## THE UNIVERSITY OF HULL

Psychosocial Outcomes of Enhanced External Counterpulsation Treatment:

Illness Perceptions and Psychological Wellbeing

Being a dissertation submitted in partial fulfilment of the requirements for the

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by

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## Overview

The portfolio has three parts.

Part one is a systematic literature review, in which the theoretical, conceptual and empirical literature relating to the relationship between illness perceptions, mood and quality of life in coronary heart disease populations is reviewed.

Part two is divided into two empirical papers:

- Paper one utilises a qualitative methodology to explore refractory angina patients' experiences of undergoing EECP, and their lives before and after the treatment.
- 2. Paper two utilises a quantitative methodology to explore the relationship between illness perceptions, mood and quality of life in chronic refractory angina patients that have undergone EECP treatment.

Part three comprises the appendices. This includes a reflective statement and supplementary information relevant to all three papers.

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Part One:

Systematic Literature Review

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# Illness Perceptions, Mood and Quality of Life: A Systematic Review of Coronary Heart Disease Patients

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This paper is written in the format ready for submission to the Journal of Psychosomatic Research. Please see Appendix 3.1 for the Author Guidelines. (Word count = 5104)

# Illness Perceptions, Mood and Quality of Life: A Systematic Review of Coronary Heart Disease Patients

## Abstract

**Objective:** To examine published literature investigating the relationship between illness perceptions, mood and quality of life (QoL) in coronary heart disease (CHD) populations.

**Methods:** Key databases were systematically searched (CINAHL, Medline, PsycINFO, Scopus and Web of Science) for studies matching the inclusion criteria. References of included studies were examined and key authors contacted. Studies were subject to a quality control check.

**Results:** 21 studies met the inclusion criteria. A synthesis of the results found that illness perceptions were correlated to and predicted QoL and mood across CHD diagnoses. Specific illness perceptions (*control, coherence and timeline*) were found to be important for patients that had experienced an unexpected medical event, such as myocardial infarction.

**Conclusion:** The results of this study provide support that illness perceptions are related to outcomes across CHD populations and disease progression, however the results do not selectively support one particular model. Recommendations are consistent with cardiac rehabilitation guidelines. Further research should focus on the systemic impact of illness perceptions.

**Keywords:** anxiety; coronary heart disease; depression; illness perceptions; quality of life.

Coronary heart disease (CHD) occurs due to an accumulation of fatty plaque in the arterial walls of the heart; a process known as atherosclerosis. This plaque narrows the arteries and reduces the blood flow to and from the heart, which can lead to myocardial infarction<sup>i</sup> (MI) and angina<sup>ii</sup>.

CHD accounted for over 7.3 million deaths worldwide in 2008 [1], and is the most common cause of death in the UK, with approximately one in five male and one in eight female deaths due to CHD [2]. The prevalence of CHD is increasing annually [3], creating a large societal burden [4]. The total cost to the UK Government, including healthcare, informal care and production loss due to morbidity and mortality was approximately £9 billion in 2006, and is increasing annually [5].

There are a variety of physical, demographic and social factors that increase both the risk of developing CHD and subsequent morbidity and mortality, such as obesity, smoking, genetics, hypertension and diabetes [3, 6, 7]. However, research has found that the degree of physical recovery is not directly linked to illness severity [8, 9] and that psychological factors are also important determinants of CHD outcome. Various psychosocial factors have been found to be key in CHD recovery, including locus of control (LoC) [10], self-efficacy [11], coping strategies [12], social support [13], mood [14] and illness perceptions [15]. Research even suggests that illness perceptions may be more important than medical factors in recovery [16, 17]. This has been found across various chronic health conditions, including chronic fatigue syndrome (CFS) [18], diabetes [19] and CHD [15]. Illness perceptions is a

<sup>&</sup>lt;sup>i</sup> A heart attack

<sup>&</sup>lt;sup>ii</sup> Chest pain due to a lack of blood supply and oxygen to the heart. Stable = Pain precipitated by activity with minimal pain at rest. Unstable = Can occur more unpredictably at rest.

pertinent research area for CHD, as studies have shown that many CHD patients (up to 83%) hold misconceptions about their illness [20, 21, 22]. Therefore, it is important to further understand the impact on CHD outcomes of holding maladaptive illness perceptions.

Illness perceptions are beliefs and expectations regarding one's own or others' illness and develop from a variety of sources, including experience and environment. The most widely applied model for explaining the relationship between illness perceptions and emotional and behavioural responses is the self-regulatory model [23]. This model describes a parallel processing framework, in which patients employ illness-related cognitive and emotional representations to make sense of their illness. These representations guide decisions regarding coping strategies, which are subsequently evaluated based on outcome (see Figure 1). Although coping appears to mediate the relationship between illness perceptions and outcome, research also indicates that there is a direct relationship independent of coping [24].



Figure 1. The self-regulatory model [23]

Leventhal, Meyer and Nerenz (1980) [23] proposed 5 core dimensions to illness perceptions. These were beliefs about illness symptoms (*identity*), expected duration (*timeline*), causal factors (*cause*), illness effects (*consequences*) and the extent to which the illness could be controlled or cured (*control/cure*). Subsequent research highlighted the importance of patients' beliefs that their illness makes sense (*illness coherence*), which has been added as a sixth core dimensions [25].

These constructs were supported by a meta-analytic review of the selfregulatory model [24], which examined various chronic illnesses, including diabetes [26] and asthma [27]. A range of outcomes were also investigated, including psychological wellbeing [26] and quality of life (QoL) [28]. The meta-analytic review provided evidence that the relationship between illness perceptions and outcomes is not disease-specific. However, most of the studies utilised a crosssectional design, leading to difficulties concluding the direction of causality. Since this review, more studies have employed a longitudinal design, demonstrating illness perceptions impacting on outcomes. Furthermore, the meta-analytic review only included two studies of patients that had experienced MI [29, 17]. Since this review, research using CHD patients has found illness perceptions to be important determinants in a variety of outcome measures, including medication adherence [30], cardiac rehabilitation attendance [31], mood [32] and QoL [33]. Mood and QoL are strong psychosocial predictors of CHD [34] and are independently associated with morbidity and mortality [35], highlighting the importance of these outcomes in research.

A systematic literature review was previously undertaken to investigate the effectiveness of interventions to change illness perceptions in CHD patients [36]. The review included a heterogeneous sample of CHD patients, including angina, MI,

CHD and patients that recently received coronary artery bypass graft<sup>iii</sup> (CABG) or percutaneous transluminal coronary angioplasty<sup>iv</sup> (PTCA). Cognitive-behavioural interventions were found to be the most effective to dispel misconceptions, irrespective of CHD patient population. The review also investigated whether these interventions would affect secondary outcomes, such as changes in QoL, health behaviour and psychological wellbeing. However, there was a shortage of consistent secondary outcomes investigated in the intervention studies, which led to a lack of clear evidence that changing illness perceptions influenced QoL and mood. As illness perceptions have been shown to be changeable through health-care interventions, it is important to focus on the specific relationship with secondary outcomes, such as mood and QoL, as these have been shown to be independently associated with morbidity and mortality [35]. Greater clarity of the relationship between these factors could potentially inform health-care interventions for CHD patients and build on the lack of intervention research that has focused on these secondary outcomes. Furthermore, it is important to review this relationship across a heterogeneous sample of CHD patients, as this will enable similarities and differences in this relationship to be highlighted across the whole disease course.

The aim of the current review was to examine published literature investigating the relationship between illness perceptions, QoL and mood in CHD populations. The following research questions were identified:

<sup>&</sup>lt;sup>iii</sup> A surgical intervention that involves removing arteries or veins from other parts of the body and using them to bypass blocked arteries. This increases blood supply to and from the heart.

<sup>&</sup>lt;sup>iv</sup> A surgical intervention that involves inflating a balloon within the coronary artery to increase blood supply to the heart.

1) How do overall illness perceptions relate to mood and QoL in CHD populations?

2) Are there differences in the strength of illness perceptions<sup>v</sup> in relation to QoL and mood in CHD populations?

3) Are there differences in these relationships dependent on the stage of CHD disease course and progression?

## Method

## Data Sources

A systematic electronic search of the literature was performed, searching the databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsycINFO, Scopus and Web of Science. Databases were selected to enable a comprehensive search of psychological, medical and sociological factors. References from selected articles were searched by hand to ensure additional relevant studies were also included. Prominent researchers in the field were also contacted to acquire further research in the process of publication<sup>vi</sup>.

## Search Strategy

The electronic search was performed in November 2011. The following search terms in Table 1 were selected to optimise likelihood of identifying relevant studies in order to answer the research questions. Search terms were chosen through initial checks of key studies and the relevant key words used in these studies.

<sup>&</sup>lt;sup>v</sup> Identity, timeline, cause, consequences, control/cure and illness coherence

<sup>&</sup>lt;sup>vi</sup> Professor Moss-Morris (Head of Health Psychology at the Institute of Psychiatry) and Professor Furze(Professor of Adult Nursing and Health Care at Coventry University)

## Table 1. Search Strategy

Search Criteria	Search Terms
Abstract	illness* OR health* (AND)
Abstract	percep* OR expect* OR belie* OR
	represent* OR cognit* OR attitud*
	(AND)
Title	"coronary heart disease*" OR "coronary
	artery disease*" OR "CHD" OR "CAD"
	OR "angina" OR "angina pectoris" OR
	"myocardial infarction*" OR "MI" OR
	"heart attack*" OR "angioplasty" OR
	"PCI" OR "percutaneous coronary
	intervention*" OR "coronary artery
	bypass surger*" OR "CABG" OR "ACS"
	OR "acute coronary syndrome <sup>vii</sup> *"
	(AND)
Abstract	"quality of life" OR "QoL" OR
	"well#being" OR emotion* OR psycho*
	OR distress* OR affect* OR depress*
	OR mood* or anxi*

## Selection Criteria

Studies were included for selection if participants were adults with a diagnosis of at least one of the following: 1) angina 2) myocardial infarction 3) CHD 4) eligible for or recently received revascularisation via PTCA or CABG. These CHD patient populations have been researched in a previous systematic literature review [36].

<sup>&</sup>lt;sup>vii</sup> One of three cardiac diseases: ST elevation myocardial infarction, Non-ST elevation myocardial infarction and unstable angina.

The studies selected included a measure of illness perceptions and at least one secondary outcome measure: either QoL (physical and/or emotional) or mood (anxiety and/or depression). The studies also needed to employ a quantitative design, to ensure statistically justified relationships. Only peer reviewed full-text studies were included to increase scientific rigour.

Intervention studies were excluded due to a previous review investigating these studies [36]. Furthermore, intervention studies did not specifically investigate the relationship between illness perceptions, mood and QoL. Studies were also excluded if they were not published in the English language due to the potential loss of meaning through translation. It was also beyond the scope of the review to extend to systemic issues, such as family illness perceptions. Therefore these were excluded at the study selection stage.

#### Quality Assessment

The quality of each included study was assessed using a modified version of Downs and Black's (1998) [37] checklist. This was originally developed to assess healthcare intervention studies, which have been specifically excluded from the current review. Therefore, the checklist incorporated questions from the CONSORT 2010 statement [38], which provided a checklist that covered the essential information to judge the relevance and reliability of the study (Appendix 4.1). The quality of each study was rated by two researchers to check for inter-rater reliability.

## Data Extraction

A data extraction form was designed to obtain information from each included study to specifically address the research questions (Appendix 4.2). Extracted data included participant characteristics, study design, method, results, conclusions and implications.

## Data Synthesis

A narrative method of data synthesis was chosen due to the anticipated heterogeneity of the included studies, in terms of participant characteristics, outcome measures and study design.

## Results

#### Details of Included and Excluded Studies

Figure 1 shows the article selection process. Of the 1672 articles identified from initial database searches, 1611 were not relevant based on reviewing abstracts and titles. Removal of duplicates and application of stated inclusion and exclusion criteria left 16 studies. Five further articles were identified through searching the reference sections of included studies. In total, 21 studies were included in the final review.



Figure 2. Article selection process

## Quality Assessment

Included studies varied in quality from 12 to 19 out of a total possible 19 points, using the selected quality assessment tool. Although all studies were included in the review independent of quality, scores were considered in formulating results. There were three items on the quality checklist that were noticed to be particularly low in the majority of studies. Eight studies did not report the differences between respondents and non-respondents, 13 studies did not provide estimates of the random variability of the data, and 15 studies did not report whether subjects were representative of the entire population from which they were recruited. An independent reviewer also rated the included articles to examine inter-rater reliability, which was found to be strong using a Pearson correlation (r = 0.889, *p* <0.001).

#### **Overview** of Results

An overview of the 21 included studies can be found in Table 1. The proportion of males and females in the studies ranged from 50% to 100% male, with an average of 72.72% for males and 27.28% for females. Research supports a higher prevalence of CHD in males [2] in western cultures, suggesting that the studies are representative. The mean age across all studies was 62.43 years. In western cultures, CHD prevalence is highest for men and women over 55 and 65 years, respectively [2]. These results suggest that the studies are representative of CHD population regarding age and gender.

A range of CHD populations were investigated, including MI (n=13), angina (n=2), acute coronary syndrome (n=1) and planned surgical procedures (n=9). Ethnicity was not reported in 15 studies. However, 5 studies reported a high percentage of white Caucasian participants. Only one study recruited participants from India (study 19).

Studies utilised cross-sectional (n=7) and longitudinal (n=14) designs, with equal proportions of studies recruiting outpatients and inpatients. Studies used correlational analysis (n=10) and regression (n=14) to analyse results. The majority used hierarchical regression (n=8), with a minority of studies using linear regression (n=2), logistic regression (n=3) and structured equation modelling (n=1).

The studies utilised a variety of measures to assess illness perceptions, mood and QoL. The majority of studies either used the Illness Perceptions Questionnaire

(IPQ) [29] (n=6) or the Illness Perceptions Questionnaire Revised (IPQ-R) [25] (n=7). A minority of studies used the Sense of Coherence Questionnaire [39] (n=4), York Angina Beliefs Questionnaire (YABQ) [20] (n=1) and the Health Perceptions Questionnaire [40] (n=1). Eight studies measured physical QoL (PQoL), 7 measured emotional QoL (EQoL) and 2 measured social QoL (SQoL). The majority of studies measuring distress used the Hospital Anxiety and Depression Scale (HADS) [41] (n=10). A minority of studies used the Profile of Mood States (POMS) [42] (n=2), Physical Health Questionnaire (PHQ-9) [43] (n=1) and Beck Depression Inventory (BDI) [44] (n=1).

Study	Authors/	Design	Response Rate	Participants	CHD	Illness Perception	QoL and/or	Key Findings	Quality
No. [Ref	Country				Classification	Measure	Distress		Rating
No.]							Measures		(/19)
1	Aalto, Aro,	L	62.5% of original	N = 3130	34% MI	IPQ-R	QoL:	QoL significantly correlated	17
[45]	Weinman,	(T2 1 year)	sample participated.	Age = 45-74 (64.38,	36% re-		Visual	with all IPQ subscales.	
	Heijmans,		84% retention at T2	SD = 7.04)	vascularisation		Analogue	Identity, consequences and	
	Manderbacka			50% Male	20% use nitrates		Scale	cure/control added	
	& Elovainio			50% Female	weekly			significantly to QoL	
	(2006)			Finnish speaking				( <i>p</i> <0.001).	
	Finland							Illness perceptions predicted	
								changes in QoL even when	
								baseline status was	
								accounted for.	
2	Alsen, Brink,	L	Not reported	N = 204	MI	IPQ	Distress:	Timeline (chronic & cyclic)	18
[46]	Brandstrom,	(T1 in		Age = 64 (SD=10)	76% first MI		HADS	& consequences were	
	Kansson &	hospital, T2		71% Male			QoL:	associated with worse QoL.	
	Persson	4 months)		29% Female			SF36	Personal control was	
	(2010)			Ethnicity not				associated with better	
	Sweden			reported				physical QoL.	
								Treatment control was	
								associated with both	
								physical and emotional QoL.	
3	Arnold,	C-S	63.3% of original	N = 124	First MI	Health	Distress:	Significant weak	17
[47]	Herrick,		sample	Age = 64		Perceptions	POMS	correlations between health	

	Pankratz &			62.1% Male		Questionnaire	QoL:	perception and anxiety &	
	Mueller			37.9% Female			SWB	depression. When	
	(2007)			Ethnicity not				controlling confounding	
	USA			reported				variables, only anxiety	
								significantly correlated.	
4	Bergman,	L	100%	N = 100	First MI	A Swedish	QoL:	Significant positive	16
[48]	Malm,	(T1 before		Age = 36-70		Version of the 13-	SF-12	correlation between SWB	
	Karlsson &	hospital		Median = 57		Item Sense of		health outlook.	
	Berterö	discharge, T2		79% Male		Coherence Scale		High vs Low SOC: High	
	(2008)	2 weeks post,		21% Female		(SOC)		had better mental health,	
	Sweden	T3 4 weeks		Ethnicity not				less angina, greater	
		post)		reported				treatment satisfaction &	
								more physical activity.	
								High vs Medium SOC: Only	
								difference was in lifestyle.	
								Medium vs Low: Only	
								differences were in mental	
								health and lifestyle.	
5	Blair,	L	81.6% completed T1,	N = 62	MI	MHLC	Distress:	Chance significantly	14
[49]	Leakey, Rust,	(T1 6 weeks	T2 & T3	Age, gender and		(Chance,	HADS	positively associated with	
	Shaw,	post MI, T2 3		ethnicity not		Internality,		depression & anxiety at T1,	
	Benison &	months post,		reported		Powerful others)		T2 & T3.	
	Sandler	T3 6 months						Internality significantly	
	(1999)	post)						negatively correlated with	

	UK							depression & anxiety at T2 & T3. No differences on powerful others.	
6 [50]	Cherrington, Moser, Lennie & Kennedy (2004) USA	C-S	94% completed questionnaires 6% excluded.	N = 49 Age = 60.8 (SD=- 13.32) 50% Male 50% Female White	MI treated by angioplasty	IPQ	Distress: STAI. BDI.	Anxiety and depression were moderately correlated with illness perceptions. IPQ scores were predictive of the likelihood of occurrence of complications. No mediating effect of anxiety and depression between illness perceptions.	17
7 [51]	Dickens et al (2008) UK	L (T1 in hospital, T2 6 months, T3 12 months)	269 (91%) completed T2.	N = 313 Age = 57.7 (SD=11.2) 63% Male 37% Female Ethnicity not reported	First MI	IPQ	Distress: HADS	IPQ at baseline was significantly associated with new depression, even after controlling for confounding variables, particularly thoughts that heart disease would last a long time. Participants that thought their CHD could be cured/controlled were half as likely to develop depression.	17

8 [52]	Dunkel, Kendel, Lehmkuhl, Hetzer & Regitz- Zagrosek (2011). Germany	L (T1 3 days before surgery, T2 1 year post)	97% of sample completed T1 63.3% of T1 sample completed T2	N = 1587 Age = 66.81 (SD=9.03) 79.1% Male 19.9% Female 99.2% Caucasian	Planned CABG	IPQ (Causal subscale)	Distress: PHQ-9	Causal attributions of personality and stress/mental load led to worsening of depressive symptoms 1 year post-surgery. Attributions to stress, personality and destiny were associated with higher depressive scores.	18
9 [33]	French, Lewin, Watson & Thompson (2005) UK	L (T1 in hospital. T2 6 months)	83% of those eligible took part.	N = 194 Age = 63.3 (SD=10.6) 75% Male 25% Female Ethnicity not reported	MI 81% First MI	IPQ	Distress: HADS QoL: QLMI	Significant correlations between HRQoL and: anxiety, depression, IPQ timeline, IPQ consequences and causal attributions of stress, state of mind and other people's behaviour. Illness perceptions measured within 24hrs of admission for MI were predictive of HRQoL 6 months later	17
10 [53]	Furze, Lewin, Murberg, Bull &	L (T2 1year)	94% of original sample approached participated.	N = 141 Age = 67.99 (SD=8.96)	Chronic stable angina	YABQ	Distress: HADS Physical	Modest significant correlations at T1 between misconceptions and all	13

	Thompson		85% retention at T2.	61% Male			QoL:	variables except angina	
	(2005)			39% Female			SAQ-PL	frequency.	
	UK			Ethnicity not				Significant differences	
				reported				between high and low	
								misconceivers on anxiety,	
								depression and physical	
								QoL.	
								A change in angina beliefs	
								was the most significant	
								predictor of physical	
								functioning.	
11	Gallagher &	L	77% completed	N = 155	Undergoing	CAS	Distress:	Higher perceptions of	18
[54]	McKinley	(T1 before	questionnaires at T1,	Age = 66.25	CABG		HADS	control predicted lower	
	(2009)	surgery, T2	T2 and T3.	(SD=4.42)				levels of anxiety and	
	Australia	day before		74% Male				depression.	
		discharge, T3		26% Female				Significant contribution of	
		2 weeks post		Ethnicity not				perceived control to explain	
		discharge)		reported.				variance at T1 and T2, but	
								not T3 for anxiety and	
								depression.	
12	Grace et al	C-S	75% of original	N = 661	Acute Coronary	IPQ-R	Distress:	Participants perceived diet,	16
[55]	(2005)		sample completed	Age = 61.22	Syndrome		HADS	genetics & stress as greatest	
	Canada		questionnaires	(SD=11.30)	-			causes of CHD.	
			_	76.2% Male				More depressive symptoms	

13 [32]	Hermele, Olivo, Namerow &	C-S	40.6% of participants approached completed	23.8% Female Ethnicity not reported. N = 56 Age = 66.13 (SD=10.36)	Planned CABG or CABG with aortic valve	IPQ-R	Distress: POMS	were significantly related to endorsement of: stress/ worry, mental attitude, overworked as causal factors. The less patients believed they had a clear understanding of their	15
	Oz (2007) USA		questionnaires	69.6% Male 30.4% Female 91.1% Caucasian	repair or replacement			illness, the most psychological distress they experienced. Significant correlations between illness coherence and total mood disturbance, anxiety & depression.	
14 [56]	Juergens, Seekatz, Moosdorf, Petrie & Rief (2010) Germany	L (T1 before surgery, T2 3 months)	58.3% of original sample (31.3% did not consent, 10.4% were not eligible) 74% retention rate at T2	N = 56 Age = 63.6 (SD=11.6) 79% Male 21% Female Ethnicity not reported	68% planned CABG 29% heart valve surgery 3% combined	IPQ-R	Distress: HADS QoL: SF-12	Negative illness perceptions were associated with higher disability 3 months later. Negative beliefs led to higher levels of depression 3 months later. Illness severity did not mediate the relationship between illness perceptions	16

								Timeline and consequence were the most significant illness perceptions.	
15	Karlsson,	L	52.9% of original	N = 111	Referred for	Modified	Distress:	Participants with an increase	16
[57]	Berglin &	(T1 week	sample	Age = 54	coronary	orientation to life	4 single	in SOC led to significant	
	Larsson	before		89% Male	angiography.	questionnaire.	statements on	decreases in depressed	
	(2000)	angiography,		11% Female	Underwent		a visual	mood, stress & anxiety.	
	Sweden	T2 day		Ethnicity not	CABG		analogue	Participants with a decrease	
		before		reported			scale (1-100)	in SOC had a significant	
		surgery, T3 3						increase in loneliness.	
		months post,						Significant difference	
		T4 6 months,						between these two groups on	
		T5 12						amount of chest pain	
		months)						experienced.	
16	Kattainen,	L	11% drop out rate in	N = 615	70% CABG	The 13-Item	Distress:	Significant correlation	15
[58]	Meriläïnen &	(T1 day	CABG	Age	30% PTCA	Sense of	5 point Likert	between HRQoL & SOC for	
	Sintonen	before	23% drop out rate in	CABG Male: 60.6		Coherence Scale	scale	CABG & PTCA at T1, T2 &	
	(2006)	operation, T2	PTCA	(SD=9.23)		(SOC)	QoL:	ТЗ.	
	Finland	6 months		CABG Female: 66.3			15D	Patients who were very	
		post, T3 12		(SD=8.35)				unhappy had the lowest	
		months post)		PTCA Male: 59.1				SOC before CABG.	
				(SD=9.54)					
				PTCA Female: 63.3					

and health-related outcomes.

