negatively affect self-management ability in patients with other chronic diseases (Deakin <i>et al.</i> , 2009; Gibson <i>et al.</i> , 2009; Lau-Walker and Thompson, 2				

Healthcare support (continued)	Cardiac rehabilitation attendance is poor (BHF, 2008b; Bethell <i>et al.</i> , 2006; Bethell <i>et al.</i> , 2001) but the purpose of it is to influence self-management in patients with CHD (BACR, 2007; Kennedy, Gask and Rogers, 2005; SIGN, 2002; Department of Health, 2000).
Self-efficacy	Could affect behaviour change / risk reduction but evidence from heterogeneous samples (O'Sullivan and Strauser, 2009; Sarkar, Ali and Whooley, 2007; Dongbo <i>et al.</i> , 2003; Clark and Dodge, 1999).
Illness perceptions	Illness perceptions are known to affect knowledge of angina symptom management (Gallagher <i>et al.,</i> 2008a; Nones- Cronin <i>et al.</i> , 2000), adherence to a treatment regime (Petrie and Weinman, 2006) and psychological wellbeing (Lau- Walker, Cowie and Roughton, 2008; Mondloch, Cole and Frank, 2001).

Although the self-management tool developed by Toobert, Hampson and Glasgow (2000) was designed for use with diabetic patients, the questions related to the adoption and maintenance of a healthy lifestyle were helpful when designing the PCI patient questionnaire. These questions used a mixture of likert scale and categorical variable responses and while cognisance had to be paid to how the different types of data would be compared, the content of the questions and wording were useful in the preparation of the new survey tool.

It was decided that the categorical variables from the Seattle Angina Questionnaire (Garratt, Hutchinson and Russell, 2001), which linked to perceived limitations on the daily life of patients, would be helpful in informing questions concerning limitations on activity for the PCI group. These questions were therefore included in Section B of the survey.

Research of patients with other manifestations of CHD indicates that selfmanagement could be influenced by the presence of anxiety and depression and so a scale to measure this was necessary to incorporate in the survey tool so that it could be explored in a PCI patient population. The most commonly used tool to identify anxiety and depression is the Hospital Anxiety and Depression Scale (HADS). The HADS has been used extensively in nonpsychiatric healthcare settings since its development by Zigmond and Snaith in 1983 and has been used with CHD patients before (Stafford, Berk and Jackson, 2007; Barth and Martin, 2005).

The HADS is a fourteen-item self-report survey tool, which comprises seven questions related to anxiety and seven for depression. It can be completed quickly and easily since the question stems are short and participants choose from four responses for each question (Snaith, 2003). Responses are scored between 0 and 3, with the larger numbers representing a higher degree of anxiety or depression in the person. Scores for each question are totaled but this screening tool has received condemnation, however, as the total score provides no information regarding whether the main problem is anxiety, depression or a combination. Consequently, most research has concluded that the sub-scales of HADS should be analysed and reported separately (Barth and

Martin, 2005). If patients score 11 or more in a sub-scale, it is indicative of the presence of anxiety or depression.

Where other questionnaires such as the General Health Questionnaire and the Patient Health Questionnaire assess for somatic symptoms related to anxiety and depression (Jackson, 2007; Kroenke, Spitzer and Williams, 2001), the HADS excludes these factors. This makes it useful to use with PCI patients as these physical symptoms (e.g. fatigue, dizziness) could be confused with angina symptoms, which would most likely skew the detection rate (Bjelland *et al.*, 2002).

There are some strengths of using the General Health Questionnaire in that it was designed specifically to identify psychological distress in adult patients in primary care and it has been validated in a number of different length formats (Aalto *et al.*, 2012) Despite being limited by the necessity to pay a fee for its use (Centre for Addiction and Mental Health, 2009), the main issue with using this survey in the current study is that it screens for somatic symptoms, which, as mentioned previously, may be confused with angina symptoms (Jackson, 2007). The Patient Health Questionnaire is a short questionnaire, which allows it to be completed and analysed swiftly and it has been used widely in clinical practice (Lowe *et al.*, 2004). It is compromised in that it includes items concerning suicidality, which is not relevant to the focus of the current study as well as including questions on somatic symptoms (Kroenke, Spitzer and Williams, 2001). Consequently neither of their survey tools were considered suitable for use in the current study.

Some of the items within the HADS could be questionable when used with a CHD patient group though. "I get a sort of frightened feeling like 'butterflies' in the stomach" could be confused with symptoms of heart palpitations. Another item, "I feel as if I am slowed down", could relate more to a person's perceptions of the CHD rather than be indicative of depression (Johnston, Pollard and Hennessey, 2000). Caci *et al.* (2003) have also criticised the scale for containing questions related to the assessment of restlessness rather than just anxiety and depression. Consequently, researchers have called for it to be

amended and re-tested for reliability and validity (Emons, Sijtsma and Pedersen, 2012).

Even though the HADS questionnaire has been found to be reliable in detecting anxiety in certain groups of cardiac patient (Roberts *et al.*, 2010; Martin, Thompson and Chan, 2004), its construct validity has been questioned (Martin, Thompson and Barth, 2008), as has its specificity and sensitivity in detecting anxiety (Davies *et al.*, 1993), even in a PCI population (Emons, Sijtsma and Pedersen, 2012). Bunevicius *et al.* (2013) found high rates of false positive detections when using HADS in a CHD patient sample and re-evaluation of the cut off scores used to determine CHD patients with significant levels of anxiety and depression has been called for to enhance its reliability (Kaur *et al.*, 2014). Despite research that indicates some limitations in the reliability and validity of using the HADS with a CHD population, researchers and clinical guidelines in the UK still advocate its use (SIGN, 2007; Stafford, Berk and Jackson, 2007; Bjelland *et al.*, 2002; SIGN, 2002). There have been recent calls for alternative screening tools for anxiety and depression to be used in patients with CHD but this would require further exploration (Burns *et al.*, 2014).

These issues raised concern about using the HADS in the PCI patient survey to assist in the detection of anxiety and depression. The tertiary Centre uses it to screen patients for anxiety or depressive illness and so the study participants may already have been familiar with it. Despite the reservations of the validity of some items within it, the lack of alternatives resulted in the inclusion of the HADS in the survey. Not using this tool could have attracted criticism since it is so widely used with cardiac patients.

The survey needed to collect information regarding the Social Cognitive Theory. The complexities of Bandura's Theory, where there is interaction between the person, the environment and behaviour, seemed to render comprehensive exploration of it through a quantitative approach difficult to achieve. Selfefficacy has, however, been explored by means of a survey before and so it was decided that questions regarding this aspect of the Theory would be included in the questionnaire. Although it would seem appropriate to use the Cardiac Self-Efficacy Scale (Sullivan *et al.*, 1998), it was felt that several questions in it focused on patients' confidence in dealing with angina symptoms and some participants may not have considered that relevant given that the PCI was performed to alleviate angina symptoms. The Cardiac Self-Efficacy Scale is quite long with sixteen questions and it was considered too lengthy to include in its entirety since self-efficacy was only one of the independent variables explored in the study. Instead, the Cardiac Self-Efficacy Scale and Bandura's guide to constructing self-efficacy scales (Bandura, 2006) were used in the development of questions on self-efficacy relevant to aspects of CHD self-management. Ordinal variable responses ranging from 'not very confident' to 'totally confident' were used for each question on self-efficacy.

Aspects of the Self-Regulation Model were also considered too complex to explore with a survey. The coping strategies patients adopt to deal with their condition could be wide-ranging and the subsequent appraisal of the success of these strategies would be more suited to exploration using narrative approaches. The illness representations patients have of their condition could however, be investigated using a survey.

A survey tool, which encompassed the five themes, which together, comprehensively look at illness perceptions, was sought to capture that information from the participants. A previously validated tool, which is considered to be reliable when used with cardiac patients, the Illness Perceptions Questionnaire, was available (Weinman *et al.*, 1996). This tool is used to measure illness representation and was developed to determine the cognitive representations of illness according to the work of Leventhal (Leventhal, Meyer and Nerenz, 1980, as cited in Petrie *et al.*, 1996). The Illness Perceptions Questionnaire (IPQ) has been used with myocardial infarction patients previously so Furze *et al.* (2002) considered it suitable for PCI patients, as the underlying disease is the same.

The IPQ has been used to gather information from patients who have a plethora of different medical conditions (Grewal, Stewart and Grace, 2010; Petrie, Jago and Devcich, 2007; Scharloo *et al.*, 1998) and so, to accommodate this, the

terminology is generic and the condition in question is referred to as the 'illness'. It was this generic use of the word 'illness' that caused some apprehension of including the IPQ in the PCI patient study. Most of the questions in the IPQ seemed relevant to include. The question however, 'how long do you think your illness will continue?' seemed a little ambiguous in that patients after PCI may have perceived the 'illness' to be their angina symptoms which should have been alleviated by the PCI, rather than CHD. Also, there was concern around a question asking respondents to list three factors that they thought had caused their illness. If the participants thought that the illness was angina, they could have thought that symptom-provoking factors were the cause, but that was not the intent of the question.

Modifying the IPQ was considered to alleviate the potential misinterpretation of these questions but this could have affected the reliability and validity of the tool. Clarity of what the illness was seemed necessary and so some guidance for participants was included immediately prior to the IPQ section (Section D) in the survey to indicate that the illness was indeed CHD.

Various versions of the IPQ are available, including a brief version allowing quick completion (Broadbent *et al.*, 2006; Moss-Morris *et al.*, 2001; Weinman *et al.*, 1996). The Brief IPQ is advocated for elderly patients and those who are very sick, who would find completing a longer questionnaire challenging (Broadbent *et al.*, 2006). The majority of questions in the Brief IPQ use a likert scale (0 - 10) response with either end of the scale relating to polarised perceptions. As previously discussed, the length of a survey can influence whether participants choose to complete it or not and so a shorter version would likely generate a higher response rate (Bryman, 2004). The brief version of the IPQ has been found to have good reliability and discriminant validity (Ng, 2012), and so, it was decided to use that since illness perceptions was only one of many factors being considered. Permission was sought and granted from the IPQ authors to use this survey (Broadbent *et al.*, 2006) (see Appendix 10).

#### Validity of the survey tool

Once the survey was drafted, it was distributed to a range of people to check the understandability of the questions and the survey's face validity. Lay people were asked if they understood what was being asked within the questions and also if they understood the pre-determined responses. Some of the wording required slight alteration to ensure it was understood in the way intended. An example of a change can be found in Figure 3.3.

#### Figure 3.3 Example of changes to survey

(Original question followed by modified question responses)

A12	Housing: Do you:	<ul> <li>Own your house</li> <li>Rent from private landlord</li> <li>Rent from housing association / Council</li> <li>Other please specify</li> </ul>
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A12	Housing:	
	Do you:	<ul> <li>Own your house</li> <li>Rent your house</li> </ul>

As content or face validity is considered by Rattray and Jones (2007; page 238) to be "...expert opinion concerning whether the scale items represent the proposed domains or concepts," experienced researchers were also asked their opinion of the questionnaire. The content validity of the survey tool was determined by a group of healthcare practitioners who are considered 'experts' in the cardiology specialty. The questionnaire was sent to five practitioners currently working in the NHS (two consultant cardiologists, one rehabilitation consultant, one nurse consultant and a nurse specialist). Four out of the five responded. Generally the practitioners felt that the relevant information would be collected using the questionnaire and that the wording was relevant for lay people. The nurse specialist suggested adding more about patients' attendance at cardiac rehabilitation, but it was felt that a simple question of cardiac rehabilitation attendance would be used in the survey and the topic could be further explored in the individual interviews, if this was deemed appropriate. The questionnaire was subsequently prepared for the pilot study.

#### Piloting the questionnaire

Pilot studies are conducted for a number of reasons and the objectives outlined by Thabane *et al.* (2010), Lancaster, Dodd and Williamson (2004) and Peat *et al.* (2002) were used to inform the piloting in the study. The objectives were:

- To test the structure and content validity of the survey tool
- To test the clarity of the participant information sheet / consent form
- To gain information about the rate of recruitment
- To identify any barriers to recruitment
- To gain information about the practicalities of conducting the research

Oppenheim (1992) suggests what may be considered the most thorough method of conducting pilot studies, in that researchers should deconstruct their questionnaires and produce separate sections to be piloted individually in the first instance, before finally combining all the sections again to test the whole questionnaire. He advocates conducting a series of unstructured interviews with participants so that revisions can be made to the wording of questions. While this method of piloting a questionnaire is likely to ensure the survey tool is well tested and scrutinised, it would consequently be a lengthy process, particularly given that he suggests that it is

"not uncommon to 'use up' several hundred respondents in pilot work." (Oppenheim, 1992: page 55)

It was important not to scrimp on the time for doing pilot work as effective planning and testing of the survey tool would enhance the reliability of the data collected and go some way to make sure the intended data were collected. Prolonged testing as Oppenheim suggests may ultimately provide more reliable data but the researcher needed to be cognisant of the time span. The study was conducted as part of a time-constrained research degree programme and so lengthy pilot work would not have been feasible. Also, the entire group of eligible PCI patients in the Centre was around 400 per year and so the pool of potential participants was relatively small for what Oppenheim suggested.

The survey tool was piloted to ensure the questions developed were accurate, unambiguous and could be answered in the intended manner, which was particularly important given that a self-completion questionnaire was used and the researcher was not available to address any dubieties participants had with interpretation of the questions (Gray, 2009; Bryman, 2004). The advice of Peat *et al.* (2002) was used to inform the procedure for the pilot study and this is outlined in Table 3.3.

#### Table 3.3 Pilot study procedure

Stage 1	Potential participants were given information regarding the study at the time of discharge after their PCI procedure			
Stage 2	Potential participants were identified and approached at their first out-patient clinic appointment regarding participation			
Stage 3	Participants were recruited to the pilot study in the same way as would be done in the main study			
Stage 4	The survey was administered in the same way as it would be in the main study			
Stage 5	Once the survey was complete, the pilot study participants were asked about any questions that they felt were ambiguous or difficult to answer			
Stage 6	The time taken for each pilot study participant to complete the survey was recorded to determine if it was reasonable			
Stage 7	Slight alterations were made to the survey in response to the participant feedback			
Stage 8	The participant responses were checked to ensure the data could be interpreted in relation to what was required			

Eight PCI patients were recruited to the pilot study, 5 males and 3 females.

Their ages ranged from 48 to 88 years. The time lapse from PCI procedure to the patients attendance at the outpatient clinic was somewhere between 8 and 12 weeks. Table 3.4 contains the demographics of the pilot study participants and their comments in a summarised format.

## Table 3.4Demographics of pilot study participants

Participant number	Age	Sex	Ethnicity	Education (highest level)	Comments re survey
1	86	Female	White UK	Secondary school	Very long but questions okay
2	67	Male	White UK	Secondary school	Too long
3	54	Male	White UK	Secondary school	No problems
4	88	Male	White UK	University	Questions okay but took too long to complete
5	66	Female	White UK	Secondary school	No problems with the questions
6	48	Male	White UK	University	Questions okay
7	66	Male	White European	University	Questions okay but took too long to complete
8	66	Female	White UK	Secondary school	Questions okay however incomplete data set

The pilot study provided some useful, practical information regarding recruitment to the study as it seemed from an early stage that it would be slower than expected (the cardiologists at the regional Centre suggested that around 10 patients per week could be recruited but that was not the case). Specialist nurses volunteered to help identify potential participants in advance but the reality of the situation was that this was not feasible for them and this became apparent almost immediately after the pilot study began. There seemed no way of obtaining information beforehand of which PCI patients (if any) were scheduled to attend the respective outpatient clinics. As the researcher was unable to attend every clinic, given that they occurred every working day over three separate sites across the region, a pragmatic decision was made to attend the clinics where most elective PCI patients were to be found. Some consultant cardiologists performed more PCI procedures than others and so their clinics were targeted. The audit trail of clinics attended and the recruitment rates is appended (see appendix 11).

The main thing fed back from the pilot study was that the survey was deemed too long at 7½ pages and participants thought that it took too much time to complete. No participant reported any difficulty with the interpretation of the questions or responses and after analysing the completed surveys, the responses given were considered appropriate and expected.

The survey tool was considered again in an attempt to remove any items that were not necessary for the research questions or those that gave duplication. Questions related to participants' knowledge of the causes of CHD were removed as these duplicated a question on this topic in the IPQ. Some questions were combined (e.g. initially two questions related to medication adherence were combined into: 'do you take medicines: everyday, most days or occasionally?'). The final survey was consequently shorter and took less time to complete.

The data from the pilot study were kept separate from the main study data as advocated by Leon, Davis and Kraemer (2011). The rationale for not including the pilot study data in the main database was that the survey content changed and combining both sets of data would have created a source of variation.

#### Data gathering

Once consent was obtained, participants were personally given the survey by the researcher to be completed either in the outpatient department at that time or later, whichever was more convenient. Those who completed it there and then (the majority of the sample) returned the completed survey directly to the researcher. The benefit of this was that they could complete it while waiting to see the cardiologist and so with little inconvenience to them. Sierles (2003) proposes that most people consider themselves to be busy and so having the ability to complete the survey tool immediately would help the completion rate. All of the participants who chose to complete the questionnaire in the outpatient department returned it.

For the 30 participants who chose to take the questionnaire home to complete, a stamped envelope with the researcher's address printed on it was provided so that they would not incur any expense when returning the survey. It was thought that this would enhance the response rate (Moule and Goodman, 2008; Bryman, 2004; Sierles, 2003). If, after two weeks, the survey was not returned, a reminder letter was sent to participant as this has been found to improve response rates (Gilbert, 2008). Gray (2009) suggests that providing some form of incentive may foster an obligation in the participants to complete the questionnaire and could influence the completion rate. Healthcare professionals must, however, ensure ethical respect and beneficence to participants (Groth, 2010). For some clinical research trials, participants will be incentivised to take part and while that certainly can improve people's willingness to participate, consideration must be given to this motivating factor, particularly with vulnerable patients. In these cases, some people may enroll into a study, against their judgment, due to the incentives given. Grant and Sugarman (2004) warn that providing incentives can be an unethical form of coercion. Also, particularly where financial incentives are offered, more vulnerable people may be enticed to participate in the research (Singer and Couper, 2008) and this could potentially skew the research findings. In view of this debate on the use of incentives, the researcher decided that none would be given. Despite no incentives being offered, few patients declined to participate and of those who did, only 6 questionnaires were not returned. This gives an overall response rate of 93.5%, which is considered excellent (Sierles, 2003).

#### 3.7.3 Data management and analysis

Numerical coding for data was decided upon before data collection started which allowed the researcher the ability to code questionnaires as soon as they were completed. Participants were allocated a unique participant code and the data obtained were entered into the statistical package SPSS to allow analysis.

Some completed questionnaires had missing data but there was no systematic pattern to missing data. The amount of data missing was minimal and so the guidance from Fox-Wasylyshyn and El-Masri (2005) was followed and so there was no need for imputation.

For the six participants who failed to return their questionnaires, no data were entered into SPSS. The database for the remaining sample (n=87) was analysed to determine if there were particular questions that were not being answered but that was not the case and missing data seemed random. Gray (2009) suggests that it is useful for researchers to distinguish between four different categories of missing data, namely: not applicable, refused, did not

know and forgot to answer. The self-completion method of administering the survey, however, did not lend itself to determining the reason for incomplete data sets.

One method of dealing with missing values is to delete the participant's entire data set, but Acock (2005) indicates though that this could result in a 20 to 50% loss of data. While there is some support for imputation (Brick and Kalton, 1996; Chatfield, 1995) where a value can be inserted which is an average of the other participant responses, this can lead to bias, which can either exaggerate or diminish statistical significance (Gray, 2009). A decision based on the guidance from Fox-Wasylyshyn and El-Masri (2005) was therefore made to include the data sets from participants who had item non-response and code the missing data as such, without any imputation.

A pre-analysis protocol was developed to guide the analysis of the quantitative data in Phase 1. The analysis was divided into three separate sections: descriptive statistics, bivariate and multivariate analysis.

#### Descriptive statistics

Descriptive statistical analysis was used initially to explore the participants' demographic details to allow inferences to be drawn about the similarity of the sample to the general population of Scotland and PCI patient group.

#### **Bivariate statistics**

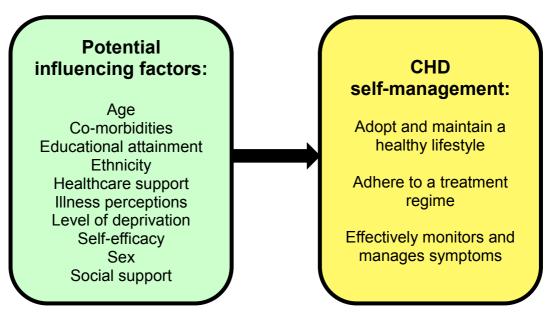
The sample data were found to be of a normal distribution and so parametric tests were used to help analyse it. Frequencies and measures of central tendency were calculated to measure the general parameters of the sample in relation to the possible influencing factors and how participants managed their CHD. The literature discussed previously in this chapter and in the literature review was used to design a schematic diagram (see Figure 3.4) to inform data analysis. The diagram provided a framework to allow possible correlations between variables to be tested.

The dependent and independent study variables were systematically paired and Pearson's product moment correlation, which is a parametric correlation test,

was used to allow any relationships to be established (Gray, 2009; Foster, Barkus and Yavorsky, 2006). This allowed the strength of the relationship between each of the influencing factors and CHD self-management to be calculated (Watson, Atkinson and Egerton, 2006). Finally the independent variables were paired with each other to identify any relationships.

Other statistical tests were used to establish how confident the researcher could be that a relationship between variables existed. A chi-square test was used to calculate whether the relationships between variables could occur on the basis of chance alone (Field, 2009). Results from the chi-square tests had to be interpreted using the associated level of significance set and they were dependent on the number of categories of the two variables being analysed, which is the degrees of freedom (Watson, Atkinson and Egerton, 2006).





Independent samples t-tests were also used to assess for any differences between participants in the sample that were statistically significant and determine whether the difference could have been due to chance, although chance is unlikely when the significance is set at p<0.05 (Foster, Barkus and Yavorsky, 2006).

#### Multivariate statistics

Once the correlations were tested and relationships between variables emerged, it seemed that some of the relationships could be quite complex and so it was decided that path analysis would be used to explicitly test causal relationships between the dependent and independent variables (Streiner, 2005). This statistical technique is used to:

"examine the comparative strength of direct and indirect relationships among variables". (Lleras, 2005; Page 25)

Path analysis was chosen as opposed to traditional structural equation modeling, since it allowed individual relationships between variables to be tested rather than the entire model (Foster, Barkus and Yavorsky, 2006). Path analysis differs from other linear equation models in that it allows mediated or indirect pathways to be examined (Stoelting, 2002). The 'pathways' in the bivariate correlation findings were tested to allow a graphic illustration to be developed which showed the relationships, as well as their strength and direction. This will be discussed further in Chapter 4.

#### 3.8

#### **Research process Phase 2**

In phase 2 of the study, individual interviews were used to build on what participants had already disclosed in their questionnaire in relation to their selfmanagement of CHD but also to further explain some of the correlations and pathways found in the analysis of the quantitative data.

#### 3.8.1 Sampling

To ensure a wide representation of participants with differing abilities in selfmanagement of CHD, criteria were developed to inform the sampling process for Phase 2 data collection. Participants were selected from the original sample based on their demographics, their knowledge of how to manage angina symptoms, their lifestyle factors and whether any changes had been made to these and their self-reported adherence to medicines. A sampling framework containing the criteria was developed and can be found in Table 3.5.

1.	<ul> <li>Effective symptom management</li> <li>a. Patients who report appropriate management of recurring angina symptoms</li> <li>b. Patients who report inappropriate management of angina symptoms.</li> </ul>
2.	Treatment adherence / risk factor reduction a. Patients who adhere to their medication regime b. Patients who are non-adherent with their medication regime
3.	<ul> <li>Adoption of a healthy lifestyle</li> <li>a. Patients who engage in activities that prevent CHD progression (e.g. exercise, low to moderate alcohol consumption, healthy body mass index, adequate fruit and vegetable consumption)</li> <li>b. Patients who engage in activities that contribute to CHD progression</li> <li>c. Patients who report risk factor modification since PCI</li> <li>d. Patients who report no risk factor modification since PCI</li> </ul>
4.	<ul> <li>Understanding of CHD</li> <li>a. Patients who understand CHD is a chronic condition that can be controlled with medication adherence and risk factor reduction.</li> <li>b. Patients who think the disease is short-lived and caused by uncontrollable factors.</li> <li>c. Patients who perceive that no treatment or intervention (personal or healthcare based) will have any effect on the progression of the CHD.</li> </ul>

It was necessary for the researcher to have information about each participant to ensure those selected met the aforementioned criteria and so the same sample of participants who had completed Phase 1 was used. Not all participants had given their consent to be interviewed and so descriptive data from Phase 1 of the study were examined and a selection of participants who had provided permission to be interviewed were chosen with the selection criteria in mind.

Participants were identified using a purposive method of sampling. Purposive sampling is where individuals are strategically chosen for their particular

characteristics and relevance to the research questions (Griffiths, 2009; Bryman, 2004). Lindsay (2007) indicates that there are different types of purposive sampling. For this particular study, case sampling was used where participants were chosen depending on their self-management efficacy. Mays and Pope (1995) indicate that this type of sampling is not done to provide a sample that is representative of the study population but instead to reflect the diversity between participants and to give as much potential for comparison as possible. This form of sampling therefore seemed reasonable. Appendix 12 provides details of those chosen for this phase of the study.

Once potential participants were identified for interview, the researcher made contact with them and ensured that they were still agreeable to be interviewed.

#### 3.8.2 Data collection

#### How the Phase 1 findings informed Phase 2 data collection

The participant interviews were included to enable a more in-depth understanding of the research phenomenon to be gained as per the notion of using an explanatory, mixed methods study design. Participants' survey responses were used to guide the questioning. For example, where participants had indicated in Phase 1 that they had made lifestyle changes, open questions were used to explore why they had made these changes and whether some were easier to make than others.

As indicated earlier in the chapter, The Social Cognitive Theory and the Self-Regulation Model could not be comprehensively explored using the survey only. Consequently, open questions were used to investigate participants' illness perceptions, how they coped with their illness and appraised their success in doing this. Likewise, open questions were used to gain more understanding of participants' self-efficacy and also how other personal and environmental factors affected CHD self-management.

#### Approach to interviews

Gray (2009) considers interviews to be a conversation held between at least two people, in which one has the role of researcher. Barbour (2008; page 114) intimates that interviews are a useful method of data collecting that provide *"relevant, valuable and analytically rich data"*. A 'good' interview is considered one where the interviewee does most talking and the interviewer mostly listens to what is being said.

The researcher was keen not to use a structured interview technique in this study as that could potentially have stifled the information the interviewees shared. The nature of structured interviews where the same questions are asked in a specific order (Lindsay, 2007) could have resulted in some topics being explored repeatedly if the interviewees raised the issue before the question was asked. An unstructured approach however, could have been difficult to manage, particularly if participants went off on a tangent, which can happen with topics that people find sensitive or worrying (Davies, 2007). Given that some participants could have found it difficult to discuss heart disease, a decision was made to use a semi-structured approach, which allowed flexibility in that the order of questioning was not pre-determined and unexpected topics raised by the interviewees were explored (Liamputtong and Ezzy, 2005; Grix, 2004). An interview schedule with topics or questions for exploration was developed and used as an aide memoir for the researcher during each interview (see Appendix 13).

#### Preparation for interviewing

As advised by Griffiths (2009), the researcher began drafting the interview schedule by writing down emergent 'themes' from Phase 1 that aligned with the research questions. Also the underpinning theories (Self-Regulatory Model and Social Cognitive Theory) were considered to determine the best approach to gathering data related to them. From these topics, basic interview questions were developed but care was taken to ensure none were considered 'leading' in any way. The questions were then grouped and categorised / themed according to their subject area. For this particular study, as the interviews were designed to explore the Phase 1 findings, the question categories mirrored those in the questionnaire. The interview schedule was kept as straightforward and short as possible to ensure the researcher did not have to turn pages during the interview as that could have been off putting for participants (Barbour, 2008; Liamputtong and Ezzy, 2005).

#### Qualitative data gathering

Speziale and Carpenter (2007) suggest that the best practice when conducting interviews is to do them at a time and place that is convenient for participants where they feel comfortable to share information. With that in mind, the researcher allowed the venue to be chosen by the interviewees, which in the majority of cases, was their own homes.

Prior to the interview starting, participants were informed that they did not have to answer any question they chose not to. The interviews began with a general question that was not considered to be threatening (Barbour, 2008) where participants were asked to talk about their understanding of why they had the PCI procedure performed. It was considered likely that they had discussed that with several healthcare personnel previously and so would not find the question difficult. The questions then gradually became more specific and the reasons for responses given in Phase 1 were explored further.

The good practice principles for interviewing from Davies (2007) were adopted. The researcher:

- Made the interviewee feel as comfortable as possible.
- Kept the interview schedule to hand, but not too prominent, as this could have been distracting for the participants.
- Allowed the interviewees to dictate the pace of the interview.
- Tried to make the interview seem more like a 'natural conversation'.
- Positioned the audio recording equipment where it captured the sound while not seeming too intrusive.
- Thanked the participants for their contribution.

The average time for each interview was about an hour and it was audio recorded. Immediately after each interview, field notes were made to document the researcher's experience (Liamputtong and Ezzy, 2005). The field notes documented observations made during the interview (e.g. participants' expressions), the assumptions about what was heard and a personal narrative related to the researcher's experience of conducting the interview (Speziale and Carpenter, 2007). The note taking was considered essential to the qualitative data collection (Gilbert, 2008).

A verbatim transcript was produced of the conversations as soon after the interview as possible. From this, preliminary analysis of the data collected was performed to ensure that emerging themes were explored in subsequent interviews. This iterative process continued until no new themes were found.

Two main themes emerged that had not been detected by the Phase 1 survey. These were the emotions participants experienced and an apparent lack of support from their friends, family and healthcare professionals. In light of these things, the interview schedule was updated and these areas were explored in more detail. For example, participants interviewed subsequent to the amended interview schedule, were asked about how certain aspects of CHD selfmanagement affected them emotionally. The following question is an example of the type of phrasing that was used to help explore that:

"You said that you took the medicines for your heart every day so how does taking them make you feel?"

(Excerpt of transcript from **Participant 57**)

In all, ten participants were interviewed.

#### 3.8.3 Management of the data

The unique code given to participants in Phase 1 of the study continued to be used to identify them in Phase 2. After the interviews were conducted, the researcher transcribed the audio recordings verbatim and annotated them using the field notes. Rather than using a third party, the researcher chose to transcribe the interviews personally as this provided further immersion in the data. When transcribing, a third party could potentially have altered the meaning of the conversation, particularly if punctuation was inserted (Barbour, 2008). Additionally, it was useful, particularly for the initial interviews, to sensitise the researcher to alternative ways of asking questions and also to cues that were missed (Liamputtong and Ezzy, 2005) as this informed subsequent interviews.

#### 3.8.4 Data analysis

#### Approach to data analysis

As the study had a sequential, explanatory, mixed methods design it was essential that the initial quantitative findings informed aspects of the qualitative data analysis (Creswell and Plano Clark, 2011). Generally it is commonplace that researchers use an inductive approach when analysing qualitative data. This was, however, not appropriate for the method and study design chosen as preconceptions gained from the findings of Phase 1 could not be suspended to enable the qualitative data analysis to be approached with an open mind (Moule and Goodman, 2009). A hybrid approach to qualitative data analysis was used and that aligned with the explanatory design of the study. Within this, it was completely appropriate (and expected) for the researcher to use the quantitative findings and underpinning theories to generate some pre-determined, A priori, topic codes to be used in the deductive analysis of the qualitative data (Ryan and Bernard, 2003; Crabtree and Miller, 1992). The A priori codes identified (see Table 5.01) reflected the findings from Phase 1. The codes were combined into a coding framework that was used as the basis for the iterative process of data analysis. An inductive approach was also used to analyse the qualitative data to ensure the findings were not 'stifled' through confinement to the A priori codes only. This was essential to make sure the interviewees' responses were comprehensively explored to enable a better understanding of how they managed their CHD and the things that prevented them being effective in this. After separate inductive and deductive coding, the researcher selected both inductive and deductive codes that could be linked together in a sub-theme. A colour coding system was used to do this. The sub-themes were then grouped into overarching themes. See an example of this in the annotated transcript from participant 90 in Appendix 13.

#### Method of data analysis

There are many different methods of analysing qualitative data and it was essential for the researcher to select the one most appropriate to provide a rigorous approach to data analysis (Coffey and Atkinson, 1996). Many analytic methods stem from a particular theoretical or epistemological position (e.g. interpretative phenomenological analysis, discourse analysis, and grounded theory). The positioning of these made it difficult, however, to use them within a mixed method study and so a thematic analysis approach was chosen as it provides the flexibility to be applied to a variety of theoretical and epistemological standpoints (Braun and Clarke, 2006). It is considered by some to be the foundation of all qualitative analysis processes and is said to have informed all of the other methods (Anderson, 2007).

Thematic analysis is a form of pattern recognition within data sets and involves the search for themes and, subsequently, categories that can meaningfully describe the phenomena in question (Fereday and Muir-Cochrane, 2006). Several phases are involved in the process and the researcher worked through these during the analysis. Table 3.6 provides an overview of this process.

# Table 3.6Overview of thematic analysis process(Adapted from Braun and Clarke, 2006)

Phase	Process
1. Development of A priori codes	<ul> <li>Phase 1 findings / research questions reviewed</li> <li>Codes developed from review to be used as basis for deductive aspect of data analysis.</li> </ul>
2. Preparation and familiarisation of data	<ul> <li>Data transcribed verbatim</li> <li>Transcripts checked for accuracy</li> <li>Transcripts annotated using accompanying field notes</li> <li>Transcripts read for the first time</li> <li>Transcripts re-read</li> <li>Initial ideas / comments noted</li> </ul>
3. Initial coding	<ul> <li>Systematic coding of interesting 'chunks' of text (descriptive). A priori codes used in this process</li> <li>Data relevant to each code collated in 'topic codes'</li> </ul>
4. Search for themes	<ul> <li>Topic codes collated into possible sub-themes and overarching themes (interpretative)</li> <li>Data related to each overarching theme gathered</li> </ul>
5. Review of themes	Themes checked against initial codes for each transcript and across transcripts
6. Theme naming and defining	<ul> <li>Themes named, ensuring wording reflected what the theme concerned</li> </ul>
7. Writing up phase	<ul> <li>Final phase of analysis</li> <li>Themes considered in relation to research questions and literature</li> <li>Quotations from transcripts chosen to aid discussion around each theme</li> </ul>

The researcher considered using a computer software package to aid analysis but the disadvantages to doing this seemed to outweigh any benefits. The software merely codes and retrieves data and none of the packages are able to analyse the data without the input of the researcher (Moule and Goodman, 2009). While using software such as Nvivo, NUD\*IST, and ATLAS.ti would have sped up the process of data searching and retrieval, a considerable time would have been spent selecting the appropriate software package, installing this and learning how to use it (Flick, 2009) which was a concern when analysing data for a time-constrained research degree. The main anxiety about using such tools, however, was that the process would become more 'mechanical', reduce the opportunity for the researcher to become immersed in the data and make the process less cognitive (Moule and Goodman, 2009). The sample selected for Phase 2 was relatively small and so the researcher considered the volume of data manageable to analyse manually using a paper and pencil technique.

#### 3.8.5 Member validation

To enhance the credibility of the qualitative findings, participants who took part in Phase 2 interviews were sent their interview transcript to seek their comments and corroboration or otherwise of the account the researcher had made (Lindsay, 2007). They were also sent an outline of the emergent themes from the qualitative phase of the study and asked to comment on whether they thought these were accurate or not (Speziale and Carpenter, 2007). This process, known as member validation / checking was undertaken to enhance the objectivity of the data analysis (Moule and Goodman, 2009) through a process whereby participants are asked to verify the researcher's interpretations of the data.

While this process was useful in obtaining the participants' comments, there was a risk that they would be reluctant to be critical and some may not have been able to make sense of what the researcher had written, particularly in relation to the theoretical frameworks used (Bryman, 2004). Corroboration was, however, received from the participants that the transcripts were accurate and the findings seemed reasonable.

## 3.9 Chapter summary

This chapter has provided an overview of research methods. The method and design chosen for this particular study were justified and the research process clearly described. The approval process necessary to conduct this explanatory, sequential design mixed methods study was outlined. Phase 1 was described in relation to the sampling approach, the data collection tool used and how this was developed, which study variables were included, and how the data were managed and analysed. The method for Phase 2 was outlined. Again, how participants were selected for inclusion was discussed and how the data were collected using an interview method. A synopsis was provided of how the qualitative data were managed and subsequently analysed.

## Chapter 4 Findings from Phase 1

## 4.1 Introduction

The research design of this study has helped to guide the presentation and discussion of the findings. The sequential nature of this explanatory, mixed methods study provided a framework for the reporting of results and so the quantitative findings are discussed first, proceeded by the qualitative results and then, finally, the interpretations from both sets of findings are discussed and contextualised (Creswell and Plano Clark, 2011).

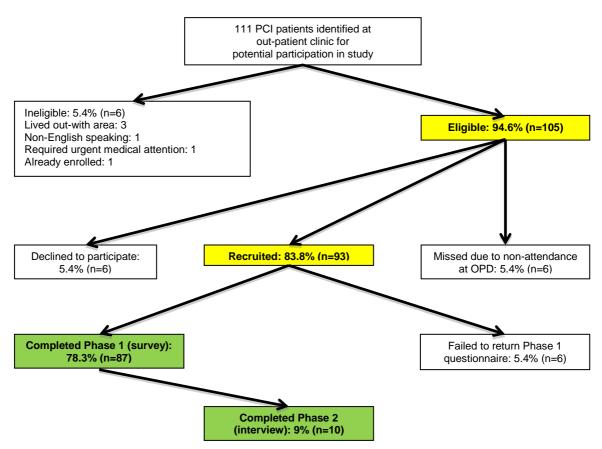
In this chapter, the findings from the first phase of the study will be detailed. The chapter will begin with an overview of the recruitment and completion rates for both phases of the study. Thereafter, having used descriptive statistical analysis, the demographics of those who gave their consent to participate will be outlined. The findings from phase 1 of the study that align with the components of CHD self-management for PCI patients will be provided (univariate analysis). This will give information regarding PCI patients' selfmanagement of CHD. An overview of the bivariate findings (relationships between variables) will be provided in a correlation matrix and, thereafter, they will be categorised into the self-management components and discussed at more length. Path analysis was used to further explore the links variables had with CHD self-management and so the findings from this will be described. The findings in relation to how the theories used to underpin the research related to participants and their self-management are discussed in the penultimate chapter. This chapter concludes with a summary of the quantitative findings.

## 4.2

### **Overview of recruitment**

The recruitment / enrolment process for the study was outlined in the previous methods chapter. The diagram in Figure 4.1 details the participants recruited and those who completed the study.

#### Figure 4.1 Recruitment to study

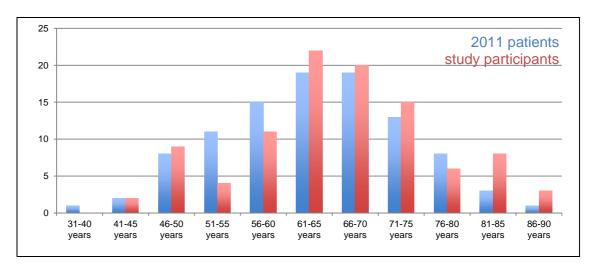


## 4.3 Description of the sample recruited

As indicated in Chapter 3, effective quota sampling could not be achieved and so a convenience sample was recruited. The age distribution of participants in the current study was compared with that of those who underwent PCI at the regional Centre in 2011. See Figure 4.2 (data presented are a percentage of the patient population or study population). It was found that the average age of the sample recruited for the study was slightly older than patients who had undergone PCI in the previous year at the Centre.

#### 4.3.1 Sample demographics

An overview of the demographics of participants who were recruited to the study is given in Table 4.1. Participants' data were compared with national survey data and findings from previous studies to ascertain how representative the sample was of the PCI patient population and general public.