				(SD=9.1) 71% Male 29% Female Ethnicity not reported					
17 [59]	Lau-Walker, Cowie & Roughton (2008) UK	L (T1 before hospital discharge, T2 9 months, T3 3 years)	77% retention rate at T2 72% of participants that completed T2 completed T3.	N = 253 Age = 65.3 (SD=10.8) 78.6% Male 21.4% Female Ethnicity not reported.	50% MI 50% Angina	IPQ	QoL: SF36v2	Identity at discharge & 9 months was significantly associated with EQoL 3 years post discharge. Patients that attribute more symptoms to their condition and have less sense of control over their condition are likely to have poor PQoL & EQoL	18
18 [60]	Ratcliffe, Macleod & Sensky (2006) UK	C-S	64.5% of original sample participated	N = 51 Age = 60.5 (SD=13.2) 73% Male 27% Female 86% Caucasian	MI not due to CABG or angiography.	IPQ-R Cardiac Version	Distress: HADS	Beliefs about the cause of illness make a significant contribution to EQoL, but not PQoL. Anxious participants that thought they were at greater risk of a further MI, experienced more symptoms on the IPQ-R identity scale,	16

								attributed more symptoms to	
								cardiac.	
								There were significant	
								differences in all IPQ-R	
								subscales between high and	
								low anxious participants.	
19 [61]	Singh & Dixit (2009) India	C-S	100%	N = 212 Age = 52.86 100% Male	MI 67.92% first MI	IPQ-R	QoL: MacNew heart disease	Significant correlations between illness perceptions and HROoL.	12
				Indian – translation			health related	Timeline (cvclic).	
				to Hindi			quality of life	consequence and coherence	
							questionnaire	were all significant	
								predictors of emotional,	
								physical and social QoL.	
								Identity was a significant	
								predictor of emotional QoL.	
								Coping did not mediate the	
								relationship between illness	
								perceptions and HRQoL.	
20	Stafford,	L	43.4% of original	N = 229	Hospitalised for	IPQ-R	Distress:	Consequences and personal	19
[62]	Berk &	(T1 3 months	sample agreed.	Age = 64.14	either		HADS	control were associated with	
	Jackson	post hospital	84% of those	(SD=10.37)	angioplasty, MI		QoL:	greater depressive symptoms	
	(2009)	discharge, T2	completed T1 (37%	81% Male	or CABG		SF36		
	Australia	9 months)	of original sample)	19% Female					

				Ethnicity not					
				reported					
21	Underhill,	C-S	58% of original	N = 149	Out of hospital	13-Item Sense of	QoL:	Adding SOC contributed an	16
[63]	Motzer &		sample approached	Age = 63.15	MI survivors	Coherence	15-item	additional 15% to the	
	Steward			(SD=11.07)	with underlying	Questionnaire	Flannagan	explained variance	
	(1996)			73% Male	CHD	(SOC)	Quality of	( <i>p</i> <0.001).	
	USA			27% Female			Life Scale	QoL was most correlated to	
				95% Caucasian				SOC than any other variable	
								studied	

*Study Design:* C-S: Cross-sectional; L: Longitudinal; T1= Time point 1, T2= Time point 2, T3=Time point 3, T4=Time point 4, T5=Time point 5.

*Classification:* CABG: Coronary Artery Bypass Graft; CHD; Coronary Heart Disease; HRQoL: Health-related quality of life; MI: Myocardial Infarction; EQoL; Emotional quality of life; PQoL; Physical quality of life; PTCA: Percutaneous Transluminal Coronary Angioplasty QoL: Quality of life.

*Measures:* BDI; Beck Depression Inventory; CAS; Control Attitudes Scale; HADS; Hospital Anxiety and Depression Scale; MCHLC; the Multi-Dimensional Health Locus of Control Scale; POMS; Profile of Mood States; PHQ-9; Patient Health Questionnaire; QLMI; Quality of Life after MI Questionnaire; SAQ-PL; Seattle Angina Questionnaire – Physical Limitation Scale; SF12; Short-Form-12; SF36; Short-Form-36; SF36v2: Short-Form-36 Version 2; STAI; State-Trait Anxiety Inventory; SWB; Spiritual Wellbeing Scale; YABG; York Angina Beliefs Questionnaire.

#### Illness Perceptions, Mood and QoL

Studies 3, 6, 10 and 14 examined illness perceptions as a whole construct. Negative illness perceptions were significantly correlated to and predicted worsened PQoL. Study 3 also found a significant correlation with spiritual wellbeing (existential, religious and spiritual). It was consistently reported that negative illness perceptions correlated with elevated anxiety and depression (studies 3, 6, 10). However, only study 14 reported illness perceptions to be a significant predictor of changes in depression.

## Identity, Mood and QoL

Four studies excluded the identity subscale from analysis. Study 9 excluded identity to reduce questionnaire burden and study 13 reported that previous research had suggested that identifying with symptoms was not a good indicator of illness identity. Studies 2 and 12 did not give a reason for the exclusion.

Mixed findings were observed in the five studies that examined the relationship between identity and QoL (studies 1, 14, 17, 19, 20). Studies 1 and 19 found significant correlations between identity, EQoL and PQoL. However, study 14 found no significant relationship between these variables. Only study 19 investigated SQoL, reporting no significant relationship. However, there was a consistent finding that identity significantly predicted changes in PQoL and EQoL at baseline assessment and follow-up. Only study 19 found identity to not predict PQoL. However, this study had the lowest quality rating (12/19).

Identity was consistently not significantly related to depression (studies 7, 14, 20). Only study 18 investigated the relationship between identity and anxiety and found a significant positive correlation and significant differences in identity scores

for anxious and non-anxious patients. Study 18 had a high quality score, demonstrating clinical validity.

#### Consequences, Mood and QoL

Perceived consequences was significantly correlated with poorer PQoL (studies 2, 9, 14, 17, 19) and EQoL (studies 2, 9, 17, 19). However, only study 19 found consequences to significantly predict changes in PQoL and EQoL. This study had a lower quality score compared to the studies that found no significance (studies 2, 9, 17, 20).

Studies 9 and 19 found a significant relationship between consequences and SQoL. Although these studies differ greatly in their quality rating (17/19 & 12/19), they both recruited inpatients that had experienced an MI.

The majority of studies reported increased negative consequences were significantly correlated with elevated depression (studies 1, 6, 12). Although study 13 found no significant relationship, it had a lower quality rating compared to the other studies. Only study 20 used regression analysis and found consequences to significantly predict changes in depression. Study 18 found a significant difference in consequence scores between anxious and non-anxious participants, whereas study 13 found no significant correlation. The quality ratings were similar for both studies (16/19 &15/19).

#### Illness Coherence, Mood and QoL

Studies 2 and 19 found a significant positive correlation between coherence and PQoL. Study 14 found no significant association. Although there is little difference in quality ratings, studies 2 and 19 recruited inpatients after an unexpected MI, whereas study 14 recruited patients before a planned operation.

Studies 4 and 19 found a significant positive correlation between coherence and EQoL, whereas studies 2 and 14 found no significant association. Studies 2 and 14 had higher quality ratings (18/19 & 16/19) compared to studies 4 and 19 (16/19 & 12/19). Only study 19 examined the relationship between coherence and SQoL and found a significant positive relationship. However, study 19 had the lowest quality rating (12/19).

Lower illness coherence was consistently significantly correlated with elevated depression (studies 4, 13, 14, 16). Studies 15 and 18 found lower coherence was also significantly correlated with elevated anxiety, whereas study 13 found no significance. However, study 15 also found that when coherence worsened, there was no increase in depression and anxiety levels, raising questions regarding causality and highlighting that other factors could have affected depression and anxiety levels. No studies investigated this using regression analysis.

#### Control, Mood and QoL

Studies 1 and 17 found a significant correlation between perceived low CHD control and worsened PQoL and EQoL. Although study 9 found no relationship between control and QoL, the quality ratings were similar for all three studies (17/19, 18/19 & 17/19).

Study 2 reported that decreased personal control was significantly correlated with worsened PQoL, whereas study 14 did not. However, personal control consistently predicted changes in PQoL (studies 19, 20). The three studies that found a significant relationship had recruited patients that had experienced an unexpected medical event, whereas study 14 had recruited patients undergoing a planned operation. Studies 2 and 14 found no significant relationship between personal control and EQoL. However, studies 19 and 20 reported a significant

relationship. Although study 19 had the lowest quality rating, study 20 scored the highest possible rating (19/19).

Decreased treatment control was consistently significantly correlated with poorer PQoL and EQoL (studies 2, 19). Study 20 found treatment control to significantly predict changes in PQoL and EQoL, whereas study 19 did not.

Perceptions of CHD control consistently predicted changes in anxiety and depression levels (studies 5, 7, 11). Study 5 reported that patients who viewed their health as due to luck, fate or chance showed the strongest relationship with depression and anxiety.

Lower perceived personal control was consistently significantly correlated with elevated depression (studies 12, 13, 14, 20) and anxiety (studies 12, 13, 20). Study 18 found significant differences between anxious and non-anxious patients for both personal and treatment control, whereas study 13 found no significant relationship with anxiety. The quality ratings for these two studies were similar (16/19 & 15/19).

#### Timeline, Mood and QoL

Negative perceived CHD timeline was significantly correlated with worsened QoL at baseline (studies 1, 9) and follow-up (studies 17, 20). Timeline was consistently found to not relate to, nor predict EQoL (studies 9, 17, 20).

It was consistently found that perceived increased CHD chronicity and variability was significantly correlated with worsened QoL (studies 2, 14, 19). Studies 2 and 14 found this relationship to be weaker in EQoL compared to PQoL, whereas study 19 reported equal strength. Only study 19 examined the predictors of
QoL using regression analysis and found cyclical to be a significant predictor of PQoL and SQoL, but not EQoL. However, study 19 had the weakest quality rating.

Study 7 reported that negative perceived CHD timeline was significantly correlated with elevated depression, whereas study 20 did not. Study 7 recruited inpatients experiencing an initial MI, whereas study 20 recruited outpatients with a diagnosis of CHD.

An increased perception of CHD chronicity was significantly correlated to elevated depression (studies 12, 14) and anxiety (study 18). However, study 13 found both relationships to be non-significant. Study 14 found that increased perception of CHD variability was significantly correlated to elevated depression, whereas study 12 found no significance. Study 12 recruited ACS inpatients, whereas study 14 followed inpatients through to discharge with planned cardiac surgery.

## Perceived Cause, Mood and QoL

Six studies excluded the causal attribution subscale. Four studies did not give a reason for this (studies 2, 7, 18, 20), but the remaining two stated that their sample size was smaller than the 81 recommended to analyse the subscale (studies 13, 14).

Various causes were related to QoL outcome, including epidemiological (study 1), stress (studies 1, 9, 19), internal (studies 1, 3, 17) and external causes (studies 9, 17). Stress was the most consistent cause related to QoL, with studies 1, 3 and 17 reporting a significant relationship with EQoL and PQoL. Although study 17 found internal causes to significantly predict changes in EQoL, the majority of studies did not find any perceived causes to predict changes in QoL (studies 1, 9, 19).

Studies 8 and 12 found that stress and personality were significantly related to depression. Personality was defined as ambitious, impatient and short-tempered in study 8, whereas it was not specified in study 12. No studies examined the relationship between patients' perceived causes of CHD and anxiety.

#### Discussion

#### Summary and Conclusions

This study aimed to undertake a systematic literature review examining the relationship between illness perceptions, QoL and mood in a heterogeneous sample of CHD patients. There was a consistent finding across CHD populations of a significant relationship between increased severity of illness perceptions, poorer QoL and elevated depression and anxiety. The results of this study suggest that illness perceptions are important determinants of outcome throughout CHD disease course and progression. This finding adds to existing literature [24] by suggesting that the relationship between illness perceptions and outcome is not only universal across illnesses, but can also be found throughout a specific disease course and progression.

The present review found that attributing more symptoms to CHD, perceiving greater negative consequences and perceiving CHD to be more chronic and variable had the strongest relationship with poorer QoL across CHD populations. Furthermore, poorer illness understanding, perceiving greater negative consequences and low personal and treatment control had the strongest relationship with elevated anxiety and depression across CHD populations.

Illness perceptions impact on outcomes, such as QoL and mood, by influencing patients' decisions to undergo positive health-behaviour changes, such as improvement in diet and increased exercise. Illness perceptions can influence decision-making abilities regarding medication adherence, treatment decisions and attendance at cardiac rehabilitation programmes [64, 65]. An increased understanding of CHD can act as a mediator between adverse experiences and psychological wellbeing [66, 67]. Patients with more positive illness perceptions are able to conceptualise the nature of CHD and believe in their ability to choose appropriate coping strategies [40]. Illness perceptions can also influence motivation and self-efficacy to adopt positive health-behaviours. Lewin (1997) [68] proposed that negative illness beliefs, such as *"angina is a mini heart attack"* and *"if you get angina you should rest as much as possible"*, lead to a reduction in activity, due to fear of further heart damage. This reduction can result in physical de-conditioning and lead to poorer outcomes (see Figure 3).



Figure 3. The relationship between illness perceptions and outcome (Lewin, 1997) [68].

Although the present review found a relationship between illness perceptions and outcome, the self-regulatory model [23] is not unique in highlighting this relationship. For example, perceived consequences is similar to the 'severity of illness' construct described in the health beliefs model [69]. Furthermore, the link between perceived levels of control, self-efficacy and health-related behaviours is one component of the theory of planned behaviour [70]. This theory posits that perceived behavioural control and motivation can influence behavioural change and achievement through choice, preparation and effort during activities [71]. The results of this study, therefore, provide support that illness perceptions are related to outcomes across CHD populations, but does not selectively support one particular model.

## Differences throughout Disease Progression.

Although the present study found illness perceptions to influence outcome throughout CHD progression, differences in the strength of specific illness perceptions dependent on disease stage were also observed.

Lower perceived control over CHD symptoms and poorer understanding of the disease was significantly related to poorer QoL in patients that had experienced an unexpected medical event, such as an MI. The present review also found that perceiving CHD to be more chronic and variable was significantly related to elevated anxiety and depression in patients that had experienced an unexpected MI. These relationships were not found to be significant in studies that had recruited outpatients.

The results of this study suggest that specific illness perceptions may have greater consequences on outcomes dependent on whether patients had recently experienced an unexpected medical event. Any unexpected medical event can be disruptive and traumatic, requiring patients to quickly adapt to the emotional, behavioural and social demands involved in treatment and recovery [72]. If, during this time, patients lack an understanding of their illness, confidence in their ability to

control symptoms, and view CHD as chronic, they may be less likely to engage in immediate health-behaviour changes, such as improved diet, increased exercise and attendance at cardiac-rehabilitation, which are essential for recovery [64]. It is, therefore, necessary to provide sufficient information regarding management of symptoms and disease course for patients that have experienced a sudden medical event. Patients should be encouraged to attend cardiac-rehabilitation, which can increase perceived control and confidence in ability to change behaviours [73]. Interventions aimed at altering maladaptive beliefs during cardiac rehabilitation after MI can result in improved QoL [74] and psychological wellbeing [73].

#### Limitations

The current review is subject to several limitations. Although the quality control checklist was combined from two valid checklists, the combination has not been tested for its psychometric properties. However, there was strong inter-rater reliability, supporting the checklist validity. It should also be noted that the quality checklist highlighted that the majority of studies did not state whether subjects were representative of the entire population from which they were recruited, making it difficult to fully generalise the findings. The review also only included peer-reviewed studies. This could have resulted in publication bias.

There were a variety of self-report questionnaires used to measure illness perceptions, QoL and mood. This could have created difficulty as different measures may define constructs differently. For example, the relationship between mood, consequences and timeline was reported to be significant when using the HADS [41], but not significant using the POMS [42].

The present review included a heterogeneous CHD sample, which led to a large variation in CHD disease course. For example some studies recruited patients that had recently experienced their first MI, whereas other studies recruited outpatients that had a diagnosis of chronic angina. There are potential confounding effects of acute illnesses and the results of the review have found differences in the significance of illness perceptions dependent on disease course.

A further limitation is the possibility of sample bias. The recruitment process in many studies enabled the possibility of a self-selecting sample bias, as patients with higher levels of distress or critical ill states may have refused or been unable to participate.

#### Strengths

The present paper reviewed all studies that met inclusion criteria. There were no studies identified that were not available to review, allowing a thorough investigation of the research questions.

Overall, the studies had good quality ratings, with thorough descriptions of aims, research questions, results and discussion. Many also acknowledged their limitations. There were also generally large sample sizes which enabled sufficient power for statistical analysis. Many studies used multiple hierarchical regressions, which enabled a degree of control over potential confounding demographic factors, such as age (study 11), gender (6) and disability (14).

## Clinical Implications

This review found illness perceptions to significantly influence mood and QoL across a range of CHD diagnoses. The results of the review suggest that screening

and identifying illness perceptions is important and relevant for all CHD patients, and should not be dependent on disease state. Illness perceptions could be assessed by a short form questionnaire and/or clinical interview by any healthcare professional involved in patient care, which could inform care planning and support.

Interventions for this patient population should focus on identifying and modifying maladaptive beliefs during rehabilitation and recovery, as recommended by Sign (2002) [75]. A review concluded that cognitive-behavioural interventions were the most effective in altering maladaptive illness perceptions in CHD patients [36]. Interventions, such as cardiac rehabilitation programmes, should be regularly offered to patients throughout CHD progression. In the present review, a range of illness perceptions were related to mood and QoL. Therefore, cardiac rehabilitation should address any identified maladaptive illness perceptions, as recommended by the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) [76].

The present review found specific illness perceptions that were significantly related to mood and QoL in patients that had experienced an unexpected medical event, such as MI. Healthcare professionals should be aware that illness coherence, perceived control and perceptions of disease timeline are important determinants of mood and QoL in patients, and should provide sufficient information regarding management of symptoms and CHD disease course after an MI. The BACPR [76] reported that increasing education of this patient population can restore confidence and increase sense of perceived personal control. However, it seems that rehabilitation should not just be about increasing education, but also targeting specific illness perceptions and facilitating change in these beliefs.

#### Future Directions

It was beyond the scope of this review to investigate systemic issues, such as the impact of family members' illness perceptions on outcomes. However, this is an important area to investigate in the future, as a mismatch between patients and family members' illness perceptions and subsequent coping strategies can impact on recovery, particularly through health-behaviour changes [78]. Future research could provide further support for the BACPR [76] recommendations that cardiac rehabilitation programmes adopt a multidisciplinary bio-psychosocial approach that is available for individuals and family members.

The review solely focused on QoL and mood as outcomes for CHD patients. Further reviews could investigate differing outcomes to assess whether illness perceptions have stronger relationships with these, for example rehospitalisation, mortality and objective health outcomes. An investigation into the cost-effectiveness of interventions to alter illness perceptions may also be useful. Although the review was designed to include only quantitative research, there were no qualitative research papers available within searched databases that investigated the specific research questions. It may be useful to investigate the breadth of concerns CHD patients have regarding their illness perceptions, QoL and experiences of mood using a qualitative design. Work has begun to use qualitative research to investigate this regarding uptake of cardiac rehabilitation [79], however, more research is needed.

The review found large variability in the measures used to assess illness perceptions, QoL and mood. Constructs need to be clearly and consistently defined to enable comparisons between studies. The HADS could be used across studies to measure mood, as it has already been widely used in cardiac patients, and has been recommended as a screening tool in CHD patients by the NSF Clinical Guidelines

[77]. A QoL measure should at least include physical and emotional QoL as separate constructs, such as the SF12 or SF36.

## Conclusions

This systematic literature review aimed to examine the relationship between illness perceptions, QoL and mood in a heterogeneous CHD population. Illness perceptions were found to predict QoL and mood across CHD diagnoses. Specific illness perceptions (*control, coherence and timeline*) were found to be important for patients that had experienced an unexpected medical event, such as MI. The results of this study provide support that illness perceptions are related to outcomes across CHD populations, but the results do not selectively support one particular model. Recommendations are consistent with the BACPR [76] guidelines on cardiac rehabilitation. Further research should focus on the systemic impact of illness perceptions.

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Part Two:

**Empirical Research** 

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# Part Two. Study One:

# Living with Chronic Refractory Angina: Experiences of Enhanced External Counterpulsation Treatment

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This paper is written in the format ready for submission to the Journal of Cardiovascular Nursing. Please see Appendix 3.2 for the Author Guidelines. (Word count = 8497)

#### Abstract

**Background:** Previous qualitative research investigating patients' experiences of living with coronary heart disease (CHD) and undergoing various treatments has enabled increased understanding of patients' experiences and perceptions of their illness. However, there has been no qualitative research into refractory angina patients' experiences of enhanced external counterpulsation treatment (EECP) or changes in their lives before and after the treatment.

**Objectives:** To explore refractory angina patients' experiences of undergoing EECP, and to gain insight into their lives before and after the treatment.

**Methods:** Ten male refractory angina participants completed a semi-structured interview about their experiences of EECP and their lives before and after the treatment. Interviews were transcribed and analysed using interpretive phenomenological analysis (IPA).

**Results:** Five themes emerged; the impact of angina; fear experienced by the individual and family as a limiting factor; attitudes towards EECP treatment; response from others; and the impact of EECP.

**Conclusions:** The study adds to existing literature by proposing that the process of undergoing EECP treatment not only leads to physiological improvement, but also effects psychological pathways, through providing hope, establishing a therapeutic relationship and increasing confidence and self-efficacy to confront positive and challenging health-behaviour changes.