#### Figure 4.2 Participants' age range compared with PCI patients at the Centre

#### 4.3.2 Summary of sample characteristics

The sample recruited for this study was a little older and there were slightly fewer females than the national average. Most of the sample was white but the representation of people with an Asian ethnicity was consistent with previous epidemiological studies that showed that particular group of people to have a higher incidence of CHD (Scottish Government, 2009b).

The percentage of homeowners was consistent with the national average but there seemed to be, however, a smaller proportion of people living alone than was expected from national statistics. Fewer participants living in deprived areas were recruited than previous research would suggest.

Three quarters of the sample were not in employment and this was expected, given the mean age of the participants was over retirement age in the UK. The level of education of the sample matched that of the general population.

The data showed that the percentage of participants with co-morbidities seemed comparable with previous studies of cardiac patients, although there were perhaps fewer participants with multiple co-morbidities. The incidence of participants with anxiety and depression was consistent with findings from previous studies of PCI patients.

Demographic	Study sample	Comparisons made	CommentsSample seemed slightly older than comparable groups, however, Centre data on mean age from 2011 was skewed by an unusually young patient having PCI that year. Also, higher incidence of younger people having PCI in the West of Scotland lowered mean age in Coronary Revascularisation Register. It is also known that the population is aging and more patients over 75 years are having PCI (Rajani <i>et al.</i> , 2011; Martin <i>et al.</i> , 2002).	
Age	Mean age 66.25 years (SE±10.56)	Mean age of patients who underwent PCI in the Centre in previous year: 63.75 years. Coronary Revascularisation Register data indicated that mean age of patients in Scotland was 63.6 years (SE±10.2) (Pell and Slack, 2010).		
Sex	70 males (75.3%), 23 females (24.7%)	Data from the Centre and national data from Scotland aligned in the proportion of males / females (72% : 28%) (Information Services Division, 2012; Pell and Slack, 2010).	Sample in current study had a slight under- representation of females when compared with national data and that from the Centre.	
Ethnicity	86% (n=80) Caucasian 5.3% (n=5) South Asian	Data from the Scottish Household Survey indicated that the ethnic mix in Scotland was not large with 96.8% of adults from a white ethnic background (Scottish Government, 2012a).	Scots of South Asian origin have higher incidence of CHD (Scottish Government, 2009b). That may account for larger than expected representation of this ethnic group in the sample. Ethnic mix not large enough to test for correlation.	
Living arrangement	67.8% (n=63) lived with someone, 23.7% (n=22) lived alone	Scottish Census data found 35% of the general population live in single person households (Scottish Government, 2011a).	Fastest growing group living alone is adults under 35 years (Klinenberg, 2012: Euromonitor International, 2008), so difficult to compare the data with a PCI patient population. Possible under-representation of those living alone in sample.	
Level of deprivation	Mean Scottish Index of Multiple Deprivation (SIMD) quintile score: 3.48 (SE±1.34). 31.2% lived in least deprived area, 6.5% in most deprived.	No data available for comparison. The SIMD was used to provide an indication of the level of social deprivation that participants lived in using their postcode for calculation purposes (Scottish Government, 2012b).	Deprivation is known to contribute to CHD (World Health Organisation, 2013a) so it was anticipated that more participants than the findings indicated would live in deprived areas. It is known that affluent people are more likely to participate in research studies.	

## Table 4.1 - Overview of participant demographics

Demographic	Study sample	Comparisons made	Comments
Home ownership	66.7% owned their homes.	Consistent with national average in 2009/10 (Heywood, 2011).	Sample has comparable proportion of homeowners.
Level of education	50.5% (n=47) educated to secondary school level. 35.5% (n=33) completed further or higher education programmes.	Scottish Annual Population Survey in 2010 indicated that 35% of adults had a post school qualification (Scottish Government, 2011b)	The educational level of the sample was reasonably representative of the general population.
Co-morbidities	Mean coronary artery disease (CAD) co- morbidity score was 1.98 (SE±2.42). 26.9% of the sample had no co- morbidities. 36 (38.7%) participants had two or more co-morbidities.	Aligns with some of the data from previous study (Sachdev <i>et al.</i> , 2004), however, the current study recruited slightly fewer participants with significant co-morbidity (11.8% in current study compared with 20% in Sachdev <i>et al.</i> 's study).	The CAD co-morbidity index was used to quantify the burden of co-existing diseases. The Index had high specificity for CHD patients as other manifestations of CHD are excluded but the usefulness of this tool was limited in that it only included the most common co-morbid conditions that affect mortality.
Anxiety and depression	HADS scores ranged from 0 – 42 with a mean of 10.95 (SE±7.35). Mean anxiety sub-scale score 6.46 (SE±4.47). Mean depression sub- scale score 4.49 (SE±3.57).	<ul> <li>20.4% of sample reported levels of clinical anxiety. In Scotland 4% of the population have consulted a healthcare professional for anxiety and this is consistent with UK average (Information Services Division Scotland, 2010a; NICE, 2004). Incidence reported to be higher in CHD patients at over 30% in some studies (Martens <i>et al.</i>, 2010; Eken <i>et al.</i>, 2010).</li> <li>7.5% of sample had depression. While UK average is 3%, it is known that it is more</li> </ul>	While average rates of anxiety and depression in the general public are lower, the incidence of participants with anxiety and depression in the current study is comparable with findings from previous studies.
		common in CHD patients (Information Services Division Scotland, 2010b; Frasure- Smith and Lesperance, 2006).	

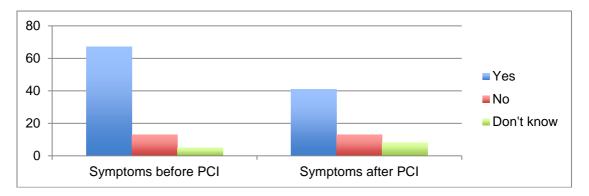
### 4.4 Self-management components

This section of the chapter will outline the findings, using descriptive statistics, in relation to the three components of PCI patients' self-management of CHD.

#### 4.4.1 Monitor and manage angina symptoms

For this component of self-management, participants were asked in the survey how often they experienced angina symptoms, whether they felt limited by these and how they would manage any recurrence.

Depicted in the bar chart in Figure 4.3 are the frequencies of reported angina symptoms prior to and after the PCI procedure (y-axis indicating the frequency of participants). The number of participants reporting angina symptoms after the PCI decreased. The findings showed that 5 participants (5.4%) did not know whether they had had angina symptoms or not before the PCI procedure and 8.6% (n=8) were unsure of this post procedure.

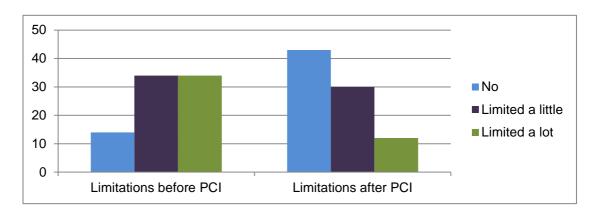


#### Figure 4.3 Frequency of participants' angina symptoms

Participants were asked to report how physically limited they felt as a result of angina symptoms before and after the PCI. Figure 4.4 illustrates the findings.

In the survey, participants were asked to indicate how they would deal with their angina if symptoms recurred. Findings from the data set indicated that about a quarter of the sample (25.8%, n=24) knew to relax and self-administer their Glyceryl Trinitrate (GTN) spray to manage the angina symptoms (NICE, 2012; SIGN, 2007). A group of just over 58% (n=54) knew to do one of these things (either take GTN or relax) but about one in ten participants (9.7%) would do neither of these things to manage any angina symptoms. A small number of

participants (4.3%, n=4) no longer thought that they would get angina symptoms after the PCI procedure and responded either 'I won't get angina now' or 'don't have angina'. No one would ignore the symptoms but some (17.2%, n=16) would call the emergency ambulance service, which would not normally be advocated at that stage for a recurrence of symptoms. Other responses included exercising, praying and taking an inhaler. Several participants gave multiple responses that could perhaps indicate that they did not necessarily know the correct management so caution must be exercised when interpreting the findings.



### Figure 4.4 Frequency of participants' limitations

Additionally, participants were asked about how they would manage a prolonged angina attack (> 15 minutes). Table 4.2 has the findings for this.

### Table 4.2Participants' management of prolonged angina episodes

Frequency (%)
47 (50.5%)
42 (45.2%)
23 (24.7%)
14 (15.1%)
4 (4.3%)
3 (3.2%)
2 (2.2%)

\* Correct management for prolonged episodes of angina (NICE, 2012)

These findings noted above provide the descriptive statistics for the sample in relation to this aspect of self-management of CHD following PCI.

### 4.4.2 Adopt and maintain a healthy lifestyle

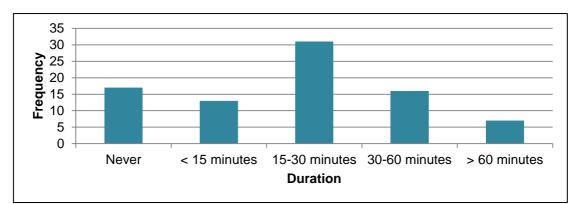
A number of questions in the Phase 1 survey related to lifestyle factors that are considered risk factors for the development of CHD. Table 4.3 provides an overview of the frequency of lifestyle changes made by the sample.

Lifestyle change	Response -	Response -	Response - About	Response -
	Yes	No	the same as before	Not applicable
Smoke less	7 (7.5%)	7 (7.5%)	3 (3.2%)	67 (72%)
Exercise more	20 (21.5%)	13 (14%)	25 (26.9%)	11 (11.8%)
Eat less fat	41 (44,1%)	7 (7.5%)	23 (24.9%)	-
Eat more fruit/	36 (38.7%)	8 (8.6%)	31 (33.3%)	-
vegetables				
Drink less	12 (12.9%)	8 (8.6%)	31 (33.3%)	29 (31.2%)
alcohol				
Weigh less	20 (21.5%)	18 (19.4%)	30 (32.3%)	-

### Table 4.3 Frequency of lifestyle changes

Participants were asked whether they smoked or not following PCI. 73 people in the sample (78.5%) reported that they either had never smoked or had given up smoking (self-reported ex-smoker). Nine participants (9.7%) admitted to continuing to smoke (8 males and 1 female) and there were a further five people who did not answer this question. They were also asked about any changes they had made to their smoking status since the PCI and seven male participants (7.5%) indicated that they had reduced the amount they smoked but this was not quantified or corroborated.

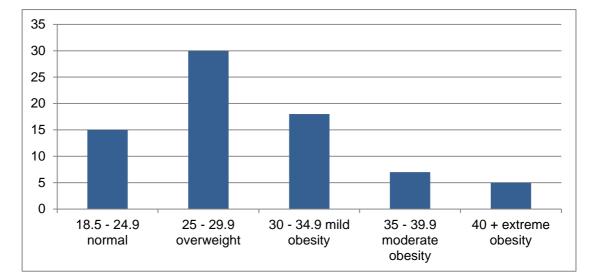
In relation to exercise, participants were asked to indicate in the survey how often they exercised. The bar chart in Figure 4.5 provides information on the distribution within the response categories.



### Figure 4.5: Amount of exercise most days

Participants were asked if they had made any changes to the amount of exercise they took following the PCI and over 1 in 5 (21.5%, n=20) participants reported that they had increased the amount. Of the 40 participants who reported that they took less than 30 minutes exercise most days, 12 had increased the amount but by how much was not quantified. There were 8 people who claimed never to exercise and none of them had started exercising post-elective PCI. Of the 17 participants who took the recommended amount of 30 minutes exercise or more most days, 8 increased the amount after the PCI procedure. Participants were given the choice of responding 'not applicable' to the question concerning the amount of exercise they took. This response was included as it was anticipated that a few of the PCI patients may have had mobility difficulties or other co-morbidities that could have prevented them from exercising. Eleven participants (11.8%) responded to the question using the 'not applicable' choice.

A number of questions in the survey related to diet. BMI was calculated for selfreports of height and weight. Illustrated in the chart in Figure 4.6 is the distribution of BMI scores according to the categories set out by SIGN (2010).



#### Figure 4.6 Body mass index range

The BMI scores ranged from 19.18 (considered normal weight) to 52.93 kg/m<sup>2</sup>, which is considered the highest category of obesity (SIGN, 2010). The mean BMI in the sample was 30.00 kg/m<sup>2</sup> (SE±6.41), which is slightly higher than the mean of the general population (BMI=27.3kg/m<sup>2</sup>) (Gray and Leyland, 2012).

One in five participants said they had lost weight since the PCI procedure (21.5%) but the amount was not quantified or substantiated and so the reliability of this could perhaps be questioned. 60 participants (64.5%) had a BMI higher than the top of the healthy range (>25 kg/m<sup>2</sup>) and of those 16 claimed to have lost weight. There were 5 participants who were found to be in the extreme obesity category with a BMI > 40kg/m<sup>2</sup> and none of them reported any weight loss after the PCI. A number of participants (19.3%, n=18) chose not to answer this question. It was not possible to ascertain whether this was due to them not knowing their weight /height or non-disclosure.

Six participants in the sample (6.5%) indicated in the survey that they ate the recommended five portions of fruit and vegetables per day. Of those who did not achieve five portions per day, 32 participants said that they had increased their fruit / vegetable intake. Participants were asked about any changes they had made to their diet since the PCI procedure, particularly in relation to eating less fat and more fruit and vegetables. 44.1% (n=41) of participants said that they had increased they were eating less fat and 38.7% (n=36) indicated that they had increased the amount of fruit / vegetables in their diet since the PCI.

The data related to diet were then combined and analysed to indicate how many of the three lifestyle factors related to diet the participants had changed after the PCI procedure (eat less fat, eat more fruit and vegetables and weigh less). Over a quarter of the sample (26.9%, n=25) had made no changes to any of these things, whereas 8 participants (8.6%) reported that they had made changes to all three.

To give a sense of any changes to lifestyle that the participants had made since the PCI (i.e. modifications to diet, exercise and smoking), the data concerning these were combined and analysed. It was noted that almost two thirds of males (n=44) compared with just over a half of the females (n=12) had made one or more changes to their lifestyle. Seven female participants and 18 males made no lifestyle modifications at all after the PCI was performed.

#### 4.4.3 Adhere to a treatment regime

Within this component of self-management of CHD following PCI, the participants were asked to indicate the regularity with which they took medicines

for their CHD. Everyone who responded (91.4%, n=85) reported that they took their medicines daily. Participants were also asked to rate their confidence in knowing how to take their medicines and all who answered this question said that they were confident (n=85).

Given that the entire sample suggested that they adhered to their daily medication regime, there was no need to perform any statistical analysis of the relationship study variables had with this.

### 4.5 Bivariate links with CHD self-management

The results from bivariate statistical tests (outlined in Chapter 3), which examined the relationship certain variables had with PCI patients' ability to selfmanage CHD after PCI are reported in this section. The relationship the variables had with participants adhering to a medication regime was not tested as all participants self-reported adherence.

An overview of the bivariate findings from the relationships between the variables and the two aspects of self-management (adopt and maintain a healthy lifestyle and monitor and manage angina symptoms) can be found in Table 4.4. An additional correlation table displaying the interaction between variables that were fixed (participants' age, sex and existence of co-morbidities) and variables that were more controllable by the patient (illness perceptions, level of education, self-efficacy and healthcare / social support) is presented in Table 4.5.

The following paragraphs will discuss the results from the correlations between the variables and the self-management components.

### *4.5.1 Bivariate links with participants' ability to adopt and maintain a healthy lifestyle*

### <u>Age</u>

An independent samples t-test was used to establish any relationship between participants' age and their ability to adopt and maintain a healthy lifestyle. The test results suggest that older participants tended to weigh less (p=0.02) and were less likely to smoke (p=0.01) than their younger counterparts in the study.

The effect that age had on the changes participants made to fruit / vegetable consumption, fat consumption and weight, was tested using independent t-tests. Age did not seem to affect PCI patients' likelihood of altering these dietary factors in the adoption of a healthy lifestyle. There was no statistically significant difference noted between the age of participants who made no dietary changes compared with those who did (66.96 vs. 67.75 years, p=0.237).

#### Existence of co-morbidities

As mentioned previously in the descriptive statistics section of this chapter, the CAD-Specific (coronary artery disease) Co-Morbidity Index was used to quantify the burden of co-existing diseases on the study participants (Sachdev *et al.*, 2004). The score generated for each participant using this Index was correlated with the different components of CHD self-management. It was found that there was a significant correlation that participants who had a high CAD-Specific co-morbidity score (i.e. significant co-morbidities) were less likely to take any exercise (r=-0.284, p=0.009). In addition, participants who had a higher CAD score tended to eat a lesser amount of fruit and vegetables although this was not statistically significant (r=-0.183, p=0.096). Those with multiple co-morbidities weighed more (r=0.342, p=0.003).

The survey questions related to participants' lifestyle were combined to provide an independent variable indicating the extent to which they had adopted a healthy lifestyle (combined smoking status, exercise frequency and dietary factors). Pearson's product moment correlation was used to test the relationship co-morbidities had with participants adopting a healthy lifestyle using this new variable and it was found that those who had a higher number of co-morbidities were less likely to adopt a healthy lifestyle. This was statistically significant at the 5% level (r=-0.351, p<0.001).

In conclusion, the existence of co-morbidities was found to link to participants' ability to adopt and maintain a healthy lifestyle. Those with fewer co-existing health conditions were more likely to make changes.

### Table 4.4 Pearson product moment correlations between influencing factors and self-management components

Self-management 1: Adopt Self-management 2: Knows how to Comments /maintain a healthy lifestyle monitor / manage angina symptoms r=-0.237\* There was a tendency for younger participants to Age r=0.129 know how to monitor and manage their angina symptoms more effectively. Co-morbidity r=-0.351\* r=0.116 Participants with co-morbidities were less likely to adopt and maintain a healthy lifestyle. The sex of the participant had no link with either r=0.051 r=0.009 Sex self-management component. r=-0.204 (hospital admissions) r=-0.196 (hospital admissions) Healthcare Hospital admissions, visits to GP and attendance at cardiac rehabilitation had no relationship with provider support r=-0.123 (GP visits) r=0.156 (GP visits) r=-0.069 (cardiac rehabilitation) r=-0.063 (cardiac rehabilitation) either self-management component. Illness perceptions r=-0.219\* r=0.325\*\* A more threatening perception of the illness made it less likely for participants to adopt a healthy lifestyle but increased the likelihood that the participant knew how to monitor and manage angina symptoms. Those who were educated beyond school level r=0.319\*\* Level of education r=0.062 were more likely to adopt and maintain a healthy lifestyle. Higher self-efficacy made participants more likely Self-efficacy r=0.364\*\* r=-0.119 to adopt and maintain a healthy lifestyle. r=-0.036 (carer) r=0.073 (carer) Social support Living arrangements and carer support had no link r=0.085 (living arrangements) with either self-management component. r=-0.023 (living arrangements)

Test used Pearson's correlation (r) \*\* Correlation significant at the <0.01 level (2-tailed) \* Correlation significant at the <0.05 level (2-tailed)

Table 4.5 Inter-variable correlation\*\* Correlation significant at <0.01 level (2-tailed)</td>\* Correlation significant at <0.05 level (2-tailed)</td>

	Age	Existence of co-morbidities	Sex
Healthcare provider support	r=-0.202 (hospital admissions) r=-0.148 (GP visits)	r=0.288** (hospital admissions) r=0.239* (GP visits)	r=0.116 (hospital admissions) r=0.068 (GP visits)
Illness perceptions	r=-0.324**	r=0.367**	r=0.012
Level of education	r=-0.165	r=-0.132	r=-0.117
Self-efficacy	r=0.130	r=-0.264*	r=-0.265*
Social support	r=0.076 (living arrangements) r=0.160 (has a carer)	r=0.207 (living arrangements) r=0.017 (has a carer)	r=-0.146 (living arrangements) r=0.225* (has a carer)

### <u>Sex</u>

Considering the number of changes participants made to their lifestyle, females made slightly more than males (mean number of changes made: female - 2.9, male - 2.8) but this was not statistically significant (p=0.643).

The proportion of current smokers in the sample was 11% and they were mainly male (n=8). Using a one-way analysis of variance test, it was found that those who continued to smoke made significantly fewer changes to their lifestyle (p<0.001; mean number of changes made: smokers - 1.8, ex-smokers - 2.8, non-smokers - 3.2).

It seemed from the findings that a larger percentage of males made changes to their diet and weight (71.0% vs. 63.0%) when compared with females, but this was not found to be statistically significant (p=0.762).

The findings therefore suggest that, apart from smoking where there is a statistically higher chance of males smoking, the sex of the participants had no link to their likelihood of adopting and maintaining a healthy lifestyle.

#### Healthcare provider support

In this sample, a quarter of the participants (25.8%, n=24) stated that they had attended a cardiac rehabilitation programme. The findings suggested that attendance at cardiac rehabilitation was not associated with a greater likelihood of lifestyle change as 95.8% (n=23) of those who had attended cardiac rehabilitation had made at least one change compared with 98.3% (n=61) of participants who had had no rehabilitation (r=-0.069, p=0.527).

Perhaps inevitably, older participants and those who had co-morbidities were more likely to have a higher number of GP consultations and hospital stays. Using cross tabulation and a chi-square test, it was found that those who had been in hospital since the PCI were less likely to adopt a healthy lifestyle but this failed to achieve statistical significance ( $\chi^2 = 28.627$ , p=0.095). The number of consultations participants had with their GP had no statistically significant relationship with the adoption of a healthier lifestyle either ( $\chi^2 = 20.819$ , p=0.408).

### Illness perceptions

There was a correlation between the perceptions participants had of their illness and their likelihood of adopting and maintaining a healthy lifestyle. Those who had higher scores in their Illness Perceptions Questionnaire, where a higher score reflects a more threatening view of the illness, were less likely to adopt and maintain a healthy lifestyle. This was found to be statistically significant using Pearson's product moment correlation (r=-0.219, p=0.045).

In addition, the bivariate analysis also demonstrated that illness perceptions correlated with other study variables. Findings showed that older participants had more chance of having a less threatening perception of their illness when compared with their younger counterparts (r=-0.324, p=0.003). As the number of co-morbidities participants had increased, the greater was their illness perceptions score (r=0.367, p=0.001). There was a correlation between illness perceptions and self-efficacy (r=-0.392, p<0.001) where greater illness perceptions equated with participants who were less confident.

From this study, it seems that positive illness perceptions, where participants had less threatening views of their illness, made it more likely for them to adopt and maintain a healthy lifestyle.

### Level of education

Using an independent samples t-test, it was found that PCI patients who were educated beyond secondary school level were statistically more likely to adopt a healthy lifestyle than participants who attended school only (p=0.001; mean number of changes made: school educated - 2.5, further education - 3.2).

### Self-efficacy

Confidence also seemed to be a factor that had a relationship with participants' likelihood of adopting a healthy lifestyle. Using correlation, it was found that there was a link between the amount of confidence / self-efficacy the participants had and them knowing how much exercise was good for them (r=0.398, p<0.001). The more self-efficacious participants were in knowing how much exercise to take, the more likely they were to change their lifestyle.

It was also found that greater confidence in maintaining normal social activity led to a greater likelihood that the PCI patient would adopt a healthy lifestyle ( $\chi^2$  = 10.781, p=0.056). There were 68 participants (73.1%) who were confident in maintaining their normal social activities who made at least one lifestyle change compared with only 15 participants (16.1%) who lacked confidence in this and made any changes (p=0.008).

72 people (77.4%) who were confident that they could maintain their normal home activities made a lifestyle change compared with only 12 (12.9%) who lacked confidence but adopted healthier behaviours (see Figure 4.7) but this was not statistically significant ( $\chi^2 = 8.181$ , p=0.147).

All of the variables related to self-efficacy were combined (confidence in: knowing how much exercise to take, knowing when to seek medical help, maintaining usual activities at home, maintaining social activities and managing their condition) to create a new variable entitled 'combined confidence level'. This new variable was used in a bivariate correlation to test the relationship between confidence and adopting a healthy lifestyle. It was found that confidence had a direct relationship (r= 0.364, p=0.001) with participants' likelihood of adopting and maintaining a healthy lifestyle.

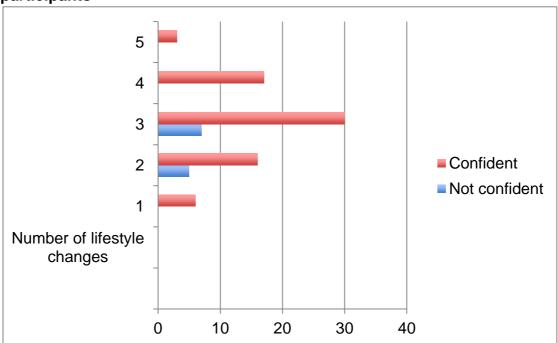


Figure 4.7 Confidence compared with number of lifestyle changes made by participants

When considering the adoption and maintenance of a healthy lifestyle component of self-management of CHD, self-efficacy seemed to increase the likelihood of this. The more self-efficacious PCI patients were, the more likely they were to adopt and maintain a healthy lifestyle.

### Social support

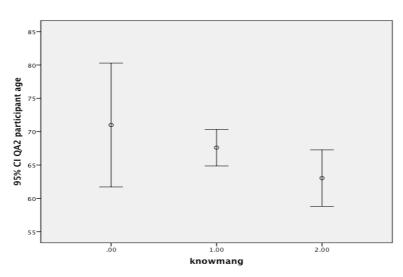
It was noted that, in the sample, 20 participants lived alone without a carer. Using an independent samples t-test, no relationship was found between the living arrangements of participants (i.e. whether they lived alone or with someone) and their adoption of a healthy lifestyle (p=0.893). Also, no statistical link was found between those who had a carer and adoption of healthier behaviours (p=0.739).

### 4.5.2 Bivariate links with participants' knowledge of how to monitor and manage angina symptoms

### <u>Age</u>

In relation to the probability that the age of the participants affected their knowledge of how to manage recurring angina symptoms, the findings suggested that younger people in the study were more likely to know how to correctly manage any recurring angina symptoms than the older participants (see Figure 4.8). (The x-axis reflects whether the participants knew both (2.00), one (1.00) or no (.00) correct angina management methods).

### Figure 4.8 Participant age compared with knowledge of angina symptom management



### Existence of co-morbidities

Correlation was used to explore the relationship co-morbidities had with the PCI sample's knowledge of how to monitor and manage any recurrence of angina symptoms but the finding was not statistically significant (r=0.116, p=0.284).

#### <u>Sex</u>

In relation to the monitoring and managing of angina symptoms component of self-management of CHD, a slightly larger proportion of females compared to males knew how to correctly manage angina symptoms but the difference was not significant ( $\chi^2$  =0.768, p=0.681).

### Healthcare provider support

In all, 25.8% (n=24) reported that they had completed a cardiac rehabilitation programme. Using cross tabulation it was noted that, if participants attended a cardiac rehabilitation programme, they were three times more likely to know how to manage any recurring angina symptoms (12.7% compared with 4.2%) compared with those who had not attended such a programme. However, there was no real difference in knowing the correct management of angina symptoms between those in the sample who were given literature about angina and its management by healthcare professionals and those who did not receive this.

GP consultations post PCI had no relationship with participants' knowledge of effective monitoring and management of angina symptoms (p=0.152). The number of times participants were in hospital did correlate with knowledge of angina symptom management as the greater number of hospital admissions after the PCI procedure, the more likely participants were to know how to manage their angina symptoms, but this did not achieve statistical significance ( $\chi^2$ =4.170, p=0.841).

#### Illness perceptions

There was a relationship between the participants' illness perceptions and them knowing the correct angina symptom management. Statistical significance was achieved in that those with more threatening views of their illness (higher IPQ scores) were more likely to know how to effectively manage recurring angina symptoms (r=0.325, p=0.002). This was confirmed using an analysis of variance test (p=0.001).

### Level of education

Although it was not statistically significant, there was a trend that participants who were educated beyond school level had more chance of knowing how to correctly manage any future episodes of angina symptoms (36.8% compared with 19.1%) when compared with those who had attended school only.

### Self-efficacy

No relationship was found between the participants' confidence level and their knowledge of effective monitoring and management of angina symptoms (r=-0.119, p=0.272).

### Social support

A cross tabulation was used to explore the association between the participants' living arrangements and their ability to know how to correctly manage recurring angina symptoms. It was found that twice as many people who lived with someone did not know how to effectively manage angina symptoms compared to those who lived alone (11.9% v. 5.0%) but this did not achieve statistical significance (p=0.594). Having a carer made no significant difference to the PCI participants' knowledge of the correct management for recurring angina symptoms.

### 4.5.3 Summary of correlations

In summary, the following variables were found to have a relationship with the PCI patients' likelihood of adopting and maintaining a healthy lifestyle: sex, existence of co-morbidity, illness perceptions, self-efficacy, level of education and the frequency of hospital admissions since the PCI procedure.

Fewer factors seemed to link with the participants' knowledge of how to monitor and manage their angina symptoms effectively. The factors that did correlate though were age and illness perceptions, although the number of times a participant had been admitted to hospital after the PCI may also have a relationship with participants' knowledge of symptom management.

### 4.6 Path Analysis

Path analysis was used to test causal relationships between the dependent and independent variables (Streiner, 2005). Path analysis differs from linear equation models in that it allows indirect pathways to be examined (Stoelting, 2002). It was chosen as opposed to linear regression models as it allowed individual relationships between variables to be tested, rather than the entire model (Foster, Barkus and Yavorsky, 2006). Using this special type of structural equation model, path analysis is able to determine the strength and significance of causal relationships between variables (Webley and Lea, 1997).

In the path models presented in Figures 4.9 and 4.10, the variables are in rectangular boxes and where variables have been combined (e.g. healthcare support and co-morbidities) the new variable is contained within an oval shape. The arrows between variables indicate the direction of the pathways and the numbers written beside each arrow are the standardised regression weights that represent the slope of the regression line between the variables. It should be noted at the outset that Path Model 1 is under fitted and Path Model 2 slightly over fitted. The results from the tests used to calculate the goodness of fit of the models can be found in Tables 4.7 and 4.9.

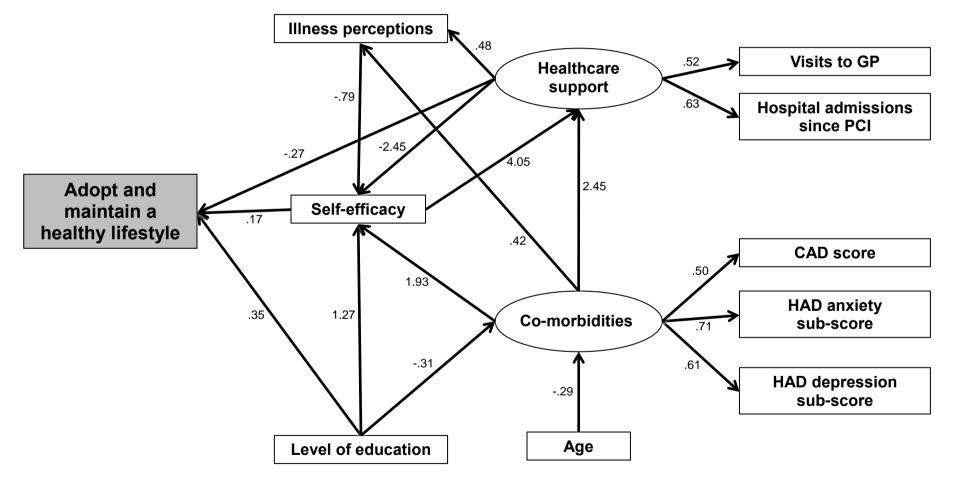
### 4.6.1 Adopt and maintain a healthy lifestyle path model

The path analysis for the 'adopt a healthy lifestyle' component of CHD selfmanagement is illustrated in Figure 4.9 and the coefficients and the significance of path coefficients are displayed in Table 4.6.

The path model was checked to ensure it had a 'goodness of fit' in accordance with the parameters set out by Hu and Bentler (1999) and the information related to these tests can be found in Table 4.6. All three tests were slightly out with the accepted parameters and so it was concluded that the model under fitted.

It can be seen from the path diagram in Table 4.6 that the main factors that directly had a relationship with participants adopting and maintaining a healthy lifestyle were the level participants were educated to (p=0.003), their self-efficacy (p=0.209) and the healthcare support they received (p=0.168). So the





### Table 4.6Coefficients of path model for 'Adopt and maintain a healthy lifestyle'

			Standardised	
Response		Stimuli	regression weights	p value
Adopt and maintain a healthy		Guinaii	Weiging	pvalae
lifestyle	÷	Education	0.347	0.003
Adopt and maintain a healthy		Healthcare		
lifestyle	$\leftarrow$	support	-0.274	0.168
Adopt and maintain a healthy				
lifestyle	<del>(</del>	Self-efficacy	0.173	0.209
Healthcare support	←	Self-efficacy	4.048	0.412
		Healthcare		
Self-efficacy	←	support	-2.454	0.22
Healthcare support	<b>←</b>	Co-morbidities	2.448	0.319
Self-efficacy	←	Co-morbidities	1.925	0.305
		Level of		
Self-efficacy	←	education	1.269	0.196
o // //		Illness	0 70 4	0.500
Self-efficacy	←	perceptions	-0.791	0.529
HAD anxiety sub-score	←	Co-morbidities	0.713	<0.01
		Healthcare		
Hospital admissions since PCI	←	support	0.631	<0.01
HAD depression sub-score	÷	Co-morbidities	0.611	_
		Healthcare		
Visits to GP	÷	support	0.524	-
CAD score	←	Co-morbidities	0.503	<0.01
		Healthcare		0.007
Illness perceptions	←	support	0.48	0.035
Illness perceptions	÷	Co-morbidities	0.418	0.021
		Level of		
Co-morbidities	<del>\</del>	education	-0.313	0.021
Co-morbidities	÷	Age	-0.29	0.02

### Table 4.7 Fit of path analysis for 'Adopt and maintain a healthy lifestyle'

Test	Statistical finding	What is considered to be a 'good fit'
Comparative Fit Index (CFI)	0.932	P value should be >0.95
Root Mean Square Error of Approximations (RMSEA)	0.068	P value should be <0.06
CMIN	1.397	Should be close to $1 \pm 0.2$

more educated and self-efficacious the participants were, the greater was the likelihood that they would adopt and maintain a healthy lifestyle. Participants who had more contact with their GP or had been admitted to hospital were less likely to change their lifestyle factors.

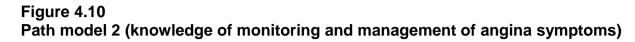
Within the path model there were several factors that had indirect relations with this self-management component. As indicated in the model, the illness perceptions of the participants seemed to link with co-morbidities (p=0.021) and healthcare support (p=0.035) where an increasing number of co-morbidities and support led to participants having a more threatening perception of their CHD. Illness perceptions also related to participants' self-efficacy; less confident participants had a higher illness perceptions score. The number of co-morbidities participants had related to their age as older participants had a greater number. This also had a relationship to the amount of healthcare support they required as well as their level of education.

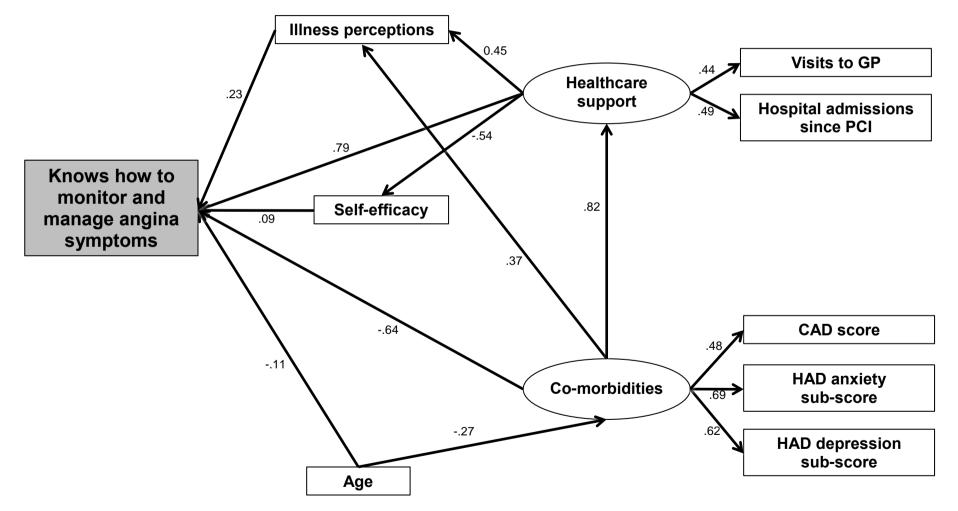
Despite achieving statistical significance at bivariate level, the findings from the multivariate path analysis suggest that the number of co-morbidities that each participant had did not have a direct relationship with their likelihood of adopting and maintaining a healthy lifestyle. Co-morbidity had an indirect link to this self-management component through self-efficacy and illness perceptions. Illness perceptions itself had an indirect link with this aspect of self-management of CHD (through self-efficacy). The multivariate findings therefore, established several pathways, which were not possible to extrapolate from bivariate analysis.

## 4.6.2 Knowledge of monitoring/ management of angina symptoms path model

Path analysis was also used to ascertain any causal influences between the variables and the participants' knowledge of angina symptom monitoring and management. Figure 4.10 illustrates the findings of this path analysis. The coefficients and their significance are displayed in Table 4.8. Again the model was tested for goodness of fit and the data for this can be found in Table 4.9.

This path analysis indicated that there were five factors that had a direct causal relationship with the PCI participants' knowledge of how to monitor and manage





### Table 4.8 Coefficients of path model for 'Knows how to monitor and manage angina symptoms'

			Standardised regression	
Response		Stimuli	weights	p value
Knows how to monitor and				
manage angina symptoms	<del>(</del>	Healthcare support	0.785	0.467
Knows how to monitor and			0.044	0.400
manage angina symptoms	<del>(</del>	Co-morbidities	-0.641	0.402
Knows how to monitor and				
manage angina symptoms	<del>(</del>	Illness perceptions	0.225	0.549
Knows how to monitor and			o	
manage angina symptoms	<del>(</del>	Age	-0.114	0.288
Knows how to monitor and		0 16 16	0.004	0 505
manage angina symptoms	<del>(</del>	Self-efficacy	0.094	0.585
Healthears augment	←	Comorbidition	0.822	0.005
Healthcare support		Co-morbidities	0.022	0.005
HAD anxiety sub-score	←	Co-morbidities	0.69	<0.01
TIAD anxiety Sub-Score	`	CO-morbialites	0.09	<0.01
HAD depression sub-score	←	Co-morbidities	0.622	_
		00-morbidities	0.022	
Self-efficacy	←	Healthcare support	-0.536	0.004
Hospital admissions since	<u>`</u>		0.000	0.001
PCI	←	Healthcare support	0.488	0.001
CAD score	←	Co-morbidities	0.482	<0.01
Illness perceptions	←	Healthcare support	0.447	0.361
· ·				
Visits to GP	←	Healthcare support	0.44	-
Illness perceptions	←	Co-morbidities	0.371	0.391
Co-morbidities	$\leftarrow$	Age	-0.269	0.035

### Table 4.9

### Fit of path analysis for 'Knows how to monitor and manage angina symptoms'

Test	Statistical finding	What is considered to be a 'good fit'
CFI	0.953	P value should be >0.95
RMSEA	0.057	P value should be <0.06
CMIN	1.28	Should be close to $1 \pm 0.2$

angina symptoms: age (p=0.288), co-morbidities (p=0.402), healthcare support (p=0.467), illness perceptions (p=0.549), and self-efficacy (p=0.585).

The path analysis results were compared with the findings from the bivariate correlations tests performed previously. Both types of analysis found that there was a relationship between younger participants and a greater likelihood of knowing how to monitor / manage angina symptoms. The link between co-morbidities and this self-management component differed between both analyses; in bivariate there was no link noted but at multivariate level, a direct relationship was discovered. It was found that the greater the number of co-morbidities the participants had, the less likely they were to know how to monitor / manage their angina symptoms. Findings from the path analysis also suggested that more threatening perceptions of CHD made it more likely for participants to know how to manage angina symptoms and this concurred with the bivariate results. Despite no relationship being found at bivariate analysis level, multivariate analysis suggested that more chance of knowing how their angina symptoms should be managed.