**Keywords:** chronic refractory angina; enhanced external counterpulsation treatment; experiences

Angina pectoris is the most common indicator of coronary heart disease (CHD), with symptoms including pain across the chest, shoulders, back, arms and jaw. This pain is temporary and can be relieved following rest or medication.<sup>1</sup> Angina is caused by a build up of fatty plaque in the arteries, leading to a restriction of blood flow around the heart, and can be triggered during increased metabolic demand, such as exercise, emotional stress and cold weather.<sup>1</sup> Although the prevalence of CHD is increasing annually,<sup>2</sup> mortality rates are decreasing<sup>3</sup> due to advancements in treatment and medication. Therefore, more people are living with angina symptoms, with approximately 95,000 new cases per year.<sup>2</sup> Furthermore, the prevalence of angina increases with age, and as life expectancy is increasing, the frequency of angina will continue to rise.<sup>4</sup> This has led to an increase in societal burden and cost to the NHS.<sup>5</sup> Allender, Scarborough, Peto and Rayner (2008)<sup>6</sup> estimated that the cost of CHD to the UK in 2006 was approximately £9 billion. It is, therefore, important to continue to develop strategies to improve the treatment and management of angina symptoms.

The two main surgical treatments for angina are coronary artery bypass grafts (CABG) and percutaneous transluminal coronary angioplasty (PTCA). CABG is an invasive procedure involving open heart surgery, where new routes are created around the narrowed arteries using veins taken from other areas of the body. PTCA is also an invasive treatment that involves inflating a small balloon on the tip of a catheter in narrow sections of the artery. A small tube of stainless steel mesh, called a stent, is left in situ to keep the artery open. Both interventions aim to increase blood flow to and from the heart.

Although there are many benefits from these treatments, there are risks involved due to the invasive nature of the procedures. Increased life expectancy and prevalence of CHD has led to many patients experiencing multiple unsuccessful

surgical treatments.<sup>7</sup> Mukherjee, Bhatt and Roe (1999)<sup>8</sup> estimated that there are over 100,000 patients in this situation every year. Many CHD patients can reach a stage where it is medically unadvisable to undergo further surgical procedures and have difficulty controlling angina symptoms through medication management. This condition is known as chronic refractory angina.<sup>9</sup> Approximately 10-15% of patients with angina meet the criteria for this condition.<sup>9</sup> Refractory angina can lead to reduced quality of life (QoL) and increased disability due to recurrent pain attacks, lack of energy and poor sleep. Furthermore, patients can develop symptoms of anxiety and depression, which can lead to reduced interest in previously enjoyed activities and increased dependence on relatives and health professionals.<sup>10, 11</sup>

There have been a variety of treatments developed for refractory angina patients that are less invasive and have fewer contraindications,<sup>9, 12</sup> such as spinal cord stimulation and enhanced external counterpulsation treatment (EECP). EECP involves wrapping paired compressible cuffs around the calves, lower and upper thighs, which are attached to an EEG machine and subsequently inflate and deflate in synchrony with the cardiac cycle. Both the inflation and deflation of the cuffs reduces cardiac load on the heart. The inflation of the cuffs during diastole<sup>viii</sup> increases the volume of blood pumped back to the heart, and deflation during systole<sup>ix</sup> decreases the resistance and cardiac workload. EECP occurs over 35 sessions, each lasting one hour, usually over a seven week period.<sup>13</sup>

Research has predominantly focused on the medical benefits of EECP, such as measurable reductions in frequency and intensity of angina pain.<sup>14</sup> However, research has demonstrated that the level of physical recovery is not directly linked to

<sup>&</sup>lt;sup>viii</sup> The period of time when the heart refills with blood after systole

<sup>&</sup>lt;sup>ix</sup> Contraction of the heart

degree of illness severity<sup>15</sup> and that psychosocial factors are also important determinants of CHD outcome. Quantitative research studies have demonstrated the importance of psychosocial as well as physical determinants in CHD outcome.<sup>16</sup> For example, Lett et al (2004)<sup>17</sup> and Arnold (2009)<sup>18</sup> found positive correlations between mood and frequency and severity of self-report angina, independent of CHD severity. Furthermore, Petrie, Weinman, Sharpe and Buckley (1996)<sup>19</sup> found illness perceptions after myocardial infarction (MI)<sup>x</sup> to predict future disability and return to work. It is, therefore, important to understand patients' psychosocial experiences of CHD, in addition to physical determinants of recovery.

There is limited quantitative research into psychosocial outcomes after EECP treatment. In a pilot study, Fricchione et al (1995)<sup>20</sup> found an improvement in overall wellbeing, whilst Springer, Fife and Lawson (2001)<sup>21</sup> found an improvement in psychological distress, depression and anxiety. Both studies found these improvements unrelated to physical recovery, suggesting an independent psychosocial benefit of EECP. Further research using refractory angina patients found this improvement to be sustained for up to two years<sup>22</sup> and five years.<sup>23</sup>

Whilst quantitative research is important, it does not seek to understand patients' experiences of illness. Qualitative research can increase understanding of these experiences and how they impact on health, wellbeing and outcome. The use of less structured research methods enables development of an understanding of patients' experiences and perceptions of their illness. Qualitative research, using methods such as interpretative phenomenological analysis (IPA)<sup>24</sup> has been used in health settings to investigate patients' experiences of CHD treatments, such as CABG<sup>25, 26</sup> and PTCA.<sup>27</sup> These studies have predominantly focused on hospital

<sup>&</sup>lt;sup>x</sup> A heart attack

patient-care experiences, and few studies have examined the effects of treatment on health and wellbeing. To date, there is no qualitative research in relation to EECP treatment. It is important to gain an insight into patients' experiences of this treatment and perceptions of the impact this treatment has on their lives.

Qualitative research has also been used in health settings to investigate patients' experiences of living with chronic illnesses, such as back pain<sup>28</sup> and multiple sclerosis.<sup>29</sup> Only one study has explored patients' experiences of living with angina symptoms.<sup>30</sup> It was reported that angina patients developed a negative spiral of reduced activity and functional ability, which seemed to be partly caused by fear of the consequences of undertaking certain activities, such as causing further heart damage. The relationship between beliefs regarding refractory angina, coping strategies and behaviour change has been demonstrated in the self-regulatory model<sup>31</sup> (Figure 1), which posits that patients attempt to make sense of an illness threat by developing parallel cognitive and emotional representations.



Figure 1. The self-regulatory model<sup>31</sup>

A review of the relationship between illness perceptions, mood and QoL in CHD patients (R. Foxwell, unpublished data, 2012) provided support for this model. It seemed that in the long-term it was important to develop coping strategies and evaluate the effectiveness of these strategies based on psychosocial outcomes, such as mood and QoL. There is limited qualitative research investigating experiences of living with chronic refractory angina and illness perceptions, and no research in relation to EECP treatment. It is important to understand patients' perceptions of their illness and their experiences of living with refractory angina to improve ways that health professionals can help to increase QoL and recovery.

Therefore, the aims of this study were to explore refractory angina patients' experiences of undergoing EECP, and to gain insight into their lives before and after the treatment.

#### Method

#### Design

Qualitative methodology, specifically interpretative phenomenological analysis (IPA), was employed for the analysis and interpretation of semi-structured interview data. Please see epistemological statement (Appendix 1.2).

#### **Participants**

The study used a convenience sample of participants from the Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) Cardiology Department's EECP service. All patients completing the full course of EECP treatment between January and December 2011 were approached to participate. All participants must have had the ability to provide informed consent. As EECP is a treatment for refractory angina patients, all met the inclusion criteria of having a diagnosis of refractory angina. A consecutive series of eligible patients were approached by the EECP nurses as they neared the end of their treatment. In total, twelve participants were approached and ten agreed to take part in the study. One patient declined and the other was willing but subsequently could not find an appropriate time to be interviewed.

## Measures

Semi-structured interviews were undertaken with ten participants. The interview schedule allowed for open-ended questions to elicit information around three main issues (Appendix 5.1 for interview schedule). Firstly, patient's experiences of the EECP treatment, which was informed by previous research investigating patient's experiences of cardiac treatment.<sup>26</sup> The second two areas (patient's perceptions and experiences of living with refractory angina both before and after the EECP treatment) were based on constructs of the self-regulatory model.<sup>31</sup> The interview schedule was piloted on two people of a similar age to the average patient age in the service (67.7 years). The aim of the pilot was to ensure the suitability of the semi-structured interview questions; ensuring that the questions were open-ended enough to enable participants to talk about their experiences and to ensure that the questions were understandable. The pilot found that the questions were suitable for the main research study. Interviews lasted between 35 and 75 minutes. All interviews were conducted, tape-recorded and transcribed by the researcher.

#### Procedure

Ethical approval was obtained from County Durham and Tees Valley Research Ethics Committee (Appendix 2.1). Research and Development (R&D) approval was obtained from Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) (Appendix 2.2). Patients completing EECP treatment between January and December 2011 were approached by the EECP nurses as they neared the end of their treatment. The nurses described the study and provided information sheets (Appendix 5.2). If the patient was interested in participating, and verbally agreed with the clinic nurses, they were contacted by the researcher via telephone to further discuss the study and to arrange a meeting at a time and place that was convenient for them. During this discussion with the researcher it was made clear that this meeting would involve the completion of written consent and undertaking of an interview. At the point of meeting, participants were given the opportunity to discuss the study further before completing the consent form (Appendix 5.3). Participants were informed that their interviews would be made anonymous. At this stage all participants agreed to continue with the study. At the end of the interview, participants were given the opportunity to be contacted by the researcher for feedback on the main findings via post or email.

#### Analysis Procedure

Ten audio-taped interviews were transcribed verbatim and allocated pseudonyms to anonymise. Transcriptions were then printed out with line numbers and read over several times by the researcher to increase familiarity with content. The researcher then analysed the data following guidelines outlined in Smith, Flowers and Larkin (2009).<sup>24</sup>

*Stage one*. The transcripts were re-read and anything of significance and interest noted in the left hand margin. At this stage comments were separated into descriptive, linguistic and conceptual comments. Descriptive comments focused on the content of the participants' comments, linguistic comments explored the specific use of language used and conceptual comments were at a further interrogative level. At this stage three other independent researchers read extracts of interview transcripts and made initial comments according to descriptive, linguistic and conceptual domains. Discussion between researchers took place to facilitate and formulate a consensus of main themes emerging from transcripts.

*Stage two*. Transcripts were re-read and emerging themes were documented on the transcripts. Emerging themes were discussed with three other independent researchers.

*Stage three*. The researcher then looked for patterns in these themes and across different participant's themes. Quotes from the transcripts were extracted to support identified themes.

*Stage four*. The most relevant themes from across all 10 participants were synthesised and re-organised to form super-ordinate and subordinate themes. Discussions with a co-analyst occurred throughout the process.

#### Results

#### **Descriptive Statistics**

Participants' age ranged from 50 to 80 years, with a mean of 64.2 (SD = 10.11). All participants were male. Out of the ten interviews that were undertaken, eight of the participants had completed the EECP treatment once (participants 1, 2, 3, 4, 5, 6, 7, 10). One participant had completed the treatment twice (participant 9) and one had

completed it four times (participant 8). Five participants were interviewed alone (participants 3, 4, 5, 7, 10), whereas the remaining five were interviewed with a family member present (participants 1, 2, 6, 8, 9).

One participant did not return the demographic information sheet. Therefore information about 9 of the interviewed participants is presented. Participants were asked whether they have visited their GP more, less or the same amount since the EECP treatment. Four participants visited their GP less than before the treatment and four visited the same amount. There was only one participant that visited their GP more frequently. Participants were also asked whether they take more, less or the same amount of medication since the EECP treatment. Five participants took less medication and four took the same amount since the treatment.

## Themes

Results of the analysis revealed 5 super-ordinate themes and 10 subordinate themes of patients' experiences of refractory angina and the EECP treatment. A summary of the themes is presented in Table 1.

Super-ordinate Themes	Subordinate Themes
Impact of angina	Different ways of coping.
	Identity
Fear	"You just associate heart attacks, angina,
	and people die"
	Restricted
Attitudes towards EECP	"Last chance saloon"
	Special and novel experience
Response from others	Supported; "You're not on your own"
	Hidden disease
Impact of EECP	"I feel now that I can do it"
	Change of focus

Table 1. Super-ordinate themes with corresponding sub-ordinate themes.

#### Super-ordinate theme one: Impact of angina

## Different ways of Coping

The majority of participants interviewed used a variety of strategies that enabled them to cope with having refractory angina.

All participants commented on how important it was to them just to keep going, and persevering with living with angina symptoms.

"This is the way, you have to keep going going going" (participant 9; 392)

"Some things in life where you can't stop, no matter what happens" (participant 4; 346)

Some participants attempted to distance themselves from the angina pain by perceiving the angina as having a separate, alive identity of its own (personification).

"It's got a life of its own, it flicks on and off" (participant 5; 214)

"...and to me it's like, don't forget me, I'm still here, sort of thing" (participant 4; 187-188)

This strategy went even further with some participants, by viewing the angina pain as an 'enemy' and having to fight a battle against the pain.

"I try to give fight, to make a happy self" (participant 9; 352-353)

"As long as I live to fight, that's good enough" (participant 10; 218-219)

The majority of participants commented that they used humour as a way of coping with their angina.

"Well, we can make a joke out of it, so to laugh over it, and I think it releases everybody's feelings being able to talk like that" (participant 2; 490-491)

"Found something to laugh about... yeah, not take it too seriously. I mean, it's a serious thing, I realise that, but we, we made the best of it" (participant 3; 505-506)

When directly questioned about the emotional impact of angina, many participants commented that they did not experience any difficult feelings.

"Well, I never think about this, I never think about whether I have to have the treatment again" (participant 9; 374-375)

"I'm not that sort of person, so I've never been depressed about it, I'm, I'm a realist" (participant 5; 384-385)

Other participants focused on their difficulties mainly being around practical issues.

"I can't go abroad because insurance is more than the flight" (participant 4;

273-274)

"Suppose I went out there and started trying to dig this garden..." (participant 2; 435-436) However, two participants did try and verbalise the emotional impact of angina and the treatment and found this difficult.

"I've been told I've got the breaking strain of a Kitkat when it comes to... and um... and I find it hard to explain, but it's just...within myself I feel.... better... than... I just... I don't know... the correct word for it..." (participant 4; 363-

364)

"That was definitely... that attitude had been swept aside, no question about that. There's no question about that. And you can't put a price on that...you can't put it into words...this is what I'm trying to do now" (participant 7; 735-

736)

# Identity

Many participants talked about what they were like before they developed heart disease and angina. This was normally a portrayal of a fit and healthy person.

"I've always been a fit person; this is what's more uh...kind of anxiety with me. If I have an anxiety problem on one level with it, is I've always been fit. Superfit. And I've kept full time employment with it as well" (participant 6; 844-846)

Most participants described holding stereotypical male occupations, such as mechanic, builder and fireman, when they were fit and healthy. Participants acknowledged the difficulties of having to give up these roles since developing angina. "I mean, I'm disappointed that uh, I lost me job through it all. A long time ago I were a fireman. I loved me job" (participant 8; 382-383)

"It's the only thing I've been actually good at is working, because I enjoyed it" (participant 4; 616)

Participants 6 and 7 seemed to be indicating that the process of developing angina and not working felt de-masculinising.

"I'm just a monkey wrench now" (participant 6, 968)

"So therefore, you tend to become a little bit of a couch monkey" (Participant

7, 85-86)

## Super-ordinate theme two: Fear

Participants described that prior to the EECP treatment they experienced a lot of fear around angina pain.

## "You just associate heart attacks, angina, and people die"

Many participants commented on the significance of experiencing pain in their heart instead of pain in another part of their body.

"...and it's not going to kill me, it's just pain. And if you felt it in your leg you wouldn't think twice about it. The fact that it's in your heart, you have to get used to the fact that each time you get it, it's not going to kill you"

(participant 5; 109-112)

"cause you just associate heart attacks, angina, and people die, you know. Um... you don't associate with people learning to live with it, um... you just associate people end up dying from it, you know. Uh... as I said, if it were your foot or your ankle or your knee or whatever, yeah painful, problematic and all the rest of it, but you don't think it's gonna kill you" (participant 5;

249-252)

Participants reported that even after being told by medical professionals that angina pain was not dangerous, when they got the pain, they immediately thought that it would develop into a heart attack and they would die.

"... and you're sitting, waiting, and no matter what anybody tells you, like angina won't kill you, I could have a doctor, consultant, all the nurses, all the machines round me, but when you get angina, nothing, nothing stops you from... thinking..." (participant 4; 170-173)

## Restricted

Many participants commented that their lives had become very restricted since developing refractory angina and that there was a barrier between themselves and the outside world.

"But there is a link between angina and depression because you really do feel as though your life is, has become a box. There's no way of getting out of that box, because to get out of it is too much, it's gonna cause pain" (participant 7; 625-629)

"If you can imagine, like a bud that's closed tight, like I'm in a cocoon, I can't do anything"(participant 8; 346-347)
Participants described that the angina pain was not the cause of this restriction and that it was more the fear of getting the pain which they thought could lead to further heart damage or death.

"I can't go somewhere if I'm thinking 'I can't go outside I'll have a heart attack' cause of the suffering pain you see. And it's scary" (participant 9; 286-288)

"Well, when it restricts you, whatever you're doing, you know, if you try to push yourself, how far could you push yourself before you did any damage? You know, there's always that in your mind" (participant 8; 92-94)

Participants commented that refractory angina not only had an impact on themselves, but also on their families. Participants said that their family were worried about them.

> "They worry about me. I know they worry about me, but I don't want them to" (participant 3; 772-773)

This worry that was described by participants led to overprotectiveness by family members and further restrictions and barriers on the participants' life. Participants described this as frustrating.

"I don't need other people to do things for you. It's very annoying for you when other people are trying to mollycoddle you" (participant 5; 427-428)

"they want to wrap you up in cotton wool" (participant 5; 415-416)

### Super-ordinate theme three: Attitudes towards EECP

Participants talked at length about the time they spent with the nurses during the EECP treatment and what it meant to them.

### Last chance saloon

Many participants commented on the number of different treatments that were now not available to them.

"He suggested trying...as other options seemed to have expired, they didn't feel they could do any more surgery, so this was virtually the only option available" (participant 1; 5-6)

Participants described how the EECP treatment was the only option left to them and that it was their last hope for improving their symptoms.

"They all hope that it's going to be a successful treatment. It's a bit like the last chance saloon really, there's not much else they can do" (participant 3; 768-769)

"So EECP were the last thing for me to go for really" (participant 8; 269-

270)

### Special and novel experience

Participants described that over the course of EECP treatment, they developed a relationship with the nurses. There were various aspects of this relationship that seemed important to participants.

Participants commented that they had conversations with nurses and talked with them during the whole process.

"I was really impressed with them, I was. They talk to you all the time, one of them talks all the time, cause to try and take your mind off the noise" (participant 3; 456-457)

Not only did it seem important that the nurses talked to them and provided distraction, but they also listened to the participant in a non-judgmental, empathic way.

"They talked, they'd have a laugh, you could share your life experiences. They were really quite understanding" (participant 4; 100-101)

"Very good personal relationships... they made us... although as I said, it wasn't a painful experience, you still have trepidation, and uh... they just help you relax" (participant 1; 79-80)

During the treatment, the EECP nurses provided participants with information about angina and treatment, which enabled them to hold realistic expectations of the outcome.

"They explained uh... as to what people will gain and what wouldn't gain. It wasn't a, it wasn't a cure. So they didn't give you any kind of false hope. It was how they explained it, it was left up to the individual how they accepted it, and I accepted that it wasn't a cure" (participant 6; 381-386) The majority of participants highlighted that the treatment was a very different experience to other medical treatments they had undergone, due to the relationship with the EECP nurses.

"You're not just lying on a bed receiving treatment, like you are invariably if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth" (participant 7; 70-73)

Participants were keen to emphasise the EECP treatment as being unique and only available to a small number of refractory angina patients every year.

"Even now, many people they are travelling abroad to have this sort of treatment, you know, at their own cost" (participant 10; 79)

(Talking about a local pharmacist): "He's been doing the job for the best part of 30 years and he'd never heard of EECP" (participant 7; 286-287)

This made participants feel special and important to the team and to the nurses. "Well, when you see her will you tell her that cold hands sends his regards, she'll know who it is. She says she's been working for eight and half years and this is the first time she's ever come across this" (participant 2; 95)

Due to experiencing a special relationship with the team, nurses and treatment, participants commented that they felt some responsibility to 'spread the word' about EECP to ensure more people have the treatment.

"It's a great shame, cause there's so few people that can have the treatment in any one year, it's a great shame more people aren't made aware of it, or are becoming aware of it. But that having been said, I, you know, as I've been saying we try to spread it around. If we who've had it can try to spread it around" (participant 7; 203-207)

### Super-ordinate theme four: Response from others

Participants frequently commented on the significance of other people and their views of angina. There were positive and negative aspects that were commented on.

### Supported; "You're not on your own"

The majority of participants highlighted that they underwent EECP treatment and lived with refractory angina with the help of family members. Participants commented that family members went through the whole process with them.

> "I suppose they've come through the process with me, day by day" (participant 5; 449)

Many participants described the importance of meeting other people that were in a similar situation to themselves. Participants found it helpful to speak to other patients that had undergone EECP treatment.

"He reassured, he, he did assure me that it was a good treatment, you know, and that kinda gave me uh... nudge further" (participant 6; 280)

This made participants feel that they would like to give some reassurance and support to patients that were going to have the EECP treatment.

"If you could talk to people that are going to have it done, put 'em at ease, like, it would be quite a good thing really" (participant 8; 197-199) More widely, participants found it helpful to get support from other people living with refractory angina.

"The positive side is, well not sure there's a positive side, but for all the people out there just the same as you that are carrying on with their lives, and, you know, managing it and living with it" (participant 5; 280-283)

"It's been a good thing, that heart group. A lot of people have benefitted from it, they've all got the same, they're all in the same boat" (participant 3; 934-935)

Participant 4 commented that hearing about people living with refractory angina provided a source of inspiration and motivation.

"...you hear different stories about Ranulph Fiennes, having a heart bypass, running seven marathons and climbing up Mount Everest. So I thought, well if he can do that, I can get back to work" (participant 4; 17-19)

Support from other people was also commented to be of importance to participants. For example, most participants described at least one incident where other people had noticed a physical improvement and commented on it after the EECP treatment.

"But certainly the people in the club have noticed, and I can't remember who is was now, but somebody three weeks ago said that he thought I was looking better as well" (participant 7; 478-480)

This acknowledgement of an outwardly physical improvement made participants feel more confident and more positive of the effects of the treatment.

"Yeah they say oh you look better, your appearance is different, and you look more happier, and things like that. And it also gives you positive feedback, which is good, you know, you feel good inside" (participant 10; 253-255)

"Which made me feel better as well, when people say oh you look alright today, you know what I mean? (yeah) Not as grey, not as...couple of people have said that, especially my friends, you know what I mean?" (participant 4; 401-405)

### Hidden Disease

Participants described angina pain as a hidden disease that is not physically obvious to other people in comparison to other illnesses.

"And again it's difficult, if you could see a swelling, or you could see a gash, or you could see a rash, you can't actually see it. To nobody else, you know, nobody else can see that you've physically got it. You know what I'm saying? It's not like a broken leg, people can physically see it. You can't see it, there's nothing to see" (participant 5; 272-274)

This led to participants feeling uneasy about being judged by other people.

"I often feel a bit, I don't know, not uneasy about it, but people get the wrong impression, they don't know you, do they? (participant 3, 327)

"If they see you on a scooter, and you park it up and then get off it and go for a walk, they think 'what's he need a scooter for?"" (participant 3; 320-322)

#### Super-ordinate theme five: Impact of EECP

### "I feel now that I can do it"

Many participants commented that their confidence to confront and accomplish more physical activities had improved since the EECP treatment.

> "Not only did it push me to do it, but also by doing it, it showed me that I don't need to worry so much about it for the future, so since I've come back I'm pushing myself that much more all the time, which is good!" and "Now there's no need for me to be worried, I tend to feel now that I can do it, whereas before, I thought I don't want to try and do it because it will hurt" (participant 7; 92-97)

Participants also described feeling less fear surrounding developing angina pain. *The fear factor has been removed completely from, from all of my actions, that relates to everything (participant 7, 400-401)* 

These improvements in confidence enabled participants to do more activities. "Before, I think if somebody had asked me to go to corner shop, I'd think I can't manage, I can't go. Very hard to go there. It's not far away. Now I can go 200 times now" (participant 9; 147-150)

> "I'm not sure that if I hadn't had the EECP, I'm not sure I would have undertaken to go camping with the boys" (participant 7; 567-569)

These improvements also made participants feel less restricted in their lives.

"If you can imagine, like a bud that's closed tight, like I'm in a cocoon, I can't do anything, but then, I've had the...uh...EECP and I feel as though it's open and there's daylight there, and I feel as though it helps so much. I feel as though I could do anything" (participant 8; 346-349)

### Change of focus

Participants commented that since the treatment they viewed their lives differently. There seemed to be a shift in focus from the fear of angina pain restricting their lives to other factors being taken into consideration. For example, participants acknowledged the restrictions they have due to their age.

> "And of course, you've got to take your age into account haven't you" (participant 3; 280-281)

"I'm not a young man anymore, and your body does have a tendency to break down in its energy and its health" (participant 6; 555-556)

Participants also commented on other illnesses that still limited their quality of life. "It's the angina that has improved, yeah. But the breathing hasn't improved a lot" (participant 3; 272-273)

"It's me leg that I came off the machine with, not me breathing. I could have gone on for a bit longer, but my leg wouldn't let me" (participant 2; 313-315)

The majority of participants focused on the short-term future:

"But I won't give them a date, because until like the week before I'll say I'll be coming next week or whatever. But I won't plan long term purely because it'll depend how I feel" (participant 5; 408-410)

"I just take it as it...every day as it comes" (participant 3; 725-726)

However, it seems that for participant 7 the treatment gave him the opportunity to think about the long-term future:

"Just basically there is potentially a future ahead of me and that I need to be planning for it, whereas before I was thinking 'what the hell' " (participant 7; 717-718)

Although most participants focused on the short-term and conveyed an uncertainty of the future, they did not seem distressed by this, and were quite accepting and positive.

"I know as time goes by there will be some other things which will crop up in the body and there will be other sort of illnesses, but I'll see, I'll wait and see" (participant 10; 499-501)

"Well, what can we say about the future? If we knew, if we knew, if we knew the idea, thing, we could look forward to it" (participant 6; 860-861)

### Discussion

### Summary of main findings

The study sought to understand patients' experiences of living with chronic refractory angina before and after EECP treatment. A further aim of the study was to understand patients' experiences of the process of undergoing EECP treatment. Some themes developed new concepts in relation to the process and outcome of EECP. However, some themes provided support for existing literature in relation to patients with CHD and angina. Themes will be discussed in relation to the research questions.

# What is life like living with chronic refractory angina pectoris? Impact of angina

Participants adopted a variety of coping strategies to cope with the emotional and practical difficulties associated with angina. Some participants adopted strategies such as stoicism and perceived the angina pain as something to fight against. Participants even personified the angina pain to view it as a separate identity with its own agenda, instead of adapting and integrating it into their own identity. Two participants attempted to describe the emotional impact of angina, but found this difficult to verbalise, suggesting that participants rarely tried to put their emotional experiences into words.

Coping has been defined as the thoughts and actions used to manage external and internal demands that are perceived as challenging.<sup>32</sup> Participants appeared to be utilising an emotion-focused coping strategy,<sup>32</sup> which involves managing emotions associated with stress. This coping style has been associated with poorer outcomes compared to problem-focused coping, which involves adopting practical strategies to

change stressful situations.<sup>33</sup> However, research has found that emotion-focused coping strategies, such as emotional-distancing, are often adopted and are more appropriate if a situation cannot be controlled or changed, and this approach can specifically assist in developing and sustaining a sense of psychological wellbeing.<sup>34</sup>

Participants also used humour throughout the interviews. This could be a further strategy to cope with the negative experiences and emotional reactions to threatening situations.<sup>35</sup> However, research also suggests that humour can be a positive coping strategy, as it has a buffering effect on negative life events and reduces the experience of negative emotions.<sup>36</sup> Humour has been found to facilitate coping and adjustment, particularly in an older male population.<sup>37</sup>

Although emotional-distancing may be an adaptive coping strategy in the short-term, adjustment research suggests that this may not be favourable in the long-term. Refractory angina is diagnosed when patients are ineligible for further revascularisation and angina cannot be improved through medication.<sup>9</sup> This diagnosis will trigger a process of physical and emotional adjustment, due to poor control of angina symptoms and uncertainty regarding the future.<sup>30</sup> Hopson and Adams (1976)<sup>38</sup> proposed a model for successful adjustment, which included seven key stages<sup>st</sup>. Most participants could be described as being at the minimisation stage, where people avoid experiencing difficult emotional reactions, such as depression and hopelessness, and are impeded in reaching the final adjustment stage of internalisation of angina into one's identity and behaviours.<sup>38</sup> Participants appeared to be trying to hold on to their old identities. Most described themselves as always being fit and healthy, holding masculine, hard-working jobs. This contrasts to their

<sup>&</sup>lt;sup>xi</sup> 1.Immobilisation 2.Minimisation 3.Depression 4. Acceptance 5.Testing 6.Searching for meaning 7.Internalisation

chronic illness identity and may be hard to integrate and accept.<sup>39</sup> Defending against emotional reactions and new identities are barriers to the uptake of health services and health behaviour change.<sup>40</sup> A dual, interacting process between identity shift and behaviour change has been found.<sup>41</sup> This highlights the importance of working with patients in a flexible and dynamic way to enable the process of adjustment.

Type D (distressed) personality is associated with negative affectivity and social inhibition.<sup>42</sup> People who have this personality trait are more likely to keep their negative feelings to themselves and not express them to others due to fear of being judged. The present study found refractory angina patients had difficulty expressing their emotions and feared being judged by others. Pedersen and Denollet (2006)<sup>43</sup> found that Type D personality can increase risk of morbidity and mortality in CHD populations. It is, therefore, important that interventions focus on encouraging refractory angina patients to share their negative feelings. However, it should be noted that there would be a need for further research to demonstrate the beneficial effects of refractory angina patients expressing their negative feelings, perhaps through a study where half of participants were encouraged to express their feelings and half were discouraged.

### Fear

Participants described that the fear of experiencing angina pain was a greater limitation than the pain itself. Although participants knew that angina was not dangerous, when experiencing the pain there was an overriding cognitive focus on angina leading to a heart attack and death. This has also been found in chronic pain populations<sup>44</sup> and similar results were found by MacDermott (2002)<sup>30</sup> in a study of patients with stable angina. Patients displayed caution regarding physical exertion

due to a fear of negative consequences. This process seems to support the fearavoidance model of chronic pain (FAM).<sup>45</sup> This model posits that the fear of physical activity increasing pain, along with catastrophic misinterpretations, will lead to avoidance, hyper vigilance, disuse and eventually increased pain and disability. In the short-term, this coping strategy of escape and avoidance is effective. However, the avoidance and withdrawal from activities in anticipation of pain, instead of as a response to pain, can lead to increased irritability, frustration and depression, along with a decrease in muscular and cardiovascular usage, known as the 'disuse syndrome'.<sup>46</sup> These factors are associated with decreased pain tolerance and increased pain intensity and disability.<sup>44, 47</sup>



Figure 2. The Fear-Avoidance Model by Lethem, Slade, Troup and Bentley (1983)<sup>45</sup>

Participants also described that their families experienced the same fears, which was causing further limitations in their lives. Developing a chronic illness can affect the whole family system and can lead to a period of adjustment to maintain family homeostasis.<sup>48</sup> Participants found that families became overprotective to cope with

the threat of loss of their significant other.<sup>49</sup> Studies have found that perceived overprotection is associated with worsened psychological wellbeing,<sup>50</sup> QoL<sup>51</sup> and decreased self-efficacy.<sup>52, 53</sup> Therefore, perceived overprotectiveness may lower patients' levels of self-efficacy for controlling symptoms and overcoming their own fears. A mismatch between patients and family members' reactions and coping strategies can impact on recovery, particularly through health-behaviour changes.<sup>54</sup> It is, therefore, important that information given with the aim of dispelling maladaptive illness beliefs is shared and understood with the whole family. Cognitive-behavioural interventions to address the FAM<sup>45</sup> should include identifying negative automatic thoughts, behavioural experiments to confront pain-related fear and relaxation techniques.

As all participants were male, this perception of overprotectiveness is consistent with existing literature on gender differences in support and adjustment,<sup>55</sup> with females more likely to be overprotective of their spouse than males.

## 2. What are the experiences of patients undergoing EECP treatment? "Last chance saloon"

Participants reported that the EECP treatment provided a last hope to improve their angina symptoms. Refractory angina patients are ineligible for further revascularisation and medication management is already at the limit. This can initiate feelings of hopelessness regarding the future. However, there are very few contraindications for EECP treatment<sup>xii</sup>, which enables most refractory angina patients to undergo the treatment. Furthermore, the enthusiasm and positive

<sup>&</sup>lt;sup>xii</sup> Severe peripheral vascular disease; arrhythmias that intervene with machine triggering; pregnancy; bleeding diathesis; significant aortic insufficiency

approach from the EECP nurses appeared to re-instil hope for the future for patients and their families. Hope is a dynamic state of existential coping among patients with a life-threatening disease.<sup>56</sup> Hope focuses on the future<sup>57</sup> and has positive effects on outcome and recovery.<sup>58</sup> Patients with renewed hope are more likely to undergo health behaviour change by modifying how they perceive and respond to a threat or a transition.<sup>59</sup> Hope can also increase optimism, which has also been linked to improved outcomes.<sup>60</sup> Although it seems crucial to renew hope in this patient population, participants commented that the nurses provided realistic expectations, which enabled them not to be disappointed when their angina was not 'cured' by the EECP. Developing realistic illness beliefs can improve recovery and outcomes in CHD patients.<sup>61</sup> This could be through boosting self-efficacy and confidence through the EECP treatment.

### Special and novel experience

Providing realistic hope and developing a strong therapeutic alliance are strongly correlated, suggesting that the clinician-patient relationship is a key factor in fostering or diminishing hope.<sup>62</sup>

Participants described developing a strong and special relationship with the EECP nurses that delivered the treatment. This relationship was identified as different to the usual medical model clinician-patient relationship. There were a variety of different aspects that seemed to contribute to this relationship, which seemed to be based on Rogerian core conditions<sup>63</sup> of empathy, unconditional positive regard and congruence. The nurses also spend 35 hours over a seven week period delivering the treatment, which likely also contributes to development of a strong therapeutic relationship.

Participants described that the nurses listened, reassured, and were understanding and non-judgemental. Empathic engagement in patient care has been found to contribute to treatment satisfaction,<sup>64</sup> better compliance<sup>65</sup> and clinical outcomes.<sup>66</sup> This could be because empathy enhances mutual understanding and trust, which promotes honesty and a stronger congruence between patient needs and care plans.

It appears that the EECP nurses have adopted a relationship-centred model of care compared to the more common medical or biopsychosocial model.<sup>67</sup> This model suggests that diagnosis is only one aspect of the relationship, and that it is equally important to give the patient space to articulate their concerns, discuss expectations, and for clinicians to show their human side.<sup>68</sup> During the 35 hours of treatment, the nurses and patients spend time talking to each other about many topics, including their angina symptoms. This space to talk enables a creation and recreation of reality and identity through dialogue, known as the dialogic model.<sup>69</sup>

### 3. What is life like for patients after the EECP treatment?

### "I feel now that I can do it"

After the EECP treatment, participants experienced an increase in confidence and self-efficacy regarding physical activity. Participants also described that the fear of experiencing angina pain had reduced. Before the treatment, participants would not try to push themselves physically, for fear of further heart damage. As proposed by the FAM<sup>45</sup> this can lead to a vicious cycle of maladaptive behaviours, including avoidance, disuse, depression and disability that delays recovery.<sup>70, 71</sup> However, after the EECP treatment, participants had less fear of experiencing angina, and were more likely to confront activities, and not become stuck in the vicious cycle.

One hypothesis for this could be participants' increase in self-efficacy. Selfefficacy is the belief that one can successfully perform new or difficult tasks to achieve a desired outcome.<sup>72</sup> Chronic pain literature has found self-efficacy to mediate the relationship between pain-related fear and pain intensity and disability.<sup>73</sup> Woby, Urmston and Watson (2007)<sup>74</sup> suggested that self-efficacy was an important addition to the FAM and that patients with high self-efficacy engage in more adaptive behaviours that aid recovery, such as exercise,<sup>75</sup> with the opposite found for low-self efficacy.<sup>76</sup> Angina is a chronic pain condition, and it appears that after the EECP treatment participants have managed to break free from the vicious cycle and engage in more adaptive behaviours through a reduction in pain-related fear and increased self-efficacy. Figure 3 depicts the adaptations to the FAM.



Figure 3. The Fear-Avoidance Model adapted by Woby, Urmston and Watson (2007)<sup>74</sup> to include self-efficacy.

The present study adds to existing literature by proposing that the process of undergoing EECP treatment not only leads to physiological improvement, but also effects psychological pathways, through providing hope, establishing a therapeutic relationship and increasing confidence and self-efficacy to confront challenging behaviour changes. It seems that participants gain confidence to confront challenging activities through a similar process to Kolb's learning cycle.<sup>77</sup> Kolb proposed 4 learning stages, which involved experiencing an activity, reviewing the experience, concluding and learning from the experience and planning further goals from what has been learnt. By establishing a therapeutic relationship, the EECP nurses seem to have provided a containing space for refractory angina patients. This containment leads to an increase in functioning by reviewing patients' day-to-day activities during the EECP treatment and developing the confidence to set further goals and learn from them. The present study suggests that EECP treatment should be viewed as a holistic therapeutic intervention as it impacts on both physiological and psychological pathways.

### Clinical Implications

Refractory angina impacts on the whole family system, not just the individual. A mismatch between patients' and families' reactions, adjustment and illness perceptions can impede recovery.<sup>78</sup> Services need to ensure patients and family members are provided with the same information, to enable congruence between their illness beliefs. A family intervention approach instead of focusing on the individual would be recommended. Services should invite family members to undergo interventions with the patient, such as self-management programmes. This could improve maintenance of health behaviour change and recovery.

Instilling hope in this patient population was important and has been found to facilitate adaptive coping strategies.<sup>79</sup> Services need to be aware of the importance of hope in refractory angina patients and identify, acknowledge, and participate in developing hope. Providing treatments that have fewer contraindications, such as EECP, maintains hope and improves recovery.

The approach adopted by the EECP nurses allowed for a strong therapeutic relationship to develop with the patient, which was acknowledged as important to participants. Health-care professionals delivering any treatment, including EECP, should adopt a relationship-centred model to develop a supportive relationship with the patient. Professionals should be aware of the importance of using Rogerian principles, <sup>63</sup> such as empathy, attentive listening and providing reassurance. However, it is also important that patients are provided with realistic expectations of treatment outcome to ensure realistic illness perceptions. Patients spend 35 hours with the EECP nurses whilst undergoing the treatment. This time could be used to provide information, identify and dispel misconceptions, discuss practical problemsolving and provide encouragement for patients to break out of the vicious cycle of fear-avoidance and increase confidence to increase physical activity. Cognitivebehavioural interventions, such as the Angina Plan<sup>11</sup> aim to dispel misconceptions, increase activity and reduce angina frequency. Research has found that it can improve the psychological and physical functioning in patients diagnosed with angina.<sup>11</sup> Clinical psychologists could implement cognitive-behavioural interventions, such as the Angina Plan, whilst patients are undergoing the EECP treatment to establish an integrated multidisciplinary model of care and service delivery.

Participants acknowledged the importance of identifying with other patients in similar situations. EECP services need to develop a support network between patients that have undergone the treatment. This could be through regular support group meetings, or through producing a contact list of people who would be willing to be contacted.

### Methodological Limitations

All participants interviewed in the study were male. Therefore, the study can only make conclusions regarding the experiences of living with refractory angina and undergoing the EECP treatment for male patients. It is unknown whether female patients with refractory angina have similar experiences. However, during the time of recruitment, no females completed the EECP treatment. The majority of patients that have undergone this treatment are male. Research provides evidence for this gender bias in treatment availability<sup>80</sup> and postulates that diagnostic and management strategies differ to the disadvantage of women.<sup>81</sup>

The study only recruited patients from one hospital, and therefore the majority of participants were from Yorkshire. Tod, Read, Lacey and Abbott (2001)<sup>40</sup> found differences in coping strategies employed based on cultural factors and found that South Yorkshire patients were more likely to use stoicism and avoid discussing emotions. Therefore, some of the findings may be specific to the culture of the participants interviewed, and may not be applicable to other areas of the UK.

Half of the interviews were conducted with a family member present and half were conducted with the participant alone. Having a family member present may have altered some participants' answers and responses. Participants may have felt more comfortable with a family member present and therefore been more open and

honest, which would have increased the richness of the data. However, participants may also have censored some information to protect their family member from more distressing information. It was interesting to get the perspective of a family member, but this was not a research question and may have limited the validity of some of the participants' answers.

A further limitation of the study is the validity and reliability of qualitative research data collection and analysis.<sup>82</sup> Interpretation of the interview transcripts is dependent on the biases and experiences of the researcher and the results can reflect the researcher as much as the researched.<sup>83</sup> However, IPA has been shown to be particularly suitable to health psychology research.<sup>84</sup> The researcher attempted to limit the influence of biases through reflection of personal biases and discussion of transcripts and themes with three independent researchers. Quotes were found from transcripts to support themes identified.

### Future Directions

It would be important to gain an understanding of female patients' experiences of living with refractory angina and undergoing EECP treatment. This would enable comparisons of experiences between genders. There is a growing evidence base that male and female patients with CHD have differing medical and psychological profiles.<sup>85</sup> Therefore it would be important to investigate gender experiences separately. Furthermore, a multi-centre study across multiple hospitals in the UK would enable comparison between cultures.

The study highlighted the importance of family members in outcomes of refractory angina. Future research should further investigate family members' experiences of living with a patient with refractory angina and the impact of EECP

treatment on the family system. It would be interesting to compare the congruence between patients' and family members' experiences of this process.

It would be important to research the relationship between pain-related fear, self-efficacy and chronic pain severity in refractory angina patients using quantitative methodology. Studies have clarified this relationship in the context of the adapted FAM<sup>74</sup> with various chronic pain populations.<sup>73</sup> However, this has not been investigated with refractory angina pain patients. Future research should also investigate the changes in pain-related fear and self-efficacy before and after EECP treatment. It would also be important to investigate the relationship between these constructs and outcomes, such as physical and emotional quality of life after the treatment. However, it must be noted that any randomised controlled trials into EECP need to account for the level of attention and time patients receive from the EECP nurses as this is potentially a confounding factor.

### Conclusion

The current investigation sought to understand the experiences of refractory angina patients before, during and after EECP treatment. Participants described being limited in their lives by pain-related fear from themselves and their families. However, during the treatment, there was a reduction in pain-related fear and an increase in confidence and self-efficacy. This enabled participants to break free from the vicious cycle of fear-avoidance and confront previously avoided activities. The present study adds to existing literature by proposing that the process of undergoing EECP treatment not only leads to physiological improvement, but also effects psychological pathways, through providing hope, establishing a therapeutic relationship and increasing confidence and self-efficacy to confront and undertake

challenging behaviour changes. It is recommended that the time spent undergoing EECP treatment be used to implement cognitive-behavioural interventions, such as the Angina Plan<sup>11</sup> to provide information, identify and dispel misconceptions and discuss practical problem-solving and adaptive coping strategies.

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### Part Two: Study Two:

### Are Illness Perceptions Predictive of Mood and Quality of Life in Refractory Angina Patients that have Undergone Enhanced External Counterpulsation Treatment?

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This paper is written in the format ready for submission to the Journal of Cardiovascular Nursing. Please see Appendix 3.2 for the Author Guidelines.

(Word count = 7364)

### Abstract

**Background:** The relationship between illness perceptions and outcome has been shown to be significant across various chronic illnesses at the beginning and middle stages of CHD progression. However, this relationship has not been investigated for refractory angina patients.

**Objectives:** To investigate the relationship between illness perceptions, mood and quality of life (QoL) in chronic refractory angina patients that have undergone EECP treatment.

**Methods:** A consecutive series of refractory angina patients that had undergone EECP treatment completed and returned postal questionnaires measuring illness perceptions, mood and QoL.

**Results:** Spearman's Rho correlations highlighted significant relationships between illness perceptions, mood and QoL. Hierarchical regression analysis found emotional representations predicted anxiety, depression and emotional QoL. Perceived consequences predicted depression and physical QoL, and personal control predicted physical QoL. Significant differences in specific illness perceptions were found to be dependent on age, gender, time since treatment and number of treatments completed.

**Conclusions:** The current study supports constructs from relevant models; the self-regulatory model<sup>15</sup>, theory of planned behaviour<sup>62</sup> and an adapted version of the fear-avoidance model<sup>64</sup>. A possible model demonstrating the process between illness perceptions and outcomes specific for chronic refractory angina patients is proposed. Future research could focus on concomitant interventions to improve physical and psychological outcomes, for example the Angina Plan could be delivered in

conjunction with EECP to establish an integrated, multidisciplinary model of care and service delivery.

**Keywords:** anxiety; chronic refractory angina; depression; enhanced external counterpulsation treatment; illness perceptions; quality of life.
Coronary heart disease (CHD) is caused by a build up of atheroma,<sup>xiii</sup> leading to narrowing of the arteries and restricting blood flow to the heart. CHD is the leading cause of mortality in the UK, causing approximately one in five male and one in eight female deaths.<sup>1</sup> The prevalence of CHD is increasing annually,<sup>2</sup> leading to an increase in the number of patients experiencing CHD symptoms, such as angina pectoris.<sup>xiv</sup> This increase has led to a continuing rise of societal burden and cost to the NHS.<sup>3</sup> Allender et al (2008)<sup>4</sup> estimated that in 2006 the total cost of CHD to the UK was approximately £9 billion. These statistics highlight the importance of research to investigate the most effective methods of prevention, diagnosis, treatment and recovery in this patient population.