### 4.7 Findings and theoretical frameworks

The third research question identified in Chapter 3 was if the Social Cognitive Theory or Self-Regulation Model helped explain CHD self-management in a PCI population.

The first stage in the hierarchical structure of the Self-Regulation Model identified in Chapter 2 relates to the representations the participants had of their illness. The PCI participants' cognitive beliefs of their CHD were measured in Phase 1 using the Brief IPQ (Broadbent *et al.*, 2006). Initial tests found that illness perceptions did correlate with two components of self-management (adopt and maintain a healthy lifestyle and monitor and manage angina symptoms).

The findings indicated that there was a greater chance that PCI participants with higher IPQ scores (greater illness threat) were more likely to know how to

monitor and manage any recurring angina symptoms. The Self-Regulation Model alone cannot explain the reason for this. As this Model's premise is that people are all problem-solvers who adopt individualised coping strategies based on a number of factors, including knowledge, past experience of illness, vicarious experiences and comparisons with society, the notion why those with the most threatening perception of their illness were more likely to know how to manage their angina symptom remains unexplained from the Phase 1 findings.

The findings suggested that the more threatening the participants' perceptions of the illness were, the less likely they were to adopt or maintain healthy behaviours. It seems difficult though to relate the results from this phase of the study to the Self-Regulation Model premise that people are problem-solvers. The findings indicate that a more threatening perception of the CHD does not stimulate a problem-solving response that sees PCI patients adopt more healthy behaviours. Illness perceptions also correlated with participants' self-efficacy (p<0.001).

The path analysis was then used to further test these correlations. It was found that illness perceptions had a direct link with the participants' knowledge of how to monitor and manage their angina symptoms but an indirect relationship (through self-efficacy) with their likelihood of adopting a healthy lifestyle. This suggested that the Self-Regulation Model could, in part, be used to explain CHD self-management but further exploration of the coping strategies adopted by the participants and the appraisal of the effectiveness of these strategies was needed before conclusions could be drawn. These findings were therefore built on in Phase 2.

Bandura's Social Cognitive Theory (Bandura, 2001) is complex and the notion that there are environmental and personal factors that influence people's behaviour and knowledge acquisition was difficult to measure using the quantitative data. The Pearson product moment correlation tests found that higher levels of self-efficacy made it more likely that study participants would change to a healthier lifestyle. No link between the confidence levels of the sample and their likelihood of knowing how to manage angina symptoms was found at bivariate analysis level. The multivariate analysis confirmed the original correlation between self-efficacy and the participants' likelihood of adopting and maintaining a healthy lifestyle. A direct link was found between knowledge of how to monitor and manage angina symptoms and self-efficacy but this was in contrast to the bivariate findings. Consequently, from these findings, it was not clear if the Social Cognitive Theory could be used to explain CHD self-management in a PCI patient population. The self-efficacy part of the theory linked to some aspects of self-management but not all.

The Phase 1 findings were, therefore, not able to address the third research question in full and so the Phase 2 data collection was embarked upon to complement what was found in Phase 1.

### 4.8 Summary of findings

The sample recruited for the study differed in some ways from the general population and previous PCI patient populations but the majority of the differences were slight and not found to be significant. This could be attributed to the sampling method chosen (convenience sampling).

Descriptive statistical tests were used to measure participants' selfmanagement of CHD. The aspects of self-management were split into three categories and the findings of each reported separately (monitor and manage angina symptoms, adopt and maintain a healthy lifestyle and adhere to a treatment regime).

### 4.8.1 Adopt and maintain a healthy lifestyle

- Most of the participants did not smoke. Of those who did, the majority reported that they had reduced the amount.
- Less than a quarter of the sample took the recommended amount of exercise but 1 in 5 participants reported that they had increased the amount of exercise they took since the PCI procedure.
- Two thirds of the sample had a BMI greater than the recommended healthy range.
- The majority of the sample did not eat five portions of fruit and vegetables each day.
- Over a quarter of the sample indicated that they had made no changes

to their diet since the PCI procedure.

- Over a quarter of the sample had made no changes to their lifestyle.
- Two thirds of males and half of the females had changed one or two aspects of their behaviour to be healthier.

### 4.8.2 Monitor and manage angina symptoms

- Almost half the sample reported that they had experienced ongoing angina symptoms after the PCI.
- A few patients in the study were unable to determine whether they had any angina symptoms or not.
- A quarter of the sample knew to take GTN spray and rest when angina symptoms returned.
- For prolonged episodes of angina, under half indicated that they would call for emergency help.

### 4.8.3 Adhere to a treatment regime

All of the participants who returned their questionnaire reported that they took the medication for their heart condition every day and that they were confident in knowing how to do this.

### 4.8.4 Bivariate and multivariate relationships with self-management

The findings from bivariate analysis showed that sex, age, co-morbidities, illness perceptions, self-efficacy, level of education and healthcare provider support correlated with participants' likelihood of adopting and maintaining a healthy lifestyle. The factors that had a relationship with that component of selfmanagement were further tested using multivariate path analysis and it was found that the level participants were educated to, healthcare support, and selfefficacy had direct relations with their likelihood of adopting and maintaining healthy behaviours. Illness perceptions and the presence of co-morbidities in participants had an indirect link through self-efficacy.

Initial bivariate analysis found fewer variables correlated with participants' knowledge of how to monitor and manage their symptoms of angina. The correlations with this self-management component were: age and illness perceptions. It also seemed that the participants' level of education and

healthcare provider support could also have had a relationship with their knowledge of how to monitor and manage angina symptoms. Multivariate analysis (path analysis) was used to explore the links and it was found that five factors had direct relationships with this self-management component: healthcare support, presence of co-morbidities, illness perceptions, age and self-efficacy. It was noted, however, that the goodness of fit for both path models could be better and so the model was not strong.

As indicated previously all of the participants reportedly adhered to a treatment regime and so it was not necessary to test the relationship the study variables had with that self-management component.

### 4.8.5 Theoretical frameworks

The self-efficacy aspect of the Social Cognitive Theory and the illness perceptions component of the Self-Regulation Model were explored in Phase 1. How these theories could help explain CHD self-management was not fully explored in the first phase of the study and so further investigation was necessary in Phase 2.

### 4.9 Findings for further exploration in Phase 2

Several variables correlated with two components of CHD self-management (knowledge of symptom monitoring / management and adoption and maintenance of a healthy lifestyle). Some of these relationships have been found in previous studies but a number of them appear to be new for this patient population. All participants reportedly adhered to their medication regime and this finding was unexpected. This was consequently followed up in Phase 2.

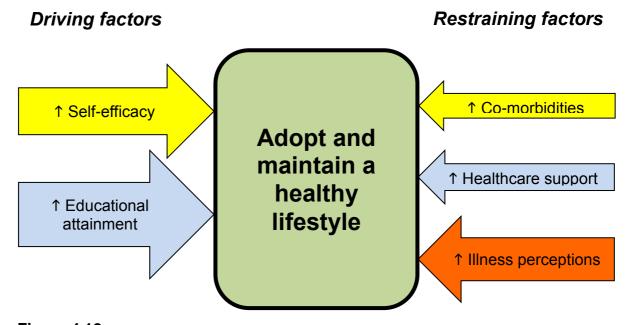
Colour-coded modified force field diagrams are used in this section of the chapter to highlight what is known about the relationships found with bivariate analysis and also to provide clarity to the variables that helped / hindered CHD self-management. The diagrams were colour coded as follows:

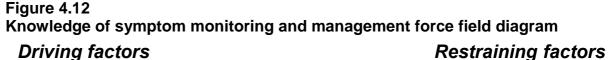
• Yellow arrows for relationships already known between variables and the self-management components in PCI patient cohorts.

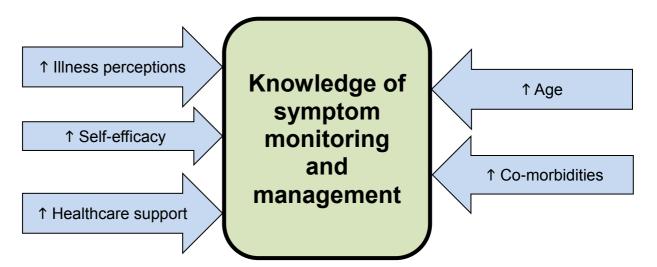
- Blue arrows indicate seemingly new relationships in PCI groups.
- Orange arrows indicate results that contradict previous research.

Figure 4.11 illustrates the force field diagram for the adoption and maintenance of a healthy lifestyle component of CHD self-management and Figure 4.12 illustrates the diagram for knowledge of effective symptom management.

### Figure 4.11 Adopt and maintain a healthy lifestyle force field diagram







Within these diagrams 'driving factors' are the variables that increased the likelihood of participants adopting and maintaining more healthy lifestyles and knowing effective symptom management. 'Restraining factors' had the opposite effect. The relative importance of each variable is indicated by the strength of the arrow in the force field diagrams (Northumbria University, 2012). Where variables were found to have a statistically significant relationship with the self-management component in both bivariate and multivariate analysis, the arrows are widest. When variables were significantly linked at bivariate level, but had no direct relationship to the CHD self-management component at multivariate analysis, the arrow.

Particular attention and exploration in Phase 2 was given to findings that had never been documented before for a PCI patient sample.

### Chapter 5 Findings from Phase 2

### 5.1 Introduction

As suggested in the methods chapter (Chapter 3), the premise within this study was that the mixed methods design would provide a more comprehensive understanding of the phenomenon in question than what could be achieved using either quantitative or qualitative analysis alone (Creswell and Plano Clark, 2011; Driscoll *et al.*, 2007). The primary intention of this sequential, explanatory mixed methods study was to use the data collected from the participant interviews to help explain the survey findings from Phase 1 so that the research questions could be answered in full. It was intended that the interview questions would explore the unexplained, unexpected and ambiguous quantitative findings (i.e. those set out in section 4.09 of the preceding chapter).

As suggested by Creswell (2010), the structure of a thesis for a mixed methods study should align with the study design. Where an explanatory, mixed method design has been used, it is important to ensure transparency when writing how the qualitative data help to explain the quantitative findings. While ensuring the explanatory nature of the study is followed, it is essential to demonstrate through methodological clarity, the rigour and trustworthiness in the 'journey' of, and the approach to, qualitative data analysis (Lincoln and Guba, 1985). This chapter will, therefore, seek to highlight the qualitative findings which further explain the results from Phase 1 but it will also ensure the 'audit trail', which is integral to any analysis of qualitative data, is outlined.

The chapter will begin with a discussion of how the qualitative data were prepared for analysis. Then an overview of the audit trail of the process adopted during data analysis and theme development will follow. The findings will be discussed within the three overarching themes that emerged from the qualitative data analysis. Within that discussion, particular emphasis will be placed on findings that contribute to new knowledge. How the theories helped to explain the phenomenon will also be discussed throughout the chapter.

### 5.2 Exploring the qualitative data

As indicated in Chapter 3, a hybrid approach to thematic analysis was used to search for themes emerging from the Phase 2 data that were important to the research phenomenon and study design. This approach complemented the study design by allowing the phase 1 findings to be integral to the process of deductive thematic analysis while enabling new themes to develop through inductive coding.

The deductive approach suggested by Crabtree and Miller (1992) used A priori topic codes based on the Phase 1 findings and the research questions to help inform the initial coding of the data. It was deemed essential to use pre-set codes to enhance the explanatory nature of the study. A list of the A priori codes can be found in Table 5.1. These codes were used as the basis of the coding framework. As indicated previously in the methods chapter, it was essential that information derived from the qualitative data was not confined to deductive coding as this could perhaps stifle the emergence of new themes specific to Phase 2. Therefore, to ensure the qualitative data were explored fully, an inductive approach to data analysis was also used. The preparation of the qualitative data and a more in depth account of the approach to data analysis is detailed in section 3.8.4 in the methods chapter but an overview of the audit trail of qualitative analysis follows.

Once the transcripts had been read and re-read several times to allow preliminary examination of the data to be carried out (Creswell and Plano Clark, 2011), initial deductive coding was completed. The transcripts were then reexamined and inductive coding was done. As the thematic analysis progressed, the researcher used an iterative process to refine the codes and categories (Barbour, 2008). Using a colour coding system, the researcher selected both inductive and deductive codes that could be linked together in a sub-theme. The sub-themes were then grouped into overarching themes. An example of an annotated transcript can be found in Appendix 13. The coding framework was then systematically checked to ensure it represented the qualitative data in each transcript and as a result, alterations were made to some of the topic codes. For example, the topic codes that related to participants' understanding were re-defined as "what CHD means to me / participants' perceptions" to more accurately reflect what the topic code concerned. The emotional response participants had to their CHD emerged as an important subject area and so the emotions were added as topic codes. Thereafter, the topic codes were considered and refined to ensure there was no duplication and that each was discrete. At that stage, the consequences of CHD seemed to overlap with the 'what CHD means to me' topic code. Also, coping strategies their appraisal appeared to be covered within the code 'how I manage my symptoms' and so these codes were removed as discrete codes to avoid duplication.

### Table 5.1 Initial Coding Framework

Topic codes	
Understanding cause of CHD	Personal support
Consequences of CHD	Social support
Understanding need for PCI	Healthcare support
Secondary prevention of CHD	Cardiac rehabilitation
Understanding need for risk reduction	Understanding of action of medication
Symptom monitoring	Medication adherence
Symptom management	Self-efficacy
Coping strategies	Appraisal of coping strategy success

After the iterative refining process was complete, the reliability of the codes and coding process was tested through comparison with the codes generated by a researcher independent to the study (i.e. outsider validation). No further alteration to the codes was made following this process.

Once the topic codes were decided upon, relevant data were collated for each topic code. Thereafter, the codes were collated into possible sub-themes and these were subsequently grouped according to their topic area to form 'overarching themes'. Within each transcript and then across all transcripts, the sub-themes and overarching themes were checked against the initial topic

codes to ensure they were representative of the data. Also the themes were reviewed to ensure the name reflected what the theme concerned. A further test of the credibility of the Phase 2 findings was carried out by means of member validation. As indicated in section 3.8.5, participants were sent their transcripts and they subsequently corroborated that the transcripts were accurate and the emerging themes seemed reasonable.

### 5.3 Emergent themes

Three main overarching themes emerged from the Phase 2 data analysis. They were:

- Emotional response
- Perceptions of CHD self-management
- Support

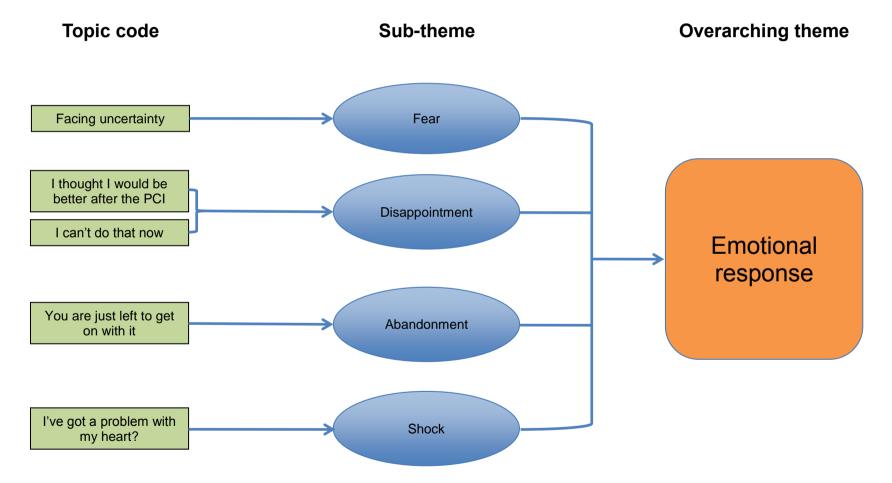
Analysis and interpretation of the Phase 2 data was guided by the research questions and the Phase 1 findings. In the following sections of the chapter, the findings from each overarching theme will be discussed. The data for each subtheme will be outlined and salient quotes from the participants will be used to support the discussion. Extracts from the transcripts will be referenced according to the participants' unique codes and to provide further contextualisation, their sex and age will also be provided in brackets.

### 5.4

### **Overarching Theme: Emotional response**

The emotional impact of having and trying to manage CHD after PCI was not evident from the quantitative data in Phase 1 but the interviews allowed participants to share their feelings with the researcher. As a result, 'emotional response' was established as an overarching theme (see Figure 5.1). This topic area and how the participants' emotions contributed to the explanatory nature of this study concerning CHD self-management will be outlined in the following section.





### 5.4.1 Fear

Fear is defined as "*a set of responses to a known, precise, well defined threat, which can be real or vividly imagined*" (Psychology Solution, 2014; no page). McGlasson (2007) suggests that fear relates to the feelings a person experiences that are caused by perceptible, realistic dangers and these feelings are proportionate to the actual threat or perceived danger. Fear is an emotion commonly cited by cardiac patients (Vosbergen *et al.*, 2013; SIGN, 2002) and, generally, this is attributed to two of the five main fears people have: fear of death and fear of disability as a result of disease (Albrecht, 2012). Fear is an important topic as it has been found to increase patients' risk of CHD progression (Spindler *et al.*, 2007).

### Facing uncertainty

Two thirds of interviewees seemed to fear the uncertainty of what the future would be like living with CHD and eight of the ten interviewed were scared that they would die as a result of their CHD.

### *"Well, you know that there's got to be something that goes wrong."* (Participant 70 – Male, 85)

"I am maintaining them [normal activities] but I don't know how long I will be able to. I mean one must face the fact that it is going to get worse..." (Participant 93 – Male, 82)

Fear appeared to precipitate a pessimistic outlook in the current study and this has been previously found in Stafford, Jackson and Berk's (2008) longitudinal study that sampled patients with mixed manifestations of CHD including myocardial infarction and those requiring coronary revascularisation. The proportion of PCI patients in the sample was not stipulated in the publication and that compromises the ability to generalise the findings to a PCI patient group. While Stafford, Jackson and Berk's study included PCI patients, all participants were treated as a homogenous group and it was not possible to extrapolate the data for different patient groups. There is a risk, therefore, that these groups differed in their illness perceptions and that the generalised findings from the study did not reflect those of the PCI patients in the sample.

Results from previous studies suggest that cardiac patients are scared of the consequences of having CHD, but most studies focused on patients after CABG surgery (Koivula, Hautamaki-Lamminen and Astedt-Kurki, 2009; Leegaard and Fagermoen, 2008) or had samples with patients of mixed manifestations of CHD e.g. myocardial infarction, CABG surgery and PCI (Vosbergen *et al.*, 2013; Rosenfeld and Gilkeson, 2000). The data from the current study indicates that fear is an important barrier to effective CHD self-management and this now has been found specifically in an elective PCI patient population.

Fear appeared to link to two factors that were found to have a relationship with CHD self-management in Phase 1: illness perceptions and self-efficacy. Around a third of interviewees in the current study had particularly threatening illness perceptions. They were frightened because they believed that they would die if they engaged in physical exercise.

### *"Exercise, I am a little scared what the effect is on my heart."* (Participant 86 – Male, 77)

A mixed sample of cardiac patients, including those who had been revascularised using PCI, in a qualitative study by Karner *et al.* (2005) had the same perception. Although Karner *et al.* collected data by means of semistructured interviews, these were not transcribed as usually done but instead were 'documented by hand' (Karner *et al.*, 2005; Page 263). Consequently, this meant that researchers may have interpreted the responses participants gave during the interviews and that could affect the trustworthiness of the findings.

LaPier, Cleary and Kidd (2009) concluded from their study of cardiac patients also with mixed diagnoses that those who were more frightened were less likely to exercise as much as they should. Two thirds of the interviewees cited examples of coping with their fear by limiting their activities as a result of what could happen and this affected their likelihood of adopting more healthy behaviours. This concurs with previous research of angina patients but not after PCI (Taylor-Piliae and Molassiotis, 2001). For example **Participant 57** was frightened of recurring angina symptoms and dying and so her coping strategy was to confine herself to her home, which severely restricted her ability to exercise. "It happened once, so could it happen again and could it be worse this time... Am I just going to just drop?...You know, you question your mortality...so I just lay about..." (Participant 57 – Female, 60)

This quote from Participant 57 was intriguing as she had also indicated during interviews that she thought the CHD had been cured after the PCI procedure and a similar situation was found of two other interviewees. The fear in the case of these people seemed to relate to the notion that they had experienced angina symptoms at least once and although these had resolved after the PCI, there was a threat of recurrence, or indeed suffering a more serious cardiac event.

The link between fear, participants' illness perceptions and subsequent coping strategies relates well to the Self-Regulation Model. It appeared that all eight interviewees who talked of their fear had adopted maladaptive coping strategies and that the emotional representations of the illness seemed to influence the cognitive representations. This has not been found in PCI patients previously, but it is known from findings of a study of diabetic patients (Jayne and Rankin, 2001).

The monitoring of angina symptoms seemed less effective in interviewees who were frightened. As suggested previously, fear caused some interviewees to perceive that they were going to die and they interpreted their bodies' normal physiological response associated with that emotion as recurring angina.

### "If you think about your heart, you hear flutterings and you think oh, is that a palpitation or a fluttering?" (Participant 90 – Male, 65)

This exacerbated their illness representations and made them believe that their CHD was a more serious illness and this is consistent with the results of Pedersen *et al.* (2006).

It is known that misconceptions about the cause of angina symptoms can affect the emotional response (e.g. fear) that can, in turn, lead to the adoption of maladaptive coping strategies (Furze *et al.*, 2001). Phase 1 data shows that five out of eight frightened interviewees would summon emergency healthcare support for any recurrence of angina symptoms which would not be advised unless the attack was prolonged (see Table 5.02). The two interviewees who did not mention fear, however, also indicated that they would summon emergency help from healthcare personnel and that suggested that they too did not feel equipped to deal with their angina symptoms alone. Therefore, it seems that fear affected participants' illness perceptions, which, in turn, influenced their coping strategies for recurring angina symptoms.

It was anticipated that fear would increase the participants' anxiety levels and so the HADS anxiety sub-scores from Phase 1 were examined. These, however, all appeared within normal limits for the interviewees (see Table 5.2) and so the HADS did not seem to detect anxiety caused by fear.

Participant	Fearful	Call	Call	*Rest	*Take	HAD anxiety sub-score
		999	GP		GTN	(>11 indicates mood disorder)
Participant 14	Х		Х		Х	4
(Female, 82)						
Participant 57	Х		Х		Х	4
(Female, 60)						
Participant 70	Х				Х	2
(Male, 85)						
Participant 80	Х		Х		Х	1
(Male, 68)						
Participant 86	Х	Х			Х	2
(Male, 77)						
Participant 87			Х	Х	Х	6
(Female, 72)						_
Participant 88	Х	Х	Х			0
(Male, 65)						_
Participant 90	Х				Х	2
(Male, 65)						_
Participant 91		Х		Х	Х	7
(Male, 66)						-
Participant 93	Х				Х	0
(Male, 82)						-

# Table 5.2Fear compared with participants' angina symptom management (fromPhase 1)

\*Correct management of angina symptoms

The fear that several interviewees spoke of also seemed to affect their confidence and this appeared to impact on their self-management, particularly their adoption of healthier lifestyles. It is known that self-efficacy can be affected by fear (Bandura, 1995) and so this links to the Social Cognitive Theory. A few participants seemed to recognise their decreased self-efficacy.

"To begin with I think I lost a bit of confidence...at the back of your mind you are thinking goodness I hope nothing happens to me." (Participant 14 – Female, 82)

It seems, therefore, that fear was a contributing factor to participants' illness perceptions, making their CHD seem more threatening. Fear also contributed to the lowering of participants' self-efficacy. This was not evident from the Phase 1 findings and helps to provide more insight into why participants perceived their condition as more threatening. It also allows more understanding of the reason for participants to have lower confidence levels. Both the threatening illness perceptions and low self-efficacy resulted in suboptimal CHD self-management. Fear appeared to be a barrier to effective symptom monitoring and management and made it less likely for the participants to adopt more healthy lives.

Summary of sub-theme findings:

- Fear was a significant factor in the majority of those interviewed and linked to their illness perceptions and self-efficacy.
- Fear affected participants' ability to monitor and manage their angina symptoms and their adoption of more healthy behaviours by influencing their illness perceptions and lowering self-efficacy.
- Participants who were fearful did not manage their symptoms appropriately.
- Participants' emotional representations of CHD influenced their cognitive representations and this links to the Self-Regulation Model.
- Anxiety caused by the fear of CHD was not detected using the HADS.

### 5.4.2 Disappointment

Disappointment is an emotion that people experience once they realise or believe that an outcome could have been better (Marcatto and Ferrante, 2008). While little is written about patients feeling disappointed after coronary revascularisation with PCI, it seemed evident from the interviewees that this was a relatively common emotion.

### I thought I would be better after the PCI

As indicated previously in the literature review, recurrent angina symptoms are relatively common in patients after PCI (Gallagher *et al.*, 2008a; Nones-Cronin *et al.*, 2000) and this affected half the Phase 2 sample. The interviewees who had experienced angina symptoms after the procedure spoke of their disappointment that it had, in their opinion, not been successful.

"It's quite disappointing because I was thinking that the heart is getting the blood through now and it should be okay...I feel I should be up and about now and really getting on with it." (**Participant 87** – Female, 72)

It is known that those who continue to be symptomatic perceive their condition as more serious (Ozkan, Odabasi and Ozcan, 2008; Pocock *et al.*, 2000; Permanyer-Miralda *et al.*, 1999) and for some, this makes them feel 'disabled' (Van Domburg *et al.*, 2001) and that can lead to a reduction in functional status (Furze *et al.*, 2005). Interviewees who were disappointed because their angina symptoms had returned appeared to have more threatening illness perceptions that reduced their confidence and restricted their activity.

### "After it I actually felt terrible...I just felt horrible...I was lying about... I thought, is this the way it's going to be? Is my life over?" (Participant 57 – Female, 60)

The recurring angina symptoms led the interviewees to perceive that they had little control over their CHD and that subsequently compromised their adoption of a healthy lifestyle.

Similar to fear, disappointment appeared to cause four interviewees to have difficulty in monitoring angina symptoms. They seemed sure that the angina symptoms were attributed to the 'unsuccessful PCI' and believed that there was little they could do to self-manage.

"I am hoping that this is just a little blip at the moment and I am trying to give it time to work because it's certainly not working at the moment... so I will just have to hope it will all sort itself out."

(Participant 87 – Female, 72)

The disappointment seemed to link to the expectations patients had that the PCI procedure would alleviate all angina symptoms. Disappointment appeared

to alter the participants' emotional illness representations and this negatively affected their subsequent coping strategies as it caused them to restrict their activity and have difficulty monitoring and managing their angina symptoms. That impacted on their CHD self-management. It seems that the emotional representation of CHD again influenced the cognitive representation and so this has clear links with the Self-Regulation Model.

No studies were found that concluded that disappointment after PCI linked to patients' self-management and so it was not possible to compare these findings with other research. It seems that this is the first study to report this.

Summary of sub-theme findings:

- Recurrent angina symptoms after PCI are commonly attributed to an unsuccessful PCI procedure and the expectations participants have of the procedure resulted in feelings of disappointment.
- Disappointment seemed to affect participants' self-efficacy, illness representations and subsequent coping strategies that led them to be less likely to exercise and have some difficulty monitoring and managing their angina symptoms.
- Disappointment that the procedure was ineffective led to feelings of powerlessness to manage their condition.
- No studies have been found which have considered disappointment as a prohibitive factor to effective CHD self-management.

### I can't do that now

Although Ghezeljeh, Nikravesh and Emami (2013) found that the majority of angina patients in their grounded theory study had come to terms with the limitations of their illness, that was not evident in the current study. Their study sought to understand the experiences of Iranian patients living with CHD. Participants (n=24) with stable angina included in the research by Ghezeljeh, Nikravesh and Emami (2013) adopted strategies to re-establish their normal life and these included having a positive emotional outlook on life, undertaking roles that they had prior to having angina symptoms and perceiving that they were in control of their lives. In contrast, in the current study, seven participants described feelings of regret that they were no longer, in their mind, able to do some of the things that they had previously. Rather than re-establish their 'normal life' they believed that their life had changed and that was disappointing for them. Perceived inability to exercise or perform certain tasks was the most commonly cited reason why participants felt disappointed. For example:

### "I put off going back to badminton...the thought of how unfit I would be...I don't think I will ever go back." (Participant 90 – Male, 65)

Le Grande *et al.* (2006) found that negative emotion impacted on PCI patients' activity but they offered no reason for the negativity, whereas this study has found that feelings of disappointment were a result of the perceived restrictions the participants had of their illness. This is important as Van Domburg *et al.* (2001) found that a significant predictor of mortality ten years after PCI was patients' beliefs that they were limited in their functional status. Although disappointment was not found to be the only inhibitor of activity, this study has found that it is certainly a contributing factor.

The perception of not being able to do certain things appeared to cause half the interviewees to become more socially isolated and it is known that this can affect patients' psychological well-being and cause depression (Furze *et al.*, 2005; Sarason and Sarason, 1985).

### "I don't play golf now. I have quit that...I hoped I would get back but I have decided that's not going to happen...I miss the pals at golf and the chat at golf you miss that..." (Participant 70 – Male, 85)

The HADS scores for the depression sub-scale in Phase 1 were within normal range and so either the disappointment had not caused any of those interviewed to become clinically depressed or the measurement tool (HADS) was not sensitive enough to detect this.

Although most of the emotional responses of the participants tended to link to exercise, disappointment was also evident in relation to diet. Patients with CHD are advised to adopt a diet that is low in saturated fat and salt and rich in oily fish, fruit, vegetables, whole grains and nuts to lessen the risk of disease progression (Joint British Societies, 2014) and with that in mind, three interviewees felt disappointed that their diet was restricted.

### "I would eat cheese until it came out of my ears...I just stopped it altogether...it's out of my diet, it's awful..."

### (Participant 91 – Male, 66)

On the whole, however, where interviewees said that they were disappointed that they could not have certain foods, they had adopted a more healthy diet.

"...what I used to do was live on these prepared meals...and I thought they were great...then the nurse told me, or pointed out to me the salt content. The salt content is horrendous. So I have stopped eating those...I decided to cut out red meat. I still eat chicken but I eat a lot of salmon and vegetables." (Participant 80 – Male, 68)

Phase 1 data showed that despite disappointment with dietary restrictions, these three participants reported that they ate less fat, more fruit and vegetables and drank less alcohol. The link between disappointment, illness perceptions and dietary restrictions, therefore, actually seemed to make participants more inclined to alter that aspect of their lifestyle and this seemed to relate to their perceptions of being able to control their CHD through dietary changes. It was not possible to compare this finding with other studies as no research was found which linked these two things in PCI patients.

The qualitative data suggest that disappointed arose when participants believed that they were restricted in their activity. This perception of reduced functionality seemed to exacerbate the problem and cause them to restrict their activity more. Other participants who felt disappointed with perceived dietary restrictions appeared to be more successful at eating foods that were healthier. Feelings of disappointment, therefore, seemed to influence participants' illness perceptions but the subsequent effect that had on CHD self-management was polarised.

Summary of sub-theme findings:

- Participants said that they were disappointed that they could not exercise, perform certain tasks or eat particular foods.
- This emotion influenced their illness perceptions.
- Those who were disappointed that they had a perceived restriction in their functional status were less likely to exercise and so their ability to adopt that aspect of a healthy lifestyle was compromised.

- Participants who were disappointed with perceived dietary restrictions were more likely to make changes to their diet to control their CHD.
- Depression caused by disappointment with physical and dietary limitations was not detected using the HADS.

### 5.4.3 Abandonment

Abandonment in the context of this study was a term used to describe an emotion generated in participants who believed that support for them was either insufficient or had ceased (Oxford University Press, 2014). The notion of abandonment was a sub-theme that was created to describe participants' feelings where they felt healthcare support was lacking.

### You are just left to get on with it

Support from healthcare staff will be discussed later but seven participants mentioned the emotional impact of apparent insufficient support from healthcare personnel that caused feelings of vulnerability and abandonment.

"I felt like kind of in limbo when I left because I wasn't guided about what to do and what not to do...I felt that was pretty poor in a way after getting four stents put in. I have never seen him again (cardiologist)." (Participant 87 – Female, 72)

Half of the Phase 2 sample craved support for their CHD self-management from the medical staff in the hospital where the elective PCI was performed. They described how after the procedure, they wanted doctors to give them information about their condition and how it should be managed but that was not forthcoming and they felt abandoned. This exacerbated the negative perceptions they had of their CHD.

*"I kind of felt that he (cardiologist) said 'well that's as much as I can do'."* (Participant 70 – Male, 85)

*"I feel that there is a lack of somebody coming and speaking to you about it."* (Participant 87 – Female, 72)

Two interviewees spoke of getting information from the cardiologist during the PCI procedure but did not feel that that was an appropriate time to absorb the information, as they felt compromised by the situation.

"You are lying on the procedure table and they are showing you these photos, you are groggy because they have given you the stuff to relax you... It would be much better if later if they would say 'look this is what we have done' when you are 'sober' again and can take it all in." (Participant 91 – Male, 66)

Feelings of abandonment increased the threatening perceptions participants had of their illness as they believed the cardiologists had done all they could to manage it. Consequently participants felt they were unable to alter the course of their illness and so made few changes to their lifestyle.

Again, the influence the feeling of abandonment had on increasing the threatening perceptions of the condition, made participants less sure of what to do if their angina symptoms arose again. This provides better insight into the link found in Phase 1 between healthcare support and better knowledge of symptom management.

Abandonment also appeared to affect participants' confidence in their ability to self-manage their CHD. Low self-efficacy was evident in five participants who felt unsupported and abandoned in their CHD self-management but they appeared to be most successful in self-management. They had made adjustments to their lifestyle (from Phase 1 data) and seemed to adhere to their medication regime. Although this finding refutes that of Phase 1, these participants gave the impression that they had greater awareness of what constituted a healthy lifestyle. The cognitive representations of their illness therefore prevailed over their emotions.

Those who had not felt abandoned appeared to believe they could self-manage their condition alone, but they seemed less successful in doing this.

### "Some people fret, worry and get anxious but you get on with it." (**Participant 90** – Male, 65)

The interviewees who had that belief seemed to have less inclination to modify their risk factors for CHD and were more likely to stop taking certain medications. Confidence in ability to self-manage, therefore, did not necessarily match effectiveness. The emotional response of abandonment seems to influence participants' illness perceptions and provides some insight into why they had such threatening perceptions of their illness. This made them less likely to adopt more healthy lifestyles. Feelings of abandonment lessened interviewees' self-efficacy but these people were more likely to adopt more healthy behaviours and that contradicts the Phase 1 findings.

Summary of sub-theme findings:

- Participants felt vulnerable after apparent abandonment by healthcare professionals once the PCI had been performed.
- Abandonment linked to participants' illness perceptions and self-efficacy.
- Feeling abandoned enhanced threatening illness perceptions and made it less likely for participants to know effective symptom management or make lifestyle changes.
- Abandonment affected confidence and participants' beliefs that they could self-manage alone but this had a positive effect on their adoption of a healthy lifestyle and adherence to a treatment regime. The opposite seemed true of those who did not feel abandoned.

# 5.4.4 Shock

Some participants in the study spoke of their surprise that they had CHD and did not want to believe it. The main reason for that seemed to be loss of health. The coping mechanism related to this emotional response appeared to be denial as participants spoke of their perceptions that they were cured of the disease. This section will outline how these feelings related to their CHD self-management.

# I've got a problem with my heart?

Denial appeared to affect interviewees' perceptions of either the existence of CHD itself or its causes. Half the participants who were interviewed spoke of their shock of being diagnosed with CHD and three found it difficult to believe that they actually still had the disease and thought the PCI had cured them.

"As far as I know I don't have a problem with my heart anymore because they fixed the problem." (Participant 57 – Female, 60) The Phase 1 data for these participants (i.e. those in denial) were reviewed and it seemed that they were less likely to make any alterations to their lifestyle and this aligned with the interview discussions. Denial that CHD was a chronic condition, which had no cure, seemed to lead to some participants concluding that secondary prevention strategies were not necessary. It is well documented that the short hospital stay associated with PCI, and the potential immediate success of the procedure in alleviating angina symptoms, helps patients to believe the underlying CHD and need for secondary prevention is of minimal personal concern (Sampson, O'Cathain and Goodacre, 2009; Ozkan, Odabasi and Ozcan, 2008; Astin and Jones, 2006b; Campbell and Torrance, 2005; Gaw-Ens and Laing, 1994; Gaw, 1992) and this seemed true for half the interviewees. Participants who thought the CHD was a short-lived illness had non-threatening perceptions of their disease and made few behaviour changes.

Those who denied having CHD after the PCI had variable adherence to their medication regime. The one person who was non-adherent thought it was no longer necessary to take the medications as he had been cured. So, as mentioned previously, the routine nature of the PCI (Gulanick *et al.*, 1997) and the immediate reduction in angina symptoms lessens the emphasis that CHD is a serious chronic illness. That, to some extent, may help explain the belief of curability from PCI but it does not help rationalise the contrasting self-management that was found from interviewees who held the same belief. Consequently, it seems that participants with similar perceptions of their CHD adopted contrasting self-management strategies. This, therefore, refutes the notion of McAndrew *et al.* (2008) that people with similar illness representations adopt similar strategies. They, however, used a heterogeneous population of asthmatic and diabetic patients in their study and so the different diseases may account for the difference in findings. No previous studies were found which had findings similar to this study.

Denial also seemed to be a factor in the beliefs of what causes CHD and this was found in Rosenfeld and Gilkeson's (2000) grounded theory study of coronary revascularisation patients (purposive sample of 3 elective PCI and 3 CABG surgery). Albeit, Rosenfeld and Gilkeson's study was limited due to the small sample size and the fact that they did not achieve theoretical saturation

which limits the reliability and validity of their findings. In Phase 1, five interviewees denied that their lifestyle had contributed to the development of CHD but instead thought that it was their ill-fated family history that had caused it. They said that this made them feel less able to control their disease by changing lifestyle factors. Of these participants, four saw no reason to adopt more healthy lifestyles and their adherence to a medication regime was variable. Two saw taking medicines as all they could do to prevent the CHD progressing.

"If I take the tablets, I have done all I can." (Participant 90 – Male, 65)

These findings align with those of the study from Peterson *et al.* (2010) reviewed in chapter 2 where PCI patients perceive that nothing can be done to stop the disease progressing.

Summary of sub-theme findings:

- Shock had a clear influence on participants' perceptions of their illness and its causes.
- Some participants coped with the shock of having CHD by denying that they had it and several related its cause to their family history, rather than modifiable risks.
- Denying that modifiable factors caused the development of CHD did not predict participants' adoption of more healthy behaviours or their adherence to medication regimes.
- Denial that CHD is a chronic condition made it seem less threatening and reduced the likelihood of participants adopting more healthy behaviours.

# 5.5

# **Overarching Theme: Perceptions of CHD self-management**

The perceptions participants had of their CHD and the self-management associated with that were evident from the Phase 2 interviews. This overarching theme contained three sub-themes (see Figure 5.2).

### 5.5.1 Perceptions of secondary prevention

As indicated many times within this thesis, one of the components of selfmanagement of CHD is the adoption and maintenance of a healthy lifestyle. When interviewed, participants were asked about the disease and what they could do to stop it getting worse after PCI.

### What CHD means to me

Studies conducted some time ago discovered that the perceptions patients had of their CHD could have a negative effect on their functional outcomes but the research mainly focused on myocardial infarction patients (SIGN, 2002; Petrie *et al.*, 1996). More recent studies, for example the one from Byrne, Walsh and Murphy (2005) critiqued in theme D of the literature review, found that patients' perceptions of their illness had a weak relationship with lifestyle changes they made for secondary prevention of CHD. As discovered when reviewing the literature, research pertinent to the influence of illness perceptions on elective PCI patients' CHD self-management is scant. Phase 1 found that participants' perceptions of their illness correlated with CHD self-management and the interviews were used to explain this more.

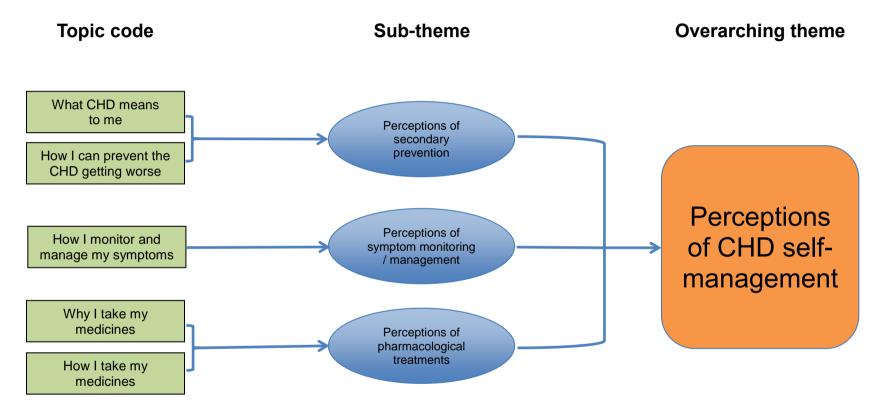
According to the Self-Regulation Model, it is known that individuals' perceptions of what has caused their illness are unique to them and can be influenced by the advice of other people (Benyamini, Gozlan and Kokia, 2004; Furze *et al.*, 2002; Johnson, 1999). An overview of the causes of CHD cited by interviewees in both phases of the study can be seen in Table 5.3.

Four interviewees could not say what they thought caused their CHD.

# *"I really don't have any idea what caused that I really couldn't tell you."* (**Participant 70** – Male, 85)

Similar to 10.7% (n=10) of participants in Phase 1, one interviewee perceived that her co-morbidities had caused the CHD.





# "You put everything down to the menopause and then there was the thyroid thing." (Participant 57 – Female, 60)

Previous studies have found large percentages of cardiac patients often attribute their CHD to their family history (Stafford, Jackson and Berk, 2008; Murphy *et al.*, 2005; Zerwic, King and Wlasowicz, 1997) but that was not found in either phase of this study (Phase 1: 16.1%, n=15; Phase 2: n=2). Murray (1989) discovered that a large proportion of patients link stress and too much work to the development of CHD, but no one mentioned this during the interviews and only a few participants (9%, n=7) cited this in Phase 1.

Deutieineut	Dhasa daawaa af			100
Participant	Phase 1 cause of	Phase 2 cause of	Changes made to	IPQ
	CHD	CHD	lifestyle since PCI	score
Participant 14	Hereditary factors	Cholesterol	Change to diet	29
(Female, 82)			-	
Participant 57	Thyroid disease	Menopause /	No changes	17
(Female, 60)		thyroid	J J J J J J J J J J J J J J J J J J J	
Participant 70	Hereditary factors	Unsure	No changes	35
(Male, 85)			C C	
Participant 80	Hereditary factors	Obesity and diet	Changes to diet	11
(Male, 68)	-		and exercise	
Participant 86	Unsure	Unsure	No changes	31
(Male, 77)			-	
Participant 87	Hereditary factors	Hereditary factors	No changes	31
(Female, 72)				
Participant 88	Unsure	Unsure	No changes	1
(Male, 65)			-	
Participant 90	Hereditary factors	Hereditary factors	Change to diet and	17
(Male, 65)			smokes less	
Participant 91	Smoking	Smoking and diet	Changes to diet	18
(Male, 66)	_	-	and weight	
Participant 93	High cholesterol	Unsure	No changes	27
(Male, 82)	_		-	

Table 5.3
Comparison of causative factors, IPQ scores and lifestyle change

It seems common for individuals to fail to recognise their own risk factors (Momtahan *et al.*, 2004; Zerwic, King and Wlasowicz, 1997) and this appeared true for eight participants in Phase 2 of the current study. For example, **Participant 90** (Male, 65) perceived family history was the cause of his CHD despite also admitting to smoking, having a raised cholesterol level and not exercising: behaviours known to increase the risk of CHD (Joint British Societies 2014; American Heart Association / American College of Cardiology, 2013). Phase 2 found that if PCI patients believed their CHD was a result of uncontrollable factors rather than modifiable risk factors, they had more threatening perceptions of their illness (higher IPQ scores from Phase 1) and were more fearful of its consequences. This aligns with research by Furze *et al.* (2002) who sampled myocardial infarction patients who experienced angina symptoms and their friends and collected data using the York Angina Beliefs Questionnaire. Their findings indicated that the patients and their peers who believed CHD to be caused by factors that they had no control over had threatening illness perceptions, particularly in the peer group (Furze *et al.*, 2002).

The participants in the current study thought there was little they could do to change the course of the disease and so made few lifestyle changes (see Table 5.03). For example, **Participant 87** (Female, 72) said:

# "I have to just come to terms with the fact that my heart is bad...It's a genetic thing, it's hereditary. It's not me if you know what I mean."

This finding contradicts that of Stafford, Jackson and Berk (2008). They found in a sample of CHD patients with mixed diagnoses that those with more threatening perceptions of their CHD were more likely to undertake secondary prevention measures like behaviour change.

It seems therefore from Phase 2, that there is a link between more threatening illness perceptions and participants' reluctance to adopt and maintain a healthy lifestyle. That helps to explain why the correlation was found in the first phase of the study.

Summary of sub-theme findings:

- Research and clinical guidelines indicate that cardiac misconceptions are common and the PCI participants often failed to identify their own risk factors.
- Interviewees who did not know what caused CHD or believed hereditary factors were to blame had more threatening and fearful perceptions of their illness.

 More threatening perceptions of CHD linked to a reduced likelihood of behaviour change.

### How I can prevent the CHD getting worse

During the interviews, participants were asked to talk about what they thought would stop the CHD getting worse. Although seven interviewees perceived non-modifiable risk factors were the cause of CHD, six spoke of making modifications to their lifestyle. For example, several discussed the alterations they made to their diet.

### "I had a look on the net and just cut anything that was to do with vegetable fat or saturated fat right out to make my diet healthier." (Participant 91 – Male, 66)

Cardiac patients are known to be more knowledgeable about coronary risk factors now than they were in the 1970s (Fernandez *et al.*, 2008) and this may account for the number of people talking about lifestyle changes during the interviews. Knowledge though does not necessarily translate into behaviour change (SIGN, 2002).

The notion that people do not always apply what they have learned is one of the main factors of Bandura's Social Cognitive Theory (Bandura and Adams, 1977) and self-efficacy is a key construct of the theory. If individuals do not believe they have the ability to achieve a desired goal or they lack confidence in doing so, their chances of success are reduced (O'Sullivan and Strauser, 2009; Dongbo *et al.*, 2003; Clark and Dodge, 1999) and this was consistent with the study findings.

In a recent survey of the general public by Nuffield Health (2014), half the sample (n=3126) had resigned themselves to being overweight due to low self-efficacy. Obesity poses a significant public health issue for the UK and previous estimations that half the population would be obese by 2050 are now thought to be underestimated (National Obesity Forum, 2014). Despite four interviewees being classed as either overweight or obese from the BMI score in Phase 1, only one person mentioned losing weight and his self-efficacy appeared to have a bearing on that.

"...I have started to exercise more because I am able to now without the anxiety of having an [angina] attack. I am finding that I am getting fitter and it's incredible. I am confident that I can belt up those hills and while I get out of breath, it's the proper getting out of breath."

(Participant 80 – Male, 68)

Self-efficacy seemed to be a strong predictor of behaviour change in Phase 2 and this helps to confirm the Phase 1 findings. Self-efficacy can also be linked to illness perceptions and so when patients believe the PCI has cured them, they will be less confident in attempting any lifestyle change (Peterson *et al.*, 2010; Perkins and Jenkins, 1998; Jensen *et al.*, 1993) and that emerged from Phase 2.

*"I don't have a heart problem...It's an awful step to just say that I am giving up. I enjoy, I have to say, yes, it's an enjoyment. A cigar is an enjoyment. I can't say with certainty I will give up."* (Participant 90 – Male, 65)

There was evidence from the interview discussions that the perceptions some participants held about their disease and how they could reduce the risk of it progressing, in some way influenced their confidence to make the necessary behaviour changes. This can be linked to the multivariate path model result from Phase 1, where illness perceptions had no direct relationship with the adoption and maintenance of a healthy lifestyle but instead mediated through self-efficacy.

Other factors also seemed to affect the perceptions participants had of what they could do to prevent the CHD progressing.

The survey findings indicated that the level of educational attainment was a significant factor in participants' likelihood of adopting and maintaining more healthy lifestyles. From the interview data, it seemed unclear whether the level participants were educated to had any link to them adopting more healthy behaviours. For example, **Participant 88** (Male, 76) who was educated to secondary school level could not say what CHD secondary prevention measures he could take but spoke unwittingly of increasing his exercise. Another participant who had a university education was, however, able to articulate what lifestyle changes would enhance health, yet he had made few

changes. He tried however, to justify his lack of behaviour change by using his knowledge that blood cholesterol is mostly uncontrollable by diet.

# "Cholesterol, you can do about 20% yourself in your diet but 80% of this is the genes...my diet is fine." (Participant 90 – Male, 65)

Other university educated participants also used their knowledge to rationalise any changes they had made to their lifestyle. These qualitative findings did not help to explain why the level a person was educated to correlated with the adoption of a healthy lifestyle in Phase 1. One possible explanation for finding a relationship between educational attainment and the adoption of a healthy lifestyle could be that participants responded in the survey what they thought they should change rather than what they actually had (i.e. social desirability bias).

Although the existence of co-morbidities was found in Phase 1 to negatively affect participants' likelihood of adopting more healthy behaviours, Phase 2 suggested that it may not necessarily be the existence of these concurrent diseases but the illness representations they provoke which prevented lifestyle change. This links to the Path model in Phase 1 (see Figure 4.09).

Three interviewees with concurrent disease perceived their co-morbidities as more serious conditions than their CHD, which seemed to lessen their concern for lifestyle modification.

"Well I think the bigger change in the diet was at the time of the diabetes...I have made a bit of a change but not as marked as it was with the diabetes." (Participant 70 – Male, 85)

Appraising which condition or disease was more serious seemed to be dependent on the inconvenience it caused to daily life and also the consequences of not sticking to the treatment regime. For instance, diabetic **Participant 70** said if he ate something sugary he quickly became symptomatic as a result of his diabetes but there would be no obvious immediate effect on his heart and so he believed the diabetes to be more serious. The social persuasion aspect of the Social Cognitive Theory was also apparent when the participants were discussing how they could prevent their CHD worsening. As indicated in Chapter 1, social persuasion is where people attempt to influence the attitude or behaviour of others (Bandura, 1994). The perceptions six participants had of what their diet should consist of and the exercise they should take seemed to be based on knowledge gained from the media or from family and friends.

# *"I pour a lot of olive oil on everything because I am told that it is good for you...I am told that Mediterranean people don't have heart attacks."* (Participant 80 – Male, 68)

Social persuasion did not always appear helpful though, as others convinced four participants that their CHD was particularly serious and this seemed to restrict their activity.

"I mean it must have been serious for the doctor to go to the bother of putting those stents in...She [wife] kept me in. I was confined to barracks." (Participant 88 – Male, 76)

The influence of social persuasion was not evident in Phase 1 but it certainly seemed to have an effect on CHD self-management, particularly behaviour change. This aspect of Bandura's theory seemed to help explain why the participants behaved the way they did.

Summary of sub-theme findings:

- Although some participants did not think modifiable risk factors were the cause of CHD, they talked about behaviour change as a risk reducing strategy.
- Knowledge of secondary prevention of CHD did not always translate into behaviour change.
- Self-efficacy was a strong predictor of behaviour change.
- Participants with co-morbidities seemed to appraise which condition was most serious and that influenced their adoption of a healthy lifestyle.
- Those educated to a higher level gave the impression that they had a greater awareness of secondary prevention of CHD but this did not always result in actual lifestyle change.

### 5.5.2 Perceptions of symptom monitoring / management

During the interviews, participants were asked about the angina symptoms they had experienced since the PCI, particularly how they monitored and dealt with them. The following section will discuss the perceptions the interview participants had in relation to this aspect of CHD self-management.

### How I monitor and manage my angina symptoms

As expected following the PCI, the majority of those interviewed (n=6) had not had angina symptoms. Reflecting on the angina symptoms they experienced pre-procedure, nine of the interviewees seemed quite clear about how their angina manifested itself, with several stating that they were sure they could distinguish between angina and other symptoms.

# "Sometimes in the day I can feel little muscular pangs and I think 'no that's not angina pain, that's muscle pain'. I can tell the difference, you know that it's not." (Participant 80 – Male, 68)

Of those who indicated that they had experienced angina symptoms after the PCI, one person, **Participant 87** (Female, 72), appeared to have effectively monitored / managed her symptoms as she identified a prolonged episode of angina, sought emergency healthcare support and required an additional PCI procedure. The others had adopted maladaptive coping strategies e.g. taking GTN spray for "*heaviness in my legs*" (**Participant 86** – Male, 77).

When discussing how they would manage an attack of angina, all interviewees said that they would appraise the severity of the angina to determine whether it was 'serious' or not and, since this was not apparent in Phase 1, it helps to explain how patients manage their angina symptoms on a daily basis. Perceptions of the degree of 'seriousness' differed from "*real breathlessness*" (**Participant 91** – Male, 66), to experiencing "*any arrhythmia*" (**Participant 93** – Male, 82) but these did not include duration of angina symptoms, which according to clinical guidelines should provoke a different management response to be adopted. The appraisal participants made seemed to alter their perception of how they would deal with it. This finding seems to align with a survey conducted in 2006 which found that the perceived seriousness of chest pain / symptoms would determine patients' likelihood of calling for an emergency ambulance (YouGov, 2006).

According to the Self-Regulation Model outlined previously in Chapter 2, when individuals experience angina symptoms (the threat), two sets of representations are generated: the cognitive representation where the individual objectively considers the nature of the threat together with the emotional representation, which is the individual's subjective reaction to the threat (e.g. fear) (Scollan-Koliopoulos, Walker and Rapp, 2011; Bishop, Yardly and Lewith, 2008; Wearden and Peters, 2008; Petrie *et al.*, 2002; Jayne and Rankin, 2001; Leventhal, Meyer and Nerenz, 1980, as cited in Petrie *et al.*, 1996). The Self-Regulation Model suggests that the appraisals individuals make determines their coping strategy.

The path model findings from Phase 1 suggested that threatening illness perceptions made it more likely that participants would know how to manage their angina symptoms but this appeared inconclusive in Phase 2. For example, **Participant 90** believed that he had a serious condition and gave an accurate account of how to manage angina symptoms:

"If it came on [angina] I would take the puffer. If it still persisted after 5 minutes I would take the puffer again." (**Participant 90** – Male, 65)

**Participant 86** who also had threatening perceptions of his illness, provided an example of incorrect initial management for recurring angina symptoms:

"If I find that the heaviness is coming back I will dial 999 and get taken to hospital...Since the operation has been done I think it's a serious matter...so the only alternative is to move to hospital." (Participant 86 – Male, 77)

It seemed therefore, that it was not so much the appraisal the patients made of their illness that determined how they coped with their angina symptoms, but more what the appraisal was influenced by. It is known that patients' illness representations can be influenced by the past experience of family and friends and this was evident in five participants in Phase 2. For example:

### "I have never had a spray [GTN]. I dinae fancy taking it. My brother-in law takes it and he finds it disnae do him a great deal of good..." (Participant 88 – Male, 76)

**Participant 88**'s perceptions seemed to be based on vicarious experience, particularly given that he believed his relative to be in a similar position to himself and so this links to the Self-Regulation Model (Shiloh, 2006; Benyamini, Gozlan and Kokia, 2004; Furze *et al.*, 2002). It could also relate to the social persuasion aspect of the Social Cognitive Theory (Bandura, 1994).

Of the five participants who spoke of vicarious experience in relation to their symptom monitoring and management, three had maladaptive coping strategies for recurring angina symptoms.

Existence of co-morbidities was found in the first phase to be a barrier to effective symptom monitoring and management. In Phase 2 participants with co-morbidities seemed to trivialise the angina symptoms and perceived that it would get better with minimal intervention on their part and no mention was made of involving or contacting any healthcare professionals. As mentioned previously, this could be related to their illness perceptions and the notion that they do not believe their CHD is as much a threat as their co-morbidities.

Other factors were found in Phase 1 to relate to effective symptom management. Although the bivariate analysis showed no link between contact with healthcare personnel and participants' efficacy in angina symptom management, a link was found between these variables in the multivariate path analysis in Phase 1. From the interviews, the four participants who appeared to have had much contact with healthcare services seemed to have a better perception of what the most effective symptom management would be. There was clear evidence that these participants had been given specific instructions about angina symptom management. "I would use the spray and wait maybe fifteen minutes and then I would phone for an ambulance. That's what they told me to do actually. In fact the ambulance men said the last time that's what you should do if it happens again." (Participant 14 – Female, 80)

Some older participants gave the impression that they perceived the emergency ambulance service as too busy to deal with them if they had a prolonged angina attack.

### "At night I wouldn't call an ambulance, I would wait until the GP opened at half past eight" (Participant 86 – Male, 77)

They seemed to have a degree of stoicism and accepted recurring pain as a sign of aging which links to a study by Johnson (2008). This perception, however, resulted in less effective symptom management and so this helps to explain the relationship between these variables found in Phase 1.

Some studies have found that males may be more reluctant than females to seek medical help when they are unwell (Hunt, Adamson and Nazareth, 2011; Smith, Braunack-Mayer and Wittert, 2006) but this was not found within the current study.

Phase 1 found that six interviewees were either totally confident or confident in knowing when to seek medical help for recurring angina symptoms. This self-efficacy did not, however, appear to predict effective symptom management in Phase 2. The Phase 1 finding that self-efficacy had a relationship with knowledge of effective angina symptom management was not further explained with the qualitative stage of the study.

Summary of sub-theme findings:

- Participants believed they could effectively identify their angina symptoms and would appraise the severity of angina symptoms to determine the seriousness and subsequent coping strategies.
- The influence of illness perceptions on angina symptom monitoring / management was inconclusive in Phase 2.
- Clear links to the Self-Regulation Model were evident. Participants' angina symptom monitoring and management seemed to be linked not

specifically to their illness perceptions but to what influenced these (e.g. vicarious experience).

- The reasons for co-morbidities and older age being barriers to angina symptom management efficacy were explained further.
- Participants who had more contact with healthcare services appeared to have a better understanding of how to manage their angina symptoms as a result of having received specific instructions.

### 5.5.3 Perceptions of pharmacological treatments

Findings from the Phase 1 data indicated that the whole sample reportedly took their medicines as prescribed and intended. This is consistent with the findings from the study by Fernandez *et al.* (2007) discussed in the literature review but contradicts the results from Aghabekyan, Thompson and Abrahamyan's research (2012) as they found that nearly a third of PCI patients were non-compliant.

Within the current study, there was a risk that most of the participants indicated that they took their medicines as prescribed as a result of completing the Phase 1 survey while in the outpatient department where the cardiologists could learn of their responses (i.e. social desirability bias) but the researcher was cognisant of that possibility. The Phase 2 data collection was, therefore, used to consider medication adherence in more detail with the interviewees.

### Why I take my medicines

Of those interviewed, there seemed to be three participants who had accurate perceptions of why they took their medicines and the action of the drugs. Five participants could not recall the names of the medicines and some of them thought that all the medicines had the same effect.

"I always thought it was strange because my idea o' the pills was that they all did the same job. They a' kind of thinned the blood to keep the blood slow and better." (Participant 88 – Male, 76)

The drug that was most easily recalled by the participants was Aspirin and no one reported any problems with that medicine. The participants perceived that Aspirin was essential to maintain the patency of the stent inserted into their coronary artery during the PCI. This belief in PCI patients seemed to be a strong predictor of adherence to Aspirin and this finding concurs with research from Hlatky *et al.* (2013) but opposes evidence from Rushworth *et al.* (2012) who discovered that PCI patients thought Aspirin was less necessary than other cardiac medicines.

PCI patients are often also prescribed another medication, Clopidogrel, which works in combination with Aspirin. Although some studies have found that patients are less inclined to take Clopidogrel (Muntner *et al.*, 2011; Ferreira-Gonzalez *et al.*, 2010) that was not found within the interviewees.

There is sound evidence that patients' lack of understanding about medicines and their pharmacological action leads to non-adherence (Ferreira-Gonzalez *et al.*, 2010). It was thought that the level of education could affect participants' understanding but that was not obvious from the qualitative data. For example, **Participant 90** has a university education:

"Clopidogrel, something called Clopidogrel. What is that now? I remember reading about it but I have forgotten what it was..." (Participant 90 – Male, 65)

Educational attainment therefore did not seem to influence knowledge of medicines.

Also, participants' perceptions of medications did not seem to be influenced by their age. The oldest female participant who was interviewed was one of the few who gave an accurate account of her medicines:

"The statin is controlling the cholesterol and em, the bisoprolol is for the high blood pressure. The clopidogrel is for thinning the blood and then the dispersible Aspirin, I suppose that also helps to thin the blood." (Participant 14 – Female, 82)

The elderly patients in a study by Henriques, Costa and Cabrita (2012) believed that they were taking medicines as a consequence of the aging process. This did not seem to be the case in the current study, however, as all of the participants perceived that they were taking the medicines for their heart, even though they did not know what the medicines did. Of the seven participants who did not know how their medicines worked, four appeared to be subservient and just took their medicines as instructed and this finding fits with the results from studies by Wiles and Kinmonth (2001) and Radcliffe *et al.* (2009).

# "The doctor said to just keep taking the tablets so I do." (Participant 88 – Male, 76)

This acquiescence could perhaps be attributed to the participants' illness perceptions as they all had threatening perceptions of their CHD.

Summary of sub-theme findings:

- Few participants understood the action of the medicines they took.
- Participants who were more educated seemed no more knowledgeable than the others.
- Some participants adhered to their pharmacological treatment regime, apparently without an understanding of why it was required and without question and this seemed to link to their threatening illness perceptions.

### How I take my medicines

Although every participant had responded in their questionnaire that they took their medicines every day, it was found from the interview data that this was not strictly the case. Generally, the interviewees knew how and when they should take their medicines and so it was surmised that the responses in the survey in Phase 1 were more what the participants thought they should do rather than what they actually did.

Of those who talked about their regime for taking the medicines, the ones most likely to adhere seemed to be the patients who had developed a habit to taking medicines and this finding concurs with previous research (Phillips, Leventhal and Leventhal, 2013; Henriques, Costa and Cabrita, 2012; Rushworth *et al.*, 2012; Wu *et al.*, 2008). Several participants discussed this during the interviews:

"Orange juice, pills with orange juice. The aspirin goes into the orange juice glass with the water while I am having my porridge and then I have the aspirin. So I have them all at the same time every day."

(Participant 91 – Male, 66)

The perceived side effects of the medications seemed the most likely reason for participants to consider or indeed cease taking some of the drugs and this aligns with previous research (Ali *et al.*, 2009). The most common medicine that the PCI patients appeared to experience side effects of and stop taking was the statin therapy to help lower their cholesterol levels.

"I stopped taking the statin because...Simvastatin has not got very good press for muscles...I don't want it to go to muscle degeneration or anything like that." (Participant 57 – Female 60)

It seemed that half the interviewees had appraised the use of statins and concluded that they caused side effects so the coping strategy adopted was to discontinue taking that particular medicine. Statins do not produce an overt benefit to patients but they often cause side effects and so patients commonly stop using them (Ali *et al.*, 2009). These findings align with research that explored patients' adherence to anti-hypertensive medicines. For example, Gascon *et al.* (2004) found from their focus group data in their qualitative study (n=44) that patients believed that the medicines made them worse rather than better and that negatively affected their adherence. Whilst the findings from Gascon *et al.* (2004) cannot be generalised to a wider hypertensive patient group due to the methodology and the non-probability approach to sampling adopted (Price, 2013), other researchers using a variety of methods to explore this phenomenon have had or reported similar findings (Okoro and Ngong, 2012; American College of Preventive Medicine, 2011; Al-Mehza *et al.*, 2009).

Another reason why it seemed participants stopped taking their statins was the lack of perceived benefit from them.

"If I remember I take some statin at night. I'm not very enthusiastic about that...I don't think it makes a lot of difference really." (Participant 93 – Male, 82)

This has been documented previously in patients with CHD (Casula, Tragni and Catapano, 2012). Rushworth *et al.* (2012) found that perceived lack of benefit affected adherence to medicines in patients who had emergency or elective PCI (Rushworth *et al.*, 2012) but the non-adherence in that study was mainly to Aspirin and that differs from the current study. That may be a consequence of

Rushworth *et al.* using a small convenience sample (n=20). Although Rushworth *et al.* used a mixed methods approach it is difficult to see from the publication how the two data sets were mixed which hints at some reporting bias or flaw in the methodology. Their data were collected 7 days post-PCI and so the medicines not taken or reasons for that at that stage may not necessarily compare with a longer time-lapse from the revascularisation procedure.

The perception that medicines are of little benefit is not unique to one group of medicines or patients. Hypertensive patients also believe that the medicines they take to help control their blood pressure do not enhance their health and when they stop taking the medicines they experience few symptoms which exacerbates the notion that they have no health benefit (American College of Preventive Medicine, 2011; Gascon *et al.*, 2004). The appraisal the PCI patients in the current study made of the statin therapy appeared to indicate no obvious benefit and so the coping strategy adopted was to stop taking this medicine. No ill effects were experienced when the medicines were discontinued and that compounded the belief that the Statin was of little benefit. This process has clear links to Leventhal's Self-Regulation Model.

Published literature suggests that there are other reasons for non-adherence to medication regimes. Aghabekyan, Thompson and Abrahamyan (2012) found that older PCI patients were more likely to take their medicines as prescribed. It was not apparent from the interview data whether the same could be said of the current study as no pattern emerged from Phase 2 findings and no correlations could be determined from the Phase 1 data.

The financial burden of medicines seemed to be prohibitive in a number of studies (Aghabekyan, Thompson and Abrahamyan, 2012; Muntner *et al.*, 2011; Ali *et al.*, 2009). This topic was never mentioned by any of the participants during the interviews and it was assumed that this was as a result of free prescription charges for everyone in Scotland. It is known that people with chronic illnesses such as CHD are better off as a result of the abolishment of prescription charges (Scottish Government, 2013) and so the high rate of reported medication adherence within the current study could perhaps be attributed to that.

Summary of sub-theme findings:

- Not all interviewees took their medicines as prescribed.
- Those who were most successful at medication adherence had developed a habit to taking them.
- Financial barriers did not play a part in medication non-adherence.
- Participants were less likely to take medicines that they perceived were of little benefit to them or caused unpleasant side effects.

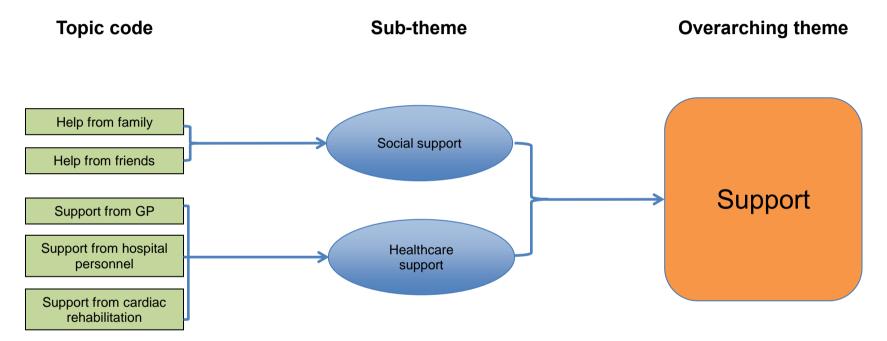
# 5.6 Overarching Theme: Support

In Phase 1, the multivariate analysis found that the support from healthcare linked to two CHD self-management components: participants' likelihood of adopting and maintaining a healthy lifestyle and them knowing how to monitor and manage their angina symptoms. Participants often mentioned during the interviews the support they had received from various places and people but also the support they felt they needed. Support was therefore identified as an overarching theme with two sub-themes within it (see Figure 5.3).

# 5.6.1 Social support

Although no relationship was established between participants' social support and the CHD self-management efficacy in Phase 1, the qualitative data suggested that the support they received from their friends and family was important and it did seem to have some bearing on their CHD selfmanagement. It is known that social support can positively influence CHD selfmanagement, particularly the adoption and maintenance of a healthy lifestyle (Peterson *et al.*, 2010; Rosland *et al.*, 2009; Gulanick *et al.*, 1998). This section of the chapter will provide an overview of how social support related to PCI patients' CHD self-management.





### Help from family

Rather than elicit support from healthcare professionals involved in their care, almost half the interviewees seemed to rely on family members to provide them with information about CHD.

"My daughter sent me a photo of my heart, of a heart and showed me exactly where it was blocked...I think I understand it because my daughter explains it to me." (Participant 87 – Female, 72)

Advice and support from family appeared to be helpful in encouraging four participants in Phase 2 to adopt and maintain a healthy lifestyle (see Table 5.4). Literature (Wood *et al.*, 2008; Daly *et al.*, 2002; Sher and Baucom, 2001) suggests that cardiac patients are more likely to embrace healthier behaviours when family members help them and the current study concurs with that.

Participant	Family support for behaviour change	Changes made to	
		lifestyle since PCI	
Participant 14	Yes, daughter and brother	Change to diet	
(Female, 82)		_	
Participant 57	No apparent support for secondary prevention	No changes	
(Female, 60)			
Participant 70	Yes, but limited from wife	No changes	
(Male, 85)			
Participant 80	Yes, sister and brother (he had previous PCI)	Changes to diet	
(Male, 68)		and exercise	
Participant 86	Yes, but limited from wife	No changes	
(Male, 77)			
Participant 87	No apparent support for secondary prevention	No changes	
(Female, 72)			
Participant 88	No, wife kept him 'confined to barracks' so	No changes	
(Male, 65)	unable to exercise		
Participant 90	Yes, daughter very supportive but has	Smokes less	
(Male, 65)	'constant nagging' from wife for smoking		
Participant 91	Yes, wife exercised with him and helped make	Changes to diet	
(Male, 66)	alterations to diet	and weight	
Participant 93	No, participant said wife was not that	No changes	
(Male, 82)	supportive	J	

# Table 5.4Comparison of family support and lifestyle change

Wood *et al.* (2008) conducted a paired-cluster randomised controlled trial exploring the effectiveness of a multidisciplinary family-based preventive cardiology programme, sampling patients from several European countries. Two groups of participants were recruited, patients with CHD and those at risk of CHD. CHD participants had suffered an acute coronary syndrome or had stable angina. The publication did not report that any patient had been revascularised with PCI but in current practice that would be unlikely. Participants were subsequently randomised to either an intervention group or a usual care, control group. Those in the intervention group had a multidisciplinary assessment of their CHD risk factors and attended secondary prevention sessions with their partner. The control group also attended these sessions but the partners / spouses were not included. The primary endpoints of the study were related to behaviour modification to reduce CHD risk. For the participants with CHD, the family based intervention led to significant changes to rates of smoking, intake of saturated fat and physical activity when compared with the CHD patients in the control group. While this study provides evidence that the input of family can influence the adoption of a healthier lifestyle, it was compromised in that the sample was underpowered as the recruitment rate was much lower than the target. There also seemed to be noticeable differences between the paired centres where participants were recruited from and that may affect the reliability of the findings. The lack of blinding to whether participants were in the intervention or control group may have biased the care providers to alter the usual care given. Some caution should, therefore, be exercised when interpreting these findings and generalising them to a CHD patient population.

Sher and Baucom (2001) reviewed the literature on couples and behaviour change and concluded that by enlisting the support of a partner or spouse, patients are more likely to change their behaviours to reduce their CHD risk and that would decrease morbidity and mortality. This is a bold claim given that there is no clear evidence from the publication that the literature was systematically reviewed and the quality of the research studies included does not seem to have been appraised, it seemed merely a summary of findings. Sher and Baucom's literature review seems to include studies using patients with different manifestations of CHD as well as those with hypercholesterolaemia and the general public and so it is difficult to generalise their findings specifically to an elective PCI population.

Daly *et al.* (2002) also conducted a literature review, this time mainly to investigate barriers to myocardial infarction patients' participation in a cardiac rehabilitation programme and encompassed in that was the role of family in supporting behaviour change. Much of the literature they included in their review was considered to be methodologically flawed and of relatively low

quality as very few experimental studies were found. The findings should therefore, be viewed with caution as to their representativeness of the study population. The search strategy was not evident and so the extent of the literature reviewed was not obvious and that further compromises the ability to accept this literature review as a robust investigation of published studies.

Although these publications have reported the influence family support may have on CHD patients' adoption of healthier lifestyles, it is not evident that this has been previously documented specifically in an elective PCI population.

It is known that spousal support can be a determinant of exercise maintenance (Sher and Baucom, 2001) and this was evident from three participants in the current study. One talked about his wife going walking with him and gave the sense that this encouraged him to walk more often.

"I feel a wee bit sorry that she doesn't get as much walking as we used to do...The length of my walk is about ten minutes and it always seems hardly worthwhile for her to come out and go just for the sake of ten minutes but she does." (Participant 70 – Male, 85)

Although not every interviewee lived with someone (2 lived alone), over half seemed to really appreciate the support from their family and indicated through the discussions that they found that helpful in coping with their CHD.

"She [wife] is a big support to me you know...I don't know how to explain to you how but she is a big support to me..."

(Participant 86 – Male, 77)

Family support has been found to sometimes hinder behaviour change though through criticism and discouragement that reduces self-efficacy (Goldsmith, Lindholm and Bute, 2006). Two interviewees spoke of having unsupportive spouses and this appeared to make them less likely to adopt more healthy behaviours. One, when asked about exercise and whether his wife went walking with him, said:

"No, I go on my own usually. She has her own routine whatever she does." (Participant 93 – Male, 82)

Not every participant seemed to appreciate the support they received from their families. One person described his wife's encouragement to stop smoking as *'constant nagging'* (**Participant 90** – Male, 65). This perhaps links to the hindrance to behaviour change mentioned previously (Goldsmith, Lindholm and Bute, 2006).

How family support relates to the other components of self-management was less clear from the qualitative data in the current study. Most of the participants spoke of support for behaviour change but no one mentioned how families helped with medication adherence or symptom monitoring / management.

Summary of sub-theme findings:

- Some participants relied on their family to give them information about CHD.
- Studies have found that family support can help but also hinder adoption of a healthy lifestyle and this study too had inconsistent findings.
- How family support relates to angina symptom management and adherence to medication is not clear from the qualitative data.

### Help from friends

Support from friends seemed to be really important for six of the participants.

"We have a dozen or so of friends that we see quite often...a major subject of conversation is health...they are all supportive." (Participant 70 – Male, 85)

Four participants described how useful it was that they had a friend who also had CHD. This gave the impression that the participants could compare themselves with these people and talk to them about self-management.

"I actually spoke to a friend who had had a heart attack...knowing you are not on your own helps..." (Participant 57 – Female, 60)

Although interviewees spoke of the benefits of having supportive friends, the extent to which that support influenced their CHD self-management was not clear. Friends seemed to help shape interviewees' illness representations and subsequent coping strategies and this fits well with the Self-Regulation Model

(Phillips, Leventhal and Leventhal, 2012). For instance, four participants seemed to have a more positive outlook on life as they had friends who had CHD and were well.

#### "...there is a neighbour below me who is 93 and he said 'oh yes, I've had 2 [stents] in when I was 82 and I have never looked back'...I can't believe it since I had a stent, I can't believe the difference." (Participant 80 – Male, 68)

This positivity seemed to enhance the participants' self-efficacy that they too, could be well and deal effectively with their CHD and so there are links to the Social Cognitive Theory. Support from friends who had CHD appeared to alter participants' confidence in monitoring and managing their angina symptoms (i.e. a modeling effect).

### "...my friend who had a small heart attack, it wasn't pain with her, she just felt unwell with clamminess, so I realise what to look for." (Participant 57 – Female, 60)

The support and advice from friends did not, however, always appear to translate into more effective angina symptom monitoring / management. There seemed to be an influence of this social persuasion on the participants' illness perceptions.

Cole *et al.* (2013) used qualitative methodology to explore myocardial infarction and angina patients' (n=45) perceptions of barriers to lifestyle change and they found that the support given by friends was deemed valuable. Although the results from Cole *et al.*'s study cannot be generalised to the wider patient population or to those who have undergone elective PCI due to the methodology used, it does suggest that support from friends may be a facilitator to adopting a healthier lifestyle and yet, little mention was made of how friends supported participants in adopting more healthy behaviours in the current study. Despite many advocates of support from friends when making lifestyle changes (including that from: Davies, 2011; Huff, 2004; British Heart Foundation, no date), few studies seem to exist that provide robust data to support the notion that support from friends positively influences successful lifestyle change in CHD / PCI patients and this may be worthy of further investigation. Summary of sub-theme findings:

- Participants seemed to benefit from the support of friends, particularly friends who had CHD.
- Increased self-efficacy, which came about as a result of supportive friends, did not appear to always cause improvements in symptom monitoring / management knowledge.
- Participants spoke little of how their friends supported them in behaviour change or medication adherence.

# 5.6.2 Healthcare support

Findings from Phase 1 indicated that participants who had frequent contact with their GPs or had been hospitalised were less likely to adopt and maintain a healthy lifestyle but seemed to have better knowledge of symptom monitoring and management. The support from healthcare professionals was discussed during the Phase 2 interviews and this topic will be discussed in the following section of the chapter.

### Support from GP

Most of the participants talked about the support they received from their GPs. Four of them seemed particularly satisfied with that and gave the impression that their GP had taken time to meet with them to discuss CHD and its management.

"He went through things about the arteries in the heart, how it got clogged, all that kind of stuff...He is actually very good. I have got a lot of confidence in him." (Participant 91 – Male, 66)

These four study participants seemed to know their GP well and that appeared to make a difference as three of them reported good adherence to their medicines. Evidence exists that patients will follow the advice from their doctors (Shah and Mountain, 2007) and, while that seemed true for some, several participants did not know who their GP was and that affected the contact they had with them. Perhaps that was a consequence of the alterations to GP contracts agreed in 2004, where less emphasis was placed on patients knowing who their family doctor was (Department of Health, 2013a).

None of the interviewees spoke about their GP giving them any advice on how to manage any recurring angina symptoms so this does not help explain why a relationship was found between these variables in Phase 1. Tod *et al.* (2001) found that angina patients often hide their symptoms from their GPs and that could account for the lack of advice given. Six interviewees knew their GPs less well and indicated that they thought the support was lacking for secondary prevention advice.

"You know I mean em he does the job [GP]... but he's very, very quick. There's no messing around. There's no let's have a talk about your life or anything like that... No, he never actually talked to me about diet." (Participant 80 – Male, 68)

"He (GP) told me to just take it easy but he said 'I reckon that you will know yourself what to do and what not to do'." (Participant 87 – Female, 72)

Although these participants had seen their GPs, they had not received any instructions or advice regarding how to reduce their risk of CHD progression. Although some patients are more likely to request more information and question their doctors (Dickinson and Raynor, 2003), this was not apparent in the current study. Both these things could perhaps rationalise why there was a link found in Phase 1 between the amount of contact participants had with healthcare personnel and a reduced chance of them adopting more healthy behaviours. Half the interviewees also spoke of seeing their GPs for health problems other than their CHD and that may also help to explain that link, as it is known that co-morbidities make behaviour change less likely.

It is known that secondary prevention of CHD in primary care is poor. Campbell *et al.* (1998) indicated that improvements needed to be made to this but years later, and in spite of financial incentives to GPs, secondary prevention has not shown much improvement (The King's Fund, 2011). Peckham, Hann and Boyce (2011) found that the majority of GPs generally do not feel equipped with the necessary skills to discuss secondary prevention of diseases with their patients. Where secondary prevention clinics have been established to support CHD patients' self-management, they have been nurse-led (Page, Lockwood and Conroy-Hiller, 2005; Murchie *et al.*, 2003; Cupples and McKnight, 1999; Jolly *et al.*, 1998) and that has been found to be more effective than a GP-led

service (Moher *et al.*, 2001). Three interviewees who had attended such clinics were, however, quite sceptical of their purpose.