Although there are widely reported physical determinants in the development and outcome of CHD, such as age, obesity, genetics and diabetes,<sup>5, 6</sup> there is no linear relationship between physical severity and outcome. Patients with similar levels of heart disease vary widely in the severity of their experience of angina pain.<sup>7, 8</sup> Thus, psychosocial factors are also important in determining the outcome of CHD, such as locus of control (LoC),<sup>9</sup> self-efficacy,<sup>10</sup> coping strategies,<sup>11</sup> social support,<sup>12</sup> mood<sup>13</sup> and illness perceptions.<sup>14</sup>

The most widely cited model explaining the association between illness perceptions and outcomes is the self-regulatory model.<sup>15</sup> This model posits that patients attempt to make sense of an illness threat by developing parallel cognitive and emotional representations. These representations are organised around five core dimensions; beliefs about illness symptoms (*Identity*), expected duration (*Timeline*),

<sup>&</sup>lt;sup>xiii</sup> An accumulation of fat deposits in the artery walls

<sup>&</sup>lt;sup>xiv</sup> The most common symptom of CHD, with pain across the chest, shoulders, back, arms and jaw. This pain is due to a lack of blood supply and oxygen to the heart

causal factors (*Cause*), illness effects (*Consequences*) and the extent to which the illness can be controlled or cured (*Control/Cure*). Subsequent research has highlighted the importance of patients' beliefs that their illness makes sense (*Illness Coherence*), which has become an additional core dimension.<sup>16</sup> These representations provide a conceptual framework for patients to develop coping strategies and evaluate outcomes of these approaches (see Figure 1).



Figure 1. The self-regulatory model<sup>15</sup>

The constructs of the self-regulatory model have been supported by a meta-analytic review.<sup>17</sup> This review included various chronic illnesses, such as chronic fatigue syndrome (CFS)<sup>18</sup> and chronic obstructive pulmonary disease (COPD).<sup>19</sup> A range of outcomes were also investigated, including psychological wellbeing<sup>20</sup> and quality of life (QoL).<sup>21</sup> Although CHD patients were not included in the review, subsequent research has demonstrated the relationship between illness perceptions and outcomes in CHD population, such as mood<sup>22</sup> and QoL.<sup>23</sup> As mood and QoL are both strong

psychosocial predictors of CHD<sup>24</sup> and are independently associated with morbidity and mortality,<sup>25</sup> they are important outcome measures to be researched.

Research has predominantly focused on the relationship between illness perceptions, mood and QoL in CHD patients at the beginning and middle stages of the disease course. For example research has been conducted after an initial myocardial infarction<sup>xv</sup> (MI) <sup>26, 27</sup> and after pre-planned surgical interventions, such as coronary artery bypass graft<sup>xvi</sup> (CABG) <sup>28</sup> and percutaneous transluminal coronary angioplasty<sup>xvii</sup> (PTCA).<sup>29</sup> No studies, to date, have investigated this relationship in patients experiencing chronic, refractory angina pectoris. Refractory angina occurs in patients when CHD chest pain cannot be adequately controlled through medication management and revascularisation procedures.<sup>30</sup> This is more likely to occur in patients that have experienced a long history of CHD<sup>31</sup> and is occasionally described as 'end-stage coronary artery disease'.<sup>30</sup> p<sup>355</sup> It is an important area to investigate as previous research has shown that refractory angina patients potentially hold maladaptive beliefs and misconceptions regarding their illness, which may subsequently impact on their health, QoL and mood.<sup>32</sup>

A systematic literature review (R. Foxwell, unpublished data, 2012) reported differences in the strength of the relationship between specific illness perceptions with mood and QoL dependent on the stage of disease course and progression. For example, patients' beliefs regarding their degree of illness control was a significant determinant of mood and QoL in patients that had experienced an unexpected

<sup>&</sup>lt;sup>xv</sup> A heart attack

<sup>&</sup>lt;sup>xvi</sup> A surgical intervention that involves removing arteries or veins from other parts of the body and using them to bypass blocked arteries.

<sup>&</sup>lt;sup>xvii</sup> A surgical intervention that involves inflating a balloon within the coronary artery to increase blood supply to the heart.

medical event, such as a first MI, but not in patients that had lived with CHD for longer. Illness perceptions are thought to be changeable with time and experience. Therefore different beliefs at various stages of CHD may be more important determinants of mood and QoL outcomes. As this relationship has not been investigated in patients that have experienced CHD for a longer period of time, such as patients with refractory angina, it is important to identify the specific illness perceptions that may impact on these outcomes.

Enhanced External Counterpulsation treatment (EECP) is a non-invasive treatment for chronic refractory angina. Although there is limited availability for this treatment in the UK, it is widely used in North America on refractory angina patients,<sup>30</sup> and is included in the SIGN guidelines on managing angina symptoms.<sup>33</sup> EECP involves wrapping paired compressible cuffs around the calves, lower and upper thighs, which are attached to an EEG machine and subsequently inflate and deflate in accordance with the cardiac cycle. Both the inflation and deflation of the cuffs reduces cardiac load on the heart. The inflation of the cuffs during diastole<sup>xviii</sup> increases the volume of blood pumped back to the heart, and deflation during systole<sup>xix</sup> decreases the resistance and the cardiac workload. EECP occurs over 35 sessions, each lasting one hour over a seven week period.<sup>34</sup>

Although research has predominantly focused on the physical benefits of EECP, <sup>35</sup> a number of studies have examined QoL and mood outcomes after the treatment. The Multicenter Study of Enhanced External Counterpulsation trial (MUST-EECP) <sup>36</sup> found QoL improved in patients that had undergone EECP compared to a sham treatment. This improvement was found across all QoL

<sup>&</sup>lt;sup>xviii</sup> The period of time when the heart refills with blood after systole

<sup>&</sup>lt;sup>xix</sup> Contraction of the heart

parameters and was sustained at a 12-month follow-up.<sup>37</sup> Further research using refractory angina patients found this improvement to be sustained for up to two years<sup>38</sup> and five years.<sup>39</sup> This sustained improvement was not found in heart failure patients,<sup>40</sup> suggesting that it could be specific to refractory angina. Studies have also found improvements in psychological wellbeing and mood. In a pilot study, Fricchione et al (1995)<sup>41</sup> found an improvement in overall wellbeing, whilst Springer, Fife and Lawson (2001)<sup>42</sup> found an improvement in psychological distress, depression and anxiety. Both studies found these improvements unrelated to physical recovery, suggesting an independent psychosocial benefit of EECP.

No research has examined the illness perceptions of patients that have undergone EECP nor investigated the relationship between illness perceptions, mood and QoL in patients with chronic refractory angina. It is important to know which illness perceptions have the strongest relationship with mood and QoL to enable the development of interventions to address specific maladaptive beliefs.

The primary aim of the present study was to investigate the relationship between illness perceptions, mood and QoL in chronic refractory angina patients who had undergone EECP treatment.

It was hypothesised that anxiety and depression would positively correlate with increased severity of illness perceptions. With regards to QoL, it was hypothesised that physical and emotional QoL would negatively correlate with an increase in maladaptive illness perceptions. Negative illness perceptions may be significant predictor variables for mood and QoL, however it was uncertain which beliefs would significantly predict these outcomes in this patient population.

#### Method

#### Design

The study employed a cross-sectional, non-experimental design. Questionnaire data were analysed quantitatively.

# Participants

Participants were recruited through the Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) Cardiology Department's EECP service at Bradford Royal Infirmary (BRI). All participants who had completed the full EECP treatment at least once under the care of the consultant cardiologist were sent postal questionnaires (n=137). All 137 patients met the inclusion criteria (diagnosis of refractory angina at the time of treatment<sup>xx</sup>, the cognitive ability to give full consent and be able to read fluent English). A questionnaire completion rate of 81 was achieved (59% response rate). Twelve participants were too ill to complete the questionnaire and 44 participants were uncontactable. See Figure 2 for flow chart of recruitment process.

<sup>&</sup>lt;sup>xx</sup> This was a necessary requirement of the treatment. A diagnosis of refractory angina requires the following 1) Presence of stable angina 2) Presence of CHD on a recently performed angiogram 3) Experience of severe angina despite optimal conventional antianginal medical therapy 4) Functional class 3-4 according to the Canadian Cardiovascular Society classification (CCS) 5) Not accessible for conventional revascularisation procedures.



Figure 2. Participant recruitment process.

# Measures

The postal pack contained a patient information sheet, consent form, bespoke demographics form and three measures.

#### Demographics Form

Demographic information was age and gender. Two further questions examined whether the participant had visited their GP and/or taken medication more, the same or less than before the EECP treatment to obtain a broad overview of cost-benefit of EECP. Details about EECP participants (e.g. number of completed treatment sessions and time since completion) were obtained from patient records by clinic nurses.

# The 12 Item Short-Form Health Survey (SF12v2)<sup>43</sup>

The SF12v2 is a 12 item scale that measures QoL on two separate domains; physical functioning (PCS) and psychological wellbeing (MCS) (Appendix 6.2). However,

throughout the paper, the physical functioning subscale will be referred to as physical QoL (PQoL) and the psychological wellbeing subscale will be referred to as emotional QoL (EQoL) for ease of interpretation. The SF12v2 produced norm based scores with a mean of 50 (SD=10). Scores below 50 on both subscales indicate a below-average physical or mental health. The SF12v2 is a shortened version of the SF36 and has been found to closely mirror the strong psychometric properties of this measure.<sup>43, 44</sup> Both the PCS and MCS were shown to have high internal reliability, with Cronbachs alpha greater than 0.80 for both.<sup>45</sup> The SF-12v2 has also been widely used to assess QoL in other cardiac patients<sup>46</sup> and the shortened version lessens the questionnaire load on participants.

# The Hospital Anxiety and Depression Scale (HADS)<sup>47</sup>

The HADS is a 14-item self-report questionnaire measuring the symptoms of depression and anxiety (Appendix 6.1). Each question is rated on a 4-point scale ranging from an absence of symptoms to frequent symptom experience. Both HADS anxiety and depression scales have good internal consistency, with Cronbach's alpha for anxiety ranging from 0.68 to 0.93 and depression from 0.67 to 0.90.<sup>48</sup> The HADS has been used extensively and found to be valid in cardiac populations,<sup>49, 50</sup> and has been recommended as a screening tool for psychological distress in CHD patients by the NSF Clinical Guidelines.<sup>51</sup>

# The Revised Illness Perception Questionnaires (IPQ-R)<sup>16</sup>

The IPQ-R comprises of 70 items assessing the cognitive representations of illness, as proposed by the self-regulatory model<sup>15</sup> (Appendix 6.3). The IPQ-R measures illness perceptions across 9 subscales. Higher scores on five of these subscales

indicates that participants perceive their CHD to be more chronic, severe, variable, distressing and identify more symptoms to their illness: identity (14), timeline acute/chronic (6), timeline cyclical (4), consequence (6), emotional representations (6). Higher scores on three subscales indicate more positive representations, with the participant perceiving more control and understanding of their illness; personal control (6), treatment control (5), coherence (5). The cause subscale (18 items) was excluded from analysis due to not reaching the required number for validly analysing this subscale (n>85).<sup>16</sup>

The IPQ-R provides a psychometrically acceptable assessment of patient's appraisals of illness and has demonstrated good internal consistency, with Cronbach's alpha ranging from 0.79 for timeline cyclical to 0.89 for timeline acute/chronic subscale.<sup>16</sup> The IPQ-R has been widely used to assess illness beliefs in chronic illness populations, including CHD groups, and to predict adjustment and outcomes after treatment.<sup>52, 53</sup>

# Procedure

Ethical approval was obtained from County Durham and Tees Valley Research Ethics Committee (Appendix 2.1). Research and Development (R&D) approval was obtained from Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) (Appendix 2.2). Participants were recruited via BTHFT Cardiology Department's EECP nurses and consultant cardiologist who provided the researcher with contact details of patients who met the inclusion criteria. Potential participants were sent the questionnaire packs. Completion of measures and return via a stamped addressed envelope was taken as indicative of consent (see Appendix 6.5 and 6.6 for information sheets and consent forms). Potential participants who had not returned

packs after 1 month were contacted by telephone to query if they had any questions or concerns about the study. 51 participants then returned completed questionnaires.

#### Data Analysis

Data was analysed using SPSS 19.0. Spearman's rho correlations were conducted to examine relationships between affect, QoL and illness beliefs due to skewed distributions. Mann Whitney U tests were used to examine differences between gender and the number of completed EECP treatments. Stepwise Hierarchical regression was used to examine illness beliefs as predictor variables of QoL and affect.

### Sample Size Calculation

Sample size was calculated based on a multiple regression power analysis. For a significant effect when adding in mood, Qol, time since treatment and illness beliefs (a total of 10 variables) into a hierarchical regression analysis, a sample size of 59 was needed to detect an effect size of 0.2, with a 5% significance level and 80% power. However, when affect, time since treatment and illness beliefs were separately analysed in a hierarchical regression analysis, a sample size of 81 was needed to detect a significant effect size, with a 5% significance level and 80% power.

#### Results

Variable distributions were tested using Shapiro-Wilk test of normality. Physical QoL, emotional QoL and certain IPQ-R scales (identity, personal and treatment control, timeline cyclical and emotional representations) were found to be normally

distributed. However, anxiety, depression and certain IPQ-R scales (timeline chronic, consequences and illness coherence) were not normally distributed (see Appendix 6.8). Therefore, non-parametric statistical tests were employed for these variables.

# Sample Characteristics

Participants' age ranged from 46 to 87 years, with a mean of 67.7 (SD = 9.4). This was not significantly different to a previous UK CHD sample<sup>54</sup> (t (415) = 0.192, p>.05). Participant's ages were grouped into five categories (41-50, 51-60, 61-70, 71-80, 81+). The highest percentage of participants was aged 71-80 (40%). No significant difference was found between the average age of responders and non-responders (t (119) = 0.2131, p>.05).

A high percentage of participants were male (92.6%). Although this proportion is higher than the CHD population in the UK (66.6%), <sup>54</sup> it is similar to previous studies recruiting EECP patients, suggesting that more males undergo this treatment. The percentage of male and female participants did not differ between responders and non-responders ( $\chi^2(1, N = 137) = 0.00, p = 1.00$ ).

A high percentage of participants were White British (84%). The remaining participants were from a South Asian culture (16%). The percentage of South Asian and White British participants did not differ between responders and non-responders  $(\chi^2 (1, N = 137) = 1.105, p = .293).$ 

Participants were asked whether they had visited their GP more, less or the same amount since the EECP treatment. The highest percentage of participants visited their GP the same amount (49.4%), with the lowest percentage visiting their GP more since the treatment (13.6%). Participants were also asked whether they

take more, less or the same amount of medication since the EECP treatment. The highest percentage of participants took the same amount of medication (61.7%), with the lowest percentage of participants taking more medication (16%). See Table 1 for frequencies of visiting GP and taking medication.

	Less	Same	More
Visited GP, % (n)	37.0 (30)	49.4 (40)	13.6 (11)
Taken Medication, % (n)	22.2 (18)	61.7 (50)	16 (13)

Table 1. Frequencies of visiting GP and taking medication

The majority of participants had only completed the EECP treatment once (81.5%). However, one participant had completed the treatment four times (1.2%). The length of time between finishing the EECP treatment and completing the questionnaire packs were calculated based on information provided by the EECP nurses. The number of months ranged from 0-92, with a mean of 32.7 (SD=25.1). Participants were grouped into four categories (0-2 years, 2-4 years, 4-6 years, and 6-8 years). The highest percentage of participants had completed the treatment within 0-2 years (49.4%). See Table 2 for frequencies of length of time since completion of EECP.

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Table 2	Time	since	treatment
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Time since treatment (years)	Percentage (n)			
0-2	49.4 (39)			
2-4	19.0 (15)			
4-6	24.1 (19)			
6-8	7.6 (6)			

A one-way ANOVA found no significant difference in the length of time since completing EECP between participants rating the frequency of GP visits as more, less or the same amount (F (2,73) = 0.432, p=.651) and medication taken (F(2, 73) = 0.833, p=.439).

# Time since CHD Diagnosis

The EECP nurses searched patient files to obtain information regarding the number of years since CHD diagnosis. This information was available for 53 out of the 81 participants. The remaining participants' information was not explicitly stated in the medical notes.

Number of years since diagnosis ranged from 2-30, with a mean of 16.9 years (SD = 7.49). A one-way ANOVA found no significant difference in the length of time since CHD diagnosis for participants rating the frequency of GP visits as more, less or the same amount (F (2,50) = 1.381, *p*=.261) and medication taken (F(2, 50) = 0.900, *p*=.413).

#### **Emotional Distress**

Mean score on HADS Anxiety subscale was consistent with the UK CHD population (t (415) = 0.211, p > .05).<sup>54</sup> Mean score on the HADS Depression subscale was significantly higher than a previous UK CHD sample (t (415) = 5.484, p < .05).<sup>54</sup> See Table 3 for descriptive statistics of this measure.

# Quality of Life

The mean score on the SF12v2 physical QoL subscale was 28.5 (SD = 10.2). The results ranged from 9.2-49.9. Scores below 50 on this scale indicate below average

physical QoL in the national population, suggesting that all participants reported themselves as experiencing lower than the average general population for physical QoL. The mean score on the SF12v2 emotional QoL subscale was 47.7 (SD = 11.1). The results ranged from 23.8-74.0. This suggests that, on average, participants were experiencing typical levels of emotional QoL compared to the average score in the general population. See Table 3 for descriptive statistics of this measure.

#### **Illness Perceptions**

Table 3 shows descriptive statistics for the IPQ-R individual subscales. The number of participants decreased to 76 due to missing data; 5 participants did not complete the IPQ-R questionnaire section. Although results cannot be compared to normative data (as the general population cannot be assumed to have an illness), mean IPQ-R scores are nearer maximum possible scores, suggesting that participants experience maladaptive illness perceptions.

	Maximum Possible Score	Minimum	Maximum	Mean (SD)	N
HADS Anxiety	21	0	17	6.2 (4.7)	81
HADS Depression	21	0	14	6.7 (3.9)	81
SF12v2 PCS	100	9.2	49.9	28.5 (10.2)	81
SF12v2 MCS	100	23.8	74.0	47.7 (11.1)	81
Identity	14	0	13	5.18 (2.99)	76
Time (acute/ chronic)	30	9	30	25.68 (4.75)	76
Consequence	30	11	30	23.01 (4.84)	76
Personal Control	30	6	30	19.71 (4.24)	76
Treatment Control	25	5	24	16.26 (3.30)	76
Coherence	25	5	25	19.79 (4.371)	76
Time Cycle	20	4	20	12.45 (3.48)	76
Emotional Distress	30	6	29	17.42 (5.62)	76

Table 3. Descriptive statistics of outcome measures.

IPQ-R scores were compared to other cardiac patient groups; patients that had experienced an MI, <sup>27</sup> undergone CABG<sup>55</sup> and diagnosed with acute coronary syndrome (ACS).<sup>56</sup> The results of this comparison are displayed in Table 4. Refractory angina patients viewed their illness as significantly more chronic and variable in nature compared to other cardiac patients. They also perceived that their illness would have significantly greater consequences and that they have significantly lower personal and treatment control compared to patients with MI, CABG and ACS. However, refractory angina patients had significantly greater illness coherence than patients experiencing MI, but no significant difference versus patients undergoing CABG. There was no significant difference in scores on emotional distress across cardiac populations.

	Refractory Angina (n = 76)	Myocardial Infarction (n = 204)	CABG (n = 56)	Acute Coronary Syndrome (n = 661)
Time (acute/ chronic)	25.68 (4.75)	20.01 (5.39)**	13.31 (5.14)**	18.37 (5.22)**
Consequence	23.01 (4.84)	18.18 (4.61)**	19.91 (4.35)**	19.88 (4.37)**
Personal Control	19.71 (4.24)	21.26 (3.94)**	23.50 (3.35)**	24.18 (3.72)**
Treatment Control	16.26 (3.30)	18.08 (3.22)**	21.11 (3.08)**	19.69 (2.67)**
Coherence	19.79 (4.37)	17.12 (3.92)*	19.33 (4.19)	Not measured
Time Cycle	12.45 (3.48)	10.80 (2.89)**	Not measured	10.98 (3.19)**
Emotional Distress	17.42 (5.62)	16.65 (4.80)	18.20 (4.45)	Not measured

Table 4. IPQ-R Mean (SD) Scores compared with cardiac populations.

\* p<.05, \*\* p<.01

#### CABG: Coronary Artery Bypass Graft

Spearman's Rho correlations were used to examine the relationship between illness perception variables (see Table 5). When participants believed that there were severe consequences to having CHD and refractory angina, they perceived the illness as having more symptoms, to be chronic in nature and experienced the illness as more distressing. In contrast, when participants viewed their illness as having less severe consequences, they perceived their illness to be more controllable (personal and treatment control).

IPQ-R Subscales (n = 76)	Identity	Time (Acute/ Chronic)	Conseq- uence	Personal Control	Treatment Control	Coherence	Time Cycle	Emotional Distress
Identity	-							
Time (Acute/	.282*	-						
Chronic)	(.014)							
Consequence	.585**	.581**	-					
	(.000)	(.000)						
Personal	.238*	243*	400**	-				
Control	(.039)	(.034)	(.000)					
Treatment	275*	321**	400**	.256*	-			
Control	(.016)	(.005)	(.000)	(.026)				
Coherence	044	.376**	.094	.017	.017	-		
	(.706)	(.001)	(.419)	(.887)	(.884)			
Time Cycle	.141	047	.261*	043	.023	144	-	
	(.224)	(.687)	(.023)	(.711)	(.846)	(.213)		
Emotional	.237*	022	.407**	317**	020	218	.327**	-
Distress	(.039)	(.852)	(.000)	(.005)	(.862)	(.059)	(.004)	

Table 5. IPQ-R Subscale Correlations (*p* values).

\*p<.05, \*\*p<.01

# **Emotional Distress and Illness Perceptions**

Spearman's Rho correlations were used to examine the relationship between illness

perceptions and anxiety and depression.

#### Anxiety

Participants that had more symptoms of anxiety perceived more symptoms associated with their illness (identity), more severe consequences, higher emotional distress and lower perceived personal control over their illness. There were no other significant correlations (see Table 6).

#### Depression

Participants that experienced higher levels of depression identified more symptoms associated with their illness (identity), more severe consequences and higher emotional distress. Furthermore, participants with more depressive symptoms perceived their illness to be less controllable (treatment and personal) and less understandable (illness coherence). There were no other significant correlations (see Table 6).

Table 6. Correlations between IPQ-R and HADS anxiety and depression (*p* values)

	Identity	Time acute/ chronic	Conseq- uences	Personal control	Treatment control	Coherence	Time cycle	Emotional Distress
HADS	.365**	018	.463**	283*	098	160	.232*	.749**
Turklety	(.001)	(.880)	(.000)	(.013)	(.399)	(.167)	(.044)	(.000)
HADS	.433**	.154	.544**	243*	228*	228*	.144	.490**
Depression	(.000)	(.184)	(.000)	(.035)	(.048)	(.047)	(.215)	(.000)

\*p<.05, \*\*p<.01

#### Quality of Life and Illness Perceptions

Spearman's Rho correlations were used to examine the relationship between illness perceptions and physical and emotional quality of life.

## Physical QoL

The better the participants physical QoL, the more control they perceived to have over their illness (treatment and personal). It was also found that participants that experienced lower physical QoL identified more symptoms associated with their illness, perceived their illness to be chronic in nature and have greater severity of consequences. There were no other significant correlations (see Table 7).

#### Emotional QoL

The better the participants emotional QoL, the more personal control they perceived. However, treatment control was not significantly correlated. Participants that experienced lower emotional QoL identified more symptoms associated with their illness (identity) had greater severity of consequences, perceived their illness to be emotional distressing and more cyclical in nature. There were no other significant correlations (see Table 7).

Table 7. Correlations between IPQ-R and Physical and Emotional QoL (*p* values)

	Identity	Timeline acute/ chronic	Conseq uences	Personal control	Treatment control	Coherence	Time Cycle	Emotional Distress
SF12	330**	416**	559**	.449**	.402**	053	.017	115
v2 PCS	(.004)	(.000)	(.000)	(.000)	(.000)	(.652)	(.882)	(.322)
SF12	423**	012	444**	.273*	.034	.127	258*	638**
v2 MCS	(.000)	(.917)	(.000)	(.017)	(.773)	(.272)	(.025)	(.000)

\*p<.05, \*\*p<.01

Age

Spearman's Rho correlations were used to examine the relationship between participants' age and illness perceptions, anxiety and depression. Significant correlations were found for 5 out of the possible 12 variables. As age increased, perceptions of personal and treatment control significantly increased (r = 0.299, p = .009; r = 0.253, p = .028). There were also significant negative correlations between age and consequences (r = -0.311, p = .006), emotional representations (r = -0.309, p = .007) and timeline chronic (r = -0.313, p = .006). The older the participants were, the better perceptions they had over the consequences and chronicity of their illness and their emotional reaction to it.

# Time since Treatment

Spearman's Rho correlations were used to examine the relationship between the time since participants completed the EECP treatment and illness perceptions, anxiety and depression. As the time since EECP completion increased, the less variable participants perceived their angina symptoms to be (r = -0.242, p=.035). No other significant correlations were found.

#### Gender

A series of Mann Whitney U tests were used to determine any differences between gender in QoL, emotional distress or illness perceptions. Significant differences were found for the identity subscale (U (75) = 126.5, Z = -2.076, p=.038), with males attributing more symptoms to their heart disease than females. No other significant differences were found.

#### Number of Times Completed Treatment

A series of Mann Whitney U tests were used to determine any differences between the number of times participants had completed the EECP treatment in QoL, emotional distress or illness perceptions. Participants were divided into whether they had completed the treatment once or more than once. Significant differences were found for the amount of perceived personal control of participants (U (75) = 301.5, Z = -2.045, p=.041), with those completing the treatment once having higher perceptions of personal control. Significant differences were also found for physical QoL (U (80) = 271.0, Z = -2.434, p=.015), with those completing the treatment once having a higher perception of physical QoL.

# Predictors of Quality of Life and Distress

Residual plots from all hierarchical multiple regression models were checked to see whether the normality regression modelling assumptions were met. These assumptions were met for anxiety, depression and physical QoL. However, residual plots were slightly skewed for emotional QoL. Therefore it could not be assumed that the residuals were normally distributed and a bootstrap analysis was performed to get revised p-values for the independent variables

Age, gender and time since treatment were controlled. Illness perceptions (identity, timeline acute/chronic, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations) were entered into the regression analyses as predictor variables of distress (anxiety and depression) and QoL (physical and emotional QoL).

#### Anxiety

After adding 8 illness perceptions to the model, 63.1% of HADS anxiety variance was accounted for ( $\mathbb{R}^2 = 0.631$ , F (11, 64) = 9.95, *p*<.001). On examining the tests of the individual variables, only emotional representations contributed significantly ( $\beta$ = 0.571, SE = 0.082, t = 6.94, *p*<.001). When the 8 illness perceptions were added into the regression individually, 4 predictors were found to be statistically significant (personal control, identity, emotional representations and consequences). However, when the 4 predictors were added together, only emotional representations remained statistically significant ( $\beta$ = 0.560, SE = 0.071, t = 7.851, *p*<.001)

# Depression

After adding 8 illness perceptions to the model, 46.7% of HADS depression variance was accounted for ( $R^2 = 0.467$ , F (11, 64) = 5.10, *p*<.001). On examining the tests of the individual variables, consequences ( $\beta = 0.384$ , SE = 0.127, t = 3.03, *p*=.004) and emotional representations ( $\beta = 0.234$ , SE = 0.083, t = 2.81, *p*=.007) contributed significantly. When the 8 illness perceptions were added individually, 5 predictors were found to be statistically significant (personal control, identity, emotional representations, treatment control and consequences). However, when the 5 predictors were added into the regression together, both consequences ( $\beta$ =0.284, SE = 0.106, t = 2.673, *p*=.009) and emotional representations ( $\beta$ = 0.257, SE= 0.077, t = 3.329, *p*=.001) remained statistically significant.

# Physical QoL

After adding 8 illness perceptions to the model, 42.0% of the Physical QoL variance was accounted for ( $R^2 = 0.420$ , F (11, 64) = 5.92, *p*<.001). On examining the tests of

the individual variables, consequences ( $\beta = -1.22$ , SE = 0.322, t = -3.79, *p*<.001) and personal control ( $\beta = 0.702$ , SE = 0.257, t = 2.75, *p*=.008) contributed significantly. Emotional representations was found to border on significance ( $\beta = 0.405$ , SE = 0.212, t = 1.92, *p*=.060). When the 8 illness perceptions were added into individually, 5 predictors were found to be statistically significant (timeline acute/chronic, personal control, treatment control, identity and consequences). However, when the 5 predictors were analysed together, consequences ( $\beta$ = -0.867, SE = 0.296, t = -2.926, *p*=.005) and personal control ( $\beta$ = 0.614, SE = 0.256, t = 2.400, *p*=.019) remained statistically significant.

# Emotional QoL

After adding 8 illness perceptions to the model, 50.9% of the emotional QoL variance was accounted for (R<sup>2</sup> = 0.509, F (11, 64) = 6.03, *p*<.001). On examining the tests of the individual variables, emotional representations contributed significantly ( $\beta$  = -1.12, SE = 0.224, t = -5.017, *p*<.001). Identity was found to border on significance ( $\beta$  = -0.822, SE = 0.412, t = -1.99, *p*=.050). Residual plots were examined and were slightly skewed. Therefore it could not be assumed that the residuals were normally distributed and a bootstrap analysis was performed to get revised p-values for the independent variables. As a result of the bootstrap analysis, the variables became weaker in predictive ability (identity:  $\beta$  = -0.822, SE = 0.412, t = -1.99, *p*=.067; emotional representations:  $\beta$  = -1.12, SE = 0.224, t = -5.017, *p*=.001).

When the 8 illness perceptions were added individually, 4 predictors were found to be statistically significant (Personal control, identity, emotional representations and consequences). However, when the 4 predictors were analysed together, identity ( $\beta$ = -0.289, SE = 0.397, t = -2.087, *p*=.041) and emotional representations ( $\beta$ = -1.142, SE = 0.195, t = -5.863, *p*<.001) were statistically significant.

## Discussion

This study investigated the relationship between illness perceptions, mood and QoL in chronic refractory angina patients who had undergone EECP treatment. Results confirmed the hypotheses that an increase in negative illness perceptions would positively correlate with elevated anxiety and depression symptoms, and poorer physical and emotional QoL. The hypothesis that negative illness perceptions would also predict mood and poorer QoL was also confirmed.

These findings add to existing CHD literature. The observed relationship between illness perceptions, mood and QoL has been reported in CHD patients at the beginning and middle stages of disease progression, for example MI<sup>22, 27</sup> and cardiac surgery.<sup>46</sup> The present study found this association in refractory angina patients at 'end-stage coronary artery disease', <sup>30 p355</sup> suggesting the interaction is significant throughout the course of CHD progression.

The present findings also add to existing literature reviewed by Hagger and Orbell (2003),<sup>17</sup> that demonstrated a relationship between illness perceptions and outcome in other chronic illnesses, including CFS and COPD. The findings from this study provide additional evidence that the relationship between illness perceptions and outcome is not necessarily disease-specific. Findings are also consistent with the self-regulatory model<sup>15</sup> that posits a relationship between illness perceptions and outcomes.

This study also observed differences in the strength of the relationship between specific illness perceptions, mood and QoL.

# Mood

Participants' emotional representations, perceived consequences and number of symptoms attributed to refractory angina correlated strongly with both anxiety and depression. Emotional representations was a significant predictor variable of mood, highlighting the importance of identifying specific emotional representations held by refractory angina patients. However, perceived consequences of angina was only predictive of depression, not anxiety. Perceiving an illness to have negative consequences on physical, sexual, social and financial functioning can lead to future disability and slower recovery.<sup>57</sup> Perceptions of worsened disability and limited capacity to function in these areas can lead to feelings of loss, which is a common trigger for depression<sup>58</sup> and could explain the findings for EECP patients in this study. Anxiety is more likely to be triggered through different mechanisms, such as perceived threat.

## QoL

Illness perceptions related to anxiety and depression (identity, consequences and emotional representations) were also found to be related to emotional QoL. This is as expected due to the constructs measuring aspects of psychological wellbeing.

Patients' negative perceptions of chronicity, perceived consequences, level of personal and treatment control and symptoms attributed to angina were all significantly correlated with poorer physical QoL. However, perceived consequences and personal control were found to be significant predictors of

physical QoL. Previous research has shown that beliefs regarding negative consequences of CHD are associated with future disability and slower recovery.<sup>57</sup> Loss of functioning and limited capacity following diagnosis of refractory angina could explain the connection between perceived consequences and physical QoL.

Experiencing a lack of control in the management of refractory angina symptoms can lead to a decrease in confidence and self-efficacy in performing activities that would have previously been easily undertaken. Patients with a higher sense of control are more likely to undergo positive health-behaviour changes, attend self-management training, cardiac rehabilitation<sup>59</sup> and exercise programmes, <sup>60</sup> which increase physical QoL.<sup>61, 62</sup> The theory of planned behaviour<sup>63</sup> posits that health-behaviour change is driven by the subjective norms of the behaviour, attitudes towards behaviour change (such as the consequences) and perceived self-efficacy of accomplishing behaviour change.

The association between illness perceptions and outcomes in refractory angina patients supports the theory of planned behaviour.<sup>63</sup> Previous qualitative research involving chronic refractory angina patients (R. Foxwell, unpublished data, 2012) has also suggested that an adapted fear-avoidance model<sup>64</sup> for chronic pain patients may explain changes in self-efficacy and health behaviour as a result of EECP treatment. The self-regulatory model<sup>15</sup> was discussed earlier as a model that was supported by the results. Hypothetically, the specific aspects of each of these models that have been described for chronic refractory angina patients could be combined to demonstrate a process that these patients may experience and the changes that may occur due to the EECP treatment (Figure 3).

The process in Figure 3 begins with refractory angina patients developing perceptions related to their illness, such as beliefs regarding control and

consequences of refractory angina. These illness perceptions impact on patients' decision-making regarding health-behaviour change, such as increased exercise and improved diet. When angina symptoms are experienced, patients' reactions will be dependent on illness perceptions. For example, negative illness perceptions may lead to fear of further heart damage and death. This link between angina pain and fear of death has been documented in a previous qualitative study of refractory angina patients, where one patient stated "...*cause you just associate heart attacks, angina, and people die*" (R. Foxwell, unpublished data, 2012, p16). Fear of experiencing angina pain can lead to patients avoiding physical activity, which consequently leads to physical de-conditioning, disability and depression. Poorer physical conditioning can increase angina symptoms and worsen illness perceptions. This process is a negative vicious cycle, which leads to increasing disability and poorer outcomes.

However, patients that undergo EECP treatment improve physically and psychologically. EECP stimulates the growth of new blood vessels, known as collateral formation, which increases blood flow to the heart. Previous research (R. Foxwell, unpublished data, 2012) has found that patients who have undergone EECP treatment develop an increase in confidence and self-efficacy and a decrease in fear of death. This leads to refractory angina patients physically pushing themselves more. This increase in confronting fears has been found previously: *"Not only did it push me to do it, but also by doing it, it showed me that I don't need to worry so much about it for the future, so since I've come back I'm pushing myself that much more all the time, which is good!"* (R. Foxwell, unpublished data, 2012, p24). An increase in physical activity leads to improved physiological and psychological functioning, which, in turn decreases the frequency and intensity of angina and

improves illness perceptions. This process involves a positive cycle of increased physical functioning and positive illness perceptions.



Figure 3. Proposed process between illness perceptions and outcome for refractory angina patients.

Significant differences in illness perceptions, mood and QoL dependent on age, gender and length of time since EECP treatment were found in the study. Younger participants were more likely to experience increased negative illness perceptions regarding consequences, chronicity, emotional representations and personal and treatment control. Similar results were found in previous studies. For example, more negative illness perceptions were found in patients that had recently been hospitalised for MI that were younger than 57 years<sup>22</sup> and CHD patients younger than 65 perceived more negative consequences.<sup>65</sup> Older adults are more likely to adopt a health-promoting lifestyle through diet, exercise and stress-management.<sup>66</sup> Older age is also a protective factor against depression in CHD.<sup>67, 68</sup> This is pertinent as the present study found depression was significantly correlated with illness perceptions. The finding from this study suggests that younger patients are at a higher risk of poorer recovery due to worse negative illness perceptions. Younger refractory angina patients may need more support in increasing activity and addressing negative illness perceptions.

Males were found to significantly attribute more symptoms to their refractory angina than females. It is a common finding that both genders view CHD as more frequent in males.<sup>69, 70</sup> Therefore, women may be less inclined to attribute specific symptoms to their heart. There may also be a greater impact of refractory angina on males' identity compared to females. Previous research has found that males with chronic refractory angina can struggle to integrate the illness into their identity (R. Foxwell, unpublished data, 2012). The physical impairments associated with refractory angina can lead to role identity difficulties which may contrast to the male masculine identity.<sup>71</sup> The finding from this study suggests that there could be

gender-specific interventions, including a focus on discussing challenges to masculine identity to increase integration for males.

Participants that had undergone EECP treatment more recently perceived their symptoms to be more cyclical in nature. During the progression of a chronic illness, such as refractory angina, patients are confronted with new situations and need to develop new coping strategies to adjust to their altered condition.<sup>72, 73</sup> This process of adjustment can take a long time, as patients need to become accustomed to the variability of the condition. Physiological and psychological changes occur due to EECP treatment, which participants may need to adjust to. Refractory angina patients undergoing EECP treatment may need to be provided with realistic expectations and information regarding adjustment to these changes.

# Cost Effectiveness of EECP

The majority of participants reported that frequency of GP visits and quantity of medication taken was either the same or less than before EECP treatment. The progression of angina and other chronic health conditions usually involves a gradual process of increased medical interventions and interactions with health professionals.<sup>74</sup> The results suggest that EECP can maintain patients on lower pharmacological treatments and delay the normal progression of chronic illness. In considering the likelihood of co-morbidity in patients with refractory angina, a deceleration of progression may also be an important outcome of this treatment. Further investigations of this deceleration process are needed.

#### Comparison of Results to Different Populations

### **General Population**

Participants reported significantly higher depressive symptoms and poorer physical QoL, but average anxiety levels and emotional QoL compared to the general population. It appears that refractory angina patients were experiencing limited capacity and increased disability, without an emotional impact. Previous research (R. Foxwell, unpublished data, 2012) reported that refractory angina patients adopted emotional-distancing as a coping strategy to avoid experiencing the difficult emotions associated with decreasing physical QoL. Participants may have accepted the physical limitations of refractory angina, but not fully accepted or acknowledged the emotional impact. Type D (distressed) personality is associated with negative affectivity and social inhibition.<sup>75</sup> People who have this personality trait are more inclined to keep their negative emotions to themselves and not express them to others due to fear of being judged. The present study and previous research (R. Foxwell, unpublished data, 2012) has found refractory angina patients to have difficulty expressing their emotions, even though they are experiencing high levels of depression. Research has investigated Type D personality with CHD populations, and has found that this personality trait is associated with an increased risk of morbidity and mortality.<sup>76</sup> It is, therefore, important that interventions focus on encouraging refractory angina patients to share their negative feelings.

#### Cardiac Populations

Refractory angina patients held significantly worse illness perceptions compared to other cardiac populations. Patients viewed their illness as significantly more chronic and variable, with more negative consequences, and as having lower personal and treatment control. However, refractory angina patients had a significantly greater understanding of their illness, compared to other cardiac populations. These results support the finding that chronic refractory angina patients hold maladaptive illness beliefs, which may subsequently impact on their health, QoL and mood.<sup>32</sup> Although interventions to modify maladaptive beliefs are mainly centred on the initial stages of CHD or after a significant medical event, the finding from this study suggests that refractory angina patients are also in need of these interventions. However, it must be noted that patients with chronic refractory angina may be further along the CHD disease course than other patient populations. Therefore, some of the worsened illness perceptions may be realistic, due to the chronic and pervasive nature of the condition. Caution should also be taken when interpreting these findings as illness perceptions can vary widely within and between illnesses.<sup>77</sup>

## **Clinical Implications**

Refractory angina patients hold maladaptive illness perceptions, which are related to mood and QoL. Although identification of these perceptions has been previously recommended during the initial stages of CHD and after significant medical events,<sup>22, 46</sup> there is a need for screening of illness perceptions to regularly continue throughout CHD progression. This screening could be completed by healthcare professionals using brief screening tools such as the IPQ-R<sup>16</sup> or the York Angina Beliefs Questionnaire (YABG).<sup>78</sup>

Interventions to alter maladaptive illness perceptions in refractory angina should be made widely available. Cognitive-behavioural interventions have been found to be effective in altering maladaptive illness perceptions in CHD patients.<sup>79</sup> The Angina Plan<sup>80</sup> is a cognitive-behavioural intervention specifically designed to

dispel misconceptions, increase activity and reduce angina frequency in refractory angina patients. Research reports an improvement in psychological and physical functioning in angina patients that have undergone this treatment.<sup>81</sup> In the service that the current study was conducted, the Angina Plan and EECP treatment were offered to refractory angina patients separately, at different times. However, it could be beneficial for patients to improve physically and psychologically in parallel. Previous research has supported the effectiveness of collaborative pharmacotherapy and psychological interventions to improve outcomes in CHD patients.<sup>82</sup> Patients spend 35 hours with the EECP nurses whilst undergoing the treatment. Cognitivebehavioural interventions, such as the Angina Plan, could be implemented whilst patients are actively undergoing the EECP treatment to establish an integrated multidisciplinary model of care and service delivery.

Healthcare professionals need to consider differences in illness perceptions dependent on age and gender when screening and implementing interventions for maladaptive illness perceptions. For example, they should be aware that younger patients are likely to hold more negative illness perceptions, which could impact on their mood and QoL. Furthermore, males attributed more symptoms to their angina; although accurate information regarding the symptoms and management of angina should be equally shared with both genders.

Healthcare professionals also need to consider the effects of patients with Type D personality. It may be beneficial for refractory angina patients to complete a Type D personality checklist, such as the Type D Scale (DS14)<sup>75</sup> to enable identification of patients that may need interventions to encourage the expression of negative emotions.

### Methodological Limitations

The study utilised correlational analysis. Therefore the direction of causality between illness perceptions, mood and QoL cannot be assumed. However, hierarchical regression analysis was also utilised to demonstrate that certain illness perceptions did predict changes in mood and QoL.

It is possible that sample bias may have occurred, as only participants willing to complete and return the questionnaires were included in the study. Although reasons for non-response were not routinely collected, anecdotally, the researcher found that some participants declined because they were too ill. The majority of respondents were also male. However, this discrepancy was found in responders and non-responders, suggesting that more males undergo EECP treatment than females. Research provides evidence for this gender bias in treatment availability<sup>82</sup> and postulates that diagnostic and management strategies differ to the disadvantage of women.<sup>83</sup>

The present study did not include an objective measure of functional ability. The six minute walk test<sup>84</sup> was routinely used after EECP treatment. However, the study was not longitudinal, and therefore participants completing the questionnaires had undergone EECP treatment up to 8 years ago. Due to the nature of chronic conditions, functional ability would have changed during this time. Furthermore, the present study was more interested in participants' perceptions of their physical health.

The questionnaires did not specifically ask participants to answer solely in relation to refractory angina. Due to the likelihood of co-morbidity in this patient population, participants may not have differentiated between conditions when answering the questions. However, investigating solely about patients' refractory

angina utilises a reductionist viewpoint. Even if the questionnaire had specified refractory angina, participants would have probably responded in relation to their whole self, including any co-morbid illnesses.

#### **Future Directions**

Future research should employ a longitudinal design, investigating changes over time in the relationship between illness perceptions and outcomes, such as mood and QoL for EECP patients. Recent qualitative research (R. Foxwell, unpublished data, 2012) has highlighted the importance of EECP in reducing fear-avoidance and promoting self-efficacy in chronic refractory angina patients. It would, therefore, be important to include measures of these in future research of this patient population. Comparisons of these measures before and after EECP treatment may demonstrate the effects of the treatment in both physiological and psychological domains. A multicentre trial with statistically robust sample size could lead to generalised findings across the UK.

Future research should focus on investigating the effectiveness of parallel physiological and psychological interventions for refractory angina patients. A randomised controlled trial (RCT) could be implemented to compare outcomes of three separate groups; EECP treatment, Angina Plan<sup>80</sup> intervention, and a combined parallel intervention of EECP and Angina Plan. Outcomes should include both physical and psychological functioning. This research would have implications for implementing an integrated, multidisciplinary, holistic approach for service delivery in this patient population.

The present research found that refractory angina patients may have similar personality traits to Type D personality. Future research should investigate Type D
personality in refractory angina patients, as it has been shown to increase risk of morbidity and mortality.<sup>76</sup> To date, this research has focused on CHD patients and patients following MI.<sup>85</sup> This could have implications on the focus of cardiac rehabilitations and cognitive-behavioural interventions for refractory angina patients.

## Conclusion

The present study found evidence of a relationship between illness perceptions, mood and QoL in chronic refractory angina patients who had undergone EECP treatment. Results from the current study and previous research supports constructs from 3 main health models and led to the development of a model illustrating the possible process between illness perceptions and outcomes specific for chronic refractory angina patients. The present study also highlights the importance of further research into parallel interventions to improve physical and psychological outcomes. Implementing the Angina Plan and EECP treatment in conjunction, to establish an integrated, multidisciplinary model of care and service delivery was suggested.

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## **Part Three:**

## Appendices

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## Appendix 1.1: Reflective Statement

This reflective statement documents my thoughts throughout the process and upon completion of this research project. I will discuss all aspects of the research process and focus particularly on challenges faced and provide insight into what I have learnt. I will also discuss the rationale for choosing specific journals for my research papers.

## **Beginnings of Research**

At the beginning of this process I was initially interested in the area of chronic pain. I had previously worked in a chronic pain service and had found research within this area particularly interesting. However, after extensive literature searches I was struggling to formulate and find a gap in the research to focus on. On reflection, this was one of the more difficult times during my research journey and I seemed to struggle more with developing an idea than implementing and organising the actual research. Perhaps this reflects my strengths in time-management and organisation and my weaknesses in creative thinking.