"They sent me a note to come in and get my cholesterol checked but none of the GPs saw me. It was the practice nurse but I don't see what use they would have had." (Participant 90 – Male, 65)

Although Campbell (2004) found that any lifestyle changes patients made would only be sustained as long as they continued to attend secondary prevention clinics, none of the interviewees who had attended a clinic had made any behaviour changes. This does not help explain why the multivariate results from Phase 1 found that participants who had more contact with their GP were less likely to adopt and maintain a healthy lifestyle.

Summary of sub-theme findings:

- Those supported by their GPs reported better medication adherence.
- The majority of interviewees felt unsupported by their GPs.
- Provision of CHD secondary prevention clinics seemed patchy and those who did attend did not report any sustained lifestyle change.
- None of those interviewed said that their GP had given them advice about angina symptom management so the Phase 1 finding which linked healthcare support and better knowledge of symptom management is not further explained by the qualitative data.

#### Support from hospital personnel

Research suggest that patients should be educated about the PCI procedure and the prevention of CHD prior to the revascularisation taking place (Steffenino *et al.*, 2007; Harkness *et al.*, 2003; Gentz, 2000; Tooth *et al.*, 1997) but none of the interviewees mentioned this at all. Much of the support given by the cardiologists and hospital staff appeared to relate to the PCI procedure itself and recovery afterwards but seven of those interviewed suggested that they did not feel well supported by the hospital-based professionals and felt that they needed more information.

"Nobody has ever said you will be fine now that you have the stents in, I mean, I don't know how my life is going to go now. Will I get fitter again? Will I be able to do everything again? I don't know."

(Participant 87 – Female, 72)

The time patients spend in hospital having a PCI is considered to be a missed opportunity to provide them with secondary prevention of CHD education (Marinigh *et al.*, 2007) and the heavy workload of the staff may account for that:

"After it's all over you are fixed and that's the hospital done their job but there's nobody really there to support you... they haven't got time to sit and talk...maybe if more time could be spent but there's not the resources now is there" (Participant 57 – Female, 60)

As the hospital personnel had not mentioned secondary prevention of CHD interviewees seemed to think it was not that important. This may account for participants in Phase 1 who had greater contact with healthcare staff being less likely to adopt more healthy behaviours.

Four interviewees recalled being given written educational material by hospital staff about managing their CHD. The others felt it necessary to resort to other ways of obtaining the information they needed.

"I just felt I didn't get enough advice. Anything I felt I needed to find out about, I found out by myself from the 'net." (Participant 91 – Male, 66)

Obtaining information from alternative, and sometimes poor, sources led to misconceptions about CHD and this appeared to affect the participants' self-management efficacy.

Six participants said during the interviews that they believed that the hospital staff gave no advice because they thought patients would know how to manage their CHD. These interviewees were more likely to call 999 to help deal with their angina symptoms rather than trying to manage on their own.

During the Phase 2 interviews, no participants mentioned that they had received any information from hospital staff about their medication. Cardiac patients' understanding of angina symptom management, risk factors for CHD and the role medicines play in secondary prevention of the disease (Karthik *et al.*, 2006) is often unsatisfactory and this may be linked to the seemingly insufficient support from hospital-based healthcare professionals or primary care.

The findings from Phase 2 do not help to explain the relationships between healthcare support and the adoption of a healthy lifestyle and better knowledge of angina symptom management. The insufficient support systems have not been previously documented though and so this study provides some contribution to knowledge regarding that topic.

Summary of sub-theme findings:

- The majority of participants said that support from hospital staff for CHD self-management was somewhat lacking.
- Lack of time for hospital staff to provide advice on secondary prevention of CHD made participants think it was not important, which helps to explain why they made fewer behaviour changes.
- Seeking information from alternative sources led to misconceptions about CHD.
- Interviewees believed that hospital staff expected them to know how to manage their angina symptoms but these people seemed more likely to summon emergency healthcare support for angina symptom management.

#### Support from cardiac rehabilitation

Despite evidence that cardiac rehabilitation can help to improve PCI patients' functional status, quality of life, and adverse events (Back *et al.*, 2008; Brugemann *et al.*, 2007; Chien, Tsai and Wu, 2006; Dendale *et al.*, 2005), Phase 1 found no evidence that this was beneficial in supporting the PCI patients' CHD self-management. Uptake is known to be poor and the survey data indicated that 24 of the 93 participants (25.3%) completed a cardiac rehabilitation programme. Of the ten participants who were interviewed, six had been contacted by the cardiac rehabilitation team, but only one person completed a programme of rehabilitation.

The interviewee who completed the rehabilitation perceived it as beneficial but continued to believe that his functional capacity was limited and this seemed to link to his illness perceptions:

"I felt I got some benefit from it, you know better breathing, better relaxation, and a lot of educational background about the heart and angina...I thought it was worthwhile...I have really not got much further in my walking than I did at the start..." (Participant 70 – Male 85) The support he received from the rehabilitation team did not seem effective in leading him to adopt more healthy behaviours. One participant had gone to meet the cardiac rehabilitation team and seemed quite keen to attend but she was apparently dissuaded from doing so by the staff.

"I was [offered cardiac rehabilitation] and I had a visit to the Astley Ainslie to see a nurse there but...the nurse was quite happy for me not to go." (**Participant 14** – Female, 82)

Despite not attending a cardiac rehabilitation programme, the interviewees' perceptions of this type of support helped to provide better understanding of how they managed their CHD on a daily basis. Eight of the interviewees seemed to have misconceptions about cardiac rehabilitation and its purpose and that seemed to be a barrier to attendance. They believed it to be exercise only and their perceptions seemed to fall into two categories: they were too fit or they were too ill to attend. Misconceptions are well known regarding this topic area (Clark *et al.*, 2004; King *et al.*, 2001). Five participants believed that they were active enough and did not need to be rehabilitated. They thought that cardiac rehabilitation was just for those who could not walk. (Two of the five had increased their exercise since the PCI and were taking the recommended amount of exercise).

"no one mentioned rehab but I wouldn't have wanted it I don't think. I mean I feel, what's the point? I don't need to be taking up someone's place on a rehab group. I'm fine." (Participant 80 – Male, 68)

The three interviewees who thought they were too ill believed that rehabilitation was inappropriate for CHD patients (these patients made no lifestyle changes).

"...being a heart patient you can't walk...I couldn't manage. The walking is too much for me. Being a heart patient I can't." (Participant 86 – Male, 77)

Again the social persuasion aspect of the Social Cognitive Theory seemed to alter three participants' opinions of cardiac rehabilitation.

"Well my brother-in-law had been there [cardiac rehabilitation] and he wasnae that impressed with it either. He didn't say why, he just said that he wasn't impressed by it...so I didnae see the sense of going." (Participant 88 – Male, 76) Generally the participants thought that the support from cardiac rehabilitation was either poor or non-existent.

# "Never offered anything. No feedback, no come back to see anybody to check me out or anything." (Participant 87 – Female, 72)

It seemed that any contact the interviewees had with the cardiac rehabilitation team was minimal and most participants did not find this helpful.

Summary of sub-theme findings:

- The uptake of cardiac rehabilitation was poor.
- Attendance at cardiac rehabilitation had not led to any sustained behaviour change.
- Cardiac rehabilitation support was deemed inadequate.
- Barriers to attendance seemed to link to participants' misconceptions.

### 5.7 Chapter summary

This chapter began by outlining the approach to qualitative data analysis. Thereafter, the audit trail of how the topic codes, sub-themes and overarching themes were developed was detailed. Three overarching themes emerged from the Phase 2 data: 'emotional responses', 'perceptions of CHD selfmanagement' and 'support'. Each of these themes was discussed in turn and salient quotes from participants used to support the discussion. The links to the theories and where the findings appear to contribute to new knowledge were highlighted throughout the chapter at the relevant sections. The following chapter will go on to discuss these findings in context.

### Chapter 6 Integration, interpretation and discussion

### 6.1 Introduction

This chapter will bring together the findings from both phases of the study and demonstrate how the qualitative data helped to explain the quantitative findings. It will provide a discussion of how the findings were interpreted and synthesised.

### 6.2 Integration and interpretation of the study findings

The aim of this study was to explore CHD self-management in a PCI patient population. The study had three research questions:

- How do patients self-manage their CHD after they have undergone elective PCI?
- What factors influence patients' self-management of CHD after elective PCI?
- To what extent do Bandura's Social Cognitive Theory and Leventhal's Self-Regulatory Model help explain self-management of CHD in patients after elective PCI?

The research questions have been used to structure the discussion of the study findings to provide clarity of the extent to which each question was addressed.

### 6.3

# Research question 1: How do patients self-manage their CHD after elective PCI?

### 6.3.1 Symptom monitoring and management

Patients have a PCI performed to reduce their angina symptoms but, as indicated in the literature review, recurring pain is a common problem. Although the symptoms are not always cardiac in nature (Jeremias *et al.*, 1999), their monitoring is essential to enable help to be sought if the episode is prolonged, the angina symptoms worsen or increase in frequency (NICE, 2012).

were clear about how their angina would manifest itself. When short-lived angina symptoms occurred, a quarter of the sample (25.8%) followed the clinical guidelines and knew to rest and administer Glyceryl Trinitrate spray (NICE, 2012; SIGN, 2007). It was found that nearly 1 in 5 in the sample would summon emergency help by calling 999 for any recurrence of angina symptoms, regardless of how short-lived they were, and this was corroborated by the qualitative data.

*"If I find the heaviness is coming back... then I will call an ambulance right away, dial 999 and get taken to hospital."* (Participant 86 – Male, 77)

Three to six months after elective PCI, the proportion of participants in this study who said that they would manage their angina symptoms by calling 999 is substantially higher than that found in previous research studies (Gallagher *et al.*, 2008a). Many Phase 2 participants said that they had not been given any information about how to manage their angina symptoms and that may help to explain the proportion calling for emergency service help but another reason was revealed in Phase 2. Participants perceived their CHD to be a serious condition that could affect their mortality and this made them fearful. These factors led them to state that they would summon an emergency ambulance so that they would be taken to hospital to deal with any angina symptoms.

Unplanned readmissions in the first six months after elective PCI are likely to be stressful for PCI patients and their families and are extremely costly for healthcare providers. Readmissions to hospital within 30 days of discharge have been estimated to cost the National Health Service in the UK around £2.2 billion annually (Bardsley *et al.*, 2012) and so, predictive models have been developed to determine patients' risk of readmission but these are not specific for any particular patient group (National Services Scotland, 2012; Daly, Mason and Goldacre, 2000). Managing any angina symptoms after PCI by calling 999 has a psychological 'cost' for the patients but it also causes a financial burden for healthcare providers.

#### 6.3.2 Adoption and maintenance of a healthy lifestyle

It is thought that 80% of CHD is preventable (Capewell, 2009) and it is recommended that patients adopt and maintain healthier lifestyles to reduce

their risk of disease progression (American College of Cardiology, 2013; Janssen *et al.*, 2013). Evidence from other CHD patient groups (CABG) found that most are motivated to adopt more healthy behaviours soon after medical intervention (Jue and Cunningham, 1998) but that did not seem to be the case in the current study.

In Phase 1 it was found that 25 participants (26.9%) made no lifestyle changes at all and, although this figure seemed much higher than the findings of Campbell and Torrance (2005) discussed in the literature review (6%), it aligned more closely with Gaw-Ens and Laing's (1994) result (20%). In this study, interview data provided evidence of participants' apparent apathy and lack of motivation to adopt and maintain healthier lifestyles.

#### "It's common sense that you should eat less fat...I could eat better. I know I could...I know I could lose weight and I keep saying that but you know..." (Participant 57 – Female, 60)

That concurred with previous research and was found to be a strong predictor of success (Kelly, 2011). According to Bandura's Social Cognitive Theory, people become discouraged by failure so each attempt to change behaviour would seem more difficult (Bandura and Adams, 1977). To enhance the success of the PCI patients' adoption of healthier behaviours, it appeared necessary to enhance their self-efficacy. There was no evidence from the study though that any efforts had been made to do this.

Lack of motivation was found to influence participants' physical activity. Judged against UK guidelines (Bull and the Expert Working Groups, 2010), only 24.7% of the sample reported being as active as they should be (i.e. >30 minutes most days). In Phase 1 of the study, 21.5% of participants indicated that they had increased the amount of exercise they took but a review of the Phase 2 data showed that for some, the change was often not sustained. A quote from one participant typifies this:

"You know when I can be bothered...we walk round the hill." (Participant 57 – Female, 60) It is well documented and publicised that inactivity increases the risk of chronic diseases, including CHD, but despite public health campaigns, the number of adults who take the recommended amount of exercise has not altered since 2008 (Scottish Government, 2014) and lack of motivation has been a key contributor to that (Hepler, Wang and Albarracin, 2012). Trost *et al.* (2002) found from a systematic review that in addition to the environment people live in psychological, physical, sociocultural and biological factors influenced their motivation to exercise. This has clear alignment with the Social Cognitive Theory but the complexity of factors that influence motivation makes strategies to enhance it challenging.

The ability to lose weight was also affected by a lack of motivation. The mean BMI for the sample was 30kg/m<sup>2</sup> (SE± 6.41) and that is higher than the general population (BMI 27.3kg/m<sup>2</sup>) (Gray and Leyland, 2012). Obesity is a significant public health issue for the UK (National Obesity Forum, 2014) and the literature review indicated that it was common in a PCI patient population (Astin and Jones, 2006b; Scholte op Reimer *et al.*, 2002; Sigurdsson, Jonsson and Thorgeirsson, 2002). Phase 1 found that almost 1 in 5 participants (19.3%) reported that they had lost weight since the PCI but self-reports of weight loss are known to be unreliable (Wetmore and Mokdad, 2012). When interviewed, some participants admitted that they had lost little, if any, weight and the main reason for that was a lack of motivation and apparent contentedness.

# "I suppose I have put on a wee bit of weight...I like food. It's one of the good things about life." (Participant 70 – Male, 85)

In addition to motivation, environmental factors may also have an influence on weight loss. The media frequently advertise the latest 'faddy' diets, which promise miraculous amounts of weight loss. Messages given out by the media about the 'best' way to lose weight are perplexing and the confusion results in people making fewer dietary changes to lose weight (Nagler, 2014). This was obvious from the qualitative data as participants were not that sure what to eat, and so few changes were made to their diet.

The diet industry, estimated to be worth around £2 billion in the UK (Elkin, 2013), relies on people failing in their attempts to lose weight. Repeated attempts at losing weight are common (Buzzacott *et al.*, 2013), indeed, losing

weight is the most frequently cited New Year's resolution (Conason, 2014). PCI patients, therefore, need to be given sound evidence-based advice to dispel the myths of 'faddy' diets and support to enhance their success in losing weight, but that did not happen in the study.

Compared to studies of PCI patients conducted some time ago where almost a third of the sample smoked (Scholte op Reimer *et al.*, 2002), recent studies (Vulic *et al.*, 2010), including this one, have found much lower levels (10 – 12%). There has been a decline in the number of people who smoke in the UK (ASH Scotland, 2014) and that trend seems to be followed in PCI patient groups. This may be as a consequence of the World Health Organisation public health treaty on tobacco control that was agreed in 2005 (ASH, 2007) and the impact of smoke free legislation brought in by all countries within the UK in 2006/7 (Bauld, 2011; Mackay, Haw and Pell, 2011).

A reason for continued smoking came in Phase 2 where evidence of unrealistic optimism to the susceptibility of diseases caused by smoking was found.

# "There is risk you are likely to have a heart attack smoking and cancer smoking...that won't happen to us." (Participant 90 – Male, 65)

This mindset has been evident in the general population for some time (Yeretzian and Afifi, 2009; Freis, 2001; Weinstein, 1994) but it can be particularly dangerous for patients with chronic diseases. The complacent attitude these patients had in relation to CHD risk factors meant that they continued with unhealthy behaviours that will lead to CHD progression. This could perhaps be one reason why a significant proportion of PCI patients require further coronary revascularisation within ten years to once again control angina symptoms.

It seemed, therefore, that participants were reluctant to make any behavioural changes or, if they did, these were often not sustained. Lack of motivation and lack of concern for health seemed to be the main reasons that participants failed to adopt and maintain healthier behaviours.

#### 6.3.3 Adherence to a treatment regime

Clinical guidelines strongly recommended that medicines for the secondary prevention of CHD are prescribed to patients after PCI to improve their outcomes and lessen the chances of CHD progression (SIGN, 2007; Task Force for Percutaneous Coronary Interventions of the European Society of Cardiology, 2005). All 85 participants (91.4%) who responded to the questions regarding medicines in Phase 1 reported that they took them every day and were confident that they knew how to take them. Phase 2 found that non-adherence was an issue and this was categorised as either unintentional or intentional.

The qualitative data indicated that unintentional non-adherence was mainly caused by simply forgetting to take the medicine and this quote typifies that:

"My statin, I take that just before I go to bed...I have forgotten it. Sometimes, not intentionally. We sometimes babysit for the grandson and it's awkward. I just never think of carrying it." (Participant 88 – Male, 76)

The interview data provided evidence that participants who had developed a habit to taking their medicines were most successful in this self-management component, and this has been found in other patient groups (Phillips, Leventhal and Leventhal, 2013; Ruppar and Russell, 2009).

"Orange juice, pills with orange juice. The Aspirin goes into the orange juice glass with the water while I have my porridge and then I have the Aspirin. So I have them all at the same time every day." (Participant 91 – Male, 66)

Intentional non-adherence has been found to occur if patients cannot afford to pay for their prescriptions (Aghabekyan, Thompson and Abrahamyan, 2012; Nunes *et al.*, 2009) but the free prescription policy in Scotland (Scottish Government, 2013) meant that this was not mentioned at participant interviews. This study provides evidence that non-adherence is not caused by the inability of patients to pay for medicines in Scotland.

Some intentional non-adherence was evidenced through the qualitative data. Cited in previous studies of patients with other chronic conditions (Ho, Bryson and Rumsfeld, 2009; Alm-Roijer *et al.*, 2006; Miller, 1997), two common reasons for non-adherence emerged: perceived side effects of medicines and perceived lack of benefit.

"I stopped taking the statin...Simvastatin has not got very good press for muscles...I don't want it to go to muscle degeneration or anything like that." (Participant 57 – Female, 60)

"If I remember I take some statin at night...I'm not very enthusiastic about that...I don't think it makes a lot of difference really." (Participant 93 – Male, 82)

The main medicine that was stopped intentionally by participants was the cholesterol lowering statin. There is a strong evidence-base that these are beneficial in reducing mortality and morbidity in CHD patients (NICE, 2014; Mills *et al.*, 2010; Scandinavian Simvastatin Survival Study Group, 1994) but controversy about their side effects has led to confusion and the notion that they harm more than provide benefit (Godlee, 2014). It was reported that side effects had a more significant impact on CHD patients' lives than previously thought (Rosenbaum *et al.*, 2012). This notion was seized upon by the media who publicised that message widely in a somewhat scaremongering manner (Smith, 2012; Cohen and Hagan, 2012). That seemed to affect the perceptions of some participants, causing them to be non-adherent with this medicine.

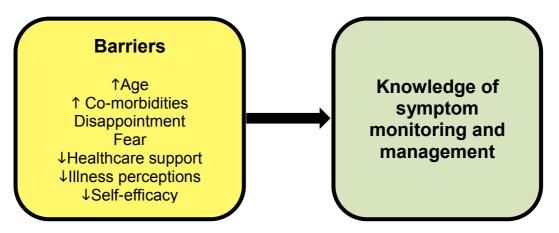
#### 6.4

# Research question 2: What and how do factors influence patients' self-management of CHD after elective PCI?

The main factors that influenced participants' adherence to a medication regime were illness perceptions and denial that CHD was a chronic condition. The findings that affected participants' knowledge of symptom monitoring / management and their adoption / maintenance of a healthy lifestyle are illustrated in Figures 6.1 and 6.2. For clarity, these diagrams show the factors that were found to be barriers to successful CHD self-management.

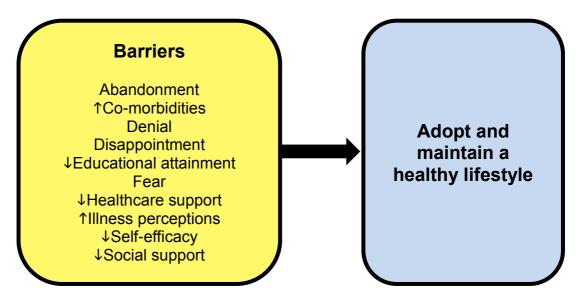
#### Figure 6.1

Barriers to knowledge of effective symptom monitoring / management



#### Figure 6.2

Barriers to the adoption / maintenance of a healthy lifestyle



#### 6.4.1 Influence of age

The quantitative data provided evidence that a statistically significant link existed between older age and less effective monitoring and management of angina symptoms in the PCI sample. This was confirmed by multivariate analysis. Moser *et al.* (2006) issued a scientific statement based on their conclusions from what seemed a meta analysis of published research findings related to why patients delay seeking treatment. They deduced that older age was one factor that increased the delay in patients seeking treatment for symptoms. While the findings from the current study concur with the conclusions from Moser *et al.* (2006) the focus of their meta-analysis was on studies of patients with acute coronary syndromes and acute ischaemic stroke and so the patient populations differ somewhat. What was not apparent from

the meta-analysis was the reasons for the delay in seeking treatment. There was qualitative evidence in the current study that provided one explanation for this as older participants were more stoic and accepted recurring pain as a sign of the normal aging process. The delay in accessing treatment could however, cause a significant risk to patients' morbidity and mortality. While the under reporting of pain has been linked to stoicism before, the research concerned arthritis in the elderly (Abdulla *et al.*, 2013; Johnson, 2008). The finding that older patients who were more stoic had less effective symptom management is a new discovery in a PCI patient population.

Older participants in the study also seemed to have a greater reliance on their GP to help them deal with any angina symptoms. There was a general reluctance by more elderly PCI patients to contact unscheduled care services when angina symptoms recurred.

#### "At night I wouldn't call an ambulance, I would wait until the GP opened at half past eight." (Participant 86 – Male, 77)

Research has found that older members of the public are less likely to contact '999' and other unscheduled care services (Department of Health, 2012). The Director General of Age Concern (England) suggests one reason for this is that they may feel they will jeopardise any relationship they have with their GP (Lishman, 2008) but this was not apparent in the current study. Evidence did emerge to suggest that stoicism in older participants meant that they endured the angina symptoms and waited until they could get help from their GPs, rather than calling for emergency ambulances. Older participants were also of the belief that by seeking help from their GP that medical attention in hospital would be expedited.

#### "I think by doing it through the surgery, the hospital knew I was coming and I didn't have to sit and wait for a long time. (Participant 14 – Female, 82)

This study provides evidence that older PCI patients think that recurring angina symptoms are normal in the aging process and are loath to contact emergency services for prolonged periods of pain, opting to see their GPs instead. Never before has this been documented in a PCI patient population.

#### 6.4.2 Influence of co-morbidities

Co-morbidities were correlated with participants' adoption of a healthy lifestyle in Phase 1. Although a link between this variable and the adoption of healthier behaviours was highlighted in the literature review (Lauck, Johnson and Ratner, 2009), the reason for it was unexplained. In this study it was found that participants thought that their co-morbid conditions were more serious than CHD and that appeared to lessen their motivation to change their behaviour to reduce their CHD risk.

"Well I think the bigger change in the diet was at the time of the diabetes but yes, I think I have changed since the angina and the major change is that I don't eat as much. I wouldn't go for the big breakfast kind of thing...I have made a bit of a change but not as marked as it was with the diabetes." (Participant 70 – Male, 85)

In the current study, this caused lifestyle factors to remain unchanged, which would pose a risk of CHD progression and the need for further coronary revascularisation. It seemed that those with co-morbid conditions trivialised their angina symptoms and believed that they would resolve with little or no personal intervention.

#### "If I suddenly got it [pain] you just stop what you are doing and it goes away. I don't think I really need GTN...My aortic valve stenosis is worse." (Participant 93 – Male, 82)

The trivialisation of angina symptoms in those with co-morbidities may be a consequence of participants experiencing few angina symptoms after PCI. This contrasts with other cardiac patients (e.g. heart failure patients) as they are more likely to have frequent symptoms and so more effort is required from the patient to manage these (Chriss *et al.*, 2004; Riegel and Carlson, 2002). Ineffective symptom management could have an impact on the morbidity and mortality of PCI patients.

Qualitative findings indicated that those with co-morbidities appraised which condition was more serious, based on the inconvenience and impact it had to their daily lives and this often meant CHD was perceived to be of less concern than other conditions.

#### 6.4.3 Influence of educational attainment

Statistical significance was found in the bivariate analysis of the relationship between educational attainment and participants' adoption of a healthy lifestyle. Quantitative data provided evidence that participants who were educated beyond secondary school level had a greater likelihood of changing their behaviour to lessen their risk of CHD progression. This finding was confirmed with multivariate analysis but it somewhat contradicts the finding from Le Grande et al. (2006) who found in their study that the educational level of their PCI sample did not alter exercise rates. Le Grande et al.'s (2006) used a cohort study to investigate patients who had undergone PCI either as an emergency procedure for acute myocardial infarction or unstable angina or an a planned procedure for patients with stable angina. Telephone interviews were used to collect data two weeks and six months following PCI from the sample of 200 participants and data analysis using Pearson's correlations found no relationship between the levels of education participants had completed and their physical activity. While Le Grande *et al.* did include patients who underwent elective PCI for stable angina, the results for that particular subgroup of patients were not separated from those who had emergency PCI despite accounting for a third of the total sample. As indicated in chapter 1, the pathophysiology of myocardial infarction and unstable angina differ from stable angina and the treatment and recovery of these patients is dissimilar to stable angina patients who have elective PCI and that may be one explanation for the difference in findings from their study compared to the current study.

Phase 2 did not provide an explanation for the current finding but it gave evidence that participants who had a university education seemed more able to articulate what lifestyle changes would reduce their chances of CHD progression and this supports research of the general public by Potvin, Richard and Edwards (2000). Despite this knowledge though, actual behaviour change did not always seem to ensue. Indeed, more educated participants would often use their knowledge to justify their lack of behaviour change.

"Cholesterol, you can do about 20% yourself in your diet but 80% of this is the genes...my diet is fine." (Participant 90 – Male, 65)

The other potential explanation for the correlation between level of education

and adoption of healthy behaviour may also be that the more educated participants had a greater awareness of how to provide survey responses that would portray them in a favourable light; essentially the influence of social desirability bias in completing surveys (Peer and Gamliel, 2011).

#### 6.4.4 Influence of illness perceptions

Phase 1 provided statistically significant evidence that threatening illness perceptions made it more likely for PCI participants to know effective symptom monitoring and management and this has not been evidenced before. It was noted in Chapter 5 that the qualitative data did not readily appear to explain that, as participants with similar beliefs talked of contrasting strategies to manage symptoms. It was clear that participants would appraise their angina symptoms and subsequent decisions regarding self-management were based on the perceptions gained. Three main things influenced how they subsequently managed their angina symptoms: emotional representations (these will be discussed later), perceptions of the seriousness of angina symptoms and how participants' friends / family deal with such symptoms.

Interpretation of the qualitative data indicated that the perceptions of the 'seriousness' of the angina symptoms appeared to relate to factors associated with what the patients considered 'typical' angina symptoms. Evidence suggested that patients would cope with classic signs of angina (i.e. chest pain / tightness) but if these were associated with factors such as breathlessness, arrhythmia, and dizziness, participants perceived their condition to be more serious, and that affected their management.

#### "If I suddenly got it and it didn't go away and I had any arrhythmias or anything of that sort or if I felt a bit woozy, it would be serious." (Participant 93 – Male, 82)

Farquharson, Johnston and Bugge (2012) found in their study that people who experienced fewer symptoms linked to acute coronary syndromes delayed seeking treatment but also that some people had difficulty appraising multiple symptoms. This finding seems to differ from the current study where additional symptoms appeared to make PCI participants more likely to access help from healthcare providers. The sample that Farquharson, Johnston and Bugge (2012) used was people who contacted a telephone helpline provided by the

National Health Service in Scotland and so not all of these people were known to have CHD and resultantly, it is difficult to generalise their results to the current study of PCI patients. Their study was limited by a very poor survey response rate (28%) and so their findings may be biased and deviate from those of the population they studied and so should be viewed with caution.

Relying on associated features to determine the seriousness of angina symptoms is not an effective method of monitoring (National Heart, Lung and Blood Institute, 2013). They are known to vary from person to person and damage to the heart can occur with relatively few or even no symptoms. Patients often expect to have 'classic' angina symptoms, the type that are often shown in films or on television, usually where men suddenly clutch their chests and collapse (National Heart, Lung and Blood Institute, 2013). Evidence exists that it is often not that dramatic, particularly for females, older people and diabetics (American Heart Association, 2014a; National Heart, Lung and Blood Institute, 2011; Ornato and Hand, 2001). Campaigns from organisations such as the British Heart Foundation, have tried to raise awareness of the range of symptom characteristics and how these should be managed (British Heart Foundation, 2008c). It seems from the current study that these campaigns have not influenced patients' perceptions much, as findings indicated that PCI patients would wait until they had multiple angina symptoms before acting.

The findings from this study provide new evidence that PCI patients do not manage their angina symptoms effectively due to the perceptions they have of their illness and its accompanying symptoms. Participants would seek help if they had classical cardiac signs. Current methods of educating PCI patients on how to recognise and manage angina symptoms seem ineffective.

Qualitative findings also provided evidence that there was a link between social persuasion / vicarious experience and participants' illness perceptions.

"I have never had a spray [GTN]. I dinae fancy taking it. My brother-inlaw takes it and he finds it disnae do him a great deal of good..." (Participant 88 – Male, 76)

This caused suboptimal symptom management but never before has this been found in studies involving PCI patients.

Phase 2 indicated that there was a significant link between participants' illness perceptions and their adoption of a healthy lifestyle. Support for the quantitative findings primarily centred round participants' perceptions of what caused their CHD and the consequences of having the disease. The causal attributions of participants were often erroneous and this is well known in cardiac patient populations (Momtahan *et al.*, 2004; SIGN, 2002) but differs from the findings from Stafford, Jackson and Berk (2008). The response from one participant typifies incorrect beliefs regarding the causes of CHD.

# "You put everything down to the menopause and then there was the thyroid thing." (Participant 57 – Female, 60)

Where participants attributed their CHD to causes other than known CHD risk factors, they perceived no need or had less inclination to make changes to their lifestyle. These findings help to explain why a link was found between these factors in the quantitative phase of the study.

The perceived consequences of having CHD appeared to differ in participants. From the gualitative phase of the study it was found that some thought that they were cured of the disease after having the PCI performed and this concurs with recent research from the cross-sectional observational study by Perk et al. (2014). They investigated the outcome of patient education after PCI and concluded from the 1073 responses to a survey that 67% of patients thought they were cured after PCI revascularisation. They also found that 38% of the sample did not think, from the information they were given, that there was a need to modify their lifestyle but it is not clear from the publication if those people also thought they were cured. Due to the way the data were analysed, it is not possible to determine what effect the perceptions of being cured had on Perk et al.'s participants' likelihood of adoption healthier lifestyles. Polarised to the notion of being cured by the PCI, others in the current study felt that they could do little to deter the progression of the disease. This aligned with evidence from the grounded theory study from Peterson et al. (2010) that explored the beliefs of patients who had been successful and not successful at lifestyle modification three years after PCI (this study was described in chapter 2). It seemed therefore, that from the current study, that regardless of whether the participants held perceptions that the PCI was curative or that nothing could

be done to prevent CHD progression, that they did not adopt healthier behaviours.

Although all participants said they adhered to a medication regime in Phase 1, the qualitative findings suggested that the perceptions they had of their CHD affected whether or not they took prescribed medicines. Those who believed that taking certain medicines provoked unpleasant side effects were less likely to continue to take them and this concurs with findings of a study of 20 PCI patients by Rushworth *et al.* (2012) that collected data both from a survey and semi-structured participant interviews to explore medication adherence and factors that influenced that. Although participants were recruited to the study within a week of the PCI procedure, it is not evident what the time lapse was between recruitment and data collection. It is only intimated that interviews were conducted over a seven-week period. The sample recruited was however, apparently sufficient to achieve data saturation which enhances the notion that the findings were reliable (Liamputtong and Ezzy, 2005).

It was also found in the current study that if participants perceived that medicines produced no overt benefit, they were inclined to stop taking them. It is known that if patients do not feel better when they take medicines, they are less likely to be adherent as they believe the medicine is not working (Society for Cardiovascular Angiography and Interventions, 2014) and that was evident in the qualitative findings.

#### 6.4.5 Influence of self-efficacy

In Phase 1 of the study, there was a statistically significant correlation between self-efficacy and PCI participants' likelihood of adopting healthier lifestyles. This concurs with previous research of CHD patients from Cleary, LaPier and Beadle (2011) and Al-Ali and Haddad (2004) but contradicts that of Perkins and Jenkins (1998) who used a PCI patient sample. Cleary, LaPier and Beadle (2011) conducted a cross-sectional study involving 50 patients who had been admitted to hospital with different manifestations of CHD. Data were collected while the patients remained in hospital via a self-administered survey. The survey asked participants to respond to questions that prospectively gauged their confidence in exercising but considering some of these patients appeared to be newly diagnosed with CHD, it is difficult to determine if their self-efficacy

would alter once discharged home as the data collection tool seemed to capture their intentions to exercise only. They concluded that confidence influenced participants' likelihood of maintaining an exercise programme but that seems to relate to reporting bias as the patients would be unlikely to exercise in hospital.

The study from AI-Ali and Haddad (2004) differs from the current study in that they recruited 98 Jordanian myocardial infarction patients and collected data using a survey administered during face-to-face interviews to explore the exercise participation using the Health Belief Model to underpin the research. They concluded that self-efficacy correlated with participants' participation in exercise. Although their patient population differed in how CHD manifested, they also were dissimilar in culture as in Jordan it is custom for females not to participate in exercise and health promotion messages are not given through the media.

Although the studies from Al-Ali and Haddad (2004) and Cleary, LaPier and Beadle (2011) used patients with different manifestations of CHD, Perkins and Jenkins (1998) included patients who had undergone PCI in their study. Perkins and Jenkins' cohort study gathered data at two timepoints, while the patient was in hospital having the PCI performed and two weeks hence. The study explored self-efficacy expectation in patients recovering from PCI and found that as self-efficacy increased between the two timepoints, role resumption did not. Although their study used a sample of PCI patients they differed from the participants in the current study in that the period of hospitalisation when Perkins and Jenkins (1998) study was conducted was around four days. This may account for the difference between the two sets of findings. The current study, therefore, is the first to establish a link between self-efficacy and this component of CHD self-management with PCI patients.

As mentioned in Chapter 5, it emerged in Phase 2 that those who seemed more confident had more success in achieving and maintaining lifestyle change.

"I have started to exercise more because I am able to now without the anxiety of having an attack [angina]. I am finding that I am getting fitter and it's incredible." (Participant 80 – Male, 68)

Keller and White (1997) suggested that behaviour change is dependent on

people having both confidence as well as conviction; essentially a link between people's perceptions of their health and their confidence of success in making it better. There was a strong indication from the qualitative findings that participants' illness perceptions linked to their confidence or self-efficacy. That helped to provide some understanding of why the multivariate analysis established that illness perceptions had no direct relationship with the adoption of healthier behaviours, but an indirect one, through self-efficacy.

This finding provides evidence that illness perceptions and self-efficacy should be considered together when supporting PCI patients' lifestyle change and it aligns with the guidance from SIGN (2002) on this topic. The study, however, found no support was afforded the PCI participants that addressed cardiac misconceptions and enhanced self-efficacy to promote behaviour change so their risk of CHD progression remained.

#### 6.4.6 Influence of support

Social or healthcare support appeared to have no relationship with any of the components of CHD self-management according to the bivariate analysis of Phase 1 data. At multivariate level, however, it was found that support from healthcare personnel had a direct relationship with both the participants' likelihood of adopting more healthy behaviours and them knowing effective symptom management. Phase 2 found that both social and healthcare support affected participants' CHD self-management and, as discussed in Chapter 5, this became an overarching theme.

#### Influence of support from healthcare

Quantitative findings provided evidence that PCI participants who had frequent contact with their GPs or had been hospitalised were less likely to adopt and maintain a healthy lifestyle. Research has, in the past, found that secondary prevention of CHD in primary care is poor (Department of Health, 2013b; The King's Fund, 2011) and this study provided qualitative evidence that substantiated that. Although not every participant in the current study accessed the services in primary care, 70% of the sample reported that they had but despite this, these people were less likely to adopt healthier lifestyles. As the needs of those with newly diagnosed CHD / angina may differ from patients who have had the condition for a longer time, it was found that 66.6% of

patients who had CHD for more than a year and 74.4% of those who were diagnosed within the previous 12 months had contact with their GP.

Although not explored in Phase 1 of the study, the qualitative phase of the study gave an indication that nurse-led secondary prevention clinics may not be that effective in encouraging lifestyle modification.

"He (GP) told me to just take it easy but he said 'I reckon that you will know yourself what to do and what not to do'."

(Participant 87 – Female, 72)

"They sent me a note to come in and get my cholesterol checked but none of the GPs saw me. It was the practice nurse but I don't see what use they would have had." (Participant 90 – Male, 65)

Strong evidence emerged from the qualitative findings signifying that participants perceived the support from healthcare staff as inadequate and this led to feelings of abandonment and vulnerability.

"I felt like kind of in limbo when I left because I wasn't guided about what to do and what not to do...I felt that was pretty poor in a way after getting four stents put in. I have never seen him again (cardiologist)." (Participant 87 – Female, 72)

"After it's all over you are fixed and that's the hospital done their job but there's nobody really there to support you..."

(Participant 57 – Female, 60)

The PCI participants felt that they were generally 'left to get on with it' and, although some seemed motivated to adopt healthier behaviours, they lacked confidence in their ability to do this unsupported.

Clinical guidelines and policy statements advocate that healthcare professionals should provide individualised support to help patients manage their CHD after PCI (British Association for Cardiovascular Prevention and Rehabilitation, 2012; SIGN, 2007; NICE, 2004), yet this did not seem to happen. Partnerships between patients and healthcare staff are regarded as essential elements to successful self-management (Self Management UK, 2013), but these were considered by the participants to be either non-existent or inadequate. Never before has this been documented in a PCI population.

Some participants were given the option of attending a cardiac rehabilitation programme and, although that may have given them support, the qualitative data provided evidence that many perceived themselves as either too fit to benefit or too sick to be able to participate. Participants' perceptions of cardiac rehabilitation often led to them not attending and so they missed out on that option of support. This has been found previously with other CHD patients (Cooper *et al.*, 2005). It appeared that healthcare providers made little effort to dispel the PCI patients' misconceptions of cardiac rehabilitation. Given that around three-quarters of PCI patients require further revascularistion within ten years to once again control their angina symptoms (BARI Investigators, 2007; Alderman *et al.*, 2004), it is clear that healthcare professionals need to support patients more with behaviour modification.

#### Influence of social support

Similar to the research from Peterson *et al.* (2010) and Campbell and Torrance (2005), support from family and friends seemed important to the participants in Phase 2. In the current study, although there was evidence to suggest that this helped some participants to adopt more healthy behaviours, it did little to enhance participants' adherence to their medication regime or their monitoring and management of angina symptoms.

A review of the qualitative data provided evidence that although some participants said that they felt supported by their friends and family, few were able to provide examples of this. The participants who had friends with CHD were really the only ones who were able to say specifically what support they received. The data from Phase 2 contained virtually no information about how social support helped participants self-manage their CHD. Evidence existed that discussions had been had with family and friends around the time of diagnosis and the PCI procedure but, by the time the participant interviews were conducted, any talk had all but ceased. The following quotations were typical responses when participants were asked if they had discussed CHD and its management with their friends and family:

"We spoke about it when I came out and was recovering and that... There's no really any support." (Participant 88 – Male, 76)

# "Once they [friends] had heard the story... You know I didn't go into it in great detail." (Participant 14 – Female, 82)

Except for the minority who had close friends with CHD, participants gave the impression that they felt let down by their friends and family as they expected and needed support. This seemed to perpetuate feelings of isolation and in some cases, loneliness, which had a detrimental effect on their CHD self-management.