The iterative process of formulating research questions and method design was a challenge for me. I have come to realise that I like to be in control, have a plan of action and implement that plan. However the development of research is not a straightforward process; I remember my supervisor frequently reminding me that it was an iterative process. Having to stay with that uncertainty has enabled me to develop this skill, which, in turn has helped me to use this during my clinical work.

My supervisor suggested a research project in the Bradford Cardiology Department investigating enhanced external counterpulsation treatment (EECP). At this stage I had limited knowledge of cardiology and had never heard of EECP! During my regular visits to Bradford to meet the EECP nurses I developed an

understanding of this patient population and their positivity and enthusiasm for this treatment made me passionate about the importance of this research. I think the positive attitudes from the consultant and the nurses maintained my enthusiasm and motivation for this research project throughout.

## **Quantitative vs. Qualitative**

During the initial stages of research design I wanted to develop a quantitative methodology, as I had only ever completed quantitative research in the past. However, due to the lack of research and knowledge of psychological issues related to EECP treatment, an exploratory study seemed equally important to implement. Therefore, I decided to undergo a mixed method design. I expected to write them into one paper; however, during the data collection stages it was obvious that both the quantitative and qualitative sections were too rich in data to combine into one paper.

Throughout the research process, my attitude towards qualitative and quantitative research has changed. I was quite apprehensive of undertaking qualitative research, as it was a new experience for me. I was worried about 'getting it right', but came to realise that the results would not only reflect patients' experiences, but also my own interpretations. I found the process of qualitative research more rewarding because I met the participants and found that I got a deeper understanding of this patient population through doing this. I found the qualitative analysis process more transparent of its strengths and weaknesses than the quantitative research.

I also found it difficult to balance research that derives from two separate epistemological assumptions; qualitative adopting a relativist perspective and

quantitative adopting a positivist perspective. It is important to acknowledge that there is inevitable contamination from each perspective to the other. However, by doing both, I feel that I understand the epistemological stances and appreciate the importance of both types of research complementing each other. I feel I have developed breadth in my research skills, not just depth.

## Write up

At the initial stages of write up I had decided to write all three papers (literature review, empirical paper 1 and paper 2) in parallel. I think this was initially to lessen my anxiety around 'neglecting' an area of my research. This worked well for the method and results sections. However, when it came to formulation of the results it was difficult to hold all three results sections in mind at the same time. As they were all investigating coronary heart disease, it was easy to get confused. I felt slightly overwhelmed by the amount of information and the process felt quite disjointed. In supervision, it was reflected upon that these feelings may be similar to how the refractory angina patient population may feel about their illness. It seems that, at present, refractory angina patients are offered various treatments, but not an integrated multidisciplinary service.

On several occasions during write up, I thought to myself "why have I created more work for myself by doing two research papers instead of just one?" However, I feel I have acquired the skills to undergo and develop qualitative and quantitative work, which I hope will be useful in the future. Also, switching from one method to the next enabled me to have a 'break' from each study and I really feel that the saying 'a change is as good as a rest' encapsulated my strategy for write up.

I remember my supervisor frequently telling me that all my reading into the chronic pain area that I initially did was "money in the bank". At the time I felt that I had done a lot of work that in the end wasn't needed. However, during write up, this phrase kept coming back to me. I came to understand that refractory angina is a chronic pain condition and that many of the models that I had researched in the initial stages fitted well with this patient population. Looking back, if I had not researched chronic pain, I may not have perceived refractory angina in the same way and would not have drawn upon the same models.

## **Parallel Processes**

Initially, there did not seem any obvious parallel processes occurring in my research. However, on further reflection during supervision, control seemed an important issue for chronic refractory angina patients, which also seemed to be an important issue for me during this research process. Furthermore, my relationship with the EECP nurses and consultant cardiologist reflected a similar relationship to refractory angina patients. I developed a strong relationship with the nurses, who provided a supportive space, whereas I spent less time with the consultant cardiologist. Although there is limited research into these types of parallel processes, it has been documented to be a common experience (Smith, 2012).

## Conclusions

Although my research was initially an important process to pass my doctoral training, the further along the journey I went, it seemed equally important that the research I completed was attempted to be published. There is limited research in this field, and funding for EECP treatment seems to be declining. This research process has highlighted the importance of developing a strong working alliance with medical

staff when undertaking psychological research in a health setting. The commitment from medical staff will ultimately determine whether your research is successful or not. I will take this valuable lesson with me throughout my career.

Throughout the research process I have developed my skills as a researcher. I am pleased that I have undergone both qualitative and quantitative research, as I have been able to reflect on the differences in methods and epistemological assumptions underlying them. I feel that I now have the skills to do both types of research again. On reflection, if I had previously had the capacity to do so, I would have completed the qualitative paper before developing the quantitative methodology. The qualitative results would have better informed my quantitative paper, for example I would have included a measure of self-efficacy. Although this was not possible, it has highlighted an important research process for the future.

## **Choice of Journals**

I chose the Journal of Psychosomatic Research for my systematic literature review. Many of the studies included in the review had been published in this journal, so it seemed appropriate to continue with this journal to enable consistency. The impact factor of the journal is quite high (2.842), which would mean my research disseminated to a wide audience. The main difficulty with this journal was the limited word count (5000 words). It was difficult to write concisely, however, I feel I have developed my skills in succinct writing.

I chose the Journal of Cardiovascular Nursing for my two empirical papers. It seemed important to disseminate the findings to medical staff, as the clinical recommendations made were directed to nursing staff. The Journal of Cardiovascular Nursing also publishes psychological papers, demonstrating that their

demographic is more likely to be psychologically minded medical staff. Finally, the Journal seems to accept both qualitative and quantitative studies.

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## Appendix 1.2: Epistemological Statement.

Epistemology is the theory of how we come to know things and believe they are true and real. All research methods derive from an epistemological position, which can vary widely depending on the methods adopted. I have utilised qualitative (empirical paper 1) and quantitative methods (systematic literature review and empirical paper 2) and will discuss the underlying epistemological assumptions for these.

Quantitative research adopts a positivist and realist epistemology. A positivist stance suggests that reality does exist independently of human perceptions (Fade, 2004) and that it can be objectively measured independently of the researcher. The idea of an independent reality allows for theories, models and hypotheses to be tested using statistical analysis (Yates, 2004). Research into the relationship between illness perceptions, mood and quality of life allowed for testing and supporting various theories and models, such as the self-regulatory model (Leventhal, Meyer & Nerenz, 1980).

Qualitative research focuses on 'knowledge', which differs from 'evidence' in quantitative methods (Scott-Findlay & Pollock, 2004). Qualitative research adopts a relativist perspective, suggesting there is no absolute truth because reality is an individual, subjective experience of human perception. This epistemological stance appeared to match the exploratory aims of the qualitative paper, which were to explore the experiences of refractory angina patients before, during and after EECP treatment.

Interpretative Phenomenological Analysis (IPA) was chosen by the researcher as the most appropriate qualitative analysis method. IPA explores how

people experience the world and how they place meaning on these experiences (Smith, Jarman & Osborne, 1999). There are 3 main theoretical underpinnings of IPA; phenomenology, hermeneutics and idiography. Phenomenology involves the study of experience, whereas hermeneutics is the theory of interpretation. People are constantly interpreting and placing meaning on their experiences. I became involved in a double hermeneutic, as a dual interpretation process occurred, where I was trying to make sense of a person who was trying to understand their own experiences. Finally, idiography is the focus on an individual's experiences in contrast to a whole population or a universal experience. Through interviewing each participant separately I focused on their individual experience of EECP and living with angina.

Although quantitative and qualitative research methods are derived from distinct philosophical assumptions, research suggests that these methods can complement each other (Patton, 2002). However, throughout this research process, a relativist perspective seems to fit better with my outlook and my clinical training, which has encouraged a person-centred, individual approach.

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# **Appendix 2: Ethical and Research Governance Approval**

Appendix 2.1: NHS Ethical Approval

Appendix 2.2: Research Governance Approval for NHS Bradford

Appendix 2.3: Confirmation of Pre-Engagement Checks

# **Appendix 3: Guidelines for Submission to Journals**

Appendix 3.1: Journal of Psychosomatic Research Author Guidelines

Appendix 3.2: Journal of Cardiovascular Nursing Author Guidelines

Appendix 3.1: Journal of Psychosomatic Research Author Guidelines

Downloaded from http://www.jpsychores.com/authorinfo on 12th May 2012.



Types of article

#### Full Length Papers

Full length research papers will not normally be more than 4000 words in length (Introduction through Discussion) and will preferably be shorter. Submission of a paper to the Journal of Psychosomatic Research will be held to imply that it represents original research not previously published (except in the form of an abstract or preliminary report), that it is not being considered for publication elsewhere, and that if accepted by the Journal of Psychosomatic Research it will not be published elsewhere in the same form in any language without the consent of the Publisher. Major papers of topical content will be given priority in publication. **Please note that this journal does not publish animal studies.** 

#### Short Reports

The journal welcomes short reports, which may be either preliminary communications or brief accounts of original research. Short Reports must not exceed 1500 words and should include no more than 2 tables and 30 references. The journal does not publish case reports.

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The Editors welcome suggestions for editorials which give personal and topical views on subjects within the journal's area of interest. They should not normally exceed 1500 words, excluding references and should have no more than 20 references.

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These are normally submitted by the Book Review Editor. In addition we welcome suggestions of books for review.

#### Special Articles

These may be invited by an editor or submitted after discussion with an editor. Special articles are designed to provide an analysis of a topic of particular interest to readers of the journal and are more extensive in scope than an editorial. They should not primarily be a commentary on an article previously published in the journal, which would be better addressed in a letter or editorial.

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The Editors welcome suggestions for other types of papers, such as conference reports, accounts of major research in progress and interviews with senior research workers. These should not be submitted without prior consultation with an editor.

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#### B) Digital Artwork Guideline Checklist

Here are the basics to have in place before submitting your digital art.

- Artwork saved as TIFF and EPS files. Do not save TIFFs as compressed files. Powerpoints are also acceptable.
- Artwork created as the actual size (or slightly larger) it will appear in the journal. (To get an idea of the size images should be when they print, study a copy of the journal to which you wish to submit. Measure the artwork typically shown and scale your image to match.)
- Crop out any white or black space surrounding the image.
- **Text and fonts in any figure** are one of the acceptable fonts: Helvetica, Times Roman, Symbol, Mathematical PI, and European PI.
- Color images are created/scanned and saved and submitted as CMYK only. Do not submit any figures in RGB mode because RGB is the color mode used for screens/monitors and CMYK is the color mode used for print.
- Line art saved at a resolution of at least 1200 dpi.
- Images saved at a resolution of at least 300 dpi.
- Each figure saved as a separate file and saved separately from the accompanying text file.
  - For multi-panel or composite figures only: Any figure with multiple parts should be sent as one file with each part labeled the way it is to appear in print

#### **Remember:**

- Artwork generated from office suite programs such as CorelDRAW, MS Word, Excel, and artwork downloaded from the Internet (JPEG or GIF files) cannot be used because the quality is poor when printed.
- Cite figures consecutively in your manuscript.
- **Number figures in the figure legend** in the order in which they are discussed.
- **Upload figures consecutively** to the Editorial Manager Web site and number figures consecutively the **Description** box during upload

#### **Supplemental Digital Content**

Authors may submit Supplemental Digital Content (SDC) via Editorial Manager to LWW journals that enhance their article's text to be considered for online posting. SDC may include standard media such as text documents, graphs, audio, video, and the like. On the **Attach Files** page of the submission process, please select **Supplemental Audio, Video, or Data** for your uploaded file as the **Submission Item**. If an article with SDC is accepted, our production staff will create a URL with the SDC file. The URL will be placed in the call-out within the article. SDC files are not copy-edited by LWW staff, they will be presented digitally as submitted. For a list of all available file types and detailed instructions, please visit <u>http://links.lww.com/A142</u>.

#### SDC Call-Outs

Supplemental Digital Content must be cited consecutively in the text of the submitted manuscript. Citations should include the type of material submitted (Audio, Figure, Table, etc.), be clearly labeled as "Supplemental Digital Content," include the sequential list number, and provide a description of the supplemental content. All descriptive text should be included in the call-out as it will not appear elsewhere in the article.

Example:

We performed many tests on the degrees of flexibility in the elbow (see Video, Supplemental Digital Content 1, which demonstrates elbow flexibility) and found our results inconclusive.

#### List of SDC

A listing of SDC must be submitted at the end of the manuscript file. Include the SDC number and file type of the SDC. This text will be removed by our production staff and not be published. Example:

Supplemental Digital Content 1.wmv

#### **SDC File Requirements**

All acceptable file types are permissible up to 10 MBs. For audio or video files greater than 10 MBs, authors should first query the journal office for approval. For a list of all available file types and detailed instructions, please visit <u>http://links.lww.com/A142</u>.

#### **Tables**

- Tables should be on separate pages placed after the references.
- Number tables consecutively and supply a brief title for each. Always define abbreviations in a legend at the bottom even if they have already been defined in the text.
- For footnotes to appear in the legend, use roman superscript alphabets. Abbreviations should be defined in a legend at the bottom of the table. List abbreviations in alphabetical order; do not include the word "and" before the last abbreviation.
- Cite each table in the text in consecutive order.
- If you use data from another published or unpublished source, obtain permission and acknowledge fully.

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#### Drug Names

The generic (nonproprietary) name of a drug should be used throughout a manuscript. Use the complete name of a drug, including the salt or ester (eg, tetracycline hydrochloride) at first mention and elsewhere in contents involving dosage. When no generic name exists for a drug, give the chemical name or formula or description of the names of the active ingredients.

# **Appendix 4: Supplementary Information for Systematic Literature Review**

Appendix 4.1: Quality Checklist

Appendix 4.2: Data Extraction Form

# Appendix 4.1: Quality Checklist

A modified version of Down and Black (1998) checklist, incorporating questions from the CONSORT 2010 statement (Schulz, Altman & Moher, 2010). The first number represents the number given by the researcher and the second number given by an independent researcher.

	Quality Checklist Question (Y =1, N=0)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Abstract	Was there a structured summary of trial design, methods, results and conclusions?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 21
Introduction	Was the scientific background and rationale for the research explained?	1/1	1/1	1/1	1/0	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 20
	Are the hypotheses/aims/objec tives of the study clearly described?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/0	21/ 20
Method Participant	Are the characteristics of the patients included in the study clearly described?	1/1	1/1	1/1	1/1	0/0	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	20/ 20
	Inclusion and exclusion criteria?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	0/0	1/1	1/1	0/0	1/0	1/1	0/0	1/1	1/1	0/0	1/1	1/0	17/ 15

1/1 0/0 0/0 1/1 1/1 16/ 17
1/1 1/1 1/1 1/1 1/1 21/ 21
D/1 1/1 0/1 1/0 0/1 6/9
1/1 1/0 0/0 1/1 1/1 19/ 15
1/1 0/1 0/1 1/1 1/1 18/ 19
<u>1/1</u> <u>1/1</u>

	Are the main outcomes to be measured clearly described in the introduction or method section?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 21
Results	Are the main findings of the study clearly described?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 21
	Have actual probability values been reported( e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	1/1	1/1	0/0	1/1	0/0	1/1	1/1	0/1	1/0	1/1	1/1	1/0	0/0	0/0	0/1	0/1	1/1	1/1	0/0	1/1	0/1	12/14
	Does the study provide estimates of the random variability in the data for the main outcomes?	0/0	1/1	1/1	1/1	0/0	0/0	1/1	1/1	0/0	0/0	1/1	0/0	0/0	0/0	0/0	0/0	1/1	0/0	0/0	1/1	0/0	8/8
	Were the statistical tests used to assess the main outcomes appropriate?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 21

Discussion	Did the study summarise key results with reference to the study objectives?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	0/0	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	20/ 20
	Did the discussion address limitations to the study?	1/1	1/1	1/1	1/1	1/0	1/0	1/1	1/1	1/1	0/0	1/1	1/1	1/1	1/1	1/0	0/0	1/1	1/1	1/0	1/1	1/1	19/ 15
	Did the discussion address the generalizability of the study and clinical relevance?	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	21/ 21
	Did the study discuss implications of results?	1/1	1/1	1/1	0/1	1/1	0/1	1/1	1/1	1/1	1/1	1/1	0/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	18/ 21
Total		17 / 17	18 / 18	17 / 17	16 / 15	14 / 13	17/ 17	17 / 16	18 / 18	17/ 17	13/ 14	18 / 18	16 / 18	15 / 15	16 / 15	16 / 16	15 / 16	18 / 19	16/ 16	12/ 13	19/ 18	16/ 16	331/ 312

# **Data Extraction Form**

Study Number		
Title of Study		
Author / Publication Date /		
Country		
Journal Source		
Details of Sample	Ν	
•		
	Age Range	
	Candar	
	Gender	
	Ethnicity	
	5	
	Population	
Response Rate		
Research Aims		
Study design and basic		
methodology		
Statistical tests used		
Psychological Factors under		
consideration		

Outcome measures used to	
assess these?	
(method of measurement,	
direct/indirect, who	
completed it, when it was	
measured – baseline/post)	
Main results/findings	
Conclusions	
Main limitations identified	
Quality Rating	

# **Appendix 5: Supplementary Information for Empirical Paper One**

Appendix 5.1: Interview Schedule

Appendix 5.2: Patient Information Sheet

Appendix 5.3: Patient Consent Form

Appendix 5.4: Advertisement

Appendix 5.5: Worked example of IPA

# Interview Schedule

- Can you tell me the symptoms that you experience that you attribute to your heart difficulties?
- In your own words, how would you describe the EECP treatment you have recently had? Can you tell me what that means to you?
- What was good/bad about the treatment?
- In what ways has the EECP treatment made your life better/worse?
  - Has any aspect of your life changed since the treatment?
- In what ways does angina/heart disease affect your life?
- What type of things do you do now that you may not have done before the EECP treatment?
  - What do your family/friends think about these changes?
- When you think about your angina/heart condition, how do you feel?
- What do you think about the future, with regards to your heart condition?
- What do you think were the main causes for developing heart disease?
  - In what ways is this different to the opinions of the doctors?
  - How do people get angina? What causes it?
- What do you think is the main cause for bringing on your angina symptoms?
- How has angina/heart disease affected/changed your relationships?
- In what ways do you feel in control of your life?
  - How in control of your symptoms do you feel?
- What does angina/heart disease mean to you?

#### **Patient Information Sheet**

We would like you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with other if you wish. Please ask us if there is anything that is not cleat or if you would like more information.

Thank you for taking the time to read this.

**Study Title:** The outcomes of patients that have previously undergone Enhanced External Counterpulsation Treatment (EECP)

#### What is the purpose of the study?

Although there is a lot of research into the medical benefits of EECP, there are limited studies into other outcomes of EECP, such a quality of life and mood, which are equally important in recovery after treatment. There has also been no research which has asked the patients directly what they think of the procedure. We want to investigate these aspects of recovery, to see whether EECP is not only medically beneficial, but also whether it helps with recovery by improving quality of life and mood.

We would like to invite you to meet with us to discuss your experiences of the treatment and in what ways it has affected your quality of life, your mood and your views about your angina symptoms.

#### Why have I been invited?

You have been invited to take part in our study because you have recently completed the EECP treatment at Bradford Royal Infirmary. We are hoping to meet with ten patients who have also, like you, recently completed the treatment.

#### Do I have to take part?

No, taking part in the study is voluntary; it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form when you come to the first meeting. You can decide to withdraw from the study at any time, without giving a reason. This would not affect the standard of care you receive.

#### What will happen if I decide to take part?

If you agree to take part, we will contact you to arrange a time and place that is suitable to meet. When we meet you will be given the opportunity to ask any questions and obtain more information about the study. At this time you will be given a consent form to sign. Once you have signed this consent form, you will be given the opportunity to discuss with

us your experiences of the EECP treatment, your views on the impact of this treatment, and your attitudes towards your symptoms. This meeting will last for approximately one hour.

#### What are the possible disadvantages and risks of taking part?

The research study consists of a one off, one hour interview. Therefore, we do not expect any disadvantages or risks. However, discussing your angina symptoms and how it has affected your life may be upsetting. If you do become upset during the interview, you have the right to stop at any time.

#### What are the possible benefits of taking part?

Whilst there are no immediate benefits for participants taking part in the study, hopefully the information you give us will improve the understanding of the benefits of this treatment and help future patients gain better access to this service.

However, taking part may give you a chance to discuss how you have been coping since the treatment finished, which some people may find helpful.

#### What will happen if I decide I no longer wish to take part?

At any point during the interview, you can decide to withdraw from the study. Your data would then be erased and not be used in future analysis.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should contact the main researcher, Rachel Foxwell, on the contact details below, and she will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the main reception desk of Bradford Royal Infirmary.

### Will my taking part in this study be kept confidential?

All data will be handled according to ethical and legal practice. All information which is collected about you during the course of the research will be anonymous. Your completed questionnaires will be given an identification number which will be used throughout the analysis of the results. The data will be stored securely on University Departmental premises for five years after completion of the study.

However, it is important to note that should you disclose anything which the researcher feels puts yourself or others at risk, then confidentiality would have to be broken.

### What will happen to the results of the study?

The results will be written up as part of a doctoral qualification and are intended to be published in a scientific journal. You will not be personally identified in any of the results. If

you wish to obtain information about the results, they will be available in the Cardiology Department upon completion in summer 2012.

#### Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded through the University of Hull and through the Bradford Cardiology Department.

#### Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Proportionate Review Sub-Committee.

#### Further information and contact details

If you have any further questions or queries, please contact Rachel Foxwell on 07702807574 or email r.foxwell@2009.hull.ac.uk.

Participant Identification number for this study:

# **CONSENT FORM**

 Title of project: The outcomes of patients that have previously undergone Enhanced

 External Counterpulsation Treatment (EECP) (Version 1.0)

Name of Researcher: Rachel Foxwell	<u>Please place</u> initials in the box
1. I confirm that I have read and understand the information sheet dated 06/01/2011. Version 1.1 (Part1), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collection during the study may be looked at by individuals from the regulatory authorities or NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I am aware of the potential risks and benefits of taking part.	
5. I agree to the interview being audio recorded	
6. I agree to the use of anonymised quotes in publications	
7. I agree to take part in the above study	

Name of participant

Date

Signature

Person taking consent Date

Signature



17/01/2011. Version 1.1. Poster for Part 2.

#### Appendix 5.5. Worked Example of IPA

A section of transcript from one of the participants is used to illustrate each stage of the IPA process from participant 7, a 62 year-old male. In this extract, participant 7 is describing his experiences of life after the EECP treatment.