#### Influence of lack of support

Participants felt abandoned and unsupported in self-managing their CHD and that seemed to lead to isolation. In this study, social isolation occurred as a consequence of the participants having to self-manage their CHD feeling unsupported. The qualitative evidence suggested that there was a 'social disconnection' between participants and their friends, family and healthcare professionals as relationships with these people were considered absent or unhelpful in supporting self-management. That appeared to result in some participants feeling that they were alone in dealing with their CHD. For example a quote from **Participant 88:** 

# "There's no really any other support...You just have to get on wi' it yersel'..."

Research indicates that isolation, particularly social isolation, is detrimental to health (Nicholson, 2012) and is a significant issue in older adults and those who live alone (Wenger *et al.*, 1996). Social isolation impedes people's wellbeing and quality of life (Zavaleta, Samuel and Mills, 2014). It increases morbidity and mortality and is considered by some to be a risk factor for CHD (Brummett *et al.*, 2001; House, 2001). Brummett *et al.* (2001) conducted a cohort study (n=430) that compared those who felt isolated with those less so and found that CHD patients with smaller social networks had a higher risk of mortality, regardless of the severity of their disease or their demographic factors. The findings from this study are relevant to the current one but cognisance must be paid to the heterogeneous sample of patients with different manifestations of CHD in Brummett *et al.*'s study. The publication from House was an opinion paper and so further exploration may be needed to determine the effects of social isolation on patients after elective PCI.

Social support is categorised into two broad domains: functional and structural support (Barth, Schneider and Von Kanel, 2010). Structural support encompasses the size and type of social 'networks' people have, as well as their frequency of contact with others, whereas functional support relates to the actual support given by individuals' networks (e.g. financial, emotional, informational) (Lett *et al.*, 2005).

Williams *et al.* (1992) found unmarried CHD patients lacked structural support and that increased their morbidity and mortality. Albeit, this cohort study from Williams *et al.* began almost four decades ago as data were collected from 1974 to 1980. It differs from the current study in that more than 80% of their sample were males and had a mean age of 52 years and so those recruited are vastly different from the PCI patients in the current study. Also, those in Williams *et al.*'s study were undergoing coronary angiography only and so the procedure was merely exploratory, no coronary revascularisation was performed. That was not found in the current study though, as the social networks participants described when interviewed in Phase 2 seemed reasonable, even those who lived alone. People can be surrounded by others and have good structural support, yet still feel isolated if functional support is poor. Within the qualitative data, there was evidence that participants perceived the functional support they received from family as good. For example:

"She [wife] is a big support to me you know... I don't know how to explain to you but she is a big support to me in my life." (Participant 86 – Male, 77)

The support they actually got was explored in the interviews and it seemed that the 'received' functional support was much more difficult to determine. A quote from the same participant (**Participant 86**) illustrates this:

"We don't talk about this [talk about CHD with wife]...I don't have any institutions where I have contact with them, any support. No absolutely nothing..."

Participants said they felt supported by their family in their management of CHD but often were unable to say what that support actually constituted. The lack of support for PCI patients caused feelings of isolation and that seemed to negatively affect their management of CHD. Consequently, the risk of disease progression and poor symptom management ensued.

#### 6.4.7 Influence of emotions

Although the influence of emotions on CHD self-management was not apparent in Phase 1 of the study, it appeared that these had a significant impact on how participants managed their condition from the qualitative analysis. It seemed that the stronger the emotion, the greater the likelihood that it influenced the cognitive representation the participants had of their illness. Within Phase 2, emotional response was developed as an over-arching theme as the significant effect on CHD self-management became apparent.

As abandonment had been discussed previously in the section on support (6.4.6), the findings related to the remaining emotional responses identified from the qualitative data will be discussed in the proceeding part of the chapter.

#### Influence of being fearful

Fear was, by some margin, the emotional factor that seemed to have most influence on participants and how they coped with their CHD. Several participants spoke of being fearful that they would die as a result of the CHD and the following quote from **Participant 57** typifies the feelings:

#### "Am I going to be okay? Am I just going to just drop dead?"

Despite usually being relieved of angina symptoms after PCI, the threat of getting these again also seemed frightening for some participants. Although the fear of disease recurrence is relatively common with other conditions (e.g. cancer), participants in the study believed that they could reduce their risk by refraining from engaging in activities that would provoke angina symptoms. Their coping strategy was therefore to restrict their activity and that compromised their ability to adopt a healthier lifestyle. This finding corresponds to that from a pilot study by Langley (2003) described in chapter 2.

As indicated in the literature review, Gaw-Ens and Laing (1994) surmised that fear caused PCI patients to restrict their activity and this study now provides qualitative evidence to confirm that. This finding, however, contrasts the

qualitative research from Peterson *et al.* (2010), described in the literature review, where participants expressed fear of undergoing the PCI procedure and saw that as a 'turning point' after which they adopted healthier behaviours. Fear seemed to stimulate behaviour change in Peterson *et al.*'s (2010) participants, which contrasts the finding of the current study.

Fear also caused the participants to have difficulty in monitoring their symptoms as confusion arose as to which symptoms were angina and which were the normal physiological responses of the body to fear and stress. Again, it was evident that those who had difficulty coping with their emotional response of fear often interpreted any slight twinge or fluttering of the heart to be cardiac in nature and this exacerbated the problem. Thus, the coping strategies adopted by frightened participants generally involved calling for emergency healthcare support, even when that would not be advocated. There appeared to be a tendency for some people to become preoccupied with their fear and that negatively affected their CHD self-management efficacy.

Fear is considered to be a short-lived immediate reaction to a threat (Lamia, 2011). Steimer (2002) states that animals adopt avoidance behaviour if they fear recurrence of a situation in which they experienced pain and the same may be said of the PCI participants who avoided activity for fear of angina symptoms returning.

Similar to anxiety, fear causes stimulation of the basic survival mechanism, the 'fight or flight' response. While some consider fear to differ from anxiety (fear is a response to a known or definite threat whereas, anxiety is a reaction to a perceived or imprecise threat), the two are interrelated (Ankrom, 2014; Schiano, 2013). Consequently, it was expected that participants who were frightened after PCI would be identifiable using the HADS tool (Julian, 2011) and yet that did not happen. While that may be a limitation of the reliability of the tool, the HADS was not designed to detect fear, and although it was mentioned in chapter 3 that it has been criticised for containing questions related to the assessment of restlessness as well as anxiety and depression (Caci *et al.,* 2003), other tools may be better suited to the detection of fear. For example, Koivula, Hautamaki-Lamminen and Astedt-Kurki (2009) developed a Coronary Heart Disease Patients Fear Scale and although this had limitations in that it is

available in Finnish language only and was tested with a CABG surgery patient group, it had good internal consistency / reliability (Cronbach's alpha 0.86). Further studies that explore emotions in elective PCI patients should consider other tools that are more sensitive to detect fear than the HADS.

As indicated in the discussion regarding sub-theme 'fear' in Chapter 5, some interviewees who were frightened by their CHD, perceived their condition as more threatening. The emotional representations these people had of this disease appeared to have a significant influence over cognitive perceptions.

As indicated in Chapter 5 three interviewees expressed their fear of CHD but also said that they perceived the CHD to be cured after the PCI. Their fear seemed to relate to the notion that they had experienced angina symptoms at least once before and although the PCI had alleviated these symptoms, there was a threat of recurrence, or two people thought there was a risk of sudden death. Fearing mortality seems relatively common in patients with CHD. For example, Coyle (2009) conducted a mixed method cohort study of 62 patients who had suffered a myocardial infarction. Participants were interviewed at two timepoints within a month of the myocardial infarction and one of the emergent qualitative themes from the study was 'fearing death'. Coyle's study differs from the current one both in terms of the CHD population sampled and the time lapse from the 'coronary event', but what it did not explore was the perceptions the myocardial infarction patients had of their CHD. For example, did some people also believe that they were cured after the myocardial infarction? The current study seems to be the first to document that patients who believe the PCI has cured them, remain fearful of the disease returning or of death.

Mennin *et al.* (2007) found that an inability to control emotions increased the distress that some people experienced. The influence of fear on participants' self-management was considerable and this study provides new evidence that PCI patients who experienced that emotion were less physically active and so were at risk from CHD progression.

#### Influence of feeling disappointed

Disappointment also featured strongly in the interview discussions. Participants believed recurrent angina symptoms after PCI were a result of an unsuccessful

procedure. The expectations they had of the procedure resolving their angina symptoms led to feelings of disappointment. Other studies, including a cross-sectional study from Kureshi *et al.* (2014) with 991 participants found that the majority of elective PCI patients overestimate the benefit of PCI revascularisation and expect it to completely relieve their angina symptoms.

The participants in the current study readily discussed their disappointment in relation to the perceived failed PCI, but this emotion appeared to render them powerless to self-manage aspects of their condition, particularly the monitoring and management of angina symptoms. Evidence was found that it reduced participants' self-efficacy and made their illness seem more threatening. This links to previous research with PCI patient samples that found that recurrent angina symptoms increased PCI patients' illness perceptions (Ozkan, Odabasi and Ozcan, 2008; Pocock *et al.*, 2000; Permanyer-Miralda *et al.*, 1999).

Disappointment was also evident in those who perceived that their functional capacity was limited. SIGN (2002; Page 20) advocates that patients should be informed that:

"if they are not as able as they hoped on their return home they should try not to view this as a setback".

Participants did not seem aware of that information and disappointment was obvious in some who displayed a rather negative affect when discussing their physical ability. **Participant 70** provides an example of the discussion related to this:

"there is no doubt ... I would like to be a wee bit more active."

Experiencing disappointment that they perceived they were more 'disabled' than they actually were gave rise to a lack of motivation and confidence in participants to make any alterations to lifestyle to reduce the risk of CHD progression and this was displayed in the participants' facial expressions as sadness. This emotion made the participants believe that they were unable to prevent the disease progressing.

Similar to the response to fear mentioned previously, participants believed that they had little control over their CHD and appeared to have difficulty dealing with their emotion. This led them to restrict their activity and for some, that resulted in self-imposed confinement to their home resulting in social isolation.

#### Influence of shock

Although not obvious from the quantitative findings, evidence from Phase 2 indicated that participants were shocked and surprised that they had been diagnosed with CHD. The qualitative data provided evidence that the shock appeared to relate to loss of health and participants' perceptions of CHD.

"Well, I got the biggest shock of my life that I even had a heart problem. I'm a person who does a lot of keep fit...I used to do a lot of hill climbing... You are not going to expect a heart condition are you?" (Participant 87 – Female, 72)

The shock appeared to lead the PCI participants to adopt denial as a coping mechanism and this seems to be a relatively common response in CHD patients (Rosenfeld and Gilkeson, 2000). In the current study, denying that CHD remained present after the PCI, negatively affected participants' likelihood of adopting and maintaining more healthy behaviours. The same effect was found when participants denied that modifiable factors were causes of CHD development. The influence that shock and denial had on PCI participants' adherence to a treatment regime however, was inconclusive.

In the study by Tod *et al.* (2001), denial seemed to be motivated by patients' fear of having CHD but that was not found in the current study. While it did not emerge from the current study, perhaps due to its design, Levine *et al.* (1987) found in their study of cardiac patients (myocardial infarction and CABG) that denial was a useful coping strategy in the early stages after hospitalisation (i.e. when they remained in hospital) but long-term over the following year, it caused non-adherence to medication regimes, mal-adaptation to the CHD condition and patients were readmitted to hospital more frequently. (It is unclear from the publication if the readmission rates to hospital were self-reported). Levine *et al.*'s (1987) study seems however, to have some methodological flaws in that a pilot study appeared to be conducted at the same time as the main study and while the pilot study sought to determine the inter-rater reliability of a new survey tool that measured denial of illness, the findings of this did not seem to inform the main study.

indicate some reporting bias in that the number of participants in the pilot study and main study are stated but there seems to be a discrepancy between the figures given in the abstract and the main body of the publication. Consequently, the findings from Levine *et al.*'s (1987) study should be viewed with some caution. Further research would be required to look specifically at the effect denial has on PCI patients' hospital admission rates.

In the current study, the qualitative data provided evidence that participants' surprise at having CHD and their perceptions of the purpose of the PCI procedure, led them to deny that CHD was chronic and that negatively affected their CHD self-management.

#### Emotions and their regulation

It was clear from the qualitative findings that the emotions the participants experienced had a significant effect on their CHD self-management and so this was explored and interpreted further. While cognisance must be paid to the time lapse between elective PCI and collection of the qualitative data, somewhere between 3 and 6 months and the effect that had on participants ability to recall how they felt and thought, some quotes from interview transcripts demonstrate the influence of emotion on cognition.

"It happened once so it could happen again and could happen again so you are a wee bit 'nervey' in the beginning... Has this not worked [PCI]? Has it collapsed or something?... I lay on that sofa for weeks. I just wanted to lie down." (Participant 57 – Female, 60)

"Since the operation has been done [PCI] I think it's a serious matter...I am scared what the effect on my heart is... It could be serious so therefore the only alternative is to call an ambulance immediately and move to hospital [If symptoms recur]." (**Participant 86** – Male, 77)

It is known that when people experience strong emotion, their recall of that '*emotional scene*' is generally very good (Christianson, 2014; page 19) and so the memory participants had of how they felt in the first few weeks after PCI may be reliable.

Emotion can be a sudden and automatic reaction to a situation, for example recoiling in fear when you see a snake (LeDoux, 1995) but it may also involve

some cognitive process (Newen and Barlassina, 2013). Theories of emotion were explored to determine if they helped to explain the process participants appeared to experience regarding their emotions. Certainly, theories such as the James-Lange theory, dating back to the late nineteenth century (Cherry, 2014a), could fit with some of the study findings as it posits that emotions are a result of physiological reactions (e.g. PCI patients were frightened when they had heart palpitations). This theory has often received criticism though, as not all emotions occur as a consequence of a physiological response (Sincero, 2012). Two physiological response can occur simultaneously (the Cannon-Bard Theory) (Alston, 2014) but that notion also fails to explain all emotional responses discovered in the current study. More theories have emerged (e.g. The Schachter Theory: Reisenzein, 1983; Facial Feedback Theory: Buck, 1980) but none seem able to fully explain the emotional response of the PCI patients.

The Influence of emotion on cognition seems to align with thinking from a Professor of Neuroscience, Joseph LeDoux (1999; Page 19), who said: *"while conscious control of emotions is weak, emotions can flood consciousness... Once emotions occur, they become powerful motivators of future behaviour.*"

It is known that emotions often affect how people behave (Dietz, 2012) but whether negative emotions cause CHD has not been conclusively proven (Steptoe and Brydon, 2009; Sirois and Burg, 2003; Smith, 2001; Kubzansky and Kawachi, 2000). Psychological and physical health, however, is dependent on people's ability to regulate their emotions (Hartley and Phelps, 2010). Selfregulation and emotional regulation are inter-connected according to Koole, Van Dillen and Sheppes (2009) and so, if emotions are not regulated, the ability of people to effectively self-manage will be challenging.

Emotional regulation is defined in many different ways, but essentially, it involves some sort of control process. According to Salters-Pedneault (2008; no page) emotional regulation refers to a person's:

"...ability to understand and accept his or her emotional experience, to engage in healthy strategies to manage uncomfortable emotions when necessary and to engage in appropriate behaviour when distressed." Gross (1998a) suggests that regulating emotions refers to the way people influence the emotions they have, when they have them and how and if they express these emotions. Essentially, emotional regulation is a process of gaining control of one's emotions and managing these emotions in social situations. Emotions can be regulated intrinsically by the person experiencing them or by another person (extrinsically) (Werner and Gross, 2009). The strategies for regulating emotions involve the person identifying that they are experiencing the emotion and whether they then go on to express or suppress that emotion. It is known from research of other patient groups that the individualistic nature of these strategies can impact on people's perceived health (Middendorp *et al.*, 2005).

Participants gave the impression that their emotions developed and changed at particular points in their 'journey' since CHD diagnosis, for example many seemed more fearful after undergoing the PCI. Phase 2 provided qualitative evidence that many participants had experienced intense negative feelings that could be considered part of a coping mechanism for basic human survival (Montgomery, 2012). These feelings influenced their behaviour.

Despite thorough searching for theories or models of emotional regulation, none seemed to exist where emotion had a significant influence on cognition. Although not ideal, the process model of emotional regulation from Gross (2002 and 1998b) seemed to provide a framework with which most of the study findings aligned. The cognitive response in this model featured much later in the process and so was interpreted as less influential, similar to the study findings. Gross found that emotions can be regulated at five different points in the process; four before the response occurs and the fifth during the implementation of a strategy (or strategies) to control the emotion. Essentially, emotional representations of a situation are well established before cognitive appraisal takes place and the last stage of the model, the response modification, appears to be affected by the influence of emotion rather than cognition. Gross indicates though that the 'cognitive change' phase of the model is used to reduce the effects of the emotion. It is this part of the model that seems to diverge from the study findings. Instead of lessening the emotional response, the cognition (i.e. participants' knowledge and perceptions of CHD and its causes) seemed to exacerbate it. A schematic representation of how one example from the study fits with Gross' model of emotional regulation can be found in Table 6.1.

As indicated in Chapter 5, the qualitative findings provided evidence that some participants suppressed their emotions but using the aforementioned model, it was clear that others used an adaptive strategy of situation modification (Kring and Sloan, 2010). For example, they talked about their fear of death but modified the situation by joking about it. It was clear though that they were frightened.

Evidence of emotion suppression was also found, for example, when participants were asked if they had discussed their emotion with anyone else, they usually had not and that appeared to make the CHD seem more threatening resulting in suboptimal self-management. It is suggested that patients suppress emotions so that they do not feel 'out of control' or are perceived by others as not being in control but also, they may be uncomfortable displaying or discussing their emotions with others (Berking and Wupperman, 2012), and this seemed true in the current study. The ability of people to express rather than suppress emotions has been found in previous studies to improve physical and mental health (Eng et al., 2003) and so evidence of emotional suppression poses a risk to health in the PCI participants who coped in this way. Suppressing emotions has been found to have a physiological effect on people in that it increases the arousal of the sympathetic nervous system, which will result in increased heart rate and blood pressure among other things (Campbell-Sills et al., 2006). Emotional suppression has also been found to reduce the body's ability to return to a 'resting state' after sympathetic arousal and so the increase in heart rate and blood pressure will have a longstanding effect on people. In patients with CHD, increased blood pressure is known to be a risk factor for CHD progression and so the consequences of suppressing emotions may result in an added risk to patients after elective PCI.

Table 6.1	
Process model of emotional regulation	(Adapted from Gross, 1998b)

Situation selection		Situation modification		Attentional deployment		Cognitive change	Response modification
(Avoidance of certain things)		(Problem-focused coping / altering one's external environment)		(Selection of which aspects of situation to focus on)		(Used to decrease emotional response. Affected by knowledge and illness perceptions)	(Evaluation of situation and controllability)
Avoid activity to lessen fear		<ul> <li>Reduce exercise</li> <li>Decrease activity (including social activity)</li> <li>Make excuses to friends / family for reducing activity</li> </ul>		<ul> <li>Worry (fear of dying and consequences of CHD)</li> </ul>		<ul> <li>CHD is cured after PCI</li> <li>CHD is due to family history</li> <li>Activity can cause symptoms to recur</li> <li>Patients with CHD should not exercise too much</li> </ul>	<ul> <li>Emotional suppression</li> <li>Isolate self from fearful situations (Social isolation)</li> <li>Cease from discussing CHD and its management with others</li> </ul>
Antecedent focused emotional regulation (regulation <u>before</u> the response is fully generated)							Response focused emotional regulation (regulation occurs <u>after</u> the response is fully generated)

Another consequence of emotional suppression is that research has found that those who regulate their emotions through suppression have less ability to experience positive emotions. Gross and Levenson (1997) conducted a case control study and found in a sample of 180 females from the general population that negative emotions remained constant but suppression diminished the ability to have positive thoughts and also the ability to express emotions. While the findings from Gross and Levenson (1997) cannot be generalised to the current study as they used a sample from the general population, it highlights an important possibility that the PCI patients in the current study may have become 'stuck' in a vicious cycle where they suppress emotions and thereafter, experience fewer positive emotions and perhaps more negative ones. Consequently, that may have resulted in them having an increase in their blood pressure due to the sympathetic system response to suppression and that would increase their risk of CHD progression.

According to Mayer and Salovey (1995) in order to regulate emotions effectively and to prevent the suppression of them, it is necessary for people to have emotional intelligence. People's response to emotions is affected by the interplay between the emotions and cognition but it is difficult to regulate emotions that you are not conscious of and that may have been the case in some of the PCI patients. Certainly it seems that where people suppress emotions they become less aware of regulating those emotions and instead this occurs almost automatically (Gross and Levenson, 1997). Emotional intelligence may therefore, be an important factor in ensuring patients after elective PCI have a greater awareness of the emotions they are experiencing and that may subsequently, allow them to have more control over how they regulate their emotions. With that in mind, strategies can then be put in place to support people into expressing rather than suppressing emotions.

Some CHD patient information literature suggests that negative emotions will subside with the passage of time (NHS Greater Glasgow and Clyde, 2014) but that does not seem to be substantiated with any research. Vosbergen *et al.* (2013) concluded from their study that fear of dying subsided over time in a mixed CHD patient sample, but the current study indicates that patients continued to grapple with their emotions several months after the PCI procedure and the fear of symptom recurrence and mortality remained. Further research

would be necessary to explore whether emotions subside over time but the current study provides evidence that intense emotions continued for several months after PCI.

It seems that most of the help given to CHD patients regarding emotional regulation is focused either at the cognitive change or response modification stage of Gross' Process Model. Patient education on CHD and its management can be provided to try to increase patients' knowledge to lessen the emotional response (SIGN, 2002), but most patients in the study claimed that they had received no information. Those who had could recall little of what they had been told. Some resorted to searching the internet for help but reliance on that could result in the PCI patients finding incorrect information or getting advice that sometimes seems to exacerbate negative emotions (Women Heart Support Community, 2011). Some patient information specifically encourages expression of emotions (American Heart Association, 2014b) but this is not aimed at UK patients and the PCI patients in the study did not receive that.

In keeping with a previous study, the emotional inexpressiveness appeared to lead some participants to become socially isolated (Amirkhan, Risinger and Swickert, 1995). There may be a possibility that intervention from healthcare professionals before the emotional response is fully generated (i.e. in the first three stages of the process model from Gross) may be effective in producing healthier responses, but no literature could be found to support or refute that.

Determining which PCI patients require support and intervention for poor emotional regulation or suppression of emotions is essential to ensure healthcare resources are allocated appropriately. It was not possible to identify which participants struggled with emotional regulation in the current study using the HADS. Berking and Wupperman (2012) propose that any assessment to identify people who have ineffective emotional regulation is challenging to perform but it is necessary, as not everyone needs help.

Little evidence exists on how to conduct a needs assessment to ensure patients effectively regulate their emotions but it is essential that these assessments and any subsequent treatment strategies are evidence-based (Volling, McElwain and Miller, 2002). Certainly within the current study there would have been no

evidence of poor emotional regulation if patient interviews had not been conducted. Poor emotional regulation has been linked to the development and progression of CHD and so without detection and treatment, patients have this as a risk factor for CHD progression (Messerli-Burgy *et al.*, 2012; Mittleman *et al.*, 1995).

Never before has a connection been documented between emotional regulation and CHD self-management specifically in a PCI patient cohort.

#### 6.5

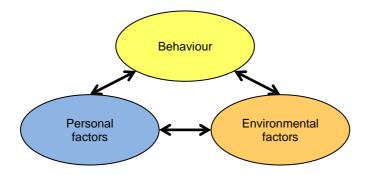
## Research question 3: To what extent do Bandura's Social Cognitive Theory and Leventhal's Self-Regulatory Model help explain self-management of CHD in patients after elective PCI?

The third research question concerned whether the two theories could explain how the PCI patients managed their CHD. The following section of the chapter will discuss this.

#### 6.5.1 Social Cognitive Theory

The Social Cognitive Theory as discussed in Chapter 2, asserts that the way in which people regulate their behaviour is influenced by environmental and personal factors (Bandura, 2001). While the diagrammatic representation of the Theory seems straightforward (see Figure 6.3), it is complex with multiple constructs.

#### Figure 6.3 Bandura's Social Cognitive Theory



As indicated in Chapter 2, self-efficacy is a key construct of Bandura's Theory and this seemed to be the most prominent feature found in the study. Selfefficacy was found to have a statistically significant relationship with participants' likelihood of adopting more healthy behaviours in Phase 1. Qualitative findings explained this by evidencing that where participants lacked confidence that they were capable of making and sustaining behaviour change for secondary prevention of CHD, they were unlikely to be successful. This has been documented previously (Sol *et al.*, 2011; Strecher *et al.*, 1986).

The basis of self-efficacy theory is that cognition can affect behaviour change and cognitive processes can be altered by what is known as 'performance mastery' (O'Sullivan and Strauser, 2009). People's beliefs about how efficacious they would be in changing behaviour are influenced by performance mastery. For example, people become discouraged when they fail in attempts to alter their behaviour (Bandura and Adams, 1977) and some qualitative findings aligned with this notion (for example participants who tried to lose weight). Performance mastery reduced participants' confidence that they would be successful in behaviour change and that compromised their ability to effectively self-manage that aspect of their CHD.

Self-efficacy though is not a generalised response, according to Clark and Dodge (1999) it is specific to a particular behaviour and not a generalised feature or response. It is individualised and specific to a particular behaviour. Indeed in their publication, Clark and Dodge (1999) cite that people may feel self-efficacious about adhering to medicines for CHD but lack confidence that they could successfully adopt healthier behaviours for secondary prevention of CHD. That may help to explain why, despite it linking to the adoption of healthier behaviours, no significant relationship between self-efficacy and participants' knowledge of effective symptom management was found in either phase of the study. The multiple responses participants gave in Phase 1, when asked how they would manage symptoms, may suggest a lack of confidence in knowing which was correct, but the role of confidence in this component of CHD self-management was not obvious from the qualitative findings. Self-efficacy did not seem to be a predictor of the effectiveness of patients' angina symptom management and so could not explain that.

Another construct of the Theory is vicarious learning where people learn and change their behaviour by observing others. Although there was evidence of this in the study related to the way participants managed their angina symptoms, it concerned a very small number of interviewees. Few in the sample said that they had the opportunity to meet, let alone observe and appraise the actions of other PCI patients. Most vicarious learning involved friends or family of the participants and this generally resulted in maladaptive coping strategies being adopted to manage angina symptoms, which increased participants' risk of mortality and morbidity. There was no evidence that vicarious learning linked to the two other components of CHD self-management.

Some evidence was found that social persuasion influenced self-efficacy. As participants had little contact with healthcare professionals, most of the persuasion seemed to come from media and confusion regarding the advice was common and this affected the adoption of healthier lifestyles. Conflicting information regarding diet and how to lose weight caused a reduction in participants' self-efficacy and they were then less likely to modify their behaviour to lessen their risk of CHD progression. Social persuasion, therefore, did not seem to convince the participants that they could be successful in achieving a healthier lifestyle.

The theory asserts that people do not always apply what they have learned (Bandura and Adams, 1977) and although this was found in the study (for example lifestyle change did not always ensue if participants knew which behaviours to modify to make their life healthier), the opposite was also found. Bandura's Theory, therefore, did not help to provide understanding of this.

Bandura (1991) professes that human behaviour is regulated by a thought process and that people develop their own beliefs about what they are able to do. They consider the consequences of their action and will set personal goals based on what outcome they want to achieve. The theory asserts that environmental factors can influence this and Bandura seems to consider people's perceptions as a component of these environmental factors (Glanz, Rimer and Lewis, 2002). The influence of illness perceptions that are personal to each individual is not obvious in the theory though.

The theory seems to focus on cognition and self-regulation without considering the influence of people's emotions. Bandura (1991) suggests that emotions evoked in people are a consequence of a self-regulatory process rather than a component of it, and he indicates that personal reflection allows people the ability to control their emotions. As discussed previously, there appeared to be evidence from the study that participants' behaviour was influenced by their emotions and their emotional regulation was poor. Consequently, it is difficult to understand how the Social Cognitive Theory could be used to explain CHD selfmanagement in a PCI patient population.

The Social Cognitive Theory is complex and despite it allowing greater understanding of some study findings, it was unable to comprehensively explain why CHD patients self-manage their condition the way they do. It appears to link closely with the adoption of more healthy behaviours but it was difficult to see how it could explain participants' adherence to a treatment regime and this finding concurs with research from Clark and Dodge (1999). While this theory forms the basis of self-management, interventions based on it, designed to enhance patients' effectiveness in self-management, are fraught with difficulty due its multiple constructs and that may provide a rationale as to why most focus is on the influence of self-efficacy (Sol *et al.*, 2011; Strecher *et al.*, 1986).

#### 6.5.2 Self-Regulation Model

The Self-Regulation Model is organised into a hierarchical system of three components of self-regulation: illness representations, coping mechanisms and an appraisal of the coping strategies adopted (Nerenz and Leventhal, 1983). It is hypothesised that people generate perceptions of their illness based on cognitive and emotional information available to them and that information determines how they appraise and cope with their illness (Hagger and Orbell, 2003). Self-regulatory processes are generally in place to maintain a 'status quo' (Bateson, 2000) and so the focus of this model is mainly on disease management rather than behaviour change.

Phase 1 found a statistically significant relationship between illness perceptions and participants' adoption of a healthier lifestyle and their knowledge of symptom monitoring / management. Qualitative data provided evidence that participants formed perceptions of their illness as a result of their knowledge, experiences, advice from others and the media, and this is consistent with the model (Shiloh, 2006; Benyamini, Gozlan and Kokia, 2004; Furze *et al.*, 2002). The coping strategies adopted and their subsequent appraisal was also evident from the interview data.

As discussed in Chapter 2, the first stage in the hierarchical structure of the Self-Regulation Model relates to the representations participants have of their illness. The model purports that these representations are formed through a parallel process involving cognition and emotion. Each should have equal weighting but it was evident from the qualitative data that the emotional representation participants had of their CHD had a significant influence on their cognitive perceptions. This is not in keeping with the model. Consequently, the schematic representation of the model in Chapter 2 has been adapted to represent how it fits with the findings from the study (see Figure 6.4). The yellow sections highlight the alterations.

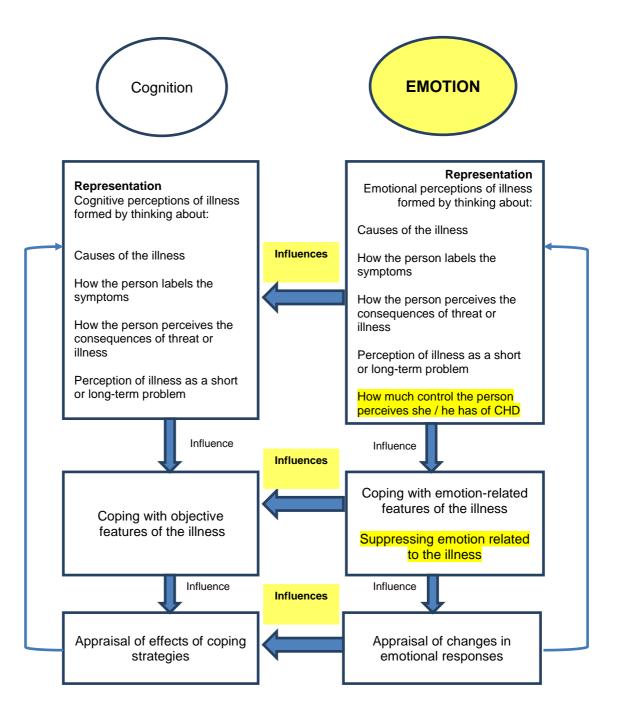
Despite cognition of the disease, the emotional perceptions participants had of their CHD appeared to determine how they coped with it. Strong emotions often led to less than effective coping strategies being adopted and the emotions also appeared to affect the appraisal of the effectiveness of these coping mechanisms. For example, PCI participants who felt frightened that exercise could kill them or induce angina symptoms coped by reducing their activities and made excuses to friends and family to account for their actions. Their appraisal of the coping strategy seemed to focus on whether their emotional response had reduced and whether they had experienced any angina symptoms. Within the model, the appraisal of any coping strategies should feedback to the representations phase of self-regulation. Participants who suppressed their emotional response, thus leading to more maladaptive coping strategies being employed.

Deary (2008) indicates that while the cognitive part of the Self-Regulation Model has been widely researched, the emotional 'arm' has received little attention. He deduced from his research with patients suffering from chronic fatigue syndrome, that the parallel process of cognition and emotion in the model was not always maintained. Patients' emotions seemed to be of significance in his research findings but he concluded that, rather than emotions influencing cognition, that the two parallel processes could not be separated.

247

#### Figure 6.4 Adapted Self-Regulation Model

(Adapted from Jayne and Rankin, 2001; page 54)



While the same inference was not made from the current study, it seemed important to highlight those studies with different patient groups have also found emotions to feature strongly. The conclusions from Jayne and Rankin (2001) and Johnson (1999) perhaps align more to the current study findings. They indicated that patients' coping strategies are geared mainly at reducing emotional response and feelings of vulnerability or fear. While Johnson's supposition was opinion based, Jayne and Rankin concluded this from their qualitative study of diabetic patients (n=30). At an outpatient clinic, data were

collected from the Chinese immigrant participants through individual interviews. Although the Self-Regulation Model was used to underpin the research and informed the data analysis, the methodology used is not evident from the publication, other than a qualitative study was conducted. Also, it seemed that the participants had other co-morbidities not readily disclosed but evident as they were attending either an ophthalmology or hypertension clinic. The reliability of the study findings is therefore questionable due to the reporting bias and methodology.

These findings suggest that the Self-Regulation Model could, in part, be used to explain CHD self-management but a revision to the model would be necessary to capture the influence of participants' emotional response.

#### 6.5.3 Conclusions from the theories

It seems that the Self-Regulation Model focuses mainly on disease management whereas the Social Cognitive Theory is concerned more with behaviour change and health promotion. Both of these theories provide some explanation as to why the PCI patients managed CHD the way they did but neither could do this comprehensively. The process model of emotional regulation from Gross (1998b) provided a framework with which the emotional response and subsequent coping strategies aligned, but that only helped to explain some participants' CHD self-management. A few other factors, such as motivation and readiness to make behaviour changes, may influence patients' self-management but these factors were not explored in this research study.

## 6.6 Chapter summary

This chapter has provided a discussion of the integrated findings from both phases of the study. The findings have been compared with contemporary literature and research from PCI and other patient studies so that they can be contextualised. The discussion was structured using the research questions to demonstrate the extent to which each question was answered. New findings, which have been documented for the first time for a PCI patient population, are highlighted. The contribution to knowledge will be discussed more fully in the next chapter.

# Chapter 7 Conclusions and contribution to knowledge

# 7.1 Introduction

In this chapter conclusions from the research are presented and the limitations from the study are identified. The contribution of the work is highlighted and the implications this research has for clinical practice, policy and future research are illustrated. The chapter closes with a reflexive account of the researcher's experience in undertaking the research.

## 7.2 Conclusions from the research

The study aimed to explore patients' CHD self-management and it was found that around three months after PCI, self-management was generally poor. Symptom management was suboptimal with patients either ignoring the angina symptoms or summoning emergency healthcare assistance to help deal with them. The adoption of a healthy lifestyle after PCI was often not attempted and, although smoking rates were low, obesity and inactivity remained problematic risk factors for CHD. Adherence to medication was generally good, particularly in those who had developed a habit to taking their medicines. Statins were the drugs most commonly not taken because of their side effects or a perception that they were of little benefit.

Knowledge of effective symptom management was compromised by the following factors: older age, more co-morbidities, lower self-efficacy, less threatening perceptions of CHD, less support from healthcare, disappointment and fear. Participants' adoption of a healthier lifestyle was less likely if they had threatening perceptions of their condition, less social and healthcare support, and a greater number of co-morbidities. Strong emotions of fear, abandonment and disappointment were also barriers to adopting more healthy behaviours. Those who were educated beyond secondary school had a greater likelihood of changing their lifestyle to lessen the risk of CHD progression.

The support these patients received from their friends and family, as well as from healthcare professionals, was perceived to be minimal and the feelings of

abandonment and vulnerability that ensued exacerbated their social isolation. That had a detrimental effect on their CHD self-management. It was concluded that the current method of supporting patients after PCI is ineffective.

PCI patients in the study had a tendency to suppress their strong, negative emotions and that significantly impacted on self-management. Fear, shock and disappointment made it less likely that healthier lifestyles would be adopted and angina symptoms managed effectively.

The process of self-regulation was clear from the study findings but there was evidence that the emotions that participants experienced had a significant influence on their cognition and that had a detrimental effect on their CHD selfmanagement. Due to the strong influence of the emotional representations of CHD on patients' behaviour, the Self-Regulation Model did not fully explain how participants self-managed their condition. Despite the Social Cognitive Theory allowing greater understanding of some study findings, it was unable to comprehensively explain why CHD patients self-manage their condition the way they did. It appears to link closely with the adoption of more healthy behaviours but it did not explain participants' adherence to a treatment regime or their management of angina symptoms.

## 7.3 Limitations of the study

The limitations of this study were judged against the criteria used to appraise the literature set out in Chapter 2 (CASP UK, 2013).

The rationale for conducting an integrative review of published literature was given in Chapter 2, but it should be acknowledged that there was a possibility, by not conducting a traditional systematic review, that literature could have been missed. Integrative reviews are considered to be robust in their ability to provide a comprehensive review of the literature though, particularly when diverse methodologies have been used to study the phenomenon (Batten, 2012; Wittemore and Knafl, 2005; Torraco, 2005). Ensuring the principles of systematic review methods were used justified using this approach to inform this study as it was conducted for a time-constrained research degree.

The non-probability sampling method chosen (convenience sampling in Phase 1) limits the ability to generalise the findings of the study to the wider PCI population, as it cannot guarantee the sample's representativeness. The descriptive statistic findings from Phase 1 indicated that there was a larger than expected proportion of the sample who lived in more affluent areas. It is known from other studies with samples of patients suffering acute coronary syndromes that more affluent people are more likely to have PCI when compared to those with a lower socio-economic status (Yong *et al.*, 2014; Casale *et al.*, 2007) and this may also be true of elective PCI patients. It is also possible that more people in higher socio-economic groups had volunteered to take part in the study and that could have been attributed to the sample with PCI populations by using both national and local (PCI Centre) statistics. This comparison allowed greater transparency of how the demographics (age and sex) of the sample aligned to the PCI patient population in the UK.

As indicated in Chapter 3, no survey tool existed that encompassed all aspects of CHD self-management and so a new questionnaire was developed. While the researcher included some tools that had already undergone testing for validity and reliability (HADS, Brief IPQ), the new questions in the survey were tested by experienced researchers and cardiology practitioners for face / content validity. Further testing would have enhanced the reliability and validity of this survey tool. The internal consistency of the survey tool should have been tested using Chronbach alpha since a survey cannot be deemed valid until reliability has been confirmed (Tavakol and Dennick, 2011). Performing a pilot project, however, helped to provide reassurance that the questionnaire functioned well.

The positioning of the HADS was considered when designing the questionnaire, however, the researcher has subsequently become aware of research from Johnston (1999) that indicates that its positioning in a survey can affect the HADS score. Johnston found that HADS scores are higher when it is placed at the end of a survey, particularly when the participants have answered questions about issues such as symptoms beforehand. In hindsight, the HADS should therefore, have been positioned closer to the start of the questionnaire than it was and so is considered a limitation of the study.

The responses participants gave were self-reported and so need to be taken at face value, as no objective corroboration was used. This is considered a limitation of the study, as there was a potential for response bias, that is the participants may not have been truthful or they could have exaggerated or forgotten certain things related to their CHD self-management (University of Southern California, 2014). Using a mixed methods study design, however, can reduce the possible biases of one single method (Brewer and Hunter, 1989).

Although it would be unlikely to affect everyone in the sample (Spector, 2013), there was a possibility that responses were also affected by social desirability bias where participants responded the way they thought the researcher would want them to. Despite the researcher being a registered nurse, it was essential for her to remain in the researcher role to minimise the risk of social desirability bias from participants.

There were two questions in the survey that related to patients' response to the recurrence of angina (questions B2.03 and B2.04). The intention was for participants to answer B2.03 "if you get angina again how would you deal with it?" in relation to their initial response to the angina symptoms and then in B2.04 "if you had angina and it lasted longer than 15 minutes what would you do?" their response to prolonged angina symptoms was sought. It is possible that participants answered question B2.03 before reading the next question and so there was a potential for misinterpretation. On reflection, it may have been beneficial to add more specificity to B2.03 and intimate that it was the participants' initial response to angina that was sought. This is therefore, considered a limitation of the survey tool.

While the sampling for Phase 2 was determined by criteria set out beforehand, not every participant consented to participate in both phases of the study and so there was a risk of volunteer bias where those who consented for both phases differed from the general PCI population (Boughner, 2010). The pool of potential participants for Phase 2 was reduced from the total sample size and this made the purposive sampling in the second phase more challenging but still achievable. The use of pre-determined criteria to inform the selection of participants for Phase 2 helped to minimise any sampling bias. An aspect of the study design that was considered to be a limitation was the variation in time lapse from participants completing Phase 1 to being interviewed in Phase 2. As outlined in Chapter 3, univariate analysis of Phase 1 data took place prior to the selection of participants for Phase 2. Some participants were interviewed after several weeks whereas others had their interviews soon after completing the survey. This in itself could have led to a difference in CHD self-management efficacy, but it was deemed more appropriate to obtain a purposive sample for Phase 2, and the only way to do that was to complete Phase 1 data analysis before selecting the next sample. This process was in keeping with the study design.

While this study had limitations, efforts were made to minimise the effects of these on the quality of the research. Despite the limitations, a clear contribution to research has been made.

# 7.4 Contribution to knowledge

In the study, and in agreement with research from Gallagher et al. (2008a), Langley (2003), and Nones Cronin et al. (2000), knowledge of symptom management post-PCI was found to be poor. This study differs from others in that it asked participants to distinguish whether their symptom management would alter between short-lived angina symptoms and those that persisted for longer. From the survey data some participants seemed unsure of how they would deal with angina symptoms of any duration by stating numerous selfmanagement strategies and that may be a consequence of the wording of the question as indicated in Section 7.3. Many interviewees, however, said they would use their subjective opinion of the 'seriousness' of the symptoms to determine how they managed it. Not duration, but accompanying clinical features such as dizziness and heart palpitations led participants to believe their angina symptoms were more serious. The coping strategies participants would adopt for recurring angina symptoms of any duration often involved the use of unscheduled care services, which could be burdensome for healthcare providers and not in keeping with clinical guidelines. The efficacy of the monitoring and management of angina symptoms was influenced by participants' emotions, their illness perceptions and vicarious experience. It was found that older PCI patients accepted recurring angina symptoms as a

normal sign of aging and were less likely to manage them effectively due to stoicism.

Current methods of educating PCI patients in how to deal effectively with angina symptoms seemed inadequate. The findings from this study provide greater insight into how and why PCI patients manage angina symptoms as they do. This may help inform clinical practice so that interventions can be focused on addressing the misconceptions and suboptimal management these patients have.

This study has contrasting findings to those of Le Grande *et al.* (2006) in that it was found to be statistically significant that PCI patients who had higher educational attainment were more likely to make changes to their lifestyle and so may require less support with that particular aspect of self-management. This particular sub-group of participants was more able to articulate what behaviours could be changed to enhance their health and this supports research using the general public from Potvin, Richard and Edwards (2000).

This is the first study to provide evidence that healthcare provider and social support after PCI is considered inadequate and this results in patients feeling abandoned, vulnerable and left to manage their condition alone. This seemed to exacerbate social isolation. Several participants felt unsupported in their attempts to modify behaviours and that may be the reason for the small percentage of the sample who adopted more healthy behaviours and maintained that change. These findings may help to inform healthcare providers that the current methods used to support patients after PCI, including those involving family, are perceived to be insufficient to meet patient needs.

Suppression of emotions after PCI seemed common and that had a detrimental effect on participants' CHD self-management. Those who were fearful of dying or experiencing recurring angina symptoms restricted their activity, which consequently affected their ability to exercise and lead a healthy lifestyle and this aligns with findings from a pilot study by Langley (2003). This study found though, that these people were more likely to call unscheduled care services, particularly emergency ambulances, for help for any recurrence of angina symptoms. Participants who had recurrent angina symptoms after PCI were

disappointed and perceived that they had little control of their illness and that affected their confidence in engaging in physical activity. Emotional suppression worsened social isolation.

Evidence that patients experience strong, negative emotions after PCI and these emotions are often suppressed, causing poor CHD self-management provides a strong rationale for psychological support to be given to patients who have CHD and undergo PCI.

In agreement with previous research with other patient groups (Phillips, Leventhal and Leventhal, 2013; Ruppar and Russell, 2009), this is the first study to document that PCI patients who had developed a habit to taking their medicines were most successful in this self-management component. Encouraging the formation of habits to enhance medication adherence may be beneficial for PCI patients' CHD self-management.

Neither the Self-Regulation Model nor the Social Cognitive Theory fully explained CHD self-management after PCI. The emotional perceptions participants had of their CHD influenced their cognition and that affected how they coped with their condition. That finding deviated from the Self-Regulation Model and an adaptation to the model would be necessary to account for the significant influence of emotions on participants' cognition. It was evident that emotions had a substantial influence on how patients dealt with their CHD.

Aspects of the Social Cognitive Theory (self-efficacy, social persuasion and performance mastery) helped to explain participants' likelihood of adopting more healthy behaviours but the other components of CHD self-management, monitor and manage angina symptoms and adhere to a medication regime, were not explained using this theory. This research gives evidence that more confident patients may require less support in adopting a healthier lifestyle.

## 7.5 Implications of the research

As outlined in Chapter 1, the need for this research emerged from anecdotal evidence from clinical practice. This study sought to provide greater understanding of how patients self-managed their CHD after PCI. The findings

that emerged may have implications for clinical practice and policy but the need for further research was also identified.

#### 7.5.1 Recommendations for practice

A key message for healthcare professionals would be that patients after elective PCI feel unsupported in their CHD self-management and require help to allow them to manage angina symptoms more effectively, modify behaviours that are known to contribute to CHD progression and regulate their emotions through expression rather than emotional suppression.

The effect of emotions on PCI patients' self-management was found to be significant but the widely used HADS was not able to identify patients who had long-standing fear and other strong, negative emotions. The HADS is widely used and advocated for use through clinical guidelines (SIGN, 2002) but it should be used as one component of a psychological assessment, not the sole focus (Mitchell, Meader and Symonds, 2010). Published studies concerning psychological assessment of patients with CHD are numerous but have been found to focus mainly on anxiety and depression (Child *et al.*, 2010; Harrison, 2005; Albus, Jordan and Herrmann-Lingen, 2004). Evidence from this study though, indicates that many PCI patients who were affected psychologically by the PCI could not be identified using the HADS. Consequently, healthcare providers need to consider alternative needs assessment tools to enable appropriate intervention and support to be put in place for patients who experience strong emotions that affect their ability to self-manage.

Additionally, healthcare providers need to consider how best to support PCI patients in the regulation of their emotions. Interventions to address this issue such as emotion-focused therapy from Greenberg (2006) and Suveg *et al.* (2006) need to be identified and tested to ascertain best practice. As mentioned in chapter 6, having a greater awareness of personal emotions may allow PCI patients to regulate their emotions more effectively and so the aim of emotion-focused therapy would be to help people to become more aware and accepting of their emotions and to allow them the opportunity to reflect on these emotions and make sense of and regulate them. Although this type of coaching session is generally conducted by clinical psychologists it may be possible that healthcare professionals involved in the care of patients after elective PCI could

be trained in its use. Although CHD patients should have access to psychological support from trained professionals (British Association for Cardiovascular Prevention and Rehabilitation, 2012), in reality the wait for such services can be lengthy and so recommendations to clinical practice may be to increase the number of clinical psychologists who are available to support patients after elective PCI.

Evidence was found in the study that patients' knowledge of angina symptom management was poor, leading to either delays in requesting medical help or inappropriate use of unscheduled care services. This poses a risk to patients as they may sustain angina symptoms over a long time-period before calling for help and that could result in irreversible myocardial damage or increased mortality. Alternatively, sending for help before it is advocated increases the demand for health service support and results in unnecessary hospital admissions that affect patients' psychological wellbeing (Goodacre *et al.*, 2005).

A systematic review conducted by Brown *et al.* (2011) found some evidence that educating patients may reduce their use of healthcare services, yet few patients in this study received information about how to manage angina symptoms after PCI and were unsure about what to do. It seemed obvious that either the current method of educating PCI patients was ineffective or the educational provision was inadequate. Educating PCI patients about how to deal with recurring angina symptoms may reduce their demand for unscheduled care. Healthcare professionals involved in PCI patients' care need to find methods that effectively enhance patients' knowledge on this component of CHD self-management.

Supporting the findings of Astin and Jones (2006b), the study found that patients made few modifications to their lifestyle after PCI, and these were often not sustained. The support mechanisms to encourage risk factor modification in PCI patients seemed inadequate from the study findings. Effort from healthcare providers is needed to support all patients in risk reduction, but particularly those who were identified as less likely to make changes (those with comorbidities, low self-efficacy, lower educational attainment, and poor emotional regulation). The ability to identify patients who may require additional support (i.e. those less likely to make changes) would allow resources to be channelled to the patients in most need of help. One method of doing this may be to use decision support interventions. These are often used as an adjunct to shared decision-making between a patient and a healthcare provider and have been found to increase the likelihood that patients take more responsibility for their behaviour and there is less reliance on healthcare providers (Frosch *et al.,* 2009). Self-report of lifestyle factors is not always reliable and so use of more objective measures may allow healthcare professionals to provide support with behaviours that patients are experiencing most difficulty modifying. Some objective measures that may help could include carbon monoxide detectors for smokers mentioned in chapter 1. Also, some tools are available that may direct patients to be more specific in their answering such as the Godin Leisure-Time Exercise Questionnaire (Sandroff *et al.,* 2012).

The support provided by healthcare professionals was perceived to be lacking but the reason for that was unclear. If some clinicians, as previous research indicates (Peckham, Hann and Boyce, 2011), feel ill-equipped to support patients in their adoption of more healthy behaviours, regular continuing professional development may be necessary to enhance their knowledge of CHD and current evidence-based approaches to foster and support behaviour change in patients. Education may also be required to address misconceptions found the health professionals themselves (Angus *et al.*, 2012).

Although cardiac rehabilitation is advocated in for all patients who undergo coronary revascularisation (NICE, 2013; British Association for Cardiovascular Prevention and Rehabilitation, 2012), the majority did not attend and this seemed to be attributed to a lack of invitation to attend or the perceptions they had of this service. To improve the rates of attendance, it is essential that all healthcare professionals in contact with patients advocate cardiac rehabilitation as a means of support after PCI. Perhaps the approach taken in the United States of America where doctors prescribe cardiac rehabilitation (primarily exercise prescribing) for their patients, may improve rates of attendance (Hansen, 2013; Russell, 2011). Consideration should be given to this in the UK and any implementation of it evaluated.

Presently, work needs to be done to dispel the misconceptions PCI patients have of cardiac rehabilitation. This study found that participants thought they were either too well or too sick to attend. The study participants seemed to lack insight into what the programmes involved, many believing it was only exercise, and so the purpose of cardiac rehabilitation and what it involves needs to be made explicit to patients.

Participants in the study felt unsupported by their friends, family and healthcare providers and this often led to an exacerbation of social isolation. Isolation is known to cause less effective coping mechanisms to be adopted (Cornman *et al.*, 2003) and this was evident in the study. Additionally, it can reduce patients' confidence (Cornwell and Waite, 2009) and so by addressing the social isolation issue, PCI patients' self-efficacy (a factor found to influence CHD self-management) may be enhanced and they will be helped to more effectively manage their CHD. Poor support and lack of patient information have been found to increase mortality and morbidity in CHD patients (Barth, Schneider and von Kanel, 2010) and so strategies to enhance the support of PCI patients need to be developed, implemented and evaluated. Involvement of friends and family in any intervention to combat social isolation should be encouraged.

Evidence of which types of support are most beneficial in helping CHD patients deal with their chronic condition and lessen the effects of isolation is scant (Lett *et al.*, 2005). Strategies that have proven successful at reducing the effects of social isolation for people with other health problems may be useful for PCI patients. Consequently, consideration should be given to strategies such as volunteer befriending which has been found to be beneficial (Peardon *et al.*, 2009), and social prescribing where interventions can be created to not only increase people's social support, but also to enhance their ability to cope with illness (Friedli *et al.*, 2012). While these non-medical interventions are becoming more common in mental health, their role in helping patients with chronic disease such as CHD is less well evidenced.

#### 7.5.2 Recommendations for policy

It is recommended that all CHD patients should have an assessment of their psychological status conducted and this should include the assessment of illness perceptions, self-efficacy, quality of life, stress and screening for anxiety and depression (BACPR, 2012; SIGN, 2002). Although rates of anxiety and depression in this study sample were found to be low using the HADS,

participants seemed to have significant negative emotional responses. This clearly affected their psychological wellbeing as well as their CHD selfmanagement but the HADS did not help to identify those affected. BACPR (2012; Page 16) indicate that all CHD patients who have clinical features of 'severe and enduring mental illness' should receive support from appropriately skilled psychologists but from the current study findings, participants who experienced a substantial emotional response to their condition would probably not fall into the severe mental illness category and so would not be referred for this type of support. The Department of Health (2013b; Page 54) talk about the 'importance of emotional and psychological support but as indicated throughout the findings and discussion, participants felt unsupported and so specificity is needed to provide clarity to how this should be achieved.

Consequently, policy may need to be altered to take account of the influence of emotions on PCI patients' wellbeing. Development of a needs assessment tool that identifies patients who have strong emotional responses to their illness appears to be required so further work is needed. Perhaps tools, such as the ones used in cancer care to identify patients who have significant fear of recurring disease (Ghazali *et al.*, 2013; Thewes *et al.*, 2012) may be helpful in informing the development of a needs assessment tool for PCI patients. Additionally, as this study has found the impact of negative emotions to significantly affect PCI patients' CHD self-management, clinical guidelines should advise that support is given to patients to help them regulate their emotions more effectively.

Guidelines suggest that rehabilitation should be individualised. This study has found that certain factors affect PCI patients' CHD self-management and so conducting a needs assessment as recommended by BACPR (2012) is essential to determine individual patient needs. Clinical guideline developers need to be cognisant of the factors that influence each aspect of CHD selfmanagement and ensure these factors are included as part of a standardised assessment of patients.

The current study found that it is important for PCI patients to receive support that helps to foster their self-efficacy. This has been reported widely in health and behaviour change literature (BACPR, 2012), yet it is hardly mentioned in the Scottish Intercollegiate Guidelines Network publication on cardiac rehabilitation (SIGN, 2002). This study provides additional evidence that patients who lack confidence are less likely to adopt more healthy behaviours and know how to manage their angina symptoms effectively. Consequently, when the SIGN guideline is updated, it should advocate that support is needed from healthcare professionals to improve patients' self-efficacy.

Although the evidence of the need for healthcare professionals in primary care to support patients in their secondary prevention of CHD appears strong, the studies that it is based on appeared to have no patients who underwent PCI (SIGN, 2007). Regardless of this, it seems reasonable that clinicians support patients with behaviour modification. The current study found that patients felt poorly supported and this may be attributed to healthcare professionals, particularly GPs, feeling ill-equipped to support patients with lifestyle alteration (Peckham, Hann and Boyce, 2011). Although one of the standards set by the BACPR (2012) recommends that any healthcare professional who is involved in rehabilitating patients with CHD, including those who have undergone elective PCI, should have the necessary training and qualifications to be competent for the role that they fulfil, therein lies a challenge that this is implemented. Personal development is key to this to ensure professionals remain updated with the evidence-base to optimise the rehabilitation of CHD patients but it would seem that the responsibility to enforce this sits with the organisations that provide the healthcare rehabilitation services. Consequently, the implementation of these BACPR standards may vary.

#### 7.5.3 Recommendations for research

This study has found that CHD self-management after PCI was suboptimal and that traditional methods used by healthcare professionals to provide support for patients were deemed ineffective. With cognisance of the findings from this study, it seems that a strategy needs to be found that provides education for PCI patients with regard to their angina symptom management and medication adherence. Patients also need greater encouragement and practical support to assist them in adopting and maintaining healthier behaviours after PCI. Emotional support and methods of alleviating social isolation (e.g. befriending / social prescribing) would be considered essential components of any support programme. It is extremely important that support is individualised and patient-

centred to enhance its success.

Research is, therefore, needed to explore different approaches that healthcare professionals can use to effectively support patients after elective PCI in their CHD self-management. For example, the use of modern technologies may be beneficial in offering telehealth solutions to support PCI patients and although their use has been tested with other manifestations of CHD (LaFramboise *et al.,* 2009), exploration of their efficacy in PCI patient populations is scant. A feasibility study would allow the investigation of how technology could be packaged into a telehealth programme specifically to support patients after elective PCI. Thereafter, an intervention study could be conducted to determine which telehealth programmes are beneficial in optimising CHD self-management. Cohort studies could also be considered to explore the effect telehealth had on PCI patients' revascularisation rates, morbidity and mortality.

Some self-help groups have been found to be beneficial to enhancing the selfmanagement of patients with chronic conditions (Department of Health, 2013b; Self-Management UK, 2013; Blenkinsopp *et al.*, 2009) but the evidence-base for this is weak or quite dated for CHD patients (Jackson, Gregory and McKinstry, 2009; Hildingh *et al.*, 1994). While it is anticipated that peer support would enhance CHD self-management, robust evidence is needed to confirm that.

As indicated previously, support to help patients regulate their emotions is required but as patients are being encouraged to be more self-reliant in selfmanaging their CHD, exploration of how aware they are of their emotions (i.e. their emotional intelligence) may be beneficial so that support can be geared to optimising their ability to process information about their emotions accurately and to subsequently regulate their efficiently and effectively (Mayer and Salovey, 1995). Several survey tools are available to measure emotional intelligence, including the Wong-Law Emotional Intelligence Scale and the Self-Expressiveness in the Family Questionnaire, both of which have been used before in patients with different manifestations of CHD (Kravvariti, Maridaki-Kassotaki and Kravvaritis, 2010).

The mixed methods approach used for this study has provided not only a

breadth of understanding of CHD self-management in PCI patients but has also given a more in-depth insight into why patients manage their condition as they do. Researchers studying CHD self-management should consider using mixed methodology to explore this phenomenon with other patient groups to gain greater insight into this potentially critical area of patients' lives.

## 7.6 Reflexivity

"Learning to reflect on your behaviour and thoughts, as well as on the phenomenon under study, creates a means for continuously becoming a better researcher." (Glesne and Peshkin, 1992; Page xiii)

It was essential that the researcher adopted an iterative process throughout to critically reflect on the research process itself and particularly consider the potential influence or effect she had on the study.

Having worked with cardiology patients for a number of years, the researcher had much experience and knowledge of caring for and helping to rehabilitate these patients but, as a novice researcher, she was less confident about exploring the phenomenon but tried to do so in a robust and rigorous manner.

The researcher used her nursing experience to identity an aspect of clinical practice that was thought to warrant exploration and this was the basis for the study. It was essential though for the researcher to remain as objective as possible throughout the research process and not allow personal biases and opinion to influence how the topic was studied. As the research was conducted in part fulfillment of a research degree, the researcher had the opportunity at regular supervision sessions to reflect upon the research 'journey' and consider the decisions made, the actions taken and the general experience of conducting this mixed methods study. This was helpful and the guidance from experienced supervisors helped to facilitate the reflection.

Additionally, the use of a reflective journal helped the researcher identify any preconceived ideas and subjectivities during the research process. Ortlipp (2008) suggests that keeping such a reflective journal helps to demonstrate greater transparency in the research by highlighting possible influence or bias.

It can also enhance confidence in a novice researcher and although normally used in qualitative research, it is considered 'best practice' in a mixed methods study (Walker, Read and Priest, 2013). Keeping a reflective journal allowed the researcher the opportunity to examine the effect she had on the method, data analysis and presentation of the findings.

Knowing the healthcare system and the busyness of outpatient departments, the researcher had insight into how participants could be recruited and when that would be appropriate. The researcher was sensitive to the fact that not everyone would perceive the study as a priority. Recruitment took longer than anticipated and the researcher was cognisant of the reasons for that (clinics reduced in size or cancelled due to cardiologists being on-call or on leave) so patience was exercised and adjustment was made to the sampling strategy adopted for participation in the study (quota became convenience sampling).

While the participant information for the study stated that the person conducting the study was a 'researcher', participants were informed that the researcher in fact worked, not in the health service, but in higher education as a nurse lecturer. It is believed that this helped them to be more honest, and during interviews, sometimes more critical, of healthcare and healthcare providers. The researcher's clinical experience in cardiac nursing, however, gave her the ability to interpret what was discussed by the interviewees and explore areas that were less well explained.

During interviews the researcher tried to make sure participants were given time to discuss their CHD and how they managed it and it is believed that affording participants that opportunity resulted in them being more open about their feelings and perceptions.

Knowing that the researcher was a nurse gave some participants the opportunity to ask questions about their CHD and its management. While the researcher was sympathetic that participants often felt unsupported and vulnerable, she was careful not to give advice that was outdated or ill advised. Participants were generally encouraged to seek help from professionals involved in their care and the researcher helped to facilitate some conversations.

An experienced statistician guided the researcher during the quantitative data analysis and so objectivity was enhanced. While rigour and trustworthiness was essential for the study in the qualitative phase of the study, neutrality was difficult to achieve, particularly as the quantitative findings helped to inform what was explored in Phase 2 and the development of A priori codes for thematic analysis. The process though was enhanced through member validation, a second researcher who independently coded qualitative data that was subsequently compared with the researcher's coding and feedback and critique of the process by the researcher's supervision team. Rather than consider the neutrality of the researcher, it was the neutrality of the data that was examined (Krefting, 1991).

It was essential for the researcher to consider the ways in which she 'shaped' the research process. A reflexive account allows acknowledgement of potential bias and the approaches adopted to minimise the effects of this. Exploring the positioning of the researcher in relation to the research has been beneficial in her professional development and development as a researcher.

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# Appendices

Appendix 1	Search strategy and key words
Appendix 2	Ethics approval 1
Appendix 3	Ethics approval 2
Appendix 4	Ethics approval 3
Appendix 5	Participant consent form
Appendix 6	Invitation to participate in study
Appendix 7	Participant information sheet
Appendix 8	Survey tool
Appendix 9	Permission to use Illness Perceptions Questionnaire
Appendix 10	Audit trail of participant recruitment
Appendix 11	Overview of Phase 2 participants
Appendix 12	Interview schedule
Appendix 13	Annotated transcript

Appendix 1 – Search strategy and key words Please note: An asterisk indicates where truncation was used at the end of a word to ensure all variations were covered.

Theme	Keywords used	Citations found	Citations that met criteria	Citations not included	Citations included
A: Patients' monitoring and management of angina symptoms	<ol> <li>Percutaneous coronary intervention</li> <li>Percutaneous transluminal coronary angioplasty</li> <li>Coronary revasular*</li> <li>Coronary angioplasty</li> <li>Coronary heart disease</li> <li>Coronary arter*</li> <li>AND</li> <li>Self-manage*</li> <li>Self-care</li> <li>AND</li> <li>Chest pain Symptom* Angina*</li> </ol>	1049	13	8 duplicates 1 was an abstract only	4

Theme	Keywords used	Citations found	Citations that met criteria	Citations not included	Citations included
B: Patients' adoption and maintenance of a healthy lifestyle	1. <u>AND</u> 2. <u>AND</u> 3. <u>AND</u> Secondary prevent* Lifestyle change Behaviour change Prevent* Risk reduc* Risk factor*	320	37	25 duplicates 2 not available	10 (+1 cited by all other studies) = 11
C:	1. <u>AND</u>	231	2	0	2
C: Patients' adherence to a treatment regime	1. AND         2. AND         3.         AND         Medication         Medication*         AND         Compliance         Adhere*         2. AND         Compliance         Adhere*         AND / OR         Aspirin         Statin*	231	2	U	

Theme	Keywords used	Citations found	Citations that met criteria	Citations not included	Citations included
D: Self-Regulation Model and CHD self-management	1. <u>AND</u> 2. <u>AND</u> Self-regul* Illness perception Illness belief*	1	1	0	2
	2. <u>AND</u> Self-regul* Illness belief* Illness perception	50	3	2 duplicates	
E: Social Cognitive Theory and CHD self-management	1. <u>AND</u> 2. <u>AND</u> Social Cognitive Theory Self-efficacy Confidence	15	2	1 duplicate	2
	2. <u>AND</u> Social Cognitive Theory Self-efficacy Confidence	507	1	0	

#### Appendix 2 – Ethics approval 1

From:	Taylor, Christine
Sent:	18 July 2011 15:37
То:	Watt, Susan
Cc:	Donaldson, Jayne
Subject:	Ethics findings

Hi Susan

Thank you for re-submitting your ethics application in connection with your project 'An exploration of how illness perceptions of cardiac patients influence their ability to self-manage their condition after revascularisation with percutaneous coronary intervention' and for making the suggested changes. The Faculty Research and Knowledge Transfer Ethics and Governance Committee is pleased to confirm that ethical approval has now been granted.

Best wishes with your project.

Regards, Christine

#### **Christine Taylor**

Executive Support Administrator Faculty of Health, Life and Social Sciences **Edinburgh Napier University** Sighthill Campus Sighthill Court Edinburgh EH11 4BN Tel 0131 455 2205

#### Appendix 3 – Ethics approval 2

6 į, South East Scotland Research Lothian NHS Board Ethics Committee 2 Waverley Gate 2-4 Waterloo Place Edinburgh EH1 3EG Lothian Telephone 0131 536 9000 Fax 0131 536 9088 www.nhslothian.scot.nhs.uk Ms Susan Watt Date 27 July 2011 Your Ref Research student / Lecturer Our Ref Edinburgh Napier University Edinburgh Napier University Enquiries to Lyndsay Baird Sighthill Campus Extension 35673 Direct Line 0131 465 5673 Edinburgh Email lyndsay.Baird@nhslothian.scot.nhs.uk EH114BN Dear Ms Watt Study title: An exploration of how illness perceptions of cardiac patients influence their ability to self-manage their condition after revascularisation with percutaneous coronary intervention. **REC reference:** 11/AL/0301 Protocol number: N/A

Thank you for your letter of 20 July 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

#### Confirmation of ethical opinion

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

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.



Headquarters Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley Chief Executive Professor James J Barbour O.B.E. Lothian NHS Board is the common name of Lothian Health Board



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

#### After ethical review

2

#### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- · Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

 11/AL/0301
 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Thomas Russell Chair

Email: lyndsay.baird@nhslothian.scot.nhs.uk

#### University Hospitals Division

Queen's Medical Research Institute 47 Little France Crescent, Edinburgh, EH16 4TJ

CPP/ MJ/approval

15/09/2011

Professor David Newby Cardiovascular Research Unit Royal Infirmary of Edinburgh Chancellor's Building 49 Little France Crescent Edinburgh EH16 4SA



Research & Development Room E1.12

Room E1.12 Tel: 0131 242 3330 Fax: 0131 242 3343

Email:

R&DOffice@luht.scot.nhs.uk

Director:

Professor David E Newby

Dear Professor Newby

Lothian R&D Project No: 2011/R/CAR/10

Title of Research: An exploration of how illness perceptions of cardiac patients influence their ability to self-manage their condition after revascularisation with percutaneous coronary intervention.

Eudract: N/A

Consent: version 6 dated 20 June 2011

REC No: 11/AL/0301

CTA No: N/A

PIS: version 6 dated 20 June 2011

Protocol No: Version 7 dated 4 May 2011

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

Chillips

Dr Christine P Phillips Deputy R&D Director

cc Paul Dearie, QA Manager

#### Appendix 5 - Participant consent form

Participant Consent Form	Edinburgh Napier	
Patient experiences after corona	ıry angioplasty	
I have read and understood the patient information sh	neet and this consent form.	
I have had an opportunity to ask questions about my participation.		
I understand that I am under no obligation to take par	t in this study.	

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I am happy for my GP to be informed about my participation in this study

I agree to participate in this study.	

Please choose one from the following two choices:

I am happy to complete the questionnaire only

I am happy to complete the questionnaire and be interviewed

Name of participant:	

Signature of participant:	
---------------------------	--

Signature of researcher:	
•	

Date:

Contact details of the researcher

Name of researcher:	Susan Watt
Address:	School of Nursing, Midwifery and Social Care,
	Edinburgh Napier University,
	Sighthill Campus,
	Edinburgh EH11 4BN
Email / Telephone:	s.watt@napier.ac.uk / 0131 455 5635

Letter of invitation



Dear Patient,

#### Patient experiences after coronary angioplasty

You are invited to take part in a research study that will explore what patients think about their heart condition and how they deal with the condition after they have had the coronary angioplasty procedure (the procedure you have had done to relieve your angina symptoms). Taking part in the study will not take up much of your time and your contribution may help to provide greater understanding of the issue being studied.

I would appreciate if you would consider participating in my research study, however, before you decide to take part it is important that you understand what the study is about and what you will be asked to do. Please read the **Participant Information Sheet** (enclosed). Feel free to contact me if anything is unclear or you want further information. My contact details are below.

Your participation would be gratefully appreciated.

Thanks in anticipation,

Susan Watt Lecturer and researcher School of Nursing, Midwifery and Social Care Edinburgh Napier University Sighthill Campus Edinburgh EH114BN 0131 455 5635 s.watt@napier.ac.uk



#### Participant information sheet

#### Patient experiences after coronary angioplasty

You are invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### What is the purpose of the study?

The aim of the study is to explore what patients think of their heart condition after the coronary angioplasty procedure and how they deal with their condition on a daily basis.

#### Why have I been asked to take part?

You have been asked to take part as you have previously been diagnosed with angina and underwent a coronary angioplasty procedure.

#### Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive.

#### What will happen if I take part?

A few weeks after your coronary angioplasty procedure you will see your cardiologist at the outpatient clinic. At the clinic you will be asked whether you wish to take part in this study or not. If you agree, you will complete a simple questionnaire that will take you around 10 - 15 minutes. The types of questions you will be asked include questions about your angina before and after the coronary angioplasty procedure, how your angina affects you in your day-to-day life and some questions about your lifestyle (including amount of exercise, diet). A few weeks after that, you may be invited to an interview (if you have agreed to this). This will take place at a location convenient for you and will last no longer than one hour. You don't have to be interviewed; you can just complete the questionnaire and still be involved in the study.

With your consent, I will inform your GP that you are taking part in this study.

If you decide to withdraw from the study, any information you provided before your withdrawal will be kept for analysis. If you have any further health concerns during the study, they will be discussed with you and you may be referred to your GP or Cardiologist.

#### What are the possible benefits of taking part?

You may not get a direct benefit from taking part in the study. The findings may help healthcare providers to understand how patients after coronary angioplasty deal with their angina, which may benefit future patients.

#### What are the possible disadvantages and risks of taking part?

It is not thought that there are many disadvantages, however if you agree to participate, completing the questionnaire and being interviewed will take up some of your time.

#### What happens when the study is finished?

At the end of the research the data you have provided will be destroyed once the findings of the study have been published.

#### Will my taking part in the study be kept confidential?

All the information I collect during the course of the research will be kept confidential and there are strict laws, which safeguard your privacy at every stage. Your name will be removed from the data so that you cannot be recognised from it. With your consent, I will inform your GP that you are taking part.

<u>What will happen to the results of the study?</u> The study will be written up as a report and published in healthcare journals.

#### Who is organising the research and why?

The study has been organised by Susan Watt, a nursing lecturer at Edinburgh Napier University for a research degree.

#### Who has reviewed the study?

The study proposal has been reviewed by the Faculty and Ethics Governance Committee at Edinburgh Napier University. A favourable opinion has been obtained from the South East Scotland Research Ethics Committee 2. NHS management approval has also been obtained.

#### If you have further questions about the study please contact: Susan Watt on 0131 455 5635 or email <u>s.watt@napier.ac.uk</u>

If you would like to discuss this study with someone independent of the study please contact:

Frances Divers, Nurse Consultant in Cardiology at NHS Lothian on 01506 523882 or email <u>Frances.Divers@nhslothian.scot.nhs.uk</u>



#### Appendix 8 - Survey tool

#### Patient experiences after coronary angioplasty

Thank you for agreeing to complete this questionnaire. It is split into four sections (A to D) and should not take you too long to complete. The information you are asked to provide relates to your health before and after the coronary angioplasty procedure (the procedure using the balloon which opens up the blood vessels to the heart to help relieve angina symptoms). If you do not want to answer a particular question, please leave it blank.

#### Section A: about you

A1	Name:	
A2	Date of birth:	
A3	Address:	
A4	Postcode:	
A5	Contact telephone number:	
A6	Are you: Please tick ✓ as appropriate	Male     Female
A7	Please indicate your ethnic origin:	<ul> <li>White UK</li> <li>Pakistani</li> <li>Indian</li> <li>Mixed background</li> <li>Other please specify:</li> </ul>
A8	Living arrangements: Do you: Please tick ✓ all that apply	<ul> <li>Live alone</li> <li>Live with wife / husband</li> <li>Live with partner</li> <li>Live with other family member</li> <li>Other please specify:</li> </ul>
A9	Do you have a carer?	<ul> <li>No</li> <li>Yes, family member</li> <li>Yes, but <u>not</u> a family member</li> </ul>
A10	Education: Please indicate the highest level of education you have.	<ul> <li>Secondary school or equivalent</li> <li>Professional / vocational qualification</li> <li>College</li> <li>University</li> <li>Other please specify:</li> </ul>
A11	Employment: If you are in employment, have you returned to work following the coronary angioplasty procedure?	<ul> <li>Not applicable</li> <li>Yes</li> <li>No: can you give the reason why?</li> </ul>

A12	Housing: Do you:	<ul> <li>Own your house</li> <li>Rent your house</li> </ul>
A13	Medical history: Are you currently receiving any treatment or take medicines for any conditions? Please tick ✓ all conditions that you have	<ul> <li>Angina</li> <li>Asthma</li> <li>Previous heart attack</li> <li>Chronic lung disease</li> <li>High blood pressure</li> <li>Kidney disease</li> <li>Arthritis</li> <li>Depression</li> <li>Anxiety</li> <li>Previous heart bypass operation</li> <li>Diabetes (diet or tablet controlled)</li> <li>Diabetes (insulin controlled)</li> <li>Other condition(s) please specify:</li> </ul>
A14	Are your day-to-day activities limited because of a health problem or disability other than your angina?	<ul> <li>☐ Yes, limited a lot</li> <li>☐ Yes, limited a little</li> <li>☐ No</li> </ul>
A15	How long have you had angina for?	<ul> <li>Don't know</li> <li>Less than 1 year</li> <li>More than 1 year</li> </ul>

#### Section B: Before and after the coronary angioplasty procedure.

## Section B1: <u>before</u> your most recent coronary angioplasty procedure

B1.01	Did you have angina symptoms <u>before</u> the coronary angioplasty procedure?	<ul><li>☐ Yes</li><li>☐ No</li><li>☐ Don't know</li></ul>	
B1.02	Do you feel that your angina limited your day-to- day activities <u>before</u> the coronary angioplasty procedure?	<ul><li>☐ Yes, limited a lot</li><li>☐ No</li></ul>	Yes, limited a little

### Section B2: <u>since</u> your most recent coronary angioplasty procedure

B2.01	Have you had angina symptoms <u>since</u> the coronary angioplasty procedure?	☐ Yes ☐ No ☐ Don't know	
B2.02	Do you feel that your angina has limited your day-to-day activities <u>since</u> the coronary angioplasty procedure?	<ul><li>☐ Yes, limited a lot</li><li>☐ No</li></ul>	Yes, limited a little

B2.03	If you get angina again how would you deal with it? Please tick ✓ all relevant	<ul> <li>I won't get angina now</li> <li>Ignore it </li> <li>Worry about it</li> <li>Rest or relax </li> <li>Call GP</li> <li>Call 999</li> <li>Take GTN (nitrate) spray or tablets under tongue</li> <li>Call / contact family or friends</li> <li>Not sure</li> <li>Other please specify:</li> </ul>
B2.04	If you had angina and it lasted longer than 15 minutes what would you do? Please tick ✓ all relevant	<ul> <li>I won't get angina now</li> <li>Ignore it</li> <li>Worry about it</li> <li>Rest or relax</li> <li>Call GP</li> <li>Call 999</li> <li>Taken GTN (nitrate) spray or tablets</li> <li>Call / contact family or friends</li> <li>Not sure</li> <li>Other please specify:</li> </ul>
B2.05	How confident are you that you know when you should seek medical help for your angina in the future?	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>
B2.06	How confident are you that you can maintain your usual activities at home?	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>
B2.07	How confident are you that you can maintain your usual social activities?	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>
B2.08	Have you attended a cardiac rehabilitation programme since the coronary angioplasty procedure?	☐ Yes ☐ Not sure ☐ No
B2.09	Have you received any self-help manuals or pamphlets about how to manage your angina?	☐ Yes ☐ Not sure ☐ No
B2.10	Is there anything that would have helped your recovery after coronary angioplasty?	<ul> <li>No</li> <li>Not sure</li> <li>Yes, please specify:</li> </ul>
B2.11	Since the coronary angioplasty procedure how many times have you been in hospital or seen your GP?	Number of times in hospital: Number of times seen by GP:

# Section B3: your general health and medicines

B3.01	Do you take the medicines for your heart condition / angina:	<ul> <li>Every day</li> <li>Most days</li> <li>Occasionally</li> </ul>
B3.02	How confident are you that you know how to take the medicines for your heart condition / angina?	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>
B3.03	Do you smoke?	<ul> <li>Yes</li> <li>No, ex-smoker</li> <li>No, have never smoked</li> </ul>
B3.04	How often do you exercise? (Most days means at least 5 days in a week).	<ul> <li>Never</li> <li>Less than 15 minutes most days</li> <li>Between 15 and 30 most days</li> <li>Between 30 and 60 most days</li> <li>More than 60 minutes most days</li> </ul>
B3.05	How confident are you that you know how much physical activity is good for you?	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>
B3.06	How much alcohol do you drink in a week? 1 unit = ½ pint of beer or small glass of wine or 1 pub measure of spirits	<ul> <li>None</li> <li>Less than 7 units per week</li> <li>7 -14 units per week</li> <li>14 - 21 units per week</li> <li>More than 21 units per week</li> </ul>
B3.07	How many portions of fruit and vegetables do you eat in a day?	<ul> <li>□ None</li> <li>□ 1-2 per day</li> <li>□ 3-5 per day</li> <li>□ More than 5 per day</li> </ul>
B3.08	How tall are you and how much do you weigh?	Height: Not sure
B3.09	In the last three months have you made any changes to your lifestyle?	Weight:       Not sure         Yes       No       same       applicable         Smoke less       Image: Constraint of the stress of the stre
B3.10	How confident are you that you can do things other than taking medicines to manage / control your angina	<ul> <li>Totally confident</li> <li>Quite confident</li> <li>Confident</li> <li>Not very confident</li> <li>Not at all confident</li> <li>Not sure</li> </ul>

# Section C: about how you feel now at present

C1 C3	I feel tense or 'wound up': Most of the time A lot of the time Time to time, occasionally Not at all I still enjoy the things I used to enjoy: Definitely as much	C2 C4	I feel as if I am slowed down:  Nearly all the time Very often Sometimes Not at all  I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all
	<ul> <li>Not quite so much</li> <li>Only a little</li> <li>Hardly at all</li> </ul>		<ul> <li>Occasionally</li> <li>Quite often</li> <li>Very often</li> </ul>
C5	I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all	C6	I have lost interest in my appearance: Definitely I don't take as much care as I should I may not take quite as much care I take just as much care as ever
C7	I can laugh and see the funny side of things: As much as I always could Not quite so much now Time to time, occasionally Not at all	C8	I feel restless as if I have to be on the move: Very much indeed Quite a lot Not very much Not at all
C9	Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time but not too often Only occasionally	C10	I look forward with enjoyment to things: As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all
C11	I feel cheerful: Not at all Not often Sometimes Most of the time	C12	I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all
C13	I can sit at ease and feel relaxed:  Definitely Usually Not often Not at all	C14	I can enjoy a good book or radio or TV programme: Often Sometimes Not often Very seldom

#### Section D: what you think of your condition now

The illness the next section refers to is coronary heart disease. For the following questions, please circle the number that best corresponds to your views.