#### **Participant 7 Interview Extract**

R: So I wasn't really able to put any.. great... measure on how I was, other than, as I said to you a few moments ago, having come back from Keswick, and those walks are incredible. There is now way that I would have do.. that I would have even attempted to do them 5 years ago, and no way I would have wanted to do them 10 years ago without having pains and the rest of it. And, the fact that I did meant that the whole experience was fantastic. And I, well I go round telling.. singing the songs of EECP without a shadow of a doubt now to anybody and everybody

- I: That's great
- R: No question
- I: Especially seeing as you came in a bit sceptical
- R: Absolutely

#### I; So would you say, like, the confidence of the team, as well, helped with it?

R: I think that has a great deal to do with it, yeah. Um.. you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through. There.. it .. it is important that you have got that enthusiasm... uh.. in the team.. uh.. and Pat and Dr. Morley and the rest of them, yeah definitely, without a shadow of a doubt.

I: Yeah.. and it seems like you noticed, um.. the improvement when you had to push yourself a bit more, like when you went on those walks and you thought, it's like in day to day life that you not [pushing yourself...

R: One of the...] One of the complications of angina.. and this is the thing that the, the, the nurses were keen to stress, is that one of the problems with angina is you tend to not do things because you know full well it's going to subsequently hurt or be painful or, or you going to get pains deedaadeedaa... and so therefore, you tend to become a little bit of a couch monkey, um.. and, and , and not take on the opportunities...

# I: Yeah

R: And to a degree, that is still true now, because after ten years of being in that sort of situation, it's really difficult to get yourself out of it, but equally so it's really important that you do get out of it, and that's why, yes, when I went up to Keswick and pushed to ... umm...do the walking, that, that helped, unquestionably. But more to the point, not only did it push me to do it, but also by doing it, it showed me that I don't need to worry so much about it for the future.

# I: Yeah

R: So since I've come back, I'm now pushing myself that much more all the time, which is, which is good!

# I: So every time you push yourself you get a bit more confidence [to push yourself that bit further...

R: Absolutely right.. absolutely right.. yeah] so it's a case of improving those confidence levels or raising those confidence levels

*Stage one analysis.* The transcripts were re-read and anything of significance and interest noted in the left hand margin. At this stage comments were separated into descriptive, linguistic and conceptual comments. Descriptive comments focused on the content of the participants' comments, linguistic comments explored the specific use of language used and conceptual comments were at a further interrogative level. At this stage three other independent researchers read extracts of interview transcripts and made initial comments according to descriptive, linguistic and conceptual domains. Discussion between the researchers took place to facilitate and formulate a consensus of main themes emerging from transcripts.

	R: So I wasn't really able to put any great measure on						
Wouldn't have attempted	how I was, other than, as I said to you a few moments						
Wouldn't have wanted to attempt	ago, having come back from Keswick, and those walks						
anempi	are incredible. There is now way that I would have do						
The experience of pushing himself was fantastic	that I would have even attempted to do them 5 years ago,						
EECP seen a special /	and no way I would have wanted to do them 10 years ago						
religious?	without having pains and the rest of it. And, the fact that						
	I did meant that the whole experience was fantastic. And						
Nagativa illness perception	I, well I go round telling singing the songs of EECP						
at the start.	without a shadow of a doubt now to anybody and						
	everybody						
	I: That's great						
	R: No question						
Comparison to other medical treatments	I: Especially seeing as you came in a bit sceptical						
metaeta ireamenis	R: Absolutely						
	I; So would you say, like, the confidence of the team,						
Talking is important to him	as well, helped with it?						
was important	R: I think that has a great deal to do with it, yeah. Um						
	you're not just lying on a bed receiving treatment, like						
	you are invariably, if you go into hospital for anything						
	else, nine times out of ten they've got some other, other						
Nurses talk about how fear	things to do and so forth. You don't get a lot of talk, of						
of pain can be limiting	time to talk to them. But when you're lying on that bed						
	for an hour you've got things to talk about and be talked						
Couch monkey – dehumanised? De-	through. There it it is important that you have got that						
masculinised?	enthusiasm uh in the team uh and Pat and Dr.						
	Morley and the rest of them, yeah definitely, without a						
	shadow of a doubt.						
Hard to break that vicious	I: Yeah and it seems like you noticed, um the						
cycle	improvement when you had to push yourself a bit						
Knows rationally that he	more, like when you went on those walks and you						
has to break the cycle	thought, it's like in day to day life that you not						
	[pushing yourself						
By confronting fears,							

gained an increase in	R: One of the] One of the complications of angina and							
<i>confidence to confront</i> <i>more fears.</i>	this is the thing that the, the, the nurses were keen to							
	stress, is that one of the problems with angina is you tend							
	to not do things because you know full well it's going to							
Understands that it is important to improve	subsequently hurt or be painful or, or you going to get							
confidence levels	pains deedaadeedaa and so therefore, you tend to							
	become a little bit of a couch monkey, um and, and ,							
	and not take on the opportunities							
	I: Yeah							
	R: And to a degree, that is still true now, because after							
	ten years of being in that sort of situation, it's really							
	difficult to get yourself out of it, but equally so it's really							
	important that you do get out of it, and that's why, yes,							
	when I went up to Keswick and pushed to ummdo							
	the walking, that, that helped, unquestionably. But more							
	to the point, not only did it push me to do it, but also by							
	doing it, it showed me that I don't need to worry so much							
	about it for the future.							
	I: Yeah							
	R: So since I've come back, I'm now pushing myself that							
	much more all the time, which is, which is good!							
	I: So every time you push yourself you get a bit more							
	confidence [to push yourself that bit further							
	R: Absolutely rightabsolutely right yeah] so it's a case							
	of improving those confidence levels or raising those							
	confidence levels							

*Stage two analysis*. Transcripts were re-read and emerging themes were documented on the transcripts. Emerging themes were discussed with three other independent researchers.

	R: So I wasn't really able to put any great	
Wouldn't have attempted	measure on how I was, other than, as I said to	
Wouldn't have	you a few moments ago, having come back	
wonted to attempt	from Keswick, and those walks are incredible.	
The experience of	There is now way that I would have do that I	Increase in QoL
pushing himself	would have even attempted to do them 5	
was juniusiic	years ago, and no way I would have wanted to	
EECP seen a special /	do them 10 years ago without having pains	
religious?	and the rest of it. And, the fact that I did	Fear as a limiting
	meant that the whole experience was	jacior
Negative illness	fantastic. And I, well I go round telling	Special
start.	singing the songs of EECP without a shadow	relationship with
	of a doubt now to anybody and everybody	EECP nurses
	I: That's great	
	R: No question	
Comparison to other medical	I: Especially seeing as you came in a bit	
treatments	sceptical	
	-	Change in illness
	R: Absolutely	Change in illness perceptions
Talking is	R: Absolutely I; So would you say, like, the confidence of	Change in illness perceptions
Talking is important to him	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it?	Change in illness perceptions
Talking is important to him The enthusiasm of the team was	<ul> <li>R: Absolutely</li> <li>I; So would you say, like, the confidence of the team, as well, helped with it?</li> <li>R: I think that has a great deal to do with it,</li> </ul>	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	<ul> <li>R: Absolutely</li> <li>I; So would you say, like, the confidence of the team, as well, helped with it?</li> <li>R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed</li> </ul>	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	<ul> <li>R: Absolutely</li> <li>I; So would you say, like, the confidence of the team, as well, helped with it?</li> <li>R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if</li> </ul>	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	<ul> <li>R: Absolutely</li> <li>I; So would you say, like, the confidence of the team, as well, helped with it?</li> <li>R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine</li> </ul>	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain can be limiting	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through.	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain can be limiting	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through. There it it is important that you have got	Change in illness perceptions
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain can be limiting Couch monkey – dehumanised?	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through. There it it is important that you have got that enthusiasm uh in the team uh and	Change in illness perceptions Developing a theraneutic
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain can be limiting Couch monkey – dehumanised? De-masculinised?	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through. There it it is important that you have got that enthusiasm uh in the team uh and Pat and Dr. Morley and the rest of them, yeah	Change in illness perceptions Developing a therapeutic relationship
Talking is important to him The enthusiasm of the team was important Nurses talk about how fear of pain can be limiting Couch monkey – dehumanised? De-masculinised?	R: Absolutely I; So would you say, like, the confidence of the team, as well, helped with it? R: I think that has a great deal to do with it, yeah. Um you're not just lying on a bed receiving treatment, like you are invariably, if you go into hospital for anything else, nine times out of ten they've got some other, other things to do and so forth. You don't get a lot of talk, of time to talk to them. But when you're lying on that bed for an hour you've got things to talk about and be talked through. There it it is important that you have got that enthusiasm uh in the team uh and Pat and Dr. Morley and the rest of them, yeah definitely, without a shadow of a doubt.	Change in illness perceptions Developing a therapeutic relationship

	I: Yeah and it seems like you noticed, um	relationship
<i>that vicious cycle</i>	the improvement when you had to push	
	yourself a bit more, like when you went on	
Knows rationally	those walks and you thought, it's like in	
that he has to break the cycle	day to day life that you not [pushing	
	yourself	
	R: One of the] One of the complications of	
By confronting fears, gained an	angina and this is the thing that the, the, the	
increase in	nurses were keen to stress, is that one of the	
confidence to confront more	problems with angina is you tend to not do	
fears.	things because you know full well it's going	
	to subsequently hurt or be painful or, or you	Increase in
Understands that	going to get pains deedaadeedaa and so	knowledge of angina
it is important to	therefore, you tend to become a little bit of a	-
confidence levels	couch monkey, um and, and , and not take	
	on the opportunities	
	I: Yeah	
	R: And to a degree, that is still true now,	Change in identity
	because after ten years of being in that sort of	
	situation, it's really difficult to get yourself	
	out of it, but equally so it's really important	
	that you do get out of it, and that's why, yes,	
	when I went up to Keswick and pushed to	Fear limiting cycle
	ummdo the walking, that, that helped,	Less anxiety
	unquestionably. But more to the point, not	
	only did it push me to do it, but also by doing	
	it, it showed me that I don't need to worry so	Confronting fears
	much about it for the future.	
	I: Yeah	
	R: So since I've come back, I'm now pushing	
	myself that much more all the time, which is,	
	which is good!	
	I: So every time you push yourself you get	
	1	

a bit more confidence [	to push yourself that	
bit further		
R: Absolutely rightabs	solutely right yeah]	Increase in
so it's a case of improvir	ng those confidence	confidence
levels or raising those co	onfidence levels	

*Stage three analysis.* The researcher then looked for patterns in these themes and across different participant's themes. Quotes from the transcripts were extracted to support identified themes.

Emerging Theme	Supporting Quotes
The EECP treatment being special and important	"well I go round telling, singing the songs of EECP without a shadow of a doubt now to anybody and everybody"
The EECP being a very different experience to normal medical professionals	"She's concentrating on the one person all the time, that's gotta be advantageous, both for the treatment, the person on the bed and of course her as well"
The limiting effect of fear	"and you think to yourself why? Why should I do that cause I know full well that it's gonna hurt, so then you don't do it and as I said before, you then retreat, you then become introverted"
Increase in freedom	"if you can imagine like a bud that's closed tight, like I'm in a cocoon, I can't do anything, but then, I've had the uh EECP and I feel as though it's open and there's daylight there, and I feel as though it helps so much, I feel as though I could do anything"
Increase in Confidence	"not only did it push me to do it, but also by doing it, it showed me that I don't need to worry so much about it for the future, so since I've come back, i'm pushing myself that much more all the time, which is good!"
A last hope	"So EECP were the last thing for me to go for really"
Fear of negative evaluation from	"Stresses you a little bit I suppose. Cause you

other people	do, you do want to work"
Coping: Stoicism	"This is the way, you have to keep going going going going"

Stage four analysis. The most relevant themes from across all 10 participants were

synthesised and re-organised to form super-ordinate and subordinate themes.

### **Appendix 6: Supplementary Information for Empirical Paper Two**

Appendix 6.1: Hospital Anxiety and Depression Scale (HADS)

Appendix 6.2: Short-Form 12 version2 (SF12v2)

Appendix 6.3: Illness Perceptions Questionnaire-Revised (IPQ-R)

Appendix 6.4: Demographics Questionnaire

Appendix 6.5: Patient Information Sheet

Appendix 6.6: Patient Consent Form

Appendix 6.7: Advertisement

Appendix 6.8: Tests of Normality

Appendix 6.9: Examples of Correlation Analysis

Appendix 7.0: Examples of Regression Analysis

Appendix 6.1: Hospital Anxiety and Depression Scale (HADS)

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Appendix 6.2: Short-Form 12 version2 (SF12v2). Page 1

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Appendix 6.2: Short-Form 12 version2 (SF12v2). Page 2

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Appendix 6.4: Demographics Questionnaires

# Participant Demographics Sheet.

Could you please answer the following questions:

What is your age?

- O 30 or under
- O 31-40
- O 41-50
- O 51-60
- O 61-70
- O **71-80**
- O 81 or older

What is your gender?

- O Female
- O Male

Have you visited your local GP ...?

- O More than before the EECP treatment
- Approximately the same
- O Less than before the EECP treatment

Have you needed medication...?

- O More than before the EECP treatment
- Approximately the same
- O Less than before the EECP treatment

# **Patient Information Sheet**

We would like you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please contact us if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this.

**Study Title:** The outcomes of patients that have previously undergone Enhanced External Counterpulsation Treatment (EECP).

# What is the purpose of the study?

Although there is a lot of research into the medical benefits of EECP, there are limited studies into other outcomes of the treatment, such a quality of life and mood, which are equally important in the recovery after treatment. We would like to investigate these aspects of recovery, to see whether EECP is not only medically beneficial, but also whether it aids recovery by improving quality of life and mood.

We will ask you to complete the questionnaires attached and return them using the stamped addressed envelope provided.

# Why have I been invited?

You have been invited to take part in our study because you have previously completed the EECP treatment at Bradford Royal Infirmary. We are inviting all patients, like you, that have previously completed this treatment to take part. We hope to find 100 patients who would be willing to take part.

# Do I have to take part?

No, taking part in the study is voluntary; it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep (and be asked to sign the consent form attached). You can decide to withdraw from the study at any time, without giving a reason. However, once you have completed the questionnaires and sent them off they will be anonymised. This would mean that your data could not be removed from the study. This would not affect the standard of care you receive.

# What will happen if I decide to take part?

You will be asked to complete the package of questionnaires attached. The package contains three questionnaires; two of which are regularly sent out by the EECP service and the third questionnaire is about your symptoms and what you think about them. There are no right or wrong answers.

#### What are the possible disadvantages and risks of taking part?

The research study consists of completing only one package of questionnaires. Therefore, we do not expect any disadvantages or risks.

#### What are the possible benefits of taking part?

Whilst there are no immediate benefits for participants taking part in the study, hopefully the information you give us will improve the understanding of the benefits of this treatment and help future patients gain better access to this service.

#### What will happen if I decide I no longer wish to take part?

You will be able to withdraw from the study at any point before sending your questionnaires back. However, once you have sent your questionnaires back they will be anonymised. Therefore, it would not be possible to withdraw your data from the study at this point.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should contact the main researcher, Rachel Foxwell, on the contact details below, and she will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the main reception desk of Bradford Royal Infirmary.

# Will my taking part in this study be kept confidential?

All data will be handled according to ethical and legal practice. All information which is collected about you during the course of the research will be anonymous. Your completed questionnaires will be given an identification number which will be used throughout the analysis of the results. The data will be stored securely on University Departmental premises for five years after completion of the study.

# What will happen to the results of the study?

The results will be written up as part of a doctoral qualification and are intended to be published in a scientific journal. You will not be personally identified in any of the results. If you wish to obtain information about the results, they will be available in the Cardiology Department upon completion in summer 2012.

# Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded through the University of Hull and through the Bradford Cardiology Department.

#### Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Proportionate Review Sub-Committee.

#### Further information and contact details

If you have any further questions or queries, please contact Rachel Foxwell on 07702807574 or email <u>r.foxwell@2009.hull.ac.uk</u>.

#### **Helpful Resources**

The British Heart Foundation: <u>www.bhf.org.uk</u> Telephone number: 0300 330 3311

NHS website: <u>www.nhs.uk</u>

# Appendix 6.6: Patient Consent Form

Participant Identification number for this study:

#### CONSENT FORM

**Title of project:** The outcomes of patients that have previously undergone Enhanced External Counterpulsation Treatment (EECP) (Version 1.0)

Name of participant	Date	Signature
Name of person	 Date	Signature
taking consent		



	Shapiro-Wilk						
	Statistic	df	Sig.				
HADS Anxiety	.932	76	.001				
HADS Depression	.937	76	.001				
SF12v2 PCS	.987	76	.641				
SF12v2 MCS	.967	76	.044				
Identity	.977	76	.174				
Time (acute/chronic)	.773	76	.000				
Consequences	.892	76	.000				
Personal Control	.929	76	.000				
Treatment Control	.915	76	.000				
Coherence	.874	76	.000				
Time Cycle	.985	76	.523				
Emotional Distress	.969	76	.060				

# Appendix 6.9: Examples of Correlation Analysis

						Timeline						
			HADS	HADS		(acute/		Personal	Treatment		Time	Emotional
		_	Anxiety	Depression	Identity	chronic)	Consequence	Control	Control	Coherence	Cycle	Distress
Spearman'	HADS Anxiety	Correlation	1.000	.709 <sup>**</sup>	.365**	.018	.463**	283*	098	160	.232*	.749 <sup>**</sup>
s rho		Sig. (2-tailed)		.000	.001	.880	.000	.013	.399	.167	.044	.000
		Ν	76	76	76	76	76	76	76	76	76	76
	HADS	Correlation	.709 <sup>**</sup>	1.000	.433**	.154	.544 <sup>**</sup>	243 <sup>*</sup>	228*	228*	.144	.490 <sup>**</sup>
	Depression	Sig. (2-tailed)	.000		.000	.184	.000	.035	.048	.047	.215	.000
		Ν	76	76	76	76	76	76	76	76	76	76
	Identity	Correlation	.365**	.433***	1.000	.282*	.585**	238 <sup>*</sup>	<b>2</b> 75 <sup>*</sup>	044	.141	.237*
		Sig. (2-tailed)	.001	.000		.014	.000	.039	.016	.706	.224	.039
		N	76	76	76	76	76	76	76	76	76	76
	Time(acute/	Correlation	.018	.154	.282 <sup>*</sup>	1.000	.581**	243 <sup>*</sup>	321***	.376***	.047	022
	chronic)	Sig. (2-tailed)	.880	.184	.014		.000	.034	.005	.001	.687	.852
		N	76	76	76	76	76	76	76	76	76	76
	Consequence	Correlation	.463 <sup>**</sup>	.544**	.585**	.581**	1.000	400***	400***	.094	.261 <sup>*</sup>	.407**
		Sig. (2-tailed)	.000	.000	.000	.000		.000	.000	.419	.023	.000
		Ν	76	76	76	76	76	76	76	76	76	76
	Personal	Correlation	283*	243*	238 <sup>*</sup>	243 <sup>*</sup>	400***	1.000	.256*	.017	043	317**

Control	Sig. (2-tailed)	.013	.035	.039	.034	.000		.026	.887	.711	.005
	Ν	76	76	76	76	76	76	76	76	76	76
Treatment	Correlation	098	228*	275 <sup>*</sup>	321**	400**	.256*	1.000	.017	.023	020
Control	Sig. (2-tailed)	.399	.048	.016	.005	.000	.026		.884	.846	.862
	Ν	76	76	76	76	76	76	76	76	76	76
Coherence	Correlation	160	228 <sup>*</sup>	044	.376 <sup>**</sup>	.094	.017	.017	1.000	144	218
	Sig. (2-tailed)	.167	.047	.706	.001	.419	.887	.884		.213	.059
	Ν	76	76	76	76	76	76	76	76	76	76
Time Cycle	Correlation	.232 <sup>*</sup>	.144	.141	.047	.261 <sup>*</sup>	043	.023	144	1.000	.327**
	Sig. (2-tailed)	.044	.215	.224	.687	.023	.711	.846	.213		.004
	Ν	76	76	76	76	76	76	76	76	76	76
Emotional	Correlation	.749 <sup>**</sup>	.490***	.237 <sup>*</sup>	022	.407**	317***	020	218	.327***	1.000
Distress	Sig. (2-tailed)	.000	.000	.039	.852	.000	.005	.862	.059	.004	
	N	76	76	76	76	76	76	76	76	76	76

\*\*. Correlation is significant at the 0.01 level (2-tailed).

\*. Correlation is significant at the 0.05 level (2-tailed).

Variables Entered/Removed <sup>®</sup>									
		Variables							
Model	Variables Entered	Removed	Method						
1	Time in Months,		Enter						
	Age in years,								
	Gender Code								
2	Timeline		Enter						
	(acute/chronic),								
	Emotional								
	Representations,								
	Illness								
	Coherence,								
	Personal Control,								
	Identity, Timeline								
	Cyclical,								
	Treatment								
	Control,								
	Consequences								

a. All requested variables entered.

b. Dependent Variable: HADS Anxiety

			Adjusted R	Std. Error of the
Model	R	R Square	Square	Estimate
1	.208 <sup>a</sup>	.043	.003	4.702
2	.794 <sup>b</sup>	.631	.567	3.098

a. Predictors: (Constant), Time in Months, Age in years, Gender Code

b. Predictors: (Constant), Time in Months, Age in years, Gender Code,

Timeline (acute/chronic), Emotional Representations, Illness Coherence,

Personal Control, Identity, Timeline Cyclical, Treatment Control,

Consequences

c. Dependent Variable: HADS Anxiety

	ANOVA <sup>c</sup>									
Model		Sum of Squares	df	Mean Square	F	Sig.				
1	Regression	71.932	3	23.977	1.084	.361 <sup>ª</sup>				
	Residual	1591.858	72	22.109						
	Total	1663.789	75							
2	Regression	1049.723	11	95.429	9.946	.000 <sup>b</sup>				
	Residual	614.066	64	9.595						
	Total	1663.789	75							

a. Predictors: (Constant), Time in Months, Age in years, Gender Code

 b. Predictors: (Constant), Time in Months, Age in years, Gender Code, Timeline (acute/chronic), Emotional Representations, Illness Coherence, Personal Control, Identity, Timeline Cyclical, Treatment Control, Consequences

c. Dependent Variable: HADS Anxiety

Coefficients									
		Unstandar Coefficie	dized	Standardized Coefficients					
			Std						
Model		В	Error	Beta	t	Sig.			
1	(Constant)	13.012	3.931		3.310	.001			
	Gender Code	076	1.879	005	041	.968			
	Age in years	103	.057	208	-1.798	.076			
	Time in Months	001	.021	003	030	.976			
2	(Constant)	-8.468	5.292		-1.600	.115			
	Gender Code	1.818	1.306	.112	1.392	.169			
	Age in years	.033	.042	.067	.785	.435			
	Time in Months	.011	.016	.061	.700	.486			
	Identity	.172	.152	.109	1.135	.261			
	Timeline (acute/chronic)	042	.100	042	419	.677			
	Consequences	.189	.125	.195	1.511	.136			
	Personal Control	070	.100	063	705	.483			
	Treatment Control	.006	.136	.004	.044	.965			
	Illness Coherence	.014	.090	.013	.154	.878			
	Timeline Cyclical	109	.121	081	902	.370			
	Emotional Representations	.571	.082	.681	6.935	.000			

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