D1		daaa		llnaaa	offect	VOUR	1402				
	How much	does	2	3	4	your i 5		7	8	9	10
		1	2	3	4	Э	6	1	0	9	
	no affect										severely
D2	at all		46.00				<u></u>	- 2			affects my life
02	How long d	io you		-					0	0	10
	0	1	2	3	4	5	6	7	8	9	10
	a very										forever
D3	short time	1				I			0		
03	How much		-		-					~	40
	0	1	2	3	4	5	6	7	8	9	10
	Absolutely									ex	treme amount
<b>D</b> 4	no control	-		•						_	of control
D4	How much	do yo		-							
	0	1	2	3	4	5	6	7	8	9	10
	not at all										extremely
											helpful
D5	How much	do vo	u exp	erienc	e svm	ptoms	from	vour ill	ness?		
	0	1	2	3	4	5	6	7	8	9	10
	no symptom	าร	_	-	-	-	-		-	-	many severe
	at all										symptoms
D6	How conce	rned a	are vo	u aboi	ut vou	r illnes	s?				
	0	1	2	3	4	5	6	7	8	9	10
	not at all			-		-	-		-	-	extremely
	concerned										concerned
D7	How well d	o vou	feel v	ou un	dersta	nd vou	ur illne	ss?			
	0	1	2	3	4	5	6	7	8	9	10
	don't unders	stand		-		-	-		-	-	understand
	at all										very clearly
D8		does	vour i	llness	affect	vou e	motior	nallv? (	e.a. da	oes it	make you angry,
	scared, up					,		<b>,</b> . (		•	,
	0	1	2	3	4	5	6	7	8	9	10
	not at all	-	_	-	-	•	•	-	-	•	extremely
	affected										affected
	emotionally										emotionally
D9		in ran	k-orde	er the	three r	nost ir	nporta	nt fact	ors tha	at voi	u believe caused
	your illness						-				
				<i>p</i> 3.							
	1										
	2.						_				
	3.						_				
							_				
	1										

Thank you for taking the time to complete this questionnaire.

If you complete this questionnaire at the outpatient clinic, please return it to Susan Watt.

If you take this questionnaire home with you to complete, please return it using the envelope provided to: Susan Watt, Lecturer and researcher, School of Nursing, Midwifery and Social Care, Edinburgh Napier University, Sighthill Campus, Edinburgh, EH11 4BN

#### Appendix 9 – Permission to use Illness Perceptions Questionnaire

-----Original Message-----From: Elizabeth Broadbent [mailto:lizbroadbent@me.com] Sent: 26 January 2011 21:41 To: Watt, Susan Subject: Re: permission to use Brief IPQ

Dear Susan

Yes you may use the scale for your research

Kind regards Liz

On 27/01/2011, at 6:15 AM, Watt, Susan wrote:

#### Dear Dr Broadbent,

At present, I am a lecturer at Edinburgh Napier University in Scotland undertaking a part-time PhD and I would like permission to use the Brief Illness Perception Questionnaire in a mixed methods study I am planning. The title of my research is "An exploration of how illness perceptions of cardiac patients influence their ability to self-manage their condition after revascularisation with percutaneous coronary intervention". The study will consider how illness perceptions affect patients' ability to self-care and determine whether there is a relationship between illness perceptions and self-care in the patient group. The patients I am interested in are those with angina who have been revascularised with percutaneous coronary intervention.

I am aware that the Questionnaire is subject to copyright and would be grateful for your consent to use it in my research study. I am happy to share any adaptations made for the specific patient group with you.

If you require any further information please let me know. Thank you in anticipation.

Kind Regards, Susan

Susan Watt Lecturer and Teaching Fellow School of Nursing, Midwifery and Social Care Edinburgh Napier University Room 4.B.19 Sighthill Campus Edinburgh. <u>s.watt@napier.ac.uk</u> 0131 455 5635

Date	Number	Number of	Number	Reason for	Number of	Reasons for
	of clinics	PCI	Of oligible	ineligibility	participants recruited	non-
	attended	patients due at	eligible patients		recruited	recruitment
		outpatient	pationto			
		dept.				
December	6	13	12	1 lived out-	11	1 declined
2011				with area		
January	5	9	8	1 non English	8	N/A
2012	8	22	19	speaking 2 lived out-	16	3 declined
February 2012	8	22	19	with area	16	3 declined
2012				1 required		
				urgent		
				medical		
				attention		
March 2012	5	10	10	N/A	9	1 did not
						attend clinic
April 2012	4	14	14	N/A	10	3 did not
						attend clinic 1 declined
May 2012	8	18	18	N/A	15	2 did not
May 2012	0	10	10	11/73	10	attend clinic
						1 declined
June 2012	8	9	9	N/A	9	N/A
July 2012	9	9	8	1 already	8	N/A
<b>A</b>	-		4	recruited		N1/A
August 2012	2	4	4	N/A	4	N/A
2012						
September	1	1	1	N/A	1	N/A
2012				-		
October	3	2	2	N/A	2	N/A
2012						
Totals	59	111	105	6	93	12

Age	Sex	Ethnicity	Marital status	Level of education	Co- morbiditie s	Angina symptom management	Risk reduction since PCI?	HAD score	IPQ score
66	Male	White UK	Married	College	Yes – 1	Reasonable – would take GTN for recurring angina symptoms but would also call 999	<b>a a</b>		18
77	Male	Indian	Married	University	Yes - 2	Reasonable – would take GTN for recurring and prolonged angina symptoms but would also call 999			31
72	Female	White UK	Married	Prof / vocational qualification	Yes – 1	Poor for prolonged episodes of angina symptoms – would take GTN / rest and call GP and family			31
76	Male	White UK	Married	Secondary school	No	Poor - no use of GTN / resting. Would call GP and 999 for any recurring angina symptoms	No modifications since PCI	0	-
82	Female	White UK	Lives alone	University	Yes – 2	Reasonable – would take GTN and call GP for any recurring angina symptoms.	Yes – less fat in diet since PCI	5	29
68	Male	White UK	Lives alone	University	Yes - 1	Reasonable – would call GP for any recurring angina symptoms.	g Yes – diet and exercise modifications		11
82	Male	White UK	Married	University	Yes – 1	Poor – no use of GTN. Would drive to A&E if prolonged angina symptoms       No modifications since PCI		2	27
65	Male	White UK	Married	University	No	Good – would not rest but otherwise accurate managementYes – smokes less and modified diet		5	17
85	Male	White UK	Married	University	Yes – 3	Poor – no use of GTN for recurring angina symptoms. No 999 for prolonged angina symptomsNo modifications since PCI		4	35
60	Female	White UK	Married	Secondary school	Yes - 2	Reasonable – would call GP for any recurring angina symptoms and call GP and 999 for any prolonged episodes	Yes – less fat in diet since PCI	6	17

# Appendix 11 – Overview of Phase 2 participants

#### Appendix 12 – Interview schedule

Understanding of CHD

- Cause of CHD
- Understanding of rationale for PCI
- Duration of CHD / angina symptoms
- How much the PCI, medication and secondary prevention methods can help
- What information / education on CHD has the patient received / sought (sources of information)

How the patient's understanding relates to their day to day management of the condition

- Medication adherence (routine, understanding of effects of medication etc.)
- Secondary prevention methods adopted

• Has the patient received any education for secondary prevention strategies

Day to day management and risk factor reduction

- Any risk reduction since PCI / diagnosis of CHD
- From questionnaire responses discuss risks (e.g. why does the patient smoke / not smoke, why do they exercise as much / as little as they do)
- Any support given to help with risk reduction

Day to day management

- What would help recovery
- Confidence about maintaining usual activities at home / socially
- Personal support (what support does the patient receive from family members / what type of support do they provide / do they discuss the patient's CHD / symptoms / how much trust does the patient have in these people?)
- Social support (what support does the patient receive from non-family members / why are these people important to the patient / what type of support do they provide / do they discuss the patient's CHD / symptoms / how much trust does the patient have in these people?)
- Contact from healthcare professionals (frequency / who do they contact / how much trust do they have in them?)

Symptom management

- Response if recurrence of angina symptoms (how would the patient feel / what would they do and why?)
- Management of a prolonged attack (would this differ in any way from angina of short duration?)

# Appendix 13 – Annotated transcript

Inductive coding	Verbatim transcript	Deductive coding
	Researcher (R): Can I start with you giving me a sense of what you	
	understand about your heart problem and why you had the	
	angioplasty procedure done.	
	P90: About the 28th of April I was walking along Princes Street and I	
	got a pain in my chest and I stopped because it was quite sharp. I	
Mally like on old man	started walking again because I walk briskly and it hit me again so I	Contra strategies
Walk like an old man	stopped. I had to walk almost like an old man, one step at a time and keep below the speed level that would induce this pain. Now	Coping strategies
	interestingly what I did do, I went into a chemist because I know my	Cause of CHD
Family has bad hearts	family has very bad heart problems. They are 'very significant' as	Cause of CHD
r anny has bad hearts	medicals would call it, family history. I went into Boots the chemist	
	and bought some aspirins and I thought because I remember	
	reading somewhere. I thought, is this the heart or is it not? I don't	Personal support
Take some Aspirin	know. I will take an aspirin just in case. Anyway, I told my daughter.	
Tell my doctor daughter	She was around at the weekend and she's a doctor and she said	
	'dad, I think you've got angina. See your doctor on Monday'. On	Healthcare support
Saw the GP	Monday I saw my doctor. It was a quick appointment. He looked at	
	the family history. Took some soundings. 'I think it's angina. You	
	are off to the clinic' [said the doctor]. Tuesday, 1 o'clock. Very	Healthcare support
Went to the clinic	prompt. I went into the clinic, onto the treadmill to do the test and I	
	couldn't do the treadmill for more than four minutes. You are	
the second second second	supposed to do it for nine I think em. One of the other doctors said 'I	
We think you have	think you've got angina we will need to get you in. Probably six to	
angina Two types of ongine	eight weeks you will hear'. Fine. So there are two types of angina I understand. Stable and unstable. So I think I was stable at that	
Two types of angina	point. However, I also said I can't wait six weeks until really the end	
	of June because my daughter is getting married so you will need to	
	give me something earlier than that. So I had phoned the woman	
	who controls the appointment times and I managed to get her give	
	me a shift to the 1 <sup>st</sup> June and I thought that should be all right.	
I wasn't going to need a	Assuming I wasn't going to need a triple bypass or anything which I	

bypass	didn't think was likely. I don't know why I thought that because I am	
I am reasonably fit	reasonably fit. Anyway, I started to get these pains at rest so I told	
	my daughter and she said 'unstable'. I went to London to the	
	Chelsea flower show as you know which wasn't a bright idea	Consequences of CHD
	because I had a very bad night in one of the hotels. I couldn't lie	
Couldn't lie down with the	down with the pain. When the pain came on three or four times I	Cause of CHD
pain	thought [participant takes a sharp intake of breath]. The train back	
	up the following day because we were due to go back up. I said to	
Drive me in to hospital	my wife on the Monday morning just drive me in. I am getting this	Symptom monitoring
It's getting too risky	too often now. It's getting too risky. Very effective. Very efficient. If	
	you have a heart complaint or any chest pain you don't wait in the	
Don't have to wait in	queue [participant slaps his hands together] with all the rest of the	
queue	people with sniffly noses and broken arms and what not, straight	Coping strategies / need
	through. Anyway the long and short of it was I was done in two days	for PCI
	ahead of when I would have been scheduled to have been done.	
Do I have angina?	So angina, because I asked Dr **** 'do I have angina?' Well he said	
	'people talk about angina but it's not, it's a symptom he says and I	
Ask him to explain	did ask him to explain fully and give me a copy of the diagram of	
	where they put the two stents in. One of my eh, one of my valves or	
Arteries clogged	arteries or whatever it was, was 99.9% clogged. My daughter said	Healthcare support
Could have keeled over	'you could just have keeled over'. I said 'don't you even think about	
	that dear, I never even thought about such a thing'. The very idea.	
I don't have pains	So, how am I? Great. I don't have any pains. If you think about	Need for PCI
Is that a palpitation?	your heart, you hear flutterings and you think oh, is that a palpitation	
	or a fluttering. You think you have got this. You lie in bed, a wee	Consequences of CHD
	sharp pain, I will lie on my other side. It's just all on your mind.	
Don't even think about it	Occasionally you do that but for the most part I don't even think	
	about it. And have I had any pains? No. Have I used that wee	Symptom monitoring
Haven't used it since PCI	puffer which I carry. No. I haven't used it since it was done. So I	
	don't have any problems at all. I know some people suffer	
Depression after heart	depression but that's mainly people with heart attacks I understand	
attacks	because a friend of mine I think suffered that. Depression. He's on	

	that recovery sort of stuff you know when you are doing regular	
	exercise.	
Almost stopped smoking	I walk. I have almost stopped smoking my cigars. Almost but three	Consequences of CHD
	weddings of course you have a cigar of an evening. Em I don't drink	
	in the sense that, I only take a glass of wine with my meal. Nothing	
	ever, a drink in my hand just only for the meal. I only started that	
	when I was 45 eh I had never tasted alcohol before. I don't touch	Secondary prevention
	whisky. I have never tasted it, now beer, I have never tasted it or	
	any other form of spirits and I like to walk. I used to play a lot of	
Used to play badminton	badminton a few years ago but I had a problem with my elbow and	
	to be honest, I put off going back to my badminton because I always	
Thought of how unfit I	played very vigorously eh because of the thought of how unfit I	
would be	would be. I used to play guys in their twenties and beat them.	
Don't think I will go back	Difficult, difficult. I don't think I would ever go back and beat them at	
	that standard again so I put that off and I don't like doubles. So I	
Maybe should exercise	haven't done anything. Maybe I should do something in the way of	
	vigorous exercise but no, I'm great.	
	R: So what do you think caused you to get angina in the first place?	
Shock of diagnosis	P90: That came as a bit of a shock because although my father had	Cause of CHD
	his first coronary at the age of 46 and he had a series of coronaries	
Father / uncle died young	and was dead at 60 and his brother dropped dead at 52 the	
	following year. That's my uncle and my younger brother year had a	
	triple bypass when he was 53. He's now 62 so he's getting to the	
-	end of his, it's ten or fifteen years and then they said it's got to be	
Favoured mother's genes	done again. I thought that I favoured my mother's side. My mother	
	has a low heart rate and low blood pressure. Not unhealthily low but	
	healthily low and I've got the same and I have more of my mother's	
	nature, rather than my father's. My brother was very much like my	
No. of a low second second	father. I remember saying to my mother 20 years ago, 'if anyone in	
Needed a bypass due to	the family is to have heart problems, it will be our Bob, that's the one	
explosive nature	who had a triple bypass just because of his explosive nature'. So I	
	didn't think I would get it. Although my mum's got angina at 90. You	

Shocked I had it	are allowed at 90 for God's sake. So it came as a bit of a shock that I had it. The doctor, my GP said to me 'it's rather like cholesterol you can do about 20% yourself in your diet but 80% of this is the	Cause of CHD
Genes to blame	genes so you have your father's genes as well'. So I must assume that was it.	
	R: How long then do you think the heart problem is going to last for?	
It's fixed	P90: I don't have a heart problem. It's fixed [exclamation]	
	R: Do you think you will ever have problems again? Do you think it's fixed forever?	
Not fixed forever	P90: No it's not fixed forever. Dr **** said that if you need any	Consequences of CHD
Know people who have stents	further work it might be into your 70s. Eh, chances are you won't, but if you do and I know people who have had a third stent and I know people who have had stents then had bypasses but he doesn't	
Lead healthy life	think that will happen to me if I lead a moderately healthy life. If I	Need for risk reduction
	have any further issues it will be in my 70s and then you might well live until you are 90. I said if you write that down <i>I will take it as a</i> <i>deal</i> ! Thank you very much.	
Heart an issue in family	So no, in our family heart is an issue. My father's side of the family,	Cause of CHD
Can't be ignored	that's obvious. It can't be ignored. My older brother by one year, he has been on statins for years. That's my mistake. My doctor	
Didn't want to go on statins	advised me years ago to do it and I thought because I was doing all this vigorous exercise I don't want to go on the statins but maybe I should have and they would have prevented all of this clogging of the arteries that has gone on. Who knows? So I can't say it's	Healthcare support
Angina removed	completed for a while because you could drop dead tomorrow but it's unlikely but em I think the problem of angina has been removed	Consequences of CHD
Arteries cleaned up	because the symptom that is causing it has been cleaned up.	
On statins for life	I am on the statins. I will be on them for life and I don't mind. My cholesterol level is up at 7 and in that short time from June until just	Secondary prevention
Cholesterol dropped	a couple of weeks ago, it has dropped to 31/2. So I texted my	
	daughter and said it's down to 3½ so I am away to buy a pizza to celebrate! [participant laughs] so I am waiting for the reply. So it	

	could happen, yes, but am I going to think about it? No. I intend to live until I am 95.	Consequences of CHD
	R: So you are on the statins then. How much do you think being on	
	the these medicines and also the procedure have helped?	
	P90: Oh immeasurably because I was just walking along the road	
the second s	then [participant slaps his hands together] pain. Thank God I got the	
It was a warning	pain, it was a warning.	
	R: Had you had any symptoms before you had it that day?	
	P90: None. None I am conscious of. No, none that I am	
Just came on [pain]	conscious of. It just came on as a pain and then it became unstable	Symptom monitoring
That worried me	pain. That's what worried me.	
	R: Okay. Can I go on to your medicines then?	
	P90: Yes, if I can remember what they are.	
	R: I just want to get an idea of what you think they are for? You said	
	the statin was for cholesterol.	
Ranitidine for indigestion	P90: Yes, I've got statin. I've got Ranitidine that's for indigestion	Action of medicines
-	because these tablets cause that. I'm on Aspirin but it's one of	
	these coated ones to stop the irritation of the stomach. So aspirin in	
	the morning. Clopidogrel, something called Clopidogrel. What is	
	that now? I remember reading about it but I have forgotten what is	
	was. Eh well I went to see Dr **** three weeks ago and he said 'I	
	might take you off some of your drugs in a year'. So he said I was	
Bisoprolol a beta	disgustingly healthy [participant laughs]. The other one is a small	
blocker?	one. What is it called? Bisoprolol. Is that a beta blocker?	
	R: Yes.	
Friend said like driving	P90: Yes, I have a friend of mine, my pal's brother is a doctor and	Action of medicines
with handbrake on	he said that it is like driving with your handbrake on. It puts a bit of a	
	drag on you because I am quite up and at it. I don't just get out of a	
	chair, I jump out of a chair. I don't enter, I make an entry I am told	
	over the years. I am not conscious of this, people have told me. It's	
	maybe just the way I am so it's fine I had mine this morning but see	
	when it comes to 8 o'clock at night, 7 or 8 o'clock I am absolutely	
	when it comes to b block at hight, 7 or b b block 1 all absolutely	1

Tired in the evening	bushed. So I get quite tired in the evening and really an energy slump so I go to my bed a bit earlier. I normally was, I wasn't a late 'bedder' anyway I used to go to bed about half ten, eleven but now I am ten o'clock, half nine and I am exhausted but I am still awake at 5 in the morning, go over again, wake at 6 and listen to the radio news. So that's, what was the other thing now? Aspirin, Clopidogrel, the other thing I mentioned, Bisoprolol, statin and the indigestion tablet. Five.	
rive tablets	R: Did they explain to you what the Bisoprolol does?	
Don't recollect detail	P90: I am sure they did vaguely in the hospital but I don't recollect the detail. I was conscious that it was a beta-blocker and sort of, I don't know what it really intends to do, perhaps you could tell me?	Healthcare support
Don't know what it does	Is it intended to slow you down? Yes, maybe that is a good thing. Yes, so I don't have any problems with these drugs. I am in the	Action of medicines
Habit of taking them	habit now of taking them. Three in the morning and the statin and the indigestion tablet at night.	Medication adherence
	R: Can you explain your habit to me?	
Wife reminds me	P90: Well my wife's on that she takes them so I'm saying 'have you taken your blood pressure tablet?' you know because on her side it is high blood pressure in the female relations. There's always something isn't there? I tend to get up in the morning and go	Personal support
Keep them in bag Take them first Try to have regime	downstairs. I keep them in a bag from the chemist and I take them first thing before I eat because if I eat something sometimes I am half way out the door and I say I haven't taken those and I go back in so I try to have a regime of doing it before I eat.	Medication adherence
	R: What about the ones at night?	
Take tablets before bed	P90: Before I go to bed. I have a bad habit of drinking Iron Bru during the night which is a diuretic which is silly because it gets you up in the middle of the night a couple of times. I know if I take water I am up fewer times but I drink Iron Bru and it makes you go to the loo three or four times. So I fill my glass up with iced Iron Bru and then I take my two tablets just before I go to bed. So I haven't	

If given them take them	missed those for a while. I remember going somewhere and having to turn back because I said 'I have missed those two tablets' and I came straight back to get them. I'm a great believer that if you are given them, take them because there is a purpose for taking them.	Medication adherence
	R: Have you had any problems with them that you are aware of?	
Haven't noticed a difference	P90: No. The statins they always say make you a bit windy. Flatulence is an issue with statins because my brother said that and that when I said I'm windy enough frankly, I don't need any statins to induce any more but I haven't noticed any difference at all. I have had no side effects, other than this, if you cut yourself shaving you bruise a bit more em, that's the only difference that I have had since I have been taking these tablets.	
	R: There are some things from your questionnaire that I want to pick up on. You said that you have had three cigars since the PCI?	
One day at a time I can go days without Haven't quite stopped That triggered me off Rather pleasant	P90: Maybe more than that but I am trying to just get to the point. It's an awful step to just say that I am giving it up. I think you have got to do the old alcoholics trick, one day at a time stuff and I think, today I won't smoke and I can go days without so I haven't quite said that I have stopped. I did stop. I smoked a pipe for many years and gave it up for over twenty years and I went on a pilgrimage to Rome and eh I was taken to this old monastery you see and we were shown round some of the basilicas and the passed around cigars in the evening. That's what triggered me off you see. It was rather pleasant sitting in the evening.	Secondary prevention
	R: What made you try to give it up this time then?	
Nagging from wife Smoking isn't good for health Fighting against another	P90: Well besides constant nagging by my wife and daughter eh smoking isn't good for the health. It isn't good for your health. You get chest complaints and all sorts of things and it only adds to the burden on the heart. I mean you get these drugs to try to slow you down and I am taking cigars which increase the heart rate so one thing is fighting against another and I do know, statistically, there is	Personal support Need for risk reduction
Have heart attack	more risk you are likely to have a heart attack smoking than cancer	Cause of CHD

smoking Won't happen to us	with smoking. We all think though that that won't happen to us. I have to say, I mean my wife's brother-in-law, he's a retired ENT surgeon, senior consultant and him and I used to enjoy a cheroot now he used to spend most of his life cutting up cancerous throats. So why do we do it? Why do people drink to excess, why do people drink at all? Em well I don't know. Why do people eat excessively sweet stuff that will give you bowel cancer. Not enough roughage. We just do things. I enjoy, I have to say, yes, it's an enjoyment. A	
Cigar an enjoyment	cigar is an enjoyment.	
-	R: What do you enjoy about it?	
Pleasurable feeling in it Sociable in companies	P90: The whole thing. Lighting up eh, I mean I don't just puff it, I inhale. That's perhaps, I wouldn't want to smoke if all there was was to puff it. I mean when I smoked my pipe, I used to inhale. There's a pleasurable feeling in it. It's calming. It is calming, the whole thing is calming. It is very sociable in some companies when you are standing outside with a group of guys all puffing away on cigars. If there's somebody smoking a cigarette I walk away. I can't stand the smell of cigarettes. Cigarettes, I mean if there were no cigars in the	Social support
	world and somebody handed me a cigarette I would say no thank	
It blissful's	you. Ghastly things. So it's the whole thing, it's blissful.	
	R: The other thing that you put on your questionnaire was that you eat more fruit and vegetables. Was that since you have had the procedure done?	
Wife encouraging	P90: My wife has always been encouraging me to eat more fruit and	Personal support
Five a day lark	vegetables. I mean this five a day lark I never get up to that I have to say em. Do I have vegetables every day? No. Do I have	Secondary prevention
	vegetables three or four times a week? Yes. Fruit, I'm fussy about	
Fussy about fruit	fruit. Apples I need to cut up as I have a plate and can't really bite into it. Em, I can take a peach if it's really sweet and soft but some people can live without any evidence of fruit. Dr Samuel Johnson, the great writer em and conversationalist. The man who wrote the first comprehensive English dictionary in 17 whatever it was. He	

	was born in 1709 and died in 1776 I think it was, no it must have been later because he was 70 odds when he died. An unusually large man for his years he was forever eating fruit, it was uncommon which probably explains why he got so fat so yes and funnily enough you know when you are abroad you eat fruit all the time because it's so fresh, it's not cold, you don't mind it and it's sweet and so on so I	
Need to eat more fruit	need to eat more I know of fruit and veg I know but not perhaps as	Need for risk reduction
and veg	much as I should perhaps.	
	R: Do you think you diet has changed since the angioplasty?	
Do not use salt	P90: A little because we did have a healthy, I mean I do not put salt, the only thing I put a pinch of salt in scrambled egg or a pinch of salt in porridge. We never add salt to food em and when we do use salt,	Secondary prevention
Family uses lots of salt	it's low salt. I don't like salty foods in fact my brother-in-law the retired surgeon you have no idea they salt their food and before he even tastes it he's got the salt cellar. It was like a frosty morning then when he's done that, he pours some in his hand and I say 'Joe, your blood must be like treacle'. His blood must be like treacle. He	
Blood like treacle	probably goes for a pee once every six months the retention he will have with the salt. So but we have always been very restrictive on salt. We never add salt to food except those two so I have never	
Use low fat butter	really. Butter, we tend to take the lower fat butters em I tried some of the spreads but they are ghastly. They are not very nice at all.	
We never fry Cheese is fattening	Grill any food we eat. We never fry. I like sausages, my wife doesn't like them because they aren't healthy so I only have them a small number of times. Bacon maybe once a week. We don't have it every day em cheese I love but I have cut down the amount of cheese I'm eating as well. I love cheese. See cheese and wine,	
	they go together there's no doubt about it. I love cheese but it's very	Need for risk reduction
Not a major change Didn't have to make	fattening and it's also not good for you so I have cut that down as	Need for risk reduction
major change	well so it's not a major change because I didn't have to make a major change. My diet couldn't have been good enough because the arteries clogged up but that's the way it is. So not any dramatic	

	change	
	change.	
	R: You drink wine you said. Do you think you have changed the	
	amount of alcohol that you drink?	
	P90: No, I think if I drink the equivalent of two bottles of wine a year,	
	that's it.	
-	R: As little as that?	
	P90: As little as that. It's not a lot. It's only because Joe said you	Social support
Family said to drink wine	should take it because it's good for your heart and I tried white and	
	didn't like it. They gave me a red and I thought that it was rather	
	nice. It was a Merlot and I thought it was quite nice with food. I	
	couldn't stand with a glass of wine in my hand talking to you, unless	
	I'm eating a meal so that the weddings for example, I had half a	
	glass of red wine with the dinner. That's the only alcohol I	
	consumed. So, it's not an issue. It's not at all.	
	R: Did anyone explain what you could do to stop the angina	
	returning?	
They mentioned diet and	P90: Mention was made of diet. Mention was made of statins eh fair	Healthcare support
statins	enough. Exercise, now I don't do exercise, I mean I walk up the hill	
Don't do vigorous	and maybe get a wee bit breathless but I don't do vigorous, vigorous	
exercise	exercise that I did and I don't know whether I should go back to that.	
	I mean I would need to work my way back to it very gradually	Secondary prevention
Just not fit enough	because I'm just not fit enough now. It's been three or four years	bootinuary provonation
bust not in chough	since I have played any serious badminton to be honest and I am	
	not all that keen to get back to start doing that knowing what I do	Coping strategies
	now. I know where I should be. When you lose your fitness and	ooping stategies
Get frustrated	you lose your accuracy you get very frustrated and I have been	
Couple of walks a day	putting it off. But I am happy to go for a couple of mile walks a day.	
Couple of walks a day	R: So the person that gave you that advice, was it a doctor or a	
	nurse?	
GP gave advice	P90: So it was eh I think it was my GP and my daughter mentioned	Healthcare support/
GF gave advice		Personal support
	it as well. I used to do, years ago, I was the only guy in a step	Personal support
	aerobics class with all these women and very vigorous it was. I	

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Haven't done that for a while	haven't done anything like that for a while. I have no notion to go back to it to be honest. I like moderate exercise like walking. I don't	
writte	<i>•</i>	
	go swimming although I can swim, I am not fussed for swimming em	Contra strategies
	and I just wander around Edinburgh for the most part. I keep telling	Coping strategies
l am a walker	everybody I am a street walker in my part-time [laughter]	
	R: Did they give you any booklets or any other literature at all?	
Book explaining angina	P90: Yes there was a book explaining about angina, what it was and	
	it was very good actually, actually I thought and it explains about the	
Explains the procedure	procedures you can get, what happens and so and so. What they	
	do and I thought it was a very, very good booklet. That was the	Healthcare support
	hospital that gave us that. Yes.	
	R: Did you look for any information anywhere else?	
Asked my daughter	P90: No. I just asked my daughter about it. If I am curious I will look	Personal support
	it up because the one thing that I wanted to know was do I have	
Is angina permanent?	angina? Is this a permanent feature? 'No'. He [cardiologist] said	
	the script is for what is wrong with you, arterial heart disease so it's	
	just all this clogging up. Atherosclerosis is that what it's called? Yes.	Cause of CHD
	R: So do you still think you have got atherosclerosis?	
Had dynarod treatment	P90: No. I had the 'dynarod' treatment didn't I so no and provided I	Need for PCI
Keep cholesterol down	can keep my eh cholesterol level down and keep my diet moderately	Need for risk reduction
	healthy it shouldn't come back in any big way and he did say that	
	the stents were the good ones with the drugs in them and I said 'I	
	don't want any cheap stuff inside me. I want the full bhuna here, no	
	nonsense if you please, I am not having any second hand stuff here	
Don't have angina	so no so I don't have angina and the problem in my heart has been	
Heart problem fixed	fixed. That's what it is.	
rieart problem lixed	So and eh they began to clear them up. I had visions of this thing	Need for PCI
		Need for PCI
	scraping em but I couldn't but I was really quite uncomfortable and	
	they gave me some morphine I think eh. I mean I really wasn't	
	conscious of it at the time, I was conscious of it because it was	
	painful getting this done. But then I was thinking about this at the	
A job to clean it up	same time it's painful but they must be having a job in there to clean	

I got the diagram	it up. Whatever it is that they have found. I mean I got the diagram	
	which they prepared of where the stents were put in the and so they	
	gave me that so that it was easier to explain to my daughter.	
	R: Did they explain what you could and couldn't do afterwards?	
Got an information sheet	P90: Eh no there was an information sheet that told you you had to	Healthcare support
	stay in bed for two hours after you get it done then four hours if you	
	got it through the groin which I wasn't thinking 'oh my God, who	
	wants it in their groin?' and I thought no no no but I never got the	
	option, they just went straight into the wrist which was fine, fine by	
Leaflet explained	me. So that leaflet explained that you had to sit around for a bit so I	
	was kept in overnight until the following day because the night	
	before I went down I had pains lying in the bed you see so it was	
Cardiologist spoke to me	virtually bang Dr **** spoke to me before I went out and he was quite	
	helpful and the nurse came in and explained broadly these tablets	
I wasn't concentrating	but I probably wasn't concentrating but I'm all right now. But yes	
Plenty of assistance	there was plenty of assistance, I can't complain.	
	R: Good and did they explain to you what to do when you went	
	home?	
	P90: They had one of these pressure cuffs they did say that. I had	
	never seen one of those before. They released the pressure at one	
	point and it started bleeding and they tightened it up. Em, some	
	people found them uncomfortable, I found it was all right I must say.	
	I thought it was a thoroughly good idea. It was great. What will they	
Told to keep an eye on	think of next? It was really quite good so I was told to keep an eye	
	on that there was no do's and don'ts. Well don't drive now yes I was	Healthcare support
	banned from driving for 48 hours not seven days which this friend of	
Friend had heart attack	mine who had a heart attack was told he couldn't drive for seven	
	days or ten days or something so I was only banned for 48 hours.	
	As it happen, I didn't drive for two or three days anyway just to give	
	it a, because there is a lot of tension driving.	
Getting more irritable	I find myself getting more irritable now or at least my wife tells me	
	that em and I get cross I used to sit and listening to things and boil	

Maybe nothing to do with	away but now I shout 'bollocks' at the television so I tend to get my threshold, my tolerance threshold has gone down. It's maybe	Coping strategies
	my threshold, my tolerance threshold has gone down. It's maybe	
heart	nothing to do with the heart, it's maybe just age I don't know what it	
	is so and but I think with the irritation you start getting annoyed and	
	that puts your blood pressure up but I don't worry about that	
	because I have a good blood pressure anyway. Then again if you	
	don't get the irritation out you bottle it which is worse. Stress is a	
Stress is a killer	killer. There is no question. My tolerance for stress has gone way	Cause of CHD
Stress is a killer	down but I have noticed the last few years, you can tolerate, in	Cause of CHD
	terms of stress when you are in your 40s, you can't even tolerate	
	even half of that in your 60s. Your tolerance for stress goes way	
Discussed it with pal	down. I discussed that with my pal and so I took early retirement a	
	year ago and I was wondering if I hadn't taken early retirement	
	would I have a heart attack with the stress of the work? Because	Consequences of CHD
		Cause of CHD
	R: Absolutely, do you think stress contributed to your angina?	
	P90: Well I had retired for nearly a year so it shouldn't have but the	
	cumulative effects of stress over the years must take a toll. I don't	Cause of CHD
Think it was just family	know, I think it was just family and the fact that I wasn't on statins	
Lucky never had heart		
attack		
		Consequences of CHD
	<u>v</u>	
Daughter was worried		Personal support
Lucky never had heart		Cause of CHD Cause of CHD Consequences of CH

	-	
	than I was. She was really quite upset my wife was telling me after	
	and she was even going to put her wedding off. I said 'you will do	
	nothing of the kind' because I think she was thinking that I needed	
	this seen to before I tip over and fall off my perch. I told her that that	
Never thought I would die	never entered my mind that I would have a heart attack far less die.	
	The very idea. Me? Oh no no no. Some people fret, worry and get	
You get on with it	anxious but you get on with it.	
	R: Do you chat about it to your wife?	
Talked to wife at time	P90: At the time yes. Yes after it was done but I didn'tmy friends	Social support
	thought I was mad to go to London with them to the Chelsea flower	
Walk slowly to get there	show and I said 'oh no if I walk slowly I will get there' and it seemed	
	to be something that needed to be managed. Actually it was	
Silly going to London	probably a bit silly I suppose going to London. I mean you have got	
Stairs were a killer	stairs to go up and down in the underground. That was a killer but	
	provided I walked slowly I could get there. We came back up	Coping strategies
	because I had that bad night from the Saturday through to the	
	Sunday so we came back on the Sunday. Eh my friends got a bit	
Friends got upset	upset at the station. 'We will get you a wheelchair' I said 'I am not	Social support
Not going in a wheelchair	going in a wheelchair' oh we might have to rush for the train' I said 'I	Coolar Support
not going in a moorenai	am not going in a wheelchair'. The very idea. Standing around I	
	never had any pain, moving was the thing. It was occasionally I	Symptom monitoring
Wee puff would clear it	would get it and the wee puff would clear it [pause] for a wee while.	Symptom monitoring
Go on Monday and get it	So I did say to the wife we will go in on the Monday. It should be the	
sorted	Thursday but we will go in on the Monday and get it sorted.	Symptom management
	R: You obviously chatted about this to your friends. Did you find	o jin promi nanogomori,
	them supportive?	
	P90: Very. So much so my pal, the big man, he's big over 6 feet. He	Social support
	would wander away and look at trees and so on and I stopped	Coolar Support
Pal would pretend to not	looking at something else because I couldn't move and he would	
notice	just pretend he never noticed. I said to him afterwards I said 'thank	
- Indiada	God you didn't have to stand looking at things you have never	
	looked at in your bloody life because you are pretending you are	
L	Tooked at in your bloody life because you are pretending you are	

They were very good Won't have to go up stairs Idea of walking like an old man	interested in some obscure thing on the pavement because I stopped' you know and he said 'yeah' [laughter]. No they were very, very good. Very good. I said 'how are we going to do this' and they said 'well we will go to the next station because it's got escalators and you won't have to go up the stairs and that kind of stuff. We just adapted around it. Mind you I would have hated to have lived like that. The idea of walking like an old man oh! [exclaimed] It's a killer so it's a great joy to dash up the stairs.	Coping strategies
	R: What about your GP then. Is he a good support to you?	
Seen GP once	P90: Well actually I have only seen the GP once since I had this done. I was to get my, what was it that I saw the GP for? Oh, no I haven't seen the GP. They sent me a note to come in and get my	Healthcare support
Saw practice nurse	cholesterol checked but it wasn't, [pause] none of the GPs saw me.	
What use would they	It was the practice nurse I think but I don't see what use they would	
have?	have had to what I already know.	
	R: How did you find the hospital staff?	
Professional know what they are doing	P90: Very good. Very, very good. They have got a very professional show there. That unit knows what they are doing, the people know what they are doing and they give you a leaflet or explain it very well so they really are on time. Even when I was waiting to get this done, they said if you have any pain let us know straight away because we want to do an ECG on you to see what's happening so they could compare it and so don't take your puffer, call us straight away. At night-time when I went to bed, that was usually when I started to get a problem. They would come and do it then I would take the puffer and then get some sleep. Really good.	Healthcare support

	R: Are you still being seen at the hospital?	
lf problems he will see me sooner	Yes, I don't know whether he will see me in a year or six months. The longer it is, the greater the benefit. If there's a problem he will be seeing me sooner so he said well we willnow what did he say? We will let you know. I will take you off the drugs in a year's time and I said 'when do I need to see you again' and he said 'that's nothing to do with me'.	Coping strategies
	R: My last couple of questions. If the pain were to return then	
Disappointed if pain came	P90: I would be very disappointed.	
	R: You would be disappointed but what would you do?	
Take the puffer	P90: I would take the puffer. I have always got it in my pocket. I mean it's probably out of date because it was the one I was using in May. I haven't renewed in under the prescription because I haven't had any pain. There is no point having these things lying around the house wasting money. If it came on I would take the puffer. If it still persisted after 5 minutes I would take the puffer again and if it still persisted 999 and off you go. I would be worried though if I missed	Symptom management
Worried if tablets missed	taking my tablets. See that would worry me. I would think oh, I would think you must take these. Okay, sometimes there's a variation of a few hours in the day when you take them but I know it	
If I take tablets I have	wouldn't be catastrophic but in my mind you are taking a risk if you	
done all I can	don't take your tablets. So if I take the tablets, I have done all I can.	Secondary prevention
	R: Thank you very much. I have no more questions for you.	

# Appendix 13 continued Key to colour coding:

Topic code	Sub-theme	Overarching theme
Facing uncertainty	Fear	
I thought I would be better after the PCI	Disappontment	
I can't do that now		Emotional response
You are just left to get on with it	Abandonment	
I've got a problem with my heart?	Shock	
What CHD means to me	Perceptions of secondary prevention	
How I can prevent the CHD getting worse		
How I monitor and manage my symptoms	Perceptions of symptom monitoring / management	Perceptions of CHD
Why I take medicines	Perceptions of pharmacological treatments	self-management
How I take medicines		
Help from family	Social support	
Help from friends		
Support from GP	Healthcare support	Support
Support from hospital personnel		
Support from cardiac rehabilitation		